

# THE COPPER CONNECTION

**September 2000**



*Attendees participating in the Tri-State Support Group meeting held in New York City on June 25, 2000.*

## Tri-State Support Group

On June 25th, a support group meeting was held for families and friends at Mount Sinai Medical Center in New York City. It was sponsored by the Division of Liver Diseases and the Recanati/Miller Transplant Institute. Dr. Michael Schilsky of Mount Sinai spoke to the group and stressed the importance of the Wilson's Disease Association. We were also joined by Dr. Rob Stall from the WDA who flew in from up-state NY to be at the meeting.

This was the first meeting for a support group in the Tri-State area of NY/NJ/CT and was attended by close to 35 people. Everyone introduced themselves and gave a short talk about Wilson's Disease and their personal situations. Most of the attendees felt that just being able to talk to other people in the same situation was most helpful. For some of the people, this was the first time they had met anyone else with Wilson's. We were fortunate to have a young lady there who had just been diagnosed one week prior.

Future support group meetings are planned and Dr. Schilsky will try to get speakers to address different aspects of Wilson's Disease. Thanks goes out to both Dr. Schilsky and Dr. Stall for their advice, encouragement and time.

If you or a friend would be interested in being notified of when the next meeting will be, please feel free to get in touch with Lenore Sillery at 203-961-9993 or by e-mail [sillerylenore@hotmail.com](mailto:sillerylenore@hotmail.com)

## Mark Your Calendars

2001 Annual Meeting  
California, here we come.....  
May 5 & 6, 2001

Long Beach, California will be the site of our 2001 Annual Meeting. Enjoy surf and sand, while learning new WD developments and meeting fellow patients and family members.

Long Beach is centrally located between both Los Angeles International and John Wayne, Orange County airports. It is a short half-hour drive to all major Los Angeles attractions, including Disneyland, Knotts Berry Farm and Universal Studios. Long Beach itself offers its own attractions, including the Aquarium of the Pacific, the beach, and the Queen Mary. There are 100 shops and restaurants walking distance to the hotel where the meeting will be held, as well as free city transportation.

Information and registration will be available in future newsletters. Save the dates, as we hope to see you in California!



*Dr. Ascher Sellner, President of the Wilson's Disease Association, sharing WD information at the Tri-State Support Group Meeting in New York City.*

Many Wilson's Disease patients have experienced difficulty in obtaining the medication Syprine from their pharmacy? Feel free to use this letter to help inform your Congressmen of the problem. You can find addresses to your local Congressmen in the blue pages of your telephone book under the listing for United States Government.

To: \_\_\_\_\_

Please accept this letter as a request to all of our legislators. I am writing to you on behalf of Wilson's Disease patients, and for all the patients, families and friends of everyone that is stricken with a rare disease. Wilson's Disease is a rare genetic liver disease, which if left untreated is fatal. Only about 1 in 30-40,000 people are afflicted with this disease. Many patients have experienced the refusal of having life saving drugs covered by their insurance companies.

Our legislators must recognize the need for all insurance companies to add all life saving drugs to their formularies and guarantee coverage.

Many families of Wilson's Disease patients have had and continue to deal with the permanent disabilities of our loved ones. To deny them and any patient access to the drugs that will keep them alive and allow them to lead productive lives is morally and ethically wrong.

Again, I urge you to please make life-sustaining drug coverage a mandatory policy for all insurance companies.

Sincerely,

## **Financial Assistance Network** **Free and Low Cost Medical Care**

Financial Assistance Network in Washington, DC has just published a new booklet, "Free & Low Cost Medical Care." The booklet includes information on a how and where to get free and low-cost medical care under the Federal Hill-Burton program.

There are currently 656 facilities that provide free or low-cost medical care. Over 1,100 prescription drugs are also available for free or very low cost to qualified individuals. Unfortunately, many qualified people do not take advantage of these programs because there is rarely any publicity informing the public. A step-by step outline guides consumers through the process of finding a participating facility and applying to determine their eligibility for free or low cost care.

Financial Assistance Network is an organization established by volunteers dedicated to helping people who cannot afford medical care or prescription medications. The primary purpose of Financial Assistance Network is to inform potentially qualified applicants about the patient assistance programs for which they appear eligible and assist them in the enrollment process.

Consumers can receive a copy by sending \$5 to cover the cost of printing, postage and handling to: Financial Assistance Network – Free & Low Cost Medical Care Booklet – Dept. MCB-0719 P.O. Box 60848, Washington, DC 20039-0848.

Consumers can also get more information about free and low cost medical care and prescription drugs by calling (202) 595-1039 or visiting the organization's website: [www.FinancialAssistanceNetwork.org](http://www.FinancialAssistanceNetwork.org)

## **WISDOM: A Wilson's Disease Organization In India**

The National Center of Wilson's Disease Observation and Management (WISDOM) in India was established in June 1996. Since its inception, 80 cases of Wilson's disease have been registered. The prime objective is to motivate, support and pursue research and scientific work for alleviation of human suffering from the Disease. This is a non-profitable organization assisted by a team of thirty voluntary members including scientists, doctors, social workers and volunteers.

WISDOM offers help to increase awareness and basic knowledge, and arrange counseling camps. It also maintains databases and thus evolves better treatment techniques. WISDOM fosters financial support to the poor and needy patients. It promotes genetic and scientific research and also helps handicap patients to get jobs. In addition, WISDOM provides up-to-date information to medical professionals and practitioners. It supports patients suffering from Wilson Disease.

WISDOM has a National Medical Advisory Board consisting of ten eminent doctors. Periodic meetings are held with steering committee members to evolve guidelines. Free consultation camps are held every month by doctors consisting of pediatricians, neurologists, gastroenterologists, hepatologists, psychologists, dieticians and social workers. Voluntary help and active support is provided by Dr. Archana Kher, Dr. Aabha Nagral, Dr. Mamta Munranjan and Rupal Sarkar and a team of steering committee members. The support for medicines for very poor patients is provided by Bina Stevenson of CTD Foundation of Australia.

WISDOM is open for research-based collaborative projects and solicits cooperation from Research Centers, Laboratories and Scientists. For cor-

respondence contact:  
Dr. D. P. Pande Ph.D. (Engg.),  
National Center of Wilson's Disease  
Observation and Management  
(WISDOM) INDIA, 4-A, Almora,  
Anushaktinagar P. O., Mumbai - 400  
094 INDIA  
Ph: 557 2947 E- Mail :  
[dppesdd@apsara.barc.ernet.in](mailto:dppesdd@apsara.barc.ernet.in)

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

### **FYI**

#### **Medical Conference Expenses Are Deductible**

The IRS has ruled that certain amounts paid for a medical conference relating to a chronic disease of a person's dependent are deductible medical expenses. Deductible expenses include registration fees and transportation costs to the conference. The cost of meals and lodging incurred while attending the conference are not deductible as medical expenses under IRC section 213.



All Wilson's Disease patients are recommended to be under the close care of a physician to have their medications and health monitored.

**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

**Drug Expiration Dates**

Are the expiration dates on pharmaceuticals valid? In 1985, the U.S. military found that the expiration dates on \$1 billion worth of their drugs were expiring so they decided to test the drugs to determine if the useful life of the drugs could be extended. They found that 90 percent of the drugs were still safe and effective long after their expiration date.

Some officials feel that expiration dates are put on drugs for marketing purposes and have no bearing on whether a drug is still useable. The company chooses the expiration date, not the FDA. However, FDA warns that the shelf life of drugs that must be refrigerated probably cannot be extended very long.

(NORD—National Organization For Rare Disorders, INC®)

**Symposium On Neurological Aspects of Wilson's Disease**

An International Wilson's Disease Meeting will be held September 13-15, 2001 at the National Institute of Health in Bethesda, Maryland. Physicians and researchers from all over the world will come together to discuss Wilson's Disease. The WDA has scheduled a support group meeting on September 15th. Additional information will be available at a later date.

**DONATIONS**

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

Rick Rader, MD  
 Orange Grove Habilitation Center

Sue Gostanian  
 Women's Counseling Center

**Regulations Regarding Dietary Supplements**

Under current regulations, the FDA must prove a dietary supplement is dangerous before it can be removed from the market. Manufacturers do not have to report deaths or adverse effects to the FDA. While some states are beginning to collect their own data and impose regulatory laws, under-reporting continues to be an issue. Safety data is largely compiled from voluntary reports from hospitals and poison control centers. In 1998, the American Association of Poison Control Centers recorded 6,914 reports of adverse reactions to dietary supplements. Meanwhile, the sales of supplements continues to grow with estimated sales reaching between \$15 and \$27 billion a year.

**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](mailto:hasellner@worldnet.att.net).

**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](mailto:DRNDVR@aol.com).

## WDA Member News

### Laughter is the Best Medicine

In the early 1960's when my tremors were really quite violent, my husband and I attended the wedding and reception for my niece and her new husband. During the reception, I had to use the restroom and when I came out there was a little boy about four years old who looked up at me and said, "Why does your head keep shaking back and forth, why don't you try going up and down instead?" I knelt down beside him and said, "Honey, I sure will try, but do you know what? I got ready in such a hurry this morning I just didn't get my head screwed on tight." The answer satisfied him, but his poor mother was embarrassed to tears, I told her, he's just a little boy.

(submitted by Pat Hanson, Sacramento, CA)

### Thank You...

I want to thank Lenore Sillery and her husband for the time and effort that they took in organizing the Wilson's Disease Association meeting at Mt. Sinai in New York. Thanks also to Dr. Robert Stall for flying in from Buffalo to speak at the meeting and to Dr. Michael Schilsky for taking time out of his busy schedule to also speak at the meeting. The meeting was very informative and it was nice to put faces with names from the internet and from phone conversations and to meet new people that are in the same situation. The attendees were very compassionate and understanding and we shared some of our stories and treatment tales.

I came away from the meeting with a new appreciation for what this disease can do if left untreated. My son Joe is so lucky that there has been no neurological damage. The damage that has been done to his body has been devastating, but when I see and hear the stories of what more can happen it makes me grateful for what our life is and the gifts that have been given.

Dorothy A. Gorbacz

### My Experience With Wilson's Disease

By Jeanne Friedman

The Setting: New York, 1970. I was a single 19 year old girl in my second year of college. I had stopped over at my married sister's house, just to hang out for awhile. While I was there, I began to feel awful— weak, sickly, needed to lie down. My sister hops onto the bed next to me and insists that I read an interesting article she'd read in her current Reader's Digest magazine. I declined; I didn't feel like lifting me head off the pillow; I wasn't up to reading anything. Ellen kept pushing me and finally we compromised. She read the article to me. It was called "Ned's Legacy".

The article was a true story about a family with Wilson's disease. Ned, who died of WD, and his sister who was diagnosed early enough and lived. The article spoke of penicillamine as the wonder drug of that era, and of Dr. Scheinberg, the U.S. expert at the time. My sister was right, it was fascinating and even a bit exciting to read.

At the time neither of us knew that we both would turn out to have Wilson's Disease. We had no idea that within the next several weeks, both of us would be put on that very same miracle drug the article spoke of. What we did know was that our father had had it and had died of it when we were small children— before penicillamine was approved for use in this country (USA).

Neither my sister nor I had guessed that the reason I felt so weak and sick that day was because I was suffering from the symptoms of WD. The copper had begun to destroy my liver. We had no idea that the article my sister was pestering me to read would actually hold the answers for why I was feeling so awful!

Later, in the hospital, despite my family history, the doctors refused to admit that I may have WD. They told my mother that it's just too rare. They quoted the familiar adage taught in medical school: "when you hear hoof-beats on the path, don't think zebras, think horses". While they explored the different types of hepatitis I might have, I almost died. It was only upon my 8th blood transfusion that they agreed to call in that very same Dr. Scheinberg for a consultation. They then found a lot of copper in my sister's liver after it was biopsied. We've both done well (I'm on Syprine, she's on Galzin) and lived to tell our stories— the zebras that we both turned out to be, after all!!

## RESOURCE SECTION

### Wilson 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](http://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](http://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: pcpoppel@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



---

(D)

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

---

*Inside This Issue:*

- *Support Meeting Summary, New York*
  - *Next WDA Annual Meeting in Long Beach, California May 5-6, 2001*
  - *Semi-annual WD Support meeting Washington, DC September 15, 2001*
- 

---

**WILSON'S DISEASE ASSOCIATION, INTERNATIONAL**

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

(FORWARDING SERVICE REQUESTED)

**TO:**