
THE COPPER CONNECTION

February, 2003

**WDA ANNUAL MEETING
WASHINGTON D.C.
MAY 2-4, 2003**

Hotel Information

Hyatt Dulles at Dulles International Airport
2300 Dulles Corner Blvd
Herndon, VA 22071

Reservations

(703)713-1234 or (800)233-1234
Special Code: "Wilson's Disease Association Meeting"

Rates

\$89.00 single/double occupancy
\$114.00 triple or \$139.00 quad

These rates are on a first come, first serve basis and are exclusive of tax. They are available two days before and two days after the meeting, as well. **After April 15, 2003, these rates may no longer be available.**

Cost of Meeting

\$80.00 per person
\$65.00 per child (8 years old – 16 years old)
This includes a reception, two breakfasts and a lunch.

Saturday Night Entertainment

The hotel is making a shuttle available to us on Saturday evening (5:30 pm - 9:30 pm) for those of you who would like to go downtown. There are only 24 seats available and the cost is \$8.00 roundtrip per person. The first 24 who request this on your registration form will be the ones to go. Others can choose to find alternative transportation downtown or go to nearby restaurants.

**WDA ANNUAL MEETING 2003
REGISTRATION FORM
Due by or before April 15, 2003**

Name: _____ Email: _____

Address: _____ City: _____

State: _____ Zip: _____ Telephone: _____

Are you interested in WDA membership information? Yes No

Names of others attending (please note ages of any children):

1. _____
2. _____
3. _____
4. _____

Payment

\$80.00 per adult and \$65.00 per child (ages 8-16). Payable by check, MC or Visa.

- Check Amount:\$ _____ (Payable to the Wilson's Disease Assn)
- Visa _____ Exp Date _____
- Mastercard _____ Exp Date _____
- Please charge \$ _____ to my credit card.
- Signature: _____ Date: _____

Saturday Night Entertainment

The first 24 people to sign up for the shuttle to downtown D.C. for Saturday night (5:30 pm -9:30 pm) will be notified at the meeting. Please indicate here if you would like to do this and the number of people with you. The \$8.00 per person charge will be collected on Saturday morning at the meeting. Please note that signing up does not guarantee you a spot.

- Yes, I want to take the shuttle on Saturday night and will pay the \$8.00 at the meeting.
Number of people total: _____

Mail registration form to: Wilson's Disease Association
Attn: Kimberly Symonds
Due by April 15, 2003 1802 Brookside Drive
Wooster, OH 44691

WDA Meeting Agenda

Friday:

5:00 pm-7:00 pm Hospitality Reception

Saturday:

8:30 am Registration/Continental Breakfast

9:00 am Opening remarks/introduction of Kimberly Symonds Executive Director & Dr. Sellner, President

9:15 - 9:45 am Stephen Kaler, M.D. M.P.H. Health risks to Wilson's Disease carriers

9:45 - 10:15 am Stephen Groft, R.Ph. The Office of Rare Diseases at the NIH

10:15 -10:45 am Ascher Sellner, M.D. Female reproductive function and Wilson's Disease

10:45 - 1:00 am Coffee Break

11:00 -12:30 pm Morning support group activities

- ◆ Psychiatric issues
- ◆ Compliance and noncompliance
- ◆ Caregivers coping with patients

12:30 pm Lunch

1:30 pm George Brewer, M.D. The quality of local care of Wilson's Disease

2:00 pm Kimberly Symonds Executive Director's Report

2:30 - 3:30 pm Afternoon support group activities

- ◆ Choosing medications
- ◆ Genetic issues: having children, testing relatives and prenatal testing
- ◆ Life expectancy, quality of life and limitations on activity

3:45 - 4:15 pm Fred Askari, M.D. Current therapy in liver disease

4:15 - 4:45 pm Michael Schilsky, M.D. Measuring the adequacy of treatment

4:45 - 5:15 pm Questions and answers about Saturday's topics

Sunday

8:30 am Continental Breakfast

9:00 - 9:45 am George Brewer, M.D. Major long term complications of Wilson's Disease

9:45 - 10:15 am Business meeting and elections

10:15 -10:45 am Fred Askari, M.D. Nutrition and Wilson's Disease

10:45 -11:15 am Coffee Break

11:15 - Noon Michael Schilsky, M.D. Support services for patients and their caregivers

12:00 Noon Questions and answers about morning topics

President's Annual Report 2002

H. Ascher Sellner, M.D.

The year 2002 was a milestone year. The Association hired an executive director. This step culminates efforts to expand our services and mission. We hope to move forward much more rapidly as a result of this step.

We had two meetings, one in Chicago (May) and the other in Miami (November). The Miami meeting was held with partial support from the NIH Office of Rare Diseases and in conjunction with the Movement Disorders Society. We had speakers from India, England, Sweden and the United States. There were also participants from Brazil and Italy. Doctors Brewer, Schilsky, Hedera, Fink and Askari also spoke. Stefanie Kaplan organized our May meeting and Mary Graper organized the November meeting.

The newsletter circulated 4 times due especially to the efforts and generosity of Delia Ruiz and Lenore and Russ Sillery. I continued to work with NORD with special effort directed to the approval of a process to make generic biological available. I was also involved in enhancing the technology services of NORD.

We participated in developing a journal article on women's reproductive health and we continued to support research at Mt Sinai Hospital in NYC to find a safer initial therapy for Wilson's Disease.

We continued to provide, by phone and email, advice and referral all over the world. The website was enhanced with a site index, new Centers of Excellence, more FAQs, and more treating physicians.

I am pleased that we did so much and I am excited that Kimberly Symonds is going to lead us to many new achievements.

Send Us Your Letters

We would like to hear from WDA members. Send us your letters, news to share, or other information that your would like to share with other WD patients and families. Please mail to:



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

or e-mail to DRNDVR@aol.com.

Dear Friends,

What an incredible two months this has been for me as your new Executive Director. I feel so welcomed and I thank all of you for that!

WDA is an incredible organization! Over the past 25 years you have been a part of great accomplishments. From the beginning – when only a few newsletters were mailed out – to today – where there are almost 1000 members, four Centers of Excellence, and a very comprehensive web site where valuable information about Wilson's Disease is available to anyone who seeks it – you are part of a progressive, supportive community. You are not alone!

Building on WDA's great successes in the past, I would like to introduce you to a new part of our web site – the "Contribute to WDA" page. (You get to it from the main page of the site, www.wilsonsdisease.org). Here you will find information on how to donate to WDA, information about corporate matching donations, an example of an easy fundraiser, and information about how to raise money for WDA by shopping online. Your Board of Directors has exciting plans for the organization, but for their planned programs to be successful, we need your help in raising the resources necessary to get these programs off the ground. I encourage you to visit these new pages on the web site and support us in these new endeavors, as they will benefit the entire Wilson's community.

Lastly, I would like to invite you to attend the WDA International Meeting in Washington, D.C., on May 2-4. The program is packed with useful information for Wilson's Disease patients, their family members, and their friends. Whether you are newly diagnosed with Wilson's Disease or you have been living with it for years, you will certainly benefit from attending. I look forward to meeting each of you there!

Sincerely,

Kimberly F. Symonds
Executive Director

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

Wilson's Disease Association

Kimberly F. Symonds, Executive Director
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Wooster, OH 44691
(800) 399-0266 or (330) 264-1450
E-mail: wilsonsdiseaseassoc@yahoo.com
WDA Website: www.wilsonsdisease.org

WDA Board Members

Ascher Sellner, M.D. - President
Len Pytlak - Vice President
Carol Terry - Treasurer
Carol Sellner - Secretary
Luke Chung
Mary Graper
Nancy Hoffman
Henry Kaplan, M.D.
Stefanie Kaplan
Kevin Peters
Jacqui Taylor

CHANGE OF ADDRESS?

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

Honorary Board Member
Janene Bowen

Kimberly Symonds - Executive Director

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WILSON'S DISEASE ASSOCIATION

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

(FORWARDING SERVICE REQUESTED)

TO: