Groups Announce "Move YOUR Way" Initiative for Rare Disease Day
Virtual Event to Raise Awareness Taking Place February 21- 28

Downingtown, Penn., (February 5, 2013) - A rare disease, by definition, will affect fewer than 200,000 people in the United States. However, in total all rare diseases combined affect close to 30 million. That's almost one in ten of us. And, while many organizations and associations work to raise awareness and research funds for a specific rare disease year round, on February 28 the National Organization for Rare Disorders (NORD) is encouraging these groups to come together for an annual, world-wide event: Rare Disease Day.

NORD's Rare Disease Day is designed to unite those who are affected, generate greater awareness and encourage support for rare diseases from the public and decision makers alike. This year, the Friedreich's Ataxia Research Alliance (FARA), an organization dedicated to accelerating research leading to treatments and a cure for Friedreich's ataxia (FA), Parent Project Muscular Dystrophy (PPMD), the largest nonprofit organization in the United States focused entirely on Duchenne, and the National Ataxia Foundation (NAF), a membership supported, nonprofit organization dedicated to serving persons with ataxia and their families through research and programs have partnered to spearhead a nationwide virtual event on Facebook called "Move Your Way."

The initiative will highlight the importance of staying active, which helps in staving off the progressive effects of many rare diseases (including FA, Duchenne and inherited and sporadic ataxias) and can help to prolong the lives of those affected. As such, NORD, FARA, PPMD and NAF are inviting other rare disease advocacy groups around the world to take part.

"Rare Disease Day presents an opportunity to remind the world that rare diseases affect more people than most realize," said PPMD President and Founder, Pat Furlong. "Through our partnership with FARA and NAF on the 'Move Your Way' initiative, we hope to bring about better awareness for the rare disease community."

"We are looking forward to a day spent celebrating those with rare diseases and emphasizing the importance of working together to beat them,' added NAF Executive Director, Michael

Parent. "We know families affected and our supporters will enjoy sharing how they 'move' to promote awareness."

How to participate:

1. **Decide how you want to move**. Cycle, use your stander, run, dance, walk, roll, yoga, cheer...ANYTHING!
2. **Decide who is moving with you.** Yourself, family, friends, co-workers, school, gym, community groups... ANYONE!
3. **Order and Wear your bib number**. Send a message to info@curefa.org with your name, address and number of people participating to get your Rare Disease Day participant bibs to wear.
4. **Share Photos**. From February 21-28th take pictures moving your way (and wearing your bib) and post to http://www.facebook.com/pages/Move-YOUR-Way-for-Rare-Disease-Day/332770276837976 along with your story!

"Acting alone there is little any of us can accomplish, whereas acting together there is little we can NOT accomplish," said Ron Bartek, co-founder and president of FARA who was recently recognized by the FDA as one of 30 heroes who have made clinical, research, advocacy and regulatory contributions related to rare diseases in the past 30 years.

FA is a rare, progressive and life-shortening neuromuscular disease for which there is no known treatment or cure. About one in 50,000 people in the United States have Friedreich's ataxia. Duchenne, the most common form of childhood muscular dystrophy, is a progressive and fatal muscle disorder affecting roughly 1 in 3,600 boys and young men. There is currently no cure for Duchenne. An estimated 150,000 Americans are affected by heredity or sporadic ataxia. Ataxia can strike anyone at any time regardless of age, gender, or race. Ataxia is a group of progressive neurological diseases which affects coordination and speech.

If you are interested in getting your community or school involved and need assistance, or if you have any questions, please contact: Jamie Young, info@curefa.org or (484) 879 6160.

To learn more about Rare Disease Day or to find a list of activities taking place across the country, visit: www.RareDiseaseDay.org.

About FARA
The Friedreich's Ataxia Research Alliance (FARA) is a 501(c)(3), non-profit, charitable organization dedicated to accelerating research leading to treatments and a cure for Friedreich's ataxia. For more information, visit: www.curefa.org

About Parent Project Muscular Dystrophy
Duchenne is a fatal genetic disorder that slowly robs young men of their muscle strength. Parent Project Muscular Dystrophy (PPMD) is the largest most comprehensive nonprofit organization in the United States focused on finding a cure for Duchenne muscular dystrophy- our mission is to end Duchenne. For more information, visit: http://www.parentprojectmd.org

About NAF
The National Ataxia Foundation is dedicated to improving the lives of persons affected by ataxia through support, education, and research. For more information, visit www.ataxia.org

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