Rare Genomics relaunches RareShare, a rare disorder social network

Washington, D.C., October, 2017. Rare Genomics Institute (RG) utilizes RareShare, an online social hub for those affected by rare medical disorders. The RareShare website, www.Rareshare.org was relaunched in February 2017 to coincide with Rare Disease Day, with the long-term goal of becoming the #1 aggregator of information about rare disorders on the Web.

RareShare aims to provide reliable information and free resources that will empower rare disease patients and families to be their own best advocate. Through RareShare, patients, families, scientists and health care professionals connect with each other in support and in hope for a cure as well as strive to alleviate the anxiety created by the unfamiliarity and isolation of rare diseases. At the time of this press release:

- RareShare membership has reached 10,170 registered users, an increase in membership of 27% since its relaunch in February.
- 5,062 of these users have been active since the Feb. 28th relaunch and of those, 58% are new and 42% are returning.
- Most users are based in the United States and English-speaking countries such as the United Kingdom, Canada and Australia. However, the website also has a strong international presence from countries such as India, Spain, Colombia and Italy.

Users within the RareShare community are engaged, trust the experts at RG as well as their partnering organizations and have explicitly expressed interest in being involved in clinical trials. Acknowledging this interest, RareShare now has an integrated clinical trial search function powered by Antidote.me. “Website enhancements such as a built-in link to the Antidote.me clinical trial tool will undoubtedly be helpful to our community members, “ says Raymond Chan, Project Manager for RareShare. “The sharing of

information within our communities reassures disease patients that their condition may be rare, but they are not alone."

In addition, rare disease patients on RareShare have the option to register with the CoRDS registry at Sanford Research (currently 3,883 participants across various organizations) and be contacted at a later date when a study is organized for their particular disease. Clinical trial registration grants current patients access to cutting edge treatments, while also aiding the approval process for life-transforming treatments for future generations.

Each RareShare disease community includes a landing page curated by scientists at RareShare and reviewed by experts within the medical and academic communities. RareShare also produces a newsletter that is distributed to all members several times a year. The "Ask the Experts" podcast features scientists, patient advocates and clinicians answering community questions and offering strategies for rare disease management - all available free through iTunes. "The relaunch of RareShare.org and the newsletter have revitalized interest in our website for both new and continuing members," Chan said. "This, in turn, has energized our RareShare volunteers to produce new rare disease informational content such as podcasts and updated disease summaries", he added. RareShare's five most recent podcasts have accumulated over 1,100 downloads. Podcast transcripts will be compiled into an ebook for future reference by community members.

RareShare is equipped with a current team of 22 volunteers, who have renewed their commitment to update disease-specific information on the site and to actively engage with its members belonging to 987 different communities. RareShare volunteers continue to receive member inquiries and make referrals for support within other parts of the organization. Moving forward, RareShare will continue to reach out to outside organizations for collaborations that serve its members.

RareShare is an online social network for patients, families, healthcare professionals and others affected by rare disease and connects communities via direct messaging and forum discussions. For more information on how to support these programs, please contact **raymond.chan@raregenomics.org**

About Rare Genomics Institute

RG is a 501(c)(3) non-profit that makes cutting edge research technologies and experts accessible to rare disease patients. Partnering with top medical institutions, RG helps custom design personalized research projects for diseases so rare that no organization exists to help. By providing an expert network, RG helps families source, design, and fund personalized research projects in diseases not otherwise studied. Ultimately, RG aims to expand on its current genome sequencing-focused approach to enable support for whatever type of research is necessary to get closer to rare disease therapeutics.