WILSON'S DISEASE ASSOCIATION, International

THE COPPER CONNECTION

March, 2004

WDA 2004 ANNUAL MEETING

"Past, Present, Future"

PHOENIX, ARIZONA

April 30 – May 2, 2004

Hotel Reservations:

Hyatt Regency Phoenix
122 North Second Street, Phoenix, AZ 85004-2379
800-233-1234 (Reservations) ***Request Wilson's Disease Assn Group Rate***
(602) 252-1234 – Hotel direct number.

Guest Room Rates:
$85.00 single/double occupancy
$110.00 triple occupancy
$135.00 quad occupancy
All above rates are exclusive of tax. A credit card is required to guarantee your room.
Rooms are on a first come, first serve basis. Rooms must be booked by April 10, 2004.

Parking/Transportation:
Parking is available at the hotel for $14.00/day for self-parking. The shuttle from the airport is called "Arrive". Individuals are directed to go to baggage claim, collect their luggage and call "Arrive" from the courtesy phone. Shuttles are waiting outside. Cost is $8.00 per person, each way.

Conference Rates:
$85.00 per person*
Please make checks payable to the Wilson's Disease Association.
Registration and checks are due by Wednesday, April 1, 2004.
After this date, registration cost is $95.00 per person.
*Registration includes the Friday night reception, two breakfasts, and lunch on Saturday.

WDA's First Annual Conference Banquet
$35.00 per person
This is a Ticketed Event— you must purchase your ticket in advance.
Keynote Speakers - Dr. Irmin Sternlieb and Dr. Michael Schilsky
Presentations and Awards for the WDA 2003 Medical Student Writing Competition
"Promoting the Early Diagnosis of Wilson's Disease"

WILSON'S DISEASE ASSOCIATION

1802 Brookside Drive
Wooster, Ohio 44691
email: wda@sssnet.com
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Phone: 1(330) 264-1450 Toll Free: 1(800) 399-0266

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The Wilson's Disease Association is a nonprofit 501(c)(3) organization.

Our Mission Statement: The Wilson's Disease Association funds research and facilitates and promotes the identification, education, treatment and support of patients and other individuals affected by Wilson's disease.

The Copper Connection is a quarterly newsletter published by the Association that informs members of findings in the area of Wilson's disease. There is no copyright. Newsletters and other publications can disseminate any information in *The Copper Connection.* Please cite attribution to the Association and the author.

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

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2003 Annual Report

The year 2003 was a year of many firsts for the WDA.

- In an effort to further professionalize the Association, a part-time Executive Director was hired.
- The Association celebrated its 20th anniversary at the annual conference in Washington D.C. by honoring Drs. Askari, Brewer, and Schilsky for their continuing dedication to Wilson's disease as Medical Advisors to the WDA; Dr. Sellner and Carol Terry for their years of service as presidents of the WDA.
- A new president was elected for the first time in 9 years.
- The membership elected the first international member, Stefan Sandler of Germany, to serve on the Board.
- A direct mail campaign to members targeted physician education.
- The first ever WDA-hosted support group meeting was held in Chicago, with plans to expand to four in 2004.

The Executive Director has had a very successful first year. She has completed many basic administrative tasks which enables the Association to respond to family requests as well as provide accurate information to those who feel they might have WD. In addition to these daily responsibilities, she has spent several months attending to administrative issues which will allow us to continue to appeal to corporate donors for funding. Tasks involved were re-working our budget, filing state registrations for solicitation, and developing a broad based funding plan. She continues to work closely with the Board of Directors in forming an Educational Program which will benefit our members as well as the medical community.

The WDA President continues to have an active role in the day to day operations of the Association, working closely with the Executive Director. The full Board of Directors now meets quarterly, and the Executive Committee meets monthly to ensure that business is handled in an expeditious manner. She has also developed, and oversees, a wonderful network of member volunteers. Member volunteers play an integral role in accomplishing many tasks which would otherwise consume the time of management. Volunteers are truly the backbone of this organization.

Ten percent of our membership responded to the direct mail campaign and due to their generosity we received $8,872.00. A portion of the donations is being allocated for an updated series of educational brochures targeted for the professional audience. The rest is being used to promote new physician interest in Wilson's disease through the Medical Student Writing Competition topic, *Promoting the Early Diagnosis of Wilson's Disease.* Entries submitted will be judged and awards presented at the WDA Annual Conference in May. Additional funding, to continue these efforts, will be sought in 2004.

Other 2003 highlights:

- Our membership increased to 986 with members in all 50 states and 41 countries. The WDA office responded to 518 calls during the year, sent out 380 information packets that resulted in 50 additional new members.

- Referrals of possible clinical trial patients to The University of Michigan; to Dr. Schilsky in New York and to other knowledgeable treating physicians continued as appropriate.

- We responded to two patient assistance requests, and were able to help one, a Romanian patient, to obtain a life saving medication while awaiting transplant.

- We have developed a formal Annual Operating Budget which will enable the Association to assure financial stability and growth. Our projected income for 2004 is $126,990 with plans to greatly expand program services. Our goal for 2004 is to allocate 65% for program expenses, 27% for administrative expenses, and retain 8% for operating reserves. Since our budget reflects the desired balance between program and administrative expenditures, we will be in a better position to attract corporate donors than we have been in the past.

2003 was a year of transition for the WDA in many ways. The work accomplished will allow us to move forward with even greater success in the years to come.

Mary L. Graper
President

WDA ANNUAL CONFERENCE AGENDA
"PAST, PRESENT, FUTURE"

Friday, April 30

9:00 am – 5:00 pm	WDA Board of Directors Meeting
5:00 pm – 7:00 pm	Complimentary Welcome Reception for Attendees

Saturday, May 1

8:00 – 8:30 am	Registration/Complimentary Continental Breakfast
8:30 – 8:45 am	Welcome and Opening Remarks
8:45 – 9:30 am	***"An Historical Perspective of Wilson's Disease Diagnosis and Treatment"*** Irmin Sternlieb M.D., Emeritus Professor of Medicine, Albert Einstein College of Medicine and Bronx Municipal Hospital Center, New York
9:30 – 10:15 am	***"The Future of Wilson's Disease: Cell Transplants and Gene Therapy"*** Michael L. Schilsky M.D., Associate Professor of Clinical Medicine, Medical Director of the Center for Liver Disease and Transplantation at Weill Cornell Medical Center, New York. WDA Medical Advisory Committee, Chair
10:15 - 10:30 am	Break
10:30 - 11:15 am	***"The Americans with Disabilities Act: Information, Rights, Resources"*** Cindy Brown, Training and Program Director, Arizona Office for Americans with Disabilities, Phoenix, Arizona
11:15 – Noon	***"Liver Manifestations and Monitoring of Wilson's Disease"*** Frederic Askari M.D. PhD., Assistant Professor of Internal Medicine, Director of Wilson's Disease Clinic, University of Michigan, WDA Medical Advisory Committee
Noon – 1:30 pm	Complimentary Luncheon
1:30 – 2:15 pm	***"Nutritional Aspects of Wilson's Disease Treatment"*** George J. Brewer M.D., Morton S. and Henrietta K. Sellner Emeritus Professor of Human Genetics, Emeritus Professor of Internal Medicine, Departments of Human Genetics and Internal Medicine, University of Michigan Medical School. WDA Medical Advisory Committee
2:15 – 3:00 pm	***"New Research: Population Screening for Wilson's Disease"*** Sihoun Hahn M.D. PhD., Associate Professor & Co-director, Biochemical Genetics Laboratory-H330, Department of Laboratory Medicine and Pathology, Mayo Clinic, Minnesota
3:00 – 3:15 pm	Break
3:15 – 3:45 pm	Breakout Sessions facilitated by Speakers
3:45 – 4:15 pm	Breakout Sessions facilitated by Speakers
4:15 – 4:45 pm	Breakout Sessions facilitated by Speakers
6:30 – 9:00 pm	*Ticketed Event – Conference Banquet -Dinner Honoring Speakers Keynote Speakers, Dr. Irmin Sternlieb and Dr. Michael Schilsky Presentations and Awards for the WDA 2004 Medical Student Writing Competition "***Promoting the Early Diagnosis of Wilson's Disease"***

Sunday, May 2

8:00 – 8:30 am	Complimentary Continental Breakfast
8:30 – 9:15 am	***"Evidence-Based Treatment of Wilson's Disease"*** Tjaard U. Hoogenraad M.D. (Invited) Emeritus Professor of Neurology, University Hospital, Utrecht, Netherlands. Presented by Mr. Jeff Eckland
9:15 – 10:45 am	***"Q & A of Physician Panel"*** Drs. Askari, Brewer, Hahn, Hoogenraad, Schilsky, Sternlieb
10:45 – 11:00 am	Break
11:00 – 11:45 am	WDA Business Meeting and Elections
11:45 – Noon	Closing Remarks

*Please see Registration Form for details

WILSON'S DISEASE ASSOCATION
2004 ANNUAL MEETING REGISTRATION

Due on or before April 10, 2004

Name:_____ Email address:_____

Address:_____

City:_____ State:_____ Zip:_____

Telephone #:_____WDA member: Yes No

May we publish your address, telephone and e-mail on the meeting attendee list: Yes No

Name of others attending with you: Relationship:

1._____ _____

2._____ _____

3._____ _____

Payment Information:

If registered by March 31, 2004 - $85.00 per person
If registered after April 1, 2004 - $95.00 per person.

_____ No. of Conference registrations @ $85.00 (or 95.00) _____
_____ No. of Banquet registrations @ $35.00 _____
Total amount: _____

Check #_____Amount: $_____ (Check payable to the Wilson's Disease Assn.)
_____ Visa #_____ Exp. Date:_____
_____ Mastercard #_____Exp. Date:_____
Name on credit card:_____
I authorize the WDA to charge my credit card in the amount of $_____

Signature_____

Mail registration form and payment to:

DUE BY APRIL 10, 2004

Wilson's Disease Association
Attn: Kimberly Symonds
1802 Brookside Drive
Wooster, Ohio 44691
Fax No.: 509-757-6418

Dear Friends:
If you haven't had a chance to return your membership form please do so as soon as possible. The Association relies on your dues to operate. Please save us the expense of a third and separate mailing by returning it to us today. Thank you.

Please complete, detach this page, and return it to the Association:

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

Name_____

Address_____

City_____ State_____ Zip_____ Country_____

Home Phone _____ Work Phone_____

Email:_____

Membership Dues:

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

Please send *The Copper Connection* to me electronically:

No
Yes, my email address is:_____

I wish to make a donation to The Wilson's Disease Association:

Name_____

Address_____

City_____ State_____ Zip_____ Country_____

I am making a tax-deductible donation of $_____

In honor of _____ In memory of _____

Send acknowledgement to:_____
Name Street

_____
City State Zip Country

Payment Information:

Membership Fee$_____ Visa Master Card Check or Money Order attached
Donation $_____ Card #_____
Total $_____ Expiration Date:_____Signature_____

Newsletter Recognitions

As the Association continues to grow, it is important for us to recognize a few individuals who have helped us in various ways over the past few months.

Thank you to:
Russ and Lenore Sillery
Delia Ruiz
Barbara Fox
Fran Corda-Whitehead

Wish List:
Conference Sponsorship
Donated Office Supplies
Donated Printing Services

The Spring newsletter deadline is May, 19,2004

Local Girl Gets A Miracle

Our granddaughter, Amy Bannick, was working at Meijer's Gas Station and began dating Greg Foco. They were enjoying their time together and decided to get engaged. Everything was great in her life.

Then, on September 11th, everything changed. We received a phone call from our daughter-in-law Val Sawyer. She told us that our Amy needed to go to the hospital. I drove over and picked her up to go to Bay Medical. Amy spent a little over a week in the hospital and they ran all kinds of tests, but could not find the real problem. They sent her home and had her come back three more times trying to do a liver biopsy. This biopsy never happened because her blood levels were not right. Her doctor said that it could be Wilson's disease so he sent her to Bay Eye Care to look for a Kayser-Fleischer ring around the cornea of the eye. Sure enough, she had the ring.

The next day, I started calling around trying to find out as much information as I could about Wilson's disease. After researching the disease, calling and recalling and all the praying, I finally contacted Mary Graper, President of Wilson's Disease Association International. At the time I called and left a message I did not know that Mary was in any way connected to Wilson's disease. She told me in our first conversation about a research clinic at the University of Michigan Hospital in Ann Arbor they treats patients with Wilson's disease. After talking to Val, Mary called one of the

(Continued on page 9)

Financial Report to the Members of the Wilson's Disease Association

With the end of our fiscal year on December 31 it is my duty to report to you, our interested readers and members, the status of the financial position of the Association. For the year ending December 31, 2003 we received cash donations, grants and membership fees of $56,800, a 27% increase from 2002.

The largest portion of this increase in income was from the Physician Education campaign that was launched in 2003. This campaign brought in just over $8,800, which represents 73% of our increase in revenues.

Unfortunately, our cash expenses were up more than our income by $5,000. This loss of $5,000 is primarily the result of us hiring a part-time executive director to help the organization expand its services and goals. Our executive director, Kim Symonds, was directly responsible for the tremendous response to the Physician Education campaign which generated the $8,800 as mentioned above.

We go into 2004 with good cash reserves and great plans for additional fund raisers so we can expand the services to our members and education programs for Doctors and others.

Respectfully submitted,

Len Pytlak, CPA
Treasurer

The WILSON'S DISEASE ASSOCIATION is a charitable organization which relies on donations to do its work. Please help us! Tax-deductible donations may be sent to:

Wilson's Disease Association
1802 Brookside Drive
Wooster, Ohio 44691

Anyone who would like to make a donation of appreciated stock, please contact WDA Treasurer Len Pytlak at 734-663-1313 for account transfer information.

We are grateful to all for their generosity to the Wilson's Disease Association.

Report of Gifts through February 29, 2003

Phillis DiGiorgio
Villegas Manuel
Linna Ding
Isabelle C. Sokoloff
Duane and Beverly Mattheis
Virgil and Mary Ann Laurain
Richard and Elizabeth Lawler
Reed and Lisa Hughes

Mei Lin Chen
Sorelle Esler
Fetzer and Rebecca Mills
Carol and 'Sparky' Terry
Susan Tarquinio
E. B. Wolk
Conrad Geyser
Kimberly and Michael Symonds

Mei Lan Chen
John Paul and Christina DeGance
Corinne Huffman
Joanne Doades
James and Suzan Daugherty
Dennis and Rhea Henderson
Randy and Linda English

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In Support of Our Physician Education Program

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Len Pytlak
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Awwad Hassouneth

Ann Palrang
Desjardins Yolande
Gerald J. Fortuna
Bob and Carol Whittier
Lori Cummings
Bertha Korzekwa

In Memory of Robert Patton
By: Bill Heaton
Greater Pontiac Sister City Club
Jeanne and Joseph Cusimano
In Memory of Ricky Wade by Frank and Bernie Wall
In Memory of Mark Laurain by Diane Laurain
In Memory of Paul Lehnerer by Mary Ann Lehnerer
In Memory of Carol Philip by Paul Rutherford
In Memory of William Eckland by Jeff Eckland

In Honor of Carrol (Butch) Cross by Edna Cross
In Honor of Courtney and Chase Adams by John Eric and Cynthia Adams
In Honor of Steve by Agnes T. Lute
In Honor of Jeanne A. Friedman by State-Wide Insurance Company
In Honor of Judge and Mrs. Fetzer Mills
By: Sophie M. Wood
Dr. Edward and Mrs. Judy Martin
In Honor of Geoffrey Nunn by Gail Nunn

In Memory of Patrick O'Flanagan
By: Miriam and Daniel Rose
MF and BK Johns
James and Christine Wise
Augustus and Marlene Mercurio
Margaret Toth
John and Iris Lyn Bradisse
Robert and Roberta Feigenbaum
Karen Gallagher
Karl Sundkvist

In Honor of Carol Terry by Arthur and Rose Plautz
In Honor of Russell Sillery by Helen Schepis
In Honor of Joshua Cohen by Mark and Liz Mirkin
In Honor of Mr. and Mrs. Gary King by Karen and Jerry Nixon
In Honor of Regis Kowcheck by Diana Kowcheck
In Honor of Harvey Katz's 70th Birthday by Ruth, Stan and Hy Hill
In Honor of Lucas Winters by Judy Winters

It is the policy of WDA that all donations to the Association are recognized by a letter or a mention in the newsletter. If you made a donation, but did not receive an acknowledgement please contact Mary Graper, President of the Association at 1(414) 961-1290.

Annual Membership Meeting Announcement

The Annual Membership Meeting for the Wilson's Disease Association will take place on May 2, 2004 at the Hyatt Regency in Phoenix, Arizona. Any Member in good standing is allowed to vote. There are two new nominees to the Board of Directors, Pat Satherstrom and Parichehr Yomtoob and two members of the Board of Directors up for re-election, Jeff Eckland and Stefan Sandler. Additionally the general membership will be asked to approve several changes to the By-Laws. The By-Laws will be available for review prior to the Annual Membership Meeting. If you have any questions, please feel free to call Kimberly Symonds at 1-888-264-1450.

(Continued from page 7)
doctors at the Wilson's Clinic. Subsequently, Amy was admitted to the clinic October 1st. This is one of many miracles to come. God still answers prayers.

Amy spent four weeks in treatment to take the copper out of her liver. They were going to send her home on October 31st, but instead Amy's health took a nose dive. She was filling up with fluids. I started prayer chains for Amy.

On Monday night, the doctors performed a tap on her tummy and drained off about 5 liters of fluids. We attended a class on liver transplants. Because of Amy's severe condition, she was placed on top of the liver transplant list on November 7th. On November 11th, a liver match was found and Amy was prepared for the transplant. I again called our prayer chain.

The surgery was a success and Amy came home 8 days later. She is doing very well because of what the Lord has done. She is working on getting the rest of her life back to normal.

We have a lot to be thankful for this year. We serve a great God who really cares for our every need.

A very thankful Grandma Prudy

Editors Note: At the time of this writing the WDA has been informed that Amy Bannick ,"is doing just great. She went to the doctors last Friday and does not have to go back until September. She is off all of her medicine except for the anti-rejection medicine."
Please continue to support the WDA so that we can attempt to prevent the trauma of liver transplants…. because of Wilson's disease.

How I Show My Support

By Corinne Huffman

"The journey of a thousand miles starts with a single step." This is a Chinese Proverb relevant to fundraising as it can appear to be an overwhelming and daunting task. The key to fundraising is to take that step forward and start the journey of giving. Motivated by the fact that my fiancé has Wilson's disease, I decided to take that step and organize a fundraiser to benefit the Wilson's Disease Association in the Fall of 2003.

This was my first time organizing a fundraiser and I set two goals for it. The first one was to raise $2000.00 and the second was to educate as many people as possible about the disease, in the process of raising the money. I was only able to raise $793.80, but due to some kind employers, professors and friends, I was able to spread information about the disease to approximately 600 people. I spoke about it in my college classrooms, to family and friends and at both of my jobs. One of my employers is Curves For Women, which is a woman's fitness gym. Curves often supports non-profit organizations, especially those associated with improving health care. They let me run part of my fundraiser there. I posted four copies of a one page informational letter about Wilson's disease. These signs were put up directly in front of the work-out stations so that every member could read about the disease. We have approximately 500 members which were exposed to the information, and many would ask me further questions. While I didn't raise the amount of money I had hoped, I am happy that knowledge about the disease has spread.

If I can organize a successful fundraiser, you can too! I raised the money because I believe that there are patients all over the world who have needs that are not always met. After attending the Wilson's Disease Conference last April, my perspective of the disease was completely altered. I learned that there were multiple dimensions to the disease. By this I mean that it not only affects the patient's physical capabilities, but that it also has a huge impact on the emotional and psychological aspects of the patients and their loved ones. Previously, I had been summing up the disease solely based on its physical effects. Meeting other people affected by Wilson's helped me understand the depth of the disease and it educated me on the personal struggles patients and there families endured.

It is important for me to show support to the Association, as they are the vehicle through which doctors can become educated, patients can receive the best care and research can be funded. I am just one person and though my financial contribution was small, it is still $793.80 more that the Association can use to better the lives of patients.

If all of us who are affected by Wilson's disease took a proactive step forward and organized fundraisers, our small individual contributions could collectively make a large impact. I encourage all of you to take that step forward and organize a fundraiser that benefits yourself, a family member or anyone else who has Wilson's disease. I am organizing another fundraiser this summer and I am excited to raise more money for a worthy cause.

If anyone is interested in organizing their own fundraiser and would like some ideas, support or encouragement on taking that first step, I would be glad to help. My e-mail address is x_99huffman1@hotmail.com.

Remember, "The journey of a thousand miles starts with a single step." So get started today and give your time to a cause close to all our hearts.

WILSON'S DISEASE ASSOCIATION, INTERNATIONAL

The Copper Connection
1802 Brookside Drive
Wooster, OH 44691

(FORWARDING SERVICE REQUESTED)

TO:

Wilson's Disease Association
Volunteer Profile

Name:_____ Connection to Wilson's Disease_____
(Please include professional designations: e.g. M.D., Ph.D.)
Spouse or Significant Other's Name_____
Home Address_____
Home Telephone Number_____ Fax:_____
E-Mail Address_____
Business Name:_____ Business Title:_____
Business Address:_____
Business Telephone Number_____ Fax:_____
Occupation and Job Responsibilities:_____
Company has a matching gift program (circle one): Yes No
Board Memberships and Professional Organizations:_____
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Personal Interests/Hobbies:_____

Areas of Experience or Expertise:

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___Legal – Non-Profit Experience
___Government Affairs
___Marketing
___Public Speaking
___Fundraising:
__Special Events
__Foundations
__Corporations
___Writing
___Media
___Graphic Arts
___Board of Directors
___Computer Technology
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___Newsletter
___Local Support Group Organizing/Leading
___Office Work
___Other (specify)_____

Please return to: Wilson's Disease Association, 1802 Brookside Drive, Wooster, Ohio 44691