



THE CHROMOSOME 18 REGISTRY & RESEARCH SOCIETY

2018 Chromosome 18 Decoded

25th Annual Conference

Sunday July 1st – Wednesday July 4th, 2018

About the Presenters & Presentations

Monday, July 2nd, 2018

Monday, 9:00 am – 10:00 am

All Tracks

Welcome / Introductions

Presenter: Neale Parker



Neale Parker is the Executive Director of The Chromosome 18 Registry & Research Society. Neale was born just outside London, England in Wimbledon. After heading through Kingston College, Neale went on to become one of the youngest Fellows of the Institute of Directors (London). Neale moved to

Chicago several years after college. After arriving in the United States, Neale had volunteered for the American Lung Association (ALA) and upon moving down to San Antonio in 2009 was asked to be part of the Board and became Board Chair in 2011. It was at this time that Neale realized that his passion to spend more of his life helping those in need that required additional support, education and research which lead him to join the ALA as a staff member organizing all aspects of running an 501(c)(3). Neale and his wife Cynthia met a few years after his arrival in Chicago and have been together for 23 wonderful years. Both Neale & Cynthia are very proud to be part of The Chromosome 18 Family and will work with all of you in any way possible to push the Registry's mission forward.

Monday, 10:00 am – 10:45 am

All Tracks

Research Update

Presenters:

Jannine DeMars Cody, Ph.D. & Daniel E. Hale, M.D.



Jannine DeMars Cody, Ph.D., is a Professor in the Department of Pediatrics at the UT Health Science Center where she serves as Director of the Chromosome 18 Clinical Research Center. Dr. Cody earned her Ph.D in the Department of Cellular & Structural Biology at the UT Health Science Center at San Antonio in 1997. In 1990, Jannine founded the Chromosome 18 Registry

and Research Society as a way to bring affected families together and to learn from each other.



Daniel E. Hale, M.D., is a former Professor of Pediatrics at The University of Texas Health Science Center at San Antonio. He has also served as the Medical Director for the Chromosome 18 Research Center and for the Chromosome 18 Registry and Research Society. Dr. Hale earned his undergraduate degree in Biochemistry at Texas A&M University in 1974 and his medical degree at the

University of Texas Medical School in Houston in 1977. He completed his Pediatric Residency at the Medical University of South Carolina, Charleston, in 1980.

Monday, 11:00 am – 11:45 am

Track 1

What to Expect Before Surgery

Presenter: Sarah Smith

Monday, 11:00 am – 11:45 am

Track 2

Resources for First Time Families

Presenter: Neale Parker (see Bio above)

Monday, 1:30 pm – 2:15 pm
Track 1

Psychiatric Medication

Presenter: Catherine Cody Larson, M.D.



Catherine Cody Larson, M.D. is a Child and Adolescent Psychiatrist and (more importantly) Elizabeth Cody's sister. After earning her undergraduate degree, she worked as a Research Assistant at the Chromosome 18 Clinical Research Center in San Antonio. She attended The University of Texas Health Science Center at San Antonio and earned her degree of M.D. with Distinction in Research in

2011. She is adjunct faculty at The University of Texas Health Science Center at San Antonio at the Chromosome 18 Research Center and has a private practice in Austin, Texas. She was the past sibling coordinator and has been organizing sibling activities at the conferences for over 10 years.

Monday, 1:30 pm – 2:15 pm
Track 2

Benefits of Music Therapy

Presenter: Melissa Ward

Participants will gain an understanding of what music therapy is and what qualifications a board-certified music therapist holds. A range of specific examples of music as a therapeutic tool will be provided. We will explore the goals and objectives for all domain areas including social, emotional, physical, cognitive, and quality of life needs. There will be moments when the audience can participate in music experiences and role play what may happen in a music therapy session.



Melissa Ward is a board-certified music therapist in Northern Maryland. She founded Augmenting Ability, LLC in 2007 and began to contract with schools, facilities, and private clients. She attended Elizabethtown College and completed her internship at Kennedy Kreiger School in Baltimore. Melissa loves working with clients of all ages

and growing to know each individual and their families. Her primary instrument is piano and she continues to be involved in music ensembles during her free time.

Monday, 2:30 pm – 3:15 pm
Track 1

Lifestyle & Transition Planning

Presenter: Andre Sam, CRPC, APMA

You wouldn't go out for an evening and not make sure that whoever is caring for your loved one with special needs or a disability knows what to do, how to do it, and how to reach you in an emergency. What would happen today if you were unable to provide care for an extended period of time or permanently? In this session, we will discuss this important topic in disability and special needs planning, what aspects need to be considered when a primary caregiver is no longer able to care for an individual with a disability or special need, how to prepare properly for the transition of your loved one from one caregiver to another, and how these decisions will impact your loved one's future. Learn the important details you need to know.



Andre Sam is a comprehensive special needs planner with SilverTree Special Needs Planning. Upon earning a Bachelor's Degree in Economics from the University of Arizona, Andre began a career in comprehensive disability and special needs planning. Andre has been in the industry for 5 years now working with individuals and families with special needs and disabilities. Andre is currently part of a non-profit

organization called the Special Needs Education & Advocacy Project. Through this non-profit organization, Andre gives back by donating his time during evenings and on the weekends by sharing his knowledge through providing complimentary educational presentations to organizations and groups who have loved ones that are part of the special needs and disability community.

Monday, 2:30 pm – 3:15 pm

Track 2

Genetics

Presenter: Dena Linder, MS, LCGC

Dena has been interested in genetics since she was 6-years-old when her youngest sister, Ellie, was diagnosed with Ring 18. Since then, her family has been active in the Chromosome 18 Research & Registry and she started leading the Genetics 101 workshop for siblings for the first time in 2015. She is very passionate about Chromosome 18 anomalies and welcoming new families into this amazing organization.



Dena Linder is a genetic counselor at the UCSF Cancer, Genetics and Prevention Program where she sees patients and families at risk for hereditary cancer syndromes. Dena has an M.S. in genetic counseling from UC Irvine and a B.S. in integrative biology from the University of Illinois Champaign-Urbana. She is licensed and board certified by the

American Board of Genetic Counseling. She is a member of the National Society of Genetic Counselors as well as the American Society of Human Genetics.

Monday, 3:30 pm – 4:15 pm

Track 1

Guardianship & Alternative Options

Presenter: Andre Sam (see Bio above)

What happens when my loved one turns 18? How do I determine if guardianship is an appropriate option? In this session, we will discuss this popular topic in disability and special needs planning and how the role of Guardianship will integrate with other Disability and Special Needs Planning financial and legal tools that will affect your decision making ability, legal authority and the future planning for your loved one. We will also discuss alternate options to Guardianship as well as Microboards and Person-Centered Planning. Learn the important details you need to know.

Monday, 3:30 pm – 4:15 pm

Track 2

Charting the Journey

Presenter: Mary Anne Elhert, CFP

This presentation will be uplifting, interactive and educational, as well as provide a good basic understanding of some important facts. Participants will develop the foundation for their family's own personal Future Care Plan™. Some topics of discussion include: Education, Employment/ Day programs,

Housing, Medical, Legal/Financial Benefits and Building a lifelong support network.



Mary Anne Elhert is a financial professional and sister to an individual with disabilities. She is highly regarded as a specialist in working with families of individuals with disabilities and serves on the boards of several organizations, including the National Disability Institute in Washington, D.C. and Special Olympics of Illinois. She speaks at conferences nationally, and locally, on planning for families

with special needs. Her book is entitled "The Gift I Was Given."

Monday, 3:30 pm – 4:15 pm

Self-Advocates & Siblings Tracks

Music Therapy with Augmenting Ability

Presenter: Melissa Ward (see Bio above)

This session will be geared towards young children. Music experiences will include singing, dancing, instrument playing, and song writing to address social, emotional, physical, cognitive, communication, and quality of life needs.

Monday, 4:30 pm – 5:15 pm

Track 1

ABLE Savings Accounts

Presenter: Andre Sam (see Bio above)

What are these ABLE Accounts I have heard about? How will these new ABLE Savings Accounts impact my loved one? In this session, we will discuss this popular topic in disability and special needs planning and how the ABLE Savings Accounts will integrate with other Disability and Special Needs Planning financial and legal tools that will affect your future planning for your loved one. Learn the important details you need to know.

Monday, 4:30 pm – 5:15 pm

Track 2

What Happens When the Bus Stops Coming?

Presenter: Mary Anne Elhert (see Bio above)

This presentation will be uplifting, interactive and educational, as well as provide a good basic understanding of some important facts. Whether you plan on your child staying in school or moving on to a day program, 4 year college, work program, you need to know what is out there. Topics of discussion include: Education, IEP's, Employment and Day programs, and building a lifelong support network.

Tuesday, 9:00 am – 10:45 am

All Tracks

Angst Movie & Panel Discussions*Presenters: Catherine Cody Larson, M.D. (see Bio above)*

Tuesday, 11:00 am – 11:45 am

Track 1

Endocrinology*Presenter: Daniel E. Hale, M.D. (see Bio above)*

Tuesday, 11:00 am – 11:45 am

Track 2

Special Needs Financial Planning*Presenter: Pat Bergmaier, CFP, ChSNC, RICP*

Our workshop provides an overview of financial & estate planning for families that have dependents with special needs. We address critical areas of concern, such as navigating and maximizing government benefits through an overview of programs such as SSI/SSDI, Waivers & Social Security. The workshop will also address important estate planning considerations such as Wills, Special Needs Trusts, and the differences between Guardianship and Powers of Attorney. Finally, it will make attendees aware of how special needs financial planning is different than traditional financial planning. Strategies will be presented to address funding of special needs trusts, tax planning considerations, and ensuring quality of life and lifetime care are maintained for loved ones. Our goal is to make sure attendees learn the importance of integrating all the necessary pieces into one cohesive plan, so the vision they have for their child's life can become a reality, whether they are here or not.



As an advisor with 1847Financial, **Pat Bergmaier** joined the agency with an expertise in special needs financial planning. Prior to joining 1847Financial in February 2015, Pat had partnered with the MetLife Center for Special Needs Planning since 2009 where he focused his

practice on working with families to address the unique circumstances and requirements of individuals with special needs.

Tuesday, 1:30 pm – 2:15 am

Track 1

Finding Your Voice in the Sea of Advocates*Presenter: Stefanie Hilarczyk*

These days everyone is advocating for something. People all over are supporting some type of cause or causes regularly. I feel more so now over the last 10 years than ever before. I'll be talking about how to stand out among the crowd. Giving your child a voice from the doctor's office to school to even your own home and everyday. Being an advocate is not a part time job, or every once in a while. It's the new way you'll love your life. If you accept the challenge. I will share with you my journey of advocacy and our journey with T18. How I created two cookbooks to raise money for various Trisomy foundations, ran successful fundraisers and raised awareness by talking about genetic disorders wherever I go. I hope you leave me more inspired, more energized and filled with more hope for an incredible 'differently abled' journey.



I was born and raised in New York and then moved when I was 10 years old to New Jersey. My background is in Recreation Therapy. I've worked in several nursing homes and Hospitals throughout NJ. In recent years I'm the owner of a mommy and me music school. I've also been a volunteer all my life. I'm the founder of a volunteer group with over 500

women who do Good Deeds all over the country. I'll be married to my best friend for 15 years this April. We have two children. Our daughter Lorelai who is 13 years old and our son Timmy who will be 10 in May. I've been an advocate for him since the day I found out I was pregnant. The greatest gift God gave us was to be his voice. Timmy was diagnosed with Mosaic Trisomy 18 on July 8, 2009. That day changed something deep inside me. It changed how I see life, love and people around me. My greatest most rewarding job is being a mom. I never knew I was capable of being a mom to a child that wasn't the 'typical'. The meaning of empathy and advocacy took a life of its own inside my mind and heart. As we were being told he wouldn't be able to do certain things - we were busy writing his story and reflecting on the greatness that he was about to overcome. I've linked arms with women all over the country who have taught me to be the best voice for my son that I could possibly be. I've worked closely over the past 9 years with hospitals, foundations and other special needs parents.

Tuesday, 1:30 pm – 2:15 am
Track 2

Pathfinders for Autism

Presenter: Neal Lichter

One in 55 children in Maryland are diagnosed with Autism Spectrum Disorder (ASD). Undoubtedly, you are interacting with someone with Autism whether in your home, your neighborhood, your school or your workplace. Understanding ASD is one way to improve your interactions with someone on the spectrum. Our presentation will provide a practical and experiential opportunity for you to learn some strategies and tips on working with someone on the spectrum.

Pathfinders for Autism is a Maryland based, parent sponsored, non-profit organization dedicated to improving the lives of children and adults with autism and their families. We accomplish this mission through our Resource Center and provider database, sponsored training activities, and free fun events. Everything we offer is free.



Neal Lichter joined Pathfinders October 2013 after 9 years as the owner/operator of Accessible Rental Vans, a wheelchair accessible van rental company. Neal is responsible for the daily intake of questions and concerns from parents, caregivers, educators, professionals and individuals with Autism Spectrum

Disorder (ASD). Neal provides support and resources through research, field work and personal experience. Born and raised in Baltimore, he is a graduate of Towson University where he majored in Communication Studies. Neal is married, with two sons, one of which has Autism. He brings his professional expertise with over 15 years of customer service experience, as well as his personal experiences as a dad in dealing with Autism to PFA.

Tuesday, 2:30 pm – 3:15 am
Track 1

Drug Therapy in Common Neurological Disorders

Presenter: Sid Atkinson, M.D.



Sid Atkinson, M.D. is a Child Neurologist who retired from the military after a long and successful career to embark on a new venture as the chief of the child neurology service at the University of Texas Health Science Center at San Antonio. He has taught Child Neurology to residents in Pediatrics and Neurology in several different programs of the Army, Air

Force, and at civilian institutions and has had extensive management and leadership experience in the Army Medical Department, tri-service and Veterans Affairs roles. Dr. Atkinson co-founded the Chromosome 18 Registry and Research Society.

Tuesday, 2:30 pm – 3:15 pm
Track 2

FUNDraising

Presenter: Neale Parker (see Bio above)

Tuesday, 2:30 pm – 3:30 pm
Self-Advocates & Siblings Tracks

D's Magic

Presenter: Dave Thomen



Mr. **Dave Thomen** of D's Magic, a CBS News "Baltimore's Best Magician" and National Theatre "Stars of Magic" recipient, is 100% pure entertainment fun! You will laugh out loud as he launches into hilarity with confounding magic demonstrations to include time travel, thought reading and illusions choreographed to music. According to Dave, "magic allows our youth to flourish" and his friendly, genuine personality will make your day enjoyable and memorable.

Wednesday, 9:00 am – 9:45 am

All Tracks

POSITIVE EXPOSURE*Presenter:* **Rick Guidotti**

Rick Guidotti, an award-winning photographer, has spent the past twenty years collaborating internationally with nonprofit organizations, hospitals, medical schools, educational institutions, advocacy groups and communities to promote a more inclusive and compassionate world where ALL differences are understood and

celebrated. Guidotti's work has been published in newspapers, magazines and journals as diverse as Elle, GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, New York Times, Atlantic Monthly and LIFE Magazine. Rick is the founder and director of POSITIVE EXPOSURE, an innovative arts, advocacy, and education organization which utilizes the visual arts to celebrate human diversity, inclusive of ethnicity, religion, age, ability, learning style, gender identity, general expression and sexual orientation. POSITIVE EXPOSURE has significantly impacted the field of human rights, mental health, medicine and education by providing new opportunities to see each individual as a human being and valued member of our society.