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On Monday, March 5, 2007, the first day of National Sleep Awareness Week, Narcolepsy Network will launch a brand new Public Awareness Campaign featuring actress Kate Walsh, from ABC's hit show “Grey's Anatomy” (Dr. Addison Montgomery-Shepherd). Three PSA versions – 15-, 30- and 60-seconds each – will begin airing on network and cable TV stations across the country and continue throughout the year.

In addition to Ms. Walsh, the 60-second version features three new stars, all members of Narcolepsy Network: Birdie Deadwiler, a member of our Board of

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Chattanooga Support Group Celebrates 20th Anniversary

By Shirley Madewell

In my fifty-two years on this earth, I've learned that we all respond to life and get through the difficult situations differently, according to what works for each person. I've met people who were diagnosed with narcolepsy who seemed to adapt pretty easily. Then there were others who struggled for months or even years trying to accept that their life was no longer the way it used to be.
Antibodies in Narcolepsy-Cataplexy Patient Serum Bind to Rat Hypocretin Neurons

For quite some time, autoimmunity has been considered the most likely cause of human narcolepsy-cataplexy, but despite numerous studies and attempts, no specific auto-antibodies or antigen(s) have yet been identified. Researchers in Denmark, Knudsen et al., report in Neuroreport 2007 finding an antibody in a narcolepsy-cataplexy patient’s blood (serum) that did bind to rat hypocretin neurons.

Although no staining was found in eight out of the nine patient samples, the serum from one narcolepsy-cataplexy patient strongly produced staining of rat hypocretin neurons. These results seem to indicate the possible presence of auto-antibodies in some narcolepsy patients.

Cataplexy during Status Cataplecticus Examined and Compared to Normal REM Sleep

A study conducted by Dorthee Chabas, MD of Paris focused on a 68 year-old woman with hypocretin-deficient narcolepsy/cataplexy, who suffered from status cataplecticus after stopping clomipramine for the control of her cataplexy. The woman underwent brain SPECT (MRI) during an episode of cataplexy. This image was compared to another brain SPECT taken during another period when she was not having cataplexy. The differences between the periods of cataplexy and basal wakefulness were evaluated.

Results showed that areas hyperactivated during cataplexy corresponded to areas that are activated during normal REM sleep – the left and right orbital cortex, the right temporal cortex and the right putamen. There was, however, no hyperactivation of the pons, amygdala or occipital cortex – as there is in normal REM sleep.

“To my knowledge, this report is the first imaging analysis comparing brain activation during a cataplectic episode with a non-symptomatic state in the same subject,” said Chabas. “Previous imaging studies have failed to show structural changes in the brains of narcoleptic patients, but functional changes could be demonstrated. The methods used in this study specifically looked at functional features related to the mechanisms of cataplexy. Capturing images of brain activity during cataplexy, a transient and unpredictable neurological state, is challenging. It is however, easier to study cataplexy during status cataplecticus.”

Italian Researchers examine Periodic Leg Movements in Narcolepsy versus in Controls and in Restless Leg Syndrome

As reported in the December issue of Sleep, Periodic Leg Movements (PLM) were analyzed during sleep in patients with narcolepsy and compared to normal controls and subjects with restless legs syndrome (RLS). Forty subjects with HLA DQB1*0602 positive narcolepsy/cataplexy, 22 control subjects and 22 RLS subjects were recruited.

Nineteen of the narcolepsy patients had a PLM index greater than 15. The patients with RLS had significantly more periodic movements at longer intervals. In both the controls and subjects with narcolepsy, the distribution of PLM’s per hour were bell shaped, whereas the RLS subjects showed a progressive decrease throughout the night.

SLEEP IN THE NEWS

French Health Minister Seeks To Study Naps

In an Associated Press article that was released January 31, 2007, it was reported that the French health minister wants to look into whether workers should be allowed to sleep on the job! Plans were launched to spend an estimated $9 millions dollars this year to help improve public awareness about sleeping troubles.

The program will include letters sent by the state-run health insurance provider explaining the importance of a good sleep. The Health Ministry’s web site offers tips on how best to get a good night’s sleep. Recommendations include cutting down on coffee, tea, colas and athletic activity after 8PM, shunning TV and working late in the evening, and listening better to the body’s own sleep signals, such as yawning.

According to the ministry, fifty-six percent of the French complain that a poor night’s sleep has affected their job performance. Health minister Xavier Bertrand called for further study and said he would promote on-the-job naps if research proved naps useful.

The French already enjoy a 35-hour work week and generous vacation allowances. Life in France certainly seems more amiable for living with Narcolepsy. Viva la France!

Disturbed Sleep and Heart Trouble go Hand in Hand, Reports the Harvard Newsletter

The connection between sleep and heart disease is a two-way street: Poor sleep can contribute to heart disease, and heart disease can disturb sleep, reports the January 2007 Harvard Heart Letter.

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Disturbed Sleep and Heart Trouble go Hand in Hand, Reports the Harvard Newsletter
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Poor sleep has been linked with high blood pressure, arteriosclerosis, heart failure, heart attack, stroke, diabetes and obesity. The thread that may tie these together is inflammation, the body’s response to injury, infection, irritation or disease. Poor sleep has been found to increase levels of C-reactive protein and other substances that reflect active inflammation. It also activates the body’s sympathetic nervous system, which responds to fright or stress.

Sometimes heart disease is a cause of poor sleep. People with heart failure may wake with trouble breathing, which stems from fluid build up in the lungs. There is also some evidence that heart failure leads to sleep apnea, causing a person to wake repeatedly throughout the night.

Interestingly, in patients with hypocretin deficient narcolepsy/cataplexy it is postulated that the absence of hypocretin may in some ways be protective for various heart problems. People with narcolepsy tend to have lower blood pressure. It was also found that levels of C-reactive protein were not high in subjects with narcolepsy despite the common symptom of disrupted nighttime sleep.

New Narcolepsy Awareness Campaign for 2007
(continued from page 1)

Trustees from Escondido, CA; professional golfer Nicole Jeray, who lives in Chicago when not on the LPGA circuit; and student Taelor Watkins, a college student from St. George, UT. We thank and applaud these members for their enthusiasm in promoting narcolepsy awareness and helping an estimated 65,000 undiagnosed PWN to identify and seek treatment for their symptoms. We also thank Jazz Pharmaceuticals, whose generous support has made these PSAs possible.

Our 2006 Campaign led to media requests from the nationally viewed “The Paula Zahn Show” and “The Montel Williams Show”, which were fulfilled by NN members Anthony Raymond (NH) and Kailey and Michele Profeta (GA), respectively. Others were called on for interviews with local TV news shows. We thank these members and look forward to an even greater number of media opportunities during 2007.

What can you do? Visit www.narcolepsynetwork.org on or after March 5 to view all three spots. This is a great time to ask family and friends to visit our website to learn more about narcolepsy. Submit an article on narcolepsy to your local newspaper, including NN’s web address. Then, call your local TV stations to ask that they air these PSAs throughout the year. Refer them to the Press Release on our website to obtain contact information for requesting the PSAs. If you plan to raise narcolepsy awareness in your local school or local area community, order PSA brochures and narcolepsy awareness wristbands on our website. If you are a patient or sleep specialist willing to be interviewed by local media, email us at narnet@narcolepsynetwork.org, including your name, full contact info and if a patient, age, a list of your symptoms and current treatment(s).

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I’m one of the latter. I didn’t take my diagnosis lightly nor did I accept that it was even authentic. I rebelled and was defiant to the point of refusing medication and was determined in my mind that I was NOT going to be a narcoleptic.

Twenty-two years after my diagnosis, and much to my dismay, I am still a narcoleptic, only now, a more well-adjusted, happy one. But my journey toward happiness was not an easy one for me or my friends and family.

A couple of things helped along the way. First, in the mid-1980s, I attended a national narcolepsy convention at Stanford University and finally got to meet the narcoleptic dogs I had heard of. Meeting them seemed to change everything for me. I was convinced that narcolepsy was a psychological problem and that if I could just get my life together, I could rise above it and no longer suffer from the debilitating symptoms of this disorder.

When I watched these dogs having sleep attacks and cataplexy over and over, I knew they were not struggling with psychological problems, but that something was very wrong inside their little bodies. It wasn’t a weakness, laziness or lack of dealing with life or emotional issues causing their symptoms, it was a neurological disorder beyond their control. Their symptoms mimicked my own. I realized then that if the dogs were not to blame, neither was I. For the first time, I began to accept my narcolepsy.

So the trip from Tennessee to California helped. And Vern, wherever you are in pooch heaven, thanks

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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
Conference on a Budget

If cost has kept you from seriously considering attendance at one of our conferences, here are a few ways to keep costs down.

Airfare: As soon as you know the conference location, look for fare sales on all airlines that service your area. The easiest way to do this is to sign up for email notifications on each of the airline’s websites. If you rely on sites like Expedia.com, be aware that some airlines like Southwest and Jet Blue are never included in the search results.

Carpooling is an option if you live in the region. Our conference committee can help you find others in your area who are planning to drive and would appreciate sharing expenses.

Ground Transportation: Consider alternatives to high-priced airport limo or shuttle services, such as public transportation or asking a friend to drop you at the airport. For instance, in the NYC metro area, it's possible to save $30 or more each way by using public transportation. A suitcase on wheels makes all the difference. We do our best to choose hotels that offer free or low-cost shuttle service to and from the hotel.

Rooming costs: Consider sharing a room with up to 3 other people to save up to 75% on hotel costs. Feel funny about sharing a bed with a “stranger”? Bring a body pillow from home to place in the middle of the bed for a more private sleeping area. Again, we can help you find others interested in sharing a room.

Meals: Your conference registration fee covers breakfast and lunch on Saturday and Sunday. If you don’t have the budget to pay restaurant prices while traveling and on Friday and Saturday nights, hotels usually have a variety of menus for take-out and delivery (pizza, Chinese food, subs, etc.). You can also bring nutritious, nonperishable foods from home. Check on whether your room has a microwave. Foods such as canned tuna, soup and fruit, sturdier fresh fruits and vegetables, and granola bars can see you through. Use the ice bucket to keep a few small items chilled.

Conference Registration: Check to see if you qualify for the low-income registration fee. (This fee covers hotel meals, speaker expenses, handout materials and coffee/tea service during the conference.) Also, be sure to get your registration in early to take advantage of the Early Bird Registration Discount.

Conference Travel and/or Registration Scholarships: Each year our corporate sponsors and a few generous members donate funds to help others in need with travel costs. The Silent Auction provides funds for Registration Scholarships. Check the conference page of our website often for the announcement of scholarship availability and an application form. If you qualify, be sure to submit the application on or before the deadline.

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buddy. You began my road to living my life fully again.

The other thing that helped was a tiny ad in the “Help Wanted” section of the Chattanooga Times in 1986 that read something like this: “Do you suffer from Narcolepsy-Catatexy Syndrome? If so, call Myra Cook at ___. I’d like to hear your story.”

I responded to the ad and went to that first support group meeting. I was completely unaware at the time, that I had just found an avenue that would facilitate a lot of healing in my life and offer a core group of friends that would eventually become like family to me.

In December of 2006, just about every one of the people who showed up for that narcolepsy support group first meeting 20 years ago, along with a myriad of others who joined the group along the way, met for a wonderful evening of celebrating 20 years being together as the Chattanooga Narcolepsy Support Group. It was a wonderful evening that we will all remember.

That night we honored Myra Cook for beginning our group and for being a faithful member for all these years. She responded by saying “As a single, working mom with severe narcolepsy and cataplexy, I felt a deep need to connect with other people who were facing life with the same issues. Meeting and talking with each other didn’t take the symptoms away but somehow in that simple connection, a sense of hope started to grow. I knew I wasn’t alone.”

From a tiny two-line ad, came a life-line for many in need of support. We came together seeking understanding. What we found were other people who knew intimately the struggles of narcolepsy and cataplexy, people who didn’t minimize the nightmarish symptoms packed into these diagnoses. We found support from people just like us who immediately knew and understood us in a way that family and friends without narcolepsy would never be able to.

Our group has looked very different through the years as we’ve grown up together. We’ve gathered everywhere from churches, restaurants, conference rooms, hospitals and beyond. We’ve had themed meetings, meetings with speakers, and meetings where we’ve just relaxed and enjoyed each (continued on page 10)
I was diagnosed with narcolepsy ten years ago, and more recently with bipolar disorder. My sleep specialist said the medications for one disorder will just make the other disorder worse. He suggested I choose one disorder to treat. Are there any wakefulness medications I can take for narcolepsy that won’t make the bipolar symptoms worse?

First, do you actually have narcolepsy? Too often patients with hypersomnolence are mislabeled as narcoleptics. Hypersomnolence is common in the depressed phase of bipolar disorder. If you have not had cataplexy and if your work-up did not include a polysomnogram with next day multiple sleep latency test then you may not have narcolepsy. If hypersomnolence is instead due primarily to the depressive phase of bipolar disorder, and presuming your mood is appropriately stabilized, then cautious treatment with an energizing or awakening anti-depressant would be worth considering. Bupropion, protriptyline, duloxetine, selegiline, venlafaxine or one of the most often non-sedating selective serotonin reuptake inhibitors (SSRIs) might be considered.

If you do have both narcolepsy and bipolar disorder then the treatments for one could potentially have an adverse effect on the other condition. However, with careful selection of medication and adequate monitoring by a physician with relevant competency, it is very likely that both could be treated successfully and simultaneously.

Some mood stabilizers can compound narcolepsy by causing cognitive impairment and excessive sleepiness. These include the “first-line” drugs divalproex, carbamazepine and lithium and also neuroleptics, including older medications like haloperidol and some newer “atypical” neuroleptics, especially olanzapine, risperidone and quetiapine. Anti-epileptic drugs used for mood stab-
Through the Looking Glass: The 2006 Narcolepsy Round Up

One person’s very individual, idiosyncratic and personal expression can illuminate and even enliven broadly shared community-wide realities. This phenomenon is why support group work can be so healing and helpful. With exponentially magnified power, this community-building dynamic happens vividly at NN’s annual conferences. Add the vigor of learning! Add the adventures of dancing together, laughing together, dining together, and creating together…. In Dallas last October, the mission of exploring narcolepsy together was orchestrated as a gorgeous tangle of work and play, introspection and communication, creativity and learning, adventure and rest. Conference attendees with narcolepsy seemed to unearth greater understanding and compassion FOR THEMSELVES THROUGH engaging with the lives of other people with narcolepsy. Gaining this essential personal support happened just as vividly among those parents and family members without narcolepsy who attended the conference.

The potential a conference holds is a thrill to anticipate, dream of and imagine, but the way it actually plays itself out in time, space and humanity is so exquisite and unique in its detail of moving experiences! Here in the newsletter, we hope to offer invigorating glimpses of the conference from the wondrous dreamy memories we hold dear. These reflections are an effort to share some of the joy generated with those of you who were not present as well as to stoke the memory-fires of those who WERE present, to reinvigorate your flame. As we offer these reflections about Dallas, we are indeed busy planning the NEXT conference. Please plan to be with us by putting the date on your calendar (see announcement, p. 1) and aiming to come. Your participation at the conference is a wonderful gift to give to yourself – and to the NN community!

Dr. Jerry Siegel, recipient of our 2006 Researcher of the Year Award, with the sincerity of a true ally, guided us through the thoughts and processes of researchers. With very limited research materials to work with, they are trying to explore our own plight. He hammers home in the most gentle but clear way how essential it is for us, as PWN, both with AND without cataplexy, to “will” our post-mortem brains to narcolepsy brain banks, where they can be explored by dedicated scientists to better help PWN in the future. Right now, we have brilliant scientists like him putting their life’s focus in our direction, yet many hundreds of narcoleptic brains each year are buried and in the words of Dr. Siegel “with them, the understanding of Narcolepsy is being buried.” On the topic of narcolepsy treatment, he expressed hope for moving toward a human trial of administering hypocretin — a process which, in both mice and dogs, has proven to be very helpful in alleviating the symptoms of narcolepsy. He was dismayed that this has not yet taken place, alluding to the low profit-incentive as one explanation. Being a natural substance, hypocretin cannot be patented and therefore promises little profit, despite its promising potential to help us. Imagine … in administering hypocretin to narcoleptic dogs, scientists found that both sleep periods AND wake periods were expanded while cataplexy was reduced. Also, Dr. Siegel let us know that we have fellow humans on this earth missing much of their hypocretin brain cells: people with Parkinson’s. We are not alone.

Dr. Rubin Naiman brought the conference community into vivid appreciation of our very special narcoleptic talent: dreaming. He encouraged us not to fear dreams (reassuring us that we will wake up safely even after dreams of dying) but instead to become appreciative witnesses to dreaming and held dialogues about this throughout the weekend. His recently published book, Healing Night, is a wonderful follow-up or surrogate read.

Our conference community has entered an experimental experience of Laughter Meditation with Laraaji Nadananda, for two years in a row. We ask the question: can we as PWN, many of whom have been afraid of laughter as a cataplexy trigger, actually relearn laughter in a new way? By laughing from breath but not AT an outer stimulus, can we find our way toward safe and invigorating laughter? It is a fine experiment with very rewarding results!

The conference was vast, and so many presenters, each wondrous, brought their gifts to bear. Here, we present the comments and contributions of a few other NN folks reflecting back on the conference.

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Happy Feet
By Joyce Scannell, PWN and NN Admin. Asst.

I can’t imagine missing this yearly opportunity to meet with old and new friends, to talk *in person* about the victories, challenges and struggles we all face, or to exchange stories and ideas with others. This year I was able to take a few breaks from working the registration desk to catch sessions I enjoy — esp. HAPPY FEET (Laraaji Nadananda’s *Laughter Meditation* session) and mingle with others. It always amazes me how a room full of PWN can become so energized! What a time we all had! See you in San Diego!

Square Dancing Deep in the Heart of Texas
By Marguerite Utley: Local Texan Host and NN Volunteer of the Year

We Texans didn’t want our visitors to go home without a real taste of Texas, so we decided to throw a square dance on Saturday night.

When I first contacted the caller, Wayne, I briefed him with as much information as I thought pertinent, but I didn’t tell him everything – like about cataplexy. While he was setting up his equipment in the ballroom, I said, “Wayne, I think there is something else I need to tell you. Some of these people have a symptom called cataplexy, which is a loss of muscle control. It’s often triggered by laughter and excitement, so we might have a slight problem here.” I told him if anyone collapsed on the dance floor to just keep on calling. The time down would probably be brief and the person would soon return to normal without any ill effects.

The fun and laughter took its toll as first one person and then another was overcome by some degree of cataplexy. The squares rose to the occasion and handled the situations magnificently. Some waited for the person to recover. Others gently pulled the person aside and sent a temporary substitute into the square. And all without skipping many beats. That’s what I call real coping!

On a personal note, I would like to commend my husband, Clyde, who is 81 years old. (I’m younger than he is!) At our church hoedowns, we sit on the sidelines and watch. He won’t dance. But on that Saturday night, when Wayne said, “Everyone up here,” Clyde trotted right on up—with me right behind him. Once the place had begun to fill up, with people waiting to get into a square, I sent a young lady in to substitute for me but it was another fifteen minutes or so before I could get Clyde out. I felt like his outstanding perseverance called for honorable mention. Aw, shucks! Everyone there did a bang up job and is to be commended. Ya’ll all deserve a tip of the old ten-gallon hat for making it a night to remember.

THE SILENT AUCTION
By Marguerite Utley

We raised almost $1100 on the silent auction at the conference—and had a good time doing it! Not only does the auction raise funds for next year’s registration scholarships (or the general fund if you request), but it adds a little spice and variety to our program.

We hope that you will start NOW planning for 2007’s silent auction at the conference in San Diego. When you find a “can’t resist” bargain, and you don’t know what in the world you’ll do with it, or when you run across things at home that you no longer want or need — but someone else might — put them back for the auction. If you have a special hobby or craft, think about making something for the auction. We welcome all desirable items which will attract bids. There is no minimum value requirement—any amount is welcome. The item may be new or used—if it is in excellent condition.

We do offer the following suggestions. It is preferable to have one-of-a kind items. Identical items make bidding more difficult. If you are going to make several of the same item, vary the colors or some other feature, if at all possible. When the time comes to submit your donations, we will ask you for certain information, letting you set a suggested price and allowing the article to be returned to you if the minimum bid is not reached. If you can’t attend the conference, you can mail your donations. Remember, most people will have to take their purchases home in a suitcase so make sure they aren’t too heavy or too large. If you have any suggestions for the silent auction, please e-mail them to the NN office in care of jscannell@narcolepsynetwork.org.

A Comparative View
By Niss Ryan, NN co-founder

One of the interesting and helpful things about the 2006 conference was the way speakers were organized. Some who spoke on Saturday, such as Dr. Jerome Siegel, had been asked to stay for a Sunday Roundtable Talk. Discussion of research on narcolepsy brings up so many questions that they can’t all be answered in the allotted Q and A time of a lecture. Dr. Siegel was very generous with his time. Some questions were addressed during the Sunday roundtable, but for those who still had more, he invited us to join him in the hall where he and a large group carried on until all were satisfied. Dr. Rubin Naiman’s presentations were structured in a similar way, presenting two major talks about Dream Work and then a roundtable, as well as (continued on page 10)
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other’s company and even holiday celebrations. In the last few years, we have met in local restaurants monthly for dinner and keep our meetings relatively informal. If someone new is there, we center the meeting around them, answering questions and giving them time to talk and share their story. If no one new is there, we catch up on what is going on in each of our lives and continue to be an avenue of support and encouragement to each other.

As a group, we have managed to survive a very long time. So what are the secrets to our longevity?

First and foremost, we keep up to date on the medical progress made in the areas of narcolepsy and cataplexy. If a new medicine comes on the market, someone in our group knows it and shares the information. Knowledge brings hope to what can seem a desperate situation.

Second, we extend unconditional acceptance to group members. We allow ourselves and others to be real about how we are coping and about the issues in our lives. Fears and experiences are addressed, not judged. We provide a safe place for narcoleptics to be transparent about what they are going through. If one person is struggling with a particular issue, someone else in the group has most likely already lived through it and can offer support.

Meeting consistently is another secret to our success. This works because we don’t lose touch and we are more likely to stay involved in each other’s lives. Staying involved means better support and we believe in doing that not only in heartfelt ways, but also in practical and tangible ways. And since narcolepsy can sometimes put a damper on one’s social life, meeting consistently gives us a way to socialize and offer support at the same time.

The most important key to our group’s success is one we discovered very early on: We have learned to laugh at ourselves. Learning to laugh at ourselves and the strangeness that is narcolepsy can be a huge step toward healing.

Shame, fear, feeling ostracized by family, co-workers and much of the world brought us together…but education, acceptance, allowing others to grow and heal at their own rate, and developing an ability to LAUGH at ourselves has kept us together and coming back to the meetings. And we DO laugh…and at times have come close to getting thrown out of restaurants for being so loud and laughing so much, especially post-Xyrem. Little do they know we’re making up for a lifetime of having to stifle those laughs…but not any more. Here’s to the next 20 years!!

Through the Looking Glass: The 2006 Narcolepsy Round Up (continued from page 7)

hosting breakfast tables to informally share dreams. Both of these speakers were extremely popular.

I loved the changes of pace throughout the conference. Next to serious topics one might want to hear lectures about, there were opportunities to do something physical, such as a session of “resting with breath awareness” or “laughter meditation.” Another change I’d noticed that the conference planners had made was to use not only Board members as hosts and speakers, but to reach out and include other NN members who have information and talents to share. If you have expertise in a subject or talent that we all might be better off for knowing about, contact the committee that is planning this year’s Conference. Email Audrey Kindred at akindred@narcolepsynetwork.com.

Trying New Things!

By Patricia Higgins, NN Trustee

I arrived at the Dallas conference already exhausted from a cancelled flight and 24-hour layover. Not the best way to start off a conference, but I was determined to arrive in good spirits as I set my feet on Texas soil. I conjured up in my head the feeling of total joy, the feeling of belonging, as I attended my fourth NN conference. Past conferences had given me hope that had been missing in my life. I can honestly shout out loud to anyone listening that this conference did not disappoint!

I took on the role of official greeter in the lobby of Las Colinas. I finally found a job I am good at! The newcomers that arrived took a big leap of faith, and it is here that they would find a group that would openly accept them. Their journey was just beginning.

Greeting these first-timers shaped the conference into exactly what I needed: I found what I hope will be lasting friendships. I connected with people just like me. That is a rare find, made possible only through our annual conference.

As I scanned the conference lineup I stretched outside my comfort zone to attend classes that were “unlike me.” What I found was totally rewarding.

Deep Rest Technique with Breath Awareness, leader Audrey Kindred, was transforming. It allowed me to relax and get in touch with a joyous peace … pure tranquility that I was sorely lacking. The urge to remain undisturbed was tempting. I returned for a second session just

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Narcolepsy Network publicly acknowledges and thanks the following donors, whose generosity made it possible for us to provide information and emotional support to thousands of people living with narcolepsy. We also thank those not listed who gave of their time and energy during 2006 to help individuals and/or to advance the narcolepsy cause.

Individuals

Jami Aldridge
Lilianne Anderson
Dominique V. Anderson
Anonymous
Michael Ansbro
Michael R. Armstrong
Paul Arnold
Lenore G. Aron
Marylyn Atkins
Beverly Austin
Fairley Baker
Emily Baker*
Edward S. Bernreuter, MD
Shameka Bennett
Judy Barnes
Emily Baker*
Fairley Baker
Beverly Austin
Marylyn Atkins
Michael R. Armstrong
Anonymous
Individuals
Roland Denzel
Bradley Densmore
Birdie Deadwiler
Andrea Cooper
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United Way of Westmoreland County
Wells Fargo Community Support Campaign
*Denotes donations partially or fully restricted as to use

In memorium

In memory of
LeRoy A. Alitz
David L. Alitz
Thomas S. Cramer
Susan J. Fries
David Hatem

In memory of
R. Clark DeVau
Arla DeVau

In memory of
Louis J. Elliott
Joe and Kathy Petrone
Frank & Marie Scheuren
Mrs. James Scheuren

In memory of
Charles Thomas Harvey
Jeanne & Bill Weber

In memory of
Charles Isley
Sue Brockway Carella
Robert L. Cloud
William S. (Bill) Johnson

In memory of
Howard “Dan” Plymale
Vicky Arbogast
Bob & Anna Lee Branner
Ellen Funston Defriese
Newburyport Sleep Diagnostics Director
Regenia M. Ervine
Catherine Berry Evans
Mildred Miller
Jodi & Warren Riddle
Michael C. Ridgway
Julian Smith
Mary Jane Wall

In memory of
Mary Vitali
Sue Brockway Carella
Dante Vitali Sr.

If ever you sense a guardian angel watching over you, surely it is one who has walked our path.

— Anonymous PWN
Everyone gave it his or her full participation. The time passed quickly. We were delighted in a competitive game of Musical Chairs. Some of us hadn’t taken part in Musical Chairs in years. The expression of simple pleasure from creative movement brought joy to my heart.

These are the feelings that I want all who attend our annual conference to feel. I want to wake up in each and every one of you the feeling of HOPE. It is a wonderful thing.

Dear Narcolepsy ...
By Kristi Rychener,
NN Conference Committee Member

Anna French and I hosted a support group for young adults with narcolepsy. To provide a format for thoughts and feelings regarding narcolepsy, people worked in small groups to write letters to Narcolepsy itself. In order to provide a neutral framework, each letter started with “Dear Narcolepsy, Living with you is interesting.” I invite you to write a letter to your own narcolepsy. What do you have to say? You might even write a response back from narcolepsy. What might it have to say to you? I hope this exercise will help you to develop a more friendly relationship with your narcolepsy, as I have since I started attending NN conferences.

A compilation of “Dear Narcolepsy” letters has been posted to our website at www.narcolepsynetwork.org/dearnarcolepsy.php. Once you have written your letter, see what others had to say!
YEAR 2007 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? ____________________________________________________________________________

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) ____ NIART (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 ongoing basis. They will be used whenever possible, as time and space permit.

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