# Madeleine Price Ball

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### Current position

Director of Research, Open Humans Foundation (previously PersonalGenomes.org)

### Current affiliations & collaborations

Co-founder of Open Humans https://www.openhumans.org

Director of Research, Harvard Personal Genome Project

http://www.personalgenomes.org/harvard/

2014- Collaborator: Human-Computer Interaction for Personal Genomics

http://cs.wellesley.edu/~hcilab/pghci.html

2015- Collaborator: PeopleSeq Consortium

http://www.genomes2people.org/the-peopleseq-consortium/

Fellow, Shuttleworth Foundation

https://shuttleworthfoundation.org/fellows/

### Previous positions & education

- 2014-2015 Senior Research Scientist, PersonalGenomes.org (now Open Humans Foundation)
- 2010-2014 Postdoctoral Researcher, George Church laboratory at Harvard Medical School.
- 2010 Pн.D. in Biophysics, Harvard University.
- B.S. in Biology, California Institute of Technology.

#### Current work

My current focus is Open Humans, a project I co-founded. Open Humans is a program of the Open Humans Foundation, a 501(c)(3) nonprofit organization dedicated to making a wide spectrum of data about humans accessible to increase biological literacy and improve human health.

Open Humans combines technology and community to advance an open and participant-centric approach to human subjects research. By working with the individuals who are contributing to research, we can enable new ways to share data and new approaches to doing science.

At Open Humans, I lead operations and collaborate on strategy with co-founder Jason Bobe. This multifaceted role includes collaborating with researchers, fundraising via grant applications, outreach through writing and speaking, and leading our technical development and operations.

### Invited Speaking & Awards

- Speaker, "Tools, Resources, and Communities" session at the Third Annual Health Data Exploration Network Meeting: "Promoting Social Justice in the Use of Personal Health Data".
- Presenter, "Uncomfortable Data" session at "Our World, Our Data: Taking Collective Responsibility for Citizen and Environmental Sensing".
- Speaker, "Open Humans" at the Participant Reflections session, Sage Bionetworks 2017 Assembly.
- Sage Bionetworks 2017 Assembly: Young Investigator/Innovator Award, jointly with Dana Lewis. "OpenAPS Commons: A citizen-driven data commons enabled by the Open Humans system".
- Panelist, "A Public Infrastructure for Data Access" at the Quantified Self Public Health Symposium.
- Presenter, "Enabling Personal Health Data Donation: Models that Work" session at the Health Data Exploration Project Network Meeting.
- Panelist, "Picked Out of a Crowd: Privacy and Re-Identification Research" at PRIM&R's Advancing Ethical Research Conference.
- 2015 Presenter, "Opening Up Access" at the Quantified Self Public Health Symposium. (On Vimeo.)
- Master of Ceremonies, "Explorers Session" at the GET (Genomes, Environment, Traits) Conference.
- Personal Genome Project talk at the 2012 Open Science Summit. (On Youtube.)
- Genome Technology: Young Investigator award.

## Selected publications

The whole genome sequences and experimentally phased haplotypes of over 100 personal genomes. Mao Q, Ciotlos S, Zhang RY, Ball MP, Chin R, Carnevali P, Barua N, Nguyen S, Agarwal MR, Clegg T, Connelly A, Vandewege W, Zaranek AW, Estep PW, Church GM, Drmanac R, Peters BA. *Gigascience*, Oct 11 2016.

2016 Social Annotation Valence: The Impact on Online Informed Consent Beliefs and Behavior.

Balestra M, Shaer O, Okerlund J, Westendorf L, Ball M, Nov O. J Med Internet Res, July 2016.

2016 GenomiX: A Novel Interaction Tool for Self-Exploration of Personal Genomic Data.

Shaer O, Nov O, Okerlund J, Balestra M, Stowell E, Westendorf L, Pollalis C, Westort L, Davis J, Ball M. Proc. CHI 2016 Computer-Human Interaction, May 2016.

Personal Data Freedom. Madeleine Ball. Quantified Self: Access Matters, Feb 11 2015.

Harvard Personal Genome Project: lessons from participatory public research.

Ball MP, Bobe J, Chou MF, Clegg T, Estep PW, Lunshof JE, Vandewege W, Zaranek A, Church GM. Genome Med, Feb 28 2014.

Our genomes today: time to be clear. Jeantine Lunshof & Madeleine Ball. Genome Med, Jun 27 2013.

A public resource facilitating clinical use of genomes.

Ball MP, Thakuria JV, Zaranek AW, Clegg T, Rosenbaum AM, Wu X, Angrist M, Bhak J, Bobe J, Callow MJ, Cano C, Chou MF, Chung WK, Douglas SM, Estep PW, Gore A, Hulick P, Labarga A, Lee JH, Lunshof JE, Kim BC, Kim JI, Li Z, Murray MF, Nilsen GB, Peters BA, Raman AM, Rienhoff HY, Robasky K, Wheeler MT, Vandewege W, Vorhaus DB, Yang JL, Yang L, Aach J, Ashley EA, Drmanac R, Kim SJ, Li JB, Peshkin L, Seidman CE, Seo JS, Zhang K, Rehm HL, Church GM. *Proc Natl Acad Sci U S A.*, July 24 2012.

Neuronal activity modifies the DNA methylation landscape in the adult brain.

Guo JU, Ma DK, Mo H, **Ball MP**, Jang MH, Bonaguidi MA, Balazer JA, Eaves HL, Xie B, Ford E, Zhang K, Ming GL, Gao Y, Song H. *Nature Neuroscience*, August 28 2011.

Targeted and genome-scale strategies reveal gene-body methylation signatures in human cells.

Ball MP, Li JB, Gao Y, Lee JH, LeProust EM, Park IH, Xie B, Daley GQ, Church GM. Nature Biotechnology, May 2009.

#### Technical skills

2015

2014

2013

2012

2011

2009

PROGRAMMING LANGUAGES

• Python

Web frameworks (Django & Flask)

REST API and OAuth2 (django-rest-framework & django-oauth-toolkit)

Module management, development, and deployment (pip, PyPI, virtualenv)

Asynchronous processing (Celery)

Scientific data processing (biopython, jupyter, numpy, pandas, scipy)

• JavaScript

AJAX and front-end development (JQuery)

Markup languages & Serialization formats

• CSS/SCSS, HTML, JSON, Markdown, XML

CLOUD SERVICES

- DevOps: AWS (EC2, S3, Route 53), Codeship, GitHub, Heroku, Sentry
- Organization operations & communications (G Suite, Desk.com, Mailchimp, Slack)

### Additional projects

Created Genevieve and GenNotes: an open source webapp and wiki-like database for collabora-2015-2017 tive, public domain genetic variant interpretation. Contributed code & public domain genetic variant interpretations in GET-Evidence, a collaborative 2011-2013 approach for genome interpretation. Created python-gedcom, a python library for parsing and manipulating GEDCOM ancestry files. Co-created ExploreTree, an open source online visualization of Newick tree structures, including 2010 a curated phylogenetic tree. ExploreTree won a prize at MIT's 2010 "Processing Time" code jam. Contributed to OLPC WikiBrowse, One Laptop Per Child's offline snapshot of Wikipedia. I created 2009 the list of included articles, using Wikipedia's traffic statistics. Contributions to various Wikipedia pages, including complete rewrites for high traffic pages 2007-2009 [[Genetics]] and [[Sex]].