



Summer 2009

# The Copper Connection

Wilson's Disease Association, International

## *\$25,000 Matching Challenge Grant*

**T**he WDA is pleased to announce that we have received a \$25,000 matching challenge grant from Drew Katz, Founder of Infinite Possibilities Foundation and a WDA Board Member. This grant is designed to help the WDA continue their educational activities.

Like many non-profit organizations, the WDA is struggling in these difficult economic times due to a decrease in donations. As our revenues have decreased, those needing our services have increased. The number of requests for information, along with those receiving an accurate diagnosis of Wilson disease has increased, showing that we are indeed making a difference through our educational activities. It is so important that we are able to continue to support all our educational programming; our families are counting on us.

\$50,000 would be an incredible boost to our Mission, but

we cannot do it without your help! There are many ways you can help us to reach our goal:

- Make a personal donation.
- Hold a bake sale or yard sale and donate the proceeds to the WDA.
- Set up a page on FirstGiving (we are happy to help you with this!) and share your own personal story regarding Wilson disease and request that your friends and family help to support our Association.

*Please help us reach this goal! Donations in response to this challenge grant should be made payable to the Wilson Disease Association and mailed to the WDA office at: 1802 Brookside Drive, Wooster, Ohio 44691. Every donation received by September 15 will be matched 100% up to the total challenge grant of \$25,000. All donations are tax-deductible.*

**THE NDRi RARE DISEASE RESEARCH NETWORK**

The National Disease Research Interchange (NDRI) works with donor families to help medical researchers obtain the human tissues needed to develop new treatments and cures.

**Medical researchers need:**

- Blood samples from rare disease donors and healthy family members
- Residual surgical specimens
- Tissues and organs donated after death

You can help. Ask your doctor or hospital to call NDRI or contact us directly at 800-222-6374 or e-mail us at [raredisease@ndriresource.org](mailto:raredisease@ndriresource.org).

NDRI is a nationally renowned resource, facilitating clinical advances for nearly 30 years.

- Not-for-profit
- Strict adherence to federal guidelines on informed consent and donor confidentiality
- Funded by the Office of Rare Diseases Research (ORDR) of the National Institutes of Health

**NDRI**  
National Disease Research Interchange  
THE NATIONAL RESOURCE CENTER  
[www.ndriresource.org](http://www.ndriresource.org)

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Wooster, OH 44691  
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www.wilsonsdisease.org

## Our Mission Statement

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

# President's Message

Dear Friends,

The past few months have been a time of many travels for me and my family. Since April my travels have taken me across the United States to Arizona, California, Georgia, and back home to Wisconsin again. These were both relaxing and busy journeys but it is good to be back home and looking forward to summer.

Though these trips began as family adventures, I seized the opportunity to include some WDA business as well. While in Arizona, I was able to meet with two WD families and spend some enjoyable time with them. From there I went to San Francisco to attend the WD Symposium on May 2. After the months of planning this event, it was wonderful to meet all those at CPMC who coordinated the meeting and the many physicians and WD families who attended. Read

In May, our family traveled to Brunswick, GA. to attend a ceremony for one of my children. While there, I had the opportunity to visit MAP International. MAP has partnered with the WDA for over five years in shipping Wilson disease medicines, donated by Aton Pharmaceuticals, to many of our international families who are unable to obtain Cuprimine or Syprine in their own countries. Together we provided 205 bottles of Cuprimine and 431 bottles of Syprine to 79 Wilson disease patients in 18 different countries last year.

I was warmly welcomed by Jodi Allison, Senior Representative of Philanthropic Services and External Relations at MAP. Jodi then introduced me to Ruth Mcleod, Customer Service Supervisor, and Belinda Bess, Customer Service Associate. These women are directly responsible for ensuring that an adequate supply of our medicines is in stock and fulfilling our requests to be shipped to patients worldwide. They are truly dedicated to making this valuable program run smoothly. It was wonderful to meet them in person after all the years of working with them through e-mail and telephone calls.

I also had the pleasure of meeting Michael Nyenhuis, President & CEO; Charles Molloy, Senior Director External Relations; Mick Smith, Chief Operating Officer; John Garvin, Director International Medical Resources, some of the executives who make MAP so successful. Mr. Smith then gave me a personal tour of MAP's new state of the art facility where I learned about their daily operations. The 40,000 sq. ft. warehouse is stocked with essential medicines used to help improve health worldwide.



“Travel Packs” waiting to be assembled



Volunteers assist in packing donated medicine

Considering the many large scale healthcare programs in which MAP engages, we at the WDA are fortunate to be included as a partner. Without MAP's professional assistance the WDA would not be as effective in reaching out to our international members.

Warm regards for a happy, healthy summer,

*Mary*



Jodi, Ruth, Belinda

# NIH Announces New Program to Develop Therapeutics for Rare and Neglected Diseases

The WDA joins the Rare Disease Community in applauding the establishment's new initiative at the National Institutes of Health to encourage the development of treatments for rare and neglected diseases.

As a rare disease, Wilson disease is one of 7,000 rare diseases. There are approximately 200 FDA-approved therapies available for those 7,000 rare diseases of which three are for Wilson disease. This new program, called Therapeutics for Rare and Neglected Diseases (TRND), will create a drug development pipeline to stimulate research and collaborations with academic scientists. With this additional funding, the new NIH program has the potential to lead to significant progress in the development of safe, effective treatments for people living with a rare or neglected disease. This could also mean additional treatments for Wilson disease.

Below is the NIH press release about TRND:

## NIH ANNOUNCES NEW PROGRAM TO DEVELOP & NEGLECTED DISEASES

The National Institutes of Health is launching the first integrated, drug development pipeline to produce new treatments for rare and neglected diseases. The \$24 million program jumpstarts a trans-NIH initiative called the Therapeutics for Rare and Neglected Diseases program, or TRND.

The program is unusual because TRND creates a drug development pipeline within the NIH and is specifically intended to stimulate research collaborations with academic scientists working on rare illnesses. The NIH Office of Rare Diseases Research (ORDR) will oversee the program, and TRND's laboratory operations will be administered by the National Human Genome Research Institute (NHGRI), which also operates the NIH Chemical Genomics Center (NCGC), a principal collaborator in TRND. Other NIH components will also participate in the initiative.

A rare disease is one that affects fewer than 200,000 Americans. NIH estimates that, in total, more than 6,800 rare diseases afflict more than 25 million Americans. However, effective pharmacologic treatments exist for only about 200 of these illnesses. Many neglected diseases also lack treatments. Unlike rare diseases, however, neglected diseases may be quite common in some parts of the world, especially in developing countries where people cannot afford expensive treatments. Private companies seldom pur-

sue new therapies for these types of illnesses because of high costs and failure rates and the low likelihood of recovering investments or making a profit.

"NIH is eager to begin the work to find solutions for millions of our fellow citizens faced with rare or neglected illnesses," said NIH Acting Director Raynard S. Kington, M.D., Ph.D. "The federal government may be the only institution that can take the financial risks needed to jumpstart the development of treatments for these diseases, and NIH clearly has the scientific capability to do the work."

## DEVELOPING DRUGS

The drug development process is complicated and expensive. Studies suggest that it currently takes more than a dozen years and hundreds of millions of dollars to take a potential drug from discovery to the marketplace. And the failure rate is high.

"This initiative is really good news for patients with rare or neglected diseases," said ORDR Director Stephen C. Groft, Pharm.D. "While Congress has previously taken important steps to help these patients, such as providing incentives for drug companies under the Orphan Drug Act, this is the first time NIH is providing support for specific, preclinical research and product development known to be major barriers preventing potential therapies from entering into clinical trials for rare or neglected disorders. While we do not underestimate the difficulty of developing treatments for people with these illnesses, this program provides new hope to many people world-wide."

Typically, drug development begins when academic researchers studying the underlying cause of a disease discover a new molecular target or a chemical that may have a therapeutic effect. Too often, the process gets stuck at the point of discovery because few academic researchers can conduct all the types of studies needed to develop a new drug. If a pharmaceutical company with the resources to further the research does get involved, substantial preclinical work begins with efforts to optimize the chemistry of the potential drug. This involves an iterative series of chemical modifications and tests in progressively more complex systems - from cell cultures to animal tests - to refine the potential medicine for use in people. Only if these stages are successful can a potential treatment move to clinical trials in patients.

Unfortunately, the success rate in this preclinical process is low, with 80 to 90 percent of projects failing in the preclinical phase and never making it to clinical trials. And the costs are high: it takes two to four years of work and \$10 million, on average, to move a potential medicine through this pre-

clinical process. Drug developers colloquially call this the "Valley of Death."

TRND will work closely with disease-specific experts on selected projects, leveraging both the in-house scientific capabilities needed to carry out much of the preclinical development work, and contracting out other parts, as scientific opportunities dictate. Its strategies will be similar to approaches taken by pharmaceutical and biotechnology companies, but TRND will be working on diseases mostly ignored by the private companies. Importantly, TRND will also devote some of its efforts to improving the drug development process itself, creating new approaches to make it faster and less expensive.

If a compound does survive this preclinical stage, TRND will work to find a company willing to test the therapy in patients. There are several stages to the clinical trials process that can take several years before the safety and efficacy of a new drug is determined. FDA will only approve a drug for general use after it passes these trials. The clinical trials process is also expensive, but the failure rate is lower at this stage.

"NIH traditionally invests in basic research, which has produced important discoveries across a wide range of illnesses," said NHGRI Acting Director Alan E. Guttmacher, M.D. "Biotechnology and pharmaceutical companies have enormous strength and experience in drug development, but to maximize return-on-investment work primarily on common illnesses. TRND will develop promising treatments for rare diseases to the point that they are sufficiently "de-risked" for pharmaceutical companies, disease-oriented foundations, or others, to undertake the necessary clinical trials. NIH's goal is to get new medications to people currently without treatment, and thus without hope."

NIH already has many components of the drug development pipeline within its research programs. TRND will begin its work in collaboration with the NIH Chemical Genomics Center (NCGC), a center initially developed as part of the NIH Roadmap for Medical Research. NCGC has developed a robotic, high-throughput screening system and a library of more than 350,000 compounds that it uses to make basic discoveries and probe cellular pathways. NCGC also has developed a team of researchers skilled in developing assays representing disease processes that can be tested in its screening system, and has extensive experience building collaborative projects with investigators from across the research community. Molecules with potential therapeutic properties that emerge from the NCGC screening process could be fed into the TRND drug development pipeline.

"With this new funding, TRND will develop teams of scientists who can do the hard work of optimizing chemicals that we or others discover that may treat rare diseases and turn them into actual drugs," said NCGC Director Christopher P. Austin, M.D., who is also the Senior Advisor for Translational Research to the NHGRI Director. "This will still be hard work and it will take time and produce failures.

Unlike traditional drug development, however, where only successes are published, we will publish our failures as well, so everyone in the drug development community can learn from them. That alone could be revolutionary."

If all the preclinical hurdles can be crossed, a possible treatment must still be tested in a series of clinical trials. TRND will seek to take advantage of several NIH resources that can help launch human studies, including the NIH Clinical Center, the NIH Rapid Access to Interventional Development (NIH-RAID), and the Clinical and Translational Science Awards (CTSA) program.

## EXTERNAL PARTNERS

Numerous obstacles impede the development of new drugs for rare and neglected diseases. In addition to the reluctance of private companies to risk their capital on a potentially low return, relatively few basic researchers study rare diseases, so the underlying cause of the illness frequently remains unknown. And, because rare diseases are rare, researchers often have difficulty recruiting enough people with the disorder to participate in a clinical trial once a candidate compound reaches the stage where it can be tested in people. Moreover, for many rare diseases, the natural history of the disease is poorly understood, so researchers lack the needed clinical measures (such as blood pressure) that can demonstrate whether a treatment is working.

To address these difficulties, TRND will seek a wide range of collaborations with academic researchers, as well as partnerships with patient advocacy organizations, disease-oriented foundations and others interested in treatments for particular illnesses. TRND's leaders hope that the collaborations will help lay the groundwork for clinical trials once that point in drug development is reached.

TRND is currently setting up an oversight process to help it decide which projects that address thousands of rare and neglected diseases will be pursued. Leadership currently envisions a small number of diseases being studied each year, with strict criteria used to determine which molecules will be studied for which diseases. NIH expects to use existing intellectual property policies to transfer licenses for TRND-discovered drugs to private companies or others for development, clinical testing and marketing.

**Frequently asked questions about this new program are available online at:**

- **FAQ on the Therapeutics for Rare or Neglected Diseases (TRND) program:**  
[www.genome.gov/27531965](http://www.genome.gov/27531965)
- **TRND FAQ on Neglected Diseases:**  
[www.genome.gov/27531964](http://www.genome.gov/27531964)
- **TRND FAQ on Rare Diseases:**  
[www.genome.gov/27531963](http://www.genome.gov/27531963)

# Zinc Digest

Zinc is the treatment of choice for the maintenance therapy of Wilson disease because of its ability to block the intestinal absorption of copper. Not all supplements are created equal. There are some important factors to consider when selecting an appropriate Zinc supplement, such as fillers and binders, as well as purity of raw materials.

Beyond a product's formulation, dosage form is also an important factor to consider. People taking Zinc supplements have run into the issue of what seems to be unnecessarily over-sized caplets. Due to the large size of the caplets or tablets, it can be very difficult to swallow many of the Zinc supplements currently on the market. These pills also contain those fillers and binders that may increase the consumer's exposure to potential allergic reactions from ingredients, such as starch.

extreme V, Inc is proud to share some good news for Zinc supplement takers. After analyzing these issues, extreme VTM has produced a pharmaceutical grade Zinc Gluconate supplement available as Gluzin™ in capsule sizes that are easy to swallow. The capsules contain the highest purity raw ingredients, the absolute minimal amount of excipient, and no starch that could cause allergic reaction to some consumers.

extreme VTM, Inc is introducing Gluzin™ in order to provide customers with an effective solution to the problem of questionable supplements. Gluzin™ is a Zinc product, which can be trusted to contain superior consistency, purity, and quality.

extreme VTM shall collaborate with the Wilson Disease Association to provide this quality product benefit directly to its members.

## GLUZIN™

### WHEN YOU THINK ZINC, THINK GLUZIN™

GLUZIN™ supports the replenishment of normal healthy Zinc levels and balances the interactions of your essential trace elements. Gluzin™ is formulated with Pharmaceutical Grade Zinc Gluconate.

Zinc is a naturally occurring mineral and is essential for immune system health. Gluzin has been formulated with minimum fillers to help reduce allergic reactions.\*

Gluzin™ induces intestinal cell metallothionein, thereby blocking the absorption of copper in the body. Please consult your physician for proper dosing and monitoring regimens.\*

#### AVAILABLE IN TWO CAPSULE DOSAGE FORMS:

25 mg (Capsule Size 3) and 50 mg (Capsule Size 1) Zinc Equivalent - Easier to swallow capsule size.

### COMING THIS SUMMER 2009!

\* These statements have not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure, or prevent any disease.

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## WDA's Online Community

The WDA is proud of our online community. In partnership with Inspire, a company that builds and manages online healthcare communities, we've created a place where you can connect with others who know what you're going through.

Among the many exciting features our WDA Community offers, you can:

- Participate in discussion groups – or even just read what others have to say
- Post personal profiles – share as much or as little as you'd like about yourself
- Post personal photos or videos (optional)
- Invite other members to be friends
- Create a personal journal (or "blog") where you can express your feelings and allow others to comment
- Read others' journals to learn about their experiences

You'll also find coping strategies and answers to your questions, as well as vital support, compassion, encouragement, and inspiration from others sharing experiences similar to yours. Upon joining, you'll have complete control of your privacy options and can communicate with others like you in a safe, secure environment.

We encourage you to join the community and start building your own online support network today. Registration is free and only takes a minute.

**To get started, please visit [www.wilsonsdisease.org](http://www.wilsonsdisease.org) and click on the "Join Now" button.**

We'd love to hear your thoughts on the new community, and are happy to answer any questions you may have – please feel free to contact <https://www.inspire.com/help/>. We look forward to seeing you there soon.

# San Francisco Regional Meeting Update

On Saturday, May 2, 2009 the Wilson Disease Association along with California Pacific Medical Center (CPMC) held a regional meeting for families, scientists, physicians and other health care personnel. It was great to see so many of our families at this regional meeting, in addition to all the physicians who attended and earned valuable CME credits! This exciting symposium provided a review of Wilson disease including screening and diagnosis, molecular genetic testing, treatment and transplantation. The morning session presentations were a clinical review of Wilson disease. While the afternoon session focused on the patient's perspective and an open discussion complete with a Questions and Answers session with the experts.

The WDA would like to thank CPMC and Dr. Gish for all the work they put into this Symposium. It takes a lot of time to organize a meeting of this magnitude and Dr. Gish, and his staff, are been terrific collaborators. The WDA would also like to thank all our sponsors: Aton Pharmaceuticals, AirTran, and 3D Sparkle. We wouldn't be able to provide this level of programming without outside support.

Thanks to an additional generous grant by Aton Pharmaceuticals, we were able to have the Symposium sessions recorded and it is available on our website [www.wilsonsdisease.org](http://www.wilsonsdisease.org). We hope you enjoy this new educational opportunity we have been able to provide.



# Letters to the Editor

The Editor, Copper Connection,

I read with interest Dr Askari's account of work in the University of Michigan, over the past two decades, on the development of tetrathiomolybdate (TM) for the treatment of Wilson disease. However, this needs, I think, some clarification. It had been known from the 1930s that sheep grazing on pastures with a high molybdate content, provided sulphur was also present, developed severe copper deficiency. In the early 1950s some workers at a hospital in Birmingham (England) decided to try and treat patients with Wilson disease with molybdate but they were unable to show any benefit. The reason was that molybdate itself has no anti-copper action, it is the tetrathio salt that is active in this respect. In sheep molybdate and sulphur are converted to the tetrathio compound in the complicated digestive process present in ruminants; a reaction which does not occur in the human gut. The idea then lay fallow until I was presented, in the early 1980s, with a patient who had proved intolerant to penicillamine, trientine, zinc and BAL. A new treatment was clearly needed. I decided to try tetrathiomolybdate. A very helpful biochemist, Professor Stuart Laurie, made some of this compound for me. As it had no safety record in man I took some myself for a week as a necessary precaution before giving it to my patient. After a year on this new treatment the copper content of her liver had fallen by more than half and the histological appearance, which had been grossly abnormal, returned to normal. The results of this study were published in 1984 and in 1986 I published detailed studies on the effect that TM therapy had on the biochemistry of copper in treated patients and also showed, using radioactive copper, how it altered the dynamics of copper metabolism in man and animals. I also showed that TM could damage the bone marrow but that this toxic effect was easily reversible. Dr David Danks also published favourable reports on the use of TM in Australia in the late 1980s. Unfortunately difficulties in establishing a reliable and reasonably priced source of TM has severely limited its use in this country since I retired at the turn of the century.

*J.M. Walsh*. **MD, ScD, FRCP.**

Dear all :

First of all thank you for your cooperation, yesterday I was received the medicine for my brother (Salah Eldeen Al-Masri ). I will inform you about any new news in the future about my brother case.

Thank you for every one  
Thanks for ever for every one

Regards,

*Rajeh Al-Masri*

Dear All,

We were delighted to receive the life giving bundle of joy containing 6 bottles of Syprine, last night.

Many many thanks. Receiving the medicines gives me and my family immense relief and happiness as we perceive Ambuja to live a healthy life. It is all because of wonderful people like Belinda, Mary, Ruth, Kimberly and others at WDA, and MAP International.

May God always be with you and Bless you.

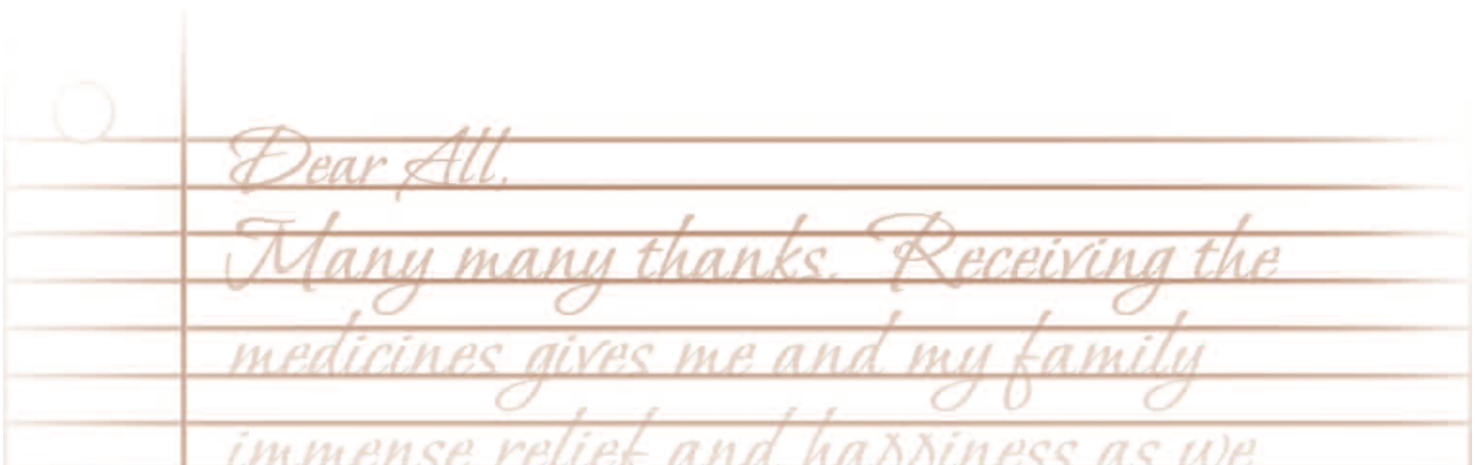
*Ashish*

Hi Kimberly,

Thank you so much (to you and Mary) for organizing and running the symposium today. I was very fortunate to live close enough to just drive up. The day was very informative and has connected me with Dr. Gish who may possibly take my son as his patient. I really appreciate your efforts.

Best regards,

*Bruno*



# The WDA mourns the passing of Israel Herbert Scheinberg

Scheinberg was born in Manhattan, New York, and educated at DeWitt Clinton high school in the Bronx. He graduated from Harvard University with a degree in chemistry in 1940, and in medicine in 1943. After service at a military hospital in Maryland he returned to Harvard as a junior fellow and stayed there until 1955, when he became a professor of medicine at the newly founded Albert Einstein College of Medicine in New York. He led the division of genetic medicine until he retired in 1992.

Wilson disease was recognized by the British neurologist Kinnear Wilson in 1912, but a simple means of detecting it did not exist until the 1950's, when Herbert Scheinberg developed a test for it while working with Dr. David Gitlin at Harvard Medical School. Scheinberg and Gitlin developed a biochemical test that detects a deficiency of ceruloplasmin, a protein that carries copper from the body.

His early research work was on the treatment of rheumatoid arthritis. After developing the Wilson's test he worked with the world's two other experts in the disease - Irmin Sternlieb, in New York, and John Walshe at Cambridge University. Walshe developed a remedy, initially penicillamine tablets and later trientine, that helps the body to excrete copper in the urine. Scheinberg contacted Walshe when he published his treatment in 1950, and the two men became friends.

Later in his career Scheinberg developed a test for Menkes disease, a rare condition in which patients cannot retain sufficient copper.



**Israel Herbert Scheinberg,**  
physician and medical researcher  
Born August 16, 1919 -  
Died April 4, 2009

## SAVE THE DATE!

**Who:** Wilson Disease Patients,  
Family, Friends

**What:** "A WD Gathering"

**When:** Friday, August 28, 2009/  
Noon – 3:00 pm

**Where:** Robert H. Lurie  
Medical Research Center

**Baldwin Auditorium - First floor  
303 East Superior Street  
Chicago, IL 60611**

Dr. Aleksandar Videnovic, Assistant Professor of Neurology, and Dr. Richard Green, Associate Professor of Medicine and Chief of Hepatology, Co-Directors of Northwestern's Wilson Disease Center of Excellence; Diane B. Breslow, MSW, LCSW, Center Coordinator, Northwestern University Parkinson's Disease and Movement Disorders Center, will be on hand to speak about their newly formed Wilson disease program and to answer any questions from the attendees. Mary Graper, WDA President and Kimberly Symonds, WDA Executive Director will be present to facilitate conversation and discuss future plans for the Chicago region. This informative event is free to attend. A complimentary lunch will be provided. Free parking will be provided at Northwestern Memorial Hospital Huron/St. Clair Self-Park Garage, 222 East Huron Street, Chicago, IL 60611 (half a block away from the Lurie Research Center)

A separate mailing will be sent to members in the tri-state area of Illinois, Indiana, and Wisconsin. RSVP deadline: August 20, 2009 to Mary Graper: [mary.graper@wilsonsdisease.org](mailto:mary.graper@wilsonsdisease.org) or 414-961-0533.

# 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 December newsletter is February 28, 2009. Please e-mail your article to the WDA office at:

wda@sssnet.com

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:

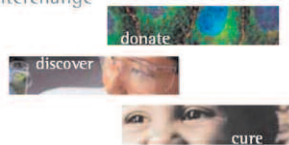
**Wilson's Disease Association  
1802 Brookside Drive  
Wooster, OH 44691**

## 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!

**NDRI** | The National Disease Research Interchange

*The power to make a difference:  
donating tissue to science in your lifetime.*



## 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](http://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's 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!

**We are now on Facebook! Check us out!  
Causes: Wilson's Disease Association**



# Thanks for Your Support!

## 2008 Year End Campaign

Duane Mattheis • Patricia Pe  
Sue Somers (In Memory of Kelsey Fink) • Carol Terry  
Paul Zandhuis (In Memory of Cheryl Zanhuis)

## General Contributions

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Erin Brooks • Chien-Hui Chung • Kerry Cooley • GMAC  
Dorothy Gorbacz • Joyce Hoggard • Tufal Khan  
Ronald Marchese • Anil Mehra • Mark Mirkin  
Margie Misciascio • Network For Good • Ng Kwong Sang  
Christina Pryor • John Siegart • Russell Sillery  
Keith Simonsen • Nancy VanArnem • Kirk Vestal  
Frank Wall

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Jodi Genrich • Darlene Gist • Maria Guillopo  
Jeffrey Hegel • Paul Hickman • Eugenia Hunt  
Randy Lieberman • Agnieszka Kaczor • Stephen Killian  
Cherie Kimbrough • Robert Kowalewski • Michelle Kress  
Megan Kreutzer • John Manini • Richard Marsh • David  
Marshall • Elizabeth Marsicano • Randolph Martin  
Christina Martinez • Rene Martinez • Lillian Martucci  
Michael and Sara Mo • Michael O'Connor • Hyster Ondrus  
Joel Richards • W. Rosenberg • Madelynn Sanchez  
Celest Schacht • Mei Shen • Kathryn Siebert  
Renee Sigmone • Michael Singer • Paula Sisilli  
Janice Smith • Patricia Smith • Troy Sonowski  
Yolanda Stewart • Scott Sumner • Rocco Surace  
Andrew Taylor • Raysa Toribio • Sylvia Valdespino  
Angela Vassallo • Linda Voss • Diniah Wallace  
Darwin and Dora Way • Arlette Williams • Peter Wilson  
Gregg Wise • Debora Zegalia • Athena Ziakos

## Honorarium

Edna Cross (In honor of Carrol "Butch" Cross)  
Cleo Hines (In honor of James Hines)  
Rochelle King (In honor of Linda Schwebke)  
Harold Leader (In honor of Elizabeth Margaret  
"Lizzie" (Smith) Lowe  
Ruth Mayer (In honor of Jean Perog and George Feldman)  
Marjorie McCardell (In honor of Ronald Koelling)

Linda Schwebke (In honor of Shelly Reuben King)  
Michael Sobkowski (In honor of Matthew Sobkowski)

## MAP

Kamal Uddin Ahamed • Larissa Frenkel  
Thanh Quoc Nguyen • Kamal Parvez • Chau Minh Vu

## Marketplace

Glenna Jo Bradshaw • Darlene Cyncora • Joann Hudish  
Brenda Oppenheim • Ron Page • Joshua Said  
Becky Scribner • Nagand Sripathi • Michael Turner

## Membership Campaign

Sam Blackburn • Harry Bostrom • Katherine Bourke  
Gary Bowen • Daniel Burger • Breeanna Cooley  
Edna Cross • Linna Ding, PhD, MD.  
Rochelle Fausneucht • Matthew Ferber, PhD.  
Donald Fishbein • Lillian Fisher • Larissa Frenkel  
Emese Greksa • Lonnie Grosman • Fred Hirt  
Joyce Hoggard • Nicki Karst • Sharon Lagas  
Virgil Laurain • Marjorie McCardell • Margie Misciascio  
Gary Misenheimer • Kelly O' Boyle • William Popp  
Christina Pryor • Michael Sobkowski

## In Memory of Beatrice Dolinger

Mark Mirkin

## In Memory of Harry Bayron's Mother

Mark Mirkin

## In Memory of Murray Krupin

Ruth Hill

## In Memory of Kelsey Fink

Kimberly Anderson • Marcy Campbell • Kristen Caton  
Elizabeth Dodson • Britinie Fitzwater • Terry Goode  
Sharon Janney • Sylvia Jenkins • Wendy Johnson  
Laura Kelly • Sheri Kibler • Julia Lam  
Luray Elementary School • Debbie Marble  
Elizabeth Osborne • Cathy Painter • Doug Raeburn  
Alice Smith • Lynn Strickler • T.W. Nicols Builders, LLC  
Cynthia Thomas • Theresa Weakley

## Memorials

Janice Anderson • Garnett Brockman  
Robert Faircloth • Sabrina Jones • James Moseley  
Marilynn Rose • Nancy Surdel • Michael Turner  
Jan Vance • Natalie Vozian

Summer 2009

# WILSON'S DISEASE ASSOCIATION, INTERNATIONAL

The Copper Connection  
1802 Brookside Drive  
Wooster, OH 44691

(FORWARDING SERVICE REQUESTED)

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**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 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 stop-watch 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).

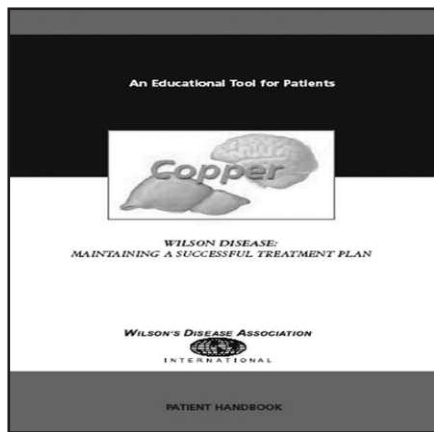
Number of Pill Boxes \_\_\_\_\_

## 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's 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 \_\_\_\_\_

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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.

**To Order:**  
Contact the WDA office by phone or e-mail to order.

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

**AWARENESS = DIAGNOSIS = TREATMENT**

Stop Copper ... Save Lives!

**Fight Wilson's Disease!**

www.wilsonsdisease.org

## WDA Bumper Sticker

Join in bringing awareness about Wilson's 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'S 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'S DISEASE ASSOCIATION:

Name \_\_\_\_\_

Address \_\_\_\_\_

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

I am making a tax-deductible donation of \$ \_\_\_\_\_

In honor of \_\_\_\_\_  In Memory of \_\_\_\_\_

Send acknowledgement to: Name \_\_\_\_\_ 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 \_\_\_\_\_