

---

---

# ◆ THE COPPER CONNECTION ◆

Wilson's Disease Association, International Newsletter

---

AUGUST 1998

---

## *President's Message*

You have helped make this a great year. We had a great annual meeting with nearly one hundred in attendance in New York City. Special thanks goes to Dr. Schilsky for putting together a great scientific program, in the morning with Dr. Gupta speaking on Cell Transplantation, Dr. Shah on Genetics, Dr. Attilosoy on Liver Transplantation Experience at Mt. Sinai Hospital, and Dr. Collins at Columbian Presbyterian Medical Center on Pediatric Wilson's disease. Susan Daniels, PAC, represented the University of Michigan Clinical Research Center. Dr. Eric Waldenstrom attended from Sweden and spoke on Psychiatric Manifestations of Wilson's disease and his associate, Pernjla Skotte, also came from Sweden to speak on Physical Therapy in Wilson's disease.

The afternoon sessions included small groups led by Drs. Schilsky, Collins, Shah and Sellner. There were two important take-home messages:

- 1) Non-compliance (failure to take the meds), is a fatal illness, and
- 2) All patients should be seen periodically by a recognized Wilson's disease authority, not just someone with a couple of Wilson's disease patients or none at all.

To have resources for you, we have made important strides to set up centers of excellence. Drs. Brewer, Schilsky and Sellner hosted a meeting in Los Angeles at Cedar Sinai

Medical Center June 3, 1998, with Dr. Vierling of Cedar Sinai Medical Center, Dr. Keffe of Stanford University, Dr. Chris Kowdley of the University of Washington, Dr. Nathan Bass of the University of California San Francisco, Dr. John Lake of the University of Minnesota, and Mr. Kripendorf of Gate Pharmaceutical Company, manufacturer of Galzin® (zinc acetate). It is the purpose of these meetings to set up centers of excellence where patients with Wilson's disease can be referred for diagnosis, treatment and the management of complications of Wilson's disease. These would also be the places to which patients would go on a periodic basis in order to make sure they are current with new developments in the management of Wilson's disease. Subsequent to the selection of these centers, it is our goal to set up additional centers in the mid-west and on the east coast. Our web site is being vastly expanded through the support of Gate Pharmaceutical Company, manufacturers of Galzin®. It will have our newsletter, reference materials and numerous other resources. Our meetings will be announced and updates made regularly.

I have been fortunate to be nominated to the Board of the National Organization of Rare Diseases. It is my hope that my participation in this organization will enable me to be of greater benefit to the Association.

I also had the privilege of meeting once again with Dr. John Walshe,  
(continued page 2, PRESIDENT)

## **Trientine Cyprine**

*A Treatment For Wilson's Disease*

Many physicians use Trientine as the initial chelating agent in Wilson's disease treatment. Trientine was approved and used for patients who could no longer take Penicillamine because of various reactions to it. It has been found to be much safer and with fewer side effects than Penicillamine. Trientine is made by Merck Sharpe and Dome, and should be available in about forty-eight to seventy-two hours notice from your pharmacist. If you have difficulty obtaining it, you can call 1-800 MerckRx, or let the Wilson's Disease Association know.

After initial therapy, which can have some side effects including anemia, zinc acetate can be used for maintenance therapy.

The initial treatment of Wilson's disease with the chelating agent Trientine, instead of Penicillamine, is becoming an increasing popular choice among physicians with substantial experience in Wilson's disease man-

---

## **NONCOMPLIANCE**

### **Is A Fatal Illness!!**



(PRESIDENT from page 1)

discoverer of Penicillamine and Trientine, this April while I was in England. As always, he is the source of a great deal of knowledge and inspiration.

We are hearing from more and more patients. We also have so much to do. We need fund-raisers, leaders of support groups, organizers of our annual meeting, and more. Please let me know if you are willing to make a commitment to the time and energy for any of these tasks. I need help from people like Len Pytlak, Luke Chung, Carol Terry, Delia Ruiz, Leticia Martinez, and Robert Stall, without whom we could not have done so much this year.

Lastly, I would like to thank my parents for a \$30,000.00 gift to the Association. We need more such gifts from members and their families, friends and associates. With these we can guarantee sources of medical and emotional support for future generations of patients with Wilson's disease. We can also expand the number of services currently being offered. There is a great deal more we could be doing at this time given the necessary funds and individuals willing to invest the time to accomplish new goals. I would also like to thank Mr. Jack Levin for a \$5,000.00 gift for capital equipment which was conveyed to Dr. Schilsky for his laboratory.

Ascher Sellner, M.D.  
President

### 1999 WDA Annual Meeting Location Selected

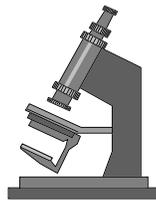
The next WDA Annual Meeting is scheduled for April, 1999 in Atlanta, Georgia. A special 2-day conference is being planned. If you live near Atlanta and would be interested in helping out with coordinating this event, give Dr. Sellner a call at 1 (800) 399-0266.

### WDA INTERNET WEBSITE

The WDA internet website has been updated with more information and links to Wilson's disease sites. We invite you to visit us at:

[www.wilsonsdisease.org](http://www.wilsonsdisease.org)

With ongoing WD research, the future can only hold promising results for Wilson's disease.



*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. The Association 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 and Address)

Donor's name & address: \_\_\_\_\_

(Please mail your donation to: The Wilson's Disease Association, 4 Navaho Drive, Brookfield, CT 06804) Thank you.

**Wilson's Disease Discussion Group On the Internet**

The Wilson's Disease Listserv Discussion Group continues to grow. The listserv was set up by Robert Stall, M.D., an internist/Geriatrician who has WD and is an active member of the Wilson's Disease Association. This discussion 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 143 members from all over the world. To subscribe to the Wilsons Listserv, go into the WDA website ([www.wilsonsdisease.org](http://www.wilsonsdisease.org)) and click on "discussion". If you do not have access to the internet, send mail directly to Dr. Stall at: [www.acsu.buffalo.edu/~drstall/](mailto:www.acsu.buffalo.edu/~drstall/)

Dr. Stall will then add your name to the List.

**Wilson's Disease and Skunks?? UPDATE**

The oddity of Wilson's Disease patients and skunks continues. The updated informal poll of WD patients includes a total of 29 responses. Of those, 6 reported the ability and sense of smell for skunks, 21 reported NO SMELL for skunks, and 2 did not know (hadn't encountered skunks).

Thanks to everyone who has participated in this informal poll. Maybe someday, we will know what (if anything) triggers this effect on WD patients. Which by the way, was found to be a welcome effect by many people. Imagine the reality of NOT smelling skunks.



Contributors to this issue of "THE COPPER CONNECTION"

**Ascher Sellner, M.D.  
Len Pytlak  
Gearik Gearman**

Thank You!

**Annual WDA Membership Dues**

Membership dues are renewed annually. Please send your renewal dues attached with the application included below. Thank you for your continued support.

**WILSON'S DISEASE ASSOCIATION**  
**MEMBERSHIP/RENEWAL APPLICATION**

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 \_\_\_\_\_

(Please mail your contribution to: Alvina Laird 8740 Sortor Drive, Kansas City, KS 66109)

**ASK THE DOCTOR**

**QUESTION:** Is vitamin E necessary as a supplement for patients who have Wilson's disease?

**ANSWER:** Vitamin E has antioxidant qualities which have been proven to benefit patients with chronic liver disease. Since Wilson's disease affects the liver, an 800 IU/day vitamin E supplement is recommended for WD patients. Consult your doctor.

(Send your questions to Dr. Sellner, WDA President, 4 Navaho Drive, Brookfield, CT 06804).

**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.

**DONATIONS**

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

**\$100 - \$999**

Carrol & Susan Cross - In memory of Diane Laurain  
(Matching gift by Mobil Foundation)  
Russell Sillery - In memory of Robert Rodick  
Diane Laurain - In memory of Robert Rodick  
Joe W. Russell  
Waldenbooks  
Mr. & Mrs. Slavin  
Vivek & Lakshmi Subramanian  
Ellen Freedman  
Bob's Pub  
Al's Friends  
Carole Bickimer  
David Clay  
Judge & Mrs. Fetzer Mills  
Charlotte Hirsch  
Dr. & Mrs. Jacobson  
Mr. & Mrs. Laurain - Matching gift from Fang-Tze Lin  
Beverly Linkins  
Fetzer Mills - proceeds from book fair  
Barbara Noci  
Gilchrist Glen & Eileen Smith - In memory of Kiara & Ambra Papa  
Mr. & Mrs. Wade  
Mr. & Mrs. Wagner  
Carol Watson

**Thank You!**

**\$1000 - \$5000**

Joe Serena Papa  
Luke Chung  
Chase Manhattan Foundation - In memory of Rick Wade  
Pat Pei

**\$5001+**

Mr. & Mrs. Sellner

**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.

**WDA Annual Meeting Cassettes For Sale**

The scientific sessions of the April 1997 WDA Annual Meeting were recorded onto three tape cassettes. The set of three (3) is for sale to WDA members at a cost of \$60.00. This price covers reproduction costs only. To order your set, please call Dr. Sellner at (800) 399-0266.

**WDA Member News**

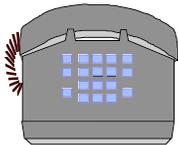
**BARBARA NOCI & RICARDO MAESTRELLI**

Married on June 28, 1998.  
 Congratulations and Best Wishes!!



Do you have some news to share? Please send it to:  
 THE COPPER CONNECTION, Editor  
 P.O. Box 1225  
 Pismo Beach, CA 93449

**Wilson's Disease Association**



**Telephone Number**

1 (800) 399-0266

**Web Site Address**

[www.wilsonsdisease.org](http://www.wilsonsdisease.org)

**Resource Corner**

Nutrition Almanac

This book includes copper content of food. Gayla J. Kirschmann and John Kirschmann. McGraw-Hill publisher.

***Wilson's Disease organization in Germany***

Morbus Wilson e.V.  
 Geschäftsstelle  
 Meraner Strabe 17  
 D83024 Rosenheim  
 Tel: 08031-249230 Fax: 08031-43876  
 E-mail: [mwev@Link-r.de](mailto:mwev@Link-r.de)

Center Of Excellence - West Coast  
 Dr. Vierling (310) 855-6139  
 Contact Nurse Vesna Grubic (310) 967-0125  
 or e-mail Dr. Vierling at: [liver@csmc.edu](mailto:liver@csmc.edu)



**Sample Letter to Request  
 Insurance Pay For Galzin**

In response to the large number of inquiries the Association has received regarding insurance coverage for Galzin® (zinc acetate), the following sample letter can be used to assist you in recommending individual insurance carriers and HMO's to approve Galzin® as a covered medication.

\* \* \* \* \*

Dear ,

Galzin®, zinc acetate, was approved by the FDA in February, 1997, for maintenace therapy in Wilson's disease. It is also widely used in children, presymptomatic patients and pregnant patients. It is less expensive than all other approved treatments. It requires few follow-up tests to monitor its side effects since it has no recognized side effects to any organ system. It also causes no major complications. Therefore, the drug is less expensive, it is less expensive to monitor, and it causes few adverse reactions which might otherwise be expensive to look after.

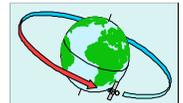
If Galzin® is not already on your formulary, then I hope that you will add it immediately. In the meantime, I hope you will pay for it for me and others, if it is requested by other insureds and their doctors.

Yours truly,

(Patient's name)

**WDA INTERNATIONAL CHAPTERS**

The WDA welcomes international members. We are looking for support groups and chapters in all areas of the world. If you are interested in forming such a group, please fax Dr. Sellner at: 1 (203) 743-6196 or e-mail [hasellner@worldnet.att.net](mailto:hasellner@worldnet.att.net)



**How to Get Galzin® (zinc acetate)**

Distributed by Athena Home Pharmacy  
 1 (800) ATHENA or 1 (650) 877-7688

## 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, answers, comments and experiences.

Dear Dr. Sellner,

I am writing to thank you on behalf of our laboratory and the Albert Einstein College of Medicine for the generous gift of \$5000 from the Wilson's Disease Association. With these monies we will be able to purchase a digital camera and associated equipment that can be utilized for data recording and presentation, as well as a tabletop micro-centrifuge....

We would like the members of your organization to know that the donations for laboratory equipment from your organization greatly help to assist our research efforts, and that we are grateful for the assistance. We look forward to continuing our work together, and hope we can count on your future support.

Sincerely,

Michael L. Schilsky, M.D.  
Associate Professor of Medicine

Dear Dr. Sellner,

It's been a great year of improvement! I have written to a lot of people who have Wilson's disease, it sure helps to be able to hear how other people deal with this disease. It seems to be a little different with everyone.

Thank you for recommending that we talk with Dr. Schilsky, his recommendations really helped.  
Best Wishes



Dear Copper Connection,

My son was diagnosed with WD in March of 1992 at the age of 11. He was on penicillamine for one year before we hooked up with Dr. Brewer in Michigan and switched to zinc. We are responding to your inquiry about the ability of WD patients to smell skunks... he cannot. He had never mentioned this oddity even though the family has had many opportunities to partake of the aroma. When I asked him whether or not he could smell skunks, he replied, "No, I never have been able to." He is now approaching eighteen years of age. Baffling information indeed!

Also, have you ever done any research on the percentage of WD patients that have red hair? I would be very interested in this since my son has red hair and three other WD patients that we met in Michigan also have red hair. Before we knew our son had a copper disease, we jokingly called him "coppertop". Please could you conduct a survey on this in the next Copper Connection? Thank you for the job you do.

Dear Sir,

My wife and sister-in-law both have Wilson's disease. (There was also a third child in their family, but that girl died at the age of nine of Wilsons). Both of these sisters are married and have (healthy!) children. They are both being treated with D-penicillamine since their sister's death. My wife's condition is quite stable, but her sister is since several months been quite sick. The doctors are even talking about the possibility of a liver transplant. You can imagine that this situation is the talk of the day in our family. Is there any (medical) information about experiences with liver transplant in relation to Wilson's disease? Is it possible that you can tell me where on the Internet I can find this information. Our entire family will be very grateful. Thank you.

Dear Dr. Sellner,

My son was diagnosed with Wilson's disease 4 years ago. His wife and I (his mother) are desperately looking for some help.

The personality change since the diagnosis has been phenomenal. What was once a very pleasant, mellow young man is now a very angry, volatile person fighting to keep himself under control. We are currently searching to find if this change is triggered by physical factors or is purely emotional.

Do you have any names of medical personnel in our area who have any expertise in the field of Wilsons, especially neurologists and psychiatrists? Also, he has a 2 year old daughter about whom they are very concerned? When can she be tested? We are anxious for your newsletter and any help you can provide. Thank you very much.

## Expanding Our Knowledge

In order to know more about conditions related to Wilson's disease, the Association will strive to gather additional information from patients. This month we will strive to do this by gathering information on female reproductive history. It is our goal to have all of the female patients with Wilson's disease complete the following survey and to add whatever additional information they may have related to their obstetrical and gynecological experiences. Please take a moment and answer the following questions. Thank you.

---

Date of Birth: \_\_\_\_\_

Age of onset of menses: \_\_\_\_\_

How would you describe your periods? regular \_\_\_\_\_ irregular \_\_\_\_\_ no longer have any \_\_\_\_\_

If irregular, at what age did they become irregular? \_\_\_\_\_

If you no longer have a period, at what age did it stop? \_\_\_\_\_

List any mentionable abnormalities \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Infertility: Yes \_\_\_\_\_ No \_\_\_\_\_

Pregnancy Total: \_\_\_\_\_ Losses \_\_\_\_\_

Voluntary Abortions: \_\_\_\_\_

Spontaneous Pregnancy Losses: \_\_\_\_\_ During what month of pregnancy did it/they occur? \_\_\_\_\_

Total number of live births: \_\_\_\_\_

Total number of premature births: \_\_\_\_\_

Type of delivery

Number of cesarean sections: \_\_\_\_\_

Number of vaginal deliveries: \_\_\_\_\_

Ob/Gyn Surgery

D&C: No \_\_\_\_\_ Yes \_\_\_\_\_ Reason \_\_\_\_\_

Hysterectomy: No \_\_\_\_\_ Yes \_\_\_\_\_ Reason \_\_\_\_\_

Other Ob/Gyn-related surgeries: \_\_\_\_\_

\_\_\_\_\_

Additional Obstetrical/Gynecological History: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you. Please mail this survey to: Dr. Sellner, WDA President, 4 Navaho Drive, Brookfield, CT 06804

---

---

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: Alvina Laird 8740 Sortor Dr., Kansas City, KS 66109 or e-mail llaird@SWBell.net

---

---

*Inside This Issue:*

*Trientine Cyprine  
Treatment for Wilson's Disease*

---

---

**WILSON DISEASE ASSOCIATION, International**

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

(Address Correction Requested)

**TO:**

---

---