Wilson's Disease Support Group - UK

NEWSLETTER **APRIL 2012**

Welcome

The Wilson's Disease Support Group - UK (WDSG-UK) is an all volunteer organisation which strives to promote the wellbeing of patients with Wilson's disease.

It publishes an annual newsletter with informative articles written by medical professionals and also articles written by patients, their families and friends about their experiences of the disease.

It promotes networking of Wilson's disease patients and their families by helping and encouraging contact with one another.

And the Group strives to promote a wider awareness of Wilson's disease within the medical profession.

AFFILIATED TO :

BRITISH LIVER TRUST

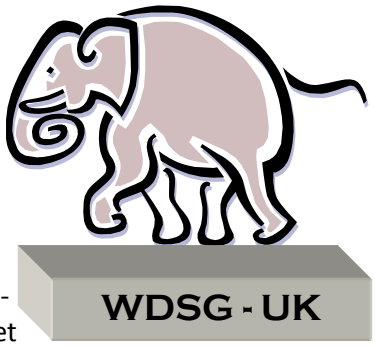
Children's Liver Disease Foundation
fighting childhood liver disease

Genetic Alliance UK
Supporting. Campaigning. Uniting.

RARE DISEASE UK

Climb
Children Living with Inherited Metabolic Diseases

Hello everyone!



Welcome to this year's bumper newsletter; I hope you'll enjoy reading it. There are plenty of articles to enjoy, including patients' personal experiences of Wilson's disease, accounts of members' fundraising activities, a page from Dr Walshe giving advice on when to take our tablets, reports by Rupert, reviews by Anne-Marie and a caption competition suggested by Dr Walshe's daughter with a £20 prize for the winner (*page 13* for those of you who can't wait to get started!) At the back of the newsletter you will find, new this year, a diary of forthcoming events. Don't forget to let us know of anything you have planned for 2013, so we can include it in next year's newsletter. And finally, we apologise to our regular readers for the absence of our usual feature on Valerie's and my annual holiday escapades but unfortunately, due to circumstances beyond our control, our plans last year were thwarted. Normal service will be resumed as soon as possible!

Our ***Facebook*** site has really taken off in the last six months. There are now over sixty members from all over the world including a patient from Nepal that you will meet later on in the newsletter and lots of new patients from the UK. There are some very interesting posts and lively discussions with new friendships formed and problems and experiences shared. If you haven't already joined us on *Facebook*, then why not give it a try? After all we are a support group and this is an excellent way of supporting one another.

Last summer's meeting was once again a resounding success and we now have a date for this year's meeting and A.G.M in Cambridge. It is the 15 July and I hope to see many of you then. I am keeping my fingers crossed for another gloriously sunny afternoon! You will find a booking form and agenda for the meeting enclosed with this newsletter, together with your membership renewal form. A big THANK YOU to everybody who renews.

Finally, I am sure you will all be pleased to know that Dr Walshe is continuing to make good progress after his recent fall. We look forward to seeing him at our meeting in July.

Wishing you a healthy and happy year *Linda*

IN THIS ISSUE ...

Chairman's Report

This last year has been a successful year for the Group and I would like to take this opportunity to thank **Linda Hart, Anne-Marie Styles, Jerry Tucker and Valerie Wheater**, together with you the members, your families, friends and sponsors for contributing to this success. I outline below our progress over the past twelve months and our plans for the coming year.

2011-12

1. WDSG-UK Committee Meetings

The committee met twice in Cambridge in October 2011 and March 2012 and, in line with our constitution, we also held our first AGM at our very successful annual get together in Cambridge last July.

2. Donations and Fundraising

I should also like to thank members who made donations last year, in particular those of you who completed Gift Aid forms allowing us to claim back an additional 25p in the £1.00. During the past year over £1,500 has been raised by our members through various events. We are grateful to them and their supporters, and to Univar who continue to sponsor us. Thank you also to everybody who responded to Linda's email about fundraising activities held on Rare Disease Day (29 February). Donations from members' fundraising on that day have been forwarded to a charity which we linked up with in 2011, and which has been very helpful to us over the past twelve months – ***Rare Disease UK*** (see also *p3* opposite).

3. WDSG-UK on the Web

The last year has seen additions (for example the *Wilson's Disease* pamphlet) and improvements to the *WDSG-UK* website, but one notable feature has been the emergence of our ***Facebook*** site as a popular and effective tool for members to share information and concerns. We are a 'Closed group' on *Facebook*, which means everyone on *Facebook* can see the *WDSG-UK* Group name and members, but only Group members can see posts among the Group. Unless you are added to the Group by another member, you will need to ask to join. You become a member when your request to join is approved.

4. EuroWilson – Meetings in Paris and Munich and Patients' Questionnaire

Your committee received financial support from EU-funded ***EuroWilson*** to attend three meetings in 2011 and 2012 organised by *EuroWilson* for European WD patient groups' representatives. In addition we were invited to a symposium on Wilson's disease in Paris for health care professionals held last November. Central to the liaison of *EuroWilson* with the patients' groups over the past year has been a *EuroWilson Patient Questionnaire*, which seeks information on the diagnosis, treatment and aftercare of patients with Wilson's disease. A first questionnaire was distributed during the summer of 2011, and I am very grateful to our members who replied so promptly and informatively. Your replies were collated in Paris together with those from the German, Swiss, French, Italian and Spanish WD Patients' Groups. The results appear on the *EuroWilson* website. Plans for a second *EuroWilson Patient Questionnaire* were discussed at the third meeting for WD patient groups' representatives held in March 2012, and circulation of this second questionnaire is expected to be arranged during this summer.

For further details of the activities of *EuroWilson*, please refer to *pp 8-10* of this newsletter.

5. NHS Blood and Transplant (NHSBT) Adult Liver Allocation Policy Meetings

In November 2011 and February 2012 Valerie represented *WDSG-UK* at two meetings in London organised by ***NHSBT*** for representatives of UK Liver Disease Charities and Patient Support Groups. The purpose of the meetings was to give patient representatives an opportunity to express their views on potential new allocation and distribution schemes for adult liver transplantation in the UK. Prof. James Neuberger, Associate Medical Director *NHSBT Organ Donation and Transplantation (ODT)* and Dr Alex Gimson, Chair *NHSBT Liver Advisory Group* each addressed both meetings explaining the differences between the current allocation system and a suggested new allocation system.

6. WDSG-UK – Affiliations Old and New

We continue our collaborations with the *British Liver Trust* (*BLT*) and *EuroWilson* and have also linked up with four new charitable organisations over the last year: ***Genetic Alliance UK***, ***Rare Disease UK***, the ***Children's Liver Disease Foundation*** and ***CLIMB*** (***Children Living with Inherited Metabolic Diseases.***) By engaging with these national organisations the profile of *WDSG-UK* is raised and, in the case of the children's charities, we can try to reach out to some patients who are perhaps under-represented in our Group. In addition, these four organisations can give advice to *WDSG-UK* on specific issues which are important to *WD* patients.

Genetic Alliance UK is a national charity of 150 patient organisations supporting all those affected by genetic disorders. Its aim is to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them.

Genetic Alliance UK established ***Rare Disease UK (RDUK)*** in conjunction with other stakeholders in November 2008 following the European Commission's Communication *Rare Diseases: Europe's Challenges*. This Communication set out proposals for a comprehensive, European Union (EU) wide, integrated strategy to support Member States on issues including diagnosis, treatment and care for rare disease patients.

In June 2009, *RDUK* successfully campaigned for the UK's adoption of the Council of the European Union's Recommendation on an action in the field of rare diseases. This recommendation calls on all EU member states to develop plans or strategies for rare diseases by 2013 in order to ensure universal access to high quality care.

More details of the work of *RDUK* and the plan for rare diseases in the UK emerged when I attended the *Rare Disease UK* Annual General Meeting last September. See *pp 14-15* for a separate report of the *RDUK* AGM.

Web links for all the organisations mentioned in this section may be found on the *WDSG-UK* home page www.wilsonsdisease.org.uk.

2012-13

1. WDSG-UK Annual Meeting and 2nd AGM

The 2012 Support Group Meeting has been arranged for **Sunday, 15 July 2012** at the clubhouse of the city of Cambridge's Rugby Union Football Club. During the course of this meeting the **2nd WDSG-UK AGM** will be convened. An agenda for the AGM is included with this Newsletter. As part of the AGM, the election of officers and members of the WDSG-UK Management Committee for the year 2012-2013 will take place. All members of the current committee have submitted their names for re-election for this period.

2. International Symposium on Wilson's Disease: London – October 2012

March 2012 is the centenary of the publication in the journal *Brain* of Samuel Alexander Kinnier Wilson's paper on 'progressive lenticular degeneration.' The hundred years which have passed since Wilson's description of the neurological and hepatic symptoms of six patients have seen notable developments in understanding and treating Wilson's disease, but leave some unsolved problems. It is appropriate therefore in 2012 to hold a symposium on Wilson's disease as a means of promoting research into WD and meeting some of the goals which are written into *WDSG-UK's* Constitution.

The symposium will take place on 5-6 October 2012 at the Royal College of Physicians, London. *WDSG-UK* is helping to organise the programme for this event.

This report has reviewed the activities of WDSG-UK during 2011 and the first part of 2012. Through the combined efforts of your committee, WDSG-UK members, family and friends, we have tried to meet the objectives of the WDSG-UK constitution, at least in part, and we will continue to do so in the future.

Rupert Purchase
March 2012

Wilson's Disease Support Group Meeting & 1st AGM

Cambridge Rugby Union Football Club, 10 July 2011

Cambridge's Rugby Union Football Club provided the venue once again for the 2011 annual get together of WDSG-UK members, friends and family. Around fifty people attended and we were particularly pleased to welcome new members **Allie Johnston** and her mother **Rita**, who had flown down from Edinburgh to be with us. We thank **Dr Walshe, Dr James Dooley** and **Kay Gibbs** for their unwavering support and for offering us their expertise during the course of the day.

Richard Hall of the BLT

Refreshments were served on arrival over which people chatted informally. While technical problems with the overhead projector were being addressed, **Linda** began the meeting by welcoming us all, running through the programme for the day and giving a resume of her activities over the past year.

As **Rupert** mentions in his Chairman's report (*pp2-3*), *WDSG-UK* has strong links with the ***British Liver Trust (BLT)*** and we were therefore delighted to welcome **Richard Hall,** their Liver Support Groups' Coordinator, who had kindly curtailed his holiday in order to be with us. Without the advantage of a working projector to show the PowerPoint presentation he had prepared, he skilfully improvised and gave us a clear and enlightening summary of the work of *the Trust*.

Valerie with Allie and her mum Rita from Edinburgh

After an excellent buffet lunch, **Dr John Walshe** began the afternoon with a short, historical and insightful account of Wilson's disease and its treatment. One of the requirements of our constitution which was submitted to HMRC last year as part of the Group's successful application for charitable status is to hold an Annual General Meeting and to elect (or re-elect) a management committee. After **Dr Walshe's** talk, the first AGM of *WDSG-UK* was held. **Rupert** reported on developments over the last year, **Valerie** presented the accounts, and a management committee was unanimously elected for the year 2011-2012.

A short discussion about future activities for WDSG-UK then merged with more specific questions on Wilson's disease for **Dr Walshe** and **Dr Dooley**, before the meeting closed with the customary raffle and Group photograph.

Drs Walshe & Dooley

Outside the Rugby Club

Elevenses

FUNDRAISING 2011

SPONSORED SWIM

by Lesley Galloway

Seven years after joining WDSG I finally got round to thinking about doing some fundraising. After years of taking Emma and her brother, Andy, swimming as children I decided it was time to take it up myself. However, I spent more time in the pool daydreaming than swimming. So I started practising and set myself a goal of swimming 70 lengths (which is just over a mile). I then cajoled Andy into joining me in a sponsored swim and together we booked a lane at Bletchley Leisure Centre for Sunday **3 July**.

Emma and Andy

Andy is now 26 years old and as he has been swimming since he was a baby he has biceps the size of tree trunks. Mine bear more of a resemblance to saplings! However, I managed 70 lengths in seventy minutes while Andy swam 140 lengths in the same amount of time. Between us we raised **£825** for the Support Group. When I told Emma, she asked for £500 of it for an iPad! She seemed to think having Wilson's entitled her to it. I said "No chance; buy your own!" Fortunately she did, so the money made it safely to Valerie and the WDSG bank account for the benefit of everyone.

Thank you to all those in WDSG who have supported Emma and me in the last few years. Emma will hopefully be leaving her care home this year and living independently in the community again. For anyone who hasn't heard the good news, she and her boyfriend, Ollie, became engaged last year.

COFFEE MORNING

Sylvia Penny

On Saturday, **27 August** our regular fundraiser Sylvia Penny from Devon, together with her granddaughter, another Emma with Wilson's disease, held a coffee morning and raffle with their friends and family at Victoria Park Church in Torquay raising the sum of **£504.94** for Group funds.

Emma and her Grandmother, Sylvia

This brings the total that Sylvia has raised for WDSG-UK over the past five years to more than £2,000. We are very grateful to her for all her hard work. Sylvia also offers friendship and support to newly diagnosed patients and their families anywhere in the UK.

SPONSORED BIKE RIDE

by Valerie

On Sunday **29 May**, I set off with two very good friends, Helen and Daniela, to take up the challenge of a 200 mile cycle ride through Austria along the River Danube, from Passau in the west to Vienna in the east.

Helen, Daniela and I – Only 200 miles to go...

But for me **that** was the easy part! Having claustrophobic tendencies and a fear of flying, by far and away more difficult was taking the EuroStar on the way out (and just my luck, it was stuck in the tunnel for over half-an-hour) and having to get on an aeroplane to come home. It was my first flight for twenty-five years and couldn't have been more turbulent!

Miraculously, I survived and lived to tell the tale (*p11*) and through the kindness of my friends, family, neighbours and fellow patients raised **£195.00** for the Group.

Scott's Story

by Dawn Walker

Scott was born in 1982 along with his twin brother, which was a bit of a surprise as we were only expecting one baby. They were born seven weeks early but they were healthy. By the time the boys were five they had been joined by two little sisters.

Scott started to develop within the normal ranges but by three was starting to lag behind. He had difficulty with fine motor skills and was a regular visitor to the local A&E department having stitches (this may have been due to his inability to walk anywhere, doing everything at full speed). At school he had a statement of special need to help him keep up. He was a great character and had lots of friends. He was popular with the children and staff alike. He managed to leave school with a few GCSEs before going off to college. After college he worked as a gardener for a while. After a period of unemployment Scott got a placement working with the Broads Authority on the Norfolk Broads. He loved this job and regularly came home covered in mud.

He then learnt to drive, passing his test first time, which was a huge achievement. Once he had a car we didn't often see him as his main interest in life was spending time with his friends, including a lot of girlfriends! Eventually Scott got a job in a toy shop in Norwich and he did this until he became unwell. He received a letter from his employers one day asking him to allow them to consult his doctor as they were concerned about his health. Shortly after this Scott decided that he couldn't face work anymore.

This was four years ago when Scott started to become very emotional if anything worried him. He became so bad that I persuaded him to visit our G.P. who started him on anti-depressants, which made no difference at all. He tried relaxation exercises and even hypnotherapy, all to no avail. He became more and more withdrawn and following a late night car crash began to lose all interest in going out. This was very worrying for us as he had been such a sociable lad. Around this time I had started to notice a tremor in his hands which to begin with I put down to stress. This gradually got worse and when we consulted our G.P., she prescribed him beta-blockers.

Next I noticed that his face started to look different. I later described it to his neurologist as if his features had *closed down*. His eyes were droopy and his smile was rigid and fixed, not at all natural. We went back to the G.P. and explained that the tremors had become so bad that Scott could no longer eat without help and I was having to clean his teeth and shave him. Scott was referred to the local hospital to see a neurologist. The neurologist was very interested and took a full medical history. He then asked how long Scott's leg had been shaking, which was a new development that was barely visible so I was impressed that he had noticed. Scott was sent for blood tests and urine tests (which are not easy when you have a small bottle and hands that tremor) and also he was filmed so that any future changes in his movements could be noted. We were given an appointment to return some months later.

After a few weeks we received a call bringing the appointment forward. The neurologist said that the copper levels in the urine and blood samples were not as expected. Scott should do a 24 hour urine test. He was being sent to a gastroenterologist and an eye specialist. He explained a little about what he thought was happening to Scott and said that he was 99% sure that his condition was something called Wilson's disease. I am sure that before diagnosis most of you, like us, had never heard of it.

We attended the eye clinic where Scott caused great excitement when the young doctor he saw could see Keiser Fleisher rings in his eyes. She went to get the consultant to check her findings and he brought lots of other doctors in to look. He explained that doctors may go through their entire careers without ever seeing these rings. By now Scott's speech was deteriorating rapidly and his legs were becoming stiff. The tremor in his hands made independent life impossible.

An appointment was made for us to see a gastroenterologist a few weeks later. While waiting for this Scott became very poorly. His behaviour became strange and a friend found him walking one day along the middle of a main road in rush hour and so brought him home. He kept trying to climb out of first floor windows and in despair we called in our doctor. Scott was admitted to a psychiatric clinic for two weeks for his own safety.

During his time at the clinic we saw the gastroenterologist who prescribed Distamine penicillamine. By the time Scott left the clinic his speech was incoherent and he drooled constantly. On one occasion he was in a music shop and the staff called security (I think they thought Scott was drunk or drugged.) He had only wanted to buy a CD but he couldn't make himself understood nor could he write down what he wanted.

He had several falls and when he fell he couldn't get up again. Scott couldn't stand up from a chair without help and when he tried to sit down he just fell backwards as he couldn't bend to sit. It was as if he had forgotten how. He became disinhibited which put him at great risk. He wanted to hug and kiss everyone, male or female and told girls they were beautiful, even commenting on a lovely bust once. This of course bothered people in the street. At one time he couldn't sleep alone and I spent some weeks sleeping on his bedroom floor. He couldn't get in the bath or shower so I had to help him which didn't bother him at all. A great moment in his recovery came the day he said, "Get out of the bathroom; I'm going in the shower." He had regained his modesty!

Eventually we managed to get social services involved and things improved in a practical way. They organised for us to have a stair lift installed, together with an inflatable bath lift and a lift on his bed (which they raised on stilts) to help him get up. Finally, they provided him with a comfy rise and recline armchair. One of the awful aspects of an illness like this is the isolation. You find out who your friends are. Only a couple of friends stuck with Scott throughout. We found a wonderful day centre run by *Headway*, who were prepared to take Scott on although they had no experience of Wilson's disease. Scott was and is picked up in a taxi to go there three days a week. I wrote to the local press who ran an article on our family in the hope that the publicity might draw in other families living locally affected by Wilson's. Then I managed to find the Wilson's Disease Support Group, what a lifesaver!

Scott has now been on penicillamine for two years. I think his neurologist is amazed at the improvement and it is certainly more than I expected. Most of what Scott says can be understood if you listen carefully to him and the drooling has disappeared. His legs are still stiff but he doesn't fall and we have removed all the aids that we had in the home. His behaviour has improved to a socially acceptable level and he can now go out on his own locally.

We have a cafe close by and the owner has been so kind to Scott, providing a straw in his hot chocolate that he thinks I don't know about. Scott's hands get quite stiff but the tremor, while still pronounced, is better and he can write a bit again. He can use his computer, which has a large key board. Originally it also had a perspex cover with holes in to stop Scott tapping the keys he didn't want, but he doesn't need that any more.

Scott is becoming more independent and is thinking of leaving home (with help). I know that everyone's experience of Wilson's is different, but what I would say to those at the beginning of this traumatic journey is "Have **hope**." It can get better. If you live in the UK involve social services who are able to make life easier. And finally, talk to anyone who will listen.

Good luck and good health to you all.

February 2012

HOPE IS THE THING WITH FEATHERS.

Emily Dickenson

"Hope" is the thing with feathers
That perches on the soul
And sings the tune without the words
And never stops at all
And sweetest in the gale is heard;
And sore must be the storm
That could abash this little bird
That kept so many warm.
I've heard it in the chilliest land
And on the strangest sea
Yet never, in extremity
It asked a crumb of me.

WDSG-UK and EuroWilson

1. EuroWilson

EuroWilson is a European network of healthcare professionals and patient groups dedicated to Wilson's disease, its purpose being to improve the quality of care for EU patients and to facilitate access to multi-disciplinary expertise for the treatment of Wilson's disease. *EuroWilson* is governed by a group of academic doctors with support from the European patient groups.

Countries (shaded) participating in EuroWilson

EuroWilson was funded from 2004-2008 through the European Commission Six Framework Programme. In 2011 *EuroWilson* renewed its public funding with a grant from DG Sanco (the European Commission Directorate General for Health and Consumer Affairs). This funding has allowed *EuroWilson* to organise and finance **three** meetings during **2011** and **2012** for **representatives of European *WD* patient groups**. As part of the second meeting for patients' representatives, which was held in Paris in November 2011, *EuroWilson* also organised a ***European Wilson Disease Congress***.

2. EuroWilson Patients' Representatives Meetings 2011-2012

a. The 1st EuroWilson Patients' Representatives' Meeting: Paris - 10 June 2011

Situated conveniently next to the Gare du Nord and therefore a mere two-and-a-half hours from St Pancras station, the stylish Parisian architecture of the Hôpital Lariboisière provided the setting for two meetings of *WD* patients' representatives organised by *EuroWilson* in 2011, which Linda, Valerie and I attended on behalf of *WDSG-UK*. Representatives of *WD* patients in France, Germany, Switzerland, Spain and Italy were also present and the meetings were hosted by Dr Jean-Marc Trocello (*EuroWilson* Network Director), Dr France Woimant (French Network Director) and Samantha Parker (*EuroWilson* Programme Manager).

Hôpital Lariboisière, Paris

Dr Trocello summarised the **aims** of *EuroWilson* as follows:

- **Promote** exchange between participants;
- **Provide** up-to-date information on the EuroWilson website (eurowilson.org) and on the Orphanet website (orpha.net);
- **Develop** and publish evidence-based clinical guidelines;
- **Develop** telemedicine within the network;
- **Enhance** the European *WD* patient register to provide epidemiological data, outcome indicators, country comparisons and to facilitate collaborative research and public health projects;
- **Support** patients and patient associations in the EU;
- **Continue** to serve as a research and knowledge centre for *WD*.

Dr Trocello then described the 'French Network' for treating *WD* patients which coordinates a register of about 400 *WD* patients in France and is linked to the European *WD* register. The French Network has two Reference Centres (Paris: coordination of *WD*, and Lyon: multi-disciplinary approach and molecular biology of *WD*) and centres in six other French cities for *WD* patients to contact.

Jean-Marc Trocello and Linda

Following Dr Trocello's presentation, each of the six patient groups described their experiences of the treatment of WD in their respective countries and their concerns and expectations for the future. Disparities between different countries in the treatment of *WD* were evident – mainly as a result of national differences in the administration of health care.

In order to achieve a better understanding of the treatment of WD in Europe, *EuroWilson* had produced a ***Patient Questionnaire*** on their healthcare needs. Patients' representatives were asked to distribute the questionnaire within their respective patients' groups during the summer and autumn of 2011.

b. The 2nd EuroWilson Patients' Representatives' Meeting: Paris – 14 Nov 2011

The second meeting for *WD* patients' representatives took place in Paris on 14 November and was part of a two-day symposium which *EuroWilson* had organised for clinicians and others with an interest in the diagnosis and treatment of *WD*.

A round table discussion of *WD* patients' representatives preceded the main scientific part of the two-day symposium and brought together most of the participants from the *EuroWilson* meeting, which had taken place in June 2011. The first meeting had highlighted some of the differences among European countries in responding to the treatment and care of Wilson's disease patients, with France and Germany seeming to offer a better coordinated approach to diagnosis and treatment compared with other parts of Europe. These differences were reiterated at the November meeting, which briefly discussed two topics – European initiatives on the treatment of rare diseases and the responses of individual patient associations to the *EuroWilson Patient Questionnaire*. Also at this meeting an English language version of ***EuroWilson Dietary Guidelines for WD Patients*** was circulated.

EuroWilson Dietary Guidelines for WD Patients

In collaboration with dieticians at the Hôpital Lariboisière, the French *WD* patient association (Association Bernard Pépin pour la Maladie de Wilson) has produced a laminated pamphlet of nutritional advice illustrating and listing various foodstuffs and their copper content: beverages, meats, seafood, eggs and dairy products, vegetables, fresh and dried fruits (including nuts), bread and starches, desserts and sugar-based products, and fats. The foods are colour-coded into four categories according to their copper content:

1. Green: **'Authorised'** (< 0.30 milligrams copper/100 grams foodstuff)
2. Yellow: **'With Moderation'** (0.30 mg to 1 mg copper/100 g foodstuff)
3. Orange: **'Exceptionally'** (1 mg to 3 mg copper/100 g foodstuff)
4. Red: **'To avoid'** (≥ 3 mg copper/100 g foodstuff).

The first two classifications cover most of our diet, with only some **chocolate-based** products, **liver** and **shellfish** in the red zone of food which *WD* patients should **avoid**. An English language translation of these Dietary Guidelines was distributed at the second meeting for *WD* patients' representatives and copies of this pamphlet are available from Linda.

c. The 3rd EuroWilson Patients' Representatives Meeting: Munich – 8 March 2012

Munich Meeting, March 2012

The German Wilson's Disease Patients' Support Group hosted the third meeting for WD patients' representatives in Munich on 8 March 2012. Delegates from Germany, France, Italy and Switzerland attended, together with Anne-Marie, Jerry and me from WDSG-UK. There was also a written submission by Señora Amparo Maudos from the Spanish WD Support Group. The aim of this meeting was to discuss the results of the first *EuroWilson* Patient Questionnaire, circulated in 2011 and to produce a second questionnaire for WD patients, families and friends for distribution during 2012.

Dr Jean-Marc Trocello opened the meeting with a PowerPoint presentation illustrating the responses from 269 individuals to the questions in the first questionnaire. Dr Trocello's presentation is available on the *EuroWilson* website. The findings from this initial survey were a first 'snapshot' of information from *WD* patients and their families. An important point which emerged was the time taken for diagnosis – from first observations of the initial symptoms to confirmation of Wilson's disease. Early and correct diagnosis clearly leads to a better outlook for the patient.

WDSG-UK and EuroWilson *continued*

Dr Trocello emphasised the importance of engaging patients and their families with the goals of *EuroWilson*. The collation and dissemination of information about the treatment and care of patients with Wilson's disease through questionnaires is an integral part of *EuroWilson's* work, and will help to secure funding for *EuroWilson* for future years.

Each of the five countries represented at this third meeting then made suggestions for the proposed second *EuroWilson Patient Questionnaire* and this was followed by a detailed discussion (chaired by Dr Trocello) on the choice of questions. Five topics emerged from the discussion:

1. **Time of diagnosis**;
2. **Treatment**;
3. **Socio**-professional and 'quality of life' issues;
4. **Women** and Wilson's disease;
5. **Information** sources for Wilson's disease.

It is likely that the second questionnaire will be initially restricted to questions arising from the first two headings (***Time of Diagnosis*** and ***Treatment***) because of the detailed information each of these two subjects can generate.

The friendly and cordial atmosphere of these first three *EuroWilson* meetings for patients' representatives has given an insight into the work of our European colleagues in their respective organisations and provided ideas for the development of *WDSG-UK*, e.g. the brochure produced by the German Support Group on the issues for women with *WD* who are contemplating pregnancy. It was also evident that whilst there are common themes across different countries, patients in some parts of the EU encounter challenges of drug availability and cost of treatment. The delivery of health care at a national level and within federal regions can also affect treatment options for *WD* patients.

3. European Wilson Disease Congress – 15 November 2011

The elegance of the Hôpital Lariboisière gave way to the more functional surroundings of the Eurosites République for the venue of the European Wilson Disease Congress, held on 15 November 2011 following the second *EuroWilson* Patients' Representatives meeting the previous day. An audience of about 100 clinicians, scientists, and representatives from WD patients' groups heard about recent research into Wilson's disease in the morning session, while some more general aspects of the disease featured in the afternoon.

European WD Congress – Eurosites République – Paris Nov 2011

Abstracts of most of the presentations from the first part of the Congress may be found on the *EuroWilson* website. Among the highlights from this session were some cautionary comments about using zinc to treat WD, the relative merits of *D-penicillamine* and *trientine* and two new research initiatives from France – 'relative exchangeable copper': a new highly sensitive and specific diagnostic biomarker for Wilson's disease, and research into gene therapy in an animal model of *WD*. New Clinical Practice Guidelines for Wilson's disease have been developed by the *European Association for the Study of the Liver (EASL)* and have now been published in the *Journal of Hepatology*, 2012, (volume 56, pp 671-685).

In the afternoon session the history of Wilson's disease was reviewed and Professor Stuart Tanner projected an optimistic assessment of diagnosis and treatment in future decades. The Spanish patients' representative, Señora Amparo Maudos (Presidente de la Asociación Española de Familiares y Enfermos de Wilson), presented an informative video of her experiences with Wilson's disease, and the meeting concluded with a brief discussion of the *EuroWilson Patient Questionnaire* and the *EuroWilson Dietary Guidelines for WD Patients* (described above).

Rupert Purchase
March 2012

Cycling the Danube – Passau to Vienna – May 2011

The previous year I had resolved never again to embark on adventure holidays with men! But I was still keen for adventure and was therefore delighted to be invited by female friends to cycle with them along the Danube early in the summer. I was determined, too, to be fitter this time and took up immediate membership of a local gym where I could be found on an exercise bike four mornings a week. At my peak I was cycling twenty miles in just over an hour.

April came and with it weather that was unseasonably warm, so I swapped the gym for the highways and byways of Cambridgeshire. But my own bicycle proved far more difficult to ride, despite the flat terrain. For one thing no matter which direction I cycled in, the wind was always against me! But I persevered, graduating to the rolling countryside of Suffolk and Essex where Helen and Daniela respectively live.

By the time we left, I could not have been more prepared. We arrived in Passau late on the Sunday evening via Brussels and Frankfurt. Early the next day I was raring to go but my fellow travellers insisted we visit the local cathedral first to see the world's *largest* organ (with 17,974 pipes). Was this to be the beginning of a cultural awakening for me? Later, when the river cruisers had long since left their moorings, we set off to collect the bicycles which Daniela had reserved some weeks earlier. After loading the panniers with our meagre possessions, we had a quick practice wobble around the square before deciding it was time to get going.

Well actually first we stopped to consult the *Cycling Guide to the Danube Bike Trail: Part 2* to work out on which side of the river we wanted to be. Bridges were few and far between, although we did come across the occasional cycle ferry which we were able to take advantage of. Once or twice we had to travel by the side of main roads but generally speaking our route took us along endless miles of river paths or on tiny country roads through sleepy Austrian villages. The bicycles proved easy to ride and had the distinct advantage of running on puncture resistant tyres. Using the aforementioned *Guide* we planned in advance where to stop each night, finding suitable low budget accommodation without any problem.

Apart from a terrific thunderstorm one evening, the weather was glorious. We averaged a distance of thirty-five miles a day including three lengthy stops exploring the cities of Linz (where Hitler was born), Melk with its magnificent baroque abbey and Krems where I had my hair done! We visited churches and monasteries that were on our route and castles, museums and art galleries that weren't! We also made a detour to the abandoned nuclear power station, which was completed in the 1970s but after a public outcry was never allowed into operation. Now **that** I did enjoy as I love social history.

One of the prettiest parts of the ride was on the Friday morning through the vineyards of the Wachau valley, which is famous for its white wine and tastings thereof! By the following afternoon we had arrived on the outskirts of Vienna, where sadly we had to hand in our bicycles. We spent the night at a friend of Daniela's eating schnitzels and strudels before one final cultural push on the Sunday, which started in the Botanic Gardens, moved to the Opera House, continued in the Stadtpark and finished in the Belvedere Palace, where we spent hours looking at the works of Klimt, Schiele and Oskar Kokoschka in microscopic detail. I was ready to come home for a rest!

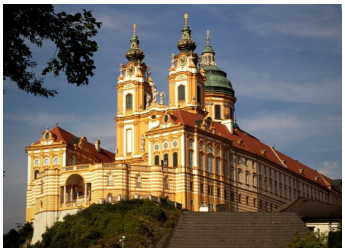
So what challenge am I taking on this year? Well, I'd like to do the next stretch of the Danube from Vienna to Budapest, but so far I've found no-one to go with. Hang on a minute...I wonder what the **men** are up to!

Men - Never Again!

Bank Hopping by Cycle Ferry

End of Day One! Nothing to it!

Not a von Trapp in sight!



Benedictine Abbey at Melk

Sunday in the Park with Strauss!

At Home With Dr John Walshe

Dr Walshe – At Home

How Many Wilson's Disease Patients have you treated Dr Walshe?

During my professional career I have cared for over **300** patients from all over the world.

The first patient ever to be treated with penicillamine came to me from the Archway Hospital in Highgate, London, in **1955** at the age of 14 and she remained a patient of mine until the year 2000, when I gave up my clinic in London. To the best of my knowledge and belief, she is still well. Since the 1950s I would say that one-quarter to one-third of my patients have come from overseas from such countries as the USA, Australia, New Zealand, South Africa, Malaysia, Iran, Iraq, Saudi Arabia, The Yemen, Egypt, Turkey, Greece, Bulgaria, Hungary, the former Yugoslavia, Austria, Switzerland, Italy, France, Germany, the Netherlands, Portugal, Tenerife and Ireland.

How Do Penicillamine and Trientine Work?

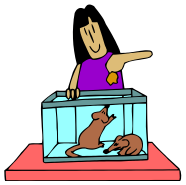
Penicillamine and trientine are known as chelating agents. The word *chelate* is derived from the Greek word *chelex* meaning *a claw* and these chelating agents work by forming what is known as a *ring compound* with the copper, rather like *a claw* picking up an object. These chelating agents are absorbed from the gut and carried in the blood to the liver, from which they enter the general circulation ready to meet the copper once it arrives. Trientine is less well absorbed from the gut than penicillamine and therefore requires a higher dosage.

Does it Matter When Patients take them?

It is most important that whenever possible penicillamine or trientine are taken approximately **30 minutes** before a meal. The reason for this is that if the drug is in the blood when the copper arrives, it removes the copper from the body very efficiently. If the food is taken first the copper in the food gets stuck on to proteins in the body and is much more difficult to mobilise and therefore remove.

It is a mistake to take all your drugs as a single dose once a day. It is much more effective to take them in divided doses. Taking your medicine as a single dose brings into action the law of diminishing returns. Say, for example, **500mg** penicillamine removes 1000 micrograms (**1mg**) of copper, then taking **500mg** twice a day would remove 2000 micrograms (**2mg**) of copper. On the other hand taking **1000mg** (**1g**) penicillamine in one single dose will probably only remove 1500 micrograms (**1.5mg**) copper, a shortfall of copper of 500 micrograms (**0.5mg**).

Should Patients on Penicillamine also take Pyridoxine (Vitamin B_6?)



Penicillamine can occur in two isomeric forms: one which bends polarised light to the left L(laevo)-penicillamine and the other which bends light to the right D(dextro)-penicillamine. All naturally occurring amino acids bend light to the left. L-penicillamine is toxic and inhibits the action of vitamin B_6 (pyridoxine). Fortunately, the penicillamine which was originally derived from penicillin is the D-form and only has a very weak action against vitamin B_6. Thus, pyridoxine is only necessary for patients to take during periods of active growth, pregnancy, secondary illness or malnutrition. Kay Gibbs and I showed this experimentally on rats many years ago.

Summary

- **It is vital to take penicillamine and trientine half-an-hour before a meal**
- **Penicillamine and Trientine are more effective in divided doses**
- **Pyridoxine is only necessary for patients on penicillamine in periods of active growth, pregnancy, secondary illness or malnutrition**

The Lifemax Pocket Pill Box Reminder

A Review by Anne-Marie

Remembering to take medication at the correct time can be a problem. A portable pill box with a built-in alarm could be the answer. One such device is the *Lifemax Pocket Pill Box Reminder*.

This plastic pill box is pocket-size. It measures 9cm x 5cm x 1.5cm (3.5" x 2.0" x 0.5") and weighs 35 grams (just over an ounce). It can be worn as a pendant using the long neck cord which comes attached. The blue transparent cover slides open without difficulty to reveal two compartments which can each hold up to **nine** penicillamine tablets comfortably. They are easily visible when the cover is closed. It uses a 1 x 1.5V button cell battery, which is included. To change the battery you need a screwdriver to open the battery cover. There is a set of easy to follow instructions, although the typeset is very small. *The Lifemax* costs £10 and is available online (e.g. from Amazon) or from high street electronic parts shops (e.g. Maplin).

The box has a small window which displays the time/countdown. Setting the time clock is straightforward, as is the countdown facility using the two control buttons, although they are very small and may be difficult to manipulate for some people. The buttons are protected by the cover when closed which means that you cannot press them accidently. You can programme the timer to count down to a set time (up to 19 hours 59 minutes). An alarm sounds and a light flashes when countdown is complete and your medication is due. You press the start/stop button to stop. If you need to count down for the same number of hours all you do is press the start/stop button again. Otherwise you have to reset the timer. The box can also be used as a stopwatch for up to 19 minutes 59 seconds count up time. Unfortunately you cannot use the alarm when in the clock time mode, nor can you switch from one mode to the other.

The pill box is certainly not a sophisticated piece of machinery like a typical mobile phone, which already has the clock, alarm and countdown features. It can only cater for very simple and straightforward needs. Anyone with complex medication requirements may find this device a little too crude.

CRYING OUT FOR A CAPTION!

This picture of Dr Walshe sitting in front of his computer was sent to us by his daughter, Susan, who suggested that we use it in a caption competition. We think this is an excellent idea and offer a £20.00 prize to the best/most humorous entry, as judged by Susan.

Please send your caption to Linda before 30 September 2012. The winning entry will be published in our next newsletter.

Rare Disease UK Annual General Meeting

www.rarediseases.org.uk

"Working together we can secure the best use of scarce expertise and resources, maximising the health gain for all those with rare conditions." **Alastair Kent** OBE, Chair of ***Rare Disease UK (RDUK)***

WDSG-UK joined ***Rare Disease UK (RDUK)*** in 2011, and I have described some of the work of this organisation in my Chairman's report (*pp 2-3*). By collectively representing many individual rare disease charities, *RDUK* is an effective organisation for action at a national (and European) level, as I learnt when I attended its AGM last September.

The *Rare Disease UK* AGM was held at the *National Council for Voluntary Organisations'* offices in London on 12 September 2011. About 50 delegates representing rare disease patient groups, the pharmaceutical industry, the ***Department of Health (DoH),*** and others, attended.

In his Chairman's report, **Alastair Kent** described the work of *RDUK* in responding to the Council of Europe's initiative on rare diseases and the involvement of *RDUK* with the UK *DoH* in producing a plan for rare diseases for each of the four countries of the United Kingdom. The report upon which implementation of this plan will be guided, *Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy*, was launched by *RDUK* on Rare Disease Day 2011 at four parliamentary receptions in the UK. Over 1000 individuals and organisations contributed to the *RDUK* report, which makes 27 broad recommendations and 85 specific recommendations.

Some insight into the government's approach to rare disease was provided by the second speaker at the AGM, **Dr Edmund Jessop**, who is a member of the *DoH* National Specialised Commissioning Team. Dr Jessop envisaged the creation of a number of **Centres of Excellence** (*CoEs*) to treat rare diseases in the UK *(*'Expert Centres'), which would facilitate early diagnosis of a rare disease. Presenting his personal (rather than Departmental) views, Dr Jessop elaborated further on the management of rare diseases in the UK and his comments (below) are also based on a report of this AGM, which is available on the web:

Centres of Excellence

- Due to the multi-disciplinary nature of *CoEs*, they will need to be supported by administrative excellence. Care coordinators will play a key role in delivering excellence. Dr Jessop was doubtful that a GP would be best placed to fulfil this role, but the economic reality is that it will almost always need to be fulfilled by someone in an existing post.
- *CoEs* should be concerned with the management of the care pathway, including the referring hospitals. There is potential for *CoEs* to run networks.

Diagnosis

- Dr Jessop believed that it is too simplistic to say that the problem of delayed diagnosis will be solved through more training to medical students at an undergraduate stage.
- There is potential to utilise a computer system which generates prompts to GPs when a set of symptoms could possibly be a rare disease.
- A system of prompts is less likely to be effective in a hospital setting however. A different approach is needed here. There is potential to offer more postgraduate training in rare diseases, but there are two different schools of thought in regard to this:

    a. **the first** would say that the training received should be in proportion to how much time a doctor is likely to spend dealing with that condition; and

    b. **the second** would argue that doctors should be trained to recognise all the conditions that they may potentially come across, despite how infrequently.

Screening

- Dr Jessop discussed the concept of whether it is unethical to screen for untreatable conditions in relation to the National Screening Committee's current line of thinking.
- A significant benefit would be that it avoids the "diagnostic odyssey" whereby a patient bounces around the system for months or even years.
- Another benefit could be that it assists family planning and reproductive choices. However, the cur rent line of thinking is that the benefit must be to the person (baby) affected by the condition itself and not the parents.
- Cascade screening through families to detect previously unknown relatives of the person screened could be seen as another benefit, but it wouldn't be considered a relevant consideration currently be cause it doesn't directly benefit the persons screened.

Research

- Dr Jessop believed registries to be an issue of great importance. However, he believed the argument for registries for rare diseases should be framed in terms of patient empowerment, i.e. every patient should have the right to be on a registry, as opposed solely to support research, as research funders are often reluctant to support registries. Dr Jessop highlighted the importance of registries being kept simple and noted the example of the cystic fibrosis registry as an example of good practice.
- Dr Jessop recommended going with the system as opposed to fighting against it in order to achieve success in the area of research funding. It will be a lot easier to, for example, to find a NIHR funding stream where rare diseases sit easily with a little adaptation as opposed to arguing for a brand new funding stream.

Future of specialised commissioning

- Looking ahead, there is a need for more strategic thinking when commissioning specialised services based around clusters of rare conditions, as it would be impossible to commission a service specific to each of the 6000+ rare diseases.

The UK Government Plan for Rare Diseases

The UK government plan for rare diseases (in response to the *RDUK* report) was published for consultation on Rare Disease Day 2012 (29 February). Details of the *DoH* document for rare diseases, which incorporates much of the work coordinated by *RDUK*, may be seen on the website:
http://consultations.dh.gov.uk/rare-diseases/rare_diseases_consultation.

In brief, the rare diseases consultation document:

- **Recommends** using specialist centres to make exact diagnosis – this will make sue people are treated earlier and in some cases this could save lives;
- **Acknowledges** that all doctors should have the correct training to be aware of the possibility of a rare disease;
- **Recommends** that the care of patients with rare diseases should be better co-ordinated.

The consultation period for organisations and individuals to reply to this document concludes on 25 May 2012. One likely complication for the implementation of a UK rare disease plan will be the reorganisation of the *National Health Service* when the *Health and Social Care Bill (2012)* is enacted – the details of which are far from clear at present.

Rupert Purchase
March 2012

Living with Wilson's Disease in My Home Country of Nepal

Hello. My name is Ashok Pandit and I am twenty-two years old. I live in Kathmandu, which is the capital city of Nepal. I was only seven years old when I was diagnosed with Wilson's disease and the following is my story which I would like to share with you.

Ashok

Nepal

Early memories

My papa was born prematurely. My mom had a normal birth. No one in my mother's or father's family had been diagnosed with Wilson's disease. So I'm not sure why I have inherited this disease. Sadly, both my elder brother and sister died within one month of each other, at the ages of 7 and 9 years respectively. My aunt told me how upset my parents were by these losses, so I have never spoken to my parents about this matter. Both my brother and sister died without Wilson's disease being suspected or diagnosed. When they were ill, I was taken away from home to live with papa's aunt, so I don't remember anything about my brother and sister. I don't even remember what they looked like. I wonder still if I could at least see them in my mind and remember them.

First symptoms

Talking about myself, when I was seven years old I remember initially I had symptoms of jaundice. My parents, especially my papa, were so worried and my mama was tense. They had already lost two children at my age. I was their only remaining child. They loved me so much. I live in a village and everyone in the village knew my parents and me. All of them became concerned about my health.

My papa and mama thought that I had 'caught' jaundice, so they took me to the vaidya (a doctor who uses natural medicines to cure diseases). I remember one thing. Every time my papa took me to see the vaidya he used to ask me, "Son, which taxi you want to travel by?" I said in loud voice "A red one papa." He always took me to the vaidya in a red taxi. I used to have a medicine that looked like wood dust. It was so bitter. I can still remember that taste. I used to have lots of sugar cane juice to sweeten the taste in those days.

My health worsens

My condition grew serious day by day. I can remember only one thing before I lost consciousness. One day I had a sugar cane juice and was sleeping on the bed. I vomited all the juice. That's what I remember before losing my consciousness. I don't know much about what happened next. There was a report where it was mentioned that I might have Wilson's disease "...he has been jaundiced for 40 days...had fulminant attack two weeks ago. Suspicion of Wilson's disease." Since my condition was now very serious, my parents finally took me to hospital, where I was seen by two Nepali doctors. My papa told me that according to the doctors my liver had failed and I would not live. When I was admitted to the hospital, for two days my papa and mama lost hope that I would survive.

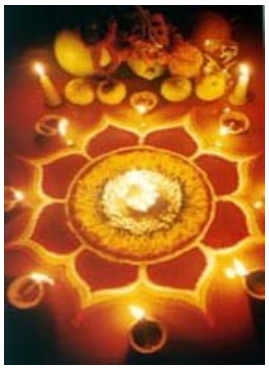
My diagnosis and treatment

But destiny was waiting for me to live my life. On the third day when I was lying unconscious the angel appeared in the form of Doctor Alex Dalzell and granted me my life. He took my case in his hands. He was from USA. According to my papa, my angel knew about Wilson's disease. He observed my symptoms. I was admitted to Patan Hospital. Then I was referred to a teaching hospital to be sure that I was suffering from Wilson's disease. The report was positive.

I was prescribed penicillamine tablets (250 mg x 3 tablets), 10 mg of pyridoxine (vitamin B_6) and vitamin K for the next nine months, after which the dose was gradually reduced. I stayed in hospital for 25 days. In those days I remember I used to read one small bible. My voice used to be loud while reading it. There were pictures of Jesus. I always read that book in those days. I still remember whole story.

Recovery

In the course of my treatment, Alex became quite close with our family. He was like a god for our family because he had saved my life. When I was ill the greatest festival of Hindu, Bada Dashain, was about to take place. The village had not celebrated the Dashain that year 2051 B.S (A.D 1994). The villagers wanted to show sympathy to my family because I was ill. I was taken back home on the laxmi puja day of Tihar. It is the second greatest festival of Hindu.



Tihar – Festival of Lights

When I returned to home, I saw the marigold flowers, which I had planted, were blooming. I sat on the bed and all the family members sat around me with smiles on their faces. Day by day my health improved. Everyone in the village congratulated me and my papa and mama. Alex became close to our family and all the villagers welcomed him and his family. He always managed to obtain the medicine that I needed. When I was thirteen years old Alex left Nepal and went back to his homeland, America.

Setbacks

Around that time I started committing a big mistake. I started having all those foods which were prohibited when I became ill. But now I didn't have the facilities to find out about my disease. And my angel was out of country. I had changed my school in class 4 and as soon as I changed my school I started eating all those things which I shouldn't. My school was far from my home and nobody knew about me. I continued having those foods for three years. At that time I used to have two capsules of penicillamine per week only. When I changed my school I topped the class.

As soon as my angel went back to his homeland he arranged to supply my medicine. He knew our family economic condition was poor. My papa used to work at Tribhuvan International Airport, the one and only international airport in Nepal. Papa had already finished his provident fund on my treatment. My papa bore all the expenses of my medicine for five years. In those days I also needed to have mineral water which cost Rs 20 (20 rupees). The penicillamine capsules cost Rs 40 per capsule. My papa's salary was hardly Rs 3000 per month. Anyway, he managed to provide for my medicine through his provident fund. My angel knew all these things so he started donating for my medicine just after he went back to his homeland. A year after my angel left Nepal my papa lost his job since he was temporary. At the time my angel left Nepal he had taken samples of well water, tap water, and my blood for testing in his country. He sent the report to the hospital. We got good news for water. In the report it was mentioned I can drink boiled water, but my blood couldn't be tested.

My handwriting worsens

Time passed on; I was a bright student. Well I topped every class up to class 8. My parents were so proud of me. I know it was beginning of class 7 my voice start to change. My parents thought that it's the sign of adolescent period. My handwriting used to be just like computer type then. I know it. It's been already two years since my angel left me and we stopped going to hospital for check-up. There was no problem to me.

Then my handwriting start degrading slowly and gradually. I didn't tell anything to my papa since I used to be afraid of him and my mom doesn't know anything. The last term of class 7 was started and in the terminal exam of class 7 I have already ruined my handwriting. I couldn't speak properly either. Still I didn't tell anything to my parents. Finally results of class 7 were published. I have topped the class, but all the teachers commented to me about my handwriting. They said I need to improve my handwriting. I came home and I told my parents I topped the class. They became quite happy. My papa met my Nepali teacher and he told papa all about my handwriting.

My medication is checked and changed

That night when my papa came home he asked me about my writing and I told him I am finding it quite difficult in writing but I don't know why. The next day he took me to hospital. I saw one of the doctors who had previously told me my liver had failed. She took my case and she said my dose of medicine was low so I am having all these problems. She had done certain tests that day and she made us wait in the hospital till 5 pm until the report came back. The result was positive. I was 16 years old then. She initially given me 3 tablets of penicillamine for a week and called me after a week for a check up. I went again after a week; she then added one more tablet of penicillamine, zinc acetate solution and a pyridoxine.

Living with Wilson's Disease continued

A new start

I start having medicine as per she said. My body turned to black initially and slowly and gradually the colour of my body has start becoming normal. My voice started becoming clear but my handwriting was same. It didn't improve. I don't know why. I started writing but my hand didn't move. I have improved a lot in everything and in my handwriting also, but still my handwriting can't go back to what it used to be like, especially if I try to move my hand as normal people do. If I move my hand slowly I can write clearly for up to one page only and after that the situation is same. Time passed by and finally our SLC came. After two years I need to prove myself that I was a bright student and I am a bright student. The school arranged a writer for my examination. I took the exam and I topped my batch and became third topper of my batch. All became happy for me too.

My education and hopes for the future

I wanted to study science, but since I was unable to write on my own I had to compromise so I took management course. I had a dream of becoming doctor since my childhood, but as I grew up I wanted to become software engineer. Since I start knowing things, I was quite interested in computers. They really amused me and still today my interest is the same. I took a management course and studied computer science. I have topped my high school in second rank. Again in my final exams writer need to be arranged because I cannot write as a normal student at a normal speed. I am grown up now. I know what is good for me and what is bad for me. I know my weakest parts. My life was hopeful when I graduated high school. I had a hope that I can improve my handwriting.

Still today I have a hope but I don't know when that day would come. I am student still and Dr Alex Dalzell is still funding my medicine but I don't go to hospital because every time I go to hospital I have to see a different doctor. There is a ward in the hospital where young and old patients are looked after. I had gone there many times, but each time I go there I don't find the doctor who has seen me previously. Each time I go there I have to see a different doctor and I need to start to tell all over again the history of my disease. I simply hated that. So nowadays at the interval of four months I only go there to obtain a prescription of my medicine, come home, and continue the same dose of four capsules of penicillamine, 25 mg of pyridoxine and 7.5 ml of zinc acetate solution. I don't have any problem except on my writing and sometimes during talking.

I am living my life with a hope that one day I am going to get rid of every problem. I know I can never get rid of my disease and I have to take the medicine for life. But I hope that one day my problems will be behind me and my future a success!

This has been my story – not only how I was diagnosed and treated for Wilson's disease, but a little of the emotions of myself, my family and people. I hope you didn't get bored. No matter what problem I have and what struggle I have to overcome I consider myself a lucky person in this world!

Ashok Pandit
February 2012

DID YOU KNOW?

The flag of Nepal is the only national flag which is not rectangular. It is believed that the flag originated in the late 19th century from two triangular flags that were placed one above the other.

Nepalese Flag

WDSG-UK 2012 EVENTS

Date	Time	Event
April 8-12		Phil and Tulin Hawkins are doing **a sponsored walk** along the Thames Path from Oxford to London. They are hoping to average 30 miles a day taking four-and-a-half days to cover 134 miles. Contact Valerie for further details, if you would like to sponsor them.
July 7	**1000 - 1600**	Linda is running a **plant, fresh produce and greetings cards stall** at the Lenton Abbey Fun Day in Nottingham.
July 15	**1100 - 1500**	WDSG-UK Support Group **Meeting and 2nd AGM** – Cambridge Rugby Union Football Club Grantchester Road Cambridge CB3 9ED.
August 25	**1000 - 1200**	Sylvia Penny is holding **a Coffee Morning and Raffle** at Victoria Park Church, Claymore, Torquay.
Oct 5-6		International Symposium on Wilson's Disease - Royal College of Physicians, London.

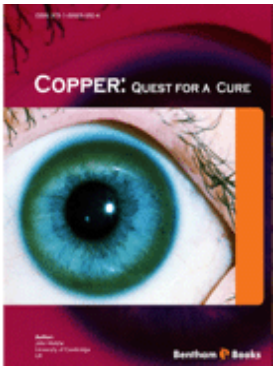
COPPER: QUEST FOR A CURE

Bentham Science Publishers

eISBN 978-1-60805-060-4, 2009
DOI 10.2174/9781608050604 109010

This autobiographical e-book, written by **Dr Walshe** in 2009, describes how Wilson's disease was conquered by a series of individual discoveries, leading to highly effective treatments. It also describes the difficulties which had to be overcome to achieve this in the face of government and institutional bureaucracy. It should be of great interest to patients, those involved in medical research and doctors in general. It is a book for the general reader which avoids technical detail.

Editor:
John Walshe
University of Cambridge
UK



It is available in an electronic format and
can be downloaded from the publishers' website:

http://www.benthamscience.com/ebooks/9781608050604/index.htm. **Price: US$ 35.00**

IN MEMORIAM

We were particularly saddened to hear of the death last September of **Nick Salt**, a WD patient who had been a stalwart member of the group since it was founded in 2000.

We would like to send our very warmest wishes to his mum Ishbel and the rest of his family at this sad time. We would also like to thank them for having a collection at Nick's funeral which raised £600 for WDSG-UK.

In addition we are grateful to Nick's hairdresser whose company, Sissatrix, held a raffle at Christmas in memory of Nick raising a further £145.00 for the group.

Wilsons Disease Support Group UK

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Dr John Walshe Honorary President, World Authority on Wilson's disease
Dr Godfrey Gillett Group Adviser, Honorary Member
Dr James Dooley Group Adviser, Honorary Member

WDSG-UK

Tell others about the WDSG-UK

Please tell others you know with **WD**, who might benefit from the Support Group and what we are doing.

Inform your family, friends, consultant physicians, GP surgery, local MPs about **WDSG-UK**

The more people who know about us, the more we can promote a better awareness of **Wilson's disease** within the community and the better the chance of early diagnosis.

If more copies of this newsletter or patients & families' correspondence lists are required, please contact:

Linda Hart

We're on the web

www.wilsonsdisease.org.uk