



National EMS Network Newsletter

Points of interest

- **Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.**
- **We do appreciate all the letters to the Editor and hope that you keep writing. We look forward to your letters and comments.**
- **We are interested in your story. Please take the time to write it and send to us for our newsletter.**
- **If you have not seen our web site yet, it's improved and holds a lot of information. Our webmaster is Robin Burkin.**

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WWW.NEMSN.ORG**

Donor Page	Page 5
From the Editor	Page 2
Genetically Engineered Foods	Page 6
In Memoriam-Dorothy Wilson	Page 1
Rare Disease Day	Page 4

In Memoriam: Dorothy C. Wilson

By Faith Rumph

Dot (Dorothy) Wilson was one of the most remarkable persons I have ever known. Keen intelligence, a sense of humor, an astonishing ability to lead others, kindness, ingenuity, honesty, loyalty, devotion to her God and others, dignity, and decisiveness characterized her. I was lucky to have worked with her on the NEMSN Board of Directors starting in early 1995 and to have met her at the 1996 NEMSN Conference in Washington, D.C. She retired from the board at the end of September 1996.



Born in 1944, Dot passed away on December 29, 2009 of complications of pancreatic cancer. When she learned she had a devastating type of cancer last fall, she sent me a letter in which she clearly stated what she knew and what she expected to happen; she then wrote simply and touchingly some personal words to me about our relationship. It was humbling to learn that she'd held me in high regard. But I know that *she* was the one who did so much for not only me but for all of us with EMS, even those who never knew her name or heard of her.

Here are words taken from the eulogy at her funeral mass:

"When I think of Dot, I remember a kind, thoughtful, generous person. She was devoted, loyal, determined, and organized. This sweet person had a great sense of humor and despite her handicap, she enjoyed life and meeting people....Dot was very devoted to God, her family, and her friends....I admired the way Dot took care of her mother....Dot loved the ocean....and loved life....Marie [friend and caregiver] had told me that she even recorded a daily wake-up call to herself in a cheerful tone which said, "Time to get up, have a wonderful, relaxing and productive day."

Who else but Dot Wilson, paralyzed from the knees down by EMS, would have thought to record such a message? One of a kind she was, indeed.

As for me, I especially loved Dot's organizational skills which, while serving on the Board of Directors, helped keep us steady and focused. For those who do not remember or never knew, Dot served NEMSN as Eastern Regional Vice President, then Executive Vice President, as well as Acting President during the critical months when NEMSN was working to finalize its non-profit status. I worked closely with her on pushing through the non-profit status from December 1995 through about February 1996,

...continued on page 3

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From The Editor...

I hope you had a wonderful holiday season and that this issue finds you feeling better in the new year. After working on the last two issues of 2009, I have done a lot of thinking about my own case of EMS.

I look back and hate what has happened to me in the past twenty years. As one of my physicians said to me, "You look perfectly normal. No one would ever guess you have so many problems." Sometimes I feel so helpless where my life is concerned and about peoples perceptions of me.

When I was first diagnosed the prognosis wasn't very good and I never expected to live twenty more years. I am very much surprised that most of us are still here and I know that I must live day by day, but some days, as most of you know, are much harder than others.

I am so very tired all the time but I push and push and then I need to collapse for a few days to make up for it. My husband does not understand how I can be sick because to

him and others, I "look normal". When you "look normal" people can't understand that you are ill.

Before EMS I worked part time, played volleyball three times a week, jogged, played racquetball, walked 18 to 36 holes of golf daily, and did many other things on top of that. Post EMS I have become a "couch potato" and exercise is a thing of the past. I miss being able to take walks, play sports and do many of the things I used to do.

I had fibromyalgia before EMS and of course that only adds to the pain and tiredness that I live with daily. I ache and hurt all over, most all of the time. My short term memory is a joke so I must write everything down or I will forget. I list everything in my Palm Pilot and set alarms for each item so they go off and remind me where or what I am supposed to be doing. Not a great way to live, BUT I am living when I hadn't expected to be here, so am making the best of it by keeping as busy as I am able or as the saying goes, "one day at a time".

Sandy

Mission Statement

The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMS is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing awareness of the cause and effects of the disease.

DISCLAIMER

The NEMS does not engage in the practice of medicine or law & does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyers & medical professionals. Opinions expressed by individual writers herein are those of the writers and not necessarily those of the NEMS Board of Directors or its committee or subcommittee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers' own physicians & attorneys.

In Memoriam: Dorothy C. Wilson

continued from page 1

and I can truthfully state that had it not been for Dot's abilities, NEMSN would never have obtained non-profit status in early 1996. Dealing with the IRS and their demanding deadlines and requests took someone with grit like Dot Wilson.

Dot stayed up through one night writing additional papers for the IRS in a way they requested (in addition to already submitted items) to satisfy last-minute requirements and deadlines. Cool-headed, clear-thinking and masterful during this time, Dot came through for us all. And so, I loved her as a mentor, friend and board colleague.

Gifted and determined, early on in EMS, Dot Wilson helped organize the EMS folks in Pennsylvania, New Jersey and Delaware. Three times a year they held "lively meetings" according to former board member Julie Allender, a resident of Pennsylvania. And though I have lost the direct quote, I paraphrase what Julie wrote to me about Dot after her death – Julie said Dot was fearless and feared neither life nor death.

Dot also testified before the Congressional Subcommittee (L-tryptophan Hearing) in July 1991. She said many things, but these ring still today:

"How could the product be contaminated? It was a pure product which the FDA controlled [Faith's note: she thought they did, as so many of us thought]. Wasn't I taking something like milk and turkey? Where was my government?... Respectfully, let me ask you – where was the FDA when this label [she read a label to them] was on a readily available product?... An editorial in the 1990 *Journal of Rheumatology* by Dr. Joseph I. Houpt, Mt. Sinai Hospital, states that L-tryptophan is associated with many illnesses, including Down's Syndrome, rheumatoid arthritis, childhood epilepsy, scleroderma and breast cancer. Wait a minute, breast cancer? I had breast cancer after I took L-tryptophan. Why didn't the FDA require a warning of possible side effects?... My heart goes out to the EMS victims.... A National Registry must be set up.... We desperately



need the CDC and the Department of Health and Human Services to follow this illness for our lifetimes and that of our children, do research and keep us and our physicians informed. I cannot think of anything more frightening than my doctors moving on and a new physician who never heard of EMS managing my care.... "

Yet, that has happened to a lot of us today. Sadly, many doctors do not even know what EMS is; some think it ended once the eosinophil count returned to normal.

Well, I could quote more or write anecdotes. I could write about all the media interviews Dot gave for the cause of EMS, the documentaries in which she was featured, and all her other good qualities and deeds.

However, above all, I just want to stress that I truly believe that during a hard time in the life of NEMSN, Dot Wilson did more than anyone to hold the group together to march on and continue to exist. When she left the board, Dot truly retired and went on to enjoy her life for more than 12 years. She deserved that time and season in her life. And so I write:

She was the epitome of wisdom and grace,

Her faults are not worth the time to name;

It's fitting we remember her talents and smiling face.

Rare Disease Day Observed on February 28, 2010



NEMSN became a partner in an international effort to promote awareness of rare diseases. The project, called Rare Disease Day, was organized in the US by the National Organization for Rare Disorders (NORD) and was observed on February 28.

As a Rare Disease Day Partner, NEMSN joined a group of over 350 patient support organizations, research groups, companies who work to develop new treatments for rare diseases, foundations, and government agencies such as the National Institutes of Health Office of Rare Diseases, in an effort, as NORD puts it, "to focus attention on rare diseases, the challenges encountered by those affected, and the importance of research to develop diagnostics and treatments. Rare Disease Day is not a single event. Instead, it is an educational and awareness campaign that began three years ago and now is rippling out around the world."

To check out the kinds of public awareness events that took place, you can check out a couple websites:
<http://rarediseaseday.us/>
www.facebook.com/RareDiseaseDay.us
 (You do not have to be a Facebook member to look at this site.)

As the organizers of Rare Disease Day remind us, "Alone we are rare. Together we are strong."

More information follows, courtesy of NORD.

Millions Around World Observing Rare Disease Day

The last day of February has been designated as worldwide "Rare Disease Day" to call attention to rare diseases, which affect nearly 30 million Americans and countless others around the world, as an important global public health concern.

"People with rare diseases remain a medically underserved population in every country," said Peter L. Saltonstall, president and CEO of the National Organization for Rare Disorders (NORD), which is sponsoring Rare Disease Day in the U.S. "This day will bring together patients and families around the globe who are dealing with some very challenging issues."

The National Eosinophilia Myalgia Syndrome Network is part of the U.S. coalition supporting Rare Disease Day. The coalition, being coordinated by NORD, includes patient organizations, professional societies, government agencies, medical researchers, and pharmaceutical and biotechnology companies.

Rare Disease Day activities in the U.S. will include a nationwide network of online videos, patient stories and blogs; newspaper, radio, and television reports; state and municipal proclamations; a Rare Disease Hall of Fame for researchers; and other activities designed to raise awareness of what it means to have a rare disease.

A rare disease is one that affects fewer than 200,000 Americans. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans.

"More than half of the people who have rare diseases are children," Saltonstall said. "Challenges faced by patients and their families include delay in getting an accurate diagnosis, few treatment options, and difficulty finding medical experts. Many rare diseases have no approved treatment. Insurance may not cover treatments that aren't approved. Also, treatments for rare diseases tend to be more expensive than those for common diseases."

In 1983, the *Orphan Drug Act* was passed by Congress to create financial incentives for companies to develop treatments for rare diseases. Since then, more than 340 "orphan" (for rare diseases) drugs and biologics have been approved by the U.S. Food and Drug Administration (FDA). FDA estimates that from 11 to 14 million Americans benefit from these products, but that still leaves more than 15 million Americans with diseases for which there is no approved treatment.

Rare Disease Day also will highlight the unique partnership that exists among the patient community, government entities such as the NIH Office of Rare Diseases Research and FDA Office of Orphan Products Development, medical professionals, researchers, and companies developing orphan products.

This will be the third annual Rare Disease Day. The concept was launched in 2008 by EURORDIS, NORD's coun-

...continued on page 6

Donor Honor Roll

December 23, 2009 through May 15, 2010

Contributors (Regular) \$5 - \$49

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Marie Rogalski in memory of Dorothy Wilson	Stephen Sheller
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Please mail your check in the courtesy reply envelope to the Treasurer, Michael Bird. If you lose the envelope, mail in your own envelope to this address: Michael Bird, Treasurer, 219 Twinlakes Drive, Fredericksburg, VA 22401

NEMSN Contribution Form

Here is my gift to support the work of NEMSN:

_____ \$15 _____ \$25 _____ \$50 _____ \$100 _____ \$250 _____ \$500 \$ _____ Other

Make checks payable to NEMSN or National EMS Network. Gifts are tax-deductible to the extent allowed by law. Thank you for your help.

Name _____ Address _____

City/State _____ Zip _____ - _____ Phone _____ - _____

- Check here if this is a NEW address and enter your previous zip code: _____ - _____
- Check here if you desire a card acknowledging your gift to be sent to you or another. Be sure to include the mailing address.

We Need A Few Good Men (and Women)

NEMSN's Board of Directors needs you. Our 9-member board is short two members. Several of our current members have served for many years and might like to pass their batons on to others.

And, we need to hold an election which is impossible to do without having candidates other than those who are

already putting time in as Board Members.

No, this isn't going to help the economy because these are non-paying positions. But, they offer unlimited opportunities to collaborate on services, publications and other activities with individuals who share the EMS experience. Please think about giving of your time and talents to help NEMSN.

Identifying Genetically Engineered Foods

Even though the FDA declared in 1992 that food which is genetically engineered (also called genetically modified) is indistinguishable from regular food, many people want to avoid eating genetically engineered products. The fear for health is that there may be unknown deleterious effects since so far, little testing has been done. Some EMS patients feel a special need to avoid genetically engineered food, given the fact that the particular tryptophan that made us sick was manufactured using genetically engineered bacteria, and this was the first time this process was used in tryptophan production. The role, if any, of genetic engineering in our EMS has never been determined, but some of us feel "better safe than sorry" and want no part of genetically engineered substances. Besides all this, a research paper from 2009, just published in the International Journal of Biological Sciences, also seems to sound a cautionary note. The paper concludes that genetically engineered corn produced liver and kidney damage in lab rats (<http://www.biolsci.org/v05p0706.htm>).

By U.S. law, stores are not required to label genetically engineered products. When you buy any unlabeled produce, you do not know if it is genetically engineered or not.

However, if the fresh produce you have your eye on has a little sticker on each piece with a few numbers on it, a PLU (Price Look-Up) code, you can tell what you're buying. The PLU codes are issued by the International Federation for Produce Standards, an organization that, among other things, has assigned a unique number to every variety of produce that is sold in bulk by weight. Plus if the PLU code on that sticker on your fruit or vegetable has 4 digits only, it is a "conventional" product, meaning that it is not genetically engineered and was grown in the usual way, with chemical fertilizers and pesticides. If the PLU code has 5 digits and the first one is "8", it is a genetically engineered product. If the PLU code has 5 digits and the first one is "9", it is an organically grown product, grown without chemical fertilizers or pesticides and not genetically engineered.

For example, here are three possible PLU codes for a Gala apple:

4135 - a conventional Gala apple

84135 - a genetically engineered Gala apple

94135 - an organic Gala apple

If the type of fresh produce you want has no PLU label, the only way to insure it is not genetically engineered is to buy something labeled "organic". A caveat to this is that certain stores, Whole Foods for example, offer assurances in writing that none of their produce is genetically engineered. Without something in writing however, don't assume this is the case. Investigate thoroughly.

With packaged food, only the designation "certified organic" means that 100% of the ingredients are organic. The phrase "contains organic ingredients" means that 70% of the ingredients are guaranteed organic. The other 30% may be conventionally produced or genetically engineered. According to one fascinating website, cited below, any food containing corn oil, soy oil, or cottonseed oil is probably from genetically engineered plants unless there is a disclaimer (<http://www.innvista.com/health/foods/organics/labeling.htm>).

Finally, if you're not a strict vegetarian, keep in mind that in 2009 the FDA issued guidelines concerning livestock. Genetically engineered meat, dairy products and eggs may already be being sold in our grocery stores. No labeling is required.

- Lois Vierk

Rare Disease Day

continued from page 4

terpart in Europe. Last year, EURORDIS asked NORD to host Rare Disease Day in the U.S. Rare Disease Day also is observed in Canada, Australia, and China. The observance is always on the last day of February.

NORD was established in 1983 by patient leaders who helped get the *Orphan Drug Act* passed. It provides advocacy on behalf of the rare disease community; research grants and fellowships; educational services; and patient assistance programs.



Remember to use iGive.com to help earn

For your shopping use <http://www.iGive.com>

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You earn money every time you shop online at any of their 778 participating stores. And when you search the web through iSearchiGive.com (a search engine powered by iGive!), you are raising a penny or more for NEMSN every time.

If you do happen to make a purchase through iGive within 45 days of joining, they'll donate an EXTRA \$5 to NEMSN! With 778 stores in the iGive Mall and the new iSearchiGive.com search engine, it's easy to find the things you need AND raise money for a good cause.

HOW IT WORKS:

1. Join iGive.com to support NEMSN. It's free, safe, and easy to join. Use this link:

<http://www.iGive.com/welcome/warmwelcome.cfm?c=7829&m=568610>

Don't feel like registering? Take iSearchiGive.com out for a spin and raise a penny (or more!) per search. Just visit <http://www.iSearchiGive.com> and type "NEMSN" in the "Select Your Cause" area.

2. Shop through iGive.com's online mall

~ OR ~

Raise a penny search at [iSearchiGive.com](http://www.iSearchiGive.com)

The iGive Mall features over 700 trusted online retailers like Amazon.com, Staples, Nordstrom, JCPenney, eBay, Expedia.com, Barnes & Noble, QVC, & PETSMART to name just a few! You'll NEVER pay more when you reach these stores through iGive.com. And if you take advantage of the coupons and free shipping deals posted at iGive, you might even save a few bucks! And with iSearchiGive.com, each qualified search earns a penny (or more!) for your cause.

3. Watch the \$\$ roll in for NEMSN! **As of this date, we have earned \$62.40 from iGive.com**

Up to 26% of EACH purchase through iGive benefits your

cause, along with a penny (or more!) per qualified search at iSearchiGive.com. Make that first purchase within 45 days and get a bonus \$5 donation, too!

Use this link to JOIN iGIVE FOR FREE and begin supporting NEMSN:

<http://www.iGive.com/welcome/warmwelcome.cfm?c=7829&m=568610>

Don't feel like registering? Take iSearchiGive.com out for a spin and raise a penny (or more!) per search. Just visit <http://www.iSearchiGive.com> and type "NEMSN" in the "Select Your Cause" area.



GoodSearch.com is also a way to help earn money for NEMSN.

As of this date, we have earned a total of \$178.74 by using it to search on the web or using GoodShop.com to shop online.

How does it work?

Simply go to www.goodsearch.com for your web searching and earn a penny for NEMSN each time you search the web, and when shopping, click on the GoodShop link or go to www.goodshop.com.

In the "Who do you GoodSearch for" box type in NEMSN. Next, click through to our partner merchants (clicking on the merchant's link will open a new browser window and redirect you to their site) and start shopping! A percentage of your purchase will go to your favorite charity or school.

How much can I generate for NEMSN by shopping through GoodShop?

The amount donated is different for each retailer but it averages approximately 3% of the total sale and can go up to 20% and beyond (the percentage donated is indicated below the merchant's logo). The total amount raised can quickly add up and the sky is the limit. The more people shop through GoodSearch, the more money will be directed towards good causes. There is no cap on how much money we will direct to charities and schools!

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