

Wilson's Disease Association, International

# THE COPPER CONNECTION

**December 2000**

## WDA Annual Meeting May 5 and 6, 2001 Long Beach, California

We have selected a fantastic location for our next annual meeting. Long Beach, California is 18 miles south of Los Angeles International Airport and 25 miles north of Orange County John Wayne airport. Long Beach also has its own municipal airport where American Airlines flies direct to and from Dallas. For airport shuttle information, please contact Super Shuttle at 800-862-7771. Shuttle from LAX is \$15.00 per person; from Orange County is \$34.50 per person.

Hyatt Regency Long Beach  
200 South Pine Avenue  
Long Beach, CA 90802  
(562)491-1234 (hotel direct)  
(800)233-1234 (reservations only)

### RESERVE ROOMS EARLY!

Guest rooms are on a first come, first serve basis. After April 16, 2001, rooms are upon availability only.  
**For reservations, call and request a room under the "Wilson's Disease Association Meeting" room block:  
\$89.00 (plus 12% tax) per night for single or double occupancy**  
Kids under 18 stay free in room with parents.

Self parking: \$6.00 Valet parking: \$8.00 ( per car per night)

The hotel is walking distance to 100 shops and restaurants. The Aquarium of the Pacific, the Queen Mary, and the beach are minutes from the hotel. Major attractions, such as Disneyland and Universal Studios are just ½ hour from the hotel.

### Meeting Agenda (Registration Fee includes the following)

Friday, May 4, 2001	Hospitality Reception	5:00pm-7:00pm
Saturday, May 5, 2001	Registration/Continental Breakfast	8:30am
	General Session	9:00am-12:00pm
	Lunch	12:00pm
	Breakouts/Afternoon Snacks	1:30pm-5:00pm
Sunday, May 6, 2001	Continental Breakfast	8:30am
	General Session	9:00am-11:30am

For questions, please contact: Stefanie Kaplan (562)799-9756 evenings or at stefaniekaplan@yahoo.com

(Please see page 3 for the Annual Meeting Registration Form)

***President's Message:***

When I was ill once in the hospital, a very intelligent doctor specializing in infectious diseases asked when I was going to have a transplant. I have been asked this even this week when I went to a doctor. Of course I explain that a transplant is only for desperately ill patients, and it is for the following reason: Transplants substitute one problem for another. (See the article and comment below).

While lives are often saved by liver transplants, for some patients death is a real complication of the procedure. The decision to transplant requires weighing the difference between the risks of one and the risks of the other. For some patients, death is inevitable without a transplant, although many recover from very severe liver failure with medication alone. Certainly patients doing satisfactorily, should not consider the procedure.

Ascher Sellner, M.D.

Long-Term Follow-up After Liver Transplantation

The University of Pittsburgh has been a world leader in liver transplantation. This report describes the outcomes for 4000 consecutive patients who underwent liver transplantation at Pittsburgh from 1981 through 1998.

Actuarial survival rates at 1, 10 and 18 years were 79%, 57%, and 48%, respectively. Ten-year survival was significantly higher for patients who received transplants after 1990 than for those who received transplants in earlier years (60% vs. 53%) and was higher for children than for adults. The death rate was 20% during the first post-transplant year and dropped to a few percent per year thereafter.

Although there was considerable variability in survival according to type of liver disease, 10 year survival was lower than 40% only for patients who received transplants because of liver cancer. The most common causes of death among all recipients were infection (28%) and recurrent or new cancer (12%). Nineteen percent of patients received 2 transplants, and 4% received more than 2.

Comment: This is the largest long-term follow-up study of liver transplantation from a single center, the data will be

helpful both for policy-makers (in deciding who should be eligible for the procedure) and for clinicians who treat patients with advanced liver disease. The authors attribute better outcomes in the 1990s in part to the use of tacrolimus for immunosuppression - AS Brett

*Jain A et al. Long-term survival after liver transplantation in 4000 consecutive patients at a single center. Ann Surg 2000 Oct; 232:490-500. (Journal Watch, November 15, 2000).*

### **IMPORTANT MEMBERSHIP INFORMATION**

We are looking to establish a calendar-year membership renewal program. In order to accomplish this, we are asking all members who renewed before 9/1/00 to renew membership by 2/15/01. If you paid membership after 9/1/00, then consider yourself paid-up until 2001.

Please complete **all items** on the membership form, and mail it to the address listed on the membership form. Please make checks payable to the Wilson's Disease Association.

If you, or someone you know, are looking to make a contribution, in addition to membership, please complete the Contribution Form.

Thank you for your continued support!

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

### **DONATIONS**

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

Barbara and Julian Fox \$1,000  
Lynne Wehmueller \$1,000

**WDA Annual Meeting  
May 5 and 6, 2001  
Registration Form**

NAME: \_\_\_\_\_ E-MAIL: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

RELATIONSHIP TO WD: PATIENT PARENT SIBLING FRIEND OTHER: \_\_\_\_\_

YOU MAY RELEASE MY NAME FOR A ROSTER OF THE MEETING ATTENDEES: YES NO

THIS IS MY FIRST WDA MEETING: YES NO

ADDITIONAL ATTENDEES: 1. \_\_\_\_\_

(please include ages of kids, 2. \_\_\_\_\_  
if any)

3. \_\_\_\_\_

4. \_\_\_\_\_

REGISTRATION FEES (BY 3/1/01): \$75.00 PER ADULT \$25.00 PER CHILD (AGES 10-17)

REGISTRATION FEES (AFTER 3/1/01): \$80.00 PER ADULT \$30.00 PER CHILD (AGES 10-17)

**\*REGISTRATION AND FEES SHOULD BE RECEIVED NO LATER THAN 4/1/01\***

CHECK # \_\_\_\_\_ IS ENCLOSED FOR \$ \_\_\_\_\_ (CHECKS PAYABLE TO:  
WILSON'S DISEASE ASSOCIATION)

PLEASE CHARGE MY VISA # \_\_\_\_\_ EXP. DATE: \_\_\_\_\_

SIGNATURE: \_\_\_\_\_ AMOUNT: \$ \_\_\_\_\_

Please mail in your registration form/check to:

Len Pytlak  
1813 1/2 Dexter Avenue  
Ann Arbor, MI 48103

Registrations are due no later than 4/1/01. Lower registration fee applies for forms mailed by 3/1/01.

## Medical News

Brought to you by the WDA  
Medical Advisory Group

### Anemia and Zinc

Fred Askari, M.D.

The risk of a Wilson's Disease patient being anemic while taking zinc can be due to excessive reductions of copper in the body. This is most common in patients who ingest a vegetarian diet which is extremely low in copper. We prevent this anemia side effect by screening urine samples for copper and zinc at least once a year while people are taking zinc. The zinc dosage can then be adjusted if copper levels get too low.

This is never an issue until people have been on copper reducing agents for years, and it is seldom an issue even then. The anemia caused by copper deficiency can mimic the anemia caused by iron deficiency, where the red blood cells are microcytic or smaller than usual. Fortunately, if the anemia is caused by copper deficiency, it means that copper levels are well reduced.

## **NORD Policy Positions**

NORD is a federation of approximately 140 not-for-profit health organizations and thousands of individuals and medical professionals serving people with rare diseases. As a voluntary health agency dedicated to helping people with rare disorders, NORD has recently posted their policy positions on genetic discrimination, Medicare prescription drug proposals and insurance reimbursement for orphan drugs.

Genetic Discrimination: NORD supports federal protections against genetic discrimination.

## DNA Patient Study

The following is an open letter written by Dr. Peter Ferenci. The WDA provides this information to all members. It is up to each member to decide whether he or she is interested in participating in this study.

Dear All,

I am interested in genotype-phenotype correlations in WD. Therefore I would like to obtain DNA from as many patients as possible. I need:  
1) A 5ml EDTA blood sample (like for a CBC) sent by express mail. DNA is stable for at least three days without cooling. You can mail your blood sample to:

Dept. Internal Medicine 4, Lab. 6P (attn Ms. Poli.)  
Wahringer Guertel 18-20  
A 1090 Wein - Austria

The analysis will be done free of charge. In addition, I offer analysis of first degree relatives of WD-patients (not part of the study - just an offer). For this analysis, DNA of the index patient and both parents is needed.

2. Mailing address of the patient. I will send a questionnaire regarding details of the history (symptoms, age at onset, how was the diagnosis made, etc.). The best source for me would be copies of medical records obtained when patient was diagnosed. The result of the analysis will be sent to the patient directly and will be used anonymously for research purposes.

Thank you for your interest.

Prof. Peter Ferenci  
Univ. Klinik für Innere Medizin IV  
AKH Wien  
Wahringer Guertel 18-20  
A 1090 Wien Austria  
Fax +43 1 404004735; Tel +43 1 404004741

Medicare Prescription Drug Proposals: NORD is committed to the enactment of prescription drug benefits for all Medicare beneficiaries.

Insurance Reimbursement For Orphan Drugs: NORD is committed to achieving a fair and balanced approach to orphan drug reimbursement by health insurers in order to ensure timely access to treatment.

More in-depth information on these policy positions, can be found on the NORD website: <http://www.rarediseases.org> or by contacting NORD President Abbey S. Meyers (203) 746-6518.

Dear Friends of the WDA,

As the year winds down towards the hectic holiday season, many of us will be thinking of ways to reduce our income taxes. If you are not thinking about it, you should be. May I suggest a donation to the Wilson's Disease Association. The WDA has been approved by the Internal Revenue Services as a 501c(3) charitable organization. This means that donations to us are tax deductible.

For those individuals that file a federal schedule A - Itemized Deductions, with their federal form 1040, a donation to the WDA will save you a few tax dollars when you file your returns next April. Depending on your income tax bracket, a \$1,000 donation could save as much as \$396 in federal income taxes. Even more if your state allows itemized deductions.

Donation	Tax Bracket	Tax Savings
\$1,000	15 %	\$150
\$1,000	28 %	\$280
\$1,000	31 %	\$310
\$1,000	36 %	\$360
\$1,000	39.6 %	\$396

In addition to your donation, your employer may have a matching contribution program that would allow us to receive double the benefit from your donation. Please check with your employer to see if they offer this type of program. If they do, let me know and I will provide them with any documentation they may require to prove that donations to us are tax deductible.

I am also aware of companies that make charitable donations at year end instead of having Christmas parties. You may want to mention this to your employer also.

Do you have family members, parents for example, that are difficult to buy gifts for because they have everything? Consider honoring them with a donation in their name to the W. D. A.. We will recognize the gift with a card to them and in a future newsletter.

If you donate to your local United Way, either directly or by payroll deduction (which a lot of employers insist that you voluntarily do), you can designate the WDA as the recipient of the donation.

Please remember that the Wilson's Disease Association is a very small organization with less than 300 paid members. Any, and all, donations to us will help us greatly to achieve the many goals that the board of directors wants to accomplish to improve the treatment, care and diagnoses of Wilson's Disease. Please support our efforts. Mail your tax deductible donation to:

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

Just a reminder, for your donation to be deductible on your 2000 income tax return, we must receive it by December 31st.

Sincerely,

Len Pytlak, CPA  
Vice President  
Wilson's Disease Association

(PS.. Want to earn more frequent flyer mileage, put you donation on your charge card).

## WDA Member News

Dr. Sellner,

I really thank God for you and the Wilson's Disease Organization for all your help and your prompt response to my plea for a much needed medication. I hope to someday be able to attend a WDA annual meeting that I might get a chance to meet with you and all the other members in person. I would like to share with all of you and others my triumphs of being a Wilson's Disease patient and how the Lord has blessed me and still is every second of every minute of my life. Dr. Sellner, please feel free to give my E-mail address to other Wilson's Disease patients who are going through the same thing. Wilson's Disease is very rare in these parts. Most people have never heard of it and need to be educated as to the seriousness and effect it can have on a person who has been diagnosed with Wilson's. Again, thank you and the Wilson's Disease Association.

Sincerely Grateful,

Annette Watts

### WDA Board Members

Ascher Sellner, M.D. - President  
 Len Pytlak - Vice President  
 Carol Terry - Treasurer  
 Carol Sellner - Secretary

### Board Members

Luke Chung	Kevin Peters
Nancy Hoffman	Stefanie Kaplan
Sparky Terry	Mary Graper

### Honorary Board Member

Janene Bowen

### 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, P.O. Box 1225, Pismo Beach, CA 93448 or e-mail to DRNDVR@aol.com.

Dear Everyone,

I would like to include the way I have been blessed by God to take on this roller coaster ride of a disease that He has given us to contend with: Thru poetry!!

*"Swimming Lessons" ©*

*As I sit here,  
 On this rock,  
 Overlooking the ocean,  
 Watching the sun begin to set,  
 Wondering whether or not  
 To dare stick my foot in the cool  
 Water, or  
 Whether or not I should be afraid of  
 The waves that could come engulf  
 And send me crashing into the ocean...*

*Suddenly I realize, that the ocean is life -  
 My life.  
 And the setting sun, is going to arise again -  
 Like I do, every day.  
 And that if I hadn't dared to stick  
 My foot into the coolness of my thoughts,  
 I wouldn't be here to tell you  
 That I've had many waves come crash down on me...  
 But then how else  
 Would I have ever gotten the courage to  
 Learn to swim into this glorious ocean called life?*

*If there's anything I would like to encourage all of you to do -  
 Is learn to swim.*

*By Ingrid Alejandra*



## WDA INTERNATIONAL CHAPTERS

The WDA welcomes international members. We have received a great response from people around the world (see page 7 for a list of formed international chapters). If you are interested in forming such a group, please fax Dr. Ascher Sellner at 1(203) 743-6196 or e-mail hasellner@worldnet.att.net.

## RESOURCE SECTION

### 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 Internet Website: www.wilsonsdisease.org

### WDA Newsletter Editor

Delia Ruiz  
P.O. Box 1225, Pismo Beach, CA 93448  
E-mail: DRNDVR@aol.com

### 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 J. 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 Medical Center  
One Gustav Levy Place  
New York, New York 10029-6574  
Telephone: (212) 241-8339  
E-mail: michael\_schilsky@mssm.edu

### 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)

1(800) Athena or 1 (650) 877-7688

## INTERNATIONAL CHAPTERS

### Australia

36 Sunningdale Circle  
Rockingham  
Western Australia  
Tel: 08 9527 5514

### Brazil (Sonia Knopf)

Associação Brasileira dos doentes de Wilson  
Rua Sao Joaquim, 188 Vila Galvao  
CEP 07064-180 Guarulhos, S. Paulo, Brazil  
E-mail: associacao@doencadewilson.org Tel/Fax: 011-6451 7859  
Dr. Egberto Reis Barbosa, Neurologist E-mail: neuro@doencadewilson.org  
Dr. Eduardo Cançado, Gastrologist E-mail: hepato@doencadewilson.org  
Web site: http://www.doencadewilson.org

### Canada (George Feldmann)

75 Wiltshire Bay  
Winnipeg, Manitoba R2J 2L6  
(204) 237-8797  
E-mail: georgefeldmann@home.com

### Austria (Susanne Danzinger)

E-mail: susanne.danzinger@chello.at

### Jean Perog

Box 21, Quilchena, British Columbia  
VOE 2R0  
(250) 372-2271  
E-mail: jean.perog@ex.thr.bc.ca

### Denmark—Wilson's Disease Patient Association

Torben Groennebaek—President  
E-mail: dk\_wilsons@hotmail.com

### Dutch Wilson's Disease Association

Peter van Poppel  
Informative web site at: [Http://home.concepts.nl/~pcpoppel/](http://home.concepts.nl/~pcpoppel/)  
E-mail: pcpoppe@westbrabant.net

### Germany-Wilson's Disease Organization

Morbus Wilson e.V.  
Geschäftsstelle  
Meraner Strabe 17, D83024 Rosenheim  
Informative web site: <http://www.morbus-wilson.de>  
E-mail: info@morbus-wilson.de  
Tel: 08031-249230 Fax: 08031-43876

### India—ROWIKEM

Dr. Ashish Bavdekar, Associate Consultant - Pediatric Research  
Liver and Gastroenterology Unit, Dept. of Pediatrics  
T.D.H. Building, Ground Floor  
K.E.M. Hospital, Rasta Peth, Pune 411011, India  
Tel: 91-020-6125600 (ext. 342 / 343) or  
91-020-6113041 (ext. 342 / 343)  
Fax: 91-020-6125603 E-mail: kemhrc@vsnl.com  
Clinics for Wilson's Disease: Mon. & Thurs. 10 a.m. -12:30

### India - WISDOM

Dr. D.P.Pande PhD (Engg)  
Wilson Disease Observation and Management  
ALMORA 4-A, Anushakti Nagar, Mumbai-94 INDIA  
Tel: 550 -5050 or 6060 or 7070 or 8080 or 9090—ext 2167  
Fax? 0091-22-550-5151 or -5150  
E-mail: dppesdd@apsara.barc.ernet.in

### Israel

Yaron Ilan, M.D.  
Liver and Gastroenterology Units, Dept. of Medicine  
Hadassah University Hospital  
POB 12000, 91120 Jerusalem, Israel  
E-mail: ilan@hadassah.org.il Tel: 972-2-6420338  
Dr. Ran Oren  
Liver Unit, Urasky Medical Center, Tel Aviv  
Tel: 972-3 6974280

### Romania (Laura Andreia Damain)

Mircea cel Batran Street, no 19  
Brasov 2200, Romania  
E-mail: laura@draculaseek.ro Tel: 040+068+165224

### South Africa (Remo and Beatrice Castellan)

Castellan Pualine, P.O. Box 73106  
Fairland 2030 Johannesburg, South Africa  
E-Mail: cstellan@global.co.za Tel/Fax: (+27) 11 6782126

### Spain (Conchi Casas)

C/Juan de Valladolid 4, 1º D  
47014 Valladolid, Spain  
E-mail: wilsons@teleline.es Tel: 983-372150

### New Zealand (Bethli Wainwright)

5A Eyre Street, Henderson Heights, Auckland, New Zealand  
Tel: (H) (+64 9) 836 7107 Fax: (+64 9) 836-7104  
E-mail: ptoli@ihug.co.nz

### United Kingdom (Dr. Caroline Simms, Ph.D.)

36 Sunningdale Drive, Woodborough  
Nottingham. NG14 6EQ, United Kingdom  
E-mail: carolinesimms@hotmail.com



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(D)

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

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**WILSON'S DISEASE ASSOCIATION, INTERNATIONAL**

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

(FORWARDING SERVICE REQUESTED)

**TO:**