Rare Disease Families Front and Center in Upcoming Caregiving Study

The National Alliance for Caregiving and Global Genes have Launched a New Study of Caregivers for Persons with Rare Disease

WASHINGTON, DC (PRWEB) August 31, 2017 -- As many as 30 million Americans are affected by a rare disease or condition, and many of these individuals receive unpaid care from friends, family, and neighbors. While much of the focus on caregiving has historically been on the aging population in America, policymakers are beginning to take notice of the impact of caring for rare disease patients on the volunteer friends and family who provide care, known as "family caregivers."

The National Institutes of Health estimates that there are nearly 7,000 rare diseases, many of which are genetic and can result in life-altering disability or shortened lifespans. Many people who have rare diseases are misdiagnosed or undiagnosed, leaving their family caregivers to experience unique challenges related to access to appropriate medical care and medications, and the emotional burden associated with the uncertainty of managing the disease and its prognosis.

To study the impact of rare disease on family caregivers, the National Alliance for Caregiving, in partnership with rare disease patient advocacy organization, Global Genes, is launching a “first-of-its-kind” national snapshot of rare disease caregivers. This fall, the two groups plan to release a national survey aimed at collecting feedback from over 1,000 family caregivers of children and adults with rare diseases. Researchers anticipate the survey link will go live at the Global Genes Rare Patient Advocacy Summit, September 14 - 15 in Irvine, California, with a final report expected next winter.

“Families are the backbone of the rare disease community,” said Founder and CEO of Global Genes, Nicole Boice. “So often, families overcome insurmountable challenges to get care for their loved ones. We want to quantify the impact that a rare disease can have, not just on the person facing the disease, but on the community of people caring for that person.”

“The caregivers we’ve encountered in the rare disease community are very effective at advocating for their friends and family,” said C. Grace Whiting, J.D., Chief Operating Officer of the National Alliance for Caregiving. “These families, friends, and neighbors often email researchers asking for new biomedical research on their disease, they write comments to the FDA, and work within insurance and health systems to get access to care. We want to capture the power behind these families and articulate what they are doing so that they can serve as a model for caregivers in other communities.”

The study will include an independent advisory committee to review the survey questionnaire and data before its release. Researchers at Greenwald & Associates will administer the survey and conduct the data analysis, in partnership with the National Alliance for Caregiving and Global Genes. The survey will be hosted online at www.caregiving.org.

Patient advocacy communities are encouraged to invite caregivers to participate in the online survey. After fielding, the data will be collected, cleaned, and aggregated into the final report. The final report will be released in a Capitol Hill briefing for Members of Congress, including the Rare Disease Congressional Caucus.

The research is made possible through generous grant funding from the following partners: Allergen
Foundation, Alexion, Amgen, Amicus Therapeutics, Biogen, Mallinckrodt Pharmaceuticals, Retrophin, Shire, Ultragenyx, and Vertex Pharmaceuticals.

About the National Alliance for Caregiving
Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.

About Global Genes
Guided by its mission to eliminate the challenges of rare disease, Global Genes® is a leading rare disease patient advocacy organization with worldwide reach that serves and promotes the needs of patients and families touched by rare and genetic diseases. Since 2009, under the unifying symbol of HOPE, the Blue Denim Genes Ribbon®, Global Genes® has been building awareness, developing patient-focused education and advocacy tools, and funding patient care programs and early investigative research. For more information, please visit www.globalgenes.org. Feel free to join the RARE conversation! Follow @GlobalGenes on Social Media.
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