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The Copper Connection

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Winter 2015

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The Big WOW!

by Marianne Collins, Core Committee member for The Big WOW and mother of a Wilson's Disease FIGHTER!

What do you get when you combine 800 walkers, 556 donors, and 104 dogs across 17 US and 2 Canadian cities, national and regional sponsors to raise \$66,972? Wow! That is The Big Wow!

On Saturday, September 19, 2015, Wilson's Disease fighters, survivors and supporters from across The United States and Canada walked together and virtually to raise much needed awareness and funds for The Wilson's Disease Association. This idea to "Walk Out Wilson's" was the brainchild of Chris Simopoulos and his wife Lisa, who have 3 sons with Wilson's Disease. They had attended their first Wilson's Disease Conference in Ann Arbor, in September 2014 and the rest is Big WOW history!

Here is Chris's statement, also found on the Big WOW website (www.wilsonswalk.org):

"Our three boys, Nicholas, Zach, and Joe were diagnosed with Wilson's disease in July of 2013. In 2014, my wife Lisa and I attended the WDA conference in Ann Arbor Michigan. We were amazed by the stories we heard of those recently diagnosed or have lived with Wilson's disease, showing remarkable strength in the face of great adversity. We realized that the Wilson's community is filled with great people and that if we could somehow bring them all together, we could do great things. Hence, we set out on creating the first nationwide walk for Wilson's disease. With the help of the WDA, we formed the Big WOW committee and we have all been working hard to make this event a reality. Thank you for joining us!"

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With the help of the president of the Association, Mary Graper, a core committee was formed in late 2014 and after a few on-line web meetings and many e-mails later we decided on a name and a date and the rest is Big WOW history. With guidance and support from the WDA, Chris, and the core committee we created a website, a video, and expert guidance about how to prepare for the walk.

- Chris Simopoulos created the timeline and kept us all on track with informative and encouraging emails.
- Jennie Spies (Graper) created a colorful and meaningful logo that we printed on the Tech shirts that were distributed to the walkers.
- Additionally, colorful bandanas were available for the dogs.
- Marianne Collins purchased and managed the domain and website.
- Judi Keller set up all of the event sites on Eventbrite and communicated with the city leaders to obtain details about their specific site.
- The city leaders planned and managed the walks in their area, advertised and obtained local sponsors.
- Mary Graper managed the T-shirt and bandana orders and coordinated shipment to each city leader. She also communicated to supporters and sponsors

As you can see, it was a concerted effort by quite a few people. We learned a lot along the way and will use our experience to expand and grow in the future. The walks ranged from just a few members to hundreds per city, but most of all, we had fun!

Our national sponsors include:

- La Croix, who provided refreshing beverages for all of the sites
- Wilson Therapeutics, who is currently in phase 2 of clinical trials for a new treatment (WTX101) for Wilson's Disease
- ExtremeV, makers of Gluzin, a pharmaceutical grade of over the counter zinc.
- Sutter Medical Group
- Kadmon Pharmaceuticals
- Univar Ltd., who produces trientine in the U.K.

We are already planning The Second Annual Big Wow for October 1, 2016 and are hoping to expand every way; cities, walkers, local and national sponsors and dollars. In 2015, we surpassed our goal of \$50,000 and have set a goal of

\$100,000 for 2016! Please consider sponsoring a walk in your city as it is really pretty easy and we will offer guidance and support along the way. Contact us at info@thewilsonsbigwow.com if you are willing to help in any way. [Back to top](#)

2015 WDA Annual Conference

By Carol Terry, WDA Secretary

The 2015 WDA Annual Conference was held on September 26 in Weehauken, NJ. We had an excellent turnout and a very interesting slate of speakers. The theme of the conference was “Blueprint for the Future”. The morning presentations began with Fred Askari, MD, PhD, Director of the WDA Center of Excellence at University of Michigan, speaking about management of complications of liver disease in Wilson disease (WD). Next, Tamir Miloh, MD, Director of Pediatric Hepatology and Liver Transplant at Texas Children’s Hospital, proposed a multicenter, randomized prospective study to measure the effectiveness of using text messaging to improve treatment adherence for WD patients. Dr. Miloh was followed by Regino “Regy” Gonzalez-Peralta, MD, Professor of Pediatrics at University of Florida College of Medicine. Regy covered the fine points of diagnosis and treatment of WD in children. Rounding out the morning’s presentations, Sihoun Hahn, MD, PhD, Professor, Department of Pediatrics, and Director, Biochemical Genetics Program, University of Washington School of Medicine, brought us up to date on potential new tools for newborn screening for WD.

After lunch, we heard from Michael Schilsky, MD, FAASLD, and Director of the WDA Center of Excellence at Yale University and several members of his Center of Excellence team. First, Anne Marie Rivard, MPH, RD, CSR, CD-N, Clinical Dietitian, led us in an interactive discussion of diet and nutrition for people with WD. Next, Psychiatrist Paula Zimbrea, MD, FAPA, FAPM, spoke about the use of psychotropic medications in WD. And, Clinical Research Nurse, Karen Starvis, RN, MSN, CCRC, discussed patient rights and responsibilities during a clinical research trial. This was followed by Dr. Schilsky, who provided an update on treatment trials for WD. Finally, Ahsan Ahmad, WD Biotech Associate, presented an overview of the proposed Wilson Disease Cooperative Network (WDCN). (See more about the WDCN elsewhere in this issue.) The remainder of the afternoon was spent in a number of breakout sessions to give attendees a chance to have some give and take about issues of interest.

Saturday night’s conference banquet was highlighted by a presentation by WDA President, Mary Graper, and Ahsan Ahmad of a proposal for developing the next generation of WDA leaders. This was followed by a lively discussion of how to involve more young people in achieving WDA’s mission. If you would like to help with this effort, please e-mail your contact info to WDA at info@wilsonsdisease.org.

As always, the conference also provided attendees the opportunity to meet other WD patients and families, talk to the presenters, and exchange information and experiences. Next year’s conference will be held in Florida. If you have never had a chance to attend one of our annual conferences, please consider attending.

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In 40 Years Not Much Has Changed; Two Patients Share Their Stories

of Diagnosis and Recovery

George Feldman Story

"My name is George Feldmann. I was born with a rare liver disease, called Wilson's Disease[.....]When I was 12 years old, I started having tremors. Then I started talking fast. Soon after, I started drooling. Embarrassed, I tried so doggone hard to keep my mouth closed, so I wouldn't drool. When I was in grade 11, I had a crush on a girl in my class. I remember talking to this girl, and I started drooling. I was humiliated! Up through grade 9, I had been an "A" student. By the time I was in grade 12, I was failing. My writing was so shaky, I couldn't finish a 3 hour exam. I was so frustrated. I knew the answers. But I couldn't finish the exams. I had gone to many doctors and speech therapists, but they were at a loss and didn't know what to do with me. Finally, on my 19th birthday, a knowledgeable intern from Boston saw the Keyser Fleischer rings in my eyes and diagnosed me with WD. I had gone undiagnosed and untreated for 7 years! Remember the two drugs with the nasty side effects? I was given one of them ... Penicillamine. I developed a high fever (105) & a rash that even covered the bottoms of my feet! I was in the hospital for 38 days. During that time, they found the proper dose of Penicillamine for me and gave me prednisone to counteract the Penicillamine. This halted the advancement of my WD.

Twenty years later, in 1986, I became the 34th patient to be involved in a research study program by Dr. Brewer, at the University of Michigan in Ann Arbor. Dr. Brewer was doing research on Zinc Acetate as a treatment for WD. For the next 11 years I went to the U of M hospital twice a year for 12 days. I took Zinc Acetate daily, and I ate the same foods every day. Everything was monitored. They even measured our salt and pepper! Also, we had to save all our urine & stool. Ultimately, they were measuring the amount of copper going into our bodies and going out of our bodies. If the same amount came out, the Zinc Acetate was doing its job. Zinc Acetate was approved by the FDA in 1997, & sold as Galzin. By the end of Dr. Brewer's study he had over 1000 patients. Today, all I take is Zinc, & my yearly lab tests have been great!

The Wilson's Disease Association has a web site for persons looking for information & support on WD. On this site are the names of physicians who work with WD patients as well as persons to contact for support. I am a contact person for the WD association for the USA. I receive phone calls or e-mails often asking questions about Wilson Disease."

And forty years later....Mason Owings Story

"I was going to University of North Texas when I started to get really bad anxiety. So bad that I didn't sleep for 10 days straight. I was told that I had GAD. Stands for General Anxiety Disorder and they put me on medication for it. Over the next few weeks, I started to lose my balance and I was drooling. I had a MRI which they said that the MRI had shown that I had several strokes. I was immediately admitted into the hospital and the doctor had said that this was signs of someone who huffs paint. I was a very good kid. I was on the honor roll. I followed the rules so my family was in shock. My family called my closest friends and asked them if I did any drugs. They all said no that I would never do anything like that! In fact, I kept them from doing drugs. So my family transferred me to the best stroke doctor in the area. I was in ICU for 4 days before they ruled out that it wasn't a stroke. Over the next week and a half, I was the hospital's mystery case. I had over 50 doctors see me. Finally, I had liver biopsy which told them that I have a very rare liver disease called Wilson's Disease. Wilson's Disease is where the liver can't metabolize copper so it stores it in the liver and brain. There is treatment for it but before you get better you get worse. Over the next few months, I had lost my ability to walk and talk. I started going to therapy and over the course of 9 months, I had learned to walk and talk again. The next 3 years were going to be the hardest to get back to the original me because I also had some

psychological problems.

So this is me 6 years later, I am a teacher to special needs adults. I feel like I have a better connection and understanding with my students because I know what it feels like to not be able to communicate, express your feelings and thoughts. If I were to go through it all again, I would in a heartbeat! I love my students and they love me!

I don't see myself as a victim or a miracle. I just love the life that I God has blessed me with. I have been through some very tough challenges but with God's help and my hard work and determination I am at a point in my life where I don't think I could be any happier. My recovery isn't over just yet. While my job has given me an amazing experience. An insight that nobody else will ever have. I will take everything that it has given me and run with it. I need to start the next part of my recovery. And that is moving beyond and into my education. In the summer I will be taking a college class while still working at my job. It will put me in a environment with people my own age. Which will give me much more opportunities and experience life in which I am so entitled to. I will finish my degree in Business Administration and a minor in Special Education and prove what the doctors said were wrong.

Please share my life changing experience. It will surely inspire you and your friends/family to never give up when life throws you a curve ball."

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The Wilson Disease Cooperative Network (WDCN): A Blueprint for the Future

By Carol Terry, WDA Secretary

WDA Board of Directors, and three support people met on Sunday, September 27th in Weehauken, NJ, to begin planning of our next big endeavor – the formation of a clinical network of specific sites for cooperative research on Wilson disease (WD). We call this network the Wilson Disease Cooperative Network (WDCN) and initially it will involve clinical sites in the US headed by investigators who are members of the MAC, led by Principal Investigator, Dr. Michael Schilsky. Eventually, we hope this will become a global cooperative network “to consolidate, innovate, and transform a new era of addressing unmet patient needs and unanswered scientific questions”. Goals of this network include development of new and better options for the diagnosis, treatment, and monitoring of WD, further study of dosing and efficacy of established treatments, comparative studies on outcomes of treatment, and establishment of a central database, or patient registry, and a repository for blood, DNA, tissue and data of enrolled patients.

We hope to obtain funding and support from public, private and non-profit sources, including the federal government, universities, pharmaceutical companies and WDA donors and members. The plan is to begin with six investigation sites located across the US and use the already established National Institutes of Health specimen and DNA repositories and a patient registry at the Medical University of South Carolina, which will act as the data coordination center.

Obviously this is a major new undertaking and we will need your help to accomplish the goals of the WDCN. How can you help? First, if you are affected by WD, be willing to participate in clinical trials. Second, allow your specimens and data to be included in the new repository and patient registry. Third, respond to surveys that you may be sent by WDCN partners to help obtain funding. And, last, become a member of the WDA, and/or make a donation to support this effort. We are very excited about the WDCN and hope you will be, too!

Editor's Note: Proceeds from the 2016 Big WOW and the Lehigh See-Saw fundraiser event will be used to kickstart this effort.

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New Medical Advisors

The WDA welcomes three new members to its Medical Advisory Committee. The Medical Advisory Committee (MAC) advises the leadership of the Association on medical and scientific aspects of Wilson disease and recommends medically related programs, policies and research, which helps the WDA to implement its mission. These fine physicians join six other internationally recognized Wilson disease physicians and researchers who have been serving on the MAC for many years. They will be a great asset to the WDA in the future. If you are not familiar with our other six medical advisors, please read about them here.

<http://www.wilsons disease.org/wilson-disease-association/wda-advisory.php>



Regino Gonzalez-Peralta, MD

Professor, Director of Pediatric Hepatology and Assistant Dean of the Office of Diversity and Health Disparity, University of Florida - Gainesville

Dr. Gonzalez-Peralta received his BA (Chemistry) from Cornell University and MD degree from the School of Medicine at Universidad Central del Este (Dominican Republic). He completed Pediatrics residency at Cook County Children's Hospital and University of Florida. At the University of Florida, Dr.

Gonzalez-Peralta also served as Chief Resident, completed Pediatric Gastroenterology fellowship training and joined the faculty as an Assistant Professor. He rose through the academic ranks and currently serves as Professor, Director of Pediatric Hepatology and Assistant Dean of the Office of Diversity and Health Disparity.

Dr. Gonzalez-Peralta's academic pursuits have focused on developing a program in Pediatric Hepatology. His laboratory work defined the pathogenesis of liver-cell damage and the importance of viral heterogeneity in chronic hepatitis C. He began to 'miss' interactions with patients and their families. Accordingly, as a way to reconcile personal and academic-research interests, Dr. Gonzalez-Peralta became actively involved in studying the clinical impact of HCV infection in children. With support from the pharmaceutical industry and NIH, he has participated in pivotal investigator-initiated and industry-sponsored pediatric trials of chronic hepatitis B and C, including ongoing studies of direct acting antivirals. He developed an interest in pediatric Wilson disease and has actively participated in WDA activities, including presenting at annual meetings of the organization. In addition, he has held elected leadership positions within the American Association for the Study of Liver Diseases and the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition.

**Tamir Miloh, MD**

Director of Pediatric Hepatology and Liver Transplant Medicine Texas Children's Hospital Associate Professor, Baylor College of Medicine

Tamir Miloh is the Director of Pediatric Hepatology and Liver Transplant Medicine at Texas Children's Hospital, Baylor College of Medicine. He completed fellowship in pediatric gastroenterology and transplant hepatology at Mount Sinai Hospital NYC and remained a hepatology attending. He later built a pediatric liver transplant program at Phoenix Children's Hospital affiliated with the Mayo clinic. Dr Miloh has taken care of dozens of children with WD. He coauthor a manuscript highlighting the good outcomes Miloh continue of liver transplantation for children with chronic liver disease over children with acute presentation and adults based on UNOS data and 2 intriguing cases of unusual presentations of the disease. Dr Miloh is an active member of SPLIT (Studies of Pediatric Liver Transplantation) and the research committee. He has been involved in collaborative multicenter registries and studies.

**Paula Zimbrea, MD, FAPA, FAPM**

Assistant Professor of Psychiatry and Surgery (Transplant), Yale University School of Medicine

Dr. Zimbrea received her medical degree from the Iuliu Hatieganu University of Medicine and Pharmacy, Cluj Napoca, Romania. She completed her psychiatry residency training at Columbia University-St Luke's Roosevelt Hospital in New York City, followed by a fellowship in addiction psychiatry and a fellowship in psychosomatic medicine at Yale University. She has been a faculty at Yale University since 2005 working primarily at the interface between medical illness and psychiatric and addictive disorders. She is currently the Director of Transplant Psychiatry Section at Yale New Haven Hospital. Dr. Zimbrea has been collaborating with Dr. Schilsky at the Yale Wilson Disease Center of Excellence since 2010 and is the author or co-author of several publications focusing on psychiatric aspects of Wilson disease.

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Living With Wilson's: An Interactive Discussion

By Aabha Nagral M.D.

Children's liver foundation had organised 'Living with Wilson's', an interactive support group meeting for patients with Wilson disease on 29th August 2015, in Mumbai, India.

All the patients and visitors were greeted by Mrs Sanjeevani Patwardhan, the oldest patient with Wilson disease. Rakshabandhan, is a festival in India where women tie wrist bands to their brothers to symbolise togetherness in happiness and sorrow alike. The festival was being observed on the same day in India. Sanjeevani excels in making these things of art - she tied

handmade Rakhi (wrist bands) to all patients. She had also made 'moong dal laddoo' (green gram sweetmeat), specially for the meeting since green gram is low in copper! There were lovely bouquets which she had made and were presented to the speakers by children with the disease

Speakers included neurologist Dr Pettarusp Wadia, Hepatologist Dr Aabha Nagral, dietician Ms Suvarna Sawant, Speech Therapist Dr. Bakul Parulkar and physiotherapists Dr Ajit and Dr Usha. Patients interacted with the panel enthusiastically. The discussion was focused on trivial but important issues faced by patients of Wilson's disease related to medication, diet and simple home based physiotherapy. Dr Nagral gave an overview of the disease and how exactly it manifested in different forms. Dr Wadia emphasised the need for good compliance and patience on behalf of both patients and the care givers front as an important part of therapy.

Patients who have been on long term treatment of the disease, shared their experiences with fellow new 'Wilsonians'. They encouraged the fairly newly diagnosed patients and advised them on the need of regular treatment. One of the patients Janice expressed her wish of writing a book on her experience with the disease. She even recited a beautiful poem on her experiences with the disease. It was heartening to see the courage and enthusiasm of the young patient.

Amongst the crowd was a boy Ojas, who had needed a liver transplant to cure his Wilson's a Now he has entered medical school and was all set to become a doctor. His story and words were truly inspiring. He stressed on the importance of taking medication its dedication and to have courage to fight the disease.

The patients urged Children's Liver Foundation to organise a picnic of all patients with no caregivers around! The response was truly encouraging.

Saba – a patient from Karachi, Pakistan with neurological problems who was in Mumbai to receive treatment, accompanied by her mother had made it to the meeting. They found the interaction very encouraging and optimistic and felt that they were a part of the Indian family of Wilson disease patients.

Mrs Sneha, a philanthropist, talked to the patients and discussed on various ways they could be helped, like providing water with lesser copper content, medicines at a sleeve price etc. The meeting gave her a direction to help the patients. She will initiate mechanisms to get medications at low cost for patients with the disease

When the meeting ended, the anxious faces of the patients and caregivers was filled with new hope and enthusiasm. They had learnt new things, cleared their doubts and discussed the difficulties they faced. They had made new friends, who were like them and exchanged phone numbers. It was heart-warming to see the patients go back happy and hopeful. With the support of all our patients and doctors, we hope to be able to keep organising many such meetings and spreading awareness and hope.

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Seesawing for a Great Cause

by Rachel Albert, WDA Board member

Life has its ups and downs-especially for those of us battling chronic, life changing and life threatening diseases. At Lehigh University, members of Sigma Chi Fraternity and Alpha Omicron Pi Sorority sponsor an annual seesaw fundraiser to try and make a difference and help those in need. Working in groups of four throughout two-hour shifts, the students take turns on a giant seesaw for over 50 straight hours. Traditionally, the proceeds have been donated to different cancer organizations. This past year, however, the WDA was the beneficiary of over \$10,000 in honor of a family member of a fraternity member who was recently diagnosed with Wilson's Disease and needed an immediate liver transplant. Representing the WDA, Ahsan Ahmad and Rachel Albert traveled to Bethlehem, PA to cheer the students on and to educate the crowd about Wilson's Disease. We owe these conscientious students our gratitude for both their fundraising efforts and for raising awareness about this rare orphan disease.



Sigma Chi and Alpha Omicron Pi students at Lehigh



Rachel Albert and Ahsan Ahmad at Lehigh

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Yale Center of Excellence News

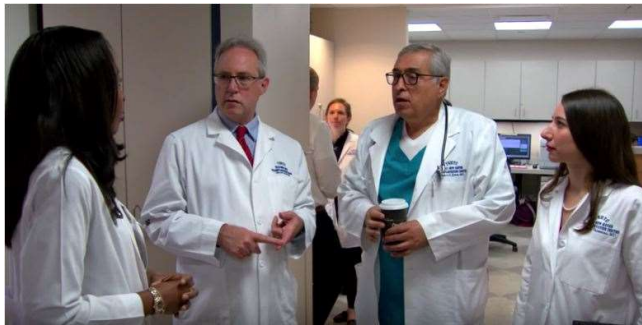
Dr. Michael L. Schilsky, Director of the Center of Excellence for Wilson Disease at Yale is pleased to announce the addition of new members of the Center at Yale who are available to see new patients.

Dr. Pamela Valentino is a pediatric hepatologist and Assistant Professor in the Department of Pediatrics at Yale University Medical School. She trained in pediatrics at Montreal Children's Hospital, McGill University, and in gastroenterology at the Hospital for Sick Children, University of Toronto. Prior to joining Yale University, she completed an advanced transplant hepatology fellowship at Boston Children's Hospital, Harvard Medical School. As a member of the Wilson disease Center of Excellence at Yale, she is involved in the diagnosis and medical management of children with Wilson disease, as well as collaborative clinical research.

Dr. Daphne Robakis recently joined the Yale Department of Neurology after completing a fellowship in Movement Disorders at Columbia University. She graduated from McGill University Faculty of Medicine in Montreal followed by neurology residency at Boston University. She is a board-certified neurologist with experience treating a full range of conditions including tremor, dystonia, parkinson's, tics, ataxia, and chorea. She is very excited to be a part of the Wilson's disease Center of Excellence at Yale and is enthusiastic about providing neurologic care for individuals with Wilson's disease and in advancing our understanding of Wilson's disease through research.

Dr. Nigel Bamford is an expert in General Pediatrics and in Pediatric Neurology. He is certified by the

American Academy of Pediatrics and by the Neurology American Board of Psychiatry and Neurology (Neurology) with Special Qualifications in Child Neurology. Dr. Bamford evaluates and treats children with a variety of neurological conditions and diseases. In addition, he has a special interest in pediatric movement disorders, including Wilson disease, and is the Director of Pediatric Movement Disorders Clinic at the Pediatric Specialty Center in Yale-New Haven Hospital.



Editors Note: The Yale Center of Excellence was featured in a video at the 2015 AASLD conference in San Francisco. The video can be viewed at <http://www.wilsonsddisease.org/wilson-disease-patients/yale.php> or on You Tube at <https://www.youtube.com/watch?v=68Tqq2enzlc>

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