

What's New with 22q?

22q Advocate nominated for Clemente Award

The International 22q11.2 Deletion Syndrome Foundation congratulates Ryan Dempster, major league baseball player and parent of a daughter with the 22q11.2 deletion, on being



Ryan Dempster poses with Louis Cavanaugh

named as the Chicago Cubs' 2011 nominee for the prestigious Roberto Clemente Award.

This annual award recognizes a player who best represents the game of baseball through positive contributions on and off the field, including sportsmanship and community involvement. After their daughter, Riley, was born with the deletion in 2009, Ryan and his wife founded The Ryan and Jenny Dempster Family Foundation, an organization dedicated

to raising awareness about 22q and supporting related charities, including The International 22q11.2 Deletion Syndrome Foundation. Since the inception of the Dempster Foundation and the support of the Cubs organization, the awareness and fight against the syndrome has spread significantly.

Summer Camp and the Livin' Was Easy

Dragonfly Forest Camp was the happy summer home for nearly 100 22q kids this August as they soaked up the atmosphere that only a week at summer camp can provide. See page 3 for more photos of their excellent camping adventure.



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.**

PO Box 424

Matawan, NJ 07747 USA

877-739-1849

www.22q.org

Email us at: info@22q.org

Call for Research Volunteers

Vivian Narcisa, a graduate student from Arcadia University in Philadelphia, is studying genetic counseling and needs help with her thesis project. She is inviting 22q families to participate in interviews and hopes to identify the unmet needs of teenagers with 22q and their families as they experience their teenager's transition into adulthood. Visit www.elwyngenetics.org/22qadultneeds.

Honor Loved Ones With Donations

Make a donation to The International 22q11.2 Deletion Syndrome Foundation to honor someone special in your life. Recognize a special birthday, anniversary or important milestone that person has achieved. When you make a donation in someone's name, they receive an acknowledgment of the donation.

You can also make a donation to the Foundation in memory of a family member or friend. A meaningful way to celebrate the life of a loved one can be achieved through a memorial contribution, in lieu of flowers, to The International 22q11.2 Deletion Syndrome Foundation. Acknowledgments will be sent to the family of the individual.

The Foundation is a registered and approved, tax exempt organization under 501c (3) of the tax code provided by the IRS. Consult with your tax advisor about the tax deductibility of your gift.

Order Photo Calendars Today

Beautiful photos of our children have arrived for the 7th Annual Calendar Contest. You can order 2012 calendars for friends, family and co-workers. Think about giving them to your child's doctor, teacher or therapist. What a great way to spread the word about 22q. Visit the Foundation website for an order form. Calendars will be ready to ship by December 10.

2012 Dates To Remember

- April 22: Second Annual 22q At The Zoo Worldwide Awareness Day
- July 6-10: The 8th Biennial International 22q11.2 Deletion Syndrome Meeting in Lake Buena Vista, Florida at *Disney's Yacht & Beach Club Resorts*.

22q Happenings

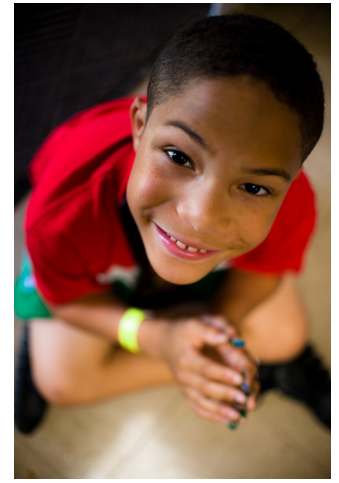
The **Tell 22 about 22q Campaign** is in full swing. We are proud to report \$6,000 has been raised so far. Congratulations to our 22q supporters who have championed the cause with friends and families so we can reach our goal of \$222,000.

Once again, the Foundation provided financial support for a **family-friendly conference on the educational and behavioral aspects of the deletion**. The latest conference, sponsored by Elwyn Genetics in collaboration with Children's Hospital Colorado, took place in Aurora, Colorado on October 1-2, 2011.

The 2nd Annual **22q at the Zoo Worldwide Awareness Day** will take place on April 22, 2012. It will be supported by the national and international organizations along with the 22q Foundation. Look for a location near you and if you would like to organize an event in your area visit our FaceBook page. We would be glad to help you get started.

Visit the 22q website to **download a helpful, easy-to-digest 24-page booklet** for parents of young children with the deletion — *During the First Years: An Introduction for Parents of Newly Diagnosed Children*.

Dragonfly Forest Camp 2011



DETECTION



CARE



CURE

Invest NOW in the 2011 22q Stock Hullabaloo

Wall Street got you down? The Foundation's Annual 22q Stock Hullabaloo Contest is underway. While we can't guarantee you'll win, you'll have fun while donating to a worthy cause. Your \$100 entry entitles you to a hypothetical \$10,000 to "invest" in stock of any four (exactly four—no more, no less) of 36 corporations. Awards will be decided by the Board of Directors of 22q Foundation. You may enter more than once (in fact, we would love that) but you must submit a separate form for each entry. Visit the 22q website to enter the contest. Here's how it works.

- **YOU DO NOT NEED TO MAKE ANY CALCULATIONS.**
- **NO ACTUAL DOLLARS ARE BEING INVESTED.**
- Your hypothetical \$10,000 will automatically be "invested" in \$2,500 increments in each of the stocks you pick (and of course will allow you to invest in the future of this Foundation).
- The number of shares of each corporation's stock will be determined based upon their closing prices as of Friday, December 30, 2011.
- The object of the contest is to make your portfolio of four stocks appreciate as much as possible based on the value of the sale of the shares as of closing prices for Tuesday, January 31, 2012.
- Awards will be based on the ranking of each participant's portfolio value at the end of the contest and will be distributed in early 2012.
- **PRIZES: Grand Prize: \$500 • 2nd Prize: \$400 • 3rd Prize: \$300 • 4th Prize: \$200**

July 6–10, 2012

2012 Biennial Meeting Lands in Orlando

The 8th Biennial International 22q11.2 Deletion Syndrome Meeting returns to North America for the first time since 2004. This superb conference, sponsored and organized by *The International 22q Deletion Syndrome Foundation, Inc.*, features presentations from top clinicians and scientists from across the globe who devote themselves to the study of the 22q syndrome. They will cover the medical, psychosocial, speech, language, and cognitive characteristics of the diagnosis with an emphasis on treatment.

The meeting, entitled *Detection • Care • Cure – The Magic of Making a Difference*, will indeed be magical as it is set in the most inviting of settings – *Disney's Yacht and Beach Club Resorts* in Lake Buena Vista, Florida. In addition to the meeting sessions, *Disney Character Greetings* are planned for children and adults alike, beginning with a Welcome Reception on Friday, July 6.

The Scientific Program will be presented July 7-8, with a subset of professionals remaining to share information with families July 9-10. The Social Program will include a Welcome Reception on Friday night; Speaker's Reception on Saturday night; and Mixed Barbeque for both families and professionals on Sunday night. All who are interested in learning more about the syndrome — from families to healthcare providers, therapists to educators — are encouraged to attend. A Call for Abstracts is forthcoming with submissions due by midnight January 22. Notification of acceptance will be made by March 22.

The conference is intended for families and professionals. It is an opportunity to learn, explore and bond. Congratulations to the 22q Foundation, which is extremely proud and is working very hard to plan and present the meeting. Visit www.22q.org for more information.