

Fall 2009

# The Copper Connection

Wilson Disease Association, International

## *Clinical trial opens at Yale for Wilson disease: Single daily dosage of trientine for maintenance treatment for Wilson disease.*

Wilson disease requires life-long medical treatment. A serious issue for patients with Wilson disease is adherence to treatment, or simply put, how well patients take their prescribed medications. We know all too well that when a doctor prescribes medications that this does not assure that patients take them properly. From experience we have learned that the more times a day that a patient has to take medications, the more likely that doses will be missed. The consequence of not taking medication for Wilson disease is serious liver injury, injury to the central nervous system, liver failure and death. Each year we hear of some patients who have stopped their medications even temporarily & have suffered terribly, leading to severe disability or death.

Treatment for Wilson disease with zinc requires multiple daily dosages of the zinc to be effective, and zinc must be taken apart from meals. The drugs penicillamine and trientine are chelation agents that act by removing copper from the body. These medications are also typically prescribed in multiple daily dosages, from two to four times daily. Like zinc, they are most effective given one hour before or two hours after meals. While zinc is ineffective if taken once daily, it was theoretically possible that taking either penicillamine or trientine as a single daily dosage would remove enough copper to keep patients in balance and prevent worsening disease. It came to our attention that a handful of patients were using their medications this way, and we reported on their experience in a medical publication in the American Journal of Gastroenterology in 2008. These patients all had stable disease and were well maintained by taking all of their daily medication, either penicillamine or trientine, at a single time during the day apart from their meals. This was very exciting since if taking medication this way would increase adherence it would prevent a number of people from missing their needed medicines. Furthermore those that took the medication only once a day would only have to worry about timing the dose around a single meal and not interrupt their daily routine. For these reasons, we were very excited about the possibility to test this out in other patients in a prospective manner in a very controlled setting so that we could assure patient safety. By studying this properly we will learn more about how safe and effective tak-

ing a chelating drug as a single daily dose really is. If we are successful in this study, we will be able to recommend to other patients with Wilson disease that they may take trientine as a single dosage, hopefully preventing or at least reducing non adherence as well as making treatment more convenient.

In order to determine that we are correct in our belief that taking the medication trientine in a single daily dose can effectively maintain the health and copper balance for individuals with treated and stable Wilson disease, we have opened a clinical trial at Yale and are now seeking patients interested in participating. To be eligible patients must have been treated for over one year for their Wilson disease and have stable liver disease or neurological signs and symptoms. Medication, trientine (Syprine) will be provided for patients free of charge during this one year trial. They will have to visit us for testing and examinations during the course of the study and any non-routine examinations and testing will be provided for free as part of the study. At the end of the one year treatment period, patients may return to their prior treatments for their Wilson disease or choose to continue the trientine at the same daily dosage. We will ask you for permission to be followed in the future to make sure that you are doing well and to learn about your treatment choices. Potential benefits from participating in this clinical trial include the provision of medication during this year, the ease of taking the medication only once a day and your clinical examinations testing that is overseen by Dr. Schilsky, one of the leading experts in the field of Wilson disease.

If you are interested in participating in this clinical trial please contact Stefania at 203-785-2068 or Dr. Schilsky at 203-737-1592, or e mail: Michael.Schilsky@yale.edu. The trial is made possible by the generous support of the Yale Center for Clinical Investigation and Aton Pharma Inc.

*Disclosures: Dr. Schilsky is on the Medical Advisory Committee to the Wilson Disease Association and is a Medical Advisor to Aton Pharma Inc.*  
PROTOCOL NUMBER: 0902004694



## The Copper Connection

### HONORARY BOARD

---

**Janene Bowen**

Logan, Utah

**Kenneth B. Peterson, MD**

Scottsdale, Arizona

**Pat Satherstrom R.N.**

Ottawa, Canada

**Michael Terry**

Luray, Virginia

### MEDICAL ADVISORY COMMITTEE

---

**Michael Schilsky M.D., Chairman**

Yale Medical Center  
New Haven, Connecticut

**Fred Askari M.D. PhD.**

University of Michigan  
Ann Arbor, Michigan

**Sihoun Hahn M.D. PhD.**

University of Washington  
Seattle, Washington

**Eve A. Roberts M.D.**

University of Toronto  
Toronto, Canada

**Dennis J. Thiele, Ph.D.**

Duke University Medical Center  
Durham, North Carolina

### BOARD OF DIRECTORS

---

**Mary L. Graper, President**

Milwaukee, Wisconsin

**Stefanie F. Kaplan, Vice President**

Long Beach, California

**Carol Terry, Secretary**

Luray, Virginia

**Jean P. Perog, Treasurer**

Quilchena, B.C. Canada

**Chien-Li Chung**

Glen Ridge, New Jersey

**Drew Katz**

Cherry Hill, New Jersey

**Ronald Pei, O.D.**

Huntington Beach, California

**Thomas Puetz, M.D.**

Mequon, Wisconsin

**Stefan Sandler**

Wuppertal, Germany

**Parichehr Yomtoob**

Riverwoods, Illinois

### NEWSLETTER EDITOR

---

**Delia V. Ruiz**

Pismo Beach, California

### EXECUTIVE DIRECTOR

---

**Kimberly F. Symonds**

Wooster, Ohio

# Table of Contents

Clinical Trial Opens at Yale .....	1
Chicago Support Group Wrap Up .....	3
2009-2010 Luminex/ACMGF Award Recipient .....	3
Milwaukee WOW .....	4
NDRI Update .....	5
WDA Holiday Shopping Ideas .....	5
2009 in Review .....	6
2010 Program Goals .....	7
Resources for Living Today .....	8
Additional Non-Profit Resources .....	9
Running in Memory of Tim Lutz .....	9
Every Life Art Contest .....	9
Newsletter Blurbs .....	10
Acknowledgements .....	11

WDA Membership Application ..... Insert

WDA Marketplace ..... Insert

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

The Copper Connection is a quarterly newsletter published by the Association that informs members of findings in the area of Wilson 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 Copper Connection  
1802 Brookside Drive  
Wooster, OH 44691  
888-264-1450  
kimberly.symonds@wilsonsdisease.org  
www.wilsonsdisease.org

## Our Mission Statement

The Wilson Disease Association funds research and facilities and promotes the identification, education, treatment and support of patients and other individuals affected by Wilson Disease.

# Chicago Support Group Wrap-Up

## A WD GATHERING - August 28, 2009 Northwestern University - By: Mary Graper

It was my great pleasure to travel to Chicago on a beautiful summer afternoon to attend the first regional support meeting at Northwestern University, the WDA's newest Center of Excellence. After a pleasant train ride from my home in Milwaukee, I met Dr. Aleks Videnovic in his office and we exchanged ideas about the new WD Center, including possible research initiatives. From his office we proceeded to walk to the meeting site at the Baldwin auditorium. On the way, Dr. Videnovic treated me to a tour of Northwestern's impressive clinical facilities.

At the auditorium I was introduced to Dr. Richard Green, the Center's adult hepatologist and Ms. Diane Breslow, MSW. The small group of 10 attendees enjoyed a delicious box lunch graciously provided by the Department of Neurology. After a short opportunity to socialize with new and familiar faces the formal program commenced.

Ms. Breslow's presentation centered around the various social services available to patients at Northwestern and provided the group with a printed resource list. Dr. Videnovic gave a general overview of the structure and services provided by the Northwestern WD Center. He gave a more detailed picture of the services he provides to neurological WD patients with movement disorders. Dr. Green then gave his presentation about the hepatology and transplant services he provides for WD patients. The afternoon ended with a valuable question and answer session with the speakers.

An expanded educational and support Mini Conference is planned at Northwestern on July 17, 2010. Please watch for details on the WDA website & in the next issue of *The Copper Connection*.



Diane Breslow



Drs. Green & Videnovic

---

## *The WDA Congratulates Sihoun Hahn, M.D., Ph.D., FACMG 2009-2010 Luminex/ACMGF Award Recipient*

The American College of Medical Genetics Foundation (ACMGF) recently awarded Dr. Sihoun Hahn of Seattle Children's Hospital and the University of Washington School of Medicine the 2009-2010 Luminex/ACMGF Awards at the American College of Medical Genetics 2009 Annual Clinical Genetics Meeting in Tampa, FL. The award includes a \$100,000 grant and is aimed at the production of safe and effective genetic testing and services, including the development of research guidelines.

"Medical geneticists play a vital role in translating genetic research into medical services and in ensuring the safe integration of genetics into health care and public health. The Luminex/ACMGF Award recognizes this crucial role of med-

ical geneticists by supporting an individual in undertaking activities that promote the highest levels of safety and effectiveness in genetic testing and genetic services," said R. Rodney Howell, MD, FACMG, President of the ACMGF.

Dr. Hahn is a member of the advisory committee for newborn screening in Washington State and the medical advisory committee member for the Wilson Disease Association. He is Director, Biochemical Genetics Program and professor, Department of pediatrics, Division of Genetics and Genomic Medicine at the University of Washington School of Medicine and Director, Biochemical and Molecular Genetics Laboratory, Seattle Children's Hospital.

# Milwaukee Walk Out Wilson - September 12, 2009

A beautiful fall day at Lake Park in Milwaukee was the setting for a very successful first annual Walk Out Wilson. The 5K event was attended by 48 human walkers and 13 canine walkers for a total of 150 legs walking it out for Wilson disease!!

Finishing the challenging course first was Greg Harrison. Mr. Harrison kindly relinquished his award, a ceramic penguin coin bank donated by DeSalvo Studios, to one of the younger walkers. Walk Committee Chair, Kelli Brooks, won a beautiful crystal award, donated by 3dSparkle.com, for raising the most funds for the WDA. The largest group of walkers attending was Team Washington County Sheriff recruited by team captain Andrew Graper.

The WDA would like to thank Kelli Brooks and her committee for planning and conducting this successful event: Brittney Berger, Pat Brooks, Ashley Foy, James Rael, and Mary Kate Springman.

A big thank you to our corporate sponsors:



## GOLD LEVEL

WaterStone Bank - Waukesha, WI.

## SILVER LEVEL

The Evictor, Inc. - Glendale, WI.  
Univar Ltd. - Buckinghamshire, U.K

## BRONZE LEVEL

Anonymous - Milwaukee, WI.

## COPPER LEVEL

Avalon Graphics - Hartland, WI.  
DeSalvo Studio - Glendale, WI.  
Sharon Gamm, Directions in Design - Fox Point, WI.  
Andy Stillman, Shorewest Realtors - Shorewood, WI.  
Dan Fitzgerald Pharmacy - Whitefish Bay, WI.  
3dSparkle.com - Troy, MI.



Top: 41 Milwaukee walkers & 10 of their 4 legged friends

Middle: First to finish, Greg Harrison

Bottom: Walk Chair Kelli Brooks receiving award

Through registrations, donations, and corporate sponsors, the Milwaukee 5K raised over \$6,000 for the WDA. Thank you Milwaukee! We'll see you again next year.

# National Disease Research Interchange Update

The National Disease Research Interchange (NDRI) is a national organization that facilitates the development of new therapies for human diseases by making tissue samples available to research scientists. NDRI recently held a meeting in Chicago where WDA Executive Director, Kimberly Symonds, was invited to attend. The purpose of this meeting was to develop ways to improve communications between WDA members, researchers, and NDRI; as well as ramp up the rare disease research in Wilson disease by developing donor and research registries and repositories for human biospecimens.

The WDA and NDRI formed a partnership in 2007 to increase the number of specimens that are available for research. NDRI has developed the Wilson Disease Donor Registry to manage the registration and consenting of patients with Wilson disease who wish to donate tissue for research. Since the start of the

program 2 individuals have been consented for donation, 1 of whom has since donated tissue. 3 individuals have been sent information and consent forms and we are waiting to add them to the registry. The Wilson disease donor registry includes comprehensive medical history data for all registered donors NDRI has created a DNA and Blood Bank for rare disease donors and 1 individual with Wilson disease had blood processed. Currently there are 7 vials of plasma and 6 vials of DNA from whole blood available to interested investigators.

We would encourage you to participate in this very important program. Researchers need tissue to study to come up with improved treatments. We are the only access they have to these important materials. Please help us help the researchers. If you have any questions, please contact Kimberly Symonds at 888-264-1450 or NDRI at 215-557-7361

*Here's an EASY way to support the WDA while doing your Holiday shopping!*

Through a simple internet ordering system, you can purchase quality Rada Cutlery kitchen knives, utensils, gift sets, scented soy candles, cookbooks, and dip, soup and dessert mixes direct from the manufacturer at very low prices. A portion of each purchase is given to the WDA. This means that not only will you get a great deal on amazing products, but you will also be helping the WDA achieve its goals on your behalf.

To take advantage of this opportunity to help us, log-on to [www.HelpOurFundraiser.com](http://www.HelpOurFundraiser.com) using the following:

Internet Ordering #: 502271

Password: fightwd

Your order will be delivered to your address in 15 working days or less. **Please note that a \$10 minimum order is required & you can get additional information about the products available or download a complete catalog at [www.RadaMfg.com](http://www.RadaMfg.com).** Your purchase also supports American workers and their families because Rada Cutlery has been proudly manufactured in America's heartland since 1948.



## 2009 in Review

<u>Goals/Program</u>	<u>Accomplished</u>	<u>Reason/Outcome</u>
Re-design WDA Website	Yes	Executive Director assumed task
Regional Mini Conference, CME Course, Online Webinar <i>California Pacific Medical Center (CPMC)</i>	Yes	Funding: CPMC, Aton Pharma, AirTran Planning: Executive Director and Board President
Regional Support Meeting <i>Northwestern University, Chicago</i>	Yes	Planning: Board President; Supported by Northwestern staff & facilities
Power of Ten Regional Challenge Raise \$25,000 to be matched by Infinite Possibilities Foundation	Partial	Limited participation. raised under \$10,000.
Family Fundraiser <i>Running in Memory of Tim Lutz</i>	Yes	Organizer: Staci Lutz. Raised \$7,000
WOW – Walk Out Wilson <i>Wisconsin, New York, Ohio</i>	Yes	Organizers: Local volunteer committees in each location. Raised \$10,000
Continue Newborn Screening Initiative <i>WD to NBS screening panel</i>	Yes	Executive Director served on HRSA subcommittee on Addition of on Heritable Disorders in Newborns and Children.
Continue Compassionate Use Program <i>Cuprimine/Syprine for foreign patients</i>	Yes	Product donations. WDA Grant to MAP International; \$15,000 annually.
Establish stronger partnership with Univar <i>U.K. manufacturer of Trientin</i>	Yes	Benefits WD patients globally. Received funding from Univar for 3 WDA events.
Explore potential less expensive alternative to FDA approved zinc	Yes	ExtremeV launches USP grade zinc gluconate, Gluzin™ <i>(Non-FDA approved product available without Rx)</i>
Maintain relationship with National Organization of Rare Disorders	Yes	Executive Director served as Treasurer on NORD's Board. Attended 3 meetings on behalf of WDA.
New Patient & Physician Education publications	No	Lack of funds and volunteer time.
Re-define research goals and issue new RFP to fund research	No	Lack of funds and volunteer time.
Medical Student Education <i>(Pilot Apprenticeship Program)</i>	No	Lack of funds.

# 2009 REVIEW

# 2010 Program Goals

<u>Goals/Program</u>	<u>Target Date</u>	<u>Needs</u>
Continued website maintenance and updates (Develop Transplant information page and others)	Ongoing	Funding and/or volunteer assistance
Re-define research goals and issue new RFP to fund research	February, 2010	Volunteer assistance
Medical Student Education Program (Pilot Apprenticeship Program)	June, 2010	Funding
New Patient & Physician Education publications	June; Dec. 2010	Funding and volunteer assistance
Increase electronic communication with membership Constant Contact, Facebook, Inspire, etc.	March, 2010	More member e-mail addresses Volunteer assistance
Regional Mini Conference, CME course Baylor University, Houston	Spring, 2010	Funding
Regional Mini Conference - New York City	Spring, 2010	Funding
Regional Mini Conference, CME course Northwestern University	July 16, 2010	Funding
International Scientific Conference Washington D.C. area	Fall, 2010	NIH Funding; Corporate funding
Develop partnerships to identify possible connections with other copper related disorders	December, 2010	Various NPO organizations under consideration
Additional Family Fundraisers	Ongoing	Organizers and volunteers
Continue Newborn Screening initiative Addition of WD to NBS screening panel	Ongoing	ED to attend HRSA Advisory Committee meetings
Attend professional medical society meetings AASLD, ANA, DDW, CNS etc.	Ongoing	Funding
Develop new WDA marketing/re-branding strategy	Ongoing	Funding and/or volunteer assistance
Continue tissue bank partnership with NDRI	Ongoing	Volunteers to donate tissue samples

**Any questions? Want to help? Please let the WDA office know!**

# 2010 GOALS

# Resources for Living Today

## The American Association on Health and Disability (AAHD) is proud to announce the creation of the 2009 AAHD Scholarship Program.

The AAHD Scholarship Program will support students with disabilities who are pursuing higher education. Preference will be given to students who plan to pursue undergraduate/graduate studies in the field of public health, health promotion, or disability studies, to include disability policy and disability research. Royalties from the Disability & Health Journal will fund the first year of the AAHD Scholarship Program.

Please visit [www.aahd.us](http://www.aahd.us) to read more about the Scholarship Program and to download the application.

## Kaiser Family Foundation Launches New Non-Profit Health Policy News Service

---

Kaiser Health News (KHN) has been established to provide extensive reporting of major health issues. Stories will examine the health care system from a consumer perspective and cover topics such as health care reform, Medicare and Medicaid programs and financing of long-term care. Video, audio, graphics and text will be used to explain these topics in multiple formats. All KHN content will be available to other news organizations and the public free of charge through its web site at <http://www.kaiserhealthnews.org/>

## Kaiser Family Foundation Provides Tool to Compare Health Reform Legislation

---

The Kaiser Family Foundation has developed an online tool to help explain the differences between competing pieces of proposed legislation related to healthcare reform. Users can choose which proposals to compare, as well as the specific characteristics about those proposals including coverage, cost containment and financing. The link to this resource is: <http://www.kff.org/healthreform/sidebyside.cfm>

## Mandatory Registry of Genetic Tests Proposed

---

The Genetics and Public Policy Center has issued a proposal for a mandatory registry of genetic tests to inform the public and health care providers about tests for over 1,700 conditions. The authors suggest that the following features are needed to make the registry effective:

- It should be mandatory with penalties imposed for noncompliance.
- Both clinical laboratories and test distributors should be required to register.
- The registry initially should be limited to genetic tests that are health-related. Providers of tests for ultra-rare disorders would be exempt from some reporting requirements that could be unduly burdensome.
- The registry would contain information adequate to assess how reliable a test is (analytic validity), how the results relate to current and future disease risk or health status (clinical validity), and how useful the results are in informing patient diagnosis or treatment or in disease prediction, management, or prevention (clinical utility).

[http://www.dnapolicy.org/news.release.php?action=detail&pressrelease\\_id=132](http://www.dnapolicy.org/news.release.php?action=detail&pressrelease_id=132)

## “Living with a Rare Disease” Study

---

An interview study of patients with rare diseases is being conducted by Susan Vitale, Assistant Professor of Nursing at Molloy College, in order to better understand the unique and common issues related to a rare diseases diagnosis. Individuals 18 years and older and/or interested family members are eligible to participate by providing a description of their experience either by email, in person or by telephone. For additional information contact Dr. Vitale at [svitale@molloy.edu](mailto:svitale@molloy.edu)

Carolyn M. Clancy, M.D., Director of the Agency for Healthcare Research and Quality (AHRQ) offers brief, easy-to-understand advice columns for consumers to help navigate the health care system. In her latest column, Dr. Clancy explains why it is important to create and maintain a personal health record that summarizes your health history and compiles information from different health care providers.

To read Dr. Clancy's latest column, go to:

<http://www.ahrq.gov/consumer/cc/cc061609.htm>

# Additional Non-Profit Resources

The following websites may have resources and information to help your family:

## [www.unos.org](http://www.unos.org)

The United Network for Organ Sharing is organized to advance organ availability and transplantation by uniting & supporting our communities for the benefit of patients through education, technology, & policy development.

## [www.rarediseases.org](http://www.rarediseases.org)

The National Organization for Rare Disorders is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them.

## [www.geneticalliance.org](http://www.geneticalliance.org)

The Genetic Alliance has the goal of building capacity within the genetics community by being fluid, dynamic, and efficient; they work to eliminate obstacles and limitations through Novel Partnerships, Informed Decision Making, and Individual, Family, and Community Perspectives.

## [www.upliftingathletes.org](http://www.upliftingathletes.org)

Uplifting Athletes is a national nonprofit organization aligning college football with rare diseases and raising the as a national priority through outreach, research, education, and advocacy.

## [www.caregiver.org](http://www.caregiver.org)

Family Caregiver Alliance is a community-based nonprofit organization addressing the needs of families and friends providing long-term care at home.

## Running in Memory of Tim Lutz

A huge thank you goes out to Staci Lutz. She ran in her first half marathon at the Columbus Marathon on October 18, 2009. Her brother, Tim, was an avid runner and a huge source of inspiration to his family and friends. Staci ran in his memory and raised over \$7,000.00!



**Deadline Extended  
to December 31, 2009**

**EVERYLIFE  
ART CONTEST**

*Empowering Artists Affected by Rare Diseases*

The Kakkis EveryLife Foundation invites artists to participate in the first annual EveryLife Art Contest.

### **PRIZES:**

Two Grand Prizes will be awarded in each age group.

### **Age Groups:**

Children 5-11: \$100 Visa Gift Card

Teens 12-17: \$250 Visa Gift Card

Adults 18+: \$500 Visa Gift Card

Each Grand Prize winner will also receive a Flip Video camera. Winners will use the Flip Video to record their story about being an artist affected by a rare disease. The artists' video stories will be posted on the Kakkis EveryLife Foundations Website.

**Awards for Outstanding Art:** All contestants with works of outstanding art will receive a \$25 Visa Gift Card.

**ELIGIBILITY:** The EveryLife Art Competition is open to all artists affected by a Rare Disease ages 5 and older. Artists may have a Rare or Undiagnosed Disease or may be close friends, family members, or care takers of those with a Rare or Undiagnosed Disease. A rare disease is one that affects less than 200,000 people in the United States. International entries are accepted. Employees or Board Members of the Kakkis EveryLife Foundation or their immediate family members are not eligible to participate.

**DEADLINE:** Entries must be received by 5pm on Thursday December 31, 2009.

**For more information & to download an application, visit [www.kakkis.org](http://www.kakkis.org)**

**Sponsored by the  
KAKKIS EVERYLIFE FOUNDATION  
77 Digital Drive • Suite 210 • Novato, CA 94949  
Phone: 415-884-0223 • Fax: 415-884-0562  
[WWW.KAKKIS.ORG](http://WWW.KAKKIS.ORG)**

# For Your Information

## WDA Wish List:

- Donated Printing Services
- Family Run Fundraisers
- Newsletter Support

## Newsletter Deadline:

The Copper Connection welcomes, and would appreciate, any articles that members would like to submit for publication consideration. If you would like to submit an article, the deadline for the Winter newsletter is January 29, 2010. Please e-mail your article to the WDA office at:

wda@sssnet.com

The Wilson 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 Disease Association  
1802 Brookside Drive  
Wooster, OH 44691**

## Join our Online Community

The Wilson Disease Association partnered with Inspire to bring our members a place for open dialogue among all Wilson disease members – no matter what the relationship is to Wilson disease. Join us by participating in a discussion, start your own discussion, create a blog, or vote in a survey. There are many ways to participate. Go to the WDA website, [www.wilsonsdisease.org](http://www.wilsonsdisease.org) and click the button on the front page. Hope to see you there!



## National Disease Research Interchange (NDRI)

Please take the time to register with NDRI. Your blood and tissue donation might be the one that helps find a cure, or a better treatment. To donate blood or tissue, please contact a Rare Disease Coordinator at [raredisease@ndriresource.org](mailto:raredisease@ndriresource.org), or by phone at 800-222-6374.



## Shopping!

Shop iGive.com and find everything you need from paper goods and decorations; to clothing and accessories; music and entertainment; - the perfect gift for everyone on your list. Plus WDA benefits from your shopping!!! There are hundreds of stores on the iGive site including: Disney Store, Eddie Bauer, Spiegel, JCPenney, Walmart.com, Barnes and Nobel, Gap, Home Depot, and Starbucks! All give a percentage back to WDA if you register and shop through the iGive.com site

## Stock Donations

Please consider the Wilson Disease Association for a 2009 stock donation. For more information, please contact the national office at 888-264-1450

## Foundation Assistance Needed

WDA members help us in so many ways. Here is one more thing you can do to help. Put us in touch with Foundations who might be willing to help fund WDA's mission. Some of you may have access to a Foundation through your company, family members, or friends. While it is true that many Foundations have very specific missions, they are often amenable to proposals that come to them from a Director or Trustee.

If you know of a Foundation that may be willing to assist us, please contact the WDA office (888-264-1450 or [wda@sssnet.com](mailto:wda@sssnet.com)). We can work with you on the best approach and what kind of proposal would be most suitable. Who knows, your efforts in this regard could pay enormous dividends!

**JOIN US ON FACEBOOK!!!**  
**Causes: Wilson's Disease Association**



# Thanks for Your Support!

**2008 Year End Campaign** - Patricia Pei • Carol Terry

## **2009 Summer Challenge**

Melissa Asgaonkar • Dina and Zoukhra Bash • Judith Chervitz  
Bill Collins • Sheila Cooper • Harvey Cova • Marjorie Emby  
Paul Fausneucht • Belva Flynn • Howard Forman • Julian Fox  
C Frankel • Jackson Fray • Sheara Fredman • William Froehlich  
Edward Goff • Cecilia Goodman • Charlotte Hirsch  
Jacquelyn Kantor • Joyce & Howard Kaplanh • Alvina Laird  
Virgil and Maryann Laurain • Ronnie Levine  
Lee & Myles Lieberstein • Jonathan Magee • Trudy McQuillan  
Ken Niehaus • Geri Novak • George Plautz • William Popp  
Vincent and Janet Scire • Frances Segal • Bill & Mildred Shannon  
Steven Smith • Carol Stern • Joel Stern • Barry Sullivan  
Kimberly Symonds • Irene Szopo • James Taylor • Carol Terry  
Jacqueline Terry • Gwenda Wasserman • Karen Weinstein  
Batya Wertman • Kim Wijmer

## **Membership**

Brenda Baker • Gary and Roberta Bowen • Janene Bowen  
Joy Carlson • Jenna Cohen • Carrol and Susan Cross  
Shai Dobrusin • Jeanne Fink • Julian and Barbara Fox  
Joseph Vincent Gaven • Joel Herskowitz • David Hickam  
Ruth Hill • James and Cleo Hines • Jean Johnson  
Stefanie Kaplan • Ernest Kerzicnik • Aaron and Mary Klouse  
Beverly Linkins • Mark Mirkin • Darole Pertz  
John and Donna Pleva • Michael Rabin • Charles Revelle  
Steven Rubenstein • Paul Rutherford • Vincent and Janet Scire  
Bill and Mildred Shannon • Tanya Simuni • Natalie Smith  
Teodor Tarachiu • Sharon Wilson • John Witort

**MAP** - Thanh Quoc Nguyen

## **Honorarium**

Brenda Baker (in honor of University of Pittsburgh  
liver transplant surgeons)  
Julian and Barbara Fox (in honor of Stefanie Kaplan)  
David Hickam (in honor of Jenna Hickam)  
Mark Mirkin (in honor of Jason Nusbaum's wedding)  
Edward and Miriam Rabin (in honor of Jeremy Rabin)  
Linda Schwebke (in honor of Ghita Reuben Olit)  
Sharon Wilson (in honor of Meredith and James Wilson)  
John Witort (in honor of Jason Witort)

## **Memorials**

Barbara Frayser (in memory of Irmin Sternlieb, MD)  
William Horman (in memory of Ron Pylak)  
Suzanne Izzi (in memory of Salvatore Latino)  
Rose Malaczewski (in memory of Michael Nicholardi)  
Robert Smith (in memory of Roland Gilchrist)

## **Marketplace**

Rita Devery • Alvina Laird • Lisa McKim • Roger Vogel • John Witort

## **New York Walk**

Stephanie Aberger • Christopher Adamo • Denise Adams  
Celestina Ando • Raquel Arias • Rebecca Ayala • Colleen Baum  
Boulat Bash • Kate Bobo • Katherine Boyle • Andrea Brault  
Saul Brokowsky • Ann Brooks • Kevin Brooks • Pat Brooks  
Sally Burns • Ladonna Card • Melissa Carley • Frank Chau  
Cassandra Clara • Jennifer Connolly • Arlene Corda  
Fran Corda-Whitehead • Mary Corda • Michele Corda

Philip Crescimanno • Catheryn Croal • Mallorie Croal • Dave Crowley  
Cassandra Davis • Therese Davis • Catherine Dearsteyne  
Katherine Delgado • Andrew Doenias • Frederic Erskine  
Shirley Feldmann • Diane Fisher • Norm Fisher • Leniece Flowers  
Rebecca Frank • Lindsey Free • Jodi Galante • Scott Goldman  
Bob Grant • Brian Grant • Thomas Grant • Mary Graper • Sarah Grey  
Gayle Guild • Erin Guimaraes • Brian Heinimann • Christopher Hoyt  
James Hoyt • Lewis and Rosemarie Kamenitz • Patricia Kim  
Yelena Kiperman • Nicholas Kolman-Mandle • Dvora Konstant  
Irene Lake • John Mackay • Karen Byron Manahan  
Nadine Mastandrea • Scott McAlpine • Patrick McCarthy  
Lauren McCusker • Kelly McHugh • McNamara Family  
Mary Ann Meiser • Michael Oddo • Alan Olsen • Peter Orlando  
Mary Pointer • Amelia Rayburn • Ricardo Rodriguez • Leela Sarathy  
Daniel Saviano • Robbie Schechter • Elizabeth Schon • Michael Schilsky  
Jess Shallcross • Nicholas Soriano • Robert Stall • Tom Staley  
Jeremy Staley • Allison Steigman • Joy Teitelbaum • Allyson Toolan  
Univar Ltd. • Kristin Webster • Candace York

## **Ohio Walk**

John Brentar • Judy Brunnett • Larry Bushnell • Barbara Drew  
Adam Esses • Joanne Flint • Clyde Gesaman • Emily Gesaman  
Todd Gesaman • Laura Hallock • Donna Martsof • May Neer  
Jane Ragozine • Ian Randolph • David Solomon • Charles Stewart  
Mark Svonavec • Mary Svonavec • Univar Ltd. • Jessica Watson • Barbara Yoost

## **Milwaukee Walk**

3dsparkle.com • Denise Adams • Anonymous • Avalon Graphics  
Elizabeth Barnett • Nancy Barnett • Jeremy Brackman • Kelli Brooks  
Kevin Brooks • Pat Brooks • Cathi Croal • Mallorie Croal • Gary Crow  
Dan Fitzgerald Pharmacy • Roger Davison • DeSalvo Studio  
Kathleen Dugan • Jason Fare • Mary Forr • Susie Fox • Nancy Futterman  
Sharon Gamm • Mel Gentile • Jaclyn Gentner • Kathy George  
Sharon Girvan • Joe Goldberger • Michael Goolsby • Michael Grant  
Thomas Grant • William Graper • Greg Harrison • John Hivko  
Rosemary Jacobson • Elizabeth Kieilty • Sharon Lagas • Kerry Long  
Jeanne Long • Norman Long • Robert Long • Georgia Loukopoulos  
Linda Luedtke • McNamara Family • Bridget Myers • Connie Myers  
Jeannette Packee • Jim Packee • Nicole Packee • Bruce Polkes  
Jan Poth • Red Cap Luggage & Gifts • Susan Roberts • Lisa & Jim Ryan  
Bryan Sadoff • Stanley Silver • Kevin Springman • Mary Kate Springman  
Matt Springman • Andy Stillman • Rhianna Swaton • Alicia Szumski  
The Evictor, Inc. • Univar Ltd • WaterStone Bank • Jamaul Webster  
Anthony Weishaar • Linda Wilhelms • Jamie Wu • Shannon Yenchsky

## **Running in Memory of Tim Lutz**

Benjamin Ball • Cynthia Batman • Douglas Brady • Melissa Campagna  
Marc Cancilla • Marilyn Cancilla • Joseph Cohn • Steven Danals  
Linda Devine • Michael Devine • Virginia Droll • Jeanette Elkanick  
Megan Falco • Lee Famiano • Amy Flemming • Daniel Forst  
Doug Griesbach • David Higie • Julie Hinkle • Gary Hobson  
Brad Howland • Michael Jonozzo • Rhonda Judd • Liz Knazek  
Terence Lau • Kristen Legerski • Cindy Leipman • Dean Lottmann  
Christopher Lowe • Diana Lutz • Jeromy Manser • Ronald Mayville  
Kelly McCrone • Brandon McIntyre • Chuck Moore • Richard Morris  
Sue Murphy • Paul Nadin • John Novak • Daniel Rauser • Kathleen Said  
Greg Sakai • Michael Sakai • Kelly Sakai • Curtis Shaw • Steve Shaw  
Suzanne Shaw • Connie Smith • Keith Solar • Brent Stehlik  
Andrea Struhar • Carolyn Swaysland • Rick Theberge • Marilyn Varough  
Kim Weber • Dana Yokoyama

Fall 2009

## WILSON DISEASE ASSOCIATION, INTERNATIONAL

The Copper Connection  
1802 Brookside Drive  
Wooster, OH 44691

(FORWARDING SERVICE REQUESTED)

PRSR FIRST CLASS  
U.S. POSTAGE PAID  
SUGARCREEK OH  
PERMIT #38

**TO:**

### Wilson Disease Association Volunteer Profile

Name: \_\_\_\_\_ Connection to Wilson 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 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:

- |   |   |
|---|---|
| <input type="checkbox"/> Auditing                     | <input type="checkbox"/> Writing                                |
| <input type="checkbox"/> Legal - Nonprofit Experience | <input type="checkbox"/> Media                                  |
| <input type="checkbox"/> Government Affairs           | <input type="checkbox"/> Graphic Arts                           |
| <input type="checkbox"/> Marketing                    | <input type="checkbox"/> Board of Directors                     |
| <input type="checkbox"/> Public Speaking              | <input type="checkbox"/> Computer Technology                    |
| <input type="checkbox"/> Fundraising:                 | <input type="checkbox"/> Web Site/Internet                      |
| <input type="checkbox"/> Special Events               | <input type="checkbox"/> Newsletter                             |
| <input type="checkbox"/> Foundations                  | <input type="checkbox"/> Local Support Group Organizing/Leading |
| <input type="checkbox"/> Corporations                 | <input type="checkbox"/> Office Work                            |
| <input type="checkbox"/> Other (specify) _____        |   |

# WDA Marketplace



## Pill Box Timer

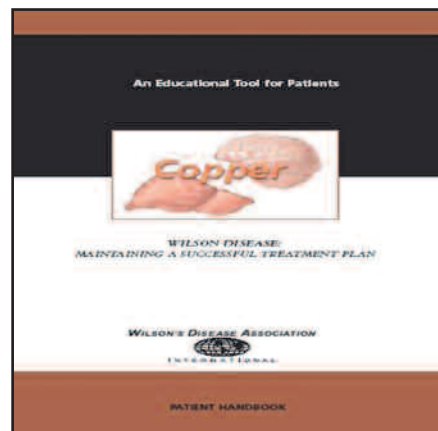
Remember to take your medication on time with WDA's new Pill Box Timer. These great timers have, in addition to the normal display, an alarm and stopwatch to ensure that you don't miss a single dose. Holds 15 aspirin-size tablets; has attached lanyard for use around neck, but small enough to fit in a pocket or purse. 3.5" L X 2" W X 5/8" Deep. Two colors available: purple and green. Donation requested is \$15.00 plus shipping and handling (\$2.50).

Number of Pill Boxes \_\_\_\_\_

## WDA Awareness Bracelet

You asked for them...we got them! WDA Awareness bracelets! They are copper in color and are designed to bring awareness to Wilson disease. The bracelets are packaged in groups of 5. The suggested donation per bracelet is \$2.50, that comes to \$12.50 per package. Copper color, inscription to read: STOP COPPER! SUPPORT WDA wilsonsdisease.org

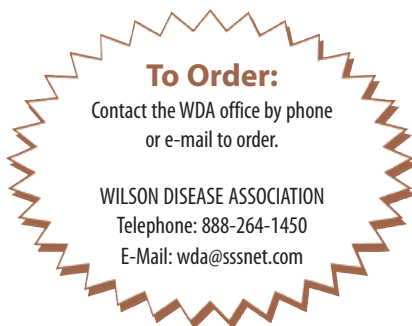
Package of Bracelets \_\_\_\_\_



## New WDA Patient Education publication available, *Wilson Disease: Maintaining a Successful Treatment Plan*

Published in March, 2008, this 8 1/2" x 11", 32 page publication includes the topics: Medical Care, Medications, Diet and Nutrition, Special Circumstances, and Family Concerns and Genetics. Also included is a glossary of medical terms, a glossary of genetic terms, and a printed copy of the "Wilson Disease Patient Lab Tracker". If you would like a copy, please contact the WDA office at: wda@sssnet.com or 888-264-1450. No fee is associated with this publication, but a donation would be appreciated.

Number of Handbooks \_\_\_\_\_



### To Order:

Contact the WDA office by phone or e-mail to order.

WILSON DISEASE ASSOCIATION  
Telephone: 888-264-1450  
E-Mail: wda@sssnet.com



## Gift Card

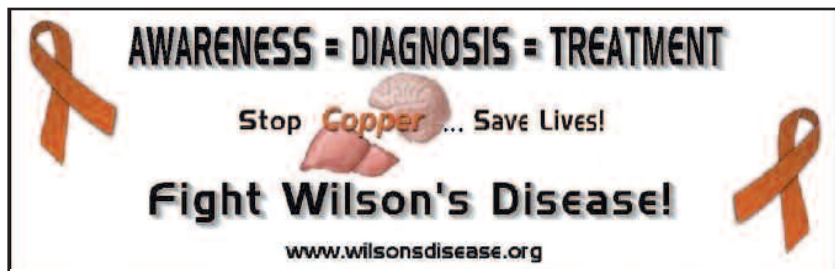
If you are looking for a beautiful and unusual gift for someone, please consider using this gift card . 3DSparkle.com is generously providing this offer to benefit the WDA. You will receive a \$10 discount on any purchase made and 3DSparkle will donate 20% of the sale to the WDA .All you need to do is enter the special code is entered during checkout. To receive one of these cards, at no cost to you, please contact Mary Graper at mary.graper@wilsonsdisease.org or 414-961-0533.



## Walk Out Wilson Disease Pet Bandana

Let your pet help support the WDA by wearing this stylish neck bandana! Available in Royal Blue, Teal, Red, and Copper colors. Your pal will be the talk of the town on daily walks and will help spread awareness of Wilson disease at the same time. Can you imagine a better conversation starter so that you can educate your friends and neighbors about WD? Donation requested is \$5.00 per bandana, plus shipping and handling (1.00)

Number of bandanas \_\_\_\_\_  
Color(s) \_\_\_\_\_



## WDA Bumper Sticker

Join in bringing awareness about Wilson disease! These stickers are 3" x 10" and have Copper color graphics with black text. Thank you to members Melissa and Patrick for designing them. And, a special thank you to Patrick for donating them to the WDA in honor of his son Jeff! Don't like sticking these things to your bumper? How about your front door, boat, work cubicle or "just about anywhere things will stick!" Suggested donation is \$5.00 per sticker, shipping and handling included.

Number of Stickers \_\_\_\_\_

# WILSON DISEASE ASSOCIATION

## MEMBERSHIP APPLICATION

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Email \_\_\_\_\_

### MEMBERSHIP DUES:

**Basic Membership - \$35**

- Receive quarterly WDA Newsletter via e-mail – (Please provide e-mail address above)

**Basic Plus Membership - \$60**

- Receive quarterly WDA Newsletter via U.S. mail or e-mail – (Please provide e-mail address above)

**Silver Membership - \$120**

- Receive quarterly WDA Newsletter via U.S. mail or e-mail – (Please provide e-mail address above)
- 10% discount on Annual Meeting registration for up to two registrants

**Gold Membership - \$250**

- Receive quarterly WDA Newsletter via U.S. mail or e-mail - (Please provide e-mail address above)
- 15% discount on Annual Meeting registration for up to four registrants
- Special recognition as a Gold Member in WDA Newsletter

**Copper Membership - \$1000**

- Receive quarterly WDA Newsletter via U.S. mail or e-mail – (Please provide e-mail address above)
- 20% discount on Annual Meeting registration for up to four registrants
- Special recognition as a Copper Member in WDA Newsletter
- 10% discount for Annual Meeting program ad
- No annual dues

### I WISH TO MAKE A DONATION TO WILSON 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 \_\_\_\_\_ Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

### PAYMENT INFORMATION

Membership Fee \$ \_\_\_\_\_  Visa  Mastercard  Check or Money Order attached

Donation \$ \_\_\_\_\_ Card # \_\_\_\_\_

Total \$ \_\_\_\_\_ Expiration Date: \_\_\_\_\_ CID# \_\_\_\_\_ (3 digits on back of card)

Signature \_\_\_\_\_