



**PAME Conference 2014
Session & Moderator Introductions**

FRIDAY JUNE 20, 2014

WELCOME & INTRODUCTION

Jeff

Gardiner

Gardiner to Introduce Bill and Jeanine Atwell

Story of a Loved One:

Bill and Janine Atwell lost their daughter Stephanie to SUDEP while she was studying in Europe. Stephanie had been a volunteer for EFMN and now Bill and Janine are involved and speak publicly about their loss to educate others about SUDEP. Thank you Bill and Janine for being here with us and sharing your personal story.

PLENARY SESSION I: Overview of Mortality in Epilepsy including SUDEP

Larry Hirsch to Introduce David Thurman

MODERATOR:

David Thurman, M.D., M.P.H.

Dr. David Thurman is an Adjunct Professor of Neurology with the Emory University School of Medicine. For 20 years, he served with the U.S. Centers for Disease Control and Prevention (CDC), and there directed its research program on the epidemiology of epilepsy. He has degrees in sociology and medicine from the University of Utah, a master of public health degree from Harvard University, and is board certified in both neurology and preventive medicine. He is a Fellow of the American Academy of Neurology, and currently serves as chair of the Epidemiology Commission of the International League Against Epilepsy.

PANELISTS:

Allen Hauser, M.D.

Dr Hauser is an Emeritus Professor of Neurology and Epidemiology at Columbia University. His main research interest has been the Epidemiology of Epilepsy and has authored many of the seminal papers in this field. He has had a long standing interest in prognosis in people with seizures and epilepsy and has conducted a number of studies of mortality. This includes studies of general mortality, cause specific mortality including cardiac deaths, mortality in status epilepticus, and SUDEP.

Roland Thijs, M.D., Ph.D.

Dr. Roland Thijs is a neurologist at the epilepsy institute SEIN-Stichting Epilepsie Instellingen Nederland, Heemstede and Leiden University Medical Centre, Leiden, the Netherlands. His main research interests include syncope and the role of the autonomic nervous system in the pathophysiology of sudden unexplained death in epilepsy (SUDEP). Thijs has authored over 50

publications and he is a member of PRISM – the Prevention and Risk Identification of SUDEP Mortality Consortium.

Dale Hesdorffer, Ph.D.

Dale Hesdorffer, Professor at CUMC in the Sergievsky Center at Columbia University, serves on several editorial boards, the professional advisory board of the Epilepsy Foundation of America, the American Epilepsy Society Task Force on psychiatric aspects of epilepsy, the American Academy of Neurology SUDEP guidelines workgroup, and is an associate editor of *Epilepsia*. She was a member of the Institute of Medicine Committee on the Public Health Dimensions of the Epilepsies and the IOM Committee on Gulf War and Health: Long-Term Consequences of Traumatic Brain Injury. Her work focuses on the epidemiology of epilepsy and most recently, risk factors for mortality related to epilepsy.

PLENARY SESSION II: SUDEP Mechanisms: Respiratory

Jeff B to Introduce George Richerson and Lisa Bateman

MODERATORS:

George Richerson, M.D., Ph.D.

Dr. George Richerson, is Professor & Chairman of Neurology, and The Roy J. Carver Chair in Neuroscience at the University of Iowa. He received a BS in Aerospace Engineering from Iowa State University in 1980, and an MD and PhD in Physiology & Biophysics from the University of Iowa in 1987. He did his Neurology Residency at Yale University, and was a faculty member at Yale for 19 years, including becoming Professor of Neurology, and Neurology Residency Program Director for 15 years. He moved to the University of Iowa in 2010 to become Chairman. Dr. Richerson performs research in mice on serotonin neurons and control of breathing, and has shown that they cause wakefulness in response to an increase in blood CO₂ levels.

Lisa Bateman, M.D.

Dr. Lisa M. Bateman is an Associate Professor of Neurology at Columbia University Medical Center. Her clinical practice involves the care of adults with complex epilepsies and her research focuses on peri-ictal changes in cardiorespiratory function and how these relate to SUDEP. She is a member of the American Epilepsy Society's SUDEP Task Force and the Advisory Committees of both the North American SUDEP Registry and the Sudden Death in the Young Registry.

PANELISTS:

Daniel Mulkey, Ph.D.

Dr. Mulkey is Associate Professor in the Dept. of Physiology and Neurobiology at the University of Connecticut. His research is centered on understanding the electrophysiological characteristics of mammalian neurons in brainstem regions associated with respiratory control. Among other things, he is currently using a combination of slice-patch electrophysiology, fluorescent imaging and genetic approaches to identify ion channels that regulate activity and neurotransmitter modulation of respiratory chemoreceptors.

Detlev Boison, Ph.D.

Dr. Boison is the Director of Basic and Translational Research at the Legacy Research Institute in Portland, Oregon. He is interested in the premise that disruption of homeostatic network functions, and in particular the contribution of dysregulated glia and maladaptive changes in adenosine homeostasis, play fundamental roles in neurological conditions.

Hua-Jun Feng, M.D., Ph.D. (Abstract presenter)

Dr. Feng is a Harvard Medical School Instructor and an Assistant in Pharmacology at Massachusetts General Hospital. His research areas of interest include: molecular mechanism for general anesthetics, GABA_A receptor function and pharmacology, and mechanisms and treatment of epilepsy and seizures.

PLENARY SESSION III: Epilepsy Mortality Surveillance and Provider Guidelines

Larry Hirsch to Introduce Orrin Devinsky

MODERATOR:

Orrin Devinsky, M.D.

Dr. Orrin Devinsky is a Professor of Neurology, Neurosurgery, and Psychiatry at NYU School of Medicine. He directs the NYU and the Saint Barnabas Institute of Neurology and Neurosurgery (INN). His epilepsy research interests include: SUDEP, translational therapies, phenome-genome correlations, autism, neural markers and imaging, therapeutic electrical stimulation, quality-of-life, cognitive and behavioral issues, and surgical therapy.

STORY OF A LOVED ONE:

Amy Haugen -- Amy is an EF MN staff member. Her daughter Jess suffered from severe epilepsy and died when she was just 3. Amy now works to educate others about epilepsy and SUDEP. Thank you Amy for all the work that you do for epilepsy and SUDEP awareness and for being with us here today to share your story.

PANELISTS:

Lindsey Thomas, M.D.

Dr. Lindsey Thomas is a board certified forensic pathologist who has worked in medical examiner offices for almost 30 years. She is currently an Assistant Medical Examiner at the Hennepin County Medical Examiner's Office. Dr. Thomas is on the Executive Committee of the Board of Directors of the National Association of Medical Examiners, the Board of the Minnesota Coroners' and Medical Examiners' Association and the Scientific Working Group on Medicolegal Death Investigation.

Vicky Whittemore, Ph.D.

Dr. Vicky Whittemore is a Program Director in the Synapses, Channels and Neural Circuits Cluster at the National Institutes of Neurological Disorders and Stroke. Her interest is in understanding the underlying mechanisms of the epilepsies including the study of genetic and animal models. Dr. Whittemore has also served as faculty at the University of Miami School of Medicine and has worked with several non-profit organizations including the Tuberous Sclerosis Alliance, and Citizens United for Research in Epilepsy (CURE).

Cynthia Harden, M.D.

Dr. Cynthia Harden is Professor of Neurology and Chief of Electroencephalography and Epilepsy at the Hofstra North Shore LIJ School of Medicine in Great Neck, NY. She had made scientific contributions in epilepsy in the areas of psychiatric issues, concerns for women, and new treatments for epilepsy. She is involved in developing evidence-based guidelines and is leading the development of guidelines on SUDEP occurrence and risk factors.

Cyndi Wright, B.A.

Cyndi Wright serves as the Director of the Epilepsy Foundation SUDEP Institute. In this role she coordinates with other leading epilepsy organizations and experts to drive awareness, education, research and support programs. She also serves on the planning committee for the PAME conference. Cyndi's commitment to SUDEP began when a dear friend lost their son to SUDEP and has strengthened over the years with the countless heartbreaking stories she has heard from families. Her nephew was also diagnosed with epilepsy.

PLENARY SESSION IV: SUDEP Mechanisms: Sleep & Arousal Systems

George to intro Gordon Buchanan and Hal Blumenfeld

MODERATORS:

Gordon Buchanan, MD, PhD

Dr. Gordon Buchanan is an Assistant Professor of Neurology at the Yale School of Medicine. Clinically he sees patients with a variety of neurologic problems, including sleep disorders and epilepsy. In his research he employs mouse models to understand mechanism by which seizures lead to respiratory dysfunction and death and specifically what role the neurotransmitter serotonin might play in this mechanism.

Hal Blumenfeld, M.D., Ph.D.

Dr. Hal Blumenfeld is Professor of Neurology, Neurobiology and Neurosurgery at Yale University School of Medicine. He is also an active clinical neurologist in the Yale Comprehensive Epilepsy Center, and is Director of the Yale Clinical Neuroscience Imaging Center. Dr. Blumenfeld's research focuses on the neural mechanisms of impaired network function in epilepsy, with consequences including impaired consciousness and impaired breathing in seizures. Research approaches include functional neuroimaging, electrophysiology, quantitative behavioral testing, optogenetics and therapeutic deep brain stimulation.

PANELISTS:

Brian Dlouhy, M.D.

Dr. Brian J. Dlouhy is an adult and pediatric neurosurgeon-scientist and currently a Fellow Physician in the Department of Neurosurgery at the University of Iowa. His research interests are focused on the function of the amygdala and the mechanisms of apnea during seizures using intracranial electrode recordings in humans.

Carl Faingold, Ph.D.

Dr. Carl Faingold is Distinguished Professor of Pharmacology, Neurology and Neurosurgery at Southern Illinois University School of Medicine in Springfield, IL. His research involves basic and translational studies in animal models of epilepsy, and most recently has been researching animal models of SUDEP. The goal of his research is to understand what neurochemicals in the brain may determine if SUDEP occurs in these models and to evaluate potential preventative treatments.

James Tao, M.D., Ph.D. (Abstract presenter)

Dr. James Tao is Associate Professor of Neurology and Director of the EEG lab at the University of Chicago. He specializes in the diagnosis and management of seizure disorders and epilepsy syndromes. He is also interested in the underlying mechanisms and prevention of SUDEP.

Gardiner to close the day - reminders for tomorrow



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SATURDAY JUNE 21, 2014

PLENARY SESSION V: Non-SUDEP Mortality in Epilepsy

Jeff B to give morning welcome and introduce Dale Hesdorffer (DALE WILL HAVE ALREADY BEEN INTRODUCED)

MODERATOR:

Dale Hesdorffer, Ph.D.

Dr. Dale Hesdorffer, is Professor at CUMC in the Sergievsky Center at Columbia University, and serves on several editorial boards, the professional advisory board of the Epilepsy Foundation of America, the American Epilepsy Society Task Force on psychiatric aspects of epilepsy, the American Academy of Neurology SUDEP guidelines workgroup, and is an associate editor of *Epilepsia*. She was a member of the Institute of Medicine Committee on the Public Health Dimensions of the Epilepsies and the IOM Committee on Gulf War and Health: Long-Term Consequences of Traumatic Brain Injury. Her work focuses on the epidemiology of epilepsy, most recently focusing on risk factors relating to causes of mortality in epilepsy.

STORY OF A LOVED ONE:

Ginny Miller's son had epilepsy and tragically and very sadly took his own life. Ginny, thank you for being here with us and sharing your story.

PANELISTS:

Nathalie Jette, M.D., FRCPC

Dr. Nathalie Jette is an Associate Professor in Neurology at the University of Calgary. Her research focuses on appropriateness of care, comorbidities and outcomes in epilepsy and other neurological conditions. She serves in many capacities, including President-Elect of the Canadian League Against Epilepsy, Chair of the International League Against Epilepsy (ILAE) Task Force on Stigma in Epilepsy, Chair of the ILAE Task Force on Epilepsy Guidelines, and Associate Editor of *Epilepsia*.

Daniel Friedman, M.D.

Dr. Dan Friedman is an Assistant Professor of Neurology and an adult epileptologist at the NYU Langone Comprehensive Epilepsy Center. His clinical interests include the surgical treatment of epilepsy. He also has active research interests in understanding epilepsy-related mortality, including prevention strategies, and methods to improve trials of epilepsy therapy. He is also a principle investigator for the North American SUDEP Registry. (NASR).

Scott Mintzer, M.D.

Dr. Scott Mintzer is Associate Professor of Neurology and Director of the Epilepsy Monitoring Unit at the Jefferson Comprehensive Epilepsy Center at Thomas Jefferson University. He is co-chair of the Neuropharmacology Special Interest Group of the AES and is a contributing editor to *Epilepsy Currents*. His major research interest is in the metabolic effects of antiepileptic drugs.

PLENARY SESSION VI: SUDEP Mechanisms: Autonomic & Cardiac

George to introduce Jeff Noebels and Jeff Britton

MODERATORS:

Jeffrey Noebels, M.D., Ph.D.

Dr. Jeffrey L. Noebels, holds the Cullen Chair in Neurogenetics, and is Professor of Neurology, Neuroscience, and Molecular and Human Genetics at Baylor College of Medicine in Houston, Texas. He is Director of the Developmental Neurogenetics Laboratory and the Epilepsy Research Center at Baylor. Dr Noebels' major research focus has been to identify genes that cause epilepsy and trace their cellular expression in the developing brain. He has recently focused on genes for SUDEP.

Jeffrey Britton, M.D.

Dr. Jeffrey Britton is Associate Professor in Neurology at the Mayo Clinic in Rochester, Minnesota with specialty training in Clinical Neurophysiology (CNP)-EEG and Epilepsy. He is the Epilepsy Fellowship Program Director and the EEG Program Co-Director of the CNP Fellowship at Mayo Clinic in Rochester, Minnesota. His clinical research involves peri-ictal physiology, including cardiopulmonary effects of seizures with implications for SUDEP.

PANELISTS:

Franck Kalume, Ph.D.

Dr. Franck Kalume is Assistant Professor in the Departments of Neurological Surgery and Pharmacology at the University of Washington. He is also a Principal Investigator with the Center of Integrative Brain Research (CIBR) at Seattle Children's Research Institute.

Lori Isom, Ph.D.

Dr. Lori Isom is Professor of Pharmacology and of Molecular and Integrative Physiology and Assist. Dean for Graduate Education at the Univ. of MI Medical School. Dr. Isom's research program focuses on voltage-gated Na⁺ channel structure, function, and role in inherited disease, especially Dravet Syndrome (DS) with SUDEP.

Rainer Surges, M.D.

Dr. Rainer Surges is the consultant neurologist at the Department of Epileptology in Bonn (Germany). He has a particular interest in cardiorespiratory function in people with chronic epilepsy. His working group has recently described abnormal cardiac repolarization possibly linking generalized seizures with SUDEP and examined the pathophysiologic role of postictal EEG depression in SUDEP.

Yi-Chen Lai, M.D. (Abstract presenter)

Dr. Yi-Chen Lai is Assistant Professor in the Section of Pediatric Critical Care Medicine at Baylor College of Medicine. His research focuses on the cardiac changes as contributing factors to SUDEP in animal models of acquired epilepsy.

PLENARY SESSION VII: Epilepsy & Grief

Gardiner to introduce Jeanne Donalty

MODERATOR:

Jeanne Donalty

Jeanne Donalty is a former Board member of Citizens United for Research in Epilepsy (CURE). She joined CURE in 2003 after her son, Christopher, died from Sudden Unexpected Death in Epilepsy (SUDEP). During the past nine years, she has worked to increase public awareness and funding for SUDEP research.

STORY OF A LOVED ONE:

Lisa Riley– Lisa's son Jordan died a year ago November. He was a US Marine but was discharged because of his epilepsy. Lisa and her daughter produced a PSA about SUDEP along with Jordan's Marine buddies. Lisa has also spoken publicly for EFMN.

PANELISTS:

Andres Kanner, M.D.

Dr. Andres M. Kanner is Professor of Clinical Neurology at the University of Miami, Miller School of Medicine, Director of the Comprehensive Epilepsy Center and Head of the Epilepsy Section in the Department of Neurology. Dr. Kanner's research has focused on psychiatric pharmacologic and surgical aspects of treatment-resistant epilepsy.

Linda Coughlin Brooks, RN, B.S.N., CT

Linda Coughlin is bereavement care provider and certified grief counselor. She has a private Practice in CO helping families struggling with grief & loss. Linda lost her 17 year old daughter Carei to SUDEP in 1997.

Paul Scribner, M.S.W., L.C.S.W.- C.

Paul Scribner is Senior Director of Information Services at the Epilepsy Foundation's National Office. He holds a Masters Degree in social work and in his current role he oversees operation of the Foundation's Epilepsy & Seizures 24/7 Helpline, the Foundation's online store, and a national health literacy initiative.

PLENARY SESSION VIII: SUDEP Mechanisms: Genetics

George to Introduce Dan Lowenstein and Alica Goldman

MODERATORS:

Alica Goldman, M.D., Ph.D.

Dr. Alica Goldman specializes in the treatment of patients with epilepsy and has a focus on SUDEP. As part of her work with Dr. Jeff Noebels, she has helped to uncover the first SUDEP risk gene, the KCNQ1 ion channel. She also focuses on human translational research of SUDEP genetics and has established a SUDEP Tissue Donation Program. Epilepsy genetics, genetic testing, and its clinical utility, as applied in SUDEP, are her overarching clinical and research interests.

Daniel Lowenstein, M.D.

Dr. Dan Lowenstein is the Robert B. and Ellinor Aird Professor and Vice-Chairman of Neurology, Director of the Epilepsy Center, and Director of Physician-Scientist Education and Training at the University CSF. Dr. Lowenstein is a clinician-scientist who has studied both basic science and clinical aspects of epilepsy. He has been actively involved in advancing the cause of epilepsy at the national and international level, and has held leadership posts in numerous organizations, including the American Epilepsy Society, the International League Against Epilepsy, and NINDS.

PANELISTS:**Jeffrey Noebels, M.D., Ph.D. (JEFF WILL HAVE ALREADY BEEN INTRODUCED)**

Dr. Jeff Noebels holds the Cullen Chair in Neurogenetics, and is Professor of Neurology, Neuroscience, and Molecular and Human Genetics at Baylor College of Medicine. He is Director of the Developmental Neurogenetics Laboratory and the Epilepsy Research Center at Baylor. Dr Noebels' major research focus has been to identify genes that cause epilepsy and trace their cellular expression in the developing brain. He has recently focused on genes for SUDEP.

Miriam Meisler, Ph.D.

Dr. Miriam Meisler, is Professor of Human Genetics and Neurology at University of Michigan. Her lab uses classical and molecular genetics and functional studies to investigate inherited neurological disease related to defective phosphoinositol metabolism and sodium channel activity.

Srinivasa Prasad Kommajosyula (Abstract presenter)

Srinivasa Prasad Kommajosyula is a graduate student in Dr. Faingold's lab, SIU School of Medicine, IL. Her work centers on the physiopathology for SUDEP and the role of brainstem nuclei in a SUDEP model.

PLENARY SESSION IX: How Organizations are Promoting Understanding of Epilepsy Mortality
Cyndi & Jeff



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SUNDAY JUNE 22, 2014

PLENARY SESSION X: SUDEP – Devices, Treatment & Prevention

Jeff B to Introduce Elizabeth Donner

MODERATOR:

Elizabeth Donner, M.D., FRCP(C)

Dr. Elizabeth Donner is an Associate Professor at University of Toronto and Pediatric Neurologist at the Hospital for Sick Children in Toronto. Dr. Donner has been involved in a variety of outreach and community-based epilepsy initiatives. She is the Secretary-Treasurer of the Canadian League Against Epilepsy and chair of the American Epilepsy Society SUDEP Task Force. In 2010, Dr. Donner received a HOPE award from Epilepsy Toronto in appreciation of her outstanding contribution to the epilepsy community. Recognizing the need for increased awareness of SUDEP among health care providers and people with epilepsy and support for those affected by SUDEP, Dr. Donner co-founded SUDEP Aware, a volunteer-run, non-profit organization in 2008.

STORY OF A LOVED ONE:

Dennis & Kari Knapp: Dennis & Kari's son Jake died 5 years ago while in college in Chicago. Like so many parents here, they too had never heard of SUDEP. Thank you Dennis and Kari for being with us and sharing your story.

PANELISTS:

Lisa Bateman, M.D. (LISA WILL HAVE ALREADY BEEN INTRODUCED)

Dr. Lisa Bateman is an Associate Professor of Neurology at Columbia University Medical Center. Her clinical practice involves the care of adults with complex epilepsies and her research focuses on peri-ictal changes in cardiorespiratory function and how these relate to SUDEP. She is a member of the American Epilepsy Society's SUDEP Task Force and the Advisory Committees of both the North American SUDEP Registry and the Sudden Death in the Young Registry.

Daniel Friedman, M.D. (DAN WILL HAVE ALREADY BEEN INTRODUCED)

Dr. Dan Friedman is an Assistant Professor of Neurology and an adult epileptologist at the NYU Langone Comprehensive Epilepsy Center. His clinical interests include the surgical treatment of epilepsy. He also has active research interests in understanding epilepsy-related mortality, including prevention strategies, and methods to improve trials of epilepsy therapy. He is a principle investigator for the North American SUDEP Registry.

Tom Stanton

Tom Stanton is the Executive Director of the Danny Did Foundation, an organization that was founded in the memory of his nephew, Danny, to create awareness of epilepsy and SUDEP. He is grateful to work with the Danny Did Foundation to help individuals and families who cope with seizures. Tom's experience focuses on the nonprofit and communication fields.

Martha Sajatovic, M.D.

Dr. Sajatovic is Professor of Psychiatry and Neurology at Case Western Reserve University School of Medicine in Cleveland, Ohio. She is a researcher, educator, and clinician who has devoted herself to the study and treatment of traditionally hard-to treat populations with central nervous system (CNS) disorders. Dr. Sajatovic's research interests have focused on health outcomes in mental illness and in a variety of neurological conditions including epilepsy and stroke.

Tanya Spruill, Ph.D.

Dr. Spruill is an Assistant Professor of Population Health and Medicine at NYU School of Medicine. She is a clinical psychologist with expertise in behavioral medicine and behavioral clinical trials. She is currently studying interventions to improve quality of life, medication adherence and other health behaviors, and disease-specific health outcomes in patients with epilepsy, stroke, hypertension, diabetes and rheumatoid arthritis.

Senay Imam, M.S. (Abstract presenter)

Senay Imam is a PhD student in the department of Mechanical Engineering at Texas Tech and holds a Master's degree in Industrial and Systems Engineering from Colorado State University.

Final Thoughts and Closing Remarks

Jeff B and Gardiner to close