Alport Family Meeting

Speaker Biographical Sketches

Paige Balgie RD, CSP, LD is a board-certified specialist in pediatric nutrition and practicing clinical dietitian at the University of Minnesota Masonic Children's Hospital in Minneapolis. She received her Bachelor of Science degree in nutrition and dietetics from the University of Wisconsin-Madison and completed her training with a dietetic internship at the Mayo Clinic – Rochester. For the past six years she has specialized in nephrology working with infants to young adults with kidney disease including dialysis and kidney transplant patients. Paige enjoys being a part of a child's life as they experience and learn about food throughout the life stages.

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.

Margaret Koeritzer, Au.D. is a licensed audiologist at the University of Minnesota Lions Children's Hearing & ENT Clinic and at the University of Minnesota Clinics and Surgery Center. She works with patients of all ages, with an emphasis in pediatrics. Margaret's interests include: diagnostics, hearing aids, electrophysiology, vestibular assessment, and cochlear implants. Margaret also teaches an online Aural Rehabilitation class for the University of Wisconsin – Eau Claire. Margaret graduated from Washington University School of Medicine in St. Louis, in 2016 with her Doctorate of Audiology. Also, she is an active member of the American Academy of Audiology (AAA) and the Minnesota Academy of Audiology (MAA).

Ryan Landwehr is a MN Native living in San Diego with his wife Cori and two young sons Asher (7) and Chance (3). Ryan began losing his hearing at a young age and finally in his teens, it was linked to Alport syndrome. He has had two very successful transplants (1997 and 2009) and has since devoted his life to living a healthy and active lifestyle. He swims, runs, and works out regularly and has been working for the same Fortune 500 company since graduating college. Ryan got involved with ASF not long after it was formed and has been participating in the Young Adult coaching since the first family conference in 2010. It is a blessing to meet so many young adults who are facing many of the same challenges he did growing up. He is an open book about his life and experiences and loves helping others know their dreams and boundaries are limitless while living with Alport syndrome.

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.

Karol Rubin, MS, CGC is a licensed and certified genetic counselor at the University of Minnesota Health. She received a Master of Science degree specializing in Genetic Counseling from the University of Michigan in 1994. Karol has been working in Pediatrics and Adult genetics clinics as well as in Maternal Fetal Medicine for 22 years. Her primary focus is seeing patients, but Karol also provides clinical supervision of genetic counseling graduate students. She holds a Faculty Instructor position in the Institute of Human Genetics with the Genetic Counseling Graduate Program at the University of Minnesota, where she teaches genetic counseling students. Karol has worked in a variety of multidisciplinary clinics including nephrology related conditions, Neurofibromatosis, 22q deletion syndrome, Down syndrome, cardiology, ophthalmology, and neurology. She is involved in new diagnosis of inpatients and counsels couples before and during pregnancy at Maternal Fetal Medicine clinics. Her personal interests include multicultural issues, dancing and kayaking. She is a member of the National Society of Genetic Counselors (NSGC).

Peter A. Santi, Ph.D. Professor of Otolaryngology received his Ph.D. in Psychobiology at the Florida State University where he studied mechanoreceptors in squid. Dr. Santi came to the University of Minnesota in 1975 and has remained here as a full professor. His training is in anatomy and has investigated the structural basis of hearing loss in mammals, including the human, after sound exposure, ototoxic drugs, and certain genetic causes including Alport syndrome. Dr. Santi developed quantitative morphological methods to assess pathology of the cochlea or inner ear regarding the hair cells, spiral ganglion neurons, and the stria vascularis. He has also developed a microscope that uses a thin sheet of light to optically section whole cochleas at high resolution. Although kidney biopsy and transplant is possible as therapy for Alport syndrome, the inner ear cannot be biopsied or transplanted. In collaboration with Dr. Clifford Kashtan in 1989, they showed the first localization of alpha 3,4,5 collagen chains in specific basement membranes of the cochlea that are associated with Alport syndrome using blood from a patient with Alport syndrome that contained antibodies against these collagen proteins. In 2004 they collaborated with investigators from Harvard University who examined cochleas from Alport patients that showed splitting of the basement membrane at the same location where they have previously demonstrated the presence of the alpha 3,4,5, collagen chains. Dr. Santi and Dr. Kashtan currently have a grant submitted to the NIH to investigate an x-linked mouse model of Alport syndrome to see if similar splitting of the basement membrane occurs. Development of a reliable animal model for Alport syndrome is essential to test and develop future therapies for this genetic impairment of the inner ear and to alleviate hearing loss in patients.

Jessica (Jesi) Spratt, AuD, PASC is a licensed audiologist with a specialty certification in pediatric audiology. She received her Doctorate of Audiology from Lamar University in 2014. Jesi works in the Lions Children's Hearing & ENT Clinic at the University of Minnesota Masonic Children's Hospital. She primarily sees patients from birth to early adulthood. Jesi's interests include electrophysiology, hearing aids and cochlear implants, as well as treatment and follow-up with patients who have had ototoxic exposure. Jesi is a member of the American Academy of Audiology (AAA) and the Minnesota Academy of Audiology (MAA).