

Wilson Disease is 100 years old

Biography of Samuel Alexander Kinnier Wilson

Samuel Alexander Kinnier Wilson was an American born British neurologist who was the first to identify Wilson's disease one hundred years ago.

Wilson was born in New Jersey in 1878. Shortly after his birth, and the death of his father, he and the rest of his family moved to Edinburgh, Scotland. In 1902, he graduated with an M.B. degree from the University of Edinburgh, and the following year received his B.Sc. degree in physiology. Wilson then moved to Paris where he continued his studies with French neurologists Pierre Marie and Joseph Babinski. In 1905, Wilson moved to London, where he worked as registrar and pathologist at the National Hospital, Queens Square in London. Later he was appointed professor of neurology at King's College Hospital, also in London.



Samuel Wilson

Wilson specialized in clinical neurology, and made important contributions to the understanding of epilepsy, narcolepsy, apraxia (*the inability to perform learned purposeful movements*) and speech disorders. He described hepatolenticular degeneration (*Wilson disease*) in his Gold Medal winning M.D. dissertation of 1912 titled "Progressive lenticular degeneration".⁽¹⁾ He was honored for his research of the disease and, subsequently, the disorder became known as "Wilson's disease". In the paper he is credited for establishing the use of the term "extrapyramidal" (*the part of the nervous system that controls muscle reflexes*) in the field of neurology.

(1) Kinnier Wilson SA (1912). "Progressive lenticular degeneration: a familial nervous disease associated with cirrhosis of the liver". *Brain* 34 (1): 295-507. doi:10.1093/brain/34.4.295. <http://brain.oxfordjournals.org/cgi/reprint/34/4/295>.

Source: Samuel Alexander Kinnier Wilson. (2012, March 11). In Wikipedia, The Free Encyclopedia. Retrieved 13:44, March 26, 2012, from http://en.wikipedia.org/w/index.php?title=Samuel_Alexander_Kinnier_Wilson&oldid=481368048

Word Cloud contest

We thought it would be fun to create a contest in celebration of the **100th birthday of Wilson disease**. Contestants used the same text, gathered from the WDA website, and created their designs on Tagxedo using colors, fonts, and designs of their choice. Entries were judged for best appearance. Prizes will be given for 1st, 2nd, and 3rd place. Winning Cloud will be featured on the WDA website, in *The Copper Connection*, and on a new WDA Marketplace item for the remainder of 2012.

The 1st Place Winner is Ellen Seghi from New Hudson, MI.

Our two independent judges awarded first place to this entry and had the following comments,

"I like the symbolism of the trunk serving of the base and supporting the various "branches" in the tree."

"Tree... this is a disease that makes us a family - we all share the same gene - so we're connected."

2nd place winner is Marianne Collins of Pittsboro, NC and
3rd place winner is Erin Chandler of Cincinnati, OH.



Winning Cloud



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Table of Contents

Wilson Disease is 100 years old	1
Word Cloud contest	1
Successful fundraiser spurs planning of Scientific Workshop	3
Carol Terry honored at Genetic Alliance event	3
New EASL Guidelines	4
Medication Assistance Update	4
WDA Canadian Pipeline	4
Research from our WDA Center of Excellence in Mumbai	5
Clinical Trial for Single Daily Dosage of Trientine Completed at Yale	6
WDA Marketplace	7
Membership Form	8
Outcome and management of 207 pregnancies in Wilson disease	9
Wilson Disease	9
Another wedding fundraiser!	10
Raise money without asking!	11
Flower Power	11
Thanks for your support	12
2012 Support meetings	14

Newsletter design courtesy of WDA member
Rui Alves, Portugal.

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The Copper Connection

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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.





Successful fundraiser spurs planning of Scientific Workshop

Mary Graper

Many thanks to you, our loyal WDA donors, for making our 2011 Direct Appeal a huge success! In the letter, *Alex and Others Like Him Need YOUR Help Now!*, mailed last August, we asked that you help us to raise at least \$50,000 by December 2012 so that we could make this important meeting a reality. Well my friends, you did it...and more!

This has allowed us to accomplish much of the preliminary planning already this year. Workshop organizers, *Svetlana Lutsenko* PhD, Professor of Physiology, Johns Hopkins University; *Mary L. Graper*, President, Wilson Disease Association; *Dominik Huster*, MD, Head, Gastroenterology and Oncology, Deaconess Hospital, Leipzig; *Stephen G Kaler*, MD, Senior Investigator, Molecular Medicine Program, NICHD, NIH; *Dennis Thiele*, PhD, George Barth Geller Professor, Pharmacology and Cancer Biology, Duke University Medical Center; and *Michael Schilsky*, MD, Associate Professor of Medicine and of Surgery, Yale University Medical Center, and Medical Director, Yale-New Haven Transplantation Center have identified the following goals for the meeting:

Objective: To bring together leading clinical experts and basic scientists working in the area of human copper metabolism; summarize recent research advances that have potential impact on diagnosis and treatment of human copper disorders; identify main translational challenges that require active research efforts to improve clinical outcomes in patients with disorders of human copper metabolism.

Anticipated Outcome: The participants will discuss latest research developments in the area of human copper homeostasis; identify the most challenging issues in the diagnosis and treatment of human disorders of copper metabolism. It is anticipated that such focused workshop will facilitate active collaboration/information exchanges between clinical and research laboratories. We will also initiate search for innovative approaches to cross-integrate the clinical and basic science aspects into training programs for young generations of physician-scientists and PhDs working in the field of copper and trace element metabolism.

A preliminary program is being developed and will be submitted to NIH in April, by Dr. Lutsenko, along with a grant application seeking additional funding. It is hoped that the NIH institutes NIGMS, NIDDK, and NINDS will support this important event. The anticipated date of the meeting is March or April 2013 at Johns Hopkins University in Baltimore.

Carol Terry honored at Genetic Alliance event

On September 22, 2011 Genetic Alliance, www.geneticalliance.org, celebrated its 25th anniversary, "*25 Years of Innovation*", at the National Geographic Society in Washington, DC. The Celebration included a [museum-quality Innovators Exhibit](#) honoring innovators from across the genetics, health, and advocacy community. Genetic Alliance defined "Innovators", for the purpose of this exhibit, as "founders of advocacy organizations, board, staff, members, volunteers, researchers, policymakers, and others who have transformed their communities".

Our own Carol Terry, co-founder and current Secretary of the WDA, was honored that evening with this beautiful plaque that now hangs in her home. Carol's response, to the WDA Board, upon receiving the award was, "I am speechless! Thank you all so much for honoring me in this way."



Carol Terry is truly the matriarch of the Wilson Disease Association. She is my inspiration.

— Mary Graper
WDA President

Carol Terry

After a horrifying journey that led Carol to her diagnosis of Wilson disease, she was instrumental in founding the WDA 28 years ago. Carol is still an active board member today, and her dedication is unparalleled and contagious. The Wilson disease community is fortunate to have a tireless advocate like Carol.





New EASL Guidelines

Pam Meadows, RN, MSN

Chair, WDA Professional Affairs Committee

The European Association for the Study of the Liver (EASL), a leading European scientific society involved in promoting research and education in hepatology, has published the first European Clinical Practice Guidelines, "Management of Wilson's Disease", for the diagnosis and management of Wilson disease. The Guidelines focus on clinical presentation and prognosis, diagnostic strategies, the importance of family screening, and treatment options. This is great news, as the EASL attracts the foremost hepatology experts and is influential in European liver policy.

The new guidelines were published in the March issue (Volume 56, No. 3) of the *Journal of Hepatology*, the official journal of the EASL. For more information, and to download the document, visit <http://bit.ly/A02vzw>

Medication Assistance Update

Facilitating compassionate use medications for Wilson disease patients continues to be an important WDA program activity. MAP International continues to fill our requests for Cuprimine and Syprine, donated by Valeant Pharma, to needy patients outside of the U.S. Last year the WDA paid the shipping costs for 507 bottles of Cuprimine and Syprine to patients in 11 different countries. Because trientine is not an approved medication, for the treatment of Wilson disease, in Canada the WDA also facilitated shipments of compassionate use Syprine to 47 Canadian patients.

Recently, underinsured U.S. patients have been paying extremely high co-pays, between \$700 and \$2,500 per month, for Syprine. There is currently no established assistance program for this group of families. A restricted donation, from an anonymous donor, has allowed the WDA to provide financial assistance to several patients for this purpose.

Univar, in the U.K., continued their generous donation of both Trientine and shipping costs. Last year they supplied Trientine to 16 patients in 5 countries. Additionally, Univar also recently agreed to assist some of our underinsured U.S. patients. Thank you Univar!

BE SURE TO ORDER YOUR REFILLS WHILE YOU STILL HAVE SOME MEDICATION LEFT AT HOME SO THERE IS NO LAPSE IN YOUR TREATMENT.

WDA Canadian Pipeline

Linda Schwabke, Ottawa, Ontario Canada



To Canadian patients with Wilson's Disease,

Spring is coming, and as you dig into the soil to plant your flowers, I, once again, ask you to dig into your pockets and contribute to your organization. True, Canadians do not benefit from a tax deduction, but we get much much more. In addition to the newsletters, research and conferences, it was President Mary Graper's countless phone calls, on behalf of Canadian patients using Cuprimine, that yielded information on the 2011 drug shortage. Through her determined sleuthing, she ascertained when Cuprimine would once again be available to Canadians. Subsequently, Mary alerted us all through the WDA website, so that we could switch medication if necessary. From my perspective, knowing that an organization represents my interest was a comfort during that most unsettling period. We do not know what the future holds, but we do know that by working together we are stronger. We also know that an organization such as WDA relies on donations. I challenge each and every Canadian to reach down deep and plant a \$100 gift of life so that no WD patient goes undiagnosed, untreated or uninformed. Happy spring to everyone!!!





Research from our WDA Center of Excellence in Mumbai

Reversal of Severe Wilson Arthropathy by Liver Transplantation Aabha Nagral and Kiran Sathe

Consultant Hepatologist, Pediatric Liver clinic, Department of Gastroenterology and Pediatric Registrar, Dept. of Pediatrics, Jaslok Hospital & Research Centre, Mumbai, India.

Wilson disease is associated with multisystem involvement. We describe a patient of Wilson disease with severe arthropathy, which completely reversed following liver transplantation. This is the first case report in literature describing the complete reversal of Wilson disease related arthropathy by liver transplantation.

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Initial review: January 11, 2010;
Accepted: February 22, 2010.*



An 11-year-old boy presented with episodes of recurrent jaundice of two years duration. On investigations he was diagnosed to have Wilson disease (low serum ceruloplasmin, high urine copper, slit lamp showing K-F rings and sunflower cataracts). He had no neurological symptoms. He had a serum bilirubin of 3.5 mg/dL, (direct 2 mg/ dL), AST-104 IU/L, ALT - 205 IU/L, ALP - 160 IU/L, serum albumin - 2.9 g/ dL, INR - 1.8, Hb - 10.8g /dL, WBC - 4800/cmm, platelets - 88,000/cmm. USG of the abdomen showed a cirrhotic liver with portal hypertension and free fluid in peritoneal cavity. He was initially treated with D-penicillamine. He was fairly well compensated for about one and half years while on D-penicillamine. However, his white cell count and platelet counts progressively decreased (lowest WBC count was 2100/cmm and platelet count of 35,000/cmm) and this was attributed to a combination of hypersplenism and D-penicillamine and he was therefore switched to trientine. After two months, his liver decompensated after an episode of fever and spontaneous bacterial peritonitis. He had a rising bilirubin and grade two hepatic encephalopathy with a deteriorating coagulation profile. He developed progressively increasing joint involvement, which started a month after the episode of encephalopathy. The joint pains involved both large and small joints (knees, ankles with small joints of the fingers and toes). The involvement was symmetrical, with tenderness and restricted joint mobility with swelling of the knee joints, which seemed to be predominantly involved. The joint pains severely affected his

activities of daily living including sleep. He was investigated for the arthropathy - Anti-Nuclear Antibody, Rheumatoid Factor, Direct Coombs' test, Chikungunya IgM antibody, and HLA B27 - were negative; serum uric acid was 1.8 mg/dL (2.5-7.8 mg/dL) and Anti Streptolysin O showed a normal value of less than 200 Todd units. X-ray of the knee joints revealed periarticular soft tissue swelling and osteopenic bones. Ultrasound of the knee joints revealed bilateral effusions of the suprapatellar bursae. MRI of the brain did not show any evidence of copper deposition. Since no other cause of joint pain was found, a diagnosis of Wilson's arthropathy was made. He was treated with paracetamol and opiate based drugs for the joint pains and local fomentations, which provided minimal relief. Subsequently, he underwent a living related right lobe liver transplantation, (donor being his mother) after 2 months of decompensation (in the form of fever, SBP & hepatic encephalopathy). At the time of transplantation, his PELD (Pediatric end stage liver disease) score was 36 and the liver profile at the time of liver transplantation revealed AST - 305 mg/dL, ALT-290 mg/dL, GGTP-275 mg/dL, total bilirubin - 20.4 mg/dL, direct bilirubin - 14.3 mg/dL, INR -3.4, serum creatinine - 0.4mg/dL, serum albumin - 2.5mg/dL. He was initially on tacrolimus and steroid based immunosuppressive therapy and later switched to cyclosporine due to tacrolimus related toxicity. The joint problem showed remarkable improvement, with complete relief of joint pain. A diagnosis of Wilson's arthropathy was made. He was treated with paracetamol





and opiate based drugs for the joint pains and local fomentations, which provided minimal relief. Subsequently, he underwent a living related right lobe liver transplantation, (donor being his mother) after 2 months of decompensation (in the form of fever, SBP & hepatic encephalopathy). At the time of transplantation, his PELD (Pediatric end stage liver disease) score was 36 and the liver profile at the time of liver transplantation revealed AST – 305 mg/dL, ALT–290 mg/dL, GGTP–275 mg/dL, total bilirubin – 20.4 mg/dL, direct bilirubin – 14.3 mg/dL, INR –3.4, serum creatinine – 0.4mg/dL, serum albumin –2.5mg/dL. He was initially on tacrolimus and steroid based immunosuppressive therapy and later switched to cyclosporine due to tacrolimus related toxicity. The joint problem showed remarkable improvement, with complete disappearance of the pain and joint swellings as soon as he was mobilized by the fourth day post transplantation He is now one and half years post transplantation and has no joint pains, with a normal liver profile and leading a normal life.

DISCUSSION

Our patient presented as an established case of Wilson disease with primary liver involvement and development of symmetric polyarthropathy. He had been treated with d-penicillamine for one and a half years. However, the arthropathy started after discontinuation of d-penicillamine, thereby ruling out d-penicillamine induced arthropathy. Unlike Wilson disease related arthropathy, which is a chronic

joint damage, penicillamine induced arthropathy is an acute problem, which subsides on stopping the drug or decreasing its dose. It is in fact a manifestation of delayed hypersensitivity reaction in response to d-penicillamine (1). The possibility of juvenile idiopathic arthritis was not considered since a minimum duration of 6-12 weeks of joint pains is an essential criteria for its diagnosis (2). This was not the case in our patient. We also ruled out other causes of arthropathy. The arthropathy of Wilson disease is usually a late occurrence in the course of the disease process, frequently occurring after 20 yrs of age although it could be the initial presenting feature of the disease. It occurred two years after the onset of liver symptoms in our patient. Symptomatic joint disease occurs in 25-50% of such patients. The joint pathology is a degenerative process resembling premature osteoarthritis in addition to generalized osteopenia (3). Synovial copper deposition has been postulated as the likely explanation for the occurrence of arthropathy (3,4). Wilson disease related arthropathy has been described more often in patients had become neurologically disabled (5). In our patient, there was no evidence of neurological involvement either clinically or on imaging. It was unlikely that the joint pains responded to steroids, as there was on evidence of other etiologies (SLE, Juvenile idiopathic arthritis) on workup, which would respond to steroids.

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Contributors: AN conceptualized and edited the paper. KS wrote the initial manuscript. Both authors approved the final manuscript.

Funding: None.

Competing interests: None stated.

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- ** **arthropathy** - A disease or an abnormality of a joint

ALWAYS TAKE YOUR
MEDICATION AWAY
FROM FOOD AND
OTHER MEDICATIONS,
AND ONLY WITH
WATER.
NON-ADHERENCE
CAN BE FATAL.

Clinical Trial for Single Daily Dosage of Trientine Completed at Yale

Michael L. Schilsky, M.D., Yale University of Medicine and Aftab Ala, M.D., Frimley Park Hospital, Surrey U.K.

We recently concluded our analysis of a prospective clinical trial on the safety and effectiveness of a single daily dosage of trientine for treating patients in the maintenance phase of therapy for their Wilson disease. This study was conducted under the direction of Dr. Schilsky at Yale. In this study, each patient served as their own control and was evaluated before and after a transition to trientine taken as a single daily weight based dosage for twelve months. Our expectations of continued stability with respect to patients liver disease and overall clinical status and laboratory testing for copper metabolism and liver function over the treatment period were achieved.

Patient questionnaires taken at the end of the study indicated that study participants viewed being able to take their medication as a single daily dosage favourably and improved their adherence to treatment. The results of this study are being submitted for publication and will be presented at a future Wilson disease meeting so that others may learn of the results. The success of this study has also led to the planning of future collaborative studies here and in the United Kingdom.





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 \$ _____

NEW WDA MARKETPLACE AT CAFEPRESS

If you have a specific request for an item you would like to see offered, please let us know. To see all customizable products available visit <http://www.cafepress.com/make/personalized-gifts>

WDA CAP



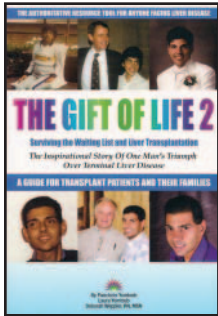
WDA AWARENESS BRACELET

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 SPECIAL EDITION WORD CLOUD MUG



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 \$ _____

WDA LAPEL PIN

Copper metallic edge and figures, with blue and white enamel background. On-half inch in diameter.



Suggested donation is \$5.00 each, or 5 for \$20.00

Number of pins _____
 Amount \$ _____

WDA DOGGY TEE

Shop for new WDA awareness merchandise at our new CafePress shop at the WDA Marketplace <http://www.cafepress.com/WDAMarketplace>. Items you purchase will be printed on demand and shipped directly to you. WDA receives a percentage of the listed retail price. Here are a few examples of what is currently available. More items will be designed and added in the future, so keep watching!



New Member Renewing Member Mr. Mrs. Miss Ms. Dr. Other_____

Name_____

Address_____

City_____ State_____ Zip_____ Country_____

Home Phone_____ Work Phone_____ Email_____

Membership Dues: Basic Membership - \$35
• Receive quarterly WDA Newsletter via e-mail – Please provide e-mail address above

Basic Plus Membership - \$60
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Silver Membership - \$120
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• 10% discount on Annual Meeting registration for up to two registrants

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Copper Membership - \$1000
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• 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:

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

In honor of _____ In memory of _____

Send acknowledgement to: _____

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Payment Information:

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Membership Fee \$_____

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Total \$_____

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Card #_____

Expiration Date:_____ CID # _____ (3 digits on back of card)

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Outcome and management of 207 pregnancies in Wilson disease

K. Weiss¹; D. Gotthardt¹; N. Eckert¹; P. Ferenci²; W. Stremmel¹

1. Internal Medicine IV, University Hospital Heidelberg, Heidelberg, Germany.

2. Internal Medicine, University Hospital Vienna, Vienna, Austria.

Presented at:

Introduction: Wilson disease (WD) is a genetic copper storage disorder, leading to liver failure and neurological deterioration. **Lifelong medical treatment is necessary** to maintain copper homeostasis. Optimal treatment regimens in pregnant women are under debate in respect to abortion rate, teratogenicity and therapeutic efficacy.



Aim: The current study aimed to assess outcomes of pregnancies in a retrospective multicenter cohort study

Patients and methods: A total of 207 pregnancies in 100 WD patients in European tertiary care centers were analysed retrospectively. Medical regimens (D-penicillamine, Trientine, zinc salts, or a combination of a chelator and zinc) were classified and files were reviewed for maternal hepatic or neurological deterioration during pregnancy. Outcome of pregnancies and abortion rate were analyzed in respect to the maternal treatment and disease presentation.

Results: Worsening of liver function tests was evident in 10 cases and occurred under all treatments to a similar extent. Liver function resolved after delivery in all cases. Neurologic deterioration in pregnancy was rare and was observed only in 2 cases (one under zinc, one under D-penicillamine therapy), but resulted in permanent worsening of the neurologic symptoms.

Overall abortion rate was 48/207 (23.2%) in the study group. Of these, 46 abortions were recorded within the first three months; two still births were associated with placental insufficiency. Abortion rate under Trientine treatment (8/20; 40%; $p=0.04$) was higher than under D-penicillamine (14/96; 14.7%) or zinc (2/19; 10.5%). We observed inborn defects in 2/159 newborn: One child presented with partial oesophageal atresia (under D-penicillamine therapy of the mother), another child was diagnosed with a Glu-6-P-DH deficiency (under zinc therapy).

Conclusion: In most cases control of liver function was maintained during pregnancy regardless of the chosen medical regimen. Neurologic deterioration was rare but resulted in severe disability in two cases. Thus, careful monitoring of WD patients during pregnancy is recommended. Contrary to previous reports we observed a higher rate of miscarriages under Trientine treatment. Potential teratogenicity remains a concern especially under D-penicillamine therapy.

Wilson Disease

Mary Graper, Wilson Disease Association President

Wilson disease (WD) is a rare genetic disorder of copper metabolism that affects 1 in 30,000 people worldwide. Mutations in the *ATP7B* gene on chromosome 13 prevent copper from being properly excreted from the body. This results in the accumulation of copper in the liver, brain, and other organs. WD is always fatal unless it is diagnosed and treated before serious symptoms develop.

WD patients typically present with hepatic symptoms, neurologic/psychiatric symptoms, or both. Hepatic symptoms can include hepatomegaly, splenomegaly, elevated serum aminotransferases (AST, ALT), fatty liver, acute hepatitis (resembling autoimmune or viral hepatitis), cirrhosis, and acute liver failure. Neuro/psych symptoms range in severity depending on the amount and location of copper deposition in the brain. Some of the effects of this are various movement disorders, drooling, dysarthria, dysphasia, dystonia, and seizures. Psychiatric symptoms are usually present in neurologically affected patients and, in fact, sometimes precede the onset of the neurologic symptoms mentioned above. Other systems that can be affected are ocular (Kayser-Fleischer rings), cutaneous, renal, skeletal, cardiac, and endocrine. Wilson disease is a complex, multi-system disorder that is all too frequently misdiagnosed as better known disorders.

Treatment is aimed at removing excess accumulated copper and preventing its reaccumulation. Chelation therapy drugs approved for treating Wilson disease include penicillamine (Cuprimine® and Depen®) and trientine (Syprine® and Trientine Dihydrochloride). Both of these drugs act by binding copper, causing its increased urinary excretion. Metallothionein inducer drugs approved for treating Wilson disease are (Galzin™) in the U.S. and (Wilzin®) in Europe. Zinc





acts by blocking the absorption of copper in the intestinal tract and removes it in the stool. This action both depletes accumulated copper and prevents its reaccumulation. The only "cure" for WD is liver transplantation, which is reserved only for patients with end-stage liver disease.

The Wilson Disease Association was incorporated as a non-profit organization in 1983. Today we are still the only U.S. organization advocating for patients with WD. Our services also extend globally to patients and families in over 50 other countries. We work closely with physicians and researchers to ensure early diagnosis and proper treatment of those now and in the future who may be affected by WD. We are dedicated to providing education and support to those struggling to obtain a diagnosis or manage their disease.

In my opinion, one of the biggest challenges the WDA faces is educating the medical community to "Think Wilson Disease" for anyone who has unexplained hepatic, neurologic or psychiatric symptoms. I look forward to the day when no patient is told, "You can't have Wilson disease, it is too rare".

For more information about Wilson disease, please visit the WDA website at www.wilsonsdisease.org

Editor's Note: This article was printed in the February edition of the University of Chicago Genetic Services newsletter.

<http://dnatesting.uchicago.edu/>



THE UNIVERSITY OF
CHICAGO

Another wedding fundraiser!

On December 31, 2011 the WDA received the following letter from the mother of the bride:

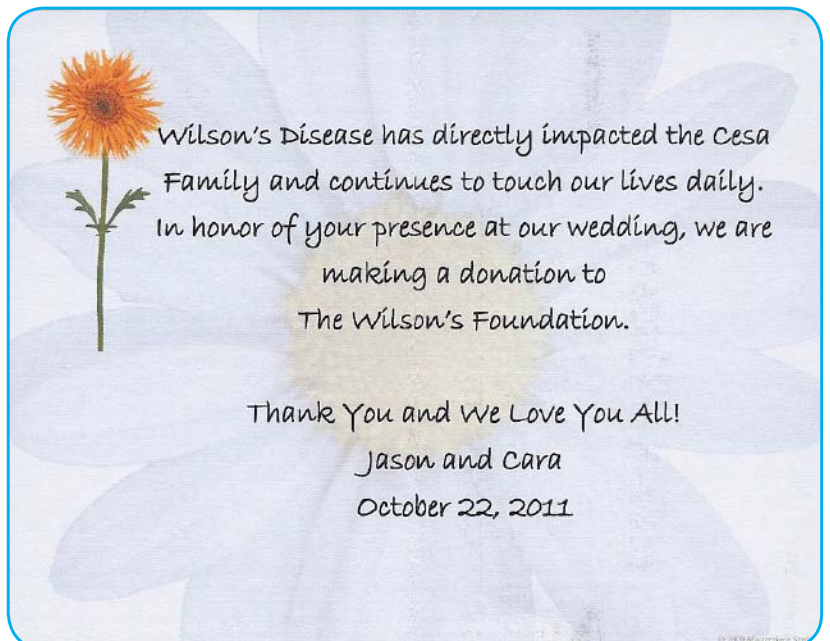
Dear Ms. Graper,

Our daughter, Cara, married Jason Cesa in October of this year. As you know, Jason is the son of Mary and Joe Cesa, whom you met when their youngest son Tim was going through his liver ransplant three years ago. At that same time, Jason was diagnosed with Wilson's Disease too.

When Jason came into Cara's life, we first learned about this disease. During the past two and one-half years we have grown to love ALL of the Cesa family members! When Cara and Jason got engaged, they decided to create the enclosed card and place on each person's plate at their wedding reception. They chose to make a donation to the Wilson's Disease Association in lieu of wedding favors for their guests.

I am enclosing the donation of (...) and hope and pray that the money will help find a cure for this disease. I appreciate all of your efforts and will continue praying for all those who have Wilson's Disease.

Thank you.





Raise money without asking!

Stefanie Kaplan, WDA Vice President

There are so many ways to raise money without directly soliciting your friends and family. One way that I raise money each year for the WDA is by hosting a Boutique at my home.

All of us have friends and family that have home-based businesses: Jewelry; Olive Oils; Make-up; Clothing, Kitchenware, etc. Invite 5-6 different vendors to your home for a "Boutique" and ask them to donate 15-20% of their proceeds back to the WDA. Then, create a flyer, a Facebook event, and a mass email to your friends and family telling them about the Boutique and that they can "shop for a good cause". Have them invite people, as well.

I held my third Boutique last fall and raised \$1000 for the WDA! I didn't have to ask anyone directly for money, and I did not have to write a check myself. My friends and family got to shop for great products; the vendors received exposure and new clients; and the money raised went to a great cause.

If you would like to hold plan and hold one of these, feel free to contact me if you would like any assistance. stefaniekaplan@gmail.com

Flower Power

Carol Terry, WDA Secretary

Last fall, I initiated a small WDA online fundraiser through Flower Power Fundraising. It was easy to set up the fundraiser online and to notify people on my e-mail contact list that they could help by buying flower bulbs, or distributing the fundraiser information to their e-mail contact list. Every sale of flower bulbs raised 50% of the sale price for the WDA. The bulbs were delivered directly to the purchaser and guaranteed by Breck's. Flower Power sent automatic reminders to my e-mail contacts at different points during the two-month fundraiser. Last fall's fundraiser produced over \$250 in revenue for the WDA, and it was easy and all done online!

RADA Cutlery

Here's an EASY way to support the WDA while doing your shopping!

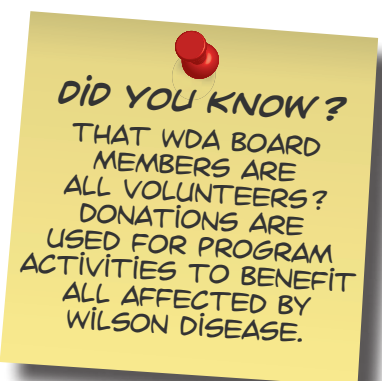
Through a simple internet ordering system, you can purchase quality Rada Cutlery kitchen knives, utensils, gift sets, scented soy candles, cookbooks, stoneware, and dip, soup and dessert mixes direct from the manufacturer at very low prices. A portion of each purchase is given to the WDA. This means that not only will you get a great deal on amazing products, but you will also be helping the WDA achieve its goals on your behalf.

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

Internet Ordering #: 502271

Password: fightwd

Your order will be delivered to your address in 15 working days or less. Please note that a \$10 minimum order is required and you can get additional information about the products available or download a complete catalog at www.RadaMfg.com. Your purchase also supports American workers and their families because Rada Cutlery has been proudly manufactured in America's heartland since 1948.



**2011 DIRECT APPEAL:**

Anonymous, Adams Household, Amitabh Upadhyaya, Ann Johnson, Melissa Asgaonkar, Brenda Baker, Bash Household, Cathleen Bergmann, Lloyd Bevan, Harry Bostrom, Janene Bowen, Susanne Brown, Harriet Burrft, Carole Carter, Carolyn Kennett, Pei Chao, Charlene Bobenrieth, Connie McGill, Maryann Coppolino, Craig Frankel, James Crees, Crim, Tava, Crooker, Peter, Carrol Cross, Edna Cross, Crystal Fontenot, Darlene Cyncora, Brasila Dimuro, Angela Doyle, Edward Goff, Ellen Einhorn, Eliza E Weckenman, Elizabeth Lawer, Ellen C Johnson, Erin LeMere, Gloria Fausneacht, George Feldmann, Belva Flynn, Fox Household, Frances Segal, Larissa Frenkel, Jeanne Friedman, Michael Gagliardi, Garlepp Household, Joseph Vincent Gaven, Marilyn Doris Gaven, George A Chapman, Regino Gonzalez-Peralta M.D., Terry Goode, Doug Goostree, Corinne & William Graper, Jenny Hall, Martha Hayes, Joel Herskowitz M.D., Joyce Hoggard, Reed Hughes, Martin Greene Gwendolyn Mancuso Irene Szopo, Isabel Smith, Jackson Fray, Joan Modrinski, Joseph and Elizabeth Laws, Joyce B Badanes, Lewis Kamenitz, Henry Kaplan M.D. J.D., Laura Kaplan, Karen Quillen, Holly Kelly, Christopher King, Michael Kirkpatrick, Sharon Lagos, Irene Lake, Leonard Household, Diane Laurain, Levin Household, Jack Levin, Leonard, Freeman, & Margareta Levin, Beverly Linkins, Karen Mandarano, Marianne Marcus, Susanne Michalski, Brenda Moosbrugger, Joelle Ng Kwong Sang, Barbara Noci, Norma Martin, Gail Nunn, Kelly O'Boyle, Olch Household, Ron Olch, Roselee Packham, Mary Lou Oster-Granite Ph.D., Ann Palrang, Patricia Pei, Lou Pelfini, Marla Pietruszka, Anne Pintozzi, Phil Portney, Pryor Household, Thomas Puetz M.D., Peter Purcell, Len Pytlak, Elizabeth Randall, Olivia Rich, Marjorie Riches, Roy P Huff, Celeste Roy, Ruiz Household, James Russo, Rutherford Co. Inc., Samantha Gross-Dorf, Stefan Sandler, Mary Scharf, Linda Schwebke, Allan Sedler, Aarti Sehgal, Sellner Household, Shannon Yenchsky, Mildred Shannon, Peter Sheptak, Angela Silvester, Ann Marie Sims, Marilyn Slavin, Eileen Smith, Robert Smith, Michael Sobkowski, Karin Tang, Teodor Tarachiu, Susan Tarquinio, Carol Terry, Thimmig, Marilyn, Tracey Panucci, Kristin Ulibarri, Sharad Wagle M.D., Ella Washburn, Elaine Widawer, Sharon Wilson, John Witort, Esther Wolk, Marilee Wolter, Margaret Yglesias, Paul Zandhuis, Sheryl Zorella,

2011 DIRECT APPEAL IN HONOR OF:

Alex Cook - Anne O Kachergis, Margaret C Linker, Mary & Loyd Tysinger; **Linda Schwebke** - Rochelle King; **Stefanie Kaplan** - Raymond & Barbara Alpert Foundation, Isabelle Sokoloff; **Janice Wagner** - Judy Wagner

2011 DIRECT APPEAL IN MEMORY OF:

Paul Bickimer - Carmen Guzman, David and Mary Ferran, Densie Novascone, Edward and Barbara Fitzgerald, Fern Rector, Jolene and Ron Byington, Patrick and Pearl Sullivan, Stephen and Angela Salem, Tammie Franck, William and Kathleen Sulley, Ward Household, Suzanne & Jack Bullington, Virgil Ray Alderson, Dale Petty, Michael Bryant, Mike Garrett; **Fred Auckeman** - Eugenia Craven; **Regis "Micky" Kowcheck** - Diana Kowcheck; **Kelsey Fink** - Melissa Deibert

ALLY COMMERCIAL JEAN'S DAY

Agnieszka Kaczor, Alexander Weekes, Ana C Pimentel, Athena Ziakos, Blanca Alava, Celeste R Schacht, Christy Bell, Coppolino, Maryann, Debora Zegalia, Diana L Guzzo, Edward and Marilyn Da Simone, George and Kimberly Grieco, Geraldine Hristakis, Glenn and Megan Kreutzer, Grace Meyer, Gregg C Wise, Janice Smith, Joel and Patricia Richards, John and Paula Matthews, John Rubineti, Joseph and Joann Skaferowsky, Joseph Galea, Kevin and Pamela Boland, Luis and Doris Acosta, Maria Viruet, Marlene Whyte, Mei H Shen, Milton Calle, Mr. and Mrs. Canavor, Paul and Madelynn Sanchez, Paul and Tricia Hickman, Puru Bahti, Randolph W Martin, Raymond and Laurie Herbert, Richard and Mary Daly, Richard and Nancy Peller, Santokh Canth, Thomas and Kathleen Brent, Timothy and Linda Voss, Troy and Karina Sonowski, Vivek Singh, Yoandra Martinez, Ally Financial (Matching)

CO-PAY ASSISTANCE

Anonymous

GRANTS

Jewish Federation of Metro Chicago
Silicon Labs (matching)
Community Foundation Alliance

FUNDRAISERS

IGive.com Holdings, Richard and Ida Bobrow, Good Search, Stefanie Kaplan Fundraiser, Barbara Shoag, Craig D Kain, Gated Distribution Inc., George and Cynde Daniels, Kaplan, Stefanie, Red Core Inc., Sarah R Stern Greenspan, Sandy Stern, Elizabeth Borrelli,

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Constantin and Nichole Langa, Derek Chapman, Linna Ding M.D. PhD., Doug Goostree, Dorothy Gorbacz, Greksa Household, Sihoun Hahn M.D. PhD., Cleo Hines, Edgar Hirt, Jeremy Hubball, John Wu, Karen Anderson, Beverly Linkins, Lois Willett, Ronald Marchese, Martin Hack, Mattheis Household, Anil Mehra, Ulises Morales, NORD, Nicolae Miron, Sylvania Nomicos, Len Pytlak, Richard Rosencrantz M.D., Robbie Schecter, Shinlan Liu, Teresa Siegart, Sobkowski Household, Suchawadee Collins, My Chi To, Candace York, John Kaib, Shari Kurzrok, Maggie Robertson, Daniel A Gottlieb, Dave D Aspirot, Catherine Palace, Melissa Asgaonkar, Lori Janow, Rachel Drummond, Susan Lencer,

MARKETPLACE:

Amanda Barrett, Anthony Frisco, Anthony Frisco, Courtney Edmunds, Jane Frisco, Jeff Frisco, Lisa Wyckoff, Marco Zours, Margaret Golis, Megan Wilson, Meghan Irwin, Karen Nixon, Research Group, Shannon Brown, Sobkowski Household, Carol Terry

IN MEMORY OF:

Matthew Graves - Rachel Frantz Jones, Patricia Hyland, Hudson Valley Community College. Patty Blacklock; **Ronald Brooks** - Erin Brooks; **Kelsey Fink** - Fink Household, Christine Chan; **Fred Auckeman** - Pryor Household, Richard L. Foltz, Juanita Auckeman; **Lars Elkin** - Joy Wenzel; **Joanne Lizak** - Christine Fitzell; **Ricky Wade** - Wall Household; **Joseph Weber** - Douglas Coleman; **Cheryl Zandhuis** - Paul Zandhuis; **David Yomtoob** - Kathleen M Schroeder, Jaynee L Tolle, David & Susan McCollum, Clinical Trial and Consulting Services, Brian and Hadley Decker, Barbara Cappel Green, Kathleen Van Fleet,

IN HONOR OF:

Alex Cook - Sharon B. Smith, Cleoanne Estrera, Marianne Collins, Patricia J Lichty, Suchawadee Collins; **Parichehr & Joe Yomtoob** - Kathleen M Schroeder, Jaynee L Tolle, David & Susan McCollum, Clinical Trial and Consulting Services, Brian and Hadley Decker, Barbara Cappel Green, Kathleen Van Fleet; **Travis and Molly Gilchrist** - Shelley Romero; **Debra Hoggard** - Joyce Hoggard; **Natalie R. Smith** - Ulibarri, Kristin; **Nicola Ulibarri** - Ulibarri, Kristin; **Arnold Gozora's Birthday** - Alison Gozora; **Ghita Reuben Ollit** - Linda Schwebke; **Mary Graper** - Linda Schwebke; **Jason & Timothy Cesa** - Kathy & Robert Stephens; **Jason & Cara Cesa's wedding** - Mona & Gary Tucker; **Randol Meadows** - Pat Meadows; **William Siegart D.O.** - Exeter Health Resources; **Dr. George Brewer** - Judith Kayam; **Karen Anderson** - Ann & Greg Melasky; **Anna Marsala** - Judith Kessler; **Annika & Cecilia Blotto** - Caroline Fischer, Joy Seppala, Karen Hack, Louise Hart; **Cecilia Blotto** - Alessandra Masoero; **Joshua Bernardo** - Liza Mysiuk; **Judge & Mrs. Fetzer Mills** - Sophie Wood

MAP:

Amitabh Upadhyaya

MEMBERSHIP DUES:

Dina Pritsker, Barbara Falk, Gerald Fortuna, Joyner Household, Agnes Lute, Aabha Nagral M.D., Bergmann, Cathleen, Gary Bowen, Janene Bowen, Chien-Hui Chung, Douglas Coleman, Dave Cook, Linna Ding, MD, PhD, Rui Esteves, Grosman Household, Janet Jorgensen, Kaelyn Everham, Wayne Kamenitz, Kim Michaux, Christopher King, Klouse Household, Patrick Lehnerer, Beverly Linkins, Mary Katherine Griffin, Nara Weyman, Joelle Ng Kwong Sang, Pamela Meadows, Peggy Norris, Peter Mills, Marla Pietruszka, Pryor Household, Richard Rosencrantz M.D., James Russo, Sobkowski Household, Susan Tarquinio,





2012 WDA BOARD ELECTIONS

Current Board members Len Pytlak and Drew Katz have agreed to run for new 3-year terms on the WDA Board this year. Elections will be held by mail-in ballot in the fall. Please look for the ballot and voting instructions in the fall newsletter.

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 **September 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.



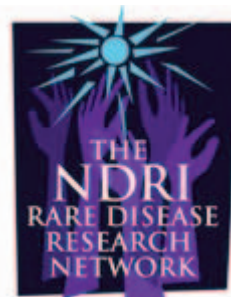
MORE SEARCHING AND SHOPPING OPPORTUNITIES AT IGIVE.COM!

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.

CONNECT WITH THE WDA ON



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and



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The Copper Connection

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(FORWARDING SERVICE REQUESTED)

TO:

2012 SUPPORT MEETINGS

Instead of a large annual conference this year, the WDA will be hosting several smaller regional meetings. Those of you who have attended one in the past know how enjoyable these meetings are. There is no charge to attend the meetings, and the WDA will provide a light meal for all attendees. WD treating physicians will be present to provide updated information and field questions from the group. Members of the WDA Board of Directors will also be on hand to answer questions and gather relevant information that will assist in the WDA's advocacy initiatives.

We have one confirmed date for September 16, 2012 in New York City. With the help of Dr. Schilsky, we have secured The Yale Club of New York City for the venue. Other tentative locations, with dates to be determined are Ann Arbor, Michigan, Long Beach, California, and Toronto, Canada. If you would like to receive updated information, as it becomes available, please write to membership@wilsonsdisease.org and ask to be added to the Regional Meeting Mailing List. Updates will also be posted on the WDA website and WDA Facebook page.