



The Recurrent Pregnancy Loss Association Launches RPL Community Registry

First-of-its-kind patient registry aims to increase understanding and accelerate medical breakthroughs into the causes of, and treatments for, multiple miscarriages

SEATTLE, Mar 08, 2022 -- The Recurrent Pregnancy Loss Association (“RPLA”) today announced the launch of a global patient registry for individuals who have experienced multiple miscarriages. The RPL Community Registry opened today to enroll anyone who has experienced two or more pregnancy losses within the first 20 weeks of pregnancy.

“We envision a future where recurrent pregnancy loss is eliminated and individuals are empowered with the information they need to make informed health care and family-building decisions,” said Megan Hanson, RPLA President. “This registry will accelerate our progress toward making this vision a reality. We are calling on all those who have experienced multiple miscarriages to become ‘citizen scientists’ by joining our RPL Community Registry to help us find answers.”

The RPL Community Registry, a database that contains information about individuals and their medical history, can help doctors and scientists answer questions, inform course of treatment, and generate new research hypotheses as it relates to recurrent pregnancy loss. The registry can also be used to help connect patients to clinical trials and other research opportunities that may be relevant to their individual circumstances.

“The formation of a patient registry is the first step toward performing meaningful research on recurrent pregnancy loss,” said Dana McQueen, MD, University of Chicago. “Couples with recurrent pregnancy loss are a diverse group with varying factors leading to their diagnosis. To effectively study recurrent pregnancy loss, a large study cohort is necessary to differentiate between types of miscarriage and achieve statistical significance.”

The RPL Community Registry was built with Promise for Engaging Everyone Responsibly (PEER), an award-winning technology solution that enables organizations to build registries and conduct the research their health community cares about. PEER is a program of Genetic Alliance, a non-profit organization. Data is hosted on Luna, which operates in compliance with international and domestic privacy regulations including HIPAA, GDPR, and CCPA. Participation is confidential. Community members control and own their data every step of the way and can delete it at any time if they no longer wish to participate in the registry.

“We believe individuals need and deserve to be active participants in their own health and research opportunities,” said Sharon Terry, president and CEO of Genetic Alliance. “We’re excited the Recurrent Pregnancy Loss Association has used PEER and Luna to create a secure

and transparent community geared toward supporting individuals who have experienced multiple miscarriages while accelerating medical breakthroughs in this space."

The RPL Community Registry is open to individuals 18 and older who have experienced two or more pregnancy losses. Residents of countries outside the United States may be able to join based on their national privacy regulations.

To learn more, join, and help accelerate discovery, visit [RPL Community Registry](#).

About Recurrent Pregnancy Loss Association

RPLA is a 501(c)(3) non-profit organization dedicated to eliminating recurrent pregnancy loss through the advancement of research into causes and treatments; to providing support and resources to those affected; and to increasing awareness of the impact of miscarriage and fertility challenges on women and families. For more information, please visit [Recurrent Pregnancy Loss Association](#).

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. For additional information, please visit [Genetic Alliance](#).

About LunaPBC

Founded in 2017, LunaPBC is a public benefit corporation headquartered in San Diego, California. The team, investors, and advisors are renowned in the patient-advocacy, health, and science fields. With participation from over 180 countries and communities advancing causes including disease-specific, public health, environmental, and emerging interests, Luna's tools and services empower these collectives to gather a wide range of data -- health records, lived experience, disease history, genomics, and more -- to advance research that addresses their unique health needs. Luna makes research representative of the real world and aligned with people's true goals by giving all participants a role from right where they are. For more information, visit [LunaPBC](#).

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