

22q at the Zoo aims to raise global awareness

Local student is face of rare genetic syndrome

While invisible to the naked eye, a small, missing piece from one chromosome 22 can cause such varied medical problems as heart defects, cleft palate, feeding, swallowing and breathing problems, learning disabilities, speech delay, autism, and compromised immune systems, among other health and developmental issues.

The problems associated with this deletion have long been evident, but only recently has a laboratory discovery revealed that many of these issues can occur from what is known as the 22q11.2 deletion syndrome.

On May 22, with the help of local Riverside Elementary School student Jacob Kane, "22q at the Zoo — Worldwide Awareness Day" drew attention to this often overlooked

genetic syndrome in 10 countries over three continents.

The International 22q11.2 Deletion Syndrome Foundation has sponsored this event due to the lack of public awareness of the 22q11.2 deletion syndrome and the continued need to focus on research and novel interventions that could allow for a higher sustained quality of life for those with the 22q11.2 deletion syndrome.

Originally developed as a local event with support from the Philadelphia Zoo and the Dempster Family Foundation, the final product is the result of an amazing cooperative venture bringing together a multitude of large national and international organizations, as well as a whole host of local groups, parents, medical institutions and zoos spanning the globe to support the cause.

22q at the Zoo kicked off at the
See 22q at the Zoo on A3



Photo by Ryan Brin

An administrator, teachers and staff at Riverside Elementary School rally around Jacob Kane (left of center) for "22q at the Zoo — Worldwide Awareness Day" just before the May 22 event brought some of them to the Como Park Zoo in St. Paul.

22q at the Zoo: Red T-shirts, bold buttons

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Sydney, Australia, Zoo and concluded at the Hilo, Hawaii, Zoo. More than 65 participating zoos — including St. Paul's Como Park Zoo, where Kane and his supporters went — engaged children and families with activities designed to entertain young and old alike as they learned more about the 22q11.2 deletion syndrome.

Participants wore the eas-

ily recognizable red T-shirt and "ASK ME ABOUT 22q" buttons.

The physical effects of the 22q11.2 deletion syndrome, like many other genetic diagnoses, vary greatly. The diversity in the manifestation of the syndrome has caused confusion for the medical community in the past. At one point, the 22q11.2 deletion syndrome was referred to by

over six names. Although quite common, the varied affects and lack of awareness can make diagnosis difficult and has resulted in a lack of support for patient families. This event seeks to change that by helping establish a bond of solidarity between families, support groups, academic centers and clinicians.