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IMC

INTERNATIONAL METABOLIC CONFERENCE

FOR FAMILIES AND INDIVIDUALS IMPACTED
BY FATTY ACID OXIDATION DISORDERS

JULY 26-28, 2024
DETROIT COUNTRY DAY SCHOOL

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THANK YOU FOR JOINING US!

I am delighted to welcome you all to MitoAction's 5th Annual International Metabolic Conference! This gathering brings together families, esteemed speakers, generous sponsors, dedicated volunteers, and our hardworking committee members, and I couldn't be more excited about the days ahead.

This year, as we celebrate our fifth anniversary, we are committed to making this conference an unforgettable experience. We have curated a diverse program featuring cutting-edge research presentations, therapeutic advancements, engaging activities for children, and numerous opportunities for meaningful connection and collaboration within our community.

Our heartfelt gratitude goes out to our conference planning committee, volunteers, and sponsors. This year we had the pleasure of connecting with the amazing geneticists at University of Michigan! Thank you Dr. Ames, Dr. Pritchard and Dr. Keegan for helping us to coordinate topics, speaking, and reaching out to your patient community about this conference! We also valued the input of Dr. Priestly and Peggy Rush! A special thank you to Dr. Jerry Vockley, Dr. Melanie Gillingham and Keith McIntire. Your expertise and dedication are the bedrock of this conference. To all our sponsors and committee members, your unwavering support is instrumental in enabling us to provide exceptional educational and support opportunities for the FAOD community.

Throughout the weekend, I encourage you to immerse yourself in the wealth of knowledge and experiences available. Our goal at MitoAction is to continue evolving and enhancing the ways we support the FAOD community. We are committed to fostering a sense of unity and actively listening to your needs and feedback. Please don't hesitate to connect with our MitoAction team members — we are here to learn from you and to ensure we meet the unique needs of you and your loved ones.

I hope this weekend inspires you, strengthens your connections, and reinforces the knowledge that you are not alone on this journey. Together, we are stronger, and together, we will continue to make strides in supporting the FAOD community.

Welcome to the conference, and let's make this a memorable and impactful weekend!

Warm regards,

Kira Mann, CEO
MitoAction

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LC-FAOD

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ENZYME DEFICIENCIES

WHAT IS DOJOLVI?

DOJOLVI (triheptanoin) is a prescription medicine used to treat long-chain fatty acid oxidation disorders (LC-FAOD) in children and adults.

DOJOLVI®
TRIHEPTANOIN
Oral Liquid

IMPORTANT SAFETY INFORMATION

Before taking DOJOLVI, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if DOJOLVI will harm your unborn baby. **Pregnancy Safety Study:** There is a pregnancy safety study for women who take DOJOLVI during pregnancy. The purpose of this study is to collect information about your health and your baby's health. You can talk to your healthcare provider or contact 1-888-756-8657 to enroll in this study or get more information.
- are breastfeeding or plan to breastfeed. It is not known if DOJOLVI passes into breast milk. Talk to your healthcare provider about the best way to feed your baby if you take DOJOLVI.
- are taking a pancreatic lipase inhibitor, such as orlistat, as it may affect how well DOJOLVI works.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of DOJOLVI?

- **Feeding tube problems.** Feeding tubes may not work as well or stop working over time when taking DOJOLVI. **Do not use DOJOLVI in feeding tubes made of polyvinyl chloride (PVC).** Check the feeding tube to make sure it is working properly and not breaking down.
- **Intestinal absorption problems in patients with pancreatic insufficiency.** If you have pancreatic insufficiency, consult with your healthcare provider as it may affect how well DOJOLVI works.
- The most common side effects of DOJOLVI include:
  - stomach (abdominal) pain
  - diarrhea
  - vomiting
  - nausea

These are not all the possible side effects of DOJOLVI. Call your healthcare provider for medical advice about side effects.

You may report side effects to Ultragenyx Pharmaceutical Inc. at 1-888-756-8657 or FDA at 1-800-FDA-1088.

Please visit www.DOJOLVI.com to see the full Prescribing Information, including Patient Information for additional Important Safety Information and instructions for use.

MRCM-UX007-00326 5/2024

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INTERNATIONAL METABOLIC CONFERENCE

FOR FAMILIES AND INDIVIDUALS IMPACTED BY FATTY ACID OXIDATION DISORDERS

2024 AGENDA

Friday, July 26, 2024			
	MAIN SESSION	**TEEN TIME**	**ALTERNATE SESSION**
12:30 PM	**Afternoon Registration**		
4:00 PM	**Welcome/ Opening** Kira Mann, CEO, MitoAction		
4:15 PM	**FAOD Therapy Updates** Jerry Vockley, MD, PhD, UPMC		
5:15 PM	**Cyclic Vomiting: What is the connection with FAOD and mitochondria?** Richard G Boles, MD, Mitochondrial & Molecular Medicine/NeuroNeeds		
5:45 PM	**Roundtable Discussions:** **The Early Years: Newborn- Preschool** **Elementary Adventures with FAODs** **Understanding the Middle School Years** **Parenting High Schoolers and Adults with FAODs** **Adulting with FAODs** **Dads Sharing with Dads** FAOD Conference Committee Members	**Understanding our Journeys:** Jerry Vockley, MD, PhD, and Keith McIntire, INFORM Program Manager	
6:30 PM	**FAOD Fun Night: Dinner, Kickball, and Snowcones!**		

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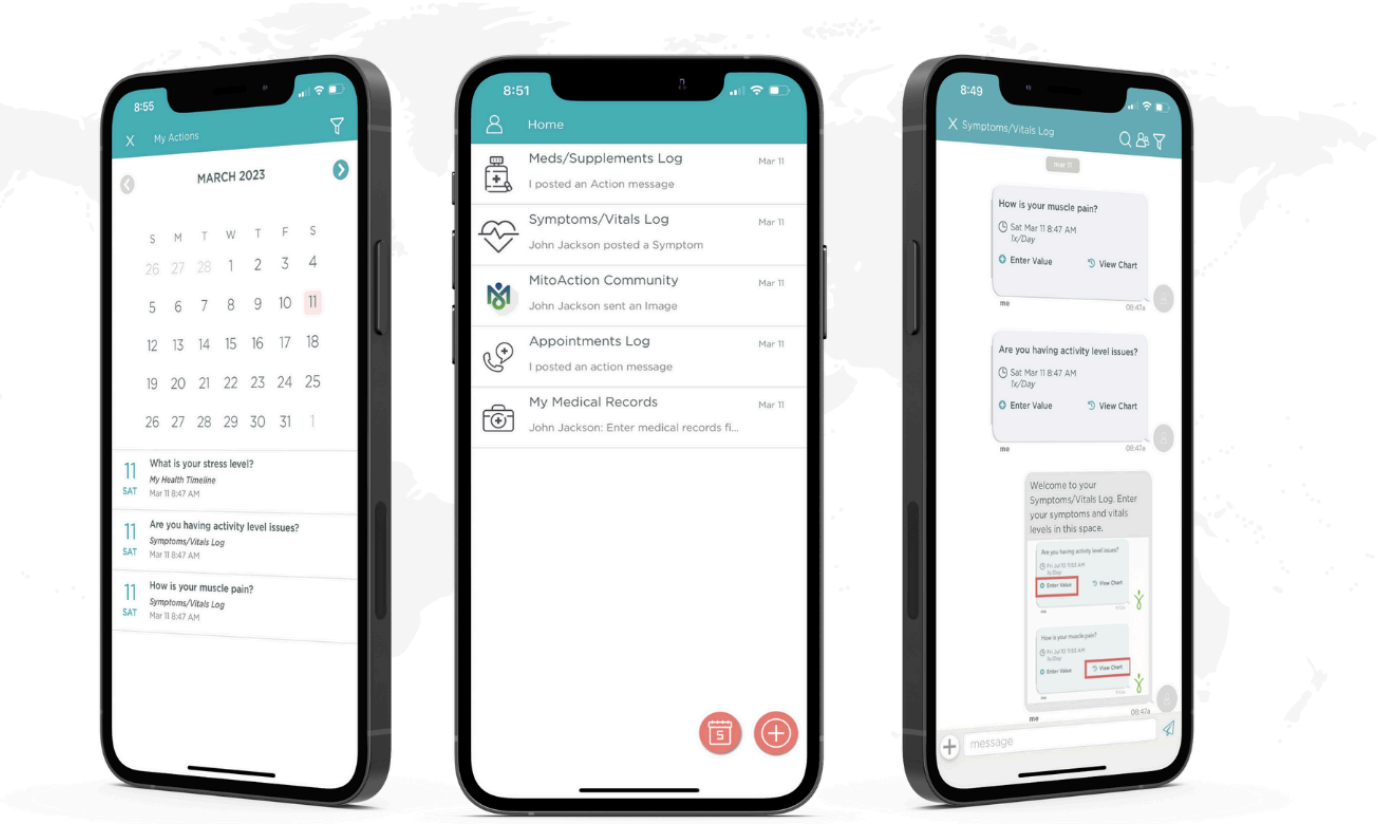

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Saturday, July 27, 2024

	MAIN SESSION	TEEN TIME	ALTERNATE SESSION
8:00 AM	**Doors Open/ Continental Breakfast Available at Detroit Country Day School**		
9:15 AM	**Morning Report** Kira Mann, CEO, MitoAction		
9:30 AM	**FAOD Cooking 101** Glenn Noffsinger, Chef and Consultant, Noffsinger Ventures INC	Teen Room Open	**Roundtable for Clinicans** Jerry Vockley, MD, PhD, UPMC
10:30 AM	**Break with Snacks**	Teen Room Open	
10:45 AM	**Logic, Benefit, Harm: Understanding Vitamins and Supplements** Melanie Gillingham, PhD, RD, LD, OHSU	Teen Room Open	
11:30 AM	**Who's Who and What's What: Navigating Hospitalizations for Pediatric and Adult Patients** Amanda Pritchard, MD, U-M	**Navigating Adolescence: A Discussion for Teens about Puberty and Wellness** Jessica Gold, MD, PhD and Alex Salser, LCHADD Young Adult	**Culinary Knife Skills 101 (limited to first 5-6 people)** Glenn Noffsinger, Chef, Consultant Noffsinger, Ventures INC
12:15 PM	**Lunch**		
1:30 PM	**Building and Maintaining Strength with an FAOD** Pamela Tucker, PT, DPT, UPMC		
2:00 PM	**Techniques in Strength Training: Clinic** Pamela Tucker, PT, DPT, UPMC		
2:45 PM	**FAODs, Puberty, and Reproductive Health** Jessica Gold, MD, PhD, Northwell Health	**Culinary Knife Skills 101** with Chef Noffsinger!	**Navigating the Early Years** Dr. Priestley, MD, PhD, MSU

	MAIN SESSION	TEEN TIME	ALTERNATE SESSION
3:30 PM	**Topical Roundtable Discussions: Culinary Knife Skills 101 (limited to 5 participants)** Glenn Noffsinger, Chef and Consultant, Noffsinger Ventures INC **Dads Sharing with Dads** Ryan Harry, LCHADD Parent **FAODs, Puberty, and Reproductive Health discussion for parents and caregivers** Jessica Gold, MD, PhD, Northwell Health **Navigating School with FAODs: Talking to Teachers and Classmates** Jessica Priestley, MD, PhD MSU, Christy Abrams, LCHADD Parent **How do you Deal with the Mental/Emotional Fatigue of Having a Chronic Health Condition?** Yi Tak (Daisy) Tsang, PhD, LP, U-M **Things that Only Parents Know: "Weird" Symptoms, Daily Tips and Tricks** Sharickah Rogers, LPC, VLCADD Parent, Jayleigh Grose, LCHADD Parent **Athletic Participation- Breaking Down Barriers to Being Active** Pamela Tucker, PT, DPT, UPMC, Elizabeth Ames, MD, PhD, U-M, Stephanie Harry, LCHADD Parent	**Teen and Young Adult Roundtable: Thinking about food as you transition into adulthood** Melanie Gillingham, PhD, RD, LD, OHSU	
4:15 PM	**Break**		
4:30 PM	**Sponsor Update**		
4:45 PM	**Expert Panel** Glenn Noffsinger, Chef, Consultant Noffsinger, Ventures INC, Melanie Gillingham, PhD, RD, LD, OHSU, Amanda Pritchard, MD, U-M, Dr. Priestley, MD, PhD MSU, Pamela Tucker, PT, DPT, UPMC, Jessica Gold, MD, PhD Northwell Health, Jerry Vockley, MD, PhD, UPMC		
5:45 PM	**GROUP PICTURE**		
6:00 PM	**Dinner (on your own)** Grab a new FAOD friend, check out our list of local restaurants and enjoy the down time!		

INTERNATIONAL NETWORK FOR FATTY ACID OXIDATION RESEARCH AND MANAGEMENT

INFORM brings together the best and brightest genetic researchers and clinicians worldwide, working to discover treatments and cures for fatty acid oxidation disorders to improve the lives of our patients and their families.

2024 INFORM Annual Conference

September 1-2, 2024

Porto, Portugal

WWW.INFORMNETWORK.ORG

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Nestlé HealthScience

Nestlé Health Science is a leader in the science of nutrition, offering an extensive portfolio of science-based medical nutrition, consumer care products and pharmaceutical therapies. Headquartered in Switzerland, we have more than 12,000 employees around the world, with products available in more than 140 countries.

We know that nutrition can transform the lives of those who need extra support during short- or long-term medical challenges, and it can enhance the quality of life of those who are already healthy. With an extensive research network providing the foundation for our products, we are committed to science-based nutritional solutions that can make a real difference for consumers, patients and caregivers.

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Sunday, July 28, 2024

	MAIN SESSION	TEEN TIME	ALTERNATE SESSION
8:00 AM	**Doors Open/ Continental Breakfast Available at Detroit Country Day School**		
9:15 AM	**Morning Report** Kira Mann, CEO, MitoAction	Teen Room Open	
9:30 AM	**Story Moments: Hearing From You! A non-traditional Family/Patient Panel** Stephanie Harry, Patient Support Coordinator, MitoAction, Patient Community		
10:30 AM	**Hospital Woes: Understanding Medical Trauma and Resilience** Yi Tak (Daisy) Tsang, PhD, LP, U-M	Teen Room Open	
11:15 AM	**Break**	Teen Room Open	
11:30 AM	**Using Mouse Models to Study LCHADD Chorioretinopathy and Other FAODs** Shannon Babcock, PhD, OHSU	Teen Room Open	**Tips and Tricks for the MCADD Cook!** Glenn Noffsinger, Chef and Consultant, Noffsinger Ventures INC
12:15 PM	**Lunch**		
1:00 PM	**FAOD: The Effect on Families and Food Relationships** Georgianne Arnold, MD, Emeritus of Pitt/VMP Genetics	Teen Room Open	
1:45 PM	**Conference Survey**		
2:00 PM	**Understanding Rhabdomyolysis** Erin Neil Knierbien, DO, U-M	Teen Room Open	
2:45 PM	**Clinician Panel** Yi Tak (Daisy) Tsang, PhD, LP, U-M Georgianne Arnold, MD, Emeritus of Pitt/VMP Genetics Melanie Gillingham, PhD, RD, LD, OHSU Erin Neil Knierbein, DO, U-M		
3:30 PM	**Closing Slideshow**		

CONFERENCE DINING

Click the links below to view our conference menu as well as some recommended, restaurants with low-fat options in the Detroit area.

CONFERENCE MENU

Click HERE to view the menu

LOCAL RESTAURANTS

Click HERE to view the list of local restaurants with low-fat options

SPEAKER BIOGRAPHIES

Thanks to our incredible group of speakers, we have a robust agenda filled with the most current research and clinical information in Fatty Acid Oxidation Disorders, in addition to valuable resources to support the community day-to-day.

CLINICIANS

ELIZABETH AMES, MD PHD

Clinical Assistant Professor
Division of Pediatric Genetics, Metabolism, and Genomic Medicine
C.S. Mott Children's Hospital
Michigan Medicine

Dr. Ames completed her undergraduate degree at the University of Minnesota in Genetics, Cell Biology and Development. She then completed an MD/PhD at the University of Virginia. Her interest in genetics began during her PhD while studying RNA processing in fetal heart development. She then moved to the University of Michigan to complete a combined residency in both Pediatrics and Medical Genetics. After residency, she completed a fellowship in Medical Biochemical Genetics. She has remained at the University of Michigan as a clinical assistant professor in the departments of Pediatrics and Internal Medicine where she sees patients of all ages. Her clinical interests include novel therapies for inborn errors of metabolism, RASopathies, and neuromuscular conditions.

GEORGIANNE ARNOLD, MD

Emeritus Professor of Pediatrics
University of Pittsburgh

Dr. Arnold graduated from Indiana University with degrees in biology and chemistry, and has a Masters degree in Medical Genetics from Indiana University-Purdue University at Indianapolis. She graduated from medical school from Upstate Medical University, and completed a residency in Pediatrics at Northwestern University. Her genetics training was at the University of Colorado and she is boarded in Clinical Biochemical Genetics and Clinical Genetics.

Dr. Arnold was Clinical Director and most recently Clinical Research Director at the University of Pittsburgh. She is an Emeritus Professor, and a consultant with VMP Genetics. Dr. Arnold is the past president of the Society for Inherited Metabolic Disorders, and recipient of the Shapira award for the best member's paper in Molecular Genetics and Metabolism. She has a long-standing interest in fatty acid oxidation disorders, working with Dr. Vockley for 13 years.

SHANNON BABCOCK, PHD

Department of Molecular and Medical Genetics
Oregon Health and Science University

Shannon Babcock received her Bachelor's of Science in Biochemistry from Gonzaga University in 2017 and has recently earned her PhD in Molecular and Medical Genetics from the Oregon Health and Science University in Portland, OR. While at OHSU, Shannon studied the molecular mechanisms involved with and potential treatments for LCHADD chorioretinopathy using a novel LCHADD mouse model. Since graduating in May 2024, Shannon has begun a laboratory genetics and genomics fellowship at the Henry Ford Hospital in Detroit, MI where she is working to become a clinical lab geneticist. In her free time, Shannon enjoys playing tennis and spending time outdoors with her dog.

RICHARD G. BOLES, M.D.

Geneticist in a Telemedicine Private Practice
Mitochondrial & Molecular Medicine
Chief Medical & Scientific Officer,
NeuroNeeds, Old Lyme, CT

Dr. Boles is a Medical Geneticist with expertise in mitochondrial, other metabolic disorders, and channelopathies. He completed medical school at UCLA, a pediatric residency at Harbor-UCLA, and a genetics fellowship at Yale. Dr. Boles' clinical and research focus has been on the genetics of common, chronic neurological disorders, including autism, ADHD, pain, fatigue, and cyclic vomiting. He has over 90 peer-reviewed published papers, including 20 on cyclic vomiting. Dr. Boles was the Medical Director of a DNA sequencing laboratory for 6 years. He currently in a virtual (Zoom) private practice, where he applies whole genome (DNA) sequencing to determine the cause of disease in his patients. Dr. Boles is also the Chief Medical & Scientific Officer of NeuroNeeds, a company that produces natural nutritional products to assist people with neurological conditions, including CVS and other conditions listed above. He has been a Medical Advisor for MitoAction and CVSA for decades.

Going beyond every day.™

Ultragenyx is proud to sponsor the 5th Annual International Metabolic Conference for Fatty Acid Oxidation Disorders (FAODs) and support MitoAction and the International Network for Fatty Acid Oxidation Research and Management's (INFORM) ongoing work with the LC-FAOD community.

We are committed to advancing research for LC-FAOD and grateful for our partnership with MitoAction and families living with LC-FAOD.

To learn more, visit **Ultragenyx.com**

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MRCM-UX007-00527 May 2024

MELANIE GILLINGHAM PHD, RD, LD

Professor, Molecular and Medical Genetics
Oregon Health & Science University

Dr. Melanie Gillingham's research in the Department of Molecular and Medical Genetics has focused on various novel therapies for fatty acid oxidation disorders. For 20 years, Dr. Gillingham and her colleagues have conducted clinical trials in subjects with disorders in the fatty acid oxidation pathway. She has examined the effects of medium chain triglycerides (MCT) supplements prior to exercise on exercise performance among subjects with long-chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency receiving the Emmanuel Shapira Award for best paper in Molecular Genetics and Metabolism. The Gillingham lab has evaluated the effects of increased dietary protein on metabolic control and energy balance in subjects with LCHAD, carnitine palmitoyltransferase 2 (CPT-2) and very long-chain acylCoA dehydrogenase (VLCAD) deficiencies. In a separate study, Dr. Gillingham conducted supervised metabolic fasting studies in young children with a polymorphism of the CPT1A gene to determine if they have an altered fasting response similar to other fatty acid oxidation disorders.

In 2014, a group of FAO researchers, under the leadership of Dr. Jerry Vockley, founded the International Network for Fatty Acid Oxidation Research and Management (INFORM), an international group working for the advancement of medical and nutrition therapies for fatty acid oxidation disorders (www.informnetwork.org). Dr. Gillingham participates on the organizing committee of INFORM.

Dr. Vockley and Dr. Gillingham completed a randomized trial to examine the effects of an odd-chain fatty acid supplement, triheptanion, on myopathy and cardiac function of patients with long-chain fatty acid oxidation disorders. This is the largest randomized controlled trial conducted in these disorders to date and was recently selected for the Garrod award by the Society for the Study of Inborn Errors of Metabolism (SSIEM). Dr. Gillingham has also conducted a series of studies examining the etiology of retinopathy in LCHAD and the role of diet in the progression of vision loss. Dr. Gillingham is currently conducting a larger natural history study of LCHAD retinopathy.

JESSICA GOLD, MD, PHD

Medical Genetics and Metabolism
Northwell Health, NY

Dr. Jessica Gold is a medical geneticist trained in pediatrics and internal medicine with a fellowship at Children's Hospital of Philadelphia. She currently practices at Northwell Health in NY. Both her clinical work and research is dedicated to helping adolescents and young adults with inherited metabolic disorders prepare for adulthood. For many young people, puberty and reproductive health are important milestones in emerging adulthood. Yet, clinicians lack information on these topics for people with FAODs, which impacts their ability to provide guidance. Dr. Gold is embarking on a project that is the first step in learning how people with FAODs approach puberty and reproductive health.

ERIN NEIL KNIERBIEN, DO

Director Pediatric Neuromuscular Program
Pediatric Neurologist
Michigan Medicine Health

Dr. Erin Neil completed her undergraduate degree at the University of Notre Dame. She completed a DO at Kansas City University of Medicine and Biosciences. Her interest in pediatric neurology began after she discovered how much can be learned from the neurologic examination, the beauty of childhood development and the possibility of strong connections with pediatric patients and their families.

She completed a pediatric neurology residency at Wayne State University/Children's Hospital of Michigan and a fellowship in pediatric neuromuscular medicine at University of Texas Southwestern/Children's Medical Center, Dallas TX. At the University of Michigan, she is a clinical associate professor in the department of Pediatrics, division of neurology and director of the pediatric neuromuscular program. She leads the coordinating center for Spinal Muscular Atrophy newborn screening at U of M for the state of Michigan. Her clinical interests include multidisciplinary care of patients with neuromuscular disorders, clinical trials for rare neurologic diseases, newborn screening, and early treatment, including gene therapy, for patients with neuromuscular disorders.

JESSICA PRIESTLEY, MD PHD

Medical & Biochemical Geneticist
Helen DeVos Children's Hospital
Corewell Health West Michigan
Michigan State University

Dr. Priestley completed graduate school at the Medical College of Wisconsin, medical school at Michigan State University College of Human Medicine, and residency/fellowship at the Children's Hospital of Philadelphia. Following her training, she returned to West Michigan to serve patients and families with rare disease. She is a Medical and Biochemical Geneticist at Corewell Health West Michigan/Helen DeVos Children's Hospital. Her clinical interests include inborn errors of metabolism and genetic conditions of the cardiovascular, hepatobiliary, and renal systems. Her research interests include newborn screening, clinical outcomes, and health equity within the field of genetics.

AMANDA BARONE PRITCHARD, MD

Assistant Professor of Pediatrics
Division of Pediatric Genetics, Metabolism, and Genomic Medicine
University of Michigan Health

Dr. Amanda Barone Pritchard is an Assistant Professor of Pediatrics at University of Michigan Health in the division of Pediatric Genetics, Metabolism, and Genomic Medicine. Dr. Pritchard attended the University of Pittsburgh School of Medicine before completing Pediatric Residency at Lurie Children's Hospital in Chicago. She then trained in Medical Genetics and Genomics and completed a Medical Biochemical Genetics fellowship at the Children's Hospital of Philadelphia. She currently practices pediatric genetics and biochemical genetics, and has research interests in delineation of new genetic disorders and treatment of genetic diseases. She has been involved in several clinical trials for inborn errors of metabolism. Dr. Pritchard is also an enthusiastic medical educator and serves as Program Director for the Medical Biochemical Genetics Fellowship and Associate Program Director for the Medical Genetics and Genomics and Combined Pediatrics-Medical Genetics and Genomics Residency Programs at the University of Michigan.

YI TAK (DAISY) TSANG, PHD, LP

Clinical Assistant Professor of Pediatric Psychology
University of Michigan Health/Michigan Medicine

Daisy Tsang is a clinical assistant professor in Pediatric Psychology at the University of Michigan Health and C.S. Mott Children's Hospital. She has almost a decade of experience working with children and families impacted by a wide range of mental health challenges and adverse events.Currently, she provides psychological assessment and treatment to children in primary care and outpatient specialty clinics. Previously, she spent two years providing inpatient psychological consults to children who were hospitalized for various medical conditions, including those admitted to the PICU and NICU. She has given seminars to medical professionals and learners on trauma-informed care, which continues to be the focus of her clinical and research passion. When she takes off her psychologist hat, Dr. Tsang enjoys baking, traveling, and taking funny videos of her almost 2-year-old son.

PAMELA TUCKER, PT, DPT,

Upstate Medical University Hospital

Following her undergraduate studies at Duke University, Pamela Tucker obtained her Doctor of Physical Therapy degree from Franklin Pierce University. Her clinical experience includes the management of outpatient and inpatient rehabilitation of infant, pediatric, and adult populations.

She is a senior Physical Therapist at the Children's Institute of Pittsburgh and UPMC with specialties in pediatric, neurological, vestibular, and concussion interventions. Her research interests include physical therapy interventions for children with inherited metabolic disorders, aquatic physical therapy, concussion management, and robotic-assisted mobility training. Dr. Tucker is currently working on a physical therapy protocol for recovering from rhabdomyolysis.

JERRY VOCKLEY, M.D., PH.D.

University of Pittsburgh
Cleveland Family Endowed Chair in Pediatric Research
Professor of Human Genetics
UPMC Children's Hospital of Pittsburgh
Chief of Genetic and Genomic Medicine
Director of the Center for Rare Disease Therapy

Dr. Vockley received his undergraduate degree at Carnegie-Mellon University in Pittsburgh, Pennsylvania, and received his MD and PhD degrees in Medicine and Genetics from the University of Pennsylvania School of Medicine in Philadelphia, Pennsylvania. He completed his pediatric residency at the Denver Children's Hospital, Denver, Colorado, and his postdoctoral fellowship in Human Genetic and Pediatrics at Yale University School of Medicine in New Haven, Connecticut. Before assuming his current position in Pittsburgh, Dr. Vockley was Chair of Medical Genetics in the Mayo Clinic School of Medicine.

Dr. Vockley is internationally recognized as a leader in the field of inborn errors of metabolism. His current research focuses on mitochondrial energy metabolism, novel therapies for disorders of fatty acid oxidation and amino acid metabolism, and population genetics of the Plain communities in the United States. He has published over 320 peer reviewed scholarly articles and is the principal or Co-investigator on multiple NIH grants. Dr.Vockley has an active clinical research program and participates in and consults on multiple gene therapy trials. Dr. Vockley has served on numerous national and international scientific boards including the Advisory Committee (to the Secretary of Health and Human Services) on Heritable Disorders in Newborns and Children, where he was chair of the technology committee. He is a Fellow in the American Association for the Advancement of Science. He is a Founding Fellow of the American College of Medical Genetics and Genomics, and currently serves on its board of directors. He is founder and chair of the International Network on Fatty Acid Oxidation Research and Management (INFORM). He has served as chair of the Pennsylvania State Newborn Screening Advisory Committee and is a past president of the International Organizing Committee for the International Congress on Inborn Errors of Metabolism and the Society for the Inherited Metabolic Disorders (SIMD). He is co-founder and editor of the SIMD North American Metabolic Academy. He provides support for numerous family advocacy groups including MitoAction, the United Mitochondrial Disease Foundation, the National PKU Association, and the Organic Acidemia Association.

EXPERT SPEAKERS

KEITH MCINTIRE

Program Manager, International Network for Fatty Acid Oxidation Research & Management, (INFORM), Division of Genetic and Genomic Medicine
Co-Founder, Dr. Bill Neches Heart Camp for Kids, Heart Institute

As the Program Manager of INFORM, Keith is responsible for the day-to-day activities of the Pittsburgh-based FAOD program including overseeing fundraising, marketing, and the development and maintenance of the INFORM website.

Keith's career focused on corporate communications, marketing, fundraising, and business administration experience. After graduating with a degree in illustration and design from the Art Institute of Pittsburgh he operated his own design studio for several years focusing on healthcare and industrial illustration. He then became the Art Director of the Public Relations Department of Seton Hill University. Keith's work gained him national attention and he was hired to work for ABS/TelCove an internet, data, and voice company focused on communications delivery to customers in 27 states and 70 markets on a dedicated end to end fiber optic network.

Keith is the oldest heart patient followed since birth by the UPMC Children's Hospital of Pittsburgh. He was born with Tetrology of Fallot with absent pulmonary leaflets and underwent three open heart surgeries for total repair by the age to 23. Keith was a member of the American Heart Association, where he held volunteer leadership positions and was a board member for the Pittsburgh chapter. Keith assisted cardiologist William Neches, MD as a Co-founder of the UPMC/Children's Hospital of Pittsburgh's, Dr. Bill Neches Heart Camp for Kids, one of the first camping programs nationally to offer a sleepover summer camping experience for children with congenital and/or acquired heart disease. In 2023 he passed the torch of his directorship to a new leadership team after 29 years of holding that position and a total of 33 years with the camp.

GLENN NOFFSINGER, CC

Chef & Consultant
Noffsinger Ventures Inc.

Chef Glenn Noffsinger has over 20 years of experience in commercial, non-commercial, personal chef, and culinary instruction services. With unique insights based on real-world experience, he focuses on the success of each client and their needs. Utilizing a collaborative consulting approach that works alongside the client to help them achieve their goals and affect impactful, sustainable changes.

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2024 ENERGY WALK

SAVE THE DATE(S)

ROCHESTER, NY
August 25, 2024

HARTFORD, CT
September 7, 2024

SYRACUSE, NY
September 15, 2024

BOSTON, MA
September 29, 2024

RIVERSIDE, CA
October 6, 2024

Dalia's Wish

Help us send deserving patients and families to Give Kids The World Village and make wishes come true for children with mitochondrial disease!

www.mitoaction.org/daliaswish

THANK YOU FOR JOINING US AT THE 2024 INTERNATIONAL METABOLIC CONFERENCE!

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