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GCAC Launches the Genetic Cardiomyopathy Patient Registry

Genetic Cardiomyopathy Awareness Consortium launches the Genetic Cardiomyopathy Patient Registry

Genetic Cardiomyopathy Awareness Consortium

DUBLIN, OH, UNITED STATES, January 23, 2025 /EINPresswire.com/ -- The Genetic Cardiomyopathy Awareness Consortium, which is part of the DCM Foundation, announced the launch of the Genetic Cardiomyopathy Patient Registry during a webinar on January 22, 2025.

The Genetic Cardiomyopathy Registry is an online registry for people with genetic cardiomyopathy, or with a gene mutation suspected to cause cardiomyopathy, or those who suspect genetic cardiomyopathy may run in their family (“eligible participants”). This registry includes a series of surveys, which ask questions about a person’s experience with cardiomyopathy over time.

> “The registry is a significant step in learning more about the disease and developing effective treatments and ultimately a cure for cardiomyopathy.”
>
> *Greg Ruf, Executive Director GCAC*

The registry is sponsored by The DCM Foundation in partnership with the Genetic Cardiomyopathy Awareness Consortium and hosted by the National Organization for Rare Disorders (NORD®) on their IAMRARE® platform. This registry is only intended to collect information from eligible participants (or their authorized representatives).

The purpose of the Genetic Cardiomyopathy Registry is to bring the genetic cardiomyopathy community together and collect data from patients to advance knowledge about genetic cardiomyopathy. This registry will empower patients and family members to become a driving force in helping academic researchers and drug development companies quicken the pace in creating potential life-saving therapies for this devastating disease.

“The registry is a significant step in learning more about the disease and developing effective treatments and ultimately a cure for cardiomyopathy,” says Greg Ruf, Executive Director and Founder of the DCM Foundation. “It will also give those registered access to information about research, clinical trials, and other important data and updates about the disease.”

Other registry goals include the following:

- Identify significant numbers of participants with genetic cardiomyopathy.
- Guide participants on where and how to obtain genetic testing.
- Notify participants of research studies and clinical trials.
- Make genetic testing, diagnosis and research of genetic cardiomyopathy more patient-centric, while increasing health equity on a geographic, socio-economic, and diversity basis through the broad reach of the DCM Foundation and Genetic Cardiomyopathy Awareness Consortium.

About The Genetic Cardiomyopathy Awareness Consortium

The Genetic Cardiomyopathy Awareness Campaign was launched in the U.S. in early 2023 by eight U.S.-based cardiomyopathy patient groups to raise awareness about the need for genetic testing for cardiomyopathy patients and family members. The purpose of this campaign is to raise awareness and to get more cardiomyopathy patients and family members genetically tested, which will help save lives and advance genetic research and therapies.

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