
Wilson disease requires lifelong 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 taking 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 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
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Wooster, OH 44691
888-264-1450
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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.
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.
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.
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**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.

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.
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.

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.

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. Your purchase also supports American workers and their families because Rada Cutlery has been proudly manufactured in America’s heartland since 1948.

To take advantage of this opportunity to help us, log-on to www.HelpOurFundraiser.com using the following:

Internet Ordering #: 502271
Password: fightwd
## 2009 in Review

<table>
<thead>
<tr>
<th>Goals/Program</th>
<th>Accomplished</th>
<th>Reason/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-design WDA Website</td>
<td>Yes</td>
<td>Executive Director assumed task</td>
</tr>
<tr>
<td>Regional Mini Conference, CME Course, Online Webinar (California Pacific Medical Center (CPMC))</td>
<td>Yes</td>
<td>Funding: CPMC, Aton Pharma, AirTran. Planning: Executive Director and Board President</td>
</tr>
<tr>
<td>Regional Support Meeting (Northwestern University, Chicago)</td>
<td>Yes</td>
<td>Planning: Board President; Supported by Northwestern staff &amp; facilities</td>
</tr>
<tr>
<td>Power of Ten Regional Challenge (Raise $25,000 to be matched by Infinite Possibilities Foundation)</td>
<td>Partial</td>
<td>Limited participation. Raised under $10,000.</td>
</tr>
<tr>
<td>Family Fundraiser (Running in Memory of Tim Lutz)</td>
<td>Yes</td>
<td>Organizer: Staci Lutz. Raised $7,000</td>
</tr>
<tr>
<td>WOW – Walk Out Wilson (Wisconsin, New York, Ohio)</td>
<td>Yes</td>
<td>Organizers: Local volunteer committees in each location. Raised $10,000</td>
</tr>
<tr>
<td>Continue Newborn Screening Initiative (WD to NBS screening panel)</td>
<td>Yes</td>
<td>Executive Director served on HRSA subcommittee on Addition of Heritable Disorders in Newborns and Children.</td>
</tr>
<tr>
<td>Continue Compassionate Use Program (Cuprimine/Syprine for foreign patients)</td>
<td>Yes</td>
<td>Product donations. WDA Grant to MAP International; $15,000 annually.</td>
</tr>
<tr>
<td>Establish stronger partnership with Univar (U.K. manufacturer of Trientin)</td>
<td>Yes</td>
<td>Benefits WD patients globally. Received funding from Univar for 3 WDA events.</td>
</tr>
<tr>
<td>Explore potential less expensive alternative to FDA approved zinc</td>
<td>Yes</td>
<td>ExtremeV launches USP grade zinc gluconate, Gluzin™ (Non-FDA approved product available without Rx)</td>
</tr>
<tr>
<td>Maintain relationship with National Organization of Rare Disorders</td>
<td>Yes</td>
<td>Executive Director served as Treasurer on NORD’s Board. Attended 3 meetings on behalf of WDA.</td>
</tr>
<tr>
<td>New Patient &amp; Physician Education publications</td>
<td>No</td>
<td>Lack of funds and volunteer time.</td>
</tr>
<tr>
<td>Re-define research goals and issue new RFP to fund research</td>
<td>No</td>
<td>Lack of funds and volunteer time.</td>
</tr>
<tr>
<td>Medical Student Education (Pilot Apprenticeship Program)</td>
<td>No</td>
<td>Lack of funds.</td>
</tr>
</tbody>
</table>
## 2010 Program Goals

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

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


“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

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

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

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!
**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 and click the button on the front page. Hope to see you there!

**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 Noble, 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). 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!

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Causes: Wilson’s Disease Association

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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 Cove • Marjorie Emby
Paul Fausneautch • Belva Flynn • Howard Forman • Julian Fox
C Frankel • Jackson Fray • Sheara Fredman • William Froehlich
Edward Goff • Cecilia Goodman • Charlotte Hirsch
Jacquelyn Kantor • Joyce & Howard Kaplan • Alvina Laird
Virgil and Maryann Laurain • Ronnie Levine
Lee & Myles Lieberstein • Jonathan Magee • Trudy McQuillian
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 • Owenda Wasserman • Karen Weinstein
Batya Wertman • Kim Wijmer

Membership
Brenda Baker • Gary and Roberta Bowen • Janene Bowen
Joy Carlson • Jenna Cohen • Carol 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 Kerzcinik • Aaron and Mary Klouse
Beverly Linkins • Mark Mirkin • Darole Pertz
John and Donna Pleva • Michael Rabin • Charles Reveille
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

Honорarium
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 Frazer (in memory of Irmin Sternlieb, MD)
William Hornan (in memory of Ron Pylak)
Suzanne Izzo (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 Aheber • 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
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Katherine Delgado • Andrew Doenias • Frederic Erskine
Shirley Feldmann • Diane Fisher • Norm Fisher • Leniece Flowers
Rebecca Frank • Lindsey Free • Jodi Galante • Scott Gold
Bob Grant • Brian Grant • Thomas Grant • Mary Graper • Sarah Grey
Gayle Guild • Erin Guimaraes • Brian Heiniman • 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 Schecter • 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 Brunnet • Larry Bushnell • Barbara Drew
Adam Esses • Joanne Flint • Clyde Gesaman • Emily Gesaman
Todd Gesaman • Laura Hallock • Donna Martsolf • May Neer
Jane Raguzine • 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 Gentry • Kathy George
Sharon Girvan • Joe Goldbergh • Michael Goolsby • Michael Grant
Thomas Grant • William Graper • Greg Harrison • John Hivko
Rosemary Jacobson • Elizabeth Kielty • Shanora Lagos • Kerry Long
Jeanne Long • Norman Long • Robert Long • Georgia Loukopoulos
Linda Luedtkke • 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 Sadow • Stanley Silver • Kevin Springman • Mary Kate Springman
Matt Springman • Andy Stillman • Rhianna Swaton • Aliza Szumski
The Evictor, Inc. • Univar Ltd. • WaterStone Bank • Jamaul Webster
Anthony Weishaar • Linda Wilhelms • Jamie Wu • Shannon Yenchesky

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 Elkanc
Megan Falco • Lee Famiano • Amy Flemming • Daniel Forst
Doug Griesbach • David Hiege • Julie Hinkle • Gary Hobson
Brad Howland • Michael Jonozzo • Rhonda Judd • Liz Knazek
Terence Lau • Kristen Legerski • Cindy Leipman • Dean Lottmann
Christopher Lowe • Diana Lutz • Jeremy Lutzy • Meron Masner
Ronald Mayville • Kelly McCrone • Brandon McIntyre • Chuck Moore • Richard Morris
Sue Murphy • Paul Nadin • John Novak • Daniel Rausler • Kathleen Said
Greg Sakai • Michael Sakai • Kelly Sakai • Curtis Shaw • Steve Shaw
Suzanne Shaw • Connie Smith • Keith Solar • Brent Stehlik
Andrea Struha • Carolyn Swaysland • Rick Theberge • Marilyn Varough
Kim Weber • Dana Yokoyama
### 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:**

- **Auditing**
- **Legal - Nonprofit Experience**
- **Government Affairs**
- **Marketing**
- **Public Speaking**
- **Fundraising:**
  - Special Events
  - Foundations
  - Corporations
- **Other (specify):** __________________________

- **Writing**
- **Media**
- **Graphic Arts**
- **Board of Directors**
- **Computer Technology**
- **Web Site/Internet**
- **Newsletter**
- **Local Support Group Organizing/Leading**
- **Office Work**
**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 __________

**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 __________

**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
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 ____________________________________________________________