Diagnosed with Narcolepsy/Cataplexy in Law School: A Personal Journey

By Julie Flygare

In the summer of 2007, between my first and second year of law school, I’d found a likely name to match my problems—narcolepsy with cataplexy. However, my sleep study and official diagnosis would not take place until September of 2007.

Over the summer, I decided to meet with the Dean of Students at school to discuss my first year grades. I had received below-average grades for law school and hoped that I might improve my academic performance in the future. First, the Dean tried to persuade me that my grades were not a reflection of my intelligence. I wasn’t listening to this nonsense—I’d always been an above-average student in the past, I didn’t see why law school should be any different. Second, we discussed what I could do to improve my exam-taking skills. I’d never met the Dean before, but she took my concerns seriously, and I appreciated her guidance. It was only after talking for an hour that I mentioned my probable diagnosis of narcolepsy.

I remember her reaction perfectly; she stopped dead in her tracks. “Narcolepsy? No wonder you had a hard time getting through your first year!”

I resisted, “No, no, that has nothing to do with my grades.”

The Dean looked at me rather skeptically. “You don’t think that narcolepsy affected your first year?” she asked.

I clarified, once again, that the two issues were not related. What did she know about me and narcolepsy? Lucky for me, the Dean had known a previous law student with narcolepsy. And at the time of our talk, she probably understood better than I did about how its symptoms were impacting my law school experience. She suggested a few ways we might improve my law school experience, taking my probable diagnosis into consideration. I said that I’d think about them, and we left it at that.

In September, my sleep study confirmed my official diagnosis of narcolepsy with cataplexy.

Eating Well in 2010

By Josette Keelor

If your New Year’s resolution is to decrease the size of your waistline, you are in good company with thousands of other Americans. But for those of us with narcolepsy, beating the battle of the bulge may be more difficult for numerous reasons. Living a healthy lifestyle is especially important for people with narcolepsy in order to maintain a healthy weight.

It has long been speculated that there is a connection between deficient sleep and obesity because the brain hormones that control appetite are inhibited when the body is fatigued. Moreover, the body more easily stores fat when stressed from too little sleep. Less sleep means more eating and lower energy, resulting in more pounds gained. Professionals recommend that everyone sleep between 7 and 9 hours each night for optimal rest and the best chances at maintaining a healthy weight. While people with narcolepsy often spend the recommended amount of time in bed, their sleep quality is usually more disrupted, creating a sleep deficiency that...
Dear Friends,

2010 is off to an exciting start following November’s distribution of our new brochure, *Narcolepsy in the Classroom*, to 8000 school nurses and further promotion of this brochure in an NASN (National Association of School Nurses) e-newsletter distributed to over 10,000 school nurses. Requests have been pouring in from school nurses across the country for more information. In February, Board member Betty Scott and member Pam Sabourin attended the 2010 Annual Conference of the Florida Association of School Nurses in Orlando where they provided information on narcolepsy to many of the 200 Florida school nurses in attendance. *Narcolepsy in the Classroom* has generated requests for speakers to talk about narcolepsy and other sleep disorders in a variety of locations. A number of our staff and Trustees paid personal visits to local school nurses to deliver copies of the pamphlet. My local school nurse here in New York shared that this information is new to her and that she was very interested to learn more. From now on she will consider the possibility of narcolepsy or another sleep disorder in sleepy and hyperactive children.

*Narcolepsy in the Classroom* is available for printing on legal-sized paper on our website under the heading ‘Resources → Brochures’. Do visit our website soon as you’ll be pleasantly surprised to find a fresh, new look! **That’s right, our entire website has been redesigned, is more user-friendly and features new content with more to come, including a Members’ Only section.** We thank our web developer, Seeds for Change, for the knowledge and skills they brought to this project.

By the time you receive this newsletter we will have launched our new email delivery system. If you have not been receiving emails from us and wish to, go the website and sign up for email alerts. Also remember to add narnet@narcolepsynetwork.org to your safe sender list and/or email account address book to make sure our messages don’t go to your spam folder.

This year I was invited to Maryland to help plan the next PIO (Public Interest Organization) meeting at the NIH (National Institutes of Health). I’m very much honored that they asked for my input. I have gone to these meetings every year and learn a great deal from other non-profit leaders. The networking aspect of the meeting is very important too. NHLBI (a section of NIH) covers the expense of attendance. NHLBI is the National Heart, Lung and Blood Institute which houses the Center for Sleep Disorders research.

We are planning some fundraising and awareness events this year and one of our focus areas will be support groups. We hope to mobilize and help interested people with all aspects of support group formation and leadership. All sleep doctors should be able to refer narcolepsy patients to a local support group. We hope to focus on support groups at our annual conference. We are already very busy planning for our Annual Conference in October. We have a great conference committee and many talented local Washington DC area members who are working diligently to bring you another wonderful conference.

Lastly, I would like to express our deep sadness on the passing of Dr. Robert Clark. Dr. Clark was a member of NN’s Medical Advisory Board from inception and a very much loved sleep doctor to many. He also shared a diagnosis of narcolepsy. We are deeply grateful for all he did for patients and for the narcolepsy cause. He will be greatly missed. His family has expressed the need to stay in touch with the narcolepsy community and they will continue to support us.

We are continuously interested in hearing from you about what you are doing in your community to promote narcolepsy awareness. We would also be delighted to have additional volunteers to help raise funds, organize support groups, assist with the newsletter and/or website and much more.

Warm regards,

Eveline Honig

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On February 5th and 6th the Narcolepsy Network was proud to present their *Narcolepsy in the Classroom* brochure to the Florida Association of School Nurses (FASN) annual conference in Lake Mary. Network members Pam Sabourin (left) and Betty Scott (right) volunteered to attend the event and promote narcolepsy awareness at the NN booth.

Check out the newly designed Narcolepsy Network Website at www.narcolepsynetwork.org and let us know how much you enjoy it!
A Novel Approach to Treating Morning Sleep Inertia in Narcolepsy

Sleep inertia is the decreased performance and/or disorientation occurring immediately after awakening from sleep. Daytime sleep inertia has been reported in some cases of narcolepsy. Sleep inertia may be more intense when waking while core body temperatures are at their lowest. Previously, researchers have shown core body temperature differences in people with narcolepsy compared to control subjects (see Research Briefs from the Summer 2008 newsletter). Other researchers have shown that the circadian rhythm of salivary melatonin levels is dysregulated in some people with narcolepsy, and this may be related to the reported sleep inertia.

A case study published in The Journal of Clinical Sleep Medicine describes a 17-year-old male diagnosed with narcolepsy who presented with the inability to awaken from sleep to attend early morning classes at school. The patient had been diagnosed with narcolepsy without cataplexy at the Vanderbilt Sleep Disorders Center in Nashville, TN the previous year. While treatment with Modafinil (200mg in the morning and 100mg at lunch) improved the teen’s daytime sleepiness, he still was not able to wake up for school in the morning. He had been reported for truancy at school and had failed two classes due to attendance issues.

The patient’s sleep schedule was erratic with falling asleep at different times at night and weekend wake-up times of noon or later. Optimizing sleep hygiene did not improve his morning sleepiness. Due to the teen’s inability to swallow immediately upon waking a nicotine patch trial was initiated after his pediatrician approved the trial. The patch was applied by a parent approximately 20 minutes before the teen’s desired wake time. After 20 minutes the patch was removed and any residual nicotine was washed off his skin. The nicotine patch allowed the patient to become alert enough to swallow the Modafinil. Waking at a consistent time in the morning also stabilized his overall sleep schedule, allowing him to develop a consistent sleep onset time at night and to avoid napping during the day.

Specific Antibody Levels Identified in Narcolepsy Patients — Elevated Tribbles homolog 2

Distinguished narcolepsy researchers in Europe, led by Dr. Mehdi Tafti, recently reported the identification of reactive auto-antibodies to Trib2 in human narcolepsy. This finding provides additional evidence that narcolepsy is an autoimmune disorder.

Narcolepsy with cataplexy occurs when there is a loss of hypocretin-expressing cells in the brain. It is thought that these cells are mistakenly destroyed by the immune system, making narcolepsy an autoimmune disease, although the actual “target” of the immune system is not known. Scientists are currently working to discover what else is unique to hypocretin cells in the brain that may make them an immune system target. Dr. Tafti and his group found that Tribbles2 may be the immune system “target” that researchers are looking for.

Dr. Tafti and his collaborators, by creating a unique mouse model, were able to determine that Tribbles2 expression is high in hypocretin-expressing cells. Further, they found that individuals with narcolepsy have antibodies against Tribbles2 in their blood. Their research showed that many patients with narcolepsy had a higher than normal level of antibody against Tribbles2, and 14% of all patients had an unusually high level of this antibody. Tribbles2 levels were highest in cases with the most recent onset of narcolepsy. High levels were not found in the control cases, nor were high levels of the antibodies found in cases of idiopathic hypersomnia or narcolepsy without cataplexy. High levels of Tribbles2 specific antibody titers also correlated with the severity of cataplexy for patients. Although it is not clear whether this Tribbles2 antibody is a cause or an effect of narcolepsy, this research supports the idea that immune function plays an important role in this disease.
Eating Well in 2010

perpetuates low energy, fat storage, and weight gain.

Following sleep experts’ advice about getting a good night’s sleep is a challenge for most people. For those with narcolepsy it is an even greater challenge due to the condition’s symptoms of excessive daytime sleepiness and nighttime sleep disruption.

Thanks to researchers who have been studying the brain chemical orexin, which regulates sleep and appetite, new insights have arisen about narcolepsy and weight management. A deficiency in orexin is related to the development of narcolepsy. In a recent research study, orexin administered to dogs and mice with narcolepsy improved their sleep. The study also found that sugar contributes to obsessive behavior and exacerbates cataplexy among mice.

“If we could get orexin into the brains of people with narcolepsy — and get it to the right places at the right times — we could, I think, completely cure this disease,” said Dr. Tom Scammell, a neurologist at Beth Israel Deaconess Medical Center, about the study in a recent Boston Globe article.

This study and others demonstrate the need for people with narcolepsy to pay special attention to their health and wellness. Another study, published in Cell Metabolism in late 2009, found that orexin helps mice resist obesity when fed a high fat diet. The results indicate that those who do not have the needed amounts of orexin have a greater chance of being overweight or obese, especially when eating a high fat diet.

Though medications containing orexin might still be a long way off, you can still give yourself the best chance at a healthy life and ideal weight beginning today.

The foods you eat each day contribute to how you feel. They form nutritional building blocks that help the body function. Like a machine, if the fuel you give your body is lacking in nutrients the machine will not work efficiently.

Food allergies can also contribute to low energy and weight gain. Eliminating energy-zapping foods and replacing them with smarter options that have greater nutritional value is important to maintaining a healthy weight. It is crucial to improve your diet choices and to build the best support system possible to keep your body and mind healthy.

Maya Paul, a holistic health counselor in San Francisco, recommends eliminating all sugar from one’s diet to promote a healthy lifestyle. Sugar causes energy swings from high to low, she wrote recently by e-mail. Sugar creates a negative cycle in the body. One craves more and more sugar to raise energy levels when they drop.

A better plan to keep blood sugar balanced through healthier means is by consuming natural sources of sugar, like fruit. Leafy green vegetables also provide energy to the body because they are loaded with many important vitamins and nutrients.

Most important to maintaining a healthy, well-balanced diet is eating breakfast every day. Eating in the morning fuels the body and gets the metabolism started, allowing your brain to remain more alert.

“A healthy breakfast can include many different foods, including protein, vegetables, and complex carbohydrates (such as steel cut oats),” Paul wrote.

According to her, a food elimination diet can help people who suffer from a food allergy or sensitivity. To start a food elimination diet, cut out all suspect foods like wheat and dairy. Then, re-introduce the foods into your diet one at a time to determine if your energy level changes based on what you are eating. If it does, then you will know that you’ve identified the culprit.

The most common food sensitivities are dairy, wheat, corn, soy, egg, shellfish, and peanuts, she explained. When your body does not have to fight against the allergy it can focus more of its energy on staying alert and healthy, according to Paul.

Since each individual is different, she recommends seeking the aid of a trained health counselor or other nutrition consultant who can better pinpoint the likely suspects behind low energy.

Do you have a recipe that you’d like to share with the sleep community?

Talk About Sleep is collecting recipes for a fundraising cookbook that will include information about sleep disorders including narcolepsy. Proceeds will provide scholarships to the annual NN Conference. Your support is greatly needed!

To contribute your favorite recipe (by April 23), buy a cookbook or contribute personal or corporate advertising in the cookbook, please visit http://www.talkaboutrightфор-thesleepcookbook.htm or contact NN member, Tracy Nasca at 952-479-7754.

You’re Invited to the 2010 NN Conference

When: Columbus Day Weekend 2010 (October 8th-10th)
Where: The Hyatt Regency Crystal City Ronald Reagan Airport Hotel in Arlington, VA

We hope to see you and your family at our annual NN conference for a special weekend of coming together to support one another. Meeting another person with narcolepsy for the first time will be an unforgettable moment etched in your memory. So take the plunge and come join us.

The conference offers the opportunity to learn about new developments in narcolepsy research and treatment, as well as advocate for our cause. Over the past few years we’ve been adding more sessions for our family members, loved ones, and supporters. Or try something new like yoga, NIA, or writing poetry.

Since the conference is so close to our nation’s capitol, plan your trip in advance so that you can make a mini-vacation out of it and spend some time sight-seeing in Washington, DC.

Keep checking the NN website for more information as it becomes available and we look forward to seeing you and your family there!
Diagnosing and Treating Older Adults with Narcolepsy

By Neil Feldman, MD, Summarized by Mike Main

Dr. Neil Feldman, one of our esteemed Medical Advisory Board members, recently wrote a paper for older adults dealing with narcolepsy. The full article, *Narcolepsy: Diagnosis and Treatment in the Elderly*, is available on the Narcolepsy Network website with a full list of references should readers want to find any of the cited research studies in the paper. Dr. Feldman examines what is known about diagnosing narcolepsy in older adults and medication options for managing narcolepsy symptoms with growing age. He stresses the importance of regular monitoring by a physician for older adults with narcolepsy who are prescribed medications.

According to Dr. Feldman, research has shown that the typical age for narcolepsy symptoms to appear is between 15 and 30, but he notes that a handful of cases show onset after age 35 and as old as age 70. Some cases are due to delays in diagnosis, especially for people who have narcolepsy without cataplexy. Cases diagnosed after age 45 are usually the result of other neurological issues, called secondary narcolepsy (for a full description of what this is, see the article by Gila Lindsley, PhD in The Network's Fall 2007 Issue). At one facility where research was conducted, of 41 consecutive patients diagnosed with narcolepsy, more than 50% were over age 40, with individuals being diagnosed in their 50s, 60s, and 70s (the oldest being 79 years old).

The age of onset does not affect the severity of symptoms for a person with narcolepsy, but most often begins with excessive daytime sleepiness, disrupted nighttime sleep, and can be accompanied by periodic muscle weakness (cataplexy). Dr. Feldman offers that other age-related changes in sleep patterns, sleep issues from declining physical and mental health, and medication effects may complicate a narcolepsy diagnosis in older adults. The actual diagnosis is made using the same tests used for younger patients, an overnight polysomnogram and a multiple sleep latency test (MSLT) the following day. It is important to remember that dream periods of rapid eye movement (REM) sleep become less frequent with age and sleep latency increases, so the diagnostic test results should be interpreted by a skilled clinician who has experience with older adult sleep patterns.

Dr. Feldman found symptom onset descriptions for 2 elderly patients with narcolepsy diagnoses. An 87-year-old man described 15 years of trancelike states accompanied by sleepiness, while a 90-year-old woman had sudden attacks of sleepiness and slurred speech over a period of 5 years. Both patients were initially treated for epilepsy.

The social and mental impairments of narcolepsy can be worsened by age, but prescribed medications to treat the symptoms are often less aggressive because many older patients are retired and no longer raising a family. A major concern, though, is that few drug trials include elderly patients. Most recently, of the roughly 1000 participants in three separate trials for Provigil, the oldest participant was 68 years old. Physicians must also use added caution when prescribing narcolepsy medications for older patients. These patients are more likely to have prescription drugs for other conditions that are more likely to occur with growing age, and older adults are more likely to experience side effects and to have medications cause sleep problems. Dr. Feldman strongly states that drug treatments must be individually designed.

The paper includes information about stimulants such as Provigil, Nuvigil, Ritalin, Ritalin-SR, and Dexedrine. Side effects for the few 65-year-olds in the clinical trials for Provigil and Nuvigil were similar to those of younger patients. Dr. Feldman recommends trying lower doses initially in older adults because the ability to eliminate these two medications could be reduced in older patients. For Ritalin, Ritalin-SR, and Dexedrine, the side effects include potential changes in blood pressure and heart rhythm primarily, but psychiatric side effects have also been noted in older adults. All three stimulants increase the risk of stroke and heart attack as well.

Dr. Feldman explores a number of medications used to treat cataplexy including Xyrem, Anafranil, Vivactyl, and Effexor. There is little data regarding the use of Xyrem by older patients with narcolepsy. Xyrem's high sodium content should be taken into account for patients with heart, blood pressure, or kidney issues. For the remaining anti-cataplexy medications (all antidepressants), Dr. Feldman has a number of concerns. All three can cause side effects that may be more concerning for older adults including blood pressure and heart issues, dry mouth, blurred vision, and constipation. Additionally, physicians must know about any other medications an individual is taking before prescribing antidepressants because they are more likely to interact with those other medications in a potentially dangerous way.

The Narcolepsy Network remains grateful for Dr. Feldman’s on-going efforts to find more and better ways to help people with narcolepsy live full, rich lives.

**Provegil/Nuvigil Registry for Pregnant Women**

If you are pregnant and/or thinking about becoming pregnant AND taking either Provigil or Nuvigil, then please consider participating in a Patient Registry developed by the manufacturer of these medications, Cephalon.

The Patient Registry has been established for anyone who has taken either of these medications within a 6-week period prior to conception and/or during pregnancy. Your participation is important so that exposure and fetal outcomes can be assessed.

To enroll in the Pregnancy Registry call 866-404-4106 or visit [www.provigilpregnancyregistry.com](http://www.provigilpregnancyregistry.com).
While snoozing in Alice in Wonderland, I think the Dormouse put it best: “You might just as well say that ‘I breathe when I sleep’ is the same thing as ‘I sleep when I breathe!’” I know that by having narcolepsy this all too often seems like the truth, though obviously to some exaggeration. Since breathing is imperative to life, why not use this necessity to help alleviate our afflictions? The holistic approach of aromatherapy is very simple and may help us sleep when we want to sleep or even energize us when we want to stay awake.

Aromatherapy is the use of selected fragrant substances in an effort to promote physical and mental health. As the day goes on, our ability to detect smell strengthens, making this practice ideal for evening time. By using aromatherapy we can put our noses to work overnight to potentially promote our own sleep. Nighttime use is the most common time to use aromatherapy in the general population because many people have trouble winding down at the end of the day, and similarly many common scents are calming and relaxing. But aromatherapy may also help energize us if we choose scents that are energizing.

There are several types of aromatherapy including candles, massage oils and bath salts to name a few. Bed sprays are also available but I don’t recommend them since the scent dissipates quickly and the residue on the sheets may cause skin irritation. Oil diffusers are quite safe, simple to use, and can be cleaned and refilled with a variety of scented oils. These are also a great choice for evening use because you don’t have to worry about accidentally leaving a flame unattended or having to turn something on or off. Most oil diffusers have long reeds to absorb the oil inside a small necked decorative glass jar. Other diffusers look like small unglazed ceramic pots. Since the clay absorbs the oil and diffuses it, there is no need for the reeds. The main drawback to the terracotta pot diffuser is that you can’t refill it because it is usually sealed shut, and it is nice to be able to switch fragrances. If you use a positive airway pressure device, place the jar in the vicinity of your air intake filter making sure that it doesn’t get tangled in the hose. The smell will waft through the air as you fall asleep.

Finding the right fragrance for you may take some practice. It may be best to do your homework and research the options before choosing a scent. There is an abundance of information on the internet and in libraries about using aromatherapy. With hundreds of essential oils available it can be helpful to know what systems you may be stimulating when you make your aromatherapy choices. Your choice may also be influenced by what mood you are in when you are going to use aromatherapy. So you may find that many scents are for you, and the right one is determined by your mood or the time of day that you want to use it. There are also mixed oil scents. I don’t recommend mixing oils on your own, as it is probably best to leave that to the professionals.

It is important to clean your vessel thoroughly for every time you change fragrances. A few of my favorites that you may want to try are lavender and sandalwood. Lavendar is a calming scent that soothes the senses, while sandalwood is more of a woody scent. Other common aromatherapy scents include rosemary, rosalina, chamomile, basil, marjoram, juniper, neroli, rose, and jasmine. Remember that your sense of smell is as individual as your fingerprint, and in time you will find a scent that compliments you perfectly.

Disclaimer: Please remember to consult your physician before trying any holistic approach to medicine such as aromatherapy. There can be risks or side effects from using herbs and/or essential oils.

NN Celebrates National Sleep Awareness Week

NN gathered for their 2nd annual New York City event on Thursday, March 11, 2010 for NIGHT at the CARNIVAL. The entire 5th floor of the Bowlmor was available to those supporting the event. The Carnival games and lively conversations proved both entertaining and delightful. Executive Director Eveline Honig and NN Trustees Mee Ng and Patricia Higgins attended to support, educate, advocate and improve narcolepsy awareness. We can’t wait for next year!

Did you see us on NBC’s TODAY Show March 13, 2010? NN greeted narcolepsy awareness day Suddenly Sleepy Saturday, the final day of National Sleep Awareness Week, with enthusiasm on March 13, 2010 by standing outside NBC Studio 1-A. The weather was dreary but our spirits soared as Al Roker, NBC’s famous meteorologist, approached our group. Please contact us if you saw us on TV or if you want to be involved in organizing a larger group to do this again in 2011.
I ended up telling a few of my teachers, if that made me more comfortable. I wanted to inform my teachers about my narcolepsy. She also offered not to speak to my teachers on my behalf about my narcolepsy. The Dean left it up to me whether or not I wanted to inform my teachers about my narcolepsy without copious reinforcement came my way because everyone around me was caught up in their own stressful law school experience. I finally decided that beating myself up was getting old. I realized that if I wasn’t compassionate towards myself, no one else was going to be.

By my last semester of law school I trained myself to muffle the negative self-talk. When tiredness became excruciating during a class I headed for a diet coke and a cookie at a nearby café. Sometimes I even stopped for a quick conversation if I saw a friend in the hallway. When I felt refreshed, I returned to class. I would miss ten or fifteen minutes of class, but the only other realistic option would have been to stay in class and fight an invisible battle against sleepiness. No thanks. I refused to feel bad about my trips to the café.

I know that I’m incredibly lucky to have received the support of my school through the Dean of Students. Along my journey I’ve met few people who understand the difficulties associated with narcolepsy without copious explanations. Yet with the Dean I never needed to explain myself; she trusted me and helped me whenever she could.

On graduation day I saw the Dean on stage as I approached to receive my diploma. She was not handing out the diplomas, but when my name was read, she rose from her seat to give me a hug. Her special congratulations caused a moment of confusion on stage since we backed up the procession line for a second. Neither of us cared. On that day I did not receive any awards or academic honors, yet the hug from the Dean reminded me just how far I’d come. Graduating from law school with narcolepsy was certainly not what I’d signed up for three years earlier, but I know now that my degree was truly an accomplishment of a lifetime.

The Dean of Students supported me throughout my second and third years of law school. After I received my official diagnosis, she requested that my doctor send a letter for the school’s records. Once I understood my narcolepsy better, we worked together every semester to design a schedule that best fit my strengths and weaknesses. We looked for classes that were discussion-oriented instead of lecture-based. I felt that participation kept me more alert. We avoided classes that started early in the morning because I liked flexibility in the mornings to adjust between Xyrem and my daytime stimulants. Another particularly helpful accommodation I received was my own cubicle in a fairly secluded section of the library basement. This spot became my own personal designated napping space.

The Dean left it up to me whether or not I wanted to inform my teachers about my narcolepsy. She also offered to speak to my teachers on my behalf if that made me more comfortable. I ended up telling a few of my teachers, mostly when I felt it was necessary to explain my sleepiness during class. I remember opening my eyes from a prolonged sleepy blink only to catch eyes with my health law professor one day. I met with him later to explain that narcolepsy was the reason I’d been falling asleep in his class. My professor said he hadn’t noticed a thing.

The Dean also recommended that I take classes with a few professors that would be particularly compassionate towards my situation. These recommended professors quickly became mentors and friends and this support system meant everything to me.

I would like to say that my last two years of law school were a breeze, but that would be a lie. Generally I was more awake in class, but I still struggled to balance the timing of my medications with my classes, studying, and social engagements. I often took extensions to finish papers and never did particularly well on exams. Sometimes, periods of sleepiness arrived in the middle of testing, so I took my exams in a private room and received extra time to give me leeway in case I needed to take a short nap. I had many vivid dreams when I napped at school. I also avoided making eye-contact with anyone when I felt that my cataplexy was bad. It was not a perfect science, but I made it through.

I learned that my biggest critic was the voice inside my head. For a while I scolded myself for every misstep. I got angry when I felt sleepy in class. I was ashamed and guilty when asking for extensions on papers or extra time on exams. Yet, little-to-no positive reinforcement came my way because everyone around me was caught up in their own stressful law school experience. I finally decided that beating

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**Racing for Narcolepsy Research & Awareness**

Julie Flygare isn’t letting narcolepsy get in the way of accomplishing her dream of running the Boston Marathon to raise awareness and funds for narcolepsy research. On March 29, 2010, the Boston Globe interviewed her about the training she had endured leading up to this amazing athletic event. To read the article, go to www.boston.com and enter “Julie Flygare” in the Search box. Or if you are looking for regular inspiration from her, check out her blog at remrunner.blogspot.com.
The Narcolepsy Network, Inc. publicly thanks the following donors whose generous donations made it possible for us to provide information and support to thousands of people living with narcolepsy and their families. We also thank those not listed who volunteered their time and energy in 2009 to help further the mission of the Narcolepsy Network, Inc. by helping individuals and families, and advocating for and/or spreading awareness about narcolepsy in their communities.

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Arline Loomis
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Ann Wellner
Jerry Stilkind
Susan Stiller
Timothy Murphy
Robert Jennings
Carolyn Taylor
Barbara Korbek
Anne Johnson
Mr. & Mrs. L. Sarkozy
Twilla Harris
Frances & Donald Mosser

Note: Supercracts next to names indicate that donations were made in response to our end-of-the-year campaign drive to raise funds for NN. There were four donation categories:

1  DreamMaker ($1000 and up)
2  DreamCatcher ($500-$999)
3  DreamKeeper ($100-$499)
4  Awesome ($50-$99)

In memory of Malcolm Hardy
Robert Jennings
Carolyn Taylor
Robert & Martha Sue Thompson
Kathy Sohars
Alice Voorhees
Jackie Bowd
Carol Fleming

In memory of Gerald A. Helim
Brodart Social Club/Jim Kramer

In memory of Charles Ilsley
Sue Brockway Carella

In memory of Erma M. Langlas
whose grandson has narcolepsy
Billie Jean Anderson
Rachel Donohoe
Ruth-Ann & Richard Muszynski
Carole Elstein
Joanne Flynn
Anne Bergstresser
Patricia & James Flynn
Sue Nestor & Robert Botschi
Joan & Gerald Schaefer
Ann Green
Jeannine Cadoret
Mary & K.V. Unquere
Helena & Gecf Macalister
Barbara Korbelik
Anne Johnson
Mr. & Mrs. L. Sarkozy
Twilla Harris
Frances & Donald Mosser

In memory of Dorothy M. Morris
NYS Dept of Health Accts Payable

In memory of Robert Sisemore
The Nelson & Hodos Families

In memory of Eldon Tollefon
Ardis Reiss
Dorris Flesher

In memory of Mary Vatalia
Sue Brockway Carella

In memory of Phil Waterman
Sue Brockway Carella

Memorial
Dr. Robert Clark (1946-2010), of Columbus, Ohio and member of our Medical Advisory Board, passed away unexpectedly on Saturday, February 6, 2010.

Dr. Clark was a renowned neurologist specializing in sleep medicine and the Medical Director of the Columbus Community Health Regional Sleep Disorders Center. Patients from four continents and all over the U.S. sought his care. He served in various professional organizations including committee memberships in the American Academy of Sleep Medicine and a directorship in the American Narcolepsy Association. He gave talks at various locations in the United States, Canada, Europe, and South America. He was named one of America's top physicians in 2006 and again in 2009, and his practice was cited for quality and excellence. Dr. Clark initiated the development and implementation of the first comprehensive sleep medicine outcomes database in the country. He was a man of integrity and determination who was well respected by his staff who described him as dedicated and kind. His patients loved him not only for the special way he treated them, but also for the way he viewed them as equals.

Robert could bring a smile to anyone's face. A talented flamenco guitarist, he will be missed by the many friends with whom he shared his love of this music. He was a dear and devoted husband, father, and brother, and he was thrilled to be a grandfather to three wonderful grandchildren. His smiling eyes, dry sense of humor, and strong hugs will be dearly missed by all those who knew him or were influenced by his work.

The family would appreciate that donations in his memory be sent to Narcolepsy Network, 110 Ripple Lane, North Kingstown, RI 02852.

Coming soon to the NN Website:

A Members-Only Section & More Personal Stories

If you are interested in submitting your personal story to the website, contact Sara Kowalczyk at skowalczyk@narcolepsynetwork.org or Ramon Werbeach at rwerbeach@narcolepsynetwork.org.
Fond Memories of Former Trustee Phillip Waterman

Phillip Waterman (1956-2009), former Narcolepsy Network Trustee, died suddenly on November 16th in his Davis, California apartment at the age of 53.

Mr. Waterman served on the Narcolepsy Network Board of Trustees from 2002 to 2003, and he worked diligently to promote awareness about narcolepsy because he suffered from the symptoms for a great many years before being diagnosed himself. Hence, one of his greatest achievements was receiving the Ruth Justice Nebus Volunteer of the Year award at the 2003 Network conference in Atlanta, Georgia. In addition to continuously updating his physician about research and medication developments about narcolepsy, Mr. Waterman also targeted students through his awareness efforts. During Sleepiness Week he set up a table in Davis, CA where he distributed literature about narcolepsy and talked to students about the Epworth Sleepiness Scale. He also recorded and edited sessions from two conferences, affording people with narcolepsy not in attendance the opportunity to benefit from the knowledge. He was always ready to help another narcoleptic in need.

Phil Waterman was an advocate for keeping gammahydroxybutyrate (GHB) as a legal medication for people with narcolepsy when California tried to criminalize it in 1995. Mr. Waterman’s testimony about how GHB helped alleviate his cataplexy symptoms strengthened the case to keep it as a possible medication for people with narcolepsy/cataplexy. Thanks partially to his testimony people with narcolepsy/cataplexy in California are able to use Xyrem to treat their symptoms.

Phil was raised in Alaska by his musician father and later moved to California where his mother lived. He shared his father’s love for music, and this passion ignited his career. He had many jobs as a DJ and was inducted into the International Discotheque Pioneers Hall of Fame in 2001.

Phil had narcolepsy symptoms extending back to his early teens, but a diagnosis of narcolepsy was never sought until he was pulled over by a policeman for dozing at an intersection and not waking up even when other cars began honking at him. Hence, his narcolepsy diagnosis didn’t occur until he was 38 years old, and it was then that he realized how significantly his need for sleep ruled his life. Through his many contributions to music and narcolepsy awareness, he will be fondly remembered and greatly missed.
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.

On the back cover:
Thank you to NN member Amy Detlefsen who sent in this remarkable oil painting to share with our community. It reminds us of how peaceful and serene nature is.