

What's New with 22q?

Summer 2009



The International 22q11.2
Deletion Syndrome Foundation, Inc.

4 State Road, #201
Media, PA 19063 • USA
Phone: 877-739-1849
Website: www.22q.org
Email: info@22q.org

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.

It's been a busy year for the Foundation! The generosity of our donors and volunteers, even during these difficult economic times, allows us to move forward with our mission of detection, care, and cure. The Foundation is proud of its many accomplishments in 2009, which include:

- co-sponsoring family conferences about the 22q11.2 deletion in Sacramento, California and Wyomissing, Pennsylvania
- donating tee shirts and other items to raise awareness about the deletion for a charity walk in Ellyn, Illinois
- placing a half page ad about the 22q deletion in a publication of the *American Academy of Pediatrics*, reaching thousands of pediatricians
- hosting exhibits to increase awareness at the annual meetings of the *American Society of Human Genetics* and the *American Academy of Pediatrics*
- offering summer camp travel stipends to children with the deletion wishing to attend Paul Newman's Victory Junction Hole-in-the-Wall Camp in North Carolina
- designing and distributing our third annual calendar featuring photographs of our children to help raise funds and awareness
- fielding frequent inquiries from parents who are desperate for information; we do our utmost to listen, support and direct them to the best resources.

Support the Foundation at a **Night in Venice**

Join us in Philadelphia on September 12, 2009 for a fun evening of food and entertainment while supporting the work of the Foundation on behalf of people with the 22q11.2 deletion syndrome and their families.

The event will be held from 7—11 PM on Saturday, September 12th at Finnegan's Wake, 537 North 3rd Street, in downtown Philadelphia.

Admission includes appetizers, a buffet dinner, dessert, draft beer, wine, soft drinks, valet parking, and entertainment. There will be gaming tables, music, and auction items — all with the goal of having fun and supporting the Foundation. Visit us at www.22q.org or call 877-739-1849 for details!





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22q11.2 Happenings!

- **Aug 22, 2009:**
Slow and Steady Wins the Race
A Walk for 22q11 Awareness
Glen Ellyn, Illinois
www.ramonamae.com
- **September 10-11, 2009**
22q11.2 Deletion Syndrome: Practical Implications for Behavior & Learning
Wyomissing, Pennsylvania
www.elwyngenetics.org/22qhome.htm
- **September 12, 2009**
A Night in Venice
Philadelphia, Pennsylvania
www.22q.org

Pennsylvania Conference to Highlight Learning and Behavior in 22q

The Foundation recently awarded a \$1,125 grant to support a conference on educational and behavioral aspects of the 22q11.2 deletion syndrome. The meeting will take place in **Wyomissing, PA on September 10-11, 2009**. The conference is geared toward families and professionals and will focus on practical information to address the educational and behavioral needs of children with the deletion. Conference information is available online at www.elwyngenetics.org/22qhome.htm. The conference is timed to coincide with the Foundation's 2009 "Night in Venice" event in nearby Philadelphia (see front page).



Get Organized with a 22q Binder

Raising a child with the 22q11.2 deletion can be especially challenging for new parents as they try to juggle information overload, specialist appointments, and piles of medical reports. The Foundation is here to help by providing families with organizational binders to help them keep track of important records and other information related to their child's diagnosis. Each binder comes with page dividers to organize records; information about the foundation; a 22q car magnet; and a copy of our booklet, "*The 22q11.2 Deletion Syndrome During the First Years: An Introduction for Parents of Newly Diagnosed Children*". Binders are free of charge for parents of children with the deletion. To order yours today, contact us at info@22q.org or call 877-739-1849.

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.



We've moved! Please make note of our new mailing address:

The International 22q11.2 Deletion Syndrome Foundation
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Media, Pennsylvania 19063

Changes and updates are also underway for our website at www.22q.org
Stay tuned.....