



Third Annual Move YOUR Way for Rare Disease Day

Join FARA for a Virtual Event Through the Month of February
Raise awareness in your local community for Rare Disease Day!

Rare Disease Day is a worldwide awareness effort to draw attention to all rare diseases. Together, rare diseases affect millions of people. Join the National Organization for Rare Disorders, the Friedreich's Ataxia Research Alliance (FARA) and other advocacy groups around the world to show the general public and decision-makers that more support is needed for rare diseases like FA. FARA invites you to join a virtual event and show the world how you move for Rare Disease Day.

Though FA is a physically limiting neuromuscular disorder, many in the FA community fight the progressive effects of the disease by staying as physically active as possible. Some cycle on adaptive cycling equipment, others work out at the gym, in the pool or in a stander. The month leading up to Rare Disease Day, from February 5th-28th, we want you to show the world how you move. Join the [Move YOUR Way for Rare Disease Day](#) virtual event on Facebook, and post photos of yourselves, family, friends, coworkers and classmates moving under your own power.

TOGETHER we MOVE to CURE FA.

How to participate:

1. Each person decides how they want to move. This can be the person living with FA and/ or someone moving in his/ her honor. *Movement Suggestions: Cycle, Go to the Gym, Use your Stander, Run, Dance, Walk, Roll, Yoga, Cheer... etc*
2. **** This year, we'd really like to emphasize this step! **** Recruit people to move with you. Whether they are pictured moving with you or you inspire someone to move in their own way- the more people involved, the more the effort grows. The more the effort grows, the more awareness is raised for rare diseases. *Please reach out to Family, Friends, Co-Workers, Your Barista, School, Gym, Community Groups... etc*
3. Be a part of the movement, and wear your Rare Disease Day Bib! The number 15,000 is in honor of the 15,000 people living with FA worldwide. Download and print your Move Your Way bib number to wear during your activity here: curefa.org/_pdf/MoveYourWay2015-bib.pdf



4. February 5th-28th take pictures of your group getting active and moving their way with their bib numbers on. Post the photo to: www.facebook.com/MoveYOURWay In your post, tell us where you're moving, how you're moving, the number of people moving with you and why you're moving.

5. Change your profile picture to the Rare Disease Day logo and/ or Post your "Move Your Way" photo to your personal Facebook page along with one of these statuses:

- a. I am moving my way for Rare Disease Day
- b. 30 million people in America have a rare disease. I am one of them.
- c. 15,000 People Worldwide Have Friedreich's ataxia. I am 1 of them.
- d. Alone we are rare. Together we are strong. Rare Disease Day February 28, 2015 with a link to the Move Your Way for Rare Disease Day Facebook site.

If you are interested in getting your community or school involved and need assistance or if you have any questions please contact:

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