

December 1, 2006



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Dear Family and Friends,

As most of you know, Meghan has a rare, genetic disorder called primary ciliary dyskinesia (PCD). We have recently learned that Rory also carries the genetic mutation that leads to chronic disease in PCD. You are probably also aware that I have made it my life's mission to organize families affected by PCD and to encourage research into this interesting and diverse genetic disorder. To this end, five years ago a group of PCD patients and parents started the PCD Foundation, a 501(c)(3) tax-exempt organization dedicated to advancing the understanding of PCD. The enclosed letter explains PCD, the work of the Foundation and why we believe PCD research could potentially benefit millions of people.

The board of the PCD Foundation is acutely aware that money is very tight for many folks and that there are an endless number of legitimate and worthy causes to support. We hope that by sharing our stories, you will agree with us that the PCD Foundation is worthy of your support and will consider a tax-deductible end-of-year donation to the PCD Foundation.

My Experience

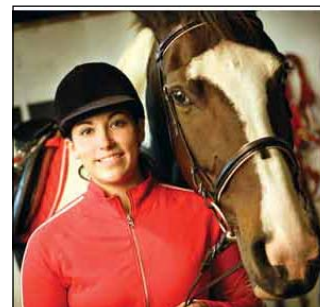
Imagine as a young parent being told that your beautiful little daughter had permanent damage to her lungs (at age 4), multiple spleens, would probably not be able to have children, would always need intervention for serious lung infections and would most likely progress to respiratory failure or the need for lung transplant as a young adult. Now imagine hearing that there was no hope for improving these outcomes because the disorder was very rare so there would be no money for research. The outlook was bleak and we felt very alone. We had never heard of this disorder, we knew no one else with it, and there was no patient education group established for PCD. Meghan's physicians could not even give us a prognosis—no one knew for sure what her future held. That was my experience back in 1991 and it is the experience of the more than 25,000,000 Americans who suffer from nearly 6,800 "rare" diseases (diseases affecting fewer than 200,000 people in the US).



Meghan age 3

As I learned more about PCD, I was surprised that the disorder was not of more interest to researchers. Children with PCD often have issues with organ placement or function. Almost all of them experience neonatal respiratory distress and are literally sick from birth. From the standpoint of birth defects and Sudden Infant Death Syndrome, it seemed like PCD provided a perfect population for study. It took years of consistent pressure on health care providers to identify researchers interested in PCD and to organize the patient population, but we did it and the results are highlighted in the attached letter.

In 1991 I was told "no" to research in PCD. In 15 short years, the answer is now a resounding "yes," with the National Institutes of Health and international researchers recognizing the importance of this research (enclosed please see the excellent new article about PCD in an NIH publication. Meghan is featured in the article and there are some very nice photos of her with her horse. For those of you with internet access the electronic link is <http://www.ncrr.nih.gov/newspub/Fall06rpt/Fall06mss.asp>).



Meghan today. Every day presents challenges, but the future now looks brighter thanks to the PCD Foundation.

In order to maintain this momentum, we need to survive as a patient organization and continue our efforts on behalf of people with PCD. We are asking for your help. If you are able to make a tax-deductible donation to the PCD Foundation, please use the enclosed envelope. A receipt for your donation will be provided by the PCD Foundation. If you would like additional copies of any of these documents to share with others, just let me know

Thank you so very much,

Michele