

# Wilson's Disease Support Group - UK



AFFILIATED TO THE BRITISH LIVER TRUST

NEWSLETTER

APRIL 2011

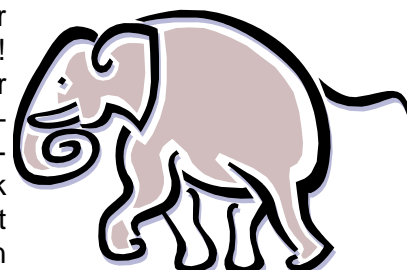
## Welcome!

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, their families and friends.

The organisation aims to provide informative articles about the nature of the disease, articles written by patients, families and friends about their experiences of the disease, recent progress in treatment and much more by way of an annual newsletter. The organisation also aims to promote networking of Wilson's disease patients and their families by helping and encouraging them to correspond with one another.

The organisation also strives to promote a wider awareness of Wilson's disease within the medical profession.

**Hello...**well this certainly has been one of our most exciting and rewarding years for a while! You can read about all the developments in our Chairman's report over the page. We are feeling enthusiastic about the future and look forward to entering our new era. When I think back to our first ever meeting in 2000 with just the handful of members that we had then, I can see how much we have progressed. That first meeting was in the upstairs room of *The Pheasant* in Nottingham, where we had a very good buffet lunch. There was a piano in the room, which one of our younger members was delighted to see and on which she treated us to renditions of *The Entertainer* and *No Matter What*. I'm pleased to say that several people who were there that day are still active in the Group, so a big 'thank you' to them for their continued support.



WDSG - UK

We have again booked the Cambridge Rugby Club for this year's meeting on Sunday, 10 July. We apologise to our members who find public transport difficult on a Sunday, but the hire charges for the clubhouse in the summer are so much cheaper on Sundays. If you have space in your car and are willing to give somebody a lift, particularly from the London and Leicester areas, please let me know. We hope you will be able to join us and attend our first ever AGM, the agenda for which is enclosed.

Also enclosed are a membership form, meeting booking form and Gift Aid form, which we hope you will complete and return, if relevant. We are grateful to all who sent donations with their membership renewals last year and also to Univar for their continued sponsorship. With our newly acquired charitable status, Gift Aid will make your future donations even more valuable to us.

I hope you enjoy reading the newsletter. Happy Easter to you all.

Linda

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We are sorry to tell you that Dr Walshe's wife, Ann, passed away in March. Our sincere condolences are offered to him and his family at this very sad time.

# Chairman's Report for 2010/11

## 1. Initiatives undertaken in 2010

The Wilson's Disease Support Group - UK (WDSG-UK) was inaugurated by Caroline Simms in 2000 and it is fitting that at the end of one decade and the beginning of another, the Group's committee has undertaken some changes which consolidate Caroline's early work on behalf of patients with Wilson's disease and their families and friends. These changes reflect three objectives for WDSG-UK, which were initiated in 2010:

- a. An application to HM Revenue & Customs for charitable status;
- b. Improvements to the WDSG-UK website;
- c. The production of a WDSG-UK pamphlet.

Alongside these developments, the Group published its **annual newsletter** for members at the end of March 2010 and organised the **annual get-together** of members, friends and families at the Cambridge Rugby Union Football Club in July 2010. A report of this meeting appears on page 4 overleaf.

### a. Application to HM Revenue & Customs for charitable status

Recognition by HM Revenue & Customs (HMRC) that a Patient Support Group has charitable status brings about many advantages, most notably financial, and in particular the benefit of gaining extra income through the Gift Aid scheme.

Our application to HMRC also required the Group to submit a **written constitution** (vide infra) and a **set of accounts** for the year ended 5 April 2010. A decision was taken in 2010 to employ a Chartered Accountant based at TaxAssist Accountants, 173 Mill Road, Cambridge, to produce the accounts for WDSG-UK. Using this expertise facilitates communication with HMRC and will be helpful in claiming for tax relief in future years.

Our application to HMRC was successful and on 1 December 2010 we received a letter from HMRC, Charity, Assets & Residence Charities, Liverpool informing us that "On the basis of the information provided, we accept Wilson's Disease Support Group as a charity for tax purposes..." "For tax purposes, Wilson's Disease Support Group is a charitable company."

At present, the annual income of WDSG-UK is below the £5,000 per year threshold which requires charities to register with the Charity Commission and so we cannot yet call ourselves a 'Registered Charity.' But the tax benefits of our charitable status are immediate and to this end you will find a Gift Aid form enclosed with this newsletter, which we hope you will complete, if appropriate, so that any future donations you make to the Group will qualify for tax relief under the Gift Aid scheme.

### b. Improvements to WDSG-UK Website

WDSG-UK is grateful to Dr Godfrey Gillett for recommending our webmaster, who always responds to changes and corrections to the WDSG-UK website (<http://www.wilsonsdisease.org.uk/WDSG-PO/asp>) with alacrity and in 2010 skilfully managed to block a rogue website that had been masquerading as WDSG-UK. This means that if you now Google 'WDSG-UK,' only the 'official' WDSG-UK website now appears.

Also in 2010, the Group's 'Welcome' paragraph on the opening Web page was translated into four other languages—French, Spanish, Arabic and Urdu and we also added a direct Web link to the Group's Facebook site. These changes will further enhance the Group's profile and encourage contact with the Group from both UK and overseas patients and friends. We have plans to develop further the WDSG-UK website and we very much welcome suggestions for additional features from our members.

Finally, a reminder that all fifteen *Wilson's Disease Support Group—UK* newsletters (2000 to 2010) are available on the Group's website.

### c. WDSG-UK pamphlet

As another way of promoting WDSG-UK, the Group's committee has written a small pamphlet entitled *Wilson's Disease*. Professionally designed and printed, this pamphlet is aimed at health professionals and explains many of the symptoms of Wilson's disease along with the current drug therapies and a brief description of the aims of WDSG-UK. We hope to distribute the printed version of this pamphlet as widely as possible as well as making it available on our Web pages. Please let us know if you would like some printed copies to give to your colleagues and friends.

## 2. WDSG-UK Annual General Meeting

As mentioned above, our application to HMRC for charitable status meant that we had to write and submit a formal **written constitution**. In this document, the structure of a **Management Committee** for the Group is defined and the constitution places several obligations on the organisation of WDSG-UK, including a requirement to hold an **Annual General Meeting** (AGM) each year.

### a. WDSG-UK Management Committee

Your committee began 2010 with **Rupert Purchase** as Chair, **Caroline Simms** (Treasurer), **Valerie Wheeler** (Secretary) and **Linda Hart** (Membership Secretary). Three committee meetings have been held so far, all at Valerie's house in Cambridge—two in 2010 and a third in March 2011. Unfortunately, due to her commitments in running a small business,



Caroline had to leave the committee at the end of 2010, but we hope her presence, experience and knowledge will not be lost to the WDSG-UK community. Valerie has taken on the additional role of Treasurer and we are delighted to announce that **Jerry Tucker** and **Anne-Marie Styles** have agreed to join the committee from March 2011.

The new Management Committee will need to be formally elected at the AGM in Cambridge in 2011. Copies of minutes of the WDSG-UK committee meetings are available upon request.

#### **b. WDSG-UK Annual General Meeting**

A brief but necessary, part of this year's Group meeting in Cambridge will be the first WDSG-UK AGM. An agenda for the AGM has been inserted into this issue of the newsletter and the occasion will be an opportunity to raise with the committee any queries you may have about the organisation and/or running of the Group. This year's WDSG-UK meeting (and AGM) will be held on Sunday, 10 July at the same venue as in the past few years—Cambridge Rugby Union Football Club, Grantchester Road, Cambridge, CB3 9ED.

### **3. Links with Other Groups**

#### **a. British Liver Trust**

For some years WDSG-UK has been affiliated to the British Liver Trust (BLT) and our opening Web page has a link to this organisation. The BLT organised two meetings in the past twelve months for Liver Support Groups to attend; one was held at the University of Birmingham Conference Centre, Edgbaston, in November 2010 and the other at an hotel near Stratford-on-Avon in January 2011. WDSG-UK was represented at both these meetings and a report of the latter event appears on pages 11 & 12 of this newsletter.

#### **b. Small Charities Coalition**

The Small Charities Coalition 'exists to help small charities access the skills, experience and resources they need to achieve their aims.' A useful-sounding organisation from their website (<http://www.smallcharities.org.uk/>) has indeed proved helpful to WDSG-UK in the few months since we joined by providing free advice—for example, on the choice of words we can use to describe our charitable status.

### **4. Enquiries to WDSG-UK during 2010**

Much unseen work is carried out by Linda and Valerie (and also previously by Caroline) on behalf of WDSG-UK. The Group's newsletter and website are now sufficiently prominent that we attract many enquiries from home and abroad from the families and friends of patients diagnosed with Wilson's disease or whose symptoms are suspected of indicating Wilson's disease. These enquiries are all dealt with by connecting those needing help with those who can help. Some examples which surfaced in 2010 illustrate the range of enquiries received by the Group:

- A father in Pakistan worried about his son's deteriorating liver, which may have been indicative of Wilson's disease. We provided him with the contact details of Wilson's disease specialists in Pakistan.
- A parent of a WD patient in Scotland who needed advice about preparing copper-free diets. We located a dietician with experience in this area of nutrition.
- A Wilson's disease patient in South Africa who had been unable to obtain a supply of D-penicillamine for several months. We were able to offer a free supply of trientine as a substitute, but as a result of the publicity generated from the enquiry, the pharmacy in South Africa changed its mind about letting the patient have D-penicillamine.

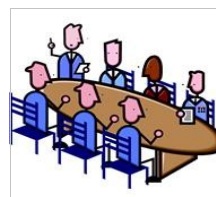
### **5. Future Goals for WDSG-UK**

The key roles for WDSG-UK remain to organise an annual meeting, publish the Group's newsletter, maintain a website and provide advice and help for patients and families. But our charitable status is an opportunity to increase the Group's funds and consider new directions; for example, the sponsorship of research into the treatment of Wilson's disease. Suggestions and ideas about how WDSG-UK should develop over the next year or two are welcome.

### **6. Acknowledgements**

This report has reviewed the work of WDSG-UK during 2010 and early 2011 - a summation of the endeavours of its committee, WDSG-UK members, sponsors and friends. Without the help of all these individuals, this report would not have been possible.

Rupert Purchase  
March 2011





## Support Group Meeting Cambridge Rugby Union Football Club, 11 July 2010

Rupert Purchase

Our venue for the 2010 Support Group Meeting was again the clubhouse of the city of Cambridge's Rugby Union Football Club with its expansive views overlooking the rugby pitches and beyond towards the outlying fields of Rupert Brooke's Grantchester. Warm sunshine (seemingly a regular feature of these events) greeted the arrival of about 45 members of the Support Group, their friends and families. Guests old and new had made the journey to Cambridge, and it was particularly pleasing to see Susheela and Alessandro Vigano from Florence, Italy whose experiences of coping with Wilson's disease were recounted in our last newsletter (March 2010).



Susheela, Linda &amp; Alessandro

After some brief opening formalities, the meeting began with an illuminating overview by **Dr Graeme Alexander**, Consultant Hepatologist from Addenbrooke's Hospital, Cambridge, about the policy and practice of liver transplant surgery in the UK. Those in most need of a liver transplant (including Wilson's disease patients) will receive one. But there are some worrying trends and concerns in the UK. An increasingly overweight population with concomitant increases in the incidence of liver diseases is placing a strain on the supply of donor organs. One solution is the automatic retrieval of organs from suitable subjects unless permission was explicitly forbidden before death. Another option is 'living donor' surgery practised in some countries.



Dr Graeme Alexander

Following Dr Alexander's presentation, **Caroline Simms**, who founded the Wilson's Disease Support Group – UK with **Linda (Hart)** in 2000, awarded the title of 'Honorary Member' of the Group to **Dr James Dooley** and to **Ms Kay Gibbs** and presented framed certificates to each recipient to mark the award. Kay Gibbs worked with Dr John Walshe at Addenbrooke's Hospital, and Dr Dooley is a Reader in Medicine and an honorary consultant hepatologist at the Royal Free Hospital, London and has an interest in the diagnosis and treatment of Wilson's disease.

Lunchtime was an opportunity for the Group to celebrate **Dr Walshe's** recent 90<sup>th</sup> birthday by presenting him with a candlelit cake, which he extinguished with great gusto and told us that his enthusiasm for contributing to the medical and scientific literature remained undiminished.



Dr Walshe

Univar's generosity to the Group was then shown by the donation of a cheque for £1000 by Univar's product manager for trientine, **Mr Ray Estall**.

The second talk at this meeting was by **Dr David Nicholl** who is a Consultant Neurologist at Birmingham's City Hospital and at the Queen Elizabeth Medical Centre. Dr Nicholl has a wide range of interests in neurological disorders, but he illustrated for us the symptoms of some of his Wilson's disease patients in a PowerPoint presentation, which incorporated video and audio sequences from his consultations.

The meeting concluded with the customary 'question and answer' session involving **Drs Walshe, Gillett and Dooley**.

An absorbing day of informative exchanges both at a social and, one hopes, a medical level, left little time for the Group's raffle draw, before we said 'arrivederci' to Cambridge for another year to meet again (we hope) in the summer of 2011.



Dr David Nicholl



"arrivederci"



The Raffle Draw



Rupert &amp; Ray Estall of Univar

## FUNDRAISING EVENTS - 2010/11

### PUPILS' CONCERT - Liz Morell

Our thanks go again to Liz Morell and her mother, Barbara Fordham, who between them teach piano, singing and flute. They arranged a concert at The New Church in Southend on 13 June 2010 and twenty-seven of their pupils, ranging in age from eight to fifty, took part and raised £160.00 towards Group funds. Refreshments were served after the concert and no admission was charged, so that all the money raised came from a collection.



Liz's daughter, Abby, opened the concert with an American folksong *The Water is Wide* and her son, Jonathan, closed it with a piece played on the xylophone. This is the third consecutive year that they have arranged such a concert and in total have raised £490.00 for the Group.

### COFFEE MORNING - Sylvia Penny

On Saturday, 10 August 2010 another regular fundraiser for the Group, Sylvia Penny from Devon, together with her granddaughter, Emma, who has Wilson's disease and other family members held a coffee morning and raffle at Victoria Park Church in Torquay raising the sum of £552.43 for Group funds.

We have looked through our records and note that over the past five years Sylvia has raised over £1,600 for us and we would like to thank her for this wonderful achievement.

Sylvia also offers friendship and support to newly diagnosed patients and their families anywhere in the UK.



L - R Geraldine (Sylvia's cousin) Emma & Sylvia

### SPONSORED WALK - Valerie

In August 2010 Valerie donned her walking boots and strode out to raise funds for the Group. She walked the Hadrian's Wall Path, a national trail, in four-and-a-half days raising a total of £150.00 for the Group. The walk is 84 miles long and runs from Wallsend, east of Newcastle over to Bowness-on-Solway on the west coast of Cumbria. She shares her diary with us overleaf.

This year she has set herself the challenge of cycling 200 miles along the Danube from Passau to Vienna to raise more funds for the Group. If you fancy sponsoring her, then please get in touch. Don't forget that if you are a tax payer and have filled in the Gift Aid form enclosed with this newsletter, the Group will be able to claim the tax back from HMRC on your donation.



### QUIZ NIGHT - Caroline and Linda



Caroline asks the questions

A quiz night organised by Caroline for WDSG-UK was held at The Soldiers & Sailors' Club in Long Eaton, Nottingham on 28 February 2011. Around twenty-five people attended and took part, with teams made up of no more than four people. There were forty questions in all on general knowledge, sport and current affairs and the winning team scored an unbelievable **38** out of **40**. The first prize was £10 and a bottle of wine and the runners-up also won a bottle of wine.

The two questions that the winning team failed to get right were, "What is the name of the cat that has recently taken up residence at 10 Downing Street?" and "What is the collective term for a group of moles?" (Answers on a postcard to Linda, please!)

A cold buffet was provided halfway through, a considerable quantity of ale was quaffed and a good time was had by all. £130.00 was raised including raffle money, the raffle prizes having been donated by those who attended.



Caroline's father, Barrie and her partner, Eamon



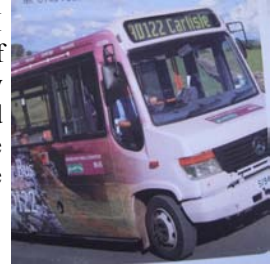
A perplexed 'quizzier'



## Veni, Vidi, Vici ©

ā Valeriā

Early in 2010 my daughter Lizzy's partner, Markus, came round with the *Trailblazer* Guide to the Hadrian's Wall Walk and asked if I would be interested in joining him in the summer. I said that I might be if a) he would carry my kit, b) I could catch the shuttle bus (AD122) that ran the length of the route, whenever I wanted and c) he would act as my medical attendant on the trip. As Lizzy wouldn't be able to come, I suggested we ask somebody else. Markus approached Haki, an old schoolfriend of his and I later coerced Adrian, an old family friend of ours. Both agreed. So now we had a party of four; three strapping, thirty year old men and me. By April Markus had planned the itinerary and we had rung up and booked the accommodation but only for the middle three nights.



*The AD 122 - just in case*

It would be the first national trail that any of us had ever walked and I knew it wouldn't be easy. I needed to get some practice in beforehand and suggested they do the same. However, my son was getting married at the end of May and I was preoccupied with that. It was not until a month before we were due to go that I ventured out on my first major walk. It didn't bode well; my big toes started to hurt immediately and the sole of my left boot dropped off halfway round leaving me hobbling five miles home. Two weeks later with another pair of boots, I set off again and still my toes were causing me problems. Meanwhile, the boys had been busy going to the gym, believing that to be sufficient preparation for the holiday.



*The Wall*

In the late afternoon of 7 August we boarded the train for Newcastle. Markus had come round with his rucksack and all his kit the night before and decided what of mine he would and wouldn't carry. As well as the flapjack I had made, I was allowed one pair of cords, one t-shirt, three pairs of pants, two pairs of socks, a toothbrush and waterproof trousers and even then there was scarcely room for them. With nowhere booked for the first night and the boys keen to get a glimpse of the North Sea before bedtime, there was much to do on our arrival.

### **Day 1: Sunday 8 August 2010: Wallsend to Wallhouses – 21 miles: Trailblazer Guide: Maps 1 - 11¼**

I only had three hours sleep, as I couldn't wait to get going. I woke the boys up early. My toes were no better, so I decided to wear sandals and that meant carrying my own boots. It was a good mile's walk to Segedunum and the starting point of the Path. Here we could collect the passports that were stamped along the route. But the museum was closed, so I had to walk to the *Total Garage*, which also gave them out. The boys weren't interested in passports and started the Walk without me, but I picked up four anyway. No sooner had I caught them up than I realised I'd left my boots at the garage. Chivalrous the boys were not as I hurried back to collect them. It was not a good start.



*We have no time to stand & stare*

We then had a leisurely stroll along the Tyne in the early morning sunshine, dodging the bicycles which were to plague us for the next 12 miles. Not only was Markus chief medical attendant but he had also appointed himself tour leader in my absence and as such we were forbidden from stopping for coffee on *The Quayside* in Newcastle. Instead, we had to press on for another four miles before resting at the side of a busy main road. Two cyclists coming in the opposite direction stopped and joined us and I tried to negotiate a swap of my flapjack for their bicycles. It was *soooo* not happening.

The route was unforgiving with the mile after mile of tarmac. Eventually we picked up the Tyne (again) and with it softer ground. We broke off for lunch in a riverside pub and Markus inspected our feet. Blisters were beginning to appear and he attended to them as necessary. Luckily his own feet were fine, having invested recently in a very comfortable pair of walking shoes that he thoroughly recommended. It was difficult getting started again; we were all very tired. We left the Tyne and worked our way up to Heddon-on-the-Wall, where most people spend their first night. But not us: we had another 6 miles to cover. Beyond Heddon we picked up the B6318 *Military Road* along which the Path ran for the next 22 miles.

Nine hours after leaving Wallsend we arrived at *The Robin Hood* pub, which was the **first** passport stamping station on route. I stamped all four passports much to the delight of the boys! Over liquid refreshment Markus removed his shoes and exposed his blistered feet. He was refusing to walk another step. I continued to our destination alone and they joined me an hour or so later, stepping furtively out of a taxi. I understand that night Markus and those shoes parted company for good.



*My Beloved Passport*

### **Day 2: Monday 9th: Wallhouses – Humshaugh - 11 miles: Maps 11¼ - 17½**

I ended up having to share a room with Adrian, who snored, so not much sleep again there. I waited for daylight to arrive and then sneaked downstairs and started writing a diary. It was a long wait before the others came down and joined me for breakfast. None of them wanted to walk today, but I told them that they had to. The landlady recommended they use a courier service to transport their luggage to our next destination and to that they readily agreed. She couldn't work out the dynamics of our party, so I explained that the Walk was an exercise I put all potential sons-in-law through to assess their suitability to marry my daughter. She thought it hilarious and so did I, but sadly Markus didn't.

Despite my sore toes, I decided I ought to wear my boots today. Markus' blisters were killing him and Adrian and Haki were having trouble with their knees. No sooner had we set off than we met ladder stiles, a new style of stile, which were a nightmare to climb over; six near vertical steps up and six near vertical steps down. We set a goal of not stopping until we reached "a delightful little tearoom" six miles further on in St. Oswald's. "But, wouldn't you just know it?" Yesterday we had been laughing at everything but today hardly even a smile. We couldn't even be bothered to deviate from the Path to see the "big fat Roman phallic symbol" on the side of a bridge that we had read about with relish!

But for Markus and Haki who like all things Roman there was some compensation ahead: milecastles started to appear together with vallums and ditches. I never quite understood how the last two worked nor what the difference between them was, but they were certainly nothing to write home about. Outside Wall we even came across our first bit of Wall: things were really hotting up.

We arrived mid-afternoon at Chesters Fort and stamping station 2. We collapsed in the sunshine and had something to eat and drink and to raise the boys' spirits I dressed up as a Roman. They were refusing to walk another step, but I persuaded them not to call a taxi again. Our accommodation that night was a bunkhouse and I wasn't terribly impressed. Luckily our host wouldn't hear of me sharing a room with the boys and offered me a caravan instead.



What day is it today?



Palm reading my speciality!

### Day 3: Tuesday 10th: Humshaugh to Greenhead - 17 miles: Maps 17½ - 27¼

Another sleepless night and there was no sign of the boys when I got up. I did however, meet a chap at breakfast with a kitchen sink on his back! He, too, was being sponsored and had carried it the day before all the way from Bowness. He would finish "the Walk" in only two days! He was still there when the boys appeared and Markus and Adrian sheepishly announced that they would be taking the bus today. Haki wanted to try walking with me despite his limping badly. We all agreed to meet at Housesteads which was 6 miles away, the largest Roman site on route and stamping station 3. It was a slow weary walk and the incessant droning of cars on the Military Road was beginning to drive me mad. It was definitely time to 'go it' alone.

Markus wasn't at all happy about it and I must confess I was a little apprehensive, but we all had mobiles phones, so there shouldn't be a problem. I grabbed something to eat and then left. There were plenty of people on the Path to begin with and, despite the rain, I soon started to enjoy myself. We rendezvoused briefly at Once Brewed, then off I went again. This was now the highest part of the Path, the most interesting and certainly the most challenging. Progress was slow and I was tired, but when eventually I arrived in Greenhead four hours later, the boys seemed pleasingly relieved to see me. The landlord was again puzzled about the dynamics of the Group, but this time I was saying nothing.



The High Point of the Trip

### Day 4: Wednesday 11th: Greenhead to Carlisle - 20 miles: Maps 27¼ - 38½

Despite having a room to myself, I couldn't get to sleep. I met a charming man at breakfast who was walking the Pennine Way, which is something I would like to do myself one day. When the boys came down they told me that they would be joining in today, but I could tell their hearts weren't really in it. We covered only 3 miles in 3 hours before arriving at Birdoswald, another Roman Fort and stamping station 4. Here the Path and the road went their separate ways. I opted for the Path, the boys the road. Whoever got to Carlisle first had to find our accommodation for the night. It wasn't likely to be me.

My feet were in agony, my map reading skills were challenged and I wished I knew the difference between cows and bulls. I met hardly anybody else on this stretch of the route. The tall buildings of Carlisle that were meant to have been visible never actually appeared. At 1700 I crossed the M6 and hoped I was nearly there. But there was still a long, lonely walk by the side of the River Eden before I finally reached the Sands Sports Centre in Carlisle and stamping station 5. The boys were there to greet me and take me back to the hotel, where Markus had arranged for a bucket of ice to be taken to my room. Apparently my feet would benefit from being immersed in it: but **oh the pain!**

### Day 5: Thursday 12th: Carlisle to Bowness-on-Solway - 15 miles: Maps 38½ - 45

It was a dreadful hotel on a main road and people were crashing around all night, but I somehow had two hours sleep at last. I rang Markus at 0600 to let him know I was up. He could hardly contain himself! The chef was late, so too breakfast. Markus taped my feet for the very last time and ordered me a taxi. It was 0800 when I rejoined the Path and I could hardly walk.

We had arranged to meet in Burgh-by-Sands for half-past tens. Mrs. Postlethwaite at the village post office was pleased to have my custom and told me that we would just be in time to see the Solway Bore. The Solway Bore is aptly named. Haki insisted on walking the final leg and as I was worried he may slow me down, I suggested he go on ahead. I eventually caught him up and we arrived together in Bowness two hours later. What an anti-climax that was. No fanfare of trumpets, nobody presenting certificates and not even a pub open. I put the **last** stamp on our passports. Hooray!

Now to get home before **Friday 13th**. We took a bus to Carlisle, a train to Newcastle and after a big bag of chips and long satisfying glass of lager on *The Quayside*, an inter-city home. "And **is** Markus son-in-law material?" you ask. "I'll tell you what, I'd make **him** a cracking mother-in-law!"



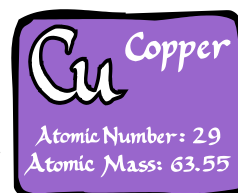
Veni, vidi, vici

# SPARE US COPPER!

by Aubrey Morris

COPPER. "Who needs it?" you may well ask. Well, actually all of us do, in minute quantities. Our problem, of course, is that we have too much of the stuff. But, if we had none at all, we'd be in even deeper trouble. The reverse of Wilson's disease (almost) is called Menkes disease. I say "almost" because, while sufferers have insufficient copper in their blood plasma, liver and brain, they have overload in their kidney, spleen and skeletal muscle, so it is a very perverse illness indeed. As with Wilson's, it is inherited, but, unlike Wilson's, its symptoms appear very quickly - when one is just a baby of two or three months - and they are dire: muscles become weak and floppy, baby has seizures, can't hold a rattle, his cheeks sag and his scalp hair becomes coarse and twisted. Because of this last symptom, Menkes is familiarly known as "kinky hair disease." Kinky hair or rings in our eyes - we all have distinctive symptoms arising from our copper imbalance. So what else do we know about this metal which looms so large in our lives?



Copper is a moderately hard reddish-brown metallic element which occurs both as the free metal and in various ores, the most notable of which is chalcopirite, otherwise known as copper pyrites. Its chemical symbol is Cu, short for the Latin *cuprum*, which is derived from the Latin name for Cyprus, the principal source of the metal in Roman times. Nowadays, it is mined in Chile, New Guinea, Australia, Zaire and Zambia. It is Zambia's biggest export, and the region of Central Africa along the Zambia/Zaire border is known as the Copper Belt. Copper can be hammered into shape without breaking, but its chief uses are as an electrical and thermal conductor. It melts at 1083°C and boils at 2595°C. Thus much is common knowledge. Here are a few random facts that are more esoteric.



- Copper is deadly to dangerous bugs! In a trial study at Selly Oak Hospital, Birmingham, a set of taps, a lavatory seat and a push plate on an entrance door were replaced with copper versions. The copper items had up to 95 per cent fewer bugs on their surface than traditional fittings. Lab tests showed that copper kills MRSA and C difficile superbugs as well as the flu virus and the E coli food poisoning bug. Scientists conjecture that the metal prevents germs from breathing and possibly from feeding.
- Copper in the soil is an essential nutrient needed for the normal growth and development of cereal crops. Chlorophyll production, protein synthesis and respiration are important plant functions that require it. About 70% of the copper in plants is found in chlorophyll. Copper deficiency can result in early ageing or lower levels of chlorophyll, which leads to yield reduction. Peat soils are prone to copper deficiency.
- Average broadband speeds in the UK are only the 37<sup>th</sup> fastest in the world - slower than Latvia and Romania - because our infrastructure relies on ageing copper wiring, whereas other countries have skipped straight to fibre-optic connections.
- Bedlington terriers can be born with Wilson's disease! Well, not exactly - but an article in the Journal of Experimental Animal Science in April 2002 stated that "Canine copper toxicosis is an important inherited disease in Bedlington terriers because of the high prevalence rate and similarity to human copper storage disease." However, it continued: "The responsible gene for copper toxicosis in Bedlington terriers has recently been identified and was found not to be related to the human Wilson's disease gene." Although copper toxicosis is commonest in Bedlington terriers, dogs in general have copper storage problems more rarely and many breeds are affected. Labrador retrievers, for instance, can get copper-associated hepatitis. In Bedlington terriers tetramine is a safe and rapid chelating agent. No research appears to have been done on using this substance on humans.
- Copper was possibly the first metal to be used by Man, and the Bronze Age was from about 4000 to 1000 BC. It came between the Stone Age and the Iron Age.
- The price of copper fell back a little from a record high of \$8,966 per tonne reached on 11 November 2010, but then took off again when a mystery buyer, believed to be a global hedge fund, started buying steadily. By early December "the fund" had acquired more than 280,000 tonnes, amounting to 80% of the copper market.
- Brass is an alloy of copper and zinc. The proportions are variable, but using more than 36 per cent zinc results in a stronger alloy. Bronze is an alloy of copper and tin, and again the proportions are variable - tin may account for between 4 and 11 per cent. "Copper" coins are not copper but bronze consisting of 95 per cent copper, 4 per cent tin and 1 per cent zinc.





- Someone with a good tan is described as “bronzed” but the makers of a popular suntan oil chose to name their product Coppertone.
- The Daily Mail recently advised its female readers on how to create a copper eyeshadow look. “Take a medium soft brush and, using a bronze shade, start from the inner eyelid and sweep across right up to under the eyebrow arch...” etcetera.
- In 1940, George Formby (Number 1 at the British cinema box office in 1939) starred in a film called “Spare A Copper.” This title was a pun, because George took the role of a policeman. George never played a ukulele, as is commonly supposed. Anyone who has seen the Ukulele Orchestra Of Great Britain (highly recommended!) will know that a ukulele is shaped like a guitar. George’s instrument was shaped like a banjo and was in fact a hybrid called a banjolele. George encouraged the misconception with songs like “With My Little Ukulele In My Hand” (“My heart it leapt with joy, I could tell it was a boy, ‘cos he’d his little ukulele in his hand”). 
- A copper in the sense of a policeman has nothing to do with the metal but is simply one who cops (catches). This pair of words - “cop” and “catch” - is unusual in that they are synonyms in two senses. Both also mean “to receive punishment” (“You won’t half cop it when your father gets home”).
- Newspaper theatre critics are fond of the phrase “a copper-bottomed hit” when they wish to forecast guaranteed success for a show. The expression is of maritime origin and refers to the period when the leaky timbers of the hulls of sea-going vessels gave way to riveted copper plates. The ships were copper-bottomed - guaranteed safe. Copperplate handwriting derives from the perfect script used when it was engraved upon a copper plate and a print was taken therefrom. An old tongue-twister runs: “Are you allumining ‘em ma’am?” “No, I’m copper-bottoming ‘em my man.”
- Last December, an 1827 book, “Birds Of America,” by wildlife artist John James Audubon became the most expensive printed book in the world when it was sold by auctioneers Sotheby’s for £7,321,250. Measuring 40 inches in height and containing life-size illustrations of nearly 500 breeds, it was printed from copper plates, a process which would cost £1,250,000 in today’s money. 
- Copper is just one of several metallic elements that are essential to human wellbeing. Most notable of these is iron - so much so that the makers of most breakfast cereals boast that their product is iron-fortified. Iron is essential to the production of haemoglobin (red blood cells) which transports oxygen in the blood from the lungs to the body’s tissues. Magnesium keeps heart rhythm steady, supports the immune system and helps strengthen bones. Zinc also boosts the immune system, promotes wound healing and is vital to reproductive health. Chromium works with insulin in the metabolism of sugar and stabilises blood sugar levels. And copper? Well, copper works with vitamin C to form elastin, a component of muscle fibre throughout the body. It helps to maintain healthy bones and assists the thyroid gland in balancing and secreting hormones. And - guess what? - the much-vaunted iron wouldn’t be much use without copper because it actually combines with copper and the protein globin in the creation of haemoglobin.
- So copper is A Good Thing. But as we know to our cost, you can have too much of a good thing. You can have too much iron as well. The disease is called haemochromatosis and, like Wilson’s, it is inherited. It is also like Wilson’s in that the excess builds up gradually, so that the symptoms don’t show until it has already damaged the organs where it has accumulated. Thus, though we need copper, iron, magnesium, zinc, chromium and others, we need them in strictly regulated amounts. The recommended daily allowance (RDA) for iron is 8mg, for magnesium 400mg, for zinc 11mg and for copper 900 micro-grams.
- In a normal healthy human-being, the liver stores what we need and converts the toxic excess into neutral urea for removal from the body through the kidneys, but for us with defective livers, we have to rely on penicillamine or trientine to remove excess copper. Some of us do, that is - in others (such as the founder of our Group, Caroline Simms) the damage before diagnosis is already so great that nothing short of a liver transplant will do. There is good news on this front. Whereas hitherto a recipient had to wait for a would-be donor to die, live donors are now being used in the UK by the NHS (it’s been standard procedure abroad for years). This is possible because the liver of a healthy person is much larger than needed and, if part of it is removed, it will regrow within weeks to almost its normal size. What an extraordinary organ our liver is! An old play upon words runs as follows. Question: Is life worth living? Answer: That depends on the liver! What I find interesting about that is, if you translate the question into French, you get an equally valid pun. *C’est une question de foie* (that depends on the liver) sounds exactly the same as *C’est une question de foi* (That’s a matter of faith).

## Liver Transplantation and Wilson's Disease



In the past 15 years more than 9,000 patients underwent liver transplantation in the UK and just over 1% of these had a liver transplant for Wilson's disease. There are two routes to the liver transplant waiting list in the UK.

### *The urgent list*

This is for patients who face an imminent risk of death (within days) from liver disease without any antecedent evidence of liver disease. The 'King's criteria', which were described more than 20 years ago, are still used by most centres worldwide because of their simplicity. These are based on the combination of blood tests that can be performed in any hospital in the UK and should be available within an hour or so, the patient's age and the underlying cause of liver disease. They are used to distinguish those patients most likely to benefit from transplantation as an emergency and are used as a guideline to be placed on a national emergency waiting list. A patient on the urgent list in the UK would be offered the first available donor liver, matched for the appropriate blood group, from anywhere in the country; patients on the urgent waiting list are transplanted in turn according to blood group. In the past 15 years 63 patients received a liver transplant for Wilson's disease as an emergency procedure. Hepatologists know that in this context the liver disease is not 'new' but the onset can be very sudden and in this setting deterioration will usually occur very quickly. Cirrhosis caused by Wilson's disease but with such a sudden onset is the only type of cirrhosis for which emergency transplantation is recommended currently.

### *The elective waiting list*

Patients with long standing liver disease who face a risk of death from liver failure in the next one to two years are assessed and placed on a waiting list in the local transplant centre. In this context liver transplant assessment is a complex process with three main aims – to assess if liver transplantation is needed, to assess if it is technically feasible and to determine if a patient is fit enough for the procedure. There is no strict age limit for liver transplantation, so many patients come to assessment with more than one disease and the focus during a liver transplant assessment is often on cardiac or respiratory disease, which some patients find disconcerting. In addition there is now an 'assessment score', based again on simple tests, a threshold which needs to be reached in order to be placed on the waiting list in the UK (UKELD, the UK End Stage Liver Disease Score). UKELD measures the likelihood that someone is likely to succumb from liver disease in the next two years. The introduction of UKELD was to help ensure equity of access to liver transplantation in the UK and to help reduce the number of patients that were dying from liver disease before a liver transplant was offered. If a patient does not reach the threshold there are a few exceptional circumstances under which that patient can be placed on the liver transplant waiting list. In contrast to emergency liver transplantation each of the UK liver transplant centres has a separate waiting list (at present) and donor livers are offered in turn to each and a decision is made locally regarding which patient is the most suitable for a particular donor, which is never an easy decision. In the past 14 years 55 patients received a liver transplant for Wilson's disease as an elective (planned) procedure.

Results following liver transplantation for Wilson's disease are similar to those for patients with other causes of liver injury. The positive news about liver transplantation in 2010 is that the vast majority of patients, around 90 - 95%, who receive a liver transplant are alive and well after one year and return to a normal life. This may be after a period of some weeks in hospital following the operation, although a period of two weeks is more typical. Following discharge some patients make a protracted return to normal health, but most have recovered by 6 months. I learned some time ago that many liver transplant recipients re-think their lives after successful transplantation, almost as if there is a subtle change in their priorities. Many who had planned to return to work and are able to do so change direction entirely.

The downside to liver transplantation, which paradoxically is probably a consequence of improved results and success over more than 40 years, is that the number of people referred for liver transplantation and who would benefit from this procedure now far exceeds the number of donors. As many as a third of patients listed for transplantation as an emergency procedure will not get an offer of a liver in time (although for those with Wilson's disease there is usually enough time to find a suitable donor) and about 1 in 6 patients in the UK listed for liver transplant on the routine waiting list will have progressive liver disease and become too ill for liver transplantation before a donor liver becomes available.

There are a number of strategies being discussed worldwide and nationally to improve donor numbers. These are controversial issues and there is no correct answer. There are also a number of ongoing discussions about how to prioritise patients on waiting lists. However the fundamental problem is that potential donors do not come forward in sufficient numbers. All the liver transplant centres in the UK would be able to do many more transplants based on the infra structure they already have in place should more donors come forward.

Looking closely at the statistics following liver transplantation, survival at the end of the first year has improved consistently since 1968 although the improvements each year now are small. The challenge for transplantation is to improve the long term survival of our patients who get through the first year. Some of the drugs that we use to control rejection in the longer term have side effects that are manifest after years or decades. We are gradually learning to use an increasing range of drugs that control rejection in different combinations, to minimise the side effects and to reduce the risk of graft loss to rejection.

Rejection is a word that causes distress for all liver transplant patients but the reality is that very few patients who survive the first year following transplantation lose their livers to rejection – probably a reflection of the fact that the drugs that are available are very effective but also that livers also appear to suffer rejection much less than all the other organs that we transplant.

Speaking as a physician I have always regarded liver transplantation as a wonderful procedure for that point when medical management stops being effective. The message for patients with Wilson's disease is to make a diagnosis at an early point in the history of the illness so that transplantation never comes into the equation; but I hope it is reassuring for patients with Wilson's disease to know that if all other options fail, then liver transplantation is such an effective procedure restoring a normal life to most patients.

**Dr Graeme Alexander**

Consultant Hepatologist, Addenbrooke's Hospital, Cambridge

## British Liver Trust Support Group Conference 22 & 23 January 2011

In January 2011, Linda and I attended the third British Liver Trust ("The Trust") Support Group conference held over two days in Wellesbourne, Warwickshire. The Trust, which is now in its twenty-third year, exists to raise awareness of liver disease in the UK, including lobbying, fundraising, providing patient information and funding research.

We were greeted by Richard Hall, the Trust's Support Groups' co-ordinator, whom we met for the first time in 2009 at a similar conference in Hinckley.

The conference was attended by representatives of many regional and national support groups related to liver disease. The speakers were introduced by **Alison Rogers**, Chief Executive of the Trust:-



Linda & Valerie with Richard Hall.

**Gordon Cave** welcomed all the Support Group representatives and emphasised the value of feedback from these groups to the success of the Trust. Gordon is a liver transplant recipient and runs a large and successful Liver Support Group in Northern Ireland; he and **Linda Waters** are recently appointed trustees of the Trust.

**Dr Alexander Gimson (AG)** (Consultant Hepatologist at Addenbrooke's Hospital) is chairman of the NHS Blood and Transplant (**NHSB&T**) Liver Advisory Group, a group advising on organ transplantation in the UK. He outlined the current criteria for liver transplantation and explained that liver transplants in the UK are performed at the following centres: Edinburgh, Newcastle, Leeds, Birmingham, Cambridge, King's College and the Royal Free Hospitals in London. Currently, when a donor liver becomes available, it is primarily offered to the nearest liver transplant centre. **AG** and his Group have been asked by the **Department of Health (DH)** to design a national liver allocation scheme, whereby a donor liver is offered to a compatible recipient with the greatest need, irrespective of region. He encouraged lively discussion about this topic. Finally, I was surprised to hear that the prevalence of liver disease in the UK was not accurately known, since no national statistics had been generated; this is something the **BLT** is planning to remedy.



**Michael Hope**, Transplant Co-ordinator from Addenbrooke's Hospital, spoke about his role in assessing and selecting recipients for transplants, providing information for potential recipients to make an informed choice about going on the transplant waiting list and also his involvement in their post-operative care. He listed the most important chronic and acute liver diseases which lead to irreversible liver failure, requiring transplantation.

**John Bedlington**, Chairman for ten years of LIVERNORTH, a large and highly successful adult support group for liver patients in the north-east based at the Freeman's Hospital in Newcastle, spoke in general about the importance of running a support group and in particular about what support LIVERNORTH offered to patients and their carers (family, friends and medical staff.) Last year the cost of running the group and buying equipment amounted to £125,000, which had been raised through donations, fundraising and regular income from the lottery. LIVERNORTH produces and distributes 1,850 copies a year of their magazine, LIVERNEWS.

**Catherine Ridgeway**, founder in 2008 of a Hep C group in Derby, spoke in contrast about running a small support group. She mentioned the stigma associated with Hep C and said that because of it her group had had difficulty recruiting members and getting them to attend meetings regularly.

**Alison Rogers** gave a short history of the Trust, founded in 1990. The Board of Trustees comprises liver patients, their carers, medical professionals and people with other skills necessary for the smooth running of the organisation. She then outlined the aims of the Trust, which included:

- funding research into liver disease
- drawing up a strategic approach to alcoholic liver disease
- reviewing all information held on liver disease every two years
- liaising with the media about current findings in liver disease
- giving importance to rarer liver diseases, such as Wilson's disease
- improving services in the north-west, where liver disease is particularly prevalent
- raising awareness of liver disease among general practitioners
- encouraging patients to write to their MPs to raise the profile of liver disease nationally
- encouraging early detection of liver disease
- working with the recently formed National Liver Strategy committee
- raising the profile of liver disease so that it is considered as important as cardiac disease and cancer
- striving for The Trust's information on liver disease to be adopted as standard, and
- holding a Support Groups' Conference annually.

**Professor Martin Lombard (ML)**, Clinical Director of the National Strategy Committee in England, who has been appointed by the **DH** to lead a committee working with Primary Care Trusts to improve services for liver patients, spoke about the policy the committee wishes to adopt which has three components: **prevention** (trying to reduce the incidence of liver disease), **infrastructure** (improving facilities and treatment for liver patients) and **pathways** (patients' experiences of pre-diagnosis and post-diagnosis management.) **ML** said that liver disease is currently the fifth biggest killer in the UK with alcohol-related liver disease fast becoming the largest component, accounting for 7% of all hospital admissions. The number of patients with liver disease has increased by around 10,000 in the last year and the number of liver transplants performed each year is around 700.



Professor Martin Lombard

Finally, the Trust has published a superb booklet about Wilson's disease. This can be accessed via their website (click on to their logo on the homepage of our website: [www.wilsonsdisease.org.uk](http://www.wilsonsdisease.org.uk)) and either download the leaflet directly from their site or telephone their offices to request a copy through the post. The leaflet is free to Wilson's disease patients.

# MY WILSON'S DISEASE STORY

Anne-Marie Styles

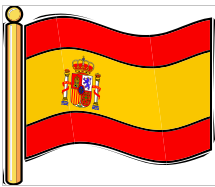


Hindsight is wonderful to trace events and to understand why certain things happen. At the time, when something is obviously wrong with you and you don't know why, it is increasingly distressing. When your whole future as you had planned it is in jeopardy, it becomes extremely frightening. My story is all of that but it does have a happy ending. I was fortunate to make an excellent recovery and achieve all that I wanted to and more.

In October 1974 I had just started my third and final year at Cambridge University studying Modern Languages. I was due to attend a supervision and I forgot. It was completely out of character for me and I was extremely upset about it. This, for me, marks the beginning of my symptoms of Wilson's disease. I developed difficulty formulating essays as well as physically writing them. I became very emotional. The diagnosis was all too easy: the stress of the final year. I did not query this - just kept taking the *Valium* the doctor prescribed me. My college was extremely supportive and I managed to finish my degree successfully.

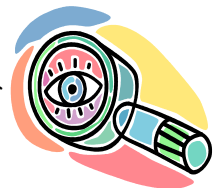


I spent 1975-6 teaching English in Spain with no further problems, except that my landlady worried about the excessive amount of saliva that I dribbled on to my pillow during sleep. She didn't think it was normal...and she was right. When I returned to England I was due to start a one year teacher training course in York in October and it was there that I took a dramatic turn for the worse. I started to have a bad tremor, couldn't control my salivating (so embarrassing when I was meeting a whole new set of people), lost my sense of rhythm and of course all my confidence. It was as if I were becoming a different person and the real me was trapped inside. Unfortunately to make matters worse I was told I had Parkinsonism and was prescribed medication that increased rather than relieved the depression that was taking hold and in the November I gave up the teaching course and went home to my parents in Bradford.



It was the worst period in my life. There was obviously something very wrong with me. My parents were horrified by the state I was in and very worried. I felt a failure and so guilty at what I was putting them through. The future appeared extremely bleak. My GP diagnosed a nervous breakdown and referred me to a psychiatrist. In fact this turned out to be my saving grace. Dr Nelson interviewed me and my parents, prescribed antidepressants that worked and said he thought my problems were neurological not psychiatric! He recommended I see a neurologist called Dr Robson Parsons in Leeds. This is the man I have to thank for diagnosing Wilson's.

I was admitted to Leeds General Infirmary in February 1977 for tests and within a week they found what was wrong. I found out from the 'eye doctor'. When I was sent to the eye department my eyes created a lot of interest. Different doctors kept coming to have a look down the microscope! Eventually I asked what all the fuss was about and was told I had Wilson's disease. It was the Kayser-Fleischer rings that confirmed the diagnosis and, being such a rare phenomenon, people were keen to see them. What a relief. I finally knew what was wrong and apparently there was a treatment. Fantastic. I never doubted (rather naively perhaps) that I wouldn't get better. Of course I wasn't out of the woods yet. I started on a course of *Penicillamine* but immediately had an allergic reaction against it. Having recovered from that, I started the treatment again, this time with antihistamine, and my body was able to accept it, thank goodness. I left hospital in April 1977 on the road to recovery.



The following year in July I embarked on a short teaching course in London and in the September went to work in France to get my French back on track. I was finally independent again. I went on to get my full teaching certificate and at last was able to embark on a career as a Modern Languages teacher. I hadn't felt so well in a long, long time.



My first 'proper' job took me down south and it was at that time that I decided to go and see Dr Walshe. I feel so privileged to have had this opportunity for it is he whom I really have to thank for being here today and for my looking forward to the future optimistically. Dr Walshe and his assistant Kay were so helpful in very practical ways which made a big difference to my day to day life. For instance I had been following a very strict low copper diet and I was now able to free this up. The important thing was to keep taking the tablets and I am able to take them twice a day, which is much more convenient than three or four times.

What of the positive side of the traumatic events that happened to me during the seventies? I feel they have given me an insight into what it's like to be seriously ill with depression and be physically handicapped: things that many people cannot empathise with. Most important, I fully appreciate the fact that I was lucky enough to make such a good recovery and have the chance to enjoy life once again.

# A Trip To 'Peter Rabbit' Country

by Linda

Last October Val and I decided to spread our wings a little and went on holiday in the Lake District. The area is familiar to Val, who grew up in Manchester and visited it often. I, on the other hand, had only passed through once before on my way to Edinburgh and was therefore excited to be visiting somewhere new.

We had rented a small cottage in Grasmere, which was an excellent choice, although the village is almost entirely given over to tourism. It still retains its character and charm, and in the words of William Wordsworth is "the loveliest spot that man hath ever found." Wordsworth lived just outside the village of Grasmere for many years and St Oswald's church is where he and his family are buried. It's not surprising that the Lake District has been home to many poets, writers and painters over the years: one cannot help but be inspired by its beauty and peace.

One such writer was Beatrix Potter, who spent most of her adult life in the Lake District, which is where she wrote her *Peter Rabbit* stories. She also became an expert in breeding the sturdy Herdwick sheep and was the first woman to be elected president of the Herdwick Sheep Breeders' Association which continues to flourish today. She left her home, Hill Top Farm near Hawkshead, to the National Trust on condition that all her belongings were left in place.

Though I was getting over a cold and Val developed one while we were away, it didn't spoil our enjoyment other than we didn't take full advantage of the free access to a swimming pool and sauna at a nearby hotel that came with the cottage. We did manage to find TWO pub quizzes that week, though probably the least I say about those the better. I've come to the conclusion that the colds we had (not to mention the hot toddies) had diminished our thinking power!

We had one arduous walk (though it wasn't meant to be) on our second day there. Val wanted to show me Dungeon Ghyll Waterfall over in the Langdales. She had been there fifty years earlier with the family. It was only meant to have been a short walk from the car park. Unfortunately, we must have parked in the wrong place and, full of enthusiasm, we set off. Well, we reached a waterfall eventually, just not the one she had planned! This one was Stickle Ghyll and was 1,000 feet higher! Refusing to go back the way we had come, she consulted the ancient Ordnance Survey map she was carrying and decided that if we continued *straight ahead and turned right*, we would drop down eventually into Grasmere. But it was all a matter of contour lines again!

The plan was that when we got back to Grasmere (which incidentally was four hours later), I would collect my car keys from the cottage and then we would drive back together to pick up her car. When we arrived she said, "I hope you've got your keys to the cottage on you, because I've left mine in the car?" "Snap!" I said, "So have I!" Despite trying to prise the kitchen window open, there was no getting in, but the owner who lived nearby soon came home and saved our day.

Val had several more walks during the week. Mind you, I think one of the reasons she set off early each morning was to buy the warm, freshly made gingerbread from the lovely little shop nearby. The smell wafted past our cottage and was pretty hard to ignore. I had decided to take it easier and do a lot of sightseeing and gentle lakeside walking instead.

One misty afternoon, we went to *Faeryland* to try our hand at rowing on Grasmere lake. We were told we musn't go over the hour, but as we spent the first twenty minutes four metres from the shore going round and round in ever decreasing circles, it seemed unlikely that we would be late back. However, then we got the hang of it and ventured further afield. It's really not as easy as it looks, particularly slapping over rowers!



Chez Nous



Wordsworth's Daffodil Garden in Grasmere



By Stickle Tarn



The Gingerbread Shop



Valerie tries her hand at rowing



Though the whole trip is one I'll never forget, my most outstanding memories are of sitting by the lakeside in Borrowdale watching the sun set over Skiddaw; it was a wrench to leave as dusk fell. I also enjoyed my visits to Castlerigg Stone Circle, which is not far from Keswick. To arrive and have the place to yourself, as I was lucky enough to do, is wonderful. Castlerigg is a magical place, particularly on an early bright morning with the sun rising over Blencathra and the complete silence of the surrounding fells. The tallest stone lines up with sunrise over High Rigg at Candlemas in February, and with the setting sun and Skiddaw at the Summer Solstice. I think I could fill several pages talking about the Lake District. I know I shall have to return.



Sunset on Skiddaw

In fact, the owner of our cottage told us we would be welcome back at any time as it seems we had brought good, bright weather with us. Apparently, it was the only rain-free week that there had been since June - How lucky can you get!?

Ah, one last thing, Grasmere is also home to the storyteller, Taffy Thomas, and on the main street is the delightful 'Storyteller's Garden.' He tours the country telling his tales and if he is ever in your area, I recommend that you go and see him. In 2009 Taffy accepted the honorary position of the first Storyteller Laureate and his storyteller's coat is a sight to behold!



Castlerigg Stone Circle

## A SNIPPET FROM JANE

by Jane Ridley

I remember someone at last year's Support Group meeting bringing up the problem of wrinkly skin on the neck as a result of long term penicillamine use and so I thought the following article which I read in my local paper might be of interest to our female readers!

### "Baby Bottom 'Face Cream' is Skincare's Best Seller

A cream that soothes babies' bottoms is the most popular skincare product at Waitrose after mothers started using it on their faces and necks to help iron out wrinkles. Rave reviews online means Waitrose *Baby Bottom Butter* at £2.54 is outselling all other moisturisers and anti-ageing creams."



So...I went out to buy some immediately from our store in Peterborough only to find that they had sold out! I returned a few days later to see if they had restocked, which they had, so I bought a tub and have been using it ever since. It is a bit on the greasy side, so you don't need a lot. I have been applying it to my face and neck (which is quite wrinkly) and although it has not got rid of the wrinkles, it has definitely helped with their appearance. It's bound to work differently according to your skin type, but I would recommend giving it a try as it's certainly cheap enough. The size of the pot is 125 ml and I have been using it morning and night. I did read a few weeks later, in another Waitrose paper, that a lot of women have been putting

it on at night-time before going to bed and perhaps this is because it is too greasy for daytime use under make-up. As I, myself, don't wear make-up, I can wear it in the daytime, too.

## BRAIN RESEARCH

by Joan Smith

While I was visiting Addenbrooke's Hospital in Cambridge recently, I read in an internal hospital newspaper that the Cambridge Brain Bank was looking for people who were willing to donate their brain after death to be used for research into disorders of the nervous system, dementia and other neuro-degenerative diseases and conditions affecting the brain.

As a Wilson's disease patient of many years and more recently a recipient of a liver transplant, I am only too happy to participate in any research that could improve treatment for others and have therefore added my name to the register in the hope that patients with neurological Wilson's disease may benefit. Registration is a very simple procedure. Should you wish to obtain further information, please telephone the Brain Bank on 01223 217336 and ask for the Brain Bank on-call officer. Alternatively, email: [brbank@addenbrookes.nhs.uk](mailto:brbank@addenbrookes.nhs.uk).

# *Wilson's Disease Support Group UK*

**WILSON'S DISEASE**

**SUPPORT GROUP - UK**

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**Dr Godfrey Gillett -** Group Adviser, honorary member  
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## *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](http://www.wilsonsdisease.org.uk)