# Madeleine Price Ball

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## 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    Keynote, "Open Sourcing Ourselves" and "Open Data" session panelist at the 18th Annual Bioinformatics Open Source Conference.

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, "Participant Reflections" session & Young Investigator/Innovator Award (jointly with Dana Lewis): "OpenAPS Commons: A citizen-driven data commons enabled by the Open Humans system", Sage Bionetworks 2017 Assembly.

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, 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.

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 Genevieve and GenNotes: an open source webapp and wiki-like database for collaborative, public domain genetic variant interpretation.

2011-2013    Contributed code & public domain genetic variant interpretations in GET-Evidence, a collaborative approach for genome interpretation.

2012    Created python-gedcom, a python library for parsing and manipulating GEDCOM ancestry files.

2010    Co-created ExploreTree, 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 OLPC WikiBrowse, One Laptop Per Child's 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 [[Genetics]] and [[Sex]].