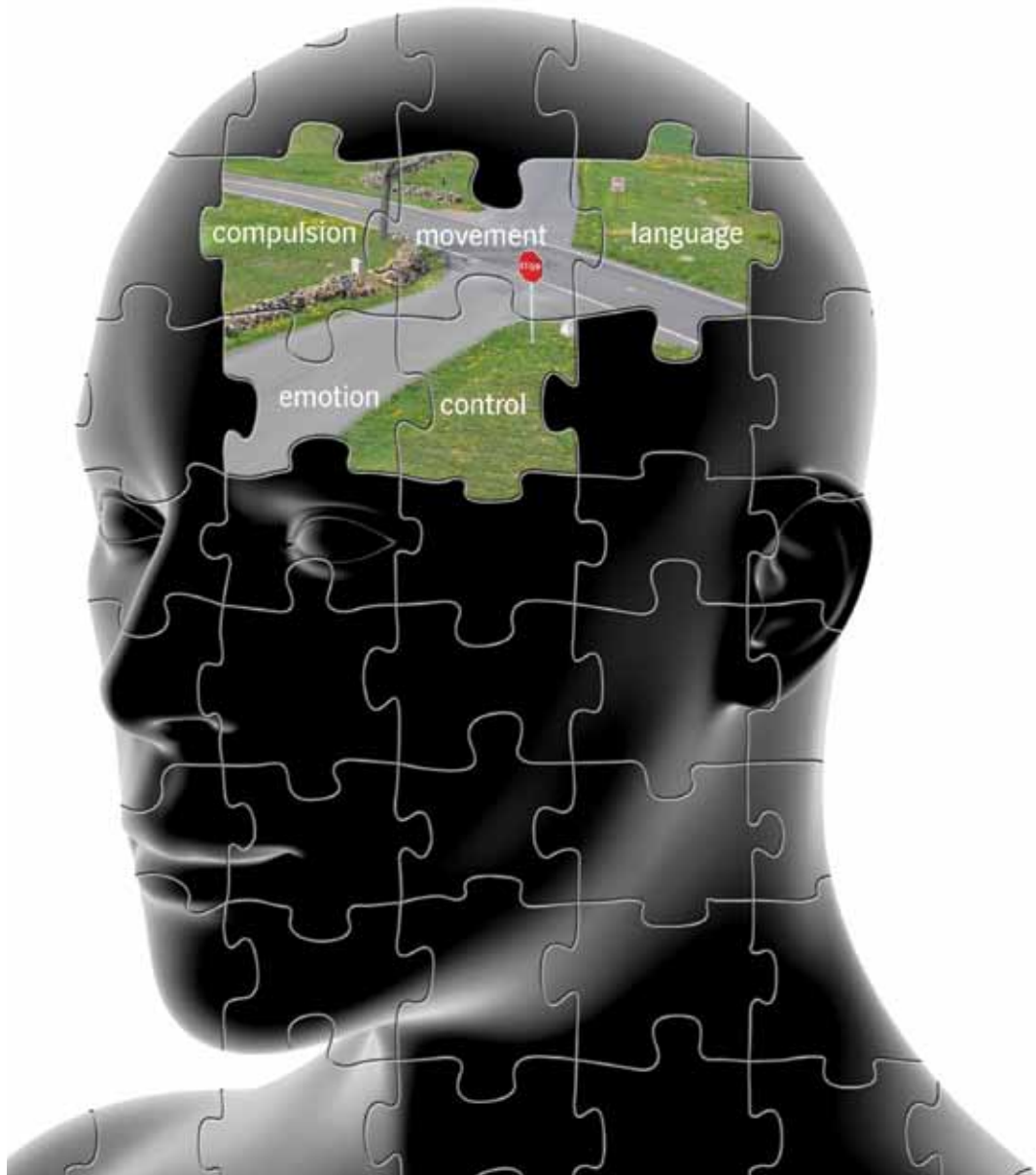


Brain Matters 3: Values at the Crossroads of Neurology, Psychiatry, and Psychology

October 23-25, 2012, Cleveland, OH



Endorsed by the International Neuroethics Society

International
Neuroethics
Society 

 **Cleveland Clinic**

Brain Matters 3: Values at the Crossroads of Neurology, Psychiatry and Psychology

October 24-25, 2012, Cleveland, OH

Dear Colleagues,

Welcome to Cleveland and to Brain Matters 3: Values at the Crossroads of Neurology, Psychiatry, and Psychology. We have a three-fold opportunity at this conference. First, we can develop better analysis and approaches to the ethical dilemmas that face patients, clinicians, and researchers in the face of Medically Unexplained Symptoms, particularly those illnesses for which we give a label of “psychogenic.” We hope to spark practical conversations about how we can better identify and approach these challenges. Second, we have an opportunity to develop networks of collaborators. This conference has brought together a group with broad disciplinary and practical training that can be leveraged for innovation. Third, in the spirit of past Brain Matters Conferences, this conference is a venue for academic work across the spectrum of neuroethics. The parallel sessions have discussion time built into them for dialogue to create rich understandings.

We are pleased that the NIH (through NINDS, NICHD, and Office of the Director) has provided support for poster presentations, non-epileptic working groups, junior researcher attendance, and video archiving of selected sessions. The primary support for this conference through the Cleveland Clinic’s Epilepsy Center and NeuroEthics Program serves our goal to help the lives of our patients, their families, and health care providers. This conference builds on a strong legacy of Brain Matters 1 (2009, Halifax, Canada) and Brain Matters 2 (2011, Montreal, Canada), which we intend to uphold in our attention to collaboration.

We are indebted to you as active participants in this conference. We look forward to the dynamic possibilities that will result from this brilliant combination of people. Please call on us at any time to help facilitate your productivity during this conference.

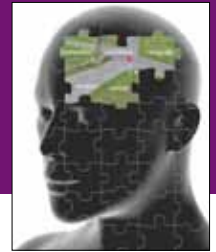
Sincerely,



Paul J. Ford, PhD
Director, NeuroEthics Program
Cleveland Clinic



Imad Najm, MD, PhD
Director, Epilepsy Center
Cleveland Clinic



COURSE DIRECTORS

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Cleveland Clinic
Cleveland, Ohio

Imad Najm, MD, PhD

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Lisa Andermann, MD, MA

Mount Sinai Hospital
Toronto, ON Canada

Grant Gillett, MD, PhD

University of Otago Medical
School
Dunedin, New Zealand

Mark Hallett, MD

Human Motor Control Section,
NIH
Bethesda, Maryland

Siri Hustvedt, PhD

International Author
New York, New York

Richards A. A. Kanaan, MD

Kings College London

Carmen Paradis, MD, MA

Cleveland Clinic
Cleveland, Ohio

Markus Reuber, MD, PhD

The University of Sheffield
Sheffield, United Kingdom

Ret. Col. Elspeth Ritchie, MD, MPH

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Danielle Debacker
Bryn Esplin
Cynthia Forlini
Katja Kuehlmeier
Olena Nikolenko
Nicole Palmour
Andrew Peterson
Carolyn Plunkett
Karen Rommelfanger
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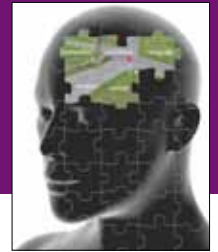
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ACKNOWLEDGMENTS

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Schedule



October 23

Pre-conference (Part of the Epilepsy Surgery Conference)

6:15-6:45 pm **Light Reception**

6:45-7:45 pm **Evening Pre-conference: Cross-Cultural Understandings of Seizures** (Marriott Hotel, 2nd Floor, Grand Ballroom)
Speaker: Lisa Andermann

October 24 – Day 1

7:00-8:00 am **Breakfast** (Fountain Room)

8:00-8:10 am **Welcome** – Paul Ford and Imad Najm

8:15-9:15 am **Patients' Perspectives on Medically Unexplained Symptoms** (Fountain Room)
Speakers: Carmen Paradis and Siri Hustvedt

9:15-9:45 am **Poster Presentations** (Chairman's Room)

9:55-11:25 am **Breakout Sessions**
A. Panel: Adult Non-Epileptic Seizure Ethics Working Session (Fountain Room)
B. Accepted Papers: Neuroimaging (Heritage Room I)
C. Accepted Papers: Stigma and Brain Disease (Heritage Room II)

11:30-12:30 pm **Lunch** (Fountain Room)

12:45-1:45 pm **Medically Unexplained Symptoms: Biological and Cultural Brains** (Fountain Room)
Speaker: Grant Gillett

2:00-3:30 pm **Breakout Sessions 2**
A. Panel: Pediatric Non-Epileptic Seizure Ethics Working Session (Fountain Room)
B. Accepted Papers: Mind and Brain (Heritage Room I)
C. Accepted Papers: Public Health and Societal Issues (Heritage Room II)

3:30-3:50 pm **Coffee Break** (revisit posters)

3:55-5:00 pm **Non-Epileptic Seizures, Communication, and Ethics** (Fountain Room)
Speaker: Markus Reuber

October 25 – Day 2

7:30-8:30 am **Breakfast** (Fountain Room)

8:30-9:30 am **Ethical Challenges Relating to Understanding the Physiology of Volition: What is free about free will?** (Fountain Room)
Speaker: Mark Hallett

9:40-11:10 am **Breakout Session 3**
A. Panel: "Parent-ectomy"/"Child-ectomy": What are the obligations and limits? (Fountain Room)
B. Accepted Papers: Disease Frameworks (Heritage Room I)
C. Accepted Papers: Somatoform Disorders and Uncertainty (Heritage Room II)

11:15-12:15 pm **Ethical Challenges in PTSD and TBI in the Military Context**
Speaker: Ret. Col. Elspeth Cameron Ritchie (Fountain Room)

12:30-1:30 pm **Lunch** (Fountain Room)

1:45-3:15 pm **Breakout Sessions 4**
A. Panel: DSM-V Redefinitions (Fountain Room)
B. Accepted Papers: Clinical Neuroethics (Heritage Room I)
C. Accepted Papers: Deep Brain Stimulation and Mental States (Heritage Room II)

3:15-3:45 pm **Break**

3:45-4:45 pm **Partial Truths, Labels, and Responsibilities in Medically Unexplained Symptoms** (Fountain Room)
Speaker: Richard A. A. Kanaan

4:45-5:00 pm **Closing**

**Cleveland Clinic**

All plenary and panel sessions will be recorded and posted to the Cleveland Clinic YouTube channel:
<http://www.youtube.com/user/ClevelandClinicCME>





Lisa Andermann, MD, MA

Lisa Andermann, MPhil, MDCM, FRCPC is an Assistant Professor in the Department of Psychiatry at the University of Toronto and psychiatrist at Mount Sinai Hospital, where she works in the Psychological Trauma Clinic as well as the Ethnocultural Assertive Community Treatment Team. She is also a psychiatric consultant with the Canadian Centre for Victims of Torture and a former Board Member. Her main areas of interest in research and teaching focus on cultural psychiatry. For the past few years, she has been very involved in an educational initiative to enhance the cultural competence of the postgraduate psychiatry residency curriculum together with colleagues from Culture, Community and Health Studies (CCHS), and led a faculty development initiative on culturally competent supervision and teaching which won the 2008 Ivan L. Silver Award for Excellence in Continuing Mental Health Education. She has been part of the Toronto-Addis Ababa Psychiatry Program (TAAPP),

assisting in the development of the first psychiatry residency training program in Ethiopia. Inspired by her parents' work in neurology and neurogenetics, she became interested in exploring the social and cultural aspects of epilepsy, and has co-edited, with Dr. Steven Schachter, a volume of patient narratives of their experiences with epilepsy from over 20 countries around the world entitled: *The Brainstorms Village: Epilepsy in Our World* (Lippincott, Williams and Wilkins, 2003; reprinted as *Epilepsy in our World: Stories of Living with Seizures from Around the World* (Oxford University Press, 2007). She has an undergraduate degree in Anthropology from McGill University, where she completed her medical studies, and a graduate degree in Social Anthropology from Cambridge University.

Cross-Cultural Understandings of Seizures

The traditional biomedical approach and scientific literature about seizures often overlooks the subjective experience of illness. This presentation will review the growing literature around the social and cultural aspects of epilepsy that has yielded many insights into understanding and improving the daily lives of persons living with seizures. This includes epidemiological clinic and community studies that look at knowledge, perceptions and attitudes towards epilepsy and impact of stigma in many countries; ethnographic studies of individuals, families and communities; studies on traditional healing and alternative medicine; international health projects focusing on the "treatment gap"; collections of patient narratives; and the growing area exploring the representation of epilepsy in the arts and humanities as well as exponential growth on the internet. The emphasis on "lived experience" of epilepsy through narrative studies combined with an ethnographic or anthropological approach provide a rich background for the clinician to improve their management of people with epilepsy.

Invited Plenary Speakers



Carmen Paradis, MD, MA

Dr. Carmen Paradis graduated from the University of Alberta Medical school in 1974 and completed her general surgery residency at McGill University in Montreal, Canada. She moved to the United States to do her plastic surgery residency at University Hospitals and Metro Hospitals of Case Western Reserve University. After doing a hand fellowship at the Orthopaedic Institute in New York City she began a private practice in plastic surgery and hand

surgery in 1981. After 20 years she retired from surgical practice for health reasons. In 2005 she obtained her Masters degree in bioethics from Case Western Reserve University and then did a bioethics fellowship at the Cleveland Clinic Foundation. She became a staff member at the Cleveland Clinic in 2006. Since then she has focused on research ethics, serving on the Cleveland Clinic's institutional review board and as a research subject advocate for the Clinical and Translational Science Collaborative Research Unit at Case Western Reserve University. She lectures and teaches in the fields of research ethics and professionalism.

Patients' Perspectives on Medically Unexplained Symptoms

What happens when someone has symptoms, signs of medical pathology but no one can make a diagnosis, and so can neither predict nor change the course of a disease? What does such a patient think? How does she cope? How do her friends and family react to the lack of a label? How do physicians treat her? Dr. Carmen Paradis was a plastic surgeon and hand surgeon who faced such a career-ending situation. Using specific encounters from this time in her life, she will recount how it affected her understanding of patients' frustration with and physicians' approaches to the unknown. Perhaps most important, from her point of view, she will discuss her evolving understanding of what it is, what it takes, to move on when illness necessitates significant life changes and whether having a specific diagnosis matters.



Siri Hustvedt, PhD

Siri Hustvedt was born in Minnesota in 1955. In 1986, she received her PhD from Columbia University in English literature. She is the author of a book of poetry, *Reading to You*, and five novels, *The Blindfold*, *The Enchantment of Lily Dahl*, *What I Loved*, *The Sorrows of an American*, and *The Summer Without Men*. She has also published works of nonfiction — *Mysteries of the Rectangle* (on painting), *A Plea for Eros*, and *The Shaking Woman or A History*

of My Nerves, an exploration of her own seizure disorder through the lenses of several disciplines. Her most recent book is *Living, Thinking, Looking*, an essay collection that reflects Hustvedt's abiding interest in questions of the self, memory, and imagination and draws on insights of philosophy, psychoanalysis, neuroscience, and literature. Her most recent publication on memory, the self, and narrative can be found in the peer-

reviewed journal, *Neuropsychanalysis*. Her work has been translated into thirty-three languages.

Patients' Perspectives on Medically Unexplained Symptoms

In my paper for Brain Matters 3, I will describe my mysterious seizure-like tremors that remain undiagnosed, my earlier neurological history, and how my thinking about my condition evolved as I explored my symptom in the book I wrote about it, *The Shaking Woman or A History of My Nerves*. By examining my tremors through various disciplinary lenses, including psychoanalysis, psychiatry, medical history, philosophy, and neuroscience, I did not come to any final conclusion about their etiology, but I was nevertheless able to ask questions and entertain ambiguities that seem highly relevant to other patients suffering from medically unexplained symptoms and to the doctors that treat them. My focus will be on the underlying philosophical issues that are essential to the ethical treatment of patients whose symptoms escape medical knowledge, but which often remained unarticulated. I will argue that a Cartesian divide between psyche and soma often haunts the treatment of patients with neurological symptoms that cannot be identified, even among physicians who wouldn't subscribe to Descartes' dualism. I will cite some interesting cases from medical history other than my own, including patients treated by Charcot, Janet, and Freud, and will further argue that even if the distinction between the physiological and the psychological is acknowledged as a false one, the subjective experience of the patient should never be discounted. The ideal medical model should not seek the reduction of an illness to purely objective, third person neurobiological terms, but rather should strive toward a dynamic model that integrates the objective and the subjective.



Grant Gillett, MD, PhD

Grant Gillett is a retired neurosurgeon and currently a Professor of Medical Ethics at the Bioethics Centre, Division of Health Sciences, University of Otago. He graduated from the University of Auckland with an MSc in Psychology and then an MBChB (equivalent of an MD). Later he graduated with a D.Phil in Philosophy from Oxford University. Professor Gillett is the author of over 200 peer-reviewed public publications and is author of *The Mind and its Discontents* (1999),

Bioethics in the Clinic: Hippocratic Reflections (2004) and over 200 articles in philosophy, medical ethics, and philosophy of psychiatry. His latest book is *Subjectivity and Being Somebody: Human identity and neuroethics*.

Medically Unexplained Symptoms: Biological and Cultural Brains

There are competing world views about biological and cultural brains in the context of unraveling the challenges in patients who have physical symptoms for which there is no biomedical explanation. Medically Unexplained Symptoms force us to consider the brain as situated in a physical and discursive context and can be usefully approached by revisit Hughlings-Jackson's views of integration and coordination as the highest level of brain evolution. Unfortunately "propositionizing", as Aristotle and Wittgenstein remind us, admit of what is true and false because as human

Invited Plenary Speakers

beings we do not have the slavery to actuality that animal nervous systems exhibit. Thus we can begin to understand that the demands that are being responded to in MUS are not purely bodily in origin and we need to draw on different discursive levels to explain what is happening in the brain and the soul of a person experiencing MUS.



Markus Reuber, MD, PhD

I am a Reader and Honorary Consultant in Neurology at the University of Sheffield and the Royal Hallamshire Hospital in Sheffield, United Kingdom. I am particularly interested in the phenomenology and treatment of epileptic and non-epileptic seizure disorders and in communication between doctors and patients.

I grew up and completed my undergraduate medical course in Germany but did my general neurological training

was in Leeds. However, I also spent two years of my time as a trainee neurologist working in the Department of Epileptology at the University of Bonn, the largest epilepsy surgery unit in Europe.

I have been involved in a number of research projects examining a wide range of issues in epileptology and general neurology. For instance, I have helped to investigate the use of new functional imaging techniques in patients with epilepsy, the long-term effects of epilepsy surgery on memory and the effects of epilepsy or anticonvulsant drugs on sex hormones. Most of my research, however, has concentrated on improvements of the diagnosis of epilepsy and similar disorders, especially nonepileptic seizures. My most recent studies have focused on the psychological treatment of patients with functional neurological symptoms, the involvement of the autonomic system in epileptic and nonepileptic seizures and the interaction between doctors and patients using the methodology of Conversation Analysis.

Non-Epileptic Seizures, Communication, and Ethics

The overwhelming majority of “psychogenic” nonepileptic seizures (NES) are currently interpreted as involuntary, dissociative events representing a pathological form of avoidance of threatening or unpleasant emotions. In the understanding of most experts the term “psychogenic” does not refer to an illness of the immaterial soul of the patient but to a perceived link between NES, emotional trauma or unresolvable dilemmas. Although most patients perceive their NES as a largely or at least partially physical problem, most neurologists consider NES a “psychological” disorder. Neurologists who question their patients about traumas or dilemmas, and doctors engaging in a reattribution of their patients’ symptoms often encounter non- or incomplete disclosures, passive or active interactional resistance.

My talk will explore the ethics of pursuing the “path of maximal resistance” to the place Sigmund Freud called the *caput nili*. Should neurologists follow this path? When and in which circumstances might the search for trauma disclosures be appropriate? How far should doctors or psychotherapists go in the pursuit of a talking cure?

I will also look at the ethics of reattribution? Whose interpretation of NES is right — that of most neurologists or that of most patients? Do doctors have the right or obligation to convince patients of their own view?

These questions will be posed by excerpts and audioclips of clinical

encounters with real patients. My answers will draw on the best available biopsychosocial evidence.

Learning points: neuroscientific background for the current biopsychosocial model of NES/interactional and linguistic manifestations of resistance/ethically aware approach to the clinical management of patients with NES.



Mark Hallett, MD

Dr. Hallett obtained his AB and MD at Harvard University, had his internship in Medicine at the Peter Bent Brigham Hospital and his Neurology training at Massachusetts General Hospital. He had fellowships in neurophysiology at the NIH and in the Department of Neurology, Institute of Psychiatry in London, where he worked with C. David Marsden. Before coming to NIH in 1984, Dr. Hallett was the Chief of the Clinical Neurophysiology Laboratory at the Brigham and Women’s Hospital in Boston

and Associate Professor of Neurology at Harvard Medical School. He is currently Chief of the Medical Neurology Branch and Chief of its Human Motor Control Section. He is now Editor-in-Chief of *World Neurology*, the newsletter of the World Federation of Neurology and Associate Editor of *Brain*. He has been President of the Movement Disorder Society and Vice-President of the American Academy of Neurology. Among many awards, in 2005 he won the Movement Disorder Research Award of the American Academy of Neurology and in 2007 he won the Wilhelm-Erb-Gedenkmünze of the Deutsche Gesellschaft für Neurologie. His research activities focus on the physiology of human voluntary movement and its pathophysiology in disordered voluntary movement and involuntary movement.

Ethical Challenges Relating to Understanding the Physiology of Volition

People have a perception that they choose when and what to move, the sense of free will. Free will is a quale of consciousness and is composed of two parts, the sense of willing and the sense of self-agency. There is a folk psychology view that in addition to the perception, there is also a free will force that aids in movement genesis. The notion of a free will force is essentially dualism, which is often implicit in our language even though we might not formally believe in dualism. Recent advances in neuroscience have given some good insights into the genesis of movement; much of this is unconscious and temporarily uncoupled from the sense of willing and the sense of agency. Movement arises from a complex combination of neural signals relating to homeostasis, emotion, reward, environmental stimuli and cognitive processes including past experience and planning. The brain can be considered to be “free” if it can function without internal or external constraint. If functioning under control of a seizure (internal constraint) or a gun to the head (external constraint), the brain would not be free. Other situations are less clear. What if under the influence of drugs? And to be provocative, what if taught to believe in a certain way? Brains are always responsible for the attached body’s behavior. The relevant question is why did the brain choose that behavior, and the answer should guide reward, punishment, treatment or further education.

Invited Plenary Speakers



Ret. Col. Elspeth Cameron Ritchie, MD, MPH

Dr. Ritchie is the Chief Clinical Officer, Department of Mental Health, for the District of Columbia. She recently retired from the Army and concluded five years as the Director of the Proponency of Behavioral Health Director at the Office of the US Army Surgeon General. She has held numerous leadership positions within Army Medicine, to include the Psychiatry Consultant. She trained at Harvard, George Washington,

Walter Reed, and the Uniformed Services University of the Health Sciences, and has completed fellowships in both forensic and preventive and disaster psychiatry. She is a Professor of Psychiatry at the Uniformed Services University of the Health Sciences.

An internationally recognized expert, she brings a unique public health approach to the management of disaster and combat mental health issues. Her assignments and other missions have taken her to Korea, Somalia, Iraq, and Cuba. She has over 130 publications, mainly in the areas of forensic, disaster, suicide, ethics, military combat and operational psychiatry, and women's health issues. Major publications include *The Mental Health Response to the 9/11 Attack on the Pentagon*, *Mental Health Interventions for Mass Violence and Disaster* and *Humanitarian Assistance and Health Diplomacy: Military-Civilian Partnership in the 2004 Tsunami Aftermath*. She is currently the senior editor on a forthcoming Military Medicine text on Combat and Operational Behavioral Health, the Textbook of Forensic Military Mental Health, and the Therapeutic Use of Canines in Army Medicine.

Ethical Challenges in PTSD and TBI in the Military Context

After 11 years of war, there are approximately 2.5 million veterans who have served overseas in wars in Iraq and Afghanistan. Side by side with the troops have been military psychiatrists. Many psychiatrists have deployed several times. This presentation will draw upon their personal experiences in Iraq, Afghanistan and elsewhere to illustrate ethic issues in the modern battlefield. In the past, and now, the question of when to evacuate out of the theater of war is a major one. Basic principles of combat stress control include staying the theater of war whenever possible. If you send a soldier home, for PTSD, TBI or depression, it may provide a temporary relief, but they usually end up leaving the Army. A related issue is when to use psychiatric medication. Complexities of balancing the needs of command and the troops will be highlighted, in the arena of fitness for duty and confidentiality. Military doctors treat not just the American military, but also local nationals, and detainees. The local nationals may be discharged to a very dysfunctional medical system. Some of the issues around treating detainees and supporting the local psychiatric systems of care will be discussed.



Richard A. A. Kanaan, MD

Richard Kanaan, MRCPsych PhD is a Consultant Psychiatrist at the Maudsley Hospital, Honorary Consultant Neuropsychiatrists at Kings College Hospital and Visiting Senior Lecturer at the Institute of Psychiatry in London. He studied mathematics and philosophy in Oxford and Los Angeles, and medicine and psychiatry in London. He has a special interest in medically unexplained symptoms, and their conceptualization in particular.

Partial Truths, Labels, and Responsibilities in Medically Unexplained Symptoms

Respect for autonomy has become arguably the paramount principle of medical ethics in the West, yet in some contexts it is routinely violated. Unexplained symptoms are one such context, and I shall explore this in one “unexplained” syndrome — Conversion Disorder: how and why it happens, and whether it matters. The ostensible reason “why” is a clash between beneficence and respect for autonomy — limiting disclosure to preserve the therapeutic relationship — but that encompasses a range of motives and prejudices on both the doctor and patient's parts. How it happens is sometimes very clear — the wrong diagnosis willfully given — but subtler, partial concealments are probably more widespread, and can profitably be considered from the perspective of communication more broadly. Whether this matters will partly depend on whether the qualification of respect for autonomy by beneficence is thought acceptable, but also whether the undoubted complexity of the condition and its management justify an exception to the expectations of truth-telling, and finally on the moral responsibility accorded to communication that is inevitably more than the sum of declarative statements.

Breakout Sessions

October 24, 2012, 9:15-9:45 a.m. (Posters)

Regular Posters:

- #1. Researching MUPS: An experiential approach interviewing patients and physicians about diagnostic uncertainty**
Chloe Atkins, University of Calgary
- #2. What we might learn from pain rehabilitation in the treatment of pseudoseizures**
Judith Scheman, Cleveland Clinic
- #3. Moral disengagement and provider neglect of treatable pain**
Kelly Dineen, Saint Louis University
- #4. Thinking outside the box: Intractable seizures in the glioma patient, is seizure surgery the answer?**
Kathleen Lupica, Glen Stevens, Cleveland Clinic
- #5. "Treating as though": An account of the moral status of children and the cognitively disabled**
Takunda Matose, Technical Resources International, INC
- #6. Ethical implications of possible competency in the minimally conscious patient**
Kathrine Bendtsen, St. Joseph's University

Late Breaking Posters:

- #7. "Let them talk": Heteroglossia, trauma narratives, and the PNES patient**
Lauren Boehm
- #8. Identical prescriptions, disparate treatment: Anticonvulsant usage in frontal lobe epilepsy and bipolar I disorder**
Bryn Esplin, University of Nevada Las Vegas
- #9. Epilepsy surgery: Structural status of neuroethics for surgical decision-making**
Olena Nikolenko, Lusiena Klaupik, Oleg Nikolenko, Inna Fokina, Institute of Cryogenic Technologies and Engineering
- #10. Epilepsy surgery and hope**
Dana Patton, Kimberly Yee, Cynthia Kubu, Paul Ford, Cleveland Clinic
- #11. Deep brain stimulation for Parkinson's disease: Intra-operative considerations of patient vulnerability and effects on informed consent**
Danielle L. DeBacker, Case Western Reserve University

(1a) Organized Panel: Working Session on Ethical Issues in Adult Nonepileptic Seizures

Moderator: W. Curt LaFrance, Jr; Panelists: Brien Smith, Susan Stagno, Eran Klein

Abstract: The goal of this session is ethical issues some of the non-traditional ethical issues found in providing care for adult patients with a diagnosis of nonepileptic seizures. The session will address three specific areas of importance: The diagnostic dilemma for psychogenic nonepileptic seizures: 300.11 (conversion disorder) or 780.39 (seizure NOS), Hidden curriculum of implicit education in the rounding "herd," and caregiver burden. The panel's discussion of these issues will encourage audience to offer new ways to resolve the ethical conflicts that arise as a result of those competing obligations

(1b) Accepted Oral Presentations: Neuroimaging

A review of evidence-based ethics literature in neuroimaging: Is the image clear?

Nicole Palmour, Eric Racine, Institut de recherches cliniques de Montreal

Abstract: Modern neuroimaging innovations have spurred discussion about current and future ethical uses of translational neuroscience. A review of the evidence-based literature in neuroimaging clearly identifies some of the salient ethical issues at play in this field. Publications which address the risks of research participation e.g.: incidental findings, participant safety and anxiety are well documented in the imaging literature. Although there are numerous publications discussing ethical issues in this domain, it is challenging to identify publications that report data from research that identifies ethical tensions beyond incidental findings or discussed approaches to address these tensions. Accordingly, we identified and reviewed the relevant data based literature, assessing it for methodology, results, identification of themes and ethical issues raised. The thematic analysis revealed 4 broad categories: risk (n=45), knowledge translation (n=10), stakeholder perspectives (n=9), and oversight (n=4). This presentation will address the contours of the issues and highlight the gaps in ethical coverage.

Ethical implications of detecting awareness in disorders of consciousness: Question asking through a binary interface

Andrew Peterson, Lorina Naci, Damian Cruse, Davinia Fernández-Espejo, Mackenzie Graham, Angela White, Charles Weijer, Adrian M. Owen, Rotman Institute of Philosophy and Western Brain and Mind Institute

Abstract: With the use of new neuroimaging technologies, researchers have recently developed techniques that successfully reveal dimensions of covert awareness in patients diagnosed with disorders of consciousness. Both Owen et al and Cruse et al have used fMRI and EEG modalities respectively to detect volitional activation of brain regions in response to

auditory questioning. This has opened a promising avenue for possible communication with patients that suffer from a variety of neurological conditions that inhibit volitional bodily movement. However, due to the instrumental limitations, these procedures are restricted to interrogation techniques that employ strict binary answers of "yes" and "no". We explore the limitations this may pose to our understanding of the patient's cognitive capacity to competently respond to questions, and outline several ethical implications that arise upon detecting this type of covert awareness. We argue that our first obligations to aware patients are derivative from the moral obligations to all sentient beings, including the duty to prevent suffering, where possible. We then suggest several interrogatory tests designed to reveal more complex reasoning features through binary answers that may satisfy the conditions of legal competency. We argue that if these cognitive tests prove sufficient, patients with disorders of consciousness may be fully incorporated into the decision making process related to their own medical care.

Investigators' ethical obligations to patients' families in disorders of consciousness research

Mackenzie Graham, Angela White, Andrew Peterson, Lorina Naci, Damian Cruse, Davinia Fernández-Espejo, Charles Weijer, Adrian M. Owen, Rotman Institute of Philosophy and Western Brain and Mind Institute

Abstract: With the use of new neuroimaging technologies, researchers have successfully developed techniques that reveal covert awareness in patients diagnosed with disorders of consciousness. Both Owen and colleagues and Cruse and colleagues have used fMRI and EEG modalities respectively to detect volitional activation of brain regions in response to auditory questioning. Furthermore, Fernández-Espejo and colleagues have successfully identified anatomical changes that may effectively distinguish between the persistent vegetative state and the minimally conscious state. This has opened a promising avenue for possible communication with patients that suffer from a variety of neurological conditions that inhibit volitional bodily movement.

However, advancing this research to detect awareness in patients and communicate with them requires enrolment of patients whose families must consent on their behalf. Oftentimes, families give their consent because of the hope that tests will reveal valuable information to them about their loved ones. We consider the questions this research raises about investigators' ethical obligations to the families who consent to enroll patients in their studies. These questions include: Who should approach family members for consent to enroll the patient, and how? What study results should families be informed of, by whom, and when? By drawing analogies to the context of genetic research and testing, we suggest ways to address the ethical issues that arise with continuing advancements in neuroimaging technologies and research.



(1c) Accepted Oral Presentations: Stigma and Brain Disease

Addiction as brain disease: Current perspectives

Rachel Hammer, Mayo Clinic; Jenny Ostergren, Mayo Clinic & University of Michigan; Molly Dingel, University of Minnesota-Rochester; Jennifer McCormick, Mayo Clinic; Barbara Koenig, UCSF

Abstract: Addiction is increasingly considered a “brain disease,” based on an interpretation of addiction neuroscience in which addictive molecules “hijack” neural networks and compromise rational thought. The disease concept of addiction originally took hold for reasons unrelated to neuroscience, however recent efforts of NIDA have capitalized on the concept’s cultural momentum. “Addiction as disease” has been the accomplishment of Alcoholics Anonymous, government-supported research institutes, political pressure from drug courts, and mass media. However, the brain-disease framework of addiction, as a theory, remains widely contested for neglecting the relational, lived experience, and socio-political contexts of addiction, also de-emphasizing the importance of “external prostheses”—family, friends, and care providers. To explore the pervasiveness of the framework and to gather current critiques from stakeholders, with NIH funding, we conducted in-depth, semi-structured interviews with a diverse sample of 64 patients from five alcohol and/or nicotine treatment centers in MN. We similarly conducted semi-structured interviews with 40 addiction scientists from a variety of research fields (genetic, molecular, behavioral, epidemiologic). We asked all participants to describe their understanding of addiction, including whether or not they considered addiction to be a disease. Transcripts were coded by multiple researchers and qualitative memos were written from themes that emerged. Among addiction patients, 61% endorsed the notion of addiction as a disease, compared with 38% of addiction scientists. We shall summarize historical highlights in the ethical debate to situate our qualitative data against the backdrop of public discourse on the stigmatized issue of addiction as brain disease.

Prediction and prevention of stigmatization of adult individuals with Asperger disorder and high function autism

Kelly Dineen, Saint Louis University

Abstract: Although stigma has existed throughout history, stigma is only recently a topic of scholarly focus, a majority of which surrounds diagnoses such as serious mental illness, HIV, and epilepsy. This stigma research is largely reactive; the beginning point is a disorder already widely associated with stigma. The understanding of the origins of stigma and interventions that effectively lessen stigma has a significant impact on the well-being and functional ability of those in the stigmatized groups. Therefore, the ability to anticipate that a disorder will be stigmatized as prevalence increases has serious implications.

Despite a body of literature identifying common traits inherent in many stigmatized disorders, virtually no research focuses on predicting stigma in new or increasingly prevalent disorders. For example, there is almost no study of stigma associated with the increasingly prevalent diagnoses Asperger Disorder and High Functioning Autism (collectively, AS), despite a growing body of anecdotal evidence of stigmatization of the affected individuals and their caregivers.

This presentation will review stigma theory, including the ethical and practical justifications for reducing and preventing stigma in general. Existing empirical research of factors associated with increased stigma in already studied populations will be described. These factors overlap strongly with the common characteristics of AS and may be useful in predicting the stigmatization of individuals with AS. An examination of AS as a potentially highly stigmatized condition may allow individuals with AS to avoid the well documented negative impact of stigma and inform public outreach and policy agendas in developing anti-stigma programs for this population.

Re-classification of autism and its ethical impact on diagnosis, treatment, and family

Julie Aultman, Northeast Ohio Medical University

Abstract: The benefits of the revised classification of Autism Spectrum Disorder (ASD) within the DSM-V (release date May 2013) includes a more appropriately matched diagnostic rubric to existing psychometric standards, which yields more reliable and valid differentiations, while prompting practitioners and the public to recognize the individual needs, abilities, goals, and values of the person diagnosed with ASD within a presumably dynamic spectrum. However, there are several ethical and pragmatic issues that may arise from this classification and require further examination. For one, the spectrum approach to diagnosis may not be as reliable and valid as researchers and clinicians purpose even if “a single spectrum disorder is a better reflection of the state of knowledge about pathology and clinical presentation” (APA, DSM-5 Development). It has been argued that diagnostic subtypes can be pragmatically useful for the clinician (Ghaziuddin, 2010), while improving the quality and continuity of care for the patient. Second, access and delivery of care for all who struggle with autism may be compromised as children may not be diagnosed with ASD, or upon diagnosis, may not be able to receive needed care and support under the new criteria. Presumably, with the expansion of a diagnostic boundary, diagnosing a larger population would further reduce access and availability of required therapeutic and educational resources, which can be emotionally, financially, and socially difficult for families. These pragmatic and ethical issues will be discussed, as well as recommendations toward the just allocation and availability of resources in anticipation of an expanding diagnostic boundary.

(2a) Organized Panel: Working Session on Ethical Issues in Pediatric Nonepileptic Seizures

Moderator: Cristie Cole; Panelists: Tatiana Falcone, Rochelle Caplan, Kristine Jares

Abstract: The goal of this panel is to identify ethical issues that are unique to the treatment and diagnosis of pediatric and adolescent patients with nonepileptic seizures and not yet addressed in the literature. The session is divided into two areas that are uniquely troublesome for pediatric and adolescent patients with nonepileptic seizures: the family and school environments. The ethical issues within each area highlight the competing obligations of providing clinical treatment and comprehensive care that respects patient, health care provider, family, and societal values. The panel's discussion of these issues will encourage the audience to offer new ways to resolve the ethical conflicts that arise as a result of those competing obligations.

(2b) Accepted Oral Presentations: Mind and Brain

Ways of knowing and unknowing: A neuroethics review of higher and lower cortical function

Hillel Braude, Hebrew University of Jerusalem

Abstract: The division between conscious and automatic cognition is recognized to be increasingly important for neuropsychology and neuroethics. Increased empirical information about predominantly unconscious neurobiological processes, such as affect and emotion, must necessarily reshape the classic conceptions of moral reasoning and key moral concepts, such as informed consent. The evolutionary architecture of the brain into cortical and subcortical regions associated with higher and lower cortical function is therefore, of central theoretical and practical importance. Delineating the neural connections between these regions in relation with knowing ("noetic") and unknowing ("anoetic") consciousness will determine how this fundamental binary division will inform and shape clinical practice and neuroethics. Despite its fundamental importance the evolutionary architecture of the brain in relation to function has not been adequately appreciated by neuroethicists who have the tendency to pay greater attention to "static" results from brain imaging studies. In this paper I shall review the implications of vertical integration between higher and lower cortical function for neuroethics reflection. As emphasized by other researchers, two classic principles of brain function are crucial for this analysis, i.e., Hughlings Jackson's principle of hierarchical integration through inhibitory control and "encephalization," i.e., increasing functional dominance of higher systems. I shall analyze higher cortical function associated with conscious declarative awareness, and the regulation of cortical representation networks by the limbic system and brainstem. This review of the relation between higher and lower cortical control has profound implications for psychiatry, neuropsychology and neuroethics and for this conference's theme – understanding neurobiological symptomatology without identifiable biological correlates.

The ethics of nudging and the architecture of the mind

Yashar Saghai, Kennedy Institute of Ethics

Abstract: "Nudge" theory has gained momentum for the design of public policies ever since behavioral economist Richard Thaler and law scholar Cass Sunstein first coined the term in 2008. For them, A nudges B when A influences B to _, by triggering B's automatic cognitive processes, while preserving B's freedom of choice. Critics of nudges argue that if an intervention bypasses deliberative capacities, it cannot genuinely preserve freedom of choice. In this paper, I challenge this way of framing the nudge debate. I argue that it is premised on an objectionable account of nudging mechanisms borrowed from a dual-process model of decision-making. According to this model, the mind processes information through two distinct systems. "System 1" is automatic, unconscious, heuristic, and cognitively parsimonious. "System 2" is reflective, conscious, analytic, and cognitively demanding. For Thaler and Sunstein, nudges always bypass deliberation because they harness System 1 processes. I suggest an alternative account of nudging mechanisms based on Keith Stanovich's recent tri-process model of decision-making. I show that while some nudges rely on nondeliberative automatic cognitive processes, many harness mental shortcuts that trigger some form of incomplete deliberation. Deliberative processes are then inflexibly locked into one pre-determined path, instead of exhaustively analyzing different hypotheses for solving a problem (full-blown deliberation). If my account of nudging mechanisms is correct, we need to expand the nudge debate to cover nudges that trigger incomplete deliberation: under what conditions (if any) are public policies that partially engage individuals' deliberative capacities to influence their behavior morally permissible?

Unlikely pairings: Spinoza, neuroscience and the mind-body problem

Robert Doyle, Loyola Marymount University

Abstract: The debate surrounding the qualities of the mind and body is continuous. Often, philosophers, theologians, and scientists are faced with difficult questions as they consider the relationship of mind and body. Recent scholarship in this area has yielded some insightful commentary as advances in neuroscience have helped move this debate into the empirical sciences. As such, the mind-body problem has truly become an interdisciplinary endeavor.

This paper considers Spinoza's doctrine that mind and body are one: Spinoza's solution no longer requires mind and body to remain as separate entities; mind and body work in unison from the same substance "fully and mutually mimicking each other in their different manifestations."

This argument has been supported by recent findings in neurobiology. In fact, not only can we say that images arise in the brain, but these images are formed from signals from the body. Thus, Spinoza's argument has been re-imagined in the empirical sciences so that the dualistic approach to mind-body has come to be regarded as mistaken.

This paper examines the implications of this argument in light of traditional Western philosophical and theological traditions that continue to assume the "transcendence of mind over body."



It concludes by exploring several points in this regard: There can be no mind without a body; the mind is not a thing; the body is in the mind and the mind is in body; logic is a matter of the body; language and symbolic interactions are also matters of the body; and the body is more than flesh.

Interdisciplinary work is clearly a linchpin in the endeavor to explore the mind-body problem. In what seems like an unlikely pairing, Spinoza has been influential as neuroscience has moved to empirically based assumptions about the mind and body. His work has found a renewal not in philosophy books but in scientific experiments. His non-dualistic approach to the mind-body problem serves as a prophetic voice from centuries ago.

(2c) Accepted Oral Presentations: Public Health and Societal Issues

Understanding concussion in Australia's "collision sports": Assessing the risks and promoting Prevention Strategies in Rugby League, Rugby Union and Australian Football

Bradley Partridge, Frederic Gilbert, University of Queensland Centre for Clinical Research (UQCCR)

Abstract: Chronic Traumatic Encephalopathy (CTE) is a degenerative brain disease caused by repeated head traumas, and has been found in the brains of some former National Football League players. Concussions are also frequently sustained by amateur and professional players of Australia's three most popular football codes (Australian football, rugby league, and rugby union), raising major concerns about long-term neurological damage in both adult and pediatric players. There is an urgent need to investigate the effects of head traumas in these sports over longer periods.

Only recently have Australia's football codes adopted concussion management guidelines at the elite level, however the effectiveness of these guidelines may be impacted by a number of ethical and practical issues. At the youth and amateur level, most teams lack medical personnel trained in the detection and assessment of concussions. As a result, some young athletes may suffer undiagnosed and untreated concussion, which increases the risk of repeated head trauma. This presentation will: 1) consider evidence of the short and long term effects of repeated football related concussions in the Australian context; 2) describe the need for research to investigate the long term effects of head injuries in Australian football codes, and explore the merits of current proposals; 3) examine issues surrounding the implementation and enforcement of concussion management guidelines at the professional level of all three codes; 4) articulate the need for education of coaches, referees, and other key decision-makers in the detection and management of concussions in pediatric athletes.

The efficacy and safety of existing medications used for cognitive enhancement in healthy individuals: Deal maker or deal breaker in the ethics debate?

Cynthia Forlini, Wayne Hall, Bruce Maxwell, Simon M Outram, Peter B Reiner, Dimitris Repantis, Maartje Schermer, Eric Racine; Institut de recherches cliniques de Montreal

Abstract: Despite a lack of evidence to fully support efficacy or refute safety, expectations related to the use of existing medications

by healthy individuals for cognitive enhancement persist in academic and lay circles. Calls have been made to further investigate the enhancement effects of these medications but discussions have been focused mainly on the regulatory and practical aspects that have impeded this type of research. Little attention has been paid to the ethical justification and responsibilities for oversight of cognitive enhancement research to clarify the role of evidence in the ethics debate. The reflections in this presentation are based on current perspectives in the bioethics literature and the outcomes of an interdisciplinary workshop focusing on the possible upstream and downstream implications of cognitive enhancement research. The first part of the presentation will examine how evidence of safety and efficacy has become a rate-limiting step in the ethics debate around cognitive enhancement. The second part will explore the ethical profiles of possible approaches to permit or prevent (or neither) cognitive enhancement research. In conclusion, we will discuss three important points that may help uncover scientific and ethical assumptions, and implicit values underlying different approaches to cognitive enhancement research. These are the relationship between demand and prevalence, responsibility of stakeholders and the social outcomes of cognitive enhancement research. These reflections are meant to foster a culturally-sensitive international discussion about the direction of cognitive enhancement research that is representative of the best scientific methods and takes due account of pluralist public perspectives.

Chronic malnutrition and neuroethics

Jorge Lazareff, David Geffen School of Medicine

Abstract: There is robust clinical and experimental data that demonstrates that chronic malnutrition (CM) alters permanently the structure of the developing brain. The evidence ranges from the microscopic, the density of dendritic buds, to the macroscopic, the volume of the hippocampus. Not surprisingly CM affects a wide range of cerebral functions including memory, learning, mood, proactive action, libido and sleep. Timely intervention has the potential to revert many of the noxious consequences of CM.

The above notwithstanding CM is not frequently considered as a separate neuro-pathological entity, thus it has seldom drawn the attention of neuro-ethicists.

In this presentation we propose to bring CM to the realm of neuroethics by emphasizing on its anatomical and physiological characteristics applying the same functional and structural parameters that we utilize for every other condition that impairs neurocognitive performance (Alzheimer, ADHD). As a corollary we propose to consider food as a neurocognitive enhancer not different from methylphenidate or bromocriptine.

The set of questions derived from the assumptions proposed in the presentation are introduced following the structures of M. Farah's et al. "Neurocognitive enhancement what can we do and what should we do" (*Nature Reviews Neurosciences* (5), 1123-1129, 2002) emphasizing on the subset of; ethical problems and policy solutions, distributive justice, personhood and intangible values.

It goes without saying that there are other conditions that affect the developing brain in the underdeveloped world that deserve similar attention. "Unequal access is not grounds for prohibiting neurocognitive enhancement" (Farah et al. as above).

**(3a) Organized Panel: “Parent-ectomy”/ “Child-ectomy”:
Ethical Challenges in Managing Caregiver and Patient
Relationships.**

Moderators: Dylan Wint and Jalayne Arias; Panelists: Gerard Banez, Barbara Daly, and Kay Kendal

Abstract: This panel will address health care providers' ethical obligations, responsibilities, and challenges associated with managing the relationship between a patient and a family caregiver. Family caregivers can provide significant support and care for patients with chronic conditions. However, in some circumstances the relationship between the family caregiver and the patient can interfere with the medical care of the patient. The three panelists will discuss ethical issues in circumstances where the family caregiver's role interferes with patient care. These challenges may ultimately require separating the family member from their caregiver role. The diverse experiences of the panelists provide three unique perspectives for an in-depth discussion of the potentially challenging dynamics between patients, health care providers, and family caregivers. Using these varying perspectives the panel will allow for an in-depth discussion relating to the potentially challenging dynamics between the patient, health care providers, and family caregivers.

(3b) Accepted Oral Presentations: Disease Frameworks

**How discourse around novel “cures” for Fragile X shapes
conceptions of best interest**

Lucie Wade, Lonnie Zwaigenbaum, and Eric Racine, University of Toronto

Abstract: Experimental pharmaceuticals developed to treat anxiety disorders (e.g., mGluR5 inhibitors) are currently being tested in clinical trials as treatments for fragile X syndrome (FXS) and associated intellectual disability (ID). However, determining whether, or when, using these drugs is in the best interests of individuals is complicated by the history of a medical model of disability, which persists in contrast to socio-cultural models.

Our study used critical discourse analysis to explore whether the persistence of competing views of disability contributes to how these drugs are justified for individual use. Using Proquest we collected a sample of 22 publicly accessible international media articles and coded them to characterize: 1) how life with FXS/ID is portrayed; 2) how the goals and outcomes of these drugs are described; and 3) whose interests are considered (e.g., the individual's, the family's, or society's)?

Our preliminary data suggest that justifying drug use through an appeal to the best interests of individuals is undermined by medicalized media discourse. The majority of descriptions of life with FXS/ID are fatalistic and the goals of treatments are communicated through biomedical outcomes. The benefits of these drugs for commercial gain, family management and society are emphasized, while their value to the individual is overlooked. As these drugs progress through trials, determining what constitutes the best interests of individuals with ID and integrating an awareness of how diverse models of disability can implicitly influence decisions related to drug use will be crucial for both families and clinicians.

**Inconsistencies and ethical issues in the treatment of
chronic pain**

Sara Davin, Cleveland Clinic Foundation

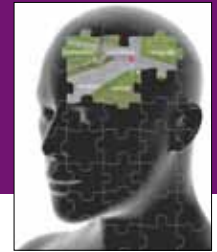
Abstract: A gap exists in funding for the interdisciplinary treatment of chronic pain that is inconsistent with the values purported by the health system in its treatment. When treatment approaches shown to be less efficacious than other approaches are disproportionately available to patients, it is reasonable to ask why. Despite the demonstrated long term efficacy of interdisciplinary chronic pain rehabilitation programs (ICPRPs), the availability of such programs has dramatically declined, without a clear rationale for their so-called demise. However, certain issues are clear. Patients and providers are likely to be reinforced more by immediate effects than delayed ones. Opioids produce immediate analgesia, and the same can be said for injections and other procedures. However, none of these have demonstrated long term benefits in the treatment of chronic pain. ICPRPs require substantial effort from patients who typically believe they are incapable of doing very much to improve their circumstances. Thus, patients naturally gravitate to various interventions that do not require effort on their part. It is also true that a capitalistic health care system risks treatment determined by “incomes, rather than outcomes,” and many of the interventions for pain are remarkably remunerative. Hospitals in financial distress are almost compelled to allocate space and resources to activities that generate revenue and dissuaded from devoting resources to activities that fail to do so. The result is an ethical dilemma in which patients are exposed to interventions that risk providing a false sense of hope, when the best they can deliver is a temporary respite.

**Metaphor and the self: A role for the arts in under-
standing suffering and treating the person in distress**

Lynn Underwood, Cleveland State University and University of Liverpool

Abstract: Research shows that the metaphors we use affect our behaviors and attitudes in significant ways that we are often unaware of. The machine metaphor recurs in our descriptions of the brain and the overall functioning of the body and has become an automatic default. It can be useful in simplifying complex systems, and medical training encourages this. Even efforts to promote humanism in medicine slide in this direction, as communication, empathy and ethical decisions are formulated in mechanistic terms.

Self-reports by the person who is suffering are essential to the identification of the roots of the problems and opportunities for treatment, even when no “physical” causes are found. However if one buys into the machine metaphor too much, the experience of the person is given less weight in the overall assessment, while objective features such as brain scans, blood chemistry and physiologically evident symptoms are given the final say. Measurements based solely on a machine model lead to interventions that presuppose a kind of person that is not congruous with the way we live our lives, and what we value most in ourselves and others. Visual art, film and literature can provide ways of viewing the human person that can counteract the machine metaphor, and open opportunities for creative



approaches to treatment and evaluation of outcomes. This presentation will specifically use self-portraits and portraits by others, of those with chronic disease, disability and mental distress, to highlight this approach.

(3c) Accepted Oral Presentations: Somatoform Disorders and Uncertainty

Catch me if you can – considerations on malingering in the movement disorder clinic

Kathrin Czarnecki, National Institute for Neurological Diseases and Stroke

Introduction: Malingering is the fabrication of medical symptoms for secondary gain such as financial compensation, drugs or avoidance of criminal sentencing. It is differentiated from factitious disorders in which symptoms are voluntarily produced or exaggerated for primary gain, usually medical attention and sympathy. While thought to be rare, these disorders are an important differential diagnosis in patients with psychogenic movement disorders, who present with unusual involuntary movements not due to a known organic etiology.

Methods: Two cases from a tertiary care academic movement disorder center are presented in which malingering was considered. A literature review was performed on diagnosis of malingering, specifically as it pertains to patient with movement disorders.

Results: Most tests for malingering focus on cognitive complaints, such as the Test of Memory Malingering (TOMM) and the Word Memory Test (WMT), although their diagnostic utility has limitations. Electrophysiological testing can help with the distinction between “organic” and “psychogenic” tremor or myoclonus. In “psychogenic” movements, it is however not possible to determine with diagnostic certainty if symptoms reported by the patient as involuntary are indeed unconsciously experienced or feigned.

Conclusion: Malingering is a difficult diagnosis to make and carries grave implications on the physician-patient relationship with important socioeconomic consequences. There is a paucity of diagnostic tests to allow a reliable distinction between psychogenic movement disorders and malingering. A better pathophysiologic understanding of psychogenic movement disorders will hopefully lead to improved diagnostic reliability and differentiation from intentionally produced symptoms in the future.

Faceless fatigue: ethical considerations on the elusiveness of CFS/ME

Smaranda Ene, Case Western Reserve University

Abstract: Chronic Fatigue Syndrome or myalgic encephalomyelitis (CFS/ME) is a condition of undetermined etiology. It has been considered by some scholars (Ware and Kleinman 1992) to be a psychosomatic manifestation of socio-cultural stress, while others have compared it to multiple sclerosis (Richman 2010) or traumatic brain injury (Bruno 2008). Although several

neurological and neuroimmune disorder mechanisms have been proposed, the treatment of physiologically unaccounted for fatigue often falls in the realm of psychiatry. By being placed in the in-between space of biomedicine, the patient’s subjective experience of suffering is deligitimized. The Western medical mind/body dualism approach to disease does not leave room for a holistic explanation of this condition. Hence current treatment approaches are inefficient at both curing the pathology and religitimizing the validity of the patient’s complaint through a non-stigmatizing diagnosis. As of now, pharmacological research is lacking and patient advocacy is not being met by initiative from the part of major health care stakeholders. The current paper will take a multifaceted approach in investigating ethical issues related to the CFS/ME illness course. It will consider the moral implications of societal views of chronic fatigue as reprehensible malingering. It will look at their medico-legal implications regarding the insurance industry and government benefits. Aspects of gender in the epidemiology and diagnostic of CFS/ME will be discussed. Finally, the recovery process and the need for person-centered management of the condition will be addressed.

Ethical tensions in the neuropsychological evaluation of the “worried well”

Cynthia Kubu, Cleveland Clinic Foundation

Abstract: Neuropsychologists frequently are asked to evaluate patients with complaints of memory impairments with no clearly discernable medical etiology. Formal testing will often reveal no deficits, yet patients are insistent that they are “not the same” and adamant that their difficulties are not in “their head.” These patients are the “Worried Well.” In this setting, the neuropsychologist must balance multiple ethical and professional obligations. Professional standards argue for the need to avoid straying from the data including evidence of “normal” test scores, knowledge of the tests’ limits, and the published literature. Professional and ethical responsibilities also include beneficence and respect for autonomy. It is important to avoid trivializing the patient’s complaints while steering clear of over-pathologizing cognitive complaints that may reflect situational factors and not permanent impairments. Careful, balanced, and transparent communication to both the patient and referral source is essential to: 1) ensure that the patients feel that their concerns have been heard; 2) minimize the likelihood that the patient will seek out another set of medical professionals to justify their complaints (i.e., “doctor shop” which may lead to harm); and 3) ultimately enlist the patient and health care team in a comprehensive treatment plan. Finally, the neuropsychologist is challenged by justice considerations. In the setting of limited access to neuropsychological services, should the “worried well” have equal access as a young adult with a traumatic brain injury or a patient with an early dementia? Is this the best use of neuropsychological resources? Who should decide? Who should pay?

(4a) Organized Panel: DSM-V Redefinitions Panel

Moderator: Barbara Russell; Panelists: Peter Whitehouse, Serife Tekin, Julie Aultman

Abstract: Throughout the DSM-5 development, professionals have expressed both considerable hope and concern. The panel will discuss and debate various aspects of the DSM-5 that remain ethically and clinically worrisome for clients and practitioners.

(4b) Accepted Oral Presentations: Clinical Neuroethics

Attitudes on mind over matter: Physician views on the role of placebo in psychogenic disorders

Karen Rommelfanger, Emory University

Abstract: Psychogenic movement disorders (PMD) mimic known movement disorders, yet cannot be attributed to an underlying neurological substrate. PMD has been reported to affect up to 15-25% of patients who visit specialized movement disorder clinics. The lack of mechanistic understanding of this disorder contributes to the hesitation of physicians to give a diagnosis of PMD, and patients often experience inordinate healthcare costs and multiple referrals between psychiatrists and neurologists who have differing views on the diagnosis and terminology of PMD. Given that the prognosis for PMD is poor, that the success of standard treatment for PMD is highly dependent on the patient's belief in the diagnosis and treatment regimen, and that case studies suggest the efficacy of placebo for PMD, placebo therapy has recently been advocated for PMD. Recent surveys report a high percentage of physicians administering placebo therapy. Therefore, perhaps, the ethical question in PMD should be, "Are we harming patients by withholding placebo treatment?" In order to determine if placebo therapy would be a viable option for PMD, we must first rigorously assess the factors contributing to the medical contexts in which placebos are offered. We conducted in-depth interviews with neurologists and psychiatrists to assess the attitudes that contribute to ethical norms and to assess physician attitudes and practices surrounding placebo therapy to psychogenic patients. These data will serve to inform the future treatment of PMD patients, to make recommendations for clinician training and healthcare policy, and to reframe and deepen our discussion of the value of placebo therapies.

Long-term care for patients with chronic disorders of consciousness: a qualitative interview study with German nurses

Katja Kuehlmeyer, Ralf Jox, Ludwig-Maximilians-University Munich Institute of Ethics, History and Theory of Medicine

Abstract: Patients with chronic disorders of consciousness (CDC) give rise to an ongoing debate about the use of life-sustaining treatment (LST). Family caregivers and nurses are closest to patients in the long-term-care setting. This paper

aims to describe how nurses perceive their role in the care for CDC patients and how they deal with decisions whether to limit LST. An interview study with 13 nurses was conducted and analyzed using qualitative content analysis (Mayring), aided by the software MAXQDA. Nurses had the goal to bring the patient into action as much as possible to enable him to participate in social life. They regarded all patients as being able to perceive and understand much of their environment and interpreted their nonverbal behavior as purposeful expressions of a will. Many were convinced that some patients reacted more to their own care than to that of other nurses. Some reported that the rehabilitation center forbids foregoing LST regardless whether a patient had an advance directive. When they discovered a patient in a life-threatening condition, the nurses were obliged to call the ambulance. Some patients were transferred to a hospital, where they died in distress without their loved ones. Several nurses reported suffering from burn-out-syndrome. Some said that their work impacts on their own way of life, persuading them to live more in the present because they became aware of their own vulnerability and mortality. Nurses are challenged by their own aspirations, the patients' deficits, the requests of family caregivers and the institutional requirements.

Clinical uncertainty and the ethics of decision making in patients with intracranial hemorrhage

Michael Kelly, Robert Weil, Cleveland Clinic Foundation Neurosurgery

Abstract: The treatment of patients with non-traumatic intracerebral hemorrhage (ICH) presents clinical and ethical dilemmas. Outcomes in this patient population are frequently poor, with mortality rates approaching 30-60% survival is often associated with severe disability. Moreover, studies have failed to show sustained benefit from treatment and demonstrate wide variability in the type and intensity of treatment offered. While prognostic accuracy has likely improved over time, how physicians use prognostic data in clinical decision-making is less understood. Inaccurate prognostication and a move by physicians, in general, toward early care limitation in patients with ICH may serve as a "self-fulfilling prophecy" for "clinical nihilism" in the treatment of ICH. Recent studies from intensive care units demonstrate that physician prognostication is not as accurate as has been assumed from outcome prediction models used in published studies. We argue that physician prognostication and clinical decision-making is an informal, sometimes inconsistent process laden with bias, value assumptions, and subjective impressions. The subjective character of these decisions must be better described to understand how clinical uncertainty influences treatment decisions and whether these biases are at odds with the ethical principles of autonomy and beneficence in patient care.



(4c) Accepted Oral Presentations: Deep Brain Stimulation and Mental States

Categorizing complexity: The ethics of translational research

Samantha Copeland, Dalhousie University

Abstract: At the crossroads of the 'basic science' of neurology and the 'clinical' science of psychiatric medicine lays translational research. Recent discussions have debated the merits of breaking down the complexity of this field by establishing categories. For example, the categories 'T1' and 'T2' create distinctions between research toward better clinical procedures and research toward better patient care. In this paper I argue that while such categories may be theoretically useful for analyzing the structure of translational research, they are in fact misleading when breaking down the complexity of the ethical terrain.

Because it is the interests and needs of various stakeholders that drive translational research, I argue that the ethics of translational research is necessarily multi-directional. I first engage the claim that adoption of what some call a 'translational ethos' toward research in general demonstrates that determining the ends of research has a potentially negative impact on practice in the basic sciences. Close examination of the multi-directionality a true 'translational ethos' would entail provides a positive counter account. Second, differences between research methods and epistemic values at the various levels of translational research indeed call for a diversity of ethical considerations. However, an overlap between stakeholders, I argue, leads to an equally important similarity in ethical considerations at each level. Finally, I look at an example, the ethical context of introducing DBS as a treatment for psychiatric indications.

Reflections on informed consent and deep brain stimulation (DBS): Untangling concerns about vulnerability in psychiatric patients

Emily Bell, Eric Racine, Institut de recherches cliniques de Montreal

Background: A set of clinical trials have demonstrated that the most treatment-refractory patients with obsessive compulsive disorder (OCD) or major depressive disorder (MDD) may respond or even remit with the stimulation of various brain targets using DBS. Patients who have exhausted approved treatment options may be faced with trying investigational approaches as a last resort. In fact, the need to develop new therapeutic options for treatment refractory patients contributes to the perspective that the investigation of invasive options might be ethically acceptable or even imperative. Certain factors in this context may be a source of vulnerability reflected in decision-

making and informed consent.¹ Method: This talk or paper will provide reflections about vulnerability and informed consent for psychiatric patients in DBS and discuss underlying assumptions regarding the relationship between vulnerability and psychiatric disorders. Our presentation will draw on current literature on the topic and be informed by a deliberative workshop of interdisciplinary scholars. Results: Our reflections will center around four main themes: a) How do objective factors modulate the vulnerability of psychiatric patients in DBS trials? b) How do idiosyncratic factors (of the patient and researcher) interact with vulnerability? c) How is the vulnerability of psychiatric patients in DBS trials contrasted with other investigational last-resort therapies (i.e., phase one oncology trials) and how does this comparison support similar or alternative ethical approaches? d) How do we measure or assess vulnerability? Reference:

¹ Lipsman N et al. 2012. *J Med Ethics* 38 (2):107-11.

Authenticity and Psychiatric Deep Brain Stimulation

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Abstract: Deep brain stimulation (DBS) of the nucleus accumbens has shown to be effective in improving symptoms of treatment-refractory psychiatric illnesses. DBS in this region induces smiles and laughter associated with mood elevation, and improves long-term symptoms of psychiatric illness. In their paper, "How Happy is too Happy? Euphoria, Neuroethics, and Deep Brain Stimulation of the Nucleus Accumbens," Synofzik et al. explore the ethical implications of psychiatric DBS in both patients and healthy persons. They conclude that there are no convincing intrinsic objections against the use of DBS either for treatment or enhancement purposes. If a patient will benefit from DBS, and the choice to undergo DBS is in line with her true values, then its use is ethically justifiable. There are, however, extrinsic arguments against the use of DBS for enhancement purposes. In response to Synofzik et al., I argue that the questions raised by the authors leave out an important normative concern when considering neuromodification and neuroenhancement: authenticity. I adopt a notion of authenticity akin to Harry Frankfurt's view of authenticity as identification. On this view, authenticity consists in a second-order identification with one's first-order states. Psychiatric DBS poses a threat to authenticity post-stimulation because first-order mental states and emotions are induced without second-order endorsement in certain contexts. Striving for authenticity will require increased scrutiny of the effects of DBS for treatment of psychiatric illness and may preclude the justification of DBS for enhancement purposes. I conclude that inauthenticity poses an intrinsic objection to psychiatric DBS for enhancement purposes.

Cleveland Clinic NeuroEthics Program

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The mission of the NeuroEthics Program is to conduct cutting-edge neuroethics research, both scholarly and empirical, provide the highest level of training in clinical neuroethics and develop and promulgate best ethical practices in the diagnosis and treatment of neurological diseases that include provision of ethics services to patients, families, and care providers.

Cleveland Clinic's NeuroEthics Program (NEP-CC) is housed in the Department of Bioethics, but constitutes a partnership between the Neurological Institute and the Department of Bioethics, with faculty from both areas. Paul J. Ford, PhD serves as the Director of the NEP with Cynthia Kubu, PhD serving as Associate Director of Neuroethics Research and Adrienne Boissy, MD as Associate Director of Clinical Neuroethics.

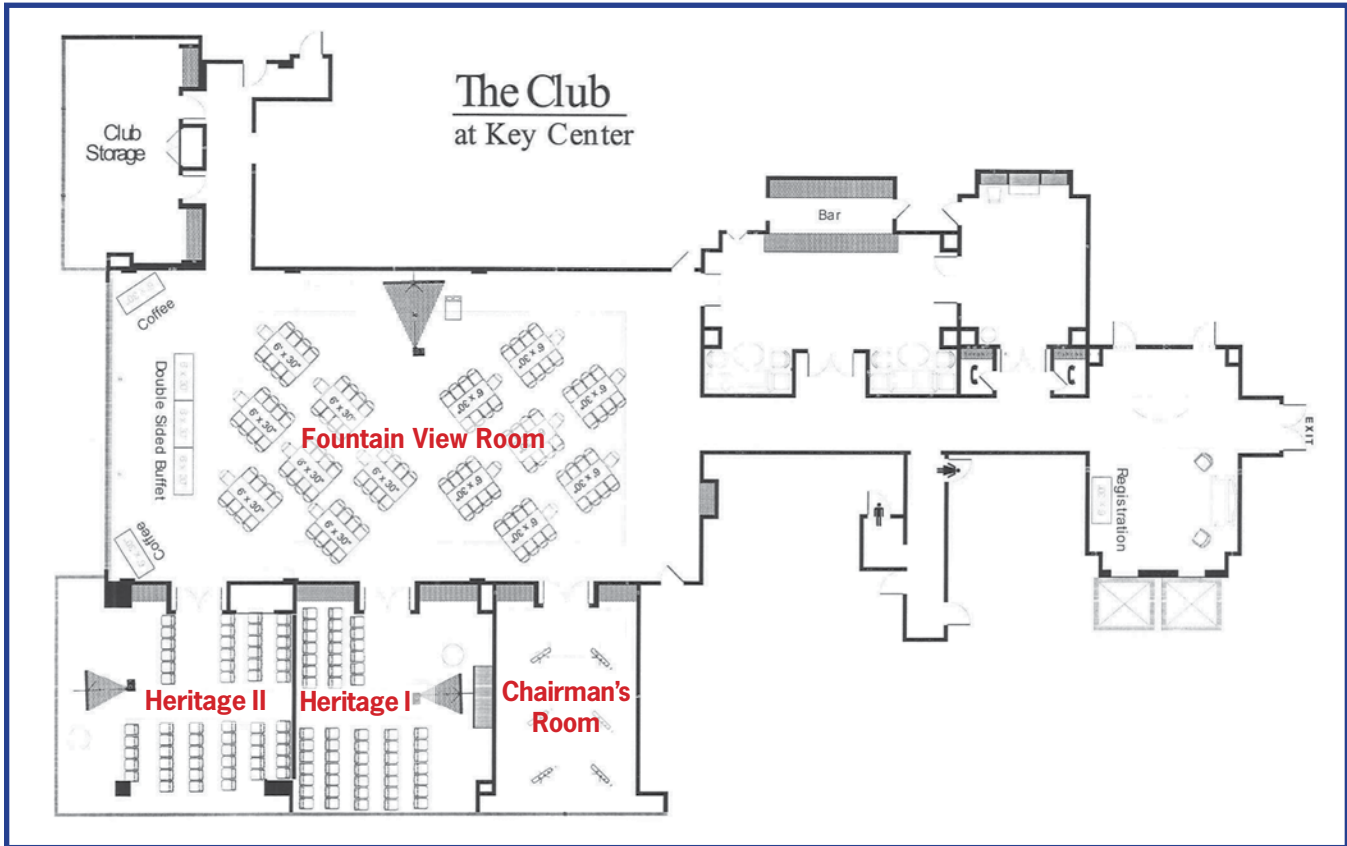
Great need exists to address the emerging ethical challenges faced by patients, families, caretakers, researchers and clinicians related to brain-based diseases. This is particularly true given the increasing incidence of brain based diseases and the resulting worldwide burden of suffering and disability. In the NeuroEthics Program at Cleveland Clinic, we approach these ethical challenges in a practical manner starting from the problems that arise in the prevention, diagnosis and treatment of neurological conditions. We undertake research, education and clinical support through collaborations with clinicians, clinical researchers and bioethicists.

The NeuroEthics Program faculty provides clinical ethics consultation services within Cleveland Clinic to patients, families, clinicians, and researchers. Further, we are actively involved on a national and international level regarding various neuroethics related work.

Other functions in Clinical NeuroEthics:

- Consent monitor for clinical research
- Participation in specialized patient management conferences, including conferences for Epilepsy Surgery and Deep Brain Stimulation, highlighting patient selection and challenging patient care issues
- Frequently consulted on specific inpatient and outpatient neurosurgical issues: called on over twenty times per year to consult on specific inpatient/outpatient surgical issues





The conference is being held at “The Club” at Key Tower. You will access this through the two gold elevators on St. Clair, inside of the Marriott and take them to 4th floor Social Center.