

April 22, 2022 Contact: <u>team@patientledresearch.com</u>

## Patient-Led Research Collaborative Receives \$3M in Funding for Long COVID Research from Balvi, A New Fund for High-Impact COVID Projects from Ethereum Co-Founder Vitalik Buterin

\$2 million will be used to establish a Long COVID biomedical research fund led by patients

Patient-Led Research Collaborative (PLRC) announced today the funding of \$3M from <u>Balvi</u>, a direct giving fund established by Vitalik Buterin, the co-creator of Ethereum, for high-impact COVID projects that aim to address pressing questions often overlooked by traditional funding sources. Balvi's investments in high-risk/high-gain projects enable key research to be fast-tracked, which will be critical to its goal of ending the COVID-19 pandemic. \$2M of the funds will be deployed by PLRC to set up a pool of Long COVID biomedical research grants awarded by the patient community, which will rapidly progress our understanding of the causes, diagnostics, and treatments of Long COVID; the remaining \$1M will fund four high-impact Long COVID research initiatives led by the Collaborative: a reinfection study, a quality of life study in a low-middle income country, a phenotyping project, and a quarterly publication of patient-generated research hypotheses.

An estimated <u>100 million people</u> across the world have Long COVID, an illness marked by debilitating symptoms which persist more than 28 days following COVID-19 infection. Patient-Led Research Collaborative (PLRC), a group of multi-disciplinary volunteer researchers with lived experience of Long COVID, was the <u>first to conduct research</u> on Long COVID. Their study in <u>The Lancet's EClinicalMedicine</u> documented over 200 symptoms of Long COVID and has been referenced by more than 500 research articles investigating the condition.

Patient-Led Research Collaborative is committed to placing experts with lived experiences in the driver's seat of research. This new funding enables the team to invest in the patient-led model and drive relevant research with scientific rigor. The team, along with the community of people with Long COVID and associated conditions, will set research agendas based on existing post-viral illness research and emerging priorities that directly serve those impacted.



With this \$3M in funding, PLRC is excited to announce five projects that will be critical to advancing knowledge of Long COVID:

- 1. **Patient-Led Research Fund:** \$2M will be directed towards providing grants to six Long COVID biomedical research projects, awarded by a panel of patient-researchers with expertise in post-viral illnesses. Eligible projects will include biomedical research, diagnostic devices, prevalence studies, and clinical trials. Uniquely, each grant will include patient engagement from PLRC at the study design, recruitment, analysis, and writing points of the research study.
- 2. **Reinfection Study:** PLRC will analyze the impact of COVID reinfections on A) people with Long COVID, B) people who did not develop Long COVID following initial infection but did after subsequent infections, and C) people who have had COVID multiple times and have not developed Long COVID.
- 3. Low-Middle Income Country (LMIC) Quality of Life Study: PLRC will research the quality of life of people with Long COVID in a select low-middle income country.
- 4. **Phenotyping Long COVID:** PLRC will identify Long COVID subtypes (clusters of characteristics and their progression) that may require different forms of treatment.
- 5. **Patient-Generated Research Hypotheses:** PLRC will produce a quarterly publication of patient-generated hypotheses shared in the public domain for Long COVID researchers to pursue.

PLRC and Balvi's shared values of public participation, global benefit, and open access will be at the forefront of all projects. Each project will include opportunities for the broader patient community to engage in. To stay up-to-date on these projects, sign up for the <u>team's</u> <u>newsletter</u> and visit <u>PLRC's website</u>, where additional information on the progress and costs of these projects will be shared publicly.

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## **About Patient-Led Research Collaborative**

Patient-Led Research Collaborative (PLRC) is a multi-disciplinary group of people with lived experience of Long COVID, formed together in April 2020 through the Body Politic COVID-19 Support Group, who were the <u>first to conduct research</u> on Long COVID. PLRC's work thus far has resulted in the <u>identification</u> of key symptoms, comorbidities, and possible treatment options for Long COVID. They have presented their work to the World Health Organization, United States House of Representatives, National Institutes of Health, and Centers for Disease Control and Prevention, and have influenced Long COVID clinical guidelines and legislation. For more on PLRC, visit <u>http://patientledresearch.com</u>.