

Thank you to our members who so generously donated to our 2011 direct appeal, this exciting scientific workshop has become a reality! We have a wonderful program planned with speakers, from 10 different countries, attending to present their most recent research on copper metabolism. Please watch the WDA website and Facebook page for updates.

## Human Disorders of Copper Metabolism: Recent advances and main challenges International Workshop

April 8—9, 2013  
Johns Hopkins University  
Wood Basic Science Building  
725 North Wolfe Street  
Baltimore, Maryland

### 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.

### Additional Information

Program inquiries:  
Svetlana Lutsenko  
lutsenko@jhmi.edu

Organizational inquiries:  
Mary Graper mary.graper@  
wilsonsdisease.org

Registration deadline:  
February 1, 2013

### Main Topics:

- Disorders associated with copper deficiency
- Recent Advances in Mechanistic Understanding of Copper Deficiencies
- New Tools for Copper Research
- Wilson disease: Clinical spectrum and current treatments
- Mechanistic understanding of Wilson disease using model systems
- Modifying factors
- Patient advocacy perspective
- Junior investigator Poster Session



### Organizing Committee

**Svetlana Lutsenko PhD**  
**Mary L. Graper**  
**Dominik Huster, MD**  
**Stephen G. Kaler, MD**  
**Michael Schilsky, MD**

Professor of Physiology, Johns Hopkins, Baltimore, MD.  
President, Wilson Disease Association, Milwaukee, WI.  
Head, Gastroenterology and Oncology, Deaconess Hospital, Leipzig, Germany.  
Senior Investigator, Molecular Medicine Program, NICHD, NIH, Bethesda, MD.  
Associate Professor of Medicine, Yale University Medical Center, Medical Director, Yale-New Haven Transplantation Center, New Haven, CT.  
George Barth Geller Professor, Pharmacology and Cancer Biology, Duke University Medical Center, Durham, NC.

**Dennis Thiele, PhD**



### Board of Directors

Mary L. Graper, President  
Milwaukee, Wisconsin

Stefanie F. Kaplan, Vice President  
Long Beach, California

Carol Terry, Secretary  
Luray, Virginia

Jean P. Perog, Treasurer  
Quichena, BC, Canada

Chien-Li Chung  
Glen Ridge, New Jersey

Edward Goff  
Long Beach, California

Drew Katz  
Cherry Hill, New Jersey

Pamela Meadows R.N., BSN  
Denver, Colorado

### Honorary Board

Janene Bowen  
Logan, Utah

Kenneth Peterson M.D.  
Scottsdale, Arizona

Patricia Satherstrom R.N.  
Ottawa, Canada

Michael Terry  
Luray, Virginia

### Medical Advisory Committee

Michael Schilsky M.D., Chairman  
Yale University  
New Haven, Connecticut

Fred Askari M.D., PhD.  
University of Michigan  
Ann Arbor, Michigan

Sihoun Hahn M.D., PhD.  
University of Washington  
Seattle, Washington

Svetlana Lutsenko, PhD.  
Johns Hopkins University  
Baltimore, Maryland

Eve A. Roberts M.D.  
University of Toronto  
Toronto, Canada

Dennis Thiele PhD.  
Duke University  
Durham, North Carolina

## Table of Contents

|  |    |
|--|----|
| Human Disorders of Copper Metabolism: Recent advances and main challenges International Workshop | 1  |
| Obituary   | 3  |
| Northwestern One of Four Wilson's Disease Centers of Excellence in United States                 | 3  |
| News from the WDA Center of Excellence in Mumbai   | 3  |
| Narendra Story   | 5  |
| The Toronto Symposium: A Birthday Trip to Remember   | 6  |
| San Diego Symposium  | 7  |
| Ann Arbor Meeting  | 8  |
| New York City Support Group Meeting  | 9  |
| Copper Research Advances at the 8 <sup>th</sup> International Copper Meeting                     | 9  |
| Thanks for your support  | 10 |
| WDA Marketplace  | 11 |
| Membership Form  | 12 |
| For your information   | 13 |
| Wilson Disease Association International 2012 Election Ballot                                    | 14 |

Newsletter design courtesy of WDA member  
Rui Alves, Portugal.

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.

### The Copper Connection

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

## Our Mission Statement

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





## Obituary

Former WDA President, Dr. H. Ascher Sellner passed away on January 25, 2013 at the age of 70 years old. Dr. Sellner was a retired OB/GYN in Danbury, Connecticut where he practiced medicine for 35 years. In 1994 Dr. Sellner became the third president of the WDA, following Carol Terry who was one of the co-founders of the Wilson Disease Association. Under his direction, the WDA continued its mostly grassroots efforts until 1998 when the Board of Directors was expanded in order to further the goals of the Association. Dr. Sellner remained President until 2003. Those of you who remember Ascher will no doubt recall his delightful sense of humor and engaging personality. He was truly an asset to the Wilson Disease Association.

## Northwestern One of Four Wilson's Disease Centers of Excellence in United States

Northwestern has had the designation "Wilson's Disease Association Center of Excellence" since 2008 and is one of four such centers in the United States. Wilson's disease is an inherited disorder in which there is too much copper in bodily tissues. The excess copper damages the liver and nervous system, possibly leading to wide-range movement disorders. Northwestern's WD center is directed by Dr. Aleksandar Videnovic, movement disorders specialist, and Dr. Richard Green, liver diseases specialist. Under the comprehensive care model, the team includes specialists in neurology, hepatology, psychiatry, physical medicine and rehabilitation, and social work.

A recent development will further center growth. The relocation of the Ann and Robert H. Lurie Children's Hospital of Chicago to the Northwestern medical campus will allow the integration of pediatric and adult care for WD patients and their families.

In 2009 Northwestern hosted the annual WDA Conference, attended by people from across the United States and five foreign countries.

More information about the center can be found at [www.parkinsons.northwestern.edu](http://www.parkinsons.northwestern.edu) or by calling 312-503-4397. Reprinted with permission: *Parkinson's Update*, Fall 2012 Vol. 15

Parkinson's Disease and Movement Disorders Center, Feinberg School of Medicine, Northwestern University, Chicago, Illinois

## News from the WDA Center of Excellence in Mumbai

by Dr. Aabha Nagral

**Wilson Disease - Caring, Supporting, Treating (An event for caregivers and patients)** was organized by **Children's Liver Foundation (CLF)** in Mumbai on the 23rd of December, 2012. This also commemorated the 100th anniversary of the first description of the disease by Samuel A. K. Wilson, a British neurologist in 1912.

This event was the first activity of CLF for patients, organised on a large scale, since its inception two years back.

The meeting was well attended by patients, family members and caregivers from all over the country. An audience of more than 150 comprised of approx. 32 Wilson disease patients, a hundred family members and rest were medical professionals and individuals interested in working for the cause.

The programme started with lamp lighting by young kids affected with Wilson disease, followed by technical talks by experts which included a hepatologist, paediatrician, psychiatrist, dietitian, and speech therapist; covering various aspects related to Wilson disease.





The panel of experts answered questions from the audience which ranged from investigations, treatment regime, when and how to take medicines, diet for patients, routine precautions in daily life routine like studies, jobs, marriage, among others. Patients narrated their experiences on the disease in terms of how their health deteriorated, when it was diagnosed, how they accessed the treatment, importance of compliance and how they were faring in personal and professional lives. Some very sick children with cirrhosis could even avoid liver transplantation after starting treatment.

Some were young patients who have completed studies and are looking forward to settle life and marrying. Couple of patients were married and blessed with kids, and also doing well professionally. A patient set an example by not only taking care of herself but also adopted two wonderful kids after marriage. Handicraft items prepared by her were also displayed at the venue.

Exhibition of paintings by one of the patients, a 26 years young man, who suffered from Neurological symptoms due to disease, was arranged at the meeting venue. His paintings were appreciated by one and all. This young man in his speech shared his ambition of arranging exhibitions of his art and raising money for treatment of Wilson Disease patients. This positive spirit of not only fighting the disease for oneself, but also contributing for the betterment of other lives, was applauded by all patients.

Gauri a 17 year old girl and Kamal a boy of the same age had end stage liver disease with liver cirrhosis and its complications, and were advised that they could be saved only with the liver transplant. Gauri was on transplant waiting list until she got so much better that the team of doctors at Jaslok Hospital felt that she did not need a transplant anymore. She recently passed her standard X exams with flying colours.

Chiranjeev a young man of 18 was referred for advanced liver disease requiring several hospitalisations for complications of cirrhosis when he bled spontaneously from various sites as his blood did not clot due to lack of clotting factors produced in the liver. He also developed ascites which needed to be drained time and again. At this stage he was referred for transplantation without a known cause of his cirrhosis. Given the young age of his cirrhosis he was thought to have Wilson disease and treatment was promptly started. His hospitalisation frequency gradually reduced and he could wait for about one and a half years to get a cadaveric organ. He got transplanted more than a year back and is leading a normal life having recently appeared for his standard XII exams.

Ashwini got diagnosed with cirrhosis and developed slurring of speech and tremors, which made even holding a cup of tea difficult. On being diagnosed with Wilson's disease all her symptoms improved and she went on to have a normal married life and pregnancy, and is blessed with a beautiful two year old daughter. She is a successful professional, working in a leading computer firm. Though she could not make it to the meeting, she had sent a video.

Almost every patient wanted to share a point or two. Nishant's father expressed his heart felt gratitude to Wilson Disease Association for getting trientene completely free of cost as he was not tolerating d-penicillamine. His son who was in liver failure is recovering well.



This forum is perhaps an example of how support and motivation provided to patients; can impact their lives; and how they in turn, tend to contribute to the well being of others.

Children's Liver Foundation has now initiated the formation of its Wilson Disease Support group, which will be a mode for continuous communication between all for sharing and supporting.

For more details contact:  
[www.childrenliverindia.org](http://www.childrenliverindia.org),  
[pedliver@gmail.com](mailto:pedliver@gmail.com)



## Narendra Story

by Dr. Aabha Nagral

Born in February 1986, Narendra Limaye hailing from Gondia a small town in Western India was a healthy bubbly child until he developed jaundice at the age of 8 years. Following this, he had repeated attacks of jaundice which were attributed to the presence of gall stones which were discovered on an abdominal sonography.

At the age of 12, Narendra's handwriting became illegible and he would take ages to write. He started losing his balance while walking, developed muscle stiffness, was drooling saliva and was unable to swallow well. He also developed slurred speech. He soon needed help to walk and was almost bed bound. He also started getting recurrent high grade fever but that too was attributed to gall stones.

When his physical condition continued to deteriorate, his father more as a desperate act surfed the internet and found that his symptoms were matching with those of Wilson disease. He went to the doctors saying that his son had Wilson's and requested testing. The disease was confirmed by a serum ceruloplasmin and an eye examination revealed KF rings. D-penicillamine was started by the local doctors but his neurological symptoms worsened. The doctors gave up on him and informed the family that he was unlikely to survive and that the family should prepare themselves for the worst.



**Narendra Limaye**

As other effective medications like trientine could not be imported in India in the year 2000, an alternative - zinc available in India was advised by Dr. Schellner of the Wilson Disease Association of America. Support and advice also came from WISDOM, a charitable organization in Mumbai in 2001 and Dr. Aabha Nagral under whose guidance, Narendra was investigated and found to have cirrhosis of the liver with large esophageal varices and low blood counts from an enlarged spleen. He was continued on zinc therapy with strict low copper diet. Within two years, he showed remarkable improvement in muscle coordination, speech and handwriting. In 2004, he cleared high school exams by writing papers on his own. Physiotherapy, yoga exercises, computer games and physical exercises in form of drawing water from the well helped him a lot in terms of improving his mental and physical activity of muscles and joints, thereby improving his posture and maintaining a good balance of his body. Narendra could now cycle on his own and became independent.

Narendra was always good at drawing and once his hand coordination improved he started sketching and painting, which soon became a passion. In January 2007, the first exhibition of his 100 paintings was organized, which received a very good response. He graduated in 2009 & has now holds Art Classes for students since March 2012. He currently aspires to hold exhibition of his paintings throughout the country. Narendra's paintings were displayed in Mumbai in the recently held meeting for patients and caregivers of Wilson disease by Children's Liver Foundation. In this meeting, he expressed his wish to raise awareness on Wilson disease. He further expressed his wish to raise money for the cause through these exhibitions as he strongly felt that no child should die because of misdiagnosis, or suffer due to delayed treatment something that he had gone through. He also wants to help those who cannot afford medicines. He is well aware of his fragile health, but he wants to use his skills, which he says is the god's gift, to help others.



## The Toronto Symposium: A Birthday Trip to Remember

Linda Schwebke, Ottawa, Ontario Canada

### To Canadian patients with Wilson's Disease,

It was mid-August, and I was in the spectacular Canadian Rockies when I opened my email invitation to the Wilson's Symposium in Toronto. I burbled to my husband with glee that the date was September 29, just one week before my 64th birthday. I had never been to a Wilson's event, so I resolved that the symposium would be my present to myself. At last, I would get to meet my Wilson's family. It was only a five hour trip from Ottawa, and I could stay with my uncle. It was a half day format on Saturday, so I wouldn't miss work. And best of all, there was no walkathon, so I wouldn't get sweaty! Everything was just right. There was no excuse for not going.

I sent my RSVP and started to make plans. I checked out the bus schedule, and found I could leave early Saturday morning and return Sunday afternoon. Everyone advised me to take the train, but there was no way I was going to risk being late on our notorious VIA rail. After a lovely ride through the autumn landscape with colors of red, gold, and yes, copper, I arrived at downtown Toronto with an hour to spare. Now I had to gird my loins. The truth was I had never met anyone with WD since my diagnosis in London, Ontario in 1974. I had my misgivings. First, I was losing my special status as rare disease survivor. Second, maybe the other patients wouldn't be doing as well as I am.

I needn't have worried because when I arrived at the lovely ballroom of the Chestnut Court Conference Center, I was delighted to see my cohorts all looking surprisingly hale and hearty. I found Mary Graper, hugged her, and began to circulate. I would have to say that the rest of the day was heaven where I received a multitude of presents. Each lecture was a gift of hope delivered by a special angel. Dr. Eve Roberts assured us that new therapies are being explored. Dr. Tony Lang explained advances in neurological diagnosis and treatment. Dr. Les Lilly reported that WD patient transplants are more successful than those performed on the general population. Mary Graper dreamed about the future work of the Wilson's Disease Association.

I also picked up some wonderful nuggets of information that added to my birthday stash. I learned that the Tim Horton's coffee I love so much is actually good for my liver. I learned that I had better hustle over to my clinic and get a Hepatitis A and B shot. I learned that the blood tests that show I am low in copper are nothing to fret about. Already the day had yielded an embarrassment of riches.

The real beauty of the day, however, was that every problem we face - from uninformed doctors to exorbitant drug costs - was met by the speakers with unbridled optimism and tenacity. I left the symposium completely transformed. Even though I was no longer the only special one with WD, I was no longer the lonely one with WD. I had been united with the Canadian branch of my family.

I want to thank the Wilson's Disease Association for an absolutely wonderful birthday party- the best ever. Let me end with one birthday wish. It is my wish that everyone send a donation to the WDA so that it can continue with its work to ensure that every Wilson's patient reaches 64 years old and beyond.



Attendees at Toronto Meeting



## San Diego Symposium

### Amber's Story

Nara Weyman

After almost three years of one misdiagnosis after another my niece, Amber, was diagnosed with Wilson Disease in 2011 at the age of 20. We were both shocked and relieved to finally be able to identify her illness. Our new knowledge of WD came with a lot of fears and apprehension especially as we began to learn more about it. I couldn't help but ask WHY this was happening to my wonderful niece who, as the only survivor of a car accident, had escaped death at the age of 7. Our next shock was the exorbitant cost of the lab work, test, and medication that overpriced student insurance only minimally covered. I set out to research as much as I could about WD, and determine our plan of action to get Amber healthy and keep her that way.

In my research, I quickly came in contact with Mary, who has been a godsend to us. I was so excited when I found out there would be a Wilson's meeting in San Diego, and I could finally meet Mary in person. To my dismay, I found out that she would not be there because of the meeting in Toronto. We would, however, see Stefanie Kaplan again who has also been so helpful and supportive.



**Dr. Robert Gish and WDA Vice President Stefanie Kaplan**

This was our first Wilson's event and we had no idea what to expect, but we were excited at the opportunity of meeting others with WD and taking home any new knowledge. We arrived at the meeting a few minutes late just as Dr. Gish, of UCSD Health System, was presenting. In his overview, we learned that there are over 500 mutations of WD which can make it difficult to diagnose particularly by a doctor not so familiar with the illness. That was definitely new to us. He did mention they are currently testing for approximately 300 mutations. We also learned that Amber's urine copper tests, which still reveal very high levels of copper, are not as alarming as we thought. Dr. Gish stressed the importance of getting a liver biopsy done every two years as the best indicator of how she is doing. Dr. Gish's view that a patient should always take trientine in some dose (lesser as copper stabilizes) was a big surprise to us. This view varies from Amber's doctor whose plan is to have her take trientine until her copper levels stabilize and then switch her to zinc therapy. Now we are faced with the likelihood or possibility that she will be taking trientine much longer than initially anticipated.

We listened to a story from a pre-med student at UCSD who'd had a liver transplant at the age of 11 and was doing exceptionally well. He discussed the importance of compliance with his particular meds. I was so impressed by his attitude and story. The parents of a very happy young boy presented their son's story, who had been diagnosed at 3. They discussed the challenges of administering medication at such a young age. They also discussed the conflicting information on copper levels in various foods. They said that according to the FDA's site, a banana contains more copper than a serving of chocolate. Have those with WD been needlessly depriving

themselves of chocolate? I couldn't imagine life without chocolate! I'm sure it is on the "do not eat list" for a reason, but this has been the hardest "food" for Amber to give up.

I left the meeting with a stronger connection to our Wilson group and feeling more confident armed with all of this new knowledge. So what did we learn? Amber is not so alone with her rare disease. Amber's doctor has been very good but we need to make sure he's the best available for Amber and in treating WD. We will be looking for one with more experience with WD or at least have him consult with other doctors. As Stefanie so simply and so profoundly stated, "there's a difference between having a good doctor and having one that really knows Wilson's". Amber had a sense of relief about the unreliability of her tests and we will be scheduling another biopsy soon. We learned that we need to get her sister tested as soon as possible. I learned that I want to bring more awareness about WD. I've yet to meet someone outside of the Wilson Disease Association who is even familiar with it. I do my best to educate those around me but I would like to do more to spread the word and get the necessary donations to help the organization continue their work. I don't know where we would be without WDA, and I take great comfort in knowing they not only have touched others in the same way but can continue to do so.



## Ann Arbor Meeting

Melissa Cunningham, Mt. Clemens, MI.

I was able to meet with other Wilson's patients in Ann Arbor, Michigan on October 27, 2012. I saw that Wilson's has many faces, one family had all three of their children diagnosed! It seems we all took different roads to get to our diagnoses; however, we each could understand what we go through! Dr. Askari, from the University of Michigan and his nurse were there and I learned more about the disease and left feeling better. I do take Syprine and I have learned that the patience/virtue thing really does mean something! I was the rookie patient, as I was diagnosed in July of 2012 at the age of 43.

"I want to work you up to see if you have Wilson's Disease," said Dr. Murphy, DO. Wilson's Disease? I had no idea what that was and he had to be making it up, because I have been sick for a year and he is trying to be funny. I am a Registered Nurse and I had no idea what this was! I must have been talking in class and missed that part of the lecture in nursing school! Well, it is real and I do have it! After seeing every physician in the Indianapolis area and a trip to the Mayo Clinic, I became so depressed, because no one could help me. Prior to being diagnosed, things were bad and now a blur. I felt like I aged many years in a few months. Mobility problems, confusion, disorientation, chronic pain, falling, changes in my personality, the list goes on and is still very present in my daily life! I was very upset when I had a "yet to be determined" illness. It made me mad. Every physician I saw said they knew there was something wrong with me; however, none could pinpoint it! Dr. Murphy had to write me off from work, because I could not work in the capacity of a RN, having the above symptoms. Consequently, my position was terminated because I was sick. My short term disability was denied, as I had no true diagnosis! Dr. Murphy appealed it, to no avail. This insurance, I paid for...oxymoron! I went through a lot of depression, not even wanting to get out of bed, I couldn't work, I had no reason! To tell you the truth, when I got the diagnosis of Wilson's Disease, my attitude changed for the better! It was Dr. Murphy in Fishers, Indiana that caught what no one else could! Everyone should have a Dr. Murphy!

I am on a mission and I won't stop until this disease is brought out! I have great enthusiasm to promote early detection and just let people know what this is! So, yes, I have a reason to get out of bed, I have a platform...Wilson's Disease Awareness. It is very cold here in Michigan, where my husband was transferred to and now is home. The cold and rapid change in weather is terrible. My symptoms seem to really show! I am very fortunate that I have the most wonderful husband in the world, Steve. He is my rock! He is the kindest, most caring, generous man on the planet and he treats me like a queen. I am so appreciate of Steve, he is the last of a dying breed! We have been married three years, having dated in high school and after we both divorced from prior marriages, we dated and now we share the last name! My best friend, Lisa, is selling Wilson's Disease bracelets, back home in Indiana to help raise awareness for this very underdiagnosed and very rare disease! I am no longer able to drive, so my awesome friend, Michele takes me where I need to go and we always have fun! So, I am so lucky for the great support.

Wilson's Awareness is now a passion to me! I am actually excited to raise awareness and will have an event in my hometown of Muncie, Indiana. Plans are in the works and it will be good! My main goal is to be on the Ellen show to talk about Wilson's! Ellen is such a philanthropist and reaches so many people. She raises my spirits every single day. I have written to Ellen, send a package, made You Tube videos and I can promise you I will not stop until Wilson's Disease is brought out to the world! In fact, at the meeting in Ann Arbor, before I took my coat off to show my Ellen sweatshirt, one gal said, "have any of you seen the You Tube video of the gal with Wilson's, wanting to be on the Ellen show?" I held my breath...then, she said, "she is awesome and you should watch it!" Whew...then I said, "that's me!" She instantly got up and hugged me. That did so much for me and inspired me to push even harder with my awareness ideas!

Life is about choices and I choose to be positive and enthusiastic. I sure do miss my job as Registered Nurse. It really is a calling and what I wouldn't give to be back. I cannot work; but, I am still a RN and it is my responsibility to care for those that can't care for themselves. I cannot work the floor anymore; but, I can use my voice to raise awareness and be a patient advocate! I may have Wilson's Disease; however, Wilson's Disease does not have me!





## New York City Support Group Meeting

By Carol Terry, WDA Secretary

The WDA sponsored a support group meeting at the Yale Club in New York City on September 16, 2012. The meeting was attended by about 50 WD patients, family members, and friends, including WDA President, Mary Graper, my husband, Sparky Terry, and me. Dr. Michael Schilsky, Chairman of the WDA Medical Advisory Committee and Director of the Yale University WDA Center of Excellence, and his colleagues Dr. Richard Rosencrantz, Dr. Paula Zibraun, and Dr. Sanjeev Gupta made very informative presentations to the group.



**Dr. Michael Schilsky, Dr. Sanjeev Gupta**

Dr. Rosencrantz, a pediatrician at Westchester Medical Center, discussed the difficulties in diagnosing pediatric WD patients and some of the new research being done on liver transplants and gene therapy. Dr. Zibraun, a psychiatrist at Yale University, told the group about the common psychiatric and behavioral manifestations of WD, pointing out that most of these symptoms are reversible with effective treatment. Dr. Gupta, of Albert Einstein University Medical Center, told the group about some exciting research using special PET scans of the liver to help diagnose WD by measuring whether the ATP7B gene (the WD gene) is removing copper or not. Dr. Schilsky discussed a recent study involving 8 WD patients taking trientine (Syprine) for maintenance therapy in which the patients took their total daily dose of medicine at one time instead of spreading the dose out throughout the day. These patients were monitored closely for a year, and all their copper parameters remained normal while on the once a day dosing scheme. Dr. Schilsky would like to see a broader study done involving more patients and looking at single daily dosing with both Penicillamine and trientine.

The meeting gave many patients in the New York area and from other east coast locations a chance to get together, compare experiences, and learn more about WD. Be sure to watch the WDA website or Facebook page for notice of a future support group meeting in your area. If you'd like to volunteer your time to help organize such a meeting, contact the WDA office.

## Copper Research Advances at the 8<sup>th</sup> International Copper Meeting

Dennis Thiele, PhD, Duke University, WDA Medical Advisory Committee

Continued advances in understanding the causes and treatments for Wilson Disease requires a detailed understanding of the basic biology of copper, from genes to proteins, from chemistry to biology and from microbes to humans. Since the mid-1990s, scientists from around the globe have gathered biannually to discuss their latest research on copper. One goal of this meeting is to challenge existing ideas, propose new ways of thinking about copper, initiate collaborations to test new ideas and, ultimately, to propel the field forward. The most recent International Copper meeting was held this past September 30th to October 4th, 2012 in the small village of Alghero, located on the northwest coast of the island of Sardinia, Italy; Italy is a centralized and convenient location that is the traditional meeting spot for this international group of scientists. At this meeting, the 8th meeting in this series, it was apparent that this field has never been so vigorous, exciting and inspired to make major advances in our understanding of copper metabolism.

Like any process in biology, copper metabolism in a single cell, such as a bacterial cell or a liver cell, is complicated. A comprehensive understanding of biology requires the reduction of complex processes down to simpler terms where they can be dissected and studied in detail, and then re-assembled into the context of a cell, an organ, or a whole organism. The 8th International Copper Meeting was well-represented by chemists, biochemists, geneticists, biologists and physician-scientists with a passion for understanding copper metabolism from unique, and complementary perspectives.

Many advances were presented and discussed at this meeting and include new, unpublished discoveries in the biology of copper in health and disease. These include the structure and biochemical mechanisms by which copper transporters



pump copper across membranes; how the genes encoding these transporters are regulated and which other cellular components communicate with and regulate the activity of copper transporters. Other presentations focused on new advances in our understanding of copper in liver disease pathology and in early embryonic development; how copper is inserted into copper-requiring enzymes and proteins within the complex intracellular milieu; how mammals use copper as anti-microbial defense weapons and, in turn, how microbes utilize their own copper detoxification machinery in infectious disease; the development of new chemical and imaging tools to visualize and quantitate copper levels in cells, tissues and whole organisms; the identification of new copper-requiring enzymes and copper homeostasis proteins in microbes, plants and animals, and their three-dimensional structures that give insights into how organisms use and properly balance copper.

Approximately 130 attendees, composed of research leaders, students, post-doctoral trainees and other interested participants contributed to the exciting advances presented and discussed at this meeting. Given that the meeting was financially supported by the United States National Institutes of Health, the Wilson Disease Association and other generous sources, there is a clear sense of commitment to advancing this field and to the career development of young investigators who will continue to make new discoveries on the basic biology of copper and its links to treating human disease. Important advances that have revolutionized human health, such as the accidental discovery of the antibiotic penicillin by Sir Alexander Fleming, often arise from basic science discoveries that are driven by curiosity, passion and intellectual exchange. Advances in understanding copper metabolism and the diagnosis, causes and treatment of diseases such as Wilson disease, will be greatly accelerated by the continuation of this meeting series where dedicated scientists and clinicians exchange ideas and map new challenges in the field.

*Editors note: The Wilson Disease Association supported this important meeting in the amount of \$5,000. More information can be found about the meeting at <http://www.copper.ch/>*

## Thanks for your support

### GENERAL CONTRIBUTIONS:

Arthur R Barter, Barbara Frayser, Bash Household, Beatris Tarachiu, Betty S Bender, Capitol Bancorp Limited, Chester Andruskiewicz, Chien-Hui Chung, Drew Katz, Fran Corda-Whitehead, Heidi Sullivan, Howard Household, IGive.com Holdings, Jeffrey Ferketic, John Wu, Karen Mally, Kelly O'Boyle, Lynne Wehmueller, Marchese Household, Margaret Yglesias, Mary Graper, Maryann Coppolino, Mehra Household, Mildred Shannon, Natalie Smith, Nigel Ayers, Paul A Mally, Peter E Protzel, Ruth Mayer, Sheptak Household, Sodexo, Stephen Walsh, Stephen Weaver, Viviana Florea.

### MARKETPLACE:

Stephen Weaver, Holly Walker, Dawn Fritz, Melissa Strelsin, Jason Witort, Melissa Cunningham, Jackie Bragg, Diana Lutz.

### IN MEMORY OF:

**Barry Silberkraus** - Dallas Jewish Community Foundation

**Cole Lemaire** - Magdalena Peixoto

**Dennis Diamond** - Mirkin Household

**Henry Kaplan** - Corinne Sherman, Michael Slack, Adam Barasch, Lori Brody, Mary Graper, Chervitz Household, Paul Cacioppo, Marshall Hall, Stanley Gould, Carol Terry

**Roland Gilchrist** - Robert Smith

### IN HONOR OF:

**Aunt Lil's 90th Birthday** - Robbie Schechter

**Dan Gottlieb** - Lisa M Owens

**Janice Wagner** -Cherrie Household

**Mark Whittier** - Whittier, Julia, David Baker, Jeanne Goulet, Jason Phelps

**Natasha Ivanuk** - Larissa Frankel

**Parker Smith** -Sandy Owens, Martha Burns, Gina Smith

**Ryan Silberkraus** - Dallas Jewish Community Foundation

**Carrol (Butch) Cross** - Edna Cross

**Cheryl Zandhuis** - Paul Zandhuis

**Linda Schwebke** - Selma Holo

**Sandra K. Neff** - Community Foundation Alliance

### MAP:

Pavan Ahuja, Amitabh Upadhyaya, Chau Minh Vu.

### MEMBERSHIP DUES:

Sourav Chowdhury, Beatris Tarachiu, Becky Scribner, Benjamin Jacob, Constantin and Nichole Langa, Douglas Moore, Elizabeth Randall, Erica Scheiblehner, Fran Corda-Whitehead, Gloria Fausneucht, Heather Lynn Abbott Demish, Howard Household, Janet Jorgensen, Martin Voigt, Mary Ladouceur, Michael Rabin, Mildred Shannon, Nara Weyman, Paul W Rutherford, Peter E Protzel, Sheptak Household, Viviana Florea, William Popp.





**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**

Good news!  
A brand new shipment of these popular bracelets has just arrived. Added to the new design is an image of the WDA globe



as shown in the picture. 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 \$ \_\_\_\_\_

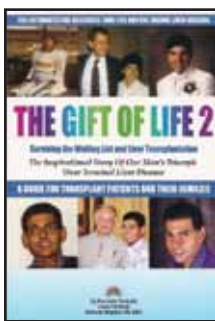
**WDA LAPEL PIN**

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 \$ \_\_\_\_\_



**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 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!

**MADE IN THE USA**



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**  
• Receive quarterly WDA Newsletter via U.S. mail or e-mail – Please provide email address above

**Silver Membership - \$120**  
• Receive quarterly WDA Newsletter via U.S. mail or e-mail – Please provide email address above  
• 10% discount on Annual Meeting registration for up to two registrants

**Gold Membership - \$250**  
• Receive quarterly WDA Newsletter via U.S. mail or e-mail - Please provide email address above  
• 15% discount on Annual Meeting registration for up to four registrants  
• Special recognition as a Gold Member in WDA Newsletter

**Copper Membership - \$1000**  
• Receive quarterly WDA Newsletter via U.S. mail or e-mail – Please provide email address above  
• 20% discount on Annual Meeting registration for up to four registrants  
• Special recognition as a Copper Member in WDA Newsletter  
• 10% discount for Annual Meeting program ad  
• No annual dues

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

Name\_\_\_\_\_

Address\_\_\_\_\_

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

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

In honor of \_\_\_\_\_  In memory of \_\_\_\_\_

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

Name Street

City State Zip Country

\*\*\*\*\*  
**Payment Information:**

Marketplace \$ \_\_\_\_\_  Visa  Master Card  Check or Money Order attached  
Membership Fee \$ \_\_\_\_\_ Card # \_\_\_\_\_  
Donation \$ \_\_\_\_\_ Expiration Date: \_\_\_\_\_ CID # \_\_\_\_\_ (3 digits on back of card)  
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@wilsonsdisease.org



**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 **April 1, 2013**.

Please e-mail your article to the WDA office at [info@wilsonsdisease.org](mailto:info@wilsonsdisease.org)

**DONATIONS:**

For your convenience, you can make your donations online by visiting our website.

Just visit [www.wilsonsdisease.org](http://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:**

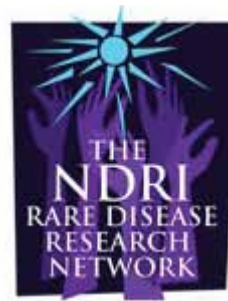
At [www.goodsearch.com](http://www.goodsearch.com) you can earn money for the WDA simply by searching the Web. Rather than using your usual browser, click on the **GoodSearch** button on the WDA website home page. From there you can browse the Web and earn 1 cent per click for the WDA. **It's that easy!** 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](mailto:raredisease@ndriresource.org), or by phone at 800-222-6374.

**CONNECT WITH THE WDA ON**

<https://twitter.com/#!/wilsondisease>

and



<http://www.facebook.com/wilsondiseaseassociation>



PRSR FIRST CLASS  
U.S. POSTAGE PAID  
SUGARCREEK OH  
PERMIT #38

Winter 2012

## WILSON DISEASE ASSOCIATION, INTERNATIONAL

### The Copper Connection

5572 N. Diversey Blvd.

Milwaukee, WI, 53217

(FORWARDING SERVICE REQUESTED)

TO:

## Wilson Disease Association International 2012 Election Ballot

Nominees for re-election to Board of Directors (3-year term):

- 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.
- Drew Katz – Mr. Katz is CEO of Interstate Outdoor Advertising, a billboard company in Cherry Hill, NJ. He was diagnosed with WD as a child and is founder of The Drew Katz Foundation, which supports WD research and patient care, as well as AIDS and cancer research.

WDA members in good standing may vote for these candidates by mail. If you have not already voted through the Survey Monkey election poll e-mailed on December 23, 2012 you may still do so by going to Please follow this link and vote on two Board Members who are up for re- election. <http://www.survey-monkey.com/s/9F8WVK6> to cast your vote. Or, submit a copy of your marked ballot, using the enclosed remittance envelope, to the WDA office by February 28, 2013.