Enroll in the WD Patient Registry – It’s Easy!

by Carol Terry, WDA Vice President

Let me introduce myself. I’m Carol Terry, Vice President and Co-founder of the WDA. I also have Wilson disease – I was diagnosed in 1973. In the 45 years since I was diagnosed, I have seen, and even been a part of by participating in clinical trials, many research developments of benefit to those with WD. When I first heard about patient registries, several years ago, the idea really caught my imagination. I began thinking of all the aspects of WD that needed investigation, and I began pushing for a WD patient registry. And now, thanks to those of you who sponsored a Big Wow event, donated to one or raised funds for or donated to the WDA in many other ways to support registry funding, and thanks to Dr. Michael Schilsky, Chairman of the WDA Medical Advisory Committee (MAC) and Director of the WD Center of Excellence (COE) at Yale University, and other members of our MAC and COE Directors for their work in designing and building the registry database and program, we are finally ready and have begun enrolling patients in our registry.

Of course, I told Dr. Schilsky, my WD doctor, that I was ready to enroll in the registry as soon as possible. After making my appointment for 9 am on May 7th, the Yale registry project manager emailed me information about the appointment location and a copy of the consent and research authorization form which describes the risks involved, data and specimens that may be collected, and how your identity and information and specimens will be stored and protected in the registry databank. The project manager encouraged me to review the form carefully and ask any questions necessary before agreeing to enroll.

The registry is not only important to current patients but is important because it will impact patients for generations. Our researchers and our donors are creating a legacy.

Our Patient Registry project started in September of 2017 and the years expressed in the chart above all run from September through August. Up the left side of the chart are dollars needed or raised and across the bottom of the chart shows which year you are looking at. Each year shows the funds needed and the funds donated so far. There is a third bar in the first year showing that registry startup costs and operations have been paid. You can see that although Year 1 is not quite finished we were able to raise the cost of year 1 and all of the cost for year 2 that begins coming September. We now started raising funds for Year 3. As we add more centers and increase patient enrollment the costs increase. Each patient enrolled in the registry will remain enrolled for the duration of the project and continue to be monitored.

We have been very fortunate to meet the needs of our first two years but we cannot become complacent considering the amount need to fund the remainder of the project.
Letter from the President

Dear Wilson Members and Supporters,

We are here to create more awareness of Wilson Disease and to help improve the diagnosis of this disease. Our mission is to fund research and continue to support those affected by Wilson Disease.

Our annual conference was in Houston, Texas, April 27-28, and many who attended expressed it as being our best conference ever. There is a brief article in this issue about the conference and we hope to put the speaker presentations on our website to share what we learned.

The Patient Registry, which launched in December 2017, is being funded by WDA and your contributions and continued support will help make this a reality. We have increased our fundraising activity and need to raise $3M over the next three to five years. All funds we raise at the Big WOW (September 29, 2018) will go toward the Patient Registry. There also is a new peer to peer fundraiser for people unable to host a walk.

To help keep our operating costs low we operate as a virtual office (we have an address without a dedicated office space – i.e., you cannot come visit us at our office as many have hoped to do). We use a Voice over Internet Protocol (VoIP) phone system. If we do not answer the phone when you call your message is emailed to us and all physical mail is scanned and also emailed to us. It has taken getting used to this process but as we can recognize much efficiency we will continue as a virtual office.

As we strive to increase awareness of Wilson Disease, we continue to increase our use of social media. This past year we launched Wilson Warriors and Faces of Wilsons and now We Are Wilson’s has began this month. We welcome any photos and stories you would like to share – the more the better. Your stories help increase awareness of Wilson Disease.

We hope to hold a support meeting this fall (1/2 day in October or November), although a location has yet to be decided. We have received potential locations and are working toward bringing a support meeting closer to you. If there is enough interest we would like this to become at least an annual event.

It was great meeting many of you in Houston and I look forward to seeing or meeting many of you at a future support meeting or conference.

Remember compliance and adherence is essential to all Wilson Disease Patients.

Jean Perog
President
Patient Registry
continued from page 1

Enrolling in the registry isn’t difficult. It involves a 3 hour appointment during which I first was asked some questions about my health history, medications, and family history of major diseases. I prepared for this by making written lists of my medications and dosages, medical procedures and surgeries, and medical conditions, along with my past lab test results as recorded on my lab tracker spreadsheet, which I provided to the project manager. Next came a brief physical exam by a hepatologist (Dr. Schilsky in my case), and then a psychiatric assessment by a psychiatrist using a standard measurement tool. These were followed by a neurological assessment by a neurologist who specializes in movement disorders (with videotaping if you agree to it). Finally, they drew about 8 tubes of blood, including blood for a genetic test (which you may also decline, if you wish). In addition, I was given a prescription for a 24 hr urine copper test to be done at home. To help with travel costs, I was offered a $50 stipend, which I declined. Enrollees are required to complete a self-report health survey every 6-12 months and to undergo similar neurological and psychiatric assessments, etc., when they visit the study site for their routine WD monitoring every 6-12 months for 5 years, with a possible extension for an additional 5 years.

Currently, the WD Center of Excellence at Yale, in New Haven, CT, is enrolling patients in the registry. Enrollment at the University of Michigan is pending on the internal review of documents necessary to officially launch the registry. Enrollment is scheduled to begin in September at the Center at University of Surrey in the UK, in October at the Centers at Baylor College in Houston, TX, and at University of Washington/Seattle Children’s Hospital in Seattle, WA. In November, Dr. Regino Gonzalez-Peralta will begin enrolling patients at Florida Hospital in Orlando, FL. Persons interested in participating at any of these sites should contact Dr. Michelle Camarata, michelle.camarata@yale.edu.

I hope you will join me and enroll in the WD registry soon.

Looking Toward the Future - WDA 2018 Annual Conference
by Jean Perg, President

The Wilson Disease Association Annual Conference was held in Houston, Texas on April 27-28, 2018. It was hosted by our Center of Excellence in Houston (Baylor and St Luke’s). The attendees were a diverse audience and the organizers did a terrific job trying to meet their needs. Learning about new developments was important to all. The speakers and presenters were impressive.

The conference evaluations indicate that the overall event was very informative (5 out of 5 rating) providing important information and clarification on specific issues. Every speaker was highly rated and it is hoped all speakers will give us permission to post their presentations on our website. A special acknowledgement to Dr. Miloh for inviting all of the presenters and organizing the topics for this conference.

The conference was well attended with over 120 registrants. The welcome reception on Friday night was well attended and gave everyone a chance to meet or reacquaint with each other. Saturday was a full day with 8 speakers followed by a gala including dinner and dance and ice cream for the kids (next year we all want ice cream).

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We are starting to plan our next annual conference which will be in the spring of 2019 (possibly April). It will be hosted by Yale and will be located at either Yale or New York City. Each year we hope to be bigger and better – challenges out to Yale! Some topics that have been requested are genetics, compliance and the update on the Patient Registry.
WDA 35th Anniversary

This is the 35th Anniversary since the WDA was incorporated and there is a sense of optimism that is almost tangible. One contributing factor may be the recent patient registry research that started last fall. One Anonymous donor pledged to match all donations up until $50,000 is reached to be used for the patient registry. This kind of gift is known as a challenge grant because it is a challenge to other donors to meet the $50,000 mark. If you are interested in challenging this donor back by making a donation you can mail a check marked in the memo line “double challenge grant.” And it will go to that account. You can accomplish the same thing online at the WDA website if you look for the ways to help tab, and then click on Double your donation. It is a smart way to leverage your donations.

Drug Benefit Plans Available for Canadian Patients

Each provincial and territorial government offers a drug benefit plan for eligible groups. Some are income-based universal programs. Most have specific programs for population groups that may require more enhanced coverage for high drug costs. These groups include seniors, recipients of social assistance, and individuals with diseases or conditions that are associated with high drug costs. For more details, please contact your provincial or territorial health care ministry.

If you are insured through an employer or group plan, please remember the rules change at the end of every year and you should check your new policy as quickly as possible. By that we mean, don’t wait until your prescription runs out in February and it is urgent. Working through insurance company hurdles takes time. Make sure you have a current prescription or don’t wait until you are out to make that doctor appointment.

Health Canada’s Special Access Programme (SAP) considers requests for access to drugs that are unavailable and for that your doctor would have to write a prescription for Trientine. Sometimes we are able to provide assistance during the process when it is not running smoothly. Contact us for help or to make us aware of any issues and we can be your advocate. Do not stop taking your medication, even if you feel fine. The consequences of doing this can be disastrous.

Contact us for help or to make us aware of any issues and we can be your advocate.

Patient Assistance Programs Guide for US Patients

Insurance won’t cover or co-pay too high to manage? No insurance or underinsured? Many people are in the same situation. The WDA tries to advocate for you until there is a new set of rules or price structure. Right now there are a few things to consider. If you are insured through an employer or group plan, please remember the rules change at the end of every year and you should check your new policy as quickly as possible. By that we mean, don’t wait until your prescription runs out in February and it is urgent. Working through insurance company hurdles takes time. Make sure you have a current prescription or don’t wait until you are out to make that doctor appointment.

When you are going to use a patient assistance program the process is much smoother when you have already done the things above. The next thing to do is to apply. These WDA patient assistance programs are not income based but based on if you are insured or not or if your insurance covers your drug or not. There are distinctions between Medicare and under insured patients. Make sure you make the notation on your application if there is a place for that. There may be two separate departments that handle those, one specializing in government processes and the other with insurance processes.

Depending on your coverage another route to consider is if your insurance company won’t cover Syprine® you might see if they will cover one of the generics available and for that your doctor would have to write a prescription for Trientine.

Sometimes we are able to provide assistance during the process when it is not running smoothly. Contact us for help or to make us aware of any issues and we can be your advocate. Do not stop taking your medication, even if you feel fine. The consequences of doing this can be disastrous.

The following information can also be found on our website under Patient Assistance Programs:

 Valeant Pharmaceuticals launched a new program, WD Rx Access – an enhanced version of the former Valeant Coverage Plus Program – which reduces the co-payment cost for all eligible patients taking CUPRIMINE® (penicillamine) or SYPRINE® (trientine hydrochloride). The program also includes an offer that makes receiving these medications more convenient.

 The co-pay for CUPRIMINE® and SYPRINE® has been reduced from $25 to $5, for eligible patients. Patients also have the opportunity to have their medicine mailed directly to their home through a specialty pharmacy. Specialty pharmacies offer 24-hour access to pharmacists, auto-fill prescriptions, direct follow-up with physicians and more.

 It is important to know that patients need to re-enroll every year for patient assistance. For those currently enrolled, a team member from WD Rx Access will proactively reach out to help re-enrollment at the start of each year. If you are interested in financial assistance, need to re-enroll, or want to take advantage of the specialty pharmacy offer, the WD Rx Access team members can be reached at 888-607-7267, Monday-Friday, 8 AM-6 PM ET.

 You can find more information on http://www.wdaccess.com and also learn about new services available for people living with Wilson’s Disease, which include access to a dedicated nurse who can provide support related to treatment, diet, HCP communication and more.

Teva Patient Assistance Program for Gabz™

Teva Select Brands sponsors a Patient Assistance Program for Gabz™ (www.gabz.com). If you have any questions regarding the Teva Assistance Program™ please contact them at (877) 254-1039 or visit www.tevacares.org.
International Patient Assistance Programs for Developing Countries

Partnerships with MAP International and Univar Ltd.

Like many things in the world our programs sometimes change. If you are currently participating in an international patient assistance program there are steps you need to take to renew your plan that may be different than last year. We describe some of these changes below.

The WDA has partnered with MAP International and Valeant Pharmaceuticals (Bausch Health Companies Inc. starting in July) to support an international medication assistance program for Cuprimine® (penicillamine) and Syprine® (trientine hydrochloride). Limited amounts of these medications are generously donated by Valeant and shipped, at the request of the WDA, by MAP International. Shipping costs for this valuable program are covered by the WDA. Donations to the WDA from recipients are welcome to help us defray the costs of this important program.

To apply for this program please contact Mary Graper at mary.graper@wilsonsdisease.org one month before you will run out of your current supply of medicine.

The WDA also has a partnership with Univar Ltd. for the compassionate use of Trientine Dihydrochloride 300mg. Again, limited amounts of this medication are generously donated and shipped by Univar, on behalf of the WDA. This valuable program is completely free to the WDA since Univar also generously donates shipping costs. A recent change to this program is that Univar is temporarily unable to ship trientine to India. We are working on a long-term solution for this issue and will try to resolve it as soon as possible. Until then, if you live in India, please contact Mary Graper at mary.graper@wilsonsdisease.org one month before you will run out of your current supply of medication so that she can point you in the right direction.

Requests for all other countries must now be shipped to the patient’s treating physician, clinic, or pharmacy. Patients or patient’s family members should not contact Univar directly. Please contact Mary Graper if you have any questions.

Putting Faces on Wilson Disease

If you are a patient or family member of a patient with Wilson Disease you know that its name is barely recognized. Not only is it hard to get proper diagnosis but it is hard to explain or raise funds to fight it. At the WDA, we are always looking for ways to expand our audience to get the disease name recognized. Our most successful effort in 2017 was from posting photos with people holding homemade signs. This single photo was shared enough to reach 15,000 new people that never heard of the disease before. If we can continue the posting of photos like this on a consistent basis we believe that we can expand our reach to over 100,000 new people and over time even more. If you love someone with Wilson Disease would you consider saying so in a sign and sending it to photo campaign@wilsonsdisease.org. If you have any message about Wilson Disease that you can share on a sign we would love to have it.

News from Yale

Wilson Disease Registry Study Update

Dr. Michelle A. Camarata MBBS, BSc, MRCP(UK) and Dr. Michael L. Schilsky, M.D., FAASLD

The launch of the Wilson Disease registry began at Yale University in December 2017 and is off to successful start. We have enrolled 23 patients, and we have begun pediatric enrollment in April. We have been busy working behind the scenes to prepare for the opening of other registry sites. The University of Michigan will begin enrollment in the near future, and we are working with colleagues at the Royal Surrey (UK), Baylor Houston, Seattle Children’s and Florida Hospital in Orlando to prepare for their future launches later in the year.

Evaluation of patients who enter this study is comprehensive and includes a medical history review, neurological and hematologic evaluation and a psychiatric assessment. The equivalent pediatric specialists are involved in assessing children. In addition, blood specimens are being accrued in a repository for genetic studies and copper analysis to aid future research. Samples from patients at the Yale site have been used to prepare blood spots for analysis by the laboratory of Dr. Shoun Hahn that is conducting a study on advanced diagnostic testing for Wilson disease. Hopefully this testing performed on blood spot samples can be used in the future to aid with newborn screening for Wilson disease.

The response to the launch of the Wilson Disease registry has been fantastic and we are filling our calendars with future enrollees rapidly. We are thrilled to have so much interest and are hopeful that this enthusiasm will allow us to reach our enrollment goals at all our future sites. If you would like to participate or have any questions, please do not hesitate to get in touch.

For more information and to register your interest please contact:

Dr. Michelle Camarata MBBS, BSc, MRCP(UK)
michelle.camarata@yale.edu
+1 (203) 737 3422

Reference to the registry study in clinicaltrials.gov: https://bit.ly/2xU3FJS

Welcome Dr. Uyen (Kim) To

We are pleased to announce that Dr. Uyen (Kim) To will join the faculty at Yale University and become the newest member of the Wilson Disease Center of Excellence. Dr. To completed her medical school training at SUNY at Stony Brook and her internal medicine residency at Yale. She went on to train at Yale as a Fellow in Gastroenterology with an additional year of training in Transplant Hepatology. During her fellowships she pursued research in quality improvement, patient reported outcomes and infections in patients with chronic liver disease. She had the opportunity to train in our Wilsons disease clinic and help with our new Registry project for patients with Wilson disease and other clinical studies. We are pleased that she will maintain a focused interest on Wilson disease and will be actively seeing patients at our Center. Dr. To may be contacted at 203-737-1592.

Michael L. Schilsky MD FAASLD
Director, Center of Excellence for Wilson Disease at Yale
Corporate Matching Gifts

The following article was so successful we decided to repeat it. Thank you to those of you that looked into the matter because we had a big jump in corporate matched giving in 2017. What is the big deal with these companies (and many others) in Canada and the US?


As a benefit to employees, many companies increase the impact of their employees’ gifts to WDA by providing matching contributions. Most corporations provide a 1:1 match; while some companies will double or even triple the matching amount to further encourage and leverage their employees’ philanthropy.

Workplace giving contributes an estimated $5 billion to U.S. charities each year. If our supporters work for companies with a workplace giving program, it can be an additional source of funding. But note that a nonprofit’s access to these programs often must be initiated by an employee. (Grantspace.org)

Many corporations are using electronic applications to match gifts; however, if your matching gift program requires a hard copy form to be validated by the WDA, please complete the appropriate section and send it to us at:

Wilson Disease Association
1732 1st Avenue, #00043
New York, NY 10128
Phone: (414) 961-0533 ext. 3000
Fax: (414) 962-3886
Or email it to Judi Keller at 414-961-0533 ext. 3000 or judi.keller@wilsonsdisease.org

We will complete our section and forward it to your corporate matching gift office for processing.

Important information to complete your matching gift: EIN # 161154397

Other Ways You Can Help

If you have a Facebook account, do you know that a feature was added so any account holder can tell their Facebook friends about their favorite charities and why they support them? The instructions are found on the left hand column of your personal Facebook page. If you scroll down you will see the word fundraiser. It takes about 5 minutes if you know what you want to say about the charity and have a photo. Facebook and Network for Good, collaborated on this feature and any money is collected and sent to the charity. It is a very passive and easy way to inform friends about Wilson Disease Association. You will know who donates. What if you invited 50 Facebook friends to look at it and $100 or more was raised? What if 1,000 other people did the same thing? Not only do more people become aware of the disease but the organization is financially helped by something that took only 5 minutes of time.

If you would like help setting one up, please call or email Judi Keller at 414-961-0533 ext. 3000 or judi.keller@wilsonsdisease.org

Our Inspire Community

181, anonymous
Facebook donations, raised $6829.46, in 2017.

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Inspire | Wilson Disease Support Group & Discussion Community

The Wilson Disease Association Support Community connects patients, families, friends and caregivers for support and inspiration. This community is sponsored by the Wilson Disease Association, an Inspire trusted partner. Topics include:

- Diagnosis
- Finding a doctor
- Parenting
- Caregivers
- Genetics
- Depression
- Pregnancy
- Transplantation
- Treatment
- Personal stories

Find our Inspire community through our website.

Our Inspire Community

4,808+ Wilson Disease Association members
10 Countries represented by WDA members
39 New members in the month of May
71 Posts in the past week

Announcing a “Will” program

The Wilson Disease Association is 35 years old and is represented by board members from across the US and Canada. We have volunteers and partners globally and spearhead research that impacts our patients directly but affects a broader population beyond our patients. The long term importance of what the Wilson Disease Association does is limited only to the imagination because it affects generations of families around the world. Please consider the Wilson Disease Association in your will. Giving in this way is not restricted to the wealthy or a gender and even residual estates help.

The EU has a new General Data Protection Regulation (GDPR).

Here’s what you need to know regarding the WDA database. We subscribe to a database, credit card processor and fundraising page company named Network for Good. They also are partnered with Guidestar and process payments for google and Facebook. They have an updated privacy policy and the first two statements were made by Network for Good.

- As a donation processor and database software provider, we have taken all necessary steps to become compliant to the GDPR and will continue to monitor our compliance status.
- We are here to assist with any data requests from EU residents regrading GDPR compliance.
- The WDA does not share data with anyone.
BIG WOW SPONSORS
Wilson Therapeutics, Extreme V, DepMed, Vivet, Kadmon, Valerant Pharmaceuticals, Sutter Medical Group, Teva Pharmaceuticals

WILSON’S WARRIORS
Our Wilson Warriors appear on our website and we post these stories on Facebook. Wilson Warriors are a select group of individuals affected by Wilson Disease through a family member patient or perhaps they are the patients. These individuals share their testimony or some aspect of their experience with you. In addition, they volunteered to raise awareness and money for the Patient Registry by hosting a Big Wow Walk. Some have volunteered in this way several times. The WDA presents the Wilson Warriors Honor roll for 2017:

- Dr. Christopher Simopoulos, past chairman for three years
- Marianne Collins and Alex Cook
- Trisha Marzolino
- Arianna Musgrave
- Amanda Gross
- Sarah Kundinger
- The Langa Family
- Michelle Houle
- Amanda Schepel
- Ginta Ginalyte
- Patricia Goostree
- Brooke Yeider
- Michelle Collins
- Cathy Bergmann
- Jen and Izzy Hoffman
- Ashley and Nicholas Scilia
- Beverly Roberts
- Sarah Herman
- Various people in Finland, Austria
- Veronica Valencia
- Kaelyn Everham
- Kathy Castillas
- Janice Wagner
- Jennifer Cook
- Stephanie Rodriguez
- Alyssa Simopoulos
- Sheryl Cota
- Mary Park
- and China

IN MEMORY OF
Elly Arabadjief by Deborah Arabadjief
Mary Graper by Mary Huffman
The Simopoulos* by David Razo
Thomas Griffin

IN MEMORY OF
Bloxur Durkee by Linda Plichter
Charles Walsh by Ann Benken, Mary Donelan, Jay Kinder, John Sullivan, Julie Zulo, Kim Roam, Stacy Sarton, Carter Automotive, Cuba Township, Erin Rowland, Jim Hochmann, Kathleen Weiss, Ken Berry, Melissa Cacciabondo, Natalie Rohde, Paula Costa, Beth Gunderson, Suite Mauer, Juliet Tschyta, Ken Berry, Tracy Lang, Debbie Ulwin, Lost James, Emily Webster, Mary Graper
Diane Laurain by Kathleen Geister, Bill Hupp, Christina Wootton, Debra Ieres, Laude Gl, Nathalie Linhster, Sue Glooss, John Gorman, Palma Krena

For your convenience, you can make your donations online by visiting our website. Just visit www.wilsongr.com to 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
1732 1st Ave., #20043
New York, NY 10128

Please mail, fax, or e-mail to:
Wilson Disease Association, 1732 1st Ave., #20043 New York, NY. 10128
Fax: 414-962-3886 E-Mail: membership@wilsongr.com

Revised August 2017

*Basic Membership - $40
- Receive WDA Newsletter via e-mail
- Entitles one person of the household to be a WDA member

*Basic Plus Membership - $65
- Receive WDA Newsletter via U.S. mail or e-mail
- Entitles two people of the household to be WDA members

*Silver Membership - $125
- Receive WDA Newsletter via U.S. mail or e-mail
- Entitles all members of the household to be WDA members

*Gold Membership - $250
- Receive WDA Newsletter via U.S. mail or e-mail
- Entitles all members of the household to be WDA members
- No annual dues

I wish to make a donation to Wilson Disease Association:
I am making a donation of $ ________

In honor of In memory of

Send acknowledgment to:
Name Address Street

City State Zip Code Country E-mail

Payment Information:
Membership Dues $ ________
Visa Master Card Check or Money Order attached
Donation $ ________
Card # ________
Expiration Date: ________ CID # ________ (3 digits on back of card)

Thank you for your support Summer 2018

TO:

The BIG WOW
September 29th, 2018

FOUR WAYS TO PARTICIPATE:

1. Become a city leader and host a walk in your city or town (details below);
2. Sign up for a walk in a registered host city, closest to you*;
3. Local businesses, sponsor an event in exchange for advertising.
4. Host a private fundraiser, inviting only those you choose.

* If there isn’t a walk in a city near you, you can still participate as a virtual walker.