



FOR IMMEDIATE RELEASE

State Government, Pharmaceutical Industry, and Patient Community partner together to raise important awareness at Pennsylvania State House for Rare Disease Day® event on February 24, 2015

“Day by Day, Hand in Hand”

Harrisburg, PA—February 17, 2015—Join legislators, people living with rare diseases, pharmaceutical industry representatives, and other health care advocates in Harrisburg, PA on February 24, 2015 to raise important awareness for rare diseases as part of **Rare Disease Day®**.

During the event, representatives from government, industry, and the patient community will join together in collaboration to raise awareness about issues affecting the 1.3 million people in Pennsylvania living with a rare disease. Participating Pennsylvania state legislators include Senator Bob Mensch (R-24), Senator Charles McIlhinney (R-10), and Representative John Galloway (D-140) among others.

The event will be held in the East Wing Rotunda of the State Capitol from 11:30am to 1:30pm on Tuesday, February 24, 2015. The event is organized by the Friedreich's Ataxia Research Alliance (FARA), who have joined with the **National Organization for Rare Disorders (NORD)® and Connexion Healthcare** to educate and inform the public, elected officials, legislative staff and the media. Sponsored by NORD and Connexion Healthcare, the event is free to attend with RSVP. For more information, please visit: <http://pararediseaseday2015.eventzilla.net/>

Many important decisions related to rare diseases are made at the state level, including newborn screening; support services to help families cope with complex medical needs; an environment that promotes innovative medical research and product development; and insurance practices that assure patient access to medically-necessary therapies. The implementation of the Affordable Care Act has highlighted the increasingly important role of state policies and programs in assuring that the health care needs of Americans are addressed.

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 Americans. One in 10 Americans live with a rare disease—affecting 30 million people—and two-thirds of these patients are children. There are more than 7,000 rare diseases and only approximately 450 FDA-approved medical treatments. Many diseases are not being studied by medical researchers. Often, research gets funded by the families and friends of patients or by patient organizations.

Rare Disease Day is an annual awareness day celebrated around the world dedicated to elevating public understanding of rare diseases and calling attention to the special challenges faced by patients. Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. It was established in Europe in 2008 by EURORDIS, the organization representing rare disease patients in Europe, and is now observed in more than 80 nations.

For more information about Rare Disease Day in the U.S., go to www.rarediseaseday.us. For information about global activities, visit www.rarediseaseday.org. To search for information about rare diseases, visit NORD's website, www.rarediseases.org.

About FARA

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501(c)(3), non-profit, tax-exempt organization dedicated to curing Friedreich's ataxia (FA), a rare neuromuscular disorder, through research. www.cureFA.org

About Connexion Healthcare

Connexion Healthcare is an award-winning, full-spectrum healthcare communications company located in Newtown, PA, currently celebrating 15 years of providing unparalleled service to its clients.

The Connexion Healthcare Rare Disease Center of Excellence specializes in effectively communicating the science behind rare diseases and orphan drugs, and prides itself on strategically partnering with many of the industry leaders in the rare disease community.

www.connexionhealthcare.com

About NORD

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is a leading independent, non-profit organization committed to the identification, treatment, and cure of rare diseases, and national sponsor of Rare Disease Day in the U.S. www.rarediseases.org

###

Media contacts:

Evelyn Wu, FARA, 484-879-6160, info@curefa.org

Connor Galloway, Connexion Healthcare Rare Disease Center of Excellence, 215-944-9400, rare@connexionhealthcare.com

Jennifer Huron, NORD, 203-744-0100, jhuron@rarediseases.org