



## International 22q11.2 Foundation Celebrates Its 15<sup>th</sup> Anniversary

**Matawan, NJ (April 20, 2018)** -- The International 22q11.2 Foundation is excited to celebrate 15 years of helping families navigate 22q11.2 deletion and duplication diagnoses this month. The International 22q11.2 Foundation's mission is to improve the quality of life for individuals affected by the 22q11.2 syndromes through family and professional partnerships.

Called the International 22q11.2 Foundation, the New Jersey-based charitable organization was created 15 years ago as a response to the supportive needs of this newly-identified diagnosis. In 2003, a small group of parents and a local professional concerned about individuals affected by 22q decided they wanted to make a difference. While sitting around a kitchen table in suburban Philadelphia, the group brainstormed about how they might help those affected by 22q. This group, shortly thereafter, created the International 22q Foundation, a family support group with the mission to support early diagnosis, appropriate clinical care, and research in an effort to promote better outcomes. The organization has also focused tremendous effort on 22q awareness.

The 22q11.2 deletion is caused by a missing section (microdeletion) of chromosome 22. The 22q11.2 duplication is caused by an extra piece of genetic material on the 22nd chromosome.

Many of the founding families shared a common bond – isolation and uncertainty. In 2003, very few professionals, let alone lay persons, had ever heard of their child's diagnosis or what the long term outcomes would be. Since the creation of the Foundation, much has been defined about the chromosome 22q11.2 syndrome.

### **15 years later, we now know that the 22q11.2 syndrome:**

- *Is the most common microdeletion syndrome; affecting as many as one out of every 1000 pregnancies.*
- *Is found in 1 in 68 children born with heart defects*
- *Is the most common cause of syndromic cleft palate*
- *Can cause many other problems such as immunodeficiency leading to difficulty fighting infection and autoimmune disease; issues with feeding and growth; hearing loss; breathing difficulties; kidney and spine differences; autism, learning and behavioral differences*
- *Has more than 180 symptoms which makes it difficult to diagnose....while displaying wide variability amongst individuals with the deletion or the duplication. Some individuals have almost all of the above issues and others have almost none. This confounding fact alone, continues to present challenges.*

The International 22q Foundation has an extensive [Board of Directors of Doctors, Parents, and Scientific and Clinical Advisors](#) that help families navigate this complex diagnosis as well as sharing the most up-to-date research and recommendations. Over the last 15 years, the International 22q11.2 Foundation has been successful in helping thousands of families through resources, valuable connections with top experts, creating awareness days, supporting research, and engaging with other support groups for advocacy and to deliver the most cutting edge information related to 22q, via the following links:

[Events](#)

[Medical information / most recent research and findings](#)

[Family support network](#)

[Resources for Families](#)



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In addition, the International 22q Foundation has a full schedule of events this year celebrating its' 15<sup>th</sup> year anniversary, including [22q at the Zoo](#) (in May each year), sponsoring the family conference at the [11th Biennial International 22q11.2 Conference in Whistler, BC Canada](#), (July 9-13 for Professionals, and July 14-16 for Families) and other events ([click here for the list.](#)) For a list of International 22q Foundation milestones, or history of the organization over the past 15 years, [click here](#).

As the Foundation approaches the next ten years, plans are to expand their footprint and make 22q a household name. If you would like to support the cause and help celebrate 15 years of making a difference, please email the Foundation at [info@22q.org](mailto:info@22q.org) or visit their [donation page](#).

The International 22q Foundation continues to work hard to help support early diagnosis, appropriate clinical care, and research. In addition, they help develop and support treatment plans to improve the long-term quality of life for those affected by the syndrome. For more information on the International 22q Foundation, please visit <http://www.22q.org> or join the conversation on Facebook (International 22q Foundation), Twitter (@22qFoundation) or Instagram @22qfoundation.

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