

THE COPPER CONNECTION

June 2001

Wilson's Disease Semi-annual Support Meeting

September 15, 2001

Bethesda, Maryland

Natcher Convention Center at the National Institutes of Health

To our good fortune, this meeting is beginning the day after the two-day scientific meeting NEUROLOGICAL ASPECTS OF WILSON'S DISEASE, sponsored by the Movement Disorder Society and the National Institutes of Health. They invited us to meet in conjunction with their meeting to help educate physicians. All WDA members are invited to attend the Thursday and Friday scientific sessions which are directed to doctors.

TENTATIVE PROGRAM

Saturday morning— A group of speakers (each allotted 15 minutes) will make presentations and answer questions. Proposed topics are *diagnosis, initial treatment, long term medication initial liver disease, liver transplant, the long term course of liver disease, geriatrics and Wilson's Disease, pediatric and pregnancy management, short and long term psychiatric problems, chronic neurological problems, treatment of tremor, dystonia, headache, convulsions and persistent neurological disability.*

Saturday afternoon— Support groups will cover topics such as dealing with children and grandchildren who have Wilson's Disease, handling neurological disability, obtaining services for the neurologically impaired, managing psychiatric problems, concerns about having a family, choosing your medications and how many should you take.

Lunch arrangements will be available at the meeting, details will follow.

HOTEL ACCOMMODATIONS

Four Points Sheraton Reservations (301) 654-1000. Room rate: \$129 per night single or double. Ask for room rate for Movement Disorder Society Group # 7512A. A free shuttle is available to the meeting from the hotel.

REGISTRATION

\$50 for the first member of a family, \$40 for a spouse or immediate family member 18 years or older, \$20 for each child under 18. Non-members will be charged \$85 or they may join for \$35 when registering. Lunch is included with registration.

Send your name, mailing address, e-mail address, and checks or credit card information to:
Mary Graper, 5572 North Diversity Blvd., Whitefish Bay, WI, 53217.

For information call (414) 961-1290. REGISTER EARLY so that we may contact you with further information. Registration will be allowed at the door.

2001 Annual Meeting Highlights

The following are abstracts of lectures by three doctors at our annual meeting in Long Beach, California on May 4-6th. The meeting was attended by 80 people including participants from Hungary and Germany. Four new board members were elected including three who are also on the board of The National Center for the Study of Wilson's Disease. Henry Kaplan is an attorney and physician, Jacqui Taylor is a patient and experienced in non-profit organizations, Carl Nacht, M.D. is an internist, and Jack Levin is a patient and retired businessman.

Medication and Wilson's Disease

By Michael L. Schilsky, M.D., Hepatologist,
Mt. Sinai Medical Center, NYC

There are now new options for the medical treatment of patients with Wilson's disease. Penicillamine is no longer the "treatment of choice" as there is a growing experience with safer and effective alternatives. Trientine may be the best first choice amongst currently approved drugs as initial therapy for symptomatic patients requiring chelation therapy, and may be even more effective when used in combination with zinc treatment. Tetrathiomolybdate is undergoing clinical testing for use in the initial treatment of patients with neurologic symptoms. Zinc is an effective medication for maintenance therapy. Further studies are needed to determine the best therapy for pregnant patients with Wilson's disease, and whether combination therapy using trientine and zinc will be the next "treatment of choice" for all symptomatic patients with liver or neurologic disease.

The Course of Liver Disease

By Fred Askari, M.D., Hepatologist
University of Michigan

The course of liver disease in Wilson's Disease stands in contrast to other forms of cirrhosis for many people. The chronic liver injury in Wilson's Disease is caused by excess free copper, and the liver disease often stabilizes or even improves once the excess copper is treated with zinc acetate maintenance therapy. While some people do progress to need liver transplantation, others may actually see long term improvement in their liver function over time. It is important to be attentive to issues such as immunizations for viral hepatitis, avoiding excess alcohol consumption, and treating complication of portal hypertension in order to give the liver its best chance to mend.

Speech Pathology in Wilson's Disease Patients

By Annie Ramos-Pizarro PhD, CCC
Mt. Sinai Medical Center

Wilson's Disease (WD) is an inherited genetic disease of copper accumulation that can result in neurological symptoms, behavioral abnormalities, and liver disease in adolescence through adulthood. Dysarthria, a speech disorder characterized by difficulty with articulation, slowing of speaking rate and weak voice is a frequent neurological feature in these patients. This presentation described in detail the speech and voice features of dysarthria associated with Wilson's Disease, specifically, respiration, phonation, articulation, resonance and prosody difficulties. In addition, assessment procedures used in the evaluation of the condition were described, as well as behavioral and surgical management alternatives currently available in the management of these problems. It is recognized that a weak, breathy, hypernasal voice can negatively impact the communication and quality of life of affected individuals. Better understanding by clinicians of the voice and speech impairment in patients with Wilson's Disease will hopefully lead to appropriate referrals for behavioral or surgical management that are available.

Save The Date

The **2002 WDA annual meeting** will be in Chicago, Illinois on May 4th and 5th. Details to follow in future

DONATIONS

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

Fetzer and Becky Mills	\$100
Carol and Ascher Sellner	\$500
Morton and Henriette Sellner	\$500
Mary and William Graper	\$9000

8. What was the total time period that you did not have periods after your initial menses?
 ____ Years ____ Months
9. Have your periods stopped due to menopause? ____ Yes ____ No
- 9a. If yes, age at time periods stopped: ____
10. Have you used birth control? ____ Yes ____ No
- 10a. If yes, please check all methods you have used, age at use and duration of use (as applicable):
- | | | |
|--------------------------|----------|--------------------------------------|
| ____ Birth control pills | Age ____ | Duration (in months and years) _____ |
| ____ IUD | Age ____ | Duration (in months and years) _____ |
| ____ Diaphragm | Age ____ | Duration (in months and years) _____ |
| ____ Tubal Ligation | Age ____ | |
| ____ Vasectomy | ____ | Condoms or withdrawal |

Pregnancies

11. Have you ever tried to become pregnant? ____ Yes ____ No
12. Did you succeed? ____ Yes ____ No
13. Have you given birth to living children? ____ Yes ____ No If yes, how many? ____
14. How many pregnancies have you had? ____*
15. Considering all of your pregnancies, please list the number of each of the following outcomes? (*total marked should equal total pregnancies in your answer to question 14.)
- | | |
|---|----------------------------------|
| ____ Term pregnancy(ies) (weighing 5 lbs or more) | ____ Miscarriage(s), spontaneous |
| ____ Premature pregnancy(ies) (weighing less than 5 lbs.) | ____ Induced Abortion(s) |
16. Have you ever been advised by a doctor not to get pregnant due to your Wilson's Disease?
 ____ Yes ____ No
17. Have you ever been advised by a doctor to have an abortion due to your Wilson's Disease?
 ____ Yes ____ No
18. Have you ever been advised by a doctor to have a sterilization due to your Wilson's Disease?
 ____ Yes ____ No
19. How many pregnancies have you had after your diagnosis of Wilson's Disease? ____
20. After treatment began, how many months or years passed until your first pregnancy? ____
21. Please describe the Wilson's Disease medication you were taking during each pregnancy after your diagnosis:
- 1st Pregnancy Treatment: _____ Dose: _____
 Any complications? _____
- 2nd Pregnancy Treatment: _____ Dose: _____
 Any complications? _____
- 3rd Pregnancy Treatment: _____ Dose: _____
 Any complications? _____
- 4th Pregnancy Treatment: _____ Dose: _____
 Any complications? _____
- (Please list additional pregnancies and treatment on an additional sheet in the format above.)
22. Did you have any of the following complications in any of your pregnancies (check all that apply)?
- | | | | |
|-----------------------------|------------------------|----------------------------|---------------|
| ____ Pre-eclampsia | ____ Hypertension | ____ Twins | ____ Triplets |
| ____ Breech birth | ____ Heart Disease | ____ Diabetes | ____ Bleeding |
| ____ Hyperemesis | ____ Incomplete Cervix | ____ Postpartum Depression | |
| ____ Other (describe) _____ | | | |

Infertility

23. Did you have infertility? Yes No
 24. Did you seek medical treatment for it? Yes No
 25. Was there male infertility? Yes No
 26. What was the given cause of your infertility? _____
 27. If you were treated for infertility, did your periods stop before treatment and resume after treatment for infertility began? Yes No
 28. Before treatment were your periods regular irregular infrequent no periods

During infertility treatment:

29. How long between the first day of each period? _____
 30. How long does or did your period last? _____
 31. Do or did you hemorrhage? Yes No
 32. Are or were your periods (check one):
 frequent irregular normal no periods
33. Have you ever had any of the following (check all that apply)?
- | | | |
|--|--|--|
| <input type="checkbox"/> Breast cancer | <input type="checkbox"/> Breast biopsy benign | <input type="checkbox"/> Uterine Cancer |
| <input type="checkbox"/> Abnormal Pap Smear | <input type="checkbox"/> Cone biopsy or leep of the cervix | <input type="checkbox"/> Abnormal uterine bleeding |
| <input type="checkbox"/> Genital warts | <input type="checkbox"/> Herpes vaginalis | <input type="checkbox"/> Chlamydia |
| <input type="checkbox"/> Fibroids | <input type="checkbox"/> Ovarian tumors benign | <input type="checkbox"/> Ovarian cancer |
| <input type="checkbox"/> PMS | <input type="checkbox"/> Dilation & Curettage (D&C) | <input type="checkbox"/> Hysterectomy |
| <input type="checkbox"/> Repair of Cystocele | <input type="checkbox"/> Myomectomy | <input type="checkbox"/> Ovarian Cystectomy |
| <input type="checkbox"/> Laparoscopy (if yes, give reason) _____ | | |

Menopause

34. Age at menopause: _____
 35. Are you taking hormone therapy? Yes No
 36. If yes, name of medication: _____
 37. Did you continue therapy? Yes No
 37a. If no, why not? _____
 38. Have you had osteoporosis? Yes No
 39. Have you had a bone scan? Yes No
 39a. If yes, what was the result? _____

General

40. List any other medical illnesses you have, besides Wilson's Disease?

41. List any surgeries you have had, other than mentioned above.

42. List any other medications you take.

43. My interest in sex is: greater _____ the same _____ less than _____ gone _____

Thank you for completing this survey. The data will be compiled by Nicki Karst of the WDA and returned to Dr. Sellner for publication.

Please FOLD survey pages together, staple and mail within four (4) weeks to Nicki Karst.

Be sure that address shows on the outside of your form.

Fold Here

Return Address:

**TO: Nicki T. Karst
 WDA SURVEY
 3005 Druvor St.
 Idaho Falls, ID 83402**

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.

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<p>Wilson's Disease Association Ascher Sellner, M.D. President 4 Navaho Drive, Brookfield, CT 06804 1 (800) 399-0266 E-mail: hasellner@worldnet.att.net WDA Website: www.wilsons-disease.org</p>
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WILSON'S DISEASE ASSOCIATION, INTERNATIONAL

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(FORWARDING SERVICE REQUESTED)

TO: