

Alport Family Meeting – Salt Lake City

Speaker Bios

Karin M. Dent, MS, LCGC, is a certified and licensed genetic counselor at the University of Utah and an Associate Professor in the Department of Pediatrics. She received a Master's of Science degree in Genetic Counseling and Human Genetics from the University of Pittsburgh in 1998. Karin has been with the University of Utah Department of Pediatrics for 19 years. Currently, Karin is the Director of the University of Utah Graduate Program in Genetic Counseling through which she directs or co-directs multiple core courses; co-chairs the UUGPGC Curriculum and Clinical Supervision Committees; serves on the Executive, Admissions, and Advisory Committees; and has been a member or chair of several student research committees. She provides clinical supervision to genetic counseling students on the required Pediatrics rotation, the Neurology rotation, and several elective rotations. She provides clinical genetic counseling in the medical genetics, neurofibromatosis, and hearing assessment clinics at Primary Children's Hospital and in the Motor Neuron Disease Clinic at the University of Utah Medical Center. Her research interests include the etiology of congenital hearing loss, the delivery of difficult news by healthcare providers, and the ethical challenges surrounding informed consent and return of results in exome sequencing and whole genome *sequencing research*. *Karin is a past president of the National Society of Genetic Counselors (NSGC)*, and has been active in the NSGC and other professional organizations for genetic counselors throughout her career. She was a member of the NSGC Ethics Advisory Group and several additional NSGC committees, the NSGC Board of Directors, and the American Board of Genetic Counseling Credentialing Examination Committee. Karin greatly enjoys working with patients and their family members!

Martin Gregory, BM, BCH, did his undergraduate and medical degrees at Otago University, New Zealand and Oxford University, England. He did residencies in Oxford, London, and Paris and a Nephrology fellowship at Oxford. He has since worked at Cape Town, Auckland, London, and Bermuda, but has worked for the majority of the last 36 years at the University of Utah, where he is a Clinical Professor of Medicine, with a principal interest in Alport syndrome. With Dr. Curt Atkin, he was a member of the team that discovered the first mutations in Alport syndrome.

Clifford E. Kashtan, MD is Professor of Pediatrics and Director of the Division of Pediatric Nephrology at the University of Minnesota. His research focuses on the pathogenesis and treatment of Alport syndrome. Dr. Kashtan is an internationally recognized authority on Alport syndrome who has authored numerous original research articles, reviews and book chapters on the disease. His original research articles on Alport syndrome include basic laboratory studies, animal experiments and clinical research. Dr. Kashtan developed methods for diagnosing Alport syndrome by examining collagen IV chains in kidney and skin biopsies. He is the author of the Alport syndrome entries at the online resources *UpToDate* and *GeneReviews*. Dr. Kashtan has lectured on Alport syndrome at numerous institutions and meetings, both nationally and internationally. He is the founder and Executive Director of the Alport Syndrome Treatments and Outcomes Registry (ASTOR) and a member of the Medical Advisory Board of the Alport Syndrome Foundation. Through these activities Dr. Kashtan aims to support clinical trials of potential therapies for Alport syndrome.

Raoul D. Nelson, MD, received his medical degree and doctorate of philosophy from Washington University School of Medicine in St. Louis, completed his Pediatric residency at University of Utah and Primary Children's Medical Center, and completed his Nephrology Fellowship at St. Louis Children's Hospital at Washington University of St. Louis. He is currently a Professor of Pediatrics in the Nephrology & Hypertension division at University of Utah and is board-certified in Pediatric Nephrology. As chief of the Division of Pediatric Nephrology & Hypertension he manages division operations and as Medical Director of Pediatric Dialysis he manages the delivery of pediatric and adolescent dialysis at Primary Children's Medical Center.

He also sees patients in nephrology clinics with a variety of problems, including Alport syndrome, hypertension, chronic kidney disease, and kidney transplant care.

Michelle Rheault, MD is an Associate Professor and Pediatric Nephrologist at the University of Minnesota. She is Co-Director of the Alport Syndrome Treatment and Outcomes Registry (ASTOR) at the University of Minnesota. Dr. Rheault's research interests include clinical research and clinical trials in nephrotic syndrome and other glomerular diseases, genetic kidney disease including Alport syndrome, and chronic kidney disease and dialysis outcomes. She is an investigator for several clinical trials for novel treatments of Alport syndrome.

Kevin Schnurr is a 31-year-old music and literature enthusiast affected by Alport syndrome. A native of Long Island, NY, Kevin was unexpectedly diagnosed at 26. He spent close to two years on peritoneal dialysis before receiving the Gift of Life from a close friend in May 2014. Since his diagnosis, Kevin has been very active in advocating for organ donation and Alport syndrome research and awareness. Kevin graduated from the University of Scranton in 2008 with a BA in Communication and is currently Alport Syndrome Foundation's Social Media Specialist and part-time Community Engagement Manager. He is greatly looking forward to meeting members of our rare disease community and implementing plans to offer them additional support in the future.

Cynthia J. Terrill, RDN, CSR, CD, is employed by the Department of Pediatrics/Division of Pediatric Nephrology at the University of Utah and is the Pediatric Renal Dietitian for patients in the Primary Children's Hospital (PCH) dialysis unit and kidney transplant program in Salt Lake City UT. She also provides nutrition care to pediatric nephrology patients with Chronic Kidney Disease stage 3-5 at PCH. Patients range in age from newborn to 24 years. Cindy is a Board-Certified Specialist in Renal Disease and has developed and recorded several webinars on pediatric and adolescent renal nutrition for the Academy of Nutrition and Dietetics Renal Practice Group and provides education to dietetic students and other health care professionals regularly. Additionally, she has written several articles on pediatric renal nutrition and has had an original research article published in the Journal of Renal Nutrition. Cindy has served in various positions for the Council of Renal Nutrition both on a local and national level and is a member of the Pediatric Nutrition Practice Group and the Renal Dietitian Practice Group of the Academy of Nutrition and Dietetics.

Shannon White, AuD is a clinical audiologist at Primary Children's Hospital in Salt Lake City. She also recently served as the Interim Audiology Manager. Before joining PCH's staff in 2015 as a clinical audiologist, Dr. White was a Senior Audiologist at UCLA Medical Center in Los Angeles, CA for 8 years. She has also worked as a Clinical Education Consultant at Natus Medical Inc and Bio-logic Systems Corp. Earlier in her career, she was an audiologist at the Hearing & Balance Center in San Diego, CA, and at the Providence Speech & Hearing Center of Orange, CA. Possessing varied audiological interests and expertise, Dr. White was the Manager of the *Noise Destroys* Program at the Agency for Hearing in Sacramento, CA. In this role, she designed, implemented, and managed a hearing conservation program for children. Dr. White was featured in an "Ask the Expert" column in *Audiology Online* on "*Performing Electrical ABRs Post Cochlear Implantation*" and has special interest in pediatrics, ABRs, cochlear implants, counseling, and literacy issues in the pediatric hard of hearing population.