Y2011 Direct Appeal

Alex, and Others Like Him Need YOUR Help Now!

On August 29, 2011, the WDA launched a major fundraising appeal to raise money toward research. Over 3,000 individuals received this letter in the mail or via e-mail. If you have not returned your remittance form with a donation yet, please do so without delay so that we can continue to plan for this important research collaboration. If you have lost your mailing, or would like extras so that your friends and family can contribute, please contact the WDA office or download extra copies at www.wilsonsdisease.org/2011directappeal

The WDA leadership is planning for the future of Wilson disease and we need your help! We all agree that there is still much to be learned about the successful diagnosis and treatment of Wilson disease. Too many young, healthy lives are cut short by the devastating effects of WD. We must stop this for the benefit of our future generations. I know that you will want to be part of the solution.

It is time to hold another international scientific workshop as we did in 2006. We will bring together esteemed Wilson disease researchers and clinicians from all parts of the world who will share their most recent data about diagnostic and treatment strategies and practices. The workshop will be co-sponsored by the Wilson Disease Association and the National Institutes of Health. One of the goals of this meeting is to determine future research priorities and form valuable collaborations to advance understanding of our disease.

Here is where you come in. A meeting of this scope and importance requires that we raise nearly $100,000. We are targeting 2013 for the meeting date but, we must raise at least $50,000 by December 2011 in order to secure the conference venue. Please join me in “Looking Toward the Future” by giving generously to support this vital initiative. Together we can make this happen. The future is in our hands!

Warm regards,
Mary L. Graper
President

DON’T MISS OUT!
• Submit your current e-mail address to info@wilsonsdisease.org
• Winning “Wordle” will be published in this edition.
• Contest to be announced on Facebook and Inspire.
• Much, much more special information will be included.
• Deadline for submission, if you would like to contribute is November 27.
The Wilson Disease Association is a nonprofit 501 (c)(3) organization. The Copper Connection is a semi-annual newsletter published by the Association that informs members of findings in the area of Wilson Disease. There is no copyright. Newsletters and other publications can disseminate any information in The Copper Connection. Please cite attribution to the Association and the author.

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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.
In Memory of Agnes
Len Pytlak

It is with great sadness that I announce the death of a long time fixture at our annual conferences. Mrs. Agnes Mattic passed away this past April at the age of 77. If you attended any of the annual conferences in the past you met Agnes. She was a fighter, and would not let the fact that she had major mobility problems getting around, and that people had a hard time understanding her speech, she still tried to attend all of the conferences regardless of where they were.

I don’t know if she was the oldest surviving WD patient but she must have been near the top of that list. Even in death she is helping WD and others. She donated her remains to science for research to see if anything can be found as to why she lived so long with WD.

Agnes was born in 1933 in Burnaby, British Columbia to parents who had immigrated from Scotland, and was one of thirteen kids. It is interesting to note that six of her siblings died of liver failure in their childhood or adolescence. Of course that was at a time when very little was know about WD.

Agnes was diagnosed with WD in her early 20’s. Early on she received chelation therapy with penicillamine at the University of Michigan, long before Dr. Brewer started working on Galzin. She was blessed with 3 children, one of whom died in 1996. She also had 4 grandchildren and 2 great-grandchildren.

My first recollection of Agnes is seeing this fragile, little lady riding a large three wheeled bike around the area were we both live in Ann Arbor. At that time I did not know her or that she had Wilson’s Disease. For that matter I did not know what WD was or that I had WD also. I learned a little more about her from a article in the news paper when her only means of transportation, her bike, was stolen. The story ended well because one of the local auto dealers stepped up and purchased her another bike.

After a while she could not ride the bike but that did not slow her down. She got a walker and put a sign on it saying she was a Wilsons Disease Survivor. I would see her with her walker getting off the bus and walking across the parking lot to do some shopping at Kmart and other places in our area.

I met Agnes at one of the conferences in the late 90’s and would frequently get phone calls from her when she needed help getting hold of Dr. Askari or some other doctor. She would frustrate us at the various support meetings by trying to monopolize the discussion and because she was so difficult to understand. But that was Agnes, always wanting to contribute.

She cared a lot about helping the WDA and must of had a very strong inner spirit that gave her the strength to continue on daily with her fragile body. Her strength and endurance should be an inspiration to the rest of us who have Wilson’s and even for those who do not. She will be missed.
Deep Brain Stimulation Surgery For Wilson Disease
Marianne Tysinger Collins

My 22 year old son, Alex was diagnosed with Wilson’s Disease in July 2010 after 6-8 months of slow speech, slurring and then drooling and food dropping out of his mouth. Then we looked back and saw the other subtle signs that we missed! Abnormal gait, tripping, psychiatric issues going back about 5 years. We dreaded the diagnosis, but glad to finally have one and move forward with treatment!

Unfortunately, the treatment of trientine worsened his neurological symptoms after an initial improvement and we ended up taking him to the University of Michigan Hospitals in Ann Arbor where he was treated by Dr. Fred Askari during a two week hospital stay. He discontinued the trientine and put him on zinc and we returned to North Carolina. e Alex was admitted to an acute Rehab Hospital for about 10 weeks and then to a Long Term Rehab Facility where he currently resides getting physical, occupational, speech and swallow therapy everyday.

To our delight, many of his neuro symptoms have improved. He is no longer fed by the PEG tube and has actually gained about 10 lbs with out it! He has gained strength and can almost rise to standing with minimal help. His right hand, which had been paralyzed since November, has regained a lot of use and he can make a decent fist and raise his fingers and often uses it to scratch his head and grasp things. He can raise up in bed and turn over. I know these things sound trivial, but considering he was basically immobile and had to be turned in bed every two hours by the nurses in Michigan, we think they are tremendous gains!

He is beginning to stand between the parallel bars in Physical Therapy and try to take a few steps, but the limiting factor for being able to walk again is the imbalance caused by his severe dystonia. There are days when it is better or worse and drugs like Artane, Baclofen, Valium, and Clonopin have only helped so much and have caused undesirable side effects. Dr Peter Hedera, a neurologist at Vanderbilt suggested Deep Brain Stimulation Surgery as an option.

I began to do research on the internet and came across the Medtronic’s Website and found much to my surprise that Wake Forest Baptist Medical Center in Winston-Salem, NC has a very large and respected Movement Disorders Program. So even though I have worked at Duke Medical Center for the past 31 years, I was open to taking him there. I contacted Dr. Tater by email, explaining Alex’s problem and was impressed that he emailed me back the next day and said his coordinator would be contacting me for an appointment.

So off we went to WFBMC for initial appointments to see if he was even a candidate for the surgery. Deep Brain Stimulation (DBS) has been around for over 20 years for effective treatment of Parkinson’s disease and recently for dystonia. It has been proven to work well for primary dystonia, but since Alex’s dystonia is a secondary disease process due to Wilson’s, the outcomes are variable. After multiple appointments with the neurologist, neurosurgeon, psychiatrist, physical and Speech/Swallow Therapists, Alex was determined to be a good candidate for the surgery. They told me that one of the reasons he was approved was because they whole family is involved in Alex’s care and he wasn’t brought to them by a caregiver. There will be lots of follow-up appointments to get the stimulator adjusted and they wanted to make sure we understood it was a big commitment. Of course, no promises were made and they warned us that it wouldn’t fix all of his problems, but they are confident that it will help him at least 50%!

After a little discussion and letting Alex make the final choice we decided to go ahead with it and the first part of the surgery was schedule for July 22nd, a mere 3 weeks after our initial appointment on July 7th.

DBS is a two-part surgery and the first part consists of implanting the leads (wires) into the brain. It is pretty uncomfortable, as Alex needed to be totally awake for the entire procedure. They numbed the skin on the scalp when they screwed on the halo but it was still painful to watch, as it looked pretty barbaric. Then he went off to get a CT scan of the head using the halo as a marker to make sure they could guide the leads in avoiding blood vessels and other important areas.
They numbed the scalp to make 2 half moon shaped incisions on the top of his head and drilled holes into his skull. Using a computer guided machine, they inserted the leads and mapped the brain, listening for the “noise” generated by the abnormal signals generated by the damaged areas of the basal ganglia in the brain. It took about 1-½ hours to map each side and it was a long day for all of us. We were finally able to see Alex at about 6:30 pm when he was admitted to his hospital room. His neurosurgeon was very pleased and feels like he got some good mapping and was able to insert the leads into the correct areas of damage.

Alex spent the night and was discharged the very next day! He was quite weak and sleepy and even though they had warned us that he may relapse neurologically, it was hard to see the decline after making a little bit of progress after many months. There were even a few days when I wished he still had his feeding tube! This decline was due to the swelling in the brain from the drilling and insertion of the leads and they said it could last anywhere from 2-6 weeks. Sure enough, though, he is improving now 5 weeks afterward and almost back to where he was!

Then on August 22nd, Alex had part two of the DBS surgery. This was to install the stimulator in the left chest just below the collarbone and tunnel the wires up his neck, behind his ear and connect them with the leads inserted in the brain. That was the easy part! Just an hour and a half and he went home the same day. Right before we left, they turned on the stimulator to the lowest setting just so the brain will get used to the impulses and we were to go back in two weeks to get it programmed according to the settings that were determined during the first surgery. They warned us not to expect any improvement at all at that low setting, but I swear I could tell a difference. He seemed a bit straighter and his chest and trunk area is a little looser and he just seems to have more ability to use his arms and bend his legs. I wasn’t sure if these changes I saw were my wishful thinking, but others made the same observations.

……: To be continued in the spring edition of The Copper Connection

New MAC Member

The WDA welcomes Svetlana Lutsenko, PhD. of Johns Hopkins University to its Medical Advisory Committee. Dr. Lutsenko received her doctoral degree from the Shemyakin-Ovchinnikov Institute of Bioorganic Chemistry in Moscow (Russia) and had her postdoctoral training at the University of Pennsylvania (Philadelphia) where she focused on the molecular mechanisms of metal ion transport. In 1994, during her postdoctoral studies, Dr. Lutsenko contributed to the first characterization of the structure of Wilson’s disease gene. Realizing how little is known about the mechanisms of copper transport in human cells, she decided to focus her future research on the chemistry and biology of Wilson’s disease. In 1996, Dr. Lutsenko became an Assistant Professor at the Department of Biochemistry and Molecular Biology at the Oregon Health & Science University (OHSU, Portland, OR) and initiated studies on the structure, function, and regulation of Wilson’s disease protein (ATP7B). Her laboratory has developed various assays that she and her colleagues use to characterize the effects of disease-causing mutations on ATP7B in vitro and in cells. Her laboratory is also developing cellular and animal models to understand the effects of copper accumulation on liver physiology; she is currently working on identifying factors that trigger neurologic manifestations in Wilson’s disease. While at OHSU, Dr. Lutsenko received NIH and NSF grant awards to study copper metabolism and rose to the rank of Professor of Biochemistry and Molecular Biology. In 2009, Dr. Lutsenko moved to Johns Hopkins University School of Medicine, where she holds position of Professor of Physiology and continues her studies of human copper metabolism in norm and disease. Dr. Lutsenko served as a member and a Chair of the NIH Biochemistry and Biophysics of Membranes Study Section, and she is a member of the Editorial Board for the Journal of Biologic Chemistry.

The MAC members advise the WDA on all medical issues and review all educational material published by the Association. They graciously volunteer their time and knowledge to the WDA leadership as well as patients and families. Dr. Lutsenko joins our five other Medical Advisors and bringing with her the expertise to complement that of the other members of the Committee.
“Power In Numbers We Can Help Others.”
Sarah Hendrix
(Continued story: Living in the shoes of a Wilson’s Patient from the Spring 2011 Copper Connection)

I remember the day so clear when I felt as if I was losing. No matter how much I begged for the truth it was kept quiet by all. I had a special angel (and others) that would listen to me cry, complain, and plead for help who would have loved to smack me to reality but my angel listened and stayed quiet to help me with the impossible. I was so high in faith that my husband and I were going to fight this so we could walk next to each other and he could hold me like he wanted to so badly again. So with my angel’s help we called doctors everywhere we could think of and my husband’s own doctors would consult as well.

Then the truth happened. James was going downhill. Even then I was blind to believe it. Deep down inside I knew, but lied to myself. We ended up in the hospital one last time because he was contracting in his neck and it scared me, but he said he didn’t feel it. Maybe it was because he was protecting me or he really was sleeping. James was going for a test when one of his doctors came in to give him some baclofan shots to help the tension. While he was gone I asked that Dr., “What did you and Dr. W talk about the other day?” He pulled me out of the room to say, “We both agree he only has two months to live.” I stayed professional held my breath and finished conversation. As my children were in the room and James was having a test I stared in the air in disbelief and wanted to fight harder. His nurse found me speechless asking me what happened and then I lost it. I didn’t give up and most of all had to stay positive even though I was crashing inside. We then went to one more doctor which was the last. The next appointment the Dr. made was for me about James. It was discussing medications. It was not fun at all in fact very painful to have this appointment.

Days and weeks were going by and all I could think of was, ‘when is it going to happen’. I was still calling doctors and my angel for desperate need of pleading help. When the day came that my husband looked at me and said “STOP”, I said, “Stop what?” as my heart pounded to not want to hear what was next “stop trying.” he said as he stared at me. That is when I knew it was time to find the words to tell him that it was time to let go. It was not easy and he didn’t like hearing it. So all I asked was since he didn’t want to tell me if it was going to happen to please call me if it does. That day came the time I dreaded; that my life as I knew it would end. He called my name and I about fell to the floor but once again I had to put my happy face on and show him it was ok. But in the end I lost it.

Prior to my last story we lost the battle to Wilson’s Disease. My husband passed away this past March early in the morning and like I said the last story I stayed by his side till the end. It was painful for both of us, more for him I am sure, but I felt the pain like it was me. Even the day he was going he stayed positive thought it all. How? I have no idea. All I can say is God had him in his arms. You could see the glow in his eyes that it was time.

I promised a few things to my husband before he passed: I would stay positive; fight for the Wilson’s patients; and go back to school. And I do so still. With my angel’s help I designed a WD ribbon to symbolize our loved ones and the ones that have Wilson’s disease. They are available on the WD website and they are amazing. I will keep his memory alive in many ways till the day we meet hand and hand in heaven. Through his children he will never be forgotten.

Sarah & James, 2006
Wedding Fundraiser
Mary Graper

On August 6, 2011 my son Andrew Graper married Emily Zimmer in West Bend, Wisconsin. It was a beautiful wedding day complete with close friends and family in attendance as we welcomed a new member into our family. As is the norm for me my emotions were high and my eyes welled up with tears many times throughout the day.

After the lovely ceremony we were off to the reception to celebrate. As is customary at wedding receptions (well at least here in Wisconsin) the guests began to clink their glasses for the bride and groom to kiss. Suddenly, Andy’s new bride Emily stood up and announced to the guests that there would be something different happening. Stating that instead of glass clinking, she and Andy would kiss every time someone brought a donation up to the head table to benefit the WDA. Well, my mouth dropped open and once again tears came to my eyes as I took this in. What a lovely thoughtful gesture for a new couple to think of doing on their very special day!

Suffice it to say, they wound up kissing a lot that evening. And, I am one proud mama!

WDA Canadian Pipeline
From Your Northern Pipeline in Canada

Hello to all Canadian Wilson’s patients. I am your new Canadian correspondent, and I hope to represent you and communicate with you through each and every future newsletter. I am writing from Ottawa, Ontario Canada. I was diagnosed with Wilson’s Disease in 1974, I didn’t learn about Wilson’s Disease International until around 15 years after I was diagnosed. When I discovered this organization, I learned many important facts about my treatment that my doctors had neglected to tell me. For example, I learned about zinc as an alternate treatment. I also learned that I didn’t need to take potassium sulfide any longer. More crucial information about maintenance doses and diet was found in the wonderful booklets and pamphlets published by dedicated WDA volunteers. I was able to bring that information to my doctors and make intelligent choices about modification of therapy during surgery and while treating other medical problems that occur over time.

We, in Canada, depend on the manufacturers, research and developments that take place in the U.S. and around the world where the largest number of Wilson’s patients reside. We also rely on much of the information that travels to us through the Wilson’s Disease International pipeline. We are blessed with a unique medical system that relieves us of the burden of many costs associated with this disease. However, many challenges lie ahead with regard to supply of medications, transplantation and genetic counseling. It is, therefore, incumbent upon us to give generously to support the work of our Association. Some Canadians argue that they can’t donate because it is not tax-deductible. I ask you, is the love and effort we give to make the world a better place tax-deductible? Remember that with the voice and work of WDA, new treatments and even a cure of Wilson’s disease are just beyond the horizon. Fellow Canadians, give to WDA with open hearts and minds. Show the world that even though or climate is cold, our hearts are warm and capacious.

May peace, health and love be with you all.

Linda Schwebke
schwebke@istar.ca
NDRI Update: Newborn Bloodspot Donation
Corinne Graper

In 2010, my life changed forever when my husband and I found out we were having a baby. I started seeing the world in a different way – imagining how every action could influence my daughter’s future. It was a scary thought – especially when I realized there was nothing I could do about many of the world issues that could affect her.

But when I heard about the partnership between Wilson Disease Association and National Disease Research Interchange (NDRI), I saw an opportunity to do something positive for her future. NDRI recovers tissues and blood samples donated from surgical procedures, transplants, childbirth, post mortem, and blood draws and provides them to designated Wilson disease researchers.

Since my husband has Wilson disease, we are aware that our daughter and future generations could also possibly have it. We decided to donate my daughter’s newborn blood spot test to NDRI. By following these simple steps we were able to make a donation:

1) I contacted NDRI about a month before my due date.
2) The organization assigned me to work with a specific staff member who had me fill out and return a donor form.
3) I contacted the lead nurse of the Labor and Delivery department at my hospital. I explained that I wanted to have an extra newborn blood spot test done on my daughter and donated to the NDRI. (This created no additional discomfort to my daughter, as they did both the standard newborn blood spot test and the additional test for the NDRI at the same time.)
4) I put the nurse in contact with the staff member at NDRI and they worked together to coordinate how the sample was collected, stored and shipped.

It’s that easy. If you’re donating tissue or another kind of blood sample, the process might be a little different, but the NDRI can walk you through the steps.

My daughter’s newborn blood spot test donation can help researchers learn how to diagnose Wilson disease earlier and if or how carriers are affected. But my daughter’s sample is not enough; researchers need more before they can advance this research.

We can’t prevent our loved ones from getting Wilson disease, but we can provide researchers with the samples they need to develop ways to better diagnosis and treat people living with it. Consider registering to donate your tissue or blood sample and encourage friends and family to do the same. Samples from people who have and who do not have the disease are valuable to researchers.

You can visit www.ndriresource.org or call (800) 222-6374 for more information.
WDA Board Members Attend NINDS Nonprofit Forum

Carol Terry, WDA Secretary

WDA President Mary Graper and I were among representatives from 60 nonprofit organizations who attended the National Institute of Neurological Disorders and Stroke’s (NINDS) fifth nonprofit forum “Partnering to Advance Therapeutics for Neurological Disorders” on June 1. The meeting gave patient advocacy groups like the WDA an opportunity to learn from each other and about the National Institutes of Health (NIH) and NINDS, provided us with an environment to share interests and information, and allowed us to interact directly with NINDS staff and certain other NIH program staff.

NINDS Director Dr. Story Landis opened the forum with an overview of NIH’s mission and makeup, NINDS’ funding basics, and a brief description of the NIH Blueprint for Neuroscience Research. Dr. Landis pointed out that “it’s the marriage of basic science and the application of that basic science that makes NIH unique.” Next was a presentation by Dr. Vicky Whittemore of the Tuberous Sclerosis Alliance about the importance of nonprofit representatives serving on the institute’s advisory council.

This was followed by a discussion of the proposed new institute the National Center for Advancing Translational Sciences (NCATS), which is scheduled to open later this year. The mission of NCATS will be “To catalyze the development of innovative methods and technologies that will enhance the development, testing, and implementation of diagnostics and therapeutics across a wide range of human diseases and conditions.” One of the main purposes of NCATS will be to address the problem of the many bottlenecks that exist in the drug development pipeline that slow the process and add expense. Of particular interest to the WDA is the fact that the NIH program for Therapeutics for Rare and Neglected Diseases and the Office for Rare Disease Research (ORDR) are proposed to become part of NCATS.

The meeting then split into four parallel breakout sessions, led by panels of NINDS program staff and nonprofit representatives. Mary attended the session on resources for patient registries, while I attended the session on clinical research. During lunch, smaller networking groups were formed. I had lunch with the Rare Disease Network group, led by Dr. Stephen Groff, head of ORDR.

Mary and I agreed that the information imparted at these sessions and at the Forum in general was very thought provoking and enlightening, and a little mind boggling. I found the discussions about using disease natural history studies to identify clinical research study topics especially interesting. We learned a lot about what other nonprofits are doing to establish patient registries, and discovered that ORDR is working on a patient registry template that will be available on their website sometime this year. We also were able to establish initial contacts with the NIH program directors who can help us with planning for our upcoming scientific workshop. We left the Forum feeling that it had been a very exhausting, but worthwhile day. I look forward to using some of the information we gained to further the goals of the WDA.

Don’t forget to participate in our autumn Flower Power Fundraiser. You can beautify your yard for spring and help the WDA at the same time. Fundraiser ends on October 28.

www.flowerpowerfundraising.com/campaign?campaign_id=7944
Thanks For Your Support

GENERAL CONTRIBUTIONS:

MEMBERSHIP:

MAP:
Thuy Tran

MARKETPLACE:
Angela Doyle, Anne Pintozzi, Brenda Baker, Ellen Seghi, Karen Quillen, Kathryn Elias, Marilyn Gaven, Mary Scharf, Shinlau Liu.

IN MEMORY OF:
Alexander Browne - Alison Holt, Carol Katona, David Bull, David Youmans, Gwen Guglielmi, Jacqueline Shu, Joan Williams, Judith Duckworth, Kate Hullfish, Kathleen Hopely, Michelle Kupiec, Suzanne Kzros
Charles Conrad - Charles Gilberson
Cheryl Zandhuis - Paul Zandhuis
Dennis P. Tyhacz - Jonathan Sullivan
Dorie Badamo - Bernard Miskevich, Dianne E Fulton, Jacqueline Mazeski, John and Caroline La Rose, Jude Matteo, Michael Solon, Mount Sinai Hospital

Dorothy Gilchrist - Bernice Gilchrist
The Gilchrist Family - Eileen Smith
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Rosa Goncalves - Anthony Lucia, Jackie Jablonski
Kelsey Fink - Christine Chang, Jeanne Fink, Jeffrey Fink
Lester Cohen - Douglas Coleman
Mark Laurain - Laurain Household
Rick Wade - Wall Household

IN HONOR OF:
Diane Laurain - Laurain Household
Bryan Clay - David Clay
Carrol Cross - Edna Cross
Debra Hoggard - Joyce Hoggard
Eileen Smith - Laura Kaplan, Eileen Smith
Frances Whitehead - Irene Lake
Janice Wagner - Judy Wagner
Joseph Vincent Gaven III - Marilyn Gaven
Judge and Mrs. Fetzer Mills - Edward Martin, Mills Household, Sophie Wood
Linda Schwebke - Rochelle King
Mary Graper - Sal Gaimaro
Melasky Family - Ann Melasky, Karen Anderson
Michelle Senske - Frizzel - Mary Ellen Senske
Natalie R. Smith - Isabel Smith
Stefanie Kaplan - Henry Kaplan, Raymond & Barbara Alpert Foundation
Ted and Laurette Prema - John Riter, Prema Household
Travis and Molly Gilchrist - Bernice Gilchrist

MATCHING:
Mass Mutual

VOLUNTEERS:
Rui Alves, Portugal; Corinne Graper; Rhonda Rowland; Linda Schwebke, Canada; Marianne Collins; Sarah Hendrix; Len Pytlak; Carol Terry
WDA RIBBON
Here they are! Ribbon designed and donated by Sarah Hendrix.
Copper metallic, with blue and white enamel image of WDA globe, lapel pin through the middle.
$7.00 suggested donation per ribbon (S & H included)

Number of Ribbons ________
Amount $ ________

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 $ ________

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.

Number of Stickers ________
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.

Number of copies ________
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.

Color(s) R _____ T _____ C _____ RB _____
Number of Bandanas ________
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 $ ________

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.

Number of Handbooks ________
Donation $ ________
Membership form

The Copper Connection

Wilson Disease Association

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Name

Address

City __________________________ State ______ Country ______________ Zip __________

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**
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  - 10% discount on Annual Meeting registration for up to two registrants

- **Silver Membership - $120**
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- **Copper Membership - $1000**
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  - 20% discount on Annual Meeting registration for up to four registrants
  - Special recognition as a Copper Member in WDA Newsletter
  - 10% discount for Annual Meeting program ad
  - No annual dues

**I wish to make a donation to Wilson Disease Association:**

Name ______________________________

Address ________________________________ State ______ Country ______________ Zip __________

- [ ] I am making a tax-deductible donation of $ ______________
- [ ] In honor of ____________________________
- [ ] In memory of ____________________________

Send acknowledgement to: ______________________________

Name ___________ Street ________________

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**Payment Information:**

Marketplace $ _____

Membership Fee $ _____

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Total $ _____

Signature ____________________________

Please mail, tax, or e-mail to:

Wilson Disease Association, 5572 North Diversey Blvd., Milwaukee, WI. 53217

Fax: 414-962-3886  E-Mail: membership@wilsonsdis ease.org
WDA WISH LIST:
• Donated Printing Services
• Family Run Fundraisers
• Newsletter Support

NEWSLETTER DEADLINE:
If you would like to submit an article to be published in the next printed edition of The Copper Connection the deadline for submission is March 1, 2012. Please e-mail your article to the WDA office at info@wilsonsdisease.org

DONATIONS:
For your convenience, you can make your donations online by visiting our website. 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:
At www.goodsearch.com 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 Association
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.
TO:

Official WDA Awareness Ribbon

Ribbon designed and donated by Sarah Hendrix.

Please see Marketplace Page inside.
Or order online at
www.wilsonsdisease.org/
marketplace.php