

# THE COPPER CONNECTION

September 2001

## NORD's Current Goals

Wilson's Disease Association is a member of NORD which provides many benefits including campaigning for people with all rare diseases. The following is NORD's current goal in Washington D.C.

On August 3, 2001, Senators Orrin Hatch (R-UT) and Edward Kennedy (D-MA) introduced the *Rare Diseases Act of 2001* (S.1379). Congress made the following findings:

- ♦ 25 million Americans suffering from over 6,000 rare disorders were denied access to effective medicines because prescription drug manufacturers could rarely make a profit from marketing drugs for such small group of patients.
- ♦ The Orphan Drug Act (ODA) created financial incentives for research and development of such "orphan drugs."
- ♦ Despite the success of the ODA, rare diseases and disorders deserve greater emphasis in the national biomedical research enterprise.
- ♦ The National Institutes of Health (NIH) has received substantial increases in research funding from Congress for the purpose of expanding the national investment in behavioral and biomedical research. Notwithstanding such increases, funding for rare diseases and disorders at the NIH has not increased appreciably.
- ♦ The Food and Drug Administration (FDA) supports small clinical trials on new treatments for rare disorders through *Orphan Products Research Grants*. Yet the appropriations in FY 2001 for such research grants were less than in FY 1995.

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## CHARITABLE GIFTS



Charitable gifts are urgently needed by the Association to continue and expand its

work. Please give and ask friends, relatives and employers to give too. Check with your employers for "matching programs". There is never any shame in asking for gifts for others. It's like passing the box at religious services. Gifts bring pleasure to the donor. We can also arrange trust and annuities which benefit you and the Association. Just the cost of a soda a day is \$180-\$365 per year.

## Save The Date

The 2002 WDA annual meeting will be in Chicago, Illinois on May 4-5, 2002. Details to follow in future newsletters.

## WDA Web Site ([www.wilsonsdisease.org](http://www.wilsonsdisease.org))

Have you visited the WDA web site lately? We have a whole new look and many new links full of information regarding Wilson's Disease. You can print out membership forms, read previous Copper Connection issues and communicate with International WD contacts. You will also find useful information about upcoming WDA annual and support meetings.



## My Story

By Nicole Rupp

I was 25 years old when I was diagnosed with this disease. The one thing that drove me nuts was all the stares that I would get. I could not help the way I looked. I was a hermit. Then I went to spend two boring months at the University of Michigan. I met a lot of nice people that understood what we are going through. I then went to be with some family in Ohio. They didn't understand my Wilson's Disease and kept telling me to get better.

I then came home to Florida. That made a world of difference. My mom found this great place called HEALTHSOUTH, which is a rehab facility. They had only seen two Wilson's patients in the past. They were treating me the same way in the area of speech. They were feeding me food like yogurt. Of course I could not swallow. The yogurt would just come out. And as my dad would say "I was drooling like a faucet". I was at HEALTHSOUTH for 22 days. I got my self-esteem back. I walked with my head held high. I then went to have a swallow study. I walked in there thinking I am going to show them. But, WHAM!—I was told I would never eat again. I was devastated. I shook my head. I said, "Yes I am going to eat again." If you are wondering why eating is so important to me, it is because I am a CHEF! Then I went to see Dr. Brewer at the University of Michigan. He told me to get on with life and to start eating. That was music to my ears. I am eating!! I went back to see the lady that told me I would never eat again. She was amazed. I got Botox for my drooling. My life is looking up.

My life is really looking up. I am driving. You have to take one day at a time. Tell your loved ones that. Thank you for letting me tell my story. Stay positive... there is a light at the end of the tunnel.

### Medical News

Brought to you by the WDA Medical Advisory Group

#### Pregnancy and Zinc Fred Askari, M.D.

Zinc is a well accepted treatment for Wilson's Disease maintenance therapy. During pregnancy, the fetus needs copper to grow. The mother's medication dosage should therefore be monitored during pregnancy to insure that the mother's Wilson's Disease is properly controlled without causing copper deficiency (over treatment) which can be dangerous to the fetus.

Dr. George Brewer, at the University of Michigan, has an open pro-

ocol to monitor zinc dosing in pregnancy. This protocol does not always require a trip to Ann Arbor and can even be done through the mail.

Women interested in this protocol may contact Dr. Brewer for involvement in this "stepped up monitoring and zinc dosing protocol" during pregnancy. He may be reached at: [brewergj@umich.edu](mailto:brewergj@umich.edu).

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#### **What does the *Rare Diseases Act of 2001* do?**

- ◆ Increases the national investment in the development of diagnostics and treatments for patients with rare disorders.
- ◆ Authorizes regional centers of excellence for rare disease research and training.
- ◆ Increases funding for the NIH Office for Rare Diseases to \$24 million for fiscal year 2002 and "such sums as may be necessary for each subsequent fiscal year."
- ◆ Increases the funding for the FDA's Orphan Product Research Grants program, which has provided vital support for clinical research on new treatments for rare disorders to \$25 million for fiscal year 2002, and "such sums as may be necessary for each subsequent fiscal year."

## Think Positively!!!

I was always an A-student. Education was very important to me. In tenth grade my grades began to slip. I was getting severe headaches, couldn't concentrate, had difficulty speaking, difficulty swallowing and my hands were trembling.

As my parents took me from doctor to doctor, each one had a different diagnosis for my disease. After having gone through a multitude of tests: spinal taps, brain scans, x-rays, etc., one of the doctors looked into my eyes and asked me if I had ever had my liver tested. After a year or so of pain, anguish and uncertainty, I was diagnosed with Wilson's Disease. I stayed in one hospital 2 months, in another 6 months, 6 months again, 4 months and 2 months again. Hospital was my home. Doctors and nurses were my extended family.

I went to school in the hospital. I kept my eyes and ears open to everything going on around me. I felt that in school I was learning reading, writing, arithmetic, but Wilson's Disease was giving me lessons in life: Lessons in patience, perseverance, fortitude and compassion. Doctors, nurses, patients, visitors, they were all my teachers.

It was time to stand on my own.. I was well anchored and my spirit was strong. I started college where I was on the Dean's List. I graduated college and started a job in the health care field.

I enjoy and appreciate life immensely. My husband and I love to travel and have traveled the world. I look at life and at things in the world with a sharper focus and never take anything for granted.

There are still residue signs of Wilson's Disease in me, but I don't complain. Wilson's Disease is a part of my life but only a small part. I'm grateful that I'm alive. I thank all the dedicated doctors and nurses who care. I thank my family and friends for always being there. To the newly diagnosed patients I want to say:

Do not despair! Others have been there.  
Be Patient! Think Positively!  
There is a light at the end of the tunnel.  
Learn from every situation/experience in life and be a stronger and better person.

Submitted by CGS

## FREEDOM PINS Handmade by Janene Bowen

Last year we attended my wife's 20-year high school reunion and we were pleased to see the impressive accomplishments of that group. We want to tell you who we think is the most successful. Her name is Janene Bowen.

Janene was in the top ten, academically, in this outstanding class. She was an accomplished pianist and a wonderful young lady with a bright future. However, during her senior year she was diagnosed with Wilson's Disease, a rare ailment where the body stored copper and made it dysfunctional.

While talking with Janene, we noticed a beautiful American Flag pin on her lapel. She explained that she made it and that it took five days to complete the first "Freedom Pin".

Janene is a remarkable lady who is high on our list of heroes. Her goal in life is service. Our "Freedom Pin" hangs in a prominent place in our home to remind us of the most important things in life.

(Told by Brad and Rosie Johnson)

## DONATIONS

We gratefully acknowledge the following people for contributing to the Wilson's Disease Association:

Mark Clements	\$600
(matched by Cal Fed)	
Julian and Barbara Fox	\$500
Janene Bowen	\$852.95
(raised selling Freedom Pins)	
Friends of Barbara Fox	\$375.00
(in honor of her graduation)	
Joe and Serema Papa	\$1000

## Nutritional Supplements

The FDA has banned imports of aristolochic acid, which is used as a nutritional supplement for weight loss. FDA reports that the herb causes kidney failure. ABC TV's "20/20" program sent 100 bottles of popular nutritional supplements to a lab for detailed analysis. The program found, "there is no way for a consumer to know what's in a pill." One in four of the bottles did not contain the ingredients that were listed on the label.

For example, out of 15 brands of the popular arthritis supplement chondroitin, eight did not have the amount listed on the label. Four bottles had less than 10 percent of the labeled dosage. The prices ranged from \$6 to \$55 per bottle. Americans spend an estimated \$15 billion per year on nutritional supplements.

On December 12, 2000, the International Olympic Committee urged increased regulatory oversight of the supplement industry. The Committee cautioned athletes of the world that many supplements contain drugs that can cause athletes to test positive for banned substances.

An independent laboratory, ConsumerLab.com is testing nutritional supplements for quality and potency, and posting the test results on its Web site so that consumers will be able to judge which brands have the highest quality products. You can access the site at: <[www.consumerlab.com](http://www.consumerlab.com)>.

(NORD Orphan Disease Update, Spring 2001, Volume XIX, Edition2)

### HOW TO OBTAIN CUPRIMINE OR SYPRIN

(If not available through their normal sources)

- 1) Call the Merck Sharp Dohme site in your country.
  - 2) If they do not have a site in your country, call the Merck National Service Center at: 1-800-672-6372, and they will forward your request to the appropriate contact.
  - 3) The National Center will request the following information:
    - Requester's name, agency, phone, fax, e-mail
    - Product shipping address/contact/phone/fax
    - Product name/strength/pack size/NDIC (catalog #)/total quantity of product expected
    - Medical emergency? Level of urgency?
    - Copy of prescription, including diagnosis
    - Regulatory/shipping/importation requirements
- If you need any further assistance, please contact: Mary Graper at (414) 961-1290 or by e-mail, [mltgraper@aol.com](mailto:mltgraper@aol.com).

### CHANGE OF ADDRESS?

Have you moved recently? Do you have a new address? Please take a moment today to send us your correct address so that you will not miss out on future Copper Connection issues. This also helps us keep our mailing list updated and the Post Office happy. Please use the Membership Form to make any changes.



The Wilson's Disease Association expresses its condolences to the families of:

**Vanessa Manalo, 16 years old  
(Phillipines)**

**Allison Bruder, 17 years old  
(Georgia, USA)**



### Send Us Your Letters

We would like to hear from WDA members. Send us your letters, news to share, or other information that you would like to share with other WD patients and families. Please mail to Delia Ruiz, Copper Connection Editor, P.O. Box 1225, Pismo Beach, CA 93448 or e-mail to DRNDVR@aol.com.

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<p><b>Wilson's Disease Association</b> Ascher Sellner, M.D. President 4 Navaho Drive, Brookfield, CT 06804 1 (800) 399-0266 E-mail: <a href="mailto:hasellner@worldnet.att.net">hasellner@worldnet.att.net</a> WDA Website: <a href="http://www.wilsons-disease.org">www.wilsons-disease.org</a></p>
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### WDA Board Members

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Nancy Hoffman	Sparky Terry
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## **WILSON'S DISEASE ASSOCIATION, INTERNATIONAL**

The Copper Connection, Editor  
P.O. Box 1225  
Pismo Beach, CA 93448

(FORWARDING SERVICE REQUESTED)

**TO:**