The Copper Connection



Spring 2011

NDRI News

You can help advance Wilson Disease research by joining the NDRI Rare Disease Donor Registry.

The National Disease Research Interchange (NDRI) was founded in 1980 by Lee Ducat, founder of the Juvenile Diabetes Research Foundation. NDRI was formed in response to requests from the biomedical research community for human tissues to advance their research 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 diseases such as HIV/AIDS, diabetes, cystic fibrosis, retinitis pigmentosa, Alzheimer's disease, Wilson disease, and hundreds of other rare and common diseases. Since its founding, NDRI has supplied over 300,000 normal and diseased human tissue samples to more than 5,000 researchers in the United States and internationally.

NDRI works with patients and researchers to provide tissues that directly meet researcher's needs. NDRI partners with members of a nationwide network of eye and tissue banks, organ procurement organizations, and major medical centers to recover tissues, which can be donated post mortem, from surgical procedures, transplants, during childbirth, or when you have blood drawn.

The first step to becoming a tissue donor is to register with NDRI by calling (800) 222-6374 or filling out the donor form on their website, www.ndriresource.org (this is for the Wilson Disease Program). You will also be asked to complete and submit a General Questionnaire for Donation to Medical Research and a form for Consent for Donation of Anatomical Gifts from Surgical/Living Donors. Once you have registered, you just need to inform your family and physician that you have done so, and call NDRI when you are scheduled for a surgical procedure or transplant or will soon be delivering a baby. NDRI will contact your physician and arrange for the tissue collection. For post-mortem donation, simply inform your family members or funeral home director of your wishes and provide them with NDRI's toll-free telephone number. A coordinator is available 24 hours / day. It's that easy!

Your personal identifying information will be kept confidential. Since the WDA pays an annual fee to run this program, there will be NO additional cost for you to participate.

The WDA has partnered with NDRI for three years for the purpose of stimulating Wilson disease research in the future. To date, there is only 1 active researcher registered with NDRI and we only have 2 registered donors who have given both surgical and post-mortem consent. Human tissue samples have been recovered from one surgical donor. 22 samples have been shipped to one Wilson disease researcher; 25 samples remain.



The WDA is determined to increase activity in this vital program. It is our belief that once more tissue samples are available it will encourage other researchers to register and engage in Wilson disease research activities.

Follow the WDA on Facebook at http://www.facebook.com/wilsondiseaseassociation for updates about this important initiative.

The Copper Connection

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The Copper Connection 5572 N. Diversey Blvd. Milwaukee, Wl. 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 Story:

Living in the Shoes of a Wilson's Patient

by Sarah Hendrix: "Power in numbers and all can heal sealed with the love"

y husband, James, and I met in high school where his locker was near mine. I was the new kid and the first time I saw his face I was drawn to him. He had those cute rosy cheeks, and the best-he was very tall. I knew there was more to why I was so attracted to him, but I just never could figure it out. We were both 15 years old then, and we are now 27 years old with three beautiful children. We enjoyed fishing, camping, James teaching me how to cook (he is the best cook), bonfires with the family, and cookouts. That was our weekend fun.

He used to jump up and say, "Hey lets go fishing", at four in the morning. He did that with his brother, who had Wilson's disease (WD). That was their thing together. That all changed in 2003, when his best friend passed away unexpectedly from a dirt bike accident. That best friend was his brother. James had a nervous breakdown a few months later. At the time I was three months pregnant with our first child. I've never seen anything like it, but the day his brother passed away, things changed with him, physically and mentally.

I knew something was not right after the breakdown. I was persistent in telling my husband that he needed to get tested for WD, but he refused. However when James would visit the doctor for regular check-ups his white blood cell and platelet counts were low. Although the doctor didn't seem to be worried about it. I was. There was also a big change in his behavior that I had not seen before. It was like something was taking over his body. That was the red flag and that's when I started researching Wilson disease more. I didn't like what I read. It scared me a lot and I wondered, can he get this bad? Of course the doctors thought that James' problem was psychiatric rather than physiological. I did not agree and asked the doctor to do specific tests for WD. We had our son in 2004 and everything thing seemed fine with my husband. Then out of nowhere I noticed there was a slight tapping of his finger. Another red flag to me. I started talking to James again about getting tested for WD since his brother had it, but he wouldn't do it. Years went by and then he started falling backwards when he was trying to get up, drooling, having speech problems, and of course out of control behavioral problems that lead him to attempt suicide several times. Yes, I thought, he was having some of the more horrible signs of WD.

Throughout 2003 to 2009 he continued to show symptoms and they worsened. He made one attempt at suicide in 2009 and was almost successful in ending the pain inside him that he was trying to hide from. But he couldn't hide it from me, I knew. I took advantage of his hospitalization (for observation after the attempt) to have every test possible done for WD. There were some signs that pointed to a diagnosis of WD, and they started to think of him as a Wilson's patient. But when the liver biopsy test came back the doctors said "no,

his copper levels are not high enough to be WD". I never believed it, and pushed to

get another opinion and although James again refused, because he was afraid of what the Dr. would tell him, In 2008 I succeeded in sending him to a different doctor. The new doctor believed he did have WD but James

never returned to receive the diagnosis.

In 2009 things got out of control and I could no longer handle it. But, I still tried, and James was taken to a mental hospital where the therapists diagnosed him with paranoid schizophrenia. I told them that it was not schizophrenia, and that my husband had WD and needed to be treated correctly. The therapist wrote it in the notes as a possibility and sent James to a "so-called" independent living facility that was supposed to teach him to live with his new diagnosis of schizophrenia. Well that's when it hit the fan. He started to have trouble with his legs and joints, and a change in his mental status. Of course the therapist had him on anti-psychotic medication but I could tell by talking to James on the phone that



Continued from page 3 - A Patient Story: Living in the Shoes of a Wilson's Patient

something was happening to him. I alerted his therapy and nursing staff and they told me he was manipulating me. I knew better.

I didn't get to visit James often because it was a 5 hour drive to the mental hospital. The second time I did get to see him, he was having such bad tremors that his body was out of control. But still the staff said he was manipulating me and refusing to feed himself. Then I paid another visit to my husband after finding out he had passed out and was unconscious, and had to go to the emergency room. I could not believe what I saw. He was so underweight, his skin was yellow (jaundiced), he was shaking, and could not walk without help. That hurt me to see him this way. That is when I had enough of the situation and arranged to legally take care of James. With his sister's help, I brought him home in March of 2010. I took him to doctors' appointments and cared for him, and believe me the pain he felt, I felt as well. It was hard to see him like that.

Well about two months after coming home, something different happened. James' arm, leg, and back muscles started to spasm and tighten. I took him to the doctor who put him on Baclofen and sent James back home. About a week later James was deteriorating so badly that he was admitted to our local hospital. 24 hours later he was moved from our local hospital the Indianapolis University hospital. That was in May 2010 where they finally diagnosed him with WD and began giving him the proper medication for the WD. It was bad when we got there: James was changing so fast the doctors couldn't keep up. They thought he would die. Being by myself and three hours, away from home, with my sleeping husband waking up to drastic changes and not knowing what was happening...it was like I was going through all of it with him. Making the right choice was hard but with me by his side to argue with them, the doctors got him stable. A few months later James was sent to a rehab therapy center where he was only getting worse with muscle spasticity, so they sent him home.

In February 2010, my husband was 50% bed-ridden, and then by May it was 100%, with very little movement. It has been almost a year now, but he is still able to talk and eat, which we are thankful for. The doctors say there is no more they can do for him, and believe me we have been up and down right and left, with many kinds of specialists everywhere. Even with the doctors consulting with their sources, they all got to the point where they say James only has a few months left to live, and it wouldn't be WD that takes him, it will be an illness. The doctors try to get me to place James in a nursing facility, but I won't. I'm here by his side with every step wherever this Wilson disease journey takes us. It has not been easy; we have had our good days and bad. My husband and I don't believe what the doctors say because he is strong and determined that he will get up, and I have faith he will. I believe that only God can make that call and there is a reason why James is still fighting. I believe in him and his faith.

My husband once told me, "I'm going to die young, and one day you will be taking care of me." Well in his mind he didn't anticipate it would be the way it is, but that's how it happened. So I stood up and put on his shoes and fight for him every day. I have been through thick and thin to fight for his safety and health and I am not going to give up. I walk in James shoes for him and it is not the easiest thing to do, but I will never give up the fight. One day he will get up and walk again even if it is to stand next to the Lord. Even then, I will never give up the fight to stop the pain my husband suffered because of Wilson disease.

Editor's Note: Since this writing, James passed away on March 17, 2011 at home with his wife Sarah by his side.



2011 WDA Election Ballot

Displayed below is the ballot that will be used for elections at the WDA Annual Membership Meeting. In the event that you are not notified of a 2011 Annual Conference in the near future, and you are a current member of the WDA, you may vote by mailing this ballot to the WDA office by November 30, 2011.

I. Nomi	nees for 1 year term on Board of Directors:
	Len Pytlak, CPA – Mr. Pytlak has his own CPA firm in Ann Arbor, MI. He has WD and has served on the WDA Board as Vice President and Treasurer in the past. He has been very active in the WDA for many years, and we are pleased he is interested in rejoining the Board.
	Drew Katz – Mr. Katz is CEO of Interstate Outdoor Advertising, LP, headquartered in Cherry Hill, NJ. He is the founder of The Drew A. Katz Foundation which supports programs and organizations that address medical, educational, social, emotional, and cultural needs of those less fortunate. Drew was diagnosed with WD as a child and has served on the WDA board for the past 4 years.
II. Nom	inees for re-election to Board of Directors (3-year term):
	Edward Goff – Mr. Goff is a Director of Revenue Management for Hyatt Hotels and Resorts, where he has worked since August 2005. He lives in Long Beach, CA and is a hotel industry professional with over 17 years of experience through his employment with various hotel companies including Hyatt, Millennium, Four Seasons, and Westin. Mr. Goff has chosen to focus his volunteer efforts on WD to help support those with the disease, like his friend Stefanie Kaplan, and to assist with teaching others about the disease. He was appointed to the WDA Board in 2010 to replace a member who resigned.
	Pam Meadows, RN – Ms. Meadows is a Registered Nurse at the Denver VA Medical Center, and is currently completing her Master's Degree in Nursing Education. She was diagnosed with WD in 2001 and has been an active member of the WDA for several years. Ms. Meadows was one of the speakers at the 2010 WDA Annual Conference and has also written articles for the Copper Connection. She was appointed to the Board in 2010 to replace a member who resigned.
3_	CUT ALONG DOTTED LINE AND MAIL TO WDA OFFICE BY NOVEMBER 30, 2011.



Meet Maddy New WDA Office Assistant

In October, 2010 Madeleine Modrinski, of Whitefish Bay, Wisconsin, joined the WDA as a part-time office assistant. Maddy is a college student at Milwaukee Area Technical College majoring in film production. Her most important function is to manage the WDA membership database ensuring that all donations are logged in and acknowledgement letters are mailed. She also performs other administrative tasks as necessary. Please join me in welcoming her aboard!

ZINC DIGEST UPDATE

WHEN YOU THINK ZINC THINK GLUZIN!

litamins and minerals play an essential role in the body's normal metabolism, growth, and development. For example, while vitamin alone is not a source of energy, it can provide the key the body needs to unlock energy stored in food. Some vitamins and minerals work together, such as the mineral zinc and vitamin A. Zinc enables the body to use vitamin A to promote good vision. Taking supplements by itself, however, is not the answer to long-term good health. Combining a healthy diet with regular exercise and a positive mental attitude has been shown to be the best bet for a healthy lifestyle.

Customers who have been using our Gluzin (Zinc Gluconate) 50 mg or 25 mg dose to support their immune system function and zinc deficiencies have also been using our Toco VE, Heartflo or Heartflo Plus with great success!*

Tell us your stories, you can join us on Facebook, Twitter or email us at info@extremeV.com

So find out what your body has been missing – www.gluzin.com
Antioxidants, mainly vitamin E, may have a role as adjunctive solution. Serum and hepatic vitamin E levels have been found to be low in Wilson's disease.[1] Symptomatic improvement when vitamin E is added to the daily regimen has been reported occasionally, but no rigorous studies have been conducted.

GLUZIN EXPERIENCE 1

"I started taking Gluzin 18 months ago. Apparently I was the first one to order, even though WDA had information in their newsletter the summer of 2009. The company has called me a few times to see how I was doing taking their product. I LOVE Gluzin. I feel great. I am not nauseous anymore...which really helps with my compliance! I am writing this as I was on Galzin 18 years (since November 1991)...and vomiting bile at least weekly was the norm. I would avoid taking Galzin if I was hungry or not up to par. Then I tried zinc piccolinate for several months...the piccolinate didn't really work. I could feel my hand tremors returning along with irritability. I am lucky to be symptom free now, and I want to encourage any Galzin users to try Gluzin. extreme V, the manufacturer worked with WDA for 2 1/2 years developing this product. It costs about \$50.00 per month, which is also a huge relief to my budget. It is life changing for me not to dread my meds. The makers of Gluzin have not asked for my endorsement, but I feel that Gluzin has distinct advantages over Galzin, just as I feel strongly that any zinc is better than penicillamine...especially for those of us that present with neurological symptoms. Do your research. Be your own advocate. -- Yours, "Coppertop" aka Mia Fiterman"

GLUZIN EXPERIENCE 2

"My daughter was on penicillamine and then switched over to Galzin for the last 5 years. But she would always complain about taking her meds, due to the fact she had a hard time swallowing the pills and her gastro pains. After reading the posts on Inspire about Gluzin, we had switched her to Gluzin's 25 mg smaller capsules. She has been on Gluzin for 9 months now is no longer complaining on taking her meds!

Thanks extreme V. — Shirley, NY"

GLUZIN EXPERIENCE 3

"I was diagnosed with WD seven years ago. Lately I have been experiencing excessive weakness and fatigue, so I decided to have a thorough check-up with my doctor. My doctor had examined my liver and had commented I have some early stages of cirrhosis, possibly due to my WD. So my doctor recommended that I should either consume more food containing high antioxidants or supplements. I had already switched to Gluzin 8 months ago and have been getting good results on my blood and urine test. So I decided to add their Toco VE to my regimen. Unfortunately, one more pill that I need to take in a day – but if it helps, it's worth it!

-- Jerry, CA"

TocoVE (natural Vitamin E), Heartflo (natural Coenzyme Q10) and Heartflo Plus (natural CoQ10 + Vitamin E) are a good source for your antioxidant supplementation needs. These antioxidants may be used with a chelator

or zinc to reduce oxidative stress causing tissue damage, particularly to the liver.*

- To learn more about extreme V Toco VE product: www.tocove.com
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Wilson Disease Association members receive 25% off your order by using promo code: WDAGLUZIN

- * 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.
- 1. Sokol RJ, Twedt D, McKim JM Jr, et al. Oxidant injury to hepatic mitochondria in patients with Wilson's disease and Bedlington terriers with copper toxicosis. Gastroenterology 1994; 107: 1788-98.

Editors Note: As with any medication or supplement, please consult your WD treating physician before changing or adding to your WD treatment regimen.

Patient Advocacy

WDA Joins Newborn Screening Coalition

Earlier this year the WDA was invited to become a member of the Preserving the Future of Newborn Screening coalition. Wilson disease has been on the radar screen for addition to the current state mandated newborn screening panels in the past. Two researchers have developed assays designed to detect Wilson disease in babies at birth.

Now this research threatens to be halted by a movement, in some states, to destroy newborn blood spots following the initial screening for diseases currently on the states' panels. If these states and others succeed it would be a serious detriment to important research for Wilson disease and other rare diseases. The WDA strongly supports the efforts of the Coalition and encourages you our members to visit www.newbornbloodspots.org to learn about how you can help.

To view a list of conditions currently screened for in your state, visit http://genes-r-us.uthscsa.edu/nbsdisorders.pdf



News From Around the World

CHILE

With great excitement and joy I inform you that as we constitute by far in fact, as the CORPORATION OF SICK OF WILSON CHILE. On Saturday October 9, 2010 we met 26 people of which four were ill, a psychologist, a neurologist, and other relatives and friends of people with the disease (So far I have contacted 10 patients in Chile).

He left with the presentation of all the participants individually, where we heard dramatic testimony in some cases. After the neurologist told Marcel Miranda where he showed the disease and answered many questions from participants. After a break that was used to meet and exchange experiences informally, we proceeded with the reading of our constitution to be approved by the assembly and form part of the deed of the corporation. There was general unanimity but they send a copy to each of the participants to ratify it.

Then we chose our policy on a temporary basis for six months, being as follows:

Director and Chairman: EYHERALDE FELIPE GOMEZ

Vice President, PAOLA LOPEZ Secretary: SOLANGE GUZMAN

Treasurer: LUZ MARIA CELEDON CARILOA.

Came the farewell was difficult, because no one wanted to go, leaving to take our next meeting on 9 November. Finally the group photo you can see in the Facebook page: Wilson Enfermedad Chile

We are happy and full of energy to walk at a steady pace to achieve our goals.

A hug to everyone.

FELIPE EYHERALDE GOMEZ Corporacion Enfermos de Wilson Chile

ARGENTINA

I am in the process of starting up a Wilson's Disease Patients Advocacy Association in Argentina, which acronym is AAPEWA (Asociación de Ayuda al Paciente con Enfermedad de Wilson – Argentina).

The contact coordinates for the new association are: Site address: http://www.aapewa.blogspot.com/Institutional e-mail: aapewa@yahoo.com.ar

Kind regards – Dadour

Dadour V. Dadourian

AAPEWA – Asociación de Ayuda al Paciente con Enfermedad de Wilson - Argentin

A lesson about true friends for those facing serious illnesses

by Danielle Leach, MPA

"A true friend walks in when everyone else walks out."

I read that on a magnet on my friend's refrigerator recently and the simple power of that saying brought me to tears. I have learned that lesson of true friends since my son's diagnosis of cancer in 2007.

Anyone who has faced a serious illness as a patient or a caregiver knows that you quickly learn who your friends are. They are the ones who are there, who listen instead of trying to fix things, who are present for you in any way you need them. Some people you love will disappoint and not rise to the occasion, and some people you never expected will be your biggest supporters.

It is hard not to resent people who are there in the crisis, and then leave once the immediate crisis is over. There are people who are not there for the long haul, for the good and the bad that a disease may bring. The initial drama draws everyone in, but sends them running afterward.

I have learned, especially when you are living a nightmare, that it takes a special person to stay with you throughout the crisis. A person who keeps checking in and knows the journey is not necessarily over once you are in remission, or when your loved one has passed away. When my son Mason had brain cancer, our family found our true friends. We were surprised by many who walked out, but also by how many true friends walked into our lives because of Mason's illness. We have learned even after Mason's death, even three years later, we continue to go through this process of discovering our true friends.

Some people are not capable of handling personal difficulties. We, as patients and caregivers, need to understand not everyone has the capacity or tools to handle a crisis of another. This knowledge does not make it any easier for us as we wade through process of dealing with disease. As a director at Inspire, a company that creates and manages online patient support communities, I see regularly the comments of patients and caregivers who talk about friendships won and lost since diagnosis. Some are surprised and profoundly saddened by the lack of support from those expected to help the most. However, many happily note those friends, family, and even strangers who surprise them with support in a time of great need.

I recall reading about a Florida woman, whose teenage son was undergoing chemo, wrote that her friends avoided her upon learning about her son's cancer diagnosis. "It's almost like they were afraid they could catch it," she said.

Another, a bladder cancer survivor from New Jersey, observed, "A lot of people walk out. . . a good 50% of my 'pre-cancer' friends I have never heard from again." He went on to say, "In my case, I am lucky. I have all strong ones, having cut weak relations a long time ago. I keep only the cream of the crop."

Sometimes finding others who are dealing with the same issues can be the most helpful strategy. You can often talk online more frankly and honestly with them than with some loved ones or friends. Dealing with an illness can be a lonely and scary process. Participating in support communities often help alleviate some of that loneliness. I have seen repeatedly how these connections are a powerful tool and establish strong personal friendships among members.

If you're a patient or caregiver, look for the people who are true friends and hold those people close. Craft a strong support network-both in person and online. If you have a chance to do so, be the kind of true friend people are often searching for in their lives when they need it the most.

Danielle Leach is Director of Partnerships at Inspire and is founder of the Mason Leach Superstar Fund, in memory of her son, Mason, who died of pediatric medulloblastoma in 2007.

**WDA Editors Note: The WDA partners with Inspire to manage the Wilson disease online community. If you are not already a member, please take a look and join us at: http://www.inspire.com/groups/wilson-disease-association/.



Thanks for Your Support!

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If you have not received an acknowlegement for your donation, please notify Mary Graper at mary.graper@wilsonsdisease.org

For Your Information

WDA Wish List:

- Donated Printing Services
- Family Run Fundraisers
- Newsletter Support

Website Support:

If you would like to submit an article to be published in the next Copper Connection the deadline for submission is September 1, 2011. Please e-mail your article to the WDA office at info@wilsonsdisease.org

Donations:

For your convenience, you can make your donations by visiting our website. online Just visit www.wilsonsdisease.org you will see the Donate button on the front page. This will direct you to a secure PayPal link where you can safely enter your information. We encourage you to donate online as it will save you time and postage!

If you prefer to mail a check, or do not have online access, please send your tax-deductible donation to the WDA office at:

> Wilson Disease Association 5572 N. Diversey Blvd. Milwaukee, WI. 53217



Easy Ways to Donate:

you can earn money for the

WDA simply by searching the Web. Rather than using your usual browser, click on the GoodSearch button on the WDA website home page. From there you can browse the Web and earn 1 cent per click for the WDA. It's that easy! Feel like shopping online? You can also do that through GoodShop and the WDA will earn an average of 20% for each purchase you make at one of the over 1000 participating stores.



JOIN US ON FACEBOOK!!!

Causes: Wilson's Disease Assocation www.facebook.com/wilsondiseaseassociation

The person who shares this page with the largest number of their Facebook friends during last week of April will receive their choice any WDA Marketplace item for free!



More searching and shopping opportunities

at IGive.com! Again, click on the IGive button on the WDA home page and get started.

Every time you shop at any of 700+ online stores in the iGive network, a portion of the money you spend benefits WDA. It's a free service, and you'll never pay more when you reach a store through iGive. In fact, smart shoppers will enjoy iGive's repository of coupons, free shipping deals, and sales. To get started, just create your free iGive account.



Find Support:

Join this valuable Forum by clicking on the **Inspire button** on the WDA home page. There you will find many opportunities to ask questions, engage in discussion, create a journal,

and gain knowledge. There are many topic areas to choose from.

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, or by phone at 800-222-6374.





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.wilsonsdiease.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.

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Pill Box Timer



Number of Stickers

Remember to take your medication on time with V 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 conation is \$17.00.

Number of Pill Boxes _____ Amount S_____

WDA Bumper Sticker

Join in bringing awareness about Wilson disease! These stickers

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.

are 3" x 10" and have Copper color graphics with black text. Thank

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.

Number of copies	
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Education Publication

AWARENESS = DIAGNOSIS = TREATMENT

Fight Wilson's Disease!

ining a Successful Treatment Plan this 8 1/2" x 11", 32 page publication al Care, Medications, Diet and Nutrition nd Family Concerns and Genetics, Also nedical terms, a glossary of genetic of the "Wilson Disease Patient Lab tions are welcome.

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(FORWARDING SERVICE REQUESTED)

TO:

Wilson Disease Association Targeted Volunteer Opportunities



Hold a Family Fundraiser to benefit the WDA
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.