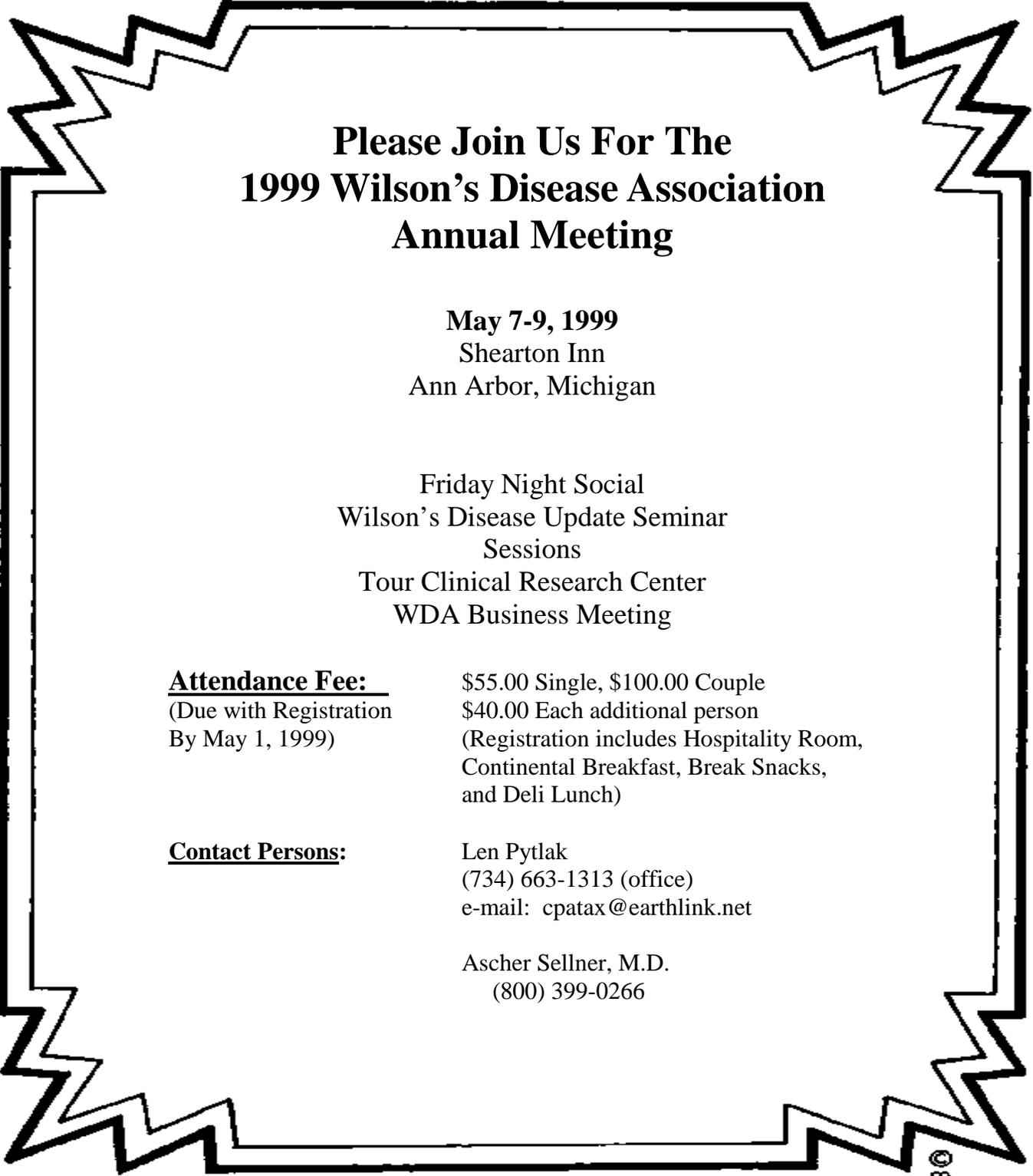

❖ THE COPPER CONNECTION ❖

Wilson's Disease Association, International Newsletter

FEBRUARY 1999



Please Join Us For The 1999 Wilson's Disease Association Annual Meeting

May 7-9, 1999
Shearton Inn
Ann Arbor, Michigan

Friday Night Social
Wilson's Disease Update Seminar
Sessions
Tour Clinical Research Center
WDA Business Meeting

Attendance Fee:

(Due with Registration
By May 1, 1999)

\$55.00 Single, \$100.00 Couple
\$40.00 Each additional person
(Registration includes Hospitality Room,
Continental Breakfast, Break Snacks,
and Deli Lunch)

Contact Persons:

Len Pytlak
(734) 663-1313 (office)
e-mail: cpatax@earthlink.net

Ascher Sellner, M.D.
(800) 399-0266

MEETING SCHEDULE

Friday, May 7

7:00 p.m. - 9:00 p.m. Social Time
Hospitality room with snacks/beverages

Saturday, May 8

7:45 a.m. - 8:30 a.m. — Continental Breakfast
8:30 a.m. - Noon — Seminar
Noon - 1:30 p.m. — Deli Lunch
1:30 p.m. - 3:30 p.m. — Break Out Sessions
3:30 p.m. - 5:30 p.m. — Tour of Clinical Research Center
Evening Dinner/Get Together - TBA

Sunday, May 9

8:30 a.m. Breakfast and Business Meeting

The Seminar and meals will be at the Shearton Inn in Ann Arbor.

HOTEL INFORMATION

Shearton Inn (800) 848-2770
3200 Boardwalk, Ann Arbor
Room rates: Single or double \$72.00 plus tax.
Tell reservation desk that you are attending the Wilson's Disease Association Conference. Forty (40) rooms have been reserved for the WDA.

*Walking Distance
(very short walk)*

Courtyard by Marriott
3205 Boardwalk 1(800) 321-2211

Fairfield Inn
3285 Boardwalk 1 (800) 228-2800

Hampton Inn South
925 Victors Way 1 (800) 426-7860

*Driving Distances
(very short)*

Crowne Plaza
610 Hilton Blvd 1 (800) 344-7829

Motel Six
3764 S. State St. 1(734) 665-9900

TRANSPORTATION INFORMATION

Fly into Detroit, Metro OR take Amtrak Train into Ann Arbor.



Ground Transportation from Metro:
Ann Arbor Sedan Service
(734)645-6060

Airport Cab: (734) 741-0033
(Advance registration available)

CONFERENCE REGISTRATION

Due by May 1, 1999

Name(s): _____ Patient ___ Family ___ Friend ___

Address: _____

City: _____ State: _____ Zip: _____

Number attending: Friday Night Social _____ Saturday Conference _____

Attendance Fee: \$55.00 single, \$100.00 couple, \$40.00 each additional person

Please mail your registration form with appropriate fee to:

Len Pytlak
1905 Pauline Blvd. Suite 5
Ann Arbor, MI 48103

Welcome Aboard
New WDA Volunteers

Stefanie F. Kaplan
Barbara Fox
Carol Choat
Kevin Burgess

We need assistance with fundraising. Anyone interested in this or other volunteer areas, please give Dr. Sellner a call at 1 (800) 399-0266.

ADVISORY COMMITTEE
ON
GENETIC TESTS

HHS Secretary Shalala is creating an *Advisory Committee on Genetic Testing* to help the government formulate policies on the development and regulation of genetic tests. The goal is to assure genetic tests are accurate, medically valid, and that results are kept confidential.

(NORD - National Organization For Rare Disorders, Inc.)

Great News From Australia

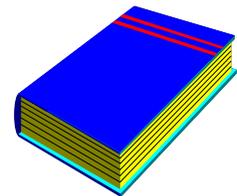
An inspiring letter was received from Mrs. Susan Kuiper from Australia. She is in contact with 22 fellow Australians who suffer from Hepatic Wilson’s Disease. At age 15, Mrs. Kuiper was diagnosed with hepatic Wilson’s Disease. The diagnosis changed to neurological WD at age 28, three years after the birth of her son.

She is currently working towards organizing an Australian Chapter for people who suffer from Wilson’s Disease. While being left permanantly disabled from WD, Mrs. Kuiper took the opportunity to write a children’s book entitled “Mrs. Wobble Goes To School”. This book has been overwhelmingly well received in Australia. She now enjoys going to Primary Schools in Western Australia to speak to children about her disability and Wilson’s Disease.

Congratulations Mrs. Kuiper on the success of your book!! You are an inspiration to everyone with Wilson’s Disease.

To request a copy of “Mrs. Wobble Goes To School”, please send \$10.00 plus \$3.00 postage to:

Mrs. Susan Kuiper
36 Sunningdale Circle
Woodbridge 6168
Western Australia



DONATIONS TO THE WILSON’S DISEASE ASSOCIATION

A donation to the Wilson’s Disease Association 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.

Enclosed is my contribution of \$ _____ . (Please check honor/memory below)

In honor ___ of _____ (PLEASE PRINT NAME).

In memory ___ of _____

Send acknowledgment of gift to: _____

(Please Print Name and Address)

Donor’s name & address: _____

(Please mail your donation to: Stefanie F. Kaplan, 869 Kallin Avenue, Long Beach, CA 90815.) Thank you.

ATTENTION ALL WDA MEMBERS: Please help us update the WDA database by completing the membership/renewal application. Thank you.

**Wilson's Disease Association
Membership/Renewal Application**

Membership (Check one): New ____ Renewing ____

Name: _____ Sex: _____

Street Address: _____

City _____ State: _____ Zip Code: _____ Country: _____

Home Phone: _(____) _____ Work Phone: _(____) _____

E-Mail: _____

Relationship to Wilson's Disease: (circle one)

Patient	Parent	Grandparent	Sibling	Child	Grandchild
Aunt	Uncle	Cousin	Friend	Other _____	

FOR PATIENTS:

Birthdate: _____

Current Treatment: (circle all that apply)

Penicillamine, Trientine, Zinc, Tetrathiomolybdate, Other: _____

Initial Symptoms: _____

Diagnosis Date: _____ Initial Treatment: _____

Other Treatments: _____

If you are unable to pay dues, please send back your form. Any amount, regardless of how small, helps. Amounts of \$50 or more will be acknowledged in the newsletter unless otherwise requested.

Basic \$35 - Sustaining \$50 - Endowing \$100 - Life \$1000 - Other \$_____

Would you like your name placed on a list with others willing to give each other support by writing, calling or meeting? Yes ____ No ____

Please mail with your check or money order to:

Wilson's Disease Association
c/o Stefanie F. Kaplan
869 Kallin Avenue
Long Beach, CA 90815

Local WD Chapter Meeting Southern California

A local Wilson's Disease Chapter Meeting was held in Long Beach, CA on January 17, 1999. Many thanks goes to Stefanie F. Kaplan, a new WDA member, who initiated and organized the event, and to each person who participated. Twenty-two people were in attendance. Dr. Brewer was the guest speaker in the morning while the afternoon was used for an open discussion session. Some key points which some members would like to share with everyone in the WDA are:

- * Diet does not really need to be altered with Wilson's patients. Liver and shell fish are the only foods that should be limited.
- * Vegetarians accumulate copper more slowly and thus may be older during a diagnosis.
- * Children of WD patients should be tested at ages 5 and 15.
- * There are over 70 different mutations of WD genes.
- * Detection of WD carriers is still very difficult.
- * There are 3 Centers of Excellence for Wilson's Disease. (Please see Resource Corner for names of centers).

This was an excellent opportunity for WD patients and families to meet. Plans were tentatively made for future meetings.

Local WD Chapters are encouraged to be formed throughout the county and internationally. For information, call Dr. Sellner, WDA President at (1800) 399-0266.

Please share your WD Chapter meeting experiences with the Wilson's Disease Association. Send a summary or highlights of the meeting to the Copper Connection Editor.

DONATIONS

We gratefully acknowledge the following gifts of \$50.00 or more:

Clyde Fausneucht
 Angela Tancredy- In honor of Mary Rose Tancredy
 Caroline Tancredy- In honor of Mary Rose Tancredy
 Lynne Wehmuller- In honor of the Villicaña siblings
 and in memory of Rosa Maria Robinson
 Mr. and Mrs. Dwayne Mattheis

Thank You!

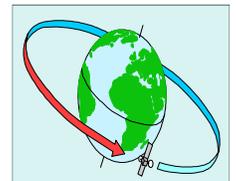
The WDA would like to express our condolences to the family of Stephen Sawyer who passed away November, 1998 due to complications of Wilson's

Reminder: Female WD Patients

Don't forget to send your survey on female reproductive histories. The survey has been reprinted on page 7 of this issue for your convenience. Results of this survey should appear in future newsletters. Thank you for your participation.

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



RESOURCE CORNER

Wilson's Disease Association

Ascher Sellner, M.D., President
4 Navaho Drive
Brookfield, CT
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
Telephone: (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

National Organization for Rare Disorders® NORD®

Rare Disease Database Reports
www.NORD-RDB.com/~orphan
P.O. Box 8923, New Fairfield, CT 06812
(203) 746-6518

How to Get Galzin® (zinc acetate)

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

Dear Copper Connection,

Hi everybody. My name is Denise Sebio, I was diagnosed with WD 24 years ago. I never knew about the WD Association until I was feeling very fatigued and seeked help through a nutritionist. She researched on the internet and brought this all to light for me. I think it's great! Everyone with WD is very special. The stages of this disease are very incredible and sometimes overwhelming. We learn to live with it and fight it till the end. I have a 5 year old son who tested negative and I pray he will stay negative for the rest of his life! Keep up the good work and I hope to meet everyone I can at the 1999 WDA Annual meeting on May 8th.

God Bless,

Denise Sebio
Pennsylvania

The Copper Connection welcomes all letters! (Please include in your letter permission for printing in future newsletters). Send your letter to:

Wilson's Disease Association
4 Navaho Drive
Brookfield, CT 06804

or

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



Take Your WD
Medications
On Time!!

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 are 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 to 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: _____ COUNTRY: _____

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

Inside This Issue:

*Wilson's Disease Association
Annual Meeting May 7-9, 1999*

WILSON DISEASE ASSOCIATION, International

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

(FORWARDING SERVICE REQUESTED)

TO:
