Spotlight on the National Sleep Foundation — 2012 Sleep Awareness Highlights

By Sara Kowalczyk, MA, MPH

The National Sleep Foundation is a driving force in raising sleep awareness and promoting the message of the positive impact of a good night’s sleep. As a group of people affected with narcolepsy and related sleeping disorders, the NN community embraces the NSF’s ‘Call to Action’ in promoting healthy sleep behavior in our society. To that end, NN has implemented an advocacy campaign including a sleep walk promoting narcolepsy awareness as part of National Sleep Awareness Week (see page 9). In addition Washington, DC hosted two events, the Sleep Health & Safety Conference and National Sleep Awareness Roundtable, both initiatives led by NSF to kick-off National Sleep Awareness Week 2012.

What is the Sleep Health & Safety Conference?
It is well known that sleep influences health and safety. There are millions of people with sleep disorders, and sleep problems are known to be under-diagnosed in the population. Societal influences, such as technological advances, have caused businesses to expand to extended, sometimes even continuous or 24-7 operational hours. Extended working hours has resulted in an increased number of people working during traditional sleeping hours.

University of Georgia Scholarship Connecting Families Affected By Narcolepsy

The NN membership was well represented at the University of Georgia’s 2011-2012 scholarship presentation. NN members, Susan and Blanton Hamilton, have generously instituted a scholarship for “a student with a chronic illness” at Georgia’s flagship university in Athens, GA. NN member and University of Georgia (UGA) freshman, Kailey Profeta, was the student chosen as the recipient of The Hamilton Scholarship.

The Hamilton family contacted the UGA Development office once they had decided to make a significant contribution to UGA in an effort
Dear Friends,

This year has been full of positive energy and enthusiasm for raising narcolepsy awareness. It is an exciting time to be leading NN and heading some of these advocacy initiatives. I have proudly represented Narcolepsy Network at so many events over the past months, and each event helped build connections, educate diverse audiences about narcolepsy, and highlight NN’s many accomplishments.

My primary goal this year is to increase the number of professional and sleep center members of Narcolepsy Network nationwide. Busy clinicians often don’t have ample time to sit with patients and coach them through the diagnostic process and helpful lifestyle adjustments. Certain questions about quality of life, including non-medical questions, arise and answers are sought out by patients. They may be related to work, school, or family life. These are important questions for patients to have answered.

Ideally, all clinical professionals and sleep centers would be Narcolepsy Network members so that they could confidently recommend NN to their patients as a place to go for additional support and information. As a result, NN is reaching out to professionals and sleep centers in order to gain exposure and improve membership for 2012. Some of the ways we are doing this outreach include:

1. Sending out letters to all accredited sleep centers encouraging affiliation with NN;
2. Developing new and improved materials that professionals receive when they join NN as members;
3. Attending events like the annual SLEEP meeting for sleep researchers and clinicians this June in Boston, MA;
4. Reviewing with our Medical Advisory Board the benefits of professional membership to find areas for growth; and
5. Developing ways to educate the professionals about narcolepsy through offering continuing education credits (hopefully in connection with our annual conference).

But in addition to these efforts, we hope that you can help us reach your doctor. Your personal connections with your sleep center and/or treating physician are invaluable. If you could bring a printed copy of our professional/sleep center membership form (from our website) to your clinician at your next visit and encourage them to become a part of our network, it would be most appreciated. You could also bring this newsletter (or contact our office for an extra copy!) so that they are aware of what NN is all about. Facilitating your physician’s involvement with NN may benefit other people with narcolepsy who see him/her as well.

The meetings I have attended in the past months have been exceptional, and I am happy to share the summaries from a few of them with you since they are not covered elsewhere in the newsletter.

**NORD Regional Meeting**
NN is a member organization of NORD (National Organization of Rare Disorders), and last December I had the opportunity to attend the regional meeting in New Jersey. One highlight was learning about Rareconnect. It began in 2010 when NORD and EURORDIS (the European organization for rare diseases) formed a transatlantic patient-driven strategic alliance for rare diseases to bring patient advocates from Europe and the United States together. More than 100 patient organizations from over 22 countries have joined the global conversation. Patients are sharing information and stories internationally with the help of a virtual translation service. For more information visit the website [www.rareconnect.org](http://www.rareconnect.org).

**Dr. Sacks’ Lecture at Columbia University**
In March 2012, NN member Sharon Link and I went to Dr. Oliver Sacks’ lecture on hallucinations at Columbia University in New York City. One chapter in his new book, HALLUCINATIONS, will be devoted to the signature hallucinations of narcolepsy that many experience either as they fall asleep or as they wake up. Many of you provided Dr. Sacks with useful information for his new book. Thank you to those of you who reached out to Dr. Sacks and provided personal stories surrounding your experiences with hallucinations. The narcolepsy community is so extremely lucky for Dr. Sacks’ interest in the associated hallucinations as the exposure provided in the book is awareness-raising itself.

Thank you 2011 Narcolepsy Network Donators! For a complete listing of all 2011 donors, please download or print the 2011 Annual Report on the NN website (under the About Us tab).

Download your free copy of the 2011 NN Annual Report anytime from the NN website.
Kentucky School Nurse Presentation
In March, I presented to the Kentucky school nurses in Lexington. I covered healthy sleep in children and then turned my focus towards pediatric sleep disorders, and especially narcolepsy. There were about 200 nurses in attendance and they had many questions for me after the presentation. Several realized that they might have a child in their school(s) with undiagnosed narcolepsy, or at least irregular daytime sleepiness that may indicate another diagnosis. One of the nurses whom I met after my presentation will attend NN’s conference this October because she herself has narcolepsy. This was a great prelude to a larger presentation I will give at the National Association of School Nurses conference in San Francisco this June.

Warm regards,

Eveline Honig, MD, MPH

NN member Sharon Link, Eveline Honig and Dr Sacks.

To pre-order your copy of Dr. Sacks’ new book, HALLUCINATIONS, visit amazon.com for details. It will be released on November 6, 2012.

Get social with Narcolepsy Network
• “Like” the Facebook page “Narcolepsy Network” and get all the latest updates
• Follow the official NN Twitter feed (coming soon)
• If applicable, add Narcolepsy Network to your professional network on LinkedIn
• Share NN brochures and educational materials online and offline – brochures and other pieces are available for download under the “Resources” menu on NarcolepsyNetwork.org
• Share the NN video spots available on YouTube.com (search “Narcolepsy Network” on YouTube)

Narcolepsy Network 2.0: The Power and Potential of Social Media

By James Bennett

Like many people living with narcolepsy, Marcia Coy is the only PWN in her immediate community. She doesn’t live near a big city. She doesn’t attend a support group—too far by car when driving is difficult. On some days, she feels like she has “cabin fever,” she says.

But Coy beats the isolation as part of a thriving PWN social media community, from her blog (manicramblings.wordpress.com) to her Twitter feed (@00Marcia00) to multiple Facebook groups. When she recently hurt her back while packing for a move, she got well-wishes from people as far away as Ohio, Arizona, Florida, and Holland. Her online activities and discussions encompass an A-to-Z list—everything from art to zombies.

“ZWN? Zombies With Narcolepsy,” says Marcia. “It’s a Facebook group on how you plan to deal with the approaching zombie apocalypse while having narcolepsy.”

On a less ghoulish note, recently Coy has been using various social media to “crowdsource” Dormez-Vous Studios, a project she’s pursuing to provide art therapy to children with sleep disorders. While it’s now very much in the brainstorming phase, Coy eventually wants to develop Dormez-Vous into a freestanding nonprofit. Putting her idea online validated this goal.

“I got such a response,” Coy says. “It really overwhelmed me. I didn’t know it was going to be such a huge need. I had colleges emailing me wanting to know when the program would start, because they had students already looking for internships.”

The speed with which Coy was able to share her idea through the Web—and get an encouraging response—attests to the reach of social media today. Often shorthanded as Facebook and Twitter, the most well-known platforms, social media encompasses an ever-growing ecosystem of online applications, from marquee brands like YouTube and Google+ to up-and-comers like Foursquare and Pinterest. While keeping up can be dizzying, these applications have one key element in common: users sharing with each other.

This simple concept, along with the technologies that support it, offers powerful possibilities to the narcolepsy community and the Narcolepsy Network. In one sense, this article is late to the party; the pulse of the online PWN community, whether on blogs, Twitter, or Facebook groups, is already very strong. But in another sense, we’ve barely scratched the surface of how social media tools might support the narcolepsy cause.

For example, when UCSD Professor and NN board member Ayelet Gneezy challenged her marketing students to craft a teacher-awareness campaign for the Network, many teams looked to...
Yoga and Narcolepsy: Exploring Mind, Body, and Dreams
By Julie Flygare, JD

Yoga promises many health benefits including reducing stress and increasing strength, flexibility and disease-resistance. Yet, living with narcolepsy, the promise of yoga may feel out of reach. For me, yoga does not improve my narcolepsy symptoms directly, but it improves my life tremendously. This article does NOT claim that yoga is cure-all for narcolepsy or “the right choice” for everyone. However, if you are interested in trying yoga, here are some practical tips from personal experience to get you started.

As a person with narcolepsy, I pay acute attention to my sleepiness, as it is perhaps my biggest daily challenge. Yoga reminds me that there is more to me than sleepiness — helping me to tune into my physical body, my thoughts and emotions.

I experience sleepiness during yoga class about 25% of the time. None-the-less, I return often for the chance to celebrate the other ways I am still healthy.

Practical tips for incorporating yoga into life with narcolepsy:

1. Scheduling: I like later evening classes that begin after I wake up from my evening nap. If I go straight from work to yoga class — a sleep attack is imminent.

2. Instructors: some instructors’ voices are too quiet and calming for me. A peppy engaging voice makes a huge difference. Also, some teachers use trendier fun music that keeps me engaged.

3. Temperature: if the room is too warm, I am much more likely to experience EDS. I politely ask if the fans or air conditioning can be turned on for a few minutes.

4. Breaks: if I experience EDS during class, there are a few options. I can either leave class for a breath of fresh air; lay in child’s pose or lay flat on my belly using my hands as a pillow. I sometimes enter a micro-sleep for a few seconds on my matt, which jolts me awake afterwards. Most of my yoga instructors know I have narcolepsy, yet they say they’ve never noticed any difference in my practice, although internally I sometimes feel that I’m totally out of sync with the others.

5. At my yoga studio, child’s pose is strongly encouraged at any time for a break. I don’t feel pressure to stay active the whole class and many people use child pose when they need it.

6. Mat Placement: I place my matt towards the back of the classroom on days I feel particularly sleepy because I know I will feel less pressure to “keep up” in the back where no one is watching me.

7. Various Forms of Yoga: There are many different kinds of yoga to explore. At different periods of my life, I’ve craved different forms.

Vinyasa (or Ashtanga) yoga — is the active dynamic flow class developing core strength and muscle tone, balance, and stamina.

Yin yoga — involves mostly sitting or lying postures to promote growth, clear energetic blockages, and enhance circulation.

Yoga Nidra — is sleep or dream yoga. In Tibetan Buddhism, among other traditional cultures, it is believed that dreams can provide important life meaning, insight and empowerment.

The ability to accessing lucidity (consciousness) while dreaming is an important step in the dream yoga practice that many people strive (for years!) to master.

People with narcolepsy may sometimes access lucidity while dreaming much quicker and more naturally than others. How could this be? The neurological boundaries between dreaming and consciousness are believed to be broken down in the brains of people with narcolepsy. In Yoga Nidra, a person with narcolepsy may be seen as gifted.

Once able to access lucidity while dreaming, dream yoga explores creativity and attempts to influence positive outcomes (in dreams and waking life).

“the yoga and lucidity training assists all participants to transform and break through old patterns by creating new endings for their dreams.” — Dr. Michael Katz

Learn more about Dream Yoga:
“Dream Yoga and the Practice of Natural Light,” by Chogyal Namkhai Norbu
“Dreaming Yourself Awake,” by Alan Wallace and Brian Hodel
Dr. Michael Katz’s website: www.dreamyoga.net
Look for local Yoga Nidra/Dream yoga workshop opportunities.
to provide assistance to students with narcolepsy. Their son, Blanton, was diagnosed with narcolepsy/cataplexy at the age of 7. Susan Hamilton is an alumna of UGA, and her son, Moore, has recently graduated from UGA as well. The Hamiltons worked with the UGA Disability Resource Center (DRC), which serves students with a variety of disabilities, to establish the scholarship criteria. The DRC selects the recipients and administers the scholarship funds on an annual basis. This is the second time that the scholarship has been awarded to a high achieving student with narcolepsy.

Kailey Profeta was nominated by a Disability Services Coordinator to submit an application for the scholarship award. The application included a written essay educating the audience at the awards reception about her condition, and how narcolepsy impacts her as a college student. Kailey also explained in the application about how the scholarship could assist her in her future educational pursuits. After the selection committee evaluated the essays, Kailey was invited to be interviewed by the committee. Several weeks later, Kailey was thrilled to learn that she had been chosen as this year’s recipient of The Hamilton Scholarship.

The awards ceremony, held in the Magnolia Ballroom on the UGA campus, was an inspiring evening where 11 students told their stories of persistence and purpose shaped by their experiences with chronic illness. Kailey had the opportunity to speak about narcolepsy and her positive experiences as a NN member and conference attendee. She was honored to meet Susan, Blanton, and Moore Hamilton at the reception. Susan said that Kailey’s essay had distinguished her as a student who would make the most of the support provided by the $1000 scholarship. Kailey had discussed the skills she has developed in advocating for herself, and her determination to succeed academically at UGA.

Susan and Blanton’s son, Blanton, is a 16 year old sophomore at Charlotte Country Day School, a rigorous independent college preparatory school in Charlotte, NC. Despite being diagnosed with narcolepsy with cataplexy at the young age of 7, Blanton leads a full and active life like his three siblings. By maintaining his medicine schedule and keeping a positive attitude, Blanton is able to focus on his studies and play on the football and lacrosse teams. Blanton has learned to be very disciplined and strategic with his schoolwork, athletics, and downtime. Being physically active keeps Blanton energized, but like most kids with narcolepsy, he benefits from an afternoon nap. For Blanton, the nap is often on a bus en route to an athletic game. After passing the Maintenance of Wakefulness Test (MWT) required by the state of North Carolina to get a driver’s license, he also has passed his driver’s test and received his driver’s license.

Kailey too believes that discipline is the key to succeeding in school with narcolepsy. She must time her medicines and naps around her class and bus schedules. A college student with narcolepsy has the added challenge of seminars and meetings often happening in the evenings after a full day of classes. All of the effort and adjustment to college has been rewarding though. Kailey has landed a summer internship with The Atlanta International Fashion Week. This is a wonderful opportunity for her because she is a Fashion Merchandising major who aspires to becoming a fashion designer. She is currently planning to use The Hamilton Scholarship funds to assist her in studying abroad in London during her junior year.

More on Conference Scholarship Applications Deadline August 1st

NN is hosting our Annual Conference this October 19 – 21. For those who have limited income and/or can’t otherwise afford to attend this year’s conference in Cleveland, Ohio, please consider applying for a full or partial scholarship.

If you are considering applying, please make sure that you are definitely able to attend prior to submitting your application and that if selected, you will be requested to volunteer for a few hours at the conference.

Full scholarships cover expenses including travel to and from the conference, hotel for two nights (with a roommate), registration, and a modest stipend for meals not included as part of registration.

Download the scholarship application from the NN website. All scholarship applications must be received electronically or by mail no later than 11:59 pm on August 1, 2011.
hours, a practice that is known to also be disruptive to the natural hormones that the body produces on a daily basis. Extended working hours have been associated with fatigue-related accidents at work and while driving.

In an effort to address broader concerns related to sleep behavior, the NSF has developed a conference with two tracks — a Healthcare Professionals Track aimed to educate primary care physicians about healthy sleep and its primary disorders and a Public Health and Safety Track targeting officials in public health, transportation, safety, government, and sleep researchers. As a result, the Sleep Health and Safety Conference highlights the health and economic burdens of sleep deprivation and poor sleep management practices in practical terms for businesses, safety professionals, and government officials. This will ultimately lead to better, more-informed policy and law making, as well as innovative public health initiatives promoting the positive impact of a good night’s rest.

What is the National Sleep Awareness Roundtable (NSART)?
NSART is an NSF program that was launched in 2004. Originally, NSF began developing partnerships with the Centers for Disease Control (CDC) and various agencies of the National Institutes of Health (NIH) that led to NSART’s development. Currently there are 20 member organizations of NSART, including two organizations devoted to narcolepsy, Narcolepsy Network and Wake Up Narcolepsy. The common goal of NSART is to increase public and professional education and awareness about sleep and sleep disorders.

2012 NSART Meeting Highlights
Representatives from five new member organizations were present at the March 2012 meeting. The NSF provided a review of the 2012 Sleep in America® poll results that focused on transportation workers. The CDC gave an update on sleep surveillance achievements and activities. The National Center on Sleep Disorders Research reviewed the goals of the Sleep Disorders Research Plan and discussed sleep and circadian rhythm funding and activities sponsored by the NIH. In addition, reports were given by all of the committees including membership, research, public awareness, and public policy.

Sleep Awareness Is Important
The National Institutes of Health estimates that sleep-related problems affect 50 to 70 million Americans of all ages and socioeconomic classes. The cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of health consequences including hypertension, diabetes, obesity, depression, heart attack, stroke, and at-risk behaviors — all of which represent long-term targets of the Department of Health and Human Services (HHS) and other public health agencies.

Promoting Healthy Sleep Behavior is a National Priority
Healthy People 2020, a 10-year national program, has incorporated objectives for promoting health and preventing disease. The following sleep-related objectives will be addressed:

- Increase the proportion of persons with symptoms of obstructive sleep apnea who seek medical evaluation;
- Reduce the rate of vehicular crashes per 100 million miles traveled that are due to drowsy driving;
- Increase the proportion of students in grades 9 through 12 who get sufficient sleep; and
- Increase the proportion of adults who get sufficient sleep.

To view the transportation industry’s results on sleep behavior from the 2012 Sleep in America® poll, visit www.sleepfoundation.org/press-releases/2012 and click on the March 1, 2012 release.

See how sleepy your state is at the CDC’s Sleep Results Website: http://www.cdc.gov/sleep/publications/factsheets.htm

Seeking Silent Auction Donations for the 2012 NN Conference
The Cleveland Conference Committee is currently accepting donations for this year’s conference. Items that are easy to transport or that can be mailed to the winning bidders are preferred. Please contact conference organizer Sharon Smith at ssmith@narcolepsynetwork.org by August 1, 2012. Please keep in mind that all donations are tax-deductible.

Examples of past donations include latest technology (iShuffle and Echo Smart Pen), women’s jewelry, artists’ own works, gift cards, donated services, sleep-themed products, calendars, and books.

Note: Silent Auction organizers kindly request all donators planning on bringing items with them to the conference to email Sharon Smith. Pre-planning the Silent Auction event will help it run smoothly and efficiently during the conference weekend.
Dr. Michael Thorpy Receives NSF Lifetime Achievement Award

Dr. Michael Thorpy, one of NN’s Medical Advisory Board members and a well-known sleep clinician, had the privilege and honor of receiving a Lifetime Achievement Award from the National Sleep Foundation at the 2012 Awards Banquet. One of the most important roles he has played in his career was serving as Chairman of the Committee that produced the first International Classification of Sleep Disorders (ICSD). The current version of the ICSD is considered a clinical standard of care and reference for all sleep physicians. Dr. Thorpy commented, “It was a great honor to be awarded the Lifetime Achievement Award of the National Sleep Foundation. Sleep Medicine is an exciting field of medicine and I feel fortunate to have had the opportunity to have been involved from an early stage of its development and having participated in its evolution into a major medical subspecialty area.” This award is further incentive to finish two cutting-edge textbooks he is currently writing on sleep and imaging, and sleep and genetics.
NN Presentation by Molly Stramburg

From March 7 – 9, 2012 the Association of Service and Computer Dealers International and the North American Association of Telecommunications Dealers held a conference in Clearwater Beach, Florida. At that conference the charity committee voted to donate $1,000 to the Narcolepsy Network. I was asked to accept the donation on behalf of the Narcolepsy Network as well as talk about the impact the Narcolepsy Network has made on my life. The presentation was very successful in educating and promoting both Narcolepsy and the Narcolepsy Network as I had many people coming up to me at different points throughout the conference with questions and positive comments.

SLEEP WALK 2012

Over 110 participants gathered on the National Mall for SLEEP WALK 2012 to raise awareness about narcolepsy and healthy sleep for all during National Sleep Awareness Week on Sleepy Saturday, March 10, 2012. Wake Up Narcolepsy hosted the SLEEP WALK 2012 with local sleep advocate Julie Flygare. The festivities began at the Sylvan Theater at the base of the Washington Monument. Representatives of the media attended SLEEP WALK 2012 to accept Media Star Awards for excellence in narcolepsy coverage in 2011. Many participants brought impressive sleep-related signs for the Spirit Award Contest. Before leaving on walk, participants warmed up with a Nia routine presented by local Nia instructors Suzworks’ Suzannah Weiss and Sue Dambrauskas. Sleep walkers departed for the 2.5 mile walk — walking on sunshine along the National Mall past the famous Smithsonian museums. It was a joyful event, with people coming together to celebrate sleep. Julie dreamed up the Sleep Walk concept in 2011 and is pleased the event spread to two other cities this year. She hopes the movement continues to grow!

Upcoming events:

Wake Up Narcolepsy is hosting the Fourth Annual Golf Outing on Thursday, August 23rd, 2012 at Wachusett Country Club in West Boylston, MA. The golf outing is a scramble-style golf outing followed by a dinner and silent auction.

On Friday, Sept 21, 2012, Wake Up Narcolepsy will host the Second Annual Wake Up Nashville musical concert at Marathon Music Works in Nashville, TN. Join some of the music industry’s greatest artists for live performances, food and fun while our winning songwriters make their debuts. Our informal atmosphere will allow for personal connection with Music Row executives, renowned sleep specialists and families of those with narcolepsy.

The Dream Big Songwriting Contest is underway. Music Row’s Savannah Music Group is looking for the next big hit. Two of the top ten winners from last year’s contest are now writing on music row with professional agencies.
Marathon recap
On Monday, April 16th, Wake Up Narcolepsy’s five Boston Marathon runners arrived at the start line — stepping into unknown territory.

The conditions were unprecedented with dense heat, sunny skies and temperatures near 90 degrees. All five WUN marathoners finished the marathon and together, they raised over $40,000 for narcolepsy research.

Congratulations to John, Kim, Ken, Monica and Tabitha on this remarkable achievement!

Narcolepsy Network 2.0: The Power and Potential of Social Media

Of course, not every social media action requires a fully formed marketing plan. Even thinking off the cuff, Marcia Coy can name several small steps NN could take to improve its presence. Noting that three “Narcolepsy Network” Twitter feeds currently exist (two of social media first to get the word out. One group suggested starting with posts to teacher groups on the professional network LinkedIn, to build followers of an NN “For Teachers” Facebook page. This group demonstrated that you don’t need to be exclusive to any one platform; in fact, with a consistent message and a well-defined audience, working across platforms can be a winning strategy.

This basic approach — interest followers on LinkedIn, then keep their interest in narcolepsy going on Facebook — could apply to any professional group NN might connect with, be it sleep researchers, physicians, or related nonprofits. In a twist on the strategy, Slideshare, a presentation site that plugs into LinkedIn, enables users to upload Powerpoints that could then be shared with key groups on the site (imagine a two-minute, teacher-oriented presentation of the NN brochure “Narcolepsy in the Classroom,” for example).

Another team in Gneezy’s class suggested building awareness through a social media counter-campaign to an offensive Dos Equis TV ad (“most interesting man in the world...cure[s] narcolepsy just by walking into a room”). Their clever turnaround reveals an advantage the narcolepsy community has in social media, which naturally favors the underdog against big players. Parodies, mashups, and exposes go viral because they affirm the “bottom-up” individual while also leveraging “top-down” brands for their own purposes. So media stereotypes of narcolepsy are ripe targets for a social media takedown.

Ming Leads First West Coast NSAW Sleep Walk
The west coast was also well represented this year with Richard Ming Lai hosting the first Sleep Walk in Sacramento, California on Saturday, March 10, 2012. Richard, who prefers to be called Ming, said “I had very little time to organize the walk, but despite this challenge, I consider it a success in raising narcolepsy awareness. Next year I plan on making it a much larger walk in State Capitol Park with many more people so the event will draw a lot of attention.” He expects to get many NN members and supporters from the entire Northern California region to walk with him. Please contact Ming if you would like to help plan and execute next year’s Sacramento walk at rkmlai@livejournal.com or 510-333-2202.

NN Celebrates NSAW with Chicago Sleep Walk
On behalf of Narcolepsy Network, Sarah Didavide organized the first-ever 2012 Chicago Sleep Walk in Millenium Park on Saturday, March 10th. In an effort to raise narcolepsy awareness, over 25 walkers accompanied her on the mission to inform, educate, and have some fun talking about sleep and narcolepsy.

NN awareness bracelets and informational materials were shared amongst the group and with the public. Meghan, one of the youngest walkers at the event, created a sign for the group with NN’s blue and orange ying-yang logo. The event was a great success and all were excited to be part of the first of many walks to come. Next year’s event will include shirts designed for the occasion and additional plans that will begin during the NSAW Brainstorming Session hosted by Sarah at the NN Conference this October. Contact Sarah to be involved in the planning of the Chicago-based 2013 events or for help with planning your own in your hometown (sdidavide@narcolepsynetwork.org).
Words of Wisdom on Navigating the Education System with Narcolepsy

A Personal Perspective

By Ashley Starr, MPH

It was my freshman year of high school when I began to exhibit signs of narcolepsy. Before that time I was the type of girl who loved school and would never think of nodding off during class. So when I began to constantly fall asleep during even the shortest lectures I knew that something was wrong. I attempted to explain to my teachers that I was not trying to be rude and that I just couldn’t prevent myself from falling asleep. I felt exasperated by the lack of control over my “sleepy” behavior. What I couldn’t explain was why it was happening, and I was becoming very frustrated with the fact that I was unable to do simple tasks the way I used to do them. It took two long years of sleep studies, tireless appointments, and several different opinions before I was finally given an official diagnosis of narcolepsy during my junior year of high school. It should have been an incredible relief to finally have an answer to the problem that had been taking an enormous toll on my life for several years, but in many ways it was also the beginning of my journey.

It is generally understood that junior year of high school is one of the most important years of your life. College is on the horizon so tests, letters, and grades all need to be in their finest shape. Due to my delayed diagnosis of narcolepsy, my grades had slipped from where they usually were, and I wasn’t feeling confident about my ability to do anything at the collegiate or professional level. Even my school counselor told me I would be lucky to get into any of the schools I was thinking of applying to. Thankfully though, my parents pushed me to apply to all the colleges that I had planned on applying to. Thanks to them I opened up about my condition and was able to get into every school. Four short years later I received my Bachelors degree from Northeastern University in Boston, MA, and in May 2012 I graduated from Northeastern with my Masters in Public Health (MPH). The journey was not the easiest, but like they say “anything worth having is worth fighting for.”

I learned so much throughout my educational career, and found new ways to cope with my narcolepsy symptoms each day. I wanted to write this article to share some wisdom that I gained from my experiences as a student with narcolepsy, and to provide advice on important information that I would have found useful to have had from the beginning. I hope that this will serve to help anyone currently struggling with the many side effects that narcolepsy can have on scholastic ability.

During secondary education the most important advice I can give is to implement a 504 Plan. Section 504 of the Disability Rights Act and the Individuals with Disabilities Education Act (IDEA) serve to help students with disabilities receive the same rights and benefits as every other student. I cannot emphasize enough how important it is to learn about these laws, and utilize them to help make the necessary accommodations that a student with narcolepsy may need.

In order to implement a 504 plan you have to meet with your sleep doctor and ask him/her to write a letter to your school with the official diagnosis of narcolepsy. The doctor should provide a list of suggested accommodations that you come up with together and agree would be helpful so that you can learn and demonstrate that learning effectively. Accommodations can include the ability to visit the nurse for a nap(s), note takers, books on tape instead of in print, additional time on tests, and/or separate testing location to name a few. There are many types of accommodations that could possibly make the academic process a little easier for a person with narcolepsy, and some of these are directly related to narcolepsy symptoms themselves while other are more indirectly related. Ultimately, though, what matters is that you receive the accommodations that are most helpful for you to succeed.

Next, speak with your school counselor and/or principal to set up a meeting in order to discuss the implementation of a 504 plan. The school will schedule a meeting for you and your parents to meet with a teacher, the principal, a nurse, school counselors, and any other educational professionals that the school deems necessary. This meeting allows you to present your doctor’s note of diagnosis and suggested accommodations, and gives you an opportunity to educate everyone on how narcolepsy affects you personally. The implementation of a 504 plan during secondary education gives you the freedom to use accommodations, when necessary, and brings awareness to the symptoms that you struggle with every day. When a 504 plan is developed with the school officials, it often helps overcome the potential misunderstandings that can generally surround narcolepsy.

When making the transition to post-secondary education it is more important than ever to advocate for yourself and
your needs as a student. When taking college tours and making the decision about where to attend, it is imperative to ask about the disability resource center. Even more, engage with representatives from colleges’ and universities’ disability resource centers so that you can learn about what their school will do to help you. By showing this initiative, you show prospective colleges your commitment to receiving an education based on your needs as a student with a condition that requires accommodations. For post-secondary education the IDEA law (mentioned above) no longer applies.

As a result, colleges and universities only have to ensure access to resources, not the success of all students. This does not mean that colleges do not have to provide accommodations, but rather that it is up to you to seek out the assistance and accommodations that you need in order to succeed. Since narcolepsy is not always the most common condition requiring accommodations, take the opportunity to educate those who would benefit from understanding the potential accommodations that students with narcolepsy might need in addition to what you, as an individual student, need.

Post-secondary 504 plans are important and some helpful accommodations include extended time on tests and papers, the option to use recording devices for lectures, note-takers, and even preferred housing on-campus. Understanding the laws that are available for students with disabilities allows individuals with narcolepsy to receive the assistance and accommodations that are deserved in order to obtain an equal and fair education. No matter what, remember that you are the expert about what you need in order to succeed in the school environment. Narcolepsy is fairly uncommon and it tends to present itself differently in every person that it affects. It is up to you to teach your college or university about how they can help you. So spread the word, educate others on what narcolepsy is and how it affects you, and don’t ever let narcolepsy stand in the way of what you want to achieve. I hope that sharing some of the knowledge and experience that I have gained through high school, college, and graduate school will help you in navigating your own success story.

**Options for Accommodations for Narcolepsy Students in High School and College**

Narcolepsy Network has been involved in advising and communicating with many high school and college students who have a narcolepsy diagnosis (and their parents). While each individual with narcolepsy is unique, the following are a list of options to consider when developing a 504 plan in secondary school or when working with Student Disability Centers in post-secondary school.

**General Options for Accommodations in High School and Beyond**
- Extended time on exams
- Opportunity to take breaks during exams (for napping)
- Extended due dates on papers/projects
- Note-takers and/or tutors
- Lecture recording devices
- Access to books on tape
- Exams limited to one per day
- Separate testing room
- Modifications in date and/or time of exams
- Wake-promoting environmental modifications, as needed

**High School – Specific**
- Delayed start time
- Ability to nap in nurse’s office
- Ability to go home for lunch (to nap)

**College or Post-Secondary – Specific**
- Restructuring finals (exams and/or papers)
- Early registration for classes
- Early selection for on-campus housing
- Medication-related accommodations, as needed

**Narcolepsy Network 2.0: The Power and Potential of Social Media continued from page 9**

which use the NN logo), and that some sleep centers follow all three, not knowing which is real, Coy recommends the Network end the confusion and clarify its messaging by creating a Twitter-verified, official account. (NN is in the midst of addressing this problem.) She also considers the success NN has had bringing board members onto Facebook for chats—why not do so on a monthly basis with sleep doctors?

As Marcia Coy’s efforts and the overall vibrancy of the online community already show, PWNs don’t need to wait on any group or individual to start making an impact. Surviving the zombie apocalypse while having narcolepsy might be taken as a concept, but many other ideas await discovery out there on the Social Web.

Want to help the Network advocate for narcolepsy awareness or raise funding? You can find strategy templates at Tony Faustino’s Social Media Reinvention Blog (Google “Tony Faustino patient advocacy”) or on the Slideshare presentation “Navigating Patient Advocacy Through Social Media.” Or you can look to other active patient-advocates for techniques and encouragement—for example, check out the Twitter handles @FMDgirl, @Lygeia, or @DCPatient, or the many other narcolepsy bloggers Coy’s blog (manicramblings.wordpress.com) or Julie Flygare’s blog (JulieFlygare.com) link to.

Or maybe you have a creative project, such as a book of writing by PWNs to publish, or a narcolepsy-inspired art show to stage? Kickstarter.com offers a social fundraising platform for art, films, and similar endeavors, helping people find the means to realize their visions.

Twitter, Facebook, LinkedIn, Google+, Slideshare, Kickstarter, Pinterest...the list of social media goes on and on, and so do the things you can do with these Web-based tools. The point is not to
Broken Dreamers
by Marcia Coy

I break things.
Pencils Break
Dishes Break
Glasses Break
And Body Parts
Especially Body Parts

Having Cataplexy means
Destruction is kind of what I am good at.
The list goes on and on….

Promises Break
Commitments Break
Dreams Break
And Hearts
Especially Hearts

Having Narcolepsy Means
Hearts will break when Dreams can’t act.

It doesn’t end here….

….What I mean is, It is not the end.

Fevers Break
Water Breaks
Dawn Breaks
Coffee Breaks
Especially Coffee Breaks

Having Hope means
Not forgetting all of that.

There is still hope for us.
We are more than Broken Dreamers.

Here I sit so broken-hearted,
Tried to work and nearly started;
But tired set in and I did yawn,
And soon after that I was gone.

In front of the boss I dozed off,
I snored a few times; he did cough.
Because he coughed, I awakened.
I tell you true, I was shakened.

Nearly in tears, I was so mad,
Wanted to beg, knew that was bad.
Control gone and wanting to scream,
Shaking set in and then a dream.

Needing to sit before I fell,
I felt my muscles turn to jell.
Spied a chair and nearly reached it,
Knew I’d fall if I couldn’t sit.

I couldn’t speak, I couldn’t yell,
I couldn’t breathe, it felt like h___.
Fighting for air, trying to stand,
Nothing like this was in my plan.

The boss stood up in such a fright,
Both his legs about to take flight;
But I detained him, that I did,
I grabbed his arm and down he slid.

He nearly had a heart attack
And I fell down across his back.
Regained my senses as he screamed,
Hoping, praying that this I’d dreamed.

Started to tell, tried to explain
That my disorders had two names;
The narcolepsy made me sleep,
The cataplexy made me weak.

Daytime sleepiness comes on quick,
I don’t feel bad, I don’t feel sick.
My head nods and right off I doze,
How long I sleep, the good Lord knows.

My nap is short, its not real long,
This is my life, it’s my sad song.
I can’t fight it nor dare resist,
Like a cloud, with sleep the brain’s kissed.

Muscle failure comes on real quick,
It hits so hard, just like a brick.
All muscles in the body fail,
I feel so tired, so weak, so frail.

My eye —l ids fall and both eyes cross,
Cataplexy causes such loss;
The lungs won’t breathe, the tongue
won’t talk,
The laughter stops, the legs won’t walk.

Any emotion causes this,
From fear, anger, or even bliss.
So vulnerable now I be,
Which causes great anxiety.

This job for me, a total loss,
So bluntly, I told the boss,
If he hired me I’d need two naps,
Understanding, no verbal slaps.

He looked at me, said I had gall,
“Now get to work, this job ain’t small;
You work real hard and prove yourself,
You’ll find a cot on that back shelf.”

Narcolepsy Network 2.0:
The Power and Potential of Social Media
continued from page 11

Put yourself on every site in the world, but to find the tool that works best for you and your goal, whether that’s building out the narcolepsy community, finding other PWNs to talk to, or otherwise supporting the narcolepsy cause.

Have a good idea?
Narcolepsy Network wants to hear from you on how we might improve our online presence, especially in social media.

Write to us at narnet@narcolepsynetwork.org

Also, stay tuned for a Facebook chat on this subject – all are welcome to take part!
26th Annual NARCOLEPSY NETWORK Conference

the weekend of
October 19 — 21, 2012
Intercontinental Cleveland Hotel
(on the campus of the Cleveland Clinic)
Cleveland, Ohio

Make your Reservation Today

Discounted Hotel Rate: $99/night (before tax), 1 King or 2 European Twins* (*slightly narrower than a U.S. double bed)
Group rate valid 10/15 through 10/25: Request Group Rate “POY”
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Online: Follow reservations link on NN website

Optional Conference Events Include:

Friday, October 19th
Group Activities
• Early afternoon visit to the Rock & Roll Hall of Fame
• Evening Reception and Meet ‘n’ Greet

Saturday, October 20th
Dinner Cruise
Celebrate the local holiday, Sweetest Day, with a Group Dinner Cruise on the Cuyahoga River

Reminder: Visit NN’s website for timely updates on confirmed speakers, session topics, full agenda, and scholarship opportunities.
Sustained arousal/attention is distinct from the executive control of attention. The neuropsychological tests used to assess these two aspects of attention are different as are the theoretical and emerging neuroimaging studies complementing the behavioral literature. This section will focus on sustained arousal/attention.

The two categories of sustained arousal/attention include phasic and tonic arousal (see diagram). Phasic arousal refers to the ability to develop an optimal sensitivity to an external stimulus over a short period of time (for example, receiving a warning to prepare for a stimulus). While this has not been repeatedly tested by narcolepsy researchers, results from Rieger and colleagues1 found that phasic alertness was intact in the narcolepsy group.

The ability to attend to monotonous and repetitive tasks over time, also called vigilance or tonic arousal, has been found to be consistently compromised in narcolepsy. Across research studies, subjects with narcolepsy took longer to respond to stimuli, made more errors, and had more variability in the time it took to respond than the control subjects against whom they were compared.J2,3,4

According to Dr. Fronczek4, the inability to remain vigilant throughout the day may be the most common complaint amongst those with narcolepsy. In that study, a vigilance task was administered throughout the day much like the Multiple Sleep Latency Test (MSLT), a test used to diagnose narcolepsy in clinical settings. Results indicated that the 4-minute vigilance test yielded similar results to the MSLT regarding ROC, specificity, and sensitivity (all statistical calculations that indicate a test is effectively categorizing those with the disease from those without the disease). Future studies are needed to replicate the results from this study indicating the potential usefulness of vigilance testing for those with narcolepsy (for example, in determining how effective a particular medication is in improving vigilance scores).

Taking a longer time to react and making more errors on vigilance tests do not appear to be related to IQ, gender, age, MSLT results, or any other factor associated with narcolepsy. There are considerable variations in vigilance test responses amongst those with narcolepsy when compared to the control group (where there is little variation between group members). It is possible that this variability could be related to narcolepsy disease severity. People with narcolepsy who have longer reaction times or greater numbers of errors may be more significantly compromised by the condition's symptoms. Vigilance test scores could also be useful in the clinical setting to provide an objective measure for quantifying improvement after starting medication therapy.

It is important to not underestimate the effect that vigilance issues could impact one's life. Variability in this type of arousal can lead to difficulties with learning and memory apart from the traditional executive system control of learning and memory. It is virtually impossible to process new information when one has diminished alertness during or immediately after learning the information1. For those with narcolepsy, exceptionally boring tasks and those involving multiple types of input (for example visual and auditory divided tasks) seem to be associated with poorer accuracy and slower speed.1 Finding a speed that is the “sweet spot” for effective learning and memorizing may be critical for people with narcolepsy.

While vigilance or tonic arousal/alertness deficits are commonly associated with narcolepsy, the next segment in this series will discuss the executive system dysfunction that also accompanies the neuropsychological aspect of narcolepsy.

The contents of this newsletter are for informational purposes only and are not to be construed as medical or legal advice. If you have questions, please consult your physician or attorney.

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We welcome contributions to this newsletter. Please send all comments regarding the newsletter to:

Sara Kowalczyk
17 Henley Street, Unit B,
Charlestown, MA 02129,
or email
skowalczyk@narcolepsynetwork.org

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.
Creative Corner

One Day I’ll Fly Away

Penelope Przekop

40” x 38” Acrylic & Pastel on Canvas

This piece speaks to the concept of having determination, hope, and resiliency despite your legs being stuck in the sand, rocks or whatever may hold you down. When I look at it, I think of fairy tales coming true, dreams being realized, and the belief that anything can happen. In reality, sometimes we can’t break free of what holds us down, but if we have hope and strength of will, we can still fly in ways that perhaps we couldn’t have imagined. This woman’s face is open to ideas and possibilities. She’s waiting for them and she will not give up! Despite perhaps being stuck in that same spot forever, she is flying!

Find Penelope on Facebook and at www.penelopeprzekop.com link.