

THE COPPER CONNECTION

September, 2002

"Neurological Aspects of Wilson's Disease Symposium"

November 14, 15, 2002

Sponsored by the Movement Disorders Society

Organizers: Dr. George Brewer and Dr. Peter Lewitt

This symposium will assemble an international group of speakers to provide an authoritative, state-of-the-art review of clinical and basic scientific understanding of Wilson's Disease. For questions about the program contact Jenny Kehoe at: jkehoe@movementdisorders.org Please mention that you are a WDA member.

On November 16, 2002, following this symposium, the WDA-sponsored conference will be held in Miami. If you plan to attend, please use the registration form in this newsletter or on the WDA website.

Save The Date

The next annual WDA Meeting is scheduled for May 3-4th, 2003 in Washington, D.C.

More details to come in the next newsletter.

WILSON'S DISEASE ASSOCIATION INTERNATIONAL

WDA Semi-Annual Meeting – Saturday, November 16, 2002

**Best Western Beach Resort
4333 Collins Avenue, Miami, Florida 33140**

PROGRAM

8:15 – 9:00 a.m. Registration and complimentary breakfast at hotel

9:00 a.m. – Noon "Initial Treatment of Neurological Disease" – Dr. George Brewer, University of Michigan
"Typical Wilson's Disease Related Neurological Signs and Symptoms" – Dr. Peter Lewitt, MI
"Liver Transplantation: When" – Dr. Irmin Sternlieb, California
"Wilson's Disease in India" – Dr. Ashish Bavdekar, India
"Treatment of Neurological Complications" – Dr. John Fink, University of Michigan
"Hepatic Disease and Treatment" – Dr. Michael Schilsky, Mt. Sinai – New York
"Psychological Aspects of Wilson's Disease" – Dr. Kersten Westermark, Sweden
"Evaluation of the Degree of Liver Failure" – Dr. Anil Dhawan, United Kingdom
"The Role of Chelators in Wilson's Disease" – Dr. Egberto Barbosa, Brazil
"Surgery for Wilson's Disease Neurological Complications" – Dr. Peter Hedera, Michigan
"Maintaining WD: Compliance, Follow-up and Associated Diseases" – Dr. Fred Askari, Michigan

Noon – 1:00 p.m. Complimentary Lunch

1:00 – 5:00 p.m. Group Support Meetings / Various Topics / Facilitated by the Speakers

** HOTEL REMINDER: Best Western Beach Resort, 4333 Collins Avenue, Miami, Florida 33140
For reservations call: 1-800 832-8332 (by October 14 to get WDA group rate of \$100)

REGISTRATION FORM

For WDA Saturday Session only

If you intend to register for the *Movement* Disorder Society (**MDS**) scientific sessions on Thursday and Friday, please use their registration form at www.movementdisorders.com, found under "Sponsored Meetings"

PLEASE PRINT CLEARLY

Name _____ Address _____

City _____ State _____ Zip _____ Phone _____

E-Mail _____

WDA or **MDS** Member..... \$50.00 \$ _____

Non-Member \$85.00 \$ _____

Interested in joining the **Wilson's Disease Association**

Others \$40.00 X _____ \$ _____

TOTAL \$ _____

Names of others attending:

Check enclosed. (Payable to the: **Wilson's Disease Association**) Visa MasterCard

Card # _____ Exp. Date _____

Signature _____

Please mail or fax **BY OCTOBER 14** to:

Wilson's Disease Association International
c/o Mary Graper
5572 North Diversey Blvd.
Whitefish Bay, WI. 53217
FAX: (414) 961-0533
Phone: (414) 961-1290

PEN-PAL PROGRAM



A Pen-Pal Program, sponsored by the children's Hopes & Dreams—Wish Fulfillment Foundation, is available for children ages 5 through 17. The Foundation helps to match "ill" and "healthy" children with pen pals. "Ill" children include those with a chronic illness and any condition or disability. "Healthy" children include those who have lost a parent or sibling through death, separation, incarceration, or military deployment; or those who have a seriously ill parent or sibling.

The program is free and the friends are priceless!!
For more information on the Pen-Pal Program call (973) 361-7366

WILSON'S DISEASE IN INDIA

Dr. Ashish Bavdekar

**Associate Consultant in Pediatric Gastroenterology
Liver Unit, Dept. of Pediatrics, K.E.M. Hospital Pune, India**

Wilson's disease (WD) is being increasingly reported from many centers in India. They have a range of presentations: (a) Neurological - seen in children as young as 7-8 years and usually the diagnosis is made months/years after the onset of illness; (b) Liver disease - this includes children presenting with acute or chronic liver disease and (c) Other presentations like bony deformities, anemia, etc., are also common.

Inadequate awareness of the disease among medical professionals is an important cause of delay in diagnosis and onset of treatment. While tests for ceruloplasmin are available in most hospitals, a reliable urinary copper estimation is not readily available. Hepatic copper estimation is possible at only 2-3 centers all over India.

D-penicillamine (DP) is the most common copper chelater used because of its availability. However, it is expensive and has caused serious side-effects in some of our children. Trientine is not easily available and is very expensive (5 times the cost of DP). An

over-the-counter zinc sulphate preparation is available in India. Though very inexpensive (1/20th the cost of DP), we have found an unpredictable response to this preparation. All the WD children diagnosed at our center are started and maintained on DP lifelong. Zinc sulphate is only used for children who develop side-effects to DP or those from economically deprived families who cannot continue DP therapy. Liver transplantation is not available in India and children presenting with acute liver failure have a uniformly poor outcome. An effort is being made at our center to look for mutations causing Wilson's disease in our country.

The common mutation in Europe His1069Gln was not found in 47 children studied so far. Some mutations seen in our children are R778R and C271X. A parent support group (ROWIKEM, RO=Rotary, WI= Wilson's disease, KEM=KEM Hospital) has been started at our hospital since 1990 to help the children with WD.

Wilson's Disease Resource Books



Dr. George J. Brewer has recently published two Wilson's disease books which are now available.

Wilson's Disease: A Clinician's Guide to Recognition, Diagnosis, and Management

This book can be ordered from Kluwer Academic Publishers (via the internet www.wkap.nl/)
ISBN # 0-7923-7354-5

Wilson's Disease for the Patient and Family: A Patient's Guide to Wilson's Disease and Frequently Asked Questions About Copper

This book can be ordered from Xlibris.com (Paperback \$17.84, Hardback \$28.79, eBook \$8.00).

Shelf-life of Galzin

Galzin capsules should last indefinitely, so long as they do not physically fall apart. Zinc itself is an element, so it does not deteriorate over time.

DONATIONS

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

TEVA	\$500
Lynne Wehmuller	\$1000

Medical News

Brought to you by the WDA Medical
Advisory Group

Erythromycin Antibiotics **Fred Askari, M.D.**

Antibiotics are chosen based on a person's medical history, allergies, potential interactions with other drugs they are taking, as well as the particular type of infection that is suspected. No antibiotic is perfect for every situation, which is one reason there are so many different antibiotics in use today.

Erythromycin is cleared from the body by the liver. Caution should be exercised when erythromycin is administered to people with impaired hepatic function. It may be cleared more slowly so the dose may need to be monitored more closely and perhaps in some instances even reduced compared to someone with a healthy liver. This does not mean it should never be used by anyone with any liver disease, but as with many medicines, people with liver disease would be wise to be extra careful and alert for side effects and toxicities. The most common side effects of erythromycin are nausea, vomiting, diarrhea, abdominal pain and occasionally confusion.

Wilson's disease patients should talk with their doctors and pharmacists about which medications are best to be used.

Copper Pipes and Drinking Water **Fred Askari, M.D.**

Question:

Should there be a concern with the use of copper pipes for plumbing in the home of a person with Wilson's Disease?



Answer:

The use of copper pipes is generally not a cause for automatic alarm, but it is cause for some careful testing. Copper can leach from the pipes if the water is acidic, which is usually not the case. For this reason, if people with Wilson's Disease choose to drink tap water, they would be well advised to have their water tested for copper content. This can be done for a nominal fee through Dr. Brewer's trace element laboratory, (734) 764-5499. This is also a good idea since even people who do not have copper pipes may have high copper levels in their drinking water either from a well or a municipality.

We call water acceptable for people with Wilson's disease if it contains less copper than 0.1 ppm or 0.1 mg/liter. Please note this is much lower than EPA guidelines for the general population.

The Wilson's Disease Association
sends condolences
to the families of:

Rajesh

Jeff Dirlam

Cindy Hayes

Maury Kesler



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.

MEMBERSHIP APPLICATION/RENEWAL

Please complete, detach this page, and mail to the address below:

New Renewing Member Mr. Mrs. Miss Ms. Dr.

Name _____

Address _____

Street

City

State

Zip

Country

Home Phone (____) _____ Work Phone (____) _____ E-Mail _____

Membership Dues:

Basic \$35 Sustaining \$50 Endowing \$100 Lifetime \$1,000 Other \$ _____

DONATION

Name _____ Address _____

Street

E-Mail _____

City

State

Zip

I am making a tax-deductible donation of \$ _____

In honor of _____ In memory of _____ Patient Care Fund

Send acknowledgement to: _____

Name

Street

City

State

Zip

E-mail

PAYMENT INFORMATION

Membership Fee \$ _____ Visa Master Card Check or Money Order attached

Donation \$ _____ Card # _____

Total \$ _____ Expiration Date _____ Signature _____

SUPPORT GROUP AND VOLUNTEER INFORMATION

As we are a non-profit organization, we are always looking for volunteers. If you would like to offer your time or services to the Association, we would like to hear from you. Below are a few ideas of services that are needed, however, if you have another idea or specialty (e.g. you own a printing shop and would like to sponsor a mailing), please let us know that too:

____ Coordinate a WDA support meeting in my area ____ Coordinate a fund raising event ____ Other:

____ Please check here if you approve of your name to be given to others in your area who are looking for support

_____ (please sign here to acknowledge this).

**MAIL TO: WILSON'S DISEASE ASSOCIATION c/o Len Pytlak, CPA, PC 180 Little Lake Drive #3
Ann Arbor, MI 48103**

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

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E-mail: hasellner@worldnet.att.net
WDA Website: www.wilsons-disease.org

WDA Board Members

Ascher Sellner, M.D. - President
Len Pytlak - Vice President
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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

The Copper Connection, Editor
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Pismo Beach, CA 93448

(FORWARDING SERVICE REQUESTED)

TO: