Hi Friends,
I wanted to take a few sentences to speak about how I live with FA…what is true for me. To say FA changed my life is an understatement. It affects everything from the minute (What’s for dinner?) to the profound (What is my career? How can I do the most good?) Yes FA is devastating; I have gone from running and riding horses to pushing a wheelchair. Can I still find ways to ride horse? You bet! Is riding horse different now? You bet. This is the kicker, for me, of FA… It is not one catastrophic loss from which you can recover and move on. It is a series of large and small loses (except for, blessedly cognition which is not affected AT ALL by FA) that is until FARA is able be the catalyst to stop FA. Those of us who have it must endure these losses every day. I am so blessed to be among such brave, resilient and inspiring people who laugh, cry, find love, lose love, eat good food, travel and just enjoy life despite the constant loss. Through the journey of having FA I have learned one important thing, it is not FA that makes me happy or sad or who I am, it is me. (I don’t mean to imply that having FA doesn’t ever make me angry or sad, it is just that, on balance I am happy.)

Some of what FARA means to me… I don’t want this disease. I REALLY don’t want anyone else to have it (including my sister who does). I have power through FARA – Power to fight FA. Through FARA no one will ever again have to endure 30 years of living with this incurable, untreatable tyrant of a disease, as I have. Through FARA we will cease having to say goodbye to friends as they die too young. Soon, not now, but soon, and certainly not soon enough, there will be a treatment and cure because of and in honor of those who have died too young. Through FARA families of newly diagnosed FA patients are given hope, hope my parents weren’t given when my sister & I were diagnosed. Through FARA, I have been able to make my disability my opportunity (almost literally). I can use my experience of living with FA to ensure that there is no more FA. So important to me and my loved ones, through FARA I am part of a community of people with FA and their loved ones.

Thank you for your support of FARA.