

What's New with 22q?

Tell 22 Campaign Takes Off For Goal of \$222,000

Great news! The first donations for the *Tell 22 About 22q Awareness and Fundraising Campaign* have already begun to arrive. Just days after the spectacular *22q at the Zoo* summer event, our volunteers leaped into action to mail the 1,500 pieces for this important awareness campaign

"Spreading awareness about 22q is one of our primary objectives," says board member Carol Cavana, who spearheaded the effort. "This campaign will put vital information into the hands of families as well as raise dollars to propel research."

The recipients of the mail-

ing are part of the largest awareness campaign in the history of the Foundation. When they send the copy of the letter to just 22 of their friends and family members, they will become a vital link in the 22q chain of awareness.

If you have not already sent your 22 letters, please take a moment to forward this newsletter to 22 people in your email list. Contact the Foundation if you want additional hard copies of the letter or extra fact cards.

Encourage them to donate just \$22, either at the website or with a check. Help us reach our goal: **\$222,000**



*Wild and wonderful at the Zoo.
See more on page 2*

Welcome to New Board Members

Fred Weiner is Executive Director of Dragonfly Forest, a recreation program for children with serious illnesses. "A few years ago, I was introduced to the 22q community via Dragonfly Forest," he says. "I am amazed at how much this community wants to get the word out about 22q so their kids get the help they need to live richer, fuller lives. I want to help with this mission and get involved with these families beyond a few summer days at Dragonfly Forest."

Sheila Parvin Kambin, MD is an obstetrician/gynecologist. She works in the Special Delivery Unit at Children's Hospital of Philadelphia and is the mother of two, one of whom has the deletion. "I am deeply committed to generating awareness for 22q," says Sheila. "I want to work with other individuals who share my visions and goals. I am a parent who avidly supports the same name campaign and the intent of uniting our very small community."

What's New With 22q is published for families affected by the 22q11.2 deletion syndrome, which is caused by a missing piece (deletion) of genetic material on chromosome 22. Symptoms of the condition include heart anomalies, immune deficiency, cleft palate, feeding problems, speech delays, learning disabilities, and social/emotional issues. Learn more at www.22q.org.

Our Mission

The mission of the 22q Foundation is to improve the quality of life for individuals affected by the 22q11.2 deletion syndrome through family and professional partnerships.



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

**The International 22q11.2
Deletion Syndrome Foundation, Inc.**
PO Box 424
Matawan, NJ 07747 USA
877-739-1849
www.22q.org
Email us at: info@22q.org

22q At The Zoo Goes VIRAL



Sacramento, California (USA) (See more photos on pages 3 & 4)

22q at the Zoo - Worldwide Awareness Day! was a fabulous event that drew more than 10,000 people to 65 zoos in nine countries, spanning three continents.

More than 300 people participated at the Philadelphia Zoo. The zoos in Cincinnati, Chicago, and Atlanta had close to 300 participants while Miami and Sacramento came in at around 100 persons. Ft. Wayne, Indiana and Cape May, New Jersey zoo groups also made a strong showing.

The same experience occurred around the globe — more than 400 in London, 250 in Madrid, and countless others in multiple Spanish, German and British cities as well as in Australia, Canada, Holland and Italy.

Our friends in the UK tell us the BBC picked up the story and it also ran in a national paper there. Ditto for many of the other locations. It all started with a single volunteer in each location then grew exponentially.

This was the start of something special — a ray of hope and solidarity. We returned home that day to find hundreds of emails, photos, mini video clips, and Facebook messages from around the globe celebrating the success.

The original plan was to hold this event every six years when May 22 falls on a Sunday. Clearly that plan has changed. We already look forward to next year's event and for many years going forward.

STAY TUNED FOR A DATE IN 2012!

22q Happenings

Mark your calendars for the **8th Biennial International 22q Conference** to be held July 7-10, 2012 in Orlando, Florida. The 22q Foundation is the lead sponsor and convening organization for the conference where hundreds of parents and professionals will gath-

er to hear about new developments, share research, network, bond and plan.

Seventy 22q kids had a great summer experience at **Dragonfly Forest Camp** this June. The chance to enjoy summer camp and each other was made possible thanks in part to the \$5000 grant made by the Foundation to

the camp.

Watch your mail for the **2011 22q Stock Hullabaloo**, the contest where, for a donation of \$100, we "invest" \$10,000 in a hypothetical portfolio for you. At the end of the contest, we value your "investment." Those with the highest value win cash prizes. Of course no real funds

are invested, other than in the important work of the Foundation.

Your tax deductible gift helps us achieve our goals— **Detection! Care! Cure!** for 22q families around the world. Send your gifts to the headquarters in New Jersey or donate at www.22q.org.



Los Angeles, California (USA)

22q At The Zoo—From Around the World



Chicago, Illinois (USA)



Sydney, Australia



Miami, Florida (USA)



Philadelphia, Pennsylvania (USA)



Shipping signature "red shirts" all over the world from the USA headquarters.



London, England



Atlanta, Georgia (USA)

22q At The Zoo—From Around the World



Hilo, Hawaii (USA)



Madrid, Spain



Dallas/Fort Worth, Texas (USA)