

Cambridge University Press

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Edited by Steven C. Schachter and W. Curt LaFrance

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Gates and Rowan's

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Preface

The first edition of *Non-Epileptic Seizures* was published in 1993 and edited by Drs. A. James Rowan and John R. Gates. Based on a 1990 symposium called “The Dilemma of Non-Epileptic (Pseudoepileptic) Seizures,” this instant classic synthesized the available knowledge and hypotheses regarding all facets of nonepileptic seizures into four sections: neurological, psychiatric and neuropsychological aspects, and fundamentals of treatment. The second edition was published in 2000 and reflected the continued outgrowth of the 1993 symposium as well as a second conference – “Non-Epileptic Seizures: A Consensus Conference on Diagnosis and Treatment” – held in Bethesda in 1996.

A third conference, the 2005 Psychogenic Nonepileptic Seizures (PNES) Treatment Workshop, sponsored by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Mental Health (NIMH), and the American Epilepsy Society and chaired by W. Curt LaFrance, Jr., brought together experts from around the world, representing many disciplines. The enthusiasm emanating from that landmark meeting reverberated widely amongst professionals interested in the evaluation and treatment of persons with PNES. Sadly, the field soon afterwards lost its pioneers: John Gates on September 28, 2005 and Jim Rowan on August 27, 2006.

Recognizing the increasingly rapid developments since the second edition, the importance of *Non-Epileptic Seizures* as the embodiment of the field, and the singular contributions of Drs. Gates and Rowan, we endeavored to organize a new edition and to forever link the names of Gates and Rowan with this topic by their inclusion in the book title. It is therefore most fitting that this edition includes dedications from Rita Meyer Gates and Rita Rowan, with our gratitude, as well as personal remembrances of Drs. Gates and Rowan.

Historically, neurology and psychiatry were practiced as a unitary model, addressing patients with neurological and psychogenic disorders with equal attention. Unfortunately, as neurologic and psychiatric practices became dichotomized in the twentieth century, the topic of PNES fell between the borderlands of neurology and psychiatry.

Bridging neurology and psychiatry again, the primary aim of this edition is to educate physicians, psychologists, clinicians, allied health providers and researchers about the diagnosis and treatment of children and adults with nonepileptic seizures. Building on the groundwork laid in the first two editions, the editors and authors of this third edition provide a multidisciplinary approach to the neuropsychiatric disorder of psychogenic nonepileptic seizures. The authors are the foremost experts in their respective fields and provide an update on the current knowledge of nonepileptic seizures from the neurologic, neuropsychological, psychological, psychiatric, and social perspectives. The structure of the book sections allows an in depth appraisal of diagnostic semiology, clinical characteristics, issues in children, comorbidities, and, finally, a significant expansion of treatment for PNES. The addition of the DVD provides video samples of different seizure types and vignettes to aid clinicians with the differential diagnosis and treatment of nonepileptic seizures.

It is our hope that *Gates and Rowan's Nonepileptic Seizures*, 3rd edn. will honor the memories and legacies of its founding editors, and serve to reflect as well as influence the continued development of the field, informing clinicians and inspiring researchers to improve the care of persons with nonepileptic seizures today and in the future.

Steven C. Schachter and W. Curt LaFrance, Jr.

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Participants, 2005 Psychogenic Nonepileptic Seizures Treatment Workshop, sponsored by National Institute of Neurological Disorders and Stroke, National Institute of Mental Health, and American Epilepsy Society.

Sitting: (left to right) Sigita Plioplys, Rochelle Caplan, Brenda Burch, Andy Kanner (floor), Joan Austin, Curt LaFrance, Margaret Jacobs, Debra Babcock

Row 2: Roy Martin, Claudia Moy, Roberto Lewis-Fernández, Daphne Simeon, Valerie Voon, Selim Benbadis, Elaine Wyllie, Donna Andrews, Patty Shafer, Linda Street, Phyllis Gilbert, Michael First

Row 3: Ken Alper, Mark Hallett, Mark Rusch, Lynn Rundhaugen, Michael Trimble, David Spiegel, John Gates, Laura Goldstein, Gabor Keitner, Cynthia Harden, Charles Zaroff, Helena Kraemer, Chris Sackellares

Row 4: Gregory Mahr, Peter Gilbert, Randall Stewart, Greer Murphy, Richard Brown, Jonathan Halford, Paul Desan, Steve Schachter, John Barry

Not pictured: John Campo, Orrin Devinsky, Frank Gilliam, Dalma Kalogjera-Sackellares, John Mellers, and Markus Reuber contributed significantly prior to the workshop but were unable to attend.

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Dedication for Dr. A. James Rowan

On the Friday afternoon before his last admission to the hospital, Jim Rowan presided over his weekly pediatric epilepsy conference. He insisted on it. He dressed himself carefully though every small movement cost more energy than he had to spare – but this was his favorite conference of the week.

More effort and energy was expended getting him into a taxicab and then up to the EEG laboratory where the conference was held. It was well attended. Jim was clearly fatigued, yet, the moment he was given the first case the “old” Dr. Rowan was again in charge – no fatigue, no effort, just joy in his competence and knowledge, and yes, his love of it. He sat before the computer screen reading EEGs, and without any evi-

dent struggle, expounded as usual on case after case. It was a dazzling performance.

Epilepsy, understanding it, treating it, and teaching about it was the work to which Jim gave his life. That afternoon he gave his last share of energy to it. He would not have had it any other way. The pediatric conference, concerning epilepsy at the beginning of life, his geriatric research, concerning epilepsy at the end of life, and this work on nonepileptic seizures suggests the range of his interests and the depth of his dedication. It is fitting that the new edition continues to advance this very important work.

Rita Rowan

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Dedication for Dr. John R. Gates

John was an intentional man who woke each morning with an explicit commitment to proffer his best in every circumstance, to everyone; who went to sleep each night weighing the day's successes and challenges, probing the "what and how" for an inspiration that might give rise to the next opportunity. What he took as a matter of course – expertise, indefatigable energy, imagination, and hustle – others found remarkable, and he devoted himself to patient care, research, writing, teaching, and organizational, volunteer, and committee work.

John was fascinated by the workings of the brain, and he believed that neurology, rather than psychiatry, held more potential for effective intervention. For this reason, as a young intern he chose to specialize in epilepsy so that he could make a difference. His wish and ambition to make that decisive difference in individual lives and in the field of epilepsy came to permeate his work, which in turn became his life. John's interests and efforts included advancing surgical techniques to improve surgical outcomes, pharmaceutical and device research, mentoring a broad range of students, physicians, and adjunct individuals, and membership in local, regional, and national organizations advancing quality assurance, professional practice, fiscal strength, and community resources.

His 25 years of work in the field of psychogenic nonepileptic seizures (PNES) were of a special order; he was determined to mitigate the primary and secondary causes of distress within this special population. The origin of his passion, the impetus that fueled his concern and commitment, was his mother's PNES. And it was his resolve to make a difference, coupled with his compassion and enthusiastic optimism, which compelled him in his work with PNES.

Based on John's vision of model collaboration, he organized and convened the initial interdisciplinary PNES consensus conferences in 1990 and 1993. These conferences were the milestones that set the stage for years of joint effort among epileptologists, psychia-

trists, and neuropsychologists to ensure the best diagnostic and treatment parameters for PNES. This early work defined and continues to influence the multifactorial, multicultural, and multidisciplinary emphases in the treatments for these patients. He would have been particularly pleased that this new volume was edited by an epileptologist and a neuropsychiatrist.

John was unabashed in his esteem and admiration for his colleagues, his respect and regard for his patients, and his love for his family and friends. He was often generous, exuberant, and forgiving to a fault. His conviction of the inherent value and goodness of people gave meaning to his life and heartened those around him.

He set great store by his Jersey street-fighter roots, which he credited for his "backbone." He had the ability to stand his ground, often alone, under terrific pressures. Never one to uphold the status quo, he made 'thinking outside the box' his mantra long before it was part of popular culture. John was always keen to work out an impossible situation. But then a brain tumor appeared at the age of 53. This was a terrific blow. Though his commitment to his treatment was 100+%, there would be no recovery. He would not live long enough to appreciate the testimonials, honors, and awards that were bestowed to pay tribute to him; he would not be cognizant of the expressions of respect, appreciation, and love he had engendered during his life.

John would applaud publication of this third edition and then press for continuation of the work. With John, whether flying his plane, guiding boy scouts, fishing in the cold of a Minnesota winter, advocating for his special needs son, writing poetry, or absorbed in his work, it was always upwards and onwards.

May his life and dedication to patients with PNES continue to be an inspiration.

Rita Meyer Gates

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In remembrance of Dr. A. James Rowan

Steven C. Schachter

Dear Jim,

You were one of my closest friends, and I miss you terribly. Your advice and genuine kindness and concern brought me through difficult times. Your fatherly pride in anything I accomplished made me try even harder to please you. You shouldered many burdens with grace, and shared a few of your own along the way, but you always kept your focus on the task at hand and on the well-being of others.

Everything important to you about the field of epilepsy became important to us, whether through your impassioned lectures, your impromptu conversations, or your writings. Your wisdom and perspectives will be passed on from us to those who follow. You had that penetrating way of looking at people in the audience, your glasses half down your nose. You wouldn't release your gaze until you were sure they understood the importance of what you were saying. Who can forget the essence of successful aging after seeing your that picture of Kin and Gin Narita, the Japanese twin sisters, joyously celebrating their 100th birthday?

The Veterans Affairs Cooperative Study was your baby. I served on the Data Safety Monitoring Board,

which conducted periodic checkups during the study's gestation. I can still picture you pacing back and forth outside the door while the committee met, like an expectant parent. And I can also see you glowing when presenting the results of this landmark study.

You never knew it, but you were the inspiration behind the Epilepsy Foundation's Seniors and Seizures Initiative, and the Board of Directors wanted you to know the Foundation authorized half a million dollars for research in the area of epilepsy in the elderly, which should make you very proud.

We shared many wonderful times together, personal and professional. Sue and I will never forget when you and Rita flew our family to New York to have Christmas dinner with you.

Whenever I recommend one of your books to one of our fellows, I say "That book was written by a good friend of mine, Jim Rowan." And now, with a few of your favorite words and phrases, I add "He was a terrific physician, and a wonderful human being, as a matter of fact."

Farewell, Jim. Your memory will always remain with us. God rest your soul.

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In remembrance of Dr. John R. Gates

Steven C. Schachter

John R. Gates, MD died September 28, 2005, at age 54 from a brain tumor. A moving memorial service was attended by over one thousand people, and centered around readings, poetry, and music – all artistic favorites of John's. He was survived by his beloved sweetheart and wife of 15 years, Rita; children, Jason, Rachel, and Stuart; and an extended family. Friends, family, patients, and colleagues around the world remember a wonderful man who made numerous and substantial contributions to the field of epilepsy and the practice of neurology. With contributions from many of those who were closest to John, I offer this appreciation.

A champion fighter from an early age

Born in the inner city of Trenton, New Jersey, John emerged from humble surroundings to graduate Magna Cum Laude from Harvard University. He was brought up by his grandparents. After both his grandparents passed away when he was 15 years old, a teacher who recognized his brilliance helped him get a scholarship for disadvantaged youth. He went on to attend elite schools in Massachusetts and England, where he excelled academically. I believe it was because of this unique background that he was able to challenge the establishment with confidence. Indeed, from his childhood until his untimely death, John “never gave up the fight.” He was “an enthusiastic paladin for the wars against epilepsies, and more.”

Standout trainee

At the University of Minnesota Medical School, John perfected his ability to question, challenge, and shake up the status quo. John was a 4th year medical student, rotating through neurology. At that time, Dr. A. B. Baker was the chairman of the Neurology Depart-

ment, and a very demanding teacher and world class scholar with tremendous clinical experiences in neurology. It is very unusual to hear a neurology resident arguing with Dr. Baker, not to mention a 4th year medical student. But John did. He once said to Dr. Baker during a teaching round, “Dr. A. B. Baker, I don't think so. . . .” We all held our breath, and didn't know what to expect. I believe even Dr. Baker was caught by surprise as well. I can't recall the detail of the conversation then, but I remember he was able to present his view in a calm and logical manner, though I don't think he was able to win the case. His unique way of dealing with authority left me with an indelible impression.

His fellow residents and teachers witnessed the growth and development of a stellar and compassionate clinician who sought the truth, sometimes in unconventional ways. I happened to be the very first chief resident he had to work with. In the beginning, it was truly a disaster; he almost constantly argued with me in the diagnosis and clinical management of cases. Sometimes in front of the whole crew in the sign-out rounds in the evening, he would challenge me for saying something not well founded. The results of these numerous arguments were that we both went to the library to look for references to back up what we said, and then Xeroxed articles for each other to prove our points. By the end of his three-month rotation at the Minneapolis VA Hospital, we both had piles of references from each other, and that is how we learned “evidence-based medicine” in the 1970s.

One of my most poignant memories is when John was chief resident. I was the attending. The case was that of a young woman with subarachnoid hemorrhage. John's team had been pared to a minimum over the holidays by scheduled vacations, and John was filling many roles – including single-handedly managing all aspects of critically ill patients, including the

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young woman. He invested everything of himself in an effort to stave off what was inevitable. He also became exhausted. Late on Christmas Eve we took a break in my office to discuss plans for the night. John told me that the young woman had just deteriorated, and he did not know what he was going to tell her family. He put his head down and cried. I think I did too. Although he projected unflappable bravado, his complete personal investment in his patients and their families was also his gift and his emotional Achilles' heel.

There is the apocryphal tale of the burr hole drilled by John in an emergency room for suspected extracerebral hemorrhage. It was dry, but a legend was born of the most swash-buckling of all neurology residents, ever. He always knew more than his fellow residents and usually more than his attendings. Even when he did not, he thought he did. He was at once the most inspiring of trainees and the most challenging, and always a force to be reckoned with.

Passion for patients and their doctors

John co-founded the Minnesota Epilepsy Group in St. Paul, a practice that grew into a world-renowned, comprehensive epilepsy center noted for clinical and research excellence, and widely emulated. A clinical professor of neurology at the University of Minnesota, John was "passionate in his commitment to patient care," tried "his hardest to be the best doctor" for his patients, and believed "the treatment of epilepsy had no boundaries" and that "people with epilepsy deserved first rate care."

Over the years, John recruited and attracted "technically superior and enormously caring staff – all of whom were a reflection of John's core values, and who will carry on his legacy through their work." John's coworkers were "dedicated to him and held him in such high esteem. Nurses, psychologists, neurologists, support staff – at every place he worked – would spontaneously talk about John and his dedication to patients. They truly held him in a special spot in their hearts for years and that is something one rarely sees."

His "strong advocacy for compassionate treatment of people with nonepileptic seizures" was widely recognized and appreciated. "Far too often, these patients are dismissed and treated as second class citizens by epileptologists. John hated that attitude."

His influence on patient care and the epilepsy movement spread out from St. Paul to around the world. "John was one of those special people, and there

are very few, who made a critical difference at all levels in the epilepsy movement – patient care, research, public policy, and volunteerism." He was a "powerful and effective voice in the world of epilepsy, one who spoke for the needs of clinicians who are truly devoted to the care of their patients."

Prodigious scholarship, impactful teaching, and a zest for work

John authored hundreds of publications and perhaps is best known for his writings and edited books on psychogenic nonepileptic seizures, efficacious use of antiepileptic drugs (AEDs), and the surgical management of epilepsy.

Everyone who knew John was impressed by his energy and commitment to "whatever the task, old or new." He "always had a smile on his face, and a zest and enthusiasm for his work," which was "marked by breadth, honest service, and courage."

Several months before he died, John participated in a National Institutes of Health (NIH)-sponsored workshop on nonepileptic seizures (NES). While he thought of himself as "one of the 'old dogs' in the pack," he was regarded as the brightest luminary in this field by the many accomplished international, interdisciplinary workshop participants. "In typical John fashion, he broke the ice very early on, with a few bold comments about the differences between neurology and psychiatry. Once the smoke settled, it proved to be a perfect entrée, loosening up everyone for an intense and invaluable discussion on NES treatment research."

He excelled at lecturing and was a "masterful teacher" who "never stood on formalities and shared his knowledge and experience with young neurologists and foreign doctors". His enthusiasm for teaching continued even after his constitutional energy was nearly depleted. "John couldn't 'turn it off' even when critically ill. To the end, John was lecturing and educating even when he needed help walking up to the podium."

Leadership and dedication to American Epilepsy Society (AES) and International League Against Epilepsy (ILAE)

John was president of numerous organizations, including the Minnesota Epilepsy Group, the American Academy of Neurology Congress of Neurosocieties,

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the Association of Neurologists of Minnesota, and the Ramsey County Medical Society. He served on the ILAE Commission for Neurosurgery and participated in projects of the Subcommission for Pediatric Epilepsy Surgery. He chaired the Practice Committee of the American Epilepsy Society and served on a number of other AES committees and task forces, as well as the AES Board of Directors while courageously battling his cancer. "John's voice on the AES board always reflected his passion and commitment to the needs and best interests of individuals with epilepsy."

As his wife Rita remarked in accepting the AES J. Kiffin Penry Award for Excellence in Epilepsy Care on John's behalf,

John loved this society. If John were here, he would turn the tables, and, looking out at you, would make it about you. He would thank you for being such great colleagues. He would talk about how much each of you contributed; how he so appreciated your hard work; how key people working together make something come alive; how grateful he was that you shared his passion for this work, work that makes such a difference for so many; and how much fun it was to "play with you in this sandbox."

A warm and friendly guy who occasionally tilted at windmills

Each of us who knew John remembers something special about him, whether serious or humorous, profound or simple. He was the kind of guy who would wake up one morning with an idea and then a few hours, days, weeks, or months later, it would become a reality. He was a grass roots organizer who gave untold time and energy to innumerable epilepsy-related projects, including summer camp for kids, assisted living for young adults, funding for the less well-off for affordable medications, and "inventing" local, regional, and national training and mentoring programs. Above all else, "he was a warm and friendly guy who made many people, especially his patients, feel special."

When I think of John, his email address always pops into my mind: gaterair@aol.com. It was so appropriate. He seemed to swoop into a room as if he was a plane landing or, under some circumstances, as a dive bomber when he wanted to destroy opposition to some point he held dearly. Gaterair@aol.com also conveys to me the sense of soaring, which also captures his personality to me. He was always a presence in any meeting, no matter how large the group. He never just went through the motions of showing up. He was always in the mix of any discussion speaking out about the issues near and dear to

him; his patients, the profession of epileptology, and the economics of running a practice.

I remember his ability to cut through or circumvent nonsense and get to the heart of any matter quickly, and directly, without causing antagonism, which is a great skill. Even when he was very sick, we appreciated his ability to do this.

The two things I will most remember about John are his jokes, mostly aimed at hospital and HMO administrators; and his unfailing willingness to serve as counselor, friend, or mentor. His passion for completing projects (the ultimate goal of which was always to help patients) was matched only by his kindness and collegiality.

A trademark of John that I appreciated was his ability to connect with whomever he was speaking to. His deep voice conveyed a deportment of seriousness, which however was countered by his wide smile and straight look into your eyes that made you feel welcomed to his attention.

John was an interesting combination of great brilliance, professional dedication, impeccable ethics and still a lovable nature.

He was deep, funny, irreverent, lovable and infuriating, all in one day. He was the brightest bulb in every group and knew it. He had vast energy, and his personal and professional agendas were always way more ambitious than most mortals would or should take on. He had enormous ego strength and self-confidence. If he thought an unproven or unconventional approach made sense for his patient, he forged directly ahead, full speed, against all resistance.

He was intense and very perceptive. He knew what he wanted and went after it with all his energy, and usually got what he wanted. I admired him for his intelligence, intense energy, drive, and his unique capacity to think on a grand scale. He was not afraid to be unconventional.

I didn't always agree with him, but I sure appreciated his passion. I also appreciated that he did not mind if you disagreed with him and I recognized that he sometimes went over the top just to spark some movement. Just like when he flew his plane, he always wanted to be moving towards some goal and he hated getting bogged down on technicalities.

As you know, he was a pilot. He flew into Seattle for one of the meetings. Apparently there are others named Gates in the Seattle area, and with John's last name, he told me with great amusement that he was treated very well indeed at the airport.

His kind face, warm smile, and ability to inspire confidence in less endowed friends were the sparks that spread the epilepsy gospel into a wheat field in the middle of the country.

I remember his saying that the first thing he told people moving to Minneapolis was to get a new Sears Diehard battery, no matter

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how old their current car battery was. Sort of a “Don’t fool yourself” approach.

I regarded him as a minor renegade with a sense of humor. John was a real gentleman who occasionally liked to tilt at windmills.

Farewell

John will be missed enormously. Many of us can still hear him say “Hi guy, how are you doing!” As one close colleague said, “He was special to me. I am not exactly sure why. Maybe it is some form of love.” One of his many grateful patients said, “You were the best doctor. I had such faith in you and I know God will be with you always.”

Farewell, John. Your memory and inspiration live on, and we are all better for having known you.

Legacies

Several funds have been established in memory of John Gates: the Minnesota Medical Foundation, Dr. John

R. Gates Memorial Award in Neurology, 200 Oak St. SE, Suite 300, Minneapolis, MN 55455-2030; Epilepsy Foundation of Minnesota, John R. Gates MD Project Fund, 1600 University Ave. W., Suite 205, St. Paul, MN 55104; and Minnesota ABC, Dr. John R. Gates Scholarship Fund, 8761 Preserve Blvd, Eden Prairie, MN 55344, attn: Gardner Gay.

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