

# Madeleine Price Ball

Email: [mpball@gmail.com](mailto:mpball@gmail.com)

Twitter: [@madprime](https://twitter.com/madprime)

GitHub: [madprime](https://github.com/madprime)

## Current position

2017- Executive Director, [Open Humans Foundation](#)

## Current affiliations & collaborations

2017- Fellow, Shuttleworth Foundation  
<https://shuttleworthfoundation.org/fellows/madeleine-ball/>

2015- Collaborator: PeopleSeq Consortium  
<http://www.genomes2people.org/the-peopleseq-consortium/>

2014- Collaborator: Human-Computer Interaction for Personal Genomics  
<http://cs.wellesley.edu/~hcilab/pghci.html>

## Previous positions & education

2015-2017 Director of Research, Open Humans Foundation (named PersonalGenomes.org until 2016)

2014-2015 Senior Research Scientist, PersonalGenomes.org

2010-2016 Director of Research, Harvard Personal Genome Project

2010-2014 Postdoctoral Researcher, George Church laboratory at Harvard Medical School.

2010 Ph.D. in Biophysics, Harvard University.

2002 B.S. in Biology, California Institute of Technology.

## Current work

My primary focus is my work as Executive Director of [Open Humans Foundation](#), a 501(c)(3) non-profit organization dedicated to making a wide spectrum of data about humans accessible to to increase biological literacy and improve human health. This mission is primarily realized through [Open Humans](#), a project I co-founded.

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.

My work also extends to related areas in participant-centered research, open science, and advocacy. This includes ongoing collaborations, as well as other organization programs: the [Global Network of Personal Genome Projects](#), and the [Genome-Environment-Traits \(GET\) Conference](#).

## Invited Speaking & Awards

- 2017 Panelist, “Tools, Resources, and Communities” session at the Third Annual Health Data Exploration Network Meeting: “Promoting Social Justice in the Use of Personal Health Data”.
- 2017 Speaker, “Uncomfortable Data” session at “Our World, Our Data: Taking Collective Responsibility for Citizen and Environmental Sensing”.
- 2017 Speaker, “Open Humans” at the Participant Reflections session, [Sage Bionetworks 2017 Assembly](#).
- 2017 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”.
- 2016 Panelist, “A Public Infrastructure for Data Access” at the [Quantified Self Public Health Symposium](#).
- 2016 Presenter, “Enabling Personal Health Data Donation: Models that Work” session at the [Health Data Exploration Project Network Meeting](#).
- 2015 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.)
- 2013 Master of Ceremonies, “Explorers Session” at the [GET \(Genomes, Environment, Traits\) Conference](#).
- 2012 Personal Genome Project talk at the 2012 Open Science Summit. (On Youtube.)
- 2012 Genome Technology: Young Investigator award.

## Selected publications

- 2016 [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, Van-

dewege 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.

2015

[Personal Data Freedom.](#) Madeleine Ball. *Quantified Self: Access Matters*, Feb 11 2015.

2014

[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.

2013

[Our genomes today: time to be clear.](#) Jeantine Lunshof & Madeleine Ball. *Genome Med*, Jun 27 2013.

2012

[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.

2011

[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.

2009

[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

### 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

2015-2017	Created <a href="#">Genevieve</a> and <a href="#">GenNotes</a> : an open source webapp and wiki-like database for collaborative, public domain genetic variant interpretation.
2011-2013	Contributed <a href="#">code</a> & public domain genetic variant interpretations in <a href="#">GET-Evidence</a> , a collaborative approach for genome interpretation.
2012	Created <a href="#">python-gedcom</a> , a python library for parsing and manipulating GEDCOM ancestry files.
2010	Co-created <a href="#">ExploreTree</a> , an open source online visualization of Newick tree structures, including a curated phylogenetic tree. ExploreTree won a prize at MIT's 2010 "Processing Time" code jam.
2009	Contributed to <a href="#">OLPC WikiBrowse</a> , <a href="#">One Laptop Per Child's</a> offline snapshot of Wikipedia. I created the list of included articles, using Wikipedia's traffic statistics.
2007-2009	Contributions to various Wikipedia pages, including complete rewrites for high traffic pages <a href="#">[[Genetics]]</a> and <a href="#">[[Sex]]</a> .