

THE COPPER CONNECTION

June 2000

WDA Annual Meeting Highlights

The annual meeting in Orlando was successful from the hospitality hour Friday night through the lectures Sunday morning. On Friday, an all day board meeting was held with three new board members. Saturday, Dr. Brewer updated us on Wilson Disease, Dr. Rick Rader discussed the psychological aspects of the disease. He asked seven members of the group to discuss their own personal feelings about death dependency, disfigurement, disability, disruption, discomfort, and disengagement. He also discussed the five steps of grief: denial, anger, bargaining, depression, and acceptance.

Sue Gostanian discussed non-compliance; the reasons for which are lack of access to good information, failure to understand that you cannot control the situation on your own, lack of resources, environment, secondary gain (manipulating others), relationships to other people. Dr. Schilsky discussed the status of liver transplantation and the fact that many severely affected people can be managed medically (without transplant). He further pointed out that transplantation trades one disease, Wilson Disease, for another, transplant rejection difficulties.

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Wilson's Disease Association Board members taken during the May 2000 WDA Annual Meeting in Orlando, Florida.

President's Message:

We have had our best year yet. I hope this coming year will be even better. The following is a list of what the Wilson's Disease Association has done in the past year:

- ♦ Dr. George Brewer was appointed the Sellner professor of Human Genetics at the University of Michigan.
- ♦ The WDA received two gifts greater than \$10,000.
- ♦ Dr. and Mrs. Sellner met President Clinton when he signed the executive order banning discrimination based on genetic information.
- ♦ Dr. Ascher Sellner met Congressman Maloney and the staff of Senators Leiberman and Dodd on Capital Hill to lobby on behalf of Wilson Disease including the availability of trientine and support for the NIH research in rare diseases.
- ♦ We began strategic planning with the assistance of a consultant Carol Weisman. We had two telephone conferences in anticipation for our annual meeting. The board will be meeting bi-annually.
- ♦ The WDA web page has expanded considerably and we have added physicians around the world.
- ♦ We will be participating in a gene study with Dr. Ferenci in Austria. Watch for details in the next newsletter and on the web site.
- ♦ We have assisted a number of patients with medications and transportation. Recently, we helped a patient who showed up quite ill at the annual meeting and assisted her with transportation for admission to the University of Michigan.
- ♦ The WDA has contributed \$3700.00 to Dr. George Brewer to study the

(Continued on page 3)

Obtaining Galzin® in Europe

GATE Pharmaceutical representative, Thomas Dietrich, recommends that Wilson Disease patients use the following resource contacts for obtaining Galzin® (zinc acetate) outside of the United States (Europe and Canada).

Germany:

Orphan Europe (Germany) GmbH
Max-Planck-Strabe 6
63128 Dietzenbach, Germany
Tel: 49 60 74 81 21 60
Fax 49 60 74 81 21 66
email: info.d@orphan-europe.com

United Kingdom:

Orphan Europe (UK) Ltd
32 Bell Street
Henley-on-Thames
OXFORDSHIRE RG9 2BH
United Kingdom
Tel: 44 1491 414 333
Fax: 44 1491 414 443
email: info.uk@orphan-europe.com

Spain:

Orphan Europe Spain
Gran Via de les Corts Catalanes
774, 5ª^a
08013 Barcelona, Spain
Tel: 34 932 440 930
Fax: 34 932 479 028
email: jrius@orphan-europe.es

Italy:

Orphan Europe Italy
Via Cellini, 11
20090 Segrate (Milano), Italy
Tel: 39 2 26 95 00 27
Fax: 39 2 26 95 36 74
email: cdutch@orphan-europe.com

Sweden, Denmark, Finland, Norway,

Iceland, or the Baltic States:

Swedish Orphan AB
Drottningatan 98
SE-111 60 STOCKHOLM, Sweden
Tel: 46 8 402 83 30
Fax: 46 8 411 12 54

France or any other country such as The Middle East countries (Israel):

Orphan Europe SARL
Immeuble "Le Guillaumet"
60, avenue du President Wilson
92046 PARIS LA DEFENSE, France
Tel: 33 1 47 73 64 58
Fax: 33 1 49 06 00 04
e-mail: fra@orphan-europe.com
Contact Names: Dr. Bielski; Dr.

Kibleur or Mr. Mambrimi

NOTE: If, when you call, the person who answers the phone is not familiar with Galzin®, then ask to speak to the Medical Director. Also, remember to use 011 before each contact number when calling from the USA.

FOR CANADIAN PATIENTS

1. Your physician must contact:

The Emergency Drug Release
Program Finance Building
Tunney's Pasture
Postal Locator 0202C1
Ottawa, Ont.
K1A 1B6
Tel: (613)-941-2108
Fax: (613)-941-3194

If a patient still has problems obtaining GALZIN® (Zinc Acetate) after contacting the organizations above, please contact:

GATE Pharmaceuticals
151 Domorah Drive
P O Box 1008
Montgomeryville, PA 18936
Tel: 1 800 292 4283
Fax: 1 215 653 0839
e-mail: tdietric@tevausa.com
Contact Name: Thomas Dietrich

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The afternoon was highlighted by support groups. In the evening, many of us got together for dinner with one another.

On Sunday morning, Dr. Schilsky discussed the choice of drugs, Tom Dietrich of Gate Inc. discussed the process of obtaining FDA approval for Galzin, and Dr. Fred Askari, from the Wilson Disease clinic at the University of Michigan, discussed the function of the clinic as well as many patient care issues. There were many questions for all.

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
Rob Stall, M.D.	Sparky Terry
Mary Graper	

Honorary Board Member

Janene Bowen

10th Anniversary of the WDA in Germany

In celebration of the 10th anniversary of the Wilson's Disease Association in Germany, there will be a big Wilson's meeting in Rosenheim, Germany on October 14, 2000.

The meeting will take place at the Culture and Congress Center in Rosenheim at 9:30 a.m. (German time).

For accommodations, please contact the tourist information center at: (your international access code) + 49 8031 365 9061 or fax: (your international access code) + 49 8031 365 9060.

Rosenheim is located at the southern border of Germany, so you have to fly in to either Munich or Salzburg, Austria. From there, you have to travel by train or car to Rosenheim.

Anyone interested in attending can contact Stefan Sandler at the e-mail address: sandler@paritaet-nrw.org.

(continue from page 1)

frequency of the Wilson Disease gene.

- ♦ We have nearly completed a study of female reproductive state in Wilson's women.
- ♦ We have provided information to doctors, patients and students.
- ♦ We have referred patients to doctors and doctors to experts.
- ♦ We handled e-mail from around the world.
- ♦ We facilitated a Brazilian and a Chinese patient in their coming to the University of Michigan for treatment.

There are still many more tasks to be done which will need ever increasing funds. I hope that each of you will pay your dues, that each of you will make additional contributions, and solicit the support of friends and relatives. One highly disabled pa-

tient walked on her treadmill during a walkathon to raise money.

We have decided to hire a part-time assistant to help with many administrative tasks so that we can get more done for the Wilson's community. This will help more people, but it will cost more money.

The WDA board has committed itself to helping everyone with Wilson's; regardless of whether dues are paid. We are counting upon you to be generous and enlightened. After all, Wilson's Disease doesn't go away. Those of you in excellent health have no guarantee that you will never need us or the work that we are getting done.

We are intensely hopeful that we can improve early diagnosis and improve the quality of care. It is appalling how often the diagnosis is missed or delayed, and how often

the treatment is incorrect or inadequate. Patients get too much medication, not enough medication or the wrong medication.

With the help of all of you, the hard work of the board, and your financial generosity, we can achieve a great deal together. Thank you for your support these past six years.

Sincerely,
Ascher Sellner

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

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 Number: _____ Expiration Date: _____

Signature: _____ Telephone (____) _____

(Please mail your donation to: Barbara Fox 6009 Neddy Ave., Woodland Hills, CA 91367). Thank you.

Wilson's Disease Association Membership/Yearly Renewal Application

Welcome to the Wilson's Disease Association. Please complete and mail this form if you are a NEW or RENEWING member. As a member, you will be notified of annual WDA meetings and receive THE COPPER CONNECTION WDA newsletter .

Membership (check one): New _____ Renewing: _____ (date dues last paid _____)

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 _____	

If you are a Wilson's Disease patient, please complete questions 1-5.

1. Birthdate: _____
2. Current Treatment: (circle all that apply)
Penicillamine, Trientine, Zinc, Tetrathiomolybdate, Other: _____
3. Initial Symptoms: _____
4. Date Diagnosed: _____ Initial Treatment: _____
5. Other Treatments: _____

If you are unable to pay dues, please send back your form. Any amount, regardless of how small, helps.

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

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

Card Number: _____ Expiration Date: _____

Signature: _____ Telephone: (____) _____

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 this form with your check or money order to:

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

State Pharmaceutical Assistance Programs

Fourteen states have created programs to provide low cost prescription drugs to low income Medicare beneficiaries. Listed here are the 14 states that have pharmaceutical assistance programs for needy elderly and/or disabled people. Additionally, the Veteran's Administration provides low cost prescription drugs to honorably discharged veterans, but many of the newer drugs are not included on the VA formulary. To learn how veterans may qualify, the VA can be contacted at 877-222-8387.

(NORD: National Organization For Rare Disorders, Inc®)

Connecticut	(860) 832-9265
Delaware	(302) 651-4405
Illinois	(800) 624-2459
Maine	(207) 287-2674
Maryland	(410) 767-5394
Massachusetts	(800) 953-3305
Michigan	(517) 373-8230
Minnesota	(800) 333-2433
New Jersey	(800) 792-9745
New York	(800) 332-3742
Pennsylvania	(717) 652-9028
Rhode Island	(401) 222-2858
Vermont	(800) 529-4060
Wyoming	(800) 442-2766

Ask The Doctor...

Question: Should Wilson's Disease patients take B6 supplements?

Answer: Only Wilson's Disease patients who are taking penicillamine should also take pyridoxine B6 supplements. Penicillamine appears to act as an antagonist to B6 and increase its excretion in the urine. Patients who are under other approved anticopper medications (zinc acetate or trientine) do not need to supplement their medical treatment with B6.



Wilson's Disease Inheritance

Wilson's Disease occurs throughout the world in all races and nationalities. It affects 1 in 30,000 people. It is transmitted as an autosomal recessive disease, which means it is not sex-linked (it occurs equally in men and women). In order to inherit the disease, each of one's parents must carry a Wilson's disease gene, which each passes to the affected child. The responsible gene is located at a precisely known site on chromosome 13. The gene is called ATP7B.

Wilson's Disease only occurs if a person inherits two abnormal recessive genes; one from each parent. If both parents carry the Wilson's disease gene, the chance of their child developing Wilson's Disease is 25%.

- ♦ Siblings of Wilson's Disease patients have a 25% chance of having the disease.
- ♦ Children of patients have 1 in 200 chance of having the disease.
- ♦ Grandchildren of patients have a 1 in 400 chance of having the disease.

WDA INTERNATIONAL CHAPTERS

The WDA welcomes international members. We have received a great response from people around the world (see page 6 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.



DONATIONS

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

Carroll and Susan Cross - \$500
(Matched by Mobil Corp.)
Luke and Beth Chung - \$2000
The Graper Family - Generous Stock gift

(Clarification from previous newsletter: \$10,000 given by the Charlotte Trust on behalf of Judge and Mrs. Fetzer Mills).

Testing Children For Wilson's Disease

If you are a Wilson's patient and have children, it is recommended to have your children tested for Wilson's Disease beginning at age 5. The test should include a 24 hour urine collection and a ceruloplasmin blood test. These should be done in a respectable laboratory.

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

Michael Mougín
Harly Ruchert
Wes Ruchert
Cheryl Zandhuis



President Clinton Signs Executive Order

On February 8, 2000, President Bill Clinton signed an Executive Order that prohibits Federal departments and agencies from using genetic information in hiring or personnel decisions. An administration spokesman said the action was designed to prevent genetic screening by employers before it becomes endemic.

RESOURCE SECTION

Wilson Disease Association

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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>

Austria (Susanne Danzinger)

E-mail: susanne.danzinger@chello.at

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

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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

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

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47014 Valladolid, Spain
E-mail: wilsons@teleline.es Tel: 983-372150

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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

It's A Boy!!

By Tammy Finocchiaro

My baby was born 8 weeks early. He weighed 3 lbs 13.7 ounces and was 16 ½ inches long. He was born on October 8, 1999. During my pregnancy, my doctor did a test on me called AFP (alpha feta protein level) to check for fetal defects and down's syndrome. My level was high (I think normal is 2.0 and mine was 5.0) so they thought something was wrong. They scared us since they said it could be spina bifida or brain exposed. We were a nervous wreck.

The doctors wanted to do an amniocentesis. It took me three weeks to decide to let them do it. The test was no big deal since it didn't hurt (it hurts more when they draw blood). The results came back fine.



The doctor said my baby was premature due from me smoking while pregnant and all the stress I was under. I was having Braxton Hick contractions and was in and out of "labor and delivery" for a week. The last time I went in, I was one centimeter dilated. The doctors gave me magnesium sulphate to try and stop contractions along with a couple of terbutiline shots and prednisone to help his lungs. The next day, I was three centimeters and the doctor did another amnio to see if my baby's lungs were fully developed and that his head was in position for delivery. If everything was fine, then stopping my labor would no longer be attempted. I was now four centimeters so the doctor broke my water. That was about 7:30 p.m. and at 12:53 a.m., he was born. I was so afraid something would go wrong. I did not have an epidural, but I did have a "stadol" IV drip. Three good pushes and he was born. He was very healthy; he did not need oxygen nor an incubator. He was a little jaundice.

My baby stayed in the hospital for two weeks to gain his weight. Now he is about 16 lbs and 7 months old. God was definitely with us so I named my angel sent from heaven James Adrian Michael Early. He is MY LIFE!!! He will be a carrier of Wilsons.



WDA Member News...

Tammy Finocchiaro had a baby boy on October 8, 1999. Welcome to the world James Adrian Michael Early!!

Barbara Noci gave birth to twins on March 25, 2000. Welcome to the world Alberto and Alessandra Noci!!



In Memory of Cheryl Zandhuis

The worst thing that a Wilson's Disease patient can have is denial about the disease. I believe that my wife went through many issues of denial that may have contributed to her death. We had several discussions (heated arguments) regarding taking naps and missing her liver medications. These were signals of symptoms that led to her tragic death. If she was not in such denial regarding her disease, she may have lived long enough to see her sons grow up to an adult age.

Cheryl was an ICU nurse at Mercy hospital in PGH. This may have complicated matters in her denial because she understood too much about liver failure, organ donation and death. She dealt with death each and every day at her work and it was not a difficult issue with her at WORK. However, once you have to think about your own mortality, the denial and thinking "that won't happen to me attitude" prevails.

I am happy that I had 12 great years with my wife and I would like to state that my love for Cheryl is undying. I would like to thank the organization the chance to express myself. I can not reiterate that you should pay attention to the signals (too much sleeping and fatigue) and be true to yourself (no denial).

Sincerely yours,
Paul Zandhuis

PLEASE NOTE:

Please complete and mail this form if your address has changed recently. Don't miss out on 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

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WILSON'S DISEASE ASSOCIATION, INTERNATIONAL

The Copper Connection, Editor
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Pismo Beach, CA 93448

FORWARDING SERVICE REQUESTED)

TO: