

2013 1p36 DSA Conference Agenda

Thursday, August 1st, 2013

11:00 – 12:00 pm	Transportation to Morgan's Wonderland from Drury Plaza Riverfront (We will have a bus that will be able to shuttle attendees to and from the hotel to Morgan's Wonderland between 11:00am and 9:00pm)	
12:00 – 2:00 pm	Meet & Greet / Registration at Morgan's Wonderland/Playtime (http://www.morganswonderland.com/)	
2:00 – 2:15 pm	Welcome 1p36 Family and Overview of the Weekend	Morgan's Wonderland Event Center
2:15 – 3:00 pm	Rupert Issacson- Motivational/Keynote Speech: Uplifting, funny, insightful and just plain useful, Isaacson will show us what the professionals often do not: how amazing special needs are, how lucky we are to live this unique life, and how much we have to hope for. He will also incorporate some of his wife, professor Kristin Neff's work, on self-compassion, teaching us how to be kinder and gentler to ourselves for this long road. Come celebrate! (http://www.horseboyfoundation.org/)	Morgan's Wonderland Event Center
3:00 – 3:15 pm	Eve Wallace (soloist)- Candle Light Memorial to Honor 1p36 Angels	Morgan's Wonderland Event Center
3:15 – 4:45 pm	Celebration of our 1p36 kids and Their Accomplishments with Eve Wallace (soloist) / 1p36 Family Introductions with Scott & Jennifer Winiecki	Morgan's Wonderland Event Center
4:45 – 5:00 pm	Break	
5:00 – 6:00 pm	Rupert Issacson - Horse boy Method: One Father's Journey from Confusion into Light, by Following his Autistic Son, Rowan. When Rupert Isaacson's son Rowan was diagnosed with autism in 2004, the situation was presented to him by the professionals as a catastrophe. A journalist by trade, Rupert couldn't help but wonder, "What's the other 50% of the story here?" What followed has been a multi- year adventure into the sheer wonder and delight of autism, resulting in a 6 step process, the Horse boy Method that helps teach autistic, ADD, ADHD, dyslexic, anxiety-disorder, and kids with any neurosensory issues (i.e. most kids) in the ways they want to be taught. Isaacson will demo with two of his own horses, and then show how these methods can be done without even needing horses. How anyone living room or backyard can be used to heal and teach, once the right approach is used. (http://www.horseboyfoundation.org/)	Morgan's Wonderland Event Center
6:00 – 6:30 pm	Demo with Horses with Rupert Issacson – Morgan's Wonderland Parking Lot	
6:30 – 9:00 pm	Pizza party / Family Dance – Mo Del's Band (http://www.mo-dels.com/index.htm)	Morgan's Wonderland Event Center
9:00 – 10:00 pm	Transportation back to Drury Plaza Riverfront	
Friday, August 2 nd , 2013		
7:00 – 9:00 am	Free hot "Quickstart" Breakfast for hotel guests 2 nd floor	

9:00 – 10:50 am	Vagdevi Meunier, PsyD - Growing Closer Through Hard Times: Managing Grief and Building Strong Relationships for Singles and Couples: This talk will focus on how to build a strong relationship with spouses and members of your support network (siblings, parents, or friends) so you can thrive through all of the challenges and surprises of having a child with 1p36 deletion syndrome. In the second hour, the talk will integrate the research on managing and flourishing through grief. With experiential exercises, group discussion, and sharing, we will look at what grief can do to relationships, how resiliency can be achieved, and what it takes to preserve hope, joy, and faith through hard times. (http://drvagdevi.com/Home.html)	
10:50 – 11:00 am	Break	
11:00 – 12:30 pm	TEAM Ability with Nancy Schwartz and Claire Heins – Active Learning: An approach developed by Dr. Lilli Nielson that emphasizes every child’s potential to learn and to be an active participant in that learning. Active Learning was designed specifically for children with multiple disabilities, including visual impairment, motor impairment, hearing impairment and developmental delays. This presentation will focus on the principles of active learning and its application. (http://www.teamability.org/)	
12:30 – 1:45 pm	Lunch	
1:45 – 2:45 pm	Barry Smeltzer, MPAS, PA-C - Raising a Healthy Family Chemical- Free: How to eat cleaner, clean with nontoxic products that work and how to eliminate the other chemicals that surround us inside our homes and out. (http://healingprovisions.net/)	
2:45 – 3:00 pm	Break	
3:00 – 4:00 pm	Dawn Thurmond – Tickle Your Stress Before It Tackles: Participants will learn to use laughter exercise to counter the harmful effects of stress in their lives. This interactive session teaches participants how to immediately implement techniques to de-stress their day.	
5:00 – 6:30 pm	Dad’s Day Out (River Boat Cruise on Riverwalk)	
5:30 – 7:00 pm	Kick Back Hour (drinks & appetizers) @ Drury or Dinner on your own	
7:30 – 9:00 pm	Mom’s Night Out (River Boat Cruise on Riverwalk)	
Saturday, August 3rd, 2013		
7:00 – 9:00 am	Free hot “Quickstart” Breakfast for hotel guests on 2 nd floor	
9:00 – 10:00 am	Daryl Scott, MD/PhD - Identifying disease genes on 1p36 Dr. Scott is a doctor and a scientist. 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. Dr. Scott lives just south of Houston in Pearland, Texas with his wife and seven children.	
10:00 – 10:15 am	Break	
10:15 – 10:25 am	Callie Hoots	
10:25 – 11:15 am	Keva D. Horry – Glamorous Sacrifice, Life...in the Shadow of Championships Glamorous Sacrifice is Keva’s poignant reflection of the unimaginable task of	

	<p>maintaining a long-distance marriage to a celebrity professional athlete, and the enormous responsibility of caring for a special-needs child with 1p36 Deletion Syndrome – all of which equaled a perfect storm of overwhelming peaks and inconceivable valleys for her. But through it all she never lost her firm grip on her faith.</p> <p>Keva D. Horry is an author, speaker, special-needs-community advocate and founder of The Ashlyn Horry Foundation.</p>	
11:15 – 11:45 am	<p>Ashley Brazil – Delineating 1p36 Deletion Syndrome in Adolescents and Adults</p> <p>Ashley Brazil is genetic counselor at the Cincinnati Children’s Hospital Medical Center in Cincinnati, OH. She specializes in working with individuals with mitochondrial disorders. She has worked with Dr. Rob Hopkin and recently completed her master’s research thesis entitled “Delineation of 1p36 Deletion Syndrome in Adolescents and Adults”. She loved attending the conference last year and is incredibly thankful to come back this year. She loves working with the 1p36 DSA and hopes to continue to do research collaboratively with the group and raise awareness about 1p36 Deletion syndrome! She would like to give a special thanks to Dr. Hopkin for encouraging her research and Ken Shirtcliff for his continuous support and enthusiasm about the project!</p>	
11:45 – 12:45 pm	Lunch	
12:45 – 2:15 pm	Roundtable: Q & A with Medical Professionals, Researchers, Therapists and Parents	
2:15 – 3:15 pm	<p>Robin Blue- The ABC’s of ABA: An Overview of Applied Behavior Analysis and principles behind creating effective interventions through prevent, replace, and respond strategies to address challenging behaviors.</p> <p>(http://www.therapyconnectionsofsouthtexas.com/index.html)</p>	
3:15 – 3:30 pm	Break	
3:30 – 4:00 pm	Robin Blue- Sing Me a Song: An overview of Music Therapy and how to effectively use music strategies to address common needs.	
4:00 – 5:30 pm	Closing Ceremonies	
5:30 – 7:00 pm	Kickback hour (drinks & appetizers) @ Drury or Dinner on your own	
6:30 – 9:30	Fun family activity To be announced	