New Research Links Histamine to Narcolepsy

by Karen Rorie

Two newly published research studies by NN Medical Advisory Board members Thomas Scammell, MD and Jerome Siegel, PhD show that histamine-producing neurons in the brain may play a role in narcolepsy.

"Increase of histaminergic tuberomammillary neurons in narcolepsy"

Dr. Thomas Scammell is a professor of neurology at Beth Israel Deaconess Medical Center in Boston. His study shows that people with narcolepsy have an increased number of neurons that produce histamine, suggesting that histamine signaling may be have potential as a treatment for narcolepsy.

“The orexin/hypocretin neuropeptides promote wakefulness, and researchers have known for 13 years that narcolepsy is caused by loss of the orexin/hypocretin neurons in the hypothalamus,” said Scammell. “We found that narcolepsy is also associated with a very large increase in the number of histaminergic neurons.”

NN Mourns the Passing of Two Leaders

Remembering Sharon Smith

On June 28, Narcolepsy Network lost a long-time volunteer and ardent supporter when Sharon Smith passed away after a long illness. Sharon was involved with NN for more than 25 years, including six years as President of the Board of Trustees. She devoted her entire being to helping people with narcolepsy, often putting in 60 to 90 hour weeks on a volunteer basis and despite having narcolepsy/cataplexy. Even while battling a terminal illness, Sharon was chair of the conference committee and driving force behind the 2012 conference in Cleveland. At that conference, she received NN’s Lifetime Achievement award for service to the narcolepsy community.

Remembering Sue Brockway Carella

On April 2, Sue Brockway Carella, one of the founders of Narcolepsy Network, passed away after a long illness. Sue helped to establish Narcolepsy Network as well as its predecessor organization, The American Narcolepsy Association. She served as NN’s president, treasurer, and secretary on the Board of Trustees and for five years she was editor of this newsletter.

Sue dedicated her life to the community and medical fields for awareness, research, treatments and the ultimate hope — cure for all sleep disorders. In 1985, she delivered the summation address at the Second International Symposium on Sleep Disorders at Stanford University. Sue also testified before Congressional committees to assure that the orphan drug legislation continued on page 3

What is Histamine?

Histamine is an organic compound found in many animals, plants, and bacteria. It is also the ingredient in wasp and bee venom that causes irritation. Histamine’s properties were first described by British scientist Henry H. Dale, a pharmacologist and physiologist, in 1910.

In the human body, histamine causes many different effects, including the contraction of muscle tissue in the lungs, uterus and stomach, the dilation of blood vessels, and it stimulates the production of gastric acid in the stomach. Though it has many different roles, histamine is best known as the cause of inflammation during allergic reactions.

Histamine also acts as a neurotransmitter that plays a role in sleep regulation. It is a wake-promoting neurotransmitter, meaning it makes you feel awake. This is why, when you take an antihistamine (a substance that blocks histamine) for allergies, it can make you feel

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Dear Friends,

The summer is always a busy time for us here at Narcolepsy Network as we ramp up preparations for our annual conference. We already have a record number of people registered and we are at a hotel that has the capacity to host a large group. We have a wide diversity of topics and speakers lined up. Atlanta is a great city for sightseeing as well, so the whole experience should be outstanding.

There is a new reason for the summer to be so demanding and, as many of you know, that is our active participation in the FDA initiative. We have been in touch with the FDA several times already and we have reached out to our membership and many other contacts to encourage attendance at the September 24th meeting or participation via webcast. Many of our members signed up and we have helped guide them through this process. The FDA is very pleased that so many people have signed up already. In fact, so many people have registered for the in-person meeting that the FDA is not taking any more registrations. There will be many opportunities to ask questions and share concerns. We hope to get a lot of attention for narcolepsy. There is still time to send in your concerns and comments after the meeting (until late November). We’ll have a full update on the meeting in the next issue of The Network.

I attended the national elementary school principal conference in July in Baltimore where I spoke with elementary school principals and other school personnel to raise their awareness of young children with sleep disorders/narcolepsy. I was there for the first time, and it was definitely an eye opener for them. There is a huge need to educate the educators!

In addition, this is the time of year when I am very involved with obtaining certification for our participation in the Combined Federal Campaign for government employees. This is another form of fundraising. We would like to be able to go to many of the events organized for this purpose. If you are interested in participating in the CFC campaign, please let us know.

I hope to see many of you in Atlanta in October.  

Warm Regards,

Eveline Honig

A Word from Our Executive Director

by Eveline Honig, M.D., M.P.H.

Dear Friends,

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Eveline Honig

Narcolepsy in the Spotlight at FDA Meeting

by Karen Rorie

On September 24, more than 500 people with narcolepsy will participate in a public meeting on narcolepsy at the United States Food and Drug Administration (FDA). The FDA is holding public meetings and gathering public comment on narcolepsy and 19 other diseases as part of its Patient-Focused Drug Development Initiative (PFDDI).

For each disease area, the agency will conduct a public meeting to discuss the disease and its impact on patients’ daily lives, the types of treatment benefit that matter most to patients, and patients’ perspectives on the adequacy of the available therapies. This is a rare opportunity for PWNs to directly and personally address the agency that guides the development of new treatments for narcolepsy.

The narcolepsy community response to the meeting has been unprecedented, with registration for the in-person meeting in Washington, DC, completely booked and hundreds of people registering for the live web broadcast of the meeting. PWNs from around the world will attend the meeting.

After the meeting, a short meeting report will be shared with FDA reviewers and posted on the FDA website. Patient points of view included in these reports will provide FDA reviewers with helpful insights when conducting benefit-risk assessments for new drugs to treat narcolepsy. Patient responses could also show the FDA that they need new ways to measure the effectiveness of treatments being reviewed.

This issue of The Network went to press before the September 24 meeting. We will have a full report on the meeting in our Fourth Quarter issue, coming out in December. We will also have an update session at our conference in Atlanta.

If you missed the meeting, it’s not too late to make your voice heard. You can submit comments to the FDA’s public docket until November 25, 2013. All comments should include the docket number FDA–2013–N–0815. Written or videotaped comments can be submitted online at www.regulations.gov. Written comments can also be mailed to: Division of Dockets Management (HFA–305), Food and Drug Administration, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852.
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neurons producing histamine, another wake-promoting neurotransmitter.”

The study involved counting the number of hypothalamic neurons producing orexin, melanin-concentrating hormone and histamine in seven narcolepsy patients and 12 patients that served as a control group. Results show that narcolepsy patients had 94 percent more histaminergic tuberomammillary nucleus (TMN) neurons. This increase was more pronounced in five of narcolepsy patients with severe orexin neuron loss compared to two patients with less severe loss.

The increase in histaminergic neurons in narcolepsy may be the brain’s way of compensating for the loss of orexin/hypocretin. It also may contribute to some of the symptoms of narcolepsy such as preserved consciousness during cataplexy and fragmented nighttime sleep.

“Previous studies have assumed that loss of the orexin neurons was a sufficient explanation for the symptoms of narcolepsy, and this large increase in histamine-producing neurons was unexpected,” said Scammell. “This new observation suggests that drugs that reduce histamine signaling at night may improve sleep in narcolepsy, whereas drugs that enhance histamine signals may be a good option for promoting alertness during the day.”

Scammell noted that medications that enhance histamine signaling are now under development.

Dr. Scammell’s findings were presented at the 2013 SLEEP meeting in Baltimore.

“Greatly increased numbers of histamine cells in human narcolepsy with cataplexy”

Dr. Jerome Siegel is the director of the Center for Sleep Research at the UCLA Semel Institute for Neuroscience and Human Behavior. Siegel and his colleagues report that an excess of a type of brain cell containing histamine may cause the loss of hypocretin cells in human narcoleptics. The study found that people with narcolepsy have nearly 65 percent more brain cells containing histamine.

For the study, researchers examined five narcoleptic brains and seven control brains from human cadavers. Prior to death, all the narcoleptics had been diagnosed by a sleep disorder center as having narcolepsy with cataplexy.

The researchers found that the humans with narcolepsy had an average of 64 percent more histamine neurons. As shown in the graphic below, the study found that the hypothalamus of narcoleptic had 1,604 histamine cells, while a brain from the healthy control group had only 917 histamine cells.

“We know that narcolepsy in the animal models is caused by engineered genetic changes that block hypocretin function. However, in humans, we did not know why the hypocretin cells die,” said Siegel. “Our current findings indicate that the increase of histamine cells that we see in human narcolepsy may cause the loss of hypocretin cells.”

The study appears in the online edition of the journal Annals of Neurology.

Help make this kind of research possible

Both studies used brain tissue from people who donated their brains for research after their deaths. Brain donation ensures that you will leave a lasting legacy for the narcolepsy community. Both Stanford University and UCLA have brain donation programs. More information is available on our website, www.narcolespynetwork.org

What is Histamine?

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drowsy. Histamine cells fire rapidly while people are awake, and slow down during periods of relaxation. During REM sleep they stop firing completely, and begin firing again just before waking.

In addition to looking at histamine’s role in narcolepsy, researchers are also exploring the part it my play in Alzheimer’s disease, schizophrenia and multiple sclerosis.

Histamine and Narcolepsy

The figures show the amount of histamine cells in the hypothalamus of a narcoleptic (right – 1,604) and a healthy control (left – 917).

Just Confirmed!

Dr. Scammell and Dr. Siegel will attend our conference in Atlanta and will speak about this exciting new research.

Jerome Siegel, PhD
Sharon was born and raised on Long Island, NY. She attended Hofstra University and graduated with a degree in accounting and later became a CPA. In addition to her NN family, Sharon leaves a husband and two sons. She is also survived by her mother, a brother and two sisters.

The NN booth at conferences
Sharon could often be found staffing the NN booth at conferences.

Remembering Sharon Smith

Here, several of her good friends offer their remembrances of Sharon.

Eveline Honig
Sharon Smith was a very special person. She felt, I believe, that raising awareness and helping people with narcolepsy was her most important mission in life.
I met her nine years ago when I applied for the job of executive director. She called me for the first time on a Saturday afternoon and we chatted for a few hours. I felt honored and felt we had known each other for years. Later I would understand that hours of calling on the phone was very normal for Sharon.
We met at the conference in Seattle and there I saw that narcolepsy and Narcolepsy Network were Sharon’s passions and she felt it was her duty and obligation to help others. I also noticed how much she knew about non-profit management and it was very helpful to have her as my mentor during the first year — to learn everything that I had never learned in medical school.
During my first years as executive director Sharon was the president and we spoke every business day and sometimes on weekends as well. We spoke about fundraising, how to help people, running conferences, research, awareness events, writing for newsletters and we also discussed our personal lives. Sharon told me a lot about her family, her children, her grandmother, her disabled sister and of course the other passion she had, bowling. The only time I could not speak with her was Thursday mornings, because that was her bowling day. I understood she was very good at bowling.

There was one problem with Sharon and that was that she was always late. Once she nearly missed the plane when we were both going to Minneapolis. Once we had a big event in New York City and Sharon promised to be early to help with a sign-up board. Sharon’s car broke down, she missed her train and was very late and arrived towards the end of the event. We realized Sharon should not be in charge of items you need at the beginning of an event, but she should only “do desserts.”
One of the endearing features of Sharon was that she tried to be friendly with everyone. She also had a great sense of humor and we would have a good laugh about things that went wrong.

Once Sharon told me that she heard there was an opportunity to write an article for a sleep journal. She asked me to write it and we discussed our ideas. I started writing it and then Sharon edited it. She was an excellent writer and helped teach me how to be a much better writer. When the article was done, I put both our names on it to send it to the journal and then she said, “don’t put my name there, I don’t need it for my career, but you do.” I appreciated this very much.
We all know how she worked for the last conference in Cleveland. She was very sick and even days before the conference she sounded so bad on the phone that I thought she could never make it to Cleveland, but she did. She would not miss it for anything, and not many people knew how sick she felt.
She organized another fabulous event and the conference was a huge success with more attendees than ever.

May Sharon finally rest in peace after a busy life full of very many challenges. She will be missed.

Oleta Elliott
I first met Sharon Smith at the NN conference in Las Vegas in 2002. I remember saying to her, “So you must be the Sharon Smith that wrote the article on advocacy. Good to put a face with the name.” Her answer was, “You read that?” And we chatted for a few more minutes with the other smokers before I was called away. The next time I spoke with her, we were assigned as roommates at a face-to-face Board meeting in Detroit. That is how our friendship began.

Over the next few years we worked closely on the Board of Trustees. While Sharon and I initially bonded over issues involving the Network, it quickly grew into a true friendship on a personal level. We often saw things from the same point of view, but Sharon was always much more diplomatic than I was. With her CPA and tax knowledge, she saved the Network on more than one occasion.

During the time I was on the Board with Sharon, we spoke on the phone several times a week, often three or four times a day. We continued to talk on the phone almost daily after I left the

Left to right, Sharon Smith, Sara Kowalczyk, Audrey Kindred and Eveline Honig at the 2012 conference just after Sharon received NN’s Lifetime Achievement award.
board. She introduced me to “McLeod's Daughters”, an Aussie television series, and I introduced her to Diane Gabaldon’s “Outlander” series of books. We traded books back and forth through the mail. We talked about everything from history to who would be the best person to head-up a project for NN. Sharon was my rock when my new doctor decided I didn’t need stimulants. Sharon’s experience with advocacy was really helpful, and having Eveline Honig and Scott Perrino in the wings didn’t hurt, either.

When I was diagnosed with cancer in 2010, I didn’t tell anyone initially. I only told Sharon shortly before the second Las Vegas conference. I was only half-way through my treatment cycle at that conference, and I knew she would know something was wrong. When Sharon was diagnosed, she called me. We talked about what was going to happen — would she lose her hair, would the chemo make her really sick — all the usual questions you don’t ask the doctor because you are too busy asking the bigger questions. At that time she was in the middle of planning the 2012 NN conference. Her main concern was whether or not she would be able to finish the job. Thank you, Audrey, for stepping in to help at the last minute.

When Hurricane Sandy hit, I knew she was due to start her treatments. My first question to her was whether or not the facility was going to be operational. I told her she could stay with me and start her treatments here if there was going to be a problem. As it happened, her treatments were only delayed by 24 hours. Our calls were limited to once a week from then on. I tried to time them so I could talk to her before the next chemo, so she would be stronger. I sent her the latest Khoury book to read during chemo.

My last conversation with her, she was tying up loose ends for her family. As the daughter of a funeral director, she knew what her family would be facing. Because she was Sharon, she wanted to have all the details ironed out for them. I told her I had a friend design a tattoo for me toward the end of my treatment and that I had planned to have DNR tattooed on my chest if the treatments failed. She laughed and said her religion wouldn’t allow that. Two weeks later I received a call from Ray telling me she was gone.

There is no way to explain to anyone how much I miss my friend. Every day there is something on the news or something in a new book that I want to share with her. The Network has lost a tremendous advocate and asset. We are all going to miss Sharon.

Mali Einen
My friend... Sharon

Sharon Smith was known to many of the members and friends of Narcolepsy Network as the generous, hard working advocate, problem solver and supporter of people with narcolepsy. She touched so many people’s lives directly and many, many more indirectly through her tireless work and accomplishments.

I first met Sharon in 1995 through a list serve called the N-list on the increasingly available internet. I first found the N-list about 13 years after I had first developed and been diagnosed with narcolepsy and like so many people with narcolepsy I knew no one else with narcolepsy. The N-list and the friends I found there were a lifeline at a time when narcolepsy had gotten the best of me. Sharon similarly had recently lost her successful career to her narcolepsy.

Sharon and I exchanged e-mails daily in those early years of the N-list. Later she introduced me to “Talk About Sleep” and we became co-hosts of two hour “live” chats two nights a week, we were both early guinea pigs in the now defunct Narcolepsy Registry and Stanford research and we both served on the Board of NN for six years. Sharon, my confidant, support and one who always finds the silver lining in any situation, who lived clear across the country in NY with me in CA introduced me to Narcolepsy Network and I finally met my dear friend in person at my first NN conference in 2000.

Over the years Sharon and I had the opportunity to meet up once or twice a year (often at the annual NN conferences, SLEEP meetings and family vacations). Sharon and I truly shared our lives with each other — we had so many things in common outside of our narcolepsy — people would be surprised. We could talk for hours. In Sharon’s last week’s talking had become difficult so phone calls became more rare and our friendship returned back to e-mail.

Sharon had two wishes at the end of her life continuing her devotion to helping PWN. It was important to her that her brain be donated to narcolepsy research and that donations made in her memory go to Narcolepsy Network.

Sharon had a brilliant mind and a delightful, contagious laugh. Not a day goes by without thoughts of Sharon bringing a smile to my face. I know that Sharon would agree — part of what NN is all about is the connections that people make — I hope each of you are lucky to make a dear friend of a fellow PWN.

Sharon, you have and will continue to inspire me to be a better person — I hold you close in my heart.

Love, Mali
was passed, lectured at the National Institutes of Health about narcolepsy, and appeared on numerous television shows including “60 Minutes,” “20/20” and “Nightline.” Sue also helped make two films, a National Geographic documentary called, “Mysteries of the Mind,” and a film about narcolepsy called, “Keep Us Awake.”

Sue was instrumental in securing Bob Hope to record radio and TV Public Service Announcements for narcolepsy and in convincing cartoonist Charles M. Schulz to feature narcolepsy in “The Peanuts” comic strip. In a series of strips, Peppermint Patty visits a sleep center and is tested for narcolepsy because she often falls asleep in class.

In 1990, as President of Narcolepsy Network, Sue boarded a 48-foot motor home and took part in the first “Wake Up America” caravan across the United States stopping to speak at 17 universities and medical centers including Harvard, John Hopkins, Columbia, and Cornell. Her speeches elicited support for the Congressional legislation that created the National Commission for Sleep Disorders Research within the Heart, Lung, and Blood Institute at the National Institutes of Health.

Sue was born in Iowa and grew up in San Bruno, CA. She graduated from Capachino High School in San Bruno in 1954. At the age of 40 she returned to school and graduated from San Francisco State University with a degree in organizational development and human behavior. In addition to her work for narcolepsy awareness, Sue enjoyed her family, collecting depression glass and button books, fishing and reading.

Sue is survived by her three sons, Steven Hansen, Skip Hansen and David Carella, grandchildren Tyler, Mallory, Megan, Nick Hansen and Anthony Carella, great grandchildren Taylor and Quinten Hansen, sister Judy Dennis, and many friends in the narcolepsy community.

In an article Sue wrote for NN several years before her passing, she said, “I always remember something the head of a national organization said once to our Board. She said, ‘Why are you giving up your Saturday and Sunday to volunteer and sit here planning events for people with narcolepsy? When you understand that feeling, translate it to other individuals with narcolepsy at the local level and allow them to experience what you experience, then you will truly have an organization that works, has purpose, and helps many.’”

Through her tireless work for people with narcolepsy, Sue did indeed help many. She will be greatly missed.

More About Sue From Friend and Fellow NN Co-Founder Niss Ryan

We lost our greatest champion when Sue Brockway Carella died. Sue did more in her lifetime for people who have narcolepsy than any other non-professional person anywhere.

It began, I believe, in 1975. Please forgive me if all of my dates are not totally accurate, but all of these things happened in more or less this order.

Dr. William C. Dement, who at the time was Director of the Stanford Sleep Disorders Center, advertised in a San Francisco newspaper for people who experienced daytime sleepiness and symptoms of what we now understand as cataplexy to contact him. Sue was one of the small group who responded. They met with Dr. Dement and, with his help, decided to form a national narcolepsy organization. They named it the American Narcolepsy Association. Since they had no funds as yet, Sue offered her house as temporary office space. Bill Baird was elected President. Sue did almost everything else, including secretary/treasurer and newsletter editor.

Sleep medicine was just beginning, due to the development of the electroencephalograph. The second sleep center in the country was the Sleep-Wake Disorders Center at Montefiore Medical Center in the Bronx, NY. In the ANA’s second year, Sue and Bill traveled to New York to make contact with the patient group that was forming at that center. They asked to meet with me since I was representing the group at that time. I must have passed muster, and Sue and I began our cross-country correspondence.

The first International Sleep Disorders Symposium was held at Stanford near that time. A few of us who were patients at Montefiore, including (NN co-founder) Ruth Justice Nebus and me, attended and visited the ANA. I can remember Sue’s daytime living space totally taken over by all the ANA’s business, with papers, pamphlets and many volunteers everywhere. Both Bill and Sue spent time impressing me with all the kinds of work involved in developing and running a national not-for-profit organization. They were good teachers, and I tried to learn it all.

From that time on, Sue and I kept in touch, and each time we talked, I learned something new. Ruth and I were cooperating as well and doing all we could to get the organization and its message recognized throughout the country.

Many exciting things were happening:

• In 1979, Dr. Dement, who was great at inspiring people, spoke to a joint meeting of the New York City and the New Jersey narcolepsy groups.

• A special radio hotline for questions and answers about narcolepsy was aired in New York for three nights. Callers who described narcolepsy symptoms were invited to become members.

• A film, “Keep Us Awake,” was developed at Stanford, with Sue making certain a copy was sent to anyone who could promise to show it to any group.

• And all of the time Sue was answering the ANA phone, advising, and
At the NN conference in New York City in 1988, NN members staged a Nap-In in Central Park. "What fun that was!," Sue later wrote. “And not bad for publicity either!”

becoming fast friends with people who have narcolepsy from all over the country. Even after the ANA had a real office, people kept calling Sue, Ruth, and me for advice. We tried to steer them to the proper places to solve their problems, such as their legislators, the EEOC, a lawyer who was knowledgeable about disability problems, another person living near them who had narcolepsy, how to start support groups, etc.

At some time, the ANA began to develop problems. One of the board members wanted to have an organization without voting members. Bill wanted groups but not chapters. Then there were some financial difficulties. When a member called a meeting, a number of us from around the country attended, and while there, discussed having an organization that had chapters. At that time I agreed with Sue that that was an important goal.

Sue took a few of us to meet with Dr. Dement and asked for his help. We pledged our support for his research and he promised to help us. A dozen or so of us met in my home in Larchmont, NY to iron out our goals. And shortly after that, Ruth hosted a meeting in New Jersey where we worked for three days writing the by-laws. I can remember Sue at the pad of paper writing all of the decisions we made. And so, Narcolepsy Network was born.

One of our early annual conferences was held in conjunction with the then Canadian Sleep Disorders Association at a meeting just north of Toronto. I convinced Sue to fly to New York and we then drove across New York state visiting sleep centers and holding patient meetings along the way. She was a natural at speaking and organizing support groups, something I tried to learn from her, but was never half as good as she was.

I saw Sue in action at annual meetings of the Association of Sleep Disorders Centers.

Sue and I visited the booths that had some logical connection with narcolepsy. And she’d always say, “Get a contact name, Niss.” We visited a number of parties during the afternoon breaks to seek out people and discuss about how they could help us expand our message. At one of those get-togethers, the idea of a cross-country caravan coalesced.

As part of the Wake Up America campaign, Sue and Ruth convinced Lori Engles and her husband, who owned a 48-foot van, to make it the main part of a caravan, to make the long trip from Seattle east to Boston and New York, down to Washington, DC and then to take a southern route back west. Many new members joined the Network as 26 sleep centers along the route convened patient meetings. The van was decorated with sleep messages on all sides, and cars trailed after them, asking for information. The caravan was a great success and quite festive. But due to some problems that had developed, it was abandoned after DC.

In DC, they connected with local members, Dr. Dement, and other sleep professionals to lobby Congress regarding the need for sleep disorders to become a part of the National Institutes of Health. Sue’s comments were an eloquent and intense description of the plight of people who have narcolepsy. Many of the rest of us were testifying in our own states as well as part of the Wake Up America campaign.

After Ruth died, Sue and I each were the Network President for a few years. We spent a lot of energy and time writing regulations for setting up chapters. The most successful not-for-profit organizations in the country have large, active chapters. Few of our groups had enough really active members to make our regs work and some groups had been active for a while and didn’t want to change their ways. As well, a few had already incorporated on their own. We slowly gave up our effort. A great disappointment. I finally had to admit that Bill Baird was right, that groups are fine but that proper chapters really don’t work very well for us.

Sue and I were roommates at a number of the Network’s annual conferences. Although still an active board member, Sue was now in a wheelchair, which I happily pushed all around the hotels. Each year she would tell old friends that this was undoubtedly the last time they’d see her because she was about to die. We all laughed since she said that every year.

Four years ago I retired from active board membership due to my husband’s health failing. I felt that Sue’s was failing as well and tried to get her to resign so she could have time to straighten out her affairs, and enjoy her boys. But she plodded on. The habit was too deeply ingrained. I think she would have been lost without it.

These are only a few highlights of Sue’s more than 37 years of working to make life better for people who have narcolepsy. Fill in the gaps with every day calls from those who were asking for help to untangle their lives that narcolepsy had
Meet Nutrition Expert
Kali Garges-Rousseau

Hello, NN Members,

I am a registered dietitian currently working in an outpatient counseling setting. My job primarily involves counseling and guiding patients to achieve their personal health goals. I have helped people lose weight, lower their cholesterol, lower their blood sugar, control gastrointestinal conditions, and improve their quality of life. I have also learned how to be a patient myself as a recently diagnosed person with narcolepsy.

Although I’d been struggling with symptoms for years, it wasn’t until I began counseling that I looked at my behavior honestly and admitted to my daytime sleepiness problem. I would be sitting in my office with a patient, listening to their goals, concerns and health struggles, but not be able to concentrate on what they were saying. I can’t express how horrible I felt when someone would be in the middle of a personal story and I would be across the desk, teeth clenched, eyes watering, trying not to yawn in their face. I would actively wish for the appointment to be over, not because I didn’t care about my patient, but so that I wouldn’t have to fight the sleepiness anymore.

Before being diagnosed with narcolepsy I had so many excuses for my symptoms. I’m cold, I’m hot, I’m hungry, I didn’t sleep well last night, morning practice was tough, I’m trying to do too much at school/work, I’m not a morning person, I stayed up too late...you name it, I thought it.

Of all the excuses for my sleepiness, my “favorite” was that my blood sugar was low. Because of my nutrition background I was very knowledgeable about the condition of hypoglycemia (hypo = low, glycemia = blood sugar). It seemed to be a logical cause for my sleepiness and could be easily remedied. I realize now that episodes of low blood sugar were not to blame for my symptoms. However, over the past four years I’ve found that controlling my blood sugar levels has helped manage my narcolepsy symptoms. Maybe preventing blood sugar swings could help you too.

I have compiled a few tips that have helped me better control my own blood sugar. I hope that you will find them useful. Finding the slightest improvement in daytime functioning is considered a success. If you have questions or comments about this article, please email me at kali.n.garges@gmail.com. Also, I have been exploring the possibility of creating an “Ask the RD” column as a regular part of the newsletter. Please send me questions or topic ideas, and I would be happy to cover them.

Cheers to healthy eating,
Kali Garges-Rousseau, RD, LDN, CDOE

Ask the RD

Kali’s Tips for Controlling Blood Sugar and Reducing EDS

by Kali Garges-Rousseau, RD, LDN, CDOE

Typically, blood sugar concerns are associated with diabetes; however controlling them is important for all of us. If one’s diet or habits cause blood sugar swings or low blood sugar throughout the day it may result in hunger or cravings, fatigue or low energy levels and/or negative changes to your mood, concentration and focus. For someone with narcolepsy, the above experiences may occur in addition to intensified and more frequent episodes of excessive daytime sleepiness (EDS) or sleep attacks.

Here are three ways to stabilize your blood sugar levels throughout the day:

1. Strive to combine carbohydrates with protein at every meal or snack, especially at breakfast.

Carbohydrates are the most influential thing on your blood sugar. Ever notice how tired you feel after a big bowl of pasta at dinner or bagel at breakfast? That’s because those foods are rich in refined carbohydrates (see Tip #3 below). These are digested quickly, cause a rapid increase in blood sugar and are used for energy by the body right away. This leaves your blood sugar lower soon after the meal and you feel lethargic and sleepy.

Adding protein to the meal (ex. ground meat to the pasta, natural peanut butter to the bagel) slows down the digestion of the meal. This causes a slow, steady increase in blood sugar and is used more gradually by the body for energy, thus preventing a spike and crash. Remember, breakfast really is the most important meal of the day (thanks mom!). If you can put protein and carbohydrates together at this meal you are “setting the tone” for the day. Great breakfast proteins include: eggs, peanut butter and nut butters, cottage cheese, Greek yogurt, nuts and seeds, cheese or deli meat.

2. Try small, frequent meals.

When too many hours elapse between meals (think breakfast at 6am, lunch at 2pm) blood sugar levels can dip too low, possibly resulting in struggles with sleepiness in between. Eating three meals and two snacks or five–six small meals throughout the day can help stabilize your blood sugar levels and energy.

3. Limit the “whites” (sugar & flour), increase whole grains.

As mentioned in Tip #1, carbohydrates in general are the main determining factor on your blood sugar levels. Beyond this, the type of carbohydrates consumed plays a greater role in how you feel. Processed foods made with refined “white” flour and sugar can cause havoc on your day and likely contribute to sleep attacks. On the flip side, foods made with whole grains and limited or no sugar may improve or stabilize your symptoms.

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Strive to find foods that list “whole” as the first word in the ingredient list (ex. whole grain flour) and avoid foods with “enriched” or “unbleached” listed first. An even better option is to bypass the packaged foods all together and go for unprocessed sources of carbohydrates like grains, fruit, beans, lentils, sweet potatoes and vegetables.

As for sugar, try for as little as possible whenever possible. Remember that sugar is listed under many names in the ingredient list and on the nutrition label, so limit it in any form (ex. sugar, honey, beet juice concentrate, high fructose corn syrup, dextrose, evaporated cane juice, etc.).

This article is intended for educational purposes only. It does not replace individual advice or treatments provided to you by your health care team.

Support Groups on Both Coasts Gather for Picnics

Narcolepsy support groups in Boston, New York, and San Diego hosted picnics this summer. Picnickers in all three cities enjoyed plentiful food and fellowship with other PWNs and their families.

On Sunday, August 4 nearly 100 people attended the New England Narcolepsy Support Group annual picnic at Castle Island in South Boston. Pictured below are many of the PWNs and their supportive family and friends who attended. They are standing behind an old Narcolepsy Network sign that was taken out for the occasion by former NN Board member Mort Rosenstein who could not make it. Everyone had fun while catching up with old friends and making new ones. Special thanks to Brigita Bangerskis, Eleanor Vieira, and Jo Breen for their work organizing the support group, and to Brigita especially for taking charge of this event.

New York City supporters enjoyed an afternoon at Waterside Plaza along the East River on September 8. More than 20 people attended the event, which was organized by Eveline Honig.

Out west, the San Diego support group welcomed 23 people to its event on July 13 at Santee Lakes Park, including eight people from the newly formed Meet Up LA Narcolepsy group. Thank you to Veronica Casale for putting the picnic together.

If your narcolepsy group enjoyed a picnic over the summer, let us know and share you photos by emailing newsletter@narcolepsynetwork.org.
Our 2013 Conference is Shaping up to be the Best Yet!

As of press time, more than 350 people were registered to join us in Atlanta. Are you among them? If not, there is still time to get in on this exciting weekend of workshops, fun and fellowship with other PWNs. To register, visit www.nn2013conference.eventbrite.com

Recently added workshops and speakers include:

- Narcolepsy researchers Dr. Thomas Scammell and Dr. Jerome Siegel (see the story about their recent discoveries on the cover of this issue)
- Service Dogs for PWNs with Andrea Clark
- ADA Law and Disability with attorney Dan Brown
- Narcolepsy: is there an environmental trigger? with Dr. Todd Swick

Visit the Georgia Aquarium!

While you’re in Atlanta, visit the world’s largest aquarium with more than 10 million gallons of water and the largest collection of sea life including dolphins, whales, penguins, sea otters, and more! Discounted tickets are available at www.georgiaaquarium.org/narcolepsynetwork

- On Friday, October 18, a shuttle bus will run between the hotel and the aquarium. Bus tickets are $5 each and the bus will run from 1:00-5:00 pm. Bus tickets can be purchased on the 18th. We recommend purchasing aquarium tickets in advance since the discount is not available at the aquarium box office.

Narcolepsy Network Annual Conference – Raffle Information

NN members and supporters continue to show their generosity by donating a number of great raffle items and buying raffle tickets. We are again reaching out to our community and friends and asking for help. Will you donate an item for the raffle and help us reach our goal of $2,000?

If you are planning on donating an item, please email us with a description. For raffle inquiries, please contact the main office at narnet@narcolepsynetwork.org or the main office at (401) 667-2523.

Q&A

What kind of items would be appropriate for the raffle?

Since most of us are traveling by plane, we would like to avoid baggage fees and keep shipping fees to a minimum. Please consider donating items that are TSA-friendly and small in size (easily fits into a carry-on suitcase).

Can I donate items that I created?

Yes, provided that the item/subject is considered appropriate for general public viewing (G-rated) and easy to carry. We will make exceptions for size if the market value of the item is greater than its shipping costs or if you pay for shipping.

How do I get the item to you?

We prefer you bring the item with you but if you are not attending or may be late, please email us and we can make other arrangements.

Will I get a receipt for tax purposes?

At your request, we will provide a donation receipt for you to fill out. For IRS rules on donations of property see IRS Publication 526, Charitable Contributions, available at www.irs.gov

I am a generous person but on a budget. Are there other ways that I can help?

Absolutely! We love volunteers. Please contact the main office.

More about Sue From Friend and Fellow NN Co-Founder Niss Ryan continued from page 7

gotten off track. Somehow, each person became a personal friend, one that she would always love and keep track of. When that person’s story inspired her with a new idea, it would become a newsletter story to help others.

Sue brought good business and fiscal training and the ability to write exceptionally well to her tasks, and the ability to listen and have great compassion and love for people she helped. My comments here are not nearly as eloquent as Sue’s would have been. She was beautiful and loved to dress for a special occasion, to join in the fun of a party, which happened all too rarely in her lifetime.

I keep thinking I should call her to answer some question or just to hear her voice, until I remember she isn’t there. I will miss her for the rest of my days, and yet, she will always be with me, as I’m sure she will be for many of you. Bless you, Sue, from all of us!
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:

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email submissions to NN are also accepted at skowalczyk@narcolepsynetwork.org

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

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