

## **Alone We Are Rare. Together We Are Strong.**

Have you ever attended an event or had a conversation that just stays with you and no matter what you do you can't forget it? Yesterday that happened to me. I attended an event produced by **MassBio** and was so moved and had such an impact on me that I had to find a way to do something. One of the "calls to action" was to leave the meeting and tell anyone that would listen about Rare Diseases. So that is what I am doing.

First, this was no small meeting. My colleague and I walked in the door and were in the middle of a crowd that exceeded 500 people. Patients, caregivers, parents, researchers, those working in the industry...collectively listening to the stories of those affected by a rare disease, and in some case more than one disease or more than one family member. It was powerful. The passion that each speaker brought to the podium was palpable. I was touched beyond measure. Not only because each of the speakers demonstrated such strength but they all conveyed the message that HOPE is essential. Essential because some of the statistics regarding rare diseases is staggering.

I learned yesterday that 1 in 10 Americans is affected by some type of a rare disease. This translates to 30 million people, many of them children, in the U.S. according to the National Institute of Health and over 350 million worldwide. I also learned that there are 7,000 different types of **rare diseases**. Drug approvals for this community are low and only 5% of rare diseases even have a treatment. For 95% of rare diseases, there is not a single approved treatment. If you stop and think about that last sentence, and really let it sink in, you would be further amazed by the inspiring stories, positivity, hope and passion of those that spoke yesterday.

***“Alone we are rare. Together we are strong.”*** That is the motto that we repeated in unison at various times throughout yesterday’s meeting at the prompting of emcee Katie Brandt, Director, Caregiver Support Services, Frontotemporal Disorders Unit, Massachusetts General Hospital. We were challenged to leave the meeting and tell everyone we knew about Rare Disease day, what we learned and to share the stories we heard. Representative Brian Ashe of Longmeadow, Massachusetts shared that passage of bill No. 1650 by the Governor has officially designated February 28th as Rare Disease Day in Massachusetts.

Some of the inspirational stories we heard were from parents, mothers and fathers or siblings that just refused to sit by and do nothing. Join me in recognizing and further their message by learning more about the following topics or rare diseases:

- Bo Bigelow & Daniel DeFabio, co-founders, DISORDER, **The Rare Disease Film Festival**
- Michelle Hirsch Donovan, mother of a child with **Neurofibromatosis**, type 1 (NF1)
- Richard P. Kennedy, President, **The Angel Fund for ALS Research**
- Jen Melanson, patient with **Hypoparathyroidism** and **CTLA4 Haploinsufficiency**

Everyone that spoke yesterday reminded those of us in the audience about the need for supporters to join together, to demand action and change, to advocate and champion this cause for those that can’t do it on their own...spread the word, do something and take an opportunity to be part of this amazing movement to make a real difference in lives of those affected by rare diseases.

Remember, Alone we are rare. Together we are strong. #patientdriven #rarediseaseday

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