Marshall Summar, M.D.

Director, Rare Disease Institute & Chief of Genetics and Metabolism
Margaret O'Malley Professor of Genetic Medicine
Children's National Health System

Chairman, Board of Directors
National Organization for Rare Disorders

Dr. Summar is well known for his pioneering work in caring for children diagnosed with rare diseases. He joined Children's National in 2010 from Vanderbilt University. At Children's National he leads the Division of Genetics and Metabolism, currently the largest clinical division in the world seeing over 8500 patients a year with rare diseases. Dr. Summar's laboratory works on both devices and treatments for patients with genetic rare conditions and adapting knowledge from rare diseases to mainstream medicine. His work has resulted in new drugs in Food and Drug Administration's (FDA) clinical trials for patients with congenital heart disease and premature birth. He has over 30 patents and patent applications. His laboratory is best known for its work in the rare diseases affecting nitrogen, ammonia, and amino acid metabolism.

Dr. Summar has also organized and led a number of international work groups to develop standards of care and treatment for rare diseases resulting in significant improvements in outcomes. He has built remote/telemedicine programs to reach patients currently without genetic care access. Dr. Summar is board-certified in Pediatrics, Clinical Genetics, and Biochemical Genetics and has been listed with Best Doctors in America since 2004.

He serves as President of the Board of Directors of the National Organization for Rare Disorders and is the past president of the Society for Inherited Metabolic Disorders. At NORD, he is spearheading an effort that has created digital registries for families to collect long-term information about poorly understood diseases. He is very active in newborn screening policy issues and in developing testing and follow-up systems.

Anne R. Pariser, M.D.

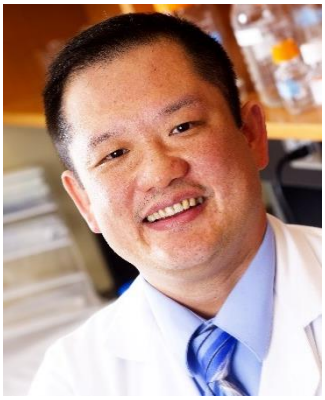
Deputy Director, Office of Rare Diseases Research, National Center for Advancing Translational Sciences
National Institutes of Health

Dr. Anne Pariser is the Deputy Director of the Office of Rare Diseases Research (ORDR) at the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health. ORDR is dedicated to accelerating rare diseases research to benefit patients through rare diseases programs such as the Rare Diseases Clinical Research Network, Genetic and Rare Diseases Information Center, and the NCATS Toolkit for Patient-focused Therapy Development.

Dr. Pariser came to NCATS in January 2017. Most recently, she served as Associate Director for Knowledge Management in the FDA's Office of Translational Sciences, which is part of the Center for Drug Evaluation and Research (CDER). Prior to serving in that role, Pariser was the Associate Director for Rare Diseases in the Office of New Drugs at CDER, where she established the Rare Diseases Program in 2010 to support, facilitate and accelerate the development of therapeutics for rare diseases.

Dr. Pariser earned her MD from Georgetown University in Washington D.C., and is board certified in Internal Medicine. Her research interests include regulatory and translational science development for rare diseases.

Eddy Yang, M.D., Ph.D.



Professor and Vice Chair for Translational Sciences, Department of Radiation Oncology
University of Alabama at Birmingham School of Medicine

Chair of the Congenital Central Hypoventilation Syndrome Network Research Advisory Board Chair
Congenital Central Hypoventilation Syndrome

Dr. Eddy Yang is Professor and Vice Chair of Translational Sciences in the Department of Radiation Oncology at the University of Alabama (UAB) School of Medicine. He is also Deputy Director of the Hugh Kaul Precision Medicine Institute and Associate Director of Precision Oncology. At UAB, Dr. Yang directs his translational research laboratory, focused on experimental therapeutics and precision medicine and has been awarded multiple grants from various funding organizations. He is also Director of the UAB Nanostring Laboratory. He aims not only to improve patient outcomes, but to preserve patient quality of life.

He received his undergraduate degree from Johns Hopkins University and his MD and PhD degrees from the University of Miami School of Medicine. He performed his internal medicine internship at Mount Sinai Medical Center in Miami Beach, Florida and his radiation oncology residency as a Holman Pathway Research Scholar at Vanderbilt University Medical Center in Nashville, Tennessee.

Dr. Yang's daughter was diagnosed at birth with Congenital Central Hypoventilation Syndrome (CCHS). He serves on the CCHS Network Board and is Chair of the Research Advisory Board, where research support has been granted to investigators to understand the biology of CCHS and find potential therapies for patients with CCHS.

To learn more about Congenital Central Hypoventilation Syndrome and the CCHS Network, visit CCHSnetwork.org.

Teryn Suhr

Executive Director and Co-Founder
MLD Foundation

Teryn Suhr is the Executive Director of the MLD Foundation. Teryn, along with her husband Dean, founded the MLD Foundation after two of their three children were diagnosed in 1995 with the juvenile form of Metachromatic Leukodystrophy (MLD) a rare, genetic, progressive, terminal, neuro-metabolic condition. Darcee passed away at the age 10 following a bone marrow transplant to try and correct the enzyme deficiency caused by the condition. Oldest daughter, Lindy, is alive and doing better than expected. She just celebrated her 37th birthday.

Teryn graduated in 1978 as a registered nurse and spent much of her time in general pediatrics, intensive care newborn nursery, and pediatric hospice home health. She took time off from nursing to raise her family until the shocking news that two of her three girls had a rare, fatal disease. Now Teryn's focus is on working with, supporting MLD affected families, and collaborating with researchers and industry to advance research for MLD and related diseases. Teryn is active on behalf of the MLD, Leukodystrophy, Lysosomal and Rare Disease communities and is a published author. Her passion over the last 17 years has led to her current work to improve newborn screening and treatments for rare diseases, especially MLD.

To learn more about Metachromatic Leukodystrophy and the MLD Foundation, visit MLDfoundation.org

Glenna Steele

Executive Director
Glut1 Deficiency Foundation

Glenna Steele is Executive Director of the Glut1 Deficiency Foundation. She holds a BS and MA in Education from Eastern Kentucky University. She has spent 15 years teaching public school kindergarten and first grade in Florida and Kentucky, and has volunteered for several years with the Epilepsy Foundation of Kentuckiana and the Special Olympics. Glenna was a founding board member of the Glut1 Deficiency Foundation and served as its first President and first Education Director. She lives in Owingsville, Kentucky with her husband, John, and their daughters Macie and Maggie. Macie was diagnosed with Glut1 Deficiency in 2008 at the age of 10.

To learn more about Glut1 Deficiency and Glut1 Deficiency Foundation, visit G1DFoundation.org.

Krista Hemming

Vice President
HSAN1E Society

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HSAN1E Society

Krista Hemming is an attorney, Vice-President of the HSAN1E Society and a rare disease advocate. Krista also serves on the HSAN1E Society's Scientific Board. She works as the link between HSAN1E patients and families, and the scientific and medical community working with this disease. Krista grew up in a family affected by HSAN1E, so has seen and experienced firsthand the struggles of HSAN1E patients, their caregivers, and their families. Krista's mission is to be a constant advocate for the needs of the HSAN1E community and continue to work with other members of the Society to raise global awareness about HSAN1E.

To learn more about Hereditary Sensory and Autonomic Neuropathy, Type 1E (HSAN1E) and HSAN1E Society, visit HSAN1ESociety.org.

John Hopper

President
Fibrolamellar Cancer Foundation

John Hopper is a recognized leader within the healthcare education, research, and patient advocacy world. He currently serves as President of the Fibrolamellar Cancer Foundation, Co-chairman of the GI Cancers Alliance — the world's largest patient-focused foundation for all GI Cancers — and sits on the board of directors/executive committee of the National Pancreas Foundation. John also helped co-found NORD's recent establishment of a Rare Cancer Coalition.

Prior to his nonprofit roles, John served in CEO and Managing Partner positions with healthcare/marketing communications conglomerates including Publicis, WPP Group, and Interpublic's McCann Healthcare — creating multi-million-dollar profit centers in the U.S. and South America focused on health/wellness professional and patient outreach. In these roles, he worked with over 70 clients ranging from Pfizer, BMS, AbbVie and Genentech, to the American College of Cardiology, National Institutes of Health, the American Diabetes Association and CNN's Larry King Cardiac Foundation, to name just a few. John also was one of the early renegades in partnering sports and entertainment celebrities and properties with health/wellness campaigns working with the MLB, NFL, NBA, NHL, Magic Johnson, Joe Namath, Julie Andrews, Jack Nicklaus and Nigel Lythgoe.

A graduate of the College of the Holy Cross and Oxford University's executive MBA program, he launched his career with Procter and Gamble in sales management and with Unilever as division head of a $1 billion business unit. He is the proud father of Jonathan, Allyson and Katey and spends free time on community and corporate boards, his Vermont farm and any tennis/platform tennis courts he can find.

To learn more about Fibrolamellar and Fibrolamellar Cancer Foundation, visit Fibrofoundation.org.

Trish Stoltzfus

Mentee Coordinator
PSC Partners Seeking a Cure

Trish Stoltzfus has been involved with PSC Partners Seeking a Cure for the past 7 years after her son was diagnosed with the disease. She has seen first-hand how PSC can effect patients and families. She is committed to the PSC community and helping to raise awareness about the disease, as well as fundraising for potential treatments and ultimately a cure.

To learn more about Primary Sclerosing Cholangitis and PSC Partners Seeking a Cure, visit PSCpartners.org.

Emily Fields

Executive Director
Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS)

Emily Fields joined Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) as the organization's first Executive Director in January 2015. A graduate with a B.A. in Human Services from The George Washington University in Washington, D.C. Emily has a background in nonprofit management, development, and community engagement. Prior to her work with PRISMS and the Smith-Magenis syndrome community, Emily served in the Development Office at the National Organization for Rare Diseases, supporting rare patient organizations like PRISMS. Emily is passionate about her work with families and is looking forward to the PRISMS 2018 International Conference in Pittsburgh, Pennsylvania, where she can continue to build relationships with the community.

Emily currently resides in Raleigh, North Carolina, where she enjoys spending time with family, trying her hand at new recipes, and seeing live shows around town.

To learn more about Smith-Magenis Syndrome and PRISMS, visit Prisms.org.