December 4 - 8 ■ Philadelphia, PA
69TH ANNUAL MEETING

Annual Course
Epilepsy and the Media

Symposium Chair:

Eric Kossoff, M.D.

Sunday, December 6, 2015
Convention Center – Grand Ballroom AB

8:45 a.m. – 5:15 p.m.

Accreditation

The American Epilepsy Society is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

Credit Designation

Physicians

The American Epilepsy Society designates this live activity for a maximum of 30.75 *AMA PRA Category 1 Credits*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Physician Assistant

AAPA accepts certificates of participation for educational activities certified for *AMA PRA Category 1 Credit*™ from organizations accredited by ACCME or a recognized state medical society. Physician assistants may receive a maximum of 30.75 hours of Category 1 credit for completing this program.

Jointly provided by AKH Inc., Advancing Knowledge in Healthcare and the American Epilepsy Society.

Nursing

AKH Inc., Advancing Knowledge in Healthcare is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is awarded 30.75 contact hours.

Nurse Practitioners

AKH Inc., Advancing Knowledge in Healthcare is accredited by the American Association of Nurse Practitioners as an approved provider of nurse practitioner continuing education. Provider Number: 030803. This program is accredited for 30.75 contact hours which includes 8 hours of pharmacology. Program ID #21547

This program was planned in accordance with AANP CE Standards and Policies and AANP Commercial Support Standards.

Pharmacy

AKH Inc., Advancing Knowledge in Healthcare is accredited by the Accreditation Council for Pharmacy Education as a provider of continuing pharmacy education.

Select portions of this Annual Meeting are approved for pharmacy CE credit. Specific hours of credit for approved presentations and Universal Activity Numbers assigned to those presentations are found in the educational schedules. Criteria for success: nursing and pharmacy credit is based on program attendance and online completion of a program evaluation/assessment.

If you have any questions about this CE activity, please contact AKH Inc. at service@akhcme.com.

International Credits

The American Medical Association has determined that non-U.S. licensed physicians who participate in this CME activity are eligible for *AMA PRA Category 1 Credits*™.

CME/CE Certificates

For those attendees who wish to claim CME or CE, there is an additional fee. Registrants can pay this fee as part of the registration process. Those who do not pre-purchase the credit will also have the ability to pay this fee at the time they attempt to claim credit. Fees for CME increase after January 16 and are a one-time charge per annual meeting.

The evaluation system will remain open through Friday, February 26, 2016. Evaluations must be completed by this date in order to record and receive your CME/CE certificate.

Member Fees:	$50 through January 15, 2016 $75 January 16 – February 26, 2016
Non-member Fees:	$75 through January 15, 2016 $100 January 16 – February 26, 2016

Attendance Certificate/International Attendees

A meeting attendance certificate will be available at the registration desk for international meeting attendees on Tuesday, December 8.

Policy on Commercial Support and Conflict of Interest

The AES maintains a policy on the use of commercial support, which assures that all educational activities sponsored by the AES provide in-depth presentations that are fair, balanced, independent and scientifically rigorous. All faculty, planning committee members, moderators, panel members, editors, and other individuals who are in a position to control content are required to disclose relevant relationships with commercial interests whose products relate to the content of the educational activity. All educational materials are reviewed for fair balance, scientific objectivity and levels of evidence. Disclosure of these relationships to the learners will be made through syllabus materials and the meeting app.

Disclosure of Unlabeled/Unapproved Uses

This educational program may include references to the use of products for indications not approved by the FDA. Faculty have been instructed to disclose to the learners when discussing the off-label, experimental or investigational use of a product. Opinions expressed with regard to unapproved uses of products are solely those of the faculty and are not endorsed by the AES.

OVERVIEW

This year's Annual Course will focus on the complex relationship between patients with epilepsy, their treating neurologists and other care providers, and the media. This topic is very timely in light of the growth and impact of the Internet and social media. The Annual Course will delve into detail about the way information is portrayed and communicated about epilepsy through the media. Rather than the usual case vignettes, vignettes will focus on the common interactions over the course of a working day between an epileptologist and patients, families and caregivers focused on media-provided information. Didactic lectures and debates will be combined with illustrative examples, interspersed before breaks. Topics will include seizure detection (dogs and devices), driving rules, cannabadiols and SUDEP.

LEARNING OBJECTIVES

Following participation in this symposium, learners should be able to:

- Recognize the complex relationship between physicians and the media in regards to epilepsy and has an improved ability to be interviewed, answer patient questions about media reports and effectively respond to media-generated debates about topics such as seizure detection devices, SUDEP, driving restrictions, cannabadiols and epilepsy stimulation techniques
- Answer patient/care giver questions about media reports related to epilepsy care including discussions of seizure detection devices, SUDEP, driving restrictions, cannabadiols, and epilepsy stimulation techniques
- Become aware of the issues related to controlled substances, black box warnings and teratogenicity as well as the evidence for and against utilization of cannabadiol for epilepsy treatment
- Be aware of the impact of media reports on patient decision-making on topics such as new detection devices, driving and therapies. Learner utilizes resources provided by patient advocacy support groups to assist in addressing psychological functioning of patients

TARGET AUDIENCE

Basic: Those new to epilepsy treatment or whose background in the specialty is limited, e.g., students, residents, general physicians, general neurologists and neurosurgeons, other professionals in epilepsy care, administrators.

Intermediate: Epilepsy fellows, epileptologists, epilepsy neurosurgeons, and other providers with experience in epilepsy care (e.g., advanced practice nurses, nurses, physician assistants), neuropsychologists, psychiatrists, basic and translational researchers.

Advanced: Address highly technical or complex topics (e.g., neurophysiology, advanced imaging techniques or advanced treatment modalities, including surgery.)

Agenda

Chair: Eric Kossoff, M.D.

Diagnostic Issues and the Media

8:45 a.m.	Introduction: The Complex Interaction of Patients, Physicians and the Media	Eric Kossoff, M.D.
8:55 a.m.	"8:00 am: A Facebook Friend Request"	Akila Venkataraman
9:00 a.m.	Lecture: Should you Friend your Patients? Facebook and Social Media	Adam Hartman, M.D.
9:25 a.m.	Lecture: Epilepsy and the Internet	Patty Shafer, MN RN
9:50 a.m.	Debate: Dogs and Devices: Does Seizure Detection Work?	Elizabeth Donner, M.D. (Pro) & Gregory Krauss, M.D. (Con)
10:20 a.m.	BREAK	

10:35 a.m.	"Noon: A Seizure-related Crash on the News"	Kathryn Davis, M.D.
10:40 a.m.	FLASH PANEL: Advocacy Groups and Their Role with the Media	
	Advocacy Groups and Their Role with the Media	Phil Gattone, M.Ed.
	Epilepsy Foundation	Susan Axelrod
	CURE	Christina SanInocencio, M.S
	Lennox Gastaut Syndrome Foundation	Pat Gibson, MSSW
	Epilepsy Information Service	
11:20 a.m.	Lecture: SUDEP and Media Resources	Lisa Bateman, M.D.
11:35 a.m.	Lecture: Driving Accidents in the News, What is our Role with the MVA?	Allan Krumholz, M.D.
11:50 a.m.	Morning wrap-up	Eric Kossoff, M.D.

Treatment Innovations and the media

2:00 p.m.	Introduction to the afternoon session	Eric Kossoff, M.D.
2:05 p.m.	"5pm: CNN Interview about surgery alternatives"	Lara Jehi, M.D.
2:10 p.m.	Lecture: Doing Media interviews: AES policy and advice	William Theodore, M.D.
2:30 p.m.	Lecture: RNS, VNS, DBS, oh my!	Christianne Heck, M.D.
2:55 p.m.	Debate: Laser Surgery is the Best Option	Dan Curry, M.D. (Pro) & Kristen Reily, M.D.(Con)
3:40 p.m.	"9pm: A Cocktail Hour Question about Cannabis"	Kelly Knupp, M.D.
3:45 p.m.	Lecture: Getting Your Message to the Public: How to Navigate the World of Reporters and Lawyers	Robert Field, Ph.D., JD
4:05 p.m.	Lecture: Epilepsy journals and free access for patients: A Good Idea?	Steven Schachter, M.D.
4:25 p.m.	Debate: Cannabadiol: Helpful or Just Reefer Madness?	Elizabeth Thiele, M.D., Ph.D. (Pro) & Eric Marsh, M.D., Ph.D. (Con)
4:55 p.m.	Conclusions	Eric Kossoff, M.D.

Education Credit
6.0 CME Credits

Nurses may claim up to 6.0 contact hours for this session.

Pharmacy Credit
AKH Inc., Advancing Knowledge in Healthcare approves this knowledge-based activity for 6.0 contact hours (0.6 CEUs). UAN 0077-9999-15-028-L01-P. Initial Release Date: 12/6/2015.

The American Board of Psychiatry and Neurology has reviewed the Annual Course Epilepsy and the Media and has approved this program as part of a comprehensive program, which is mandated by the ABMS as a necessary component of maintenance of certification.

Commercial Support Acknowledgement
Supported in part by an educational grant from GW Pharmaceuticals.

FACULTY/PLANNER DISCLOSURES
It is the policy of the AES to make disclosures of financial relationships of faculty, planners and staff involved in the development of educational content transparent to learners. All faculty participating in continuing medical education activities are expected to disclose to the program audience (1) any real or apparent conflict(s) of interest related to the content of their presentation and (2) discussions of unlabeled or unapproved uses of drugs or medical devices. AES carefully reviews reported conflicts of interest (COI) and resolves those conflicts by having an independent reviewer from the Council on

Education validate the content of all presentations for fair balance, scientific objectivity, and the absence of commercial bias. The American Epilepsy Society adheres to the ACCME's Essential Areas and Elements regarding industry support of continuing medical education; disclosure by faculty of commercial relationships, if any, and discussions of unlabeled or unapproved uses will be made.

FACULTY / PLANNER BIO AND DISCLOSURES

Eric Kossoff, M.D. (Chair)

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. 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. Dr. Kossoff is also the Director of the Pediatric Neurology Residency Program.

Dr. Kossoff discloses receiving support for Royalties from UpToDate; Demos Medical Publishing.; for Consulting from DSMB - GW and Lundbeck. Scientific Advisory Boards - Nutricia and Atkins Nutritionals.; for Contract Research from Nutricia, Vitaflo (to Institution); as Service from Epilepsy Foundation, Charlie Foundation, GLUT1 Deficiency Foundation.

Susan Axelrod

Susan Axelrod is Founding Chair of CURE (Citizens United for Research in Epilepsy). Susan's daughter, Lauren, was born in 1981 and, at the age of seven months, was diagnosed with epilepsy. In 1998, Susan and a few other mothers---frustrated by their inability to protect their children from the severe impact of uncontrollable seizures on their children as well as the intolerable side effects of epilepsy medications--joined forces to spearhead the search for a cure for epilepsy. CURE has catalyzed the epilepsy research community to accelerate their research efforts, and has become the largest private funder of epilepsy research globally.

Ms. Axelrod has indicated she has no financial relationships with commercial interests to disclose.

Lisa Bateman, M.D.

Dr. Lisa M. Bateman is an Associate Professor of Neurology at Columbia University Medical Center. She received her medical degree from Dalhousie University, followed by a Neurology residency at the University of British Columbia and fellowships in Clinical Neurophysiology and Epilepsy/EEG at the University of California, San Francisco. Her clinical practice involves the care of adults with epilepsy and her research focuses on peri-ictal physiology and 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. She is also an investigator in the NINDS-funded Center for SUDEP Research.

Dr. Bateman discloses receiving support for Contract Research from Research support from Citizens United for Research in Epilepsy (CURE) - The Henry Lapham Memorial Award, "SUDEP Risk and Biomarkers in the Surgical Epilepsy Population".

Daniel Curry, M.D.

Baylor College of Medicine / Texas Children's Hospital
Associate Professor/Pediatric Neurosurgery
Director, Epilepsy Functional and Movement Disorders Program
MR-guided Stereotactic Laser Ablation in Epilepsy

Dr. Curry has indicated he has no financial relationships with commercial interests to disclose.

Kathryn Davis, M.D.
Dr. Kathryn Davis is an Assistant Professor of Neurology at the University of Pennsylvania. She is the medical director of the EMU and EEG Labs at Penn. Her research focuses utilizing both the advancing fields of invasive neurophysiology and neuroimaging to better localize epileptic networks in medication refractory epilepsy patients.

Dr. Davis discloses receiving support for Honoraria from Advisory Board, Lundbeck.

Elizabeth Donner, M.D., FRCP(C)
Dr. Elizabeth Donner is the Director of the Comprehensive Epilepsy Program at the Hospital for Sick Children in Toronto and an Associate Professor in the Faculty of Medicine at University of Toronto. She is a graduate of the University of Pennsylvania and McMaster University, and completed post graduate training The Hospital for Sick Children and Children's Hospital Boston. Dr. Donner is a leader in SUDEP advocacy, and co-founded SUDEP Aware in 2008. She is PI of the Canadian Pediatric SUDEP Registry, a member of the Executive of the North American SUDEP Registry, Chair of the AES SUDEP Task Force and a member of the Steering Committee of the Epilepsy Foundation SUDEP Institute.

Dr. Donner has indicated she has no financial relationships with commercial interests to disclose.

Robert Field, Ph.D., JD
Robert I. Field is professor of law at the Kline School of Law and professor of health management and policy at the Dornsife School of Public Health at Drexel University. He is also lecturer in health care management at the Wharton School of the University of Pennsylvania. He is author of numerous scholarly articles and two books on health policy: Mother of Invention: How the Government Created "Free-Market" Health Care and Health Care Regulation in America: Complexity, Confrontation and Compromise. He also writes a blog on health policy for the Philadelphia Inquirer called The Field Clinic. He earned a PhD in psychology from Boston
University, MPH from Harvard School of Public Health, and JD from Columbia Law School.

Dr. Field has indicated he has no financial relationships with commercial interests to disclose.

Philip Gattone, M.Ed.
Phil Gattone is the President and CEO of the Epilepsy Foundation. He came to the Foundation's national office from an affiliate, the Epilepsy Foundation of Greater Chicago, where he was the affiliate's President and CEO. He is currently on the International Executive Committee for the International Bureau for Epilepsy. Phil has a long personal history with the epilepsy community, which began when his son Philip, now 28, was diagnosed with epilepsy at the age of four. Since then, Phil has educated thousands of people about epilepsy and its impact on families. Phil received his bachelor's degree in marketing in 1981 from Bradley University in Peoria, Ill., and master's degree in education in 2000 from National Louis University in Chicago.

Mr. Gattone has indicated he has no financial relationships with commercial interests to disclose.

Patricia Gibson, M.S.S.W., ACSW
Ms. Gibson is Associate Professor and Director of the Epilepsy Information Service at Wake Forest University School of Medicine. She has served on the Scientific Committee as well as served as chair of a number of committees of the ILAE, She serves on the professional advisory board of the Tuberous Sclerosis Alliance and is acting volunteer director of the Epilepsy Foundation of North Carolina. Ms. Gibson has organized more than 60 national and international conferences on epilepsy.

Patricia Gibson, M.S.S.W., ACSW discloses receiving support for Consulting from Sunovion Advisory Board; for Honoraria from serving on the UCB scholarship committee.

Adam Hartman, M.D.
Dr. Adam Hartman received his MD from Northwestern University Medical School. After completing a residency in Pediatrics in the National Capital Uniformed Services Pediatric Residency Program, he served as a general pediatrician in the US Navy for five years (the last as division head of general pediatrics at Naval Medical Center San Diego). He completed his residency in pediatric neurology and a fellowship in clinical neurophysiology/pediatric epilepsy, both at Johns Hopkins. Now an Associate Professor at Johns Hopkins, Dr. Hartman focuses on treating children with medically intractable epilepsy. He has a K08 from NINDS to study metabolism-based antiseizure treatments.

Dr. Hartman discloses receiving support for Other Service from Wiley Publishing (Associate Editor for Epilepsia), from PAB, Abilities Network; PAB, Carson Harris Foundation; PAB, Hemispherectomy Foundation; National Conference and Exhibition Planning Group, American Academy of Pediatrics.

Christianne Heck, M.D., M.M.M.
Dr. Christi Heck is Professor of Clinical Neurology and Biomedical Engineering, Medical Director of the Comprehensive Epilepsy Program, and Co-Director of the USC Neurorestoration Center at the University of Southern California. Dr. Heck's research focuses on human brain machine interfaces applied to neurologic conditions including epilepsy, spinal cord injury, and memory dysfunction. She has worked for 20 years in the field of clinical epilepsy developing a multi-disciplinary approach to care for epilepsy patients at Keck Medical Center of USC and at the LAC+USC Medical Center, the largest public safety-net hospital in the region. Dr. Heck has served as the PI for clinical trials at USC in RNS, VNS and TNS for epilepsy.

Dr. Heck discloses receiving support for Contract Research from Associated Research funding as PI for Neuropace, Inc.; as Other Service from EF PAB Medical Director, USC Comprehensive Epilepsy Program.

Dr. Heck does intend to reference unlabeled/unapproved uses of drugs or products – DBS and TNS for epilepsy.

Lara Jehi, M.D.
Dr. Lara Jehi is an adult epileptologist, the head of the Outcomes Research Program, and the Director of Research at the Cleveland Clinic Epilepsy Center. Her interests have focused on understanding and improving outcomes of epilepsy treatment. She serves as the Associate Program Director of the Clinical Research Unit at Cleveland Clinic within the auspices of the NIH-funded Clinical and Translational Science Collaborative, is serving in leadership roles on many educational committees within the American Epilepsy Society and American Academy of Neurology, and is a reviewer for the Epilepsy Study Section at NIH. She has authored several original manuscripts, editorials and book chapters and spoke at multiple national and international meeting.

Dr. Jehi has indicated she has no financial relationships with commercial interests to disclose.

Kelly Knupp, M.D.
Kelly Knupp received her MD from the University of New Mexico - School of Medicine. She completed her residency in Pediatrics at Children's Hospital of New York followed by Pediatric Neurology Residency at Columbia University at Children's Hospital of New York. After her residency, she trained as a Clinical Fellow in Pediatric Epilepsy at the Columbia Comprehensive

Epilepsy Center at New York Presbyterian Hospital. Dr. Knupp now practices at Children's Hospital Colorado in Aurora, CO and is Associate Professor of Pediatrics and Neurology at the University of Colorado. She is the Director of the Dravet Program.

Gregory Krauss, M.D.
Professor of Neurology, Johns Hopkins University. Research in many areas of epilepsy, including driving crash risks, photosensitivity test models, new anticonvulsants, global medicine, Johns Hopkins Digital EEG Atlas, EpiWatch research app developer.

Dr. Krauss discloses receiving support for Consulting from Eisai: consulting on study results Accorda: consulting on study; as Other Service from PAB: Epilepsy of the Chesapeake

Allan Krumholz, M.D.
Dr. Allan Krumholz is professor of neurology at the University of Maryland Medical Center and School of Medicine. Dr. Krumholz was previously the director of the Maryland Epilepsy Center, and he is currently the director of the Veterans Affairs Northeast and Baltimore Epilepsy Center of Excellence. He was the 2009 recipient of the J. Kiffin Penry Award for Excellence in Epilepsy Care presented by the American Epilepsy Society. His clinical and research interests include psychological and social epilepsy issues in epilepsy care, and he has been particularly active in the area of driving and epilepsy.

Dr. Krunholz has indicated he has no financial relationships with commercial interests to disclose.

Eric Marsh, M.D., Ph.D.
Dr. Marsh is currently an Assistant Professor of Neurology and Pediatrics at the Perleman School of Medicine at the University of Pennsylvania and the Children's Hospital of Philadelphia. He obtained his MD, PhD from NYU school of medicine and completed his pediatrics training at NYU and Child Neurology training at Penn. He has been involved in the open access program studying CBD in intractable epilepsy as well as recently been a site PI for the GW pharma CBD trials.

Dr. Marsh discloses receiving support for Consulting from SBSE- advisory board meeting; for Contract Research from GW pharma- PI on expanded access program, local PI on GW sponsored phase 3 trials for Dravet and LGS; for Other Service from Advisory Board member for LGS foundation.

Dr. Marsh does intend to reference unlabeled/unapproved uses of drugs or products – CBD.

Kristen Riley, M.D., FACS
Dr. Riley is Associate Professor of Neurosurgery at the University of Alabama in Birmingham. She completed Neurosurgical training at UAB in 2004 and a fellowship in Epilepsy Surgery at Great Ormond Street, London, UK in 2004. Since that time she has directed the University of Alabama at Birmingham Adult Epilepsy Surgery program. In addition to Epilepsy surgery, she also focuses on brain tumor surgery and directs the Neurosurgical Pituitary Disorders Clinic with specialization in endoscopic skull base surgery.

Dr. Riley has indicated she has no financial relationships with commercial interests to disclose.

Christina SanInocencio, M.S.
Christina SanInocencio is the Executive Director of the Lennox-Gastaut Syndrome Foundation. She serves as a steering committee member on the Rare Epilepsy Network (REN), as a member of the AES Communications Council, and as a board member for the Epilepsy Leadership Council. She received her graduate degree in Media Studies from the City University of New York Brooklyn College and her undergraduate degree in Communications and Electronic Media from Long Island University.

She is currently enrolled in the Advanced Graduate Certificate Program in Health Communications at Stony Brook University. Her research interests include public health issues in epilepsy and rare diseases, the media and epilepsy, caregiver QOL, and transitioning.

MS. SanInocencio discloses receiving support for Consulting from Eisai, Lundbeck.

Steven Schachter, M.D.
Dr. Steven Schachter is Chief Academic Officer and Program Leader of NeuroTechnology at the Consortia for Improving Medicine with Innovation and Technology (CIMIT) and a Professor of Neurology at Harvard Medical School (HMS). He is Past President of the American Epilepsy Society. He is also past Chair of the Professional Advisory Board of the Epilepsy Foundation and currently serves on their Board of Directors. Dr. Schachter is the founding editor and editor-in-chief of Epilepsy & Behavior and Epilepsy & Behavior Case Reports. He has published over 200 articles and chapters, compiled the 6-volume Brainstorms series, and edited or written 30 other books on epilepsy and behavioral neurology.

Dr. Schachter discloses receiving support for Salary generating W2 from Compensated as Editor-in-Chief by Elsevier for Epilepsy & Behavior.; for Other Service from Board of Directors, Epilepsy Foundation.

Patricia Shafer, M.N., RN
Patricia Osborne Shafer, RN, MN, is an epilepsy clinical nurse specialist at the Comprehensive Epilepsy Center, Beth Israel Deaconess Medical Center in Boston, Massachusetts, and the associate editor and community manager of epilepsy.com for the Epilepsy Foundation. She has been involved in many national and international public policy and advocacy efforts and has held volunteer and leadership positions in the epilepsy and health care community. Her clinical and research interests include self-management education and technology in epilepsy, women's issues, patient safety, and treatment and consequences of refractory epilepsy.

Ms. Shafer discloses receiving support for Salary generating W2 from Epilepsy Foundation - associate editor of epilepsy.com which is a non-profit organization; for Consulting from Accorda Therapeutics Nursing Advisory.

William Theodore, M.D.
I am Chief, Clinical Epilepsy Section NINDS and Professor of Neurology at the Uniformed Services University of the Health Sciences. I have provided care to patients with epilepsy, at the NIH Clinical Center, National Naval Medical Center, and Walter Reade Army Medical Center, and performed clinical research in epilepsy since 1979. I worked with the Pan American Health Organization, World Health Organization and World Federation of Neurology on international projects and am Visiting Professor at the University of Zambia in Lusaka where I perform patient care and teaching. My research focuses on experimental trials, fMRI for language and memory mapping, PET neuroreceptor and inflammatory imaging as well as innovative drug trials.

Dr. Theodore discloses receiving support for Salary generating W2 from National Institutes of health; for Ownership (i.e. stocks, stock options or other ownership) from MCHFX, MAPTX, VFIAX, VWNFX, VTSMX, VEURX, VPACX, NUBVX, PRSVX, VWLTX, VIPSX, VGSLX, IBM, CSCO, HON, XOM, PG, SJM.; for Other Service from Federation for Advanced Education in the Sciences—Board.

Elizabeth Thiele, M.D., Ph.D.
Dr. Thiele is Director of the pediatric epilepsy program and Director of the Herscot Center for Tuberous Sclerosis Complex at the Massachusetts General Hospital and Professor of Neurology at Harvard Medical School. She received her MD and PhD from the Johns Hopkins University School and

Medicine, where she also completed 2 years of pediatric residency. She completed her child neurology and neurophysiology training at Boston Children's Hospital and the Longwood Neurology training program. She has been at the Massachusetts General Hospital since 2001. Her research interests include the role of dietary therapy in the treatment of epilepsy,tuberous sclerosis complex, Dravet syndrome and Lennox Gastaut syndrome.
Dr. Thiele discloses receiving support for Contract Research from GW Pharma – research grant for EAP, the site PI for Dravet and LGS RCTs

Dr. Thiele does intend to reference unlabeled/unapproved uses of drug or products – EAP data re GW Pharma epidiolex.

Akila Venkataraman, M.D.
Dr. Akila Venkataraman is the Director of Pediatric Neurology and Pediatric Epilepsy at the NYU Lutheran Medical Center in Brooklyn, NY. She has been a long standing active member of the Epilepsy community and serves on the Professional Advisory Board of the Epilepsy Foundation of Metropolitan New York.

Dr. Venkataraman has indicated she has no financial relationships with commercial interests to disclose.

CME Reviewers
Lauren Frey, M.D.
Dr. Frey specializes in the care of adults living with epilepsy. She has an outpatient clinic at the University of Colorado Hospital and is the Director of the Epilepsy Monitoring Unit and an active participant in the Epilepsy Surgery program there. Dr. Frey is also the Director of the Quantitative EEG (QEEG) Laboratory and the Neurofeedback Clinic at the University of Colorado Hospital. Dr. Frey's research interests include how mind-body and lifestyle interventions can affect seizure control and quality of life in people whose seizures are not completely controlled by seizure medications.

Dr Frey discloses receiving support for Ownership (i.e. stocks, stock options or other ownership) from stock in two health care companies (GlaxoSmithKline and Johnson and Johnson). I do not perform any work for these entities or have any contractual arrangement with them.; for Other Service (with or without compensation) from Professional Advisory Board member for the Epilepsy Foundation of Colorado.

Manu Hedge, M.D., Ph.D.
I am an Assistant Professor of Clinical Neurology at the University of California, San Francisco. I completed an MD and a PhD (Neuroscience) at UC Davis, and completed a neurology residency and clinical neurophysiology/epilepsy fellowship at UCSF thereafter. Currently, I serve as a clinical epileptologist at UCSF, as well as at the Epilepsy Center of Excellence at the San Francisco VA Medical Center. My primary research interest is the discovery of biomarkers in focal epilepsy. Toward this end, I serve as the site PI and chair of the peripheral biospecimens core for the Human Epilepsy Project, a large multi-center prospective observational study of people with newly diagnosed focal epilepsy.

Dr. Hegde discloses receiving support for Other Service for Attended a meeting to discuss CBD and epilepsy; All travel, food, and lodging expenses paid by Insys, but no other compensation provided

Jack Lin, M.D.
Dr. Jack Lin is an Associate Professor and the Director of the Comprehensive
Epilepsy Program at the University of California, Irvine. Using advanced neuroimaging techniques, his research has uncovered neurodevelopemental impacts of new-onet pediatric epilepsies, examined

brain network alterations associated with mood disorders in temporal lobe epilepsy, and delineated relationships between brain structural changes and cognitive deficits in a wide range of epilepsy syndromes. He serves as a a grant reviewer for the Epilepsy Foundation, an Ad hoc reviewer for many journals, a member of editorial board of Epilepsy and Behavior, member of several committees at the American Epilepsy Society

Dr. Lin discloses receiving support as Speakers Bureau from UCB and Sunovion Pharmaceuticals.

Juliann Paolicchi, M.D., M.A.
I have been honored to serve as an academic pediatric epileptologist, as Director of Pediatric Epilepsy at several institutions and as Director of Pediatric Neurology. I am currently a Clinical Professor of Pediatrics at Rutgers University, and developing a pediatric epilepsy program for a multidisciplinary epilepsy group. My research interests are in new treatments, devices, and surgical outcomes in pediatric epilepsy, as well as the genetic basis of epileptic encephalopathies. I am also committed to educating various groups and professionals about many aspects of epilepsy.

Juliann Paolicchi, M.D., M.A. discloses receiving support for Consulting from Cyberonics, Lundbeck Pharm.; for Speakers Bureau from Cyberonics, Lundbeck Pharm; for Contract Research from GW Pharm (indirect - CoI), UCB Pharma (indirect - CoI); for Service (with or without compensation) from PAB, EFA.

John Pollard, M.D.
Dr. Pollard is an adult epileptologist who focusses on clinical care, fellowship education, clinical trials, and clinical research at the University of Pennsvlvania. As a member of the exectutive committee of the Epilepsy Study Consortium, he is interested in helping to design and execute early stage clinical trials. In order to help improve the quality of subjects enrolled in clinical trials he has been conducting research using biospecimen biomarkers to aid in seizure diagnosis.

Dr. Pollard discloses receiving support for Consulting from Brain Sentinel; for Contracted Research from Clinical trials grants paid to the University of Pennsylvania: H. Lundbeck, Glaxo-SmithKline, Brain Sentinel, SK pharmaceuticals, Upsher-Smith Laboratories, Alexza and Eisai.; for Ownership (i.e. stocks, stock options or other ownership) from part owner of a company Cognizance Biomarkers, LLC that has no current value. It exists on a NIH SBIR grant.

Jay Salpekar, M.D.
Jay Salpekar, M.D. is Director of the Neuropsychiatry in Epilepsy Program at Kennedy Krieger Institute, and on the full time faculty of Johns Hopkins University Medical School. He received B.A. and M.D. from Washington University in St. Louis and continued at Barnes Hospital for psychiatry residency. He completed a child and adolescent psychiatry fellowship at Yale University. Dr. Salpekar has over 70 publications including journal articles, abstracts, editorials, and book chapters. He is a reviewer for a dozen scientific journals and grant review panels, and serves on the editorial board for Epilepsy and Behavior. He is active in the American Epilepsy Society, American Neuropsychiatric Association, and the Epilepsy Foundation.

Dr. Salpekar has indicated he has no financial relationships with commercial interests to disclose.

David Wheeler, M.D., Ph.D.
After completing undergraduate training at the University of Montana, Dr Wheeler attended Oxford University on a Rhodes Scholarship where he received a Masters degree in physiology. He then went on to Stanford University completing an MD and PhD in Neurosciences with research focused on the role of calcium channels in neurotransmitter release in the hippocampus. He received Neurology training and

fellowship in Clinical Neurophysiology through the Partners Program at Mass General and the Brigham in Boston. Dr Wheeler is in private practice in Casper, WY. His practice covers general neurology with emphasis on epilepsy as well as acute stroke care. He is active in numerous organizations for both clinical medicine and health care administration.

Dr. Wheeler discloses receiving support for Contracted Research from Novartis; for Other Service from AHA SouthWest Affiliate Stroke Advisory Committee. Chairman Wyoming Dementia Care. Vice Chairman, Wyoming Medical Center Board of Directors.

Coutrney Wusthoff, M.D.
Dr. Wusthoff is Assistant Professor of Child Neurology and by courtesy, Pediatrics (Neonatal and Developmental Medicine) at the Stanford University School of Medicine. She is also Neurology Director for the Lucile Packard Children's Hospital Stanford Neuro-NICU. She conducts clinical research in neonatal neurology, focusing on neonatal seizures, critical care EEG monitoring, and early onset epilepsies. Her clinical work includes inpatient and outpatient neonatal neurology, clinical neurophysiology, and pediatric epilepsy care.

Dr. Wusthoff has indicated she has no financial relationships with commercial interests to disclose.

Paul Levisohn, M.D. (Medical Content Specialist, AES)
Dr. Levisohn is a member of the faculty of the section of Pediatric Neurology at The University of Colorado School of Medicine and Children's Hospital Colorado Neuroscience Institute, having joined the faculty over 15 years ago following a similar period of time in the private practice of pediatric neurology. His academic career has focused on clinical care for children with epilepsy with particular interest in clinical trials and on the psychosocial impact of epilepsy. Dr. Levisohn is currently a consultant on medical content for CME activities to staff of AES. He is a member of the national Advisory Board of EF and has been chair of the advisory committee for the National Center of Project Access through EF.

Dr. Levisohn has indicated he has no financial relationships with commercial interests to disclose.

AKH STAFF / REVIEWERS
Dorothy Caputo, MA, BSN, RN (Lead Nurse Planner) has indicated she has no financial relationships with commercial interests to disclose.

Bernadette Marie Makar, MSN, NP-C, APRN-C (Nurse Planner) has indicated she has no financial relationships with commercial interests to disclose.

John P. Duffy, RPh, B.S. Pharmacy (Pharmacy Reviewer) has indicated he has no financial relationships with commercial interests to disclose.

AKH staff and planners have nothing to disclose.

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Nursing and Pharmacy credit (per session) is based on attendance as well as completion of an online evaluation form available at:

WWW.AKHCME.COM/2015AES

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2015 Annual Course

Introduction: The Complex Interaction of Patients, Physicians and the Media

Eric H. Kossoff, MD
Johns Hopkins Hospital

December 6, 2015

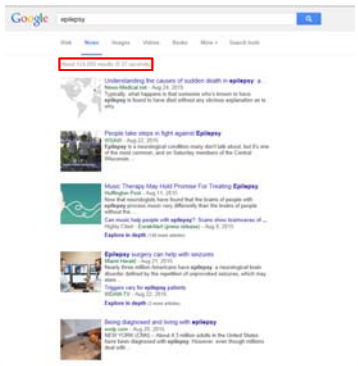
AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosures

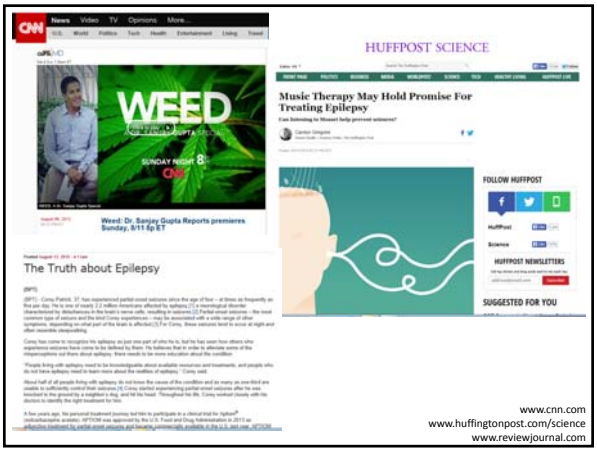
Consultant:	Nutricia, Atkins Nutritionals, NeuroPace
Data Safety Monitoring Boards:	GW Pharmaceuticals, Lundbeck
Royalties:	UpToDate, Demos
Grant support:	Nutricia, Vitaflo

Learning Objectives: Morning Session

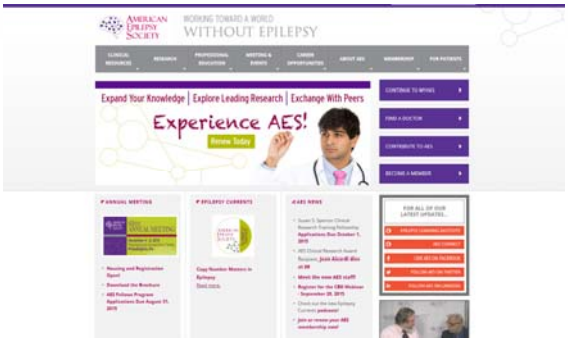
- Recognize the complex relationship between physicians and the media
- Be able to answer patient (or parent) questions about reports from the media
- Discuss complex issues regarding epilepsy and social media, seizure detection, SUDEP, and driving

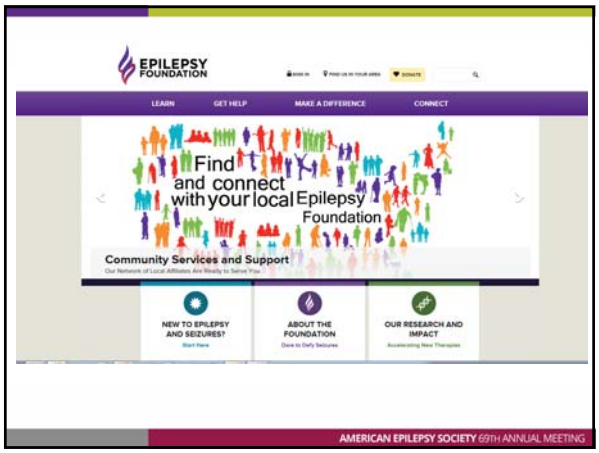


www.google.com



www.cnn.com
www.huffingtonpost.com/science
www.reviewjournal.com





ARS Question 1

1. I often am interviewed and extremely aware personally of the news and Internet in regards to epilepsy
2. I check the Internet and news regularly about epilepsy
3. I look at articles and news about epilepsy only in response to patient/parent request
4. I stay off-line as much as possible!

ARS Question 2: Of the following, which have NOT been used successfully for patient information?

1. www.facebook.com
2. www.epilepsy.com
3. www.journals.elsevier.com/epilepsy-and-behavior
4. www.callalawyer.com
5. www.aesnet.org

Today's Annual Course: Epilepsy and The Media

- Many epilepsy providers are frequently asked to comment by patients about new therapies discussed by the media and feel very unprepared and reactive

- How best to answer these questions?
- Where to get assistance?
- What is the data on a few of these "hot topics"?

ARS Question 3: Which is true?

1. SUDEP is more common in young children than adults
2. Cannabadiol is currently in trials for Dravet syndrome and Lennox Gastaut syndrome
3. Driving rules have been standardized across the USA as of July 21, 2015
4. RNS, VNS, and the DBS (thalamic stimulator) have been approved by the FDA for use

"Johnny"

- 62 year old patient in the ICU with refractory status epilepticus
- No etiology found
- Discharged to rehab facility on 3 anticonvulsants having sporadic seizures
- He's back!!!

AMERICAN EPILEPSY SOCIETY 2014

A “day in the life”

www.clipartsheep.com

8:45 a.m. **Introduction: The Complex Interaction of Patients, Physicians and the Media**
Eric Kossoff, M.D.

8:55 a.m. **"8:00 am: A Facebook Friend Request"**
Alda Venkataraman, M.D.

9:00 a.m. **Lecture: Should You Friend Your Patients? Facebook and Social Media**
Adam Hartman, M.D.

9:25 a.m. **Lecture: Epilepsy and the Internet**
Patty Shafer, M.N., R.N.

9:50 a.m. **Debate: Dogs and Devices: Does Seizure Detection Work?**
Elizabeth Donner, M.D. (Pro)
Gregory Krauss, M.D. (Con)

10:20 a.m. **Break**

10:35 a.m. **"Noon: A Seizure-related Crash on the News"**
Kathryn Davis, M.D.

10:40 a.m. **Flash Panel: Advocacy Groups and Their Role with the Media Epilepsy Foundation**
Phil Gattone, M.Ed.

CURE
Susan Axelrod

Lennox Gastaut Syndrome Foundation
Christina Saninocencio, M.S.

Epilepsy Information Service
Pat Gibson, M.S.S.W.

11:20 a.m. **Lecture: SUDEP and Media Resources**
Lisa Bateman, M.D.

11:35 a.m. **Lecture: Driving Accidents in the News, What Is Our Role with the MVA?**
Allan Krumholz, M.D.

11:50 a.m. **Morning Wrap-up**
Eric Kossoff, M.D.

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

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#AESmtg15

AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

8:00 am: A Facebook Friend Request

Akila Venkataraman, MD
NYU Lutheran Medical Center

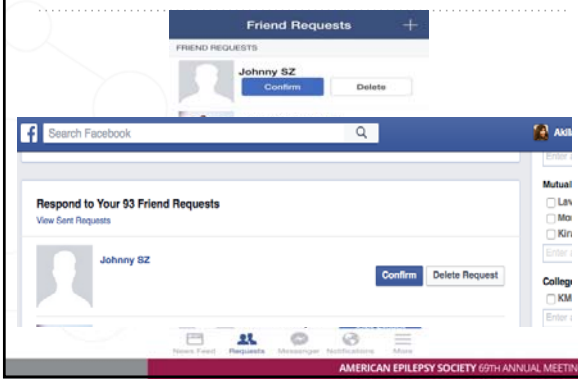
December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Nothing to disclose

8:00 am : A Facebook Friend Request



To "friend" or not to "friend"…

ARS question:

When a patient "friend" requests you on Facebook:

1. You never accept patients as Facebook friends
2. You have a separate Facebook page for patient friend requests
3. You have many patients as your friends on Facebook and find it helpful
4. What is Facebook?

Social media and Professionalism

Some considerations when using social media:

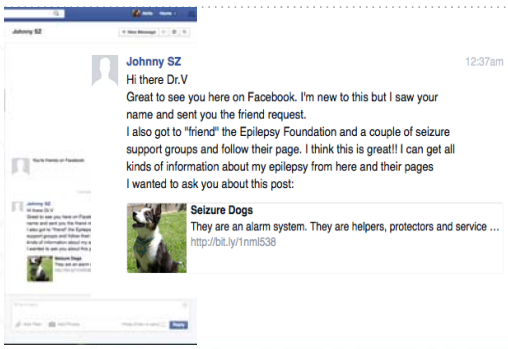
- Institutional guidelines/regulations
- Patient privacy
- Personal privacy
- Separate professional profile

8:05 am : Friend request accepted

Johnny SZ
Request accepted

So now what?

8:10 am : Facebook messenger



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What is the role of social media in our professional lives?

- Impacts and redefines the patient-physician relationship
- Provides forums for information, education and advocacy
- Has become an integral part of our daily lives

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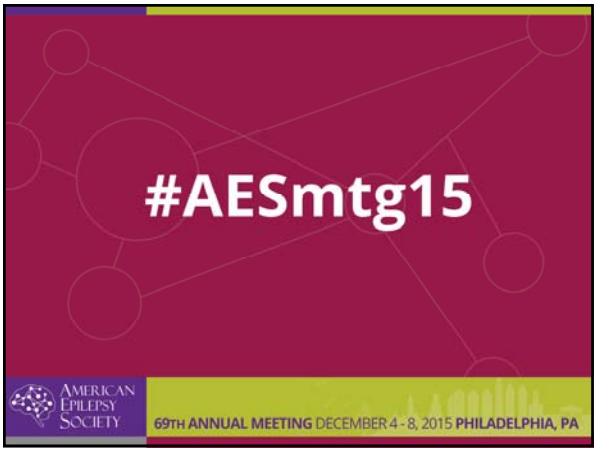
There's no escaping social media

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING



Should You Friend Your Patients? Facebook and Social Media

Adam L. Hartman, MD
Johns Hopkins Medicine

December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Name of Commercial Interest	Name of Commercial Interest
None	

Professional/Medical Advisory Board Member
-The Hemispherectomy Foundation
-The Carson Harris Foundation

I have accounts on Facebook, LinkedIn, ResearchGate, Doximity, Google+, and probably a few others that I never check – not Twitter

Learning Objectives

• List the potential outcomes of social media and nonprofit organizations in epilepsy-related conditions
• Consider <u>your</u> role in interacting with social media and nonprofit organizations

Impact on Clinical Care and Practice

- Patient privacy is a primary concern
  - Ethical and legal guidelines/rules
- We are all judged on our professionalism
  - "You only make a first impression once."
- Liability concerns

What roles do social media play?

- <u>Entertainment</u>
- Public awareness & education
- Connections between families
  - Emotional support
  - Advice/education
- Funding
  - Research
  - Financial aid for families
- Connections between investigators

Image: http://medicaleconomics.modernmedicine.com/medical-economics/news/minor-results-so-far-major-icd-10-conversion?page=0,3

Facebook

- Follow your favorite restaurants, sports teams, and medical practices!
- See pictures of your physician on vacation!
- Get to know her/his favorite food and music – for the perfect holiday gift!
- Ask a quick question about that seizure you just had (what you remember of it)!

  Oops…

Logo: chicagobears.com

What do professional societies say about personal friend requests?

- OK (with caveats)
  - American College of Obstetricians & Gynecologists
- Not OK
  - American College of Physicians/Federation of State Medical Boards (2013)
  - American Academy of Family Physicians

http://journals.lww.com/greenjournal/Fulltext/2015/02000/Committee_Opinion_No__622___Professional_Use_of.47.aspx
https://www.acponline.org/newsroom/online_medical_professionalism.htm
http://www.aafp.org/dam/AAFP/documents/about_site/SocialMediaFamPhys.pdf
http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion9124.page

Concerns (it's all discoverable…)

- Patient privacy
  - HIPPA
- Physician privacy
  - Includes trainees raised in the era of Facebook, Instagram, Snapchat, others
  - 2010 survey of surgery residents & faculty
    - 64% of residents, 22% of faculty had Facebook pages
    - 50% were publicly accessible
    - 31% of them discussed work – **14% related to patients**

Landman MP, et al. J Surg Educ. 2010;67:381-6.

BUT IT'S NOT QUITE THAT EASY, IS IT?

Professional use of Facebook

- Feature your practice: it's discoverable!
- Get your practice ranked higher in an Internet search than physician ranking sites
- You control the content
- Ethical question: are there privacy concerns?

Other uses of social media: Summer 2014/5: Cool off!

THE ALS ICE BUCKET CHALLENGE

http://www.alsa.org/fight-als/ice-bucket-challenge.html

Results

- **Facebook: 1.2 million videos (after 6 weeks)**
- Twitter: 2.2 million tweets (after 6 weeks)
- $115 million USA (Aug 26, 2015), $220 million worldwide, hundreds of thousands (?millions) of new donors
- **Conclusion: social media increase visibility and donations!**

http://en.wikipedia.org/wiki/Ice_Bucket_Challenge
http://www.ibtimes.com/ice-bucket-challenge-2015-can-als-association-turn-last-years-viral-phenomenon-annual-2067736

Epilepsy fundraising: Slash the 'stache

msnbc

Explore Watch Join In Speak Out

Axelrod 'stache slash brings Obama, Trump together

By Jane C. Timm

Ever think you'd see President Barack Obama and Donald Trump agree on anything?

Well, when it comes to slashing David Axelrod's mustache – and raising money for epilepsy research – they're on the same team.

The group – as well as many other generous donors like George Clooney, Mark Cuban, Tom Hanks, Carole King, and *Morning Joe*'s own Joe Scarborough – all came together in a bipartisan effort to raise funds for CURE, Citizens United for Research in Epilepsy.

The 'stache off in progress/Louis Burgdorf / Morning

http://www.msnbc.com/morning-joe/axelrod-stache-slash-brings-obama-trump-tog

Another example

ABOUT US

The Hemispherectomy Foundation, a 501(c)(3) non-profit organization, was founded to provide emotional, financial, and educational support to individuals and their families who have undergone, or will undergo, a hemispherectomy or similar brain surgery. We provide help which includes, but is not limited to: college scholarships, trade school scholarships, camp fees, life-aid equipment, travel expenses, and other aid as approved by the officers.

We are also dedicated to hemispherectomy education, awareness, fundraising, and research of the medical conditions causing intractable epilepsy that lead to surgery and the surgery itself. As the cause of these medical conditions are unknown, much research is needed.

http://hemifoundation.homestead.com/aboutus.html

Beyond Facebook: What a patient advocacy group can do

- "Dear Members of the Hemispherectomy Foundation Medical Advisory Board…"
- Story of a patient with atypical symptoms **discussed on Facebook**, later found to be hydrocephalus
- Concern that diagnosis was being missed in others, prolonging suffering for patients and families
- Purpose of e-mail: raise awareness
- Result of e-mail: proposal (from a Board member) to study the question

Epilepsia, 54(2):383–389, 2013
doi: 10.1111/epi.12010

FULL-LENGTH ORIGINAL RESEARCH

Posthemispherectomy hydrocephalus: Results of a comprehensive, multiinstitutional review

*Sean M. Lew, *Anne E. Matthews, †Adam L. Hartman, and ‡Neil Haranhalli, on behalf of the Post-Hemispherectomy Hydrocephalus Workgroup

*Department of Neurosurgery, Children's Hospital of Wisconsin, Medical College of Wisconsin, Milwaukee, Wisconsin, U.S.A.; †Department of Neurology, Johns Hopkins Hospital, Baltimore, Maryland, U.S.A.; and ‡Department of Neurosurgery, New York University, New York, New York, U.S.A.

SUMMARY

Purpose: Hemispherectomy surgery for medically intractable epilepsy is known to cause hydrocephalus in a subset of patients. Existing data regarding the incidence of, and risk factors for, developing posthemispherectomy hydrocephalus and were excluded from analysis, yielding 690 patients for this study. One hundred sixty-two patients (23%) required hydrocephalus treatment. The timing of hydrocephalus ranged from the immediate postoperative period to 8.5 years after surgery, with 43 patients (27%) receiving shunts >90 days after surgery. Multivariate

Time to hydrocephalus

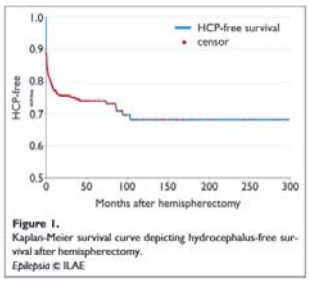


Figure 1.
Kaplan-Meier survival curve depicting hydrocephalus-free survival after hemispherectomy.
Epilepsia © ILAE

Total N = **690** patients
162 shunted

Lew et al., Epilepsia 2013;54:383

Real results

- Family-driven question
- New clinical scientific knowledge
  - "Dr. Hartman, have you heard about this? I saw it on the Internet."
- Increased professional and family awareness
- Empowering families in the setting of multiple specialists (neurologists, epileptologists, neurosurgeons)
- **Better patient management**

The good side of social media – patient/family perspective

- Increase the size of the affected community
  - "You are not alone"
- Advice at a peer level
  - Nonmedical issues (e.g., social resources/support)
  - Medical advice (e.g., rehabilitation)
- Ethical question: should professionals advocate membership in these groups?

Other uses of Facebook: Surveys

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Brief Communication

Report of a parent survey of cannabidiol-enriched cannabis use in pediatric treatment-resistant epilepsy

Brenda E. Porter, Catherine Jacobson *

ARTICLE INFO

ABSTRACT

Severe childhood epilepsies are characterized by frequent seizures, neurodevelopmental delays, and impaired quality of life. In these treatment-resistant epilepsies, families often seek alternative treatments. This survey explored the use of cannabidiol-enriched cannabis in children with treatment-resistant epilepsy. The survey was presented to parents belonging to a Facebook group dedicated to sharing information about the use of cannabidiol-enriched cannabis to treat these difficult seizures. Nineteen responses met the following inclusion criteria for the study: a diagnosis of epilepsy and current use of cannabidiol-enriched cannabis. Thirteen children

Other uses of Facebook: Diagnosis

BMJ Case Reports

Novel diagnostic procedure

Facebook: can it be a diagnostic tool for neurologists?

Manoj K Mittal,[1] Jeff A Sloan,[2] Alejandro A Rabinstein[1]

[1]Department of Neurology, Mayo Clinic, Rochester, Minnesota, USA
[2]Department of Biostatistics and Oncology, Mayo Clinic, Rochester, Minnesota, USA

Correspondence to Manoj Kumar Mittal, drmanojkumarmittal@gmail.com

Summary

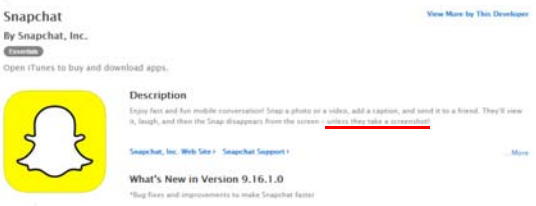
A 56-year-old woman presented with acute ischaemic stroke with NIHSS 13. She had right eye ptosis and miosis. She and her husband were not sure if her facial features were different than usual. With her consent, we compared her face with her pictures on Facebook. In the absence of any ptosis or miosis in her pictures, she was diagnosed with acute Horner syndrome. Facebook may be a useful tool for

Mittal et al., BMJ Case Rep 2012. doi:10.1136/bcr-2012-006426

The downside of social media

- Institutional, professional society policies vary
- Anecdotal nature of posts/tweets – and ability to follow up
- "Medical" advice of variable quality – consider the source
- Should medical providers be allowed to participate in online chat groups?
  - Do families even want our input in chat rooms?

Other social media – all sorts of new problems



Snapchat

By Snapchat, Inc.

Open iTunes to buy and download apps.

Description

What's New in Version 9.16.1.0

Not easy to keep track of these texts – liability?
Reliability of the source of information?

Other considerations

- Are these concerns that different from those of physicians who live in small communities (where everyone knows your business, sometimes before you do)?
  - Issues: privacy, physician-patient relationship
- How about patients who you bump into at the supermarket, airport, etc.?
  - Issues: privacy, liability (if they ask you a medical question)
- Should we limit our involvement in patient advocacy groups/local chapters of national organizations?
  - Issues: privacy, liability (if they ask you a medical question)

Conclusion

- Social media play important roles for patients, families, and clinicians
  - Would you want this splashed on the front page of The Washington Post?
  - Public awareness/fundraising
  - Connections between families and between investigators
  - Emotional support, advice/education
- Consider potential outcomes of "friending" someone on Facebook

http://www.aafp.org/dam/AAFP/documents/about_site/SocialMediaFamPhys.pdf

Where do we go from here?

- Know the policies of your group
- Then, decide what you are comfortable doing
  - **Define the goals for your presence on social media**

Additional references

AMA Guidelines: Shore et al., J Clin Ethics 2011;22:165

DeJong SM. Blogs and Tweets, Texting and Friending: Social Media and On-line Professionalism in Health Care. New York:Academic Press; 2013

#AESmtg15

AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Epilepsy and the Internet

Patricia Osborne Shafer RN, MN
Associate Editor/Community Manager
Epilepsy Foundation

Epilepsy Nurse Specialist, Beth Israel Deaconess Medical Center, Boston MA

December 6, 2015

Disclosure

Commercial Interest

- Acorda Therapeutics
  - Consultant, Advisory Board

Non-Profit Interest

- Epilepsy Foundation
  - Part-time salary support

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Learning Objectives

- Recognize complex issues influencing internet use by people with epilepsy, families and other stakeholders
- Explore how emerging trends in patient education and internet use can influence clinical practice and patient education.
- Be able to use the internet to help patients/families find credible information about epilepsy, health and wellness.

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IOM 2013: Education for People with Epilepsy and Families

- Upon diagnosis and throughout care
- Meets specific needs, clearly written and communicated, appropriate health literacy, linquistically and culturally appropriate
- Knowledge & self-management skills
- Regardless of socioeconomic status, demographic group, or location

Current State of Patient Education for Epilepsy

- Often provider focused
- Not tailored
- Potential bias
- Not available 24/7 or at critical junctures

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Complex Issues: Internet Use for Education and Care

- Diversity of epilepsy, audiences, user needs and behaviors
- Increasing use of internet and social networking
- People not aware of available information and resources
- Attention spans, how people read and use the internet

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Diversity of Needs and Priorities

- Providers
  - Generalists
  - Specialists
- People with epilepsy
- Caregivers
- Advocates
- Stakeholders
- Age, gender
- Epilepsy-specific
  - New onset
  - Refractory
  - Specific syndromes
  - Rare epilepsies

What do we want people with epilepsy and families to do?

- Be aware of seizures, epilepsy and the organization
- Perceive the organization as helpful
- Learn and get help
- Get involved, advocate, be engaged
- Give and get support
- Donate and support
- Change health behaviors

Using Internet for Epilepsy Education

- Comfort with internet resources
- Knowledge of credible resources
- Concerns about patient privacy
- How internet education can affect "meaningful use"
- Access to computers by people with epilepsy

Social Media Use: 2005-2015

- 2/3 of U.S. adults
- **Age:** Since 2010, use by older Americans 3x higher
- **Gender** – Since 2014, no significant differences
- **Race** - Differences less in past decade (56-65%)
- **Income & education**
  - Higher education and income more likely
  - Half of those with lowest income households
- **Geographic area**- Little difference

Social media usage: 2005-2015; Pew Research Center, October 8, 2015

Looking, Scanning, Viewing Then and Now

Look	
30 seconds	10 seconds
Scan	
3 minutes	30 seconds
Read/View	
30 minutes	2 minutes or >

Impact of Shorter Attention Spans and the Internet

- Need to be credible, accurate, engaging in shorter words, chunks, or time periods
  - Twitter - 140 characters
  - Vine - 7 seconds
  - Website – 10 seconds - 30 seconds – 2 minutes
- Use of multiple methods
- Avoid cognitive overload
- Write for all types of devices

Analytics: Assess User Needs, Content, Engagement

- Global trend on **using search engines** rather than go to one site
  - *Ask Google or Siri the question*
  - *Use preview info without entering site*
- Analytics informs user behavior, but not helpfulness or behavior change
  - Inferences from average data
  - Social media likes and shares - level of engagement and satisfaction
  - Commenting

The Evolution of *epilepsy.com*

Early years

- Adapted from articles and chapters, largely by professionals
- More depth & details to avoid "plain vanilla"
- Clicks/pathways to keep person on site
- Home page major focus

Most recent revision

- More targeted content
- Multiple short pieces
- Crosslinks & pathways
- Diverse mediums
- Engagement critical
- Responsive design – less clicks to stay on site
- Home page less relevant

The Epilepsy Foundation's Digital Enterprise Now

- The main interface or service for many people- *builds brand awareness*
- Often first entry or main way of engaging with the Foundation
- Information also goes out *to* users, rather than user coming to the website

Reach: *epilepsy.com*

Since March 2014

- 13.5M user sessions
- 8.5M unique users
- 25M pageviews

Monthly

- 800K user sessions
- 600K unique users
- 1.4M pageviews

Daily: 46K page views

Weekly nl- 90K subscribers, 900K total opens

Reach & Engagment: Social Media

Since March 2014: ~134.3K followers

Monthly Facebook/Twitter(October):

- 101.7K interactions
- 92.4K unique users
- 1.4K reach – brand engagement
- 7M impressions – brand awareness, potential reach

Daily: average 3,250 messages

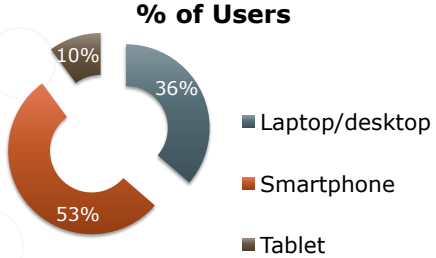
Changing Digital Enterprise

- Internet is no longer passive - allows and encourages…
  - instantaneous interaction and engagement
  - very large yet individualized touch
- Requires developing community – for reach, interactions and engagement
- Creates and demands resources

Lessons from The Epilepsy Foundation: *epilepsy.com*

- ~25% of traffic begins in the community
- Most traffic from organic search engines to specific pages
- Social media referrals growing rapidly- simple posts drive reach and engagement

How people access epilepsy.com in 2015



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Analytics: CDC Epilepsy Website: September 2015

- **Page Views:** 35,204
- **Unique Visitors:** 20,655
- **Views by Device**
  - 66.9% unspecified
  - 13.7% smartphone
  - 4.7% ipad
- **Top Page Views**
  - Seizure First Aid
  - Home page
  - FAQs
  - Epilepsy Fast Facts
  - Epilepsy Basics
  - SUDEP
  - Types of Seizures
  - Seizure Training for Professionals

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CDC in Spanish

- Seeking health information - **3rd most popular online** activity among adult Internet users in the US[1]
  - Latinos comprise 65%
- CDC en Español: 6.5 M in 2014
- CDC social media
  - Facebook > than 54,000 in 2014
  - Twitter - 36,000 by Dec 2014

1-PEW Hispanic Center survey

Launch of CDC Epilepsia Website update!
www.cdc.gov/epilepsy/spanish

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Google Search Terms Results Leading to epilepsy.com - Sept 2015

Page	Clicks	Impressions	CTR %
Absence seizure	4,118	19,302	21.3
Seizure medications	3,878	1,1711	33.1
What is a seizure	3,778	11,554	32.7
Temporal lobe epilepsy	3,201	12,919	24.8
Types of seizures	2,917	15,685	18.6
Complex partial seizures	2,607	7,419	35.1
Tonic clonic	1,490	5,059	29.5
Simple partial	1,441	4,198	34.3
Signs of a seizure	1,204	2,641	45.6
Marijuana and epilepsy	261+	628+	41.6

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epilepsy.com Top 10: 8/1/15 – 10/15/15

Page	Page Views	Avg Time
Epilepsy.com	131,049	
Types of seizures	103,937	
What happens during seizure	70,712	
Absence seizures	65,237	
Search	54,264	
Seizure meds	53,324	
What is a seizure	50,368	
Simple partial	45,270	
Complex partial	45,213	
What is epilepsy	44,239	

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epilepsy.com: Likes and Engagement 8/1/15 – 10/15/15

Page	Page views	Share	Likes
Types of seizures	103,937	7000	7000
What happens during seizure	70,712	13,000	12,000
Absence seizures	65,237	12,000	12,000
What is a seizure	50,368	7,000	6,700
Simple partial	45,270	2,000	2,000
Complex partial	45,213	21,000	20,000
What is epilepsy	44,239	5,000	5,100
Triggers	29,638	13,000	12,000

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Other Selected Topics: Likes and Engagement

Page	Page views	Shares	Likes
How serious are seizures	20,977	8,000	8,200
About epilepsy: The Basics	17,427	5,000	4,700
Epilepsy syndromes landing -TLE -BRE, Dravet, JME, LK, EMA, Reflex	15,051 +	 7,000 9,000	 7,000 9,100
Seizure 1st aid	14,209+	2,900+	3,100+
Sleep: Trigger/lack sleep impact/sleep	12,866	3,000 5,000	2,900 5,100
Marijuana		4,000	4,300

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Types of Information

- **Passive**
  - Written information
- **Active**
  - Find a Doctor, Center
  - Videos, podcasts, infographics
  - Toolbox resources
  - Training programs
- **Interactive**
  - online diary and self-management tools
  - 24/7 HelpLine
- **Engaging**
  - Commenting, posting
  - Forums- 25% of pageviews
  - Chat rooms
  - Targeted groups
  - Speak Up, Speak Out

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Audio Podcasts: Hallway Conversations

- Blog Talk Radio – avg 7,000 users in 30 days
- Medical marijuana
  - May 2014 - 17,000 users
  - Dec 2014 – 3,000 users
  - Sept 2015 – 750 users
- First Seizure Guidelines
  - Spring 2015 – 1,500 users

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epilepsy.com: Emerging Video Trends

Length of Videos

- Avg length of videos viewed ~44%.
  - Videos 20 min or > - 28%
  - Videos 2-4 min – 80-85%
  - Videos ~1 min- 90%

Most Often Viewed

- Types of Seizures – 62,241 (6 yrs)
- Seizures in School – 39,422 (4 yrs)
- Seizure Management for Emerg. Med. Responders – 32,186 (2 yrs)

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Video Length, Topic, Style

- Synapps 26 & EF: Seizure First Aid
  - 17,241 views (2 yrs), 2 ½ min
- Seizure First Aid
  - 2,462 views (1 yr), 11 min
- Heroes Reborn: Noah Gray Cabey
  - 1,255 views (3 wks), 30 secs
- Medical cannabis
  - 3 parts
  - 4,877 views (7 mos)
  - 3-5 min each
- Spotlight on NES
  - 3 parts
  - 4,256 views (8 mos)
  - 10-14 min each
- Status Epilepticus
  - 2,298 views (8 mos)
  - 10 min

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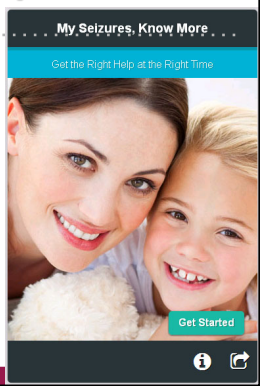
IOM: Improve Early Identification

- Screening tool
  - For early identification of people with persistent seizures & comorbidities
  - To educate people about referral to an epileptologist
- Collaborative effort
- 3,290 sessions to date – majority since April 2015



IOM: 24/7 Nonmedical Helpline

- Epilepsy Foundation's call line expanded
- Available in English and Spanish
- Accessible by
  - Phone, email
  - Website, mobile device

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IOM: Community Services & Engagement of Families

- Educational & training opportunities for community service providers
- Develop innovative partnerships for learning, supporting and connecting

SENIORS & SEIZURES

EPILEPSY FOUNDATION

SUDEP INSTITUTE

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IOM: Engaging People in Research

- Engage families in research
- Increase the power of data, the understanding of rare epilepsies and of comorbidities
- Strengthen stakeholder collaboration

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Measuring Change in Behavior

- Webinar on Epilepsy, Anxiety and Mood (1.5 hr)
  - Viewed live – 280, online – 2,462
  - 16% of traffic - suggested video by Youtube
  - 5,000 shares, 4,400 likes
- 90 day follow-up of 92 people
  - 60% found webinar very helpful
  - ~80% more aware of mood/anxiety changes
  - ~ 40% talked to neurologist about symptoms after viewing webinar

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Designed to increase knowledge, adherence, stress management, sleep time and quality, perceived support

WebEase

- Web-based, theory driven self-management program
- Tailored, response-dependent, interactive
- Self-paced modules
- Fact sheets, My Log, polls, resources, quizzes

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Twitter Chat on Epilepsy #abcDrBchat

- 15.9 million estimated impressions
- 1,372 twitter mentions from 270 users
- 68% retweet
- 62% 1 tweet

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Impact on Care: Improving Online Content and Access

- Content that user wants and needs - *involve audience*
- Analytics evaluate needs and outcomes
- Multiple ways to share similar content
- Target content depths, details, and length to purpose of content
- Time is of essence
- Clear communications
  - Common words in epilepsy raise literacy level
  - Use action words
  - Avoid talking down
- Relevant and credible links, tags, titles
- *Assess change in behavior*

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Summary: Benefits of Internet Use for Education on Epilepsy

Public

- Any time
- Interactive
- Easy to use
- Mobile friendly
- Responds to changes quickly
- Immediate feedback
- Safety
- Doorway to content behind 'pay walls'

Health Care Providers

- 24/7, year-round
- Allows short and return sessions
- Continuing education
- Resources for providers
- Research
- Online collaboration
- Credible patient/family education and resources

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Acknowledgement

- Epilepsy Foundation
- Epilepsy Program, Centers for Disease Control

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Debate: Dogs and Devices: Does Seizure Detection Work?

Pro: Elizabeth Donner, MD, FRCPC
The Hospital for Sick Children
Con: Gregory Krauss, MD
Johns Hopkins University

December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure: Gregory Krauss

PI: EpiWatch. ResearchKit investigational app to collect data from the Apple Watch to form a seizure detector

PI for sponsored trials: Upsher Smith, SK Lifescience, UCB Pharma, Novartis, Pfizer, NIH.

Consultant: SK Lifescience, Acorda, Sunovian

Disclosure: Elizabeth Donner

Nothing to declare

Learning Objectives

- Identify the difference between seizure detection and seizure prediction
- Understand current use of mobile devices to detect and track seizures
- Critique the use of seizure dogs for alerting and support

Dogs and devices: Does seizure detection work?

- Seizure prediction "after the fact"
- Seizure detection
  - Seizure dogs:
    - Detect or alert?
    - Assist or support?
  - Mobile devices:
    - Non-EEG seizure detection?
    - Seizure monitoring?

Impact on Clinical Care and Practice

- Improve referrals for seizure dogs
  - Importance of accurate seizure evaluation
  - Use for alerting versus support
- Recognize potential uses of non-EEG seizure detection
  - Seizure alerting
  - Limitations in accuracy and role in seizure management

Noon: A Seizure-related Crash on the News

Kathryn Davis, MD, MTR
University of Pennsylvania

December 6, 2015

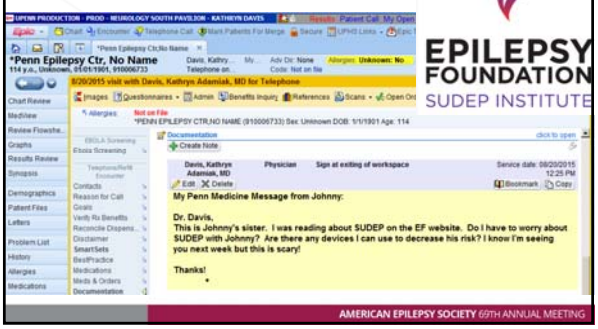
Disclosure

Lundbeck	Advisory Board

12:00: In the EMU on social call…

12:05: Walking to clinic with the fellow…

12:05: My Penn Medicine Message



EPILEPSY FOUNDATION
SUDEP INSTITUTE

What do I tell Johnny's sister about SUDEP?

- Drug resistant epilepsy on 3 AEDs
- Complex partial seizures ~1/month
- No known secondary generalized tonic clonic seizures

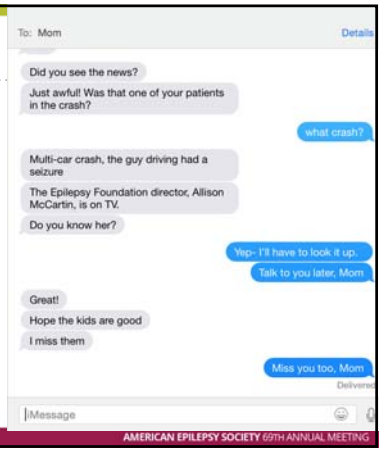
Can anti-suffocation pillows prevent SUDEP?

How can I reduce my risk?

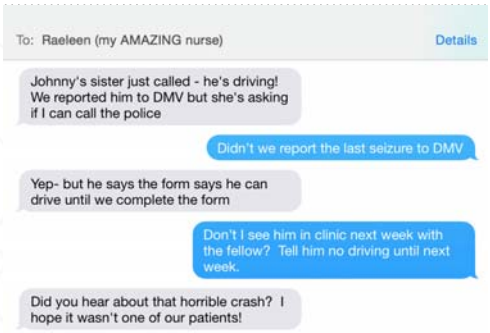
Do audio and video monitoring devices or sleeping with someone else in the room help prevent SUDEP?

12:07:

Text comes in…



12:08: Still walking to clinic…



My fellow is going to see Johnny with me next week… how should she prepare?

- SUDEP
  - What is Johnny's risk of SUDEP?
  - How should I council him and his family?
  - Are there ways to decrease the risk?
- Driving laws
  - What is my role now that I have already reported the most recent seizure to DMV?
  - Can I force Johnny to stop driving?

Epilepsy Advocacy Groups – How best to help?

- Provide trusted information
- Alleviate patient concerns
- Advocate for research
- Advocate for patients

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Social, Celebrity and Partnership:
Helping Drive the Media Conversation

Philip M. Gattone, M.Ed., President and CEO
Epilepsy Foundation

EPILEPSY FOUNDATION

December 6, 2015

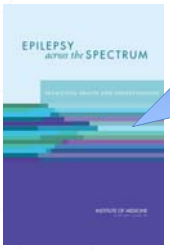
Disclosure

No Disclosures to Report

Learning Objectives

- Understand activation practices of IOM media and awareness recommendations within voluntary health space
- Realize importance of media mobilization to effect change in public policy
- Comprehend the impact of partnership to achieve media and social awareness

Institute of Medicine Report



- Recommendation #10: Inform Media to Improve Awareness and Eliminate Stigma
- Recommendation #11: Coordinate Public Awareness Efforts

EPILEPSY FOUNDATION

talk! about it! .org

Recognized Leader in Epilepsy Public Awareness
(Founded by Greg Grunberg, Actor and Father of Child with Epilepsy)

"To improve public awareness and knowledge, the following … should be considered priorities for future research:

- Evaluation of websites seeking to promote accurate knowledge about epilepsy ("Talk About It!") to determine effective strategies for educating the public…"

-- 'Epilepsy Across the Spectrum: Promoting Health and Understanding'
Published: March 30, 2012

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Epilepsy.com and Social Media: Driving the Media Conversation

- In the last year, 6.5 Million Users on Epilepsy.com
- In the last year, 16.6 Million Page Views
- Over 145,000 Social Media Followers
- In October 2015, over 7 Million Social Media User Impressions

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Congress Unanimously Passes Legislation to Improve Access to New Therapies

- On Monday, November 16 Congress unanimously passed the Improving Regulatory Transparency for New Medical Therapies Act (H.R. 639)

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Patent Reform

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12

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Citizens United for Research in Epilepsy (CURE)

Susan Axelrod
Founding Chair

CURE Citizens United for Research in EPILEPSY

December 06, 2015

Disclosure

None

About CURE

- Founded in 1998
- Over $32M to fund research
- >180 projects in 15 countries
- Signature Programs
  - Post-Traumatic Epilepsy
  - Infantile Spasms (Team Science Approach)
  - Epilepsy Genetics Initiative (EGI)
  - SUDEP
  - HHMI & Young Investigators
  - Conference Support

The Complexity of the Epilepsies

- Many syndromes
- Broad spectrum of impact on patients
- How do we communicate this to the media?

Seizing Opportunities

- Media Advocacy
  - Inflammatory language
  - Misrepresentation
  - Epilepsy Literacy

Seizing Opportunities

CURE as a Resource

CURE's mission is to cure epilepsy, transforming and saving millions of lives. We identify and fund cutting-edge research, challenging scientists worldwide to collaborate and innovate in pursuit of this goal. Our commitment is unrelenting.

Questions?

?

Thank You For Your Time

#AESmtg15

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69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Understanding the Media

Christina SanInocencio, MS
LGS Foundation

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

December 6, 2015

Disclosure

Eisai	Consultant
Lundbeck	Consultant

Learning Objectives

- What we mean by the "media"
- Understand how media chooses health stories
- How advocacy organizations work with media
- Opportunities

What do we mean by the "media?"

Mainstream media in the U.S:
- Network TV News
- Newspapers
- Online News Sites
- Cable News
- Radio News

Other communication Channels
- Social Media
- Magazines
- Blogs
- Films

News-Making Process in Health Topics

"Triggers" of Health Stories Include:
- Hard news (42%)
- Medical Research (11%)
- Celebrity Illness (10%)
- New treatments and trials (10%)

Televised health stories last a median of 97 seconds

Chapman, et al 2009

How Advocacy Groups Work with Media

proactive VS. responsive

How Advocacy Groups Work with Media

- Proactively:
  - Developing relationships with the media
  - Approaching media for coverage of issues
  - Attracting interest from media
  - Offering to provide expertise on subjects
- Responsively:
  - Responding to stories
  - Responding to interview requests

Mindframe Media, 2011

Proactive Epilepsy & Media Initiatives

Excellence in Epilepsy Journalism Award 2012

HOLLYWOOD HEALTH & SOCIETY

neuro film festival

The Rosalynn Carter Fellowships for Mental Health Journalism

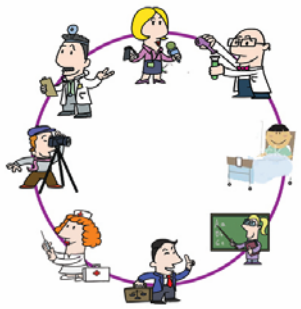
Proactive Opportunities in the Epilepsy Field

- Fact Sheets & Up-to-date information on websites
- Content creation
- Stronger use of social media
- Wikipedia
- Position Statements
- Press Releases
- Public Policy Efforts
- Awareness Campaigns
- Communications Plan
- Storylines and interactions with content producers
- Human Interest Stories/ Letters to the editor

Responsive Opportunities in the Epilepsy Field

- Responding to interviews
- Hotlines
- Harnessing “hot topics” in the media to benefit the epilepsy community
- Responding to disinformation
  - On TV Shows
  - News Reports
  - Social Media
  - In print or blogs

A lot of work needs to be done!



#AESmtg15

EPILEPSY AND THE MEDIA

Patricia A. Gibson, MSSW DHL ACSW
Wake Forest University School of Medicine

Wake Forest School of Medicine

December 6, 2015

American Epilepsy Society 69th Annual Meeting December 4 - 8, 2015 Philadelphia, PA

Disclosure

UCB – Scholarship Committee

Sunovian Advisory Committee

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Learning Objectives

- Discuss the Epilepsy Information Service
- Identify the most common topics of callers to the Epilepsy Information Service
- List key suggestions for working with the media

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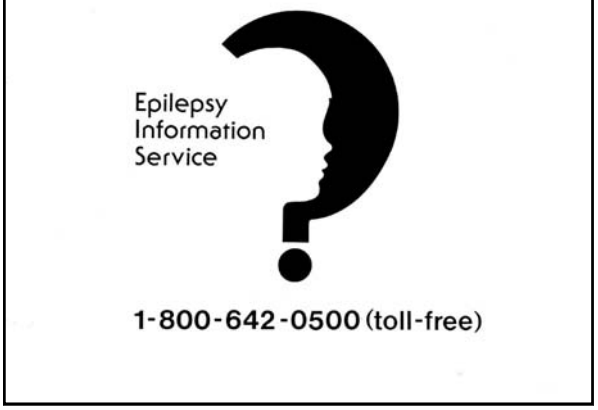


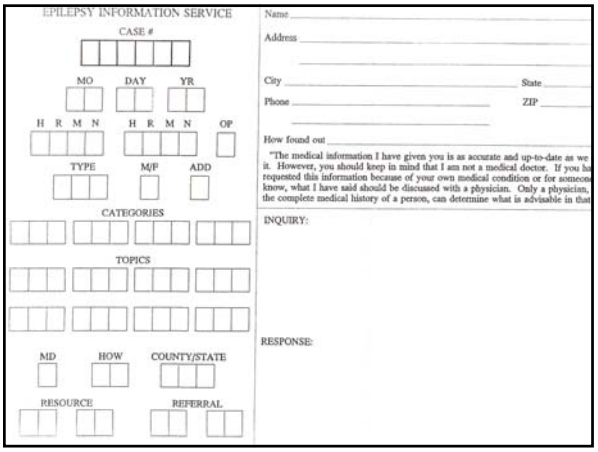
EPILEPSY INFORMATION SERVICE

EPILEPSY INFORMATION SERVICE

- In operation since 1979
- More than half a million calls

1-4 ratio of male to female callers

most typical caller is young white 24-35 year old mother



Most Frequent Topics

MEDICATION (side effect complaints, anything better?)
ECONOMIC
DRIVING
NEED FOR MORE INFORMATION, BETTER UNDERSTANDING OF EPILEPSY
SCHOOL/LEARNING ISSUES
EMPLOYMENT

DRIVING

COMMON QUESTIONS:

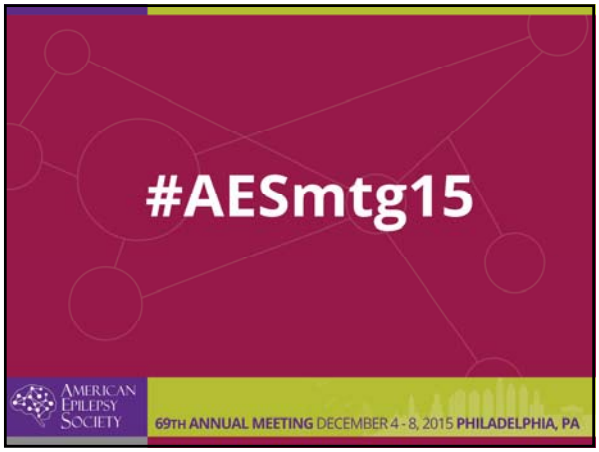
- What are the restrictions?
- If I can't drive, how am I going to get to work?
- Will my doctor report me?
- My doctor said I could drive after one month, is that ok?

MESSAGE TO THE HEALTH CARE PROVIDERS

DOCUMENT!
DOCUMENT!
DOCUMENT!

THINGS I HAVE LEARNED IN WORKING WITH THE MEDIA

- If they are writing a story, ask to see it before it goes to print (insist on it)
- Never answer a question until you know who you are talking to AND where he/she is coming from
- For advance notice situations, do what the politicians do…..tell your message, regardless of the question



SUDEP and Media Resources

Lisa M. Bateman, MD, FRCPC
Columbia University

December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Research Support	NIH/NINDS (Center for SUDEP Research) CURE DARPA
Advisory Committee	North American SUDEP Registry Sudden Death in the Young Registry

Learning Objectives

- Review the epidemiology and risk factors for SUDEP
- Review the literature on SUDEP risk reduction
- Identify media resources providing information about SUDEP, SUDEP research and support for those bereaved

The Case of Johnny

- His sister was reading about SUDEP and is scared!
- Does she have to worry about SUDEP with Johnny?
- Are there any devices she can use to reduce his risk?

What do I tell Johnny's sister about SUDEP?

- Drug resistant epilepsy on 3 AEDs
- Complex partial seizures ~1/month
- No known secondary generalized tonic clonic seizures

Can anti-suffocation pillows prevent SUDEP?

How can I reduce my risk?

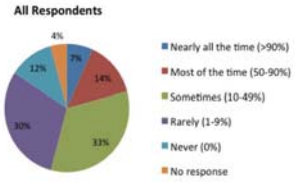
Do audio and video monitoring devices or sleeping with someone else in the room help prevent SUDEP?

Myth: SUDEP isn't a big deal

- Fact: SUDEP has a substantial public health burden
- Overall crude annual incidence rate:
  - 0.81/100,000 population
  - 1.16 cases per 1,000 patients with epilepsy
- Cumulative risk in childhood onset epilepsy:
  - 7% at 40 years overall
  - 12% for those not in long-term remission and not receiving medication.
- SUDEP ranks second only to stroke in potential years of life lost from neurologic diseases

Thurman, et al., 2014; Sillanpaa and Shinnar, 2010

Fact: We do a poor job communicating with patients about SUDEP



- Patients and families want to know about SUDEP and they want us to tell them about it
- One of the most devastating things for those bereaved by SUDEP is the lack of knowledge that this could happen

Friedman, et al., 2014; Morton, et al., 2006

"Do I have to worry about SUDEP with Johnny?"

- Who is at risk?

- Male gender
- Epilepsy onset <16 years
- Epilepsy duration > 15 years
- Symptomatic etiology
- GENERALIZED TONIC-CLONIC SEIZURES

Hesdorffer, et al., 2011

What do we know about risk reduction?

- Controlling seizures, especially generalized tonic-clonic seizures, is the best strategy we currently have for reducing SUDEP risk
  - Medications?
  - Surgery?
  - Other techniques?

- Nocturnal supervision may be protective
  - What is "supervision" exactly?

- What about other interventions or devices?

Is Supervision Protective?

- UK residential school study of 14 SUDEP cases
  - All occurred after leaving school or on holidays
  - School protocols/age
- 10 unwitnessed (2 unknown circumstances)
  - 1 of witnessed cases was assumed to be sleeping by witness with intellectual disabilities

- Community study of 154 SUDEP cases
  - Most found dead in bed
  - 23 witnessed
    - 21 with seizure
  - 77 suggestive of seizure
- Nocturnal supervision protective, independent of seizure control
  - Intervention/observation
- Asthma also protective
  - Better supervision/medical care?

Nashef, et al., 1995; Langan, et al., 2005

What is "Supervision"?

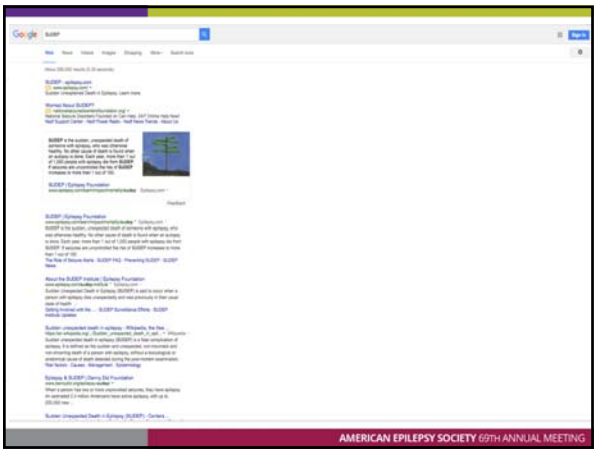
- Someone sleeping in the same room*
- Regular checks at night
- Simple video and/or sound monitors
  - Baby monitors
  - Web cams
- Specific devices
  - Movement/seizure detectors
  - Cardiac/respiratory monitors

*Sufficient age, cognitive and physical ability to intervene in the case of a life-threatening event

Do antisuffocation pillows or seizure detection devices reduce the risk of SUDEP?

- Nobody knows
- There is one study of simulated adult ventilation and CO2 rebreathing with lattice vs. cotton/latex pillows
  - Lattice pillows appeared to reduce asphyxia risk
  - Accumulated CO2 could still reach levels threatening to health and survival
- While a number of devices have been studied for efficacy at seizure detection, none have been studied for efficacy in SUDEP risk reduction

Catcheside, et al., 2014



On-line Resources

CSR THE CENTER FOR SUDEP RESEARCH — www.csr.case.edu

nasr north american sudep registry — www.sudep-registry.org

stopsudep@bcm.edu

On-line Resources

National Institute of Neurological Disorders and Stroke — Ninds.nih.gov

CURE EPILEPSY — www.cureepilepsy.org

CDC — www.cdc.gov

EPILEPSY FOUNDATION SUDEP INSTITUTE — www.epilepsy.com/sudepinstitute

American Epilepsy Society — www.aesnet.org

On-line Resources

SUDEP the global conversation — www.sudepglobalconversation.com

SUDEP Action — Making every epilepsy death count — www.sudep.org

Danny Did Foundation — www.dannydid.org

SUDEP Aware — www.sudepaware.org

Chelsea Hutchison Foundation — www.chelseahutchisonfoundation.org

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American Epilepsy Society 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Driving Accidents in the News: What is Our Role with the MVA

Allan Krumholz, MD; Director, Veterans Affairs
Epilepsy Center of Excellence, Baltimore;
University of Maryland School of Medicine

December 6, 2015

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- Sources
  - Newspaper
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- Consequences
  - Influence public and political opinion
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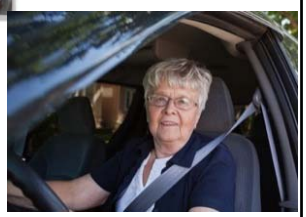

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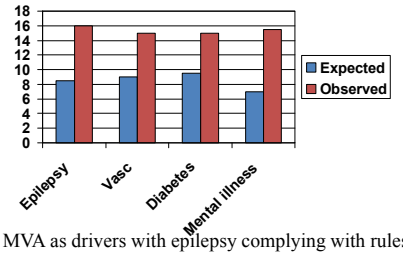

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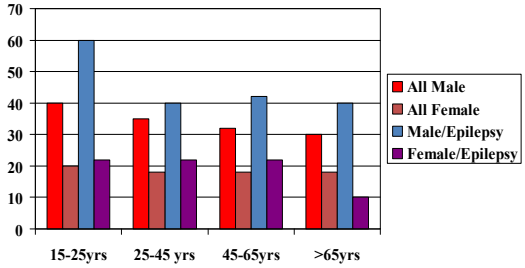

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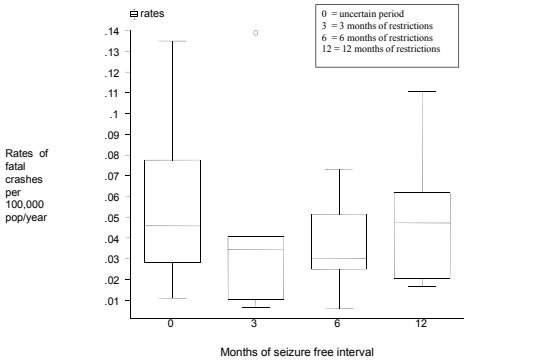

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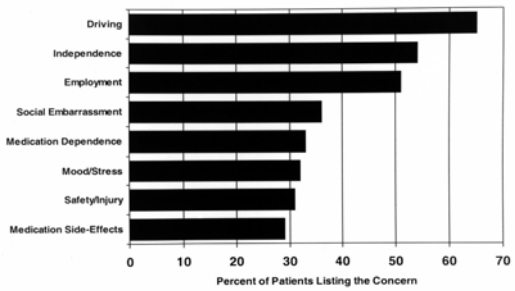
Driving: major listed concern of people with epilepsy



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Epilepsy and Driving: Patient Concerns

Social function

Employment

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

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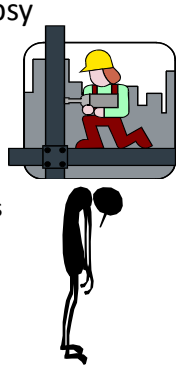

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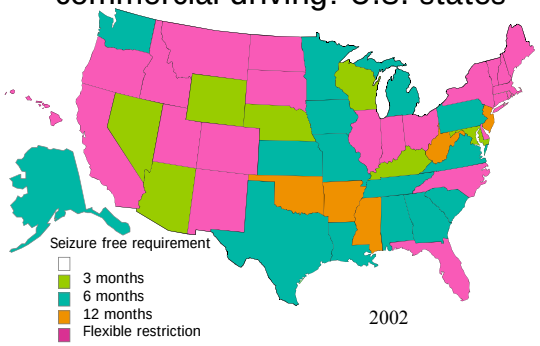

States are the laboratories of democracy"

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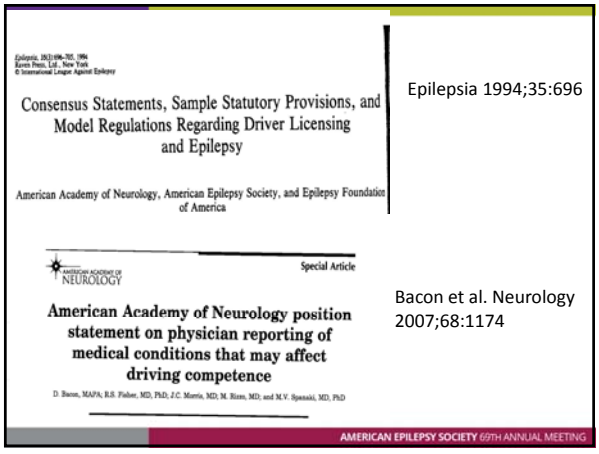
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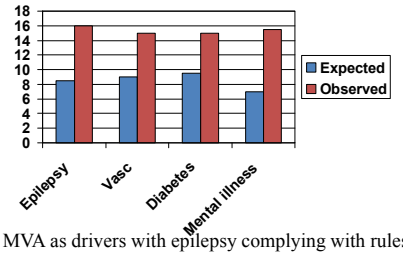

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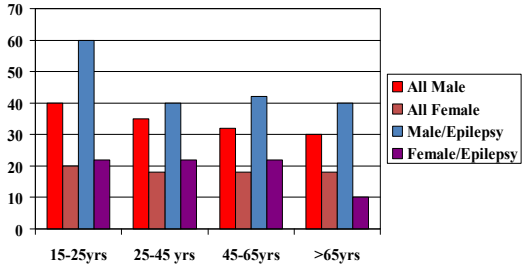

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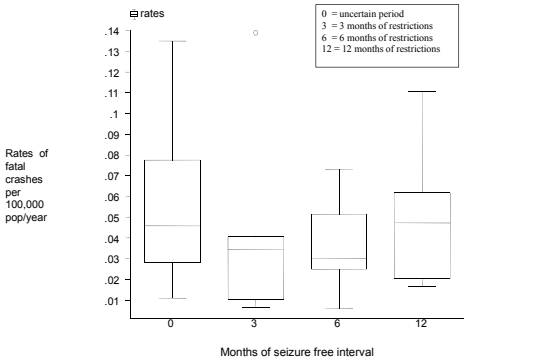

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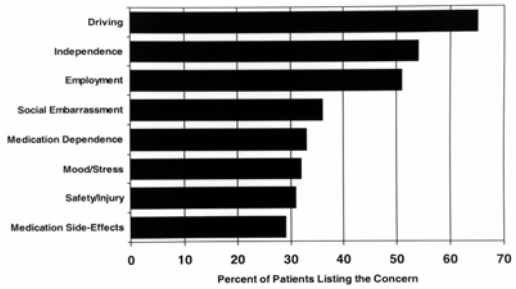

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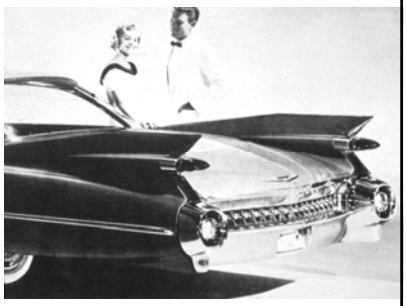

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Sometimes risk is predictable

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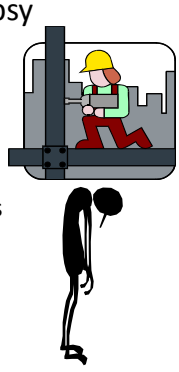

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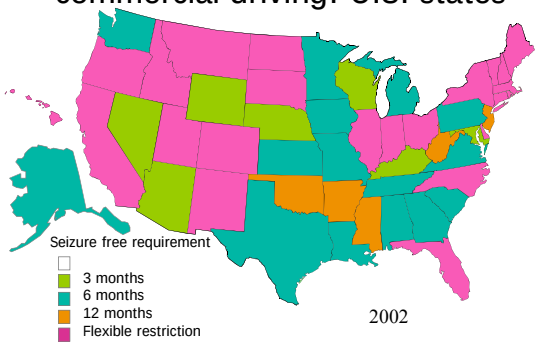

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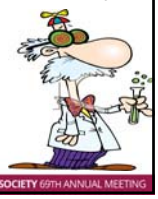

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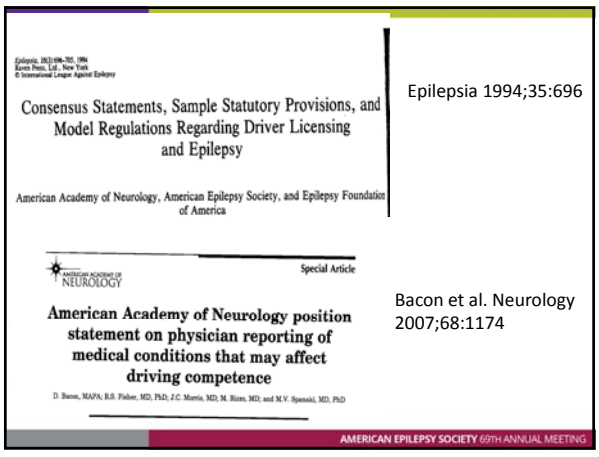

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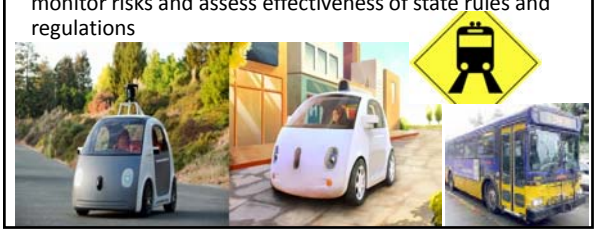

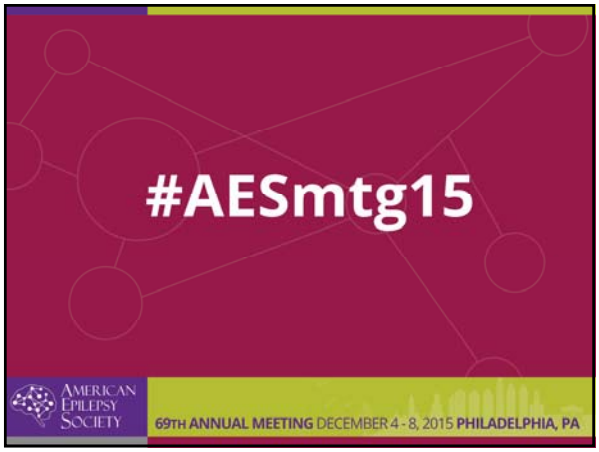

2015 Annual Course

Morning Wrap-up

Eric H. Kossoff, MD
Johns Hopkins Hospital

December 6, 2015

www.patient.info

Impact on Clinical Care and Practice: Morning Session

- You are now aware of the very complex relationship between physicians and the media
- You can answer questions from patients about reports they have seen in the media and give resources for them to find out more
- You are aware of issues regarding epilepsy and social media, seizure detection, SUDEP, and driving

ARS Question

1. I feel very comfortable deciphering and addressing the information about epilepsy in the media
2. I feel more comfortable than earlier this morning
3. I plan to never watch TV or get on the Internet again!

Please return at 2:00pm!

- *Treatment Innovations and the Media*
- How best to be interviewed?
- How to get *your* message to the public
- Hot topics: neurostimulation, laser surgery, cannabanoids

#AESmtg15

2015 Annual Course

Afternoon : Treatment Innovations and the Media

Eric H. Kossoff, MD

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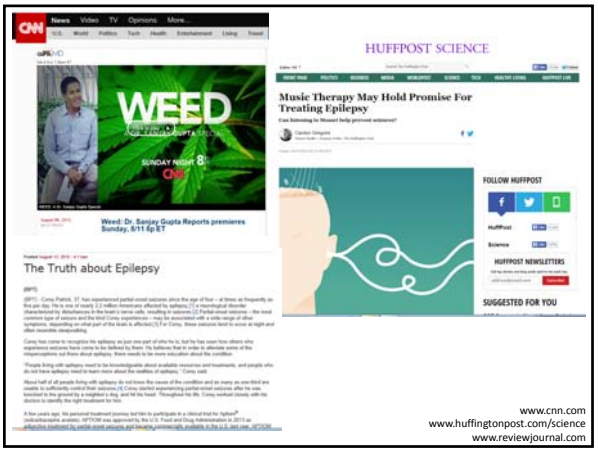
AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA



www.cnn.com
www.huffingtonpost.com/science
www.reviewjournal.com

ARS Question

1. I am interviewed by the media regularly
2. I have been interviewed a few times in my career (and enjoyed it)
3. I have been interviewed a few times in my career (and hated it)
4. I have never been interviewed by the press

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Today's Annual Course: Epilepsy and The Media

- We will continue to discuss how epilepsy providers interact with the media
- How to be PROACTIVE and get your message to the public
- Hot topics in epilepsy *treatment*

http://www.themortonreport.com/2014/01/22/Trauna1.JPG

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Treatment Innovations and the Media

2:00 p.m **Introduction to the Afternoon Session**
Eric Kossoff, M.D.

2:05 p.m **"5pm: CNN Interview about Surgery Alternatives"**
Lara Jehi, M.D.

2:10 p.m **Lecture: Doing Media Interviews: AES Policy and Advice**
William Theodore, M.D.

2:30 p.m **Lecture: RNS, VNS, DBS, Oh My!**
Christianne Heck, M.D.

2:55 p.m **Debate: Laser Surgery Is the Best Option**
Dan Curry, M.D. (Pro)
Kristen Riley, M.D. (Con)

3:25 p.m **Break**

3:40 p.m **"5pm: A Cocktail Hour Question about Cannabis"**
Kelly Knupp, M.D.

3:45 p.m **Lecture: Getting Your Message to the Public: How to Navigate the World of Reporters and Lawyers**
Robert Field, Ph.D., J.D.

4:05 p.m **Lecture: Epilepsy Journals and Free Access for Patients — A Good Idea?**
Steven Schachter, M.D.

4:25 p.m **Debate: Cannabadiol — Helpful or Just Reefer Madness?**
Elizabeth Thiele, M.D., Ph.D. (Pro)
Eric Marsh, M.D., Ph.D. (Con)

4:55 p.m **Conclusions**
Eric Kossoff, M.D.

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

A "day in the life"

- It is near the end of your day at work
- Rather than being able to go home to your family, another media interaction is coming your way
- And yes…it involves Johnny!

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Title of "5pm: CNN Interview about surgery alternatives"

Lara Jehi, MD
Cleveland Clinic

December 6, 2015

Disclosure

NCATS, UCB Inc	Research funding
Epilepsia	Editorial Board
Epilepsy Currents	Contributing Editor

Time: 4:55 pm; place: rounds on the floor…

You are **hectic** because you have to "transform" yourself in 5 minutes from this …

..to this …

Because…

Johnny is having laser surgery

Your hospital is pioneering this surgery in your state

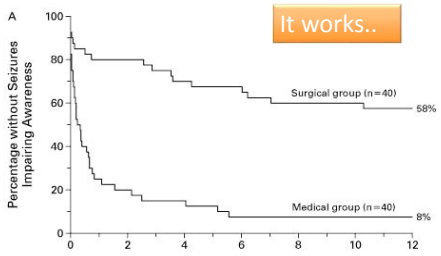
Your hospital "media team" is working really hard

So….

CNN interview: Any alternatives to epilepsy surgery??

Drug-resistant epilepsy is a very challenging problem..

Epilepsy Surgery is NOT a "media frenzy" though..



It works..

Wiebe S et al. N Engl J Med 2001;345:311-318.

Epilepsy Surgery is NOT a "media frenzy" though..

It prolongs survival..

Epilepsy Surgery for Pharmacoresistant Temporal Lobe Epilepsy
A Decision Analysis

Hyunmi Choi, MD, MS
Randall L. Sell, ScD
Leslie Lenert, MD, MS
Peter Muennig, MD, MPH
Robert R. Goodman, MD, PhD
Frank G. Gilliam, MD, MPH
John B. Wong, MD

Context Patients with pharmacoresistant epilepsy have increased mortality compared with the general population, but patients with pharmacoresistant temporal lobe epilepsy who meet criteria for surgery and who become seizure-free after anterior temporal lobe resection have reduced excess mortality vs those with persistent seizures.

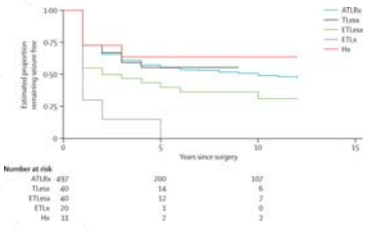
Objective To quantify the potential survival benefit of anterior temporal lobe resection for patients with pharmacoresistant temporal lobe epilepsy vs continued medical management.

Design Monte Carlo simulation model that incorporates possible surgical complications and seizure status, with 10 000 runs. The model was populated with health-

On average:
For a 35 yo undergoing temporal lobectomy:
average life expectancy increases by 5 years

Epilepsy Surgery is NOT a "media frenzy" though..

It is tested over time..



Jane de Tisi, Gail S Bell, Janet L Peacock, Andrew W McEvoy, William FJ Harkness, Josemir W Sander, John S Duncan
The long-term outcome of adult epilepsy surgery, patterns of seizure remission, and relapse: a cohort study
Lancet, Volume 378, Issue 9800, 2011, 1388–1395

But…

It comes at a cost:
- invasive
- Surgical risks
- Financial burden
- Possible neurological deficits

Of course we ask for "alternatives"..

There are many options:

- More medications
- Diet
- Vagus Nerve Stimulation
- Responsive Neurostimulation
- *Deep Brain stimulation*
- Gamma Knife
- Laser therapy
- .....

How do I highlight all these options in a 7 minute interview??

How do I stay objective ??

How do I stay clear ??

How do I balance hope vs. reality ??

...and look good !!

Objective:
- personal/hospital interest vs. patient interest
- Comprehensive vs. subjective interpretation of data

Clear:
- Technical details of procedures vs. main principles
- Focus on "politically correct" or saying the truth

Hope vs. reality:
- Role as a physician to give "most positive message possible" vs. delivering data
- Balancing "hype" about a new treatment vs. caution awaiting the test of time.

Media Relations: AES Policy and Advice

William H. Theodore, MD
Bethesda, MD

December 6, 2015

Disclosure

Name of Commercial Interest	Name of Commercial Interest
None	

Learning Objectives

- Describe the AES media policy
- Discuss communication options
- Understand barriers to communication with media

AES White Papers

- Authoritative Policy Report
  - Outlines policy, explains official positions
- Initiated by committee or task force
- Must have board approval

AES Position Statements

- A position on a specific issue
- Substitution of Different Formulations of Antiepileptic Drugs for the Treatment of Epilepsy
- Starts with a board-appointed work group
- Must have board endorsement before release
- "No society documents or activities can contradict or challenge!"

Standards and Guidelines

- Summary of best practices
  - Voluntary
  - Mandatory
  - Criteria
- Board-appointed work group
- Needs board approval
- Often created in concert with another organization, eg AAN

Other Documents
Council on Clinical Activities

- Quality indicators
  - Usually more specific than guidelines
  - Have more direct practice and reimbursement implications
- Expert consensus statements
  - Data less solid than for guidelines
- Review articles
  - Topics suggested by CCA or Epilepsy Currents

Media Inquiries

- Received by Staff
- President is primary spokesperson
- May delegate to specific expert
- Possible responses
  - Appropriate general commentary
  - Provide official position if it exists
  - Develop official statement in concert with executive committee
- Speed of response often overriding issue.

Press Materials

- Press releases
- Press Statements
- Op-ed columns
- Letters to the editor
- Fact and background sheets
- Prepared by AES media staff and member (s) involved with the issue
- Approval by president

Responding to Breaking News

- Rapid response essential to get message out
  - Will be old news tomorrow, or in an hour
- Alert executive director, president, media relations staff/consultant
- President decides on nature of response, individuals.
- Media relations staff distributes
- Calls to reporters, editors may be used

Do Reporters Get it Right?

- Response to Women's Health Initiative 2002 JAMA paper on hormone replacement risk
  - JAMA. NIH made major communication effort
- Analysis of 198 articles in 22 US papers
- major study finding that hormone therapy risks outweighed benefits reported consistently and accurately.
- When risk numbers included in newspaper stories, absolute risk used > relative risk.

Canales et al 2008

Table 4. Absolute risk compared across documents

Health outcome	JAMA article[6] and editorial[18]	NHLBI press conference[21]	Accurate newspaper accounts	Inaccurate newspaper accounts
Invasive breast cancer: Individual risk.	8 more invasive breast cancers per 10,000 person years.	It [individual breast cancer risk] was less than a tenth of 1 percent per year.	For example, (WHI) study results show that during one year, for every 10,000 women, eight more will have breast cancer if they are taking estrogen and progestin than if they are not (*Charlotte Observer*, [NC] July 9, 2002). For any individual woman, however, the risk was extremely slight - less than a 10th of a percentage point a year for breast cancer (*Boston Globe*, [MA] July 12, 2002). According to the data, if 10,000 women took the drugs for a year and 10,000 did not, women in the first group would have 8 more cases of invasive breast cancer (*New York Times*, [NY] July 15, 2002).	. . . it still translates to a relatively small increase in risk to an individual woman. Breast cancer hit 1.5 percent of women on the placebo, and 2 percent on the hormone combination (*Albuquerque Journal* [NM], July 29, 2002). But the chance that an individual woman on hormone therapy will get breast cancer is 38 in 10,000 or less than four-tenths of a percent (*Seattle Times* [WA], July 14, 2002). . . . the increased risk of cancer and heart disease is small – less than one-half of 1 percent per year . . . (*Santa Fe New Mexican* [NM], August 18, 2002).

Canales et al 2008

Individual Reporters Spin Stories

- "A type of hormone replacement therapy taken daily by 7 million women nationwide *significantly* increases the risk of breast cancer, strokes and heart attacks"(Greensboro News & Record [NC], 7.10.2002)
- " Gynecologists are reacting cautiously to the news that a combination of estrogen and progestin, often taken in the pill Prempro, *slightly* increases the likelihood of strokes, blood clots, heart attacks and breast cancer" (7.12.2002)

Canales et al 2008

Helping Journalists Get it Right

- Be clear about your message
- The audience wants to know "what does it mean for me?"
- Explain information clearly
  - 0nly 61% of medical students interpreted risk reduction data accurately
- Avoid jargon and acronymns
- Try not to answer hypothetical questions

Stamm et al 2003

Communicating Statistics

- Present absolute event rates
  - Benefit and risk
- Try to explain odds ratios and relative risk as well as possible
- Discuss uncertainty
  - Political pole reports give confidence intervals, so this is a good analogy
- Put results in context

Stamm et al 2003

Odds Ratios Versus Relative Risk

Risk	Disease status	
	Present	Absent
Smoker	a	b
Non-smoker	c	d

$$RR = \frac{p_{\text{event when exposed}}}{p_{\text{event when non-exposed}}}$$

$$RR = \frac{a/(a+b)}{c/(c+d)} = \frac{20/100}{1/100} = 20.$$

$$OR = \frac{ad}{bc}$$

The higher the base disease rate the more the OR will overstate the relative risk.

wikipedia

Telephone Interviews

- Your voice reveals your feelings
- If the interview is being taped, incorporate question into your answer
  - You don't know what will be cut
- State your point first when responding, then add support
  - You want your sound bite to be clear
- State your position firmly, but acknowledge opposing views if asked

Stamm et al 2003; http://www.acep.org/Advocacy/Effective-Media-Interview-Techniques/

When Speaking with the Media on Camera, Make Yourself Comfortable

- Try to control the scene
  - What is the message of the environment?
    - Clinic, lab ?
- Look at the reporter, not the camera
- Speak in normal voice
- "Before giving a talk, make sure your bladder is empty."
  - Attributed to Houston Merritt.

Impact on Clinical Care and Practice

- News media are our major means of communicating with the public
  - Accurate news stories contribute to good clinical care
- Simple techniques can improve communication with media
  - Reporters want to get the story right
  - They may have their own biases, just as we do.

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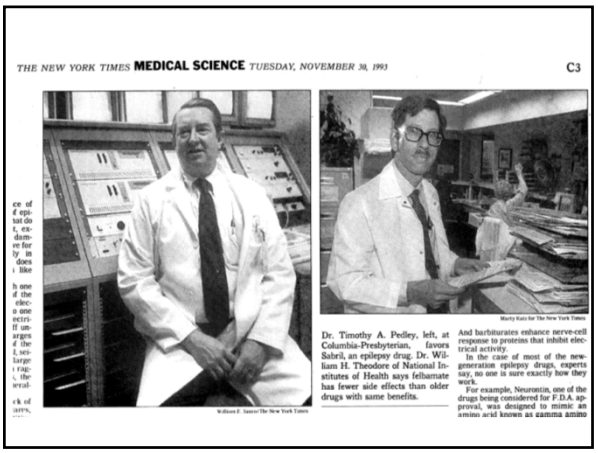


THE NEW YORK TIMES **MEDICAL SCIENCE** TUESDAY, NOVEMBER 30, 1993 C3

Dr. Timothy A. Pedley, left, at Columbia-Presbyterian, favors Sabril, an epilepsy drug. Dr. William H. Theodore of National Institutes of Health says felbamate has fewer side effects than older drugs with some benefits.

And barbiturates enhance nerve-cell response to proteins that inhibit electrical activity.

In the case of most of the new-generation epilepsy drugs, experts say, no one is sure exactly how they work.

For example, Neurontin, one of the drugs being considered for F.D.A. approval, was designed to mimic an amino acid known as gamma amino

#AESmtg15

AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

"RNS, VNS, DBS, TNS oh my!"

Christi N. Heck, M.D., M.M.M.
Professor Clinical Neurology
Keck School of Medicine
University of Southern California

Keck Medicine of USC

December 6, 2015

Disclosure

Neuropace, Inc.	• Consultant and Prescriber • General Payments Received • Associated Research funding
Cyberonics, Inc.	• Prescriber • General Payments Received

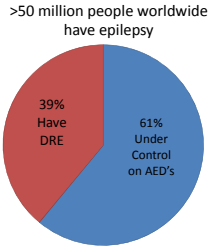
https://openpaymentsdata.cms.gov/physician/10488

Learning Objectives

- Provide updated evidence for use of device therapies in patients with medically refractory epilepsy
- Be able to individualize device selection
- Be able to field patient and family questions regarding benefits and drawbacks of each device therapy for epilepsy
- Be able to provide resources for patients and families to find out more

Unmet Need drives Treatment Innovation in Drug Resistant Epilepsy (DRE)

- 1% of the population has epilepsy.[1]
- One of the worlds top 4 causes of neurological disability.[2]
- Drug Resistant Epilepsy (DRE): defined as failure of two or more appropriate AEDs to achieve complete seizure control.[3]
- DRE is associated with:
  - Increased risk of death, injury
  - Major Depression
  - Cognitive, attention deficits
  - Lower Quality of Life
  - Increased healthcare costs



1. WHO Fact Sheet No. 999, October 2012
2. WHO Report, Neurological Disorders and Public Health Challenges, 2006
3. Kwan et al. *Epilepsia*, 2010

Unmet Need Remains

- Despite new medications, drug resistance rates remain unchanged[1]
- Side effects are common and can interfere with daily living[2,3]
- Side effects are the primary cause of treatment failure in 13% - 42% depending on the drug.[4, 5]

1. Kwan et al. *NEJM*, 2000
2. FDA Labels: Fycompa, Vimpat, Potiga
3. Walia KS et al. *Pain Pract*, 2004
4. Marson AG, *Lancet*, 2007

5

What about Surgery?

Resective surgery is appropriate for ~50% of those who undergo pre-surgical work-up

The other 50%:
Epileptic zone not defined
Epileptic zone localizes to eloquent cortex

Devices for Epilepsy

* EU Approved

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Devices for Epilepsy

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Devices Provide an Alternate Approach to Epilepsy Care

- Devices in Epilepsy are *similar*
  - Devices provide electrical stimulation to the brain to reduce seizure activity
  - Devices are automated, making compliance a non-issue
  - All have demonstrated improvement in QOL and mood scores
  - Devices have demonstrated effectiveness over time
- Devices in Epilepsy are *different*
  - Closed loop vs open loop
  - Direct brain stimulation vs peripheral nerve stimulation
  - FDA approved vs Non-FDA approved

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Open Loop

- Less new
- Provide continuous or near continuous (scheduled) therapy
- Aim to control excess electrical activity in the brain using regular electrical impulses to reduce the frequency and severity of seizures

Closed Loop

- "Newest" technology
- Responsive to physiologic triggers
  - Seizure detection
  - Other "biomarkers" of seizures
- "Smart" Devices

But really, do they work any better? Lets look at the data.

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Responsive Neurostimulation

Courtesy of Neuropace, Inc.

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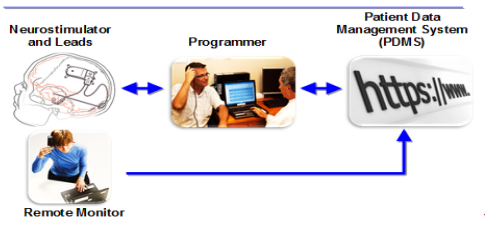
Responsive Neurostimulation



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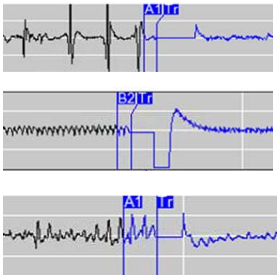
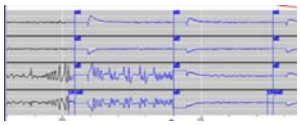
Responsive Neurostimulation

1. Physician identifies electrocorticographic activity to be detected
2. Detection settings specific to that activity are programmed
3. Stimulation is enabled using standard settings
4. Detection and stimulation is adjusted as needed



RNS® System: Responsive Neurostimulation

- Closed loop system
- Cortical targets must be identified – Individualized
- Cranial implant- not visible
- Brief, small stimulation pulses delivered through leads directly to brain
- Therapy in response to detected electro-corticographic activity



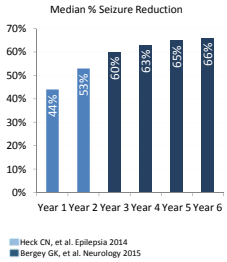
Long-term outcomes of treatment with responsive brain stimulation in adults with refractory partial seizures

[1]Heck CN et al., Epilepsia. 2014 55(3):432-41
[2]Bergey GK et al., Neurology. 2015 84:810-817

RESULTS:

- 6 year median % reduction = 66%
- 6 year responder rate = 59%
- Patients experiencing seizure-free periods of
  - At least 3 months = 37%
  - At least 6 months = 23%
  - At least 1 year= 13%
- Significant improvements in QOL included cognition and seizure worry.

† Study ongoing, interim results as of Nov 01, 2013



RNS® System: Responsive Neurostimulation

PROS

- Automated therapy provides for easy compliance
- Detects seizure onsets via continuous Ecog to treat as needed
- Minimal side effects

CONS

- No prediction of response
- Requires clear seizure localization
- Requires surgical implant and battery replacement
- Complex programming

Vagus Nerve Stimulation

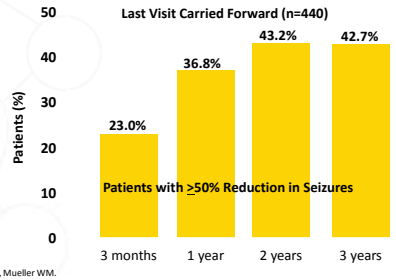
Indication
The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications.

Benefits of VNS therapy
Broad coverage, non pharmacologic, automated therapy, sustained response

Risks of VNS therapy
Battery life, Vocal cord effects

VNS Long-term Seizure Control

Response Rates Increase Over Time (E01-E05)



Morris GL III, Mueller WM. *Neurology.* 1999;53:1731-1735.

Vagus Nerve Stimulation

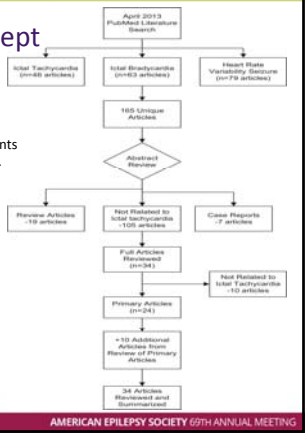
- First Neurostimulation Device for Epilepsy
- Utilizes Peripheral Nerve Access to Brain
- Automated Therapy
- Minimal Side Effects
- Open Loop Therapy Option

"Doc, that VNS will never work for me. I can't know when to use the magnet!"

- Closed Loop Therapy Option

VNS Closed Loop Concept

This review describes the prevalence and characteristics of ictal tachycardia in patients with epilepsy as reported in the literature.



Eggleston; Seizure 2014

Tachycardia as Biomarker for Seizure Onset

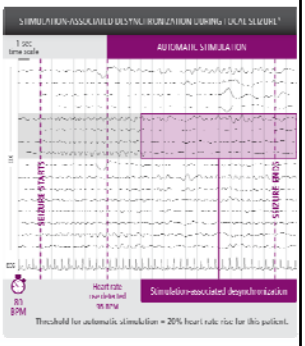
Definition of Ictal Tachycardia	Percent of Patients with ictal HR change/tachycardia for at least 1 seizure	Number of Studies
HR change/tachy NOS	38-100%	10
HR inc 10 bpm above baseline	43-100%	2
HR inc 15 bpm above baseline	83%	1
>98%ile for age	76%	1
>100 bpm	7.7-93%	3
>120 bpm	23-92%	2
>140 bpm	100%	1

Eggleston; Seizure 2014

VNS Closed Loop System

How AspireSR VNS therapy works:

- Detects rapid heart rate rise
- Delivers automatic stimulation
- Has customizable parameters to meet patients' needs
- Works in conjunction with Normal and Magnet M



Cyberonics, Inc. website

VNS Therapy Pros and Cons

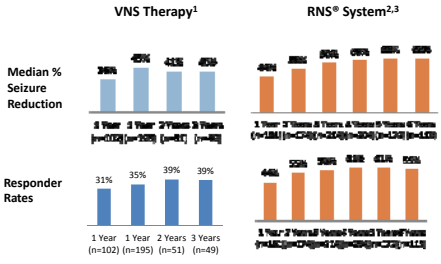
PROS

- Automated therapy provides for easy compliance
- Magnet activation for seizure abortive therapy
- Minimal side effects

CONS

- No prediction of response
- Requires surgical implant and battery replacement
- Voice changes

Prospective Data from Patients with Refractory Partial Onset Seizures



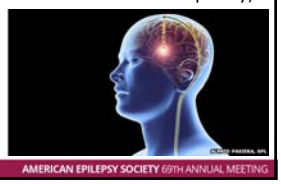
For comparability, the data included here are:

- Only from multi-center, prospective, controlled studies
- Only in patients with partial onset epilepsy

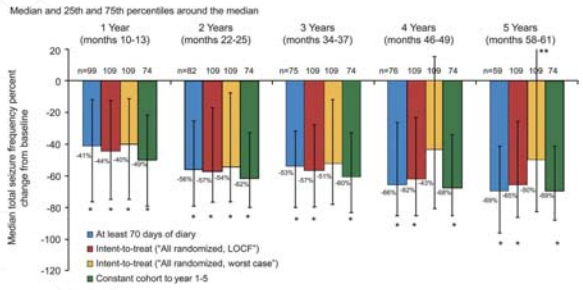
1. Cyberonics. Vagus Nerve Stimulation System: SSED. FDA, P970003, S050. 2005
2. Heck, CN. Epilepsia. 2014 Mar;55(3):432-41
3. Bergey GK. Neurology. 2015 Feb 24;84(8):810-7

Deep Brain Stimulation: DBS

- Target: Anterior Nucleus of Thalamus
- Patients may activate device on demand with hand held programmer
- SANTE trial: 110 subjects, 6 seizures per month
  - Long Term Follow up: 105 patients
  - Responder Rate (50% or more reduction in seizure frequency): 43% at 1 yr, 68% at 5 yrs
  - Adverse Event Rate: 34%



SANTE Trial: Percentage seizure reduction over time



Vicenta Salanova et al. Neurology 2015;84:1017-1025

© 2015 American Academy of Neurology

TNS: The External Trigeminal Nerve Stimulation System (eTNS)

Primarily used in sleep ~8 hours

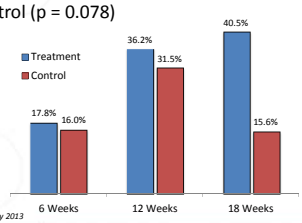
- Non-invasive
- Easy-to-use
- Pre-set stimulation algorithm, no device programming
- Patient simply adjusts current to comfort
- Worn at night
- Does not interfere with daily activities
- Approved for prescription use in EU, Canada, and Australia as an adjunctive treatment in epilepsy, age 9 and older

Courtesy NeuroSigma

Trigeminal Nerve Stimulation

Responder analysis (≥50% reduction in seizure frequency)

- Responder Rate in Treatment group improved significantly: 17.8% to 40.5% (p = 0.01), sustained over time (12 months, 50 patients)
- Between groups at 18 weeks: 40.5% treatment vs. 15.6% control (p = 0.078)



DeGiorgio et al., *Neurology 2013*

Patient Concerns/Misconceptions

RNS: Newer technology = Better
Brain Surgery
Battery life

VNS: Magnet use or Inability to detect seizure onsets
Voice changes
Scar location

DBS: Not yet approved in US
Invasive to brain
Battery life

TNS: Must be worn/requires compliance
Could it be predictive of device therapy prior to implants?

THERE ARE NO HEAD TO HEAD COMPARISON STUDIES

RNS, VNS, DBS, TNS, oh my! How Does One Decide?

Individualize just as you would with any treatment.
Consider:

- Are seizures localizable?
- How often must patient come in?
  - Long distance travel complicates ability for close follow up
- How compliant is the patient?
  - Implantables may improve seizure control
- What is the patient's occupation or pastime?
  - Singing, Long distance running, Swimsuit modeling
  - Intra-cranial device may be more conducive

Patient resources: Epilepsy.com

Annual Course

Laser Surgery is the Best Option (Pro)

Daniel Curry, M.D.

Slides not available

Laser Surgery is NOT the best option

Kristen Riley, MD, FACS
University of Alabama at Birmingham

December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosures

None

Learning Objectives

- Review the literature regarding laser surgery for epilepsy
- Recognize limitations of laser surgery
- Discuss potential applications and directions for the future

Impact on Clinical Care and Practice

- Laser surgery is a "hot topic"
  - Patients may hear about the technique thru the media
  - Epileptologists and surgeons need to be informed of evidence based data regarding laser surgery
- Paucity of outcomes data available
  - Publications on safety profile
  - Recognize industry influence

Background

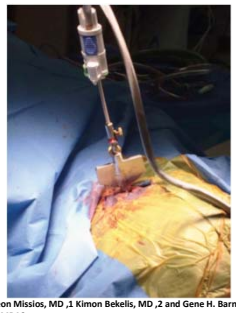
- 1983: Description of laser interstitial therapy published, Brown
- 1990: Sugiyama treating brain lesions
- 2012: Curry et al. described use for epilepsy
- Recent: MRI guided LITT

Perception

- "not surgery"
- "cheaper than open surgery"

Reality

- Surgical procedure
- General anesthesia
- Head fixation
- Burr hole
- Cannula into brain
- Intentional damage to brain resulting in cerebral edema
- Hospital stay



Symeon Missios, MD ,1 Kimon Bekelis, MD ,2 and Gene H. Barnett, MD , MBA3
Renaissance of laser interstitial thermal ablation
Neurosurg Focus 38 (3):E13, 2015

COSTS: Capital approx $400,000

Laser ablation therapy: An alternative treatment for medically resistant mesial temporal lobe epilepsy after age 50
Waseem H, Osborn K , Schoenberg M, Kelley V, Bozorg A, Cabello D , Benbadis S, Vale F

OR charges (USD)	AMTL	MRgLITT
Mean	63,991	89,759
Range	55,255 to 76,716	79,184 to 106,687
Total hospitalization charges (USD)		
Mean	98,471	119,818
Range	86,594 to 122,199	99,303 to 140,586

Laser Surgery for Epilepsy

Not all nails are created equal

Evidence in Epilepsy

- Publications support safety
- Efficacy?
- Case series: Curry (5 peds, 14 HH), Miami group (17 peds), Gross (13 adults), Vale (7 adults)
- Case reports: dominant insular, HH with complication, nodular heterotopia, cavernous malformations
- Multi-institutional series: not yet published

Periventricular Heterotopia

Stereotactic laser ablation of epileptogenic periventricular nodular heterotopia
Yoshua Esquenazi, Giridhar P. Kalamangalamb,Jeremy D. Slater, Robert C. Knowlton, Elliott Friedman, Saint-Aaron Morris, Anil Shetty, Ashok Gowdad, Nitin Tandon

2 cases-
Safe
Initially seizure free, then recurrent seizures
1- then sz free with med
2- seizure free after further IM and ATL

Conclusion: MRgLITT possesses significant potential as a minimally invasive technique for ablation of PVNH, and more generally, as an adjunct in the surgical management of lesional epilepsy. In this study we demonstrate the safety, feasibility and limited efficacy of MRgLITT in PVNH-associated epilepsy, though its long-term efficacy will be revealed as more centers adopt the technology in the future.

Dominant Insular Case Report

Case Report

Stereotactic and Functional Neurosurgery

Stereotact Funct Neurosurg 2014;92:397–404
DOI: 10.1159/000366001

Received: January 22, 2014
Accepted after revision: July 14, 2014
Published online: October 29, 2014

Laser Ablation as Treatment Strategy for Medically Refractory Dominant Insular Epilepsy: Therapeutic and Functional Considerations

Ammar H. Hawasli[a] S. Kathleen Bandt[a] R. Edward Hogan[b] Nicole Werner[b] Eric C. Leuthardt[a, c, d]

Departments of [a]Neurosurgery, [b]Neurology and [c]Biomedical Engineering, and [d]Center for Innovation in Neuroscience and Technology, Washington University School of Medicine, St. Louis, Mo., USA

Hypothalamic Hamartoma

Epilepsy, 56(Suppl. 1):108–114, 2015
doi: 10.1111/epi.12854

TUMORS AND TUMORAL EPILEPSY

Hypothalamic hamartomas: Optimal approach to clinical evaluation and diagnosis

*Angus A. Wilfong and †Daniel J. Curry

Divisions of *Pediatric Neurology and †Pediatric Neurosurgery, Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, U.S.A.

SUMMARY

Hypothalamic hamartomas (HHs) present a difficult medical problem, manifested by gelastic seizures, which are often medically intractable. Although existing techniques offer modest surgical outcomes with the potential for significant morbidity, the relatively novel technique of magnetic resonance imaging (MRI)–guided stereotactic laser ablation (SLA) offers a potentially safer, minimally invasive method with high efficacy for the HH treatment. We report here on 14 patients with medically refractory gelastic epilepsy who underwent stereotactic frame-based placement of an MR-compatible laser catheter (1.4 mm diameter) through a 3.2-mm twist drill hole. A U.S. Food and Drug Administration (FDA)–cleared laser surgery system (Visualase, Inc.) was utilized to ablate the HH, using real-time MRI thermometry. Seizure freedom was obtained in 12 (86%) of 14 cases, with mean follow-up of 9 months. There were no permanent surgical complications, neurologic deficits, or neuroendocrine disturbances. One patient had a minor subarachnoid hemorrhage that was asymptomatic. Most patients were discharged home within 1 day. SLA was demonstrated to be a safe and effective minimally invasive tool in the ablation of epileptogenic HH. Because use of SLA for HH is being adopted by other medical centers, further data will be acquired to help treat this difficult disorder.

KEY WORDS: Hypothalamic hamartoma, Treatment, Stereotactic laser ablation, Visualase, Surgery.

Hypothalamic Hamartoma

Contents lists available at ScienceDirect

Epilepsy & Behavior Case Reports

journal homepage: www.elsevier.com/locate/ebcr

Case Report

Disabling amnestic syndrome following stereotactic laser ablation of a hypothalamic hamartoma in a patient with a prior temporal lobectomy☆

Sarah Zubkov[a], Victor A. Del Bene[b], William S. MacAllister[a], Timothy M. Shepherd[a], Orrin Devinsky[a,*]

ARTICLE INFO

ABSTRACT

A 19-year-old man with cortical dysplasia and intractable focal seizures underwent a right temporal lobectomy. A hypothalamic hamartoma was subsequently recognized, and he then underwent MRI-guided stereotactic laser ablation. Unfortunately, he sustained damage to the bilateral medial mammillary bodies and suffered significant memory loss. We review laser ablation therapy for hypothalamic hamartomas and the anatomy of the memory network. We postulate that his persistent memory disorder resulted from a combination of the right temporal lobectomy and injury to the bilateral medial mammillary bodies.

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Magnetic Resonance Imaging-Guided Focused Laser Interstitial Thermal Therapy for Intracranial Lesions: Single-Institution Series

Ammar H. Hawasli, MD, PhD
Swapnil Bagade, MD
Joshua S. Shimony, MD, PhD
Michelle Miller-Thomas, MD
Eric C. Leuthardt, MD

BACKGROUND: Surgical treatments for deep-seated intracranial lesions have been limited by morbidities associated with resection. Real-time magnetic resonance imaging–guided focused laser interstitial thermal therapy (LITT) offers a minimally invasive surgical treatment option for such lesions.

OBJECTIVE: To review treatments and results of patients treated with LITT for intracranial lesions at Washington University School of Medicine.

METHODS: In a review of 17 prospectively recruited LITT patients (34-78 years of age; mean, 59 years), we report demographics, treatment details, postoperative imaging characteristics, and peri- and postoperative clinical courses.

RESULTS: Targets included 11 gliomas, 5 brain metastases, and 1 epilepsy focus. Lesions were lobar (n = 8), thalamic/basal ganglia (n = 5), insular (n = 3), and corpus callosum (n = 1). Mean target volume was 11.6 cm³, and LITT produced 93% target ablation. Patients with superficial lesions had shorter intensive care unit stays. Ten patients experienced no perioperative morbidities. Morbidities included transient aphasia, hemiparesis, hyponatremia, deep venous thrombosis, and fatal meningitis. Postoperative magnetic resonance imaging showed blood products within the lesion surrounded by new thin uniform rim of contrast enhancement and diffusion restriction. In conjunction with other therapies, LITT targets often showed stable or reduced local disease. Epilepsy focus LITT produced seizure freedom at 8 months. Preliminary overall median progression-free survival and survival from LITT in tumor patients were 7.6 and 10.9 months, respectively. However, this small cohort has not been followed for a sufficient length of time, necessitating future outcomes studies.

CONCLUSION: Early peri- and postoperative clinical data demonstrate that LITT is a safe and viable ablative treatment option for intracranial lesions, and may be considered for select patients.

KEY WORDS: Laser, Laser interstitial thermal therapy, LITT, Minimally invasive surgery, Stereotactic surgery

Neurosurgery 73:1007–1017, 2013

www.neurosurgery-online.com

Received, April 21, 2013.
Accepted, August 22, 2013.
Published Online, September 19, 2013.

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Temporal lobe epilepsy

Better object recognition and naming outcome with MRI-guided stereotactic laser amygdalohippocampotomy for temporal lobe epilepsy

*†‡Daniel L. Drane, *†David W. Loring, §Natalie L. Voets, *Michele Price, ¶Jeffrey G. Ojemann, *#Jon T. Willie, **Amit M. Saindane, ‡Vaishali Phatak, *Mirjana Ivanisevic, ††Scott Millis, *†Sandra L. Helmers, ‡¶John W. Miller, *†Kimford J. Meador, and *#Robert E. Gross

Epilepsia, 56(1):101–113, 2015
doi: 10.1111/epi.12860

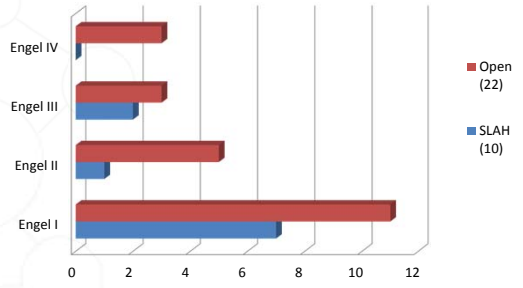
"Finally, future research needs to assess the clinical significance of declines in famous face recognition and naming."

Table 3. Change in cognitive function by surgery type, laterality of procedure, and seizure outcome

	Cognitive outcome – same or improved	Cognitive outcome – declined
Dominant TL procedures		
Engel I	SLAH – 7; Open – 1	SLAH – 0; Open – 10
Engel II	SLAH – 1; Open – 0	SLAH – 0; Open – 5
Engel III	SLAH – 2; Open – 0	SLAH – 0; Open – 3
Engel IV	SLAH – 0; Open – 0	SLAH – 0; Open – 3
Nondominant TL procedures		
Engel I	SLAH – 4; Open – 5	SLAH – 0; Open – 8
Engel II	SLAH – 0; Open – 0	SLAH – 0; Open – 2
Engel III	SLAH – 2; Open – 1	SLAH – 0; Open – 1
Engel IV	SLAH – 3; Open – 0	SLAH – 0; Open – 0

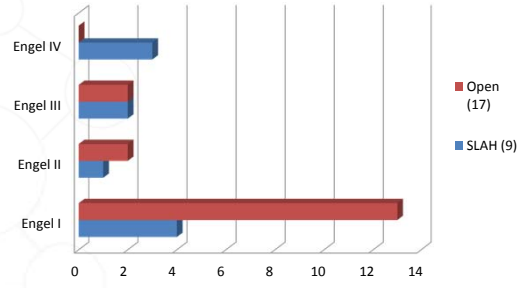
TL, temporal lobe; SLAH, selective laser amygdalohippocampotomy. In this study, cognitive outcome is limited to object and face recognition and naming.

Dominant TL



Data from Gross et al; Better object recognition and naming outcome with MRI-guided SLAH for TLE

Non-Dominant TL



Data from Gross et al; Better object recognition and naming outcome with MRI-guided SLAH for TLE

Patient preference

- Cognitive risk versus seizure freedom
  - Need to define/clarify cognitive risk
- Patients will often select a deficit over continued seizures
- Repeat procedures: SLAH or open resection
  -key to understand reason for failure

Future

- Comprehensive outcome data
- Delineation of indications and limitations
- Long term follow up

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AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

9pm : A Cocktail Hour Question about Cannabis

Kelly Knupp, MD
University of Colorado

December 6, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Nothing to disclose

9:07 pm

Cocktail party meeting the new neighbors who are a lawyer and a news director for the local TV station

9:12 pm "I saw your hospital was on the news"

Would you be willing to speak to our reporter?

9:20 pm: I saw this recent article ..

I saw this article online, are you able to get a copy for me? My cousin Johnny is considering surgery and I thought this might work better.

9:33pm "You must get this question a lot…"

What is your opinion on this medical marijuana thing?

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

How should you answer all these questions?

- Media
  - How do you get your message to the public?
  - Making sure your talking points are heard?
- Journal access
  - Should it be more open?
- What to tell people about cannabis?
  - Is there any data?
  - Is it harmful?

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

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AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Getting Your Message to the Public: How to Navigate the World of Reporters and Lawyers

Robert I. Field, JD, MPH, PhD
Drexel University

December 6, 2015

Disclosure

None

Learning Objectives

- Understand the use of scientific expertise by the media
- Understand the use of scientific expertise in legal proceedings
- Identify risks of miscommunication

Impact on Clinical Care and Practice

- Opportunity to accurately explain clinical concepts to the broader public

What do reporters want?

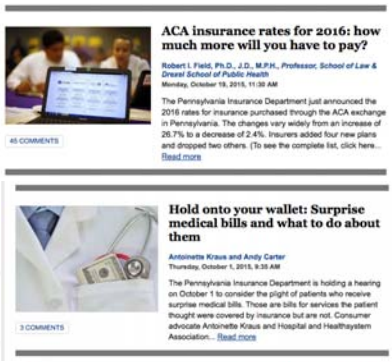
What kind of story is the reporter is working on?

- •Medical breakthrough
- •How-to advice
- •Breaking news
- •Medical curiosity
- •Human interest
- •Expose

What do reporters want for a story?

- A story line
- Human interest angle
- Situations readers can identify with
- Information readers can use

What do reporters want? – advice, relationship to reader



ACA insurance rates for 2016: how much more will you have to pay?

Robert I. Field, Ph.D., J.D., M.P.H., *Professor, School of Law & Drexel School of Public Health*
Monday, October 19, 2015, 11:30 AM

The Pennsylvania Insurance Department just announced the 2016 rates for insurance purchased through the ACA exchange in Pennsylvania. The changes vary widely from an increase of 26.7% to a decrease of 2.4%. Insurers added four new plans and dropped two others. (To see the complete list, click here... Read more

45 COMMENTS

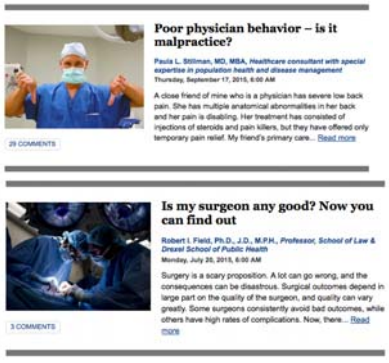
Hold onto your wallet: Surprise medical bills and what to do about them

Antoinette Kraus and Andy Carter
Thursday, October 1, 2015, 9:35 AM

The Pennsylvania Insurance Department is holding a hearing on October 1 to consider the plight of patients who receive surprise medical bills. Those are bills for services the patient thought were covered by insurance but are not. Consumer advocate Antoinette Kraus and Hospital and Healthsystem Association... Read more

3 COMMENTS

What do reporters want? – strong reader response



Poor physician behavior – is it malpractice?

Paula L. Stillman, MD, MBA, *Healthcare consultant with special expertise in population health and disease management*
Thursday, September 17, 2015, 6:00 AM

A close friend of mine who is a physician has severe low back pain. She has multiple anatomical abnormalities in her back and her pain is disabling. Her treatment has consisted of injections of steroids and pain killers, but they have offered only temporary pain relief. My friend's primary care... Read more

29 COMMENTS

Is my surgeon any good? Now you can find out

Robert I. Field, Ph.D., J.D., M.P.H., *Professor, School of Law & Drexel School of Public Health*
Monday, July 20, 2015, 6:00 AM

Surgery is a scary proposition. A lot can go wrong, and the consequences can be disastrous. Surgical outcomes depend in large part on the quality of the surgeon, and quality can vary greatly. Some surgeons consistently avoid bad outcomes, while others have high rates of complications. Now, there... Read more

3 COMMENTS

What to do first if a reporter calls or emails

- •Respond quickly
  - •Reporters on deadline may not wait for a reply
- •Are you an expert or a subject of the story?
  - •If an expert, the reporter wants to make you look good
  - •If a subject, tread carefully, contact your institution's PR department
- •Find out the reporter's deadline
  - •Usually the same day
  - •If not, you may be able to call back when you have more time and can prepare

What to say during an interview

- Keep it accurate
  - Reporters' greatest concern is getting facts wrong
- Disclose any conflicts of interest
  - The reporter can decide if they are relevant
- Simplify – but don't dumb down
  - Imagine you are explaining your work to an intelligent family member
  - Think about what a patient would understand

What to say during an interview

- Use metaphors and sound bites
  - Having a seizure is like _____
  - An image of brain activity during a seizure looks like _____
- Add anecdotes about patients, if identities can be disguised
  - Readers relate to patients
  - Offer to contact a patient to see if he or she would agree to an interview

What to avoid during an interview

•Think before you speak
- Declare "off the record" or "not for attribution" before speaking

•Do not ask to see the story before publication
- It suggests you don't trust the reporter
- Instead, offer your cell phone number or email for follow-up questions
- Offer to review the story for accuracy

- Do not oversell
  - Do not over-hype a drug, device or discovery
  - You may mislead the reporter or come across as a salesperson

What to do after an interview

•Let the reporter know you liked the story

•Offer your assistance again, even if just for background

•Send the reporter compliments on future stories you like

Remember

If the reporter contacts you as an expert, he or she wa

Sample quote from an expert

New York Times May 16, 2008
"Easing the Seizures, and Stigma, of Epilepsy"

"There is an ongoing, significant embarrassment level about it," said Dr. Orrin Devinsky, director of the Epilepsy Center at New York University. "The feeling, for a lot of people, is that it does carry a lot worse stigma than a cancer, or an H.I.V. even. At some level, **it's society that needs to wake up and realize it's just another neurologic disorder**."

Sample quote from an expert

New York Times, February 8, 2012
"Study Explores Electrical Stimulation as an Aid to Memory"

"**People should run to replicate this study**, because the implications are incredibly exciting, both for understanding the mechanism for encoding new memories, and ultimately for the treatment of neurological diseases" like dementias, said Michael J. Kahana, a neuroscientist at the University of Pennsylvania, who was not involved in the research.

Advice for broadcast media - radio

Live

- Don't think about the audience, have a conversation with the interviewer
- Live in the studio is always better than remote
- Over-prepare to feel confident, but avoid unnecessary details
- Keep responses to the point
- Remember the intelligent family member

Taped

- Think in sound bites, metaphors, personal anecdotes
- Don't hesitate to request do-overs

Advice for broadcast media - television

Live

- Dress nicely
- Don't think about the audience, talk to the interviewer
- If studio is remote, imagine the interviewer
- Do not look at the monitor

Taped

- Dress nicely – from the waist up
- Straighten up your office
- Don't hesitate to ask if your hair is neat, tie is straight, etc.
- Make friends with the cameraman
  - Ask if the lighting, background, etc. are alright
- Look at and speak to the interviewer

Using social media - Twitter

- Open a Twitter account
- Build followers
- Regularly post interesting developments
- Follow other researchers, reporters, organizations
- Post broadcast appearances in advance so followers can watch or listen
- Post links to stories or podcasts of interviews
  - Add a key point you made
  - Use hashtags
  - Direct posts to reporters, colleagues, your PR office

Using social media – Facebook and LinkedIn

- If you have a Facebook or LinkedIn account
  - Post broadcast appearances in advance
  - Post links to interviews and podcasts
  - Add a key point you made

Epilepsy in legal proceedings

- Most common kinds of cases
  - Pharmaceutical liability
  - Reimbursement
  - Patient restrictions and rights
  - Malpractice

What do lawyers want – compelling understandable case

Detroit Legal News, February 9, 2011
Lawsuits over anti-seizure drug Dilantin turn into a mini mass tort
About 100 cases have been filed nationwide

"**It's a nasty disease so there will be very sympathetic plaintiffs. Plaintiffs' lawyers are going to be interested in death cases, especially young kids with high pain and suffering [damages]**," said James Beck, a products liability defense attorney at Dechert LLP in Philadelphia who co-authors a drug and device law blog.

Epilepsy in legal proceedings

What is your role?

- Party
  - Plaintiff or defendant
- Expert
  - General advice
  - Background report
  - Formal opinion about which you can testify

Advice for communicating with lawyers

- Keep it accurate
  You will regret misstatements if you later testify
- Disclose conflicts of interest
  The lawyer can decide if they are relevant
- Remember who the client is
- Stick to the facts
- Be direct – admit when you don't know something, or when something is not known

What do lawyers want from an expert?

Understandable science

Explanation of personal impact

Compelling story

Opinion that supports the case

Credibility as an expert

When is expert scientific testimony admissible?

***Daubert v. Merrell Cow Pharmaceuticals*, Supreme Court, 1993**

- Judge decides whether to admit expert scientific testimony
- Bases decision in part on credentials of the expert
- If you have strong credentials, you have great value in litigation

What do lawyers want?

What makes a credible expert?

- Training
- Clinic experience
- Research and publications
- Professional leadership
- Lack of prior conflicting testimony
- Personal persuasiveness

What do lawyers want, if you are a defendant?

- What makes a sympathetic defendant?
  - Humble, not arrogant
  - Hard-working
  - Concern for patients
  - Contributions to science/profession

How to avoid malpractice claims

- Spend time with patients
  - Listen to their concerns
  - Answer their questions
  - Explain options as thoroughly as you can
  - Show concern
  - Take time, do not seem rushed or preoccupied, even if you are
  - Return phone calls
- An investment of time can pay off later
  - Patient communication is usually more effective than ordering more tests

Advice for communicating with lawyers

Remember –

The lawyer wants to win a case, not become a scientist

He or she wants to understand a lot in a short amount of time

He or she has no interest in unnecessary details

Bottom Line in Speaking with Reporters and Lawyers

You are an ambassador for science and medicine

Effective public communication is part of effective public health

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AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Epilepsy journals and free access for patients: a good idea?

Steven Schachter, MD

Harvard Medical School and
Beth Israel Deaconess Medical Center,
Boston, MA

December 6, 2015

Disclosure

Editor-in-Chief:	*Epilepsy & Behavior*
Royalties:	UpToDate, Elsevier
Board of Directors:	Epilepsy Foundation

Learning Objectives

- Describe how persons with epilepsy, family members, and others can access current articles published in *Epilepsy & Behavior,* full-text, via the internet
- Contrast this user experience with other methods for learning about newly published research
- Evaluate the early response of the public to this new web-based initiative

Overview

- Background
- *patient*INFORM
- New EF – *E&B* – *patient*INFORM initiative
- Initial metrics and future plans

Background

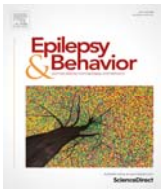
- Published articles in subscription-based medical journals are generally available to the public only when open access or indexed in PubMed Central
- Open access articles and journals, including epilepsy journals, are increasing in number on the internet, and include *Epilepsy Currents*, *Epilepsy & Behavior Case Reports* (Elsevier), and *Epilepsy Research and Treatment* (Hindawi)

Background

- In all cases, however, articles are accessed as stand-alone materials; i.e., not embedded in an educational epilepsy-related resource for lay persons

Background

- *Epilepsy & Behavior* was launched in 2000 and features patient-centered research that has potential to improve the day-to-day lives of persons with epilepsy and their families (Schachter, *Epilepsy Behav* 2014;40:4-7)



Background

- Quality of life, stigma, perception and attitudes, non-pharmacological treatments, and psychosocial problems are frequent topics of original research, reviews, and editorials
- While scientifically rigorous and peer-reviewed, a large subset of articles in *E&B* do not require specialized knowledge to read

Background

- Beginning in 2005, through a unique arrangement between the Epilepsy Foundation (EF) and Elsevier, two articles selected by EF from each issue of *E&B* were made available, full text, on the EF website upon publication for free access by anyone
- These pages quickly became some of the most visited pages on the entire EF website, and frequently generated comments and discussion in chat rooms and blogs, moderated by an epilepsy healthcare professional

Background

- This initial relationship resulted in what appeared to be the only example at that time of a subscription-based medical journal in which some articles were made freely available in full-text upon publication

*patient*INFORM

- *patient*INFORM (www.patientinform.org) is a collaborative private-sector initiative of medical publishers, health organizations, medical societies, and health information professionals
- Created in 2005 under the leadership of the Association of American Publishers, the American Cancer Society, the American Diabetes Association and the American Heart Association

patientINFORM
ACCESS + INTERPRETATION = UNDERSTANDING + EMPOWERMENT

*patient*INFORM

- *patient*INFORM (www.patientinform.org) therefore enables patients and their families/caregivers to access some of the most up-to-date research on diagnosis and treatment of specific diseases through the web sites of participating health organizations, provided free of charge

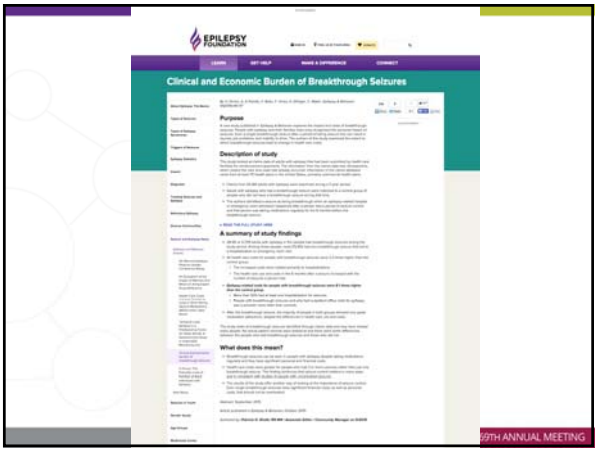
*patient*INFORM

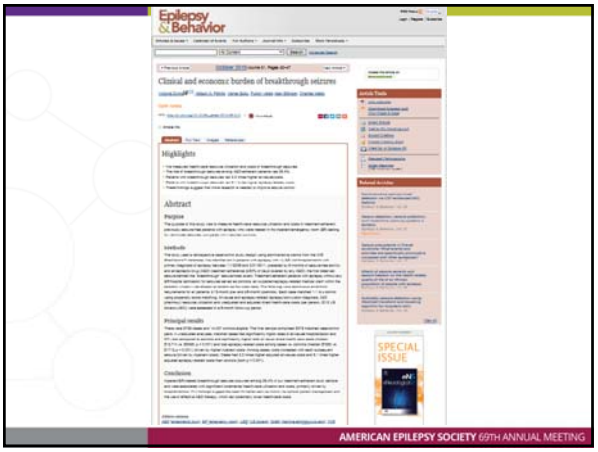
- As of October 15, 2015, there were 21 participating organizations (including EF and the Tuberous Sclerosis Alliance) and 23 participating publishers (including Elsevier), representing many leading medical journals in a variety of medical specialties

EPILEPSY FOUNDATION Tuberous Sclerosis Alliance NORD National Organization for Rare Disorders

New EF – *E&B* – *patient*INFORM initiative

- EF and Elsevier re-launched their partnership in June, 2015 to leverage the expanded content on the EF website epilepsy.com, after the merger with ETP, and the advent of *patient*INFORM
- Epilepsy.com editors select up to two articles to feature from each issue of *E&B*, and provide summaries of those articles on epilepsy.com with a link that opens a new window with the full-text article





New EF – *E&B* – *patient*INFORM initiative

- Visitors to epilepsy.com can readily access related educational and advocacy content elsewhere on the EF site and submit questions to professional epilepsy experts
- This is one advantage for lay persons over stand-alone materials obtained through open access or via media reports

Welcome to Epilepsy.com!

Related Links
Seizures in Newborns and Infants
Kids with Epilepsy and Seizures
Teens with Epilepsy and Seizures
Talking to Kids about Epilepsy
Find your local Epilepsy Foundation
Epilepsy Foundation Individual & Family Services
National and Community Resources
Getting Your Child Ready for School

Epilepsy Foundation 24/7 Helpline

Initial metrics and future plans

- Over the first four months, six articles have been featured and 8,000 people have viewed the summaries and articles
- The two top-read articles to date:
  - "Clinical and economic burden of breakthrough seizures"
  - "In focus: the everyday lives of families of adult individuals with epilepsy"

Initial metrics and future plans

- Other selected articles:
  - Temporal lobe epilepsy is a predisposing factor for sleep apnea
  - 4th Biennial Epilepsy Pipeline Update Conference recap
  - Health care costs and use related to long or short acting seizure medications (AEDs) when used alone
  - An evaluation of the impact of memory and mood on antiepileptic drug adherence

Initial metrics and future plans

- Plans are underway to build stronger engagement with website visitors through
  - rich media interaction tools such as podcasts led by *E&B* article authors
  - discussion forums to allow greater audience connectivity with *E&B* article authors, which could result in ideas for further research studies

Initial metrics and future plans

- Plans are underway to build stronger engagement with website visitors through
  - soliciting feedback from users
  - assessing outcomes of the user experiences
  - Identifying who the users are (PWE, family members, friends, etc; US, Europe, Asia, etc)
  - understanding and addressing any unanticipated consequences (none have been seen so far)

Conclusions

- Evolving technology now makes it possible for patients with epilepsy to read current articles in a wide range of medical journals
- The EF – *E&B* – *patient*INFORM model facilitates access to articles of particular interest to visitors to epilepsy.com in the context of a customized summary and access to other educational and advocacy content on the site

Conclusions

- Early metrics seem to show that significant numbers of visitors to epilepsy.com view *E&B* articles
- Free access for patients to epilepsy journals in this model appears to be a good idea
  - However, this initiative is still evolving
  - Feedback will be obtained from users and outcomes of their experiences will be assessed

Photo credit: http://www.virginiawomenscenter.com/patient-resources.html

#AESmtg15

AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Cannabidiol - Helpful or just reefer madness?

Elizabeth A. Thiele, MD, PhD
Director, MGH Pediatric Epilepsy Program
Director, Herscot Center for Tuberous Sclerosis Complex
Professor of Neurology, Harvard Medical School

December 6, 2015

American Epilepsy Society
69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Novartis Pharmaceuticals
Upsher-Smith Pharmaceuticals
Marathon Pharmaceuticals
Eisai Pharmaceuticals
Zogenix Pharmaceuticals
GW Pharma

Effective treatments for refractory epilepsy: significant remaining unmet need

- 1/3 of epilepsy patients develop medically intractable or refractory epilepsy
- And this has not changed even with all of our new medications. Why?
  - Do we need different models?
  - Do we need to identify different mechanisms of action?
- Effective "alternative" therapies do exist
  - Dietary therapy
  - Stimulators: VNS, RNS
  - Epilepsy surgery

Effective treatments for refractory epilepsy: significant remaining unmet need

- In 2015, there continues to be a significant unmet need for patients with refractory epilepsy
  - Focal epilepsies
  - Genetic epilepsies
    - Dravet syndrome
    - Tuberous Sclerosis Complex
    - Angelman syndrome
  - "Catastrophic" epilepsy syndromes
    - Lennox Gastaut syndrome
    - Infantile spasms

The unmet need in refractory epilepsy: making a case for cannabidiol

- Not a new idea - what can history teach us?
- Do possible mechanisms of action make sense?
- What do the preclinical studies suggest?
- What is the clinical "data"?
- What do we need to know?

The unmet need in refractory epilepsy: making a case for cannabidiol

- Cannabis used as medical treatment for thousands of years
  - 2200 BCE, Sumaria
    first documented use in epilepsy
  - 1100 CE, *al-Mayusi*
    nasal treatment with cannabis leaf for seizu
  - 1400's CE, *al-Badri*
    regular use of cannabis for epilepsy

Making a case for cannabidiol: Use of cannabis in treating epilepsy

- 1842: O'Shaughnessy reported cannabis reduced infantile convulsions, hydrophobia (rabies), lockjaw (tetanus) and rheumatism
- 1878: Sinkler reported cannabis led to seizure freedom in 10 year old boy with focal epilepsy: previously having 4-5 seizures nightly and cognitive/behavioral regression

Making a case for cannabidiol: Use of cannabis in treating epilepsy

- 1881: William Gowers reported cannabis had been recommended for epilepsy by Russell Reynolds in 1861 as "sometimes, though not very frequently, useful…small value as an adjunct to the bromide, but is sometimes of considerable service given separately…"
- Gowers administered cannabis in many cases, with the effect of delaying paroxysms and mitigating the severity in some individuals

Making a case for cannabidiol: Use of cannabis in treating epilepsy

- 1851: US Dispensary
  Cannabis compounds suggested for neuralgia, depression, hemorrhage, pain relief and muscle spasm, convulsive disorders and other ailments
- 1860: Ohio Medical Society Committee on Cannabis Indica
  Efficacy claimed for infantile convulsions, epilepsy and many other disorders

Making a case for cannabidiol: Use of cannabis in treating epilepsy

- 1911: Massachusetts first state to outlaw cannabis (in setting of prohibition of alcohol)
  - Other states quickly followed with marijuana prohibition laws
- 1970: US Controlled Substances Act passed, classifying marijuana as a drug with "no accepted medical use."

Making a case for cannabidiol: Use of cannabis in treating epilepsy

- 1996: California becomes first state to legalize medical marijuana
- 2015: Medical marijuana legalized in 23 US states
  - Regulated at state level
  - CBD specifically made legal in an additional 16 states
- Increasing anecdotal reports about efficacy of medical marijuana, especially CBD-enriched formulations in the treatment of refractory pediatric epilepsy

Medical marijuana: is it effective in treating refractory epilepsy?

- Solicited data from an online Facebook survey of 150 families whose children were using cannabidiol-enriched cannabis to treat drug resistant seizures
- 19 responses (12.7%): 13 Dravet syndrome, 4 Doose syndrome, 1 Lennox-Gastaut syndrome, 1 idiopathic epilepsy
  - Average of 12 prior AEDs

Porter & Jacobson, Epilepsy Behav 2013

Medical marijuana: is it effective in treating refractory epilepsy?

- Overall, 84% noted decreased seizure frequency on CBD:
  - 2 (11%) had complete remission
  - 8 (42%) had >80% reduction in seizure frequency
  - 6 (32%) had 25-60% reduction
- Cannabidiol was associated with adverse events:
  Drowsiness: 37%, Fatigue: 16%
- and with some side benefits:
  Better mood: 79%,Increased alertness: 74%
  Better sleep: 68%

Porter & Jacobson, Epilepsy Behav 2013

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Medical marijuana: is it effective in treating refractory epilepsy?

- Online survey of parents of children with epilepsy who had used CBD products
  - 117 responses
    - Mean latency from epilepsy onset to CBD use 5 years
    - Mean of 8 prior medication trials
  - Included 53 with IS or LGS
- 85% reported reduction in seizure frequency
  - 14% seizure free
  - Many reported improved sleep, alertness and mood

Hussain et al, Epilepsy Behav 2015

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Medical marijuana: is it effective in treating refractory epilepsy?

- Survey study limitations:
  - Subject to participation bias
  - Unknown formulations
  - No control group

Porter, B. E. & Jacobson, C. Epilepsy Behav 2013
Hussein et al, Epilepsy Behav 2015

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Cannabidiol: why a possible seizure treatment? Does it work through the endocannabinoids?

- Cannabis is the only plant species with cannabinoids
- Cannabinoid receptor family
  - CB(1) and CB(2)—CB(1) most abundant
  - G protein coupled transmembrane receptor
    - Activate voltage-gated Ca channels
    - Enhances K channel conduction presynaptically
- "Endocannabinoids"
  - 2-arachidonoylglycerol (2-AG) and anandamide
    - Endogenous lipid signaling molecules
    - Generated at cell membrane from phospholipid precursors
    - Modulate neuronal excitability

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Cannabidiol: why a possible seizure treatment? Does it work through the endocannabinoids?

- Is there evidence?
  - Lower levels of anandamide in CSF of patients with newly diagosed temporal lobe epilepsy
  - Tissue resected during epilepsy surgery with lower levels of CB1R mRNA and reduced expression of enzyme responsible for synthesis of 2AG
- But cannabidiol does not exert main neural effects through activation of CB1R
  - May function as indirect antagonist at high levels

Romigi et al Epilepsia 2010
Ludanyi et al, J Neurosci 2008

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Cannabidiol: why a possible seizure treatment? What are other possible mechanisms of action?

- Decreases presynaptic release of glutamate
  - By binding to members of TRP family of cation channels
- Activates 5HT 1A receptors
- Inhibits adenosine reuptake
- Anti-inflammatory?
- Antioxidant?
- Modulation of mTOR pathway?
- ?????

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Cannabidiol: why a possible seizure treatment? What have animal models shown?

- CBD shown to be effective in several acute seizure models
  - PTZ-induced seizures
  - MES-induced seizures
  - Pilocarpine-induced temporal lobe seizures
  - Penicillin induced partial seizures
- Less convincing data in chronic seizure models
- CBD increases afterdischarge (AD) threshold and reduces AD amplitude, duration and propagation in electrically kindled limbic seizures in rats

Reviewed in Devinsky et al, Epilepsia 2014

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Cannabidiol (Epidiolex, GW Pharma): US Expanded access compassionate use program

- 261 patients with >3 months of CBD treatment between 2013 and 2015
  - Compassionate use, open label---not controlled trial
  - All patients with significant medically refractory epilepsy
  - Shared trial design to allow data to be pooled

Devinsky et al, AES 2015

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Cannabidiol (Epidiolex, GW Pharma): US Expanded access compassionate use program

- 48.8% median reduction of seizures between 8-12 wks of treatment (52.3% in DS patients)
- 47% with >50% reduction in seizures
- 71.1% reduction in atonic seizures in LGS patients
- 9% seizure free at 3 mo (13% of DS patients)
- Adverse events in >10% included somnolence, diarrhea, fatigue, decreased appetite and vomiting

Devinsky et al, AES 2015

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Cannabidiol – Helpful or just reefer madness? What do we need to know?

- All efficacy data to date is anecdotal or open label
  - Need for randomized controlled trial data
- Cannabidiol is NOT medical marijuana!
  - Significant variability in "artisanal" medical marijuana preparations
  - And what about those >500 other chemicals in cannabis?
    - Could some of them or some combination be more effective? Be more toxic?
  - Need for reproducible, "vetted" CBD

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

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AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

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AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Cannabadiol — Helpful or Just Reefer Madness? (Con)

Eric D Marsh, MD, PhD
Children's Hospital of Philadelphia
Perelman School of Medicine at the University of Pennsylvania

December 6, 2015

Disclosure

Stanley Brothers Social Enterprise -advisory board-past	Name of Commercial Interest

Learning Objectives

- Place the extent of media hype around cannabis in perspective to little clinical data
- Understand the evidence for and against CBD
- Appreciate my victory in this debate

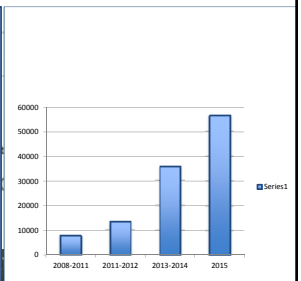
Why CBD? Why Now?

- Long history of possible medicinal use of Cannabis for multiple disorders
  - Chinese Emperor Fu Hsi (ca. 2900 BC)- Both yin and yang properties
  - Evidence of its use in Egyptian, Greek, Roman, and Indian cultures for many ailments
  - Western medicine documents use since 1800s
- Some interesting preclinical data supporting CBD as anti-epileptic

1) "Dr. Sanjay Gupta" by Dnd523 - Own work. Licensed under CC BY-SA 3.0 via Commons ;2) http://resources1.news.com.au/images

Extent of Typical Media Hype

- ~529,000 hits for cannabis and epilepsy in Google search and increasing
- 3- 1 hour Sanjay Gupta shows
- ~320 NY Times articles since 2013
- Thousands of other articles on this subject since 2013



From Google Search

Huge on Social Media

- Over 86,000 posts on CBD and epilepsy on Facebook
- Many families get their information from social media
- People who do not have a positive response don't post

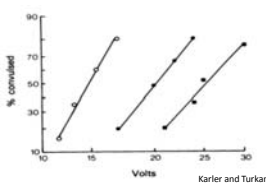
Media Hype = Increased Placebo

- The placebo response can be defined as any therapeutic improvement on placebo
- Epilepsy placebo rate- 9-15%[1]
  - Slightly higher in children (up to 19%)
- Factors that impact placebo rate in trials[2].
  - The degree of positivity with which a treatment is presented
  - Perception that the medication used is novel or has very potent characteristics
  - Positive expectations of patients

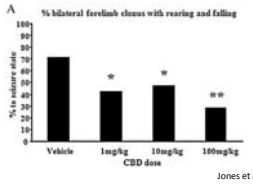
1. Zaccara et al Epilepsy & Behavior, 43 (2015) 128–134
2. Sanderson et al J. Pain and Symp Man, 46 (2013) 722-730

7

Not exciting preclinical data



Karler and Turkanis



Jones et al

- 4 early studies showing some effect on electrical models
- Recent studies with positive effects on both electrical and chemo-convulsant models
- A few studies with no effect of CBD on different models
- Mechanisms unclear

Izquierdo et al J Pharm 1973 (Right Graph); Karler and Turkanis Br J Pharm 1980 **(Right Graph)**; Turkanis Epilpesia 1979; Jones et al *JournPharmacol Exper Therap* 2010; Jones et al Seizure 2012 **(Left Graph)**; Shirazi-zand Z et al Epilepsy Behav. 2013; Hill et al Br J Pharm 2013

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First clinical data

STUDY	INCLUSION CRITERIA Notes	PT #	DOSE TIME	EFFICACY	SAFETY
Mechoulam (1978)	TLE/TRE Groups not matched; ? AEDs, no stats	9 4 CBD 5 PLA	200/d x 3 mos	5 Rx'd: 2 Sz free, 1 better, 1 unchanged 4 Placebo: unchanged	No adverse events
Cunha (1980)	TLE/TRE >= 1 TCSz/wk DB?	15 7 CBD 8 PLA	200-300 mg/d 3-18 wks	4 CBD seizure free; 1 control seizure free	Seizure-free: 1 placebo 4 CBD
Ames (1985)	Residential/MR /TRE -baseline data	12 ? CBD v PLA	200 mg/d x 4wks	No group differences	Mild drowsiness
Trembly (1990)	TRE adults Conflict of 90 paper and 92 chapter	12 ?CBD v PLA	PLAC x 6 mos, CBD 300/dy x 6 mos	No group differences on seizures or cogn-behavior tasks	No data

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Pediatric clinical data

- Parent survey on Facebook support page
  - ~150 'friends' of support group for medical marijuana
- 20 filled out survey
- 19 children (2-16 years) used a CBD-enriched marijuana strain (1-22mg/kg/day)
  - 13 with Dravet syndrome; 4 with MAE
- 16 (84%) reduction in seizure frequency
  - 2 were seizure free
  - 8 (42%) >80% reduction in seizures
  - 6 had a 25-60% reduction in seizures.

(Porter & Jacobson, Epilepsy & Behavior, 2013)

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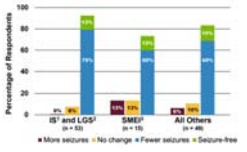
Open label Data

	Baseline (n = 184)	Month 1 (n=184)	Month 2 (n=184)	Month 3 (n=184)	12 week average
Mean/Median seizure frequency (range)	82/28 (0-1057)	57/16 (0-904)	45/14 (0-770)	68/14 (0-3600)	
Responder rate (>50% reduction) n[%]		42%	48%	49%	
median % reduction from baseline		57%	45%	45%	58%
Seizure free n [%]		18%	16%	12%	



- 127 patients as of the abstract
- Varied dosing increases
- Followed closely for AE and SAEs
  - oHigh degree of Aes
  - oOnly ~5% stopped drug

Devinsky et al AAN Abstract 2015

- 117 patients surveyed
- Varied formulations
- Improvement in AED side effects
- Response rate = to Porter and Jacobson (Epilepsy&Behav 2014)

Hussain et al. Epilepsy & Behavior (47) 2015

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But not all good

- 75 patients enrolled
- 57% reported any improvement in seizure control
- 33% reported a 50% reduction in seizures (responders).
- If the family had moved to CO for cannabis the responder rate was 47% but only 22% for those already in CO.

Table 2
Epilepsy characteristics and response rate.

Seizure type	N	Responders	% Responders
Generalized tonic–clonic	30	9	30%
Focal	21	8	38%
Absence	18	5	28%
Myoclonic	15	3	20%
Epileptic spasms	14	5	36%
Tonic	12	2	17%
Atonic	9	4	44%
Syndrome type	**N**	**Responders**	**% Responders**
Doose syndrome	3	0	0%
Dravet syndrome	13	3	23%
Lennox–Gastaut syndrome	9	8	89%*

Responders reported >50% decrease in seizures.
* $p < 0.05$ Fisher's exact.

- The background EEG of the 8 responders where EEG data were available was not improved.
- Adverse events occurred in 44% of patients: increased seizures (13%) and somnolence/fatigue (12%)
- Rare adverse events included developmental regression, abnormal movements, status epilepticus requiring intubation, and death.

Press, Knupp, Chapman; et al Epilepsy Behav. 2015 Apr;45:49-52

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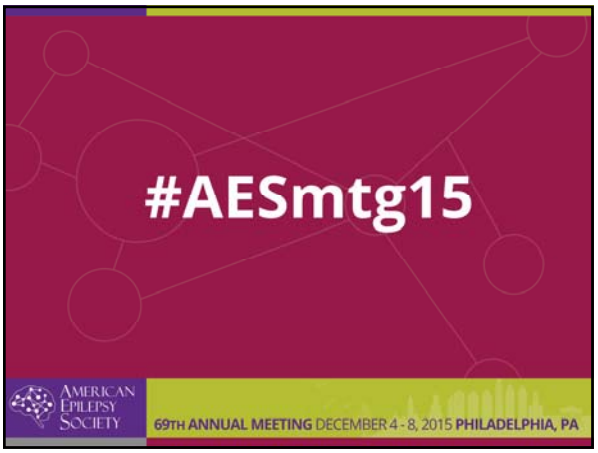
All hype?

- All factors that increase placebo effect exist
- All data is anecdotal, from surveys or an open label trial
- Results vary from 28-83% response rate
  - With better results in patients where families make effort
- Persistent findings of adverse events
- Fair preclinical data
- If cannabis was that good for epilepsy (in adults) wouldn't this have been uncovered by now

13



2015 Annual Course

Course Wrap-up

Eric H. Kossoff, MD

Johns Hopkins Hospital

December 6, 2015

Impact on Clinical Care and Practice

- You are now aware of the very complex relationship between physicians and the media
- You can answer questions from patients about reports they have seen in the media and give resources for them to find out more
- You are comfortable speaking with the press and being proactive to get your personal message to the public

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