**Talking about SUDEP is first step to understanding it**

Q: **Can you die from epilepsy?**
A: Anyone who has witnessed a generalized tonic-clonic seizure (also known as grand mal seizure) can imagine that such a seizure can be lethal—not only through trauma or drowning, but also just through the impact of the seizure itself. The person with the seizure may lose consciousness for the event, often realizes this only when listening to family and friends who witnessed the event. We tend not to think and talk about it too much, but it is self-evident that a seizure in the wrong place and time can be very dangerous.

Many topics in medicine come and go like a pendulum, meaning different aspects of a medical problem get more or less attention at different times in history. Scientists in the mid 19th century realized an increased risk of death related to epilepsy seizures and speculated about the potential causes and possible prevention. Numerous and often unnecessary restrictions were then imposed on patients with seizures. This changed in the second part of the 20th century when the “began” aspects of epilepsy, like the chance of full seizure control in over half of all patients or the low risk of seizure recurrence after a first event became apparent. “Out of the Shadows” has been an ongoing movement for several decades to encourage patients and society to deal with epilepsy and seizures in a more open way and raise awareness that seizures do not preclude patients from an active and fulfilling life. With the optimism that came along with modern medical and surgical treatment options, the pendulum went to the other side and physicians even questioned if there is a shortened life expectancy associated with epilepsy.

Unfortunately, there is a real risk of dying from epilepsy. A study of Minnesota residents over a period of 40 years showed that the risk of death in patients with epilepsy was three times higher than that of the general population. The risk for sudden unexpected death is even greater and can be 25 times higher for patients with epilepsy in their 20s to 40s compared to the general population. Around 10% of patients with epilepsy die either from seizure related traumatic causes or directly from a seizure itself.

The risk of traumatic death from seizures can often be prevented with adequate cooldown, absence of high altitudes, heavy and dangerous machinery, unsupervised swimming or bathing and adequate driving restrictions) and optimal treatment. A large study in 2008 demonstrated that mortality in epilepsy is significantly higher for patients who are not compliant with their medications, outweighing any possible suicide risk related to taking antiepileptic medications.

**Talking about SUDEP** is a recurrent topic at national neurological and epilepsy meetings. There are still many steps to go. First, we will have to better understand the mechanisms of SUDEP. Is it caused by a sudden failure of the heart or lungs or does the brain shut down after a seizure and is unable to recover? Do we need a cardiac pacemaker, something that will keep the patient breathing, or a medication that prevents the post-seizure atonia? Who is at higher risk, and how can we prevent SUDEP without unnecessarily restricting quality of life and independence? Hopefully, we can repeat the success seen in neonates in the prevention of sudden infant death syndrome (SIDS). The risk of SIDS has been reduced by more than half by a campaign emphasizing proper positioning and bedding. Before we are able to change things, we have to be willing to talk about it, in society and with our patients.

---

**JIM DAVIES HONORED FOR THREE DECADES OF DEDICATION TO EPILEPSY COMMUNITY**

For the past 33 years, Jim Davies has been tirelessly serving the epilepsy community as a vital part of the Epilepsy Foundation of Greater Chicago’s staff. Recently, Jim retired from the Foundation and was honored at an August 7 reception hosted by Garrett Ripley’s, 712 N. Clark Street, in Chicago. There, over two dozen guests celebrated Jim’s dedication, skills, and achievements. Fellow staff members, colleagues, and prominent figures in the epilepsy community came together to show their admiration for Jim, and to honor the lasting impact he has had on those living with epilepsy in the Greater Chicago area. Over the years, he has covered all the bases at the Foundation, from leading support groups to directing the Client Services Department. Special thanks to Brian and Pam Farley for their generous support of this event.

**GREATER CHICAGO EPILEPSY WALK STARTS SUMMER OFF ON THE RIGHT FOOT**

Walkers, runners, and supporters of all ages raised more than $170,000 for the Epilepsy Foundation of Greater Chicago’s 2009 Greater Chicago Epilepsy Walk on May 10 at the Danada Forest Preserve in Wheaton. Over 1,300 individuals attended the combined events, which included appearances by Ronald McDonald, and the Chicago Wolves mascot Skates. The Jesse White Tumblers also performed—and Illinois Secretary of State Jesse White himself stopped by to join in on the fun! Mara Goldman’s team Seizure Free was the top fundraiser with over $7,400 raised and Chita Garcia’s Anaya’s Angels came in second, raising over $6,400. Both have been active participants of the Greater Chicago Epilepsy Walk over the years, and continue to rank among the highest fundraisers. Photos from the Walks can be found at www.epilepsy.org and on the Foundation’s Facebook page at www.facebook.com/Epilepsy.Chicago.

**GOLFERS TEE OFF TO SUPPORT EFGC’S CAMP BLACKHAWK AT NINTH ANNUAL GOLF OUTING**

On September 1, over 80 golfers enjoyed blue skies and a light breeze at the Ruffled Feathers Golf Club in Lemont for the Epilepsy Foundation of Greater Chicago’s 9th Annual Golf Outing. A round of golf, followed by cocktails, dinner and a live auction made this a sunny perfect day. This year, participants were “Teeing Off for Camp Blackhawk,” our week-long retreat for kids ages 6-18 with epilepsy seizures and specula
ted about the potential causes and possible prevention.

Numerous, and often unnecessary, restrictions were then imposed on patients with seizures. This changed in the second part of the 20th century when the “began” aspects of epilepsy, like the chance of full seizure control in over half of all patients or the low risk of seizure recurrence after a first event became apparent. “Out of the Shadows” has been an ongoing movement for several decades to encourage patients and society to deal with epilepsy and seizures in a more open way and raise awareness that seizures do not preclude patients from an active and fulfilling life. With the optimism that came along with modern medical and surgical treatment options, the pendulum went to the other side and physicians even questioned if there is a shortened life expectancy associated with epilepsy.

Unfortunately, there is a real risk of dying from epilepsy. A study of Minnesota residents over a period of 40 years showed that the risk of death in patients with epilepsy was three times higher than that of the general population. The risk for sudden unexpected death is even greater and can be 25 times higher for patients with epilepsy in their 20s to 40s compared to the general population. Around 10% of patients with epilepsy die either from seizure related traumatic causes or directly from a seizure itself.

The risk of traumatic death from seizures can often be prevented with adequate cooldown, absence of high altitudes, heavy and dangerous machinery, unsupervised swimming or bathing and adequate driving restrictions) and optimal treatment. A large study in 2008 demonstrated that mortality in epilepsy is significantly higher for patients who are not compliant with their medications, outweighing any possible suicide risk related to taking antiepileptic medications.

Q: **What can we do about this “sudden unexpected death from epilepsy,” also known as SUDEP?**
A: Families and physicians are often hit even harder when losing a family mem-

**Foundations**

Richard Roner, MD, a board member of EFGC’s Board of Directors, Professional Advisory Board, and Leadership Circle, was on hand to celebrate Jim Davies’ tenure with the Foundation.

**Epilepsy Answers**

By Stephan Schuele, MD

**Talking about SUDEP is first step to understanding it**

Q: **Can you die from epilepsy?**
A: Anyone who has witnessed a generalized tonic-clonic seizure (also known as grand mal seizure) can imagine that such a seizure can be lethal—not only through trauma or drowning, but also just through the impact of the seizure itself. The person with the seizure may lose consciousness for the event, often realizes this only when listening to family and friends who witnessed the event. We tend not to think and talk about it too much, but it is self-evident that a seizure in the wrong place and time can be very dangerous.

Many topics in medicine come and go like a pendulum, meaning different aspects of a medical problem get more or less attention at different times in history. Scientists in the mid 19th century realized an increased risk of death related to epilepsy seizures and speculated about the potential causes and possible prevention. Numerous, and often unnecessary, restrictions were then imposed on patients with seizures. This changed in the second part of the 20th century when the “began” aspects of epilepsy, like the chance of full seizure control in over half of all patients or the low risk of seizure recurrence after a first event became apparent. “Out of the Shadows” has been an ongoing movement for several decades to encourage patients and society to deal with epilepsy and seizures in a more open way and raise awareness that seizures do not preclude patients from an active and fulfilling life. With the optimism that came along with modern medical and surgical treatment options, the pendulum went to the other side and physicians even questioned if there is a shortened life expectancy associated with epilepsy.

Unfortunately, there is a real risk of dying from epilepsy. A study of Minnesota residents over a period of 40 years showed that the risk of death in patients with epilepsy was three times higher than that of the general population. The risk for sudden unexpected death is even greater and can be 25 times higher for patients with epilepsy in their 20s to 40s compared to the general population. Around 10% of patients with epilepsy die either from seizure related traumatic causes or directly from a seizure itself.

The risk of traumatic death from seizures can often be prevented with adequate cooldown, absence of high altitudes, heavy and dangerous machinery, unsupervised swimming or bathing and adequate driving restrictions) and optimal treatment. A large study in 2008 demonstrated that mortality in epilepsy is significantly higher for patients who are not compliant with their medications, outweighing any possible suicide risk related to taking antiepileptic medications.

Q: **What can we do about this “sudden unexpected death from epilepsy,” also known as SUDEP?**
A: Families and physicians are often hit even harder when losing a family mem-

**GREATER CHICAGO EPILEPSY WALK STARTS SUMMER OFF ON THE RIGHT FOOT**

Walkers, runners, and supporters of all ages raised more than $170,000 for the Epilepsy Foundation of Greater Chicago’s 2009 Greater Chicago Epilepsy Walk on May 10 at the Danada Forest Preserve in Wheaton and on May 17 in Chicago’s Lincoln Park. Over 1,300 individuals attended the combined events, which included appearances by Ronald McDonald, and the Chicago Wolves mascot Skates. The Jesse White Tumblers also performed—and Illinois Secretary of State Jesse White himself stopped by to join in on the fun! Mara Goldman’s team Seizure Free was the top fundraiser with over $7,400 raised and Chita Garcia’s Anaya’s Angels came in second, raising over $6,400. Both have been active participants of the Greater Chicago Epilepsy Walk over the years, and continue to rank among the highest fundraisers. Photos from the Walks can be found at www.epilepsy.org and on the Foundation’s Facebook page at www.facebook.com/Epilepsy.Chicago.

**GOLFERS TEE OFF TO SUPPORT EFGC’S CAMP BLACKHAWK AT NINTH ANNUAL GOLF OUTING**

On September 1, over 80 golfers enjoyed blue skies and a light breeze at the Ruffled Feathers Golf Club in Lemont for the Epilepsy Foundation of Greater Chicago’s 9th Annual Golf Outing. A round of golf, followed by cocktails, dinner and a live auction made this a sunny perfect day. This year, participants were “Teeing Off for Camp Blackhawk,” our week-long retreat for kids ages 6-18 with epilepsy (read more about it on pages 4 and 5). Thanks to the participants and sponsors of “Tee Off for Camp Blackhawk” — including our Presenting Sponsor USG Corporation, and Hole Sponsors Enterprise Rent-A-Car, Scott Early (in honor of Michael S. Early), Richard Kinch, and Doug Walker — the Epilepsy Foundation of Greater Chicago was able to raise over $21,000 to support this very special cause.