

██████████ Street  
Cleveland, OH 44113-3831  
January 7, 2007

The Shannon Foundation  
1331 Seventeenth Street; Suite 1000  
Denver, CO 80202

To whom it may concern:

This letter is to express our **sincere appreciation** to the Shannon Foundation for agreeing to pay for Rachel's rehabilitation therapy at the Cleveland Clinic Foundation Center for Rehabilitation.

Our daughter, Rachel Pestak, turned 12 years old on New Year's Eve. She was born with a very rare chromosome abnormality call Alfi's Syndrome, which is also known as 9P-. The web site, [www.9pminus.org](http://www.9pminus.org) (which was organized and is maintained by the families of children with 9P-) describes a little more about the syndrome. Rachel attends Cleveland public schools in a multi-handicap classroom a few blocks from our home. She is a beautiful girl with a gift for finding a "soft spot" in even the most outwardly ornery people.

Despite all the abnormal twists, curves, and bends in her skinny body, Rachel walked independently. She had a "growth rod" surgically installed along her spine and she wore a thoracic lumbar sacral orthotic (TLSO) brace most of the day to forestall her scoliosis. But the abnormal muscle tone associated with 9P- kept making it worse. Her lung capacity was gradually decreasing, so another surgery was unavoidable. The most recent surgery in October 2006 was to permanently correct (as much as possible) her severe scoliosis. The surgeon told us to expect that she would be able to return to her regular activities 3 to 5 weeks after surgery.

It has been over 10 weeks since the surgery. We have exhausted our health insurance plan's therapy coverage for the plan year and Rachel is only able to walk very short distances with a wheeled walker. The muscles in her legs and hips are so contracted that she is bent over almost 90 degrees at the waist. Her best hope for being able to walk independently again is to continue intensive therapy, the cost of which has become prohibitive. Through the Shannon Foundation's generosity, Rachel has a chance to walk independently again!

Enclosed is a recent picture of Rachel to "put a face with the name." If you want any additional information, please free to contact us. Again, thank you very much!

Sincerely,

  
Judy & Mark Pestak

