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# THE COPPER CONNECTION

June, 2003

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## Outgoing President's Report

H. Ascher Sellner, M.D.

Congratulations to the Board for taking the giant step of hiring an executive director. This step will help to insure the perpetuity of our organization and allow the expansion of our services. The achievement of our strategic plan depends greatly on our having paid staff. While I plan to continue to contribute as best I can, my status is uncertain because of my health and because my tenure will expire.

Further growth will depend upon a commitment of the board to fundraise, expansion of paid services and deep commitments of individuals to assure the success of the organization. Fund-raising will also require greater personal commitment by the board and an enthusiastic pursuit of grants to support specific activities.

In November, we collaborated with the Movement Disorder Society and the NIH Office of Rare Diseases to sponsor an international Wilson's Disease meeting with participants from Italy, Sardinia, Sweden, India, and Great Britain. We are grateful for the help of Drs. Brewer, Schilsky and Askari.

This past year the president's discretionary fund has allowed us to contribute \$24,000 for research into safer alternative medications for Wilson's disease. Tetrathiomolybdate will be ready for submission to the FDA hopefully this year.

Additional projects include:

- ◆ Contribution to a study of female reproductive function in WD patients which will soon be published (see page 6).

- ◆ Quarterly circulation of the Copper Connection newsletter.
- ◆ Continued distribution of information to the physician population through the auspices of NORD. This organization continues to labor on our behalf and that of the rare disease community. It now has a full time office in Washington, DC and was instrumental in increasing the budget for rare diseases from \$10 million to \$25 million dollars last year. Furthermore, the NIH Office of Rare Diseases has been codified, which means it will always have a line item for its funding and will no longer be dependent upon the NIH director for funding.
- ◆ Planning for a workshop sponsored by the NIH May, 2004 which is to be combined with a consensus meeting and annual meeting of the Association. This will be paid for substantially by the NIH Office of Rare Diseases directed by Dr. Stephen Groft and assisted by Dr. Stephen Kaler at the NIH whose specialty is research into Menke's Disease and Wilson's Disease.
- ◆ Changing the labeling of penicillamine to protect patients from its adverse reactions. The label would reflect the high percentage of patients experiencing neurological worsening, immunosuppression, skin disease and arthritis.

We have invited a new member, attorney Jeff Eckland, to the WDA Board. He is interested in professional education and planned giving.

*(Continued on page 2, REPORT)*

## **Incoming President's Message**

Dear Friends:

Greetings from your new president! It is with great pleasure that I accept the challenge of serving the WDA in this capacity. Since joining the WDA Board of Directors in 2000, I have met many of you. I hope to meet many more of you.

For those of you who don't know me, let me tell you a little bit about myself. My husband, Bill, and I have three children and live in Wisconsin. Our daughter, Jennifer, is 24 years old. Our son, BG, is 22 and our son, Andrew, is 17. Our sons were diagnosed with Wilson's disease in 1998.

In the past three years of serving on the Board of Directors I have been involved in many facets of the organization. I bring to this new position the passion and will to succeed in perpetuating the mission and vision of the Association to help all affected by Wilson's Disease. This is a tall order since I follow in the footsteps of two excellent past presidents of the WDA, Dr. H. Ascher Sellner and Ms. Carol Terry. I hope to build on the past successes of Dr. Sellner, Ms. Terry, and the Wilson's Disease Association. I begin this journey on the 20<sup>th</sup> anniversary of the WDA.

You, as members, have a great group of Board members and an energetic Executive Director working enthusiastically on your behalf. I can't say enough about Kimberly Symonds, Executive Director; Stefanie Kaplan, Vice President; Len Pytlak, Treasurer; and Carol Terry, Secretary. Nancy

*(Continued on page 2, MESSAGE)*

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*(REPORT, Continued from page 1)*

Another anticipated board member is Stefan Sandler who has worked in Germany for IBM as an engineer specializing in information technology. We anticipate he will be able to help us get our newsletter into e-mail circulation, upgrade our website and enhance our database.

I am very grateful for the continued support and assistance of the Board. I wish to give thanks and acknowledgment to Sparky Terry for his years of participation, to Jacqui Taylor for her contributions, to Chris Juliette for his commitment and technical assistance, to Delia Ruiz for her untiring and unwavering efforts editing the newsletter, and to Lenore and Russ Sillery for their generosity in printing and circulating the newsletter as well as sponsoring a support meeting in New York City.

*(MESSAGE, Continued from page 1)*

Hoffman, Henry Kaplan M.D., J.D., and Luke Chung also continue to use their expertise for the Association. Two new exceptional people have also joined the Board: Stefan Sandler from Germany and Jeff Eckland, J.D., from Minnesota. We are truly a diverse group, dedicated to supporting the cause of Wilson's disease.

BUT, we also need your help! Please freely give of your time and/or resources to help us out. Working together, we can all make a difference. Please contact our Executive Director, Kimberly Symonds, to offer your assistance, and take the time to complete and return the Volunteer Form included in this issue.

Regards,

Mary L. Graper  
Newly elected WDA President

## Newly Diagnosed Wilson's Disease Patients Presenting with Liver Disease Clinical Trial

The University of Michigan is conducting a randomized double blind study to compare efficacy and toxicity of three anti-copper drugs, penicillamine, trientine, and tetrathiomolybdate, for the initial treatment of Wilson's disease patients presenting with liver disease. The objectives are to compare rate and degree of recovery of liver function, and to compare side effects.

To be eligible, patients must be untreated or not treated for longer than three weeks with an anti-copper drug. Patients must have at least one of the following laboratory abnormalities: serum albumin, 2.5 g/dl or less; serum bilirubin 2.0 mg/dl or more; prolongation of prothrombin time, 4 seconds or more, or an INR of 1.3 or more. Patients with moderate degrees of hepatic decompensation will be accepted, although not those likely to be in need of immediate hepatic transplantation. Patients with concomitant neurological or psychiatric symptoms from Wilson's disease are excluded from this protocol, although they may be eligible for our neurological Wilson's disease tetrathiomolybdate protocol.

The treatment period is 24 weeks; the first 4 weeks of which are spent in the General Clinical Research Center of the University of Michigan Hospital, with free medical care and hospitalization provided to the extent required for Wilson's disease. The next 20 weeks involves home treatment with the appropriate anti-copper medication provided. It will be necessary to have blood tests every 2 weeks during the 20 week period at home with the results sent to us. The blood tests involve blood counts and liver function tests, readily available anywhere. Patients will be followed with the referring physician, as desired.

Referrals should be directed to either:

George J. Brewer, M.D.  
University of Michigan  
5024 Kresge Bldg. II,  
Ann Arbor, MI 48109-0682  
Telephone: (734) 764-5499

Fred Askari PhD., M.D.  
University of Michigan  
6520 MSRB I  
Ann Arbor, MI 48109-0534  
Telephone: (734) 763 7722 or 647-2964  
Email: faskari@umich.edu

### Medical News

Congratulations to **Dr. Michael Schilsky** of the WDA's Center of Excellence at The Mount Sinai Medical Center in New York and **Dr. Eve Roberts** of the Hospital for Sick Children in Toronto, Canada, for their newly published article "**A Practice Guideline on Wilson Disease.**"

The Guideline has been accepted by the American Association for the Study of Liver Diseases as the preferable and most current approach to be used by physicians for the diagnosis and treatment of Wilson's disease. The AASLD, "represents more than 2,400 physicians, researchers and allied hepatology health professionals," and is known to be the leading organization of its kind focusing exclusively on advancing the science and practice of hepatology. The published Guideline is the result of the authors' review of over 200 pieces of published medical literature and their 40 years of combined experience in the study and treatment of Wilson's disease.

The Guideline may be viewed on the AASLD web site at [www.aasld.org](http://www.aasld.org) under "Practice Guidelines."

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## Major Long Term Complications of Wilson's Disease and Comments on Tetrathiomolybdate Development

George J. Brewer, MD

Any discussion of long term complications of Wilson's disease must begin with poor compliance in the taking of maintenance anti-copper medication. In our experience the probability of being "done in" by poor compliance is much higher than from other risk factors. Even in well-monitored patients, serious poor compliance reached 10% and episodic poor compliance 25-30% in our experience. Various devices can be used to improve memory and one of these should be utilized if compliance begins to fail. One advance for those patients on zinc therapy would be to develop a formulation requiring only one dose per day.

Most patients with Wilson's disease have some liver involvement, and many, particularly those who present with clinical liver disease, have some cirrhosis. This very often causes portal hypertension, which is an elevated pressure in the large vein bringing blood from the intestine, stomach and esophagus into the liver. This increased pressure can cause the veins along the esophagus and stomach to become enlarged (esophageal and gastric varices). These varices can occasionally rupture internally, causing bleeding

into the esophagus or stomach. The patient would first notice this either by vomiting of blood or passage of tarry-black material in the stool. If either of these occurs, the patient should immediately go to an emergency room because it is not possible to predict how severe the bleeding will be.

Another risk from the liver standpoint is for the liver to fail. Generally, during maintenance treatment, at least with zinc, the liver disease is not progressive. However, episodes of non-compliance can allow the liver to further deteriorate. Or, new injuries to the liver can occur from alcohol, from taking drugs that are toxic to the liver, or from a bout of viral hepatitis. Any of these can further damage the liver to the point where liver failure occurs and transplantation is required. We advise abstinence from alcohol, immunization against viral hepatitis, and avoidance of prescription or of other drugs where the main toxicity is in the liver.

Patients with neurological involvement are at risk for aspiration (material going down the wrong tube) if they have severe enough swallowing problems. Aspiration can lead to pneumonia, and if chronic, can lead to lung damage and respiratory failure. Such patients should have a gastrostomy (stomach

tube) and primarily receive tube feedings. Patients with in-coordination problems are at increased risk of accidents.

All patients taking anti-copper drugs are at risk for the side effects and complications from the drug they take. Each patient should familiarize themselves with the risks from the drug they're on.

Turning to tetrathiomolybdate (TM), we have made good advances with TM in the initial treatment of Wilson's disease presenting neurologically, and are now studying it for initial treatment of patients presenting with liver disease. Because cancer requires blood vessel growth (angiogenesis) and angiogenesis requires high levels of copper, we are also developing TM as an anticancer drug. We have positive results in 5 mouse tumor models, in a dog cancer study, and in human trials. Most recently we have discovered that TM has anti-inflammatory and anti-fibrotic properties. In animal studies it has protected against lung and liver injury by toxic agents that normally injure those organs. Human trials are now beginning to explore its potential to treat patients with inflammatory diseases such as lung fibrosis, cirrhosis, and scleroderma.

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### Diet And Wilson's Disease

Fred Askari, MD, PhD

Nutritional requirements for Wilson's Disease can vary greatly; people should follow a prudent well balanced diet and avoid alcohol or other liver toxins. In general, during the initial treatment period during which toxic free copper reduction is occurring in the initial hepatic and neurologic presentation, the goal is to maintain a diet with less than 1.5 grams of copper for the first eight to twelve weeks of therapy. Subsequently, the diet is liberalized with the avoidance of ingesting liver and lobster or excess shellfish. Strict dietary restrictions such as never eating chocolate or nuts are generally not necessary if the copper levels are well controlled, particularly during maintenance therapy with zinc acetate. Prudent restraint is recommended, for example it would be unwise to eat five pounds of chocolate every day! If someone has difficulty maintaining weight, dietary supplements may be used with the goal to avoid dietary supplements enriched with high copper levels. SCANDISHAKES are one nutritional supplement rich in calories that lacks excess copper supplements.

The situation of tube feeds is unique, as many liquid diet supplements such as ENSURE and SUSTACAL are enriched with extra copper. An example of a tube feeding regimen for Wilson's disease patients was presented at the annual meeting noting the time separations between zinc and the tube feedings.

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## **The Quality of Care for Wilson's Disease Patients**

George J. Brewer, M.D.

In my opinion, the quality of medical care in the U.S., even for common diseases, is spotty. There are good physicians at all levels, good nurses, good caregivers of other types, good nursing homes, etc., but we can all cite far too many examples of inadequacies and poor treatment from all of the above. Add to this a disease as rare as Wilson's disease, and the care problems are magnified.

What are the major care problems and what can be done to improve them? Failure by physicians to recognize the disease remains a major problem. Delay in diagnosis and treatment results in progressive additional liver and/or brain damage, limiting eventual recovery and increasing the amount of permanent disability. The best hope for mitigating this problem, in my opinion, lies in an educational and awareness approach aimed at hepatologists, neurologists, and psychiatrists, the specialists to which most of these patients are eventually referred.

Failure to appropriately treat patients initially after diagnosis is another care problem. Neurological/psychiatric patients must not be treated with penicillamine because of the high risk of making them permanently worse. Failure to understand how to monitor the treatment of patients, to pick up inadequate compliance, to minimize side effects from medication, and to avoid over treatment are all very common in the medical community.

Failure to appreciate the usefulness of ancillary treatment, such as treatment of neurological and psychiatric symptoms, physical therapy, speech therapy, occupational therapy, psychiatric counseling, and other such services, as patients struggle to rehabilitate themselves, is also common. Failure to understand the treatability and recoverability with this disease are all too common.

Physicians and other medical personnel are so accustomed to common liver and brain diseases that are not treatable that they often have an air of negativity and inevitability that can influence the level of care the patient receives while trying to recover, and as bad, be transmitted to the patient and harm their recovery. For all of these failures, education and awareness are the best hope.

Finally, when we talk about care, we must not forget that the patient and/or the family are critical links in the chain of getting good care. Compliance with anti-copper therapy rests not with the medical care team, but with the patient and family support system. Serious long-term non-compliance in our series of patients was over 10%, and intermittent poor compliance was over 25%, and this is in a series of patients who were monitored and reminded every 6-12 months. There are a variety of systems to help remind patients to take their medication, but none are foolproof, and compliance ultimately depends on the patient. For those on zinc therapy, a big help would be to develop a formulation that would require only one-a-day dosing, and eliminate any stomach side effects.

Education and awareness are a general key to all of the failings. This can be helped in a variety of ways using office materials, distribution of pamphlets and/or scientific papers, and spreading information about appropriate books on Wilson's disease.

## **Current Therapy of Wilson's Liver Disease**

Fred Askari, M.D.

While many textbooks and older treatment protocols for hepatic Wilson's disease still use penicillamine, the contemporary treatment of Wilson's disease often involves the use of other medications. Initial copper reduction may use Tetrathiomolybdate or Trientine and zinc acetate, while subsequent maintenance therapy is often achieved with zinc acetate alone. Liver transplantation is reserved for the sickest patients who would otherwise likely die

without this life saving therapy. The decision as to who to treat medically and surgically is assisted using the prognostic index of Nazer. The need for transplantation needs to be re-assessed on routine follow-up as co-morbid liver diseases, non-compliance, or potential patients with an atypical natural history may manifest liver disease progression even on therapy. Immunizations for hepatitis A & B should be given when pre-existing immunity does not exist to prevent further liver disease.

Details of a study were discussed. The study treated nine patients who presented solely with hepatic decompensation from Wilson's disease with a combination of trientine and zinc.

In summary, we believe the trientine/zinc combination therapy should be the present "standard" for initial treatment of hepatic failure in Wilson's disease, because it has equal or slightly superior efficacy to penicillamine, and has a much reduced frequency of side effects. Moreover, TM warrants study to see if therapy for hepatic Wilson's disease can be further improved. We are currently conducting a randomized clinical trial comparing penicillamine, trientine and TM for the initial treatment of Wilson's disease as described on page 2 of this newsletter.

## **Measuring the Adequacy of Treatment of Wilson Disease**

Michael L. Schilsky, M.D.

Therapy specific for Wilson's disease (WD) includes pharmacological therapy and liver transplant. Pharmacological treatment of WD aims to prevent the accumulation of copper or reverse the toxic effects of this metal. Chelating agents promote the excretion of copper in the urine or bile while zinc salts reduce copper absorption from the intestine. Pharmacological therapy is lifelong.

Patients with more severe liver disease may experience complications due to

*(Continued on page 5, TREATMENT)*

## ***Health Risks in Wilson's Disease Carriers*** **Research Study Presented At Annual WDA Meeting**

A presentation of the health risks in Wilson's disease carriers was made by SG Kaler, MD, MPH, National Institutes of Health, Bethesda, Maryland. He discussed how abnormally increased urinary copper excretion has been documented among some siblings of Wilson disease patients, although genetic confirmation of carrier or non-carrier status for these individuals was not available. He presented details of his new research study using the hypothesis:

### **Wilson disease gene carriers 50 years of age have subtle, detrimental health effects related to chronic decreased hepatic copper excretion.**

Relatives of Wilson's disease patients in whom two mutant alleles have been identified previously will be recruited and enrolled in this study to formally assess this hypothesis. The protocol will define 1) the potential clinical, neurological, and biochemical sequelae, if any, of heterozygosity at the Wilson disease locus, and 2) the possible molecular correlations, in a cohort of individuals 50 years of age residing in the United States. A chronological record of lifetime geographical residence will be ascertained for each participant. Participants will be involved in a single 3 day inpatient visit on an Adult Patient Care Unit at the National Institutes of Health Clinical Center (see web site at <http://www.cc.nih.gov/>). A medical history and neurological examination will be performed. Clinical laboratory tests will be conducted and Wilson disease genotype will be established through knowledge of the family proband's mutation.

This study will offer travel assistance to individuals for their participation.

\*\*For questions or comments related to this study, please contact:

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Clinical Director, Intramural Research Program  
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#### *(TREATMENT, Continued from page 4)*

cirrhosis of the liver. Problems requiring other medical management include development of ascites, spontaneous bacterial peritonitis, variceal bleeding and encephalopathy. Patients with psychiatric symptoms may require treatment for psychosis or depressive disease. Neurological complications include dystonia, dysarthria and dysphagia. Specific treatments for dystonia may require systemic medication or local administration; speech and swallowing therapy may improve symptoms of dysarthria and dysphagia.

Liver transplant has played an important role in saving the lives of patients suffering from fulminant

hepatic failure due to WD, and for those in whom medical therapy was ineffective or interrupted. The use of liver transplant for neurological Wilson's disease is controversial. Liver transplant requires the use of life-long immunosuppressive therapy to prevent the loss of the donor graft.

Treatment monitoring for patients includes serial physical examination to monitor changes in the signs or symptoms of liver or neuropsychiatric disease, and biochemical monitoring for efficacy of treatment and for adjusting medication dosages. Specific physical findings to follow include jaundice, ascites tremors, speech changes and swallowing patterns as well as changes in Kaiser Fleischer rings and presence or absence of esophageal varices on endoscopic evaluation. Laboratory

testing at these visits should include coagulation profile (INR), albumin and bilirubin, and serum and urine copper. Stabilization and improvement following initial treatment may occur slowly, and in some with advanced disease, not at all. Some individuals may worsen with respect to their neurological disease during initial therapy, and careful monitoring and assistance with symptom management may be necessary. Monitoring of long-term maintenance therapy should be performed at least twice yearly, and includes serial physical examination and laboratory testing that includes blood counts, liver functions and copper parameters, serum and/or urine. For patients where adherence is problematic, enlisting the assistance of family members or other caregivers in the monitoring process is critical.

## Reproductive Health of Patients With Wilson's Disease and Other Chronic Liver Diseases

Kedia S, Bach N, Gutierrez JA, Holender T, Sellner HA\*, Schilsky ML Division of Liver Diseases and The Recanati/Miller Transplantation Institute, The Mount Sinai Medical Center, NY, and \*The Wilson's Disease Association, Danbury, CT.

**Background:** Limited data are available regarding the reproductive health of patients with chronic liver diseases. We surveyed patients with Wilson's disease (WD), primary biliary cirrhosis (PBC) and other chronic liver disease (CLD) to determine whether reproductive ability/capacity and outcome of pregnancy differed from a control population.

**Methods:** The study group consisted of female patients from the Liver Diseases and Pre-Liver Transplant clinics and a control population from the Orthopaedic clinics at The Mount Sinai Hospital. Patients were divided into 3 study groups: WD (n=24); PBC (n=32); CLD (n=22) with chronic hepatitis B or C, alcoholic liver disease, autoimmune liver disease, non-alcoholic steatohepatitis and cryptogenic cirrhosis, and control patients (n=31) without liver disease. The survey included questions pertaining to menstrual history, birth control measures, pregnancies, complications during pregnancy, medications during pregnancy, infertility and treatment, menopause and sexuality. Medical chart review was performed to determine the presence or absence of cirrhosis and concurrent medical illnesses.

**Results:** The mean (range) patient age in years was as follows: WD 35.8 (20-72), PBC 56 (39-76), CLD 50 (24-66) and control 52(21-81). The mean age (years) of disease diagnosis was lower in patients with WD (24.5), compared with PBC (47) and

CLD (40.7). The frequency of cirrhosis was higher amongst patients with WD (29%) and CLD (68.2%) than in patients with PBC. Mean age of menarche was not different amongst the groups. By contrast, the frequency of menstrual problems after menarche was greatest in WD (45.8%), but was also increased in PBC (9.3%) and CLD (18%) compared to controls (3.2%). Fertility problems were greater in patients with WD and PBC compared to CLD or controls. Nine WD patients had cessation of menstrual cycle for >2 months, however 5/9 had successful pregnancies with treatment of the WD. The mean numbers of pregnancies was greater (highest in PBC at 3.0) and ratio of live births to pregnancies was significantly decreased in all patients with liver disease, regardless of cause, compared to controls (p<0.05). The mean number of miscarriages was significantly greater in WD (3.6) compared to PBC (1.3), CLD (1.7) and controls (1.0). The number of complications associated with pregnancy (preeclampsia, hypertension, gestational diabetes, hyperemesis and others) was increased in patients with PBC but was not in patients with WD or CLD compared to controls. The mean age of menopause (yrs) was less in patients with CLD (41.5) compared to PBC (49.0), WD (47.6) and controls (48.3).

**Conclusions:** The earlier onset of liver disease and cirrhosis in many WD patients during their reproductive years is likely responsible for the more frequent menstrual irregularities and rates of miscarriage observed in patients with this disorder compared to those with PBC or other CLD. A reduced ratio of live births to pregnancies in WD, PBC and CLD suggests that reproductive capacity is altered in patients with chronic liver disease. Treatment of WD can restore fertility and allow successful live births in some individuals.

## Newsletter Recognitions

As the Association continues to grow, it is important for us to recognize a few individuals who have helped us in various ways over the past few months.

### Thank-you to:

*Luke Chung* for providing software.

*Len Pytlak* for the use of a copier.

*The Symonds Group* – for the use of three file cabinets.

*Diane Taylor* – for her willingness to volunteer in the office.

*Mary Graper* – for donating the printing for the thank you cards.

*Russ and Lenore Sillery* – for donating the printing and mailing of the newsletter.

*Delia Ruiz* – for formatting the newsletter.

In kind donations are always appreciated.

### Wish list

Donated Office Supplies - Copy paper

Donated Printing Services

Donated Air Miles

Long Distance Sponsorship

800 Number Sponsorship for Family Support

## We are grateful to all for their generosity to the Wilson's Disease Association

William Carter

Stella Gillmann

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William Hines

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Anvar Minnigoulou

Helen and Jim Moseley

Neodesha High School

Randy Paxson

Brian Paland

Mark and Alexa Recchi

Dr. Ascher H. Sellner

Sophie Wood

James Finn

F.O.E. #3862

Ruth Hill

Lori Janow

**WILSON'S DISEASE ASSOCIATION  
MINUTES OF THE GENERAL  
BUSINESS MEETING**

**MAY 4, 2003**

Len Pytlak, Vice President, called the meeting to order in the absence of Ascher Sellner, M.D., President.

Mr. Pytlak expressed Dr. Sellner's regrets at not being able to attend the meeting and briefly highlighted the past year's events, including the hiring of an executive director.

Kimberly Symonds, Executive Director, and Mr. Pytlak presented a clock to Carol Terry, Treasurer, in appreciation for her 20 years of service to the Association as Founder, Past President, and Treasurer. Additionally, it was announced that Dr. Sellner was presented with a similar clock at the Board of Director's meeting, which was held on Friday, May 2, 2003.

Ms. Symonds and Mr. Pytlak, with the assistance of Stefanie Kaplan, presented appreciation plaques to Drs. George Brewer, Mike Schilsky, and Fred Askari for their dedication and commitment to WDA.

All the current board members present, Len Pytlak, Vice-President, Carol Terry, Treasurer, Stefanie Kaplan, Dr. Henry Kaplan, Mary Graper were called to the front of the room. Jeff Eckland and Stefan Sandler, two board members elect, were also called to the front of the room.

In absence of the chair of the nominating committee, Mr. Pytlak introduced the slate of officers for the next three years.

President - Mary Graper  
Vice President - Stefanie Kaplan  
Treasurer - Len Pytlak  
Secretary - Carol Terry

Board Members Elect - Jeff Eckland and Stephan Sandler

It was announced that Dr. Sellner would continue to serve on the Board for two years as Immediate Past President. Other members of the Board are not up for re-election at this time.

Len asked for nominations from the floor; none were

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Good through 12/31/03. © iGive.com Holdings, LLC

forthcoming. He then asked for a show of hands by all paid members as to all in favor of electing the slate of officers and new members of the Board of Directors. The slate was elected without opposition.

Mary Graper, the newly elected President, made a few remarks about the direction the Association will take in the next year. The meeting was turned back over to Mr. Pytlak, who thanked everyone for coming and adjourned the meeting.

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**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, Ohio 44691

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### A Message From Your Executive Director

The purpose of our Association became very clear for me while I was attending my first Wilson's Disease Association (WDA) conference. Like many who attended, I wasn't quite sure what to expect. But I can assure you that I never would have been able to prepare myself for the experience.

Every person who attended the conference is an inspiration of strength and courage to me. As I watched attendees interacting and sharing stories, it became obvious that I have joined a community of caring and giving people whose only goal is to help others with Wilson's disease obtain all information that is available. Many of you volunteered to help the Association in various ways and we are extremely grateful for the contributions you are making. If you were unable to attend the conference and want to become involved, please take a moment to fill out the Volunteer Profile, which is included in this edition of *The Copper Connection*, and send it back to me.

What else can all of us do? We can spread the word about Wilson's disease to persons outside the Wilson's disease community as to how disabling and cruel the disease is. Every WDA family can do this by sharing the Association's information with friends and family and the general community. Hand out printed materials about Wilson's Disease; send people you know to the WDA web site to see all the information that's available there. Help to educate everyone about Wilson's disease. After all, with proper diagnosis, the disease is treatable.

We can help raise funds so that the Association can build a strong international presence and increase awareness about Wilson's disease. Contact the Association or look on our web site ([www.wilsonsdisease.org](http://www.wilsonsdisease.org)) to see how you can help with WDA's fundraising efforts.

We can't wait! Take action now to educate, inform, and advocate for persons with Wilson's disease through the Association and your local resources.

Warm regards,  
Kimberly Symonds  
Executive Director

#### 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 Name: \_\_\_\_\_ 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

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Legal – Non-Profit Experience

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Government Affairs

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Marketing

Board of Directors

Public Speaking

Computer Technology

Fundraising:

Web Site/Internet

Special Events

Newsletter

Foundations

Local Support Group Organizing/Leading

Corporations

Office Work

Other (specify) \_\_\_\_\_

Please return to: Wilson's Disease Association, 1802 Brookside Drive, Wooster, Ohio 44691



The Wilson's Disease Association gratefully acknowledges partial support of this newsletter by Gate Pharmaceuticals, manufacturer and developer of Galzin®.

**Wilson's Disease Association**

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E-mail: [wda@sssnet.com](mailto:wda@sssnet.com)  
WDA Website: [www.wilsonsdisease.org](http://www.wilsonsdisease.org)

**WDA Board Members**

Mary Graper - President  
Stefanie Kaplan - Vice President  
Len Pytlak - Treasurer  
Carol Terry - Secretary  
Luke Chung  
Jeff Eckland, J.D.  
Nancy Hoffman  
Henry Kaplan, M.D., J.D.  
Stefan Sandler

**Honorary Board Member**

Janene Bowen  
Sparky Terry

Kimberly Symonds - Executive Director

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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 up-to-date.

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- ◆ *WDA Annual Meeting Summaries*
  - ◆ *Outgoing and Incoming Presidents*
  - ◆ *Newly Elected Board Members*
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**WILSON'S DISEASE ASSOCIATION, INTERNATIONAL**

The Copper Connection  
1802 Brookside Drive  
Wooster, OH 44691

(FORWARDING SERVICE REQUESTED)

**TO:**