

Science Discussion Series: What should and shouldn't be done with your personal genetic data? Who should benefit? We are researchers and advocates who are working on new models for DNA research. Let's discuss!

ScienceModerator<sup>1</sup> and r/Science AMAs<sup>1</sup>

<sup>1</sup>Affiliation not available

April 17, 2023

## Abstract

Hi reddit! We're a group of scientists and advocates who believe that the traditional genetics research model is outdated. We think that people who participate in genetic studies should be involved in decision-making, that research projects should collaborate, that samples should be diverse, and that studies should use real world data. We need these changes to improve our ability to discover treatments and cures for diseases. But at the same time, researchers also need to ensure participant privacy, data security, and give participants the chance to weigh in on and directly benefit from research- medically, informationally, and financially. Let's discuss! With us today are an array of researchers and leaders from a variety of genetics backgrounds working with a company, LunaPBC, on these questions. Dawn Barry (u/Dawn\_Barry): I'm the President and Co-founder at LunaPBC, Board Chair at Alzheimer's Association San Diego/Imperial Chapter, and former VP Applied Genomics at Illumina. The twelve years I spent at Illumina, Inc., I led pioneering teams in preemptive health screening, nutrition security, and transplant diagnostics. I was also the co-founder of the Illumina Understand Your Genome symposium, which is now owned by Genome Medical. Bob Kain (u/Bob\_Kain): I'm the Chief Executive Officer and Co-founder at LunaPBC, 2019 World Economic Forum's Tech Pioneer, and former Chief Engineering Officer at Illumina. During my 15-year tenure, Illumina grew from a research start up of 30 employees to a global genomics leader of 3,000 employees with \$1.5 billion in revenue. My team helped reduce the cost of genome sequencing from a million dollars in 2006 to \$1,000 in 2015. The products developed enabled new applications for DNA sequencing in agriculture, pathogen identification and precision medicine. Today, I'm building a talented, ethical team with unifying visions to create a world-changing solution and improve the quality of life for all at LunaPBC. Scott Kahn, Ph.D (u/Scott\_Kahn): I'm the Chief Information Officer at LunaPBC, Board of Directors at Rady Children's Institute for Genomic Medicine, and former Chief Information Officer and Vice President Commercial, Enterprise Informatics at Illumina. I'm integrating data privacy and security provisions that comply with GDPR and HIPAA at the world's first community-owned health database that offer shares of ownership to health data contributors. Kirby Bloom (u/Kirby\_Bloom): I'm the Chief Architect at LunaPBC, former Head of Software for Applied Genomics at Illumina, and MIDS candidate at the University of California, Berkeley. I'm helping bridge the gap between research scientists and large scale data analytics by building the tools needed to produce better insights for health discovery. Sharon Terry (u/Sharon-Terry): I'm the President and CEO of the Genetic Alliance, a network transforming health by promoting openness and is founding CEO of PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE). My memberships and advisories include the International Rare Disease Research Consortium and the Institute of Medicine Science and Policy Board. I was instrumental in the passage of the Genetic Information Nondiscrimination Act. Among other awards I received was the Clinical Research Forum, Foundation's Annual Award for Leadership in Public Advocacy in 2011, and PMWC 2019 Luminary Award Recipient. Yaniv Erlich, Ph.D (u/Yaniv-Erlich): I'm the creator of DNA.Land, Chief Science Officer of MyHeritage.com, and until recently, an Associate Professor of Computer Science and Computational Biology at Columbia University. I'm a TEDMED speaker (2018), the recipient of DARPA's Young Faculty Award (2017), the Burroughs Wellcome Career Award (2013) and the Harold M.

Weintraub award (2010). Aristides Patrinos, Ph.D (u/Aristides\_Patrinos): I am the Chief Scientist and Director for Research of the NOVIM Group, Former Lead at the Human Genome Project, LunaDNA Advisor, and leading authority on structural biology, genomics, global environmental change, and nuclear medicine. I'm dedicated to the development of synthetic biology and in the development of clean and renewable fuels and chemicals, sustainable food products, and novel medical applications. EDIT: Thank you to everyone who participated in this important discussion about the future of health discovery. We believe the fastest, most impactful change can only happen at the level of community. Your voice matters. Please feel free to continue the conversation at [lunadna.com](http://lunadna.com) and @LunaDNA\_ on Twitter. Until then, it was our pleasure chatting with you!

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