I first met Dr. Sternlieb when I was a medical resident at the Albert Einstein College of Medicine. He at first appeared a very proper person with a quiet nature, but beneath that thin veneer I found a warm, kind and generous person. He was well regarded by his peers as a respected member of the faculty for the Department of Internal Medicine, the Division of Gastroenterology and a founding member of the Liver Research Center. During one of my training rotations I worked on the metabolic ward with Dr. Sternlieb and his colleague, Dr. Scheinberg. I had the opportunity to learn about their interest in Wilson disease, and years later I worked directly with Dr. Sternlieb during my Fellowship in Gastroenterology and Liver Disease at Einstein, and subsequently as a Post-doctoral Research Fellow at the Liver Research Center. I have a great debt of gratitude to Dr. Sternlieb for his willingness to share his experiences in science and medicine and serve as my mentor. I will always have great memories of his thoughtful and caring manner and of his wise counsel as I charted my own career path. I will always cherish walking into his office and hearing him converse in French one minute, Hebrew the next, of seeing his Bedlington terrier resting comfortably beneath his desk waiting for his master for a walk, and most importantly, for being there whenever I needed him.

Many other physicians around the world knew Dr. Sternlieb for his work on Wilson disease and more importantly, as a generous fount of information and a resource upon whom they could rely for advice on how to diagnose and treat their patients. I never knew how much work this entailed until some of this duty passed on to me. I still regularly receive calls, notes and greetings from the many colleagues with whom he worked.

A very important side of Dr. Sternlieb was his dedication to patient care. His patients knew him as a dedicated physician and warm human being. He viewed his patients as his extended family. He surprised many by remembering many details of their personal lives that they shared with him; rejoicing in their triumphs over illness and in life in general, and pained over their losses and failures.

Dr. Sternlieb lived to see many of his patients he helped as children grow into adulthood and marry, have children, succeed at their own careers and live to see retirement and enjoy their own grandchildren. This was unthinkable for a former generation of patients with Wilson disease, but came to pass during his time due in part to his contributions to patient care.

There is a Hebrew phrase “tikkun olam” which means “repairing the world”. One accomplishes this by performing good deeds or “mitzvot” in hopes of a creating a better world for all. In his way, Dr. Sternlieb lived by the principle of “tikkun olam” and was selfless in his work and his giving to others. In the selected anecdotes below from some of his patients who graciously shared their memories of Dr. Sternlieb and thoughts about his recent passing it is apparent that the world is a better place for his good works. As physician and colleague to many, loving husband to his surviving wife Anne and as my personal mentor, the world is surely a better place for his time with us. He is missed but his spirit and good works live on in each of us.

STORY CONTINUED ON PAGE 3

In Memorium – Dr. Irmin Sternlieb – October, 2008
A Tribute to Dr. Irmin Sternlieb by Michael L. Schilsky M.D.
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<td>Our Mission Statement</td>
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<td>The Wilson’s Disease Association funds research and facilities and promotes the identification, education, treatment and support of patients and other individuals affected by Wilson’s Disease.</td>
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PATIENT ANECDOTES/TRIBUTES FOR DR. STERNLIEB

From his many patients, families, and members of the Wilson disease community...

“Dr. Sternlieb was my doctor, my friend and my hero. I owe my life to him. Once I asked him, ‘Dr. Sternlieb why don’t you have children?’ He answered, ‘but I have; all of you are my children.’ It was great having a father who was a Wilson disease doctor. He loved; he cared and always did what he thought was right for us. He gave his heart to his profession and to us. I’m so very grateful. His wife, Anne said, ‘He had a good life.’ He did a lot of good and enjoyed what he was doing. I’m sure that he is in the RIGHT place now.

I’m so very happy that I visited Dr. Sternlieb in September of 2007. We had a nice visit. Dr. Sternlieb is going to be missed. He was part of my life for 40 years and he will remain in my heart forever.” - C.S

“Dr. Sternlieb was the one who checked my oldest son for Wilson’s disease. After that he was always available to talk to us on the phone and answered our questions even after he retired. With his passing we will lose one of the most knowledgeable Doctors on Wilson’s disease in the world. He was one of the few doctors with life time experience with Wilson’s disease patients. He always cared for his patients with a lot of passion.” - P.Y.

“What I remember most about Dr. Sternlieb was that he always had his Bedlington Terrier, Winnie, with him at the clinic. Winnie had the canine form of Wilson disease, and was treated with penicillamine. If you’ve never seen a Bedlington Terrier, they look like small sheep -- very cute… Dr. Sternlieb was involved in much of the early research on Wilson’s disease. The WD community owes him much. He will be missed.” - C.T.

“I thank him for nurturing an interest in the condition that affects our lives so significantly.” - B.S.

“That is sad, I knew him many years ago….Dr. Sternlieb always used to chat with me when I’d come for my check-ups.” - J.F.

“I offer my condolences to Dr. Schilsky and other members of the Wilson disease family who knew him.” - D.K.

“I was deeply saddened to hear of the passing of Dr. Sternlieb. He was a major contributor to the Wilson disease community, as well as the medical profession. He mentored one of the finest physicians, who is now a major contributor to the Wilson disease community in his stead. His contribution continues.

“Personally, I will always cherish the fond childhood memories he gave me. As a child with WD, he always treated me like a member of his own family; and to this day would ask of the well being of mine.

“Although it was 40 years ago, it feels like yesterday that his strong arms picked me up as a sick child, and stood me on a hospital table. He made me feel important enough to snap my picture with his Polaroid - I still have the picture of the little girl with the big belly. I can still remember looking up and up and up (he was very tall to me!) in response to his deep, distinctive, special calling of my name “Hello, -----, how are you? You look well.

“Whenever I saw him, be it in the hospital, or in the office, he always made time for me whether I had an appointed time with him or not. “He even brought his dog, who was afflicted with WD, to the office and pointed out that she was so well because she took her medication -- to encourage us to remain vigilant in treatment.

“He offered new entries to the Healthcare Community, whether patients or caregivers, a strong, secure, knowledgeable beginning --- and remained our strongest allies to encourage us onward, and show us how proud he was of our progress.

“Even as an adult, I still felt secure to see his e-mail name on my computer screen when he was logged on. I looked forward to his generous responses to e-mails sent. He still reminded me to take my medication, and listen to my doctor - and he always asked about the well-being of my family.

“You will be deeply missed, our Dear Dr. Sternlieb. I pray that you rest in peace after a job so well done, and so many people’s life and quality of living positively impacted.”

With Love, Appreciation, and Gratitude, - F.C.W.

“Though I never had the opportunity to meet Dr. Sternlieb in person, it has been my great pleasure to get to know him through the eyes of his patients and fellow physicians, during online chats with him, and through his published work on Wilson disease. Though I can only sense what a kind and caring man he was, it is evident that his past work in the study of Wilson disease has made a profound impact on the present and will continue to do so in the future. I applaud and thank Dr. Sternlieb for adopting the “orphans” and devoting his career to this needy rare disease. His thoughts and ideas will live on in the hearts, minds, and bodies he has left behind. What better legacies can one leave behind?”

Mary Graper
President, Wilson Disease Association

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Editor’s Note: If you are reading about Dr. Sternlieb’s passing for the first time and would like to contribute your own personal anecdotes/tributes please send them to the WDA office via mail or e-mail. They will be published in the next edition of The Copper Connection.
Vilma Dee tried to hold back the tears as she handed the medicines for Marielle. Marielle was a bubbly twenty-year-old who had a rare kind of disease that “poisons” the body because it absorbs too much copper. When Vilma finished praying for her, Marielle beamed and asked for a kiss. “Fight, okay?” Vilma plants a kiss on her cheek. “And don’t forget to pray to Jesus.”

As she takes the 3-hour bus ride from Bulacan back to her home in Las Pinas, Vilma can’t help thinking about the exacting toll of this illness. She is not a doctor, but Vilma knows Wilson disease very well, all too well, in fact. It’s the same hereditary disorder that claimed the life of her daughter Vanessa seven years ago.

**The Face of Wilson disease**

Vilma Dee’s daughter, Vanessa, lost her fight to Wilson disease in 2001. Although broken hearted, Vilma was inspired by Vanessa’s fight and continues to fight for patients with Wilson's disease. Read on to learn about Vanessa’s daughter and how one woman has changed the lives of so many living in the Philippines.

Vanessa was a happy, healthy kid who loved to sing. Growing up normally, graduating from elementary school with a Best in Science Award. That all changed in 1999, when she was 14, Vanessa suddenly got sick. Her complexon turned yellow, and she kept vomiting. At a private hospital in Cavite (35 km South of Manila), doctors gave her a blood transfusion and concluded that she had viral hepatitis – even though she had tested negative for that disease.

For about a year, she was in and out of the hospital, but doctors could not sufficiently explain her illness. Her motor skills were affected; she walked like a robot and had difficulty speaking. Sometimes her condition would improve. But once, she became suddenly violent, kicking and screaming to the point where doctors had to tie her to the bed. She couldn’t recognize people and her speech was incomprehensible. Her condition deteriorated and she had to stop attending her second year of high school. Ultimately, Vanessa fell into a coma.

Vilma knew she had to fight for her daughter’s life and took her to Manila for care, but was turned away at a well known public hospital. Vilma turned to prayer and was inspired to just go to the nearest hospital, which happened to be the Medical Center Manila. There, Vilma was met by Dr. Leticia Ibaneza-Guzman, a specialist in Internal Medicine and Gastroenterology.

Dr. Ibaneza-Guzman assessed Vanessa and gave her only a 20% chance for survival. Vilma continued to pray for her miracle. The next day, Vanessa awoke from her coma. By a stroke of luck, or perhaps divine intervention, Dr. Ibaneza-Guzman had treated two patients previously with similar symptoms and began testing for Wilson’s disease. Vanessa was screened through the 24-hour urinary copper test, serum ceruloplasmin test and slit lamp examination for Kayser-Fleischer rings. Strongly suspecting Wilson disease at this point Dr. Ibaneza-Guzman explained to Vilma that sadly, there were no medicines available in the Philippines to treat the disease. She referred Vilma to her former patient who lived more than 100 kilometers south of Manila for help.

Vilma’s family tracked the patient down seeking help for Vanessa. He had received Cuprimine from family members living in the US and sold some of the medicine for Vanessa. The test results were complete and the diagnosis was definitive, Vanessa had Wilson disease. They now had their diagnosis and a way to treat it. Vanessa took the Cuprimine and restricted the copper in her diet and her condition improved. She was able to go home.

Vilma did all she could to learn about this strange and mysterious illness researching on the internet all the while trying to balance her life as a single mother caring for her two other children, attending to her job and caring for Vanessa.

Even with Vilma’s diligence, constant medication and regular checkups, Vanessa’s abdomen again became enlarged and her liver disease progressed. Vanessa told her mother one day, “Mommy, something will happen today. I want you to be ready. The only reason I still fight is you. But if it were only up to me, I’m already tired…” Vilma didn’t understand what her daughter meant. She tried to give Vanessa her medicine, but Vanessa refused. Then fluid, like water, flowed out of Vanessa’s mouth. Vanessa told her mother that the fluid was “The pain felt by people who are sick like me (with Wilson disease). I just brought it out…” Vanessa continued telling her mother “My whole heart, my whole soul, I’ve already given to Jesus…Please tell all those who’ve helped us, ‘Thank you.’”

Dr. Ibaneza-Guzman had called and told Vilma to convince her daughter to go back to the hospital, Vanessa agreed, but lost consciousness in her mother’s arms on the cab ride there. Doctor’s tried to revive her several times, but could not. Vanessa stopped fighting on March 27, 2001. She was 16.

**Vilma’s Fight**

Vilma has not stopped fighting. Since her daughter’s death she has worked closely with the Wilson Disease Association helping others in the Philippines so that they would not suffer the same loss that she did. Vilma has established the Wilson Disease Awareness Center – Philippines, seeking to spread awareness about the disease so that it is properly diagnosed and treated. She has worked with the WDA to bring medications to patients through the MAP International program. Vilma has traveled many miles at her own expense to deliver these medicines to patients because their families have been too poor to come to her to get them. Mothering the patients too, she reminded families of the importance of submitting the requirements to the program so that there would be no delay in requesting their next supply.

Vilma also provides endless moral support to the patients and their families. She helps them understand what is happening and the medical-ese which can be so confusing.

Vilma says that her daughter’s death would have been in vain if she didn’t seek to help others with Wilson disease. She believes that is what Vanessa was trying to tell her in her final moments with her. Vanessa’s words inspire her to fight for Wilson disease patients, to help them to lead normal lives and to comfort them when they need comforting. Vilma’s work inspires us all.
President’s Message

With the beginning of 2009, and spring just around the corner, I write to you with a sense of hope that this will be a much better year than last. I want to thank all of you who responded to the year-end letter requesting donations. Your continued support is vital to the continuing success of the WDA!

I would like to tell you about some of the exciting plans in store for 2009. This year we will not be holding a large annual conference as in the past. Instead we are planning 3 – 4 large regional meetings in an attempt to reach out to more of you with the same valuable information provided at the annual conferences. As you will see in this newsletter, plans are well underway for a fantastic full day meeting in San Francisco on May 2, 2009. We are grateful to Dr. Robert Gish and his staff at California Pacific Medical Center for collaborating with the WDA to hold this special event for physicians and patients/families. Other such meetings are being planned in collaboration with: Dr. Michael Schilsky for the New York area; Dennis Thiele PhD. at Duke in North Carolina; Dr. Aleks Videnovic at Northwestern in Chicago. Dates are yet to be determined but please watch the WDA website, future newsletters, and your e-mail for updated information.

Speaking of fundraising…a few of our members are planning some fundraising events to benefit the WDA. The Tri-State group is organizing another W.O.W. Walk-a-Thon this spring in New York! More information will be forthcoming soon. Another member engaged his employer in a nationwide company fundraising event that took place on February 13, 2009. We are excited to see those results! Do you have a local grocer like I do? I approached the owner about a fundraising event in his stores. I anxiously await an answer. There are endless ways to help. Join in, you can do it too! Can’t help raise funds but would like to help in another way? Not a problem, there are many other ways to help. This important cause is not just about you or me. It is about all of us working together to make the WD world a better place. After all, “We are Family” and family pulls together to help one another. In this wonderful new year of hopes and dreams, let us all work together for the benefit of our WD family!

With my warmest regards for all of you,

Mary

The WDA Collaborates with California Pacific Medical Center for SF Regional Meeting

The WDA is pleased to announce that with the generosity of Dr. Gish, Medical Director Liver Transplant Program and Chief Division of Hepatology, we will hold our first Regional Meeting in San Francisco on May 5, 2009.

This one day seminar and patient/family educational regional meeting will begin at 8:00 a.m. and end at 4:00 p.m. There is also a pending application for CME credits. Please check the WDA website for further updated information.

This meeting promises to provide current educational information regarding the early diagnosis and treatment of patients with Wilson disease followed by an opportunity to ask questions of the experts and meet other patients and families with Wilson disease.

The preliminary subjects to be covered are as follows and subject to change:

- Screening and diagnosis
- Molecular genetic testing
- Treatment of Wilson disease
- Wilson disease and contaminant liver disease
- Wilson disease and transplantation
- Wilson disease and chronic liver disease
- Dietary recommendations and supplements
- Patient perspective on Wilson disease.

For a full, updated schedule, please check the WDA website for more information.

To register to attend this meeting, or for additional information, please contact Kimberly Symonds at 888-264-1450 or info@wilsonsdisease.org
Congratulations to Evelyn Nardo and her helpers Alexis Topham, Bob and Renee Nardo, and Marc Davidson for the fantastic job they did on the 2nd Walk Out Wilson in Boston, Massachusetts!

Together, with their army of walkers, they raised over $11,000 for the Wilson Disease Association. This year the Kiss 108 Boston radio station team came and set up a broadcast from the walk and played music to get everyone into the spirit. Additional sponsors of the walk include: Whole Foods, Stop & Shop, California Pizza Kitchen, The Real Deal Deli, Wal-Mart, Bertucci’s, TGI Friday’s, Designs Unique, Beacon Telecom, Inc, and Infinite Possibilities Foundation, Inc. Thank you to all for your support! Together we will make a difference!!!

Global Rare Disease Day Set for Feb. 28th

The Wilson Disease Association will participate in a global Rare Disease Day on February 28th, 2009. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies and companies in focusing attention on rare diseases on that day.

This will be the Second Annual Rare Disease Day. The first was observed in Europe last year and was organized by EURORDIS, the European Rare Disease Organization, and the national alliances of rare disease patient organizations in each country.

This year, EURORDIS invited NORD, the National Organization for Rare Disorders, to organize a similar observance in the United States. Activities are also being planned in some other countries. The ultimate goal is to have a global Rare Disease Day on the last day of February each year.

The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

Watch our website, or the following sites, for more information on these and other activities:

Global Rare Disease Day website: www.rarediseaseday.org.
Thanks for Your Support!

Boston WOW
Ernest Brady • Susan Breitman • Christine and Mark Bugden
Catherine Carroll • Janet and Scott Dixon • Allison Frommeyer
Corinne and Andrew Garland • Clive Godwin
Lee and Sandra Graham • Brett Harvey • Noreen Henrich
Steven Lamond • Pamela Lapon • Sharon LeBlanc
Kathleen Macisaac • Linda and Joseph McCracken
James Morrissey • Evelyn Nardo • Mary and Frederic Peterson
Melissa Riccioli • Dennis and Gail Ronan
Teresa and William Siegart • Meryl andnd Richard Waldman
Ann Walsh • Julia Whittier (in memory of Mark Whittier)
Robert Whittier • Beacon Telecom, Inc
International Association of Firefighters Local 1707 Natick

Challenge
Carol Terry

Fundraiser
Johnny Ferrara

General Contributions
Eugene and Susanne Brown • Darlene Cole • Maryann Coppolino
Butch and Susan Cross • Edna Cross • Steve Earley
Gloria Fausneautch • Paul Fausneautch • RP Gonzalez
Corrine Graper • Brian Higashi • Richard Hodes • Quang Lam
Marci Levins • Xiuling Liang • Pat Meadows • Rebecca Mills
Thong Nguyen • Thomas Puetz • Len and Diann Pytlak
Karl Reichard • Lourdes Reyes • Ruth and Jim Russo
Emi Shaland • Mildred Shannon • Michael Smith • Gail Sweeney
Liang Xiuling • Community Foundation Alliance
Lowell General Hospital • Washtenaw United Way

Honorarium
Mark Mirkin

In Honor of Gary and Sherry King
Jerry and Karen Nixon

In Honor of Drew Katz
Joseph Salema

In Honor of Judge and Mrs. F. Fetzer Mills
Edward Martin • J. Franklin Martin

MAP
Chadi Bou Diab • Anthony and Sara Denham
Maria Fuentes • Julie Holland • Ajith Kuriakose
Amil Mehra • Marina Pavlova • Marina Pavlova
Congregation Shaaarey Yeshua

Marketplace
Nancy Bourke • Mary Irwin • Karyl Richards • Heather Wallman

Membership
Mark Affeldt • Eileen Smith and Glen Gilchrist
Cathleen Bergmann • Jimo Borjigin • Janene Bowen
Erin Brooks (in memory of Ronald Brooks)
Pat Brooks • Eugene and Susanne Brown
Alexandru Caranica • Darlene Cole • Sylvia Coleman
Butch and Susan Cross • Rui Esteves • Paul Fausneautch
Scott Fausneautch • Barbara Frayer • Jeanne Friedman
Joseph Vincent Gaven • Martin Greene • Charlotte Hirsch
Marianne and Joseph Joyner • Kurt and Nicki Karst
Rajinder Kaur • John Kovarik • Xiuling Liang • Agnes Lute
Karen Mandarano • Nancy Marsala • Lori Mason
Duane and Beverly Mattheis • Tony Maynor • Valentina Medici
Ashish Mehta • Ann Melasky • F. Fetzer Mills • Rebecca Mills
Howard Mitz • Dan and Amber Morgan • Thong Nguyen
Barbara Noci • Ron Olch • Maria Pietruszka • Thomas Puetz
Charlie Pursley • Marjorie Riches • Stephanie Robl
Lorenzo Rossaro • Delia Ruiz • Cindy Russell
Ruth and Jim Russo • Burton Scott • Emi Shaland
Mildred Shannon • Jit Singh • John Sisti • Bonnie Smelser
Robert Smith • Robert Stall • Robert Steiner • Gail Sweeney
Susan Tarquino • Manuel Villegas • Frank and Bernadine Wall
Liang Xiuling • Margaret Yglesias • Parichehr Yomtoob
Aton Pharma, Inc • Qualtrain International • Laura Weinberger
Sophie Wood

In Memory of James Badamo
Dolores Badamo

In Memory of Therese Fraher
Cathleen Bergmann

In Memory of Tiffany Culy Modic
Michael Franceschi

In Memory of Carrie Kastroll
Merry Haberman • Amy Sebastian
Hal and Diane Waldman

In Memory of Brenna Nicholson
Theodor Prema

In Memory of Rick Wade
Frank and Bernadine Wall

Year End Contribution
Cynthia Adams
Frederick and Juanita Aukman (In memory of Alicia Gozora)
Zoukhra Bash • Cathleen Bergmann • Patricia Charache
Bryan Clay • David and Naida Cohn (in memory of David Yomtoob)
MaryAnn Coppolino • Gordon and Tavalyn Crim
Anne Pintozzi (In thanksgiving of David Villanueva)
Phyllis & Kristen Digiorgio (in honor of all Wilson's disease patients)
Thomas & Jeanne Fink (in memory of Kelsey Fink & Michael Fink)
Lilian Fisher • Gerald Fortuna
Bernice Gilchrist (In memory of Roland Gilchrist)
Sandor and Emses Greksa
Mr. and Mrs. Cornelious Hoggard (in honor of Debra Hoggard)
Reed Hughes • Henry and Marcia Kaplan
Laura Kaplan (in memory of Hoda Kaplan)
Diane Laurain (in memory of Mark Laurain)
Virgil & Mary Ann Laurain (in memory of Mark Laurain, in honor of Diane Laurain)
Jack Levin • Duane and Beverly Mattheis • Pauline McNulty
Fetzer Mills • John Misciascio (in honor of Nick Misciascio)
Donna Pleva (In memory of Carol Louise Pleva)
Phil Portney • Edward and Miriam Rabin • Michael Rabin
Teresa & William Siegart (in honor of Emily Siegart & Evelyn Nardo)
Marlyn Slavin • Michael and Lucinda Sobkowski
Isabelle Sokoloff • Vivek and Lakshmi Subramanian
Carol and Sparky Terry
Frank and Bernadine Wall (in memory of Rick Wade)
Aton Pharma, Inc • Sal Gaimaro and Larissa Frenkel
Fundraising Ideas

Thank you to those who have responded looking for ideas to raise awareness about Wilson disease and raise funds to help us with our mission. Below are a few ideas and there are more on the WDA website. If you have an idea to share, let us know! We are happy to let others know about it.

Dress Down Day for Wilson disease
Contact HR dept or Office manager to see if they will designate a Friday as Dress Down Day for Wilson disease. Then hang posters around the office to promote the idea.

Virtual Tea
Send an invitation around to all your friends asking them to join you in a Virtual Tea. We can set this up on Firstgiving – for each tea party!

Thanksgiving Letters
Send around a letter stating what you are thankful for and asking people to make a donation on your behalf for everything you are thankful for – good idea around birthday’s or the Thanksgiving Holiday. This can also be set-up on Firstgiving.

Restaurant Fundraisers
The restaurant gives you a percentage of the sales on a designated night for all the customers that you bring into their business.

For more information on how to hold a successful fundraising event please visit www.wilsonsdisease.org for a detailed, step-by-step instructions. Or call the WDA office at 888-264-1450.

Letters from Families

Dear Kimberly:
I wanted to send you a quick note to thank you for being so incredibly thoughtful and helpful in getting information for my sister, a Wilson’s disease patient, “EL”. You have been incredibly gracious and informative, and we are so grateful to you for putting us in touch with Dr. Schilsky. Through him, we were able to obtain some sound and reliable medical advice about seeking further treatment for Wilson disease in our area, and are comforted in knowing that he is an expert in this field.

And thank you for the information about the availability of travel reimbursement for medical need and for the information you provided about obtaining an emergency prescription of Cupramine. You can only imagine the stress you relieved! The Wilson’s Disease Association International is truly a blessing! Thank you so much for everything you have done for us.
Sincerely,
A.G.

Dear Kimberly:
I just want to thank you so much for listening to me and talking to me when I had nobody to go to. I know you were busy, but you were a very big help to me. I can’t thank you enough. This Thanksgiving I am very thankful for you. Here is a picture of me so you can put a face with the name and I also gave you a picture of y family because you also helped them. It is not a very good picture as you can tell the sun is in our eyes. I hope you had a happy and healthy Thanksgiving.
Sincerely,
A.C.

New WDA Publication
“Algorithms for Assessment of Wilson Disease”

The revision of the AASLD Practice Guideline by Drs. Roberts and Schilsky, “Diagnosis and Treatment of Wilson Disease: An Update”, was printed in Hepatology in 2008. The publication reflects the many advancements made in the study of WD and necessitated a revision of the original WDA brochure printed in 2004. The brochure now contains three separate diagnostic algorithms in addition to other valuable information. Currently it is available in printable pdf format on the WDA website or by contacting the WDA office. As soon as funds become available, a professionally printed version will also be available.

2008 GRANT AWARD

The WDA was pleased to receive three applications for research projects. Unfortunately, due to the current state of the economy and the research community, the WDA Board of Directors determined that the funds would better serve the WDA research initiatives if they were held until a clearer path is identified.

The WDA is looking to bring on a volunteer research director and redirect this important project in 2009. Please look for these announcements in the coming editions of The Copper Connection and on our website – www.wilsonsdisease.org.
WILSON’S DISEASE ASSOCIATION

MEMBERSHIP APPLICATION

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

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 e-mail address above)

☐ Silver Membership - $120
  • Receive quarterly WDA Newsletter via U.S. mail or e-mail – (Please provide e-mail 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 e-mail 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 e-mail 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’S DISEASE ASSOCIATION:

Name ____________________________________________

Address ____________________________________________

City ___________________________ State ______ Zip ______ Country ____________

I am making a tax-deductible donation of $______________

☐ In honor of ____________________________  ☐ In Memory of ____________________________

Send acknowledgement to: Name ____________________________ Address ____________________________

City ____________________________ State ______ Zip ______ Country ____________

PAYMENT INFORMATION

Membership Fee $ ________  ☐ Visa ☐ Mastercard ☐ Check or Money Order attached

Donation $ ________  Card # ____________________________

Total $ ________  Expiration Date: ___________  CID# ____________ (3 digits on back of card)

Signature ____________________________________________
For Your Information

**WDA Wish List:**
- Donated Printing Services
- Family Run Fundraisers
- Newsletter Support

**Newsletter Deadline:**
*The Copper Connection* welcomes, and would appreciate, any articles that members would like to submit for publication consideration. If you would like to submit an article, the deadline for the December newsletter is February 28, 2009. Please e-mail your article to the WDA office at: wda@sssnet.com

The Wilson’s Disease Association is a charitable organization which relies on donations to do its work. Please help us! Tax-deductible donations may be sent to:

**Wilson’s Disease Association**
1802 Brookside Drive
Wooster, OH  44691

**Join our Online Community**
The Wilson Disease Association partnered with Inspire to bring our members a place for open dialogue among all Wilson disease members – no matter what the relationship is to Wilson disease. Join us by participating in a discussion, start your own discussion, create a blog, or vote in a survey. There are many ways to participate. Go to the WDA website, www.wilsonsdisease.org and click the button on the front page. Hope to see you there!

**Shopping!**
Shop iGive.com and find everything you need from paper goods and decorations; to clothing and accessories; music and entertainment; - the perfect gift for everyone on your list. Plus WDA benefits from your shopping!!! There are hundreds of stores on the iGive site including: Disney Store, Eddie Bauer, Spiegel, JCPenney, Walmart.com, Barnes and Nobel, Gap, Home Depot, and Starbucks! All give a percentage back to WDA if you register and shop through the iGive.com site

**Stock Donations**
Please consider the Wilson’s Disease Association for a 2009 stock donation. For more information, please contact the national office at 888-264-1450

**Foundation Assistance Needed**
WDA members help us in so many ways. Here is one more thing you can do to help. Put us in touch with Foundations who might be willing to help fund WDA’s mission. Some of you may have access to a Foundation through your company, family members, or friends. While it is true that many Foundations have very specific missions, they are often amenable to proposals that come to them from a Director or Trustee.

If you know of a Foundation that may be willing to assist us, please contact the WDA office (888-264-1450 or wda@sssnet.com). We can work with you on the best approach and what kind of proposal would be most suitable. Who knows, your efforts in this regard could pay enormous dividends!

**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.
**Pill Box Timer**
Remember to take your medication on time with WDA’s new Pill Box Timer. These great timers have, in addition to the normal display, an alarm and stopwatch to ensure that you don’t miss a single dose. Holds 15 aspirin-size tablets; has attached lanyard for use around neck, but small enough to fit in a pocket or purse. 3.5” L X 2” W X 5/8” Deep. Two colors available: purple and green. Donation requested is $15.00 plus shipping and handling ($2.50).

Number of Pill Boxes __________

**WDA Awareness Bracelet**
You asked for them…we got them! WDA Awareness bracelets! They are copper in color and are designed to bring awareness to Wilson’s disease. The bracelets are packaged in groups of 5. The suggested donation per bracelet is $2.50, that comes to $12.50 per package. Copper color, inscription to read: STOP COPPER! SUPPORT WDA wilsonsdisease.org

Package of Bracelets___________

**New WDA Patient Education publication available, Wilson Disease: Maintaining a Successful Treatment Plan**
Published in March, 2008, this 8 1/2” x 11”, 32 page publication includes the topics: Medical Care, Medications, Diet and Nutrition, Special Circumstances, and Family Concerns and Genetics. Also included is a glossary of medical terms, a glossary of genetic terms, and a printed copy of the “Wilson Disease Patient Lab Tracker”. If you would like a copy, please contact the WDA office at: wda@sssnet.com or 888-264-1450. No fee is associated with this publication, but a donation would be appreciated.

Number of Handbooks __________

**WDA Bumper Sticker**
Join in bringing awareness about Wilson’s disease! These stickers are 3” x 10” and have Copper color graphics with black text. Thank you to members Melissa and Patrick for designing them. And, a special thank you to Patrick for donating them to the WDA in honor of his son Jeff! Don’t like sticking these things to your bumper? How about your front door, boat, work cubicle or “just about anywhere things will stick!” Suggested donation is $5.00 per sticker, shipping and handling included.

Number of Stickers __________
Wilson's Disease Association
Volunteer Profile

Name: __________________________ Connection to Wilson's Disease: __________________________
(Please include professional designations: e.g. M.D., Ph.D.)
Spouse or Significant Other's Name:
Home Address: ______________________________________________________________________
Home Telephone Number: __________________________ Fax: __________________________
E-Mail Address: __________________________________________ Business Title: _____________
Business Address: ____________________________________________________________________
Business Telephone Number: __________________________ Fax: __________________________
Occupation and Job Responsibilities: ____________________________________________________
Company has a matching gift program (circle one): Yes  No
Board Memberships and Professional Organizations: ________________________________________
Social Affiliations/Clubs and Organizations: ____________________________________________
Personal Interests/Hobbies: ____________________________________________________________

Areas of Experience or Expertise:

Auditing
Legal - Nonprofit Experience
Government Affairs
Marketing
Public Speaking
Fundraising:
  Special Events
  Foundations
  Corporations
  Other (specify) __________________________
Writing
Media
Graphic Arts
Board of Directors
Computer Technology
Web Site/Internet
Newsletter
Local Support Group Organizing/Leading
Office Work