



## **Genetic Alliance and LunaPBC Partner to Support Personal Health and Accelerate Medical Breakthroughs**

*People-powered platforms to integrate under a unified mission to empower individuals and organizations to create health communities and drive medical discovery*

Solana Beach, Calif. — January 22, 2019 — [LunaPBC](#), founder of [LunaDNA](#), the first community-owned genomic and health data platform, announced today its partnership with [Genetic Alliance](#), a non-profit dedicated to providing ordinary people with powerful tools to transform research. Over the course of 2019, the organizations will merge Genetic Alliance's Platform for Engaging Everyone Responsibly engagement platform with LunaDNA to provide individuals and communities with more resources to support health management while maximizing research opportunities.

The partnership enables LunaPBC and Genetic Alliance to unite their shared mission and technologies to create seamless solutions to support individuals, disease foundations, and patient advocacy organizations while also powering disease research at scale. Shared values across both organizations will ensure the ongoing focus of honoring a person's preferences and rights for data transparency, privacy, and control while accelerating science and creating shared value.

In December 2018, LunaDNA received precedent-setting approval from the U.S. Securities and Exchange Commission (SEC) to recognize an individual's health data as currency with which to acquire shares of ownership in the company. Researchers from nonprofits, for-profits, disease organizations, and research communities can request access to the LunaDNA platform to conduct research studies. LunaDNA members' de-identified, aggregated, and encrypted health data helps power research at the scope and scale needed for medical breakthroughs.

"The joining of Genetic Alliance's patient outreach and engagement with LunaDNA's person-centered data management expertise takes advantage of both organizations' exceptional strengths. This will accelerate the research opportunities afforded by rich, longitudinal data, and a cohort of research-aware participants and has the potential to change the clinical research paradigm and how participants are connected to clinical trials," said Michelle Penny, co-chair of the National Academies of Sciences, Engineering and Medicines Roundtable on Genomics and Precision Health.

Genetic Alliance's Platform for Engaging Everyone Responsibly (PEER) is an award-winning technology solution for collecting health data directly from individuals. The platform gives individuals complete control over how their data is shared for research. Organizations and communities interested in using PEER to collect individual health data for a specific purpose do so by creating customized registries. PEER participants will join the LunaDNA community and be invited to receive ownership shares in LunaDNA when contributing their personal health information. Dividends from shares may be donated to charitable organizations of the individual's choosing. Currently, PEER is used by 45 disease communities representing more than 50,000 individual participants. The Genetic Alliance network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organization. In 2015, PEER was honored by the White House as one of nine leading platforms in the advancement of precision medicine.

“Most research endeavors leave out the most critical stakeholder: people. While health data is a critical component to the advancement of new treatments, research, and medical technology, data alone will not lead to solutions that alleviate suffering. The biomedical research enterprise tries to cut corners and sever people's connection to their data, or keep it opaque how individual health data is used and who gains access to the data individuals provide. We are excited to partner with LunaPBC because, like us, they believe individuals need and deserve opportunities to be active participants in their own health and research opportunities. The day of de-identified data is over - we need to understand what happens over time, we need people to be partners in their own research to care cycle. Together, we're providing a people-centric model that empowers the individual to offer access to their health data and also receive support. We are building secure and transparent communities and connections geared towards supporting the individual that will accelerate medical breakthroughs,” said Sharon Terry, president and CEO, Genetic Alliance.

“By putting people truly at the center of the model versus just leveraging them as sources of specimens, we engage individuals as true partners in creating a dynamic, real world asset for research. Rather than having researchers wait for sufficient data to pose questions, the community-owned data is poised to address their novel hypotheses. The opportunity to reshape research and be inclusive is good for both people and discovery,” said Dawn Barry, president and co-founder, LunaPBC.

### **About Genetic Alliance**

Genetic Alliance, a non-profit organization founded in 1986, is a leader in deploying high tech and high touch programs for individuals, families and communities to transform health systems by being responsive to the real needs of people in their quest for health. The alliance is comprised of 10,000 organizations, 1,200 of which are disease and patient advocacy foundations and include community health programs, employee wellness programs, local nonprofits, religious institutions, and community-specific programs to grow and expand their reach and mission.

### **About LunaDNA and LunaPBC**

LunaDNA is the first health and genomic data platform owned by its community of personal health information donors. LunaDNA empowers individuals to share their health data for medical research and the greater good of the community. As community owners in the LunaDNA platform, members share in the value created from health discoveries and medical breakthroughs.

LunaDNA was created by the privately-owned Public Benefit Corporation, [LunaPBC](#), founded in 2017 and headquartered in Solana Beach, California. The LunaPBC team, investors, and advisors are renowned in the patient-advocacy, health, and science fields, including several former chief executives of Illumina, industry academics, and financial executives.

For more information visit [www.lunadna.com](http://www.lunadna.com).

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