

THE COPPER CONNECTION

March 2002

**Please Join Us For The
2002 Wilson's Disease Association
Annual Meeting**

**May 4 & 5, 2002
Hyatt Rosemont Hotel
Chicago, Illinois**

This meeting is an excellent opportunity to learn more about Wilson's Disease and meet others that share similar experiences.

Meeting Agenda

Friday, May 3, 2002

5:00pm-7:00pm Hospitality Reception

Saturday, May 4, 2002

8:30am Registration and Continental Breakfast

9:00am-12noon Topics to include:

Initial therapy, the place for penicillamine and use of other drugs
(Mike Schilsky, M.D.)

Medication and adverse effects (Fred Askari, M.D.)

Compliance with medication (Eyel Shemesh, M.D.)

Liver transplant –when, how, why, longevity and consequences
(Mike Schilsky, M.D.)

Noon-1:00pm Lunch

1:30pm-5:00pm Support Group Sessions

Sunday, May 5, 2002

8:30am Continental Breakfast

9:00am-9:30am Business Meeting

9:30am-noon Topics to include:

Genetics of Wilson's Disease (Gabor Firneisz, M.D.)

Zinc therapy (George Brewer, M.D.)

Managing therapy and when to change it (Fred Askari, M.D.)

Registration fee includes the hospitality reception, both breakfasts, lunch, and an afternoon snack

WDA Annual Meeting Hotel Information

Hyatt Rosemont
6350 North River Road
Rosemont, IL 60018
(847)518-1234
(800)233-1234 reservations

Hyatt Rosemont is located just outside O'Hare airport. Do not get this confused with the Hyatt Regency O'Hare. They are two different hotels. You can see the Hyatt Rosemont on Hyatt's web site at www.hyatt.com.

Guest Rooms: Call either telephone number above and identify yourself as attending the "Wilson's Disease Association" meeting. Room rates are \$99.00 for single or double occupancy. Triples are \$124.00 and quads are \$149.00. These rates are exclusive of tax. Our room block is for Friday, May 3 and Saturday, May 4. We also have a few rooms blocked before and after the meeting dates, but these are on a first come, first serve basis. Higher rates may apply if we fill our block. The hotel does have Accessible rooms available, so please make sure that this room type is blocked for you at time of reservation.

Transportation: Hyatt Rosemont has free shuttles from O'Hare airport to the hotel. The shuttles run every 15-20 minutes. If you have wheelchair needs, please email Stefanie Kaplan at stefaniekaplan@yahoo.com with your flight number and time of arrival. The hotel will arrange a shuttle for you.

For other questions, please email Stefaniekaplan@yahoo.com.

See you in the windy city!

Wilson's Disease Association Annual Report 2001

The year two thousand one has seen the Wilson's Disease Association outgrow its infrastructure because of the unusual commitment of several individuals who have given enormously of their time and efforts.

The Association held its annual meeting in Long Beach, California, in May. It was attended by 100 people from the United States and overseas. A meeting scheduled in September in conjunction with the Movement Disorders Society at the NIH, was unfortunately cancelled. We had arranged an all day membership meeting with eight speakers, five from the countries of Austria, India, Poland, Sweden, and England.

Research was supported to study speech patterns in 19 patients. The results of the study will be published in several different journals. The expense for the speech study was \$7,546. Research of a new drug for initial therapy that was started at the University of Michigan was expanded at Mt. Sinai Hospital in New York City with a contribution from the president's discretionary fund. The fund was established with \$38,000 from Dr. Sellner and his parents. As a result of the study, two patients were admitted to Mt. Sinai in 2001. Thus far, the cost for the drug study is \$17,000 (\$5000 initial fee and \$6000 per patient for eight weeks in the hospital including all drugs, physician fees, and laboratory costs for the two patients).

The National Center for the Study of Wilson's Disease closed its NYC facility. Three members of its Board have been voted by the Association for a one-year membership on our Board. They have been generous in their financial support and in their efforts on behalf of the Association. Another member of the Center's Board has accepted a leadership role on both the Education Committee and the Medical Advisory Committee.

The Association President attended the World Symposium on Wilson's Disease in Leipzig, Germany, in April. He presented a paper entitled "The Function of the Female Reproductive System in Wilson's Disease, a Preliminary Report." The investigation described in the report is ongoing.

The WDA database was entirely revised, which enabled us to send our first direct solicitation to members in November for dues and contributions. This resulted in approximately \$10,000 income at an expense of less than \$1,000. In turn, this enabled us to track which of

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DONATIONS

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

Lenore and Russell Sillery	\$500
Sillery and Partners	\$1200
Carol and Ascher Sellner	\$1000
Kevin Peters	\$250
TEVA Pharmaceuticals	\$1000
Franklin Martin	\$100
(In honor of Mr. & Mrs. Fetzer Mills)	
Gerral Felson (in honor of Jeanne Friedman)	\$1000

**WDA ANNUAL MEETING – CHICAGO
MAY 4 AND 5, 2002
REGISTRATION FORM**

Name: _____ E-mail: _____

Address: _____

Telephone: _____

Relationship to WD: Patient Spouse Parent Sibling Friend

Other: _____

You may release my name for a roster of the meeting attendees: Yes No

This is my first WDA meeting: Yes No

Additional attendees (Please include children who will be attending):

1. _____

2. _____

3. _____

4. _____

Registration Fees (postmarked by 3/20/02): \$75.00 per adult
\$35.00 per child (ages 10-17)

Registration Fees (postmarked after 3/20/02): \$85.00 per adult
\$45.00 per child (ages 10-17)

Fees include the hospitality reception, two breakfasts, one lunch and one afternoon break.

*****Registration and fees should be received no later than 4/5/02*****

Check # _____ is enclosed for \$ _____ (checks payable to the Wilson's Disease Association)

Please charge my credit card: VISA MC OTHER: _____

Credit Card Number: _____ Exp. Date: _____

Signature: _____ Amount: \$ _____

Please mail this form and payment to: Len Pytlak
180 Little Lake Drive #3
Ann Arbor, MI 48103

(REPORT, continued)

the people in our database are active members of the Association and to choose different categories of people for distributing the Association's mailings.

The web site was entirely revised with professional help. It was expanded with new centers of excellence and medical contacts. It has a completely new design and new navigation system for finding information about Wilson's Disease and the Association.

The Association continues to actively support NORD (National Organization for Rare Disorders, Inc). The WDA President is a member of the Board of NORD.

Other 2001 WDA accomplishments include:

- ◆ The WDA Board had two meetings and the new Executive Committee met every six weeks.
- ◆ The bylaws were entirely revised and approved by the membership.
- ◆ The Medical Advisory Committee policies and procedures have been carefully written and the committee has been expanded.
- ◆ For the first time ever, the Copper Connection newsletter circulated four times this year instead of three.
- ◆ Members of the board contributed opinions about a Patient's Guide to Wilson's Disease and a Physician's Guide to Wilson's Disease, both written and published by George Brewer, M.D.
- ◆ The mission statement was revised. A conflict of interest policy was developed and incorporated into the Association.
- ◆ An initiative is in progress to make drugs more available to patients in the USA and in foreign countries.
- ◆ Our income was \$23,388. It was all used for member programs; none was used for overhead.

The year produced many fine accomplishments. There remains an enormous amount to do, especially in educating physicians and patients and relieving psychiatric and physical disabilities.

Efforts are underway to reschedule the September 2001 Movement Disorder Society meeting to its next annual meeting in Miami, Florida in October 2002. To continue growth and service, I recommend for the Association to have a salaried executive and a paid consultant to assist in

raising revenue. Without taking these steps, growth in services, and probably even the maintenance of existing programs, are in jeopardy.

H Ascher Sellner President

Medical News

Brought to you by the WDA Medical
Advisory Group

Elastosis Perforans Serpingosa

Michael L. Schilsky, M.D.

Elastosis perforans serpingosa is an uncommon dermatologic lesion associated with use of penicillamine. The cause of these skin lesions is thought to be an immune reaction of the body to the drug. These lesions are typically darkly pigmented and are cheloid like in appearance. They can be mistaken for skin cancers at times. The occurrence of these lesions is unpredictable as to when and where on the body they appear. They may appear and then disappear without predictability, whether penicillamine is continued or withdrawn. In some of my patients in whom this disorder was identified, the lesions have dissipated following change to zinc treatment and have not reappeared since. The use of topical or injection therapy is therefore not recommended at this time. The occurrence of these lesions in patients that I see in my practice is now less frequent as fewer patients are opting to remain on penicillamine therapy. Though elastosis perforans serpingosa should be considered as a cause for the appearance of skin lesions for patients on penicillamine therapy, a careful evaluation by a dermatologist is important to exclude other potential problems such as skin cancer.



*Dr. George Brewer became Emeritus
Professor of Human Genetics at the
University of Michigan Medical School. He
continues his active research programs in
the role of copper in human disease.*

A Letter to Wilson's Disease Patients

By Kathy Kiefer



This letter is a gift, a gift of words I pass to all Wilson's Disease patients.

On Sunday, June 24, 2001, my beloved partner, Charlie - who had been diagnosed with Wilson's Disease in 1961 when he was thirteen years old - was airlifted from Eastern Washington, over the Cascade Mountains to the University of Washington Medical Center in Seattle. It was a forty-five minute flight that felt like an eternity. He was in acute liver failure. His kidneys had failed, he was bleeding internally, and his potassium levels were life threateningly high. By Monday morning he was sedated and intubated and we began a "fast track" process to list him for a liver transplant.

In the four days that followed I participated in a drama that has changed my life forever. I learned more about the function of the liver, transplants, nursing care, dialysis and the type of routine that goes on day in and day out in the ICU of a research/teaching hospital than I would have ever known without the experience.

Within 36 hours of our arrival, Charlie was at the top of the list for a matching liver, should one arrive. For three agonizing days we waited. We waited and watched as his body fought to overcome the tremendous stress of transfusions, drugs, sedation, and dialysis. He died on June 29th. The most tragic and painful reality of Wilson's Disease is what can happen if things go wrong, and no matter which of the few drugs that you take to treat this disease, things can still go wrong.

Charlie was 52 years old. He was diagnosed with Wilson's Disease when he was 13. His sister had been diagnosed several months earlier. Her symptoms had neurological manifestations. Charlie had no symptoms when he was diagnosed. Charlie participated in studies conducted by Dr.'s George Courtwright and Andrew Deiss at the University of Utah. He was treated with Penicillamine for about twenty-two years. By 1992 he was complaining of recurring urticaria and migratory swelling and pain in the joints and hives, both on the surface and beneath his skin. His doctor at the time took it upon himself to learn about Wilson's Disease and contacted Dr. Brewer at the University of Michigan. Dr. Brewer advised that Charlie be switched to Trientine. He switched in October, 1992. He was treated with Trientine up until 1994. Charlie continued to have migratory polyarthralgia and occasional urticaria that he controlled with Seldane or Claretin. Trientine also caused him considerable gastric distress. In 1994 Charlie began participation in Dr. Brewer's study and started treatment

with zinc acetate. When I met him in late 1994 he continued to complain of migratory polyarthralgia and both deep and surface hives. When he told me about the drugs he had taken for his disease I dove into the PDR (Physicians Desk Reference) to learn as much as I could. From late 1994 until the day Charlie was airlifted to the University of Washington Medical Center he took his daily dose of zinc acetate. We watched the copper content of the foods we ate, and avoided foods high in copper. The water from our home tested negative for copper.

What I have learned after looking over Charlie's life, his disease and the way it progressed, his treatment and the way he reacted to his disease is advice I can offer to all patients with Wilson's Disease. First of all, know your disease. Learn everything you can about it. Know the drugs; their clinical pharmacology, indications, contraindications and side effects. Participate in your care. Ask about the results of your liver panels, know what each of the tests mean and how that relates to the function of your liver. You can live a long and productive life with this disease, but never forget that this disease and its treatment is still a subject of research by medical doctors.

When people ask me what Charlie died from and I tell them Wilson's Disease and explain what it is, I am always pleased by the rapt attention they give my explanation. It is truly an unusual disease and a difficult one and certainly not one that elicits widespread fundraising activities or community support. If you have the disease, own it. Treat it like someone whose story you want desperately to hear and understand. Listen to your body, accept your disease, and work with your doctor as a team in your treatment. A team where players are equal in their self-interest and desire for success. If I could wind back the clock for Charlie and I, we would have paid more attention to details. I hope this helps for others with



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.

HOW TO OBTAIN CUPRIMINE OR SYPRINE

(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.



PLEASE NOTE

Change of E-mail address/website

- ⇒ George Feldmann, head of the Canadian Chapter for the Wilson's Disease Association, has a new E-mail address: Georgefeldmann@shaw.ca
- ⇒ New Danish WDA website: www.wilsons.dk
- ⇒ India—Wisdom, Dr. D.P. Pande, PhD
Wilson Disease Observation and Management
Voice mail/Phone: 91-22-559 5515
Patient support— E-mail: indiawisdom@yahoo.com, Research-Academic Collaborations:
indiawisdom@hotmail.com

A Challenge To All Who Support Wilson's Disease Patients And Their Treatment

Every year for the last three years I have participated in the Cancer fundraising event, Relay for Life. Up until 2001, my best friend who had Wilson's Disease participated with me.

In May, 2001 I traveled for two weeks in China. When I returned on June 4, my best friend was sick. His liver was failing as a complication of Wilson's Disease. A week after I returned I decided to participate in the Cancer Relay. My friend died two weeks later. I have taken on a challenge that I want to share with others.

On February 23rd, 2002 I will have an exhibit of the photographs I took in China. All the money raised from the sale of these photographs will go to the Wilson's Disease Association. I am lucky to be gifted with the ability to take photographic images that people enjoy and appreciate. I know there are many people out there who have the same and similar gifts with art, music and performing arts.

My challenge to Wilson's Disease patients and all who support them is to undertake one small fundraising event each year in their communities; an event that focuses on raising money through the talents of someone who is willing to give to the cause of educating others about Wilson's Disease. After coming to understand the disease as I do now, I am willing to commit a portion of my work each year to any effort that would educate others about this disease. The Association can expect a check in early March that will amount to the entire proceeds of my effort. I look forward to learning about the efforts of others who want to do something similar in their communities.

Kathy Kiefer
23218 N. Highway 17
Soap Lake, WA 98851
(509) 246-6282

New York Metro Area Support Group Meeting Update

On Sunday January 13, 2002 over 30 people attended a Support Group meeting held at Mt. Sinai Medical Center in New York City. Dr. Michael Schilsky spoke briefly on new studies in the area of Wilson's Disease. Also speaking briefly was Dr. Ayal Shemesh who is a Psychiatrist. He spoke about the concerns of compliance, which in turn opened a conversation on non-compliance and how family and friends can help patients be compliant. We also heard from Joe Iamarino who recently had a liver transplant. Joe, we all agree, you look great! Thanks to Dr. Schilsky, for his help in organizing the meeting. If there is anyone in the New York Metro area that would be interested in future support groups please contact Lenore Sillery 203-762-2372 or e-mail at sillerylenore@hotmail.com.

The Wilson's Disease Association gratefully acknowledges partial support of this newsletter by Gate Pharmaceuticals, manufacturer and developer of Galzin®.

Wilson's Disease Association
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WDA Board Members

Ascher Sellner, M.D. - President
Len Pytlak - Vice President
Carol Terry - Treasurer
Carol Sellner - Secretary

Board Members

Luke Chung	Kevin Peters
Nancy Hoffman	Sparky Terry
Stefanie Kaplan	Jack Levin
Carl Nacht, M.D.	Jacqui Taylor
Henry Kaplan, M.D.	Mary Graper

Honorary Board Member

Janene Bowen

CHANGE OF ADDRESS?

Please notify the Wilson's Disease Association of any address changes so that we may keep our database updated. Please use the Membership Form to make any changes.

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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: