

# THE COPPER CONNECTION

September, 2004

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## Penicillamine Labeling

Last year the WDA was asked by several treating physicians to pursue a "Black Box" label warning for penicillamine, due to its many adverse reactions and toxicities. We consulted with an attorney who is an expert in providing legal advice, counsel, and representation in Food and Drug Administration matters. Upon review of all information we were advised that it would not be in the best interests of the WDA to pursue labeling changes for penicillamine. Rather, we were advised to pursue removing the limitation on the trientine HCl (Syprine) indication so that it is labeled for primary use for Wilson's disease. Subsequently, the attorney reviewed all current medical literature to determine whether there was sufficient published clinical data to support such a change. To date, there is not. When adequate such data becomes available to us, we will once again pursue this project.

Meanwhile, YOU as patients and/or your healthcare providers can assist in the important change in penicillamine labeling. The FDA makes available to consumers and healthcare providers, through MedWatch the Food and Drug Administration's (FDA) program for reporting [serious reactions](#) and [problems](#), with medical products, such as drugs and medical devices, a Voluntary Reporting Form.

If you or someone in your family has experienced a serious effect from the use of penicillamine, we encourage you and/or your healthcare provider to complete this form, and return it to the FDA. For your convenience, we have included this form as an insert in this issue of *The Copper Connection*. If you need additional forms, you may also print them out from the FDA website at: <http://www.fda.gov/medwatch/SAFETY/3500.pdf>.

Additional information on this program and an online reporting form may be found at: <https://www.accessdata.fda.gov/scripts/medwatch/>



## My Story

By Stefan Sandler

Dear friends,

I would like to take this opportunity to introduce myself, to those of you whom I have not yet had the pleasure of meeting. My name is Mr. Stefan Sandler and I am 34 years of age living in Wuppertal, Germany. I suffer from neurological Wilson's disease and I too, like so many sufferers of the disease, ran from one physician to another trying many different types of medications. It all began in 1988 when I was in the middle of my high school exams. My parents and my friends recognized that my speech had changed and that I was slightly losing my movement controls. We thought at first it was caused by the stress of my exams. I went to a neurologist and he sent me for further testing.

In a way, I was a lucky guy because I was admitted to the University Hospital of Dusseldorf in Germany where the two main WD experts worked at the time. After a few tests it was clear that I had WD and the physicians put me on d-pen, which was a mistake. My symptoms got worse. Within one year my speech was not understandable and I couldn't walk, write or do anything else. So the docs put me on zinc sulphate, but this brought no improvement. My physicians tried almost everything including BAL-injections. BAL was originally used in wars with chemical weapons. It's an anti-poison, but it was also used on WD patients. This trial phase lasted three years and I got very depressed. I could not do anything without help and there were also moments when I didn't want to live anymore.

The change was in 1991. At this time trientine got approved in Germany and my physicians switched me to this drug. It was amazing how my physical situation changed enormously for the better. Also, my other symptoms started to improve.

In 1993, I began studying software development and I

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## WILSON'S DISEASE ASSOCIATION

1802 Brookside Drive  
 Wooster, Ohio 44691  
 email: [info@wilsonsdisease.org](mailto:info@wilsonsdisease.org)  
 website: [www.wilsonsdisease.org](http://www.wilsonsdisease.org)  
 Phone: 1(330) 264-1450 Toll Free: 1(888) 264-1450

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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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## *President's Message*

Dear Friends:

Greetings as we watch another summer turn into Fall, or for those of you in the southern hemisphere, the reverse. For me, the coming of Autumn has special feelings, sounds, sights, and smells. I love the falling of leaves, apple season, Packer games, back to school, a new television season, pumpkins, etc. (so, I'm a diehard Wisconsinite). But, most of all I feel re-energized from the lazy days of summer. I feel a new sense of purpose, commitment, and drive! And, whatever your season, I hope you will join me in the energy of making the Wilson's Disease Association all it can be.

I never cease to be amazed at the wonderful doctors who have dedicated their careers to caring for Wilson's patients. Without them, where would we be? There are several physicians who have made life a whole lot easier and healthier for our Wilson's family; you know who they are. In that light, I would like to speak about one physician in particular, Dr. George Brewer. It has been my pleasure and good fortune to be associated with him. I cannot overstate the spectrum of his contributions to Wilson's disease care and expertise. So, it is with regret that I must tell you of his decision to step down from the WDA's Medical Advisory Committee. While Dr. Brewer will no longer be officially affiliated with the Wilson's Disease Association, he has assured us that he will continue to advise and treat patients as before and continue his research studies.

Dr. Fred Askari will continue to be in charge of the Wilson's Disease Clinic at the University of Michigan, and is an active physician advisor to the WDA. Dr. Michael Schilsky, the Chair of the WDA Medical Advisory Committee, continues to be involved in clinical care and research as well. The WDA is working diligently to ensure the succession of these great physicians by continuing physician education programs.

Board members, in conjunction with the Medical Advisory Committee, are working to identify and designate additional Centers of Excellence and treating physicians. Standards for existing Centers of Excellence are being reviewed and contact with them will be made to ensure that they continue to provide

*(PRESIDENT, Continued on page 5)*

## *Executive Director's Message*

Dear Friends:

What a great summer 2004 this has been thus far! The WDA has been very busy with several important projects and we are happy to provide you with more information in this edition of *The Copper Connection*.

Mayo Medical Laboratories (MML) and the WDA have worked together to come up with a process for WD individuals to have their 24-hour urine collections for copper and zinc tested. This information is being provided because of the numerous phone calls the office has received regarding availability of urine testing. MML is not the only choice and there are many considerations one needs to take when choosing a lab. The WDA is only providing information and does not recommend one laboratory over another.

The WDA will hold two support group meetings during the month of September. The first will be in Ann Arbor, Michigan with Dr. Fred Askari. It is being held on Saturday, September 18, 2004 at 11:00 a.m. Jonathan's Family Restaurant is donating its banquet room for our meeting. The WDA would like to thank Len Pytlak for helping us organize this meeting.

The second support group meeting will be in New York City with Dr. Mike Schilsky at Weill Cornell Medical Center on Sunday, September 26, 2004 at 11:00 a.m. The WDA would like to thank Lenore and Russ Sillery for helping us organize this meeting. There is more information available in this newsletter, but if you would like to attend either of these meetings, please RSVP at 1-888-264-1450. If you would like to hold a support group meeting in your area, please contact the office for more information.

In May, the WDA unveiled its new brochure "A Diagnostic Tool for Physicians: Unexplained Hepatic, Neurologic or Psychiatric Symptoms?" Since that time many members have called the WDA office and requested the brochure to distribute to their local hospitals and physicians offices. If you would like a few to distribute, please call the office at 1-888-264-1450. The brochure is a great resource and teaching tool!

We would like to thank everyone for the positive support the Penny Campaign is receiving. This Campaign will run as long as we have Penny Cards to

*(EXECUTIVE, Continued on page 5)*

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*(STORY, Continued from page 1)*

finished with an IT-System-Engineer degree. Today I work as a main system administrator of one of the central organizations for welfare and healthcare in Germany; an organization with more than 400 employees.

I joined the WDA in the year 2000 and used my love of traveling as a way of helping patients and families of sufferers. I have traveled to Romania countless times where I have assisted many people. I have even traveled halfway across the world to South Africa where I helped a young woman obtain the correct medication. The year 2003 I achieved one of my greatest achievements. I was nominated to become a member of the Board for the Wilson's Disease Association for my hard work and dedication. I have met many wonderful people through this job, most of whom I work with on the Board. My journey has not been easy to get where I am today and I would have never made it without the love and support of my family and friends. Will and determination also played an important role in my improvement.

My story is living proof that anything is possible and dreams can come true. I'd like to thank each and every person whom I have met and who has touched my life in some way or another.

Thank you.

Take care and God bless.

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### **Update on Hepatoma Screening**

Fred Askari, M.D.

Hepatoma is a primary malignancy or cancer of the liver that most frequently develops in people with cirrhosis caused by viral hepatitis and hemochromatosis. This cancer is the result of unregulated growth of liver cells. These cancers are hard to treat, although in some cases early diagnosis can lead to removal by liver transplant, surgical removal of the part of the liver containing the cancer, or local ablation of a small cancer. Several practice guidelines are in the process of being issued by liver doctors that recommend surveying people with cirrhosis or scarring of the liver with an ultrasound and AFP (alpha-feto protein, serum marker of liver cancer) every six months. This kind of testing is similar to ordering mammograms or prostate exams to check for breast or prostate cancer as people age. The doctors who wrote these liver cancer testing guidelines

not surprisingly did not address the relatively rare incidence of liver cancer in people with rare diseases like Wilson's disease. The issue of who to survey periodically for liver cancer remains contentious as it's not clear that all people with Wilson's disease are at a markedly increased risk for liver cancer. In fact, the risk of liver cancer in people with Wilson's disease seems to be significantly less than one in four hundred, and even these cases may be attributable to a second injury triggering the risk for liver cancer. Because of the rarity of liver cancer in people with Wilson's disease, most Wilson's patients have not routinely been getting testing for liver cancer every six months as it is not clear that this is necessary or beneficial in people with a relatively low risk of liver cancer.

The people who have the greatest risk of developing liver cancer are those who have established cirrhosis caused by viral hepatitis. Particularly people with Wilson's disease who are also infected with viral hepatitis or who drink excessively may wish to discuss liver cancer screening with their physician. Reducing the risk of liver cancer is another good reason to minimize alcohol intake and keep copper levels under good control. So people with Wilson's disease that is poorly controlled or have a second form of liver injury should consider surveillance for liver cancer. Surveillance for liver cancer would involve having an ultrasound and AFP measure performed every six months. Since surveillance for liver cancer in patients with cirrhosis has become accepted by most hepatologists, consideration of the special situation of those with Wilson's disease is bound to come up.

Measurement of AFP and ultrasonography every six months is commonly performed in patients with cirrhosis who would be suitable candidates for partial liver removal if a liver cancer were discovered, and in those patients who are candidates for liver transplantation or ablative therapies. If you would like to have this screening done, discuss it with your doctor. People with Wilson's disease who do not have cirrhosis do not appear to be at any increased risk for liver cancer. Some have even argued that the treatments for Wilson's disease may actually be used to treat cancer as well, and Dr. Brewer has studied the use of TM to treat liver cancer with some exciting preliminary results. Naturally, a person with Wilson's disease should take medicine to lower copper levels and monitor for signs of over or under treatment. For some, following up with a physician who is experienced with Wilson's disease treatment can help.

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## Gnisiardnuf

(That's "Fundraising" spelled backwards)

I know, some of you read the title on this article and are probably thinking..."Oh no, not again. I don't want to hear anymore about FUNDRAISING or GNISIARNUF. " Nonetheless, "that word" is exactly what allows the WDA to continue its work in offering members the best in Research, Education, and Support.

Granted you may be thinking, "I wasn't able to write a check for the Physician Education campaign; I couldn't figure out how to sell the Penny Cards; I simply do not have any extra income to donate to WDA, and I need every penny just to live." That is true for many of us. But, WAIT; there is a way you and your friends can contribute without using any of your own income.

Ever notice the **iGive.com** logo in these newsletters, or on the WDA website? Don't know what it is all about? Haven't taken the time to find out? Well, that is exactly what this article is all about **iGive.com**. This is a great way to maximize contributions to WDA without always asking good friends and supporters, like you, to dig into their own pockets. All you and your friends need to have is: a computer, internet access, a credit card, and the need to shop...for almost anything. Donations to WDA come out of the merchants' pocket, as a percentage of what you purchase through them. This enables you to purchase the things you normally do locally, right from home and benefit WDA at the same time. It's as easy as that!



There are 550 popular stores to choose from whose donation to WDA, as a result of your purchases, vary from .4% - 26% of your total purchase. WDA currently has 52 shoppers registered with **iGive.com** who have raised \$320.21. Think how we could easily multiply this amount! From now until November 30, 2004 each new person who joins and shops means an additional \$5.00 bonus for WDA, on top of the percentage of each sale! So, please take the time to register and shop at **iGive.com**, and tell your friends to do the same.

*(PRESIDENT, Continued from page 3)*

high quality care for Wilson's patients. Additional options for 24 hour urine testing have been established as you will see on Page 7 of this *Copper Connection*.

Our website is in the process of being updated, thanks to Stefan Sandler. Gate Pharmaceuticals is providing us with increased server space which will allow us to build a bigger and better website. Additional features have been added and more will be soon. A Guestbook feature is already in use and a Chatroom feature is being developed which will enable visitors to discuss various topics of interest. It will soon be a secure site with the addition of PayPal to make it easier to submit membership renewals, donations, conference registrations, etc. Please visit the site often to keep apprised of new features and content.

Warm regards,

Mary L. Graper, President

*(EXECUTIVE, Continued from page 3)*

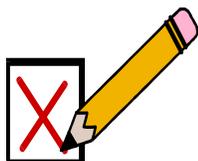
distribute. So if you run out and want more, please do not hesitate to contact the office! The WDA office also has fundraising information and how-to's for various events. Please call the office for information.

We could not accomplish all these projects without the support of our families. We thank you! Together we will make a difference!

Sincerely,  
Kimberly Symonds  
Executive Director

*The Next Wilson's Disease Association  
Annual Meeting will be held in  
Coral Gables, Florida  
April 29 - May 1, 2005*

## **Be An Informed Voter!**



Over the next several months you will have the opportunity to examine the candidates for president, congress, as well as local offices. Should you live in a state that is considered to be a 'swing state,' as I do in Ohio, you are already experiencing the increasing political ad campaigns. Unfortunately, more is to come as election time gets closer.

It is very important that we, members of the rare disease community, get out and vote in November. It is equally important that we fully understand for whom we are voting, and where the candidate stands on the issues that are important to us.

We are lucky to be living in the age of communication. There is so much information available on the internet, though one needs to be cautious when searching the web. Make sure the publication and author of the article have a credible reputation. Even then, if something doesn't seem right, challenge and investigate it for yourself. Don't take everything stated at face value.

There are several places you can go for information. The individual candidates have websites that explain their platform. Realize however, that you will only get one side of the issue. Be sure to investigate both sides. The League of Women's Voters has a valuable website and provides resourceful links. Their website is: [www.lwv.org](http://www.lwv.org). If you haven't registered to vote, you will also find registration information here. Additionally, Project Vote Smart has a nice, user-friendly site at [www.vote-smart.org](http://www.vote-smart.org). There you can search for candidates/officials by their zip codes, campaign finance data, voting records, score cards from various groups across the spectrum, and brief plain-English descriptions of current legislation and status.

The right to vote is your privilege as an American citizen. Along with that privilege comes the

responsibility of being an informed voter and thus promotes good, sound government. Please take the time to educate yourself on the issues that affect you as a member of the rare disease community.

If you need further assistance, please feel free to contact Kimberly Symonds at 888-264-1450. I will be more than happy to guide you to additional resources. Remember, good sound decisions are made by those who cast their informed vote on election day!

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**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

*The Next Wilson's Disease Association  
Annual Meeting will be held in  
Coral Gables, Florida  
April 29 – May 1, 2005*

## **Change of Address**

Moving????? Please let WDA know. We try to take advantage of non-profit bulk mail, and they do not forward mail under that rate. The only way we will know where to send your newsletter is if you tell us – so please remember to do this in the future if you move. You can send an e-mail to , call 1-888-264-1450, or notify us via postal mail. Thank you!

Newsletter deadline for the next  
*Copper Connection* issue is  
November 17, 2004. Please submit any items  
to Kimberly Symonds, Executive Director.

## **WDA Sponsors Two Support Group Meetings in September**

The WDA is sponsoring two support group meetings during the month of September. The first one is being held in Ann Arbor, Michigan. Dr. Fred Askari has graciously accepted our invitation to lead this group. This meeting will be held at Jonathan's Family Restaurant (directions available by calling the office) on Saturday, September 18, 2004 from 11:00 a.m.– 3:00 p.m. A light lunch will be provided. Board treasurer Len Pytlak will be present to help facilitate this meeting. To RSVP please call 1-888-264-1450 no later than September 2, 2004.

The second support group meeting is being held in New York City. Dr. Mike Schilsky has graciously accepted our invitation to lead this group. This meeting is being held at the New York Weill Cornell Medical Center on Sunday, September 26, 2004 from 11:00 a.m.– 2:00 p.m. in room M529. Please enter the building at 525 East 68<sup>th</sup> Street and stop at the information desk in the reception area. A light lunch will be provided. Board president Mary Graper will be present to help facilitate this meeting. To RSVP please call 1-888-264-1450 no later than September 10, 2004.

Both of these meetings are open to WDA members, their families, physicians and friends. This is a great way to connect with those in your area, have questions answered, and learn about the latest in Wilson's disease from our experts.

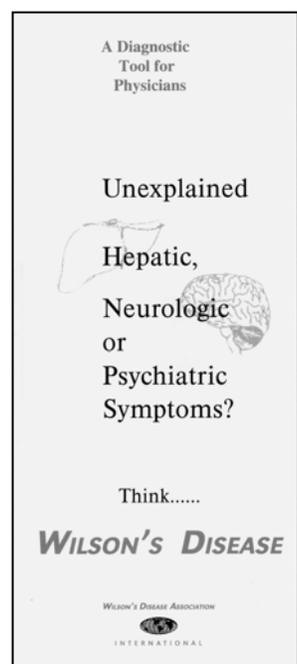
### **NOTE:**

*If you have not yet called to RSVP for the New York City support meeting, please do so as soon as possible!!!*

## **WDA Brochure Available**

We now have a new brochure for the diagnosis of Wilson's disease. This tri-fold brochure is perfect for hospitals and doctors offices to display or distribute to colleagues. It is also a good tool for those physicians less knowledgeable about Wilson's disease.

If you would like to receive a free supply to help educate those in your area about Wilson's disease, please contact us at or (888) 264-1450.



## **Newsletter Recognitions**

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

### **Thank you to:**

*Russ and Lenore Sillery*

*Delia Ruiz*

*Barbara Fox*

*Len Pytlak*

### **Wish List:**

Conference Sponsorships - Miami

Donated Office Supplies

Donated Printing Services

Donated Air Miles

Long Distance Sponsorship

800 Number Sponsorship for Family Support

## IN MEMORIAM

Jeremy Hayes

On April 14, 2004 Jeremy Hayes, of El Paso, Texas died from complications of Wilson's disease at age 23. Jeremy was diagnosed in 1994 and participated in Dr. Brewer's study at the University of Michigan. He was doing well medically until he stopped going to Michigan for treatment. Then he gave up and began engaging in self-destructive behavior. He, "started smoking pot and drinking—he wouldn't take his meds correctly", according to his mom.

"Our lives went downhill when we stopped going (to Michigan) and we were on our own. We couldn't get insurance when he stopped going to school". "The last four years were hell for me. How I wish I could do it again differently. I miss him terribly!"

Jeremy played soccer at the El Paso Community College; was an accomplished graphic artist and auto mechanic. He was always friendly with the nurses and other patients at Michigan; and is remembered by his friends and family as a young man with a big heart and gentle spirit. Jeremy is survived by his parents and two brothers.



Jeremy at  
UM in 1994

## Donating Stock Certificates

### To The WDA

LEN PYTLAK, CPA  
TREASURER, WDA

Two questions should come to mind when you think about donating stock certificates to us. The first one is, how do I do it? And the second one should be, what are the advantages of giving stock certificates instead of cash? I will answer the second question first.

Donating stock certificates instead of cash could save you some federal and state income tax dollars, and it will not directly affect your checkbook. For example, if you wanted to give the WDA \$2,000 (which we will be happy to accept), you can either do it by check or by giving us a few shares of your Microsoft stock.

A check for \$2,000 would put a dent in your check book which you could replace by selling some stock and depositing the sales proceeds into your check book. Selling the stock requires you to report the sale on schedule D of your federal income tax return form 1040, and thus pay federal and state income tax on the profits. You will also report the \$2,000 donation on federal schedule A, Itemized Deductions and possibly reduce your income taxes because of it.

However, the itemized deduction for \$2,000 may not offset the reportable income of \$2,000 because of income limits or the fact that you may not be qualified to take the itemized deduction. In addition, many state's income tax liabilities are based on the front page of your federal tax return, which is where the sale of the stock would be reported, but the donation is reported on page two of the federal tax return so you do not receive any state benefit for it.

If you donate the stock certificate to us, you do not report it, or pay income tax on the disposition of the stock on your federal and state income tax returns. But you do get to take a deduction on your tax return if you itemize the market value of the stock that was given to us. Here is an important point that bears repeating: You deduct the "market value" of the stock, not your original purchase price.

If the stocks you wish to donate cost you \$500, but the market value was \$2,000, you get a \$2,000 deduction yet you are only out-of-pocket the original \$500 that you paid for the stock years ago.

***Non-Compliance is Fatal!***

## Testing Available at Mayo Medical Laboratories

Following our inquiry, Mayo Medical Laboratories (MML) of Rochester, Minnesota has advised the Wilson's Disease Association (WDA) that its facility is available to test 24-hour urine collections for copper and zinc. The choice of a laboratory is one which each patient should make with his or her physician, and may be influenced by personal insurance considerations. The WDA does not recommend one laboratory over another.

MML has indicated that patients should have their testing ordered through their physician, working with their local community hospital laboratory to collect and forward. Many local hospitals contract with MML.

### **MML Test Information:**

Published Name: Zinc, Urine

Unit Code: 8591

Published Name: Copper, Urine

Unit Code: 8590

Specimen Required for Zinc and/or Copper Testing (Kits are available through MML contracted facilities):

1. 10 mL from a 24-hour urine collection. No preservative.
2. Collect in clean, plastic urine container(s) with no metal cap(s) or glued insert(s).
3. Send specimen in a plastic, 13-mL urine tube or a clean, plastic aliquot container with no metal cap or glued insert.
4. Refrigerate specimen within 4 hours of completion of 24-hour collection. Send specimen refrigerated.

NOTE: 24-HOUR VOLUME IS REQUIRED ON REQUEST FORM FOR PROCESSING.

If you need further information contact Mayo Medical Laboratories at  
 Mayo Medical Laboratories  
 200 First Street S.W.  
 Rochester, MN 55905  
 800-533-1710

{ *Urine testing is available at various other laboratories, as before. Consult individual facilities for their specimen requirements and procedures.* }

*(STOCKS, Continued from page 8)*

Of course there is a caveat when donating stock. **YOU SHOULD ONLY DONATE STOCK THAT HAS APPRECIATED IN VALUE FROM WHEN YOU PURCHASED IT.** If you have stocks that have loss value below your original cost, it is more advantageous to sell the stock first, take a current, front page, tax deduction of up to \$3,000 and then donate the cash to us. You still get the itemized deduction for the donation, but you also get a tax deduction for the loss of the stock. If you donate stock that has decreased in value, you do not get a tax deduction for the loss in value, just the market value at the time of the donation.

In regards to question one, the best way to donate the

stock to us is for you to call the Association's investment broker, Mr. Tony Rocco, VP at Comerica Securities 1-800-258-1188. This way he can determine how the stock is held, certificate form, or electronic form, and make the transfer arrangements correctly

You should also drop a note to Kimberly Symonds, our executive director, informing the Association of your generous gift so when Mr. Rocco contacts us we have a heads-up about the donation.

I also recommend you contact your own tax accountant to determine the effect a stock donation will have on your tax return since all tax situations are different.

**We are grateful to all for supporting the Wilson's Disease Association. It is because of your generosity we are able to continue our very important, life-saving programs.**

Report of Gifts through August 31, 2004

**General Donations from:**

Charles and Ruth Giberson	Linda Schwebke	Janice Dilley	Robert Smith
Boulat A. Bash	Dalia Mikha	Jorge Areias	Charles and Betty Perinka
Gloria and Clyde Fausneucht	Catherine Dilney	Mildred Shannon	Joanne and Ronald Doades
David and Jeanette Keyworth	Cathleen Bergmann	Henry and Annette Tilley	Duane and Beverly Mattheis

**Thank you to all who have helped make our Penny Card Campaign a success:**

Agnes T. Lute	Lillian and Max Fisher	Dan and Marilyn Slavin	Ronald and Cindy Olch
Richard and Jean Corman	Pei Chao	Joyce Russell	Duane and Beverly Mattheis
Robert and Beverly Linkins	Steven Rubenstein	Sherrill Neff	Fetzer and Pennington Mills
Kenneth and Bonnie Sheffield	Lillian M. Albano	Mary E. Kobe	Dr. George and Jo Rickard
Dr. Fred and Judith Hurt	Tamra and Eric Laird	Thomas Martin	Floyd and Alice Huffman
Gerald and Sandra Price	Nancy Lyon	Kay Cochran	Mary and Thomas Bickimer
George and Maria Gour	David Boettner	Diane Laurain	Bernard and Laura Kalmus
Jeffrey and Debbie Harris	Nina and Patrick Decker	Ellen W. Millerick	Margaret and Nick Misciascio
Marianne Pennington	Joyce Kline	Toshi Lederer	Matthew and Lorene Hartigan
Duane and Margaret Rortvedt	William Dvoretzky	Nancy and Paul Brown	Charles and Donna Pursley
Evelyn Forman	E. B. Wolk	Ramiro Arroyo, Jr.	Raymond and Lorraine Lemoine
Kristen Sayles	Carmae Patchen	Herbert R. Moeller	Suzanne and Edward Lemoine
Lloyd and Connie Bevan	Glenda Lewis	M. Lehnerer	Anvar and Zoukhra Bash
Ghita Olit and Selma Holo	Dolores Rightenburg	Robert and Lisa Parker	Themis Gianopoulous
Thomas Sadowski, Jr.	Hazel Abbott	E. Lee Jr.	Dennis and Susan Browning
Sandra Hastie	Frederick E. Taylor	Arron and Mary Klouse	

**Thank you to the following organization for their continued support of WDA:** GATE Pharmaceuticals

In Memory of Kelsey Fink by: Jo Amburgey, Bonnie (Leverence) and Tom Brown and Luray Elementary School

In Memory of Stacia Mabry by: Brittney Tree and Montville High School

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In Memory of Carol Philip by: Paul Rutherford

In Memory of Rick Wade by: Walter and Lori Wall

In Memory of Mark Whittier by: Michael Garcia

In Celebration of my love for the family: Anonymous

In Celebration of Russell and Michael Sillery by: Carmine and Helen Schepis

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In Honor of Butch Cross by: Edna Cross

In Honor of Teresa Petree by: Eagles Ladies Aux 3862

In Honor of Jennifer Doades by: Leonard Levin and Margareta Freeman

In Honor of Travis and Molly Gilchrist by: Shelley and Louis Romero

In Honor of Mark Kline by: Mark and Jean Rortvedt

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) 961-0533.



## 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: \_\_\_\_\_

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