In an ironic twist of fate, the final requirement for the Master of Public Health degree that I have been pursuing at Boston University for the past two years led me to become Narcolepsy Network’s first intern. At the time, I had been recently diagnosed with narcolepsy, albeit somewhat informally. So in January, 2011 you can imagine how surprised I was to find NN as one of the organizations where I could potentially complete this required practicum, or internship, experience. When I found NN, I began a journey of self-exploration and knowledge-seeking that I previously had not taken the time to do. And that, combined with the other aspects of the internship, has made a tremendous impact on my life personally and professionally.

At just the age of 23, I have already spent half a dozen years, through high school, college, and even graduate school, searching for answers to my battles with sleepiness and I would like to share with you my story:

My mother laughed and called me Frankenstein. But it felt like a fitting term as I looked in the mirror at the electrodes covering my head, wondering how I would wash the glue out of my hair. The sleep technician stuck colored circles to my chest, face and legs. He then attached wires to each electrode, connecting them to a machine. Next, he tied a belt around my chest and another around my stomach, in order to monitor my breathing. I laid there motionless, afraid to move and risk knocking something loose. But as I sat there feeling physically uncomfortable and unbecoming, I also felt relief that this was finally a chance to find...
the preliminary findings show that the risk of developing narcolepsy is nine times higher in individuals vaccinated between the ages of 4 and 19 as compared to their unvaccinated counterparts. No cases of narcolepsy were noted for children younger than four, and risk for individuals older than 19 did not increase. Following the release of this report, the World Health Organization (WHO) published a report stating that there are at least 12 countries which have noted an increase in narcolepsy cases following the 2009 H1N1 vaccinations. The WHO, while acknowledging that further research is required, continues to recommend H1N1 vaccination. Thus far, the rate of new narcolepsy diagnoses does not appear to be increasing worldwide, and similar increases in the onset of narcolepsy have not been noted with any previous flu vaccines.

Pandremrix®, the H1N1 vaccine used extensively throughout Europe, includes an adjuvant compound which helps the body create a stronger protection against the virus. This type of vaccine was not used in the United States, where the H1N1 vaccine strongly resembled yearly flu vaccines and included only dead H1N1 virus or pieces of the virus. Theoretically, adjuvants provide additional protection against disease for the individual who is administered the vaccine. No adjuvants are used in any vaccine approved for use in the United States. Pandremrix® was used in over 30 countries, however the increase in the rate of new narcolepsy cases appears to be primarily located in Finland, Sweden and Iceland (and may be associated with ages 4-19 predominantly).

The Task Force developed three hypotheses based on facts they collected during their investigation. A hypothesis is an educated guess based on current knowledge that can be later tested scientifically and either proven or disproven. The first

Dr. Jerome Siegel recently received the William S. Middleton Award; the Veterans Administration’s (VA) most prestigious award in Biomedical Laboratory Research and Development. Dr. Siegel accepted the award on May 4th at the VA National Research Week Forum in Washington, DC. The William S. Middleton Award is the highest award for Biomedical/Clinical Research in the VA.

Dr. Jerome Siegel, Chief of Neurobiology Research at VA Greater Los Angeles Healthcare System (VAGLAHS), focused his research on understanding sleep physiology including sleep apnea and narcolepsy. Dr. Siegel's group, in parallel with a team from Stanford, discovered the cause of human narcolepsy, a loss of brain cells containing the peptide hypocretin/orexin. Dr. Siegel’s group also discovered that patients with Parkinson’s disease have reduced levels of the peptide. Dr. Siegel's group is currently investigating the operation of this system at the neuronal level to better understand its role in health and disease.

We look forward to catching up with Dr. Siegel in an upcoming issue of The Network.
Dear Friends,

Happy 25th anniversary to Narcolepsy Network!

On May 9, 2011 NN marked 25 years of community service. Many of you sent in donations for this monumental occasion, and we are very grateful for your continued support and appreciation. These funds will help NN continue its mission through raising awareness for, and serving the needs of, people diagnosed with narcolepsy and related sleep disorders.

My focus this year has been strongly centered on children diagnosed with narcolepsy who need the support of the Network. There are numerous issues that arise even after teachers, school nurses and school administrators have been informed that the child has received a narcolepsy diagnosis. One case included a child in middle school who was not allowed to go on a week-long school trip until I was able to better inform the guidance counselor about his condition. He was eventually allowed to attend the school trip. Advocacy like the type I provided in this case is sometimes necessary when the school system makes decisions for the child based on a lack of experience in dealing with the condition. School systems sometimes err on the side of caution when they are unfamiliar with a condition like narcolepsy, and I can understand their perspective. However, in certain cases, that conservative nature is actually detrimental to the child because it can be limiting. It can be challenging to find a good balance, and I plan on continuing to work with parents and school systems to aid in developing that balance.

I also spoke with a Michigan high school principal about one of the students at his school. The principal wanted to learn more about narcolepsy and cataplexy, as well as to better understand how to help a recently diagnosed high school student. NN applauds the initiative that this principal took in order to help the student and develop accommodations specific to her needs.

Narcolepsy Network continues to make a tremendous impact on school personnel by informing them that they can make a huge improvement in the quality of life for children with narcolepsy. These combined efforts are helping to give children with narcolepsy a positive learning environment tailored to their needs. Several schools have been willing to make necessary accommodations for their students with narcolepsy, and I hope to report that soon all schools are doing the same.

In May, I attended the Public Interest Organization (PIO) meeting in Bethesda, Maryland, sponsored by the National Heart, Lung and Blood Institute (NHLBI) at the NIH. I met many interesting leaders of non-profit organizations and we shared a lot of useful information. I also met with Dr. Michael Twerky, a representative from the NIH, who spoke at our last conference in Arlington, VA about the NIH research and grant processes.

There were several presentations at the PIO meeting this year. One presentation captured my interest about the Undiagnosed Diseases Program, a trans-NIH interdisciplinary program. It is organized by the National Human Genome Research Institute (NHGRI), the NIH Office of Rare Diseases Research (ORDR) and the NIH Clinical Center. The Undiagnosed Diseases Program began in 2008 and receives 5200 inquiries from patients and physician referrals each year. Of these, only 425 cases annually are chosen by the program leaders for further consideration, and even fewer, about 50, lead to patients visiting one of the 27 NIH centers for additional testing and/or potential diagnosis. This is a truly remarkable program and a testament that the NIH is acknowledging the needs of patients with cross-disciplinary and rare medical issues. I encourage you all to visit the NIH Office of Rare Disease Research website and learn more about their programs.

To keep up-to-date with relevant narcolepsy and sleep information, keep checking our website and/or subscribe to our RSS feed. Our Website Chair, Ramon Werbeach, has been continuously updating the site with pertinent announcements. If you have something that you would like to see on our website that is sleep or narcolepsy related, please contact Ramon at rwerbeach@narcolepsynetwork.org for consideration.

We are very busy preparing for our 25th anniversary conference in October in Las Vegas. It will be our first three-day event with many activities and interesting speakers. Our website has all of the information you will need to make your plans to join us for our 25th year celebration. I look forward to seeing you there!

Warm Regards,

Eveline Honig, MD

Help NN celebrate our 25th Anniversary by helping us grow!

Announce the celebration to your family and friends, and that you would appreciate their support through their membership and/or donation to NN.
And remind them that BOTH are tax-deductible!
Obesity Increases Metabolic Syndrome Risk

By Josette Keelor

With the obesity epidemic ravaging the country, anything Americans can do to improve their health and ward off future health problems is important. Obesity can affect anyone, but those with a predisposition to pack on the pounds need to be extra vigilant to remain at a healthy weight.

While all Americans need to take stronger action to tighten their ever growing waistlines, those who also suffer from narcolepsy have an even greater risk of obesity. And obesity increases risk of developing metabolic syndrome, a collection of risk factors that can predict the development of other diseases. Metabolic syndrome is becoming more common in America because of increased incidence of obesity and other obesity-related problems. People with narcolepsy are no exception.

Metabolic syndrome affects twenty-two percent of U.S. adults and increases in prevalence with age, affecting more than 40% of individuals older than 60. Weight is a big factor since 5% of people with normal weight, 22% of overweight individuals, and 60% of obese individuals have metabolic syndrome.

According to a study published in *Advances in Medical Sciences* in 2007, metabolic syndrome can lead to the development of many chronic diseases. A study by the All India Institute of Medical Studies in New Delhi describes metabolic syndrome as the co-occurrence of cardiovascular risk factors including abdominal obesity, hypertension, impaired glucose tolerance and dyslipidemia.

Obesity, listed as a prime factor contributing to metabolic syndrome, already affects many people with narcolepsy because of their low levels of hypocretin (also known as orexin). Hypocretin is a hormone that regulates weight by acting on the arcuate nucleus of the hypothalamus, which in turn regulates metabolism and energy expenditure, and suppresses the consumption of fatty foods.

Those with narcolepsy have a high risk of obesity, and those who are obese have an increased risk of being diagnosed with metabolic syndrome. Whether or not having narcolepsy influences the development of metabolic syndrome independent of the shared correlation with obesity is unknown. Currently, there are not enough research articles published about the relationship between narcolepsy and metabolic syndrome in traditional, scientific, peer-reviewed medical journals to make a reliable conclusion.

Recent studies have connected narcolepsy and metabolic syndrome to obstructive sleep apnea. Known as Syndrome Z when diagnosed with metabolic syndrome, obstructive sleep apnea also affects many people diagnosed with narcolepsy. A risk of developing cardiovascular disease is also greater in those with metabolic syndrome or with obstructive sleep apnea.

While those with metabolic syndrome may not complain of physical symptoms at the time of diagnosis, it is an indicator for future trouble. People with metabolic syndrome have a greater risk of diabetes and coronary artery disease, in addition to cognitive decline, fatty liver disease, polycystic ovary syndrome, and chronic kidney disease. The consequences of living with metabolic syndrome can be costly, and potentially deadly.

Optimally, warding off metabolic syndrome is the best case scenario. There are steps you can take to decrease your risk of developing metabolic syndrome. The first step is to know all of the risk factors. The National Cholesterol Education Program defines metabolic syndrome as a combination of any three of the following symptoms:

*continued on page 5*
IH. At one point I had to deal with my health insurance company informing me they could no longer pay for physicians that were out-of-state (for college). Once I did have that in-state appointment with a sleep specialist, he said to me “I honestly do not know what is wrong with you.” In May 2011, after six years and a total of five sleep studies, I was again diagnosed with Idiopathic Hypersomnia. The continuous back and forth between diagnoses has been very confusing for me, and honestly, I hope that this is the end so I can finally move on and concentrate on treatment rather than the diagnosis.

I believe that the first step in coming to terms with a sleep disorder diagnosis is accepting it so that you are able to learn more about your condition and how to deal with it. This was the most difficult part of the process for me because once I began to accept a diagnosis, it quickly changed. From all that I have learned, I identify with the symptoms of Idiopathic Hypersomnia the most. Naps do not refresh me and I don’t have sudden sleep attacks, but I continuously fall asleep from persistent tiredness throughout the day, pretty much everyday. I can also be a ‘long’ sleeper, sleeping over 10 hours a night, and even then I may not wake feeling refreshed.

Despite feeling like my actual sleepiness symptoms are more in line with those of IH, I have experienced times of losing muscle control during laughter. I recalled to some of my physicians how I often asked my basketball teammates to refrain from making me laugh because I would not be able to shoot, often dropping the ball. Only my most recent physician put a title to this sensation - cataplexy. After learning that the symptom of cataplexy is unique to narcolepsy, I began to think that maybe I did have narcolepsy. Then I read Julie Flygare’s REMRunner blog and identified closely with her post about her first experience with cataplexy.

Upon reading additional blogs where she wrote more about her experiences with cataplexy, I began to fear that my cataplexy would progress to full body collapses. I no longer wanted to have narcolepsy or cataplexy.

After my fifth sleep study in March 2011, my diagnosis was changed back to Idiopathic Hypersomnia based on the lack of sleep-onset REMs during my Multiple Sleep Latency Test (MSLT). Although I understand this cognitively, I wonder how it is possible for me to have been diagnosed with cataplexy, and now no longer even be considered to suffer from narcolepsy. Perhaps my disorder is not REM based at all. While that seems to be the story from my most recent sleep test, and the IH diagnosis suggests the same, it has not been clear from testing over several years.

I was never considered to be textbook narcolepsy despite at least one of my previous sleep and nap tests to have shown some sleep-onset REM. Narcolepsy may have been overlooked at first because there are a lot of reasons why short REM onset can happen. I also tested positive for the HLA allele that most people with narcolepsy and cataplexy have, however, 20-25% of the general population also have the allele.

For now, I have happily accepted that I probably do not have true cataplexy nor will I be worrying about how it may influence my life. I have also accepted Idiopathic Hypersomnia as the condition that best describes my symptoms.

During the past year, and despite my struggle to find an accurate diagnosis, I was able to find a balance between medication and napping that made my daily responsibilities as a both student and worker manageable. However, during my last semester in my public health program something changed. Despite having an easier workload I felt much more fatigued than usual. My normal routine of napping and taking medication no longer sufficed; I knew something was wrong. Blood work reaffirmed my suspicions — I am deficient in Vitamin D and am now taking supplements.

People with sleep disorders often attribute medical issues or changes, especially those involving fatigue, to their diagnosed disorder. But just as we recognized a problem during the onset of our sleep disorders, we must continue to listen to our bodies and recognize that there may be other explanations for unexpected and additional fatigue. Although Vitamin D may not be the source of additional fatigue for everyone, it is important to not be hesitant to approach your physician when you feel that something else could be causing a change in your fatigue level.

To the reader: If you would like to ask Vanessa additional questions about her story, please feel free to contact her at vanessao@bu.edu.

Obesity Increases Metabolic Syndrome Risk continued from page 4

• An abdominal waist circumference of greater than 40 inches in men and 35 inches in women

• A blood pressure of more than 130/85 mm Hg or drug treatment for elevated blood pressure

• Serum hypertriglyceridemia greater than 150 mg/dl (1.7 mmol/L) or drug treatment for elevated triglycerides

• Serum high-density lipoprotein (HDL) cholesterol less than 40 mg/dl (1 mmol/L) in men and less than 50 mg/dl (1.3 mmol/L) in women or drug treatment for low HDL-C

Healthy lifestyle changes can treat metabolic syndrome once it develops. These include options like losing weight, doing regular physical activity, following a healthy diet, and quitting smoking, according to the National Heart Lung and Blood Institute. Under the supervision of a doctor, there may be medications available to those not aided enough by lifestyle changes, and a suitable exercise program can be tailored to individual needs.

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WUN Boston Marathon Team Raises $28,000 for Narcolepsy Research

On April 19, 2011 three runners representing Wake Up Narcolepsy (WUN) ran the Boston Marathon to benefit narcolepsy research. Together, the WUN Team raised $28,000 for the cause. These funds will go directly to expert clinicians, scientists, and NN Medical Advisory Board members Dr. Emmanuel Mignot and Dr. Thomas Scammell (at Stanford University and Harvard University, respectively) in order to continue their studies on narcolepsy.

John Leahy, Monica Gow, and Kim Grady were among over 10,000 runners making the 26.2 mile journey. Their dedication to the WUN cause is inspiring and they once again have evinced themselves as true leaders of the narcolepsy community. Thank you to those who supported and followed them.

NN also congratulates Monica Gow who finished this year’s race with a time of 3:50:43. This automatically qualifies her for next year’s race, and is quite an accomplishment despite the treacherous winter weather she trained in.

We hope to see more from the WUN Boston Marathon group next year. But in the meantime, visit www.wakeupnarcolepsy.org for more about WUN’s upcoming events.

Swinging for Sleep to benefit NN

LPGA Golfer, Nicole Jeray, and Jazz Pharmaceuticals have partnered together to raise funds for the Narcolepsy Network this summer. Jazz will make a donation to NN each time Nicole has a great hole in a tournament. Birdies and Eagles benefit NN with a $25 or $100 donation, respectively, by Jazz.

As of June 1st Nicole has had 21 Birdies and raised $567.

Keep up the good work!

Please help NN cheer for Nicole in her numerous summer tournaments by following her through her website www.nicolejeray.com or on Twitter.

Are you having an overnight Polysomnogram (PSG) anytime soon?
Check out the following YouTube Video to complement your PSG preparations: http://www.youtube.com/watch?v=crZ-GF8lm4I
If you have questions or concerns about an upcoming sleep test, please contact your sleep center or healthcare provider before the test.

Picnicking Returns for Summer 2011

During the 2010 summer narcolepsy communities from across the country gathered together to celebrate and support one another with some funds provided by NN for snacks and refreshments. Did your group miss out last year? Or did you have so much fun that you have been thinking about it all year hoping for another fun event? Now is your chance! If you are interested in hosting a picnic in your area please contact Sarah DiDavide at sdidavide@narcolepsynetwork.org or 312-498-2381 to get started.
Every year, Bill Johnson ’73, a retired Army nurse, stands up in front of the medical students at Duke University and explains what it is like to live with narcolepsy. Sometimes he explains the situation one-on-one to someone who will face the same challenges he has.

“Last year, we met a med student with narcolepsy,” Johnson says. “He didn’t ask, but you could see it in his eyes: ‘Am I going to get through med school and end up like you?’ ”

For his efforts to spread the word about living with narcolepsy, last October Johnson received the Public Education Award from the Narcolepsy Network. That he can stand up and speak to a group at all is a major accomplishment. His wife, Charlotte, often accompanies him because his symptoms include cataplexy, in which he simply goes limp. Johnson describes a typical episode at the grocery store: “I was going into the store, and I couldn’t move. I couldn’t get the cart through the door.”

Johnson controls his symptoms with the prescription drug Xyrem. That’s what pushed him to speak out. In the 1980s, there was a move to ban the active ingredient in Xyrem, a form of gamma-hydroxybutyrate. Johnson was in clinical trials for the drug, and it was making it possible for him to continue in his job. He went to Chicago to speak to an approval panel. “At that time, I had been taking Xyrem twice a night for more than 10,000 doses,” Johnson says. “The cataplexy was controlled. There I am standing up in this room with all these really hostile people, and I was able to ask my question.”

Johnson says it’s hard to pinpoint his onset of narcolepsy. He remembers taking a history of religion course at UNC in which he had read all eight books assigned for the midterm but at the end of the exam, he looked down at his blue book and it was empty. He suspects he had fallen into micro-sleeps, another symptom. “You are burning the candle at both ends. If someone had told me in school, you have a sleep disorder, I would have laughed.”

— Susan Simone

Symptoms of Narcolepsy

Excessive daytime sleepiness (EDS) and micro-sleep: The person will fall asleep no matter what is going on and often not notice he has fallen asleep. Bill Johnson has visited the school where his wife, Charlotte, teaches. He can help see the difference between a child who is tired and a child who might be in the early stages of narcolepsy. In addition to dosing off, twitches and jerking motions can be the first signs of micro-sleep.

Cataplexy: Any emotion can trigger an episode of cataplexy, in which the body goes limp and the person slumps over and falls. For Johnson this has happened laughing at the Crocodile Dundee movie or hearing about the murder of Eve Carson ’08, the UNC student body president. “I didn’t know Eve Carson, but every time I heard about her on the news, I found myself so moved. It was like it happened personally and that triggered the cataplexy.”

Hallucinations: There can be visual and sensory illusions that are extremely vivid. They can be dangerous because the person is convinced that what he sees is real. “My wife said that’s the one thing she would leave me over — if hallucinations are not controlled. One night I brought my daughter down the stairs because I thought the house was on fire.”

Waking up to Narcolepsy

Retired nurse receives award for raising awareness

Bill Johnson ’73 — here with his wife, Charlotte, and their granddaughter, Lorelei — says it might be hard for college students to recognize they have a sleep disorder because of their lifestyles. “You are burning the candle at both ends. If someone had told me in school, you have a sleep disorder, I would have laughed.”

Bill Johnson ‘73 — here with his wife, Charlotte, and their granddaughter, Lorelei — says it might be hard for college students to recognize they have a sleep disorder because of their lifestyles. “You are burning the candle at both ends. If someone had told me in school, you have a sleep disorder, I would have laughed.”

See What Narcolepsy Is Like

There is no cure for narcolepsy, but the earlier it is diagnosed, the better the treatment outcomes. Awareness is key. Bill Johnson encourages people to search for “cataplexy” on YouTube to see how symptoms can present themselves.
A Waking Dream
By Sandra Todd

I sit and wonder in silent pain
How will I manage this again
The ghostly sound of no sound at all
A lonely shadow on the wall

A fear that never goes away
It breaks my night, invades my day
Scattered, shattered thoughts of you
Visions, smells, tastes and hues…but they are not you.

I hear your soft breath in the night
The warmth of your arms, holding me tight
I let escape a sigh of relief
And then I wake…Oh God, more grief

The tears that I shed sting my eyes
My broken heart feels twice its size
My hands feel numb, my body cold
Cos you my love, I cannot hold

Yes, I know, it won’t be much longer
And thinking this, I should feel stronger
But in the chill and dark of night
I feel too tired and weak to fight

And so I wake as I go to sleep
Alone and scared, and again, I weep
I know that I am needy and should be ashamed
But these thoughts and fears I CANNOT change

Two weeks is not a long time
Two weeks is forever

The Power of Poetry and Community

By Sara Kowalczyk

A Waking Dream was written by the late Sandra Underwood in the late 90s. The poem was originally part of a 1999 N[ART] exhibition coordinated by Laura Evert in New York City. Sandee, as she was known in the virtual narcolepsy community in the 1990s, wrote the poem while her husband, Peter (also known as ‘Briton’), was traveling abroad to renew his Visa. Because she was also on disability, she was extremely isolated and sleepy. In her own words she comments “Since we have been together, it is hard when he has to go back to England to get his Visa renewed. I have a terrible time fighting the loneliness and my sleeping gets terribly erratic.”

Peter recently contacted NN about the unfortunate passing of his wife looking for this creative outlet of her spirit so that he could share it with her family and friends at her Memorial Service. He couldn’t find a copy anywhere as this poem really was most important to them when they were apart (so why would he look for it when they were together?). The narcolepsy community came through, banded together, emailed one another, and tracked down the poem. The Underwoods are lucky and grateful to Laura Evert for finding the word document from a fellow person with narcolepsy dating back a decade. As a result, the poem was read at Sandy’s Memorial Service by Peter’s son, Richard, with whom she shared a love of reading and writing poetry. The community has learned the power of the written word through the creative spirit that lives on as art for others to enjoy, even when we may not be there to enjoy it with them. Not only are creative outlets important for ourselves, because they can be cathartic and healing in and of themselves, but they also become important to those who know and love us.

Calling Creative Corner Submissions

NN wants you to keep writing, drawing, painting, composing, and share these works of art with others. They are little pieces of you to share with your family and friends. And don’t forget the narcolepsy community!

Send submissions for future issues to
narnet@narcolepsynetwork.org.

NN is looking for female opinions about managing past, current, and/or future pregnancies with narcolepsy and/or idiopathic hypersomnia.

The survey takes between 10-20 minutes to fill out and can be found at: http://tinyurl.com/NNPregnancy

Please contact Sara Kowalczyk at sknarnet@gmail.com if you have any questions about the survey.
NN Will Host 2011 Conference in Las Vegas

Please come celebrate the conclusion of NN’s 25th year with 3 Full Days of conference sessions and support groups. This year’s conference promises to be extremely comprehensive and opportunities for attendees to enjoy of the attractions Las Vegas.

Events run Thursday, October 13 — Sunday, October 16, 2011
Welcome Reception: Thursday evening, October 13
Full Day Conference Sessions: Friday — Sunday, October 14-16

Highlighted Speakers*
Dr. David Rye
Dr. Eve Rogers
Dr. Michael Thorpy
Dr. Rubin Naiman
Dr. Neil Feldman

Location: Stratosphere Hotel
Address: 2000 Las Vegas Blvd. South, Las Vegas, NV 89104
Phone: 800-998-6937 (mention ‘narcolepsy’ for room rate)
  * Hotel part of the famous Vegas Strip

Check NN Website for updated conference details
*Conference speakers are subject to change

Conference Scholarship Applications Due August 1st

NN wants to see you at the 26th Annual NN Conference this October 13—16. For those who have limited income and/or can’t otherwise afford to attend this year’s Las Vegas conference, please consider applying for a full or partial scholarship.

To Download the Scholarship Application: Go to the NN website, click on The 26th Annual NN Conference, and then scroll half-way down the page.

Due Date: All scholarship applications must be received no later than August 1, 2011.
Finland Reports Higher Narcolepsy Risk in 4-19 Year Olds Vaccinated Against H1N1

continued from page 2

Task Force hypothesis was that specific batches of the vaccine might have been tainted or flawed. However, it appears that this is not the case as a number of batches sent to Finland were also sent to other countries. Moreover, the cases in Finland do not appear to be restricted to the same batches. The second hypothesis was that the vaccination was given at a specific time either after the person was already infected with H1N1 or before the person was infected. In this hypothesis, the timing of the vaccination and the H1N1 infection are the key factors potentially related to the development of narcolepsy. The Task Force currently believes that this theory does not explain the increase in cases as the timing of H1N1 epidemic and H1N1 vaccination in Finland was similar to the pattern in Norway where an increased rate of new narcolepsy cases has not been reported.

Narcolepsy has been associated with a specific form of the HLA II gene, the HLA DBQ1*0602 allele. However, less than one percent of individuals with this allele actually develop narcolepsy. It is currently believed that something triggers the onset of the disease in individuals with the predisposing allele. Specific triggers have not been identified. Infections have been suggested as a possible cause, but this has not been definitively proven. For this reason, the third hypothesis set forth by the Task Force was whether there were additional factors that these children were exposed to that may be necessary in order to trigger the onset of the disease. So far, all possibly Pandemrix®-associated narcolepsy cases tested for HLA II type have been positive for the predisposing allele. Unfortunately, the only available data is date of vaccination and date of diagnosis. No questionnaires or tests were done to determine other possible triggers during the same time.

The Task Force is working to determine whether this association between Pandemrix® and narcolepsy can be established outside of Finland. Researchers are trying to determine whether the immune system reacts differently to Pandemrix® in those with the predisposing HLA allele. Additionally, studies are underway to determine possible co-factors that trigger narcolepsy in the predisposed. The Task Force currently believes that the increased incidence of narcolepsy in individuals vaccinated with Pandemrix® is most likely due to the presence of another environmental or genetic co-factor.

To read more about this topic visit these websites:


Obesity Increases Metabolic Syndrome Risk

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Tips for Preventing Metabolic Syndrome

Making healthy lifestyle choices are the best way to prevent metabolic syndrome according to The National Heart, Lung and Blood Institute's website, www.nhlbi.nih.gov.

1. Keep a healthy weight - If you’re trying to maintain your weight, diet and exercise are important, but keeping an eye on your waistline is a good indicator of your risks in developing metabolic syndrome. Health problems can occur in greater intensity when waist measurements exceed 40 inches in men or 35 inches in women.

2. Follow a heart-healthy diet - Following a heart healthy diet rich in fruits, vegetables, whole grains, lean protein, and healthy fats can help prevent metabolic syndrome. Focus on staying away from fatty foods, processed foods or foods made with trans fats. Look for low-salt foods also, because a high salt intake can increase blood pressure, which is another indicator of metabolic syndrome.

3. Maintain a good BMI - A BMI between 25 and 29.9 is considered overweight, and a BMI of 30 or more is considered obese. A BMI of less than 25 is the goal for prevention and treatment of metabolic syndrome, according to the institute’s website.

4. Exercise - Getting regular physical activity helps you maintain a healthy weight and can help ward off other health problems. Any type of exercise is useful to preventing metabolic syndrome.

5. Do not smoke - If you smoke, quit, and try to avoid second-hand smoke. Smoking can lead to heart disease, heart attacks, and stroke.

6. See your doctor - Schedule regular doctor’s visits (at least annually) to keep an eye on your blood pressure, CDL, and cholesterol to make sure their values are in a healthy range. A doctor can also recommend a healthy diet that accounts for food sensitivities and/or an exercise plan to suit your needs.

Editor’s #1 Sleep Info Website: www.webmd.com/sleep-disorders
The Network thanks Cephalon, Inc. for an unrestricted grant that has partially funded graphic design, printing, mailing and other costs of publishing and distributing this issue.
Creative Corner

If we rush to solve a problem, the solution will need to be something ready-made or quickly put together, and will most likely be a project of the ego: but if we sustain the tension created by two worlds colliding, an unexpected solution will emerge eventually from the opening to soul that tension creates.
— Thomas Moore, *Soul Mate*