



December 1, 2006



Dear Family, Friends & Neighbors,

Most of you know that I was diagnosed with a rare genetic disorder (Kartageners syndrome, now known as primary ciliary dyskinesia) at age 9. I suffered a collapsed lung and then had a part of my lung removed (lobectomy). After the surgery, doctors told my parents I'd be lucky to live 6 months to a year. I overheard my mom tell someone and was just devastated. I was afraid to sleep when I was sick. I thought I may not wake up. I was scared about what would happen to my family if I died. It was a very hard time. I'm 37 now and obviously the doctors were wrong. However, PCD is a progressive disease. It may happen slowly, it may happen quickly but it will progress. Currently my health is stable even though I have mild bronchiectasis (irreversible lung damage in both lungs). I had sinus surgery a couple years ago. I have daily medications, breathing and sinus treatments and what seems like endless doctor appointments. It sounds like a lot, but it's worth it to be able to enjoy quality time with my husband and son (who is a PCD carrier).

You might wonder if my diagnosing physicians were bad doctors. I don't believe so. They did the best they could with the information they had at the time. That is why I'm sending my personal note along with the foundation's annual letter. I volunteer for the foundation in hopes of educating other patients, parents and physicians. I want you to see the personal side and the importance of patient organizations like the PCD Foundation. It's my hope that another child will never have to go through the emotional stress I went through. I don't want a child to ever be afraid of dying in their sleep.

If you can, please support the PCD Foundation by sending your tax deductible donation in the envelope provided. There is much work to be done in PCD research & education. It can't be done without the generous support of family & friends.

Sincerely,

Lynn Ehrne