
◆ THE COPPER CONNECTION ◆

Wilson's Disease Association Newsletter

DECEMBER 1997

President's Message

Exciting developments have occurred since our annual meeting and the last newsletter.

1) Zinc acetate usage is catching on quickly. Physicians are prescribing it on their own initiative and when patients ask them. Patients need simply start 50mg. zinc acetate three times daily on an empty stomach and eat nothing afterward for an hour. Follow-up requires 24 hour urine for copper; which should be less than 2 mg/24 hours. In addition, an annual history and physical with complete blood count and chemistry profile are also necessary. Zinc is available with a prescription. The medication is available from Athena Drug 1(800) 5 ATHENA.

2) Dr. Brewer and Dr. Schilsky have submitted a new drug investigation application comparing tetrathiomolybdate to trientine as initial therapy in Wilson's Disease. The study will be carried out in the clinical research units at the University of Michigan and the Albert Einstein College of Medicine. Patients just diagnosed or being diagnosed, including those informed that they may have Wilson's Disease can contact Dr. Brewer at (313) 764-5499 or Dr. Schilsky at (718) 430-2091. For additional information or assistance, please call me at 1(800) 399-0266.

3) I have met with Dr. Scheuer, Chairman of the Department of Medicine at the Albert Einstein Col-

lege of Medicine to work on the details of his department becoming a Wilson's Disease center of excellence. Such centers are also being developed at Johns Hopkins with the help of Dr. Pat Charache, Professor of Pathology, who also has Wilson's Disease. In addition, Dr. John Vierling is proceeding with the development of his center at Cedars Sinai in Los Angeles and at the Denver Children's Hospital with the direction of Dr. Sobel.

4) Arrangements have begun for our next annual meeting thanks to the direction of Bonnie Smelser. It is scheduled for April 18 and 19, 1998 in New York.

5) A used slit lamp was purchased for Dr. Schilsky by contributions from the president's discretionary account and Mr. Jack Levin who, in addition, matched my parent's \$5000 gift to the president's discretionary account.

6) Special thanks to the increasing number of people who have been of help to me and the Association, including Leticia Martinez, Len Pytlak, Luke Chung, Carol Terry, Phyllis King, James Moseley, Delia Ruiz, Dr. Brewer, Dr. Schilsky, and Dr. Stall. If you have offered to help or wish to begin to help, please give me a call.

Ascher Sellner, M.D.
President

An Effective New Weapon in the Treatment of Wilson's Disease

GALZIN™ (zinc acetate), an effective new weapon in the treatment of Wilson's Disease, has been approved by the FDA. Used as a maintenance treatment for Wilson's Disease, this drug is a vital alternative to chelating agents - until now the only form of therapy for this disease. Although persons with Wilson's Disease must initially undergo a treatment with a chelating agent. These agents are known to cause serious, even life threatening, adverse reactions in patients and may be associated with a greater incidence of fetal abnormalities.

GALZIN™ is a particularly effective alternative for maintenance treatment because it has shown no long-term or major side effects in patients. Most importantly, GALZIN™ can be taken by pregnant women and young children. In studies of patients using GALZIN™ during pregnancy, there has been no evidence of increases in the risk of fetal abnormalities with its use. GALZIN™ can be used, long term, in place of nontolerable chelating agents and can therefore be a major weapon to fight this rare, otherwise progressive illness.

Until the advent of GALZIN™, chelating agents (penicillamine and
(continued page 4, GALZIN)

One More Nightmare by Carol Sellner

I woke up startled. My husband was nudging me and moaning, "I can't see. You need to take me home" he said. It was 4:00 a.m. and we were in Maine, 350 miles from home. He was extremely argumentative and delusional. I knew I had to get him to his physician in New York City, a specialist in Wilson's Disease. I knew I could not handle the situation on my own. One minute he would be sitting with his head tilted back, eyes and mouth wide open as if he were in a coma and the next minute he'd insist I was on the wrong side of the highway and try to get out of the car. I stopped and picked up his son on the way to the doctor in New York.

My husband was diagnosed with hepatic encephalopathy. He had progressed into liver failure. We were told he should stop all activities and take the steps necessary for a liver transplant. He was also put on medication that within 24 hours cleared up his symptoms. The change in his behavior was so fast I almost felt I had simply awakened from a nightmare.

My husband's sudden loss of vision was one symptom in a series of symptoms that had been building for months. His symptoms did not seem related and the progression of these events was gradual. Six months prior to his sudden loss of vision, he went on a diet to lose a few pounds. He simply cut back on his food intake and started losing weight. The weight came off easily and without effort, he continued to lose weight. Then suddenly in two weeks time, he gained 20 pounds. His legs and stomach were swollen. He also had periods of loss of balance and occasionally he would stumble over his words. His moods went from very high to very very low. The weight loss and gain had caused us to see his physician in New York. He was told to cut back on his salt and take diuretics.

When we were told to prepare for a liver transplant, we were in shock.

(continued page 3, NIGHTMARE)

FREEDOM PINS

A great big thanks goes to Janene Bowen of Bountiful, Utah for making her U.S. Freedom Flag pins to raise money for the Wilson's Disease Association. Janene has raised over \$400 from the sale of her pins. She is on the WDA Board of Directors and has been a loyal supporter of the Association for many years. Although she has a difficult time getting around due to the neurological effects of WD, she always hands out WDA brochures at church and wherever she does go.

If anyone is interested in purchasing one of Janene's Freedom pins, please send a check for \$9.95 per pin to:
Carol Terry, WDA Treasurer
P.O. Box 75324
Washington, DC 20013

All proceeds go to the Wilson's Disease Association.



THANKS JANENE!!

WILSON'S DISEASE ASSOCIATION MEMBERSHIP APPLICATION

A donation to WILSON'S DISEASE in honor/memory of a family member or friend could be the best present of all to receive and give. WILSON'S DISEASE will send a card notifying the person or family named below of your contribution.

In honor of In memory of Enclosed is my contribution of \$ _____. (PLEASE CHECK ONE)

In honor/memory of _____ (PLEASE PRINT NAME).

Send acknowledgment of gift to: _____

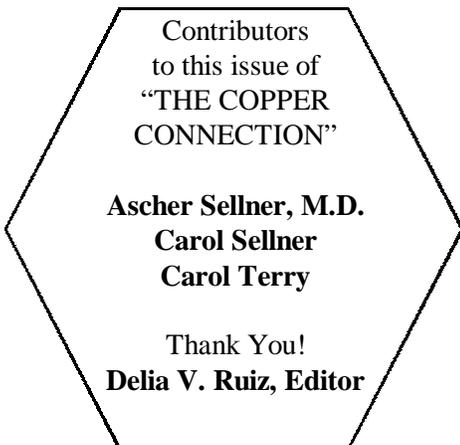
(Please Print Name)

Donor's name & address: _____

**Upcoming WDA Annual Meeting
Date and Location Selected**

The next annual Wilson's Disease Association meeting is planned for **April 18 and 19th, 1998**. It will be held at the Albert Einstein College of Medicine in New York. This will provide an opportunity to familiarize the organization with the new center of excellence. The next issue of THE COPPER CONNECTION will include more information.

Thanks to all of you who voted in the annual meeting selection survey.



(NIGHTMARE, from page 2)

My husband also consulted with his other Wilson's Disease specialist. The two physicians gave us conflicting advise. We also met with two liver transplant specialists whose advise was conflicting.

It has been three months since the onset of my husband's encephalopathy. He watches his salt intake and keeps his protein intake to a minimum. His mood swings are what I would call normal for him. His fluid retention is under control. He feels good about his weight. He still has his liver.

So what does all of this mean? My husband was diagnosed with Wilson's Disease 30 years ago and has remained strictly compliant about always taking his medication. Unfortunately, compliance is not a guarantee that the disease is completely under control. He has had countless health problems complicated by this disease. Whenever physical problems arise, we immediately contact the Wilson Disease specialists.

Wilson Disease patients can not be treated like any other patient. Their disease makes them different. We have been involved with the most knowledgeable physicians in this country and we attended an international symposium with physicians worldwide specializing in Wilson's Disease. We have heard hundreds of stories from patients and families from around the world about the nightmares of Wilson's Disease. Two issues are very clear. Compliance to medication and consulting Wilson's Disease specialists in times of health problems are absolutely essential. Unfortunately, Wilson's Disease is unpredictable and there are questions that have no answers.

It's at times like these that the importance of the Wilson's Disease Association rings loud and clear. The Association not only is a support system for patients and their families, but it promotes research into this ugly disease. Yes, there can be confusion about this rare disease, but at least there is some place to call and someone to talk to.

Yes, I want to join in the effort to help Wilson's disease patients. My membership/contribution will help continue WILSON'S DISEASE programs of education, research, advocacy and support services. Dues are renewed annually.

Membership Annual dues (Please make checks payable to Wilson's Disease Association):

BASIC INDIVIDUAL/FAMILY	\$ 35.00
SUSTAINING	\$ 60.00
ENDOWING	\$ 100.00
LIFE	\$1000.00
OTHER	\$ _____

I cannot afford dues at this time, but please accept my contribution \$ _____

(PLEASE PRINT NAME/ADDRESS)

NAME: _____ PHONE:_(____)_____

ADDRESS: _____ STATE: _____ ZIP _____

(GALZIN from page 1)

trientine) had been the sole treatment available for patients with Wilson's Disease. Used as an initial therapy, chelating agents appear to work in different ways; penicillamine, for example, works by bonding with copper (and other heavy metals) to form stable complexes that are excreted in the urine.

A patient with Wilson's Disease who is treated initially with a therapy of chelating agent can then be maintained with GALZIN™ (zinc acetate). This is particularly important for patients who have developed adverse reactions to chelating agents. GALZIN™ appears to induce the intestinal production of metallothionein, a protein with a high affinity for copper. This action blocks copper absorption by binding copper with enterocytes. This means that any newly ingested copper does not reach the circulation system and so is excreted mainly in the stool.

GALZIN™ is a breakthrough in the treatment of Wilson's Disease. For more information about GALZIN™ consult your physician or inquire at the Wilson's Disease Association by phone: (800) 399-0266, or on-line: HASellner@worldnet.att.net.

Wilson's Disease Discussion Group On the Internet

A Wilson's Disease Listserv Discussion Group has been set up by Robert Stall, M.D.. Dr. Stall is an internist/Geriatician who has WD and is an active member of the Wilson's Disease Association. The Listserv allows an individual to join (at no cost) and to participate in on-going discussions about WD. Mail is sent to the Listserv address and everyone on the mailing list receives mail.

There are currently about 30 members from all over the world. To subscribe to the Wilsons Listserv, go to the web site:
<http://www.acsu.buffalo.edu/~drstall/>

You can send mail directly to Dr. Stall who will then add your name to the List.

Wilson's Disease and Skunks??

Odd, but true, some WD patients are known to NOT be able to smell skunks. An informal poll was recently taken from the Wilsons Listserv and out of 24 responses, 6 reported the ability and sense of smell for skunks, 14 reported NO SMELL for skunks, and 2 did not know (hadn't encountered skunks).



D-Penicillamine was considered the culprit since sense of taste is a known side effect of penicillamine, although further inquiries of the respondents showed that a few of the "NO's" had never taken Penicillamine. Baffling information suitable for research? Hmm!!

Anyone interested in being a respondent in this informal poll, please send your response (specify medication used) to THE COPPER CONNECTION editor.

Wilson's Disease Support Groups

Support Groups provide an excellent opportunity for WD patients, families and friends to come together to share and learn new information about WD; its treatments and resources. If you are interested in starting a group in your area or joining an existing one, contact Dr. Sellner, WDA President at (800) 399-0266.

Support groups have been formed in Los Angeles and Florida. Call for more information.

Congratulations to Dr. Charache for getting Chicago Hope (television series) to include an episode about Wilson's Disease on Monday, October 27th. The episode involved a student who came to the emergency room with a fracture. His blood test before surgery showed abnormal liver function and a bleeding disorder. His behavior was abnormal for the situation and he also had neurological symptoms. After much puzzlement, the diagnosis was made and he was placed on medication.

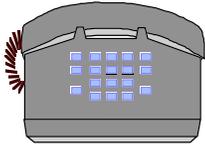
Do You Have Some News To Share?

Our next issue of THE COPPER CONNECTION will include a section for WDA member news such as marriages, births, new jobs, support groups formed, etc...

To share your "news", send it to:
 THE COPPER CONNECTION, Editor
 P.O. Box 1225
 Pismo Beach, CA 93449

or E-mail to DRNDVR@aol.com

Wilson's Disease Association



Telephone Number

1 (800) 399-0266

Web Site Address

www.medhelp.org/wda/wil.htm

A Letter From Bernadine Wade Wall

On January 5, 1996, Bernadine Wade Wall's eldest son passed away from Wilson's Disease. The following is an excerpt from her sincere letter she wrote to Dr. Sellner:

"...Rick would have been 40 years old on September 28th. Since we were unable to celebrate his birthday, I decided to do something in his memory. I sent out over 50 letters to family and friends asking that they please make a contribution to the Wilson's Disease Association. The letter explained a little about the disease and how it affected Rick...

Again, I want to thank you for being very informative and compassionate at a time when our world had fallen apart. There isn't a day goes by that I don't think of Rick and miss him. He will always be in my heart."

*Sincerely,
 Bernadine(Bernie) Wade Wall*

DONATIONS

We gratefully acknowledge the following gifts of \$100.00 or more:

\$100 - \$999

- Verônica de Mello Barros
- Carol and Susan Cross
- Arlene Gottlieb
- Steven Ortel
- Mr. & Mrs. Charles Shannon
- Mr. & Mrs. Slavin
- Edward Wade in memory of Rick Wade
- Mr. & Mrs. George Wagner
- Walter and Lori Wall in memory of Rick Wade
- John and Karen Wall in memory of Rick Wade
- Eugene Williams

\$1000 - \$5000

- Frances Fang-Tze Lin
- Joyce Kline
- Jack Levin

Thank You!

Book Resource

Wilson's Disease

Author: Tjaard U. Hoogenraad
 Publisher: W.B. Saunders Co. Ltd.
 24-28 Oval Road
 London NW1 7DX UK
 Price: approximately \$90

Canada and U.S.A. addresses:

Harcourt Brace & Co.
 55 Horner Avenue
 Toronto, ON, M*Z 4X6, Canada

The Curtis Center
 Independence Square West
 Philadelphia, PA 19106-3399, USA

PLEASE NOTE:

Volunteers are always needed to help Dr. Sellner with the many activities and projects planned by the Wilson's Disease Association. If interested, please call Dr. Sellner at (800) 399-0266.

NOTE:

If you have changed your address, please send us your current address so you will not miss the next edition of "THE COPPER CONNECTION".

NAME: _____ TELEPHONE __ (____) _____

ADDRESS: _____

STATE: _____ ZIP CODE: _____

Please mail your change of address to: Leticia Martinez, P.O. Box 1225, Pismo Beach, CA 93449

Inside This Issue:

*An Effective New Weapon in the Treatment
of Wilson's Disease*

WILSON DISEASE ASSOCIATION

H. Ascher Sellner, M.D., President
4 Navaho Drive
Brookfield, CT 06804

(Address Correction Requested)

TO:
