An Interview with Oliver Sacks

Interview by Jamie Bennett, Editor, The Network

Readers of The Network may remember a note we published in late 2010 from physician and writer Oliver Sacks, asking PWNs for accounts of their hallucinations. Now, two years later, Sacks has finished Hallucinations, which he describes in its Introduction as a “natural history or anthology of hallucinations.” The book examines these perceptual phenomena, their roots in neurology, and people’s widely varying experiences with them.

Narcolepsy has its own chapter in the forthcoming book. Sacks originally intended to discuss narcolepsy within a broader chapter on hypnagogic and hypnopompic (falling asleep and waking) hallucinations, but then decided to devote an entire chapter to such hallucinations as experienced by people with narcolepsy.

Sacks worked closely with the Narcolepsy Network and its members in gathering many of the accounts for the narcolepsy chapter. I spoke recently with Dr. Sacks, and he immediately expressed his gratitude:

“I owe a lot to the Narcolepsy Network. I hope that my book will draw attention to people with narcolepsy and to the disorder generally and especially be useful to families and friends and doctors, and will bring the subject out in the air for open discussion. That’s what’s needed.”

Our conversation also included his book, more on how the Network assisted him, and why he wishes he had worked in a sleep clinic.

New AWAKEN Survey Finds Public, Physician Awareness of Narcolepsy Lagging

by Anthony Tam

This July, we learned the results of AWAKEN (Awareness and Knowledge of Narcolepsy), a national online survey launched by Jazz Pharmaceuticals and conducted by Harris Interactive to assess public and physician knowledge of narcolepsy. The participants included 1,000 adults, 300 primary care physicians (PCPs), and 100 sleep specialists. Unfortunately, the survey only confirms the anecdotal sense many PWNs have that both the general public and health care providers remain ill-informed about this serious illness.

Among the sample from the public, 70% indicated that they have heard of narcolepsy. However, only a little more than half of the participants (55%) rated narcolepsy a very or extremely serious disease. Among medical doctors, 24% of primary care providers (PCPs) and 62% of sleep specialists considered themselves very or extremely knowledgeable about narcolepsy. Even smaller was the proportion...
Dear Friends,

It has been a very busy, productive summer, and we are fortunate to have more people working with us, including many volunteers. There have been a number of additions to the board of directors, which has many different and exciting projects on its schedule. We welcome Andrea Podolsky and Louise O’Connell and look forward to working with you!

As you may know, we also have a new part-time staff member: Karen Rorie, our new communications coordinator. Karen started her new job on August 1st and she has already taken on many projects, including the conference and the website. In addition, beginning with the fourth quarter issue, Jamie Bennett will become editor of The Network newsletter. If you want to write an article, contribute a story idea, or simply wish to give feedback, he wants to hear from you: newsletter@narcolepsynetwork.com.

As we move towards 2013, it looks like we are starting to grow again after some “thin” years, and the times are certainly very exciting ones for NN. In the coming period, we will be making a push towards increasing the number of sleep centers and sleep professionals involved with us.

The amount of work before us on this front was reconfirmed when the health assessment survey “AWAKEN,” which was commissioned by Jazz Pharmaceuticals, came out a few months ago. It found that only 42% of sleep specialists are “very or extremely comfortable” diagnosing narcolepsy. This is clearly a huge problem and one we can help fix by making these specialists more aware of narcolepsy and its diagnosis. Many sleep specialists, especially in small towns or rural areas, may not have seen many people with narcolepsy, a disparity the AWAKEN survey likely reflects. Reaching these practitioners is critical to bringing relief to PWNs in the form of more accurate diagnoses and improved care. We hope to bring you more news on our initiative in the coming year; you can help by asking your doctor if she or he is an NN member.

For National Sleep Awareness Week 2013, coming this March, we would like to see many more of you involved. Just last week we received such a nice letter from a young man. His girlfriend was recently diagnosed with narcolepsy, and he wants to organize a large fundraiser and awareness event on their college campus. We would like to work with all of you who have experience putting together such events, and with those of you who have ideas or would like to organize an event in your area. Find out more about how you can help by contacting us at narnet@narcolepsynetwork.org.

Lastly, the Combined Federal Campaign is going on now. We receive funds every year from this campaign, however we need to market ourselves more to improve our results. There are events and charity fairs going on everywhere in the country this time of year, so if you would like to participate or donate, please let us know at narnet@narcolepsynetwork. Ask us about a charity event in your area. You can participate by working a table with our information, or you may even get a chance to speak about narcolepsy and encourage people to donate funds to us via their work campaigns.

I hope the fall season has been a rewarding one for you, and I look forward to us rounding out a productive year for the Narcolepsy Network!

Warm regards,

Eveline Honig, MD, MPH

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**New AWAKEN Survey Finds Public, Physician Awareness of Narcolepsy Lagging**

of PCPs and sleep specialists very or extremely comfortable diagnosing narcolepsy (9% and 42% respectively).

These results reveal the lack of awareness of narcolepsy in the general public, as well as a serious education and knowledge gap among physicians, especially sleep specialists. While PCPs need to have training in a wide range of medical knowledge, they are not always able to diagnose every possible disease and condition. However, PCPs should have resources such as narcolepsy and sleep websites, along with a list of sleep specialists and their area of specialties.

Sleep specialists, on the other hand, should be extremely knowledgeable and comfortable diagnosing narcolepsy. As 82% of sleep specialists consider narcolepsy a serious medical condition, one may expect a large proportion of sleep specialists to know and understand narcolepsy extremely well. These AWAKEN results show that even some sleep specialists may require more training in order to help stem the chronic under-diagnosis of narcolepsy.

The results from the sleep specialists are particularly disappointing, with 82% believing narcolepsy to be a very or extremely serious disease, and even less rating themselves very knowledgeable or comfortable diagnosing narcolepsy. As a specialist in sleep, I would have thought all (100%) sleep specialists would have the medical knowledge to consider narcolepsy to be a very serious condition. One wonders what proportion of sleep specialists who do not believe narcolepsy
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before. Indeed, I’d once been a patient of his when I had some sleep problems twenty years ago. I would tend to fall instantly into REM sleep in about ten seconds as some narcoleptic people do. But Thorpy didn’t think my symptoms were narcoleptic. He thought I was merely chronically sleep deprived.

I spoke to quite a number of people at that meeting in New York. They could often give very interesting, detailed descriptions of what they were going through, although in a social context like that there’s only so much one can say. I was very grateful afterwards, when, after I’d expressed an interest in the hallucinations which might occur with narcolepsy, lots of people wrote to me, and indeed continue to write to me.

NN: After the meeting, you followed up on the stories?

OS: I put a notice in the Narcolepsy Network newsletter saying that I was especially interested in hallucinations, which of course do not occur in every patient but do occur in some, and I would appreciate people contacting me about their hallucinations. Then I got a lot of—and continue to get—replies from that, and some of the replies I have included in my book with the writer’s permission.

NN: Can you say anything about your process for selecting among all the letters you received, how one [story] made it and one didn’t?

OS: First, I wish all could have made it because they’re all interesting. I’ve had this problem all through. In the course of the book I think I quote somewhat over a hundred letters from correspondents. But I could have quoted a thousand. I think careful and detailed description was perhaps the most important criterion, and people’s insight into [their experience], and how they might have been misdiagnosed. I think quite a number of people with narcolepsy, their hallucinations have been misdiagnosed and they’ve been regarded as psychotic or schizophrenic.

Often I would write back to the correspondent asking for more detail, and if they in turn would give me more detail, this then would be a particularly good, as it were, case to cite. Some of the cases—‘case’ is a dry word—some of the letters were very emotionally moving as well, indicating the life problems which people had gone through with a disorder that is often not even recognized by their own doctors, let alone anyone else.

I suspect if the book has a paperback edition I will include more [letters]. I know this happened with an earlier book of mine, Musicophilia. After the hardback came out, many people wrote to me and said they’d read the book and they’d been interested, but they had, apparently, an experience I hadn’t mentioned. Sometimes I would write back and say, ‘Yes, you’re quite right. Can I quote your letter?’ I suspect this will happen here. I think narcolepsy needs more exposure of the right sort.

NN: You interact with a lot of different patient communities, sometimes for rare diseases. So what were some of your impressions of the Narcolepsy Network as a patient community?

OS: I thought it was doing a very valuable job, firstly in introducing people with narcolepsy to other PWNs, letting them know that they weren’t alone in the world. I think narcolepsy is relatively rare compared to, say, autism. If real narcolepsy only occurs in one person in 2,000, then people with narcolepsy can be isolated and misunderstood and may not know what’s going on themselves. Merely meeting other people with narcolepsy is very important. Then getting speakers like Thorpy, at least at some of the meetings.

I’ve had a lot to do with various patient networks, with Tourette’s syndrome and autism in particular, but also with the Achromatopsia Network. This is again a congenital disorder in which the cones, the color receptors, don’t develop in the retina, or they develop and they then degenerate and the people only have black and white vision. This is pretty rare, like one in 40,000. But the Narcolepsy Network has been crucial in allowing people to meet their fellows and to learn about the latest research and the latest drugs. So I think the support network and its newsletter are very important indeed.
New AWAKEN Survey Finds Public, Physician Awareness of Narcolepsy Lagging  

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to be very/extremely serious actually have patients with narcolepsy. Unfortunately, the survey does not offer that level of detail. Perhaps those sleep specialists who never had a patient with narcolepsy are unaware of the hardships and struggles PWNs face. Regardless of the reason, sleep specialists should be at the forefront of knowledge when it comes to narcolepsy and idiopathic hypersomnias.

According to the Narcolepsy Network website, approximately 25% of people with narcolepsy have been diagnosed. As less than half of the sleep specialists and less than 10% of primary care providers are very comfortable diagnosing narcolepsy, it’s no wonder why the 75% of people who have narcolepsy but don’t know it remain undiagnosed. Clearly there is a need for increased education, awareness, and compassion regarding people with narcolepsy and sleep disorders.

While this need, especially as it pertains to physician education, is overwhelming, NN member Julie Flygare’s recent efforts do offer one hopeful example to build on. “Recognizing that many doctors were not familiar with narcolepsy,” Flygare said, “in 2009 I worked with Dr. [Thomas] Scammell to create a five-hour curriculum based on my story that is now taught to all Harvard Medical students. I imagine this five-hour unit makes Harvard one of the nation’s leaders as far as medical school narcolepsy education.”

Elaborating on the medical education gap, Flygare also pointed to the more in-depth, more policy-oriented Sleep Disorder Report written by the Institute of Medicine in 2006. It found that, at last check in 1993, medical schools whose curricula included sleep disorders averaged just over two hours of instruction in all sleep disorders, not to mention narcolepsy. The report also suggested little has changed since this last survey; this in turn indicates why so many primary care physicians continue to feel underequipped to diagnose narcolepsy in 2012. This disparity also suggests that, by including a five-hour narcolepsy module in its core curricula, Harvard Medical School likely is the nation’s leader in narcolepsy education, and a potential model for other schools.

The AWAKEN survey puts hard numbers behind what most PWNs know from personal experience: we still face a public that does not understand the illness we deal with, and too often we find ourselves in the care of doctors who do not know how to diagnose or effectively treat our condition. The survey outlines the challenges that Narcolepsy Network continues to address: the twin need for greater knowledge among the public, and better understanding among professional health care providers. The Network’s response mixes ongoing efforts, such as the education drive among school nurses or our many fundraising/awareness events, with newer initiatives, such as this year’s drive to increase sleep center membership.

Despite the scale of the problem, Julie Flygare’s experience shows that a determined individual, working with a caring and interested physician such as Thomas Scammell, can sow the seeds for change. By making such connections with practitioners and educators, as well as fostering mutual support among PWN patient-advocates, Narcolepsy Network will create a virtuous circle of education that will truly “awaken” the public to narcolepsy.

Please let me know any comments, questions, input, and even disagreements you have: awtam@ucdavis.edu.
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NN: Had you ever treated or worked with people with narcolepsy before in your long career?

OS: I hesitate to give an answer. I don’t know that I’ve worked with people with congenital narcolepsy, if that’s the right word, but quite a lot of my patients with the sleepy sickness, encephalitis lethargica, the “awakenings” patients I saw, had narcolepsy-like syndromes. The midbrain and hypothalamus are involved in such patients and I think they could well have been upsetting their sleep/wake cycles. Sleep/wake disorders were very typical, both in the acute stage of the [encephalitis] epidemic and later. So that’s probably the nearest I came.

NN: You describe how before coming into contact with the Narcolepsy Network, you didn’t know too much about narcolepsy as a condition. In working with people with narcolepsy for this book, what struck you about the human experience of this illness?

OS: It may be lifelong, and quite an important part of one’s life. Sometimes a disabling part of one’s life, or part of one’s life which seems to isolate one and make one different from other people. I think as with any disorder one has to come to terms with it somehow, and this makes all the difference. One can become comfortable with it, and I think it’s very important to be comfortable with a disorder and whatever it produces, which may include hallucinations. This is sometimes a minor part of peoples’ lives, sometimes it’s a major part. It partly depends on how severe it is, and partly on one’s personal reactions.

Much the same might be said of Tourette’s syndrome. Children with Tourette’s are sometimes tormented by other children or bullied and misunderstood by teachers. But once the Tourette’s is understood then life is much easier. Understanding doesn’t cure it, but it makes life much easier for the person and everyone who knows them.

Another thing I’ve written about, which I have myself, is inability to recognize faces [prosopagnosia]. One could spend a lifetime inadvertently offending people and apologizing and wondering if there’s something deeply the matter with one. Knowing it’s a perceptual thing, and that two percent of the population has it, is rather reassuring to me. But certainly it’s not just a medical condition to be diagnosed and given medication for.

NN: Why do you wish you’d worked in a sleep disorder clinic?

OS: Well, for somewhat the same reason as I am glad I worked in a headache and migraine clinic. It would have introduced me to an unusual, interesting, and complex condition which could play an important part in people’s lives. It would have been a learning experience. Perhaps it would have taught me more about being a doctor.

NN: Dr. Sacks, we’re very excited with this book and hope that you continue your interest in the Narcolepsy Network.

OS: I think I will.

Caring Voice Coalition Helps with Medication Copays

by Stephanie Warner

Kim Washburn had finally had enough. “I wanted to be able to leave the house more than maybe once a month for a few hours,” Kim said in a recent telephone interview. Exhausted and sleeping frequently during the day, she remembered the energy she had been able to marshal five years earlier when she had been taking Xyrem. But Kim had lost the private insurance that paid for the medication.

“Finally, I just decided to go for it,” Kim said. She knew it wouldn’t be possible to pay the $836 copay required by her Medicare insurer for her first month of Xyrem. Nor would she be able to pay thousands of dollars for her second month on the medication once she entered the Medicare “donut hole.”

But when her sleep specialist encouraged her to investigate sources of help, Kim resolved to fight to find it. “I was prepared to write everybody in the government from my state on up!” Kim said.

Help paying medication copays

Help was easier to find than Kim had expected. After Kim’s sleep specialist ordered the Xyrem prescription from SDS Pharmacy, the SDS representative referred Kim to the nonprofit organization Caring Voice Coalition for help with her copay. Since May 2011, the nonprofit has helped several hundred people with narcolepsy to pay high copays for Xyrem, Provigil, and/or Nuvigil.

Kim Washburn resolved to fight to find help paying for her treatment.

Hallucinations (Knopf) goes on sale November 6, 2012.
Caring Voice Coalition Helps with Medication Copays  continued from page 5

Applying for help
Both Julie Ann and Kim found that it was easy to apply for financial help from Caring Voice Coalition. Caring Voice staff will take applications by phone (at 1-888-267-1440) or via their website, www.caringvoice.org.

Patients are asked to describe their household income and insurance coverage. Neither Kim nor Julie Ann were asked to provide Caring Voice Coalition with tax returns or other documents proving their income levels. “They told me they rely on the honor system,” Julie Ann said.

Kim waited about a month to hear that Caring Voice Coalition had approved her grant to cover her Medicare copays and “donut hole” costs for Xyrem through the end of 2012. “I was scared to death,” Kim said. “This was my one shot at getting this medication.”

When the pharmaceutical company that makes Xyrem, Jazz, recently raised the cost of the drug paid by insurance companies, Kim was concerned that she would lose access to her medication. However, Caring Voice Coalition continued to pay her copay.

Independent Copay Charities
A pharmaceutical company may help patients with medication copays because the company cares about those patients. But the company also benefits when additional patients get the medications that it manufactures. This is because the patient’s insurance plan pays the pharmaceutical company for the remaining cost of that medication. So paying a patient’s copay both helps the patient get access to needed medications and helps the pharmaceutical company get access to the insurance revenue stream.

Pharmaceutical companies like Jazz routinely offer to decrease or waive copays for patients with private medical insurance. But the federal government bars pharmaceutical companies from paying medication copays for Medicare patients. That’s because paying a patient’s copay is illegal if it results in health care that the federal government must reimburse.

To prevent this problem, the federal government requires that any copay help given to Medicare patients that is funded by a pharmaceutical company must be administered by a bona fide independent charity. That insulates decisions regarding funding for specific drugs from direct influence by the drugmaker. A Health and Human Services Inspector General opinion posted on the Caring Voice site affirms that their decision-making structure is insulated from this influence.

Caring Voice Coalition is such an independent copay charity. Independent copay charities accept donations from pharmaceutical companies. The charities are only required to use the donated money to pay for medication approved for treatment of the patient’s illness, regardless of which medication is prescribed. Pharmaceutical companies may insist that their donations be used to treat a specific disease, but cannot designate which drugs are used to treat that disease.

Getting medication makes the difference
Kim put off asking her doctor for Xyrem because she thought it would be impossible to pay for the medication. “I could have scheduled an appointment with my sleep specialist probably 6 months sooner than I did,” she said. “But I was looking for help, and it didn’t seem like there was any. I had never even heard of Caring Voice Coalition.”

“When the lady called me and told me I was accepted, I cried,” Kim said. “Without them, I would never have been able to afford my medication.” Kim is pleased at how much more energy she has now that she is able to get the medications she needs. “I was able to get out and drive to my friend’s house!” she said. “I can get up and I’m functioning better. It’s amazing,” Kim said.

Caring Voice Coalition was founded in 2003 to assist patients who already have insurance in obtaining expensive medications for any of nine different orphan diseases. Caring Voice Coalition can help people with private insurance, Medicaid, and Medicare to cover copays for Xyrem, Provigil, and/or Nuvigil.

Although she has private health insurance, Julie Ann Funk also needed help to get medications to treat narcolepsy. Before the company that makes Xyrem lowered copays for people with private insurance, Xyrem cost Julie Ann far more than she could afford. “My copay for the Xyrem every month was more than $900. My Nuvigil wasn’t going to be covered at all,” Julie Ann said in a recent telephone interview. Caring Voice Coalition covered Julie Ann’s costs for both medications.

Help paying insurance premiums
Caring Voice Coalition will sometimes pay part of a patient’s insurance premium instead of medication copays. After Julie Ann’s copay for Xyrem dropped significantly, she asked her case worker at Caring Voice to provide her with a grant to pay most of her premium instead. Julie Ann explained, “They asked me to pay whatever I could afford toward my regular medical insurance premium. I pay $25 towards that, and then they pay the entire remaining amount.”

Instead of copay assistance, Julie Ann Funk received a grant that paid most of her monthly private insurance premium.
How old were you when you began playing golf? Did you play other sports growing up, and to what extent was golf a primary interest?
I was eleven years old when I first picked up the game of golf. A few years later I became a caddy at a country club and by age fifteen I held a summer job at a local golf course. Since I was very athletic, sports came easily to me. Baseball, basketball, and golf were the primary sports I played. I took a special liking to golf. I seemed to be the only girl playing it, and I was able to compete and hang out with the boys.

When did you know that you wanted to be a professional golfer?
As a junior in college, I qualified to play in an LPGA event. It was then that I fell in love with the idea of playing professional golf.

How did that drive to play golf professionally affect decisions you've made in your life?
Every decision I make seems to revolve around my golf career. When I started falling over (from cataplexy), all I was worried about was being able to continue to play golf professionally. I was worried that perhaps I was suffering from a condition or disease that would have prevented me from continuing my golf career. I was so happy when I found out that I had narcolepsy because I could still play golf with effective treatment.

Do you have family members who play golf?
My mom plays in a ladies league and my sister recently took up the game. I am hoping my nieces and nephews will want to play when they are older.

Who is your role model, related to golf or otherwise, and how has he/she inspired you or influenced your thinking?
I attended a one-day seminar long ago with Anthony Robbins, a motivational speaker. His enthusiasm and energy were amazing. His books have helped me handle my narcolepsy and persevere in my golfing career.

When do you recall first having symptoms of narcolepsy and what were they?
During my junior year in college, I began falling asleep everywhere from class to driving to studying, and even on some dates! I was constantly fighting to stay awake. I thought my sleepiness was normal because other people always complained about being tired, took naps, and fell asleep in class. I also had wild dreams throughout college and sleep paralysis (although I didn’t know the term at the time). I even had some muscle weakness with laughter, but I thought that was normal too. I just thought that was where the saying, “I laughed so hard, I couldn’t stand up” came from, and that the muscle weakness was normal.

Where were you in your career when you were diagnosed with narcolepsy?
It wasn’t until I started having full body collapses from cataplexy with paralysis that I was finally diagnosed with narcolepsy. I had been experiencing narcolepsy symptoms for five years at the time. I was in my third year on the LPGA Tour. I was playing golf at the highest level in the world and doing well.

What types of medications and/or behavioral changes have you made to successfully manage your narcolepsy symptoms?
I had to learn how to listen to my body, and this took some time to finesse. I drink lots of water and eat smaller, more frequent meals. Foods with sugar tend to make me sleepy. I nap when necessary, but I try not to nap unless I have to. I have also tried many medications. Currently I find that a combination of Xyrem, Effexor, and Provigil are very effective at preventing the majority of my narcolepsy symptoms. Prior to that, I was on a medication to control cataplexy, Anafranil, that was effective but had significant side effects including additional sleepiness and a weight gain and hallucinations with my doctors prior to my diagnosis because I thought everyone experienced these sensations surrounding sleep. My poor memory was something I attributed to my personality. And prior to my narcolepsy diagnosis, the doctors that I brought up my sleepiness with reasoned that it was a result of my lifestyle because I was otherwise quite healthy.
Advocating for Narcolepsy One Birdie at a Time  continued from page 7

of over fifty pounds over four years. Once I discovered Narcolepsy Network, I learned about other medication options, and that has now served me well.

Are there particular health behaviors that you practice that may benefit your golf game as well as potentially improve your narcolepsy symptoms (diet and exercise, sleep timing)? If so, what are they?

Everything that improves my narcolepsy symptoms benefits my golf game. Drink water, eat healthy, exercise, rest, sleep well, and prioritize. Most things that benefit my golf game improve my narcolepsy symptoms. I’d like to practice even more than I already do, but I have to pace myself to ensure that I am rested for the tournaments.

As potentially the only professional golfer with narcolepsy and cataplexy, how and when did you become an advocate for people with narcolepsy? Was this a natural progression or an interest you sought out?

My advocacy for narcolepsy was a natural progression. First off, it took me years to really get a handle on this relatively rare disorder. Then all I was worried about was me and my ability to stay awake. Once I realized just how well I did (for a PWN), I saw a need to be a good role model. This then led me to talk more about narcolepsy to others. I also saw that not many people understood narcolepsy or how debilitating and serious narcolepsy can be. Narcolepsy is perpetually misunderstood and that still frustrates me sometimes.

How and when did you become affiliated with the Swinging for Sleep fundraiser for Narcolepsy Network and Wake Up Narcolepsy?

I’m always participating in golf outings and events for various charities. I’ve also seen other campaigns like “Birdies for Breast Cancer,” “Birdies for Babies,” and so on. I wanted to do something for Narcolepsy so I created “Swinging for Sleep.”

When is the deadline for donating for 2012?

We are taking donations until the end of October.

How does the Swinging for Sleep fundraiser work?

Whenever I play on the LPGA and LPGA Futures Tour I am “Swinging for Sleep” and creating awareness about narcolepsy while I raise money for the Narcolepsy Network and Wake Up Narcolepsy. Each birdie* I make in competition brings in money for this campaign, including $250 per birdie from Jazz Pharmaceuticals. Anyone can make a pledge for each birdie, too. Just visit my web site for details: www.nicolejeray.com. Anyone can also make a donation in a lump sum.

Where will my donation funds go?

All donations go directly to the Narcolepsy Network and Wake Up Narcolepsy, equally distributed. I trust that these organizations will put the money to good use.

Do you have any general advice for young athletes with narcolepsy about playing sports in college or at the professional level?

Never give up. Prioritize so you can take advantage of your time and energy. Work hard. Take care of your body. Never use narcolepsy as an excuse, just manage it.

Will you be attending the Narcolepsy Network’s annual conference in Cleveland, Ohio this year? How many conferences have you attended, total?

Yes, I’m attending the conference in Cleveland. I’ve been to ten conferences. First one was in St. Louis in 2000, the turning point for me and my narcolepsy.

Thank you so much for sharing your perspective on being a professional athlete with narcolepsy. Your honesty and continued interest in supporting the narcolepsy community are greatly appreciated.

*Birdie: A score on a golf hole that is one shot better than the expected number of strokes; one shot better than par on a golf hole.
Pediatric Narcolepsy Events Are a Hot Summertime Topic
by Sara Kowalczyk, MA, MPH

Perhaps hotter than the steamy summer temperatures sending the masses flocking to the beaches were three groups across the country dedicated to advocating and raising awareness about narcolepsy, including how the youngest of those affected are impacted by the diagnosis. Only recently have researchers and clinicians coined the term pediatric narcolepsy, often referring to cases where onset and/or diagnosis occurs prior to puberty. It is a possible, but unsubstantiated, trend that the diagnosis of pre-pubertal narcolepsy is rising. However, technically speaking, narcolepsy has always been part of pediatrics because it includes all those diagnosed under the age of 18 years. Since many people with narcolepsy report age 16 (roughly high school) as when their symptoms became apparent, often the pediatrician is first-in-line to hear about potential excessive daytime sleepiness and other related narcolepsy symptoms.

The summer of 2012 has made history as the largest growth in narcolepsy awareness and advocacy events tailored to or by school-aged children across the nation. Kansas City proudly hosted the Second Annual Narcolepsy Education Day at Children’s Mercy Hospital. The New England Narcolepsy Support Group (NENSG) hosted a family advocacy and support event including an interactive workshop for parents, children with narcolepsy, and their siblings. And, on the same day, one little girl with narcolepsy, Makenna, along with her parents, family, and friends, hosted a walk to benefit narcolepsy research at Stanford University.

Makenna’s Walk for Narcolepsy Research
On July 14, 2012 a courageous youngster, Makenna, and her parents organized a walk to benefit narcolepsy research. Together, they walked 5 kilometers to raise nearly $1400 for narcolepsy research at Stanford University. Makenna was diagnosed with narcolepsy in 2010 after battling pneumonia that required hospitalization. Within 10 days of experiencing excessive sleepiness, she also began experiencing cataplexy attacks as often as 50 or 100 times per day! A narcolepsy with cataplexy diagnosis followed only eight weeks later after ruling out a variety of other possible medical conditions and undergoing a sleep study and MSLT. Today, her cataplexy is much less frequent but still very much a part of her everyday life.

Makenna’s sign for the walk clearly demonstrates that she is an amazing narcolepsy awareness advocate. It stated Don’t Mess With My Sleep – Walking for Narcolepsy Research. It is a powerful and succinct message developed by one courageous young lady. For more information about Makenna’s story, please visit Julie Flygare’s August 30, 2012 blog at JulieFlygare.com.

Boston Family Advocacy and Support Event
The New England Narcolepsy Support Group (NENSG) hosted a family advocacy and support event including an interactive workshop for parents, children with narcolepsy, and their siblings. And, on the same day, one little girl with narcolepsy, Makenna, along with her parents, family, and friends, hosted a walk to benefit narcolepsy research at Stanford University.

Parents had the opportunity to attend a workshop led by an Educational Specialist, Cristina Graves, who informed the group about Individualized Educational Plans (IEPs) and 504 plans, as well as how to better advocate for their children’s needs within their school systems (including role playing). Children with narcolepsy meanwhile spent half of the time interacting with one another and discussing their personal situations with the condition.

For Ashley Starr, a NENSG member who played an integral part in planning the children’s part of the event, the best part of the event was working with the kids and learning about how they handle the daily obstacles that narcolepsy presents. She was not surprised when she heard that most of the kids chose not to tell their friends about the fact that they have narcolepsy. This decision personally hit home for Ashley. “I didn’t tell my friends about having narcolepsy when I was younger, but the ability to attend the annual NN conferences and meet others who shared the same struggles as me made a tremendous difference,” Ashley commented. “I learned how to open up with others. I hope that by talking with other kids with narcolepsy will encourage these children to feel more comfortable talking about narcolepsy with others and how it affects them personally.”

Kansas City Narcolepsy Education Day
If you could go back in time and give your younger self a bit of advice, what would you say?
That is the opportunity Ann Austin had this year during her return visit to Children’s Mercy Hospital in Kansas City. Ann began the Second Annual Narcolepsy Education Day conference with a message of hope and practical tips. She enjoyed reuniting with the multi-disciplinary “dream” team, which now treats 35 patients, many of whom she met last year at the first annual education day. Most attendees had never met an “adult” with narcolepsy, nor had they heard about the support available continued on page 10
A New Line Links PWNs to Resources

by The Network staff

A well-known and well-regarded patient advocacy organization, Patient Advocate Foundation (PAF), has partnered with Jazz Pharmaceuticals to create the Narcolepsy CareLine, in an effort to help people with narcolepsy gain better access to health care, support programs, and related resources.

According to a press release put out by the two partners, as well as the CareLine website (narcolepsy.pafcareline.org), PWNs can call the CareLine at (866) 538-7617 and connect with case managers who have nursing, social work, or insurance billing experience. This promises to offer individualized service, as well as greater continuity of service, for PWNs who are trying to navigate:

- Insurance appeals and reimbursements, as well as understand what insurance covers
- Enrollment in employer-related programs like the Family Medical Leave Act (FMLA), short and long-term disability insurance, and COBRA
- The disability process, including education, application, and appeals
- Medicare and Medicaid enrollment
- Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs
- Services for uninsured patients

The CareLine also serves as a link to additional local, state, and national resources, including charities, for assistance, as well as information including disease-specific literature, managed care information, and financial resource information.

This is a positive development for many people with narcolepsy, who often have to work with multiple systems and programs in the midst of grappling with their diagnosis and treatment, not to mention their workplace. We at The Network look forward to learning more about the CareLine, and to hearing about the results it achieves.

Have you contacted the CareLine? Was it helpful or not? The Network wants to know for a possible follow-up story. Contact us confidentially at newsletter@narcolepsynetwork.org.

Research study in Atlanta, GA area

NeuroTrials Research is conducting a new, 12-week research study evaluating the safety and efficacy of an investigational drug for excessive daytime sleepiness in individuals with narcolepsy. All study-related care will be provided at no cost, and qualified participants will be compensated for time and travel.

To qualify, you must:
- be 18-65
- have a diagnosis of narcolepsy
- have a typical bedtime before midnight

Call (404) 851-9934 OR visit www.neurotrials.com

Participants needed for a research survey

Narcolepsy Network member Linda Ferris and Medical Advisory Board member Dr. Gila Lindsley are starting a research project on the onset of narcolepsy. The researchers are seeking two groups of people:

1. Those who may have developed narcolepsy, or at least a set of symptoms that look like narcolepsy, following a head injury
2. People with known narcolepsy for whom narcolepsy onset was not related to a discrete event

If you are interested in participating in research by filling out a survey about your narcolepsy symptoms and diagnosis, please visit our Research webpage (www.narcolepsynetwork.org/get-involved/research-participation) to download the survey and related materials.
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We welcome contributions to this newsletter. Please send all comments regarding the newsletter to:

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Deadline for Submissions:
Submissions are always welcome and reviewed on an on-going basis. They will be used whenever possible, as time and space permit.

On the back cover:
My artistic style is naturally lighthearted, so I wanted to communicate the narcoleptic’s struggle without conveying all of the anxiety and embarrassment that can accompany it. “The Narcoleptic in its Habitat” depicts a woman who has succumbed to sleep in a variety of environments. Instinct might tell us that these are the wrong places at the wrong times, but I playfully propose that the world is her bedroom.

-Emily Graham

The Network thanks Jazz Pharmaceuticals and Teva Pharmaceuticals for an unrestricted grant that has partially funded graphic design, printing, mailing and other costs of publishing and distributing this issue.

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