



## More Than 90 Cities Expected to Participate in the Ninth Annual International 22q11.2 Foundation's "22q at the Zoo" Worldwide Awareness Day

### Families across the world unite on behalf of chromosome 22q11.2 syndromes – cities joining daily!

**Matawan, NJ (April 23, 2019)** The International 22q11.2 Foundation, Inc., an organization dedicated to improving the quality of life for people affected by differences in chromosome 22q11.2 (22q) through family and professional partnerships, is hosting the ninth annual "22q at the Zoo" Worldwide Awareness Day at zoos, parks and playgrounds around the world on **Sunday, May 19, 2019**. The event will kick off at 11:00 a.m. local time in Auckland, New Zealand and literally circle the globe, closing at 2:00 p.m. local time in San Diego, Los Angeles and Sacramento, CA. The event aims to raise the public profile of conditions associated with differences in chromosome 22q11.2, such as the 22q11.2 deletion and duplication syndromes, with patients, families, healthcare providers, and educators partnering in friendship to make this an amazing day for all in attendance, as well as those who are unable to participate.

"22q at the Zoo is the largest awareness event for this condition, in fact, more than 12,000 people in more than 85 cities worldwide participated last year," said Sheila Kambin, parent of a child with a chromosome 22q11.2 deletion and International 22q11.2 Foundation Board Chairman. "The number of people walking around undiagnosed is staggering. With increased awareness, we will drive enhanced detection and care for individuals with 22q and their families."

The 22q at the Zoo Worldwide Awareness Day is on track to have more than 90 cities across five continents participating this year, in support of more awareness for this common, yet relatively unheard of condition, right in time for the celebration of the Foundation's 16<sup>th</sup> Anniversary. The International 22q11.2 Foundation, founded in 2003, was created to support families affected by 22q11.2 deletions (due to a small piece of chromosome 22 missing) and later changed its name to include families with duplications (an extra piece of chromosome 22 material included). The Foundation offers the following to 22q families: opportunities to connect with other 22q families, educational seminars and conferences for families to learn more about the conditions from medical experts across the world, informational updates providing the latest on 22q from researchers in the field, and strengthening support of one another via friend-raising events.

"These conditions may cause a variety of medical problems such as heart defects, problems fighting infection, differences in the palate (roof of the mouth), and developmental delay or autism, to name a few, but no two children are affected in the same way," said Donna McDonald-McGinn MS, LCGC, Director, 22q and You Center; Associate Director, Clinical Genetics Center; Chief, Section of Genetic Counseling at The Children's Hospital of Philadelphia; Clinical Professor of Pediatrics, The Perelman School of Medicine at the University of Pennsylvania; and Founding Board Member of the International 22q11.2 Foundation, Inc. "The 22q11.2 deletion is generally identified as a new difference in the child born with associated features, but at times can be found in a parent as well, whereas the 22q11.2 duplication, is frequently identified in many members of the family over several generations. Most importantly, the chromosome 22q11.2 deletion and duplication syndrome are very common, and likely affect thousands of children and adults around the world. A recent study found both conditions to occur in ~1/1000 pregnancies. Importantly, new diagnostic testing in combination with increased awareness events are bringing more and more affected individuals to attention where they may have gone undiagnosed in the past. Awareness days like **22q at the Zoo** help us partner with families towards improving detection, care, and ultimately better treatment capabilities."

For information on the Worldwide Awareness Day event, please visit <http://www.22q.org/awareness-events/awareness/annual-22q-at-the-zoo/> or join the 22q at the Zoo *Worldwide Awareness Day* group: <https://www.facebook.com/groups/22qAtTheZooWorldwideAwarenessDay/>. Donations to support the Foundation are accepted at [www.22q.org](http://www.22q.org). For more information on 22q11.2 deletion or duplication, visit <http://www.22q.org>.

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