



PERSONAL GENOME PROJECT

[www.personalgenomes.org](http://www.personalgenomes.org)

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New Research Building (NRB) Room 238 • Harvard Medical School • 77 Ave Louis Pasteur • Boston, MA 02115

# **PersonalGenomes.org**

## **Board of Directors**

## **Handbook and Materials**

**February 10, 2009**

## **The Mission of PersonalGenomes.org**

To encourage the development of personal genomics technology and practices that are effective, informative and responsible, and to disseminate them for the benefit of the general public.

**PersonalGenomes.org Board of Directors**  
**Important Dates**

**I. Upcoming Board Meetings (Tentative)**

June 9<sup>th</sup> or 10<sup>th</sup>: PG.org Board Meeting (to coincide with the Consumer Genetics Show in Boston, MA)

Fall 2009: PG.org Board Meeting and 3<sup>rd</sup> Annual Personal Genome Project Meeting

**II. Important PGP Milestones**

2009 Events (Tentative)

- February 2009: HMS IRB approves revised PGP protocol.
- Spring 2009: Enrollment of PGP-100 begins.
- Fall 2009: Initial data release for the PGP-100.

2008 Events

- October 30, 2008: PersonalGenomes.org is qualified as a charitable organization under Section 501(c)(3) of the Internal Revenue Code.
- October 21, 2008: Initial data release for the PGP-10.
- October 20, 2008: 2nd Annual Personal Genome Project Meeting, held at Harvard Medical School.
- April 15, 2008: Harvard Medical School Institutional Review Board (IRB) approves protocol to expand the PGP to 100,000 participants.

2007 Events

- July 18, 2007: 1st Annual Personal Genome Project Meeting at Harvard Medical School

2006 Events

- July 25, 2006: Harvard Medical School IRB grants permission to expand PGP to ten participants.
- February 22, 2006: Harvard Medical School IRB grants permission to expand PGP to three participants.

2005 Events

- August 31, 2005: Harvard Medical School IRB approves the Personal Genome Project protocol for one participant.

2004 Events

- September 16, 2004: First protocol describing the Personal Genome Project submitted to the Harvard Medical School IRB.

2003 Events

- June 01, 2003: Submitted NIH-NHGRI-CEGS Proposal; see ELSI Section

**PersonalGenomes.org Board of Directors  
Contact List**

<b>Name</b>	<b>Phone Number/ Email</b>	<b>Address</b>
Jason Bobe	(415) 846-8005 jasonbobe@gmail.com	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115
George Church	[phone number] gmc@harvard.edu	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115
Esther Dyson	[phone number] edyson@edventure.com	EDventure Holdings c/o Meetup, 10th floor 632 Broadway New York, NY 10012 USA
John Halamka	[phone number] jhalamka@caregroup.harvard.edu	1135 Tremont, 6th Floor Boston, MA 02120
Ryan Phelan	[phone number] ryan@dnadirect.com	Ryan Phelan Pier 9, Suite 105 San Francisco, CA 94111
Joseph Thakuria	(917) 774-3346 Joe.Thakuria@childrens.harvard.edu	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115
Daniel Vorhaus	(704) 377-8111 dvorhaus@rbh.com	101 N. Tryon Street, Suite 1900 Charlotte, NC 28246

## MEETINGS

1. February 10, 2009 Board Meeting

## February 10, 2009 Board Meeting

- (a) Inaugural Board Meeting Powerpoint
- (b) Organizational Resolutions
- (c) Board Resolution Approving Solicitation License Applications



# PersonalGenomes.org

## Inaugural Board of Directors Meeting

February 10, 2009

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# PGP Developments and Strategy

- **The Big Picture: Why Are We All Here?**
- **2008: Key Project Milestones**
  - Informed consent protocol approved by IRB for 100,000 participants (April)
  - Continued participation of PGP-10, culminating in public launch; first public release of PGP data (October)
  - Revision and expansion of informed consent protocol(s) and submission to HMS-IRB (January '09)
- **2009: Key Project Goals**
  - Open enrollment of “PGP-100” (Spring?)
  - Public release of PGP-100 data (Winter?)
  - Substantial PGP fundraising, development
  - Discussion of other goals, milestones?

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# The Role of PG.org

- **Implementation:** design and implement the PGP’s publicity, educational and fundraising efforts, including the solicitation and receipt of both cash and non-cash (tangible and intangible goods, services, etc.) donations.
- **Intellectual Property:** manage the PGP’s out-licensing of non-patent intellectual property, including (i) trademarks (i.e., use of the PGP brand), (ii) copyright (i.e., use and access to PGP data) and (iii) materials, including cell lines.
- **Insurance:** provide insurance coverage with respect to certain risks and liabilities associated with the PGP.

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## PG.org: Organizational Matters

- Board of Directors Matters
  - Committee formation
  - Board size and composition
  - Purpose and designation of Board chairman
  - Schedule of future/regular Board meetings
  - Authorization of organizational decisions
- PG.org Organizational Details
  - 501(c)(3) corporation (July incorporation; October IRS determination)
  - Solicitation licenses submitted and majority received; free to fundraise throughout United States

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## Fundraising Activity

- Solicitation Letters
  - Summer/Fall: Personalized solicitation letters drafted and revised
  - January '09: Begin mailing solicitation letters (Helicos, Rothberg)
- Fundraising to Date
  - Monetary Contributions: Google, individuals
  - Goods and Services: Isilon, Complete Genomics, Dover/Danaher, RBH, Goloby (?), Counsyl (?)
- Proposed Fundraising Activities
  - Personal/direct solicitation of funds
  - Online contributions
  - Development and implementation of comprehensive fundraising strategy (external consultant?).

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## Commercial Agreements

**To be ratified by the Board:**

- **Dover/Danaher:** POLONATOR trademark license agreement completed on 1/20. Royalty-free, worldwide license in exchange for trademark control, MFN pricing and supply of reagent kits for use by PGP.
- **Complete Genomics:** Material Transfer and Collaboration Agreement completed on 12/23 to provide CGI with material in exchange for CGI conducting high throughput sequencing.
- **Isilon:** Letter agreement signed on 1/30 to provide for the donation of high-performance data storage equipment to PG.org in exchange for agreement to participate in certain publicity activities.
- **RBH:** Engagement letter signed on 1/12 to provide for ongoing and comprehensive legal services in exchange for two monthly retainers totaling \$10K/mo, amount to be revisited after 6 months.
- **Cellular Dynamics:** proposed Material Transfer and Collaboration Agreement for creation of iPS cell lines.
- **Coriell:** proposed Memorandum of Understanding to facilitate collaboration between PGP and Coriell Personalized Medicine Collaborative (CPMC).

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## Additional 2009 Objectives

- **Commercial and Logistical Needs**
  - Develop and negotiate PGP Structural Division with Harvard
  - Obtain adequate insurance coverage (D&O, CGL, Research, etc.)
  - Engage third-party accounting and fundraising support.
  - Consider additional service needs (e.g., patent/IP counsel)
- **Publicity**
  - Proposed PGP-branded projects and activities (e.g., BioWeatherMap, public launch for PGP-100).
  - Proposed writing and speaking engagements for PGP-RBH team (development of law review essay, abstract submission for APHA, Consumer Genomics Conference, white paper comments to NHGRI, etc.).

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**CONSENT OF DIRECTORS OF  
PERSONALGENOMES.ORG  
TO ACTION WITHOUT MEETING**

The undersigned, being all of the directors of PersonalGenomes.org, a North Carolina nonprofit corporation (the “Corporation”), do hereby adopt the following resolutions by signing their written consent thereto:

**Approval of Budget**

**RESOLVED**, that the Corporation’s budget for the 2009 year, as presented to the Board, is hereby approved.

**Fundraising**

**RESOLVED**, that the President of the Corporation be, and hereby is, authorized to engage an independent contractor to provide fundraising services to the Corporation in such manner and for such compensation as may be determined to be fair and reasonable by the President in his discretion.

**Auditor**

**RESOLVED**, that the President of the Corporation be, and hereby is, authorized to engage a certified public accountant to provide accounting and auditing services to the Corporation in such manner and for such compensation as may be determined to be fair and reasonable by the President in his discretion.

**Relationship with Harvard**

**RESOLVED**, that the President of the Corporation be, and hereby is, authorized to negotiate, execute and deliver a memorandum of understanding or other agreement between the Corporation and Harvard Medical School and/or the President and Fellows of Harvard College, as appropriate, setting forth the respective rights and obligations of such parties regarding their respective roles in carrying out the purposes of the Personal Genome Project; and

**RESOLVED, FURTHER**, that the directors have been informed that the President of the Corporation is a member of the faculty of Harvard Medical School.

### **Agreements for the Provision of Goods, Services and Intellectual Property**

**RESOLVED**, that the President of the Corporation, be and hereby is, authorized to enter into agreements for the provision of goods, services and intellectual property to the Corporation **[for the purpose of promoting the objectives of the Personal Genome Project? Dianne, is this acceptable or does this need to be restricted to charitable purpose?]** in exchange for such provision of or access to information, publicity or other consideration, including the payment of money and the licensing of intellectual property, by the Corporation as the President may determine to be fair and reasonable in his discretion.

### **Ratification of Acts of Officers, Directors and Incorporator**

**RESOLVED**, that all things done and all actions taken by any or all of the officers, directors or incorporator of the Corporation in connection with any matters preliminary to or necessary for the organization, incorporation, investigation or promotion of the Corporation be, and they hereby are, in all respects ratified, confirmed and approved.

**RESOLVED, FURTHER**, that all things done and all actions taken by the officers of the Corporation in entering into agreements with Kollmorgan Corporation (sometimes referred to as Dover/Danaher), Complete Genomics, Inc., Isilon Systems, Inc. and Robinson, Bradshaw & Hinson, P.A. are hereby ratified, confirmed and approved.

### **Further Actions**

**RESOLVED**, that the officers of the Corporation are authorized to take further action and execute such additional instruments as they may deem appropriate to meet all requirements of law necessary to enable the Corporation to conduct its business.

This action is effective February 10, 2009.

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George Church

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John Halamka

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Jason Bobe

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Joseph Thakuria

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Ryan Phelan

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Esther Dyson

**CONSENT OF DIRECTORS OF  
PERSONALGENOMES.ORG  
TO ACTION WITHOUT MEETING**

The undersigned, being all of the directors (the “Directors”) of PersonalGenomes.org, a North Carolina nonprofit corporation (the “Corporation”), do hereby adopt the following resolutions by signing their written consent thereto:

**Application for Solicitation Licenses**

WHEREAS, the Corporation desires to solicit and raise funds in each jurisdiction of the United States of America; and

WHEREAS, some such jurisdictions require the Corporation to apply for and to receive a solicitation license, or comparable registration.

NOW, THEREFORE, IT IS RESOLVED, that the Directors deem it to be in the best interest of the Corporation to take any and all necessary steps to apply for and to receive solicitation licenses, or comparable registrations, in all such jurisdictions;

RESOLVED FURTHER, that the proper officers of the Corporation, acting singly or together, are hereby authorized and directed to apply for such licenses, or comparable registrations, and to take any and all such other actions as they may deem necessary or appropriate in furtherance of or to give effect to the foregoing resolutions, and that any and all actions heretofore taken by such officers, or any of them, in furtherance of the foregoing resolutions are hereby approved, confirmed and ratified.

This the 12th day of December, 2008.

George Church

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Jason Bobe

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Ryan Phelan

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John Halamka

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Joseph Thakuria

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Esther Dyson

## Strategic Plan

## Annual Budget

## Fundraising

1. Sample Solicitation Letter
2. Draft Media Kit
3. General Fundraising Slides



## PERSONAL GENOME PROJECT

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New Research Building (NRB) Room 238 • Harvard Medical School • 77 Ave Louis Pasteur • Boston, MA 02115

George M. Church

21-Jan-2009

To: Stan Lapidus, Chairman, Helicos

Dear Stan,

Thank you for your generous and patient support of PGP as a research participant, and for graciously offering to help us to seek additional support from individuals and/or companies. We put off most such activities until we obtained IRB approval to expand the PGP to 100,000 volunteers and established PersonalGenomes.org a 501(c)(3) non-profit corporation designed to coordinate worldwide PGP components and to enable individuals and companies to join together to support the PGP. The wait is over and we're prepared now to grow our support, scale-up, and continue our dedication to educating and motivating a truly broad audience.

One of the most important aspects of PersonalGenomes.org will be forging effective research partnerships with other national and international institutions seeking to implement the PGP model. In order to do so, the PGP is seeking cash donations, equipment, supplies, and/or licenses of intellectual property owned by third parties for use by the PGP. Donations are tax-deductible to the extent of the law and would also provide a substantial public relations boost as PersonalGenomes.org continues to grow in size and prominence, with Helicos as one of its initial benefactors or other individuals/companies who you think might help support the mission of the PGP. We would be grateful for any donations that Helicos can make, or any other assistance you may be able to provide with fundraising this year.

Current donors to the PGP are listed on this web page: [www.personalgenomes.org/people.html](http://www.personalgenomes.org/people.html). We are thankful for the support of our existing corporate donors, whose generous gifts of up to \$1M, provided the PGP with the resources necessary to establish itself as an organization dedicated to the development of personal genomics technologies and practices that improve our ability to understand and manage human health worldwide.

As an experienced biotechnology entrepreneur, any feedback you provide that might help us achieve our goals in 2009 and beyond would be greatly appreciated. Please feel free to contact me directly by cell phone at 617-462-1347 or set up a time to talk further via email: [gmc@harvard.edu](mailto:gmc@harvard.edu).

Sincerely,

George M. Church, Professor of Genetics, Harvard Medical School  
Director of the Personal Genome Project



# Genomes for ALL

By George Church  
Scientific American, January 2006.

*Next-generation technologies that make reading DNA fast, cheap and widely accessible are coming in less than a decade. Their potential to revolutionize research and bring about the era of truly personalized medicine means the time to start preparing is now.*



Press conference at the 2nd Annual Personal Genome Project Meeting, Harvard Medical School, October 20, 2008.

## WIRED MAGAZINE: 16.08

### How the Personal Genome Project Could Unlock the Mysteries of Life

By Thomas Goetz 07.26.08



George Church is sequencing the DNA of 100,000 volunteers. Photo: Lloyd Ziff



## THE WALL STREET JOURNAL

OPINION | JULY 25, 2007

### Full Disclosure

By ESTHER DYSON

In a couple of months, my genome, my answers to a substantial health question, medical records (as many of them as I can collect, anyway) will be posted on the web to see.

I'm one of 10 members of Harvard geneticist George Church's Personal Genome Project. We come to this with slightly different motivations, histories and medical records. But theory, the equivalent of a master's degree in genetics, an age between 30 and 40, and willingness to come to Boston to give blood, get our faces professionally photographed with one another to discuss strategy.

What are my motives? First, I want to show that there's nothing especially magical about a genome. It doesn't hold secret knowledge that will allow others to harm me as they stick pins into a voodoo doll. In fact, I feel more trepidation about releasing our

The New York Times

October 20, 2008

### Taking a Peek at the Experts' Genetic Secrets

By AMY HARMON



Laura Rauch for The New York Times

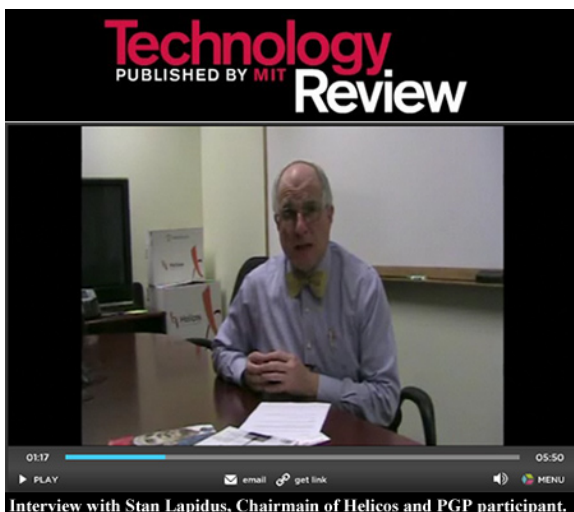
## xconomy | Boston

Business • Technology in the Exponential Economy

### Google Supporting George Church's Personal Genome Project

Rebecca Zacks 2/29/08

The Personal Genome Project, led by Harvard Medical School professor George Church, got a boost from Google late last year, according to a [report today](#) from Bloomberg.




Interview with Stan Lapidus, Chairmain of Helicos and PGP participant.



### Group Led by Harvard's George Church Will Bid for Genomics X Prize

Rebecca Zacks 12/4/07


A local group has finally [thrown its hat into the ring](#) for the \$10 million Archon X Prize for Genomics, and it's a biggie: the newly minted Personal Genome X-Team (PGx), led by genomics pioneer George Church.



## Diversified Fundraising for the Personal Genome Project

January 12, 2009


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## Overview

- Everyone's responsibility
  - Not just George and Jason, but the Board as well
- Highly Relational
- Effort = Reward


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## Current Climate

- Challenging economy
  - “No” means “not now”
  - Keep the door open and build connections for the next round of donations
- Uncertainty Prevails
- Need mix of funding sources

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## Recordkeeping and Technology

- Donor database (e.g., eTapestry)
  - Tracks and sorts prior donors (individ. vs. corp.), participants/families, etc.
  - Enables targeted solicitation of high-value vs. low-value donors
- Information
  - Consider types of donor knowledge/information to collect
  - Name, address, prior giving, events attended, other narrative information
- Target marketing to database


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## Fundraising Cycle

- Cultivation
- Solicitation
- Stewardship

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## Delegating Fundraising Duties

- Fundraising feasibility study
  - Excellent local firms; find somebody knowledgeable in the subject area
  - ~ \$20K for high-level feasibility study
- Consultant vs. Full-Time Fundraiser
  - Implementation of fundraising plan could be by either, but probably too much work for a single full-time, in-house fundraiser
  - Simpler and cleaner to rely on firm to implement


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## Grants

- Family Foundations
- Institutional Private Foundations
  - Bigger dollars
  - Formal requirements; ~ 6-12 month lead time, so start soon for round two founding
- Corporate Foundations
- Governmental Agencies (CEGS, others?)


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## Grants (cont.)

- Labor intensive
- Unpredictable
- Long lead time
- Often not renewable

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## Corporate dollars

- Evaluate PGP demographic
  - Individuals: participants (incl. friends and family), sci-tech altruists and/or early adopters
  - Pharma R&D (cell lines)
  - Genomic sequencing companies (proof of concept, generate market demand)
  - Health care providers
  - Academic researchers and institutions
  - [Brainstorm other market segments]


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## Corporate marketing dollars (cont.)

- Potential Benefits of sponsorship (PGP is sought-after brand):
  - Website presence
  - Donor lists
  - Participation in PGP events (e.g., BioWeatherMap)
  - Early/preferred access to PGP participants?
    - Specify optional trait collection, insertion of questions into safety questionnaire
    - Cross-promotion/enrollment of participants (e.g., Coriell)
  - Preferential enrollment in PGP
- Consider PGP brand preservation

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## Major Gifts from Individuals

- Key Source of Funds for PGP
  - George, early enrollers (PGP-10/100), Board all need to tap personal networks
- One time vs. multi-year gifts
- Lifetime vs. testamentary
  - Given likely age of PGP enrollee demographic, consider pursuing testamentary gifts
  - Supports long-term fundraising (25-50 year PGP timeline)
  - Requires specialized legal and fundraising expertise
- Formal gift agreements
  - Generally better to take \$ without an agreement, but will be required for multi-year, testamentary gifts
  - Consider unrestricted vs. restricted gifts
- Endowments
  - Can be used to establish separate accounts protected from creditors, legal claims, etc.
  - Useful to protect large gifts
  - Requires specialized legal and fundraising expertise

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## Major gifts from individuals (cont.)

- Often cultivate for years
- Considerable investment of time
- Need staff or volunteer continuity


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## Online/mail appeals

- Combine with general marketing plan
  - Mass marketing through website, etc.
  - Appeal to friends/family of participants or potential participants (e.g., Pan-Mass challenge)
- Watch graphic identity
- Benefits of on-line appeals:
  - Cost effective
  - Easy to respond
  - Avoid: sending low-dollar solicitations to potential high-dollar donors (eTapestry, etc. can help prevent this)


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## In-kind gifts

- Fundamental to PGP Strategy
  - Donative licenses (IP)
  - Goods (machines, reagents, etc.)
  - Services (administrative, financial, legal, technical (sequencing, CGI), etc.
  - Logistical support, time, etc.


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## Special events

- Dual Purpose:
  - Friend-raiser & fundraiser
  - Drive participants and sponsors to PGP
  - Example: BioWeatherMap as a way to generate interest in PGP
- Carefully consider event-related costs, time commitment
- Consider income sources:
  - Event sponsorships (corporate, etc.)
  - Ticket sales or participation fee

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## Earned income

- Participation/enrollment “pledge”
  - Develop model for suggested giving, strategies to increase giving (e.g., public donor lists/rankings)
  - Determine FMV for tax-deduction
- Unrelated business taxable income:
  - Watch mission dilution
  - Not more than 15% gross income

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## Legal compliance matters

- Solicitation licenses in progress in all jurisdictions
- Develop solicitation letters (Helicos, etc.) and acknowledgement
- Uniform disclosure statements for solicitations and acknowledgements
- Retain accounting/financial services firm to provide tax and accounting guidance, determine boundaries between PGP, Harvard and PG.org, etc.

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## Stewardship

- Thank, Thank, Thank!

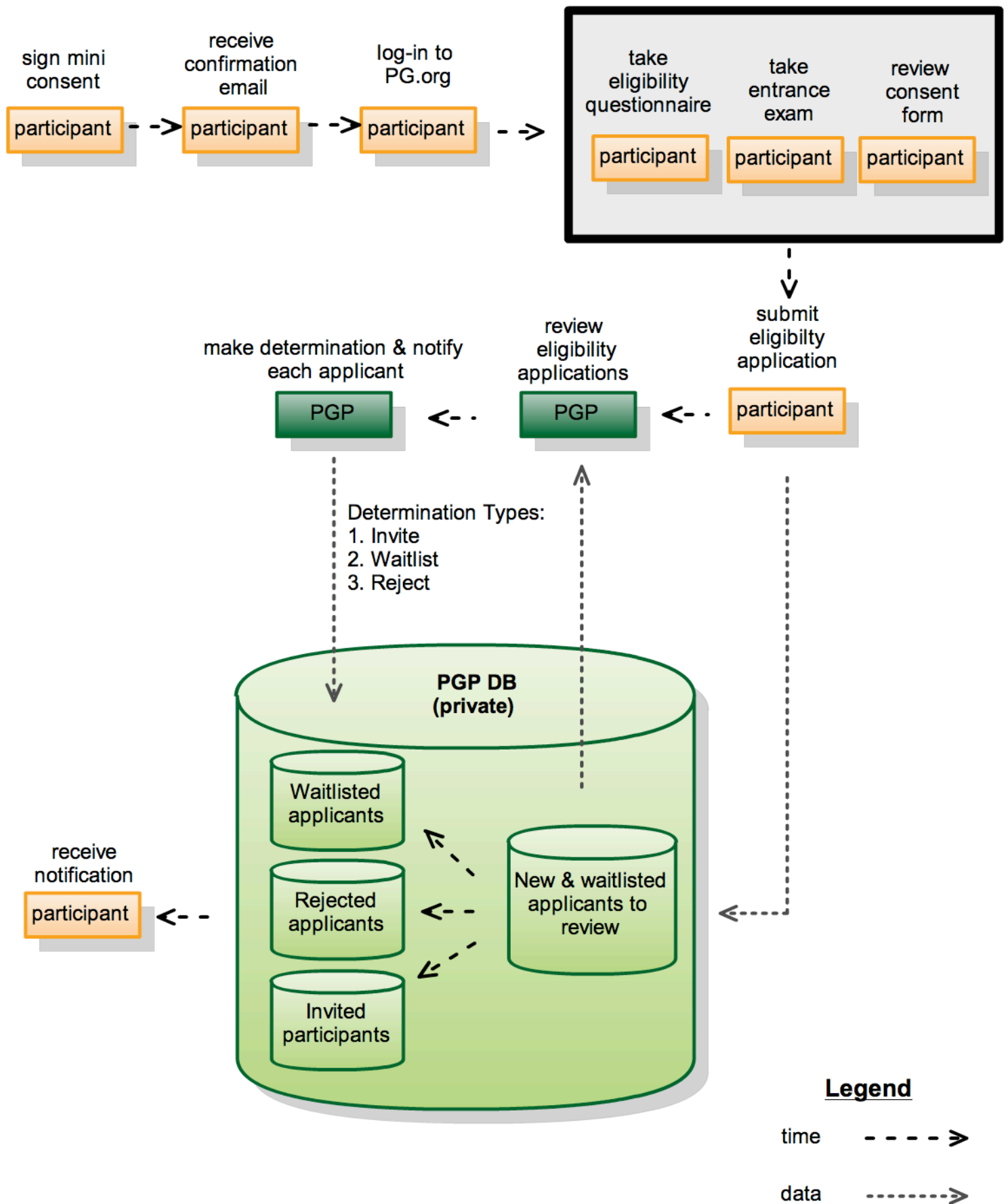
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## **PGP Informational Materials**

1. PGP Workflow
2. Final Informed Consent Agreements
3. Article Abstract

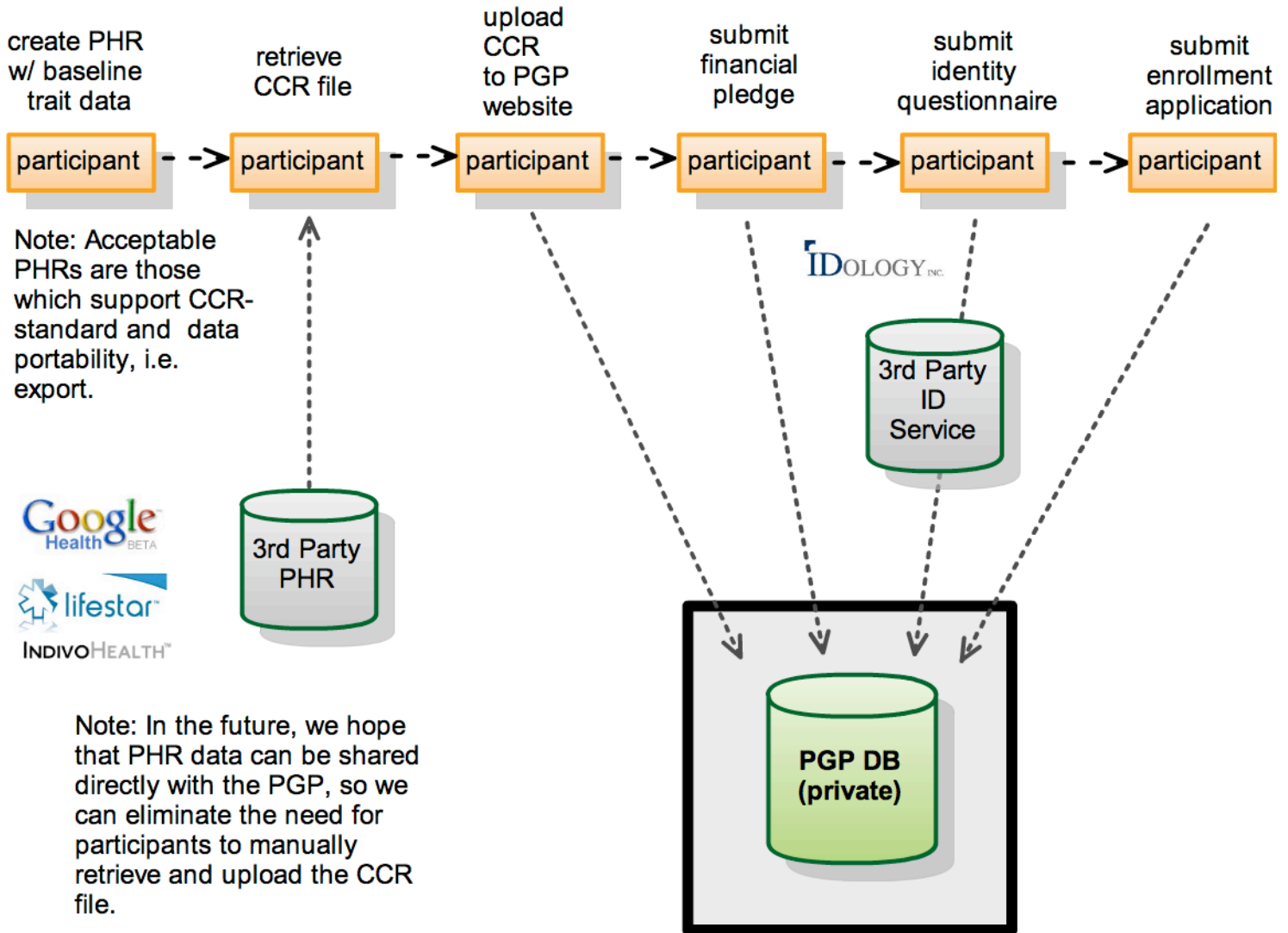


## ELIGIBILITY SCREENING PROCEDURES

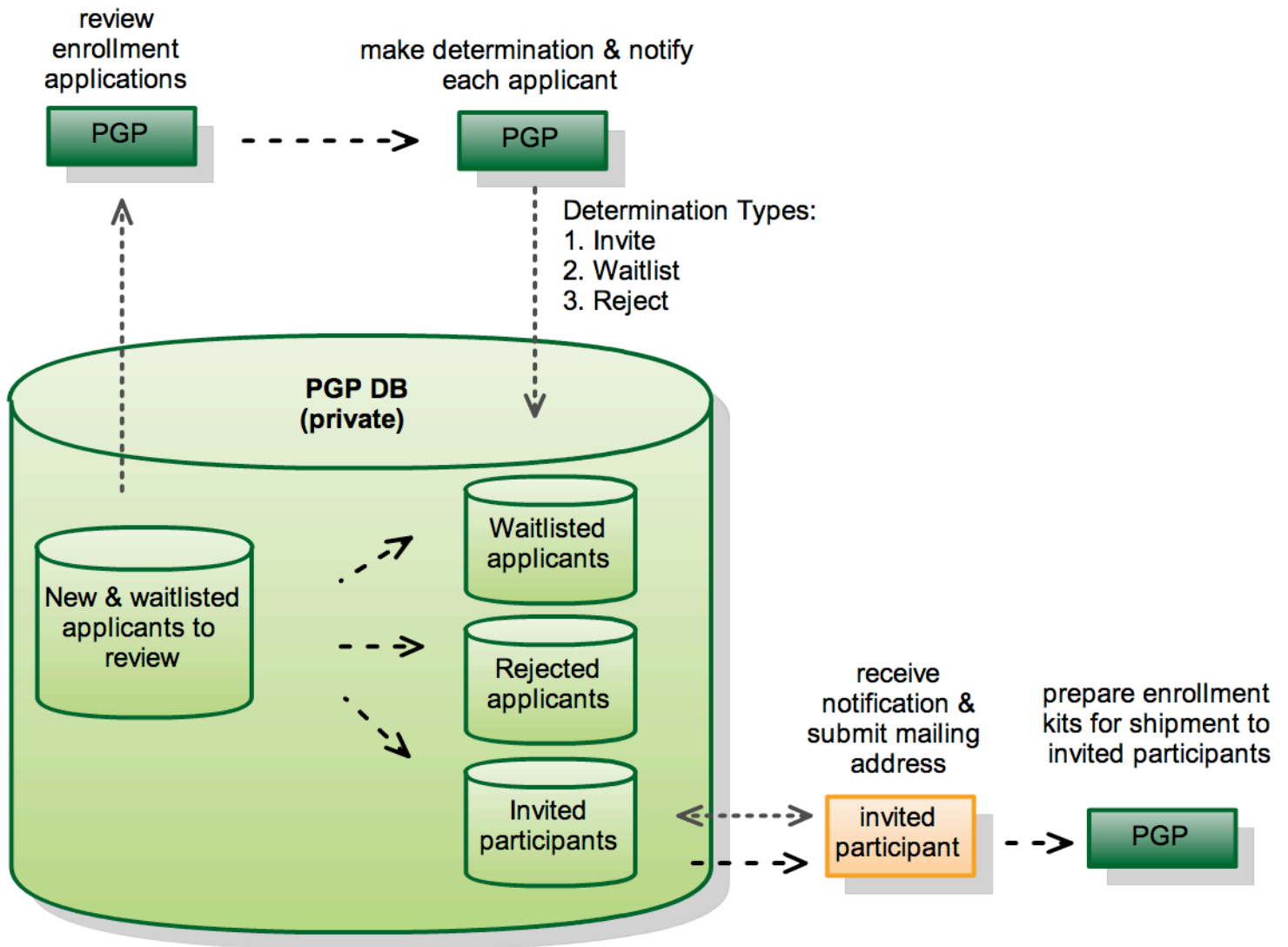




# PRE-ENROLLMENT PROCEDURES



## REVIEW APPLICATIONS FOR ENROLLMENT



### Legend

time - - - - - ➤

data ..... ➤

# PRE-ENROLLMENT TISSUE COLLECTION

## Participant Home

ship enrollment  
kit to invited  
participants

PGP

receive  
enrollment  
kit by mail

invited  
participant

collect  
saliva  
and/or hair  
specimens

invited  
participant

ship  
specimens  
to PGP

invited  
participant

receive saliva  
and/or hair  
specimens

PGP

deliver  
specimens

PGP

Biobank  
(private)

PGP DB  
(private)

make  
contribution

enrollee

receive  
notification

enrollee

enrollees

schedule appt

visit req  
participant

visit req  
participant

visit req  
participants

waitlisted  
participant

waitlisted  
invited  
participants

Invited  
participants

destroy  
tissue/data

PGP

rejected  
participant

rejected  
participants

make enrollment  
determination &  
notify participant

PGP

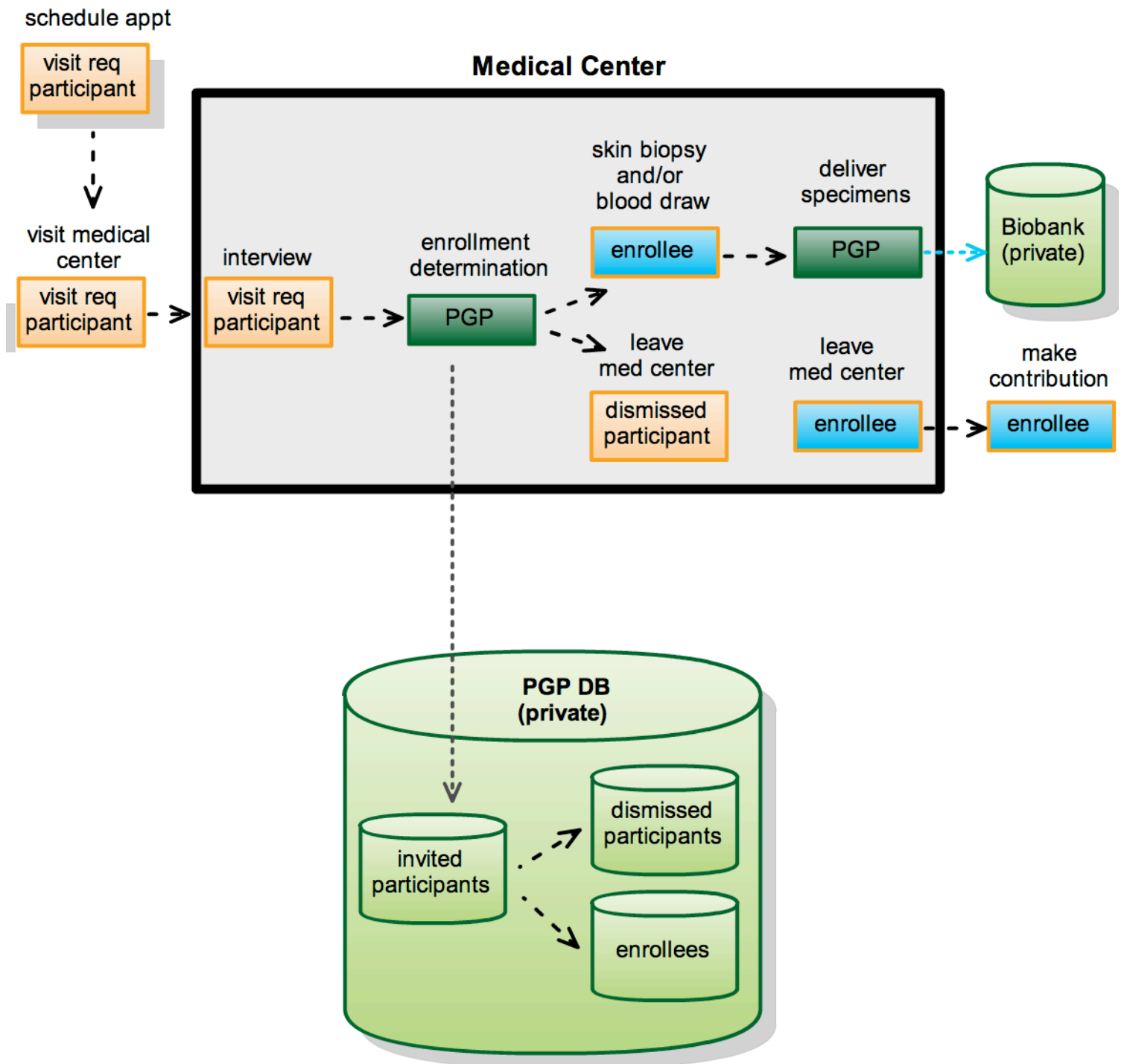
Determination Types:

1. Enroll
2. Visit request
3. Waitlist
4. Reject

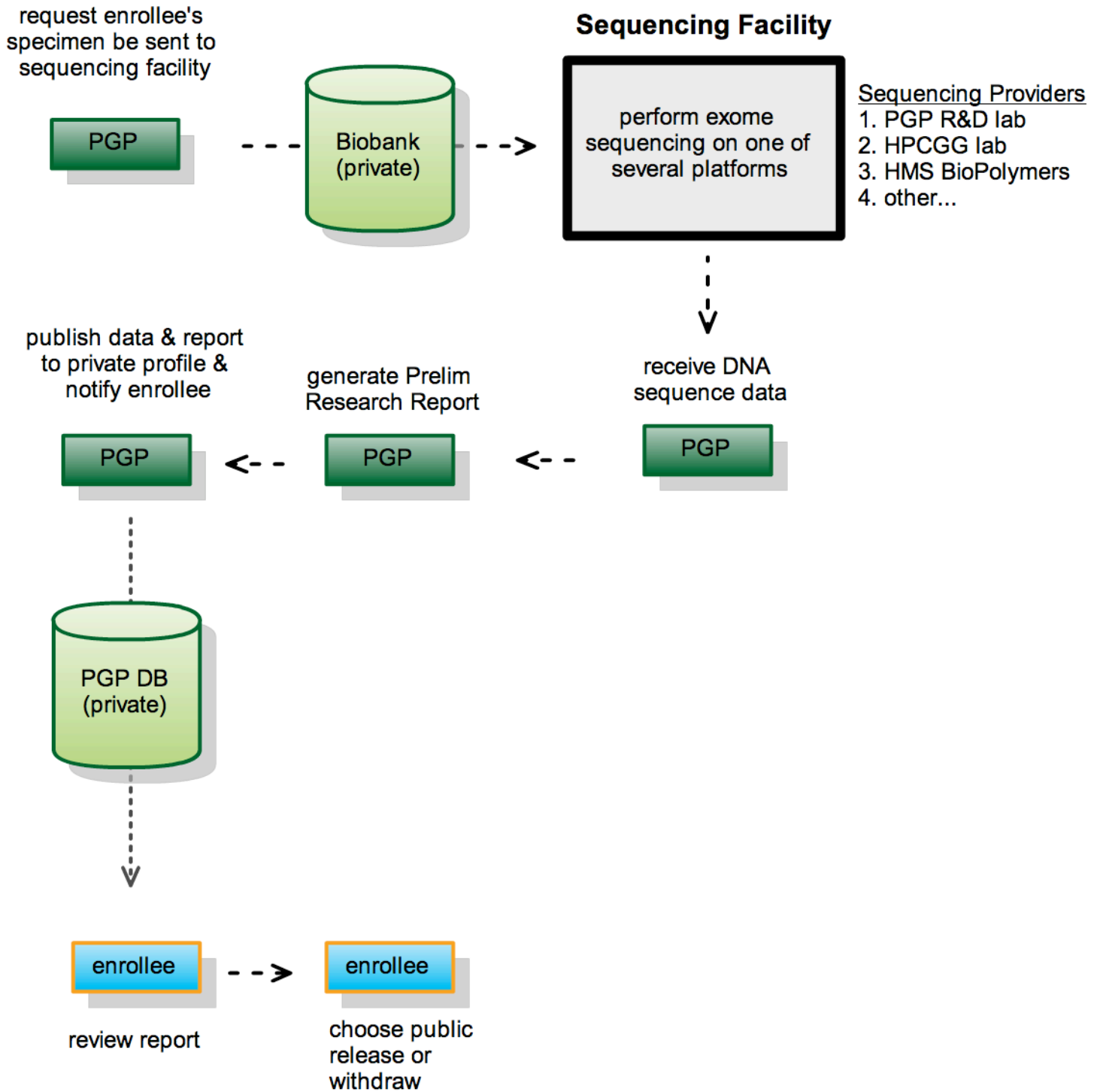
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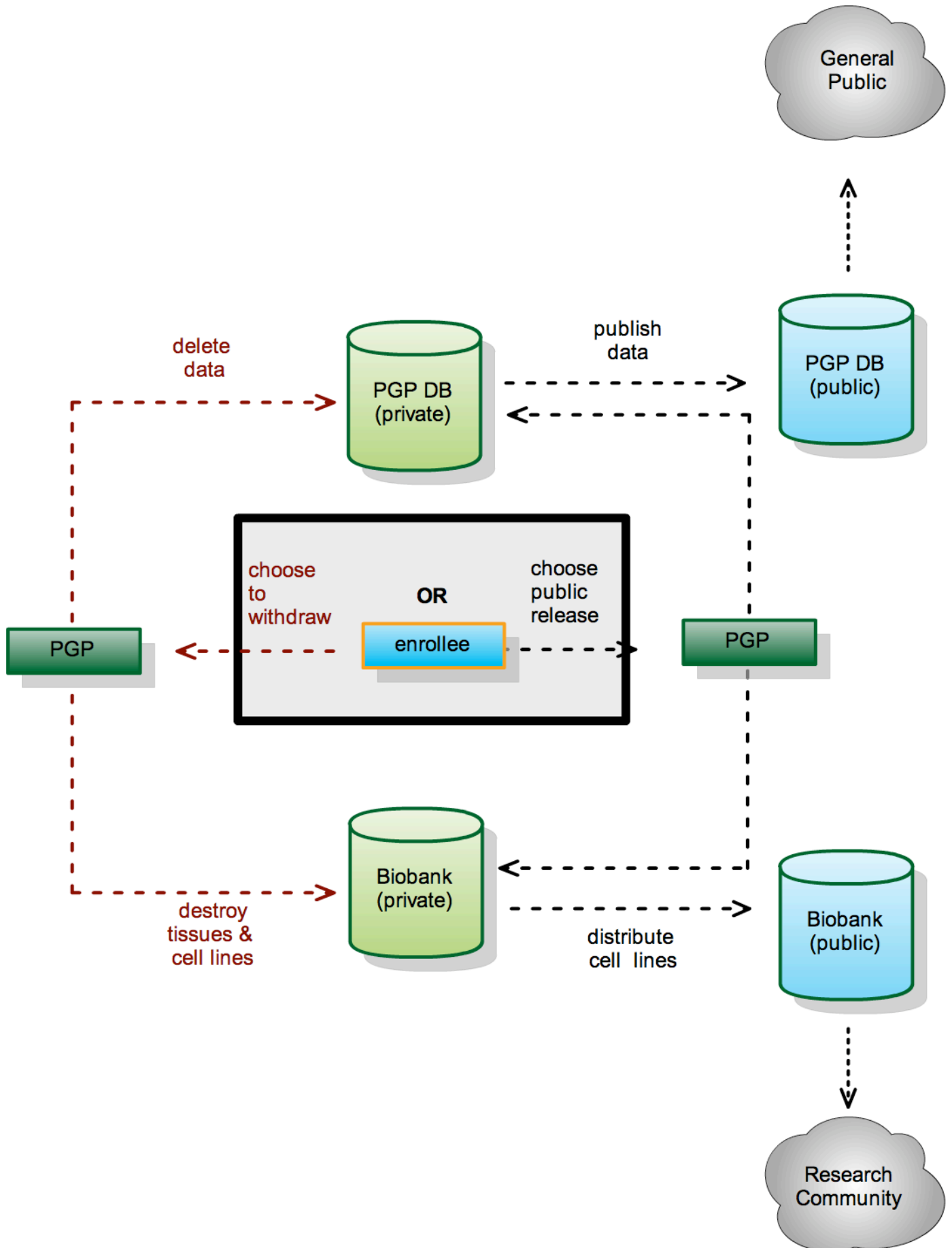
# MEDICAL CENTER PROCEDURES



# DNA SEQUENCING & REPORT GENERATION



## PUBLIC RELEASE OR WITHDRAW



# ONGOING PARTICIPATION

## 1. Manage Public Profile

Info mgmt activities might include:

- (a) updating PHR, adding data or data feeds from 3rd parties
- (b) reviewing journal articles published or other research by researchers with access to their data, tissues, or cell lines
- (c) reviewing the names of individuals who have accessed cell lines derived from their submitted tissues
- (d) responding to inquiries from PGP staff or affiliates

## 2. Additional Traits

Enrollees will publish additional personal and trait information to public profiles:




- (a) Traits may be requested by the PGP and submitted voluntarily by enrollees.
- (b) Enrollees collect traits at 3rd party sites and add this data or links to data feeds to profile.

## 3. Safety Questionnaires

Every 3 months the PGP will request that all enrollees respond to a safety questionnaire.

## 4. Additional Tissue Collection

Additional tissue specimens may be requested by the PGP and submitted voluntarily by enrollees.

**Public Profile**   

**Baseline Traits**  
traits.ccr (updated today)

**Genetic Data**  
dna.txt [PGP]

**Additional Biological Data**  
23andMe.txt  
navigenics.txt  
counsyl.txt  
coriell.txt

**Additional Traits**  
cognitive [Counsyl]  
chronic pain [ReliefInSite]  
travel [Dopplr]  
dietary habits [Indivo]  
family history [PGP]  
exercise [Nike]  
education [LinkedIn]  
etc...

**Tissues**  
fibroblasts [Coriell]  
iPS [CDI]  
  
[more...]

### PHR Providers



INDIVOH<sup>HEALTH</sup><sup>TM</sup>



### Trait Mgmt Providers



### BioBanks



## Consent Form

Protocol Title: <b>Eligibility Screening for the Personal Genome Project</b>
Principal Investigator: <b>George M. Church, Ph.D.</b>
Site-Responsible Investigator's Institution: <b>Harvard Medical School</b>
Co-Investigators & Study Staff: <b>Joseph Thakuria, MD</b>
Description of Volunteer Population: <b>Volunteers knowledgeable of the benefits and risks of personal genome sequencing and relevant concepts from genetics and human subjects research. We are seeking a diverse range of volunteers, male and female, from as varied a set of genetic and environmental backgrounds as possible.</b>

### I. PURPOSE

This Eligibility Screening for the Personal Genome Project (this "Eligibility Screening") is intended to help determine whether you are a candidate for enrollment in a public and open-ended research study such as the Personal Genome Project (the "PGP"). If you successfully complete this Eligibility Screening you may be invited to enroll in the PGP.

The main scientific goal of the PGP is to explore ways to connect human genetic information with human trait information (i.e., human DNA sequence, medical information, tissue samples and physical traits) so that such data may be used for hypothesis-generating research and other scientific, clinical and commercial development efforts worldwide. Additional goals include (i) the determination of the risks of studies such as the PGP; (ii) developing a fully consented and public dataset to aid in the development of computational tools and user interfaces for scientists, clinicians and individuals; and (iii) the education of participants and the general public about the potential benefits, risks, and uncertainties posed by the widespread availability of genetic information. The PGP also seeks to develop a model system to allow a meeting place for experts on health care, molecular biology, genetic counseling, public health, law, education, and research. We hope that the PGP's proposed specific datasets will help extend such discussions to planned case studies. We also hope, through the PGP, to discover what individuals, clinicians, and researchers might want or not want in such datasets, and why.

If you successfully complete this Eligibility Screening and are then subsequently enrolled in the PGP, your genetic and trait information will be made available on a publicly accessible website and database, as described in the separate PGP consent form. You will be asked to review the PGP consent form as part of your participation in this Eligibility Screening. In order to complete this Eligibility Screening and to be considered for enrollment in the PGP, you are first required to complete certain eligibility screening procedures online, including the eligibility questionnaire and entrance exam, and to review the separate PGP consent form. This Eligibility Screening is intended to help determine whether you are a candidate for enrollment in the PGP.



## **II. WHAT IS INFORMED CONSENT**

Informed consent means you understand the procedures, risks, possible benefits, and alternatives before you voluntarily agree to participate in a research study. Before you elect to participate, you need to understand if or how this Eligibility Screening may affect you and your family. This Eligibility Screening consent form, along with other documents available on the PGP's website (<http://www.personalgenomes.org/>), is intended to help you make an informed decision about your participation in this Eligibility Screening. Should you successfully complete this Eligibility Screening you will need to complete a separate informed consent form before you may be invited to participate in the PGP. The PGP website will be revised as needed, possibly on a frequent basis, and you should check the website regularly to obtain the most current information about this Eligibility Screening and the PGP.

## **III. DURATION**

- 1.1. The eligibility questionnaire will take approximately 5-15 minutes.
- 1.2. The entrance exam will take approximately 30-90 minutes, but may take longer depending on your familiarity with genetics and other concepts relevant to being a participant in the PGP.
- 1.3. Reading and reviewing the PGP consent form will take approximately 15-20 minutes, but may take longer depending on your familiarity with genetics and other concepts relevant to being a participant in the PGP.

## **IV. ELIGIBILITY SCREENING PROCEDURES**

### **1. ELIGIBILITY QUESTIONNAIRE**

- 1.1. You will be asked to respond to 5-30 questions online and provide the following personal information: name, year of birth, zip code, and email address. The full list of personal information required may be found on the PGP website. [Link]

### **2. ENTRANCE EXAM**

- 2.1. You will be asked to respond to 15-45 questions online.
- 2.2. Correct responses to all exam questions are required to successfully complete this Eligibility Screening and to be considered for enrollment in the PGP. The entrance exam may be taken as many times as necessary to achieve correct responses to all questions.

### **3. REVIEW OF PGP CONSENT FORM**

- 3.1. You will be asked to review the consent form for enrollment in the PGP. You should carefully read and understand the procedures, risks and discomforts of participation in the PGP.
- 3.2. A copy of the PGP consent form is available on the PGP website. [Link]

### **4. COMPLETION AND SUBMISSION OF ELIGIBILITY SCREENING**

- 4.1. After you have completed the eligibility questionnaire, the entrance exam and any other required eligibility screening procedures, and reviewed the PGP consent

- form, you will be given the option to submit the results of your Eligibility Screening to the PGP for review.
- 4.2. If you choose not to submit the results of your Eligibility Screening no determination will be made by PGP about your eligibility status and your participation in this Eligibility Screening will be terminated. You may choose to participate in this Eligibility Screening again at a later date.
  - 4.3. If you choose to submit the results of your Eligibility Screening your information will be transmitted to the PGP. Your information will be reviewed by the PGP and you will subsequently be notified by the PGP that you are either: (1) eligible to continue, (2) waitlisted, or (3) rejected.
  - 4.4. If you are waitlisted, the PGP may attempt to notify you if your eligibility status changes.
  - 4.5. Regardless of whether or not you choose to submit the results of your Eligibility Screening, and regardless of whether the PGP determines that you are eligible to continue, you will not be compensated, including for any time lost, for your participation in this Eligibility Screening.

## **V. CONFIDENTIALITY**

- 1.1. If you choose to submit the results of your Eligibility Screening, as described above, your name or identity will be linked to your responses and shared with PGP staff. The PGP will take reasonable precautions to ensure that your name and your Eligibility Screening responses and results are kept confidential.

## **VI. RISKS AND DISCOMFORTS**

- 1.1. There are no known risks or discomforts associated with your participation in this Eligibility Screening.
- 1.2. There are risks and discomforts associated with enrolling in the PGP, as described in the PGP consent form and on the PGP website. We strongly encourage you to discuss your interest in enrolling in the PGP study, and the potential risks of doing so, with your immediate family members.

## **VII. BENEFITS**

- 1.1. There are no proven benefits to you from your participation in this Eligibility Screening.

## **VIII. INTELLECTUAL PROPERTY**

- 1.1. Your personal information will not be sold by the PGP to any person, institution, or company for financial gain or commercial profit.
- 1.2. Neither you nor your heirs will gain financially from any discoveries, whether or not of a commercial nature, made using the information that you provide.

## **IX. REFUSAL OR WITHDRAWAL OF PARTICIPATION**

- 1.1. Participation in this Eligibility Screening is voluntary. You do not have to participate in this Eligibility Screening.
- 1.2. You may withdraw your participation from this Eligibility Screening, and request that the PGP delete any personal data that you may have submitted, at any time, as described in this consent form.
- 1.3. The PGP may decide, at its sole discretion, to end your participation in this Eligibility Screening at any time.
- 1.4. If you choose to submit the results of your Eligibility Screening, regardless of whether you are (1) eligible to continue, (2) waitlisted or (3) rejected, the PGP may retain certain information about you, including your name and the date of submission of your Eligibility Screening results. The PGP will delete all other data supplied by you within 6 months of your withdrawal or rejection from this Eligibility Screening.

## **X. ALTERNATIVES**

- 1.1. The alternative is not to participate in this Eligibility Screening.
- 1.2. If you choose not to participate, your medical treatment at your hospital and other medical care providers will be unaffected.

## **XI. RESEARCH-RELATED CONTACT INFORMATION:**

- 1.1. If you have any questions or concerns about this Eligibility Screening, or if you suffer a research related injury, you may contact the Principal Investigator: George Church, PhD, at (617) 432-7562 or [screening@personalgenomes.org](mailto:screening@personalgenomes.org)
- 1.2. If you wish to discuss your rights as a participant in a research study, or if you feel under any pressure to enroll in this Eligibility Screening you may contact: Carolyn Connelly, PhD, the Director of the Office for Research Subject Protection at Harvard Medical School (617) 432-0651 or [carolyn\\_connelly@hms.harvard.edu](mailto:carolyn_connelly@hms.harvard.edu)

## **XII. SIGNATURE**

I have read this entire form and I understand it completely. I confirm that I understand the purpose of the research, the study procedures, possible risks and discomforts, potential benefits that I may experience, and alternatives to my participation in this Eligibility Screening. All of my questions have been answered to my complete satisfaction.

I understand that by typing my name and email address in the box below I am signing this form and am thereby providing informed consent for this Eligibility Screening.

Failure to accurately represent your full name on this informed consent will invalidate your eligibility for enrollment.

Once you submit this consent form, you will not be able to change the name associated with your account. We recommend that you enter your name as it appears on government issued identification, such as a valid driver's license.

<b>First name</b>	<b>MI</b>	<b>Last name</b>
<input type="text"/>	<input type="text"/>	<input type="text"/>

(optional)

**Email**

**Submit**

# Consent Form

<b>Protocol Title: Personal Genome Project</b>
<b>Principal Investigator: George M. Church, Ph.D.</b>
<b>Site-Responsible Investigator's Institution: Harvard Medical School</b>
<b>Co-Investigators &amp; Study Staff: Joseph Thakuria, MD</b>
<b>Description of Volunteer Population:</b> <b>Volunteers knowledgeable of the benefits and risks of personal genome sequencing and relevant concepts from genetics and human subjects research. We are seeking a diverse range of volunteers, male and female, from as varied a set of genetic and environmental backgrounds as possible.</b>

## What is Informed Consent?

Informed consent means you understand the procedures, risks, possible benefits, and alternatives before you voluntarily agree to participate in a research study. Before you elect to participate, you need to understand if or how this study may affect you and your family. This form, along with other study documents available on the project website (<http://www.personalgenomes.org/>), is intended to help you make an informed decision about your participation in this study. The PGP website will be revised as needed, possibly on a frequent basis, and participants and prospective participants should check the website regularly to obtain the most current information about this study.

## Why have you been asked to participate in this research study?

You have been invited to participate because you are an individual 21 years of age or older and your performance on the entrance exam indicates that you are able to give informed consent for this public and open-ended study. This study (the "Personal Genome Project," the "PGP" or the "study") is being conducted by researchers at Harvard Medical School.

## I. PURPOSE

The main scientific goal of this study is to explore ways to connect human genetic information with human trait information (i.e., human DNA sequence, medical information, tissue samples and physical traits) so that such data may be used for hypothesis-generating research and other scientific, clinical and commercial development efforts worldwide. Additional goals include (i) the determination of the risks of studies such as the PGP; (ii) developing a fully consented and public dataset to aid in the development of computational tools and user interfaces for scientists, clinicians and individuals; and (iii) the education of participants and the general public about the potential benefits, risks, and uncertainties posed by the widespread availability of genetic information. The PGP also seeks to develop a model system to allow a meeting place for experts on health care, molecular biology, genetic counseling, public health, law, education, and research. We hope that the PGP's proposed specific datasets will help extend such discussions to planned case studies. We also hope, through the PGP, to discover what individuals, clinicians, and researchers might want or not want in such datasets, and why.

## **II. OVERVIEW**

The PGP will collect from each participant tissue samples and personal and trait information submitted online. If you are enrolled in the PGP research study, your genetic and trait information will be made available through a publicly accessible website and database, according to the procedures described below.

Participants will receive only research data from the PGP, and any data or other information that you receive due to your participation, including DNA sequence data, is not intended to substitute in any way for professional medical advice, diagnosis or treatment, and it may not be used by you for any medical or clinical purpose unless the relevant sequence or other data, including any interpretations or findings presented in your Preliminary Research Report (described below) are first confirmed at the direction of and in consultation with a licensed healthcare professional.

We expect to enroll 100,000 participants in this project, although the pace at which we expand the project to large numbers of enrollees is unknown.

Participation in this study is voluntary. You do not have to participate in the PGP. You may withdraw your participation from this study at any time, as more fully described in this consent form.

## **III. DURATION OF THE PROJECT AND YOUR PARTICIPATION**

You will be deemed to be a participant of the PGP from the time that you sign this consent form and submit it to the PGP. Signing and submitting this consent form does not guarantee your full enrollment in the PGP. Although signing the consent form means that you are a participant in the PGP, your enrollment in the study is contingent upon the availability of resources, your completion of certain pre-enrollment and enrollment procedures requested by the PGP, and other relevant considerations as may be determined by the PGP at its sole discretion and communicated to you.

The duration of your participation is intended to be 25 years from the time of your enrollment, however your participation is entirely voluntary and you may choose to opt-out of the PGP at any time.

Sample analysis and data processing may continue for up to an additional 25 years following completion of your participation in the PGP, unless you choose to withdraw or are removed from the PGP. Cell lines and the public version of your genetic, trait, and other data may be maintained for up to 50 years (or longer, if approval for the continuation of the study is sought by the PGP and granted), unless you request removal of your data and/or cell lines in writing before that time, in which case your data and/or cell lines will be removed in accordance with this consent form.

## **IV. PRE-ENROLLMENT PROCEDURES**

### **1. COLLECTION OF BASELINE TRAIT DATA**

- 1.1. To be considered for enrollment in the PGP, you are required to electronically submit baseline trait data about yourself, including: date of birth, medications, allergies, vaccines, personal medical history, race/ethnicity/ancestry, and vital signs (e.g. height, weight, blood pressure). The full list of personal information required for enrollment may be found on the project website.
- 1.2. Submitting this information will take an estimated 1-3 hours, and that time may be lost if you are not selected for enrollment. You will not be compensated for any lost time.
- 1.3. Additional personal and trait information may also be requested or required by the PGP, such as a facial photograph, family medical history, or lifestyle traits in order to be considered for enrollment.

### **2. PLEDGE**

- 2.1. You will be asked to make a financial pledge to the PGP and to specify the amount of the pledge in the event that you are invited to enroll in this project.
- 2.2. Participants will be enrolled without regard to whether a financial pledge is made or the amount of the pledge, but contributions are encouraged and will be used to subsidize the costs of research and related activities.
- 2.3. Your enrollment is not guaranteed and will depend, in part, on the availability of funds.

### **3. IDENTITY VERIFICATION**

- 3.1. The PGP will ask you to provide your mailing address and may ask you to respond to up to 20 questions about your identity based on information available in public data records.
- 3.2. If we are unable to verify your identity, we may request that you send additional information to the PGP by mail, fax, and/or online. If we are still unable to verify your identity, you will be notified that (1) you must visit a designated medical center to enroll or (2) your enrollment is rejected.

### **4. MONOZYGOTIC TWIN**

- 4.1. If you have any living siblings who are your identical (monozygotic) twin, such sibling(s) will need to provide consent for your participation in this research study before the PGP will consider you for enrollment.

Do you have a living identical (monozygotic) twin? ☐ Yes ☐ No

### **5. APPLICATION FOR ENROLLMENT**

- 5.1. After submitting your trait information, specifying your pledge, completing your identity verification and completing any other applicable pre-enrollment activities, your application for enrollment will be considered by the PGP.

- 5.2. You will then be notified that you are either: (1) selected for the next stage of the enrollment process (2) waitlisted or (3) rejected.

## **6. TISSUE COLLECTION AT HOME**

- 6.1. If you are invited to continue the enrollment process, you will be asked to supply a mailing address where pre-enrollment and enrollment materials will be sent, including a saliva collection kit and/or a hair collection kit that may be self-administered as directed by the PGP.
- 6.2. The saliva sample collection kit may be self-administered and requires you to provide 2-4 milliliters of your saliva. The sample will be used for the production of DNA sequence data and other data, as more fully described below.
- 6.3. The hair sample collection kit may be self-administered and requires 1-5 hairs to be plucked from your body. The skin cells (i.e. keratinocytes) attached to the hair sample will be used to create a living tissue sample known as a cell line, as more fully described below. Cell lines provide a renewable supply of your cells and DNA. The PGP may attempt to generate cell lines from your hair sample once it is received, but will not distribute either your cell line or data derived from your cell line unless and until you have been enrolled in the PGP. The PGP is unable to make any guarantees about the success of cell line creation.
- 6.4. To be eligible for enrollment in the PGP, you must submit a saliva sample and/or a hair sample, as directed by the PGP in the pre-enrollment materials sent to you at the address you provide. Samples must be collected and returned as instructed. The PGP will provide sample collection materials, including instructions and mailing packages.

## **V. ENROLLMENT PROCEDURES**

### **1. ENROLLMENT**

- 1.1. After your tissue specimens are received, you will be notified that you are either: (1) enrolled, (2) waitlisted, (3) rejected, or (4) requested to visit a medical center to complete enrollment.
- 1.2. If you are notified that a visit to medical center is needed to complete your enrollment, you will be asked to schedule an appointment at a designated medical center.
- a. The PGP will also notify you at this time whether tissue specimens will be collected during your visit. You may request to be enrolled without undergoing a skin biopsy procedure by marking NO below.

Willing to undergo skin biopsy procedure? ☐ Yes ☐ No

- b. Please review the locations of participating medical centers because they may be located a long distance from your home and the PGP will not reimburse you for any costs you may incur traveling to or from the medical center. A list of participating medical centers may be found on the PGP website.
- c. Costs that you might incur the day of your visit to a medical center include, but are not limited to, transportation costs to and from the medical center (tolls, gas,



- etc.) and the loss of personal time. You will not be compensated for these or for any other costs associated with your visit.
- d. The day of your visit to a medical center, you will meet with one or more PGP staff members who will verify your identity and consent, confirm your familiarity with the study protocols, and/or review and confirm your baseline trait data. The interview will take approximately 1 hour.
  - e. Following the conclusion of the interview, you will be notified that you are either: (1) enrolled, (2) waitlisted, or (3) rejected.
- 1.3. Following the conclusion of the interview and if you are enrolled, the PGP will notify you that either (i) a skin biopsy procedure and/or (ii) a blood draw will be performed at the medical center by trained professionals appointed by the PGP, or (iii) that no tissue samples will be collected at all. If you have not indicated your willingness to undergo a skin biopsy procedure above you will not be requested to do so as part of your enrollment in the PGP.
- a. A skin punch biopsy (1/8 inch block, 3 mm diameter) is collected from the underside of the upper arm or hip and requires local anesthesia.
  - b. A blood sample is collected from your upper arm and requires a minimum of 5ml of blood.
  - c. The skin cells (i.e., fibroblasts) or blood (i.e., lymphoblasts) that you provide will be used to create a living tissue sample known as a cell line. Cell lines provide a renewable supply of your cells and DNA.
- 1.4. If you are rejected for enrollment, within 6 months the PGP will permanently delete the trait data that you submitted and destroy any tissue samples you submitted.

## **2. CONTRIBUTION**

- 2.1. After you are enrolled in the project, your financial contribution may be paid by check or online via a secure credit card transaction.
- 2.2. Analysis of your tissue samples may be delayed and your participation in the PGP otherwise limited until your contribution is received according to your pledge. If at any point you should choose to withdraw from the PGP or the PGP should decide to terminate your participation in the project your financial contribution will not be refunded.
- 2.3. Contributions will be made to the PGP's implementing and fundraising organization, PersonalGenomes.org, a North Carolina charitable organization qualified under Section 501(c)(3) of the Internal Revenue Code. Contributions to PersonalGenomes.org are tax deductible to the extent permitted by law.

## **3. DNA ANALYSIS**

- 3.1. DNA analysis and other research will be performed on the tissue samples collected from you and/or the cell lines created from such samples. The nature and extent of the analysis and research will be determined by the PGP at its sole discretion.
- 3.2. The PGP is unable to make any guarantees about the accuracy or completeness of any DNA analysis or the turn around time for any of these activities.

#### **4. RETURN AND PUBLIC RELEASE OF RESEARCH DATA**

- 4.1. Upon completion of certain DNA analysis conducted by the PGP, your DNA sequence data will be made available to you via a password protected area on the PGP website. This information is for research purposes only and may not be used by you for any medical or clinical purpose unless the relevant sequence or other data, including any interpretations or findings presented in your Preliminary Research Report (described below), are first confirmed at the direction of and in consultation with a licensed healthcare professional. Examples of DNA sequence data similar to what you will receive as an enrollee may be found on the project website.
- 4.2. In addition to your DNA sequence data, the PGP will provide you with a preliminary research report (the "Preliminary Research Report" or the "Report") intended to help you make a more informed decision about whether or not to release your DNA sequence data to the PGP's public website and database. This Report will contain a non-comprehensive list of genetic variants present in your DNA sequence data that are currently believed by the PGP to be of significance in clinical practice, as well as any additional information, resources or interpretation that the PGP may deem appropriate to provide to you as part of your Report. In preparing your Report, the PGP may review your DNA sequence data in conjunction with the trait data and other information that you have submitted to the PGP.
  - a. The Preliminary Research Report represents only preliminary research findings and neither the accuracy nor the completeness of the Report is guaranteed. The databases, knowledge and tools used to generate the interpretations contained in the Report are not comprehensive and are also subject to change. Only one Preliminary Research Report will be provided to you. The PGP will not be responsible for updating or supplementing the Report.
  - b. The Preliminary Research Report is not intended to substitute in any way for professional medical advice, diagnosis or treatment and may not be used by you for any medical or clinical purpose unless the relevant sequence or other data, including any interpretations or findings presented in your Preliminary Research Report, are first confirmed at the direction of and in consultation with a licensed healthcare professional
  - c. Examples of other Reports similar to what you may receive as an enrollee are available on the project website.
- 4.3. After receiving your DNA sequence data and your Preliminary Research Report, you will be able to choose whether to (i) make your DNA sequence data available, along with your trait information and any other information that you have voluntarily submitted to the PGP, on the PGP's public website and database or (ii) withdraw from the PGP.
- 4.4. Following the initial receipt of your DNA sequence data and your Preliminary Research Report the PGP may, at its sole discretion, choose to re-process and/or supplement your DNA sequence data at any time thereafter, consistent with the provisions of this consent form, as new data, information or techniques, whether relating to you or to the PGP generally, become available. Should this occur, and if after reviewing your Report you previously consented to the release of your DNA sequence data, your re-processed and/or supplemented DNA sequence data may be released, at the PGP's discretion, directly to the PGP's public website and database without your prior receipt or review of such re-processed and/or supplemented DNA sequence data. You will not be provided an

additional or revised Preliminary Research Report or other analysis of your DNA sequence data and you will not be given an opportunity to choose whether or not to release or publicize your re-processed and/or supplemented DNA sequence data.

- 4.5. By signing this consent form, you hereby agree that, should you review your Preliminary Research Report and authorize the PGP to proceed with the public release of your DNA sequence data and other personal information, any research data made available to you by the PGP in any form (including your DNA sequence data, whether or not re-processed and/or supplemented, and your Preliminary Research Report) along with your trait information and any other information voluntarily submitted by you to the PGP, may be made publicly available by the PGP, without legal restriction and without your further consent, through the PGP's publicly accessible website and database, or in such other formats and/or locations as the PGP may designate, and you hereby acknowledge the risks associated with the receipt, return and/or public release of such data and information.**

## **5. ESTABLISHMENT, DISTRIBUTION AND ANALYSIS OF CELL LINES**

- 5.1. Tissue samples submitted to the PGP will be used by the PGP for a range of research purposes, including creation of cell lines, transformation into adult stem cells (i.e., induced pluripotent stem cells or iPS cells, which are cells with the ability to divide for indefinite periods and to give rise to specialized cells), the study of biological characteristics, DNA, RNA (gene expression), physical traits, and/or the presence and characteristics of micro-organisms and viruses in the specimen samples.
- 5.2. If you consent to participate in this study, the PGP will, at its discretion, create or attempt to create cell lines from your tissue samples. Cell lines provide a renewable supply of your cells and DNA.
- 5.3. Cell lines will be deposited in and distributed by the Coriell NIGMS repository and/or other biorepositories, as determined by the PGP.
- 5.4. The PGP is unable to make any guarantees about the success of cell line creation, or turn around time for any of these activities.
- 5.5. At the sole discretion of the PGP, cell lines may be made available by the PGP to third parties under agreements approved and entered into by the PGP or its affiliate, PersonalGenomes.org, without your additional notification or consent. These agreements may permit your cell lines to be used for research, clinical or therapeutic, commercial or other purposes, including involving humans and/or animals. Other than for purposes of cost recovery, neither the PGP nor PersonalGenomes.org will license or otherwise make participant cell lines available to any third party for the financial gain or commercial profit of the PGP or PersonalGenomes.org.
- 5.6. Unless otherwise determined by the PGP, the results of any analysis, development or other work performed by third parties with access to your tissues or cell lines will not be returned to you by the PGP. However, because such results may be made publicly available, and may be identified as deriving from your tissues or cell lines, you may be made aware, even without your consent, of the results of such activities.
- 5.7. At the PGP's sole discretion, the PGP may return to you certain results deriving from your tissues or cell lines and request that you voluntarily choose whether to make the

results available, along with your genetic and trait data, on the public website and database.

- 5.8. By signing this consent form, you agree that the cell lines created from your tissues may be made available by the PGP without your notification or further consent for the uses and upon the conditions more fully described above and throughout this consent form, and you hereby acknowledge the risks associated with such creation, distribution and use of your cell lines.**

## **VI. ONGOING PARTICIPATION FOLLOWING ENROLLMENT**

### **1. RECONTACT**

- 1.1. Other than the Safety Questionnaires described below, you are under no obligation to receive study notices or participate after providing the tissue samples and exchange of the information outlined above. If you choose YES to the question below, you may be contacted by the PGP at a future date and asked if you would like to voluntarily submit additional tissue specimens and/or trait or other information and/or participate in research studies or other activities coordinated by the PGP. You may change your choice on this option at any time by notifying the PGP in writing.

Willing to be recontacted? ☐ Yes ☐ No

### **2. ADDITIONAL TRAIT COLLECTION**

- 2.1. Additional personal and trait information may be requested by the PGP and submitted by you on a voluntary basis. Any additional information disclosed by you may be made publicly available by the PGP via the public website and database without your additional consent.

### **3. ADDITIONAL TISSUE SPECIMEN COLLECTION**

- 3.1. Additional tissue samples, such as buccal swabs, skin swabs, hair samples, saliva samples, urine samples and/or fecal samples, may be requested by the PGP and submitted by you on a voluntary basis. Any additional samples submitted by you may be analyzed or otherwise incorporated into the study, and the results may be made publicly available by the PGP via the public website and database.

### **4. ADDITIONAL RETURN AND RELEASE OF RESEARCH DATA**

- 4.1. At the PGP's sole discretion, the PGP may return to you certain research results or analysis generated by the PGP or by its affiliates and deriving from your participation in the project, and request that you voluntarily choose whether or not to make such results available, along with your other information already on the public website and database.

## **5. SAFETY QUESTIONNAIRES**

5.1. Every 3 months the PGP will circulate a “Safety Questionnaire” to all enrollees and request that each enrollee answer the following questions:

- a. What negative and/or positive events have happened to you and/or your relatives or acquaintances due to your participation in the PGP?
- b. What are the reactions or responses of your relatives and acquaintances to the posting of your genetic, trait and other data?
- c. Please report incidents of being contacted by acquaintances or by strangers (including researchers, health care providers or members of the media) regarding your data being posted online.
- d. In what ways has this study positively or negatively influenced your interactions with your medical care providers or your receipt of or access to health care services?
- e. Has your involvement in this study triggered any medical work up, investigations, or treatments that would not otherwise have been done? If you answer yes, please describe (a) the specific medical intervention and (b) the findings or consequences of the medical intervention with regard to your health. Medical work up that would have been performed had you not participated in this study, whether due to symptoms, a personal or family medical history, routine screening or any other reason, should not be included.

5.2. It will be requested that answers to the Safety Questionnaire or a "no change" reply be returned to the PGP within 1 week of receipt.

5.3. Additionally, at 5 year intervals and at the end of participation in the study, enrollees will be requested to write their thoughts about the PGP overall, including whether this consent form adequately described the procedures and risks associated with your participation.

5.4. We request that enrollees report immediately to the PGP any material differences between their experiences as an enrollee and the contents of this consent form or other study documents.

5.5. The Safety Questionnaire, including the number of questions and the frequency of circulation to enrollees, may be modified by the PGP from time to time.

## **VII. RISKS AND DISCOMFORTS**

You are strongly encouraged to discuss this study and the potential risks, as outlined below and on the project website, with your immediate family members as well as with your physician and/or other qualified health care providers. You are also encouraged to discuss with the Principal Investigator directly any additional concerns that you may have regarding the risks to you of participating in this study. You are advised that the PGP website will be revised, possibly on a frequent basis, and participants and prospective participants should check the website regularly to obtain the most current information regarding potential risks and discomforts as they become apparent.

- 1.1. The risks of public disclosure of your genetic and trait information could affect your employment, insurance and financial well-being and social interactions for you and your

immediate family. The following is a non-comprehensive list of hypothetical scenarios that could pose risks for you and/or your family:

- a. Data that you provide (such as facial images, other trait data or DNA sequence data) may be used to identify you, resulting in higher than normal levels of contacts from the press and other members of the public motivated by positive or negative feelings about the study. This could mean a significant loss of privacy and personal time.
  - b. Anyone with sufficient knowledge and resources could take your DNA sequence data and/or posted trait information and use that data, with or without modification, to (1) infer paternity or other features of your genealogy, (2) claim statistical evidence that could affect your employment, insurance or ability to obtain financial services, (3) claim relatedness to criminals or incriminate relatives, (4) make synthetic DNA and plant it at a crime scene, or otherwise use it to falsely identify you, or (5) reveal the possibility of a disease or unknown propensity for a disease.
  - c. Whether or not it is lawful to do so, you could be subject to actual or attempted employment, insurance, financial or other forms of discrimination or negative treatment on the basis of the public disclosure of your genetic and trait information by the PGP or by a third party.
  - d. The distribution of your cell lines could result in the creation and further distribution by a third party of additional cell lines, organs or tissues containing your DNA for research, commercial, clinical or other uses, including certain forms of assisted reproduction, some of which you may find objectionable or upsetting. For instance, if scientific technology were to improve, it may one day be possible for a third party to use, without authorization by you or by the PGP, cell lines or biological materials derived from your cell lines for novel or unexpected reproductive or other purposes, including cloning. You may be made aware, without your consent, of the results of such research, commercial, clinical or other uses, whether or not authorized, of your cell lines.
  - e. If you have previously made available or intend to make available genetic information in a confidential setting, for example in another research study or in a clinical trial, the data that you provide as part of the PGP may be used, on its own or in combination with your previously shared data, to identify you as a participant in otherwise confidential genetic research or trials. This means that any data or other information you may have shared pursuant to a promise of confidentiality or privacy may become public despite your intent that it be kept private and confidential. Depending on the nature and context of the data or information, this could result in certain adverse effects for you, including ones not contemplated by this consent form.
- 1.2. Your DNA sequence data, trait data and other information related to you that is made publicly available by the PGP, while directly associated only with you, may also have relevance to your family members. Although in many instances any conclusions that may be inferred from your publicly available information may be speculative with respect to you, and even less predictive with respect to your family members, the complete set and magnitude of the risks that the public availability of this information poses to you

and your relatives is not known at this time. You are strongly encouraged to discuss this study and its potential risks with your immediate family members.

- 1.3. If you are enrolled in the PGP research study and based on your review of your Preliminary Research Report or otherwise according to the procedures described in this consent form, choose not to make your DNA sequence data publicly available, the public disclosure of your DNA sequence data due to unintended data breaches, including hacking or other activities outside of the procedures authorized by the PGP, is still possible and, should this occur, you would be subject to the various risks and discomforts described in this section and throughout this consent form.
- 1.4. You are advised that the PGP is unable to guarantee the accuracy or the validity of any research data, including your DNA sequence data and your Preliminary Research Report, provided to you by the PGP. The data provided to you by the PGP, including your DNA sequence data and your Preliminary Research Report, is not a suitable substitute for professional medical or clinical advice, diagnosis or treatment, and may not be used by you for any medical or clinical purpose unless the relevant sequence or other data, including any interpretations or findings presented in your Preliminary Research Report, are first confirmed at the direction of and in consultation with a licensed healthcare professional.
  - a. Comprehensive screening of DNA sequence data for pathogenic genetic variants is not done clinically or routinely at this time. The clinical importance of even well established pathogenic variants that are found through this type of screening is not known with certainty at this time. Furthermore, although there is considerable information discussing possible connections between genetic information, such as may be disclosed by your DNA sequence data, and clinical or medical outcomes, some of these connections, especially when screened for in the general population, remain uncertain, subject to further research and neither their validity nor their clinical usefulness can be confirmed by the PGP at this time.
  - b. Regardless of any specific interpretations or findings provided in or omitted from your Preliminary Research Report, you are likely to be subjected to additional interpretations - both accurate and inaccurate - of your public data by outside sources.
  - c. If you choose to make your DNA sequence data and other information available it will be published via the PGP's publicly accessible website and database, and it will be available to third parties without legal restriction. As a result, neither you nor the PGP will be able to control or restrict the access, use, reproduction, modification or analysis of your data and other public information. Your data and other public information may be made public in other forms beyond its inclusion in the PGP database. It may also be altered or modified, without either your or the PGP's consent, in a way that might be inaccurate and/or upsetting to you. For instance, a third party could access your publicly available sequence data, alter it and republish it to suggest that you had a propensity for a disease or other detrimental trait. Additional adverse effects are also possible.
  - d. Knowledge of potentially detrimental genetic variants may cause anxiety. As a result, you may be motivated to seek Health or Medical Care, as defined below, to verify the accuracy of such interpretations, whether provided by the PGP or by

other sources. Should you choose to pursue such Health or Medical Care you could be exposed to additional risks and/or discomforts, several of which are identified below.

- 1.5. The PGP will not (i) provide you with, (ii) arrange for, (iii) pay for, reimburse you for or otherwise subsidize or (iv) provide you, your physician or any other health care provider with any recommendations, advice or other guidance with respect to, any of your Health or Medical Care. For purposes of this consent form, “Health or Medical Care” means both of any (i) current medical or clinical advice, diagnosis or treatment, preventative action or other related course of action of any kind and (ii) follow up clinical or medical advice, diagnosis or treatment, preventative action or other related course of action of any kind.
- a. The PGP is not responsible for any aspect of your Health or Medical Care, including, without limitation, accurately predicting disease or disease risk, informing you of pathogenic sequence variants, or providing you with accurate or valid DNA sequence data or interpretations of your DNA sequence data. No Health or Medical Care will be made available by the PGP and, as described above, no special arrangements, for compensation or otherwise, will be made by the PGP should you require or choose to pursue any Health or Medical Care as a result of your participation in the PGP.
  - b. You should seek the advice of your physician or other qualified health care provider if you have questions regarding any information provided to you by the PGP, including with respect to your DNA sequence data or Preliminary Research Report. You should not ignore professional medical advice from your doctor or any other qualified health care provider on the basis of any information contained or not contained in your Preliminary Research Report or in other information provided to you by the PGP, and you should not interpret your DNA sequence data or your Report as recommending or discouraging any specific treatment plan, product or course of action with respect to your Health or Medical Care.
  - c. In the event that you, in conjunction with your physician or other qualified health care provider, decide that any change in your Health or Medical Care is necessary or advisable as a result of any information you obtained as a participant in the PGP, you (or your third party payer, if applicable) will be solely responsible for all resulting payments and costs associated with such Health or Medical Care.
  - d. Any Health or Medical Care that you may determine, after consultation with your physician or other qualified health care provider, is necessary, whether as a result of your participation in this study or otherwise, may be invasive and have its own associated risks and expenses. Serious risks, including death, may be involved in any such Health or Medical Care. You should carefully consider these risks, as well as whether or not you have access to the financial and other resources to pursue such Health or Medical Care.
  - e. In the event that your physician or other qualified health care provider is directly or indirectly involved with the PGP, as either a researcher or a participant, any Health or Medical Care that you receive from such provider, including medical advice or clinical management, represents Health or Medical Care provided by such provider pursuant to your existing physician-patient relationship, and is not



to be construed or interpreted as the provision of Health or Medical Care by the PGP.

- 1.6. A Data Safety Monitoring Board (DSMB) will monitor the progress of the PGP, including the risks to study participants. Although the PGP will take reasonable measures to notify you of any additional risks identified by the DSMB, including through updates to the project website, the DSMB will be unable to monitor all of the risks of participation in this project, and it may not be able to advise you or the PGP of those risks that it monitors or identifies.
- 1.7. There are no known or foreseeable risks or side effects associated with saliva, hair, buccal, skin swab, urine, or fecal sampling procedures. The blood draw and skin biopsy may involve a small amount of pain, bleeding and/or fainting, and may also cause temporary bruising and/or infection at the site of puncture. Some degree of permanent scarring can be expected from the skin biopsy procedure.
- 1.8. If physical injury resulting from participation in this project should occur, please seek medical care immediately and contact the Principal Investigator. Although, as described above, the PGP will not normally provide any Health or Medical Care to participants it may, in rare instances and at its sole discretion, provide Health or Medical Care in the event of an emergency. Should this occur, you (or your third party payer, if applicable) may be billed for the cost of such Health or Medical Care. Should the PGP make any Health or Medical Care available neither the PGP, nor any individual associated with the PGP, are admitting any fault or liability for any injury that you may have suffered.

## **VIII. BENEFITS**

- 1.1. There are no proven benefits to you from your participation in the PGP.
- 1.2. The study may benefit the medical science and research community as a whole. For example, the PGP may help establish genetic causes and predispositions for common diseases or that preventative measures observable in existing populations might be due to variation in lifestyle. You may experience satisfaction from participating in research that may benefit medical science.

## **IX. INTELLECTUAL PROPERTY**

- 1.1. Other than for purposes of cost recovery, neither the PGP nor PersonalGenomes.org will license or otherwise make available your tissue specimens, cell lines, DNA samples, DNA sequence data, and personal information to any person, institution, company or other third party for the financial gain or commercial profit of the PGP or PersonalGenomes.org. However, information and materials that you provide, including DNA sequence data and cell lines derived from your tissue specimens, may be made available to third parties for research, clinical or therapeutic, commercial or other purposes.
- 1.2. You will not be compensated for your participation in the PGP. Neither you nor your heirs will gain financially from any discoveries, whether or not of a commercial nature, made using the information and/or specimens that you provide.

## **X. CONFIDENTIALITY**

- 1.1. If you are enrolled in the PGP, your genetic and trait information will not be maintained or made available in a confidential or anonymous fashion. Your genetic and trait information will be made available via a publicly accessible website and database, according to the procedures described above. Public disclosure of your information due to unintended data breaches, including hacking or other activities outside of the procedures described above, is also possible.
- 1.2. Your genetic and trait data will not be sent to your health care provider by the PGP and will not become part of your medical record due to any activities of the PGP. However, because this information will be publicly available, and may be identified as yours, it could become part of your medical record or be shared with your health care provider or provided to others due to the activities of one or more third parties.
- 1.3. Your reply to the Safety Questionnaires will be confidential by default. However, the DSMB, governmental agencies or study sponsor may request or require this information in order to judge the risks to you and any other study participants and the PGP will share your replies to the Safety Questionnaire with such entities to the extent required or reasonably requested.
- 1.4. Responses to the Safety Questionnaires that may impact other PGP participants or the public generally will be paraphrased and/or will have all information reasonably likely to identify you removed prior to making this information publicly available on the public website or elsewhere for purposes of public education or risk management. If you would like your answers to be identified as yours, then you will need to indicate that as part of your response to the Safety Questionnaires. Although the PGP will take reasonable steps to ensure that your responses to Safety Questionnaires, if published, are not identified as yours without your consent, the PGP is unable to guarantee the anonymity of your responses.
- 1.5. The results of this study may be published in a medical book, journal, website or webpage, or used for teaching purposes. Your name and other identifiers (such as your photograph and medical information provided during the course of your participation in the study) may be used in such publications or teaching materials. You will not be notified by the PGP prior to such use.

## **XI. REFUSAL OR WITHDRAWAL OF PARTICIPATION**

- 1.1. Participation in this study is voluntary. You do not have to participate in the PGP. You may withdraw your participation and/or your data from this study at any time, as described in this consent form, and you need not provide a reason.
- 1.2. You are free to decide at any time that you no longer want your tissue samples, DNA sequence data, cell lines or other information to be used as part of this research study, but you are advised that there are significant limitations on your ability to prevent the future use of such data and/or information.

- a. If you choose to withdraw from the study and request that your genetic and trait data to be removed, within 6 months the PGP will delete all DNA sequence and trait data pertaining solely to you and held by the PGP, and issue requests to any organizations or researchers with whom the PGP has any formal data sharing agreements to likewise delete such data within a reasonable time frame. You are advised, however, that once any information obtained about you during the course of your participation in the study is posted on the Internet, other organizations and individuals who have no formal data sharing agreement with the PGP may acquire copies of it, and there will be no mechanism to ensure that they delete their copies or for the PGP to even know what copies may exist.
  - b. If you decide to withdraw from participation and request that the PGP remove cell lines created from your tissues, the PGP will destroy all tissue samples and cell lines held by the PGP and send a notice to all biorepositories with which the PGP has formal agreements requesting that such biorepositories destroy your cell lines. You are advised, however, that once tissue samples and/or cell lines have been distributed, the ability to control their use by you, the PGP or the biorepository to which they were distributed will be limited. Because your cell lines and/or tissue samples will have been widely distributed, it will not be possible to retrieve and/or destroy all copies of your cell lines and/or tissue samples.
- 1.3. The PGP may decide, at its sole discretion, to end your participation in this study at any time. If the PGP terminates your participation it will provide an explanation for its doing so.
- 1.4. Your participation in the PGP may be ended if you do not comply with the instructions related to Safety Questionnaires, as described above.
- 1.5. If the event that you are refused enrollment in the PGP or your participation in the PGP is terminated by the PGP, you may request that the PGP destroy any of your tissue samples and/or cell lines and delete any of your data in accordance with the provisions set forth above.
- 1.6. In order to comply with the terms of this consent form, as well as with other requirements, the PGP may continue to maintain certain information about you, including your name, date of first participation, date of enrollment and date of termination or withdrawal, following the conclusion of your participation in the PGP, including if your participation is terminated or you should decide to withdraw.

## **XII. ALTERNATIVES**

- 1.1. The alternative is not to participate in the PGP.
- 1.2. If you choose not to participate, your medical treatment at your hospital and other medical care providers will be unaffected.

### **XIII. RESEARCH-RELATED CONTACT INFORMATION:**

- 1.1. If you have any questions or concerns about the study, or if you suffer a research related injury, you may contact the Principal Investigator: George Church, PhD, at (617) 432-7562 or [consent@personalgenomes.org](mailto:consent@personalgenomes.org)
- 1.2. If you wish to discuss your rights as a participant in a research study, or if you feel under any pressure to enroll in this study you may contact: Carolyn Connelly, PhD, the Director of the Office for Research Subject Protection at Harvard Medical School (617) 432-0651 or [carolyn\\_connelly@hms.harvard.edu](mailto:carolyn_connelly@hms.harvard.edu)

### **SIGNATURE**

I have read this entire informed consent form and I understand it completely. I confirm that I understand the purpose of this study, the study procedures, the possible risks and discomforts of participating in this study, the potential benefits that I may experience, and the alternatives to my participation in this study. All of my questions have been answered to my complete satisfaction.

I understand that by typing my name and email address in the box below I am signing this informed consent form, I am acknowledging and agreeing to all of the terms and conditions of participation set forth above, and I am providing my informed consent to participate in the PGP.

Name:

Email:

## **Enabling Public Genomics**

It has been 100 years since Danish biologist Wilhelm Johanssen first coined the word “gene” to describe the (then-conceptual) mechanism by which traits passed from parent to offspring. A century of research has identified the gene—a stretch of both coding and non-coding DNA sequences—as the primary biochemical mechanism of inheritance. But research has also revealed that the traditional understanding of genetic inheritance as a binary Mendelian linking of genes and traits is most often simplistic and incomplete. Instead, the majority of gene-trait relationships appear to be fiendishly complex and largely inexplicable by current knowledge. Geneticists are currently attempting to unravel the tangled pathways between genes and traits, and are developing new and often conflicting theories describing the role of common and rare variants, coding and non-coding regions, genomes, exomes, proteomes and transcriptomes, and a host of other genomic and environmental factors. Given the progress made in their first century of research, geneticists look ahead to a second century of genetic research with justified optimism.

Genomics thrives on data. Robust datasets that combine genomic and trait data, including medical and environmental measurements and histories, are the lifeblood of genomic research. As further complexities in the relationship between genes and traits emerge, researchers need increasingly rich and large-scale datasets in order to continue teasing out the relationship between the human genomic code and the manifestations of that code: flesh and blood human beings.

The original effort to sequence a composite human genome took more than a decade and cost several billion dollars. In recent years, however, the cost of genomic sequencing has

declined precipitously, spurred by scientific and technological advances that continue to defy predictions and seem likely to render genomic sequencing a commodity, perhaps as soon as the end of this decade. Partial genomic sequences (or “exomes”) may soon be available for under \$1,000, and the proliferation of consumer and commercial genomic sequencing companies seems certain to further drive down the cost of genomic sequences.

The decline in genomic sequencing costs means that researchers will shortly be able to generate the massive amounts of information that large-scale genomic research requires. But developing the ability to generate these rich datasets overcomes only a first, scientific hurdle. To understand how genes relate to human health, researchers require datasets that link individuals’ genetic data with their personal information—medical history, physical traits, diet, lifestyle, and environmental exposures. Further, longitudinal studies require the ability to update individuals’ personal information to account for changes in that information over time. Thus, unlike many human research projects, where the nature of the research requires subjects to be anonymous to researchers, large-scale genomic research often demands a lack of anonymity. Complicating matters further, an individual’s genomic information inescapably contains clinically significant or actionable information, although the significance of, and appropriate clinical response to, that genomic data is constantly changing as new discoveries are made, new associations are put forward, and old associations are discredited.

These two features—lack of anonymity and clinical significance of genomic information—challenge the established legal and ethical framework governing human subject research. For example, what duty does a researcher have to explain the clinical significance of a study participant’s genomic sequence data? Where does the boundary between genomic research and the practice of genomic medicine or counseling fall? What does it mean to require an

individual to provide informed consent when genomic sequence data remains constant even as the significance of that data changes with each new discovery? And how is the sensitivity of an individual's genomic data and personal information to be respected when, despite best efforts to the contrary, it may be technically impossible to maintain the anonymity or confidentiality of that data? These and other questions must be resolved if the next generation of human genomic research is to be pursued in a responsible and open fashion.

In response to this suite of emerging issues, this Article offers a novel approach to genomic research—a “public genomics” premised on the idea that ethically, legally, and socially responsible genomic research requires openness, not privacy. Large-scale genomic research should be carried out in full view of the public, leveraging both the data contributed by information altruists (individuals who are willing to forego traditional expectations of informational privacy and control in order to further scientific research) and the research potential of crowds that is tapped only by making rich datasets freely and globally available.

The purpose of this Article is to examine the risks and benefits of the public genomics model, and to do so in the context of what may be the most ambitious genetic research project currently under way: the Personal Genome Project (the “PGP”), a project sponsored by Harvard Medical School which, among its other goals, aims to establish a publicly-available dataset containing comprehensive genomic, phenotypic and personal information of up to 100,000 individually identifiable participants. This Article will consider how public genomics projects, including the PGP, may be conducted in an ethically, legally, and socially responsible fashion, and what features of the current legal and regulatory landscape may complicate such research.

Part I begins with a detailed review of the present state of genomic science and research, concluding that large-scale genomic research projects are both inevitable and desirable. Part II

delves deeper into the risks and issues presented by public genomics research, including (i) an exploration of the distinction between research and clinical activities, (ii) the implications of informed consent given a rapidly evolving knowledge base, and (iii) the feasibility and desirability of conducting anonymized or confidential genomics research. Part III assesses the current legal and regulatory regimes and determines that they are ill-defined, inconsistent, and inadequate to meet their presumed objective of protecting the rights of individual research participants while simultaneously enabling promising and responsible scientific inquiry. Finally, this Article concludes by proposing a modified legal regime—largely federal and supported by a national Institutional Review Board for public genomic projects—that would be far more likely to advance these objectives than the current mélange of state and federal statutes, regulations, and common law decisions.



**ARTICLES OF INCORPORATION  
OF  
PERSONALGENOMES.ORG**

Pursuant to Section 55A-2-02 of the General Statutes of North Carolina, the undersigned hereby submits these Articles of Incorporation for the purpose of forming a nonprofit corporation under the laws of the State of North Carolina.

1. The name of the corporation is PersonalGenomes.org.
2. The corporation shall be a charitable corporation within the meaning of Section 55A-1-40(4) of the General Statutes of North Carolina. The corporation was incorporated after the effective date of Chapter 55A of the North Carolina General Statutes.
3. The corporation is organized and operated exclusively for charitable and educational purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code of 1986, as amended, or any corresponding United States Internal Revenue Law (the “Code”), including, without limitation, to encourage the development of affordable and responsible personal genomics research and technology application by building a framework for scaleable prototyping and evaluation of personal genomics technologies and research efforts in the public domain.
  - (a) Notwithstanding any other provision of these Articles of Incorporation, the corporation shall not carry on any other activities not permitted to be carried on (i) by a corporation exempt from federal income tax under Section 501(c)(3) of the Code or (ii) by a corporation to which contributions are deductible under Section 170(c)(2) of the Code.
  - (b) No part of the net earnings of the corporation shall inure to the benefit of, or be distributable to its directors, officers or other private persons, except that the corporation shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of its tax-exempt purposes.
  - (c) No substantial part of the activities of this corporation shall consist of carrying on propaganda, or otherwise attempting to influence legislation, and the corporation shall not participate or intervene in any political campaign (including the publishing or distribution of statements) on behalf of, or in opposition to, any candidate for public office.
4. The corporation shall have no members. The method of election of the directors is set forth in the bylaws of the corporation.
5. The period of existence of the corporation is unlimited.
6. The address of the initial registered office of the corporation in the State of North Carolina is Robinson Bradshaw & Hinson, P.A., 101 N. Tryon Street, Suite 1900, Charlotte,

North Carolina 28246, which initial registered office is located in Mecklenburg County; and the name of its initial registered agent at such address is Daniel Brandt Vorhaus.

7. The street address and mailing address of the principal office of the corporation are NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115, which principal office is located in Suffolk County in the Commonwealth of Massachusetts.

8. To the fullest extent permitted by the North Carolina Nonprofit Corporation Act as it exists or may hereafter be amended, no person who is serving or who has served as a director of the corporation shall be personally liable for monetary damages for breach of any duty as a director. No amendment or repeal of this article, nor the adoption of any other amendment to these Articles of Incorporation inconsistent with this article, shall eliminate or reduce the protection granted herein with respect to any matter that occurred prior to such amendment, repeal, or adoption.

9. In the event of the termination, dissolution or winding up of the affairs of the corporation in any manner or for any reason whatsoever, the directors shall, after paying or making provision for payment of all liabilities of the corporation, distribute all of the remaining assets and property of the corporation to one or more organizations exempt under Section 501(c)(3) of the Code as designated by the directors.

10. The name and address of the incorporator are Daniel Brandt Vorhaus, Robinson Bradshaw & Hinson, P.A., 101 N. Tryon Street, Suite 1900, Charlotte, North Carolina 28246.

11. These Articles of Incorporation shall be effective as of filing.

This the 10th day of July, 2008.

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Daniel Brandt Vorhaus  
Incorporator

**BYLAWS  
OF  
PERSONALGENOMES.ORG**

**INDEX OF BYLAWS**  
**OF**  
**PERSONALGENOMES.ORG**

<b>ARTICLE I.....</b>	<b>1</b>
<b>OFFICES .....</b>	<b>1</b>
Section 1. <i>Principal Office</i> .....	1
Section 2. <i>Registered Office</i> .....	1
Section 3. <i>Other Offices</i> .....	1
<b>ARTICLE II .....</b>	<b>1</b>
<b>BOARD OF DIRECTORS.....</b>	<b>1</b>
Section 1. <i>General Powers</i> .....	1
Section 2. <i>Number, Term and Qualifications</i> .....	1
Section 3. <i>Election of Directors</i> .....	2
Section 4. <i>Removal</i> .....	2
Section 5. <i>Vacancies</i> .....	2
Section 6. <i>Compensation</i> .....	2
<b>ARTICLE III.....</b>	<b>2</b>
<b>MEETINGS OF DIRECTORS .....</b>	<b>2</b>
Section 1. <i>Regular Meetings</i> .....	2
Section 2. <i>Special Meetings</i> .....	2
Section 3. <i>Notice of Meetings</i> .....	2
Section 4. <i>Waiver of Notice</i> .....	3
Section 5. <i>Quorum</i> .....	3
Section 6. <i>Manner of Acting</i> .....	3
Section 7. <i>Presumption of Assent</i> .....	3
Section 8. <i>Informal Action by Directors</i> .....	3
Section 9. <i>Committees of the Board</i> .....	3
Section 10. <i>Advisory Board</i> .....	4
<b>ARTICLE IV .....</b>	<b>4</b>
<b>OFFICERS .....</b>	<b>4</b>
Section 1. <i>Officers of the Corporation</i> .....	4
Section 2. <i>Election and Term</i> .....	4
Section 3. <i>Compensation of Officers</i> .....	4

Section 4.	<i>Removal</i> .....	4
Section 5.	<i>President</i> .....	4
Section 6.	<i>Vice President</i> .....	5
Section 7.	<i>Secretary</i> .....	5
Section 8.	<i>Treasurer</i> .....	5
<b>ARTICLE V</b> .....		<b>5</b>
<b>CONTRACTS, LOANS, CHECKS, DEPOSITS AND GIFTS</b> .....		<b>5</b>
Section 1.	<i>Contracts</i> .....	5
Section 2.	<i>Loans</i> .....	6
Section 3.	<i>Checks and Drafts</i> .....	6
Section 4.	<i>Deposits</i> .....	6
Section 5.	<i>Gifts</i> .....	6
<b>ARTICLE VI</b> .....		<b>6</b>
<b>GENERAL PROVISIONS</b> .....		<b>6</b>
Section 1.	<i>Seal</i> .....	6
Section 2.	<i>Indemnification</i> .....	6
Section 3.	<i>Fiscal Year</i> .....	7
Section 4.	<i>Amendments</i> .....	7
Section 5.	<i>Books and Records</i> .....	7
Section 6.	<i>Construction of Terms</i> .....	8

**BYLAWS**  
**OF**  
**PERSONALGENOMES.ORG**

**ARTICLE I**

**OFFICES**

- Section 1. *Principal Office.* The principal office of the corporation shall be located in the Commonwealth of Massachusetts or any other location designated by the Board of Directors.
- Section 2. *Registered Office.* The registered office of the corporation required by law to be maintained in the State of North Carolina shall be at a location designated by the Board of Directions.
- Section 3. *Other Offices.* The corporation may have offices at such other places, either within or without the State of North Carolina or the Commonwealth of Massachusetts, as the Board of Directors may designate or as the affairs of the corporation may require from time to time.

**ARTICLE II**

**BOARD OF DIRECTORS**

- Section 1. *General Powers.* The business and affairs of the corporation shall be managed by its Board of Directors.
- Section 2. *Number, Term and Qualifications.* The number of directors constituting the Board of Directors shall be at least three and not more than fifteen as may be fixed or changed from time to time, within the minimum and maximum, by the Board of Directors. Each director shall be elected for a three-year term and until his successor is elected and qualifies. The Board of Directors shall be divided into three classes with staggered terms, with each class as nearly equal in number as may be. Accordingly, approximately one-third of the directors' terms of office shall expire each year. Each director shall be eligible to serve on the Board of Directors for two full consecutive three-year terms. Thereafter such director must cease to serve for a least one year before being eligible for election to the Board of Directors of the corporation. Any person who is elected to replace a director whose term has expired shall be elected to serve a three-year term. Any person elected to replace a director who dies, resigns or is removed prior to the expiration of his term shall serve for the remainder of such director's unexpired term and also shall be eligible to serve two additional

consecutive three-year terms. Directors need not be residents of the State of North Carolina.

- Section 3. *Election of Directors.* The directors shall be elected by the vote of the directors then in office; and those persons who receive the highest number of votes at a meeting at which a quorum is present shall be deemed to have been elected. If any director so demands, the election of directors shall be by ballot.
- Section 4. *Removal.* Any director may be removed at any time with or without cause by the vote of a majority of the directors present at a meeting at which a quorum is present. Without limiting the generality of the foregoing, any director who fails to attend at least fifty percent (50%) of the meetings of the Board of Directors in any fiscal year shall be removed unless a majority of the directors present at a meeting at which a quorum is present shall vote to permit such director to complete the unexpired portion of his term as director.
- Section 5. *Vacancies.* Any vacancy occurring among the directors may be filled by the affirmative vote of a majority of the remaining directors even though less than a quorum or by the sole remaining director. A director elected to fill a vacancy shall be elected for the unexpired term of his predecessor in office.
- Section 6. *Compensation.* Directors shall not be compensated for their services as such but may be reimbursed for any or all expenses incurred in attending regular and special meetings of the Board.

### **ARTICLE III**

#### **MEETINGS OF DIRECTORS**

- Section 1. *Regular Meetings.* A regular meeting of the Board of Directors shall be held annually at the principal office of the corporation or at such other place as the Board may designate. In addition, the Board of Directors may provide, by resolution, the time and place, either within or without the State of North Carolina, for the holding of additional regular meetings.
- Section 2. *Special Meetings.* Special meetings of the Board of Directors may be called by or at the request of the President or any two directors. Such a meeting may be held either within or without the State of North Carolina, as fixed by the person or persons calling the meeting.
- Section 3. *Notice of Meetings.* Regular meetings of the Board of Directors may be held without notice. The person or persons calling a special meeting of the Board of Directors shall, at least ten days prior to the meeting, give written notice thereof delivered personally or sent by mail, facsimile

transmission or electronic mail to each director at his address as shown by the records of the corporation. If mailed, such notice shall be deemed to be delivered when deposited in the United States mail in a sealed envelope so addressed with postage thereon prepaid. If sent by facsimile transmission or electronic mail, such notice shall be deemed delivered when confirmation of delivery to the designated number or mailbox is received. Such notice need not specify the purpose for which the meeting is called.

- Section 4. *Waiver of Notice.* Any director may waive notice of any meeting. The attendance by a director at a meeting shall constitute a waiver of notice of such meeting, except where a director attends a meeting for the express purpose of objecting to the transaction of any business because the meeting is not lawfully called or convened.
- Section 5. *Quorum.* A majority of the members of the Board of Directors shall constitute a quorum for the transaction of business at any meeting of the Board of Directors.
- Section 6. *Manner of Acting.* Except as otherwise provided in these bylaws, the act of the majority of the directors present at a meeting at which a quorum is present shall be the act of the Board of Directors.
- Section 7. *Presumption of Assent.* A director of the corporation who is present at a meeting of the Board of Directors at which action on any corporate matter is taken shall be presumed to have assented to the action taken unless his contrary vote is recorded or his dissent is otherwise entered in the minutes of the meeting or unless he shall file his written dissent to such action with the person acting as the secretary of the meeting before the adjournment thereof or shall forward such dissent by registered mail to the Secretary of the corporation immediately after the adjournment of the meeting. Such right to dissent shall not apply to a director who voted in favor of such action.
- Section 8. *Informal Action by Directors.* Action taken by the directors without a meeting is nevertheless Board action if written consent to the action in question is approved by all of the directors, such approval may be evidenced by signature or electronic indicia of assent, and filed with the minutes of the proceedings of the Board, whether done before or after the action so taken.
- Section 9. *Committees of the Board.* The Board of Directors, by resolution adopted by a majority of the directors present at a meeting at which a quorum is present, may designate certain directors to constitute an Executive Committee and other committees, each of which, to the extent authorized by law and provided in such resolution, shall have and may exercise all of the authority of the Board of Directors in the management of the



corporation. The designation of any committee and the delegation thereto of authority shall not operate to relieve the Board of Directors, or any member thereof, of any responsibility or liability imposed upon it or him by law.

- Section 10. *Advisory Board.* The Board of Directors, by resolution adopted by a majority of the directors present at a meeting at which a quorum is present, may designate persons to serve as members of an Advisory Board. Such Advisory Board shall provide counsel to the Board of Directors and shall have no authority to manage the affairs of the corporation.

## ARTICLE IV

### OFFICERS

- Section 1. *Officers of the Corporation.* The officers of the corporation shall consist of a President, one or more Vice Presidents, a Secretary, a Treasurer and other officers as the Board of Directors may from time to time elect. Any two or more offices may be held by the same person, but no officer may act in more than one capacity where action of two or more officers is required.
- Section 2. *Election and Term.* The officers of the corporation shall be elected annually by the Board of Directors and each officer shall hold office for one year or until his successor shall have been elected and qualified. A vacancy in any office because of death, resignation, removal, disqualification or otherwise may be filled by the Board of Directors for the unexpired portion of the term.
- Section 3. *Compensation of Officers.* The compensation of all officers of the corporation, if any, shall be fixed by the Board of Directors and no officer shall serve the corporation in any other capacity and receive compensation therefor unless such additional compensation shall be authorized by the Board of Directors.
- Section 4. *Removal.* Any officer or agent elected or appointed by the Board of Directors may be removed by the Board whenever in its judgment the best interests of the corporation will be served thereby; provided that such removal shall be without prejudice to the contract rights, if any, of the person so removed.
- Section 5. *President.* The President shall be the principal executive officer of the corporation and, subject to the control of the Board of Directors, shall in general supervise and control all of the business and affairs of the corporation. He shall, when present, preside at meetings of the Board of Directors. He shall sign, with the Secretary or any other proper officer of the corporation thereunto authorized by the Board of Directors, any deeds,

mortgages, bonds, contracts or other instruments which the Board of Directors has authorized to be executed, except in cases where the signing and execution thereof shall be expressly delegated by the Board of Directors or by these bylaws to some other officer or agent of the corporation, or shall be required by law to be otherwise signed or executed; and in general he shall perform all duties incident to the office of president and such other duties as may be prescribed by the Board of Directors from time to time.

Section 6. *Vice President.* In the absence of the President or in the event of his death, inability or refusal to act, the Vice President, unless otherwise determined by the Board of Directors, shall perform the duties of the President, and when so acting shall have all the powers of and be subject to all the restrictions upon the President. If there is more than one Vice President, the Board of Directors shall determine which shall perform the duties of the President in the instances described above. The Vice President shall perform such other duties as from time to time may be assigned to him by the President or by the Board of Directors.

Section 7. *Secretary.* The Secretary shall (a) keep the minutes of the meetings of the Board of Directors and of all committees in one or more books provided for that purpose; (b) see that all notices are duly given in accordance with the provisions of these bylaws or as required by law, (c) be custodian of the corporate records and of the seal of the corporation, if any, and see that the seal of the corporation is affixed to all documents the execution of which on behalf of the corporation under its seal is duly authorized; and (d) in general perform all duties incident to the office of secretary and such other duties as from time to time may be assigned to him by the President or by the Board of Directors.

Section 8. *Treasurer.* The Treasurer shall (a) have charge and custody of and be responsible for all funds and securities of the corporation; receive and give receipts for moneys due and payable to the corporation from any source whatsoever, and deposit all such moneys in the name of the corporation in such depositories as shall be selected in accordance with the provisions of Section 4 of Article V of these bylaws; and (b) in general, perform all of the duties incident to the office of treasurer and such other duties as from time to time may be assigned to him by the President or by the Board of Directors, or by these bylaws.

## **ARTICLE V**

### **CONTRACTS, LOANS, CHECKS, DEPOSITS AND GIFTS**

Section 1. *Contracts.* The Board of Directors may authorize any officer or officers, agent or agents, to enter into any contract or execute and deliver any

instrument in the name of and on behalf of the corporation, and such authority may be general or confined to specific instances.

- Section 2. *Loans.* No loans shall be contracted on behalf of the corporation and no evidences of indebtedness shall be issued in its name unless authorized by a resolution of the Board of Directors. Such authority may be general or confined to specific instances.
- Section 3. *Checks and Drafts.* All checks, drafts or other orders for the payment of money, issued in the name of the corporation, shall be signed by such officer or officers, agent or agents, of the corporation and in such manner as shall from time to time be determined by resolution of the Board of Directors. In the absence of such resolution, such instruments shall be signed by the Treasurer and countersigned by the President or Vice President of the corporation.
- Section 4. *Deposits.* All funds of the corporation not otherwise employed shall be deposited from time to time to the credit of the corporation in such depositories as the Board of Directors may select.
- Section 5. *Gifts.* The Board of Directors may accept, on behalf of the corporation, any contribution, gift, bequest or devise for the general purpose or for any special purposes of the corporation.

## ARTICLE VI

### GENERAL PROVISIONS

- Section 1. *Seal.* The corporate seal of the corporation, if any, shall consist of two concentric circles between which is the name of the corporation and in the center of which is inscribed SEAL; and such seal, is hereby adopted as the corporate seal of the corporation.
- Section 2. *Indemnification.* Any person who at any time serves or has served as a director, officer, employee or agent of the corporation, or in such capacity at the request of the corporation for any other corporation, partnership, joint venture, trust or other enterprise, shall have a right to be indemnified by the corporation to the fullest extent permitted by law against (a) reasonable expenses, including attorneys' fees, actually and necessarily incurred by him in connection with any threatened, pending or completed action, suit or proceedings, whether civil, criminal, administrative or investigative, and whether or not brought by or on behalf of the corporation, seeking to hold him liable by reason of the fact that he is or was acting in such capacity, and (b) reasonable payments made by him in satisfaction of any judgment, money decree, fine, penalty or settlement for which he may have become liable in any such action, suit or proceeding.

The Board of Directors of the corporation shall take all such action as may be necessary and appropriate to authorize the corporation to pay the indemnification required by this bylaw, including without limitation, to the extent needed, making a good faith evaluation of the manner in which the claimant for indemnity acted and of the reasonable amount of indemnity due him.

Expenses incurred in defending a civil or criminal action, suit or proceeding shall be paid by the corporation in advance of the final disposition of such action, suit or proceeding, as authorized by the Board of Directors in the specific case, upon receipt of an undertaking by or on behalf of the director, officer, employee or agent to repay such amount if it shall ultimately be determined that he is not entitled to be indemnified by the Corporation as authorized in this bylaw.

Any person who at any time after the adoption of this bylaw serves or has served in any of the aforesaid capacities for or on behalf of the corporation shall be deemed to be doing or to have done so in reliance upon, and as consideration for, the right of indemnification provided herein. Such right shall inure to the benefit of the legal representatives of any such person and shall not be exclusive of any other rights to which such person may be entitled apart from the provision of this bylaw.

In addition to the foregoing, the Board of Directors shall have the right and power to purchase and maintain insurance on behalf of any person who is or was a director, officer, employee or agent of the corporation, or is or was serving at the request of the corporation as director, officer, employee or agent of another corporation, partnership, joint venture, trust or other enterprise against any liability asserted against him and incurred by him in any such capacity, or arising out of his status as such, whether or not the corporation would have the power to indemnify him against such liability.

Section 3. *Fiscal Year.* The fiscal year of the corporation shall be the calendar year.

Section 4. *Amendments.* Except as otherwise provided herein, these bylaws or the corporation's articles of incorporation may be amended or repealed and new bylaws (or amended articles of incorporation) may be adopted by the affirmative vote of two-thirds of the directors then holding office at any regular or special meeting of the Board of Directors at which a quorum is present, provided that at least ten days' written notice is given of intention to alter, amend, repeal or adopt new bylaws (or articles of incorporation) at such meeting.

Section 5. *Books and Records.* The corporation shall keep correct and complete books and records and shall also keep minutes of the proceedings of the Board of Directors and committees having any of the authority of the

Board of Directors. The books, records and papers of the corporation shall at all times, during reasonable business hours, be subject to inspection by any director. The articles of incorporation and the bylaws of the corporation shall be available for inspection by any director at the principal office of the corporation.

Section 6. *Construction of Terms.* Where appropriate, any word denoting or referring to one gender shall be deemed to include the other gender.

Approved by the Board of Directors on July 10, 2008

**PERSONALGENOMES.ORG**  
**CONFLICT OF INTEREST POLICY**

**ARTICLE I**

**PURPOSE**

The purpose of the conflict of interest policy is to protect the interests of PersonalGenomes.org (the “Organization”) when it is contemplating entering into a transaction or arrangement that might benefit the private interest of an officer or director of the Organization or might result in a possible excess benefit transaction. This policy is intended to supplement but not replace any applicable state and federal laws governing conflict of interest applicable to nonprofit and charitable organizations.

**ARTICLE II**

**DEFINITIONS**

**1. Interested Person**

Any director, principal officer, or member of a committee with governing board delegated powers, who has a direct or indirect financial interest, as defined below, is an interested person.

**2. Financial Interest**

A person has a financial interest if the person has, directly or indirectly, through business, investment, or family:

- a. An ownership or investment interest in any entity with which the Organization has a transaction or arrangement,
- b. A compensation arrangement with the Organization or with any entity or individual with which the Organization has a transaction or arrangement, or
- c. A potential ownership or investment interest in, or compensation arrangement with, any entity or individual with which the Organization is negotiating a transaction or arrangement.

Compensation includes direct and indirect remuneration as well as gifts or favors that are not insubstantial.

A financial interest is not necessarily a conflict of interest. Under Article III, Section 2, a person who has a financial interest may have a conflict of interest only if the appropriate governing board or committee decides that a conflict of interest exists.

## **ARTICLE III**

### **PROCEDURES**

#### **1. Duty to Disclose**

In connection with any actual or possible conflict of interest, an interested person must disclose the existence of the financial interest and be given the opportunity to disclose all material facts to the directors and members of committees with governing board delegated powers considering the proposed transaction or arrangement.

#### **2. Determining Whether a Conflict of Interest Exists**

After disclosure of the financial interest and all material facts, and after any discussion with the interested person, he/she shall leave the governing board or committee meeting while the determination of a conflict of interest is discussed and voted upon. The remaining board or committee members shall decide if a conflict of interest exists.

#### **3. Procedures for Addressing the Conflict of Interest**

a. An interested person may make a presentation at the governing board or committee meeting, but after the presentation, he/she shall leave the meeting during the discussion of, and the vote on, the transaction or arrangement involving the possible conflict of interest.

b. The chairperson of the governing board or committee shall, if appropriate, appoint a disinterested person or committee to investigate alternatives to the proposed transaction or arrangement.

c. After exercising due diligence, the governing board or committee shall determine whether the Organization can obtain with reasonable efforts a more advantageous transaction or arrangement from a person or entity that would not give rise to a conflict of interest.

d. If a more advantageous transaction or arrangement is not reasonably possible under circumstances not producing a conflict of interest, the governing board or committee shall determine by a majority vote of the disinterested directors whether the transaction or arrangement is in the Organization's best interest, for its own benefit, and whether it is fair and reasonable. In conformity with the above determination it shall make its decision as to whether to enter into the transaction or arrangement.

#### **4. Violations of the Conflict of Interest Policy**

a. If the governing board or committee has reasonable cause to believe a member has failed to disclose actual or possible conflicts of interest, it shall inform the member of the basis for such belief and afford the member an opportunity to explain the alleged failure to disclose.

b. If, after hearing the member's response and after making further investigation as warranted by the circumstances, the governing board or committee determines the member has failed to disclose an actual or possible conflict of interest, it shall take appropriate disciplinary and corrective action.

## **ARTICLE IV**

### **RECORDS OF PROCEEDINGS**

The minutes of the governing board and all committees with board delegated powers shall contain:

a. The names of the persons who disclosed or otherwise were found to have a financial interest in connection with an actual or possible conflict of interest, the nature of the financial interest, any action taken to determine whether a conflict of interest was present, and the governing board's or committee's decision as to whether a conflict of interest in fact existed.

b. The names of the persons who were present for discussions and votes relating to the transaction or arrangement, the content of the discussion, including any alternatives to the proposed transaction or arrangement, and a record of any votes taken in connection with the proceedings.

## **ARTICLE V**

### **COMPENSATION**

a. A voting member of the governing board who receives compensation, directly or indirectly, from the Organization for services is precluded from voting on matters pertaining to that member's compensation.

b. A voting member of any committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from the Organization for services is precluded from voting on matters pertaining to that member's compensation.

c. No voting member of the governing board or any committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from the Organization, either individually or collectively, is prohibited from providing information to any committee regarding compensation.

## **ARTICLE VI**

### **ANNUAL STATEMENTS**

Each director, principal officer and member of a committee with governing board delegated powers shall annually sign a statement which affirms such person:



- a. Has received a copy of the conflict of interest policy,
- b. Has read and understands the policy,
- c. Has agreed to comply with the policy, and
- d. Understands the Organization is charitable and in order to maintain its federal tax exemption it must engage primarily in activities which accomplish one or more of its tax-exempt purposes.

In connection with the execution of the annual disclosure statement, each director, principal officer, and member of a committee with governing board delegated power also shall submit a complete and accurate list of persons or entities from which such person receives compensation (as defined in Article II) and/or in which such person holds a material ownership or investment interest (other than the beneficial ownership of less than 5% of the outstanding capital stock of any publicly traded entity).

## **ARTICLE VII**

### **PERIODIC REVIEWS**

To ensure the Organization operates in a manner consistent with charitable purposes and does not engage in activities that could jeopardize its tax-exempt status, periodic reviews shall be conducted. The periodic reviews shall, at a minimum, include the following subjects:

- a. Whether compensation arrangements and benefits are reasonable, based on competent survey information, and the result of arm's length bargaining.
- b. Whether partnerships, joint ventures, and arrangements with management organizations conform to the Organization's written policies, are properly recorded, reflect reasonable investment or payments for goods and services, further charitable purposes and do not result in inurement, impermissible private benefit or in an excess benefit transaction.

## **ARTICLE VIII**

### **USE OF OUTSIDE EXPERTS**

When conducting the periodic reviews as provided for in Article VII, the Organization may, but need not, use outside advisors. If outside experts are used, their use shall not relieve the governing board of its responsibility for ensuring that any transaction or arrangement is fair to the Organization and that periodic reviews are conducted.

Dated as of July 10, 2008

**PERSONALGENOMES.ORG**  
**CONFLICT OF INTEREST POLICY**  
**ANNUAL DISCLOSURE STATEMENT**

I hereby affirm the following:

- a. I have received a copy of the conflict of interest policy,
- b. I have read and understand the policy,
- c. I have agreed to comply with the policy, and
- d. I understand PersonalGenomes.org is charitable and in order to maintain its federal tax exemption it must engage primarily in activities which accomplish one or more of its tax-exempt purposes.

Following is a complete and accurate list of persons or entities from which I receive compensation (as defined in Article II of the Policy) and/or in which I hold a material ownership or investment interest (other than the beneficial ownership of less than 5% of the outstanding capital stock of any publicly traded entity), which list demarcates compensation that is received by family and ownership or investment interests held by family or through business.

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Signature

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Name (please print)

---

Title

---

Date

## **PERSONALGENOMES.ORG**

### **WHISTLEBLOWER POLICY**

#### **General**

The directors, officers and employees of PersonalGenomes.org (the “Organization”) are expected to observe high standards of business and personal ethics in the conduct of their duties and responsibilities. As employees and representatives of the Organization, we must practice honesty and integrity in fulfilling our responsibilities and comply with all applicable laws and regulations.

#### **Reporting Responsibility**

It is the responsibility of all directors, officers and employees to report violations or suspected violations of the Organization’s governance documents, policies and procedures, and state and federal law in accordance with this Whistleblower Policy.

#### **No Retaliation**

No director, officer or employee who in good faith reports any such violation shall suffer harassment, retaliation or adverse employment consequence. An employee who retaliates against someone who has reported a violation in good faith is subject to discipline up to and including termination of employment. This Whistleblower Policy is intended to encourage and enable employees and others to raise serious concerns within the Organization prior to seeking resolution outside the Organization.

#### **Reporting Violations**

The Organization has an open door policy. Employees are encouraged to share their questions, concerns, suggestions or complaints with someone who can address them properly. In most cases, an employee’s supervisor is in the best position to address an area of concern. However, if you are not comfortable speaking with your supervisor or you are not satisfied with your supervisor’s response, you are encouraged to speak with anyone in management whom you are comfortable in approaching. Supervisors and managers are required to report suspected violations to the Organization’s Compliance Officer, who has specific and exclusive responsibility to investigate all reported violations. For suspected fraud, or when you are not satisfied or uncomfortable with following the Organization’s open door policy, individuals should contact the Organization’s Compliance Officer directly.

#### **Compliance Officer**

The Organization’s Compliance Officer is responsible for investigating and resolving all reported complaints and allegations and, at his discretion, shall advise the board of directors. The Compliance Officer has direct access to the board of directors and is required to report to the board of directors at least annually on compliance activity.

### **Accounting and Auditing Matters**

The board of directors shall address all reported concerns or complaints regarding corporate accounting practices, internal controls or auditing. The Compliance Officer shall immediately notify the board of directors of any such complaint and work with the board until the matter is resolved.

### **Acting in Good Faith**

Anyone filing a complaint concerning a violation or suspected violation must be acting in good faith and have reasonable grounds for believing the information disclosed indicates a violation of the Organization's governance documents, policies and procedures, and state and federal law. Any allegations that prove not to be substantiated and which prove to have been made maliciously or knowingly to be false will be viewed as a serious disciplinary offense.

### **Confidentiality**

Violations or suspected violations may be submitted on a confidential basis by the complainant or may be submitted anonymously. Reports of violations or suspected violations will be kept confidential to the extent possible, consistent with the need to conduct an adequate investigation.

### **Handling of Reported Violations**

The Compliance Officer will notify the sender and acknowledge receipt of the reported violation or suspected violation within five business days. All reports will be promptly investigated and appropriate corrective action will be taken if warranted by the investigation.

Dated as of July 10, 2008

# Application for Recognition of Exemption

## Under Section 501(c)(3) of the Internal Revenue Code

OMB No. 1545-0056

**Note:** If exempt status is approved, this application will be open for public inspection.

Use the instructions to complete this application and for a definition of all **bold** items. For additional help, call IRS Exempt Organizations Customer Account Services toll-free at 1-877-829-5500. Visit our website at **www.irs.gov** for forms and publications. If the required information and documents are not submitted with payment of the appropriate user fee, the application may be returned to you.

Attach additional sheets to this application if you need more space to answer fully. Put your name and EIN on each sheet and identify each answer by Part and line number. Complete Parts I - XI of Form 1023 and submit only those Schedules (A through H) that apply to you.

<b>Part I Identification of Applicant</b>		
<b>1</b> Full name of organization (exactly as it appears in your <b>organizing document</b> ) <b>PersonalGenomes.org</b>		<b>2</b> c/o Name (if applicable)
<b>3</b> <b>Mailing address</b> (Number and street) (see instructions) <b>NRB 238, 77 Avenue Louis Pasteur</b>	Room/Suite	<b>4</b> Employer Identification Number (EIN) <b>26-2973607</b>
City or town, state or country, and ZIP + 4 <b>Boston, Massachusetts 02115-5727</b>		<b>5</b> Month the annual accounting period ends (01 – 12) <b>12</b>
<b>6</b> Primary contact (officer, director, trustee, or <b>authorized representative</b> ) <b>a</b> Name: <b>Daniel Brandt Vorhaus</b>		<b>b</b> Phone: <b>(704) 377-8111</b>
		<b>c</b> Fax: (optional) <b>(704) 339-3411</b>
<b>7</b> Are you represented by an authorized representative, such as an attorney or accountant? If "Yes," provide the authorized representative's name, and the name and address of the authorized representative's firm. Include a completed Form 2848, <i>Power of Attorney and Declaration of Representative</i> , with your application if you would like us to communicate with your representative. <b>See Exhibit A.</b> <b>Daniel Brandt Vorhaus, Robinson, Bradshaw &amp; Hinson, P.A., 101 N. Tryon Street, Suite 1900, Charlotte, North Carolina 28246</b>		
<b>8</b> Was a person who is not one of your officers, directors, trustees, employees, or an authorized representative listed in line 7, paid, or promised payment, to help plan, manage, or advise you about the structure or activities of your organization, or about your financial or tax matters? If "Yes," provide the person's name, the name and address of the person's firm, the amounts paid or promised to be paid, and describe that person's role.		
<b>9a</b> Organization's website: <b>http://www.personalgenomes.org</b>		
<b>b</b> Organization's email: (optional) <b>N/A</b>		
<b>10</b> Certain organizations are not required to file an information return (Form 990 or Form 990-EZ). If you are granted tax-exemption, are you claiming to be excused from filing Form 990 or Form 990-EZ? If "Yes," explain. See the instructions for a description of organizations not required to file Form 990 or Form 990-EZ.		
<b>11</b> Date incorporated if a corporation, or formed, if other than a corporation. (MM/DD/YYYY)		<b>07/14/2008</b>
<b>12</b> Were you formed under the laws of a <b>foreign country</b> ? If "Yes," state the country.		

**Part II Organizational Structure**

You must be a corporation (including a limited liability company), an unincorporated association, or a trust to be tax exempt. (See instructions.) **DO NOT file this form unless you can check "Yes" on lines 1, 2, 3, or 4.**

- 1** Are you a **corporation**? If "Yes," attach a copy of your articles of incorporation showing **certification of filing** with the appropriate state agency. Include copies of any amendments to your articles and be sure they also show state filing certification. **See Exhibit B.** ☒ **Yes** ☐ **No**
- 2** Are you a **limited liability company (LLC)**? If "Yes," attach a copy of your articles of organization showing certification of filing with the appropriate state agency. Also, if you adopted an operating agreement, attach a copy. Include copies of any amendments to your articles and be sure they show state filing certification. Refer to the instructions for circumstances when an LLC should not file its own exemption application. ☐ **Yes** ☒ **No**
- 3** Are you an **unincorporated association**? If "Yes," attach a copy of your articles of association, constitution, or other similar organizing document that is dated and includes at least two signatures. Include signed and dated copies of any amendments. ☐ **Yes** ☒ **No**
- 4a** Are you a **trust**? If "Yes," attach a signed and dated copy of your trust agreement. Include signed and dated copies of any amendments. ☐ **Yes** ☒ **No**
- b** Have you been funded? If "No," explain how you are formed without anything of value placed in trust. ☐ **Yes** ☐ **No**
- 5** Have you adopted **bylaws**? If "Yes," attach a current copy showing date of adoption. If "No," explain how your officers, directors, or trustees are selected.. **See Exhibit C.** ☒ **Yes** ☐ **No**

**Part III Required Provisions in Your Organizing Document**

The following questions are designed to ensure that when you file this application, your organizing document contains the required provisions to meet the organizational test under section 501(c)(3). Unless you can check the boxes in both lines 1 and 2, your organizing document does not meet the organizational test. **DO NOT file this application until you have amended your organizing document.** Submit your original and amended organizing documents (showing state filing certification if you are a corporation or an LLC) with your application.

- 1** Section 501(c)(3) requires that your organizing document state your exempt purpose(s), such as charitable, religious, educational, and/or scientific purposes. Check the box to confirm that your organizing document meets this requirement. Describe specifically where your organizing document meets this requirement, such as a reference to a particular article or section in your organizing document. Refer to the instructions for exempt purpose language. Location of Purpose Clause (Page, Article, and Paragraph): **Page 1, Section 3** ☒
- 2a** Section 501(c)(3) requires that upon dissolution of your organization, your remaining assets must be used exclusively for exempt purposes, such as charitable, religious, educational, and/or scientific purposes. Check the box on line 2a to confirm that your organizing document meets this requirement by express provision for the distribution of assets upon dissolution. If you rely on state law for your dissolution provision, do not check the box on line 2a and go to line 2c. ☒
- 2b** If you checked the box on line 2a, specify the location of your dissolution clause (Page, Article, and Paragraph). Do not complete line 2c if you checked box 2a. **Page 2, Section 9**
- 2c** See the instructions for information about the operation of state law in your particular state. Check this box if you rely on operation of state law for your dissolution provision and indicate the state: ☐

**Part IV Narrative Description of Your Activities**

Using an attachment, describe your *past*, *present*, and *planned* activities in a narrative. If you believe that you have already provided some of this information in response to other parts of this application, you may summarize that information here and refer to the specific parts of the application for supporting details. You may also attach representative copies of newsletters, brochures, or similar documents for supporting details to this narrative. Remember that if this application is approved, it will be open for public inspection. Therefore, your narrative description of activities should be thorough and accurate. Refer to the instructions for information that must be included in your description. **See Exhibit D.**

**Part V Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Employees, and Independent Contractors**

- 1a** List the names, titles, and mailing addresses of all of your officers, directors, and trustees. For each person listed, state their total annual **compensation**, or proposed compensation, for all services to the organization, whether as an officer, employee, or other position. Use actual figures, if available. Enter "none" if no compensation is or will be paid. If additional space is needed, attach a separate sheet. Refer to the instructions for information on what to include as compensation.

Name	Title	Mailing address	Compensation amount (annual actual or estimated)
<b>See Exhibit E.</b>		-----	
		-----	
		-----	
		-----	
		-----	

**Part V Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Employees, and Independent Contractors (Continued)**

- b** List the names, titles, and mailing addresses of each of your five highest compensated employees who receive or will receive compensation of more than \$50,000 per year. Use the actual figure, if available. Refer to the instructions for information on what to include as compensation. Do not include officers, directors, or trustees listed in line 1a.

Name	Title	Mailing address	Compensation amount (annual actual or estimated)
<b>None</b>		-----	
		-----	
		-----	
		-----	
		-----	

- c** List the names, names of businesses, and mailing addresses of your five highest compensated **independent contractors** that receive or will receive compensation of more than \$50,000 per year. Use the actual figure, if available. Refer to the instructions for information on what to include as compensation.

Name	Title	Mailing address	Compensation amount (annual actual or estimated)
<b>None</b>		-----	
		-----	
		-----	
		-----	
		-----	

The following "Yes" or "No" questions relate to *past, present, or planned* relationships, transactions, or agreements with your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed in lines 1a, 1b, and 1c.

- 2a** Are any of your officers, directors, or trustees **related** to each other through **family** or **business relationships**? If "Yes," identify the individuals and explain the relationship. ☒ **Yes** ☐ **No**  
**1) George Church is an employee of Harvard University; Jason Bobe is a paid consultant of Harvard University;**  
**2) George Church is on the scientific advisory board of 23andMe and DNADirect; Esther Dyson is a director of 23andMe; and**  
**3) Ryan Phelan is the CEO and founder of DNADirect; Jason Bobe is a former employee and shareholder of DNADirect.**
- b** Do you have a business relationship with any of your officers, directors, or trustees other than through their position as an officer, director, or trustee? If "Yes," identify the individuals and describe the business relationship with each of your officers, directors, or trustees. ☐ **Yes** ☒ **No**
- c** Are any of your officers, directors, or trustees related to your highest compensated employees or highest compensated independent contractors listed on lines 1b or 1c through family or business relationships? If "Yes," identify the individuals and explain the relationship. ☐ **Yes** ☒ **No**
- 3a** For each of your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed on lines 1a, 1b, or 1c, attach a list showing their names, qualifications, average hours worked, and duties. **See Exhibit E.**
- b** Do any of your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed on lines 1a, 1b, or 1c receive compensation from any other organizations, whether tax exempt or taxable, that are related to you through **common control**? If "Yes," identify the individuals, explain the relationship between you and the other organization, and describe the compensation arrangement. ☐ **Yes** ☒ **No**
- 4** In establishing the compensation for your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed on lines 1a, 1b, and 1c, the following practices are recommended, although they are not required to obtain exemption. Answer "Yes" to all the practices you use.
- a** Do you or will the individuals that approve compensation arrangements follow a conflict of interest policy? ☒ **Yes** ☐ **No**
- b** Do you or will you approve compensation arrangements in advance of paying compensation? ☒ **Yes** ☐ **No**
- c** Do you or will you document in writing the date and terms of approved compensation arrangements? ☒ **Yes** ☐ **No**

**Part V Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Employees, and Independent Contractors (Continued)**

- d** Do you or will you record in writing the decision made by each individual who decided or voted on compensation arrangements? ☒ **Yes** ☐ **No**
- e** Do you or will you approve compensation arrangements based on information about compensation paid by **similarly situated** taxable or tax-exempt organizations for similar services, current compensation surveys compiled by independent firms, or actual written offers from similarly situated organizations? Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation ☒ **Yes** ☐ **No**
- f** Do you or will you record in writing both the information on which you relied to base your decision and its source? ☒ **Yes** ☐ **No**
- g** If you answered "No" to any item on lines 4a through 4f, describe how you set compensation that is **reasonable** for your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed in Part V, lines 1a, 1b, and 1c.
- 
- 5a** Have you adopted a **conflict of interest policy** consistent with the sample conflict of interest policy in Appendix A to the instructions? If "Yes," provide a copy of the policy and explain how the policy has been adopted, such as by resolution of your governing board. If "No," answer lines 5b and 5c. **The policy was adopted by resolution of the Board of Directors. See Exhibit F.** ☒ **Yes** ☐ **No**
- b** What procedures will you follow to assure that persons who have a conflict of interest will not have influence over you for setting their own compensation?
- c** What procedures will you follow to assure that persons who have a conflict of interest will not have influence over you regarding business deals with themselves?
- Note:** A conflict of interest policy is recommended though it is not required to obtain exemption. Hospitals, see Schedule C, Section I, line 14.
- 
- 6a** Do you or will you compensate any of your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed in lines 1a, 1b, or 1c through **non-fixed payments**, such as discretionary bonuses or revenue-based payments? If "Yes," describe all non-fixed compensation arrangements, including how the amounts are determined, who is eligible for such arrangements, whether you place a limitation on total compensation, and how you determine or will determine that you pay no more than reasonable compensation for services. Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation. ☐ **Yes** ☒ **No**
- b** Do you or will you compensate any of your employees, other than your officers, directors, trustees, or your five highest compensated employees who receive or will receive compensation of more than \$50,000 per year, through non-fixed payments, such as discretionary bonuses or revenue-based payments? If "Yes," describe all non-fixed compensation arrangements, including how the amounts are or will be determined, who is or will be eligible for such arrangements, whether you place or will place a limitation on total compensation, and how you determine or will determine that you pay no more than reasonable compensation for services. Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation. ☐ **Yes** ☒ **No**
- 
- 7a** Do you or will you purchase any goods, services, or assets from any of your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," describe any such purchase that you made or intend to make, from whom you make or will make such purchases, how the terms are or will be negotiated at **arm's length**, and explain how you determine or will determine that you pay no more than **fair market value**. Attach copies of any written contracts or other agreements relating to such purchases. ☐ **Yes** ☒ **No**
- b** Do you or will you sell any goods, services, or assets to any of your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," describe any such sales that you made or intend to make, to whom you make or will make such sales, how the terms are or will be negotiated at **arm's length**, and explain how you determine or will determine you are or will be paid at least fair market value. Attach copies of any written contracts or other agreements relating to such sales. ☐ **Yes** ☒ **No**
- 
- 8a** Do you or will you have any leases, contracts, loans, or other agreements with your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," provide the information requested in lines 8b through 8f. ☐ **Yes** ☒ **No**
- b** Describe any written or oral arrangements that you made or intend to make.
- c** Identify with whom you have or will have such arrangements.
- d** Explain how the terms are or will be negotiated at **arm's length**.
- e** Explain how you determine you pay no more than fair market value or you are paid at least fair market value.
- f** Attach copies of any signed leases, contracts, loans, or other agreements relating to such arrangements.
- 
- 9a** Do you or will you have any leases, contracts, loans, or other agreements with any organization in which any of your officers, directors, or trustees are also officers, directors, or trustees, or in which any individual officer, director, or trustee owns more than a 35% interest? If "Yes," provide the information requested in lines 9b through 9f. ☐ **Yes** ☒ **No**



**Part V Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Employees, and Independent Contractors (Continued)**

- b** Describe any written or oral arrangements you made or intend to make.
- c** Identify with whom you have or will have such arrangements.
- d** Explain how the terms are or will be negotiated at arm's length.
- e** Explain how you determine or will determine you pay no more than fair market value or that you are paid at least fair market value.
- f** Attach a copy of any signed leases, contracts, loans, or other agreements relating to such arrangements.

**Part VI Your Members and Other Individuals and Organizations That Receive Benefits From You**

The following "Yes" or "No" questions relate to goods, services, and funds you provide to individuals and organizations as part of your activities. Your answers should pertain to *past*, *present*, and *planned* activities. (See instructions.)

- 1a** In carrying out your exempt purposes, do you provide goods, services, or funds to individuals? If "Yes," describe each program that provides goods, services or funds to individuals. **See Exhibit D.** ☒ **Yes** ☐ **No**
- b** In carrying out your exempt purposes, do you provide goods, services, or funds to organizations? If "Yes," describe each program that provides goods, services, or funds to organizations. **See Exhibit D.** ☒ **Yes** ☐ **No**
- 2** Do any of your programs limit the provision of goods, services, or funds to a specific individual or group of specific individuals? For example, answer "Yes," if goods, services, or funds are provided only for a particular individual, your members, individuals who work for a particular employer, or graduates of a particular school. If "Yes," explain the limitation and how recipients are selected for each program. ☐ **Yes** ☒ **No**
- 3** Do any individuals who receive goods, services, or funds through your programs have a family or business relationship with any officer, director, trustee, or with any of your highest compensated employees or highest compensated independent contractors listed in Part V, lines 1a, 1b, and 1c? If "Yes," explain how these related individuals are eligible for goods, services, or funds. **Project participants may include officers or directors, as well as family members and individuals with business relationships to officers or directors. All project participants, including those described in the foregoing sentence, will meet the eligibility requirements more fully set forth on Exhibit D, including payment of the enrollment fee, and no project participants shall receive preferential treatment.** ☒ **Yes** ☐ **No**

**Part VII Your History**

The following "Yes" or "No" questions relate to your history. (See instructions.)

- 1** Are you a **successor** to another organization? Answer "Yes," if you have taken or will take over the activities of another organization; you took over 25% or more of the fair market value of the net assets of another organization; or you were established upon the conversion of an organization from for-profit to non-profit status. If "Yes," complete Schedule G. ☐ **Yes** ☒ **No**
- 2** Are you submitting this application more than 27 months after the end of the month in which you were legally formed? If "Yes," complete Schedule E. ☐ **Yes** ☒ **No**

**Part VIII Your Specific Activities**

The following "Yes" or "No" questions relate to specific activities that you may conduct. Check the appropriate box. Your answers should pertain to *past*, *present*, and *planned* activities. (See instructions.)

- 1** Do you support or oppose candidates in **political campaigns** in any way? If "Yes," explain. ☐ **Yes** ☒ **No**
- 2a** Do you attempt to **influence legislation**? If "Yes," explain how you attempt to influence legislation and complete line 2b. If "No," go to line 3a. ☐ **Yes** ☒ **No**
- b** Have you made or are you making an **election** to have your legislative activities measured by expenditures by filing Form 5768? If "Yes," attach a copy of the Form 5768 that was already filed or attach a completed Form 5768 that you are filing with this application. If "No," describe whether your attempts to influence legislation are a substantial part of your activities. Include the time and money spent on your attempts to influence legislation as compared to your total activities. ☐ **Yes** ☒ **No**
- 3a** Do you or will you operate bingo or **gaming** activities? If "Yes," describe who conducts them, and list all revenue received or expected to be received and expenses paid or expected to be paid in operating these activities. **Revenue and expenses** should be provided for the time periods specified in Part IX, Financial Data. ☐ **Yes** ☒ **No**
- b** Do you or will you enter into contracts or other agreements with individuals or organizations to conduct bingo or gaming for you? If "Yes," describe any written or oral arrangements that you made or intend to make, identify with whom you have or will have such arrangements, explain how the terms are or will be negotiated at arm's length, and explain how you determine or will determine you pay no more than fair market value or you will be paid at least fair market value. Attach copies or any written contracts or other agreements relating to such arrangements. ☐ **Yes** ☒ **No**
- c** List the states and local jurisdictions, including Indian Reservations, in which you conduct or will conduct gaming or bingo.

**Part VIII Your Specific Activities (Continued)**

<b>4a</b>	Do you or will you undertake <b>fundraising</b> ? If "Yes," check all the fundraising programs you do or will conduct. (See instructions.)	<input checked="" type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
	<div style="display: flex; justify-content: space-between;"> <div style="width: 48%;"> <input checked="" type="checkbox"/> mail solicitations  <input checked="" type="checkbox"/> email solicitations  <input checked="" type="checkbox"/> personal solicitations  <input type="checkbox"/> vehicle, boat, plane, or similar donations  <input checked="" type="checkbox"/> foundation grant solicitations </div> <div style="width: 48%;"> <input checked="" type="checkbox"/> phone solicitations  <input checked="" type="checkbox"/> accept donations on your website  <input type="checkbox"/> receive donations from another organization's website  <input checked="" type="checkbox"/> government grant solicitations  <input type="checkbox"/> Other </div> </div>	
	Attach a description of each fundraising program. <b>See Exhibit G.</b>	
<b>b</b>	Do you or will you have written or oral contracts with any individuals or organizations to raise funds for you? If "Yes," describe these activities. Include all revenue and expenses from these activities and state who conducts them. Revenue and expenses should be provided for the time periods specified in Part IX, Financial Data. Also, attach a copy of any contracts or agreements.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>c</b>	Do you or will you engage in fundraising activities for other organizations? If "Yes," describe these arrangements. Include a description of the organizations for which you raise funds and attach copies of all contracts or agreements.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>d</b>	List all states and local jurisdictions in which you conduct fundraising. For each state or local jurisdiction listed, specify whether you fundraise for your own organization, you fundraise for another organization, or another organization fundraises for you. <b>All states (for own organization).</b>	
<b>e</b>	Do you or will you maintain separate accounts for any contributor under which the contributor has the right to advise on the use or distribution of funds? Answer "Yes" if the donor may provide advice on the types of investments, distributions from the types of investments, or the distribution from the donor's contribution account. If "Yes," describe this program, including the type of advice that may be provided and submit copies of any written materials provided to donors.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>5</b>	Are you <b>affiliated</b> with a governmental unit? If "Yes," explain.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>6a</b>	Do you or will you engage in <b>economic development</b> ? If "Yes," describe your program	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>b</b>	Describe in full who benefits from your economic development activities and how the activities promote exempt purposes.	
<b>7a</b>	Do or will persons other than your employees or volunteers <b>develop</b> your facilities? If "Yes," describe each facility, the role of the developer, and any business or family relationship(s) between the developer and your officers, directors, or trustees.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>b</b>	Do or will persons other than your employees or volunteers <b>manage</b> your activities or facilities? If "Yes," describe each activity and facility, the role of the manager, and any business or family relationship(s) between the manager and your officers, directors, or trustees.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>c</b>	If there is a business or family relationship between any manager or developer and your officers, directors, or trustees, identify the individuals, explain the relationship, describe how contracts are negotiated at arm's length so that you pay no more than fair market value, and submit a copy of any contracts or other agreements.	
<b>8</b>	Do you or will you enter into <b>joint ventures</b> , including partnerships or <b>limited liability companies</b> treated as partnerships, in which you share profits and losses with partners other than section 501(c)(3) organizations? If "Yes," describe the activities of these joint ventures in which you participate.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>9a</b>	Are you applying for exemption as a childcare organization under section 501(k)? If "Yes," answer lines 9b through 9d. If "No," go to line 10.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
<b>b</b>	Do you provide child care so that parents or caretakers of children you care for can be <b>gainfully employed</b> (see instructions)? If "No," explain how you qualify as a childcare organization described in section 501(k).	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
<b>c</b>	Of the children for whom you provide child care, are 85% or more of them cared for by you to enable their parents or caretakers to be gainfully employed (see instructions)? If "No," explain how you qualify as a childcare organization described in section 501(k).	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
<b>d</b>	Are your services available to the general public? If "No," describe the specific group of people for whom your activities are available. Also, see the instructions and explain how you qualify as a childcare organization described in section 501(k).	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
<b>10</b>	Do you or will you publish, own, or have rights in music, literature, tapes, artworks, choreography, scientific discoveries, or other <b>intellectual property</b> ? If "Yes," explain. Describe who owns or will own any copyrights, patents, or trademarks, whether fees are or will be charged, how the fees are determined, and how any items are or will be produced, distributed, and marketed. <b>See Exhibit D.</b>	<input checked="" type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>

**Part VIII Your Specific Activities (Continued)**

<b>11</b>	Do you or will you accept contributions of: real property; conservation easements; closely held securities; intellectual property such as patents, trademarks, and copyrights; works of music or art; licenses; royalties; automobiles, boats, planes, or other vehicles; or collectibles of any type? If "Yes," describe each type of contribution, any conditions imposed by the donor on the contribution, and any agreements with the donor regarding the contribution. <b>See Exhibit D.</b>	<input checked="" type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
<b>12a</b>	Do you or will you operate in a <b>foreign country</b> or <b>countries</b> ? If "Yes," answer lines 12b through 12d. If "No," go to line 13a.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
	<b>b</b> Name the foreign countries and regions within the countries in which you operate.	
	<b>c</b> Describe your operations in each country and region in which you operate.	
	<b>d</b> Describe how your operations in each country and region further your exempt purposes.	
<b>13a</b>	Do you or will you make grants, loans, or other distributions to organization(s)? If "Yes," answer lines 13b through 13g. If "No," go to line 14a. <b>See Exhibit D.</b>	<input checked="" type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
	<b>b</b> Describe how your grants, loans, or other distributions to organizations further your exempt purposes. <b>See Exhibit D.</b>	
	<b>c</b> Do you have written contracts with each of these organizations? If "Yes," attach a copy of each contract.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
	<b>d</b> Identify each recipient organization and any <b>relationship</b> between you and the recipient organization. <b>N/A</b>	
	<b>e</b> Describe the records you keep with respect to the grants, loans, or other distributions you make. <b>See Exhibit D.</b>	
	<b>f</b> Describe your selection process, including whether you do any of the following:	
	<b>(i)</b> Do you require an application form? If "Yes," attach a copy of the form.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
	<b>(ii)</b> Do you require a grant proposal? If "Yes," describe whether the grant proposal specifies your responsibilities and those of the grantee, obligates the grantee to use the grant funds only for the purposes for which the grant was made, provides for periodic written reports concerning the use of grant funds, requires a final written report and an accounting of how grant funds were used, and acknowledges your authority to withhold and/or recover grant funds in case such funds are, or appear to be, misused.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
	<b>g</b> Describe your procedures for oversight of distributions that assure you the resources are used to further your exempt purposes, including whether you require periodic and final reports on the use of resources. <b>See Exhibit D.</b>	
<b>14a</b>	Do you or will you make grants, loans, or other distributions to foreign organizations? If "Yes," answer lines 14b through 14f. If "No," go to line 15.	<input type="checkbox"/> <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b>
	<b>b</b> Provide the name of each foreign organization, the country and regions within a country in which each foreign organization operates, and describe any relationship you have with each foreign organization.	
	<b>c</b> Does any foreign organization listed in line 14b accept contributions earmarked for a specific country or specific organization? If "Yes," list all earmarked organizations or countries.	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
	<b>d</b> Do your contributors know that you have ultimate authority to use contributions made to you at your discretion for purposes consistent with your exempt purposes? If "Yes," describe how you relay this information to contributors.	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
	<b>e</b> Do you or will you make pre-grant inquiries about the recipient organization? If "Yes," describe these inquiries, including whether you inquire about the recipient's financial status, its tax-exempt status under the Internal Revenue Code, its ability to accomplish the purpose for which the resources are provided, and other relevant information.	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>
	<b>f</b> Do you or will you use any additional procedures to ensure that your distributions to foreign organizations are used in furtherance of your exempt purposes? If "Yes," describe these procedures, including site visits by your employees or compliance checks by impartial experts, to verify that grant funds are being used appropriately.	<input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b>

**Part VIII Your Specific Activities** *(Continued)*

- |           |  |                                     |   |
|-----------|--|-------------------------------------|---|
| <b>15</b> | Do you have a <b>close connection</b> with any organizations? If "Yes," explain.   | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>16</b> | Are you applying for exemption as a <b>cooperative hospital service organization</b> under section 501(e)? If "Yes," explain.  | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>17</b> | Are you applying for exemption as a <b>cooperative service organization of operating educational organizations</b> under section 501(f)? If "Yes," explain.  | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>18</b> | Are you applying for exemption as a <b>charitable risk pool</b> under section 501(n)? If "Yes," explain.   | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>19</b> | Do you or will you operate a <b>school</b> ? If "Yes," complete Schedule B. Answer "Yes," whether you operate a school as your main function or as a secondary activity.   | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>20</b> | Is your main function to provide <b>hospital</b> or <b>medical care</b> ? If "Yes," complete Schedule C.   | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>21</b> | Do you or will you provide <b>low-income housing</b> or housing for the <b>elderly</b> or <b>handicapped</b> ? If "Yes," complete Schedule F.  | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |
| <b>22</b> | Do you or will you provide scholarships, fellowships, educational loans, or other educational grants to individuals, including grants for travel, study, or other similar purposes? If "Yes," complete Schedule H.<br><b>Note:</b> <b>Private foundations</b> may use Schedule H to request advance approval of individual grant procedures. | <input type="checkbox"/> <b>Yes</b> | <input checked="" type="checkbox"/> <b>No</b> |

**Part IX Financial Data**

For purposes of this schedule, years in existence refer to completed tax years. If in existence 4 or more years, complete the schedule for the most recent 4 tax years. If in existence more than 1 year but less than 4 years, complete the statements for each year in existence and provide projections of your likely revenues and expenses based on a reasonable and good faith estimate of your future finances for a total of 3 years of financial information. If in existence less than 1 year, provide projections of your likely revenues and expenses for the current year and the 2 following years, based on a reasonable and good faith estimate of your future finances for a total of 3 years of financial information. (See instructions.)

**A. Statement of Revenue and Expenses**

	Type of revenue or expense	Current tax year	3 prior tax years or 2 succeeding tax years				(e) Provide Total for (a) through (d)
		(a) From 7/1/08 To 12/31/08	(b) From 1/1/09 To 12/31/09	(c) From 1/1/10 To 12/31/10	(d) From ..... To .....		
<b>Revenues</b>	<b>1</b> Gifts, grants, and contributions received (do not include unusual grants)	\$400,000	\$3M	\$20M			\$23.4M
	<b>2</b> Membership fees received	0	0	0			0
	<b>3</b> Gross investment income	0	0	0			0
	<b>4</b> Net unrelated business income	0	0	0			0
	<b>5</b> Taxes levied for your benefit	0	0	0			0
	<b>6</b> Value of services or facilities furnished by a governmental unit without charge (not including the value of services generally furnished to the public without charge)	0	0	0			0
	<b>7</b> Any revenue not otherwise listed above or in lines 9-12 below (attach an itemized list)	0	0	0			0
	<b>8</b> Total of lines 1 through 7	\$400,000	\$3M	\$20M			\$23.4M
<b>Expenses</b>	<b>9</b> Gross receipts from admissions, merchandise sold or services performed, or furnishing of facilities in any activity that is related to your exempt purposes (attach itemized list) <b>See Exhibit H.</b>	\$100,000	\$1M	\$10M			\$11.1M
	<b>10</b> Total of lines 8 and 9	\$500,000	\$4M	\$30M			\$34.5M
	<b>11</b> Net gain or loss on sale of capital assets (attach schedule and see instructions)	0	0	0			0
	<b>12</b> Unusual grants	0	0	0			0
	<b>13</b> Total Revenue Add lines 10 through 12	\$500,000	\$4M	\$30M			\$34.5M
	<b>14</b> Fundraising expenses	0	0	0			0
	<b>15</b> Contributions, gifts, grants, and similar amounts paid out (attach an itemized list) <b>See Exhibit H.</b>	0	\$50,000	\$100,000			\$150,000
	<b>16</b> Disbursements to or for the benefit of members (attach an itemized list)	0	0	0			0
	<b>17</b> Compensation of officers, directors, and trustees	0	0	0			0
	<b>18</b> Other salaries and wages	0	\$200,000	\$500,000			\$700,000
	<b>19</b> Interest expense	0	0	0			0
	<b>20</b> Occupancy (rent, utilities, etc.)	0	0	0			0
	<b>21</b> Depreciation and depletion	0	0	0			0
	<b>22</b> Professional fees	0	\$550,000	\$1,900,000			\$2,450,000
	<b>23</b> Any expense not otherwise classified, such as program services (attach itemized list) <b>See Exhibit H.</b>	500,000	\$3.2M	\$27.5M			\$31.2M
	<b>24</b> Total Expenses Add lines 14 through 23	500,000	\$4M	\$30M			\$34.5M

**Part IX Financial Data (Continued)**

<b>B. Balance Sheet (for your most recently completed tax year)</b>		<b>Year End: 8/31/08</b>
<b>Assets</b>		(Whole dollars)
1	Cash . . . . .	1 0
2	Accounts receivable, net. . . . .	2 0
3	Inventories. . . . .	3 0
4	Bonds and notes receivable (attach an itemized list) . . . . .	4 0
5	Corporate stocks (attach an itemized list). . . . .	5 0
6	Loans receivable (attach an itemized list). . . . .	6 0
7	Other investments (attach an itemized list) . . . . .	7 0
8	Depreciable and depletable assets (attach an itemized list). . . . .	8 0
9	Land. . . . .	9 0
10	Other assets (attach an itemized list). . . . .	10 0
11	Total Assets (add lines 1 through 10) . . . . .	11 0
<b>Liabilities</b>		
12	Accounts payable . . . . .	12 0
13	Contributions, gifts, grants, etc., payable . . . . .	13 0
14	Mortgages and notes payable (attach an itemized list) . . . . .	14 0
15	Other liabilities (attach an itemized list). . . . .	15 0
16	Total Liabilities (add lines 12 through 15). . . . .	16 0
<b>Fund Balances or Net Assets</b>		
17	Total fund balances or net assets. . . . .	17 0
18	Total Liabilities and Fund Balances or Net Assets (add lines 16 and 17) . . . . .	18 0
19	Have there been any substantial changes in your assets or liabilities since the end of the period shown above? If "Yes," explain.	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

**Part X Public Charity Status**

Part X is designed to classify you as an organization that is either a **private foundation** or a **public charity**. Public charity status is a more favorable tax status than private foundation status. If you are a private foundation, Part X is designed to further determine whether you are a **private operating foundation**. (See instructions.)

1a	Are you a private foundation? If "Yes," go to line 1b. If "No," go to line 5 and proceed as instructed. If you are unsure, see the instructions.	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
b	As a private foundation, section 508(e) requires special provisions in your organizing document in addition to those that apply to all organizations described in section 501(c)(3). Check the box to confirm that your organizing document meets this requirement, whether by express provision or by reliance on operation of state law. Attach a statement that describes specifically where your organizing document meets this requirement, such as a reference to a particular article or section in your organizing document or by operation of state law. See the instructions, including Appendix B, for information about the special provisions that need to be contained in your organizing document. Go to line 2.	
2	Are you a private operating foundation? To be a private operating foundation you must engage directly in the active conduct of charitable, religious, educational, and similar activities, as opposed to indirectly carrying out these activities by providing grants to individuals or other organizations. If "Yes," go to line 3. If "No," go to the signature section of Part XI.	<input type="checkbox"/> Yes <input type="checkbox"/> No
3	Have you existed for one or more years? If "Yes," attach financial information showing that you are a private operating foundation; go to the signature section of Part XI. If "No," continue to line 4.	<input type="checkbox"/> Yes <input type="checkbox"/> No
4	Have you attached either (1) an affidavit or opinion of counsel, (including a written affidavit or opinion from a certified public accountant or accounting firm with expertise regarding this tax law matter), that sets forth facts concerning your operations and support to demonstrate that you are likely to satisfy the requirements to be classified as a private operating foundation; or (2) a statement describing your proposed operations as a private operating foundation?	<input type="checkbox"/> Yes <input type="checkbox"/> No
5	If you answered "No" to line 1a, indicate the type of public charity status you are requesting by checking one of the choices below. You may check only one box.	

The organization is not a private foundation because it is:

- a** 509(a)(1) and 170(b)(1)(A)(i)—a church or a convention or association of churches. Complete and attach Schedule A. ☐
- b** 509(a)(1) and 170(b)(1)(A)(ii)—a **school**. Complete and attach Schedule B. ☐
- c** 509(a)(1) and 170(b)(1)(A)(iii)—a **hospital**, a cooperative hospital service organization, or a medical research organization operated in conjunction with a hospital. Complete and attach Schedule C. ☐
- d** 509(a)(3)—an organization supporting either one or more organizations described in line 5a through c, f, g, or h or a publicly supported section 501(c)(4), (5), or (6) organization. Complete and attach Schedule D. ☐
- 
- e** 509(a)(4)—an organization organized and operated exclusively for testing for public safety. ☐
- f** 509(a)(1) and 170(b)(1)(A)(iv)—an organization operated for the benefit of a college or university that is owned or operated by a governmental unit. ☐
- g** 509(a)(1) and 170(b)(1)(A)(vi)—an organization that receives a substantial part of its financial support in the form of contributions from publicly supported organizations, from a governmental unit, or from the general public. ☒
- h** 509(a)(2)—an organization that normally receives not more than one-third of its financial support from gross **investment income** and receives more than one-third of its financial support from contributions, membership fees, and gross receipts from activities related to its exempt functions (subject to certain exceptions). ☐
- i** A publicly supported organization, but unsure if it is described in 5g or 5h. The organization would like the IRS to decide the correct status. ☐
- 6** If you checked box g, h, or i in question 5 above, you must request either an **advance** or a **definitive ruling** by selecting one of the boxes below. Refer to the instructions to determine which type of ruling you are eligible to receive.
- a Request for Advance Ruling:** By checking this box and signing the consent, pursuant to section 6501(c)(4) of the Code you request an advance ruling and agree to extend the statute of limitations on the assessment of excise tax under section 4940 of the Code. The tax will apply only if you do not establish public support status at the end of the 5-year advance ruling period. The assessment period will be extended for the 5 advance ruling years to 8 years, 4 months, and 15 days beyond the end of the first year. You have the right to refuse or limit the extension to a mutually agreed-upon period of time or issue(s). Publication 1035, *Extending the Tax Assessment Period*, provides a more detailed explanation of your rights and the consequences of the choices you make. You may obtain Publication 1035 free of charge from the IRS web site at [www.irs.gov](http://www.irs.gov) or by calling toll-free 1-800-829-3676. Signing this consent will not deprive you of any appeal rights to which you would otherwise be entitled. If you decide not to extend the statute of limitations, you are not eligible for an advance ruling. ☒

### Consent Fixing Period of Limitations Upon Assessment of Tax Under Section 4940 of the Internal Revenue Code

For Organization

..... **George Church** .....  
 (Signature of Officer, Director, Trustee, or other authorized official) (Type or print name of signer) (Date)  
 ..... **President** .....  
 (Type or print title or authority of signer)

For IRS Use Only

..... Date .....  
 IRS Director, Exempt Organizations

- b Request for Definitive Ruling:** Check this box if you have completed one tax year of at least 8 full months and you are requesting a definitive ruling. To confirm your public support status, answer line 6b(i) if you checked box g in line 5 above. Answer line 6b(ii) if you checked box h in line 5 above. If you checked box i in line 5 above, answer both lines 6b(i) and (ii). ☐
- (i) (a)** Enter 2% of line 8, column (e) on Part IX-A. Statement of Revenues and Expenses. \_\_\_\_\_
- (b)** Attach a list showing the name and amount contributed by each person, company, or organization whose gifts totaled more than the 2% amount. If the answer is "None," check this box. ☐
- (ii) (a)** For each year amounts are included on lines 1, 2, and 9 of Part IX-A. Statement of Revenues and Expenses, attach a list showing the name of and amount received from each **disqualified person**. If the answer is "None," check this box. ☐
- (b)** For each year amounts are included on line 9 of Part IX-A. Statement of Revenues and Expenses, attach a list showing the name of and amount received from each payer, other than a disqualified person, whose payments were more than the larger of (1) 1% of line 10, Part IX-A. Statement of Revenues and Expenses, or (2) \$5,000. If the answer is "None," check this box. ☐

- 7** Did you receive any unusual grants during any of the years shown on Part IX-A. Statement of Revenues and Expenses? If "Yes," attach a list including the name of the contributor, the date and amount of the grant, a brief description of the grant, and explain why it is unusual.

☐ Yes ☒ No

**Part XI User Fee Information**

*You must include a user fee payment with this application. It will not be processed without your paid user fee. If your average annual gross receipts have exceeded or will exceed \$10,000 annually over a 4-year period, you must submit payment of \$750. If your gross receipts have not exceeded or will not exceed \$10,000 annually over a 4-year period, the required user fee payment is \$300. See instructions for Part XI, for a definition of **gross receipts** over a 4-year period. Your check or money order must be made payable to the United States Treasury. User fees are subject to change. Check our website at [www.irs.gov](http://www.irs.gov) and type "User Fee" in the keyword box, or call Customer Account Services at 1-877-829-5500 for current information.*

- 1** Have your annual gross receipts averaged or are they expected to average not more than \$10,000? ☐ Yes ☒ No  
If "Yes," check the box on line 2 and enclose a user fee payment of \$300 (Subject to change—see above).  
If "No," check the box on line 3 and enclose a user fee payment of \$750 (Subject to change—see above).
- 2** Check the box if you have enclosed the reduced user fee payment of \$300 (Subject to change). ☐
- 3** Check the box if you have enclosed the user fee payment of \$750 (Subject to change). ☒

I declare under the penalties of perjury that I am authorized to sign this application on behalf of the above organization and that I have examined this application, including the accompanying schedules and attachments, and to the best of my knowledge it is true, correct, and complete.

**Please  
Sign  
Here**



.....  
(Signature of Officer, Director, Trustee, or other authorized official)

**George Church**

.....  
(Type or print name of signer)

.....  
(Date)

**President**

.....  
(Type or print title or authority of signer)

**Reminder:** Send the completed Form 1023 Checklist with your filled-in application.



# Form 1023 Checklist

(Revised June 2006)

## Application for Recognition of Exemption under Section 501(c)(3) of the Internal Revenue Code

**Note.** Retain a copy of the completed Form 1023 in your permanent records. Refer to the General Instructions regarding Public Inspection of approved applications.

**Check each box to finish your application (Form 1023). Send this completed Checklist with your filled-in application. If you have not answered all the items below, your application may be returned to you as incomplete.**

- ☒ Assemble the application and materials in this order:
- Form 1023 Checklist
  - Form 2848, *Power of Attorney and Declaration of Representative* (if filing)
  - Form 8821, *Tax Information Authorization* (if filing)
  - Expedite request (if requesting)
  - Application (Form 1023 and Schedules A through H, as required)
  - Articles of organization
  - Amendments to articles of organization in chronological order
  - Bylaws or other rules of operation and amendments
  - Documentation of nondiscriminatory policy for schools, as required by Schedule B
  - Form 5768, *Election/Revocation of Election by an Eligible Section 501(c)(3) Organization To Make Expenditures To Influence Legislation* (if filing)
  - All other attachments, including explanations, financial data, and printed materials or publications. Label each page with name and EIN.
- ☒ User fee payment placed in envelope on top of checklist. DO NOT STAPLE or otherwise attach your check or money order to your application. Instead, just place it in the envelope.
- ☒ Employer Identification Number (EIN)
- ☒ Completed Parts I through XI of the application, including any requested information and any required Schedules A through H.
- You must provide specific details about your past, present, and planned activities.
  - Generalizations or failure to answer questions in the Form 1023 application will prevent us from recognizing you as tax exempt.
  - Describe your purposes and proposed activities in specific easily understood terms.
  - Financial information should correspond with proposed activities.
- ☒ Schedules. Submit only those schedules that apply to you and check either "Yes" or "No" below.
- |            |          |             |            |          |             |
|------------|----------|-------------|------------|----------|-------------|
| Schedule A | Yes ____ | No <u>X</u> | Schedule E | Yes ____ | No <u>X</u> |
| Schedule B | Yes ____ | No <u>X</u> | Schedule F | Yes ____ | No <u>X</u> |
| Schedule C | Yes ____ | No <u>X</u> | Schedule G | Yes ____ | No <u>X</u> |
| Schedule D | Yes ____ | No <u>X</u> | Schedule H | Yes ____ | No <u>X</u> |

- ☒ An exact copy of your complete articles of organization (creating document). Absence of the proper purpose and dissolution clauses is the number one reason for delays in the issuance of determination letters.
- Location of Purpose Clause from Part III, line 1 (Page, Article and Paragraph Number) **Page 1, Section 3**
  - Location of Dissolution Clause from Part III, line 2b or 2c (Page, Article and Paragraph Number) or by operation of state law **Page 2, Section 9**
- ☒ Signature of an officer, director, trustee, or other official who is authorized to sign the application.
- Signature at Part XI of Form 1023.
- ☒ Your name on the application must be the same as your legal name as it appears in your articles of organization.

Send completed Form 1023, user fee payment, and all other required information, to:

Internal Revenue Service  
P.O. Box 192  
Covington, KY 41012-0192

If you are using express mail or a delivery service, send Form 1023, user fee payment, and attachments to:

Internal Revenue Service  
201 West Rivercenter Blvd.  
Attn: Extracting Stop 312  
Covington, KY 41011

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit A (Form 2848)

See attached.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit B (Articles of Incorporation)

See attached.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit C (Bylaws)

See attached.

### **Background:**

In an unprecedented achievement, the Human Genome Project provided the first drafts of nearly complete human genome sequences in 2001 after more than a decade of effort by scientists worldwide. This information is now being used to advance medicine, human biology, and knowledge of human origins. Increasingly, individuals are seeking to have their own genome sequenced so that they may use this information to understand such things as their individual risk profiles for disease, their physical and biological characteristics, and their personal ancestries. But to reach this point will require a critical mass of interested users, tools for obtaining and interpreting genome information, and supportive policy, research, and service communities. PersonalGenomes.org was launched in an effort to help reach those goals.

### **Mission:**

To encourage the development of personal genomics technology and practices that are effective, informative and responsible, yield identifiable and improvable benefits at manageable levels of risk, and are broadly available. To disseminate such information without charge for the benefit of the general public.

### **Activities:**

PersonalGenomes.org will build a framework for prototyping and evaluating personal genomics technology and practices at increasing scales.

The primary activities of PersonalGenomes.org include:

- Develop a broad vision for how personal genomes may be used to improve the understanding and management of human health and disease.
- Provide educational and informational resources for improving the general understanding of personal genomics and its potential.
- Recruit individuals interested in obtaining and openly sharing their genome sequences, related health and physical information, and reporting their experiences as a participant of the project on an ongoing basis. To be eligible to participate, individuals must successfully complete an online assessment of their comprehension of concepts relevant to providing informed consent and submit an Institutional Review Board-approved informed consent form. Participants also must pay an enrollment fee of \$1,000, which amount represents a substantial subsidy as compared to the fair market value of the genome sequencing services provided. The online assessment and consent form are attached hereto as **Exhibit D-1**.
- Develop technologies to improve the accessibility of personal genome sequencing and obtain intellectual property rights in such new technologies developed by PersonalGenomes.org. PersonalGenomes.org, with approval from the Board of Directors, may license certain of its intellectual property rights. License fees may be charged in the discretion of the Board of Directors at fair and reasonable fees as determined by the Board of Directors. At this time, the only such license contemplated by PersonalGenomes.org is a license of certain of its rights in the

“POLONATOR” trademark to Dover Systems, a division of Danaher Corporation, pursuant to which PersonalGenomes.org will receive trademark maintenance cost reimbursement only.

- Accept contributions of intellectual property rights in personal genome sequencing and related technologies that further its exempt purposes, as determined by the Board of Directors. No such contribution arrangement exists or is specifically contemplated at this time.
- Foster dialog with research communities, industries, and public and governmental bodies with interests in personal genomics, and related ethical, legal, and social issues.
- Develop tools for interpreting genomic information and correlating it with related personal medical and biological information.
- Award grants and other distributions, including the provision of seed funding for regional project sites, to Section 501(c)(3) organizations furthering personal genomics technology and practices and related charitable, scientific and educational activities. All recipients of distributions will be approved by the Board of Directors in advance and in accordance with PersonalGenomes.org’s conflict of interest policy.
- Reports related to performance benchmarks and progress toward achieving such goals will be required at least annually and upon completion of each personal genomics technology project. Such reports will be retained for seven (7) years in accordance with PersonalGenomes.org’s document retention policy.

Visit [www.personalgenomes.org](http://www.personalgenomes.org) for more information on the activities and goals of PersonalGenomes.org.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit D-1 (Online Assessment and Project Consent)

See attached.



Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit E (Directors, Officers and Highly Compensated Employees and Independent Contractors)

Name	Title(s)	Address	Qualifications	Avg. Hrs. Worked Monthly	Duties	Compensation
George Church	President / Director	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115	Professor of Genetics, Harvard Medical School; Professor of Health Sciences Tech at Harvard and MIT	10	See Bylaws, Article IV, Section 5 and Article II, Section 1	None
Jason Bobe	Treasurer / Director	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115	Director of Community for Personal Genome Project	80	See Bylaws, Article IV, Section 8 and Article II, Section 1	None
Daniel Vorhaus	Secretary	101 N. Tryon Street, Suite 1900 Charlotte, NC 28246	Attorney at Robinson, Bradshaw & Hinson P.A.	30	See Bylaws Article IV, Section 7	None
Joseph Thakuria	Director	NRB 238, 77 Avenue Louis Pasteur, Boston, Massachusetts 02115	Medical Genetics Fellow, Harvard Medical School; Harvard Scholars in Clinical Science Program	10	See Bylaws, Article II, Section 1	None
Ryan Phelan	Director	Ryan Phelan Pier 9, Suite 105 San Francisco, CA 94111	CEO and founder of DNADirect	10	See Bylaws, Article II, Section 1	None
John Halamka	Director	1135 Tremont, 6th Floor Boston, MA 02120	Chief Information Officer of the CareGroup Health System, Chief Information Officer and Dean for Technology at Harvard Medical School.	10	See Bylaws, Article II, Section 1	None
Esther Dyson	Director	EDventure Holdings c/o Meetup, 10th floor 632 Broadway New York, NY 10012 USA	Board of Directors, 23andMe, WPP Group; chairman, EDventure Holdings.	10	See Bylaws, Article II, Section 1	None

A full curriculum vitae for each Director of PersonalGenomes.org is attached to **Exhibit E-1** hereto.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit E-1 (Curriculum Vitaes of Directors of PersonalGenomes.org)

See attached.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit F (Conflict of Interest Policy)

See attached.

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit G (Description of Fundraising Program)

Personalgenomes.org will seek contributions from state and federal government entities, corporations, foundations and individuals. Most contributions will be solicited personally by PersonalGenomes.org's officers, directors and community volunteers. PersonalGenomes.org will also hold and license intellectual property rights in the personal genomics technology and practices. PersonalGenomes.org does not expect to engage the services of professional fundraising consultants or solicitors.

**Part IX.9 Itemized List (Gross Receipts)**

**2008 (7/1/08-12/31/08)**

\$100,000 = 100 participants x \$1000 participant fees

**2009 (1/1/09-12/31/09)**

\$1,000,000 = 1000 participants x \$1000 participant fees

**2010 (1/1/10-12/31/10)**

\$10,000,000 = 10,000 participants x \$1000 participant fees

**Part IX.15 Itemized List (Contributions, gifts, grants paid out)**

**2008 (7/1/08-12/31/08)**

\$0

**2009 (1/1/09-12/31/09)**

\$50,000 Seed funding for 1-2 regional project sites

**2010 (1/1/10-12/31/10)**

\$100,000 Seed funding for 2-4 regional project sites

**Part IX.23 Itemized List (Expenses, e.g. program services)**

**2008 (7/1/08-12/31/08)**

\$450,000 Reagents and laboratory supplies

\$40,000 Laboratory services and tissue specimen management

\$10,000 Office materials and supplies

\$500,000 Total

**2009 (1/1/09-12/31/09)**

\$2,800,000 Reagents and laboratory supplies

\$320,000 Laboratory services and tissue specimen management

\$80,000 Office materials and supplies

\$3,200,000 Total

**2010 (1/1/10-12/31/10)**

\$24,500,000 Reagents and laboratory supplies

\$2,400,000 Laboratory services and tissue specimen mgmt

\$600,000 Office materials and supplies

\$27,500,000 Total

Name of Organization: PersonalGenomes.org  
Employer Identification Number: 26-2973607  
Form 1023  
Exhibit I (Grant Letter)

See attached.