
❖ THE COPPER CONNECTION ❖

Wilson's Disease Association, International Newsletter

NOVEMBER 1998

President's Message

Our next annual meeting will be in Ann Arbor, Michigan. Please read the update information in this issue of the Copper Connection. I hope to see many of you there.

In order to reach many who cannot make it to Michigan, we are also planning new WDA Chapters and meetings in Atlanta and California in 1999. Please let me know if you can help with organizing any of these meetings.

The FDA has approved a grant by Drs. Brewer and Schilsky to study tetrathiomolybdate and trientine. They will need at least 20 new neurologic patients the first year to continue the grant the second year. If you can spread the word that we are looking new neurologic patients, please do so.

We had a good response to our questionnaire on women's reproductive history. If you have not sent one in, please do so now. You will find it in the last newsletter or on the WDA website. You may also contact me for one.

The Association needs more contributions. Please learn to ask those who may be able to give. They may be friends, relatives or employers. We received \$1000.00 in matching gifts from two corporations last year.

Remember your flu shots. Remember your hepatitis A and hepatitis B vaccines. **REMEMBER: NONCOMPLIANCE IS A FATAL ILLNESS.**

I wish you all a healthy and happy New Year. For those of you with substantial health problems, I wish you improvement and I send you my prayers.

H. Ascher Sellner, M.D.
President

1999 WDA Annual Meeting Location Update

The 1999 WDA Annual Meeting will be held on Saturday, May 8th in Ann Arbor, Michigan. This new location was necessary in order to guarantee a fulfilling program. A Friday night social is planned for those who arrive in town Friday night.

The conference will include a visit to the clinical research center at the University of Michigan. Flights can be reserved to arrive in Detroit, which is less than one hour away from Ann Arbor.

Specific information regarding the conference agenda and hotel accommodations will be included in the next Copper Connection issue. For questions regarding this event, please contact Dr. Sellner at 1 (800) 399-0266.

CHANGE OF ADDRESS?

Have you recently moved? 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. Use the form on the last page of this issue. Many thanks to all of you!!

NONCOMPLIANCE

Is A Fatal Illness!!



The Wilson's Disease Association volunteer staff apologizes for any donation misprints published in the last issue of the Copper Connection.

LETTERS

The Wilson's Disease Association receives many letters from members. Some of these letters include personal experiences from individuals who either have WD, their families or friends. This page is included as a way to help us all keep in mind that real people are involved in this Association and we can all learn from each other's questions, comments and experiences.

We welcome all letters!! (Please include in your letter permission for printing in future Copper Connection issues). Send your letter to: The Wilson Disease Association, 4 Navaho Drive, Brookfield, CT 06804.

Dear Dr. Sellner and Wilson's Disease Association Friends,

I am deeply grateful for your recent financial help with travel expenses. Our son Charlie is in Jack Weiler Hospital in the Bronx. We have about a two hour drive and just the incidental costs were becoming significant. Your help has given relief and hope.

Also Dr. Sellner's earlier recommendation that we have our son see Dr. Michael Schilsky has been a blessing from God for us. Charlie was almost a lost cause in the eyes of my wife and I until Dr. Schilsky's quick and decisive intervention.

Before now, the management of Charlie's case was continuous, but we now realize it was also almost fatally flawed, due to the attending physicians we've seen before not knowing what was unacceptable deterioration, nor what rehabilitative procedures could accomplish.

Dr. Schilsky has taken command of Charlie's situation... It is awe-inspiring to find someone so knowledgeable, efficient, and personable. Truly he cures the patient more than the disease, in a manner of speaking.

There are so many we are indebted to. I can only ask that God might bless you all with grace for helping give Charlie a new life.

•D.C.

Dear Copper Connection,

I am a 30 year old woman with WD, and I was diagnosed a year and a half ago. I would like to thank the editors of this newsletter, the WDA, Dr. Brewer and his staff and the nurses at the University of Michigan. You have all helped me feel like I'm not alone. Thank you for the good work that you do!

I would also like to respond to a couple of the letters in the last issue of the Copper Connection. I, too, have never been able to smell skunks and I also have red hair. To the parents of the son with WD with the personality change, I would like to say that this is typical WD. I used to be reserved, and conservative... now I am a joker and kind of impulsive. I get angry like their son although my anger comes out in tears instead of aggression. I have two doctors—one that treats the WD and another local doctor that is a neuropsychiatist that is in contact with my other doctor to help me with day-to-day problems.

•Cindy Popp
St. Louis Missouri

Hello, I am a high school senior diagnosed with Wilson's Disease. The diagnosis was made after a liver biopsy about seven years ago. At first, the doctors thought I had Mono, but after many months of fatigue, they began to search for other answers. After visiting with my specialist today and hearing about the new Zinc, I decided to do some research on it, and found your page. It was very informative, and gave me some information that I never knew about the disease and it's medications. I have been on Syprine (Trientine) for the past five years, and my liver enzymes continue to look great and there has never been any sign of neurological symptoms (or the Kayser-Fleischer ring). My doctor feels that I have made so much progress that the Zinc is the way to go, especially since I am now 18 and having a family will be something that will be considered not too far away. Thanks for your time and the great info on your page.

•Denise Belk

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Resource Corner

Wilson's Disease Association

1 (800) 399-0266

WDA Internet Website

www.wilsonsdisease.org

Centers Of Excellence

John Vierling, M.D.

Cedar Sinai Liver Center
Los Angeles, California
Contact Nurse Vesna Grubic (310) 967-0125
e-mail: liver@csmc.edu

George Brewer, M.D.

Department of Human Genetics
University of Michigan
Ann Arbor, Michigan
Phone: (313) 764-3784

Michael Schilsky, M.D.

Liver Research Center
Albert Einstein College of Medicine
Bronx, New York
(718) 430-2091
e-mail: schilsky@aecom.yu.edu

Wilson's Disease Organization in Germany

Morbus Wilson e.V.
Geschäftsstelle
Meraner Strabe 17
8200 Rosenheim
0 80 31-44 119

Wilson's Disease Listserv

Discussion Group

Click on "discussion" in the WDA website
or send e-mail directly to:
www.acsu.buffalo.edu/~drstall/

Wilson's Disease Patient Histories

www.gourmandizer.com/wilsons

Los Angeles Chapter Meeting

A Los Angeles WDA Chapter meeting is scheduled for **Sunday, January 17, 1999 from 10 a.m. to 3 p.m.** Dr. Brewer will be the guest speaker at this important meeting. Anyone interested in attending, please call Stefanie Kaplan at (562) 799-9756 (during evening hours - Pacific Time). This is a great opportunity to meet other WDA members who live near you. You might even meet someone who lives in your same town.

One Thursday Morning...

by Ascher Sellner, M.D.

Thursday morning during my office hours, I received an urgent phone call from Dr. Michael Schilsky at the Albert Einstein College of Medicine. He had a Wilson's Disease patient whom I had referred to him who could not swallow, walk, speak or write.

In order to treat the young patient age 17, and to treat him with medications which are only available to take by mouth, the patient needed a gastrostomy tube, a hole directly into his abdomen. Without such a tube, medicine and food given by mouth might be breathed into the windpipe causing aspiration which can result in pneumonia and death. To create such a feeding arrangement required a small surgical procedure. This would have been quite simple, but the patient had a serious bleeding disorder which could result in a hemorrhage during the minor surgery. Therefore, the safest way to do it was to admit him to the hospital so that he could be watched properly after the surgery. Physical therapy was also extremely important. It was best to start this too in the hospital.

The patient's HMO would not approve his hospitalization. Dr. Schilsky wanted me to write to them. I felt that immediate action was necessary. From my experience, a letter was not going to do any good.

I had my assistant find the telephone number of the governor of New Jersey, Christy Whitman. We called and spoke to her secretary and sent her a fax giving her the details of the case. Governor Whitman contacted her insurance commissioner and learned that the insuring company was in Illinois, so she called the governor of Illinois who contacted his insurance commissioner. By 5 p.m. that Thursday, the boy's hospital admission had been approved.

I believe this story is a tribute to the governors of New Jersey and Illinois and to the power of our Association.

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: _____

CITY: _____ STATE: _____ ZIP CODE: _____

Please mail your change of address to: Stefanie Kaplan 869 Kallin Ave., Long Beach, CA 90815

Inside This Issue:

*1999 Wilson's Disease Conference
Updated Information*

WILSON DISEASE ASSOCIATION, International

The Copper Connection, Editor
P.O. Box 1225
Pismo Beach, CA 93449

(FORWARDING SERVICE REQUESTED)

TO:
