

EMMA WILLIAMS, MBE
CEO/Founder: Matthew's Friends –
Ketogenic Dietary Therapies



Emma is the CEO and Founder of the 'Matthew's Friends – Ketogenic Dietary Therapies' Charity and the Director of Matthew's Friends Clinics for Ketogenic Dietary Therapies based in the UK. They also have Matthew's Friends branches registered in New Zealand and Canada as well as working with other ketogenic groups around the globe.

Emma is the Parent Advisor on the Ketogenic Professional Advisory Group in the UK, the Chair Trustee on the board of Dravet Syndrome UK as well as being the Chair of the newly formed 'Matthew's Friends Glut1 UK'. In 2013 she was honoured with an MBE from HM the Queen for Services to children with epilepsy. Most importantly, she is a very proud mother to Matthew (aged 20) and Alice (19). Alice has just finished her first year at Medical School and has been presenting at meetings since the age of 12 on what it is like to be a sibling of someone with severe refractory epilepsy and is assisting Emma at this Glut1 meeting on the Matthew's Friends Stand.

BETH ZUPEC-KANIA, RDN, CD
The Charlie Foundation for Ketogenic Therapies



Beth Zupec-Kania is a Registered Dietitian and Nutritionist who works to promote safe and effective use of ketogenic therapies. She has written many publications and designed KetoDietCalculator, a web-based program for calculating ketogenic diets. Beth is a consultant to The Charlie Foundation for Ketogenic Therapies and has provided ketogenic training

to over 150 medical centers worldwide.

The Glut1 Deficiency Foundation is honored to welcome this exceptional group of speakers to lead the way as we come together to meet, share, and learn.

Their presence here reflects their concern for and commitment to our community. We are grateful for all they do to bring help and hope to us and to so many others.



www.G1DFoundation.org



Family & Professional
Conference Speakers

2015 Conference

ORLANDO

— meet • share • learn —

Family Program July 6-7 | Professional Program July 8



STACEY BESSONE, RD, LD/N **All Children's Hospital, Johns Hopkins Medicine**



Stacey Bessone is the registered dietitian at the Neuroscience Institute Epileptology Center at All Children's Hospital, Johns Hopkins Medicine in St. Petersburg, Florida. She sees patients exclusively for all forms of the ketogenic diet, inpatient and in ketogenic clinic. Stacey received her BS in Dietetics and Nutrition from Florida International University in Miami, Florida and has been a dietitian for almost 19 years with all her clinical practice in pediatrics. She routinely provides presentations to physicians and residents and has also spoken nationally on the classical ketogenic diet. Stacey has a passion for the diet and enjoys educating others to increase awareness of the diet as an option for treatment. She lives in Tampa with her husband and son.

DOMINIC D'AGOSTINO, PhD **University of South Florida Morsani College of Medicine**



Dr. Dominic D'Agostino is an Assistant Professor in the Department of Molecular Pharmacology and Physiology at the University of South Florida Morsani College of Medicine and also a Senior Research Scientist at the Institute for Human and Machine Cognition. The primary focus of his laboratory is developing and testing metabolic therapies, including ketogenic diets, ketone esters and natural and synthetic molecules to target metabolic processes. These metabolic therapies are formulated and tested to enhance neurological and physiological resilience under environmental extremes associated with changes in oxygen and pressure. His research also explores the use of these metabolic therapies for a broad range of disorders linked pathophysiologically to metabolic dysregulation, including seizures, neurological disorders, inborn errors in metabolism, muscle wasting and cancer. D'Agostino's laboratory uses in vivo and in vitro techniques to understand the physiological, cellular and molecular mechanism of metabolic therapies. His research is supported by the Office of Naval Research (ONR), Department of Defense (DoD), private organizations and foundations.

NORMA CONNER, PhD, RN **University of Central Florida**



Dr. Norma Conner is currently an Assistant Professor, in the College of Nursing at the University of Central Florida, where she teaches courses in community and public health, nursing theory, and health policy across the undergraduate and graduate programs. She earned her Bachelor's Degree in Nursing from Towson State University, Towson, Maryland, and both a Master's Degree and a Ph.D. in Nursing from the Rutgers, the State University of New Jersey. Her nursing practice has included oncology, hospice, case-management for Medicaid Waiver. Her research interests include caregiving and health care decision making, spirituality, health services use, and hospice and palliative care.

DARRYL DE VIVO, MD **Columbia University Medical Center**



Dr. De Vivo received his M.D. Degree from the University of Virginia Medical School. Residency training in Medicine, Pediatrics, Neurology and Pediatric Neurology followed at Harvard, National Institutes of Health and Washington University. He then joined the Medical School Faculty at Washington University and over the next decade was promoted from Assistant Professor to Professor as he developed his clinical research skills in neurochemistry, metabolic diseases and neuromuscular disorders. He joined the Columbia University Faculty in 1979 as the Sidney Carter Professor of Neurology and Pediatrics and Director of the Pediatric Neurology Service. Currently he continues to fulfill his duties as Founding Director, Colleen Giblin Research Laboratories; Director, Pediatric Neuromuscular Disease Center, Co-Director of the Center for Motor Neuron Biology and Diseases (MNC) and Associate Chairman (Neurology) for Pediatric Neurosciences. Dr. De Vivo receives funding from the NIH, DOD, SMA Foundation, MDA, Colleen Giblin Foundation, Milestones for Children, The Glut1 Deficiency Foundation, and the Will Foundation. He serves as the Director for the PNCR Clinical Trials Network for SMA.

Dr. Darryl C. De Vivo, M.D., is the Sidney Carter Professor of Neurology, Professor of Pediatrics, and Director Emeritus (1979-2000) of the Pediatric Neurology Service at Columbia University Medical Center in New York City. He also is the Associate Chairman for Pediatric Neurosciences and Developmental Neurobiology, the Founding Director of the Colleen Giblin Research Laboratories for Pediatric Neurology at Columbia University Medical Center and the Co-Director of the Center for Motor Neuron Biology and Disease (MNC). Dr. De Vivo was a Director for Neurology and President of the American Board of Psychiatry and Neurology, Secretary of the American Academy of Neurology, and President of the Child Neurology Society. He completed postgraduate training in medicine, pediatrics, and neurology at the Massachusetts Memorial Hospital and the Massachusetts General Hospital, as well as at the National Institutes of Health where he was a Clinical Associate in Neurology. He has published more than 400 original articles and reviews, lectures extensively in the U.S. and abroad, serves on several editorial boards and advisory committees, and is a former associate editor for Rudolph's Textbook of Pediatrics. He is a current editor of "Neuromuscular Disorders in Infancy, Childhood and Adolescence: A Clinician's Approach", recognized as the standard reference in the field.

KRIS ENGELSTAD, MS, CGC **Columbia University Medical Center**



Kristin Engelstad MS CGC is a Genetic Counselor and Study Coordinator in the department of Neurology at Columbia University in New York City. She has interacted with Glut1 families for over 10 years. She coordinates several Natural History Studies and Clinical Trials in mitochondrial disorders and as well as for Glut1 Deficiency Syndrome. She is also involved with a patient contact registry and biobank for mitochondrial disorders. Her areas of expertise in genetic counseling include: pediatric neuromuscular disorders, Glut1 Deficiency Syndrome, and mitochondrial disorders.

ANA HERNANDEZ, MS, CBIS

Children's Medical Center of Dallas



Ana Hernandez earned her Master's in Clinical Psychology in 2003 from Barry University in Miami Shores, Florida and became a Certified Brain Injury Specialist (CBIS) in 2011. She completed her internship at Children's Psychiatric Center in Miami, Florida where she worked with children, adolescents, and families in a variety of contexts including individual and group therapy, as well as psychological testing. She joined Children's Medical Center in 2007 as an Assessment Specialist in the Perot Family Center for the Care of Brain and Nerve Injuries, a clinical research program for children with brain and nerve injuries. She presently works within Neuropsychology conducting neurobehavioral testing for research looking at a variety of conditions that affect neuropsychological functioning and neurodevelopment, such as pediatric traumatic brain injury, extreme prematurity, low birth weight, pediatric cardiac arrest, and rare brain disorders.

PROF. DR. JÖRG KLEPPER

Aschaffenburg Children's Hospital (Germany)



TRAINING:

- Medical Degree
Frankfurt and Würzburg University, Germany
- Paediatric Training
Würzburg und Essen University, Germany
- Postdoc Fellowship
Columbia University,
New York, USA

- Consultant for Paediatric Neurology
Essen University, Germany
- Lecturer for Paediatrics
Essen University, Würzburg University

POSITION:

- Medical Director of Aschaffenburg Childrens' Hospital,
Aschaffenburg, Germany

FIELDS OF CLINICAL AND RESEARCH INTEREST:

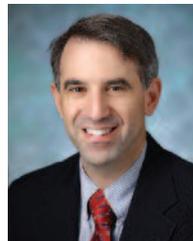
Disorders of brain energy metabolism such as Glut1 Deficiency or pyruvate dehydrogenase deficiency. Both disorders are associated with intractable epilepsy and respond to the ketogenic diet. Research interests are mechanisms and adverse effects of the diet, as well as establishing international protocols for the use of the diet in epilepsy and metabolic disorders.

MEMBERSHIPS:

- German Paediatric Society (DGKN)
- Neuropaediatric Society
(GNP; German-speaking countries; board member)

ERIC KOSSOFF, MD

Johns Hopkins Hospital



Dr. Kossoff is a Professor of Neurology and Pediatrics at Johns Hopkins University in Baltimore, MD. He received his medical degree from SUNY at Buffalo School of Medicine in New York, followed by a residency in pediatrics at Eastern Virginia Medical School in Norfolk, Virginia. He completed a fellowship in child neurology and then pediatric epilepsy and clinical neurophysiology at The Johns Hopkins Hospital in Baltimore. He has been at Johns Hopkins since 1998.

His research and clinical practice focuses on the diagnosis and treatment of childhood seizures and epilepsy, particularly treatments other than medications such as diet, neurostimulation and surgery. He is a world expert on the ketogenic diet and created the modified Atkins diet for children and adults in 2003. He is dedicated to bringing the use of diet therapies for neurologic disorders to the entire world and is the head of a Task Force within the International League Against Epilepsy to help achieve this goal. He is a coauthor of *Ketogenic Diets: Treatments for Epilepsy and Other Disorders*. Dr. Kossoff is also published in the fields of Sturge-Weber syndrome, the interaction between migraine and epilepsy in children, infantile spasms, Doose syndrome, and benign rolandic epilepsy.

Dr. Kossoff is also very involved in teaching and mentorship and is the Director of the Pediatric Neurology Residency Program at Johns Hopkins.

CAROLINE LYNN, MSN RN CCRC

Glut1 Deficiency Parent



Caroline holds a Master's degree in Nursing with many years of experience in pediatrics and emergency care. She currently works as a clinical research coordinator at Indiana University Health Methodist Research Institute in Indianapolis, Indiana. She is the mother of seven children ages 19-32. Her daughter Meredith, age 21, was diagnosed with Glut1 Deficiency in 2012 at the age of 18.

DAWN MARTENZ

KetoCook.com



Dawn is an Air Force wife and a mother of two, currently residing in Washington, DC. Her daughter, Charlotte, was diagnosed with Dravet's Syndrome in 2007 and was subsequently started on the Ketogenic Diet in June 2010. Since starting the diet, Dawn worked tirelessly to fine tune its performance for optimal seizure control for Charlotte. In 2011,

Dawn collaborated with Laura Cramp, RD from Children's National Medical Center in Washing D.C. to write "The Keto Cookbook", the first book dedicated entirely to Ketogenic recipes at the 4:1 ratio. Dawn innovated new, flavorful, and aesthetically pleasing Ketogenic recipes to improve the palatability of the diet while maintaining overall compliance and diet adherence. Following the success of the book, www.ketocook.com was created as a means to continue sharing recipes with families worldwide. Currently, Dawn is partnered with The Charlie Foundation to continue providing high quality,

dietitian-approved recipes for all types of Ketogenic diets. She regularly attends conferences and offers ketogenic cooking demonstrations. She also recently authored a second cookbook, "The Modified Keto Cookbook", dedicated to 2:1 ratio ketogenic recipes. She is dedicated to creating enjoyable, reliable recipes and to help others achieve success with ketogenic diet therapies.

JUAN PASCUAL, MD, PHD **University of Texas Southwestern Medical Center,** **Children's Medical Center of Dallas**



Juan M. Pascual is the inaugural holder of The Once Upon a Time Foundation Professorship in Pediatric Neurologic Diseases. He is a tenured faculty member in four Departments at The University of Texas Southwestern Medical Center at Dallas: Neurology and Neurotherapeutics, Physiology, Pediatrics and the Eugene McDermott Center for Human Growth & Development / Center for Human Genetics, and is Director of the Rare Brain Disorders Program (Clinic and Laboratory). He is also a member of the Division of Pediatric Neurology, of the graduate Ph.D. programs in Neuroscience and Integrative Biology, and of the postgraduate clinical training programs in Neurology, Pediatric Neurology, Pediatrics and Medical Genetics. He also teaches at the UT Southwestern Medical School.

In addition, Dr. Pascual is an adjunct professor in the Department of Biological Sciences at the School of Natural Sciences and Mathematics, The University of Texas at Dallas. Dr. Pascual directs a highly collaborative research laboratory and is credentialed campus-wide at Children's Medical Center Dallas, UT Southwestern University Hospitals and Clinics and Parkland Memorial Hospital, where he consults on inpatients and outpatients with particularly complex or severe diseases. Much of his research is funded by the National Institutes of Health.

Dr. Pascual received his M.D. degree from the Universidad de Granada, Spain (founded in 1531 by Emperor Charles V). He received his Ph.D. degree in Molecular Physiology and Biophysics from Baylor College of Medicine in Houston, Texas. His postdoctoral research was conducted at the Center for Molecular Recognition, College of Physicians and Surgeons of Columbia University and at the Colleen Giblin Research Laboratories for Pediatric Neurology at the same institution under a Neurological Sciences Academic Development Award from the National Institute of Neurological Disorders and Stroke. He also received residency training in Pediatrics at Washington University School of Medicine - St. Louis Children's Hospital and in Neurology and Pediatric Neurology at the Neurological Institute of New York - Columbia University Medical Center. He received certification in Neurology with Special Qualification in Child Neurology from the American Board of Psychiatry and Neurology.

As one of few actively practicing pediatric neurologists in the nation who is also a laboratory scientist, Dr. Pascual is interested in the molecular mechanisms that cause inherited metabolic and excitability disorders using electrophysiology and nuclear magnetic resonance (MRI) both in human subjects and in models of human diseases. His laboratory is located in the newest biomedical research building (NL) at UT Southwestern and is an integral part of the Department of Neurology and Neurotherapeutics. The laboratory is home to scientists from very broad backgrounds and levels of training and expertise who have joined efforts to endow both pediatric neurology and human developmental neuroscience with a strong scientific basis.

As a clinician, Dr. Pascual specializes in genetic and metabolic diseases of the nervous and neuromuscular systems of infants, children and adults with a particular emphasis on complex diagnostic problems, second opinions for patients visiting from the rest of the U.S. and abroad, and in clinical trials. Dr. Pascual has special clinical research expertise in rare diseases, glucose metabolism, mitochondrial, degenerative, and multi-organ disorders.

Dr. Pascual has co-authored over two dozen scientific, medical and philosophical textbooks. He is the editor, together with Dr. Roger Rosenberg of Rosenberg's Molecular and Genetic Basis of Neurological and Psychiatric Disease (5th edition, Academic Press, 2015). He is now writing his new textbook Progressive and Degenerative Brain Disorders in Children (Cambridge University Press).

Dr. Pascual has no interest in – nor is he sponsored by – any business that conducts medical research or lobbies for financial gain.

CHEF NEIL PALLISER-BOSOMWORTH **Nutricia/KetoCal**



Neil Palliser-Bosomworth is an independent consultant Chef working exclusively with Nutricia Medical. He is a specialized medical diet chef in ketogenic, diabetic, and gluten-free diets as well as specialty diets for PKU and Dysphagia. Previously he worked for many years in a number of NHS hospitals and as Head Chef at the Marie Curie Hospice and St. Oswalds Hospice in the UK. As a result, he has vast experience of catering for a diverse patient population and their specific medical needs. In 2001 he worked with Lloyd Grossman on the UK Better Hospital Food project to develop improved menus for hospital food throughout the UK. Neil spends the majority of his time working with Nutricia to train hospital and nursing home chefs how to cater for the needs of patients. Neil also does a lot of work with Nutricia Medical research and product development to ensure their new and existing products meet the highest standards of quality and safety for patients.

TONI PEARSON, MBBS **Icahn School of Medicine at Mt. Sinai Hospital**



Dr. Pearson is a child neurologist with specialty training in movement disorders. A native of Australia, she obtained her medical degree from the University of Adelaide and trained in pediatrics in Australia and Canada. She then completed a Child Neurology residency and Movement Disorders fellowship at Columbia University Medical Center in New York.

Dr. Pearson evaluates and treats children with movement disorders, including dystonia, ataxia, and chorea. Her clinical research focuses on movement disorders in pediatric genetic and metabolic diseases.

RAFFAELE PILLA, PHARMD, PHD

**University of South Florida (USA),
University of Salerno (Italy),
Fatebenefratelli Hospital of Benevento (Italy)**



Raffaele Pilla, Pharm.D., Ph.D., Doctor Europaeus, received his Master's degree in Pharmacy at G. d'Annunzio University in Chieti-Pescara, Italy in 2005, where he also served internships at the Cell Physiology Laboratory and Molecular Biology Laboratory. Prior to his degree, he was an Erasmus Student at Faculté de Pharmacie de Reims in Reims, France. He received his Doctor Europaeus in 2010 from Pitié-Salpêtrière Institute in Paris, France. Also in 2010, he received his Ph.D. in Biochemistry, Physiology, and Pathology of Muscle at G. d'Annunzio University in Chieti-Pescara, Italy. He was hired as a Postdoctoral Scholar in the Department of Pharmacology and Physiology at the University of South Florida in Tampa, on two research grants respectively funded by the Office of Naval Research (US Navy) and Divers' Alert Network. He has written and lectured widely on his experiences. Dr. Pilla has been involved in ongoing research at the University of South Florida with the use of ketone esters. The initial work, funded by the Office of Naval Research, focused on using ketone esters to prevent CNS oxygen toxicity. Dr. Pilla is working to coordinate efforts in the United States and Italy to expand the ketone ester research to other conditions such as epilepsy and cancer and its use as an alternative metabolic fuel. Dr. Pilla has also served extensively in various international medical missions, orphan and homeless programs, emergency medicine rescue and training, and animal rescue and fostering. He is fluent in Italian, English, French, and Spanish. He has a special interest in journalism and photography, and he enjoys sailing, SCUBA diving, ultralight airplane piloting, soccer, volleyball, jogging, and motorcycles.

PROFESSOR INGRID SCHEFFER, AO MBBS PHD FRACP FAHMS FAA

**Professor of Paediatric Neurology,
Florey Institute and the University of Melbourne**



- Chair of Paediatric Neurology Research, Departments of Medicine and Paediatrics, The University of Melbourne, Austin Health and Royal Children's Hospital, Melbourne
- Senior Principal Research Fellow, The Florey Institute of Neuroscience and Mental Health
- Director of Paediatrics, Austin Health, Melbourne, Australia

Professor Ingrid Scheffer is a physician-scientist whose work as a paediatric neurologist and epileptologist at the University of Melbourne and Florey Institute has led the field of epilepsy genetics over more than 20 years, in collaboration with Professor Samuel Berkovic and molecular geneticists. This resulted in identification of the first epilepsy gene and many more genes subsequently. Professor Scheffer has described many novel epilepsy syndromes and refines genotype-phenotype correlation. She recently led the first major reclassification of the epilepsies in two decades as Chair of the International League Against Epilepsy Commission for Classification and Terminology. She has received many awards: 2007 American Epilepsy Society Clinical Research Recognition Award, 2009 RACP

Eric Susman Prize, 2013 GSK Award for Research Excellence, ILAE Ambassador for Epilepsy Award, 2013 Australian Neuroscience Medallion, 2013 Emil Becker Prize for child neurology and the L'Oréal-UNESCO Women in Science Laureate for the Asia-Pacific region for 2012. In 2014, she was elected as a Fellow of the Australian Academy of Science and also Inaugural Vice-President of the newly formed Australian Academy of Health and Medical Sciences. She was awarded the Order of Australia in the Queens Birthday Honours List. Together with Professor Sam Berkovic, she was awarded the 2014 Prime Minister's Prize for Science for their work in the genetics of the epilepsies.

DARLA SIMS

Glut1 Deficiency Parent



Darla has been married for 32 years to Steve Sims and is the mother of son Craig, 30, and daughter Chelsea, 25. Chelsea was diagnosed in 1993 with Glut1 Deficiency at the age of 3.

Darla is the proud Mimi of two grandsons Cooper and Cohen, and lives in Midlothian, Texas with her family.

PETER STAVINOHAN, PHD

**University of Texas Southwestern Medical Center,
Children's Medical Center of Dallas**



Dr. Stavinoha is a licensed psychologist with specialized training and experience in neuropsychology with children and adolescents. He is board certified in Clinical Neuropsychology by the American Board of Professional Psychology and American Board of Clinical Neuropsychology. He directs the neuropsychology service at Children's Medical Center of Dallas, and he is a Professor of Psychology/Psychiatry at the University of Texas Southwestern Medical School.

Dr. Stavinoha has extensive training and experience evaluating the neurocognitive, educational, social, and emotional aspects of a variety of developmental disabilities, learning issues, disruptive behavior disorders, brain injuries, and other neurological conditions.

Dr. Stavinoha was named Distinguished Psychologist for 2005 by the Dallas Psychological Association. He has lectured extensively on topics including ADHD, dyslexia, learning disabilities, autism and pervasive developmental disorder, traumatic brain injury, the effects of childhood cancer on learning and behavior, the effects of epilepsy on learning and behavior, brain development in children, and general parenting. Dr. Stavinoha is a member of the American Psychological Association, the International Neuropsychological Society, the American Academy of Clinical Neuropsychology, and the Texas Psychological Association.