

The Copper Connection



Fall 2010

New WDA Logo and Website!

As mentioned in the spring edition of *The Copper Connection*, the WDA has a new look! With the same integrity, compassion and dedication, the WDA is truly *Looking Toward the Future™*

Go take a look.....
www.wilsonsdisease.org!



President's Message

Annual Conference

As many of you know the WDA conference has traditionally been held in the month of April, so this year's July date was somewhat of a departure for us. Whether it was the date or the wonderful downtown Chicago venue that contributed to the success of the conference, I think all who were there would agree that it was truly a valuable weekend. This year we were a diverse group of 55 individuals who traveled from 13 different U.S. states and 6 other world countries.

We had an excellent scientific program that provided all with an opportunity to acquire the most relevant knowledge about Wilson disease. As usual the breakout sessions gave everyone the chance to interact informally with our professional speakers and others. The banquet Keynote Address, *It's Time to be Heard*, listed no speaker name in the program. When I was planning the program, it occurred to me that it might be interesting to invite the banquet guests up to the podium and have their say! I believe this was quite popular with the crowd as many did step up to give their very own "Keynote Address".

As I reflect on the 2010 conference I am once again reminded that, as a wise friend once told me when referring to the WDA, "The Whole World is One Family." From near and far we were all united in the same place for a weekend for common purpose.

Warm regards,

A handwritten signature in black ink that reads "Mary D. Gujer". The signature is written in a cursive, flowing style.

Mary



The Copper Connection

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Table of Contents

WDA New Look & President's Message	1
A Patient Perspective	3-4
Research Update	4
Laboratory testing of copper in blood	5-6
Fundraising that doesn't ask for money	6
2010 Annual Meeting Minutes	7
Patient Advocacy	7
Conference Speaker Abstracts	8-9
Annual Conference Sponsor Thank You's	9
WDA Marketplace	10
Acknowledgements	11
Newsletter Blurbs	12
WDA Membership Application	13

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The Copper Connection
5572 N. Diversey Blvd.
Milwaukee, WI. 53217
414-961-0533 • Toll Free: 866-961-0533 • Fax: 414-962-3886
mary.graper@wilsonsdisease.org
www.wilsonsdisease.org

Our Mission Statement

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

“A Patient Perspective:

My Journey in Medication Compliance”

Pamela Meadows, R.N., BSN, M.A.



I enjoyed speaking at the 2010 Wilson Disease Association conference in Chicago this year. I spoke of my own journey in medication non-compliance, and I was overwhelmed by the responses afterwards from attendees: “Thank you for speaking on this, I really needed to hear that....You know what I am going through, thank you for the encouragement...It’s like you were speaking directly to me in my own struggles...Someone knows exactly what we are going through.....” Following is a summary of my presentation, My Journey In Medication Compliance: A Patient’s Perspective.

Mosby’s Medical Dictionary defines health behavior as: “An action taken by a person to maintain, attain, or regain good health and to prevent illness.” Adherence and non-adherence to a medication regime are health behaviors. If a person is non-adherent to their medication regimen, a behavior change is required to improve adherence.

The Wilson Disease Center for Excellence at the University of Michigan, lead by Dr. Fred Askari, states that “Compliance can be difficult particularly for people who do not have disease symptoms, for people who have an inability to focus, or for people who have depression.” In my own journey with Wilson Disease, I have experienced all three of these contributing factors with medication compliance, or adherence.

What contributed to my own non-adherence? Peers’ warning about medication side effects: “I don’t know if I would let the doctor put me on that much right away....it’s awfully risky...” When I thought of taking a “stronger” medicine than zinc, I thought.... agranulocytosis, alopecia, anorexia, epigastric pain, nausea, vomiting, diarrhea, aplastic anemia, blurred vision, degenerative changes of the skin, initial hypersensitivity: hives, rash, fever, anaphylaxis, lymphadenopathy....**The “nurse” in me—it’s true:** Sometimes we are our worst enemy....we can “know too much” that hinders our own compliance. Afraid of the doctor’s “ignorance” on managing my medications: I did not have a trusting relationship with my doctor. Complexity of medication regimen: I have several other health issues that require taking medications, and taking them a specific way. Several are more than once daily. Several have to be on an empty stomach, apart from food and other meds. Several have to be with food. This is very frustrating, and causes me inconvenience, because I have an extremely... **Busy life:** I work fulltime, attend graduate school full time, and have several regularly scheduled commitments outside of these things. I get tired of taking medications and trying to take them all correctly; some on an empty stomach, some with food, etc. **Stress:** My personal life has been turned upside down in the past two years with a divorce, my daughter moving 2,000 miles from me, financial stressors and....**Physical Challenges:** due to sporadic non-adherence in my medication regime, 1) my liver and spleen became swollen for a while, causing discomfort; I also had a “gall bladder attack” at one point, and a kidney stone at one point. 2) I have struggled with severe thyroid issues causing extreme loss of energy, loss of concentration, severe muscle aches and short stents of depression. 3) Keeping my diabetes under control.

My turning point: In early 2009, eight years into my WD diagnosis, I was at work, and felt funny. I looked at my colleague and said, “I can feel my spleen. It feels swollen.” I called my specialist, who had scans done immediately, and sure enough, my liver was enlarged more and so had my spleen. Scared, I broke down and decided to take a “stronger” medicine. Syprine was the drug of choice. Within six months of beginning Syprine, all of my WD laboratory tests were normal. Even my liver function tests were all completely normal...for the first time since my WD diagnosis! I had no unpleasant side effects from Syprine, either.

How does one stay adherent?

- ✓ Empower yourself. While we value and need clinicians, only you are ultimately responsible for your own health. Stay educated, and in charge of your own health.
- ✓ Understand potential impact of diagnosis—particularly if you are asymptomatic, you MUST remember this at all times.
- ✓ Know the prescribed treatment will help.

Article continued next page →

- ✓ Know exactly how to take the medication and realize this is a life-long treatment.
- ✓ Understand that you are ultimately in charge of making sure your treatment plan is carried out.
- ✓ Value the outcome of treatment more than the cost of the treatment. (Waking up early to take medicine, being inconvenienced, etc.)
- ✓ Find ways to fit medication regimen into your daily routine.
- ✓ Have a provider you trust. This is critical. If you don't have one you trust and have a good relationship with, look for another. The WDA can help guide you to WD providers if you need assistance.
- ✓ Find what works for you: There is usually no single reason for medication non-adherence, therefore there can be no "one size fits all" approach to improving adherence.
- ✓ Address the problems and reinforce positive behaviors. Get regular follow ups. You must have a trusting relationship with your provider. Have a support system in place to encourage you.
- ✓ If you struggle with taking your medications in a timely manner, buy a pill box with a built in alarm, or set your watch, or set an alarm clock to take your medications in a timely fashion.
- ✓ Find your "mantra." Stick with it! I personally have several medications that must be taken separate from each other and on an empty stomach. After grumbling to myself a bit about having to wake up early to take my Syprine apart from all other meds, it hit me, "All you have to do is wake up and swallow." From then on, it just seemed that simple to me.

Empower yourself and balance your life for the fullest, healthiest life you can have with Wilson Disease. The WDA and its members are here to encourage and support each other! Healthy living to you!



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Research Update

The National Disease Research Interchange (NDRI) was founded in 1980 by its president, Lee Ducat, a Philadelphia mother of a diabetic child. After founding the Juvenile Diabetes Foundation, Ms. Ducat formed NDRI in response to requests from the biomedical community for human tissues to corroborate their animal studies. As a non-profit corporation, funded primarily by the National Institutes of Health, NDRI is dedicated to the procurement, preservation, and distribution of human cells, tissues, and organs to researchers studying various diseases.

In 2006 the Wilson Disease Association formed a partnership with NDRI, through their Rare Disease Program, to promote Wilson disease research. To date, only 9 biospecimens from 2 Wilson disease patients have been collected. We need more patients to register and consent to donating tissue samples when the opportunity presents itself.

One of the WDA's important program goals for 2011 is to focus on stimulating research that is in the best interest of those affected by WD. One of the ways we are doing that is through this program. In collaboration with NDRI we are creating a survey to be sent to all known WD researchers to determine what tissue samples would be of use to them and mailing updated information packets, including registration and consent forms, to all of the WDA Centers of Excellence and to major transplant centers that typically perform liver transplants on Wilson disease patients.

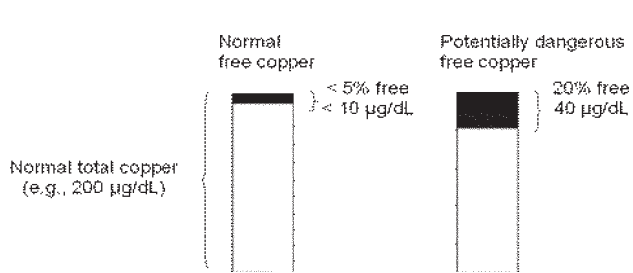
Laboratory testing to evaluate the free fraction of copper in blood

Contributed by: Dr. Gwen McMillin; University of Utah, School of Medicine, Department of Pathology and ARUP Laboratories; Salt Lake City, UT

Address: ARUP Laboratories / 500 Chipeta Way / Salt Lake City, UT / 84108

Phone: 800-242-2787, ext 2671 • Fax: 801-584-5207 • Email: gwen.mcmillin@aruplab.com

It has long been appreciated that excess copper in the body is responsible for the progression of Wilson Disease (WD). Measuring the amount of copper in the blood is one laboratory tool used to diagnose and monitor WD. Traditional laboratory methods for blood copper testing measure the “total” amount of copper in the liquid portion of the blood (plasma or serum). This total plasma or serum concentration represents the sum of the copper that is bound to circulating proteins (e.g. ceruloplasmin), as well as the amount of copper that is not bound to proteins. While one might expect that total plasma or serum copper concentrations are elevated in WD, it has been demonstrated that the total plasma or serum copper concentration can be low, normal, or elevated in WD. Total copper concentrations can be elevated for other reasons as well, such as pregnancy, malignancies, myocardial infarction, some infectious diseases, use of dietary supplements and use of oral contraceptives. Thus, an elevated total copper concentration (plasma or serum) can be difficult to interpret. (1-2)



The portion of the total copper concentration that is most associated with WD is the portion that circulates free from proteins in the blood. This portion of copper that is not bound to proteins is called “free” or “non-ceruloplasmin-bound copper.” Ceruloplasmin is the most prevalent copper binding protein in the blood. Because 90-95% of circulating copper is typically bound to protein, a change in the concentration of free copper may not be detected by performing a total

copper test alone. As illustrated in the figure below, the total concentration of copper can mask an abnormally high free copper concentration.

Until recently, the free copper concentration has been estimated mathematically, based on the total serum or plasma copper concentration, and the ceruloplasmin concentration. For example, the “copper index” is calculated based on subtracting 3-times the ceruloplasmin (in mg/dL) from the total copper concentration (in µg/dL). Thus, the copper index = (total copper) – (3 x ceruloplasmin). There are many limitations to calculating the free copper concentration, such as variation in the ceruloplasmin methodology, failure to consider other proteins to which copper might be bound, and an assumption that ceruloplasmin is saturated. The calculation has in fact, been shown to produce abnormal (low or high) results in the vast majority of healthy individuals. Our laboratory, and others have shown that the copper index does not accurately reflect free copper concentration and cannot reliably diagnose WD. (3-5)

The most specific way to determine the free fraction of copper is to measure the concentration of free copper directly. First, plasma or serum is prepared from whole blood. Second, the protein-bound copper in the plasma or serum is separated from the free copper. There are many ways in which protein-bound and free copper can be separated. (2, 6-9) Our laboratory separates the bound from free copper by preparing an “ultrafiltrate.” To prepare ultrafiltrate, plasma or serum is poured onto a special filter with known pore sizes (30kDa). The constituents of the plasma or serum that are larger than the pore size in the filter (e.g., proteins, and thereby the protein-bound copper) are trapped on one side of the filter, and the protein-free (and thereby free copper) portion passes through the filter into a collection tube below the filter. The liquid that passes through the filter is called an ultrafiltrate. Finally, the amount of copper in the ultrafiltrate is measured. In our laboratory, copper concentration is measured using a standard technology for elemental analysis known as inductively-coupled mass spectrometry (ICP-MS), which identifies the copper based on its characteristic size and charge. Other techniques such as atomic absorption spectroscopy (AAS) may also be used to detect and quantify free copper concentration.

Article continued next page →

To help doctors interpret the free copper results generated using our direct method, we collected and tested blood from healthy consenting adults (20-59 yrs, 69 males, n=137) and also from six patients diagnosed with WD. We found that the free copper concentrations in patients with untreated WD were at least six-times higher than the concentrations of free copper in the healthy population. We also found that the concentration of free copper in patients with WD fell to reside within the normal range after treatment. (9) This data suggests that the measurement of free copper concentrations may be useful for diagnosing WD, and also for monitoring success of therapy. Note, however, that results obtained from different laboratories may not always agree, and that accuracy of the result is also dependent on appropriate handling and processing of the blood. (10) For example, falsely elevated free copper results will occur if the proteins in the blood are disrupted during blood handling and processing. To reiterate, if conditions in the blood collection tube change between the time of blood collection and the time of laboratory testing, such that the proportion of copper bound to proteins changes, the free copper results will be inaccurate. It is important for doctors and laboratories to discuss esoteric laboratory testing such as the free copper test, to minimize risk of inaccurate results.

In conclusion, free copper testing for plasma or serum is available today, and can be much more useful for screening, diagnosis and monitoring of WD than measuring total copper concentrations in plasma or serum.



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Fundraising that doesn't ask for money!!!

Stefanie Kaplan, WDA Vice President



We all have friends that have their own home businesses: Mary Kay, CABI, Beijo Bags, Pampered Chef, Silpada Jewelry, etc. Well, I do, anyway. One of these friends asked me to have a "party" at my house for my friends where she could sell her products. My first question to her was, "Will you donate a portion of the proceeds to a charity?" She gladly said, "Yes!" So my thoughts went a little further and I thought why not contact ALL of my friends who have home businesses and see if they are interested in participating in a "boutique" at my house and donate a portion of the proceeds. ALL of them agreed and I held a very successful boutique with about 50 of my friends and family, and their friends and family attending. The vendors loved the new clients and with the donations made by each vendor, over \$1000 went to the Wilson Disease Association. **Some of those who were unable to attend wrote a check to the WDA, voluntarily!**

So I didn't have to directly ask anyone for money. I simply asked them to come for a fun afternoon of shopping! **I provided snacks & the place & then we had an instant fundraiser!**

2010 Annual Meeting Minutes

Chicago, IL --July 17,2010

WDA President Mary Graper summarized the highlights of the past year:

- **Fundraising** — 3 successful WDA Walk a Thons in Ohio, New York, and Wisconsin; a Family Fundraiser 5K in Ohio; and the WDA Board conducted the “Power of 10” regional fundraiser. These events raised ~\$30,000.
- **Meetings** — No annual meeting last year but instead had a small regional meeting in Chicago and a large regional meeting at CPMC in San Francisco. During the San Francisco meeting we were able to present our first ever CME course for physicians. The online webinar is still available for viewing on the WDA website.
- **Compassionate use programs** — Due to Aton’s generous donation of Cuprimine and Syprine, we continued to serve 62 patients in 15 countries. Early in 2010, the WDA was able to establish another compassionate use program for trientine with our friends at Univar who generously donated a limited amount of bottles per year and covering shipping charges as well, allowing us to supplement the Aton program at no additional cost to the WDA.
- **Financial situation** — In January of 2010 we found ourselves suffering from a shortage of funds and unable to accomplish the many other important program activities that must be done. The WDA Board took immediate steps to decrease expenses and rebuild our financial resources. In view of our situation we decided to decrease our full time Executive Director, Kimberly Symonds, to part-time. Subsequently, Ms. Symonds resigned her position entirely on March 1, 2010 and the former WDA office in Ohio was disbanded. The new WDA office has been moved to President Graper’s home in Wisconsin and she is personally assuming, as a volunteer, all of the previous duties of our salaried employee. Since then, the WDA Board is proud to report a substantial savings and rebuilding of assets so that we can move on toward the future.
- **Board of Directors** — Two Board members resigned during the past year, Ron Pei and Pari Yomtoob. A new board member, Edward Goff was appointed to fill the vacancy left by Mrs. Yomtoob.
- **Elections** — The WDA nominating committee presented the following slate of Officers who were up for reelection to 3 year terms at this meeting:

President – Mary Graper

Vice President – Stefanie Kaplan

Secretary – Carol Terry

Treasurer – Jean Perog

In addition, a revision to Article IV, Section 2.b. of the Bylaws to change the minimum number of Directors to the Officers plus at least 3 Directors, instead of 5, was also proposed.

Nominations from the floor were requested, but none were received. A motion to accept the slate as presented was made and seconded, and a vote was taken. The slate of officers and the proposed bylaw revision were approved without opposition.

Patient Advocacy

In July the Wilson Disease Association signed on to endorse the **Kakkis Every Life Foundation’s CURETHEPROCESS (™) campaign for rare disease treatment development**. The campaign strives to inspire science-driven public policy to increase the predictability of the regulatory process for rare disease treatments. The WDA supports Kakkis Foundation’s goal of giving even the most rare diseases access to the accelerated approval process and fulfill more completely the original intentions of the Orphan Drug Act.

The Foundation’s Goals Are To:

- Establish a new Office of Drug Evaluation for Genetic and Biochemical Diseases, consolidating expertise to ensure safe, effective and timely patient access to needed treatment.
- Create a new standard for the surrogate and biomarker endpoints used for rare disorders, to allow treatments for these diseases to have full access to the accelerated approval pathway.
- Devise new clinical study design paradigms for rare diseases that properly account for clinical heterogeneity and disease complexity to properly capture treatment effects.

For more information please visit <http://www.curetheprocess.org/> to learn more about how you can take action to support this important initiative.

CONFERENCE SPEAKER

Liver Transplantation for Wilson Disease: *when is it indicated and how do we avoid it?*

Richard Green, M.D.

Liver transplantation represents a curative therapy for Wilson disease that is indicated for the treatment of both decompensated chronic liver disease and acute liver failure. Cadaveric (*deceased donor*) liver transplantation has been utilized for the past two decades with excellent post-transplantation results and outcomes. More recently, living-donor liver transplants (*LDLT*) have been used as another option for liver transplantation when cadaveric donor livers are not available. The indications and results of liver transplantations in patients with Wilson disease will be discussed.

However, with the early diagnosis and therapy for Wilson disease, one can typically avoid the need for liver transplantation. With early diagnosis and appropriate therapy, the hepatic manifestations of Wilson disease can be effectively treated and prevent disease progression. Although controversies exist, the diagnosis and medical therapies will also be discussed.

Genetic Testing for Wilson Disease

Melissa Dempsey, M.S.

Wilson Disease is caused by mutations in the ATP7B gene. Changes in the ATP7B gene lead to accumulation of copper in the liver, which then distributes throughout the body (*especially in the nervous system and eyes*) causing problems. Wilson Disease is inherited in an autosomal recessive pattern. This means that both copies of the gene have a mutation. A person with only one copy of the mutated gene is a carrier of the disease, but has no symptoms. When two carriers have children, they have a 25% chance of having a child with Wilson Disease during each pregnancy.

Patients with Wilson Disease can be diagnosed by biochemical testing (*copper and ceruloplasmin levels*) or by genetic testing. Approximately 98% of patients with Wilson Disease have a mutation in each copy of their ATP7B gene that can be detected by full gene sequencing. Once a mutation is found in an affected individual, testing other family members, even during a pregnancy, is fairly easy, quick and inexpensive. This presentation will discuss the genetic testing method, the process of ordering genetic testing, the possible results, and some related issues.

Metabonomics: *A New Potential Diagnostic Tool for Wilson Disease* - David Huffman, PhD.

Wilson's disease is difficult to diagnose &, many times, no single test is conclusive. New analytical methods that measure global metabolic profiles may provide additional diagnostic markers. Metabonomics is the study of multiple metabolic changes in a body fluid or tissue as a function of disease, environmental factors, or drug regimen. Sophisticated analytical techniques can be used to study metabolic profiles & provide a unique fingerprint of an individual. This has the potential to speed diagnosis & further knowledge of disease etiology in the clinical setting.

Coping and Caring: *Family & Emotional Support for Living with Wilson Disease* - Diane Breslow, MSW, LCSW

As the title implies, this session will focus on the many meanings of "support," from physical to emotional, and from the clinic to the community. We will examine the benefits of individual and group support. We will discuss strategies for coping with the behavioral symptoms of Wilson disease. Finally, participants will be empowered to reach out for help and support from a wide array of suggested resources.

Neurological Manifestations of Wilson Disease

Aleksandar Videnovic, MD, MSc

Wilson's disease (WD) is an autosomal recessive disease caused by mutations in the ATP7B gene which leads to impairment of biliary excretion of copper. Clinical manifestations of WD may include hepatic, neurological, and psychiatric disease, or a combination of these. Possible clinical manifestations of neurologic Wilson's disease are numerous. Most commonly patients present with a movement disorder. A movement disorder is a neurological syndrome in which there is an excess of movements or a paucity of movements. Most common movement disorders in WD are tremor, dystonia and choreoathetosis. In addition, patients may have impaired speech (dysarthria) and a gait disorder. Despite significant understanding of WD, it remains a commonly misdiagnosed disorder. Unlike most of the other movement disorders, WD can be treated successfully. Timely diagnosis of WD is therefore critical. Several chelating agents and zinc salts remain the mainstream of therapy. Symptomatic pharmacological and non-pharmacological therapies (*physical and occupational therapy*) play significant role in the treatment of neurological WD.

“A Patient Perspective: *My Journey in Medication Compliance*” Pamela Meadows, R.N., BSN, M.A.

My challenges with medication compliance began shortly after my Wilson's disease diagnosis in 2001. My steadfast refusal to take anything harsher than zinc to control my liver abnormalities eventually led to a series of elevated liver functions, an enlarged liver and spleen, and, finally, submission to take Syprine. I will share my journey from my beginning fears to better health through better medication compliance, and address everyday challenges I still face to remain compliant.

Speech & Swallowing Issues in Wilson Disease

Kristen Larsen, M.A., SLP

Wilson's Disease can affect the Central Nervous System. Resulting neurological problems may include difficulty speaking (dysarthria), difficulty swallowing (dysphagia), or drooling. Consultation with a Speech Pathologist can be useful in evaluating & treating these problems.

Much Gratitude to Corporate Sponsors of the 2010 Annual Conference!



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WDA Marketplace

WDA Awareness Bracelet

You asked for them...we have them! WDA awareness bracelets! The bracelets are packaged in groups of 5. The suggested donation per bracelet is **\$2.50**, that comes to **\$12.50/package**. Orange/yellow swirl design, inscription reads "STOP COPPER!" and "www.wilsonsdisease.org".

Packages of Bracelets _____
Amount \$ _____



Walk Out Wilson Disease Pet Bandanas

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? Suggested donation is **\$5.00** per bandana.

Number of bandanas _____
Color(s) R _____ T _____ C _____ RB _____
Amount \$ _____



Pill Box Timer

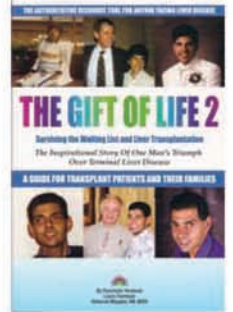
Remember to take your medication on time with WDA's Pill Box Timer. These great timers have, in addition to the normal display, an alarm and stopwatch to ensure that you don't miss a single dose. Holds 15 aspirin-size tablets; has attached lanyard for use around neck, but small enough to fit in a pocket or purse. 3.5" L X 2" W X 5/8" D. Two colors available: purple and green. Suggested donation is **\$17.00**.



Number of Pill Boxes _____ Amount \$ _____

The Gift of Life 2

This 382 page book is a valuable resource for anyone facing a liver transplant. Co-author and former WDA Board member, Parichehr Yomtoob, has generously donated a number of copies to benefit the WDA. Mrs. Yomtoob's son David was a Wilson disease patient who underwent 3 liver transplants during his lifetime. Sadly, David passed away following his third transplant in 2006. Suggested donation is **\$22.00**.

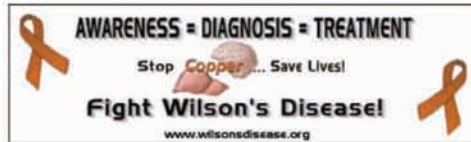


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WDA Bumper Sticker

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.

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WDA Patient Education Publication

Wilson Disease: Maintaining a Successful Treatment Plan

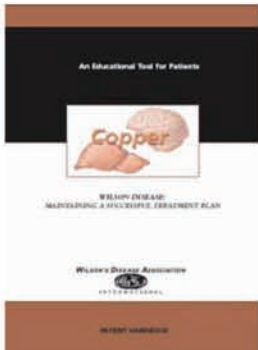
Published in March, 2008, this 8 1/2" x 11", 32 page publication includes the topics: Medical Care, Medications, Diet and Nutrition, Special Circumstances, and Family Concerns and Genetics. Also included is a glossary of medical terms, a glossary of genetic terms, and a printed copy of the "Wilson Disease Patient Lab Tracker". **FREE**, but donations are welcome.

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Zinc

extreme V™ was honored to participate in this year's 2010 Wilson Disease Association conference in Chicago. We had a chance to showcase and discuss the exciting synergies between our Gluzin™ (*zinc gluconate*) therapeutic supplement and WDA. Gluzin has been introduced to several clinics and hospitals. If you or your doctor(s) are interested to participating and having the Gluzin™ experience, please contact us at info@extremeV.com

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Fall 2010

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- Assist in writing material to develop the "Transplant" page on the WDA website
- Hold a regional support group meeting in your area
- Assist in identifying new WDA research initiatives
- Assist in creating, facilitating regular electronic communication with WDA members
- Serve as Volunteer Coordinator
- Grant writing
- I have my own idea(s)! _____

If you are interested in any of the above opportunities please contact the WDA office at 866-961-0533 or mary.graper@wilsonsdisease.org for additional information.