

# *What's New with 22q?*



**8th Biennial 22q Conference**

July 6 - 10, 2012  
Disney's Yacht and Beach Club Resorts  
Lake Buena Vista, Florida, USA

*Detection. Care. Cure...*  
*The Magic of Making a Difference.*



Saturday and Sunday mornings, July 7 and 8, allowing participants to spend their afternoons and evening in the parks. Concurrently, the Professional Program will open on Saturday morning and conclude on the following afternoon.

A speaker dinner will be held Saturday evening while a "22q BBQ Character Dinner for All" will be served up to all attendees on Sunday. On Monday, July 9, the medical and educational sessions will open for families with the conference concluding on Tuesday afternoon, July 10.

### **Disney Hospitality**

The headquarters hotel, *Disney's Yacht and Beach Club Resort*, is holding a block of rooms at \$179/night plus tax under the Code "22q Meeting." This rate is also available before and after the conference but please contact the hotel for details and availability at (407) 939-4686 .

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## *Make Your Plans!*

Pick a reason — to learn about available treatment...to discover educational strategies...to hear clinicians share the latest in research...to bond with other families who are living what YOU are living. Whatever is your reason for attending this conference, held only every two years and known as one of the most significant gatherings on the globe of families and professionals who live the 22q experience, DON'T MISS THIS CONFERENCE.

### **Learn, Share and Bond**

One of the key long term objectives of the lead sponsor, The International 22q11.2 Foundation, is to create an environment where parents, grandparents, siblings, clini-

cians, physicians, and 22q children and adults can spend time together to build a network for the future to help one another navigate the challenges of 22q. Come take advantage of the multitude of workshops, social events, demonstrations, panel discussions, question and answer sessions, and insights from international sources, all set against the magical background of a *Disney* resort.

### **Disney Characters Kick It Off**

The preliminary program is scheduled to kick off with a welcome reception for all participants on the evening of Friday, July 6, which will feature a visit by *Disney* characters. Family-focused sessions will run on

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*Something for everyone!*

# Jam Packed Family Program Delivers Treasure Trove of Insight and Information

Dozens of sessions, excellent speakers, choices of workshops and intriguing activities geared to all ages and experiences are packed into the Family Program. The ambitious schedule starts on Friday night, July 6, and rolls through Tuesday, July 10. If you spend an hour, a day or all five days at the 22q Conference, you will come away so much smarter. Consider these topics, which are just a sampling of what the schedule holds.

Hear how to **“Customize the Learning Environment: Effective Strategies to Support Behavior and Learning.”** Get insights about **“Dealing with Behavioral Differences During Adolescence and Adulthood.”** Delve into the details of Newborn Screening and the **“Impact of Early Detection of 22q11.2DS Related Congenital Heart Disease.”** The talk entitled **“The Odd Man Out! When the Patient Does Not Fit the Profile – One Family’s Diagnostic Odyssey”** will definitely stimulate discussion.

Targeting parents, grandparents and caregivers, **“Go to Sleep! Hands-On Demonstration to Help Fall and Stay Asleep”** addresses a fundamental coping issue. The same is true for **“Puberty and Emerging Sexuality”** and **“Sharing the Diagnosis Across the Lifespan.”**

Basic health concerns will come to light with program that examine **“The Heart...Infection and Related Problems,” “Allergy and Asthma,” “Digestion,” “Feeding,” “Ear, Nose and Throat,”** and **“The Eye as a Window to the Brain.”** You will also be taught about

**“Thyroid Disease and Growth Issues,” “Growth Charts,” “Calcium Problems,” “Bleeding,” “Teeth,” “Bones,”** and **“Keeping It All Together By Establishing a Medical Home.”**

Caregiver stress is a universal challenge. Tune into **“Care for the Caregiver: Use of Mindfulness Based Stress Reduction for Parents of Adolescents with Autistic Spectrum Disorders.”** Or go deeper into the relationship you have with your child’s school with **“Feeding, Swallowing and Speech...Navigating IEPs”** and **“Creating Positive School Partnerships.”**

Health care guidelines, international perspectives, issues of early childhood development, and a discussion of **“The Brain, Behavior and Transitions to Adulthood”** will be on tap. Sit in on **“State of the International 22q11.2 Consortium,” “Developing an International Registry – Why and How”** or **“The Newly Established International Brain Behavior Consortium.”**

Check out the workshop on photography (you’ll need to bring a camera). The session on **The School Years** will feature a talk on **“Setting the Stage for Success: Effective Strategies to Enhance Social Skills.”**

Meanwhile, it’s not all work. Come hungry to **“A 22q BBQ,”** complete with Disney characters. How does a scavenger hunt for the teens sound? Little kids ages 3 and up will get glamorous at the **“22q and Sassy Doo”**

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## In the Who's Who of 22q, It's Who You Know. You Know?

Yes, the 22q Conference is a priceless opportunity to get informed. But it is also a chance to make connections. The conference presenters are people you have either heard about, emailed with, talked to on the phone, or seen in photos. Now, you can meet them face to face.

Here is a partial list of who will be sharing information at the workshops and presentations. Get ready to meet Rick Guidotti, Brenda Finucane, Alice Bailey, Wendy Rose, Carol Cavana, Anne Bassett, Donna McDonald-McGinn, Christina Persson, Oksana Jackson, Margaret Souders, Meg Maguire, Ann Swillen, Cindy Solot, Michelle Breedlove-Sells, Sheila Kambin, Oksana Jackson, Anne Lawlor, Daniella Krijger, Nancy Unanue,

Alex Habel, Lorraine Katz, Michele Lambert, Rosario Mayro, Dino Colo, Annique Hogan, Julie Wootton, Maria Kamper, Mindy Dodge, Chris Moriconi, Elizabeth Goldmuntz, Kathleen Sullivan, Terri Brown-Whitehorn, Maria Mascarenhas, Peggy Eicher, Solveig Oskarsdottir, Brian Forbes, Anthony Lamantia, Christian Marshall, Paul Wang, Peter Scambler, Bernice Morrow, Barbara Haas-Givler, Tony Simon, Carrie Bearden, Jennifer Janusz, Ed Moss, Natalie Blagowidow, Raquel Gur, Solveig Oskarsdottir, Natalie Blagowidow, Sixto Garcia-Minaur, Hillary Joyce, Daneen Whinna, Eamon Anderson, David Goldenberg, Missy Disibio, Ayne Lawlor, Monica Jennings, Kayla Disibio, Maria Mascarenhas, and Marilyn Cohen.

## Make Your Plans!

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Located within walking distance of Disney's Epcot® theme park and BoardWalk area, The *Disney's Yacht Club Resort* is a lakeside Disney Deluxe Resort featuring lush landscaping and the formal grace of a grand New England yacht club.

Behind the Resort lies *Stormalong Bay*, spanning 3 acres, with water slides emerging from the life-size replica of a wrecked ship, lagoons, a slow river to float along in inner tubes and a sand-bottom pool. At 25-acre *Crescent Lake*, Guests can rent a variety of watercraft .

## Packed Program

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**Beauty Parlor!** Everyone will love **"22q Bingo"** and **"Video Gaming "** and **"Zumba Dancing With International Meet and Greet"** will be a hoot.

Of course, DisneyWorld is a shuttle ride away. But most important, the time you spend connecting to fellow conference goers will be some of the most productive time you can spend.

For details about all the offerings during the 22q Conference, visit the 22q website.

## Professionals Explore Critical Issues

As families take in vast amounts of information in the Family Program, the professionals will meet to address such topics as: Speech and Language, Education, Brain and Behavior, Interventions, Imaging and Adulthood, Genetics, Registries, Cross-Fertilization, Clinical Centers, Navigating the Electronic Record and Developing Order Sets, Hearts and Minds in Mouse Models of the 22q11.2 Deletion Syndrome, Cardiac and Craniofacial Development, and CNV's in Autism, and Neuro-Psychiatric Disease.

## To: You the 22q Community

The 22q11.2 Deletion Syndrome Conference is right around the corner. As you make summer plans, I strongly encourage you to consider attending this excellent meeting created to benefit 22q families like yours!

We (the 22q community) often feel unnoticed. It is meetings like this that provide not only excellent clinical/educational information but also serve as the largest gathering for the 22q community in the world. Meetings like this are where great ideas, awareness projects, programs, partnerships, and campaigns that positively impact our community are born. It is a place where everyone is included and where feedback is welcomed. It is a place where not only the most up-to-date medical/educational information is available but where you have access to workshops specifically created for kids, tweens, teens, young adults, siblings, moms, dads, and even grandparents. It is at this meeting and others like it where the seeds of change are planted.

If you are unable to attend, you can still jump in and ensure the conference is successful. It can be as simple as making a humble donation to 22q.org or encouraging your Facebook/Twitter friends to donate to the conference. Maybe you commit to spread the word by sharing information on your social media profile pages twice a week.

So I ask you to please take a look at [www.22qconference.com](http://www.22qconference.com). Help with one of these tasks:

1. Post a link to this page ([www.22qconference.com](http://www.22qconference.com)) on any forum/group/or 22q/VCFS related website and help promote this incredible 22q resource at least twice a week.
2. Place a tribute ad from your family or on behalf of your 22q Family Support Group in the conference program to support the conference in a creative and fun way. (Think fun, back-of-your-high-school year book type ads. You can even include a family picture. Prices are based on ad size and range from \$22 to \$220.)
3. If you are attending this meeting, go to The International 22q11.2 Foundation on Facebook and post a message. Tell them why you decided to go and what part of the meeting you're looking forward to most.

If we do not put our collective community support behind ventures like this we will never achieve greatness for our cause. Be a part of the magic and show your support for the 22q Orlando Conference TODAY!

Most Sincerely,  
**Michelle Breedlove Sells**  
Director of Development of The Dempster Family Foundation

*"I long to accomplish a great and noble task, but it is my chief duty to accomplish humble tasks as though they were great and noble. The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of the tiny pushes of each honest worker."*

-Helen Keller

**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](http://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.



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