

What's New with 22q?

Fall 2009



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The 22q11.2 deletion syndrome is caused by a missing piece (deletion) of genetic material on chromosome 22. The condition is associated with a wide range of symptoms that include heart anomalies, immune deficiency, cleft palate, feeding problems, speech delays, learning disabilities, and social / emotional issues. To learn more, visit our website at www.22q.org.

Remembering Angelo DiGeorge



The 22q community was saddened in October to learn of the passing of Dr. Angelo DiGeorge, the Philadelphia-based pediatric endocrinologist whose early descriptions of children with immune deficiency led to the recognition of the syndrome that bears his name. Dr. DiGeorge's work contributed a key piece to our current understanding of the 22q11.2 deletion syndrome, a condition that encompasses DGS, VCFS, and other symptom constellations. On a personal

level, the *Philadelphia Inquirer* described Dr. DiGeorge as "a compassionate physician who viewed the patient as a whole person, a superb diagnostician, a keen observer, a great teacher, a masterful lecturer, an absorbing storyteller, an avid reader, a literary writer and above all, a kind-hearted, fair-minded person". Dr. DiGeorge's family may find some comfort knowing that he lives on in the smiles of the many children and adults with DGS who each carry with them a part of his legacy.

An Unforgettable Night in Venice

On September 12, 2009, over 130 people turned out for a fun evening of food and entertainment on behalf of the Foundation. The event raised over \$15,000! "A Night in Venice" was held at Finnegan's Wake in downtown Philadelphia. Guests enjoyed great food and drinks while trying their luck at gaming tables and auctions — all with the goal of supporting the Foundation's efforts toward detection, care, and cure. Many thanks to board members Donna McDonald-McGinn and Carol Cavana who organized the event and coordinated the work of many volunteers to make the evening a success. Most amazing of all was the transformation from an Irish pub to a Venetian-themed wonderland! At the end of the night, guests were already asking about plans for next year's event. We'll keep you posted.....



Many auction items had 22q theme, like this "TuTu and Q" wine set



22q11.2 Happenings!

- **December 14, 2009:**
**Positive Exposure:
The Spirit of Difference**
Media, Pennsylvania
www.22q.org
- **February 27-28, 2010**
**Behavior & Learning in Children with
the 22q11.2 Deletion syndrome**
Gainesville, Florida
www.elwyngenetics.org
- **July 29-31, 2010**
**7th Int'l 22q11.2 Deletion
Syndrome Conference**
Coventry, England
www.maxappeal.org

The New Face of 22q!

A major accomplishment for the Foundation this year was the re-design and launching of our new website at www.22q.org. We hope you'll find it to be a useful source of information, support, and inspiration. We encourage you to explore the site, check back often, and contact us with feedback.



Contact Us:

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Getting the Word Out to Pediatricians

In October, the Foundation placed a half page ad about the 22q deletion syndrome in a publication of the American Academy of Pediatrics, reaching thousands of pediatricians. We also hosted an exhibit at their annual convention in Washington, DC. Foundation administrator, Tom Bell, and Board member, Terry Ferrari, personally spread the word about 22q to hundreds of pediatricians who visited our booth. Tom and Terry sent them home with brochures and goodies, including bright red 22q tape measures, in the hope that they will always remember to "think 22q" in their practice.



It's Time for a 2010 Calendar

Back by popular demand, the Foundation held its 4th Annual Calendar Contest this fall. Calendar sales represent a significant fundraiser for the Foundation, and families participate by submitting photos of their smiling children. Do your part to increase awareness about 22q by showing off our beautiful 2010 calendar. Order forms are available on our website; calendars will be shipped in the new year. Proceeds will help us to realize our mission of detection, care, and cure.

Our Mission

The mission of the International 22q11.2 Deletion Syndrome Foundation, Inc. is to improve the quality of life for affected individuals and their families by sustaining clinical care, education, research, public awareness, support and advocacy.

Won't you help? The Foundation is a non-profit organization founded by interested parents and professionals. Your tax-deductible donation helps us to achieve our goals for families around the world. Donations are greatly appreciated and can be sent to our administrative office in Media, Pennsylvania.