Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Grace Anto

Fronto Nasal Dysplasia Advocate

Grace was born with fronto nasal dysplasia syndrome with craniosynostosis. Despite her medical challenges, she has chosen to live life to the fullest. Grace is an outgoing, caring, and joyful young lady. She loves school, and is involved in competitive dance, theatre, piano, and choir. She will tell you her dream is to be on Broadway! When she steps on stage, she lets go of all life's challenges and leaves her heart on the dance floor! She loves to be social and hang out with her friends. Each one of them has a special place in her heart, and she looks to them for support during difficult times. Oh, and let's not forget her dream to travel the world – Paris, France is her first stop! Grace has had 13 surgeries to-date and faces life's challenges with a can-do attitude, leaning on the love and support of her family. Her own life motto is one that everyone can live by: "Don't let fear take over happiness!"

Dr. Michael J. Bamshad, MD

Professor and Chief of the Division of Genetic Medicine in the Department of Pediatrics at the University of Washington and Seattle Children's Hospital
Director of the Center for Clinical Genomics.
Allan and Phyllis Treuer Endowed Chair in Genetics and Development at Seattle Children's.
His research is focused on understanding the impact of population structure and natural selection on human genetic variation; developing innovative ways to discover genetic variants underlying monogenic disorders, modifiers of monogenic traits and complex traits; and testing novel ways to translate genomic advances into practice to advance implementation of precision genetic medicine. He and his colleagues pioneered the use of exome and genome sequencing for discovery of genes underlying Mendelian conditions and to date, has contributed to the identification of hundreds of genes for Mendelian disorders. He has also been a leader in understanding the relationship between genetic ancestry and notions of race, developing innovative ways to openly share phenotypic information and genetic data (i.e., MyGene2) and building platforms for self-guided return of genetic testing results (i.e., My46) from exome and whole genome sequencing in both research and clinical settings. He has published more than 300 scientific manuscripts as well as papers in periodicals such as *Scientific American*, and co-authors a popular textbook entitled *Medical Genetics*.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Tara Britt

Founder and President, Rare Disease Innovations Institute, Assoc. Chair, NC RDAC

Tara currently serves as Associate Chair of the North Carolina Rare Disease Advisory Council and Network. The council was created as a result of co-authoring legislation with a North Carolina patient advocate to create a Rare Disease Advisory Council signed into law, August 2015. Tara has created a unique rare disease ecosystem within the state that brings together patients, caregivers, academics, clinicians, foundations, industry and any entity in rare disease.

Tara is also the President and Founder of Rare Disease Innovations Institute (RDII), which is a global non-profit focused on educating, engaging and equipping the rare disease community to achieve a higher quality of life, accelerating diagnosis and enabling access and treatment. Through this non-profit and her rare disease network, RDII has developed exclusive toolkits for other states to build upon the learning and success of North Carolina enabling creation of successful councils and unique rare disease networks. The toolkits are state tailored to the unique rare disease population. RDII also partners with rare disease advocacy groups, academia, foundations, healthcare systems, state and federal government and industry to build disease specific models to support targeted disease populations and the challenges to accessing care and managing their disease. These models are currently developed in North Carolina and can be modeled globally by the RDII team.

Tara previously worked in the finance, human resources and policy arena and worked with researchers and clinicians in rare disease in the University of North Carolina Gene Therapy Center where she engaged with patient advocates supporting research in Gene Therapy.

Max Brown

Principal Consultant & Lobbyist, **Desimone Consulting Group**

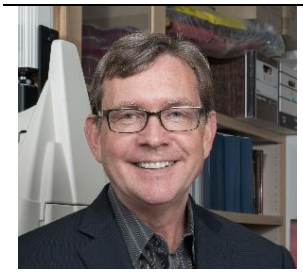
Max plans, manages, and executes encompassing lobbying, public affairs, government relations, and communications strategies for life science industry clients in the Seattle area – activating key stakeholders to create positive systems change at both the state legislative and federal levels in support of life science cluster development, new therapeutic discovery, and to boost the profile of local industry affiliates. Additional client portfolio issue area responsibilities include food insecurity issues, opioid crisis response, cross-laminated timber manufacture, statewide electoral campaign consulting, and clinical provider engagement.

Matthew Caffet

Strategic Operations Manager, Genetic Alliance, PEER Registry

Matthew is passionate about engaging everyone from individuals to entire communities in order to transform and improve health. He works on developing tools and processes and assisting communities with their establishment and advancement efforts. Matthew truly believes that creating a culture which empowers people and makes them the champions of not only their own health, but the system-wide state of healthcare, is essential. Matthew graduated from Stanford University, with a B.S. in Biological Chemistry.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)



Dr. Jeffrey S. Chamberlain, Ph.D.

McCaw Endowed Chair in Muscular Dystrophy
Professor, Departments of Neurology, Medicine and Biochemistry
University of Washington School of Medicine
Director of the Senator Paul D. Wellstone Muscular Dystrophy Specialized Research Center

Dr. Chamberlain is a geneticist with expertise in the muscular dystrophies. His research focuses on understanding and developing treatments for the muscular dystrophies and other muscular disorders, with a focus on Gene Therapy. His lab has developed a variety of 'micro-dystrophins' and associated vectors, which are being tested in human gene therapy trials for DMD. Dr. Chamberlain has served on numerous NIH study sections, as well as advisory boards for NIH, the FDA the Muscular Dystrophy Association and several Biotech companies focused on muscle therapeutics. He is the current Vice President of the American Society for Gene and Cell Therapy, transitioning to President in 2023.

Stephanie Christopher

Associate Director, Research Programs, National Organization for Rare Disorders

Stephanie Christopher is the Associate Director of Research Programs at the National Organization for Rare Disorders (NORD), where she oversees the IAMRARE™ patient-powered registry program, which allows patients and organizations to inform and shape medical research for rare diseases by launching high-quality, customized registries to collect the data needed to define the natural progression of their disease.

Prior to joining NORD, Stephanie helped advance real-world evidence research at one of the largest healthcare systems in the western US, helped develop tools to advance patient input in the regulatory review of new medical technologies and was part of a research team seeking to improve the quality of communication between physicians and patients.

Stephanie received her bachelor's degree from Pacific Lutheran University (Tacoma, WA) and master's from Marquette University (Milwaukee, WI).

Jessie Conta

Manager, PLUGS® & Laboratory Stewardship Program, Seattle Children's

Jessie is a licensed genetic counselor in the Department of Laboratories at Seattle Children's Hospital. She formerly worked as a clinical genetic counselor for many years. Her transition to the laboratory at Seattle Children's Hospital was predicated by a desire to help develop the laboratory stewardship program. In her current supervisory role, Jessie provides pre- and post-analytic support to the genetics subspecialty labs, participates in genetic test case review, guides the laboratory stewardship program, and leads insurance advocacy efforts related to genetic testing.

Jessie is Co-Founder and Director of Genetic Counseling Services for Pediatric Laboratory Utilization Guidance Services (PLUGS), a national collaboration whose mission is to improve test ordering, retrieval, interpretation, and reimbursement. She received a BA in Biomedical Ethics from Brown University, and a MS in Genetic Counseling from Brandeis University.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Lindsey Cundiff

Associate Director of Patient Engagement, EveryLife Foundation for Rare Diseases

Lindsey administers all Patient Engagement programming and maintains overall responsibility for all Patient Engagement activities at the EveryLife Foundation. She champions the needs and challenges of the patient community, and oversees all patient programming including Rare Giving, Rare Artist, RARE on the Road, Community Congress and the Young Adult Representatives of Rare Disease Legislative Advocates (YARR). Lindsey received a BS in Psychology from the University of California, Santa Cruz.

Dr. John Dahl

Pediatric Otolaryngologist, Seattle Children's; Assistant Professor in the Department of Otolaryngology, Head and Neck Surgery at the University of Washington

Dr. Dahl obtained a PhD in Pharmacology and an MBA from The Pennsylvania State University and earned his medical degree from Sidney Kimmel Medical College of Thomas Jefferson University. He completed residency training in Otolaryngology- Head and Neck Surgery at the University of North Carolina, Chapel Hill, and a fellowship in Pediatric Otolaryngology - Head and Neck Surgery at Seattle Children's Hospital. Dr. Dahl has a significant interest in basic and clinical scientific research related to tracheal development, tracheal malformations, and airway management in patients with complex craniofacial disorders.

Dr. Katrina Dipple

Professor and Associate Chief and Medical Director, Division of Genetic Medicine, Department of Pediatrics, University of Washington and Seattle Children's Hospital. Principal Investigator, Seattle Children's Research Institute

Dr. Dipple did a combined MD/PhD degree at Indiana University School of Medicine. Her PhD is in biochemistry and molecular biology. After finishing graduate school, she went to UCLA for a pediatric residency and training in Genetics and Genomics. She is board certified in Clinical Genetics and Genomics and in Clinical Biochemical Genetics. After being on the faculty at UCLA for many years, she joined the faculty at University of Washington and Seattle Children's Hospital in 2016. Her career has focused on combining research and clinical care of pediatric patients with Genetic and rare diseases. Her research career has been on understanding the complexity of genetic disorders as well as gene discovery in rare mendelian disorders in children. Currently she directs the NIH funded Undiagnosed diseases network clinical site at Seattle Children's hospital and sees patients in the Genetics clinic at Seattle Children's Hospital.

Tyler Downs

Pfeiffer Syndrome Advocate

Tyler was born on August 3rd, 2007 with Pfeiffer Syndrome. He has had 12 surgeries so far. He is an active, friendly 13-year-old currently in 8th grade. He likes to play basketball, baseball, flag football and Xbox with his friends. He does well in school, taking an advanced Math class and accelerated Reading. He plays trombone in the school band. He's not sure what he wants to do when he grows up, but he'll surely be great, whatever it is!

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Io Dolka

Founder and Chief Care Advocate, GreyZone LLC

GreyZone LLC is a medical advocacy company helping people with difficult to diagnose, rare and complex medical conditions find answers and improve their quality of life. Io formed GreyZone after experiencing as a patient how complicated it was for those with chronic and complex medical conditions to obtain an accurate diagnosis of their symptoms. Io has been devoted to supporting diagnostic improvement and patient advocacy efforts for more than a decade. She was co-founder, and past Executive Director of the Washington State Health Advocacy Association (WASHAA), currently HealthAdvocateX. She served on the Advisory Board for the Care Management Certificate of the University of Washington, and she was a founding member of the Patient Advocate Certification Board (PACB). Locally, Io currently serves on the Washington Patient Safety Coalition Diagnostic Workgroup and the Washington Rare Disease Advisory Council. Nationally, she has been an active member of the Society to Improve Diagnosis in Medicine (SIDM) Patient Engagement and Practice Improvement Committees for several years. Io holds a post-graduate certificate in Patient Advocacy from University of California, Los Angeles (UCLA), a Master of Science (MSc) in Biotechnology Studies from the University of Maryland and a Bachelor of Science (BSc) in Business Administration, Marketing Management from The American College of Greece.

Dr. Aris Economides

Vice President, Research, Regeneron Pharmaceuticals

Dr. Aris N. Economides received his Ph.D. in Biochemistry from Michigan State University in 1992, and promptly joined Regeneron Pharmaceuticals. He currently holds the position of Vice President, leading two groups: Genome Engineering Technologies, and Skeletal Diseases Therapeutic Focus Area. In addition, he is a co-founder of Regeneron Genetics Center (RGC), where he is also Head of Functional Modeling.

Hugh Ewart

Senior Director, State and Federal Government Relations, Seattle Children's

Hugh Ewart has worked in the broader child health policy and advocacy area for over 25 years. This includes roles in Congressional offices, as a community health Peace Corps Volunteer in a small village in Senegal, West Africa, and as a health policy analyst for Washington's community health centers. In his current role at Seattle Children's, Hugh is responsible for sustaining and improving support for child health and wellness at both the state and federal levels of government. He currently chairs the Health Coalition for Children and Youth, a broad, multi-sector coalition of advocates and stakeholders collaborating to move positive policy change and reduce health inequities for kids in Washington State. Hugh holds a Master's degree in Social Policy and Planning from the London School of Economics and Political Science.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Allison Fine

Founder & Executive Director, The Center for Chronic Illness

For the past 15 years, Allison has worked as a clinical social worker in private practice, nonprofits, hospitals, and senior living settings. Allison founded the Center for Chronic Illness (CCI) in 2016 to improve the emotional health for those impacted by ongoing health challenges and their loved ones. The organization works to decrease isolation and promote well-being for those with all types of chronic illnesses and rare diseases. Allison serves as the executive director for CCI. She holds a Master of Social Work degree from the University of Kansas and is licensed in the state of Washington as a clinical social worker.

Dr. Ian Glass

Medical Genetics; *Principal Investigator, University of Washington Birth Defects Research Laboratory and Seattle Children's Research Institute*

Research interests: Hindbrain malformations. Ian is Director of Medical Genetics, Seattle Children's and Co-Director, Alaska Genetics & Birth Defects Clinic. He received a MBBS from the University of Otago.

Jill Hawkins

Parent, FAM177A1 Advocate, Charlotte and Cooper's diagnostic quest

Jill is the captain of her family's 15-year diagnostic odyssey. She and her first-mate Doug have two children, Charlotte and Cooper, who are challenged by macrocephaly, seizures, intellectual disability, autism, sleep disturbance, declining motor function and a myriad of other medical issues. The UDN-Stanford is confident that FAM177A1 is Charlotte and Cooper's disease-causing gene but the function of this gene remains a mystery. FAM177A1 knock-out Zebrafish are being studied at the MOSC in St. Louis and a handful of other patients with overlapping phenotype and disturbance on FAM177A1 have been identified. Jill's goals are to find more patients, determine the function of FAM177A1 and develop therapies that might be helpful to Charlotte and Cooper and others like them.

Jill was raised in Buffalo, NY and attended the University of North Carolina, Chapel Hill (BA) and The University of Washington (M. Ed). She was a school psychologist before transitioning to full time mom and captain of her family's ship, the SS FAM177A1. The SS FAM177A1 has all the joy of a Disney Cruise but the seas are turbulent. Welcome aboard!

Joshua Henderson

Head of Rare Diseases, Pulse Infoframe

Joshua partners with patient advocacy groups and biopharma companies globally to generate high quality, regulatory-grade real-world data. By powering registries and natural history studies using a centralized infrastructure, called healthie 2.0, we enable cross-disease insights and empower patients to accelerate the development of new treatments to rare diseases.

Joshua is helping to launch the WA Rare Disease Advisory Council, a group dedicated to understanding, analyzing, and responding to the needs of rare disease patients across the state with a goal of accelerating rare disease research through collaboration. Joshua received a BS from Georgetown.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Dr. Edward Hsiao

Associate Professor, USCF School of Medicine

Dr. Edward Hsiao is an endocrinologist who specializes in metabolic bone diseases, such as severe osteoporosis and osteogenesis imperfecta, and other bone disorders. He also cares for patients with calcium, phosphorous, vitamin D, and parathyroid hormone disorders. He has particular interests in fibrodysplasia ossificans progressiva (a condition in which bone gradually replaces muscle and other connective tissues) and fibrous dysplasia/McCune-Albright syndrome (a disorder that causes fibrous tissue to develop in bones). Dr. Hsiao received his MD and PhD from Johns Hopkins University School of Medicine, and a BA from Harvard University.

Mike Jackson

Parent Advocate, CLN2 Batten Disease, Evelyn's Law for Genetic Testing

Mike is a Navy veteran who now resides in the greater Seattle area. He is the father of 2 children, Evelyn (5) and Dominic (2). In 2019 his daughter Evelyn was diagnosed with CLN2 Batten Disease and became his inspiration to co-create "Evelyn's Law", a Washington State bill that would require insurance to cover all forms of genetic testing when determined necessary by a medical provider.

Dr. Richard James

Principle Investigator, Seattle Children's Research Institute

Dr. James runs a research lab at Seattle Children's Research Institute, focusing primarily on understanding how disease processes and pharmacological treatments alter cell signaling in immune diseases. The lab uses a variety of approaches including quantitative proteomics and genome engineering to identify signaling pathways are upregulated during disease and in response to therapies. The lab's overall goal is to identify novel patient-centered therapies for immunological disease. Dr. James received a PhD from Harvard University in Genetics.

Dr. Ethylin Wang Jabs

Vice Chair, Department of Genetic and Genomic Sciences, Icahn School of Medicine, Mount Sinai Medical Center

Dr. Jabs received the endowed Mount Sinai Professorship of Developmental Genetics. She was the Chief of the Division of Medical Genetics and Genomics from 2007-2012 and served as Director of the Medical Genetics Residency and Clinical Laboratory Fellowship Training Programs from 2007-2011. Prior to November 1, 2007, her appointment was at Johns Hopkins University School of Medicine. She was the Dr. Frank V. Sutland Professor of Pediatric Genetics, Director of the Center for Craniofacial Development and Disorders, and Director of the International Collaborative Genetics Research Training Program. She continues to have an adjunct Professor appointment at Johns Hopkins.

Dr. Jabs received her MD and Fellowship in Genetics at Johns Hopkins School of Medicine.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Ben Kjar

Crouzon Syndrome Advocate, 3-time State Wrestling Champion, 4th place in 2011 Wrestling National Championship

Ben's story is not typical. He was born with Crouzon syndrome, a cranial facial anomaly. Doctors indicated that he would need several reconstructive surgeries and that he would be unable to participate in contact sports. Ben talks about the difficulty of dealing with the syndrome as a child.

Through the support of family and friends, he defied the odds and became a standout wrestler. Kjar talk about how you have to create opportunities for yourself and to never create a personal "ceiling" that may hold you back.

Jono Lanacaster

Treacher Collins Syndrome Advocate; Co-Founder, Love Me, Love my Face Foundation

When Jono Lancaster was born 30 years ago, his parents took one look at his face, and abandoned him. Today Jono, who has Treacher Collins syndrome, travels the world meeting kids with the condition and encouraging them to harness the greatest tool against that or any genetic disease – a positive attitude. Jono kicked off the National Organization for Rare Disorders (NORD) Breakthrough Summit October 21 in Washington, D.C., by sharing his story.

Mary McDirmid

Founder, Plan ABZ Special Needs Planning; Managing Director, MassMutual NW

When our founder isn't helping families navigate the world of special needs financial planning, she is being a wife to Jay and a mom to Charlie and Ruth. Not to mention her leadership role as managing director at MassMutual Northwest and a volunteer advocate for kids with rare disease. She takes the title Mom Boss seriously, just ask her!

Mary McDirmid is a registered representative of and offers securities and investment advisory services through MML Investors Services, LLC. Member SIPC (www.SIPC.org) Supervisory Office 701 Fifth Ave, Suite 1100, Seattle, WA 98104 (206)628-8800

Melissa McGowan

Board Member and Newsletter Editor, Born a Hero Research Foundation

Melissa McGowan was born and raised in Wheeling, West Virginia. After earning an M.A. in elementary education with a specialization in middle school mathematics from West Virginia University, Melissa worked as a teacher, grant writer, and project director for programs that targeted schools in low-socioeconomic areas. When her daughter, Abby, was born with Pfeiffer syndrome in 2012, Melissa transitioned to being a stay-at-home mom and an advocate for children with craniofacial differences. Her stay-at-home mom duties have expanded since then; she now cares for 4 girls, ages 8, 6, 5, and 2, and an infant son with her husband in their home in Wheeling, WV. In addition to being an active volunteer in her church and community, Melissa is also a member of the Children's Craniofacial Association's Speaker's Bureau and gives presentations to help raise awareness and understanding of craniofacial differences. In her free time, Melissa enjoys training for and running long-distance races.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Louis Mendoza

Manager, Washington State Fathers Network, Kindering

Louis came to Washington by way of Louisiana, Texas, Colorado and California. He spent the early part of his career as a corporate trainer and then spent 10 years as a stay-at-home dad. He returned to the workplace as a paraeducator in a special needs classroom before working at United Way managing a program called Project LEAD, which trains people of color to serve on the boards of non-profits. He currently manages the WA State Fathers Network, working to support men who have a child in their life with special health care needs. He has served on multiple boards and currently serves on several advisory and steering committees.

Ellen Morgan

Founder & President, Pathways for Rare and Orphan Studies (PROS) Foundation

PROS is a 501(c)(3) non-profit organization founded in 2013, with a mission to accelerate the development of effective treatments for rare diseases. Using our wealth of clinical development experience, PROS is committed to guiding Rare Patient Groups with their registries, natural history studies, and preparing them for the clinical trial phase.

Ellen has over 25 years of drug development experience, in large pharma, small biotech and CRO. She founded and led 2 successful Clinical Research Organizations – Synteract and Agility Clinical, most recently serving as President, Rare Diseases at Precision for Medicine. Agility was founded with a focus on clinical trials for rare diseases and supporting patient organizations.

Ellen received a BS in Chemistry and MS in Management and Industrial Engineering from Rensselaer Polytechnic Institute.

Effie Parks

Founder & Host, Once Upon a Gene Podcast

Effie was born in the magical land of Montana, where she was raised with her 12 loving siblings. After moving to Washington and marrying her husband, they were blessed with the birth of their son, Ford Canon Parks. When she learned that Ford had been born with an extremely rare genetic condition – CTNNB1 syndrome, she dove into the world of advocacy. Now, she is the host of her own podcase, “Once Upon a Gene”, where she speaks to others about their journey through life with a rare disease.

Alyss Patel

State Policy Manager, Western Region, National Organization for Rare Diseases

Alyss is responsible for the development and implementation of NORD’s policy and advocacy efforts in support of the rare disease community at the state level. She focuses on rare disease policy issues related to access and affordability of health care coverage, treatment and medication access and affordability within Medicaid, CHIP and state regulated private health insurance plans, creating and implementing robust Rare Disease Advisory Councils and ensuring strong state newborn screening programs. Alyss received a BS in Sociology from the University of Arizona.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Jennifer Pratt and Heather Heyer

Dance Instructors, Journey Fitness REFIT

Jennifer & Heather (also known as Journey Fitness REFIT®) have been leading fitness classes in the Bothell, WA community for over 8 years. Their goal has always been more than fitness. They seek to empower everybody and every body, build community, bridge cultures, and create a space where an hour of fitness creates a ripple effect for positive transformation from the inside out.

Sanath Ramesh

Founder & CEO, OpenTreatments Foundation

Sanath is a bold and visionary software leader, open source pioneer and a rare disease drug developer. In his career, he has built and launched several successful open source software products. He is now using open source software to enable treatments for 400 million patients worldwide affected with rare genetic diseases through his non-profit organization, OpenTreatments Foundation. He is building the world's first software platform to decentralize drug development and empower anyone in the world to create a treatment for a genetic disease. He is also the father of a 2-year-old boy who is one of 9 kids worldwide with an ultra-rare genetic disease called SSMD (curegpx4.org)

Charles Sang

Biotech Executive (Retired)

Charles has lead commercialization efforts for three first-in-class innovative health technologies making these new advances available to patients. Most recently he served as Senior Vice President at Adaptive Biotechnologies where he launched high-throughput sequencing and expert bioinformatics to profile T-cell and B-cell receptors and count cancer cells for patients with select blood cancers. Prior to his time at Adaptive, Charles served in various leadership positions at NanoString, SeaGen, and Enzon pharmaceuticals, and has spent over 30 years in healthcare ensuring patients have access to innovative therapies.

Scott Schliebner

Senior Vice President, Scientific Affairs and Therapeutic Expertise, Center for Rare Diseases, PRA Health Sciences

Scott is an innovative clinical drug development executive with 25+ years of experience in leadership roles across the CRO, biotech, and non-profit sectors. He is especially passionate about leveraging technology to modernize how we design and conduct clinical trials, partnering with patients to improve the clinical research experience, ensuring clinical research is a care option and using data, analytics, and AI to accelerate clinical development.

Scott received a BS in Psychology from the University of Colorado, an MPH from the University of Utah School of Medicine, and a Research Fellowship at the NIH/NINDS

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Lauren Simonds, M.S.W

Executive Director & CEO, National Alliance on Mental Illness - Washington State

Lauren is a visionary leader with 25 years' experience in not-for-profit management, including extensive supervisory, budgeting, fundraising, communications, public speaking, program planning and evaluation, as part of practicing advocacy and direct service within diverse populations of individuals, family and groups, in interdisciplinary collaborative settings.

Lauren received a BS in English from Boston University and MSW in Social Work Administration from the U of Washington.

Carolina Sommer

Founder & CEO, Born a Hero Research Foundation

Carolina is the Host of the FGFR Syndrome Collaborative Research Network Virtual Conference, Founder of Seattle Rare Disease Fair, author of the Lucy's Journey book series, founder of the ABC Kind Program with Gerry Ghanooni (A National curriculum that teaches kids about loving differences, including medical differences.) Carolina is a member of the Rare Disease Access Working Group with EveryLife Foundation, We Work for Health, Voters for Cures, and the WA Health Access Network. Carolina is currently working to launch a Rare Disease Council in Washington State with Max Brown and Joshua Henderson. She has also partnered with a few organizations around the country in hopes to start the BUILD Hub (To Build, Unify, Include, Learn, and Diversify our community.)

David Sommer

Vice President, Born a Hero Research Foundation

David Sommer is currently serving as Vice President of Born a Hero, and also happens to be married to Carolina CEO/Founder of Born a Hero. Their daughter Mariana was born with Pfeiffer Syndrome in 2012. Sometimes it is just about all he can manage to keep up with all the rare disease advocacy activities Carolina has going on at any one time. Aside from Born a Hero, David Sommer is an Associate at Degenkolb Engineers.

Saira Sultan

Policy Consultant, Haystack Project; President and CEO, Connect 4 Strategies

Saira Sultan has represented corporate, nonprofit, and government interests in the legislative and regulatory health policy arena for more than 20 years in Washington, D.C. She has had repeated success in designing business solutions by identifying and creating advocacy opportunities and translating them into strategic legislative and regulatory results. Saira brings a decade of experience working with market access, health outcomes, and commercial teams in pharmaceutical companies, including Pfizer and Sanofi. Saira is an experienced project management lead for large cross-functional efforts at Medtronic, Pfizer, Sanofi, and more. Focusing in areas such as oncology, rare and extremely rare therapies, vaccines, and specialty products in sickle cell, pain, addiction, cell and gene therapy and more, Saira has worked extensively with CMS, FDA and Capitol Hill. Saira holds a JD from the University of Virginia in Charlottesville, VA.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Dean Suhr

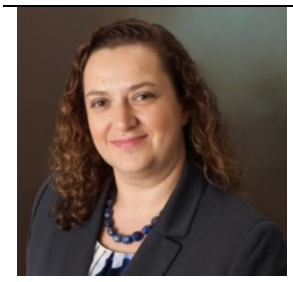
President/Founder, MLD Foundation

Dean co-founded MLD Foundation in 2001 to support families, improve clinical care, and advance therapies for metachromatic leukodystrophy (MLD), a rare genetic condition affecting two of his three children. Celebrating its 20th year in May 2021, MLD Foundation continues its global support of families and research, including facilitating clinical trials and basic science research in academic, medical & academic institutions, biopharma, government, and with other public and private partners. Dean got involved in Newborn screening around 2010 and has attended a majority of the ACHDNC advisory committee meetings since then. In 2016 he provided the RUSP-alignment language tying California's condition review timeline to the federal RUSP (SB 1095). In 2015 Dean launched the RUSP Roundtable (not MLD-specific) as a forum to bring together key perspectives from the NBS, public health, research, clinical care, biopharma, advocacy, payor, regulatory, and other ecosystems to address current and future opportunities to improve the system. Dean is currently leading MLD's efforts to implement MLD newborn screening by addressing policy, biochemical, state public health, access & reimbursement, Standards of Care, and the federal RUSP nomination. He is also shepherding the MLD Patient Powered Registry and several clinical trials, while working to enable access & reimbursement for the recently approved MLD gene therapy in the EU while preparing for FDA review in the US. Dean is very engaged with broader rare disease policy and research initiatives.

President & Founder, Rare Army

Rare Army is engaging, educating, encouraging, and empowering the 100 million people in direct contact with the 1 in 10 of us with a rare disease. We've developed and are currently refining a platform and process to engage, educate, empower, enable, and embolden rare disease families, and those who love and care them, to easily and quickly show their support for rare disease initiatives in policy, media, and awareness. Rare Army seeks to create a common ground for advocacy, biopharma, and umbrella organizations to maintain their momentum on their specific issues, while support the mainstream of rare disease issues, while expanding their base of support.

Dean has a BS in Electrical Engineering from the University of Southern California and spent 30 years working primarily in high tech executive leadership positions in marketing, operations, strategic planning, sales, and business development.



Jamie Sullivan

Director of Public Policy, Everylife Foundation for Rare Diseases

Recently Jamie joined EveryLife Foundation for Rare Diseases after a spending 15 years with the Alpha-1 and COPD Foundations. Jamie's work has focused on achieving patient-centered federal, state and regulatory policy changes in the areas of health appropriations, public health infrastructure and access to care. In her role at the COPD Foundation, Jamie also focused on building programs to engage and train patient advocates as well as advocating for the robust inclusion of patient and caregiver perspectives in all aspects of treatment development and review. Prior to joining the COPD Foundation, Jamie supported the research and clinical programs of the Alpha-Foundation. She obtained her master's in public health policy and management at the Florida International University.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Dr. Eric Tham

Interim Senior Vice President, Seattle Children's Research Institute

Eric Tham MD, MS, FAAP, FAMIA is currently interim Senior Vice President, Seattle Children's Research Institute. Prior to this taking this interim position, Eric was the Vice President, Information Technology and Clinical Research, and Associate Chief Information Officer. In this role, he provided executive leadership for the Epic implementation including the Epic Research module as well as development of the Clinical Research Integration Hub. Eric joined Seattle Children's as Chief Research Information Officer in 2014. He previously cared for acutely ill and injured children in the Seattle Children's emergency department.

Prior to moving to Seattle, Dr. Tham was Associate Professor of Pediatrics and Emergency Medicine at the University of Colorado School of Medicine. As Director of Research Informatics at Children's Hospital Colorado, he developed the research informatics program there, and he was active in Colorado CTSA informatics program. He received his MD from Northwestern University Medical School and MS in Biomedical Informatics at the University of Pittsburgh. He completed his pediatric residency and pediatric emergency medicine fellowship at the Children's Hospital of Pittsburgh. He is currently board certified in general pediatrics, pediatric emergency medicine, and clinical informatics.

Dr. John Thompson

John Thompson is the Director of the Newborn Screening (NBS) Program at the Washington State Department of Health's Public Health Laboratories.

The NBS Program tests blood samples collected from babies shortly after birth for a panel of 32 disorders that if you wait until the babies show symptoms, it is too late. The testing leads to early diagnosis and treatment that prevents death and disability for the affected babies.

John received a bachelor's degree from Brigham Young University in molecular biology. He then pursued concurrent master's degrees in public administration and public health genetics at the University of Washington. His research in graduate school focused on newborn screening policy. John finished his PhD in public health genetics from the University of Washington. His dissertation examined the impact the choice of newborn screening strategies for cystic fibrosis has on newborn screening programs and individual families. He lives north of Seattle with his wonderful wife and five fantastic children.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)

Sarah Tompkins

Advisory Committee Member, RDLA; Ms. Wheelchair Pacific Coast USA, 2021

Sarah lives in Bridle Trails in Bellevue, Washington with her family, husband, Troy, & their Jack Russel Terrier, Russell Wilson. Sarah is a Patient Advocate for Rare Diseases, Connective Tissue Diseases including her own patient communities of Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders (EDS/HSD), Dysautonomia Syndrome, Gastroparesis Syndromes, and more. Sarah advocates for invisible illnesses & disabilities, chronic pain patients, ADA rights, and for the awareness of the self-confidence, power, and beauty in sharing your story, voice, and experiences in one's advocacy journey.

Sarah was honored to be nominated in 2019 for The Rare Voice Awards Nomination for Federal Patient Advocacy for her work advocating for such legislation and causes as 21st Century Cures, NIH & FDA Funding, the OPEN Act, establishing a Rare Disease Center of Excellence, now Speeding Therapies and Treatments STAT Act, and more.

Sarah advocated for and helped in establishing Rare Disease Day in Washington State through a Proclamation of Rare Disease Day Feb. 28th, 2015. Sarah currently serves on the Rare Disease Legislative Advocates (RDLA) Advisory Committee as an EDS & Hypermobility Patient Advocate and is Advocacy Vice Chair of Virtual Rare Disease Week 2021.

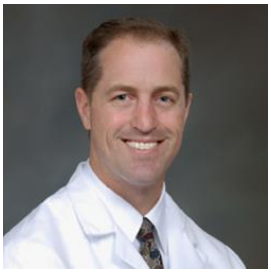
In July 2020, competing for Ms. Wheelchair USA, Sarah was awarded the title, crown, and sash of Ms. Wheelchair Pacific Coast USA 2021 with a National Disability Pageant for the Ms. Wheelchair USA this July 2021 in Ohio.

Leslie Urdaneta

Director of Family Support and Communication, National MSP Society

Leslie Urdaneta is a licensed clinical social worker and the Director of Family Support and Communication for the National MPS Society. She began work with children and families in the mucopolysaccharidosis (MPS) community in 2005. Within the Society, Leslie works in the Pathways program for newly diagnosed families, then continues to provide direct assistance and connection with services throughout the entire journey by overseeing family support programs. She spearheads communication efforts through social media, printed material, and electronic means. Leslie seeks to fulfill the mission of the Society to cure, support, and advocate for MPS, from diagnosis through bereavement.

Seattle Rare Disease Fair and Summit, June 4 & 5, 2021
Speaker Bios (alpha by last name)



Dr. Klane White

Director, Skeletal Health and Dysplasia, Seattle Children's Hospital; Principal Investigator, Seattle Children's Research Institute

Dr. White is a pediatric orthopedic surgeon and Director of the Skeletal Health and Dysplasia Program at Seattle Children's Hospital and a diplomate of the American Board of Orthopedic Surgery. Dr. White is an internationally recognized expert and advocate in the care of mucopolysaccharidosis and skeletal dysplasia. He serves on the Medical Advisory Board of Little People of America and is an executive founding member and current president of the Skeletal Dysplasia Management Consortium. Following three terms on the National MPS Society board of directors, he continues to chair the technical grant review committee, and serves on the Scientific Advisory Board

In addition to skeletal dysplasia and the mucopolysaccharidoses, Dr. White's clinical and research interests also include the diagnosis and management of early onset scoliosis (including VEPTR and magnetic growing rods), metabolic bone disease, and complex spine deformity. As a key opinion leader in these fields, he trains residents, fellows, visiting scholars, and is a frequent invited lecturer at national and international conferences, courses, symposia, and patient advocacy meetings. His research is routinely presented at national and international scientific and specialty society congresses, and he is principal investigator in several multicenter research studies for rare disease.

Dr. White received his MD from George Washington University School of Medicine and Health Sciences, and MS from the University of Southern California.
