



## The International 22q11.2 Foundation Inc.

Dear Friend,

This letter has come home in your child's book-bag today as part of a worldwide awareness initiative for a very common yet poorly recognized genetic syndrome. This syndrome is called 22q. It is more common than Cystic Fibrosis, and may be as common as Down syndrome, affecting an estimated 1/1000 pregnancies, yet most parents, teachers and even many medical professionals have never heard of it.

22q is caused by a microdeletion (missing piece) or microduplication (extra piece) of genetic material on the 22nd chromosome. Many children go undiagnosed with this syndrome. In most cases, it is a new or spontaneous mutation although in 10 percent of cases it can be inherited. In fact, it is not uncommon for an adult parent to learn about their own diagnosis for the first time only after their child is diagnosed.

There are hundreds of ways that children with this syndrome are affected, though the most common ways include developmental delays, learning differences, behavioral problems, speech abnormalities, and congenital heart disease.

The enclosed fact sheet was made in preparation for The International 22q11.2 Foundation's sixth annual "22q at the Zoo/ Worldwide Awareness Day". This event will take place on Sunday, May 21, 2017 at the Philadelphia Zoo along with over 115 other cities around the world. The event is aimed at generating awareness for families, clinicians and educators. There will be food, a children's DJ, face painting and many other fun activities.

Please take a close look at the fact sheet, as it is likely that you may know someone with this syndrome. While there is no cure, early intervention can dramatically improve outcomes for our wonderful children.

If you would like more information, or you wish to join us on May 21, 2017 at the Zoo, you may feel free to contact me or visit [www.22q.org](http://www.22q.org).

Thank you for your consideration.

Sincerely,

Sheila P. Kambin, MD  
Proud Parent and Chair  
The International 22q11.2 Foundation, Inc.