

# What's New with 22q?

Fall 2008



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

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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](http://www.22q.org).*



## Welcome Tom Bell!

In order to better help us accomplish our mission, the Foundation recently hired a part-time administrator. Tom Bell has many years of experience in sales and IT, and he's been putting his organizational talents to good use for the Foundation. Tom will now be the central administrative point of contact for inquiries. Please welcome Tom as he gets to know our 22q families and community!

The Foundation is happy to report that we have had an outstanding year in promoting awareness and supporting families and children with the 22q11.2 deletion. Our new focus is on "Detection, Care, Cure" which has energized projects and development in each of these areas. Our accomplishments this year include:

- publishing our first educational booklet for families of children in the birth-to-five age group
- compiling a notebook for newly-diagnosed families with information about the deletion and sources of help. It also acts as a repository to hold key information from doctor's visits, team meetings, etc.
- funding summer camp travel stipends to Paul Newman's Victory Junction Hole-in-the-Wall Camp which sponsors a "genetics week" for affected children
- designing and distributing our second annual calendar featuring photographs of our children which helps raise funds and awareness (see below for more information)
- supporting relevant conferences given by a wide variety of medical and other appropriate organizations which allow professionals and lay people to share insights and research on the deletion
- providing travel grants for young investigators to attend the 6<sup>th</sup> Int'l 22q11.2 Deletion Conference in Utrecht, Netherlands
- fielding frequent inquiries from parents who are desperate for information; we do our utmost to listen, support and direct them to the best resources.

## You Ought to be in Pictures!

Back by popular demand, the Foundation's *3rd Annual Calendar Contest* is underway.

Calendar sales represent a significant fundraiser for the Foundation, and families participate by submitting photos of their smiling children. Although the submission date for photos for this year's contest has now passed, our beautiful 2009 calendars will be available for purchase during the winter holidays. To order, visit our website in December or contact the Foundation by phone or email for an order form. Proceeds will help us realize our mission of detection, care, and cure.





## It's Time to Think About Summer Camp!

Winter may be upon us, but it's never too early to start thinking about summer camp. As we have done for several years, the Foundation awards travel grants for children with the 22q11.2 deletion who would like to attend Paul Newman's Victory Junction Hole-in-the-Wall-Gang camp for children with special needs. For more information about the camp, go to [www.victoryjunction.org](http://www.victoryjunction.org). Applications for travel grants are available on our website or by contacting the Foundation office.



## Conference to Highlight Learning and Behavior in 22q

This year, the Foundation awarded a \$5,000 grant to help support a conference on educational and behavioral aspects of the 22q11.2 deletion syndrome. The conference, which is co-sponsored by Pennsylvania-based Elwyn and the U.C. Davis M.I.N.D. Institute, will take place in **Sacramento, California on March 7-8, 2009**. The conference is geared toward families and professionals and will include a special presentation and photo shoot by photographer Rick Guidotti of Positive Exposure ([www.positiveexposure.org](http://www.positiveexposure.org)). For conference details and registration information, go to [www.elwyngenetics.org](http://www.elwyngenetics.org) or contact Brenda Finucane at 610-891-2313.

## Wall Street Got you Down?

The Foundation's annual Stock Market Sweepstakes is underway, and while we can't guarantee you'll win, you'll have fun while donating to a worthy cause. Here's how it works:

- For a \$100 contribution, we will "invest" a hypothetical \$10,000 for you in four company stocks of your choosing. Of course, no real funds will be invested (other than in the work of the Foundation).
- Your entry must be postmarked by Wednesday, December 31, 2008.
- At the end of the sweepstakes on January 31, 2009, we will value your "portfolio" - whomever has the highest value will win.
- Prizes will be awarded based on the highest valued portfolios and range from \$125 to the Grand Prize of \$1000.

For more information about this unique fundraiser, please email us at [info@22q.org](mailto: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  
4 State Road, #201  
Media, Pennsylvania 19063**

Changes and updates are also underway for our website at [www.22q.org](http://www.22q.org)  
Stay tuned.....