

# What's New with 22q?

Winter 2009



## 22Q

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).*

## Calling all Campers!

### Dragonfly Forest to Host a One Week Summer Camp for Kids with 22q

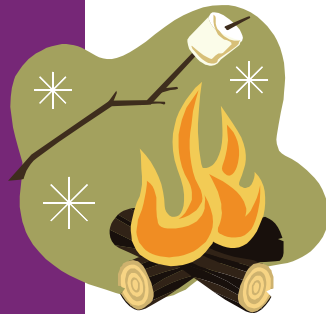


Thanks to the efforts of the Foundation, children with the 22q11.2 deletion are being offered an exciting opportunity this summer!

Dragonfly Forest, located in Westtown, Pennsylvania, is a not-for-profit organization committed to offering children with serious illnesses and disorders the opportunity to enjoy a free overnight camp experience in an environment that is designed to meet their needs. Dragonfly Forest will host a week-long camp exclusively for kids with the 22q11.2 deletion from June 28 - July 2, 2010. Camp is offered free of charge, thanks to generous donations to Dragonfly Forest, including a significant gift from the Int'l 22q11.2 Deletion Syndrome Foundation.

Westtown is located about 40 minutes west of Philadelphia, and the camp is open to families from all across the US. Dragonfly Forest will provide free transportation by bus from Philadelphia International Airport or designated pick-up locations, such as at The Children's Hospital of

Philadelphia. The camp is open to children between the ages of 7 and 14 years old; teens between 15 and 17 may attend "The Leadership Program", and those 18 and older can serve as volunteer counselors. Camp registration runs from January to April 2010, so don't delay if your child may be interested. To learn more about the camp, visit [www.dragonflyforest.org](http://www.dragonflyforest.org) and click on "Camp Program" to find the link for the session titled "Chromosome 22q11.2 Deletion". We hope to see you there!



## Join our Parent Network

When faced with a new diagnosis or a 22q-related illness, a parent's best source of comfort is often another parent. An important goal of the Foundation is to provide emotional support for families in need. Whenever possible, we will attempt to locate a contact person for a family requesting support through our parent network. If you would like to hear from another parent who's been in your shoes, please contact the Foundation at [info@22q.org](mailto:info@22q.org) or call 877-739-1849.

Are you a parent willing to reach out to another family in need? Often all that is required is a sympathetic ear or a comforting email to let another parent know that he or she is not alone. Visit the [Helping Families](#) section of our website and complete our [parent network form](#) to be added to our list of available contacts for new families seeking support.



## 22q11.2 Happenings!

- February 27-28, 2010**  
**Behavior & Learning in Children with the 22q11.2 Deletion syndrome**  
 Gainesville, Florida  
[www.elwyngenetics.org/22qhome.htm](http://www.elwyngenetics.org/22qhome.htm)
- July 29-31, 2010**  
**7th Int'l 22q11.2 Deletion Syndrome Conference**  
 Coventry, England  
[www.maxappeal.org.uk](http://www.maxappeal.org.uk)

## Florida Conference to Focus on Behavior and Learning in 22q

As part of its ongoing efforts to improve the quality of life for people with the 22q deletion, the Foundation recently awarded a \$5,000 grant to support a conference on educational and behavioral aspects of the condition. This popular conference is sponsored by Genetic Services at Elwyn and has been held at several sites throughout the US since 2006. The upcoming meeting will take place in **Gainesville, FL on February 27-28, 2010**. 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. Complete conference information is available online at [www.elwyngenetics.org/22qhome.htm](http://www.elwyngenetics.org/22qhome.htm)



## Contact Us:

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## 7th Int'l 22q Conference, Coventry England

This biannual meeting will be held July on 29-31, 2010 with a theme of "Treatment as we Move into a New Decade".

The conference will take place over three days with back-to-back meetings for parents and professionals.



A common social function on the second evening will bring all together for a splendid time! Mark your calendars and check out the Max Appeal website for updates ([www.maxappeal.org.uk](http://www.maxappeal.org.uk))

## Still Time to Order Your 2010 Calendar!

Back by popular demand, the Foundation held its 4th Annual Calendar Contest this fall. Calendar sales represent a significant fundraiser for the Foundation, and families participate by submitting photos of their smiling children. Do your part to increase awareness about 22q by showing off our beautiful 2010 calendar. Order forms are available on our website at [www.22q.org](http://www.22q.org). Proceeds will help us to realize our mission of detection, care, and cure.

## 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.