

# 2014 1p36 DSA Conference Agenda

## Thursday, July 17, 2014

9:00am	Cincinnati Children's Hospital Study appointments begin <a href="http://www.1p36dsa.org/storage/1p36dsa-docs/1p36%20Deletion%20Syndrome%20Study%20Information.pdf">http://www.1p36dsa.org/storage/1p36dsa-docs/1p36 Deletion Syndrome Study Information.pdf</a>	NW Territory Rooms B-C-D
12:30 – 2:30 pm	Conference Registration at Conference Center Check-in Desk Early hotel check-in available at main desk. You can Pre-Register and they will call you when your room is ready.	Conference Center Check-In Desk
2:30 – 2:45 pm	Welcome 1p36 Family and Overview of the Weekend	Sequoia Ballroom
2:45 – 3:15 pm	<b>Overview of Cincinnati Children's Hospital Studies of individuals with 1P36</b>  <b>Robert J. Hopkin, MD</b> - Dr. Hopkin is an Associate Professor of Clinical Pediatrics at Cincinnati Children's Hospital Medical Center. The majority of Dr. Hopkin's time is spent in caring for patients with genetic disorders. He participates in clinics from Fetal Care to Adult Genetics.  <a href="http://www.cincinnatichildrens.org/bio/h/robert-hopkin/">http://www.cincinnatichildrens.org/bio/h/robert-hopkin/</a>  <b>Cassandra Bac</b> - Cassandra is a second year Graduate student at University of Cincinnati and works with Dr. Hopkin in the Genetics department at Cincinnati Children's Hospital. She is interested in Pediatric Genetics and specifically 1P36 Deletion Syndrome. She is coordinating these studies as part of her Master's Thesis and is very excited to meet all the families at the conference.	Sequoia Ballroom
3:15 – 4:15 pm	<b>Our Fabulous 1P36 Children</b> Video Introduction with Jennifer and Scott Winiecki	Sequoia Ballroom
4:15 – 4:30 pm	<b>1P36 Family Photo</b>	Pavilion
4:30-4:45	<b>Balloon Release to Honor Our 1P36 Angels</b>	Pavilion
4:45-5:00	BREAK	
5:00 – 9:00 pm	<b>Pizza Party, Laughter, Dancing and Photo Booth Fun!</b>	Sequoia Ballroom

## Friday, July 18, 2014

8:00-9:00	Buffet Breakfast	Sequoia Ballroom
8:45	Childcare Rooms Open	Fallen Timbers A-B-C and NW Territory A
9:00	Appointments for Cincinnati Children's Hospital Studies Begin	Sequoia Ballroom Sections 4-5-6
9:00 – 9:15am	<b>Opening Announcements</b>	Sequoia

		Ballroom
9:15-10:15am	<p><b>The Role of Individual Genes in 1P36 Deletions</b></p> <p><b>Daryl Scott, MD/PhD</b> - Dr. Scott is a doctor and a scientist. He is Assistant Professor of Molecular and Human Genetics at Baylor College of Medicine and sees patients in the Genetics Department of Texas Children's Hospital. When he is in the hospital, he works as a clinical geneticist taking care of children and families affected by 1p36 deletions and other genetic disorders. When he is in the lab, he works to identify the genes that cause the medical problems associated with 1p36 deletions like heart defects, cardiomyopathy, hearing loss, and cleft palate.</p> <p><a href="https://www.bcm.edu/departments/molecular-and-human-genetics/?pmid=11041">https://www.bcm.edu/departments/molecular-and-human-genetics/?pmid=11041</a></p> <p><a href="http://www.texaschildrens.org/Locate/Doctors/Scott-Daryl/">http://www.texaschildrens.org/Locate/Doctors/Scott-Daryl/</a></p>	Sequoia Ballroom
10:15-10:30	BREAK	
10:30-11:30	<p><b>1P36 and Seizures</b></p> <p><b>Tom Koprowski, LSW</b> - Mr. Koprowski has been employed by the <b>Epilepsy Foundation</b> for the past 25 years. He has served in many different capacities at the agency including positions as a Home Manager in a residential facility for individuals with uncontrolled seizures and as the Director of an Adult Day Activity Program. Currently Mr. Koprowski is the Director Of Community Education.</p> <p><a href="http://www.cincinnatipilepsy.org">http://www.cincinnatipilepsy.org</a></p>	Sequoia Ballroom
11:30-11:45	Time allotted For run-over-transitions	
11:45-12:00	Pick up children from childcare to eat with you.	Fallen Timbers A-B-C and NW Territory A
12:00-1:00	<b>LUNCH</b> -Please remember to only take the lunch that you registered for. You can find your selection on the back of your conference badge.	Sequoia Ballroom
12:45	Childcare re-opens	Fallen Timbers A-B-C and NW Territory A
1:00-2:00	<p><b>1P36 and The Heart</b></p> <p><b>John L. Jefferies, MD, MPH, FAAP, FACC</b> - Dr. Jefferies is the Director of Advanced Heart Failure and Cardiomyopathy at The Heart Institute of Cincinnati Children's Hospital Medical Center. He is also Associate Professor of Cardiology at UC Department of Pediatrics.</p> <p><a href="http://www.cincinnatichildrens.org/bio/J/john-jefferies/">http://www.cincinnatichildrens.org/bio/J/john-jefferies/</a></p>	Sequoia Ballroom
2:00-2:15	BREAK	
2:15-4:00	<p><b>1P36: Speech, Communication and Feeding</b></p> <p><b>Emily Buckley MS, CCC-SLP</b> is a Speech-Language Pathologist at Cincinnati Children's Hospital Medical Center. Her area of interest and expertise is working with children and families impacted by delays Birth to 3 and dysphagia (feeding challenges). Emily has been with the Division of Speech Pathology for over 5 years.</p>	Sequoia Ballroom

	<b>Karen Rizzo MS. CCC-SLP</b> is a Speech-Language Pathologist at Cincinnati Children's Hospital Medical Center. Her area of interest and expertise is working with children and families impacted by dysphagia (feeding challenges) and fluency. Karen has been with the Division of Speech Pathology for over 8 years.	
4:30-6:30	Dad Time Appetizers and cocktails on the patio	Pavilion
7:00-9:00	Mom Time Cocktails on the patio	Pavilion
<b>Saturday, July 19, 2014</b>		
8:00-9:00	Buffet Breakfast	Sequoia Ballroom
8:45	Childcare Rooms Open	Fallen Timbers A-B-C and NW Territory A
9:00-9:15	<b>Opening Announcements</b>	Sequoia Ballroom
9:15-10:15	<b>Panel Discussions and Open Question Time</b>  Dr. Daryl Scott Dr. John Jefferies Dr. Robert Hopkin  Parents of Children with 1P36	Sequoia Ballroom
10:15-10:30	BREAK	
10:30-11:45	<b>Navigating the IEP</b>  <b>Beth Peloquin</b>  Beth is an Early Childhood Special Education consultant who provides professional development for school districts and preschool providers to improve the quality of their inclusion practices. She also works as adjunct faculty for the University of Vermont in the early childhood special education department and for Champlain College in the early education department.  Before that, Beth taught in early childhood programs, or worked with young children individually for more than 20 years. She used the principals of universal design for learning to include children with all levels of ability into her fully inclusive classroom. She also worked with children with disabilities in their homes, childcare, and outside preschool settings, being part of collaborative teams in order to work with children in their least restrictive environment.  Beth currently serves on the Vermont Association for the Education of Young Children Board, which is the local affiliate that focuses on the well-being of all young children birth through eight years old. She joined this board in order to make sure there was a voice for children with disabilities present.  Beth has a Bachelor's degree from Northwestern University and a Masters Degree from the University of Massachusetts. In the fall, she will be starting a Doctoral program at the University of Vermont in Educational Policy and Leadership. Her focus will be on preschool special education and inclusive environments.  Table will be set up with examples of existing students with 1P36	Sequoia Ballroom

11:45	Pick children up from childcare to eat lunch with you	Fallen Timbers A-B-C and NW Territory A
12:00-1:00	<b>LUNCH</b> -Please remember to only take the lunch that you registered for. You can find your selection on the back of your conference badge.	Sequoia Ballroom
12:45	Childcare rooms re-open	Fallen Timbers A-B-C and NW Territory A
1:00-2:00	<p><b>Safety Solutions For Sleep Time</b></p> <p><b>Aaron Clow</b></p> <p>Aaron is president and founder of Beds by George, a company that manufactures and distributes medical safety beds to the US and Canada. Aaron also owns a few patents and trademarks for safety bed design and function. He has spent the last 7 years as an advocate for safe sleeping solutions focusing on educating dealers, therapists, and funding sources on the need and solutions for safety among the medically fragile and special needs community during sleep. He has been a speaker on this topic at numerous trade shows, symposiums, and in-services for therapists and ATP's across the US. He is the accredited presenter for the NSM RESNA CEU course on safety beds used by hundreds of durable medical equipment retailers.</p> <p>Aaron also has a daughter with 1P36 Deletion and that was his original primary inspiration for this field!</p> <p><a href="http://www.bedsbygeorge.com">http://www.bedsbygeorge.com</a></p>	Sequoia Ballroom
2:00-2:15	BREAK	
2:15-3:15	<p><b>Building Lifelong Networks of Support</b></p> <p><b>Tim Vogt</b></p> <p>Tim lives in Bellevue, Kentucky and is the Executive Director of Starfire. He has worked in this field since 1997. For the first ten years of his career, he worked in and created programs that he is spending the next ten years undoing. He has been working most recently with families and citizens around discovering how neighborhoods and families might work to build meaningful, creative and supportive connections.</p> <p><a href="http://www.starfirecouncil.org">www.starfirecouncil.org</a></p>	Sequoia Ballroom
3:15	Pick-up children from childcare	Fallen Timbers A-B-C and NW Territory A
3:30-4:00	<b>Closing</b>	Sequoia Ballroom
4:00-	<p><b>GO HAVE SOME MORE FUN TOGETHER!!!!</b></p> <p>--there is time to meet with other families in the waterpark or enjoy the outdoor pool. Grab a bite to eat at one of the many restaurants that Great Wolf Lodge and the surrounding area has to offer or just have nice conversation with your 1p family.</p>	