Living and WINNING with Narcolepsy  By Sharon D. Smith

He’s had narcolepsy for over 50 years, yet he’s chosen not to treat his REM-related symptoms, including full-blown cataplexy because the medications stifle his creativity. Therein lays part of the secret to Dennis L. Maitland’s success, culminating in his receipt of the prestigious Cinema Audio Society’s (CAS) 2009 Career Achievement Award.

President Tricia Higgins and I had the immense pleasure of attending the 2009 CAS Award Dinner in Los Angeles on February 14. While we certainly were thrilled to share this event with Dennis, our motivation for attending had more to do with supporting a fellow PWN in a highly visible and vulnerable setting and spreading narcolepsy awareness within the vibrant CAS community. Here we present the inside story that you won’t find in the entertainment publications.

Dennis’ CAS membership is a tribute in itself; only the most accomplished sound artists are invited to join. Hundreds of colleagues came out to honor Dennis, the man behind the sound in hundreds of films. Continuation of this story can be found on page 2.

New DNA Technique Furthers Narcolepsy Research  By Emmanuel Mignot, MD PhD

A New Genetic Factor for Narcolepsy in Japanese
A quiet revolution is ongoing, and a recent publication by Miyagawa et al in the prestigious journal Nature Genetics leads the way to a new wave of genetic results in narcolepsy and other diseases. As many of you know, the genome has now been entirely sequenced in several individuals. It is constituted of 3 billion “base pairs”, coming in 54 flavors, 1% of which is genes that can be read to produce proteins, the key components of the body.

Genetics of Narcolepsy: HLA
An example of a protein involved in narcolepsy is Human Leukocyte Antigen (HLA) DQ, a protein expressed on the surface of circulating immune white blood cells called B-cells (specialized to produce antibody molecules, or immunoglobulin, that can trap foreign antigens) and T-cells (specialized in coordinating the action of B-cells, which themselves have specialized immune fighting abilities). The DQ81 protein is produced by the DQ81 gene.
of television productions and over 80 Hollywood films including Mars Attack (Jack Nicholson), Three Days of the Condor (Robert Redford) and Moscow on the Hudson (Robin Williams). Film director Norman Jewison, with whom Dennis worked for many years in television and later on Moonstruck (Cher, Nicholas Cage), And Justice for All (Al Pacino) and the New York portions of three other films, introduced Dennis and presented him with the actual diamond-shaped engraved crystal award. While Dennis’ narcolepsy was not mentioned, and those who had not worked with Dennis (or been tipped off by Tricia and I earlier in the evening) will not have understood the remark, Mr. Jewison good-naturedly prefaced his introduction with a public heads-up for Dennis to “wake up”.

Dennis learned the basics of sound recording while serving in the U.S. Army. At the time of his discharge television was in its infancy. Dennis took an entry level position at CBS, working his way up to Audio Man on the sets of television productions starring Jackie Gleason, Ed Sullivan and the like.

While still at CBS, Dennis began to experience daytime sleepiness. It lead him to fall asleep while driving home, wrecking two automobiles but lucky to walk away without serious injury to himself or others. Concerns about his uncontrollable sleepiness heightened when he fell asleep during a steamy date with a well-known but unforgiving actress. He sought medical help soon afterward and was diagnosed with narcolepsy.

Dennis never informed anyone at CBS of his narcolepsy. In time, though, he was caught napping during his lunch hour so often that his sleepiness became common knowledge. Coworkers would even take pictures of Dennis sleeping, so soundly at times that props could be and were added for extra amusement.

Many of the television directors Dennis worked under during his 12 years at CBS eventually branched out to feature films. Dennis had always strived to be the best at his craft. His impeccable standards, innovation and the high quality of his work had not gone unnoticed. When Dennis himself made the switch to feature films he found his services in great demand. Inevitably, his narcolepsy and cataplexy would present during his work time, but he offered no apologies. He would explain his condition to the film director, pointing out that merely calling out his name or saying “Let’s roll” would bring him to. In no-nonsense fashion he asserted. “This is who I am.” His narcolepsy was accepted. Some, like close family friend Robin Williams, who calls Dennis “Captain Cato”, have even played into Dennis’ cataplexy, rattling off a succession of jokes to get him on the floor and keep him there. To a comedian known for brilliant ad-libbing, cataplexy is likely the strongest gauge of effectiveness, and so while Dennis admits he was powerless, he also accepts that it was done in a good-natured way by a friend who accepts him just as he is.

Dennis is a man of countless stories that invariably include humor and a full range of other strong emotions. So how was it that he was able to receive the CAS award and deliver an acceptance speech without dropping to the floor? It was all about months of preparation.

New DNA Technique Furthers Narcolepsy Research

In the DNA sequence of the DQB1 gene, as for many other genes, specific changes that make us different from each other, called “polymorphisms” can be found, changing slightly the characteristics of the DQB1 protein. One of those is involved in creating the subtype of DQB1 called DQB1*0602, present in 25% of the general population and almost all narcoleptic patients with hypocretin deficiency. Whereas approximately 1/2000 people have narcolepsy/hypocretin deficiency, about 1/500 people who have DQB1*0602 have narcolepsy, a 4-fold increased risk.

Going from 1/500 individuals to narcolepsy involves many other factors, some of which are environmental, some of which are likely to be genetic. The nature of the environmental factors are unknown, and could for example be an infection that could trigger an immune fighting reaction that then goes awry and leads to an autoimmune destruction of hypocretin cells, the leading theory for the pathophysiology of narcolepsy. It could also be a multiple number of other things, from head trauma to sleep deprivation.

**Genome-Wide Associations**

Unfortunately, at the present time, there is no easy way to look at all the possible environmental triggers. Even a simple infection like the cold probably involves thousands of slightly different viruses and we are only aware of the large families (for example rhinovirus, adenovirus, etc), but have very little knowledge of the subtype diversity, which is immense. In contrast, recent developments starting with the sequence of the human genome a few years ago, and followed now with the identification of many of the most common polymorphisms across the entire genome, are making it possible to pretty much test the entire genome for millions of DNA changes that make us different from each other at the genetic level. Although not all DNA changes are tested, 1 million DNA polymorphisms is sufficient to allow for the indirect testing of most common DNA changes. This technique is called a Genome-Wide Association. It is now used by thousand of researchers; genes predisposing to cancer, autoimmune diseases and many other problems are being discovered and studied. A problem with this technique is that a large number of comparisons, let’s say up to one million, are made, thus many differences are found by complete chance and are not real. Only
A Word from Our Executive Director
By Eveline Honig MD MPH

Dear Friends,

We’ve greeted 2009 with a hearty list of both new and renewed ideas and projects to pursue. At the same time, we remain ever mindful of the economic challenges ahead and assure you that we will continue to run a lean and efficient operation. We are very appreciative of the year-end donations we received from so many of you. I want to thank you again for your generosity and to invite all of you to consider giving of your time and talents to further our cause in the coming year.

In keeping with NN’s mission to raise awareness and advocate for people yet to be diagnosed, last Fall I wrote an article titled “Narcolepsy Diagnosis in the Home Testing Era” for the journal Sleep Review. Home Sleep Testing is expected to become the gold standard for diagnosing sleep apnea in the near future. My article highlights several reasons home studies carry the risk of overlooked narcolepsy diagnoses. This article was published in the January 2009 issue and can be viewed in full at http://www.sleepreviewmag.com/issues/articles/2009-01_04.asp.

Home Sleep Testing (HST), as its name suggests, involves a tradeoff, with the primary advantages of patient convenience and economy, but the potential disadvantage of a more limited test that does not include the recording of brain activity, the results of which are essential to diagnosing narcolepsy. Patients with co-existing sleep apnea are at most at risk for a missed narcolepsy diagnosis since continued sleepiness may be attributed to lack of CPAP compliance. Narcolepsy diagnoses may also be missed in the absence of sleep apnea as HST paves the way for primary care physicians to order HST and bypass the sleep specialty completely.

The American Academy of Sleep Medicine recommends HST be used only for people with a high probability of obstructive sleep apnea and no other sleep disorder or other medical conditions suspected.

During 2008 Florida member Rosalee Kalwara (formerly of Phoenix and San Diego) donated “seed money” to facilitate fundraising initiatives. Our Board and I considered many possible events before deciding on a Cocktail Social to be held in New York City. This location is convenient to my office, a large number of active members and donors and four of our Trustees.

We will honor Rosalee Kalwara during this party, with special recognition given to NY member Dennis Maitland, a retired Hollywood sound engineer who recently received the Cinema Audio Society’s 2009 Career Achievement Award.

Our social will feature a talk on narcolepsy by Dr. Michael Thorpy, Director of the Sleep Center at Montefiore Medical Center. We’ve also arranged for several artists (dancers, singers, musicians) in the community who are happy to donate their services to our cause. We are anticipating a financially successful event and a wonderful evening for the attendees. Many of our members in the Metro New York area are working with us to bring colleagues, friends and family members to this social event. Not only do we hope to raise money; we also hope to raise awareness of narcolepsy among the many invited guests who do not live with the disorder.

We hope to replicate this event in other major cities in the country. If you live in or near a major city and would consider helping to plan such an event in your area, please contact me.

National Sleep Awareness week is the first week in March, with Saturday, March 7th again designated “Suddenly Sleep Saturday”. This will be a day devoted to narcolepsy. While NSAW is a great time to promote narcolepsy awareness, every day of the year provides this opportunity. Please consider conducting a narcolepsy awareness activity in your community, at schools, libraries, the offices of your elected officials and even physicians outside the sleep specialty. Wear a NN button and/or bracelet wherever you go to elicit inquiries from the people you encounter. Don’t forget to let us know how you raised awareness in your community! This year’s SLEEP meeting will be held in Seattle in early June and as always we welcome volunteers to help us greet the sleep professionals who visit our exhibit. Our own annual meeting and patient conference will be held in Jacksonville, FL the weekend of October 23—25. Given the developments Dr Mignot tells us about in this issue, we look forward to conference coverage of other breaking research advances as well as workshops, support sessions, energizers and plenty of time to socialize.

Happy Spring to all!
Warm regards,

Eveline Honig MD MPH
When I started this writing, I had a few ideas in mind that I wanted to explore and hopefully incorporate into its content, the main focus being a breaking out and then a reaching forward. The breaking out is my own personal one from a world or system that I have created in order to deal or live with my condition of narcolepsy and its accompanying situations. The reaching out is to find a support system and a safe house where you and I can explore where we’ve been and where we’re going. Thus, I came up with the concept of “being told where to go”.

Often the occasion arises when we are in need of advice, counsel, help, or a different outlook or opinion and so we seek that assistance from different sources such as family, friends, doctors, social workers, and professional people. When I have in fact asked for that help or assistance, there are some important components that I’ve needed to address. For instance: that the respondent does in fact understand the question and has some experience or knowledge as to an adequate answer. This is essential in obtaining information from others as to the service or product that I am inquiring about as well as being actually supportive and not harmful to the questioner. However there are many times when people have told me where to go that their advice is not only not beneficial, it can be very harmful and often their meaning has an entirely different tone. Which brings us to the problem of the meaning of what is has been said and how it is interpreted or used.

Examining this subject takes some additional information so as to set the scene and provide some parameters within which to work as we are opening this plane: I am an individual who has had narcolepsy since I was born, from all accounts that we are able to compile. When I was born in 1945; narcolepsy was not a known disease or condition that was recognized by the core medical profession, to say nothing of society itself. This was a time when sleeping during class or falling asleep on a date was considered a bad behavior, rude, disrespectful, disinterested, the manifestation of a badly behaved child or juvenile delinquent, or interpreted in any number of other negative ways, with no consideration that there might be a valid cause beyond my control, no less a neurological disorder.

My life progressed and odd things just happened to me, but this is true for all of us whose diagnosis was delayed. How those oddities were handled varies greatly. Each of us was brought up differently, products of different ideals, values and preferences that make society what it is: “diversified.” I did not enjoy sports events, at least not participating in them. I was not the cheerleader type or the studious one either. What I wanted to be when I grew up was a mystery to me as I did not know what was available for me or what I might be good at. Women at this time were only being groomed to be nurses, teachers, secretaries, wives, and mothers. None of these appealed to me at the time. So, I trudged on and made it through high school with an average to below average grade level and nothing

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**Visiting NN’s Online Community for the first time? Here are some handy directions on how to get there:**

1. Go to www.narcolepsynetwork.org/forums/

2. Register. Choose a User Name (we recommend one that does not reveal your identity) and password. Provide the information requested and submit. (Note: You do not need to enter name, address or other personal identifying information in order to register for the message boards.)

3. You will receive a confirmation email containing the user name and password you’ve selected. Be sure to save it! You must validate your registration by clicking on the link in this email.

4. Return to www.narcolepsynetwork.org/forums/ and log in.

5. Scroll down to “Help Center” (white letters against a blue background); locate and click on the forum “Being Told Where to Go”.

6. Click on an existing topic to read and/or respond. To start a new topic, click on “New Topic” in the upper right corner, just above the blue band.

7. Need help? First try in the “Help” horizontal menu on top. If your question or issue is still not resolved, contact Stu, our webmaster, at scarpenter@narcolepsynetwork.org.
to use as a focus or brass ring to try to grab.

This brings us to being told where to go. We are given guidelines in school as to the subjects that we should study and learn in order to qualify to continue on to college or find a job on a level that does not require further academic study. There were the school counselors that were there to guide us and point us in the direction of our future lives, “telling us where to go” but often these counselors did not now where they were going themselves. I wonder who told them where to go!

I graduated and then went to work at a bank and felt there was nothing abnormal about me. So what if I fell asleep while people were talking to me — most of those times they did not even know I was asleep, and sometimes neither did I. Then I got a promotion to working on what they called “the machines”. These were big electronic noisy contraptions that sorted the checks to be returned to the smaller banks. A very repetitive job, this is where my problem became somewhat evident, at least to me. I’d sit all day just sorting checks into the proper pockets, entering the amounts in the machine and be expected to come up with the right amount at the end of the run. Easy enough, except when you fall asleep at the machine you can really screw up the data. They could not figure out what I had done or how I had done it and neither could I. This led to my first job firing and the search for what I was going to be now that I was out of school and out of work.

With this as background, let us turn to the involvement of others who are in the same situation as I am, or have a loved one who is or will be. I am reminded of the mother who in recent articles for this newsletter wrote of her unending attempts to get help for her son from his school and the authorities involved. Here is a prime example of relying on the people we go to for expert advice only to obtain conflicting results when we bring that expertise forward into the public. I am often confused by the response of officials in different situations when they ask for an expert opinion and then question that expert opinion and even refuse to accept it after receiving it. This has been an unending occurrence in my life and it seemed a formidable problem in her situation as well. If our doctors are board certified in neurology and sleep medicine, why does a general practitioner or other professional with no equivalent qualifications find the information from the neurologist/sleep physician inadequate? Here we have been told where to go for advice, seek out the best and then are told that is not the right answer, not good enough, or we do not know what we are talking about.

With the above as background, I want to ask for your help. Help me to bring the complications of living with narcolepsy into the light and debunk the misconceptions of the general populace. I invite you to join me in NN’s Online Community, in the forum “Being Told Where to Go” (see inset) or write to me c/o this newsletter if you don’t have internet access. Tell us of the complications you have experienced in trying to get advice or help. Also, let’s discuss some of the other issues involving our lives like the content of dreams and the effect they have on our lives, the understanding of others regarding our “condition”, the apprehension to discuss these things with others because of what they might think or do to us if we “tell”. Trust me; I know it is hard to open these doors to others because so often we have been punished or frightened when we have done so. Let’s come together in a supportive setting to help each other explore these topics and bring some positive insight into the narcoleptic condition. “Tell me where to go!”

About Jill

Jill returned to school in her mid-40s, receiving a BA from Toledo University in Interdisciplinary Studies with a focus on Women’s Studies. She went on to earn a Masters in Psychology/Women’s Studies from Antioch University, where she concentrated on the psychology of Dr. Carl Jung and his theories of the archetypes. This led her to many different disciplines of research, including Jung’s theories regarding the dream states.
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 2008 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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Trustee Nominations  By Sue Brockway Carella

Each year, Network members elect Trustees to fill annually vacated positions on the Board. The Board is composed of 9 to 15 individuals elected from the Network’s membership who serve for three year terms. Two-thirds of the Trustees must have narcolepsy; the remaining members may be family members or friends wishing to help our cause. If you are interested in serving as a Trustee or would like to recommend someone for NN’s Board, now is the time to do so.

The Nomination Committee seeks members willing and able to meet most, if not all, of the following:

1. participate in 12 Board meetings, eleven by telephone and one face-to-face following the Annual Meeting/Conference,
2. absorb personally some or all of necessary travel costs to NN meetings,
3. participate actively in program planning and implementation,
4. support the mission and purpose of the Network,
5. provide input towards the development of the strategic plan,
6. participate in fundraising to sustain and expand the Network,
7. monitor the effectiveness of current programs,
8. meet the fiduciary responsibilities of the Board by reviewing the monthly financial statements,
9. chair and serve on standing and/or advisory committees, and
10. participate in discussions pertaining to hired personnel for purposes of operation of the corporation.

It is the Nomination Committee’s charge to find these people and they are actively soliciting your recommendations for strong candidates at this time. You can recommend yourself or nominate another by writing a letter to the Network. When submitting the nomination for candidacy, send information about how you think that person could contribute to the effectiveness of the Network. This would include the person’s background, skills and/or contacts.

You can assure your nominee will be considered for nomination by submitting his or her name accompanied by the endorsement of ten Network members. Petitions for this purpose are available from the Network office. Petitions must be received by July 2, 2009 to be considered for October 2009 elections.

Living and WINNING with Narcolepsy  continued from page 2

so none could occur to him suddenly to trigger cataplexy. For added protection, Dennis’ son Tod Maitland, a three-time Academy Award Nominee, most recently for the sound in Seabiscuit, escorted Dennis on stage and stood in the background, ready to intercede in a milli-second.

Soon after learning he was to receive this year’s Career Achievement Award, Dennis’ thoughts turned to non-medication methods of managing his severe cataplexy during such an emotionally-charged event. Years before, Dennis had shared with our local support group a technique that had worked well for him but required a family member in the know to stand ready at his side. At the first sign of cataplexy, his son or daughter would deliver a strong pinch to his neck or arm.

More recently, Dennis discovered a new and novel use for a remotely-controlled electronic dog training collar. Fitting it to his thigh, with remote in hand and finger on the button, he found he had just enough time at the first sign of impending cataplexy to depress the button to deliver a shock to his leg. This shock, like the pinch, likely wards off cataplexy by redirecting Dennis’ thoughts away from the trigger. It may also work in the same way that the stimulus of touch is reported to help one recover more quickly.

Dennis had hoped to devise a hands-free cataplexy defense that could automatically sense subtle but detectable physical changes that occur at the outset of cataplexy. Possibilities include breathing rate, blood pressure and/or pulse. We had consulted a cataplexy expert on Dennis’ behalf who knew of only one patient who had worked on developing such a device but with only mediocre results. As we are all too well aware, it’s practically impossible to obtain funding for development of a product with a limited market. Interestingly, a recently reported study conducted to resolve complications of cataplexy occurring during surgery raises the possibility that brain waves could be monitored to detect cataplexy at the earliest sign.

We congratulate Dennis on his accomplishments and hope that his story will inspire you to tap into the source of creativity to which the REM-related symptoms of narcolepsy grant us unique access.
Keeping Watch  By Michele Profeta

I am a seasoned worrier. The matters were largely trite and transient in retrospect, until the summer of 2001. That is when my youngest daughter’s health began to crumble, and worry proliferated. My child was eight when her brain stopped making hypocretin. Without this neurotransmitter, she developed narcolepsy. The symptoms were harsh: no sustained sleep, perpetual tiredness, vivid, frightening dreams, and loss of muscle control with any strong emotion. For several difficult years, we sought a diagnosis and titrated medications. At that point, mothering was not about homework done and vitamins taken. Tidy bedrooms and please and thank-yous meant nothing. It was, how do I stop her headache? What will happen when she swallows this new medicine? Will she ever go back to school? How do I help her when she is begging for sleep that won’t come? Can I stop the 40, 50, 85 lbs. weight gain?

With time and good doctors, my daughter’s symptoms eased. Now, Xyrem enables her to go smoothly into a deep, restful sleep. No frightening hallucinations. She wakes up and goes to school. With Provigil and little naps she stays alert for an after school job and homework time. Jubilant that she is leaving the house again, I can accept the new parenting challenge, which is, how do I keep her safe when she is out, even doing the most ordinary things?

“Can I go to the party?” she wants to know. She being the child who had stayed nuzzled asleep on the couch through many years of birthday parties. She is the one I watched disappear into the MRI machine several times, and who’d had dozens of electrodes glued to her. This is the girl who pressed against my shoulder asleep in the doctor’s waiting room for countless tedious hours, and whose head I cradled as she vomited from medication every morning. Yes. She can go to the party. However, it is a paintball party. You must sign a waiver. The owners want the players to know the game is risky. They want to know if you are a risk. There is no box to check for cataplexy. Still, I want her to go. Will there be a safe place to nap if the day gets too long?

You worry about these things when you are the parent of a young person with narcolepsy. Can you really send your child to a sleepover with a pillow, a toothbrush, and a bottle of GHB? Who will watch over her when she is under the influence of the drug and totally vulnerable? But the doctors’ visits, the tests, the experimenting with medications were all done for this exact reason: the simple invitation to a birthday party. You want your child to have every opportunity of a life without narcolepsy. Yet you are the warden of safety for your child with narcolepsy, and there are real concerns.

Swimming, skiing, even bike riding could all be dangerous if excitement elicits cataplexy. Medication surely diminishes chances of cataplexy, still a mother’s heart pounds at the thought of a mishap. Protection is a greater challenge as the child becomes a teenager, and your presence is intrusive. I can meet my daughter at her Saturday job at a bridal shop for a lunchtime nap in the car. She won’t want me with her when they work all day at a fashion show in the city an hour away. Surrounded by strangers, will she nap? Will they understand the necessity?

At this point, I appreciate that my child and her illness have synchronized. She has adapted to the challenges that have in many ways matured her. She is no longer the little eight year old who asked, “Mommy what did happen to me?” She is fifteen and aware of her limitations. I guess I must let her go — take a deep breath and wait on the couch for her safe return. Yikes.

NN Founder Niss Ryan Elected Trustee Emerita  By Sue Carella

In 1990, the Network Board created the special position of Emeritus for Board Trustees of long standing whose work as Trustees has been exemplary. While Trustees Emeriti are relieved of the fiduciary duties of full Trustees and do not vote, they retain the right to attend Board meetings in order to learn of new Board decisions and plans and to share their expertise and knowledge of the organization with the Board.

Ruth Justice Nebus, the Network’s incorporator, was the first Trustee to be elected to the Emeritus position. The 2008-2009 Board recently elected Niss Ryan Trustee Emerita following her resignation at the conclusion of its Milwaukee Annual Meeting.

Niss’ narcolepsy was diagnosed in 1975, at the age of 51, after reading two articles about narcolepsy written by...
New: Chicagoland/Midwest Narcolepsy Support Group
By Sarah Didavide

Support Groups – noun; groups of people who meet regularly to support or sustain each other by discussing problems affecting them in common.

My husband was diagnosed with Narcolepsy four years ago. We knew very little about narcolepsy and had so many questions. Jason and I realized his doctor could answer some questions, but the doctor did not live with narcolepsy and therefore could not provide insight into all the ways in which narcolepsy was going to and still is affecting our everyday lives. It was hard for those who love us the most — our family and friends — to understand some of the challenges we were going through.

Soon after Jason was diagnosed he was introduced to a nurse at the sleep center who also had narcolepsy. They would talk on the phone for hours. He was younger, in law school, no kids and newly diagnosed; she was older, a nurse with a child and working in a sleep center. Despite their differences, they had so much to talk about and found each really understood and could help the other.

When we moved back to Chicago, we searched for a support group, but could not find one. Later that year, I attended the Sleepy Person Conference at the University of Illinois at Chicago Center for Narcolepsy, Sleep and Health Research, which is only held every three years. At the Conference, I met Loretta Smith, a nurse with North Shore University Health System, in Evanston. She mentioned that she was working to start a support group. We had our first support group meeting a couple of months later.

The Chicagoland/Midwest Narcolepsy Support Group
continued on page 12
For several years Dr. Honig and our Trustees have scheduled Patient Information Meetings in conjunction with the various professional meetings we attend each year. Locations have included Milwaukee, Atlanta, Baltimore, Minneapolis, and Nashville, with others on the horizon!

To maximize our trip to Los Angeles, on Sunday Feb. 15, 2009 Sharon Smith and I traveled to nearby UCLA to host a Narcolepsy Patient Information Meeting Jerome Siegel, PhD, (Director, UCLA's Center for Sleep Research and Member; NN Medical Advisory Board) kicked off our meeting with an overview of and update on his recent research. He compared the specific HCRT (hypocretin) cell loss in narcolepsy to the more generalized cell loss in Parkinson’s disease. (PD is characterized by an overall loss of all types of brain cells, including HCRT neurons, and, in fact, many PD patients experience narcolepsy-like symptoms.

For HCRT-deficient patients, the future lies in treatments aimed at reversing the HCRT deficit. For many, the most exciting information came from Dr. Siegel’s analysis of the brain tissue of one narcolepsy-without-cataplexy patient: he found significant HCRT cell loss in the posterior hypothalamus, vs. the widespread HCRT cell loss seen in all three hypothalamic regions of narcolepsy-with-cataplexy patients. The brain donor's hypocretin levels are unknown; it is possible fewer cells could still produce normal amounts of hypocretin. The message here is clear: More brains of narcolepsy patients are needed in general, with those of narcolepsy-without-cataplexy patients essential to determine if Dr. Siegel’s findings are representative of the majority of cases. (See inset on page 5 on arranging for brain donation.)

Alon Avidan, MD, MPH, D’ABSM (Associate Director of UCLA’s Sleep Disorders Clinic and Director, UCLA Neurology Residency Program & UCLA Neurology Clinic) presented next on the latest treatments in narcolepsy. Much success is being achieved with effective medications and lifestyle management, including optimal sleep hygiene and scheduled power naps. One of Dr. Avidan’s take-home points is to consider taking your wake-promoting agents (stimulants) as soon as you wake up. Many patients report that they keep morning meds on the nightstand. Wake-promoting agents should ideally be taken on an empty stomach. Dr. Avidan also explained the benefit of drug holidays as a way to improve the efficacy of treatment. He is also an advocate of prescribing wake-promoting agents “on demand” to be taken as needed to give patients flexibility and the ability to achieve peak alertness when most needed and according to subjective need such as driving, work or school. On medication side-effects, Dr. Avidan advised us certain cataplexy medications may cause unpleasant anticholinergic side effects and newer alternatives (such as sodium oxybate) may be reasonable alternatives. He provided a short discussion of the use of Provigil (modafinil), a non-sympathomimetic wake promoting agent in narcolepsy as well as newer FDA indications. Dr. Avidan concluded that clinical follow-up of patients with narcolepsy should focus on development of new symptoms of sleepiness, snoring and gasp awakening as narcolepsy patients may have a tendency to have a higher body mass index (BMI) and could be at risk for sleep apnea which could co-evolve with narcolepsy.

Tracy Kuo, PhD, D’ABSM (Certified Behavioral Sleep Medicine Specialist; Clinical Assistant Professor; Stanford Sleep Disorders Clinic & Private Practice) addressed “Living Well with Narcolepsy”. Her presentation was remarkable and inspirational! The message that struck me most was about investing in oneself. It had never occurred to me before that it actually might matter to someone that I invest in myself. She told us “You are worth the investment.” Wow, what a concept! This one statement energized me. It will help me focus on personal issues needing attention. Dr. Kuo also advised that we must be realistic when setting personal goals. A person with narcolepsy is already starting out with a deficit in quality time. We must ignore what others do and set our own unique standards of accomplishment. Work backwards to determine how many good hours of the day we can function well. Then, develop a plan that meets your time needs. As Dr. Kuo summarized, “Make mindful choices and let the rest go.”

What would a narcolepsy patient meeting be without the opportunity for networking? Margaret White, PhD and Leader of the Narcolepsy Support Group at St. Jude’s Medical Center in Fullerton, CA, also participated in the meeting. A number of long-time members from her group were in attendance; several others learned of this group for the first time. Making a personal connection with Dr. White, one of few professionally trained and experienced support group coordinators, is sure to motivate people to attend her meeting.

Each of the presenters listened to the other’s presentations. It was an awesome display of reverence. We thank our presenters for donating their time and expertise to our group. Special thanks go to Dr. Siegel for arranging the space for this meeting. We welcome Dr. Avidan to our community and look forward to working with him in the future. We also commend family members and friends who, accompanied their loved ones, making it possible for them to attend. Those in attendance left the meeting with new knowledge that can be applied to living a full life with narcolepsy. The messages presented were valuable, timely and positive.

We look forward to visiting more cities across the country. If you live in the Northwest region, please mark your calendars for this important event. Details will follow by mail and/or email.

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**Los Angeles Patient Information Meeting**  
*By Patricia Higgins, RN*

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**Narcolepsy Patient Information Meeting**

Seattle, Washington  
June 6 or 7, 2009  
*Exact location and speakers TBA.*

*An opportunity to donate a blood sample for the latest narcolepsy research will be offered.*
Call for Poetry: The Narcolepsy Poetry Project

Writing poetry and sharing it with others encourages people with narcolepsy to explore a greater mindfulness of their symptoms while responding to their creative psyche. Narcolepsy is a lifelong condition that calls upon us to consider questions of deeper, personal meaning we might attribute to our condition.

Cataplexy, one of the most challenging symptoms of narcolepsy, ultimately represents a heightened permeability between the waking world and the world of dreams. If we recognize the creative and spiritual potential of dreaming, we may be able to draw something positive even from cataplexy.

What might we discover if we kept our spirits strong when our muscles weaken? What might we learn about where cataplexy takes us if we were a bit less concerned about what it removes us from?

The Narcolepsy Poetry Project seeks to capture and share these experiences of narcolepsy through poetry written by PWN. In cooperation with the Narcolepsy Network, Dr. Rubin Naiman is interested in your poetry submissions for inclusion in a special book to be published later this year. Poems will be selected by a committee of professional poets, and profits from the sale of this book will be donated to the Narcolepsy Network.

Even if you have never written poetry before, please consider exploring poetry as an outlet to your feelings and experiences living with narcolepsy. Perhaps you will provide comfort to others who struggle as well.

Please submit poetry as well as any questions or comments via email to poetry@drnaiman.com. Submissions are due no later than April 30, 2009.

Dr. Rubin Naiman is the sleep and dream specialist and clinical assistant professor of medicine at the University of Arizona’s Center for Integrative Medicine, directed by Dr. Andrew Weil. He maintains a private practice, provides consultation and training internationally, and is the author of a number of groundbreaking works on sleep, including Healing Night, and with Dr. Andrew Weil, Healthy Sleep. Visit his website at http://drnaiman.com.

“Poetry is the response of our innermost being to the ecstasy, the agony and the all-embracing mystery of life. It is a song, or a sigh, or a cry, often all of them together.” — Charles Angoff (Lerner, 1994)

Message Board

Medication Update
Cephalon, Inc. is planning the market launch of Nuvigil® (armodafinil) in the third quarter of 2009. Nuvigil®, a longer-acting formulation of modafinil (the active ingredient in Provigil®), was approved by the FDA in June 2007 for treatment of excessive daytime sleepiness associated with narcolepsy, sleep apnea and shift work sleep disorder. The company held off bringing Nuvigil® to market in order to research it potential for treating bipolar depression, cognition associated with schizophrenia, excessive sleepiness in medical conditions such as Parkinson’s disease, and fatigue in patients who are being treated for cancer. Patients may obtain additional information and sign up for email updates on Nuvigil at www.nuvigil.com.

Dream Quilts
Dream Quilt creator Michelle Hemingway reminds us that there are six dreams quilts available upon request for display in your community to raise awareness of sleep and sleep disorders.

Contact the NN office for additional information and to make arrangements.

We’ve moved!
Please make a note of our new street address:

110 Ripple Lane

All else remains the same.
New DNA Technique Furthers Narcolepsy Research  continued from page 2

differences that have a huge probability can be considered “real” and thus a very large number of patients must be included.

The First Genome-Wide Association in Narcolepsy: CPT1B and CHKB associated with susceptibility to narcolepsy

In this study, the group led by Dr. Tokunaga tested approximately 300,000 markers markers (the maximum using an older platform for genome-wide association) in 300 cases and 300 controls using this technique. As expected they found an enormous effect in the HLA region on chromosome 6 (p<0.000000001), reflecting the DQB1*0602 association and demonstrating that the HLA gene has the strongest genetic effect for narcolepsy when compared to all others. Of note, however: as 300,000 comparisons were made, it was necessary to divide the original probability by this number to see the real probability, which even for HLA is just barely significant, and thus confirmed. In addition to these effects, they found many other more modest “suggestive” effects, and, to see if any were real, these DNA changes were checked again in a separate sample of 159 Japanese narcoleptic individuals and 190 Japanese controls. One of the DNA changes was found to still be significant in this separate sample, and overall increased the probability of having narcolepsy by 79% (versus more than 400% for the HLA DQB1*0602 marker…). The Japanese researchers next contacted the Stanford group and we replicated the DNA change study in Koreans and Caucasians. We found that the same DNA change indeed predisposed to narcolepsy in Koreans, but not Caucasians. The fact that the effect was NOT found in the Caucasians could be due to the fact that the DNA change was very rare in Caucasians (only 5% of the population versus 17% in Japanese and Koreans).

What does that mean for patients with narcolepsy?

First, this DNA change CANNOT be used to diagnose narcolepsy even in Asians (it is very rare and has no effect in Caucasians). Indeed, the large majority of Japanese subjects with DQB1*0602 AND this DNA change still don’t have narcolepsy (maybe 1/300 instead of 1/500 for DQB1*0602 positivity). What is interesting about this discovery is that it may point to a new way to study the cause of narcolepsy. Indeed, the DNA change does not seem to modify gene activity for genes of the immune system like HLA does. Rather, it affects the activity of two metabolic enzymes (enzymes are proteins produced to carry out chemical changes in the body). One of them, CPT1B, is involved in fat metabolism and energy transfer in mitochondria in cells. The other, CHKB, is involved in the metabolism of a chemical called choline, a precursor of the important neurotransmitter acetylcholine, a well known chemical in the brain that regulates REM sleep. Now researchers can look at these metabolic pathways in narcolepsy and try to see what is abnormal about it, and maybe try to correct it. We have to go back to research.

Only the Beginning!

Before doing this, however, patients should know that several other such Genome-Wide Association studies in narcolepsy-cataplexy are ongoing, one at Stanford, where we have already studied about 800 patients and 1000 controls (a much bigger sample than the Japanese sample, thus giving more definitive results), and one in Switzerland, where the sample is smaller but growing. We are currently analyzing the data, and excitingly, have much stronger results than the Japanese group in a different gene. Clearly, this area of study is going to help us to finally answer the question.

New: Chicagoland/Midwest Narcolepsy Support Group  continued from page 9

Support Group now meets every month; we have just started rotating between Saturday mornings and Thursday evenings. The group size differs each week but it is always very diverse. Our group includes moms, dads, spouses and children of PWN, and, of course, PWN young and old. It is amazing to be able to connect with other people each month and share things that you may not share with those in your daily life because you are fearful that they will not understand. At our last meeting, in January, Dr. Ristanovic, director of NorthShore’s Sleep Center, talked to us and answered questions about the types of medications used to treat narcolepsy. Many members also contributed to the discussion by sharing their experiences with different medications. It was nice to hear how others were able (or not able, in some cases) to adapt to a medication and its side effects in their daily lives. Being able to share your joys and trials with other people who better understand and are able to relate to what you are going through can definitely make you feel better. In the past couple of weeks I have been talking to PWN that I have meet on Facebook who may join the support group and the more I talk about this group of people the more excited I feel.

In the future we hope to host guest speakers to help guide our group meetings on topics such as mental health, legal issues, workplace problems, educating family and friends, fostering our creative sides, and how we can incorporate healthy habits into our everyday lives. We hope the support group will become another form of treatment for people in the area who live with narcolepsy (and educate those who live and work with them).

The Chicagoland/ Midwest Narcolepsy Support Group meets every month for one and a half hours. We would love to see new faces and everyone is welcome. Please feel free to contact me at sdidavide@hotmail.com or Loretta Smith at LSmith@northshore.org for additional information.
New DNA Technique Furthers Narcolepsy Research continued from page 12

of what causes narcolepsy, whether autoimmune or not, and possibly to devise new therapies.

I would like to take this opportunity to ask any interested narcolepsy-cataplexy patients to contact Mali Einen at 1-650-721-7550 if they are willing to donate a blood sample for a Genome-Wide Association.

Once we have solved narcolepsy-cataplexy, we will be also be able to see what overlap there is in the cause of narcolepsy without cataplexy, and move on to study this other important subgroup using the same technique.

Once in a lifetime, a technique such as Genome-Wide Association comes along and can make a big difference in understanding the causes of many human diseases. Patients should however know this is only the beginning, as soon, we should be able to entirely identify all DNA changes in each individual, thus having more and more precision in identifying genetic factors associated with diseases. As explained above, however, this will also mean more comparisons, and thus we will need even bigger numbers of patients to make sure the findings are real. As never before, researchers will need the help of all patients to make progress in the understanding of their problem.

NN Founder Niss Ryan Elected Trustee Emerita continued from page 9

The Board will miss many of Niss’ other qualities: her professional standards, her self-discipline which always ensured her “work” was done on time, her ability to cooperate with all kinds of people, the special flexibility which allowed her to change her mind, adapt a program or take the best she could get at the moment and go forward from there. She knew how to learn from the recorded experience of others and even though she did not experience, for instance, a symptom of narcolepsy, she understood it and could transmit that knowledge accurately to others.

The narcolepsy community owes a great debt to Niss. Without her guidance and work, it would not be where it is today. As a volunteer she gave 32 continuous years of service to our movement: 10 with the ANA and 22 with the Network.

Her plans for the future include spending more time with husband John at the couple’s condominium in Puerto Vallarta, working with digital camera art and enjoying her three children, grandchildren and great grandchildren.

Save time and postage. Register online at www.narcolepsynetwork.org!

YEAR 2009 INDIVIDUAL MEMBERSHIP FORM

Name: ___________________________________________________________ Date: __________________________

Street Address: __________________________________________________ City: ___________________________

County: ________________________ State: ______________ Zip +4 Code: __________________

Telephone Home: __________________________ Business: __________________________ Cell: __________________________

E-mail*: __________________________ Fax: __________________________ Age** (opt’l) _______

*For privacy and to avoid blocked emails, we recommend providing a non-work email address.

** Helps us match members looking for one-on-one support.

How you would like to receive the quarterly newsletter: _____ postal mail OR _____ email attachment (PDF)

I _____ do _____ do not wish to receive email from Narcolepsy Network.

New members: How did you hear about us? __________________________________________

Winter 2009
**First Annual WAKE UP NARCOLEPSY Golf Outing**

*When:*  
Tuesday, May 19th, 2009  

*Location:*  
Wachusett Country Club  
(http://wachusettcc.com/)  
187 Prospect St.  
West Boylston, MA 01583  

*More information:*  
Contact Kevin Cosgrove  
Email: kcosgrove@wakeupnarcolepsy.org  
Tel. 617-935-2211  
Website: www.wakeupnarcolepsy.org  

NN is excited to be working with MA member Kevin Cosgrove, founder of the nonprofit *Wake Up Narcolepsy*. Kevin’s goal is to raise funds for public education and scientific research. Spread word of this inaugural event to family and friends and join Kevin and members of NN’s Board of Trustees for the day! Never played golf? This is your chance (and ours!) to find out what it’s all about in an accommodating, supportive setting.

2009 INDIVIDUAL MEMBERSHIP DUES  
_____ new _____ renewal  
_____ $35 - 1 Year Member _____ $150 - 5 Year Member _____ $750 - Lifetime Member  
_____ $__________ Complimentary: Please include me as a member, although I can’t pay all or any annual dues at this time, for the following reasons: ____________________________________________________________________________________________

_____ DONATION: I have included an additional donation of $__________

_____ PLEDGE: I wish to pledge an annual gift of $__________ to be paid with the enclosed amount and three (3) more quarterly installments of $__________ each. (Reminder notices will be sent).

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Narcolepsy Network, Inc. • 110 Ripple Lane • North Kingstown, RI 02852.

Forms with credit card payments may be faxed to (401) 633-6567.

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**Professionals, Organizations, Sleep Centers:** Please visit our website for information on Professional Membership.
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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.

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