
◆ THE COPPER CONNECTION ◆

Wilson's Disease Association, International Newsletter

January 2000

Please Join Us For The 2000 Wilson's Disease Association Annual Meeting

May 5-7, 2000

Hyatt Orlando (near Walt Disney World Resort)
6375 West Irlo Bronson Memorial Hwy
Kissimmee, Florida, USA

REGISTRATION:

\$60.00 per person (before April 1, 2000)

\$65.00 per person (after April 1, 2000) (Registration includes Hospitality Room,
2 Continental Breakfasts, Break Snacks and Deli Lunch)

HOTEL RESERVATIONS:

(407) 396-1234 *Identify yourself as being with the WDA Meeting*

\$89.00 single/double \$114.00 triple \$164.00 quad

Above rates are exclusive of tax and will also be offered before and after the meeting.

Rooms are based on a first come, first serve basis.

HOTEL INFORMATION:

Hyatt Orlando is 20 miles from Orlando International Airport. Hotel is just 1.5 miles from
Disney World, Epcot, Disney, MGM Studios, Sea World, Universal Studios, Busch Gardens and the
Kennedy Space Center are just a short drive away.

*Heated pool * Whirlpool * Children's pool *Tennis Courts

* Beauty salon * Sports Bar * 3 Restaurants * Fitness Center

AIRPORT TRANSPORTATION:

Taxi (\$36- \$38 each way)

Mears Transportation (\$25 round trip) (407) 423-5566 - not a direct shuttle

Transportation to theme parks and attractions available daily from 8am-close for \$6.00 round
trip

WDA MEETING REGISTRATION FORM

Name: _____ (before 3/1/00) \$60.00

Address: _____ (after 3/1/00) \$65.00

City: _____ State: _____ Zip: _____

Additional family members: \$75.00 1st adult; \$60 additional adult; \$25 per child (10-17 years)

1 _____ \$ _____

2 _____ \$ _____

3 _____ \$ _____

4 _____ \$ _____

Total: \$ _____

Telephone: (_____) _____

E-Mail _____

Check here to have your name included in the directory to be distributed at the meeting.
Registration form must be received by April 15th for inclusion in the directory.

Please mail your registration form with appropriate fee to:

The Wilson's Disease Association
c/o Len Pytlak
1905 Pauline Blvd. , Suite 5
Ann Arbor, MI 48103

or FAX to Len Pytlak (734) 663-4326

Check _____ Credit Card: MasterCard _____ VISA _____

Card Number: _____ Expiration Date: _____

Name on Card: _____

Signature: _____

*Financial assistance is available for registration costs. Please notify Stefanie Kaplan (562)799-9756 (evenings and weekends) if you need assistance. Limited funds are available.

**Wilson’s Disease Association
Annual Meeting Agenda**

Friday, May 5

- 1:00 -5:00 p.m. Board Meeting - Board members only
- 5:00 -7:00 p.m. Hospitality Room Social, Registration - complimentary
- 7:00 -10:00 p.m. Join other attendees for dinner - at own expense

Saturday, May 6

- 8:00 a.m. Registration / Complimentary Breakfast
- 8:30 a.m. Welcome/Opening Remarks - Dr. Sellner, WDA President
- * 8:45 -9:45 a.m. Scientific Developments in Wilson’s Disease - Dr. George Brewer, Professor of Human Genetics, University of Michigan Medical Center
- 9:45 a.m. Break
- 10:00-11:00 a.m. Psychiatric Aspects of Chronic Illness - Dr. Rick Rader, Director of Orange Grove Habilitation Center, Chattanooga, TN
- 11:00-11:30 a.m. Liver Transplant Developments - Dr. Michael Schilsky, Hepatologist Mt. Sinai Medical Center, NYC
- 11:30-12 noon Business Meeting and Elections
- Noon-1:00 p.m. Lunch - complimentary
- 1:00 - 1:30 p.m. Dealing With Non-Compliance/ A Fatal Disease - Susan Gostanian
- 1:30 - 4:00 p.m. Support meetings led by Drs. Rader, Schilsky, Brewer, Sellner
- 6:00 - 10:00 p.m. Join other attendees for dinner - at own expense

Sunday, May 7

- 7:45 a.m. Breakfast - complimentary
- 8:15- 9:00 a.m. Medications for Wilson’s Disease, How To Choose Between Them - Dr. M. Schilsky
- 9:00 - 9:45 a.m. Programs For Patient Care at the Univ. of Michigan Med. Ctr. - Dr. Frederick Askari
- 10:00- 10:30 a.m. Break
- 10:30- 11:00 a.m. Development and Approval of New Drugs - TEVA Pharmaceutical Company
- 11:00- 12 noon Follow-up Group Support Session

*A separate program is planned for young adults on Saturday morning.

The Wilson’s Disease Association
would like to express our condolences
to the families of:

Joe Johnson
Cheryl Zandhuis

DONATIONS

We gratefully acknowledge the following gifts to
the Wilson’s Disease Association:

Bill and Mary Graber	\$9,000
Charlotte Foundation South Carolina	\$10,000

Thank You!

ATTENTION ALL WDA MEMBERS:

Beginning March 2000, The Copper Connection will be mailed to updated and renewed members only. This is due to the high cost of mailing newsletters. If you have not yet mailed your application, please do so today. Thank you.

**Wilson's Disease Association
Membership/Yearly 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 \$_____

Memberships/Renewals may be made using a MasterCard or Visa charge card. Please complete section below:

Card # _____ Exp. Date: _____

Signature _____ Phone (____) _____

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

**NO-COST, LONG-DISTANCE
MEDICAL AIR TRAVEL AVAILABLE**

One of America's best kept secrets is the existing charitable medical air transportation system **Mercy Medical Airlift**. It's purpose is to ensure that no financially-needy patient is denied access to distant specialized evaluation, diagnosis or treatment for lack of funds to pay for long-distance travel.

During this year (2000) the system will serve in excess of 18,000 patients plus family members. The system provides transportation either via the airlines (for longer trips) or via private aircraft flown by highly qualified FAA licensed volunteer pilots.

Many charities are involved - but the largest and only "full service" system in the county is that of Angel Flight America.

Mercy Medical Airlift can be reached through the National Patient Travel HELPLINE at 1-800-296-1217. Information help is available 24 hours a day, 7 days a week, 365 days a year. Internet assistance can be accessed on: www.PatientTravel.org.

Patient families and medical centers need to know about this system and make use of its resources.

One out of eight Americans is over 65 years old. By 2030, one out of 5 Americans will be over 65 years old."

The Medicare Rights Center, New York City.

(NORD, 1999)

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/Patient Care Fund below)

In honor ___ of _____ (PLEASE PRINT NAME).

In memory ___ of _____

Patient Care Fund _____

Send acknowledgment of gift to: _____

(Please Print Complete Name and Address)

Donor's name & address: _____

e-mail: _____

Contributions may be made using a MasterCard or Visa charge card. Please complete section below:

Card # _____ Exp. Date: _____

Signature _____ Phone (____) _____

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

RESOURCE SECTION**Wilson's Disease Association**

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1(800) 399-0266 e-mail: hasellner@worldnet.att.net

WDA Internet Website: www.wilsons-disease.org

WDA Newsletter Editor

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Centers of Excellence**John Vierling, M.D.**

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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: (734) 764-5499

Michael Schilsky, M.D.

Division of Liver Diseases Box 1633
Mt. Sinai Hospital
One Gustav Levy Place
New York, New York 10029-6574
Telephone: (212) 241-8339
E-mail: michael_schilsky@mssm.edu

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

Kid's/Teen Group

E-mail Nicole Russell: Princesspussycat@hotmail.com

INTERNATIONAL CHAPTERS**Australia** (Susan Kuiper)

Box 1038, Rockingham 6168
Western Australia
Tel: 08 9527 5514

Brazil (Lúcio Mazza)

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Rua Sao Joaquim, 188 Vila Gaviao
CEP 07060-180 Guarulhos, S. Paulo, Brazil
E-mail: oiulazzam@zipmail.com.br
Tel/Fax: 011-6451 7859

Denmark - Wilson's Disease Patient Association

Torben Groennebaek - President
E-mail: dk_wilsons@hotmail.com

Dutch Wilson's Disease Association

Peter van Poppel
Information web site at <http://home.concepts.nl/~pcpoppel/>
E-mail: pcpoppel@westbrabant.net

Germany- Wilson's Disease Organization

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Fax: 08031-43876

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Aucknak, New Zealand
Tel: (H) (+649) 836 7107
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E-mail: bvw@wand.co.nz

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: _____ E-MAIL: _____

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 - Registration
Annual Meeting: May 5-7, 2000*

WILSON DISEASE ASSOCIATION, International

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

(FORWARDING SERVICE REQUESTED)

TO:
