WILSON'S DISEASE ASSOCIATION
INTERNATIONAL

THE COPPER CONNECTION

December, 2002

WDA APPOINTS EXECUTIVE DIRECTOR

The Board of Directors is pleased to announce that it has hired Kimberly Symonds to serve as Executive Director of the Wilson's Disease Association. Kimberly is the first non-volunteer staff member to join the WDA in its twenty year history. The move was made to assure the continued growth and success of the Association.

Kimberly has been involved in the orphan disease community for over ten years. She comes to us with a diverse background, which includes community and public relations, patient services, and experience as a legislative director for another rare disease organization. She currently serves on the Board of Directors of NORD as Treasurer.

Kimberly feels that her first order of business will be to expand upon the services that the WDA now offers.

> "This will require implementing a development plan, since everything we need to do in supporting those individuals with Wilson's requires resources. We need to ensure that the WDA will be here to help those in need today and in the future. This won't happen overnight, but with persistence and hard work from everyone this can be accomplished."

The Board feels Kimberly's skills will enable the WDA to take the next step forward in achieving its mission. WDA members can meet and welcome Kimberly to the Association at the annual conference in May.

Kimberly and her husband Michael have been married for thirteen years and have one son, Andrew. They live in Wooster, Ohio.

Mark Your Calendars

The next WDA annual meeting is scheduled for May 3-4th, 2003 in Washington, D.C.

A registration form and hotel information will be provided in the next issue of The Copper Connection.

Inside This Issue:

Tributes to Wilson's Disease patients.

A Tribute To My Daughter

By Linda English

My daughter, Tara Graham, died at age 19 in April 2000, just 3 days before the Columbine tragedy in Colorado. Tara died about 2 ½ months after she was diagnosed with Wilson's Disease. It was unfortunate that she did not respond to the medical therapy, penicillamine, because she had cirrhosis and her health was rapidly deteriorating.

It took over two years and a long legal process to learn about her unfortunate medical condition, information that was not revealed to us by her HMO doctor, for unknown reasons. I learned from medical experts that she had severe liver disease, tense ascites and significant portal hypertension. Further, the HMO doctor mismanaged her medical care, did not recognize the severity of her illness, and delayed the referral to the transplant center. The transplant hospital was, therefore, unable to respond promptly with an urgent liver transplantation.

I hope that from my own experience, I can help to share with you some important issues: 1) Maintain excellent communication with your doctor; 2) Know that HMO care can be restrictive; and 3) Learn and understand liver disease.

I wish to thank many people with the WDA for their initial support and kindness, especially two people I will mention by first name, George and Stephanie. I would also like to thank the Wilson's Disease doctors for their work with the WDA and the support I received from their medical expert opinions.

I wish to share with each of you just a little about Tara's heart. She was involved in community service in high school and volunteered to help the homeless at the local rescue mission in Denver. She was born on Christmas Eve, and I especially like the time of year when "giving" diminishes the pain of her loss. It is my faith that has allowed me to receive much joy in extending her love by giving to small charitable organizations . . . IN HER MEMORY.

I would like to share with the teenage Wilson's Disease patients a poem that Tara wrote four months before her diagnosis of Wilson's Disease. I think she expressed some of her symptoms of Wilson's Disease.
God Bless,

Linda (englg@attbi.com).

JUST ME

From the time I was little, I knew I was great,
'cause my family would tell me, "You'll make it—just wait"
But they never did tell me how great I would be
If I ever played someone who was greater than me

When I'm in my own home, I'm king of the hall
To outsmart all the little things is no sweat at all
But all of a sudden there's a struggle in my face
And it doesn't seem to realize I'm king at my place

So the pressure gets to me, and I start to panic
My efforts and test scores go down like the Titanic
My grades keep falling, my mistakes not sure
My hand is not steady, my eyes are not pure

The fault is my family—they don't understand
The fault is my teachers—what a terrible plan
The fault is the call by all these blind referees
But the fault is not mine; I'm the greatest, you see

Then finally it hit me when I started to see
That the face in the mirror looked exactly like me
It wasn't my family who was causing it all
And it wasn't that hard to fix after all

That face in the mirror that was always so great
Had some room for improvement that wasn't just hate
So I stopped blaming others, and I started to grow
My grades got much better, and it started to show

And, all of my family didn't seem quite so bad
I learned to depend on the good friends I had
Now I like myself better, now that I started to see
That I was lousy being perfect—I'm much better being ME

Tara Graham, age 19

Dear Editor,

I am writing you on behalf of my sister Carole Janow who died suddenly on October 28, 2002. She was diagnosed 23 years ago. Prior to her diagnosis she suffered indignity after indignity. Doctors telling her she was mentally unstable, eating poorly or imagining her hand shaking. When she was finally diagnosed, she was put on penicillamine (16 pills/day). That regimen drove Carole nuts and created more neurological problems.

It wasn't until she heard about Carole Terry's story in The New Yorker that she finally got the care she deserved. She met Dr. Brewer and was finally being taken seriously. Unfortunately, the visits to Michigan stopped several years ago and Carole's fate was sealed. She had to rely on day- to-day medical care in South Florida. Doctors refused to give Carole preventive medical care because she was "going to die of Wilson's Disease" anyway. She finally succumbed to a severe case of diarrhea.

I am writing to warn other family members of Wilson's patients who are neurologically impaired. Be vigilant and not so trusting. Carole had no children; for you see, she got sick in her mid 20's. She did leave a legacy: Her poetry; a notebook of Carole's words of hope and despair.

Lori Janow

FEELINGS

My skin has been badly burned by the sun
Now it is tender and peeling
Soon a new growth will appear
Making me all smooth and soft

But I will have changed in many ways,
More sensitive and vulnerable
But stronger and tougher too,
With a resilience that will last a lifetime.

I have learned compassion
And the value of human dignity,
For what I want for myself
I must give to others

By Carole Janow

Like Eve with the apple
Your doctors are your serpent
Feeding you lies and making them your crutch
And you still don't believe I'm sick

You have a volcano living inside
It erupts unexpectedly
You erupt periodically
And you still don't believe I'm sick

You are the ones who make me feel worthless
You are the ones who make me feel bad
But one day I'll be well
And I won't believe you are sick

By Carole Janow

I have been on an odyssey
That Homer never dreamed of
The sirens, amazons or poppies
Pale in comparison

Mine has been one of anger
Rage so fierce I thought I could kill
All the questions I have
That remain unanswerable

Mine has been one of indignity
The drooling, the stumbling
The feeling that your worth
Is reduced to nothing

Mine has been one of suffering
Not only to me but to the people around me
Who cry and ache when they see what's happened

Mine ultimately has to be one of acceptance
I must forget the past and ingest the present
And hug myself for all I'm worth
For it's all I got

By Carole Janow

Medical News

Brought to you by the WDA Medical Advisory Group

Question: Are medications effective after their expiration dates?

Answer: Expiration dates on drugs are often much shorter than the actual date after which the drug should not be used. Manufacturers usually indicate that a drug is safe and effective for 2-3 years. In fact, there is no evidence that drugs used after their expiration dates have any toxic products whatsoever from age or decay. When drugs are opened by the pharmacist, he/she is required to show a "do not use beyond date", which is usually one year.

Generally, drugs retain 90% of their potency during the period before the assigned expiration date. In another study, it was shown that most drugs are safe and effective 5 years after their expiration date. All of this information assumes that the drugs have not been opened.

The above information is supported by the Medical Letter October 28, 2002.

Wilson's Disease Resource Books

Dr. George J. Brewer has recently published two Wilson's disease books which are now available.

Wilson's Disease: A Clinician's Guide to Recognition, Diagnosis, and Management

This book can be ordered from Kluwer Academic Publishers (via the internet www.wkap.nl/)
ISBN # 0-7923-7354-5

Wilson's Disease for the Patient and Family: A Patient's Guide to Wilson's Disease and Frequently Asked Questions About Copper

This book can be ordered from Xlibris.com (Paperback $17.84, Hardback $28.79, eBook $8.00).

Merck's Patient Assistance Program

If you are taking a Merck medicine such as Syprine or Cuprimine, you may be eligible for Merck's Patient Assistance Program.

All three of the following conditions must apply: 1) you live in the United States and have a prescription for a Merck medicine from a doctor licensed in the United States, AND 2) you do not have insurance coverage for your prescription medicine, AND 3) you cannot afford to pay for your medicine.

If you believe you might qualify, call Merck at 1-800-727-5400 to request the "Patient Assistance Program" pamphlet and application.

The Wilson's Disease Association sends condolences to the family of:

Carole Janow

Send Us Your Letters

We would like to hear from WDA members. Send us your letters, news to share, or other information that your would like to share with other WD patients and families. Please mail to:

Delia Ruiz, Copper Connection, Editor
P.O. Box 1225,
Pismo Beach, CA 93448

or e-mail to DRNDVR@aol.com.

MEMBERSHIP APPLICATION/RENEWAL

Please complete, detach this page, and mail to the address below:

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

Name_____

Address_____
Street City State Zip Country

Home Phone (____)_____Work Phone (____)_____ E-Mail _____

Membership Dues:

Basic $35 Sustaining $50 Endowing $100 Lifetime $1,000 Other $_____

DONATION

Name_____ Address_____
Street

_____ E-Mail _____
City State Zip

I am making a tax-deductible donation of $_____

In honor of _____ In memory of _____ Patient Care Fund

Send acknowledgement to: _____
Name Street

_____
City State Zip E-mail

PAYMENT INFORMATION

Membership Fee $_____ Visa Master Card Check or Money Order attached
Donation $_____ Card #_____
Total $_____ Expiration Date_____ Signature_____

SUPPORT GROUP AND VOLUNTEER INFORMATION

As we are a non-profit organization, we are always looking for volunteers. If you would like to offer your time or services to the Association, we would like to hear from you. Below are a few ideas of services that are needed, however, if you have another idea or specialty (e.g. you own a printing shop and would like to sponsor a mailing), please let us know that too:

____Coordinate a WDA support meeting in my area _____Coordinate a fund raising event _____Other:
_____

____Please check here if you approve of your name to be given to others in your area who are looking for support
_____ (please sign here to acknowledge this).

MAIL TO: WILSON'S *DISEASE ASSOCIATION c/o Len Pytlak, CPA, PC 180 Little Lake Drive #3*
Ann Arbor, MI 48103

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CHANGE OF ADDRESS?

Please notify the Wilson's Disease Association of any address changes so that we may keep our database updated. Please use the Membership Form to make any changes.

WDA Board Members

Ascher Sellner, M.D. - President
Len Pytlak -Vice President
Carol Terry - Treasurer
Carol Sellner - Secretary

Board Members

Luke Chung
Nancy Hoffman
Stefanie Kaplan
Carl Nacht, M.D.
Henry Kaplan, M.D.
Kevin Peters
Sparky Terry
Jack Levin
Jacqui Taylor
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Honorary Board Member
Janene Bowen

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WILSON'S DISEASE ASSOCIATION

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(FORWARDING SERVICE REQUESTED)

TO: