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# THE COPPER CONNECTION

December, 2003

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Dear Friends:

**Happy Holidays!** What a great time of year this is! Here at WDA the Holidays mean it's time for our annual membership drive.

This year we will *not* send out a separate letter for membership renewal. Please fill out the application below and return it to WDA in the envelope provided in this edition of *The Copper Connection*. We are in the process of updating our database and this membership renewal will aid us greatly in that effort. We need to hear from you, even if you have recently filled out a membership form.

We are also offering a new service to our members, the option of receiving *The Copper Connection* electronically in your e-mail mailbox. If you are interested in this option, please check the 'yes' box below and supply your email address. If you have questions, please call Kimberly Symonds at 1-888-264-1450.

Please complete, detach this page, and return it to WDA in the enclosed envelope. Thank you!

New Member                      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 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 \_\_\_\_\_

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## WILSON'S DISEASE ASSOCIATION

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

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Logan, Utah

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**Kimberly F. Symonds**  
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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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## **The Control of Pain and Fever With Tylenol and Aspirin in Wilson's Disease**

*Fred Askari, M.D.*

Recommendations about the use of aspirin and Tylenol by people with liver disease may vary depending on the extent of scarring or fibrosis in the liver, as well as whether they are children or adults. People who have cirrhosis should avoid using aspirin-like drugs. Aspirin, Motrin, and Ibuprofen are part of a family of drugs called NSAIDs or non-steroidal anti-inflammatory drugs. These drugs are used to control pain, particularly joint aches or pains, and fever. One other effect they have is to inhibit blood clot formation, which is why aspirin is sometimes used to prevent blood clot formation in the heart.

One bad side effect aspirin and drugs like it have is to break down the lining of the stomach and gut at times, which can lead to ulcer formation. As those of you who have visited Michigan or watched football on TV may know, we have a big stadium here in Ann Arbor called the Big House that seats over 100,000 fans. Every year, enough people in this country have significant bleeding from their stomachs caused by NSAIDs to fill every seat in the Big House. This bleeding side effect is more worrisome for people with liver disease who are prone to large bleeding problems, because they may have low platelet counts, disrupted stomach lining or dilated blood vessels in the food pipe caused by elevated pressures in the blood flowing to or around the liver. These NSAID drugs also can decrease blood flow to the kidney. Aspirin should never be taken by children because of the risk of the drug causing Reyes syndrome. For these reasons, it is best for people with significant liver disease to avoid taking aspirin, Motrin, or NSAIDs.

Tylenol or acetaminophen is a safe drug for reducing fever and treating pain, but only when taken in prudent amounts. At higher doses, Tylenol can cause liver injury or failure. Tylenol can be dangerous when combined with alcohol, because alcohol changes the way Tylenol is processed in the liver. People with Wilson's disease should feel comfortable taking Tylenol as long as they do not exceed 2000 milligrams per day, which is generally three or four pills depending on the strength or number of milligrams in each of the pills used.

There are many warnings about liver damage on

Tylenol bottles. Tylenol abuse is the leading cause of acute liver failure in this country; the liver failure occurs in people taking doses that are excessive. The dose necessary to damage the liver is lower in those who drink alcohol, so Tylenol should be avoided by those who actively use alcohol as well. People also should watch out for excessive acetaminophen consumption caused by its packaging in combination with other pain pills. One common pain medicine that contains acetaminophen is Vicodin. Taken prudently, Tylenol is one of the safest pain and fever medicines, even for people with liver disease.

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## **Immunizations Against Viral Hepatitis For Patients with Wilson's Disease**

Michael L. Schilsky MD

Hepatitis A and B are viruses that invade and propagate in the liver. Hepatitis A is acquired mainly by oral ingestion. The recent news about the outbreak of the virus from contaminated food in Pittsburgh is a reminder that we all are vulnerable at unexpected times! Hepatitis B is mostly acquired from blood or sexual contact. The vast majority of people that are infected by these viruses overcome their illness, but there are a number that suffer severe liver injury and liver failure, and for hepatitis B, even develop a chronic infection. People with liver diseases, and many patients with Wilson's disease, do have some degree of impairment of liver function and reserve despite treatment that prevents further progression. These individuals may suffer worse damage and even liver failure if they become infected with Hepatitis A or B.

The good news is that there are vaccines that are effective in preventing infection with these viruses. For this reason, we recommend that all patients with Wilson's disease undergo screening and vaccination. If you were previously vaccinated for hepatitis B, you should also periodically check that your body still has maintained an adequate level of protection against this virus. This can be done by a blood test to look at the quantity of antibody to hepatitis B in the circulation. If the level is not detectable or very low, a booster is recommended. These vaccines are typically given by primary care physicians, so ask your physicians to check your blood tests (many of you were probably checked for these viral infections before Wilson's disease was diagnosed), and to administer vaccine for these viruses to you. Vaccination is given as a series of injections to

*(Continued on page 4)*

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## *Executive Director's Letter*

Dear Friends:

I hope this newsletter finds each of you well and eagerly looking forward to the upcoming Holidays.

WDA is trying something new with our annual membership renewal drive. Included in this edition of *The Copper Connection* is the membership renewal application on Page 1. Among the many reasons we are doing our membership drive this way is the significant amount of money WDA saves by not sending out a separate mailing. That, of course, means there are more resources available for research and programs.

We understand that many of you joined WDA during this year, but it would be very helpful for us if you take the time to fill out the form and return it to us so that we can update our database. We also ask that our lifetime members please fill out the renewal form and simply write in "lifetime member." We thank you in advance for your participation!

Following the Board of Directors meeting in October, WDA held a support group meeting for WDA members, families, and friends in the Chicago area. I would like to, once again, thank Dr. Askari for giving his time and knowledge to help our families who were able to attend the support group meeting. It was a great time for learning about Wilson's Disease and forming friendships. I enjoyed meeting each one of you and I look forward to seeing you at another WDA event.

I hope you all enjoy the holidays!

In friendship,

Kimberly Symonds

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## *President's Message*

Dear Friends,

Warm greetings to all of you! I hope this holiday season finds you all well. At this time of year, it seems appropriate to reflect on the past years accomplishments, and look forward to a new year of even greater ones. It has indeed been a year of transition with positive outcomes for all in our Wilson's disease community.

Our first ever direct appeal, for donations to the Physician Education program has been very successful. To date we have received over \$8000 toward this effort. Thanks to the generosity of our membership, we currently have two physician education projects in the works. We have begun to update and create new brochures aimed at the

professional audience. The first, which should be printed within the next month, promises to be a great diagnostic tool for those physicians unfamiliar with Wilson's disease. To follow, as funds become available, will be treatment and monitoring recommendations. We are also sponsoring a writing competition for medical students, "Promoting the Early Diagnosis of Wilson's Disease". Announcements are being mailed to 100 medical schools in the United States. Awards for the best original paper will be given, with the first place author winning a trip to the WDA Annual Conference.

The WDA Board of Directors met in Chicago on November 1, 2003. The following day we hosted a support meeting for interested members in the area. Dr. Askari kindly attended, gave an informative presentation, and facilitated an informal discussion. Plans to host more such events, in other locations, are in the works.

In closing, I would like to extend warm season's greetings from my home to yours. Again, I thank all of you who have given generously of your time and resources this past year and wish you all a healthy and prosperous New Year!

Warm regards,




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*(Continued from page 3)*

ensure that adequate response is obtained in almost all individuals, so make sure you know when you are to return for your next shot.

Many children born after 1991 were likely to already be vaccinated for hepatitis B as infants, and many who were born outside of the US or have traveled extensively may have already been exposed to hepatitis A. If you are not already immune, be smart and get vaccinated!

### NEW CONTACT INFO FOR DR. SCHILSKY Effective January 2, 2004

Michael L. Schilsky MD  
Associate Professor of Clinical Medicine  
Medical Director, Center for Liver Disease and Transplantation  
Weill Cornell Medical Center  
525 East 68<sup>th</sup> Street, Box 98  
New York, NY 10021

Ph 212-746-4129  
Fax 212-746-8974  
E-mail address: TBA

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

Report of Gifts through November 30, 2003

Gwenda and Bernard Wasserman  
Dorothy A. Gorbacz

Isabelle C. Sokoloff  
Charles and Betty Perinka

Eva L. Koster  
Luke and Beth Chung

**Foundations support for WDA**

- Katz Foundation – Mr. Lewis Katz
- The Community Foundation Alliance, Sandra K. Neff Memorial Fund
- Teva Pharmaceuticals for their continued support of our educational programs

From Mary Graper in Thanksgiving to the following individuals for continued dedication to the Wilson's Disease Association:

Carol Terry	Len Pytlak	Stefanie Kaplan
Stefan Sandler	Luke Chung	Jeffrey Eckland
Henry Kaplan	Nancy Hoffman	Kimberly Symonds
Delia Ruiz	Lenore and Russ Sillery	
Barbara Fox	Dr. George Brewer	
Dr. Fred Askari	Dr. Michael Schilsky	

In Memory of Robert Fenton Patton by Joyce K. Hawkins,  
Nancy and Philip VanHull, Jacqueline and Alfred Adams  
In Memory of Charles Conrad by Charles and Ruth Giberson  
In Honor of Carrol "Butch" Cross by Jim and Vicki Harker  
In Honor of Honey Karasyk by Ruth and Stan Hill  
In Honor of Jason Witort by John G. Witort, Sr.

**Thank you to all who gave so generously to the Physician Education Program**

Dolores Y. Righenburg  
Sylvia Coleman  
Michael Nicolardi  
John A. Kovarik  
Penny and Fetzer Mills  
Cathleen and Pete Bergmann  
John and Carla Watson  
Jerome and Ellen Einhorn  
Paul S. Fausneucht  
Daniel and Patricia Frame  
Carole K. Bickimer  
Vivek and Lakshmi Subramanian  
Mei Lin Chen  
Mei Lan Chen  
Clyde and Gloria Fausneucht  
Sandor and Emese Greksa  
Robert A. Peck  
Helen and Jim Moseley  
Marcia and Henry Kaplan  
Duane and Beverly Mattheis  
Barbara and Julian Fox  
Michael and Lucinda Sobkowski  
Lisa and Reed Hughes  
Cleo and James Hines  
Lillian Albano  
Conrad Geysler  
Marilyn Slavin

Emmet B. Keffe, M.D.  
Michael and Maree Kirkpatrick  
Joyce Russell  
Jeff Eckland  
Diane Laurain  
Delia and David Ruiz  
Christine and Randy Pullin  
Cathlene and Robert Smith  
Anvar and Zoukhra Bash  
John and Cynthia Adams  
David and Georgia Barton  
Randy and Linda English  
Pauline McNulty  
Michael and Rosemary Gagliardi  
Anita and Norton Scherzer  
Mr. and Mrs. Cornelious Hoggard  
Barbara and Erol Morey  
Linda Schwebke  
Mahesh and Monika Sehgal  
Judith Kesler  
Ana and Henry Gomez  
Mildred Quinn  
June Nystrom  
Sharad, Lalita and Nikhil Wagle  
Eileen Smith  
Glen Gilchrist  
E. B. Wolk

Ronald and Joanne Doades  
Courtney and James Smith  
Jane and Jeffrey Ferketic  
Mary and Bill Graper  
Carrol and Susan Cross  
Ron and Cindy Olch  
Dragoslav Neskovic  
Rochelle Fausneucht  
Ruthann Siebert  
John Seibert  
Jacie Rae and John Daschel  
Dana and Jeffrey Nehal  
Charles and Donna Pursley  
Carol and Sparky Terry  
Joy and James Bestgen  
Liang Xiuling, M.D.  
Hsiao-Ching Wan  
Tin Liu  
Mario Guy de Faria Mariz  
Steven and Susan Radant  
Mildred and William Shannon  
Jeff Dunn  
Judy Wagner  
The Crees Family  
Darlene Cole

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.

## **CHICAGO AREA SUPPORT MEETING**



*Nancy Marsala, Executive Director Kimberly Symonds, Dr. Frank Roemisch, President Mary Graper, Marla Pietruszka, Parichehr Yomtoob, Secretary Carol Terry*

On November 2, 2003 the WDA hosted a support meeting for area patients and friends, at the O'Hare Hilton in Chicago. Seventy-five invitations were mailed to member families in Illinois, Indiana and Wisconsin. There were 25 in attendance, including one Chicago area physician who was interested in learning more about treating Wilson's disease.

Dr. Fred Askari of the University of Michigan accepted an invitation to be the keynote speaker. Dr. Askari gave a powerpoint presentation which provided some new information, along with a review of Wilson's diagnosis and treatment issues. An informal question and answer session followed. Old and new members alike found the meeting interesting and beneficial.



*Board member Jeff Eckland and new members John and Jan Witort*



*Dr. Fred Askari*

This was the first meeting of its kind hosted by the WDA, with plans to sponsor several more in 2004. Locations are yet to be determined, but suggestions are welcome. Every attempt will be made to establish diverse geographic locations in order to accommodate as many members as possible.

### How can your everyday shopping benefit WDA?



Who hasn't uttered the words, "I wish there was something I could do to help"? Now you can. Start shopping! At [www.iGive.com/WDA](http://www.iGive.com/WDA), you can buy the items you've always wanted— like that CD box set, expensive cologne, or the oversized, coffee-table photography book you've had your eyes on, only without the guilt.

It's FREE, no invisible costs or tricky obligations. Shop for everyday items at the over 400 stores at the Mall at iGive.com, like Barnes & Noble, Eddie Bauer, Lands' End and Amazon.com. Up to 26% of each purchase is donated to WDA.

Join now at [www.iGive.com/WDA](http://www.iGive.com/WDA)

Good through 12/31/03. © iGive.com Holdings, LLC

**WDA Board Member Nominations Open**

New Board members will be elected at the Annual Meeting in Phoenix, Arizona in May.

If you would like to nominate yourself, or someone else, please fill in the application below and send it to Kimberly Symonds, Executive Director, Wilson’s Disease Association, 1802 Brookside Drive, Wooster, Ohio 44691. The deadline for nominations is **January 15, 2004**. The nominee needs to be a member in good standing and have the ability to attend two Board Meetings each year at their own expense.

**Board Member Application**

Name \_\_\_\_\_

Address \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ E-Mail \_\_\_\_\_

Occupation \_\_\_\_\_

Relevant experience and/or employment (attach a resume if relevant) \_\_\_\_\_

\_\_\_\_\_

Why are you interested in our organization? \_\_\_\_\_

\_\_\_\_\_

Area(s) of expertise/contribution you feel you can make \_\_\_\_\_

\_\_\_\_\_

Other volunteer commitments \_\_\_\_\_

\_\_\_\_\_

**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

Newsletter deadline for the March newsletter is February 18, 2004



**Mark Your Calendars**

**WDA Annual Conference  
April 30—May 2, 2004  
Phoenix, Arizona**

The Registration and Meeting Agenda will be included in the next issue of *The Copper Connection*

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.

**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: \_\_\_\_\_

Social Affiliations/Clubs and Organizations: \_\_\_\_\_

Personal Interests/Hobbies: \_\_\_\_\_

Areas of Experience or Expertise:

Auditing

Writing

Legal – Non-Profit Experience

Media

Government Affairs

Graphic Arts

Marketing

Board of Directors

Public Speaking

Computer Technology

Fundraising:

Web Site/Internet

Special Events

Newsletter

Foundations

Local Support Group Organizing/Leading

Corporations

Office Work

Other (specify) \_\_\_\_\_

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

**WILSON'S DISEASE ASSOCIATION, INTERNATIONAL**

The Copper Connection  
1802 Brookside Drive  
Wooster, OH 44691

(FORWARDING SERVICE REQUESTED)

**TO:**

**Membership Renewal Enclosed**