NN, Inc.
79A Main Street
North Kingstown, RI 02852

forwarding service requested — return postage paid
Dear fellow people with narcolepsy (PWN), and all of you who care for PWN as well:

On behalf of Narcolepsy Network's 2006 Conference Committee, allow me, Audrey Kindred, as Conference Committee Chair and NN Officer, to extend an invitation to you. Readers, you are each and all invited to gather – as people have for the past twenty years now, to honor, explore, grow and even transform your lives' journeys of living with the rare and unique experience of…..narcolepsy. Narcolepsy Network has made a consistent and committed mission of providing the only annual conference which is planned by and 100% dedicated to the needs and interests of people with narcolepsy. We hope you will make plans now to attend the fall adventure that awaits us in Dallas, Texas. October 20 – 22, 2006 is THE weekend of Narcolepsy Network's 21st Annual National Conference.

You bet your boots, Narcolepsy Network is fixin’ to give you a mighty welcome to its fall “Round-Up” – the one and only national conference dedicated exclusively to narcolepsy! We’re lookin’ yonder for folks with narcolepsy, with and without cataplexy, to help us bring in the strays, and we’re offerin’ a reward of unlimited fun and learning with the posse. So y’all saddle up your favorite nightMARE and pack up your saddlebags to meet us in Texas at the Marriott Las Colinas, just outside of Dallas.

Together, we’ll shoot down a few myths about narcolepsy and get hot on the trail of new medications, as well as alternative treatments, coping devices, and empowering choices. Deep in that heart of Texas, we’ll tap into our natural resources, mine our energy fields, and discover alternative sources of personal fueling. And when we’re done, well, we’ll sleep peacefully . . . DEEP in the heart of Texas.

A treasured group of member volunteers throughout the year help to create and plan the upcoming conference. Hats off to them, their thoughtful brainstorms, talented offerings and concerted efforts toward community contribution. Charlie Severson and Anna French (aka Glucklich, as she is credited in the flyer itself) created the flyer you’ve perhaps received in the mail by now. Thanks to very generous support from Jazz Pharmaceuticals and Cephalon. From them, scholarship monies have been made available for those in need. Scholarship applications and guidelines can be obtained by writing to Oleta Elliott (profnapper@aol.com) and submitted through September 9th.

The conference location is the specially selected Dallas Marriott Las Colinas, 223 W Las Colinas Blvd., Irving, TX 75039,
A Narcolepsy Round Up! (continued from page 1)

halfway between the two Dallas airports. We have secured a special Conference room rate of $92.00 per night (before taxes) for dates between October 18 – 25, pending availability. You must register separately for the hotel, airport shuttle and Conference. To make reservations, refer to the insert on this page. Registering early IS important – and it’s also less costly. Your early registration truly helps the planning process be more effective and efficient, and we thank you for your efforts in this ahead of time. Also note however that refunds for cancellations made after September 15th will be subject to a $25.00 processing fee.

The conference gathering opens on Friday late afternoon, with a welcoming sign-in process which will begin at 4:00 p.m. on Friday, followed by a mixer. While breakfasts and lunches on Saturday and Sunday are covered by registration costs, dinners provide a chance to stroll in the neighborhood with new-found and old cherished friends. Conference events come to a close at 5:00 p.m. on Sunday afternoon. A diverse selection of workshops, lectures, support forums, and activities will be offered at the 2006 Narcolepsy Network Conference to meet the needs, support forums, and interests of our unique and growing community; distinguished narcolepsy researchers Dr. Jerome Siegel and Dr. Masashi Yanagisawa; pediatric sleep specialists Dr. Daniel G. Glaze and Dr. Joshua Rotenberg; sleep psychologists Dr. Kristyna Hartse on narcolepsy and intimacy; and Dr. Rubin Naiman on behavioral and dream medicine; anthropologist Nicole Eugene on cultural

OOPS!

By now you have probably received your conference brochure in the mail. We have a couple of corrections for you regarding hotel contact information for your reservations. The URL www.dallasmarriottlascolinas.com does not take you to the correct website. Please use the other URL, www.marriott.com/dalcl if you wish to make reservations online. You will need the Group Code, which is “LETLETA.” We are giving this code to you in uppercase letters to be sure you use the correct letters, but they should be entered in lowercase without the quotation marks. If you are calling to make reservations there are three different numbers you can call:

800-228-9290 or 800-Marriott (627-7468). If you call the hotel direct at 972-831-0000, they will transfer you to one of the two previous numbers. Both numbers have been checked and the reservations people should be able to assist you. Please tell them you are with the Narcolepsy Network Group and/or use the Group Code to be sure you will receive the proper room rate. Please DO NOT CALL (866) 900-9330, the toll-free number listed in the conference brochure, as it is incorrect. We apologize for any inconvenience.

IF YOU ARE A SMOKER: — Marriott recently announced they will become a non-smoking facility starting September 1, 2006. Some of you will no doubt be pleased, while some of you are fuming mad, no pun intended. DON’T PANIC!! Since our contract was in effect before this change was announced, Marriott has agreed to make special arrangements to accommodate smokers. However, you cannot get a smoking room through the reservation line. Please call Oleta Elliott at 480-354-1854 between 12 noon and 4 pm PT prior to October 14 for detailed instructions on registering. We are making every effort to accommodate all members of the Network. Please accept our apologies for this inconvenience.

SILENT AUCTION ITEMS NEEDED

Do you have something of value that’s just gathering dust? Turn it into a tax-deduction by donating it to the Silent Auction that will take place at the Conference! Proceeds will be used to fund 2007 conference registration scholarships. If you prefer, you may request proceeds be used for general needs.

In the past, we have auctioned everything from antiques to nightshirts, from handmade items to jewelry and toys. You don’t need to attend the conference to donate items to be auctioned! There is no minimum value required, BUT NO WHITE ELEPHANTS, PLEASE!

Silent Auction donations may be mailed in advance to:

Silent Auction 2006 c/o Ms. Marguerite Utley
238 Linda Lane
Duncanville, TX 75137-4012.

Please include your contact information and a minimum value or suggested selling price for each item. If you are attending and wish to personally deliver Silent Auction items, please drop them off at the registration table, preferably on Friday evening. Allow a few extra minutes to complete the paperwork so we can set an appropriate starting bid for your item(s).
A Word from Our Executive Director
By Eveline v.V. Honig, MD MPH

The summer is in full swing and I hope everyone has been able to relax a little.

We have been very busy at the Network due to an increase in demand for our services. We have also participated in many meetings these past months.

One relatively new group whose meetings I have attended is the National Sleep Awareness Roundtable Meeting (NSART). We are a national coalition of governmental, professional, voluntary and other organizations whose mission is to raise awareness and understanding of sleep disorders; and to reduce the public health and safety impact of sleep disorders and sleep deprivation by improving communication and collaboration among health agencies, professional organizations and the public. The vision statement is: “Healthy sleep is recognized (along with exercise and nutrition) as a key pillar of health and wellness in the United States.”

Four taskforces were created to address goals related to NSART. Narcolepsy Network has chosen to work on a taskforce to promote recognition of sleep disorders and access to care for all affected people. We met for the first time in Atlanta on June 5 to discuss and set goals and will meet again in September.

In mid-June our President, Sharon Smith, represented NN at the semi-annual meeting of the Sleep Disorders Research Advisory Board, which met in Washington DC in mid-June. This body includes government and non-government sleep researchers and sleep-related agencies. They collectively set the agenda for the National Center on Sleep Disorders Research, the NIH agency that coordinates public and private sleep research and grants. Members of public organizations such as NN are invited to attend and provide input.

For the first time, NN attended the National Association of School Nurses meeting, held in New York City, where we promoted greater awareness of narcolepsy in schools. We had a booth at this very well-attended meeting and spoke with many nurses and nurse administrators about narcolepsy and NN. They were very interested and took our brochures to share with their home communities. The NASN conference agenda had nothing on sleep or sleep disorders. It is so important for this group to know about sleep disorders and to be able to make an educated assessment when presented with a sleepy child or young adult. One nurse from Oklahoma told us that she was dealing with a difficult case in her community of a 12 year-old boy sleeping in school all the time. The boy is from a dysfunctional background with two alcoholic parents who are not interested in finding out why their son is sleepy. The school nurse had suspected this child might be drinking or that he just may not be getting enough sleep. She thought he was too young to have a sleep disorder. Now she plans to recommend the boy undergo a sleep study.

Some of our staff and board members went to the SLEEP meeting in Utah (previously known as the APSS meeting), where they were very busy networking and sharing our information. The Watkins family from Utah, who have two children with narcolepsy, helped us at this meeting and were a great support.

I hope you have had a chance to see one of our Public Service Announcements featuring actor Isaiah Washington. This campaign is supported by Jazz pharmaceuticals. We have noticed increased interest in narcolepsy, thanks to this campaign, and know it has increased the awareness of narcolepsy across the country.

Our annual Membership Meeting will be held in Dallas, Texas this year in conjunction with our Conference. I hope to welcome many of you there. If you have never been to one of our Conferences, you should not postpone it one more year. If you have been to our meetings, you know that these meetings are a great learning experience. They are also interesting, fun, energizing, validating and inclusive. Please join us, even if you know “everything” already; you can still be supportive for all the new people.

APSS Meeting
By Mort Rosenstein

I had the pleasure of representing the Narcolepsy Network at the 20th Anniversary Meeting of the Associated Professional Sleep Societies, officially called SLEEP 2006, June 17-22, 2006 in Salt Lake City, Utah. The other NN members who staffed the booth and helped set up the display were Kathleen Randell, Tricia Higgins, Paula Watkins, Karston Watkins and Dr. Kirk Watkins. Ramon Werbeach, a NN member and narcolepsy/sleep apnea patient who was there to represent the Board of Registered Polysomnograph Technicians, was very helpful in assisting to set up the display.

The 2006 Sleep Convention can be divided into three parts: technical presentations, exhibition, and evening presentations. On the technical side were many new ideas and the latest research taking place in the sleep medicine and sleep research field. 1100 abstracts were received and posted on bulletin boards and over 200 were given in oral presentation form. These presentations were limited to 10 minute speeches followed by questions. Although I attended a few of these presentations and I have a technical background, I found it difficult to

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News and Views

Amphetamines and Citrus Juices Don’t Mix

In case your doctor or pharmacist has not given you the heads up, you should know that amphetamines (Dexedrine, Adderall and Desoxyn) should not be taken with acid-containing juices such as citrus (orange, lemon, lime, grapefruit, etc.), tomato or pineapple juices. Why? The acid works in the intestines to flush these meds right out of the body. You can still enjoy that glass of juice …just do so in the evening.

A potentially life-threatening drug interaction has been reported specifically involving grapefruit juice. Researchers at UNC – Chapel Hill found that a substance called furanocoumarins present in grapefruit juice but not orange juice prevents the action of an enzyme that works in the intestines to block full absorption of certain medications. The increased concentrations of affected medications that enter the blood stream can reach toxic levels. Among the medications affected are cholesterol-lowering drugs, some antihistamines, erectile dysfunction drugs and blood pressure medications.

This study tested only one medication for blood pressure. Other, but not all medications that could be affected by grapefruit juice were mentioned. Be sure to discuss this and other possible drug interactions with your physician and/or pharmacist. When in doubt, err on the safe side: wash your meds down with water!

Glaxo-SmithKline Admits to Shortage of Brand Dexedrine 5mg Tablets

There is currently a nationwide shortage of 5 mg dextroamphetamine tablets manufactured by Glaxo-SmithKline (GSK) and sold under the brand name Dexedrine. A company spokesperson attributed this shortage to “several challenges with [their] own internal processes” that have led to "supply issues", and estimates the shortage will continue until October 2006.

Note that this shortage applies only to brand Dexedrine 5 mg tablets. Neither short- nor long-acting generic versions of dextroamphetamine, including Dextrostat, are affected.

GSK had notified its distributors of this anticipated shortage in March. No public announcement was made. Distributors communicated this information to pharmacies, but patients only learned of the
Discovery May Explain Why PWN Have Difficulty Waking (continued from page 4)

brains during deep sleep, they were “quickly extinguished and did not travel beyond the stimulated cells”. Their conclusion: during deep sleep, the various parts of the brain do not communicate with each other.

How might Dr. Tononi’s findings apply to people with narcolepsy? One hypothesis researchers can test relates to the disordered sleep stages often experienced by PWN. Where deep sleep typically occurs in the first half of the sleep period, it’s not unusual for a person with narcolepsy to be cycling through deep sleep towards the end of the sleep period. If the disconnect observed by Dr. Tononi and his team occurs in the same way in the brains of people with narcolepsy, PWN in deep sleep when the morning alarm goes off wouldn’t be able to process the sound.

*This research did not include any subjects with narcolepsy, so its application to PWN is unknown at this time. While we, as patients, look for possible explanations for our symptoms, researchers would caution us not to jump to conclusions. On the other hand, possibilities such as this are what spark further research. Dr. Emmanuel Mignot tells us “this study is very important as it shows fundamentally how differently the brain is wired during sleep.” In establishing how the brain works, Dr. Tononi’s research opens the door for Dr. Mignot and other narcolepsy researchers to look at how the PWN brain functions in comparison.

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NARCOLEPSY NETWORK, INC.

2005 ANNUAL REPORT

STATEMENT OF FINANCIAL POSITION

<table>
<thead>
<tr>
<th>ASSETS:</th>
<th>2005</th>
<th>2004</th>
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<tr>
<td>Cash and cash equivalents</td>
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<td>Prepays and other assets</td>
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<tr>
<td>Property and equipment, net</td>
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<tr>
<td><strong>Total Assets</strong></td>
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<td><strong>$  63,284</strong></td>
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<table>
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<tr>
<th>LIABILITIES:</th>
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<td>Accounts payable and accruals</td>
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</tr>
<tr>
<td>Payroll withholdings/payroll accruals</td>
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<td>$  3,241</td>
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<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>$  601</strong></td>
<td><strong>$  6,027</strong></td>
</tr>
</tbody>
</table>

| NET ASSETS | | |
| Unrestricted | $ 112,931 | $  56,740 |
| Temporarily restricted | - | $   517  |
| **Total Net Assets** | **$ 112,931** | **$  57,257** |

| **Total Liabilities and Net Assets** | **$ 113,532** | **$  63,284** |

REVENUES AND EXPENSES

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<thead>
<tr>
<th>Revenue Categories</th>
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<th></th>
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<td>Corporate Grants</td>
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<td>Donations</td>
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<tr>
<td>Other</td>
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<table>
<thead>
<tr>
<th>Expense Categories</th>
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<tr>
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</tr>
<tr>
<td>Other</td>
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<td></td>
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</tbody>
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| REVENUE | | |
| Contributions | $ 114,062 | $  83,394 |
| Membership dues | $  55,825 | $  30,012 |
| Conference and related fees | $  28,107 | $  18,500 |
| In-kind contributions | $   31,213 | - |
| Investment earnings | $   1,094 | $   450  |
| Educational materials | $   717  | $   966  |
| Other revenue | $   1,221  | $   4,498  |
| Gains (losses) on asset disposal | - | $(2,333) |
| Realized gains (losses) on investments restrictions: | - | $(219) |
| Expiration of time and purpose restrictions | - | $(219) |
| **Total Revenue** | **$ 232,239** | **$ 135,268** |

| EXPENSES | | |
| Salaries | $  35,023 | $  49,825 |
| Payroll taxes | $   3,020 | $   4,067 |
| Conference | $   26,411 | $   26,544 |
| Printing and reproduction | $   26,411 | $   26,544 |
| Travel, meals & lodging | $   8,102 | $   8,964 |
| Telephone and utilities | $   5,424 | $   9,510 |
| Postage and shipping | $  10,014 | $  17,962 |
| Office supplies | $   2,715 | $   5,597 |
| Professional fees | $   3,600 | $  10,100 |
| Insurance | $   5,960 | $   4,863 |
| In-kind expense | $  18,250 | - |
| Office rent | $  1,091 | $   7,445 |
| Depreciation | $  2,825 | $   4,208 |
| Internet and technology | $  1,865 | $   255 |
| Advertising | $   1,223 | - |
| Dues and registrations | $  2,780 | $   2,340 |
| Miscellaneous | $   7,953 | $   6,420 |
| **Total Expenses** | **$ 178,515** | **$ 183,328** |

| Increase (decrease) in net assets | $  53,724 | $(48,060) |

To obtain a complete copy of the 2005 audited financial statements, contact our National Office at narnet@narcolepsynetwork.org or (401)667-2523.
NN ended 2005 in a stronger financial position than 2004. The increase in net assets is largely attributable to close containment of expenses during 2005, and to a $40,000 unrestricted grant received from Cephalon, Inc. late in 2005.

The Board continues to focus on increasing membership as the primary means to achieve financial self-sufficiency. Corporate grants are generally restricted for use in funding specific programs and special projects. These funds are not intended to cover the basic costs of operations, such as salaries, office and communications expenses, insurance, filing of state registrations or audit fees.

Our goal is to reach critical mass, the point at which membership dues, donations and other revenue cover the costs of basic operations. We estimate this goal will require doubling membership at all levels, from an all-time high of 1200 at year-end 2005 to approx. 2500. This should be an attainable goal, given that an estimated 50,000 Americans are diagnosed with narcolepsy. To this end, the 2006 Public Awareness Campaign has brought us many hundreds of contacts already whom we will pursue for membership, together with former members who have not renewed. We are also promoting membership among sleep centers and professionals, with benefits that provide tools to address the needs of PWN beyond strictly medical care. Total membership as of August 9, 2006 is at 1100, with almost 5 months of the year remaining.

Our financial statements do not reflect one of our most valuable assets: the time of board and member-volunteers who provide support and information to fellow members. They are an integral part of our organization. They are what makes us a Network.

Narcolepsy Network thanks you for supporting our organization with your membership and donations. Your continued membership is vital as we look to grow and expand to better serve you and all people with narcolepsy. You can further help our cause by encouraging your local sleep center, physician and any non-member PWN you know to become members, and also by volunteering your time. If anyone should question the value of membership, ask them to consider where they would turn if there were not an organization fully versed in our needs and the issues we face, to which they could turn when N presents an unexpected curve.

Sharon D. Smith
President, Board of Trustees

President’s Report

Combined Federal Campaign and United Way

By Sue Carella

Anyone who donates to the Combined Federal Campaign or United Way this Fall can earmark all or part of their donation to the Network. By doing so, you’ll be making a vital contribution to the Network’s success.

As a contributor to the Network through these programs, you’ll know you are helping to educate the public about narcolepsy, helping those who need a diagnosis find a sleep disorder center where their problem can be defined, helping provide support for our self-help groups and, generally, making a very important contribution to the Network’s success.

MILITARY AND FEDERAL EMPLOYEES

The Combined Federal Campaign (CFC) is an annual workplace fund drive for federal employees, including all military, civilian agency and postal workers. The 2006 CFC Campaign begins after September 1 and lasts through December. Simply designate Number 0208 and the Network’s name on your payroll deduction card. Every year Federal employees and military personnel in more than 400 campaigns pledge millions of dollars through the CFC. If you are a federal employee, tell your workplace friends about the Network, maybe even give them brochures about narcolepsy. We would be happy to provide brochures should you wish to distribute them at your workplace fair. Together, contributions from you and your fellow workers can significantly impact our programs and our ability to expand our services. If you don’t work for a federal facility, you can help by writing the office for brochures and giving them to your local postal employees or, if you live near a federal facility, distributing them to personnel at their workplace.

(Continued on page 12)
Addressing Duke’s Freshmen Medical Class

By William C. Johnson

I was honored recently with an invitation from Dr. Andrew D. Krystal, MD of Duke University Medical Center to give a brief presentation on narcolepsy to the freshman medical class, as I had done the previous year. When you consider that the medical curriculum at Duke and all medical schools calls for a mere two hours of instruction on all 150+ sleep disorders, you can understand why I felt a bit honored, flattered, and humbled that Dr. Krystal would allow me to devote one of these two hours exclusively to narcolepsy!

*(With specialties in Psychiatry, Clinical Neurology and Sleep Medicine, Dr. Andrew D. Krystal wears a wide range of hats at Duke. He is the Director of the Quantitative EEG Laboratory; Director of the Duke Clinic Sleep Lab; Associate Director of the ECT Program, and has a specialty in treating Affective Disorders.)*

Dr. Krystal began his first hour’s discussion on sleep with illustrations as to how various species through the years had evolved such as dolphins swimming in a counter-clockwise circle when one side of their brain was asleep and a clockwise circle when the other half of the brain was asleep, with opposite hemisphere’s of the brain “taking turns” sleeping to prevent drowning. Early birds were thought to precede man’s development of Rapid Eye Movement (REM). Dr. Krystal concluded the first hour by touching on classifications of sleep such as Disorders of Excessive Somnolence (DOES) which includes diagnoses like narcolepsy and sleep apnea; and, Disorders of Initiating and Maintaining Sleep (DIMS) which would include a diagnosis like insomnia.

During the second hour’s presentation, Dr. Krystal announced that I had agreed to share with the group my history of having narcolepsy, from onset of symptoms to getting a correct diagnosis; various medications I had been on, their effectiveness, side effects; how narcolepsy had affected my ability to work; and, social and family aspects of this illness.

Before opening the second hour up to a question/answer type forum, the students were shown a clip from an episode of ABC TV’s “Good Morning America” narrated by Dr. Tim Johnson, showing Dr. Mignot at Stanford and the narcolepsy dog colony. Dr. Mignot discussed researchers’ attempts to isolate a single gene responsible for human narcolepsy similar to the gene found to cause narcolepsy in canines; the eventual discovery that human narcolepsy with cataplexy was caused by a lack of hypocretin in the brain; and that if somehow this hypocretin could be replaced in humans, a cure might be found for this disorder. The film showed a student having severe cataplexy with her mother unable to video tape the scene without (Continued on page 11)

Tricia’s Narcolepsy Story

By Sharon D. Smith

A popular saying suggests that strangers are friends we haven’t met. We can’t think of a more appropriate way to describe NN member Tricia Higgins to members who don’t yet know her. Tricia will be running for a position on our Board of Trustees in October, so you’ll be hearing more about and from her in future issues and can count on meeting her in Dallas and/or at future annual conferences. Tricia is a registered nurse with 20 years Critical Care experience in emergency room settings. With her sparkling blue eyes, ready smile and friendly personality, she’s the nurse you’d hope to have taking care of you!

I had met and spoke with Tricia briefly at the Seattle Conference (’04) and knew her then as Co-Chair of the NAPS Support Group (Narcolepsy Association of Philadelphia and Suburbs) and one of the local volunteers who greeted visitors to our booth at the 2004 APSS meeting in Philadelphia. I saw her again briefly at our Boston Conference (’05), but none of these encounters so much as hinted at the struggles Tricia had encountered in obtaining her narcolepsy diagnosis, or the fact that she had written and published her narcolepsy story in the American Medical Association’s Virtual Mentor magazine (October, 2004) as a way of educating other medical professionals about narcolepsy. Usually, when you read another PWN’s story, you are surprised to find so many similarities to

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Narcolepsy and Raising Children

Part II – The Toddler Years

By Sharon D. Smith

The first article in this series, “Narcolepsy and Raising Children – Baby’s First Year” appeared in the Fall ’05/Winter ’06 issue of The Network. Readers of this series may also be interested in the article “Pregnancy and Medications” in the Spring ’05 issue. We present this series for PWN who ask how narcolepsy will affect their ability to meet the demands and responsibilities of parenthood. It will also be useful to grandparents and other part-time caregivers with narcolepsy. Since our focus is limited to areas that present special challenges to people with narcolepsy, readers are advised to consult resources such as the popular “What to Expect” series of books to gain a comprehensive understanding of the toddler years.

Toddlers are so named for the short, unsteady steps they take as they are learning to walk, around their first birthdays. They are so cute, so lovable, and more precious than life itself. As they progress through the toddler stage, from ages 12 to 36 months, they are bursting with energy fueled by unending curiosity. During this period, toddlers are ‘just learning’ about the world around them and acquiring the foundation of skills they will need to ultimately become self-sufficient, from language to motor and self-help skills. You are their primary teacher, caregiver, and protector. To any parent, and most especially to the parent with narcolepsy, the toddler years are almost certainly the most challenging period of child-rearing. The keys to survival are knowing in advance what to expect and developing a plan that balances your needs with your toddler’s needs.

Taking care of a toddler is demanding. It’s hard work. If you’ve been med-free during the infant years, you will need to reconsider whether changing demands warrant a return to medications in order to put you in the best possible position to properly care for your toddler. If you have cataplexy, you will probably find that your toddler provides many new triggers. There are times when you’ll have to act quickly to remove your toddler from a dangerous situation. If your cataplexy is triggered by fear, you may be helpless to protect your child from harm.

Mother Nature has been kind to parents with narcolepsy in one important area: most toddlers will continue to need an afternoon nap even beyond the toddler years. It’s more important than

(Continued on page 10)
ever that you take advantage of your child’s nap time to take your nap. While their curiosity leads them to explore and investigate anything and everything, toddlers do not yet have an understanding of or ability to recognize danger. They need to be supervised at all times. If there is any risk that you may fall asleep unintentionally or need to nap while your toddler is awake, you must do so in a “safe” room that you’ve created for that purpose. Additional childproofing is needed once your child is walking and climbing. You may need to remove furniture, lamps and knick-knacks so your toddler cannot pull them down or be hit by them. Bookcases and other open furniture can be turned to face the wall to keep junior from climbing it or emptying its contents at every opportunity. Some furniture can and even should be secured to the wall to prevent accidents. Do a thorough floor-to-ceiling review to identify dangers. Consult childproofing guides. Windows, curtains, draperies and the cords from blinds can be particularly dangerous.

Toddlers need opportunities to interact with peers in order to develop social skills. At the same time, you will find yourself yearning for adult interaction. Mother-and-child activities, whether formally organized by your public library or a local business catering to children, or informally by a group of like-minded parents in your neighborhood, can provide both. If you are a Dad, you will have to look harder, but such groups do exist for at-home fathers as well. One of the most important benefits of meeting others in your situation is that they likely also need and value free time, for anything from doctor visits and shopping to pursuing hobbies and even taking naps. Whether you call it a play date or babysitting, if you have predictable awake and alert time during which you can mind your child and theirs, you and one or more parents can arrange to look after each other’s toddlers to provide each other with free time.

When narcolepsy is thrown into the mix, a parent’s role as teacher will run the gamut from fun and stimulating to challenging to downright impossible. The more physical activity you can inject into learning opportunities, the easier they will be. There will be some things you can manage only at your most wakeful times, and others that you find you can’t manage. This latter category may include sedentary activities such as reading books to your child, floor play and even sitting by while your toddler splashes in the bathtub. Understand your limitations and be resourceful in finding alternatives and improvising. Your public library will have education videos and books with accompanying tapes or CDs. Your “better” half, a grandparent or even an older child in your neighborhood can take on some of the roles you cannot easily fulfill.

The toddler period includes the “terrible twos”, a foreboding name for the period during which a toddler is learning to assert his or her independence, when “NO!!!” becomes the predictable response to any and all requests. This phase will likely be one of the most challenging to the parent with narcolepsy. The patience it takes to weather this period can be hard to muster during your sleepy times. Your sleepiness also makes you more likely to give in when you should hold fast. The best defense is to be prepared. Read all you can on this period of your child’s development, learn about the dynamics at play, and accumulate an arsenal of practical tips to get you through. One general bit of advice that goes a long way is to choose your battles. For example, your pediatrician will probably advise that your child be weaned off bottles not long after his or her first birthday. Many young children relax more easily and are soothed by a bottle at nap time and bedtime. Are you up to the difficulties you may face while your toddler adjusts to falling sleep without a bottle? You may find it easier to wait 6 months or even longer in order to avoid the hassles. Your toddler will eventually give up the bottle in his or her own time.

There’s no predicting the temperament of your toddler. Every child is different, even within the same family. Some are relatively easy-going while others will have you tearing your hair out full-time. You will need to adapt your parenting skills, management and coping strategies

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Narcolepsy and Raising Children Part II – The Toddler Years
(continued from page 10)

to the personality and behavior of your toddler. Ironically, the parent with narcolepsy may have a much easier time staying awake and alert with the more difficult or demanding toddler. Perhaps Mother Nature has a peculiar sense of humor. Be aware that the limitations of a parent with narcolepsy pose the risk of neglecting some of the needs of the “easy” child. You will need to be more proactive in exposing this child to a variety of opportunities for learning and developing. Appreciate the easy child and remember that even the difficult or demanding toddler is passing through a phase that will end. With any luck, easier times lie ahead. What worked for Susie may not work for Johnny. Your child’s version of the terrible two’s and your unique way of handling the challenges they present may differ greatly from those of extended family members and friends. Try your best not to get caught up in comparisons or set yourself up for criticism. Your ways and means are shaped by necessity to meet a set of needs that others may not understand very well.

As you come to the end of the toddler years, your child will be able to do many things for themselves. The need for “hands-on” physical control has, for the most part, yielded to the spoken word, although this is just the beginning of a new phase. Your baby-turned-toddler is about to graduate to the preschool years, with Nursery School just around the corner. If you can’t imagine saying “I can’t wait”, just wait and see!

Readers: If you’d like to share advice and/or suggestions from your personal experience parenting with narcolepsy, please write to us at narnet@narcolepsynetwork.org.

Tricia’s Narcolepsy Story
(continued from page 8)
your own narcolepsy history. You will certainly relate to Tricia’s symptoms and the impact narcolepsy has had on her life, and some will have traveled a similarly long and circuitous route in seeking a diagnosis, but most of us will be thankful that our diagnoses were made in less time and with less bumps along the way.

You are invited to read Tricia’s article, My Story: Living with Narcolepsy, available online at http://www.ama-assn.org/ama/pub/category/13197.html. If you don’t have Internet access, contact our office at 1-888-292-6522 for a copy of the article. We also hope that Tricia’s article will inspire you to write an article for a local newspaper to raise narcolepsy awareness in your community. If you do, please let us know the name of the publication and the date it appeared.

Addressing Duke’s Freshmen Medical Class
(continued from page 8)
going to the aid of her daughter to prevent the daughter from injuring herself from falling during the cataplexy attack. Dr. Johnson mentioned that two new drugs were now on the market to help individuals with narcolepsy to better manage their condition but alluded back to Dr. Mignot and the quest for researchers to solve the missing hypocretin problem.

After the seven minute clip had been shown, I was asked various questions from students as to how old I was when I was first diagnosed; what cataplexy “felt” like; was there a “warning” like with some epilepsies of impending attack; questions about micro-sleeps, sleepwalking and staying awake for academics, movies, sports; demographics; etc. Questions were asked right through the next professor trying to start his presentation and several students took a break (the sessions were recorded) so they could ask me personal questions about the disorder after the next session had started. There was not time for a formal summation or closing as Dr. Krystal and I both felt as long as hands were being raised with questions, it was more important to try and answer those questions versus trying to structure the experience along some academic format.

After last year’s presentation (Jan 2005), one Duke Med student who had questions during the narcolepsy presentation was diagnosed as having narcolepsy and is still in med school. This year (Jan 2006) another student whose history suggests cataplexy is in the process of being tested and diagnosed for narcolepsy.

Bill Johnson, a retired Air Force First Lieutenant, a registered nurse and former NN Trustee, has narcolepsy with severe cataplexy. He is a die-hard narcolepsy advocate and activist. He lives in Fayetteville, N.C., where he can frequently be found composing Letters to the Editor of local newspapers and other publications, calling or emailing his US Senators’ offices or networking with narcolepsy docs and patients at medical facilities such as Duke, the Durham VA and UNC-Chapel Hill.

A Narcolepsy Round Up!
(continued from page 2)

politics of narcolepsy/sleep; RN Katja Hardenfels on living with cataplexy; Laraaji Nadananda on laughter meditation; Andrea Clark and service dog, Olivia; NN’s Executive Director, Dr. Eveline Honig on quality of life; Pam Twitchell, parent of teen PWN; writers Marguerite Utley and Linda Black, and more!

These folks are such precious gems to mine, and together with fellow PWN, are sure to make you shine – so, let’s get down to work! See you in Dallas! Be in touch with me if and as you find necessary until that time.

Art Display
“Creative arts expressing narcolepsy may be displayed. Please contact conference organizer, Audrey Kindred, if you plan to bring something for display.”
Glaxo-SmithKline Admits to Shortage of Brand
Dexedrine 5mg Tablets (continued from page 4)

shortage when pharmacies were unable to refill their Dexedrine prescriptions.

Most patients will be able to substitute a generic version of dextroamphetamine or switch to a longer-acting formulation. This shortage will have a significant impact only on narcolepsy patients who cannot substitute a generic form of dextroamphetamine due to allergies or other adverse side effects attributable to inactive ingredients in generics, and/or who do not respond well to alternative medications. Generics may also have greater or lesser effect because the FDA allows small differences in active ingredients. We urge every narcolepsy patient who might be adversely affected by this shortage to discuss options and alternative treatments with his or her treating physician as soon as possible.

If you are unable to work due to the inability to obtain needed medication and a lack of viable alternatives, options may include temporary work-at-home arrangements, use of vacation and sick leave, short-term disability and/or unpaid leave under the Family Medical Leave Act. We recommend the Job Accommodations Network as a resource in exploring your options. Visit JAN’s website at www.jan.wvu.edu or call them at 800-526-7234.

If lack of medication creates financial hardship or prevents you from taking care of your basic needs, we recommend you contact your local Independent Living Center, an organization that assists persons with disabilities, to learn of resources in your community. Visit their home page at http://www.ilusa.com/links/ilcenters.htm to find the ILC nearest you.

For assistance with other issues, please write to us at nurnet@narcolepsynetwork.org.

Discovery May Explain Why PWN Have Difficulty Waking (continued from page 5)

Other questions arise, such as: How exactly is this disconnect achieved? Does it involve hypocretins? Could PWN experience it outside of deep sleep? For instance, might it explain the memory problems that are so often reported by PWN? We hope to see research that will provide answers to these and other questions raised by Dr. Tononi’s findings.

For the inventors among us, the time may be right for an alarm clock that can monitor one’s sleep stages and be set to sound off when one enters Stage 2 sleep.

2005 Conference Recordings Available on CD ($8.00 ea., incl. S/H)

(For complete list of educational materials, see http://www.narcolepsynetwork.org/info.php or call us at 1-888-292-6567.)

- BUILDING SELF ESTEEM; TAPPING INTO YOUR STRENGTHS WITH NARCOLEPSY, Stephen Amira, PhD
- EMPLOYMENT, DISABILITY, & INSURANCE ISSUES, Mark Bronstein, Esq.
- NAPPING IN THE WORKPLACE AND IN THE PUBLIC SPHERE, Prof. William Anthony, PhD
- OTHER SLEEP DISORDERS INTERACTING WITH NARCOLEPSY, James O’Brien, MD
- QUALITY OF LIFE FOR PEOPLE WITH NARCOLEPSY, Meeta Goswami, PhD
- TRACKING YOUR NARCOLEPSY: PROBLEMS AND SOLUTIONS, Quentin Regestein, MD
- THE BRAIN IN NARCOLEPSY: WHAT’S DIFFERENT?, Michael Biber, MD
- NARCOLEPSY AND THE AMERICANS WITH DISABILITIES ACT, Rosa Lily Palacios, Esq., EEOC
- PROMOTING WAKEFULNESS: THE SECOND GENERATION COMPOUND, NUvigil (ARMODAFINIL) C-IV,Gwendolyn Niebler, MD, Cephalon, Inc.
- BUILDING SELF ESTEEM; TAPPING INTO YOUR STRENGTHS WITH NARCOLEPSY, Stephen Amira, PhD
- EMPLOYMENT, DISABILITY, & INSURANCE ISSUES, Mark Bronstein, Esq.
YEAR 2006 MEMBERSHIP FORM

Name: ______________________________________________________________________________ Date: ____________________________________________________________________________
Organization/Sleep Center (if applicable): ________________________________________________________________________________
Member’s Street Address: ______________________________________________________________________________________________
City, State, County & Zip Code: ______________________________________________________________________________________________
Telephone (home): ______________________________ (business): ____________________________ Fax: __________________________
E-mail: ____________________________________________________ Web Site: _________________________________________________
How did you hear about us? ___________________________________________________________________________________________
How you would like to receive the quarterly newsletter: _____ snail mail or _____ email attachment (.pdf)
I _____ do _____ do not wish to receive communications from Narcolepsy Network via email.

2006 MEMBERSHIP DUES ☐ new membership ☐ renewal membership ☐ upgrade current membership
$35 Individual ☐ $75 Professional ☐ $150 Sleep Center ☐ $ ________ Complimentary: Please include me as a member, although I can’t pay all or any annual dues at this time, for the following reasons:
_____________________________________________________________________________________________________________________

DONATION: I have included an additional donation of $ ____________
PLEDGE: I wish to pledge an annual gift of $ __________ to be paid with the enclosed amount and three (3) more quarterly installments of $ __________ each. (Reminder notices will be sent).
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Please make your CHECK payable to NARCOLEPSY NETWORK, INC.
Mail form and payment to: Narcolepsy Network, Inc. • 79 Main Street • North Kingstown, RI 02852
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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.

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NAME (as appears on card): ____________________________________________________________________________________________
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Credit card number: _____________________________ expiration date: _______ signature: __________________________
Summer ’06

Please see back of form for Survey or Interests, Needs and Skills.
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. Support Groups
   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.