Wilson's
Wilson's Disease Support Group - UK
www.wilsonsdisease.org.uk

NEWSLETTER

APRIL 2016

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

The Liver Patients' Transplant Consortium

Genetic Alliance UK
Supporting. Campaigning. Uniting.

RARE DISEASE UK

Children's Liver Disease Foundation
fighting childhood liver disease

Climb
Children Living with Inherited Metabolic Diseases

Welcome to the 16th edition of our newsletter in which we hope there will be something to interest everyone. A big thank you to all our contributors without whom there would be no news at all. Special thanks go to our fundraisers **Belinda, Sylvia,** the **Goss family** and **Shaun Galloway**, to **Katie, Alicia** and **David** who have shared their stories of diagnosis with us and to **Alan Stevens** whose clear style of writing explains complex medical matters in simple terms. In the Members' section at the end we learn of the current exploits of **Linda** and **Dr Walshe** and on a more serious note hear how our Nepalese friend, **Ashok**, thankfully survived the ravages of nature thrown at him last year. And last but not least, for a bit of fun, members will find a quiz enclosed which hopefully will provide them with hours of entertainment!

This has been another active and fulfilling year for me, pottering around the country visiting patients old and new, sharing in their various activities and collecting my Christmas pudding orders direct from their kitchens! I never know quite where I shall end up next. However, I do know that on Thursday, **28 April** I shall be sitting in front of the television watching a programme called *Medical Mysteries* which not only follows **Alicia's** diagnosis of Wilson's disease but apparently features **Dr Gillett** too: (see *pp6 and 23* for further details.) Be sure not to miss it!

You may remember that in last year's newsletter we enclosed details of the Wilson's Disease Patient Register - UK. I should like to thank everybody who kindly took the time to complete and return the forms. I am happy to report that we now have 40 people on the Register, although there must be many more patients that we haven't reached yet. Remember, the more of us on the Register the louder our voice and the greater the chance of attracting research into Wilson's disease in the future. Forms for those who haven't received them or have mislaid them are available to download off our website ***<www.wilsonsdisease.org.uk>***

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WILSON'S DISEASE SUPPORT GROUP – UK
www.wilsonsdisease.org.uk
WILSON'S DISEASE PATIENT REGISTER – UK

Facebook is still very popular with over **485** members. It can offer a lifeline to many people and is an excellent way of patients from all over the world communicating with one another. It is also a perfect way for the committee to get news out to you and equally importantly, for you to get news back to us. Why not join us, if you haven't already?

Finally, we missed the company of **Allie** and **Rita** at last year's annual meeting, but thank them for sending some greetings cards to sell to raise money for the Group. This year's meeting will take place on **Sunday 24 July** and we very much hope that you will join us then. **Dr Walshe** has the date firmly noted in his diary and will look forward to being available to help where he can. Meanwhile, please don't forget to renew your membership, complete your booking forms and submit your entries to the quiz. *Happy Dingbats* everyone!

Valerie

IN THIS ISSUE ...

Chairman's Report for 2015-2016

Usually this opening paragraph highlights the Group's progress in building bridges within the rare disease community and our expanding role as a voice for patients with Wilson's disease, their families and friends. However, the news late last year of a sharp increase in the price of 300 mg trientine dihydrochloride capsules, announced by the UK manufacturer of the drug, has overshadowed the more usual and positive aspects of our Group. Your committee's response to the increased cost of trientine is summarised in this report, and an article explaining some of the underlying science of trientine, which has implications for its cost, features on *pp 12-14.*

300mg Trientine dihydrochloride capsules (trientine)

In November 2015, *WDSG-UK* learnt of a steep increase in the UK price of trientine. According to information received from different sources, the manufacturer increased the price by 50% in 2014 and announced an additional 366% increase in the price in 2015. Assuming the latest price increase is implemented, in just under two years the cost of trientine would have been increased by 600%.

In the UK, the possible repercussions of the increased cost have caused much worry for Wilson's disease patients and their families, as expressed by e-mails to *WDSG-UK* and messages on our *Facebook* pages. Some patients are concerned that their treatment may be switched from trientine.

In response to the price increase, your committee has undertaken a number of initiatives:

- We have received advice from the UK's *Department of Health*
- We have asked for guidance from *Rare Disease UK*.
- We are monitoring e-mails and *WDSG-UK Facebook* pages for comments about the price increase and any effects it might have on our members.
- Valerie visited Univar's offices at Milton Keynes to talk about the price increase with Graeme Manley, Trientine Business Manager, Univar and has prepared a report on *p.15.*
- We have responded to requests from hospital pharmacies and other health professionals about the distribution of *WDSG-UK's* patients and the concerns expressed by them on the availability of trientine.

At the time of writing (Mar '16), the impact and consequences of the price increase for trientine on patients and on health service budgets are unclear. We will endeavour to keep *WDSG-UK* members informed of developments.

WDSG-UK Meetings

The *WDSG-UK* management committee met twice during 2015-2016 – in May 2015 and in February 2016, both times in Cambridge. We held the fifth *WDSG-UK* AGM as part of our annual meeting for members, family and friends in Cambridge on 12 July 2015, and a report of this meeting appears on *p.4*.

Donations and Fundraising

I should again like to thank everybody responsible for the magnificent additional income for 2015-16 of just under **£4,750** that has been raised through fundraising and donations. I would particularly like to thank Belinda Diggles, Sylvia Penny, the Goss family and Shaun Galloway for their fundraising (see *pp 5-7*), members who made donations with their membership fees and Jon Tarbin's parents who held a collection for *WDSG-UK* at Jon's funeral in April 2015 (see *p23*). Finally, we thank Univar for their sponsorship last year of £2,000.

WDSG-UK Facebook Site

Currently there are over 485 members of the *WDSG-UK Facebook* site (a Closed Group.) Not only is this site a useful way for members to exchange news, views and concerns, but it has also become a valuable repository for demographic information on Wilson's disease. I thank Valerie and Linda for their hard work and expertise in managing the site. We encourage all *Facebook* Group members to take out an annual subscription to *WDSG-UK.*

Wilson's Disease Patient Register – UK

The Wilson's Disease Patient Register – UK (the Register) was successfully launched by *WDSG-UK* in 2015. The aim of the Register is to compile an index of Wilson's disease patients residing in the UK. Leaflets publicising the Register are being circulated at various hospital clinics, and we are in contact with *Public Heath England*, whose *National Congenital Anomaly and Rare Disease Registration Service* coincides with our goals in establishing a Register which will help in the diagnosis and treatment of UK patients with Wilson's disease. Valerie and Jerry have worked hard on your behalf to establish the Register, and deserve our special thanks and I should like to thank all of you who have already joined. For those who have not, details are available on our website.

Rare Disease UK

Over the past year, *WDSG-UK* has continued to support Rare Disease UK (*RDUK*) and, in particular, its work in promoting the implementation of the *UK Strategy for Rare Diseases* in the health services of the four home nations. I have attended several meetings in London organised by *RDUK* over the last year. Brief details of these events are given below. Further information is available on request.

Rare Disease UK Patient Empowerment Group Meetings (10 September 2015 and 19 January 2016): Rare Disease UK (*RDUK)* and Genetic Alliance UK set up the UK Patient Empowerment Group as part of its involvement in monitoring progress of the *UK Strategy for Rare Diseases*. The meetings are helpful in reiterating the five main strands of the *Strategy*: (i) empowering those affected by rare diseases; (ii) identifying and preventing rare diseases; (iii) diagnosis and early intervention; (iv) coordination of care; (v) the role of research.

Rare Disease UK AGM (19 January 2016): At this year's AGM, *RDUK* launched its latest report – *The Rare Reality* – an insight into the patient and family experience of rare disease. Dr Larissa Kerecuk described the work of the rare disease centre, which has been established at Birmingham Children's Hospital (and which operates in conjunction with the rare disease centre at the Institute of Translational Medicine, Queen Elizabeth Hospital, Birmingham). Following Dr Kerecuk, we heard the experiences of living with a rare disease from a parent of a child with an undiagnosed condition and from a patient affected by a rare disease. Details of the 2016 AGM will be posted on the *RDUK* website http://www.rarediseases.org.uk/governance.htm.

Rare Disease Day (2 March 2016): Rare Disease Day in England was again commemorated with a parliamentary reception at the Palace of Westminster. Introducing the event to an audience of about 170 representatives of patients' groups and health professionals, plus Members of the House of Commons and the House of Lords, Alastair Kent, Chair of *RDUK*, emphasised the importance of *the patient voice* in driving the agenda for improvements in the treatment of patients with rare diseases. George Freeman MP, Minister for Life Sciences, whose remit includes implementing the *UK Strategy for Rare Diseases*, highlighted the opportunities offered by genomics, proteomics, and other technologies for discovering new treatments for rare diseases. There is a growing realisation that *personalised* medicine and rare disease therapies are coalescing as research targets. Full details of the events held to mark Rare Disease Day 2016 in England, Scotland and Wales may be found on the *RDUK* website.

NHS Blood & Transplant *(NHSBT),* **British Liver Trust***,* **and Liver Patients' Transplant Consortium**

On behalf of *WDSG-UK*, Valerie attended a meeting organised by *NHSBT* in London on 14 July 2015. The meeting was chaired by the Liver Patients' Transplant Consortium *(LPTC)*, a sub-group of the British Liver Trust *(BLT)* which specifically represents the views of Liver Patients' Charities in the UK. *LPTC* has been actively involved in advising on the new proposals by *NHSBT* for liver allocation in transplants in the UK.

Wilson's Disease Network – UK

Prof. Oliver Bandmann (Royal Hallamshire Hospital, Sheffield) convened a fourth meeting of the *Wilson's Disease Network – UK* in London last September. Valerie, Jerry and I attended on behalf of *WDSG-UK* together with Dr James Dooley (Royal Free Hospital, London), Dr Emmanuel Tsochatzis (Royal Free Hospital), Dr Karl-Heinz Weiss (University Hospital, Heidelberg) and Dr Aidan Ryan (University Hospital, Southampton). The meeting discussed how to collate data on UK Wilson's disease patients, a research proposal on patients' responses to different treatment regimens, and ways for UK and European Wilson's disease specialists to collaborate.

WDSG-UK Annual Meeting and 6th AGM

The 2016 Support Group Meeting has been arranged for **Sunday, 24 July 2016** at the clubhouse of the city of Cambridge's Rugby Union Football Club. During the course of this meeting the 6th ***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 **2016-2017** will take place. All members of the current committee have submitted their names for re-election to the committee for this period. New committee members are encouraged to join. Please forward your names to the *WDSG-UK* Secretary, Valerie Wheater.

I am once again grateful to members of the *WDSG-UK* management committee for their hard work and commitment during the past year: Linda Hart, Valerie Wheater, Jerry Tucker, Anne-Marie Le Cheminant and Mary Fortune. We look forward to helping our members in the UK plus our very many virtual members worldwide during the forthcoming year.

Rupert Purchase
March 2016

Wilson's Disease Support Group Meeting & 5th AGM

Cambridge Rugby Union Football Club, 12 July 2015

Cambridge Rugby Union Football Club's HQ was again the venue for the annual meeting of the Wilson's Disease Support Group – UK. About 50 people attended and we were particularly pleased to welcome three new members, **Katie Hibbard**, **Jamie Vaughan** and **Alicia Goss**, and to welcome back the **Jeon family**, **Scott Walker**, and **Charlie Watsham†,** together with regular attendees **Linda Asher**, **Jane Ridley**, **Helen Khan**, **Emma Collcott** and **Anusha Joseph** (our photographer for the day.) Finally, the meeting was enhanced by the presence of nonagenarians **Dr John Walshe** and **James Kinnier Wilson**, and the participation of clinicians **Dr Godfrey Gillett** and **Dr James Dooley**.

Front: Dr Walshe (l) & James Kinnier Wilson (r)

The meeting began with two short talks by **Rupert Purchase** and **Jerry Tucker**, respectively. Rupert described the colours of copper compounds in aqueous solution, and explained how we have adopted these colours for our new Group logo and in publicity material for the Group. Jerry reported on the new Rare Disease Centre at the Queen Elizabeth Hospital, Birmingham. Wilson's disease will be one of the diseases treated at the new Centre, which will provide one-stop clinics where patients can see all specialists relevant to their care at one visit. He also reported on progress with the *Wilson's Disease Patient Register – UK*, details of which will shortly be advertised in Wilson's Disease Clinics in the UK.

Anusha and Scott

WDSG-UK was founded by **Linda Hart** and **Caroline Simms**, PhD in 2000. To mark this fifteenth anniversary, Linda and Caroline reminisced before lunch about the Group's early days, when the annual meeting was held in Nottingham, and the highs and lows of a meeting on Wilson's disease they both attended in Leipzig in 2001. The 15th anniversary was recognised during lunch with a cake decorated with fifteen lit candles, which, appropriately, our youngest member, **Olivia Jeon**, expertly extinguished.

Linda, Caroline, Jerry and Rupert

After lunch, the **5th WDSG-UK AGM** saw the re-election of the current committee for a further year, with Valerie taking over Linda's role as Membership Secretary for the year. The customary raffle, which was expertly organised by **Dawn Walker**, was then held raising **£116** for the Group, to which was added a donation of **£2,000** from Univar which **Graeme Manley** kindly presented. Graeme briefly described a new initiative by Univar to produce an information leaflet for patients with Wilson's disease.

Olivia blowing out the candles

The meeting concluded with a question and answer session between the audience and the three consultant physicians present. Whilst stressing the need for Wilson's disease patients to take their medication regularly, Dr Dooley acknowledged this is not easy, and expressed his admiration for patients facing this task. Our thanks go to **Valerie**, **Linda** and **Mary** for organising the meeting, and for making this get-together for patients and friends such a success.

Patients' Group Photo

† Not long after writing this report, we received the very sad news of the death of Charlie. We all recognised the courage Charlie displayed in trying to overcome her illness, and we extend our deepest sympathy to her family and friends.

Fundraising 2015-16

Belinda Diggles continues to think of innovative ways of raising funds for *WDSG-UK* and also for other charities such as *Children in Need, Comic Relief* and *Tickled Pink.*

At the time of writing last year's newsletter she had raised £248 since **July 2014** selling her home made Christmas puddings and assorted chutneys and jams to members of her family and friends. She had set herself a target of raising £400 before our meeting last July, when she planned to present us with a cheque. Unfortunately, her husband Barry underwent knee surgery the week before the meeting and they were unable to make the journey to join us. By then she had raised **£380,** which was just £20 short of her original goal.

But her fundraising continued and in late **July 2015** she held a very successful tea party at her house in St Helen's, Lancashire, providing home made sandwiches and cakes and serving tea from her finest bone china. On that occasion she raised **£130**. By the time I went to visit her in November to collect the Christmas puddings that I had ordered, she had astonishingly raised a further **£170** and I came away with **£680** in all**.** She was now motivated, she told me, to take the total up to £1,000 before this year's meeting in **July 2016.**

Since then, I understand that she has made a further **£251.50** through sales of Christmas puddings, produce filled Christmas gift bags and most recently jars of marmalade. This puts her well in reach of her latest target. Many thanks Belinda.

Belinda awaiting her guests

Enjoying the Occasion

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Sylvia's Summer Bring & Buy Sale

Emma Coombes was diagnosed with Wilson's disease in 2007 at the age of 26 (see her story in the 2014 newsletter) and her grandmother **Sylvia Penny** has been holding fundraising events for *WDSG-UK* at the Victoria Park Methodist Chapel every August ever since.

Sylvia and the immediate family, her daughter Sheila, granddaughters Daisy and Emma and Emma's children Amy and Tom spend the entire year collecting raffle prizes and goods for the stalls from friends and local businesses, which all help to make the day such a resounding success.

This was the ninth such bring and buy sale and coffee morning that she has organised and it is the third consecutive year that I have been able to travel down to Torquay to join them. An impressive **£555.65** was raised for the Group bringing the overall total that Sylvia has raised since Emma was first diagnosed to more than **£4,000.**

We offer our sincere thanks to everybody involved in continuing to raise funds for us in this way and hope that one day Sylvia, Sheila and Emma will manage the trip to Cambridge to join us at our annual meeting. Meanwhile, **I** have the **27 August** noted on my calendar, when I look forward to visiting them all again. Have **you**?

L-R : Sylvia, Sheila, Daisy, Tom (behind), Emma and cousin Geraldine with Geraldine's 7 year old grandson, Ashton at the front.

The Goss Family Tea Party

Alicia Goss was diagnosed with Wilson's disease in December 2014, after struggling with neurological symptoms for some time. She was forced to abandon her first year at university because of her health and spent the first nine months of 2015 getting herself well again. She has since become somewhat of a celebrity, having been filmed for a television medical documentary series **(*Medical Mysteries*, Channel 5** on **Thurs. 28 April 8.00 p.m.),** together with having her story published in two national newspapers earlier in the year. If you turn to *pp 10-11* of this newsletter, you can read her story for yourself.

I first met Alicia, together with her mum and dad Trixie and Patrick, and her cousin, Lisa, at our annual meeting in Cambridge last July. There followed email exchanges between us, through which I was delighted to be invited down to Kent on behalf of the Group to join them at a Tea Party they were holding at St Paul's Church, Orpington, close to where they live. The event took place on Saturday, 12 September and was an opportunity for them to thank friends and family for their support during Alicia's illness and slow road to recovery. We were grateful to them for using the occasion to raise funds for the Group.

I arrived reasonably early and yet the hall was already full. It was only two months since I had first met Alicia and I immediately noticed an improvement. Considering that she had been in a wheelchair from March until July, her progress was remarkable. It was also nice to see her mum and dad again and meet new family members. Her mum, I learnt, is the youngest of seven children and I was soon introduced to a host of uncles, aunts and cousins, who had come to help out. They busied themselves in the kitchen, ran competitions, manned the various stalls and sold tickets for a bumper raffle which promised lots of fantastic prizes.

It was such an uplifting occasion as there was a definite buzz in the air. Everybody expressed their delight that Alicia was continuing to make such good progress. She had been so poorly when she was first diagnosed and yet here she was hoping to be well enough to return to university in a month's time. Patrick had printed off some information sheets for people to read explaining what Wilson's disease was and I readily chatted about the Support Group and my own experience of the disease, answering questions where I could.

At the end of the afternoon Alicia and her mum gave very moving speeches in which they thanked their family and friends for their tireless support, mentioning many individuals by name and explaining in what way they had helped. Special mention was given to Lisa, who as well as taking Liss out every week for some downtime with younger people, had also given her Reiki, a modern treatment based on the principle that through touch, energy can be channelled into the patient activating a natural healing process and restoring physical and emotional well-being - although tablets are essential too!

The raffle was then drawn and the afternoon sadly brought to a close. A few weeks later we were delighted to hear that Patrick had credited the Support Group account with a staggering £1,021.50, which together with a cash donation sent directly to us from a friend of Alicia's in Oundle, brought the overall total raised to **£1,031.50**. We would very much like to thank everybody involved on the day for coming together, spending their money and supporting the Group in this way.

Don't Mess with Liss, Wilson's!

Trixie and Liss's older sister Elise running the Cake Stall

Trixie and Liss giving emotional speeches before drawing the raffle

Patrick, Lisa and other family members being specially mentioned in the speeches

Samworth Brothers Charity Challenge

On Saturday, 6 June 2015 Shaun Galloway, who is the father of two Wilson's disease patients, took part in a team of four in the *tough* section of the Samworth Brothers Charity Challenge. The challenge takes place every two years at a different venue and is a triathlon style event raising funds for different charities. Shaun very kindly decided to compete and raise funds for the Wilson's Disease Support Group - UK.

The 2015 event was held in and around Lake Vyrnwy on the southern edge of the Snowdonia National Park in Wales and Shaun's team had to compete in a 10k canoe race, cycle over gruelling terrain for 30k and then run through the mountains for a further 10k. And just when they thought it was all over, they were presented with a *surprise* assault course which really finished them off!

Not surprisingly, they were particularly pleased when out of forty teams in their section, they finished second. For each member of their team this commanded a quarter share of the prize money of £750.00 and together with the £500 sponsorship money that he raised before the event and a £25.00 donation from the Friends of St Petroc Church in Bodmin, Shaun managed to raise the grand sum of **£712.50** for the Group.

Asked about the day Shaun commented, "It was nice to remind my two sons who have Wilson's disease, Ross and Rory, that their *old man* is not that old ...yet! It was also nice to stand on the podium for the prize-giving and receive our medals from Alistair and Jonny Brownlee, the Olympic triathletes, who also competed on the day and won the *elite* section of the competition."

We congratulate Shaun and his team on their outstanding achievement and thank Shaun for the money that he has raised for the Group.

"This is a picture of our team with the Brownlees: I'm the tall one middle right!"

We would again like to thank those of you who generously make donations to ***WDSG-UK*** with your subscriptions and also our fundraisers who have raised over **£10,500** for us over the past 11 years.

In particular we are grateful to **Sylvia Penny** and family from Torquay, **Barry** and **Belinda Diggles** from St Helen's**, Liz** and **John Wood** from Southend**, Rita** and **Allie Johnston** and **Stephanie** and **David Reid** from Edinburgh**, Lesley Galloway** and family from Leighton Buzzard, **Philip** and **Tulin Hawkins** from Oxford, the **Goss** family from Kent and the **Galloways** from Cornwall. They and committee members have held tea parties, run coffee mornings and bring and buy sales, undertaken sponsored walks, cycle rides, swimming events and sky dives, run quiz nights, marathons and triathlons, put on concerts and golfing events, baked puddings and cakes and made jams and chutneys, sold handicrafts and held raffles, and most unusual of all have taken part in Loony Dooks (a Hogmanay tradition taking place in the Firth of Forth.)

With ***WDSG-UK*** no longer accepting sponsorship from Univar (see *p 15*), we shall be reliant more than ever on your continued support. If you have a special talent or interest and feel that you would like to use it to raise funds for the Group, then we would be delighted to hear from you. Sponsorship and Gift Aid forms are available on request. Do use the *Events* diary on *p23* to advertise your event.

What are "LFTs?"

by Dr A. Stevens

All Wilson's disease patients will be familiar with the term **LFTs.** LFTs is doctors' shorthand jargon for **L**iver **F**unction **T**est***s***, which are tests done in the laboratory on a blood sample to see if the liver is functioning properly. There are other ways of investigating the liver, such as ultrasound and liver biopsy, but the liver function tests are the first line in the investigation of possible liver disease.

First, a bit of revision about the functions of the liver.

In my previous article about the normal liver on *pp 8-9* of the **2014** *WDSG-UK* newsletter (available to download from www.wilsonsdisease.org.uk), I explained that the liver is a sort of large chemical factory, with many functions. The main functions are:-

1. the making of many substances which the body needs to function properly, e.g. proteins such as albumen and the chemicals (clotting factors) needed to make the blood clot when a blood vessel is torn, the clot preventing excessive loss of blood from the damaged vessel.

These substances are made by the liver cells, called **hepatocytes**, using raw materials supplied to the liver by the portal vein system. These raw materials (e.g. amino acids, simple sugars and fatty acids) are produced by the digestion of food in the gut, and then transferred to the liver where they are built up into much larger molecules by the hepatocytes. The chemical reactions in the hepatocytes require the presence of a range of different **enzymes** (see below) before they can take place;

2. the breakdown of toxic substances to harmless compounds which can be safely excreted from the body, mainly in the urine, without causing damage. These toxic substances can be either produced by the body itself (e.g. toxic ammonia compounds) or ingested by mouth (e.g. alcohol and some drugs). The breakdown of toxins by the hepatocytes also requires the presence of enzymes;

3. the production of bile. This is made in the liver from the compounds released when red blood cells die. Bile is passed from the liver, via the bile ducts and gall bladder, to the gut where it helps in the breakdown and digestion of food material, before being excreted in the faeces.

Second, a note about enzymes.

Enzymes are important chemicals that are found in every cell in the body, but they are present in high concentration in cells which are biochemically active, and liver cells are packed with a wide range of them. Enzymes are vital for the chemical reactions which occur in cells, for they act as **catalysts** for the reactions. Catalysts are substances which increase the rate at which a chemical reaction takes place, but do not take part in the reaction, and are unchanged at the end of the process. They are the 'trigger' which gets the reaction moving quickly.

When a cell dies, the enzymes it contains leak out into the blood stream. In normal healthy tissues where cells are always dying but in very small numbers, the quantity of enzymes released into the blood stream is very small, but when there is disease, many cells may die at the same time and the large amount of enzyme which is released can be detected by blood tests. This forms the basis of some of the liver function tests.

What liver function tests are done?

Here is a list of the standard liver function tests (LFTs):-

Serum albumen - this measures how competent the liver is at synthesising protein molecules. A low level is an indication that the liver has lost a lot of functioning hepatocytes, an indication of chronic liver disease. It suggests that the liver is failing to make a whole range of proteins as well as albumen, but albumen is the easiest to measure.

Note that there are other causes of a low albumen level; in some forms of kidney disease, the damaged kidney leaks excessive amounts of albumen out into the urine, at a rate that the normal liver cannot re-supply.

Clotting studies (prothrombin time PT or international normalised ratio INR) - these tests show whether the liver is making enough of the clotting factors essential to form blood clot and stop bleeding. It is another measure of whether the liver is synthesising substances properly.

ALT (alanine aminotransferase) - is one of the **enzymes** in liver cells. When large numbers of liver cells die at the same time, the level of this enzyme is raised in the blood. A high level is an indicator of active liver cell destruction, the higher the level, the more severe the destruction. The highest levels are seen in acute hepatitis.

AST (aspartate aminotransferase) - another **enzyme** released when liver cells are damaged. It is not as specific to the liver as ALT, and can be raised in other conditions e.g. after a heart attack

Gamma GT (gamma glutamyl transferase) and ALP (alkaline phosphatase) - are **enzymes** found particularly concentrated in the bile canals and ducts in the liver. They are raised when bile canals and ducts are damaged, impeding the free flow of bile around and out of the liver. High levels are found when the patient has jaundice due to liver disease.

Serum bilirubin - bilirubin is the major component of bile, and rise in blood level is indicative of actual or developing jaundice. It is usually associated with high GGT and ALP levels.

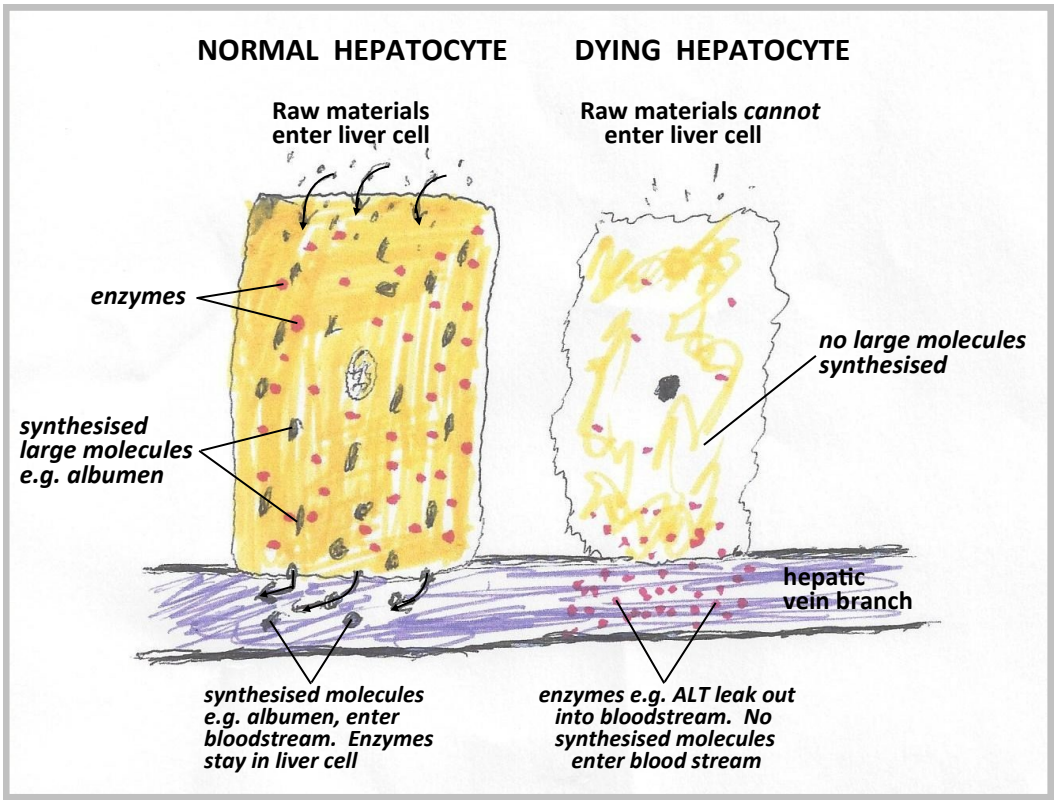


Diagram: **Explaining why liver damage causes low serum albumen and high serum enzyme levels.**

Why are liver function tests done in Wilson's disease patients?

In Wilson's disease, excess copper is deposited in many tissues, but the main targets are the brain and the liver. In the liver, the excess copper acts as a toxin to the liver cells (hepatocytes), causing them to die in increased numbers. Liver function tests are done at the time of initial or suspected diagnosis to:-

- establish whether there is already significant liver damage;
- provide baseline measurements of current liver function, so that repeat LFTs in the future can assess whether there is deterioration, or whether there is improvement with treatment.

The LFTs do not prove the diagnosis of Wilson's disease, for many other diseases cause liver damage. Wilson's disease is diagnosed by more complex tests of copper metabolism.

Alicia's Story

by Alicia Goss

Hi everybody. I'm Alicia Goss, known to my friends as Liss. I was born in March 1996 and will shortly be celebrating my twentieth birthday. My older sister, Elise and I were born and brought up in Farnborough, Kent where we have lived ever since. I have always been optimistic and bubbly by nature and had a very happy childhood. I loved school, being popular with both my teachers and peers, and after gaining 11 GCSEs stayed on into sixth form to study A levels. I chose sociology, psychology, Philosophy and Ethics, and English Literature and applied to read sociology at Canterbury in Autumn 2014. That's my background: now the rest is about how I came to be diagnosed with Wilson's disease.

At the end of the first year of A levels, I was doing part-time work at a local bakery. I was having severe nosebleeds and joint pains in my knees and my back. One day while I was working, I bent down to get something out of a drawer and my knees and back locked altogether, making it difficult to get up again. I ignored it at the time but my joints continued to ache and cause me a lot of pain. At Easter 2013 I was about to go on holiday and I developed a bad cough. I am asthmatic and decided I ought to see my doctor to get a spare inhaler to take away with me. I mentioned my nose-bleeds and joint pains to her and she immediately offered to do some blood tests on me.

She had the results by the time I came home and I was told that my liver function tests were normal but my platelet count was very low: 32 where the normal range is 150 - 400. Because my liver function tests were normal, she didn't connect my low platelet count with anything to do with liver disease. I understand now that it is common for Wilson's disease patients to have a low platelet count. Anyway, I was then sent to a haematologist who ran further tests and told me that I had ITP (Idiopathic thrombocytopenic purpura) which is a disorder that can lead to easy or excessive bruising and bleeding due to a low platelet count. Mum asked if I could have been born with it and he said, "No." So as to exclude leukaemia, under local anaesthetic I had a bone marrow biopsy and this too came back normal. I was told that I would have to live with the condition. During this time I was missing quite a bit of school through attending various hospital appointments but I was lucky, the teachers were all very supportive and helped me to catch up afterwards.

Nothing of note happened then until I came to sit my A levels. I found in the examinations that I was having difficulty writing. In fact, I was so concerned that the examiners might not be able to read what I had written, that I asked my teachers to look through my papers to check they would be able to do so. They did and said that they had seen worse and assured me that there wouldn't be a problem. When the results came out in August I was relieved to find that I had passed them all and so prepared to take up my place at Canterbury a month later. I was excited to be leaving home and starting a new chapter of my life. Not long into my course, however, I was sitting in a lecture theatre taking notes one day, when suddenly without warning my pen flicked uncontrollably out of my hand, landing on the floor. The lecturer wasn't amused and thought that I was fooling around and, not knowing what had happened myself, I began to think he was right!

When I was home at half-term at the end of October, I visited my cousin one day and she asked her mum and dad why my hands were shaking. My parents had noticed it too. There was clearly something wrong, but I argued it was probably just my recent change of lifestyle, the stress of starting university, making new friends and getting to grips with the work I was having to do: my nerves were getting the better of me. I returned to university and as November wore on my hands started to shake all the time and I noticed my speech was beginning to slur. On one occasion I went to a club with my friends and the bouncers thought that I was drunk or on drugs and refused to allow me in. People were even starting to shout at me in the street because I was having difficulty walking straight and they would give me funny looks because they thought that I was drunk. It was very frustrating, embarrassing and hurtful at the time.

By December mum and dad made me return to my G.P. and request an immediate appointment with Dr Britton, a neurologist dad knew, who could be seen privately at the local Chelsfield Park Hospital. On my first visit to see him, Dr Britton booked me in for an MRI scan at a hospital near Waterloo in London. When I returned for the results a couple of weeks later, he said he thought he knew what the matter was with me but needed to do some further tests. These included blood tests, having my eyes examined for Kayser Fleischer rings and doing a 24 hour urine collection to test for copper. He mentioned Wilson's disease to us then, but none of us had ever heard of it before and because Christmas intervened, it wasn't until the New Year that the diagnosis was officially made.

So on 10 January 2015, I began my treatment taking 750 mg penicillamine per day in two doses. We had expected that I would be able to return to university within just a few weeks, but instead things started to go from bad to worse. When I was first diagnosed I could still just about get around on my own, but my symptoms then started to get even worse. I remember at the end of January I was determined to share my friend's birthday celebrations with her at a local nightclub, but almost as soon as I got there my legs just collapsed from under me and I fell to the floor. My friends and the nightclub staff helped me on to a chair, but my body stiffened up and I immediately fell straight back on to the floor again. Mum and dad had been reluctant to let me go out in the first place and came out immediately to pick me up and take me home.

Concerned that my condition was deteriorating further, dad found the name of Dr Gillett, a Wilson's disease specialist, off the internet and emailed him straight away. Dr Gillett holds a monthly clinic at Queen Square, London, and very kindly agreed to see me at his next clinic in March. He increased my penicillamine dose to 1000 mg per day and also prescribed Vitamin E which I hadn't previously taken. By then I couldn't stand at all and was having to use a wheelchair. It was like I was paralysed. For quite a time dad was even having to carry me to the bathroom, which being 5'8" tall was no mean feat! My speech which was already bad became more slurred and my hand and head tremors got even worse. I wasn't even able to put my own make-up on any more! I had been so outgoing in the past, but now I had retracted into myself because I didn't want to hear what I sounded like or see how I looked. The slurred speech in particular really upset me.

I remained in a wheelchair for a further four months, which was the darkest point of my life. A deep depression hung over me. Fortunately, I have got the best parents in the world and they have supported me every step of the way. In May they joined *WDSG-UK* and arranged to take me to their annual meeting in Cambridge in July. At the beginning of July I was still shuffling downstairs on my bottom and then extraordinarily one day, I was suddenly able to walk down standing up. Mum was absolutely amazed. The meeting took place shortly afterwards and I was very nervous about going. I had never met any other patients with the disease and didn't know what to expect. On arriving at the Rugby Club I felt very self-conscious and decided to leave my wheelchair in the car. I folded my arms resolutely in front of me and slowly walked in. It wasn't easy. Linda gave us a warm welcome and I sat down as soon as I could. I didn't want anybody to notice my tremors. I gradually started to relax and was pleased to see Dr Gillett there who noticed an improvement in me straight away. He offered me plenty of encouragement and assured me that things would get better and that I just had to be patient.

And thereafter, day by day things did quickly start to get better. I felt I had turned a corner. I was so keen to thank my friends and family for all that they had done to help and support me while I was so ill, that we decided to hold a tea party for them in September and through it raise funds for the Group. It was a wonderful day and I was touched that so many people made the effort to come. By then, I was feeling well enough to return to university in October and I can happily report that I did exactly that. I carry a medical card to explain my condition, but so far I haven't needed it. I am still going out to pubs and clubs and enjoying the life of a student, but with an affected liver I don't drink alcohol at all!

My doctors are all very pleased with me, too. I see Professor O'Grady, who is a hepatologist at King's College Hospital London, Dr Britton my neurologist who first made the diagnosis and every six months I see Dr Gillett in London. I am so lucky that everything is going well, although I do still get very tired, but with all that has happened to me in the past eighteen months, I suppose it's hardly surprising.

Liss in her university room at Canterbury

The production of pharmaceutical grade trientine dihydrochloride for the treatment of Wilson's disease: a personal account

Introduction

The news last November of a steep rise in the price of trientine dihydrochloride capsules imposed by the manufacturer of the drug, Univar, has caused dismay in the Wilson's disease community in the United Kingdom. Patients are worried about a potential dislocation to their treatment, and hospital pharmacists and other health professionals view the financial impact of the price increase on health service budgets with great concern. For me personally, the increase in cost is a big disappointment. Trientine dihydrochloride is a relatively cheap drug to manufacture, and by building on the experimental and clinical work of Dr Hal Dixon and Dr John Walshe, respectively, I played a part, in the 1970s, in securing the supply of pharmaceutical grade trientine for Wilson's disease patients. No one denies that business is driven by the need to make a profit, but the checks and balances of society demand a degree of reasonableness between suppliers and consumers. Let us hope that Univar's current distortion of the business model is temporary, and one day trientine will be readily available worldwide at a price all countries can afford.

I have previously written three notes on trientine: (i) a summary of some experimental work on the purification of technical grade triethylenetetramine, which was published in the *Journal of Chemical Research*, 2005, 233-235; (ii) an account of the discovery of trientine (and other drugs) for treating Wilson's disease, which appeared in *Science Progress*, 2013, **96**, 19-32; (iii) a description of Hal Dixon's suggestion that triethylenetetramine might be used to treat Wilson's disease (available on the WDSG-UK website http://www.wilsonsdisease.org.uk/documents/March2010Extract.pdf).

In this additional note, I should like to explain a little more of the chemistry of triethylenetetramine and why trientine is relatively inexpensive to manufacture. I also wish to recount Hal Dixon's role in establishing trientine dihydrochloride as the preferred salt for therapeutic use.

Triethylenetetramine and trientine

By selecting *tri*, *en*, *t*, and *ine* from *tri*ethyl*enet*etram*ine*, the British Pharmacopoeia Commission chose trientine in 1978 as the British Approved Name for pharmaceutical grade triethylenetetramine. In all countries except the USA, the dihydrochloride salt of triethylenetetramine is named trientine dihydrochloride. Confusingly, the US Approved Name for the same compound is trientine hydrochloride.

Triethylenetetramine, a polyamine and a liquid organic base, was first characterised by the German chemist A. W. Hofmann in 1860-1862 whilst he was researching amine chemistry at the Royal College of Chemistry in London. Hofmann's early work on the synthesis of polyamines has been summarised by F. G. Mann, *Journal of the Chemical Society*, 1934, 461-466.

Triethylenetetramine evolved from a laboratory curiosity into an industrial chemical produced on a large scale during the 1930s. Utilising Hofmann's aminolysis chemistry, technical grade triethylenetetramine is manufactured from the reaction of ethylene dichloride (EDC) and ammonia. A mixture of linear, branched and cyclic amines is obtained from this reaction. The triethylenetetramine content of the mixture is about 75%. A glance at the Dow website for triethylenetetramine (http://www.dow.com/amines/prod/ethyl-teta.htm) reveals the very many commercial uses of technical grade triethylenetetramine. The manufacture of epoxy curing agents, fabric softeners, lube oil and fuel additives, asphalt additives and paper wet-strength resins are just some of the many applications for this versatile polyamine mixture.

Consider the cheapness of the two ingredients used to make technical grade triethylenetetramine – EDC and ammonia. Ethylene dichloride results from the combination of ethylene with chlorine. Ammonia is made from hydrogen and atmospheric nitrogen by the Haber process. Ethylene is manufactured by cracking petroleum fractions, and chlorine can be obtained by the electrolysis of brine (aqueous sodium chloride). By manipulating the most readily available and cheapest chemicals on the planet – air, water, evaporated seawater, and hydrocarbons – chemists can produce tonne quantities of technical grade triethylenetetramine with only energy as the meaningful cost! (One tonne = 1,000 kilograms). A current quotation from the laboratory chemicals supplier Sigma-Aldrich UK for 18 kg technical grade triethylenetetramine is £474.50 ≡ 2.6 pence per gram. The unit cost from one of the manufacturers of technical grade triethylenetetramine (e.g. Huntsman or Dow) would be considerably cheaper.

The cheapness and multiple applications of technical grade triethylenetetramine made by the EDC route have two consequences. First, despite its longevity as a chemical process, and the many patented alternatives, the EDC

method is still in use for manufacturing technical grade triethylenetetramine. Secondly, the cheapest and only realistic option for preparing pharmaceutical grade triethylenetetramine for the treatment of Wilson's disease is by purifying the technical grade material.

Coordination chemistry of triethylenetetramine

The characteristic blue colour (**Figure 1**) formed on mixing cupric sulfate with triethylenetetramine, synthesised in the laboratory, was reported by D. H. Peacock, *Journal of the Chemical Society*, 1936, 1518-1520. With the ready availability of commercial triethylenetetramine from the EDC process, the coordination chemistry of this ligand (L) with copper and other metals (M) could be explored more fully. By the early 1950s, triethylenetetramine was characterised as a quadridentate ligand, which formed a 1:1 complex ML (a 'chelate') with cupric ions, M + L □ ML. The stability constant for the complex ML is the equilibrium constant K_{ML} where K_{ML} = [ML]/[M][L].

Figure 1

The blue colour of Cu[trientine]$^{2+}$, obtained by adding a 300 mg trientine dihydrochloride capsule to aqueous copper sulfate.

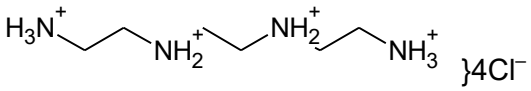
A large stability constant indicates the formation of a stable complex. Stability constants are usually quoted as $\log_{10}K_{ML}$. For example, for the chelation of cupric ions with trientine, Cu^{2+} + trientine □ $[Cu(trientine)]^{2+}$, $K_{ML} = [Cu(trientine)]^{2+}/[Cu^{2+}][trientine] = 10^{20.1}$ mol^{-1} dm^3, i.e. $\log_{10} K_{ML} = 20.1$ (a typical experimental value). The definitive study of the aqueous chemistry of trientine and cupric ions is by S. H. Laurie and B. Sarkar, *Journal of the Chemical Society, Dalton Transactions*, 1977, 1822-1827. Trientine can chelate other essential transition (e.g. manganese, iron, cobalt, nickel) and non-transition (e.g. zinc) metal ions.

Trientine, Dr Hal Dixon and Wilson's Disease

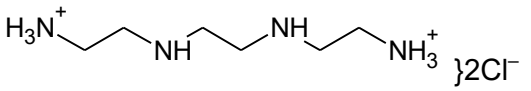
The stage was set to link the copper chelating properties of triethylenetetramine with Wilson's disease. The happy coincidence of Dr John Walshe, the clinician who had introduced the first chelating agent, D-penicillamine, for the treatment of Wilson's disease, and Hal Dixon, an erudite biochemist, both working at the University of Cambridge in the 1960s, led to the introduction of trientine dihydrochloride as the second oral drug for the treatment of Wilson's disease in 1969 (J. M. Walshe, *Lancet*, 1969, **294**, 1401-1402).

Apart from its strong affinity for cupric ions, Hal Dixon recommended triethylenetetramine as a candidate drug because its structural similarity to the naturally occurring polyamines, spermine and spermidine, suggested triethylenetetramine was unlikely to be toxic in humans. A recent account of the acute toxicity of trientine in man supports this view: A. Hashim, N. Parnell, 'A case of trientine overdose', *Toxicology International*, 2015, **22**, 158-9.

The administration of triethylenetetramine required the conversion of the liquid base into a solid form suitable for drug encapsulation and administration to patients. The salts of amines with simple inorganic (e.g. hydrochloric acid, sulfuric) and organic (e.g. maleic, succinic) acids are invariably solid compounds. Triethylenetetramine tetrahydrochloride had been prepared as a crystalline solid by R. G. Fargher (*Journal of the Chemical Society, Transactions*, 1920, **117**, 1351-1356). Instead of making the tetrahydrochloride, Hal Dixon chose to prepare triethylenetetramine dihydrochloride, previously characterised in aqueous solution (S. Lapanje et *al*, *J. Amer. Chem. Soc*., 1961, **83**, 1590-1598), but which had not been hitherto isolated. One of the reasons for not using the tetrahydrochloride therapeutically was as follows. In trientine.4HCl, all four (primary and secondary) amino groups are protonated:



In trientine.2HCl, only the two terminal (primary) amino groups are protonated:



The molecular weight of trientine.2HCl is 219.2 (i.e. 66.7% trientine free base). The molecular weight of trientine.4HCl is 292.08 (50.1% trientine free base). (The molecular weight of trientine free base is 146.2). Therefore for a 300 mg capsule 300 mg trientine.2HCl ≡ 200.1 mg free base; 300 mg trientine.4HCl ≡ 150.2 mg free base. Therefore a daily dose of 1200 mg trientine free base ≡ 6 capsules trientine.2HCl ≡ 8 capsules trientine.4HCl.

The preparation of pharmaceutical grade trientine dihydrochloride

Components of technical grade triethylenetetramine: Although conventional synthetic routes to trientine have been published (e.g. United States Patent Application Publication, US 2015/0057466), the cheapness and availability of technical grade triethylenetetramine mean this substance is the only economically viable starting material for preparing the pharmaceutical grade material. As mentioned previously, technical grade triethylenetetramine is a mixture of amines – predominantly a linear amine (75% triethylenetetramine) plus three impurities: a branched amine (5% tris(2-aminoethyl)amine) and two cyclic amines (20% substituted piperazine derivatives).

Removal of the impurities in technical grade triethylenetetramine: Preparation of pharmaceutical grade trientine dihydrochloride requires the complete removal of the three major, bioactive, amine impurities from technical grade triethylenetetramine. This cannot be achieved (without a drastic reduction in the percentage yield) by the addition of hydrochloric acid to technical grade triethylenetetramine followed by fractional recrystallisation of the resulting mixture of hydrochlorides. Technical grade triethylenetetramine is an azeotropic mixture, so neither can the individual amine components be separated easily by fractional distillation.

Preliminary purification of technical grade triethylenetetramine before the addition of hydrochloric acid: In order to achieve an efficient production route for trientine dihydrochloride, a preliminary purification of technical grade triethylenetetramine is needed before its conversion into the dihydrochloride. A literature search using *Chemical Abstracts* revealed a way of accomplishing this additional step for the preparation. With a fortuitous choice of solvent (R. Purchase, *Journal of Chemical Research*, 2005, *loc. cit.*), successful laboratory and pilot plant preparations of trientine dihydrochloride were developed between 1977 and 1979. Incorporation of the additional purification step is achieved with minimal expense, and, overall, the cost of converting technical grade triethylenetetramine into pharmaceutical grade trientine dihydrochloride is <u>not</u> influenced by the price of the chemicals or by the complexity of the chemistry for making this drug.

Conclusion

The starting material for the production of pharmaceutical grade trientine dihydrochloride is technical grade triethylenetetramine, a bulk chemical commodity available at a very low unit cost. Although the large-scale production of trientine dihydrochloride, based on the initial laboratory preparations of this drug, is accomplished with considerable skill by process chemists and chemical plant operatives, the unit cost of manufacturing trientine dihydrochloride is relatively low.

In the 1970s, much goodwill was extended to Dr Walshe by the *UK Department of Health*, the Laboratory of the Government Chemist, and others, to facilitate the availability of encapsulated trientine dihydrochloride for the treatment of Wilson's disease. Let us hope that some of this goodwill returns to those responsible for the current hiatus.

Rupert Purchase, D.Phil., C.Chem., FRSC
Chair, WDSG-UK, 2015-2016
25th February 2016

Stock availability of penicillamine 250mg tablets for UK Patients, updated 9 March 2016

Product Licence Holders:

Alliance Pharma has reported that the manufacturing problem with the branded product **Distamine** 250mg x 100 tablet pack has now been resolved. Supplies of this product are available *via* the wholesalers **AAH Pharmaceuticals** and **Alliance Healthcare (Distribution) Ltd**.

Kent Pharmaceuticals is still out of stock of its generic product with no date yet for resolution of this problem.

Mylan Pharmaceuticals only has limited supplies of its generic penicillamine 250mg x 56 tablet pack. More stock is expected in early July 2016. Hospital contract supplies could be honoured preferentially to community supplies, depending on the wholesaler.

Pharmaceutical Supply Wholesalers

AAH Pharmaceuticals (Head Office: 024 7643 2000): AAH confirmed that it has stock of penicillamine (Distamine) tablets at certain branches with no apparent restriction on supplies to hospitals or to the community.

Alliance Healthcare (Distribution) Ltd. (Head Office: 020 8391 2323): Penicillamine (Distamine) tablets are available from Alliance Healthcare. This wholesaler also has some stock of generic penicillamine 250mg x 56 tablet packs, with no apparent restriction on supplies at present. However, this is the Mylan product, so this source might run low before July.

My Meeting with Graeme Manley, Univar's Trientine Business Manager - Valerie

On Monday, 21 March 2016, I went to Univar's offices in Milton Keynes to talk to Graeme Manley about *WDSG-UK's* concerns following the recent price increase of trientine dihydrochloride capsules (trientine). Graeme has been a close supporter of *WDSG-UK* in the past, taking an interest in our patients, attending our annual meetings in the summer, organising our sponsorship each year on behalf of Univar and responding to enquiries that the Group receives from overseas patients needing help acquiring trientine. In 2015 Univar supported 75 patients worldwide through the US *Wilson Disease Association's* global compassionate use programme in countries where trientine is unlicensed.

As regards the history of Univar's involvement with trientine, I learnt that Univar is a chemical distribution company which was founded in 1924, but that thirty-five years ago it acquired the business which manufactured trientine and whilst not dealing in any other pharmaceutical drug products, Univar has safeguarded its manufacture ever since. In addition, it has invested in improving its supply chain, logistics and in-house capabilities to ensure a smooth supply of trientine to patients. Univar is also currently working towards holding a minimum of twelve months' stock of the finished product further ensuring continued supply.

Trientine has a small patient base in the UK (although numbers cannot be verified). It is a second line chelating treatment following penicillamine (NICE guidelines). Univar is significantly investing in making trientine a licensed medicine in Europe, enabling European Wilson's disease patients to access the medicine more easily. Although getting trientine accepted as a first line of therapy is under consideration, the programme of work and related investment required would be higher and take longer.

It's understandable that improvements cost money. However, I explained that the more than quadruple price increase, which we are told has been introduced to trientine recently, has not escaped the attention of the NHS through the concerns of patients, doctors, pharmacies and *Clinical Commissioning Groups* (*CCGs*). The cost of a bottle containing **100** x **300 mg** capsules has risen from **£600** to **£2,700**, which means that it will now be costing the *NHS* a minimum of **£40,000 - £60,000** a year to treat each Wilson's disease patient in the UK on a typical maintenance dose of **4 - 6** trientine capsules a day.

A patient's 83 day supply of trientine: 5 bottles: Price - £13,500

I explained that whereas patients were once routinely prescribed trientine directly by their GPs, which they then had dispensed by their local community chemist, now some GPs and pharmacists were refusing to *touch* it because of the very high cost. These patients were having to get their medication from the hospital that treats them, which in some cases can be many miles away from where they live. However, there are problems here too because hospital pharmacies are also now reluctant to cover its significant expense out of their own budgets.

In addition, I told Graeme that most worrying of all was that some patients had even been asked by their hospital consultants to consider changing back to penicillamine or to swap to alternative therapies such as zinc. For a patient who has been stable on a particular medication for years, the thought of having to change to something else is stressful and worrying in the extreme. I pleaded with him to make representation on our behalf to those at Univar responsible for setting the price of trientine, asking that the cost of any investment in getting a European licence be recouped from profits across its many other product ranges rather than taken solely out of the profits from current sales of trientine.

And finally, I emphasised that *WDSG-UK* felt so strongly about the price increase that they no longer wished to accept sponsorship from Univar. I suggested that instead this money be put into a hardship fund managed by them for patients reliant on trientine who are affected by the current situation. We can only hope if my remonstrations fall on deaf ears, that when Univar's customer base for trientine increases, a price reduction will follow.

NOTE: We are aware that several of our UK patient members are experiencing difficulty obtaining their trientine medication through their usual channels because of the recent price increase. The Department of Health and local Clinical Commissioning Boards are aware of the problems and our Vice-Chair, Jerry Tucker (jerry@wilsonsdisease.org.uk) is currently in correspondence with them about this. Do please contact Jerry if you have any specific concerns.

Katie's Story

by Katie Hibbard

Katie

My name is Katie and I'm 35 years old. I live in a little village called Blyton in Lincolnshire with my husband Ryan and my 18 month old son, Jacob. I am the youngest of three children and was diagnosed with Wilson's disease (WD) back in **2006** when I was **25.** My sister was also found to have it, though my brother was not. I attended the Support Group meeting in Cambridge last summer and have since been asked to give a short account of my Wilson's disease history.

I noticed my first symptoms in April 2006. They started with tremors in my little fingers. I didn't think anything of it, but my mum noticed and made me go to see my G.P. He said he would refer me for a brain scan and I waited two months for a letter to arrive and then when it came it was just to ask me to select which hospital I wanted to go to. I then had to wait for an appointment from my hospital of choice. My G.P. thought I had the start of Parkinson's disease or possibly even Multiple Sclerosis.

It was July before I got an appointment by which time my symptoms had worsened. I was at work one day when my speech suddenly went. I knew what I wanted to say but when I spoke it sounded like I was drunk and nothing made any sense – at this point I knew something was seriously wrong! I got home that night and tried to speak to Ryan to tell him what had happened. Over the next few days I started losing my balance, my co-ordination was poor and swallowing was difficult as it felt like something was stuck in my throat. I spent a few days just retching over the toilet. Ryan rang my doctor to get an emergency appointment and I was seen by Dr Hunt, who took one look at me and knew something was seriously wrong. He rang the hospital immediately and requested I have an emergency brain scan. The following day I went to Lincoln County Hospital (LCH) where they did various tests. Of these I remember two weren't particularly pleasant. One involved a wooden stick which was poked in my mouth to test my gag reflex and the other I had cotton wool put in my eyes (I've no idea why.) The junior doctor I saw didn't know what was going on as he said all the test results were normal. I was admitted on to the short stay ward to wait for my brain scan, which wasn't performed for a further five days.

The neurologist at the LCH, Dr John Bowen, was away at a conference in Helsinki. He was contacted about my condition and my brain scan images were forwarded to him. He suggested the diagnosis of Wilson's disease and recommended I be sent to the eye clinic, where they looked in my eyes with a slit lamp and found Kayser-Fleischer rings. I was in LCH for just over a week. From there I was sent straight to Sheffield Hallamshire Hospital where there were two Wilson's disease specialists, Professor Oliver Bandmann and Dr Godfrey Gillett. They ran further tests and started me on medication. They wanted me to have a liver biopsy, but I refused as they already knew my diagnosis and the blood work in my Liver Function Tests (*LFTs*) showed that my liver was fine. I remained in Sheffield for a further week.

I started on a low dose of D-Penicillamine working up to a higher dose. However, I began to get very bad sores on the corners of my mouth and about ten minutes after taking the medication I felt I wanted to be sick. As a result I practically stopped eating and survived on one banana a day, eating half after my morning tablets and the other half after my evening ones. During that time I went down from nine-and-a-half stone to seven-and-a-half stone. I returned to Sheffield where they changed my medication to trientine, which I am still taking.

Throughout my acute illness I only had two months off work (although I was told that I returned too soon!) I consider myself lucky to have been diagnosed only four months after my symptoms started. My speech is so much better now, although when I am tired it sounds slow and slurred. And my handwriting has improved too, although it is still somewhat messy!

I feel as if I lead a normal life. I have yearly check ups in Sheffield. I avoid liver and organ meats and shellfish, but otherwise eat everything else (in moderation.) I have a beautiful, healthy little boy who was born in 2014, having remained on trientine throughout the whole of my pregnancy.

I still get some bad days where I feel nauseous, but I get on with it because I have Jacob to care for now. I would like to thank Dr Bowen for his speedy diagnosis and Prof Bandmann and Dr Gillett for their excellent care. We hear so much negativity about the NHS, but my experience has always been very positive.

European WD Support Groups

With the EU Referendum taking place in less than three months' time, I thought it would be timely in this year's newsletter to remind ourselves of the geography of our continent and at the same time highlight the different *WD* Support Groups in Europe working hard to represent the interests of their patients. Through EuroWilson we have already met the organisers of the French, Spanish, Swiss, German and Italian Groups and this year we have had email exchanges with the organisers of the Danish, Icelandic, Bulgarian and Romanian Groups too. Below, we highlight some of these Groups and underneath the photographs list their current patient organisers. We offer all Wilson's disease patients, wherever they are, our friendship and wish them good health for 2016.

Iceland - Guðmundur Pálmason

Team GB

Denmark - Lisbet Ottesen

NW Germany - Regine Bielecki

Switzerland - Helga Bonny

Romania - Emilia Costache

Spain - Amparo Maudos Gimeno

Italy - Salvatore Dilorenzo

Bulgaria - IvaNova Ivelina

David's Story

by David Lin

Hello, everyone! I am David. I am from Taiwan, an island state in the west of the Pacific. I grew up in Taiwan's agricultural heartland with my grandparents, who were farmers. Rolling in the pungent tang of dill, garlic and chive, and the musky scent of ripe rice land, I began to help out at a tender age. Chasing after my grandparents' ducks and chickens in the yard, I was also a troublemaker. Now that I look at it, I must have had an attention span longer than that of most children of my age. By the time I was five, I had already reached the reading age of ten. But I also had an anger issue which often resulted in violent assaults upon other children. These, I suspect, could have been recognised as early signs of Wilson's disease.

David

Due to the political disputes with China, Taiwan was under decades of martial law. It was a difficult time, but a series of economic reform policies seemed to work and the country became more affluent. Wealth was then followed by public opinions, debate and disputes. By the time I was three, the imposition of martial law was lifted. Nevertheless, freedom was still novel, and democracy young. For all the public polls, diversity was still a pipe dream. In fact, our neighbour still had his concrete fence painted with slogans such as 'It's everybody's duty to fight communism and spies.'

Growing up with my Grandparents

I was different from other children. In an age when social and political conformity was still an integral part of school curriculums, I was all too often misunderstood. I was a frustrated glutton for knowledge. While we weren't really encouraged to ask questions, I was quite vocal with my doubts, which was often deemed to be revolt or dissent. What made matters worse was that I couldn't see the logic in illogical guidelines such as unfair rules and practices. I was one of the 50 seven-year-olds in the class when our tutor commented on bribery to us with an imposing smirk, 'I will put the money in my pocket, but I will never vote for the candidate.' Perhaps it is not hard to understand after all why I used to throw a tantrum from so much added pressure and repression.

Chinese Medicine

Neither is it difficult to establish how obvious signs of my illness were overlooked. As a child, I didn't know. I was an underdog, licking my wounds from a lot of physical punishments, degrading verbal reprimands, or maledictions. One day, when I was eight, I had some cold soymilk before I went to school. At school, I had a very bad case of diarrhoea and had to be sent home. Very soon, I began to develop a bad rash, and was rushed to a regional teaching hospital. The doctor shrugged and told my trusting family that it was allergic purpura, the cause of which was unknown.

A year later, I had a relapse after which my mother insisted that I had blood tests taken routinely. When I was about ten, the lab results began to indicate that my AST and ALT levels were elevated. At that time, there was no effective treatment for hepatic disorders. Meanwhile, there was a general mistrust of Western medicine in managing chronic illnesses. People were superstitious with rumours of adverse effects from Western drugs. Seeing little noticeable benefits or amelioration, people seemed to consider the chemical compounds in Western remedies poisonous which would more likely kill a patient. Therefore, for illnesses without a specific cause, people preferred seeking Chinese medicine, trusting its substance of natural properties. After all, they thought that Chinese medicine was mostly comprised of essences of herbs, barks and roots. Funnily enough, though, by then, Chinese medicine doctors had begun to consult the scientific approaches, technologies and conveniences of Western medicine, particularly in taking references from blood test results which weren't part of the Chinese medical tradition at all. My old doctor was in his 80s, his white hair shining with a metallic sheen. Barring the fact that I had no viral hepatitis, he kept shaking his head and mumbling in complete bewilderment, "...nor B, nor C."

What were they going to do with me!

It was not until I left primary school at the age of 12 that my jaundice and even more elevated AST and ALT levels were brought to my parents' attention. I remember the day when I was rushed to A & E at a Western medicine hospital. When we left home, the sky was a slate grey and the sunset was amber in colour. A few days before that, I had discovered unbroken bright blue-green rings in my eyes. Looking in the mirror, I was surprised with my discovery. Were they always there? I didn't know. No one else took any notice, either. After administering an agonising gastroscopy, my paediatrician pronounced it liver cancer in my father's and my presence. My father asked him how long I would live. The doctor said, three months at most. While my father's tears went pelting down like the sky that opened, I had a feeling that I would survive.

A week later I was transferred to a private teaching children's hospital. After seeing an oncologist and having all the necessary tests done, my new paediatrician told my worried parents that it was *Wilson's disease*. It seemed a fancy name that finally coined my unknown illness, but the story didn't end there.

Although we did see a nutritionist, my family didn't change our diet at all. In fact, I ate farmed salmon and kale (both with high copper content) the whole time through my admission to the hospital. Like any typical Taiwanese family's diet, ours also contained generous amounts of mushrooms, tofu, soymilk, offal and oysters, which are all high in copper content. It was not until recently that I decided to keep a low copper diet. For almost ten years, I had to take penicillamine. While I was recovering, I was still quite unpopular, bullied by both teachers and students. I wasn't very confident with myself, and quite often, I couldn't conceal my anger. When I could, I became passive and I hid from people. I had a nervous breakdown in university and was introduced to Zinc for the first time. However, since Zinc didn't seem to work efficiently for me, I was in turn introduced to trientine. Possibly because of a lot of unresolved psychological wounds, I had difficulties at work and at home. That made it even harder for me to get used to trientine at the time. For almost six years, I was tossed around trientine, penicillamine and zinc. At work, I lacked proper people skills, and at home, my family were very disappointed with me. Worst of all, I couldn't have an effective communication with my then doctor. Sadly, I was too young and naïve to pursue second opinions.

It was not until my visit to England in 2013 and meeting Dr Gillett in Sheffield that I began to have a better understanding of Wilson's disease. I joined the Wilson's Disease Support Group - UK and attended their meeting in Cambridge in summer 2014. It was my positive experience in the UK that helped me commence a long journey towards building up my confidence and making peace with my past. I tried to communicate with my family and make them understand the difficulties I had been facing in life, which wasn't easy. A patient's illness could have just as grave an effect on the family. However, patience and appreciation are halfway to acceptance. In May 2015, I had an MRI scan on my head and no visible copper deposits were found. My eyes have also been clear of copper sediments for a few years now. As of January 2016, I've been on trientine. I feel very grateful for everything. Life is often sad, but there are happy moments. Happy memories are more fragile than sad ones, so it is up to the individual to cherish happy experiences, and the instrument is love. My experiences have made me more appreciative of the world around me, and I am able to do a little bit of story writing. Whilst English is not my native language, I am having a go at writing fiction in English. Looking back on my life, I think I have been used to taking up challenges. Therefore, I am looking into my future with confidence.

The most important thing I have learned from Wilson's disease is that illnesses or sufferings do not make anybody different. The truth is that everyone *is* special.

The stunning sunrise of Taipei City symbolises Taiwan's industrial strength. Taipei 101 is the tallest building inTaiwan standing at 1,670 ft tall, exactly 666 ft taller than The Shard.

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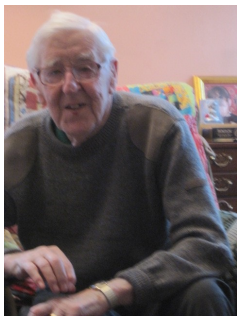

Our President **Dr John Walshe** follows the Group's activities closely and is always willing to offer medical advice, when requested. Having devoted his professional life to the treatment and management of over three hundred Wilson's disease patients worldwide, he has a wealth of experience from which to draw. He will be ninety-six at the end of April and is hoping to join us at our meeting on **Sunday, 24 July**.

On Bonfire Night last year he had a bit of a shock! He received a letter from the *GMC* (*General Medical Council*) revoking his licence after sixty-five years, which meant that he could no longer write his own prescriptions. He was paying around £480 p.a. for his licence and was comforted only by the fact that he would be saving himself a lot of money in the future, his prescription costs currently costing him around £240 each!

Well Dressing

He continues to enjoy the surroundings of his beautiful home and garden in Hemingford Grey and to take short breaks with the family in the UK. Last year his daughter Susan and her husband, Phil, took him on holiday to the Derbyshire village of Tideswell in the Peak District. Tideswell is well known for its annual Well Dressings in the summer and also boasts a magnificent 14th century church which is known as the *Cathedral of the Peak*. Well dressings almost certainly date back to Pagan times, when sacrifices were made to water gods to ensure an endless supply of water, but nowadays generally have a religious theme with pictures made from flowers, leaves and a variety of natural objects, inserted into a panel of clay.

Dr Walshe inspecting the copper composition of the reclining bronze figure

I live fifteen miles away from Dr Walshe and so from time to time I offer to take him out for the day to different places in and around the region. Our first such outing at the end of July was to the studio and gardens of the Henry Moore Foundation in the small village of Perry Green in Hertfordshire. It was his first visit there and he much enjoyed the freedom of touring round the grounds on a nifty mobility scooter, from which he was able to admire and touch the monumental sculptures that he passed along the way. Susan accompanied us on this occasion and after enjoying a hearty pub lunch together, we set off home indulging in a little antique shopping on the way.

The Church on the Sandringham estate

Our second trip took us to Norfolk on a sunny September day to visit the Queen's country estate at Sandringham. This was my first experience of pushing a wheelchair and it wasn't long before I was having an embarrassing altercation with a kerb. In so doing, I quickly learnt the art of catapulting Dr Walshe several feet into the air before catching him again! With no permanent damage done, the day continued in a more demure fashion with a stroll through the Queen's apartments, an inspection of the highly ornate and glittering interior of the much televised Sandringham church and a trip to the nearby seaside town of Hunstanton, where we briefly stopped to dip our toes in the icy waters of *The Wash*.

Outside the Operational Headquarters at Bletchley Park

And most recently, we ventured to Bletchley Park near Milton Keynes, the secret headquarters of British Intelligence during World War II, where the country's best mathematicians and cryptic crossword solvers came together to break the ciphers and codes of the enemy. The most famous of these ciphers and codes were those generated by the German *Enigma* and *Lorenz* machines. We were told on our guided tour that by the end of the War there were just under **10,000** people working at Bletchley Park, all of whom had signed The Official Secrets Act which meant that they remained under its blanket obligation of silence even after they left. That said, it is still astonishing that it wasn't until nearly forty years later that the rest of the world knew anything about its wartime significance.

And if Dr Walshe had once worked there himself, he was certainly *keeping mum*!

Lenka Jonasova from Edinburgh, whose story appeared in our 2015 newsletter, writes to say that her Wilson's disease which was diagnosed in 1995 continues to be well managed, but unfortunately she is still suffering from a mystery muscle condition that struck her in 2011 and has left her feeling weak ever since. Referred to as a "myopathy," she is hoping to get some answers from a specialist in rare genetic muscle conditions, whom she is seeing for the first time in Newcastle next week. At home she is receiving physiotherapy and occupational therapy, while still working 18 hours a week. She does her best not to get overtired as it makes the muscle spasms worse. Her young son, Jamie, has started school this year and is doing very well. They hope to join us at the meeting in Cambridge later in the year.

* * * * *

For most of you Linda Hart will need no introduction at all. She co-founded the Group with Caroline Simms in 2000 and has been the linchpin of it ever since. Here she brings us up to date with her latest antics:

In the Spring of 2014, I felt that I needed to do something new! My life had changed drastically within the last few months and I suppose I was feeling rather *fish out of water-ish*. I'd noticed an advertisement from an old acquaintance saying that she was starting a drumming group in Swadlincote, Derbyshire, for anyone who'd like to learn to play *djembe*, the *djembe* being a rope tuned, skin covered goblet drum played with bare hands, originally from West Africa.

At the Gladefest, Rosliston 2014

As drumming is said to relieve stress and enhance feelings of wellbeing, I decided to give it a shot: possibly a touch of March madness! Anyway, I went along to the first session. I've always loved music, but have been incapable of learning to play anything with any degree of aptitude! And believe me, I have tried with a succession of various instruments.

I'm happy to say I got along a little better with the *djembe*: I loved the first session and have continued to attend twice a month since. It has proved very popular with others too so that there are around 25-30 of us meeting regularly. It certainly is true that drumming does increase feelings of wellbeing and helps with positivity, and I think that the act of simply sitting in a circle with like minded people making music encourages a feeling of camaraderie and jollity.


Swadlincote Festival of Leisure 2015

Originally it was all very low key, but then Nikki our teacher made plans for bigger things! Calling ourselves the South Derbyshire Community Drummers (www.tribalvibes.net), we were invited in the first year to play at two local festivals. Such was our success that we played the following year at another two festivals and also at the two day *Rockstock & Barrel Festival* in the nearby village of Willington. People seem to love us. There's something about drumming that draws people of all ages in, from children to senior citizens. They come over and listen and then start to dance and generally join in. It's so lovely to see and be a part of, and everyone seems to leave smiling.

Then last September we were told about Taiko drumming! Nikki was trying to arrange a monthly session in Derbyshire with a world class teacher and being a born again drummer, I signed up immediately (www.tailkowest.com.) and WOW! It's a completely different kettle of fish! Taiko is an ancient Japanese form of percussion using large drums. The drums range in size from the smallest – a *shime* (like a snare drum), to drums as large as a car – the *o-daiko*. The most common drum size is the *chu-daiko* which is the size of a wine barrel. I've been to three or four sessions now and it's certainly challenging, but huge fun.


Practising Taiko 2016

On the whole I'm so glad I had that touch of March madness two years ago! I've met some wonderful new friends, had some lovely happy and memorable times and to my utter surprise, I've found I'm a natural at *banging my own drum*!

Ashok Pandit, a Wilson's patient from Kathmandu in Nepal, whose story featured in the 2012 newsletter and whose contributions to our Fb site and newsletter are always widely appreciated, writes about the troubles of 2015, which started with an earthquake that hit Nepal killing over 9,000 people:

25th April 2015, the date everyone is aware of. It was summer but weather was chilly and every Nepali was busy in regular activities unaware of upcoming catastrophy. The astrologist's casting for the year was ready to be true (i.e. the year is not good for Nepal, every Nepali going to face lot of problems.) The devastating quake of 7.9 on Richter scale hit Nepal. Well everyone's misfortune began with the hit. Problems as predicted by astrologist knocked on the door of every Nepalese.

Talking about me, I stood on my bed thinking that this is end of everything, and prepared myself to face it. But I was still there and life has to continue even after the moment. The shake stopped and I came out of house and went to an open place. The people of our place along with me are fortunate that no casualty has happened in our area but we all were put to dreadful situation for a month due to aftershocks and another earthquake on 12 May.

Well the experience was pretty dreadful yet fascinating, running to reserve a bed for the night and sleeping with all the other villagers until we had our own tent. We all feared to go inside our houses as the earth was shaking every minute and made us feel unsafe, so we were out of access of televisions and in addition I couldn't be in contact with anyone for 11 days, which reminds me how life was before 1990 when there was no internet.

My house before the earthquake

Well finally one month of staying out came to an end. We have renovated our house and made it one storey. But we were unaware about upcoming vulnerabilities of embargo created by India. The Nepal government was drafting new constitution when quake hit. But leaders from southern districts of Terai went against it, stating the new constitution doesn't include them and take their interest into consideration. Well we all knew Terai leaders could never hold their agitation without support from India. We also believed government of Nepal was weak and seemed to be puppet of Indian government.

Structural damage due to the earthquake

So Nepal, which has been recently devastated by quake, was now going through another hardship caused by undeclared embargo by India. We all were out of supply of foods, cooking gas, fuel etc. and hospitals were out of stock of medicine. I got problem with penicillamine but I managed to get it from local market. We however managed to live our life, as we were grateful we haven't lost anything due to quake. But still we have been forced to pay higher prices for cooking oil and vegetables and black market has increased.

The government in order to control it turned deaf ears to everything. India was busy creating false rumours around the globe about Nepal and our Constitution and the leaders of Nepal did nothing. When the new Constitution was promulgated and a new government was formed, people had hope that soon hardship would come to an end.

Renovated house now one storey lower

I am writing this article on 10th of February and good news is that embargo ended few days ago, 10 months after quake hit Nepal. But the life of victim of quake has been worse than hell. This year Kathmandu faced minimum temperature of ever and so did other places in Nepal. Because of embargo, rehabilitation of victims of quake couldn't be carried on smoothly and in addition nature presented its cruelty to optimum level to people this year.

One thing is sure, the astrologists were right!

WDSG-UK 2016 EVENTS

Date	Time	Event
Thursday April 28	**2000 - 2100**	***Medical Mysteries*** - Channel 5 - Featuring Alicia Goss and Dr Godfrey Gillett
Saturday Jun 11	**0900 - 1830**	**Morbus Wilson e.V.** Annual Symposium - University of **Heidelberg,** Germany
Sunday July 24	**1100 - 1530**	**WDSG-UK Meeting and 6th AGM** – Cambridge Rugby Union Football Club Grantchester Road **Cambridge** CB3 9ED.
Saturday August 27	**1000 - 1200**	Sylvia Penny warmly invites you to **a Coffee Morning, Bring and Buy and Raffle** in aid of **WDSG-UK** at Victoria Park Methodist Church, St Marychurch Road, Claymore, **Torquay.**

WILSON'S DISEASE MULTIDISCIPLINARY CLINICS

The Birmingham WD Clinic

Dr Gideon Hirschfield (Consultant Hepatologist) and **Dr David Nicholl** (Consultant Neurologist) hold a one-stop Wilson's disease clinic at **University Hospital Birmingham** on a Friday morning four times a year. This clinic offers patients the opportunity to have their management reviewed by a hepatologist and a neurologist at the same time and is intended to supplement otherwise established care. Referrals must come from the clinician looking after the patient and should be addressed to *Dr Hirschfield* at *Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston, Birmingham, B15 2WB.*

The Sheffield WD Clinic

The Sheffield clinic is jointly run by **Prof Oliver Bandmann** (Consultant Neurologist), **Dr Mohammed Karajeh** (Consultant Hepatologist) and **Dr Godfrey Gillett** (Consultant in Clinical Biochemistry, Inherited Metabolic Disease, and adviser to WDSG-UK). Clinics take place every six months at the **Royal Hallamshire Hospital, Sheffield** on a Tuesday morning. Patients may be seen in interim clinics by arrangement. Referrals should be addressed to *Prof Oliver Bandmann, Department of Neurology, Royal Hallamshire Hospital, Glossop Road, Sheffield, South Yorkshire S10 2JF*. Either GPs or hospital specialists may refer to this Sheffield WD clinic.

IN MEMORIAM

It was with great shock and sadness that we learnt that Jon Anthony Tarbin had died on 29 March 2015 aged thirty-one. He and his parents had been stalwart members of the Group attending our annual meetings every year. He will be sadly missed. Linda and Valerie attended his funeral service at St John's The Evangelist, Gravesend and we thank his parents, Brian and Cynthia, for holding a collection for *WDSG-UK* in his memory, which raised the very generous sum of **£1,160** for the Group.

* * * * *

We were also deeply saddened later in the year to hear that Charlie Watsham (Charlotte Elizabeth) had died on her 28th birthday, 11 August 2015, just a month after attending our meeting in Cambridge with her mum, Shirley. Charlie was diagnosed with Wilson's disease when she was 13 and over the years had three liver transplants, all of which unfortunately eventually failed. She bore her illness with tremendous courage and will be sadly missed. Jerry, Linda and Valerie attended her funeral at St. Chad's Church, Lichfield and the Group made a £75 donation in her memory to her chosen charity, the *QEHB*.

Wilson's

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Dr Godfrey Gillett Group Adviser, Honorary Member
Dr James Dooley Group Adviser, Honorary Member
Dr Caroline Simms Group Co-Founder

WDSG-UK

Tell others about WDSG-UK

Please encourage anybody else that you know with Wilson's disease to join **WDSG-UK**

Inform your family, friends, consultant physicians, general practitioners and local MPs about the work of **WDSG-UK.**

The more people who know about **WDSG-UK**, 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