WE NEED YOU!

Network Volunteer Opportunities

By Sharon D. Smith

At its meeting in Dallas this past October, our Board of Trustees devoted a significant portion of the meeting to appointing Committees and discussing goals for each Committee over the coming year. Throughout this process, it became increasingly clear that we cannot hope to realize our visions for the Network and its members unless our Committees recruit talented individuals from our general membership to help. In fact, until every member feels connected in a meaningful and fulfilling way to our organization, we have not made the most of our ‘Network’.

A few of our Committees need individuals with specific skills. For instance, our Website Committee needs volunteers familiar with HTML. The Fundraising Committee needs the help of members who have grant-writing experience. Other Committees, such as Membership and Support, need people with more general skills, e.g., individuals who enjoy meeting and communicating with new members and/or PWN experiencing specific problems. There are unlimited opportunities on the Public Education/Outreach Committee, from local speaking engagements and TV/radio interviews to writing articles for local publication, visiting area schools and distributing educational material. In particular, our Newsletter Committee needs people to develop content, write and coordinate articles, con-

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Narcolepsy without Cataplexy; CSF Hypocretin Findings

Collaborating researchers from several Universities throughout Japan studied the cerebral spinal fluid (CSF) samples of patients diagnosed with narcolepsy without cataplexy according to the International Classification of Sleep Disorders. The goal of the study was to evaluate the CSF hypocretin values and their relationship to clinical characteristics of these patients.

Of the seventeen patients that were evaluated, only five had markedly decreased CSF hypocretin levels. The remaining 12 patients’ hypocretin levels were normal. Of the five patients with hypocretin deficiency, MSLT REM latency was significantly shorter and the age of onset was significantly younger when compared to the 12 with normal levels. All five of the hypocretin-deficient patients were HLA positive for DQB1*0602, whereas only 33.3% of the patients with normal hypocretin were positive.

The conclusion of the study was that some patients diagnosed with narcolepsy without cataplexy are hypocretin-deficient and the measurement of CSF hypocretin levels is helpful in identifying such patients. Cases of narcolepsy without cataplexy have been thought to have a variety of underlying causes whereas narcolepsy with cataplexy is a more uniform entity.

Primary Hypersomnias and Adult ADHD

Researchers at Leiden University Medical Center in the Netherlands administered the Epworth Sleepiness Scale (a measure of daytime sleepiness) and the ADHD rating scale to a study group consisting of 61 adults diagnosed with narcolepsy (PWN), 7 diagnosed with idiopathic hypersomnia (PWIH) and 61 patients diagnosed with adult ADHD. Test scores indicated that almost 19% of patients diagnosed with N or IH met the criteria for adult ADHD. Meanwhile, only 77% of the ADHD patients met the criteria for adult ADHD.

Excessive Daytime Sleepiness was considered to be present in study participants who scored 12 or higher on the Epworth Sleepiness Scale. More than 37% of those diagnosed with adult ADHD scored 12 or above, while 95 percent of PWN/IH group scored 12 or higher. A correlation was seen in the Epworth and inattention scores of the ADHD group. Further research is needed to explore the underlying reasons for the overlap in test scores. Possibilities include mistaken diagnoses, sleep problems specific to ADHD, sleep disorders or sleepiness contributing to ADHD symptoms, validity of these self-assessment tools and whether the disease processes of the separate conditions is similar.

Altered Skin Temperature Regulation in Narcolepsy Relates to Sleep Propensity

In healthy subjects (without narcolepsy), sleepiness increases when extremity skin temperature increases relative to the core body temperature. The increase in temperature is due to increased blood flow in the skin of the extremities and is, among other factors, controlled by the hypothalamic circadian clock, as is sleep itself. Because narcolepsy is characterized by hypothalamic alterations, researchers from the Netherlands studied skin temperature in narcoleptic patients in relation to their characteristically increased sleep propensity during the day.

Extremity skin and core body temperatures were measured during a Multiple Sleep Latency Test, allowing for temperatures to be studied during wakefulness, at sleep onset and during sleep. Study subjects included fifteen unmedicated patients with narcolepsy and fifteen controls. Studies showed that throughout the day narcolepsy patients, when awake, had higher extremity and lower core body temperatures than controls. Once asleep, narcoleptics maintained their elevated extremity skin temperatures while their core body temperatures increased to normal levels (that of controls). These studies are the first to demonstrate the dramatic alteration of daytime skin temperature control in narcolepsy. Even awake, narcoleptic patients have higher skin temperature than healthy controls achieve during sleep. This observation suggests that hypocretin deficiency in narcolepsy affects skin temperature regulation. Skin temperature control might ultimately even have therapeutic implications for the alleviation of narcoleptic symptoms.

Seeking African American Subjects for Narcolepsy Research

The Center for Narcolepsy at Stanford University is conducting a study in African Americans diagnosed with narcolepsy. Patients may or may not have cataplexy. We will ask participants to complete questionnaires, provide a blood sample for HLA typing and copies of their sleep related medical records. In some cases we will fly subjects to Stanford for further testing.

Please call for more information: 800-497-5337
A Word from Our Executive Director
By Eveline Honig MD, MPH

It has been a very busy fall with several sleep conferences now behind us.

In the next newsletter we will share more about our Annual Conference in Dallas. I can say that it was a very warm and invigorating experience. Even though I’ve heard so many touching stories through the years, I was still moved to tears many times during the conference. For many people, I know the Conference is a “life-changing” experience and everyone goes home with a very rich weekend behind them.

We have a very exciting year coming up. We will be focusing more on support groups; some of our thinking about support groups is presented later in this newsletter.

As a member of the National Sleep Awareness Roundtable, we will support a new Sleep Awareness effort being planned for National Sleep Awareness Week, which takes place next year in early March. Plans are also underway to launch an updated 2007 Narcolepsy Awareness Campaign of our own during the same week. In June 2007 we will present at the annual meeting of the National Association of School Nurses in Tennessee, on “How to Help a Sleepy Child Learn”. We are very pleased to have this opportunity to speak to school nurses about narcolepsy and related sleep disorders in school age children and feel that this will have a big impact because school nurses are on the “front line” with respect to overcoming problems that children with narcolepsy face.

Enjoy the Holiday season and remember us in your charitable giving.

(Dr.) Eveline Honig

Importance of Sleep Hygiene and other considerations in the narcolepsy patient’s overall treatment  By Mali A. Einen

Anyone with narcolepsy knows that disorders of sleeping and waking lead to a lowered quality of life and reduced personal health. Although good healthy sleep habits and other behavioral changes will not make one’s narcolepsy disappear – healthy choices in general can have positive effects.

Living successfully with narcolepsy or other disorders of excessive sleepiness involves more than just getting diagnosed and treating the symptoms with appropriate medications. Overall healthy life choices and good sleep hygiene can help make the difference between success and barely getting by.

What exactly is good hygiene? There are generally accepted practices of good sleep hygiene that for the most part apply to everyone, including people with narcolepsy. There are other practices that warrant modifying due to the unique nature of narcolepsy and other disorders of excessive sleepiness. Below I will address good sleep hygiene practices with emphasis on the differences in narcolepsy.

Only use the bedroom for sleep and sex — Although people with narcolepsy can arguably sleep “all the time”, staying in bed after waking from a nap or lounging in a reclining position all day will lead to one sleeping more than they actually need. In general people with narcolepsy rarely need more than a normal amount of sleep in a twenty-four hour period of time. Because the sleep in narcolepsy is fragmented, getting a consolidated 8 hours of sleep at one time is nearly impossible. Newer medications approved for narcolepsy can help regulate fragmented sleep. Whether one is taking the newer medications or not, time in bed should be limited to sleep and not used for watching TV, reading or serial napping.

Maintain a regular bedtime, nap and wake time — “Regulating sleep and sleeping consistently at the same time every day along with pharmacological treatment is as important to people with narcolepsy as the population in general,” according to Dr. Emmanuel Mignot. Being disciplined about sleep and wake times can be difficult... much like following a diet. It may take a lot of work but the effort should be rewarded. In addition to feeling better, sleep and wake times should become more predictable. A person’s daytime sleepiness will not go away, but if it occurs consistently at the same time of day, schedules can be planned allowing for more productive wake times. One of the difficult aspects of narcolepsy is the unpredictable nature of sleepiness. Again, medications can help but disciplined sleep and wake schedules and nap times can make overall management of sleepiness more predictable. In cases of narcolepsy without cataplexy and idiopathic hypersomnia, often getting light exposure upon first waking can help with wakefulness. Twenty minutes in natural light or with a light box immediately after waking can help set and maintain your circadian clock.

Naps — Typical sleep hygiene will encourage avoiding naps. In narcolepsy naps are often quite helpful if not neces-

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WE NEED YOU! Network Volunteer Opportunities (continued from page 1)

duct interviews, design graphics and edit copy. We will match your skills and interests to our needs. All assignments can be done from home; you set your own hours.

If you have time to spare, whether it's one hour per week or a block of time during the month or year, please give it a try. There is nothing to lose, yet so much to gain. In return, you will likely find great satisfaction in helping others, gain new friends, add new meaning to your life, and build your self-esteem.

I recently read that Habitat for Humanity draws many of its vol-
unteers from the disabled population. The article mentioned that one of their volunteers in Hawaii has narcolepsy. Like me and many of you, having a career sidelined by narcolepsy doesn't mean we've exhausted our usefulness. Narcolepsy Network may not offer its volunteers physical exertion, but we are about build-
ing just the same … building and empowering a community of people to be the most we can be.

To volunteer, write to us at info@narcolepsynetwork.org or call us at 1-888-292-6522.

Above and Beyond (continued from page 1)

program. It was after flying over 700 hours as a jet fighter pilot that he consulted the squadron’s physician one day about some unusual occurrences. His doctor replied that it was “sleep paralysis” and that Charles probably had narcolepsy. He often recalled that it was a rather scary name, but the doc-

tor was so nonchalant that he was rather unconcerned and he went back to flying until the Navy decided to send him to Bethesda, Maryland for further testing. He had four months left of his four year tour of duty when testing proved positive. Rather than discharge him, the Navy returned him to active duty at the Pentagon.

While in Washington, D.C., he was contacted by some of his old friends who asked him to help them organize a play. Charles suggested they create a musical review patterned after the Princeton Triangle Club shows which he had participated in while in college. They elected him President, he named the organization “The Hexagon Club” (which meant twice as much as triangle), wrote much of the music for that first show of pure fun and nonsense, and managed to raise a little money for cancer. Now, 50 years later, The Hexagon Club's annual “pun” musical is one of the most looked forward to non-profit events in Washington, D.C.

Charles worked in the Marshall-Ilsley family banking business in Milwaukee for several years following his discharge from the Navy, but realized that the eight-hour work day wasn’t easy and that banking therefore wouldn’t hold his interest as a career. He had always wanted to teach so entered the teaching profession which he said never bored him for a minute. It also allowed him the ability to nap after school and mid-afternoon which was much more compatible with narcolepsy. A true educator at heart, he often said teaching first grade students to read was one of his most rewarding life experiences. He ultimately built and became Headmaster of his own elementary school on a 120 acre farm he owned near Rochester, Michigan.

Charles was generous in many ways to his narcoleptic family.

When the American Narcolepsy Association filed bankruptcy, he could not understand why the organization's members had not been informed of the situation and felt the newly elected Directors had been unfair to all the little merchants listed in the bankruptcy papers. He personally and quietly paid each and every merchant account. Recognizing the need, and at his suggestion, he also funded a face-to-face Network Trustee meeting for an entire weekend at a very special place known as Festival Hill in Round Top, Texas, where the Board could work long hours without disruption. When asked to contact Network people who needed someone with whom to talk, he always responded and often befriended those he telephoned. When called upon for advice or assistance he never said “no,” and frequently used his administrative ability to help the Network untangle problems not only with his trained professional mind, but also with his heart. He never let a note or letter (no matter how small) go unanswered, always returned a call, and to all who knew him possessed those uncommon virtues of an old-fashioned conscience with integrity and character.

During his whole life, music was very important to Charles. He played the piano, and sang during college with The Princeton Triangle Club. During his last illness, it was his music which brought him much comfort. But above all else, it was about more than just the same … building and empowering a community of people to be the most we can be.

To volunteer, write to us at info@narcolepsynetwork.org or call us at 1-888-292-6522.
Excessive Daytime Sleepiness (EDS) is a symptom of numerous sleep disorders. While the patient's history, presentation of symptoms and their frequency can help a physician narrow down the likely causes of EDS, a sleep evaluation consisting of overnight polysomnography and a Multiple Sleep Latency Test (MSLT) is advisable and almost always necessary to confirm a suspected diagnosis. Even when the patient presents with cataplexy, which is the only symptom that is diagnostic of narcolepsy when occurring in patients with EDS, overnight monitoring is still needed to check for co-existing sleep disorders such as sleep apnea, which occurs more frequently in narcoleptics than in the general population.

Idiopathic hypersomnia is a diagnosis of exclusion. In laymen's terms, it translates to 'EDS with no known origin'. It is given to patients with EDS who do not meet the diagnostic criteria established for narcolepsy or any other sleep disorder, and in whom other causes of sleepiness such as thyroid problems and sedating medications have been ruled out as the cause of their EDS.

The latest diagnostic criteria for narcolepsy established by the American Academy of Sleep Medicine include an MSLT that shows an average length of time to fall asleep that is eight minutes or less, with demonstration of REM sleep in two or more naps. Prior to testing, REM may not be seen in any of the naps — and also, such can occasionally occur on a given day by chance even in narcoleptics with cataplexy. I also have seen a few patients with definite narcolepsy who had severe anxiety or panic disorders to the point that they did not fall asleep quickly in any of the naps!

The new criteria for idiopathic hypersomnia include the same short average latency to sleep (eight minutes or less), but with REM sleep noted in fewer than two naps.

It is important to stress that these criteria are not at all diagnostic of idiopathic hypersomnia. While idiopathic hypersomnia certainly does exist, it is not nearly as common as we once thought. In fact, a large percentage of patients who are given that diagnosis instead have subtle breathing abnormalities in sleep, such as upper airway resistance syndrome or UARS, as the entire cause of their sleepiness.

UARS involves continuous but successful struggling to maintain air exchange through a narrowing upper airway. While patients with UARS may never stop breathing, their increased work of breathing causes daytime sleepiness. In fact, one study found that patients with UARS are as likely to fall asleep at the wheel as are patients with sleep apnea!

UARS occurs in patients of all ages. It is quite common in young women who are not obese, and it frequently afflicts children. Loud snoring is often not present in UARS, and this diagnosis is easily missed by conventional sleep monitoring techniques since pauses (apneas) or reductions in depth of breathing may never be noted.

I would urge all patients who are given a diagnosis of IH to ask their sleep medicine physicians whether UARS was excluded as a possible cause of their sleepiness: ideally, prior to institution of any treatment attempts. Such is vital, since UARS is easily treated in nearly all cases without chronic medications.

Beyond the objective sleep study results, there are certain characteristics of sleep that often differ in the two disorders. Fragmented sleep at night is more common in narcoleptics, and patients with idiopathic hypersomnia are usually more prone to sound sleep and difficulty awakening. Naps are more likely to be refreshing in narcoleptics. There are exceptions to the above comments, though, and these characteristics do not reliably distinguish between the two disorders.

The diagnoses of narcolepsy and idiopathic hypersomnia are, by definition, mutually exclusive. It is possible, however, for a diagnosis of idiopathic hypersomnia to be revised to narcolepsy at some later time when cataplexy develops or a follow-up sleep evaluation satisfies the criteria for narcolepsy.

While there are differences, people with narcolepsy can easily relate to the symptoms of idiopathic hypersomnia and vice-versa. Both groups have similar issues and can benefit from the same support systems, particularly since many of the same medications are used to treat EDS in both disorders.

Dr. Clark, a member of NN's Medical Advisory Board, is the Medical Director of the Columbus Community Health Regional Sleep Disorders Center in Columbus, Ohio. He also maintains an award-winning website at http://www.thesleepsite.com.
Support groups are so called because they are groups formed to provide support to individuals in need. For many people with narcolepsy, participation in a support group provides their first contact with others with narcolepsy.

Our organization, Narcolepsy Network, was originally formed to provide structure for local support groups. After twenty years, we have learned this is more difficult than it first appears. There are currently a number of support groups throughout the country that are associated with us, but not actually part of the Network. We provide support for these groups in terms of information and printed materials. I have even spoken to several groups, but speaking to all is proving to be a Herculean task.

We would like to see this area continue to grow and expand in the coming years. To that end, we would like to support the growth of local groups by both helping to set up new groups and to help to maintain and grow the membership of existing groups. There are three things that we can do to help you. First we can offer training for support group leaders; second, we can help you to identify funding sources, including advice on grant applications; and finally, we can assist you to identify speakers and provide information about different activities that encourage interchange of information among members.

Being part of a support group or leading a group is often a very rewarding experience. Most of those attending for the first time are newly diagnosed and have been directed to your support group by their doctor. They are eager to find out everything they can about narcolepsy and to meet others who have lived with narcolepsy. They frequently have questions about the different medications, the latest research, and what to expect as they get older. Your existing members are more concerned about the psychological and social issues associated with work, school, and interpersonal relationships. When parents, partners and/or friends join, they too have many questions and need support in their roles as caregivers.

There are some basics you must address before you begin to contact local persons with narcolepsy (PWN). First, you need a location. If you are planning a meeting for a region of your state or county, the meeting place needs to be centrally located with ease of access to freeways and/or public transit. It also needs to be in a safe location. If you are meeting at night, the parking area needs to be well lighted, and security officers are a welcome bonus. The room should be comfortable and relatively quiet, such as a hospital conference room or a local library meeting room. Hopefully, this room will be available on the same day/night of the month, every month, and at the same time.

Once you have the location, you need to determine the day and time of the meeting. If you are meeting in a public building, others will be competing for this same space. If possible, you need to be able to ask for the space every month, on the same day and at the same time. If you are using public facilities, you must remember that most holidays fall on Mondays, and most public buildings are closed Sundays, many on Saturday as well. Weekends are difficult because of family activities, Friday night begins the weekend, so you are down to Tuesday, Wednesday or Thursday, probably evenings. Why evenings? Most people work during the day, and if they aren’t working, their driver may be. If your meetings are held consistently, i.e., the third Wednesday of the month, it is easier to remember. The meeting time should allow time for those working to get to the meeting site without having to leave work early. If you can find a meeting location with a restaurant or coffee shop close by, then you can encourage your members to stop for dinner before the meeting. Let’s face it. If you have worked all day, then fought the commuter crowds to get home, how likely are you to go out again? Two hours is a good target time. The length of your meeting may be determined by outside forces, such as the closing time of the library, etc. In general, people have an attention span of about 50 minutes. For PWN, after a day of work, two hours is more than enough. To try to keep your members awake, snacks and drinks will help. Again, this will be controlled by the location of the meeting. If there are food and drink restrictions at the ideal location, you may want to keep looking for a more suitable meeting place.

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To start and to continue a support group successfully is not easy. It is important to have more than one leader, as there is too much to do for one person to be able to do it all successfully. Each meeting requires an agenda or program of some type in addition to the notification process. Today you will be able to contact many of your members by email, which will save postage and mailing costs, as well as time. Regardless of how you do it, every member needs to be notified of every meeting. Getting the word out to the public about your support group is also very important. You should attempt to get the cooperation of doctors who treat people with narcolepsy, place announcements in local papers or even on a local radio station about upcoming meetings, place notices on bulletin boards for libraries or colleges, and ask your members to talk to others about the meetings.

There are basically two types of support group meetings — informational updates and individual sharing. Your membership should be informed of the type of meeting you will be holding. One specific topic or speaker can significantly increase the attendance.

It is good to have speakers regularly and many health care providers are happy to share their expertise with a group. Your local pharmacist may also be willing to speak to your group about over-the-counter medications and their interaction with prescription medications. A support group meeting without a speaker should still have a discussion topic listed or announced. Often there is a lot of frustration with medical providers or disability reviewers. Many people find it a tremendous relief to know that many others with narcolepsy struggle with the same issues.

At any support group meeting it is important that everyone has a turn to talk and share their concerns and issues. It is very important to have a facilitator, someone who makes sure that the meeting runs smoothly. Every group will have people who talk too much, people who are too shy to talk, and people who are too negative. The facilitator will gently stop the person who talks too much, invite the shy person to answer a question, and steer the negative person in a more positive direction. Groups may choose to talk about realistic issues and expectations, but these do not have to be negative. An efficient facilitator can guide the meeting effortlessly.

Membership retention is one of the more difficult aspects of managing a support group. Many individuals come to support groups initially to learn about their condition. After a few meetings, they find their need for information satisfied and begin to think they no longer need to attend support group meetings. This is not the case. Once you become part of a group, your presence is always needed. You may know a lot about medications, side effects, work related problems etc. This information is important to other members of your group. Once upon a time you came to a meeting to gain knowledge, now it is time to share that knowledge with others. It can be very rewarding to be a positive influence by showing others that you can have a fulfilling, high quality life and still have narcolepsy, and sometimes it is just nice to visit with your friends that also have narcolepsy.

As you can see, there are many things to consider when you begin to plan a support group. Narcolepsy Network does have a Support Group Manual available at the office, for those of you who are committed to starting a group. We at the Narcolepsy Network hope to be able to give leaders more help in the near future with respect to many of these issues.

**Nuvigil Update**

In a Dec. 7, 2006 news release, Cephalon announced that final FDA approval of Nuvigil (armodafinil), originally anticipated by December 31, 2006, may be delayed due to a labeling issue. The FDA is continuing to evaluate the one case of serious rash that was reported in a clinical study of Sparlon, another modafinil formulation, in order to establish more complete safety information to be included in the Nuvigil product labeling. Sparlon was developed to treat ADHD but failed to receive FDA approval due to safety concerns.

Nuvigil is a single-isomer formulation of modafinil, the same active ingredient contained in Provigil. Cephalon has applied for FDA approval of Nuvigil for the treatment of excessive daytime sleepiness associated with narcolepsy, obstructive sleep apnea, and shift work sleep disorder. Clinical studies showed that Nuvigil stays in the bloodstream longer than Provigil, providing a longer period of action. In clinical trials, NUVIGIL was generally well tolerated, with a safety profile consistent with that observed in studies of PROVIGIL. The most common adverse effects observed included headache, nausea, dizziness, insomnia and anxiety.
Kailey is Sleeping. By Michele Profeta

Kailey is sleeping. She looks peaceful, ethereal, as a fine white line from the light through the window above her outlines her lovely features. It is a soothing sight to see her resting, but I am not fooled. I know beneath the pillow, Narcolepsy waits with claws poised. This monster is no stranger; we know him well. He entered my child’s room 5 years ago with the intent of gobbling up any and all of the ease and pleasure of an 8-year old’s childhood. He chose the wrong girl! Kailey, with the zest and resolve of a superhero, has been battling back. It has not been easy. Kailey told me recently, “I wish I could give my life to someone else, just for a few days, so I could have a break from it.”

Kailey did once possess that carefree life she covets, but it ended shortly after her eighth birthday, in the summer of 2001. Kailey had responded with a sparkling, “Yes!” to almost every flyer announcing summer activities that came our way. However, by mid-July she was literally on the floor. I remember us walking in the kitchen door and having her drop in front of me to sleep, unable to go another step. With siblings and visiting cousins jumping and playing around her, Kailey, usually the liveliest, was asleep. Why? That summer Kailey had asked the swimming instructor to show her a racing turn because she wanted to join a swim team, but I watched her put her elbows up on the side of the pool and put her head down to sleep after only a few strokes. Was this Kailey? Why was she asleep in the car before we got to the end of our street? She had not done this, even as a toddler. Why now? The sleepiness was the first symptom of narcolepsy to appear.

Maybe we would have considered one doctor’s assessment that she was simply “over committed”, but other dramatic changes were rapidly occurring. Although Kailey seemed so tired that she needed these daytime catnaps which, oddly, never lasted more than 15 minutes or so, nighttime came, and Kailey spent most of it awake. Even when we accomplished the nearly impossible task of keeping her from napping during the day, as the doctors suggested, she still could not stay asleep. Nights became hellish. Not only was this little girl exhausted and craving sleep that would not come, but now when she put her head on the pillow and closed her eyes, terrifying dreams would begin. Being still partially awake, the dreams would take center stage in the middle of her room. This is a symptom of narcolepsy called hypnagogic hallucinations that is actually REM sleep happening too early in the sleep cycle. The dream starts while the person is still awake. Without this understanding that first summer, we were all terrified.

Then Kailey began having tantrums. Maybe it was the extreme lack of restful sleep. Maybe it was due to the diminishing of the neurotransmitter, hypocretin, that we learned is responsible for controlling sleeping and waking and contributes to other brain functions as well. Narcoleptics have lost the cells that make this chemical. This raging child was not the sweet, delightful girl we’d sung happy birthday to just weeks before. What was happening to Kailey? Surely, the doctors could now see that she even LOOKED different. Suddenly and rapidly, she began to gain weight. Having been 66 lbs on her birthday in June, she was 100 lbs. by Thanksgiving. In two years, she gained 85 lbs. We were told this was normal growth. How could this be normal? In fact, almost nothing was normal for her anymore. Even laughing was a big problem. When she was laughing or excited, her head would drop, her tongue would curl, she couldn’t speak, and her knees would buckle. She looked drunk. This is a scary and dangerous symptom of narcolepsy because people experiencing complete cataplexy lose muscle control and collapse. Laughing or any extreme emotion can trigger a REM sleep response that causes the muscles to relax, like in sleep. In just a few weeks time, Kailey displayed all of the symptoms of narcolepsy.
Narcolepsy: excessive daytime sleepiness, fragmented nighttime sleep, hypnagogic hallucinations, cataplexy, and sleep paralysis, which is the inability to move upon falling asleep or waking. Kailey’s little self was in chaos.

Summer vacation ended. My three children slipped on their backpacks to start a new school year. How could I let Kailey go? She had danced off to kindergarten, first grade and second grade, bright eyed and eager. Now, she stood for a back to school photo, foggy-eyed, slurring, puffy and exhausted. Narcolepsy was smashing on top of her, and still no doctor could see it. We had sought out intelligent, caring doctors, but the unfortunate fact is that narcolepsy is misunderstood in the medical community. Little time is spent on it in medical schools.

No one was suspecting narcolepsy, especially in a child. When no blood test or physical exam revealed an abnormality, it was concluded that she was having behavioral issues, depression, perhaps. Behavioral? Why would the girl who had just won the school recitation contest in May decide to slur her words in July? How could she make her tongue curl like that? This was absurd to me. One doctor said, “You have a healthy girl here. Maybe that’s just her new thing, letting her tongue hang.” These new doctors, a lengthening list of endocrinologists, infectious disease specialists, psychiatrists, and pediatric neurologists had not known the endearing, gentle Kailey that we were mourning. She would not purposely try to stay awake just to have her mother stay in her room as they claimed. Ridiculous, I thought. We agreed to treat Kailey for depression even though we doubted the diagnosis. We had to do something

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Kailey is Sleeping. (continued from page 9)

to help her. We put her on two anti-
depressants. Thankfully, the tantrums
subsided. Still she did not return to
normal like the people I knew who
were now generously sharing their
stories of depression and anti-depres-
sants with me had. “She looks like she
has cerebral palsy when she laughs”, I
told the psychiatrist. Her eyes were
cloudy, like she was not seeing us any-
more. As she got chubbier and chubbier,
she began early puberty. This was
quite upsetting for an eight year old.
It became increasingly impossible to
function on the two hours of sleep per
day she was averaging in spite of the
sleep medications we were now giving
to her. School attendance had become
sporadic, and at this point, it just
seemed cruel to send her. She began
an absence that lasted four years.

We watched Kailey withdraw, missing
Halloween and Christmas. She was
getting larger and larger and at the
same time seemed to be disappearing
from us. Frantically we searched for a
reason for why our precious Kailey was
now a very different child. I continually
scoured the Internet, at this point
focusing mostly on sleep disorders. I
had been told months earlier that it
could not be narcolepsy, but when I
found it again, I realized Kailey had
ALL of the symptoms. When I learned
that cataplexy is only associated with
narcolepsy, I was convinced. I phoned
the doctor, and an MSLT was per-
formed. No. It seemed she did not
have narcolepsy. Completely frustrated,
I called the Center for Narcolepsy at
Stanford University and spoke with
Mali Einen, the research coordinator.
An expert and patient herself, Mali told
me it sounded like a case of classic nar-
colepsy. She said to take Kailey off the
heavy doses of anti-depressants which
repress the REM being tested and
repeat the test. Also, Kailey must spend a night AND the next day
doing the sleep test. She had only
done part of it. The test was repeated
and this time the result was conclusive
for narcolepsy. Kailey has since had a
spinal puncture, which revealed that
her cerebral spinal fluid is completely
lacking hypocretin.

This absolutely confirms
narcolepsy/cataplexy.

• • •

Kailey is awake now. Having finished
a short mid-morning nap, I take her
back to school. She walks quickly with
her long hair swinging. I watch her
disappear behind the big glass double
doors of her middle school. We had
been inseparable for four difficult
years and I still feel the tug when she

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leaves. Just for a second, before I pull the car away, I catch the reflection of the bright blue sky in the glass. It is a gorgeous October day, and I am contented with the thought that the world is hers again. At age thirteen, Kailey is thriving. She is an A student, enjoying the power one feels when huge effort yields great results. She knows well that the ability to do this is a gift to be appreciated. Still there have been losses. Kailey once told me, “I feel like I fell asleep at age 8 and woke up at 12. I want to be older, but I do wish I had experienced those years.” Enduring the physical and emotional pain of a chronic illness has matured Kailey beyond many of her middle school peers. Many strenuous physical activities like cheerleading and team tennis have proven impossible. Swimming with the risk of cataplexy is uncomfortable and dangerous. She may have lost too many years to attain her dream of being an en Pointe ballerina. Fortunately, Kailey is able to take a modern dance class, an acting class, and she sings in the school chorus. Kailey’s weight has returned to normal and her green eyes are crystal clear again. There are two primary reasons why she is doing so well today. First, we found a doctor with a thorough knowledge of Kailey’s disease, and second we found Xyrem.

After we received the diagnosis, I sought help from the Narcolepsy Network. Experimenting with many sleep medications, stimulants, and anti-depressants was only making Kailey feel worse. The medications caused side effects, and she still was not sleeping! I asked who would be the most expert neurologist to treat Kailey in our area. They said David Rye MD, PHD was a world-renowned sleep researcher at Emory University, just an hour from our house. He said he would see her, even though he is not a pediatric neurologist. We felt great relief and hope from our first visit. For two years we had been trying to explain Kailey’s symptoms to doctors, and now Dr. Rye was explaining to us. Fantastic! We discussed Xyrem as a treatment but thought Kailey’s young age might prohibit using this strong medication. Fortunately, I was able to attend the Narcolepsy Network annual conference that year and meet many wonderful people with narcolepsy who warmly shared their histories with me. I heard over and over that Xyrem had been the medication that had changed their lives. Kailey is now making that claim herself!

We are so thankful for the many people who helped us through the years with encouragement, prayers, and expertise. Hopefully telling Kailey’s experience with diagnosis and treatment will reinforce the message that children do get narcolepsy, and this is what it looks like.

Importance of Sleep Hygiene (continued from page 3)

sary. Resisting naps can leave one drowsy and unclear. Scheduled short naps, 15 minutes to no longer than one hour in duration once or twice a day, are often an “important tool” of successfully managing narcolepsy. The majority of people with narcolepsy find naps very refreshing. The “trick” is to take a real nap, lying down, and get up immediately upon waking. Long naps or reclining for hours can leave one lethargic. Drowsy dozing is less refreshing. In cases of idiopathic hypersonnia short naps may leave a person feeling worse rather than better. Naps are not recommended if they are not refreshing.

Avoid caffeine, alcohol and nicotine within four to six hours of bedtime — Although many with narcolepsy can drink a pot of coffee and still fall asleep with no problem, caffeine is a drug and should be avoided in the hours before bed. Stimulants doses that are too high or taken too late in the day can also interfere with the best possible sleep at night. The goal is to set ourselves up for the best possible quality of sleep. Alcohol and nicotine not only affect quality of sleep but can affect sleep stages as well.

Food and eating before bed — While a light snack before bedtime can help promote sound sleep, avoid large meals. Recent research has shown that eating habits may have their own “circadian” rhythm. Eating late at night or even...
Alien Visit  By M. Hamilton

The positive thing about N is that sometimes it can just make you laugh. Over the weekend we bought a fan for our bedroom. I was thinking the background noise might be calming and a nice change. Well, the fan has two lights on the top, 1 green and 1 purple. This fan turned into the UFO that landed in my dream. As the dream continued, a fairly large alien emerged from the small spacecraft and walked to my side of the bed and just stood there staring at me. I became scared when the creature started talking to me in Spanish! We did eat dinner at a very ethnic Mexican restaurant last night but this is the first time I have dreamed in a different language! I was completely freaked out when I realized I could not move!

Finally, I was able to move and sat straight up in bed. I looked over, expecting the creature to be gone. Instead, my 7-year old daughter was standing there with a terrible look on her face. (I must have been looking at her like she was an alien). Usually sleep paralysis is not frightening for me because I am rarely being attacked by an alien when I figure out I can’t move. When I am not being attacked, I am able to use my brain and think myself through it: “It’s OK, your body just isn’t ready to wake up yet.”

We all survived the alien visit and hopefully tonight’s will be a better night’s sleep! If I keep getting visits, I may have to return the spacecraft. :)

Importance of Sleep Hygiene  (continued from page 11)

during the night may simply become a “habit” that needs to be broken much like the habits of poor sleep hygiene.

Other Health Concerns

People with narcolepsy are shown to have a higher incidence of sleep apnea. This may be due to several factors: sleep apnea in a person with narcolepsy is more likely to be detected because they are having sleep evaluations; people with narcolepsy tend to be heavier and excess weight can contribute to sleep apnea, and/or the loss of hypocretin may cause metabolic changes that contribute to weight gain. Keeping one’s weight down can help prevent the incidence or worsening of sleep-related breathing disorders. Sleep apnea left untreated is harmful to one’s health and must be treated before narcolepsy symptoms can be successfully treated. This sentence is bolded for the emphasis it deserves. People diagnosed with narcolepsy may need repeat overnight testing to be sure that sleep apnea has not developed over time, particularly in cases where sleepiness has worsened, significant weight gain has occurred or a lengthy period of time has passed since last being evaluated.

People with narcolepsy aren’t immune to having health problems unrelated to their narcolepsy. The following four conditions are worth asking your doctor about if lethargy, fatigue and sleepiness have worsened or aren’t improved with traditional narcolepsy treatments.

Anemia — A condition in which the number of red blood cells, or the amount of hemoglobin they contain, is low, so that they don’t deliver enough oxygen to the body’s tissues. Most common in women age 15 to 50 due to a lack of iron, most commonly caused by heavy menstrual periods but may also be caused by insufficient intake of iron-rich foods, hemorrhoids, a Vitamin B-12 deficiency or stomach ulcers.

Hypothyroidism — When your thyroid gland doesn’t produce enough hormone, your body functions at a slower rate than normal, making you feel both mentally and physically sluggish. Other signs of low thyroid include weakness, weight gain, constipation, intolerance of cold, joint and muscle pain, brittle fingernails and temporary hair loss.

Depression — Aside from depression’s obvious emotional symptoms (sadness, loss of interest in usual activities, feelings that life isn’t worth it), depression can dramatically affect the body, draining energy, even causing difficulty sleeping and dramatic changes in appetite.

Pre-diabetes or Undiagnosed Diabetes — According to the National Institute of Diabetes and Digestive and Kidney Disease, over 41 million American’s between the ages of 40 and 74 have pre-diabetes, a condition that raises the risk of not only getting diabetes but also developing heart disease and stroke. High or low glucose indicates your body is having a hard time converting food into energy, and can cause feelings of terrible fatigue. Other flags of diabetes can include constant hunger and thirst, itchy skin, blurry vision and feeling weak.
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?

2007 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).

Please make your CHECK payable to NARCOLEPSY NETWORK, INC. Mail form and payment to:

Narcolepsy Network, Inc. • 79 Main Street • North Kingstown, RI 02852. Forms with credit card payments may be faxed to (401) 633-6567.

All amounts are payable in U.S. DOLLARS by check, money order, or credit card. Funds may be sent from outside the U.S. or Canada by wire transfer. Please call for information. Narcolepsy Network, Inc. (NN) is a 501(c)(3) non-profit organization. Any donation over the amount of dues is tax deductible. NN will send a receipt for all donations. An annual report is available upon request.

CREDIT CARD payments accepted. Please provide the following:

NAME (as appears on card): __________________________________________________________________________________________

Credit card type (please circle): Visa Master Card

Credit card number: __________________________ exp. date: __________ signature: ____________________________________________________________________________
SURVEY OF INTERESTS, NEEDS AND SKILLS
(Requested of new members only, or renewing members who have not previously completed.)

We are a nonprofit patient organization, governed by and existing for our members. We wish to be an expanding network, serving present members and extending our resources to all persons with narcolepsy. Your personal interests and participation are important. Please help us by completing this brief survey.

I. INTERESTS

A. My primary interest in narcolepsy is ___ for myself ____ for a family member or friend ____ professional.

B. We often receive requests from persons with narcolepsy for names and contact information of others with narcolepsy who live in a certain area or who share a common interest.
   1) ____ You may provide my: ____ name, ____ phone number, ____ address, ____ e-mail to others.
   2) ____ Please keep my name, phone number, address, and e-mail strictly confidential.

C. 1) I presently a) ____ take part, b) ____ do not take part, c) ____ wish to take part in a support group
   2) I ____ am willing ____ am not willing to co-lead and/or assist in the development of a new support group

II. NEEDS

The greatest benefits I hope to receive from this organization are, in order of importance, the following:

1) ____________________________________________________________
2) ____________________________________________________________
3) ____________________________________________________________
4) ____________________________________________________________

III. SKILLS

Highest Educational Level _____________________________________
Main Work Experience ____________________________________

I have the following interests, experience, abilities, or professional skills in which I am willing to volunteer in order to improve our organization's network, resources, and programs on behalf of all persons with narcolepsy.

1) ____ contacting other members with important information: a) ____ telephone; b) ___ letter; c) ___ e-mail
2) ____ contacting state and federal legislators: a) ____ telephone; b) ___ letter; c) ___ e-mail
3) ____ distributing educational materials to schools, libraries, health fairs, etc.
4) ____ personally meeting newly diagnosed persons with narcolepsy
5) ____ being available for interviews by media reporters: a) ____ newspaper; b) ___ magazine; c) ___ T.V.; d) ___ internet
6) ____ writing personal and/or informative articles for: a) ____ newspaper; b) ___ magazine; c) ___ internet
7) ____ appearing to talk about narcolepsy: a) ___ schools; b) ___ colleges; c) ___ civic groups; d) ___ health care groups
8) ____ I have, from my training or experiences, professional or special skills which I am willing to provide for activities of Narcolepsy Network. (Please describe) __________________________________________________________
   a) ____ fundraising; b) ____ accounting; c) ____ legal; d) ____ writing; e) ____ graphic; f) ____ layout; g) ____ filming;
   h) ____ website design; i) ____ programming; j) ____ health care; k) ____ research; l) ____
   other: __________________________________________________________________________

9) ____ I am willing to assist these Narcolepsy Network committees and programs
   a) ____ Advocacy (tracking and assisting in response to laws and issues affecting persons with narcolepsy)
   b) ____ Conference (assisting in planning and conducting national and local conferences)
   c) ____ E-mail (receive and correspond to e-mail questions and communication from members and others)
   d) ____ Fundraising (develop and help implement local and national fundraising projects)
   e) ____ Membership (outreach to invite new members and to develop support groups)
   f) ____ N[ART] (create and contribute to artistic expressions representing narcolepsy)
   g) ____ Newsletter (writing, illustrating, printing and layout of quarterly newsletter)
   h) ____ Publications (review, write, design and plan new educational materials)
   i) ____ Website (design, maintenance, contribution to our website, and review of others)
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: 7 Greenway Circle, Syosset, NY 11791, email ssmith@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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