

What's New with 22q?

Fall 2010



22Q

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

PO Box 424
Matawan, NJ 07747 • 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.

Your support helps the Foundation achieve its mission of detection, care, and cure! Visit our website to see what we've [accomplished](#) this year!

A Rose by Any Other Name....

Because of the way our understanding of the 22q11.2 deletion evolved, several different names continue to be used for what we now know to be the same condition. These older terms include DiGeorge syndrome (DGS), velo-cardio-facial syndrome (VCFS), conotruncal anomaly face syndrome (CTAF), Opitz G/BBB syndrome, and Cayler cardiofacial syndrome.

Genetically speaking, there is no detectable difference in the microdeletions found in people with VCFS versus those with DGS or the other related syndromes. Individuals with these diagnoses all have the same underlying condition: the 22q11.2 deletion syndrome.

Unfortunately, having a syndrome with several different names can lead to negative consequences, not to mention the general confusion it creates among parents and professionals. For example, parents of a baby

diagnosed with DGS may be frustrated by the lack of information about the syndrome, not realizing that VCFS and 22q resources (including this Foundation!) also pertain to their child. Healthcare providers may not access all current and available information if they are searching for literature under an older name.

*Did You Know?
Genetically speaking, there is no detectable difference in the microdeletions found in people with VCFS versus those with DGS or the other related syndromes.*

Perhaps most importantly, having several names splinters precious resources, hampering a united approach to research and support.

To address this important issue, the Foundation is pleased to launch the *Same Name Campaign*, an educational effort aimed at professionals and families, with the goal of establishing consistent terminology for the 22q11.2 deletion syndrome. As a parent-driven organization, the Foundation acknowledges that families who have lived for years with a diagnosis of VCFS, DGS, CTAF or a related condition may find it difficult to switch to a different name. We encourage you to support the aims of the *Same Name Campaign* by mentioning the 22q11.2 deletion, along with or without its older diagnosis name, when describing yourself or your child. Over time, as professionals more consistently use the 22q11.2 designation, fewer and fewer people will be newly diagnosed with VCFS, DGS, or other outdated names; our goal is that eventually, all will be on the same page, moving in the same direction, supporting our worldwide 22q community.

Check out our website for more information about the Foundation's *Same Name Campaign*

www.22q.org



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Save the Date

Wall Street Got you Down?

The Foundation's annual **22q Stock Hullabaloo** contest is now 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).
- At the end of the sweepstakes, we will value your "portfolio" - those with the highest value will win cash prizes.

Look for more information coming to your email *Inbox* soon, or visit our website at www.22q.org



Grab Your Cameras!

The Foundation's 6th Annual Calendar Contest has begun. Submit a photo of your child with the 22q11.2 deletion for a chance that he or she will be chosen as a "child of the month" in the 2011 calendar.

In addition to the photo contest, you can celebrate your child's special day by "**buying a birthday**". The Foundation will include an acknowledgement (first name only) on your child's calendar month. The cost to buy a birthday is \$25.00 (US). Proceeds go to support the work of the Foundation.

For more information and an order form, visit our website at www.22q.org. Don't delay — the deadline for photo and buy-a-birthday submissions is October 30, 2010!



Contact Us:

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22q and BOO!

What? A Haunted Halloween Party to Benefit the Int'l 22q11.2 Deletion Syndrome Foundation

When? Saturday, October 30th, 2010

Where? Finnigan's Wake
(A former coffin making facility!)
537 North 3rd Street
(Corner of 3rd & Spring Garden Sts)
Philadelphia, PA 19123-2936
Phone: (215) 574-9240

Time? 7:00 PM – 11:00 PM

Cost? \$50.00 per person, including valet parking

Pre-purchase gaming chips and save! Get 2500 chips for \$100 if you pre-pay in advance. (Get 1000 chips for \$100 if you wait until the night of the event.)

Includes? Devilish Dining, Draconian Dancing, Barbarian Beers and Bewitching Wines! Not to mention Ghoulish Gaming, Cauldrons for Auction, and Potent Prizes for Best, Worst, and Silliest Costumes – just to name a few!

To register, visit our website at www.22q.org
Come with your costume or purchase a mask on site – but either way don't miss the best party of the season while benefitting a great cause!

Our Mission

Improving the quality of life for individuals affected by the 22q11.2 deletion syndrome through family and professional partnerships.

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 Matawan, New Jersey.