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

NEWSLETTER

#wdsguk JUNE 2020

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

RARE DISEASE UK

Children's Liver Disease Foundation fighting childhood liver disease

Climb Children Living with Inherited Metabolic Diseases

Happy 100th Birthday, Dr Walshe

Hello Everybody! The best laid plans and all that! On 24 April 2020, **Dr John Walshe**, our President, reached his 100th birthday. It had been our intention as a Group to mark the occasion with a birthday celebration at the beginning of May (combined with our AGM) and to delay issuing this year's newsletter until after the event so that those that couldn't attend would be able to read all about it. But as with so many other plans, coronavirus put a stop to that and the party has had to be postponed. However, the day was not entirely overlooked. Dr Walshe's daughter Sue and son-in-law Phil, with whom he lives, made the day special, the Queen remembered (and sent a card ⟶) and we presented him with a commemorative book filled with your messages and with messages from patients across the world.

So here is the newsletter—at last! As well as Dr Walshe's special birthday, WDSG-UK this year celebrates 20 years since **Caroline** and **Linda** founded the Group. In 2010 the Group attained charitable status and a committee was formed. **Jerry Tucker** joined the committee from the beginning, but sadly stepped down last summer. We were very sorry to lose him as he has worked tirelessly for the Group and been deeply committed to improving all aspects of healthcare for patients. In his place as chair, I am delighted to welcome **Graeme Alexander**, a retired hepatology professor from Addenbrooke's Hospital in Cambridge, who introduces himself overleaf and explains his interest in WD.

Thank you to **Dr Godfrey Gillett** who continues to work closely with the Group and supports us in any way he can and to **Dr Bill Griffiths** who heads the BASL WDSIG, an initiative which was started by Graeme to pool WD expertise and to standardise treatment for patients. Thank you also to **Dr Jake Mann** who gave us a talk at our meeting last year about estimating the prevalence of WD using genetics and who now summarises it here in the newsletter.

Our patients continue to supply us with their varied stories of diagnosis and this year we thank **David, Katie, Laura** and **Ambuja** for sharing them with us. We are reminded of the importance of having our children tested (and sometimes retested), how difficult a Wilson's diagnosis continues to be and how handy it is to have a doctor in the family! In addition to these stories, may I thank all patients who responded to my call for news during the Covid-19 lockdown.

And the Group couldn't continue without the generosity of our fundraisers, who this year include **Rushden & Diamonds** again**, Gemma Anderson, Sam Panchal** and **Lyndsay Kelly** and our patient donor **Giuseppe Cardone.** Their income helps us meet our everyday expenses and also allows us to fund research projects across the country. We are always looking for new ways of fundraising and are sorry that the two people destined to run on our behalf in this year's London marathon have had to put their plans on hold.

Please don't forget to keep up to date with our Facebook page, through which we are able to deal quickly with your queries, such as difficulty accessing your meds. We now have 1000 members worldwide and your shared experiences and advice to others are always well received.

Please renew your subscriptions promptly as these are already late. Details of our AGM are outlined on p3 and as soon as an alternative date for Dr Walshe's party is fixed , you will be the first to know!

Valerie

IN THIS ISSUE ...

Chairman's Report for 2019-20

It was a surprise to be approached to take on the role of Chair of the WDSG-UK, but it was also impossible to refuse such a request, particularly coming from a friend I have known so well for nigh on 30 years; I hope I can repay Valerie's confidence. I stepped back from clinical work in 2017 after 41 years in the NHS, almost all of that time spent pursuing my interest in liver disease as a clinical academic, first in the Liver Unit at King's College Hospital, London and then from 1991 at Addenbrooke's Hospital in Cambridge. I have been fortunate to be allowed to pursue some 'loose ends' on the research side on my third liver unit at the Royal Free Hospital, London on a part time basis, a unit that has a very strong clinical association with Wilson's disease. The long-term (and now imminent) plan is to move to our home yards from the sea in the Scottish Highlands.

2020 will eventually become a memory for all of us, but a strong one. Covid-19 has played havoc with all our personal hopes and plans and will leave far too many with profound regret. There have been no *direct* links between the virus and Wilson's disease. However, patients with cirrhosis, especially those hospitalised with advanced liver disease in the UK, may have a higher mortality than otherwise would have been expected. As the newsletter goes to press, shielding for patients with cirrhosis in the UK has been withdrawn (by text message) and that may have unfortunate consequences for those patients who had until now been under a degree of protection.

Unfortunately, Covid-19 also prevented the group celebrating John Walshe's 100th birthday in a manner that a physician who has made such an enormous contribution to managing Wilson's disease in the UK and worldwide, merited. Valerie presented Dr Walshe with a bound volume containing birthday messages from patients and families across the globe on 'the day' and I was pleased to see that the British Association for the Study of Liver Disease (BASL) as well as the British Liver Trust (BLT) also celebrated the event.

With a physician's focus, I consider the BASL Wilson's disease Special Interest Group (WD-SIG) an important step forward. For the first time in the UK physicians with an interest in Wilson's disease across *all* specialities and including patients are meeting regularly to share experience and to plan for a more rational approach to clinical care in specialist clinics that will circumvent geographic variation in the quality of care. With a little push on the political side we may be able to establish these long term within NHS specialist services. Speaking with one voice helps the NHS to set appropriate standards for clinical practice and strengthens discussions with the Pharmaceutical industry over matters such as cost and availability. Too many patients will be familiar with these latter issues, especially in the past 18 months. In a rare condition a strong national group has an enormous advantage in research, already an important component of the WD-SIG. For me it was wonderful hearing recognised experts in the field *learning* from each other. We are already linked in with NCARDRS, the national registry for rare diseases in England with strong links to similar programmes in Scotland, Wales and Northern Ireland. This means that data are already being generated from hospitals, clinicians and *patients* that will highlight strengths and weaknesses in the care of patients with Wilson's disease and allow us to focus on the weak spots.

The group continues to contribute expertise and money to important research; these are detailed elsewhere in the newsletter. As someone involved actively in clinical research, I am all too aware that getting new ideas off the ground can be very difficult without access to charitable funds; getting early data as proof of concept allows you to apply for more conventional funds, so speaking on behalf of all recipients of your donations over many years – an enormous thank you.

Two people deserve particular mention. First, Valerie Wheater, whose enthusiasm drives the group and who puts the annual newsletter together (this is no easy task) and who takes the bulk of external enquiries on behalf of the group. I have felt compelled to (try to) complete each of her 'Dingbats' that accompany the annual newsletter. Did anyone *really* manage to get 'Moldova' last year??

Second Jerry Tucker who has a long association with the group. He was Vice-chair of the group between 2010 and 2017 and then took on the chair's role from 2017 until he stepped down at the end of 2019. We can only hope that Jerry continues to take an active interest in the support group. Unless you have volunteered to help run a support group you can have no idea just how much time needs to be sacrificed to do the job properly. On behalf of the group our grateful thanks to Jerry for his invaluable contributions over the past decade.

Graeme Alexander
May 2020

Donations and Fundraising

We rely exclusively on our members and their families and friends for our income. We should therefore like to thank all of you who made generous donations with your subscriptions last year. In addition, we should like to thank **Giuseppe Cardone** who, together with a group of fellow Google employees, raised a further **£600** for us via Google.org support for non-profits. We also very much appreciate the **£60.00 Joan Smith** donated by hiring out the front drive of her old house in Southend to a holidaymaker needing off street parking and to the **Joseph** family who gave us **£100** to mark Anusha's **40th** birthday.

We thank our fundraisers AFC Rushden & Diamonds, Lyndsay Kelly, Gemma Anderson, Samantha Panchal, Chris Billinghurst, Seb Novell and Valerie who have brought in an additional combined income of **£2,300.** Their enterprising pursuits are detailed on *pp6-7*. When sponsorship is collected online through ***Virgin Money Giving,*** donors can choose to gift aid their monies, which this year have generated an extra **£160.** Any donations to us, of course, can be gift aided. Forms are available from **Valerie** direct or off our website www.wilsonsdisease.org.uk.

Genetic Alliance and Rare Disease UK

Rupert Purchase has kindly volunteered to take over from Jerry Tucker and represent WDSG-UK at Rare Disease UK and Genetic Alliance–UK meetings. He attended their AGM on 15 October 2019 and reported:

- the 100,000 genome project will continue to be developed to assist in diagnosis and personalised medicine;
- A national conversation (a survey) on rare diseases was launched in October 2019. (A link to it was posted on the WDSG-UK Facebook page shortly after).
- The NIHR BioResource—Rare Diseases has been established to identify genetic causes of rare diseases (https://bioresource.nihr.ac.uk/rare-diseases). Funding for new drugs is a priority.
- Genetic Alliance UK recommended NICE adopt a single approach about rare disease patients accessing medicines and called for the government to explain the process for setting medicine prices for such patients.

NHSBT Organ Donation & Transplantation Directorate (ODT), the Liver Patient Group (LPG) and the Liver Patients' Transplant Consortium (LPTC)

Valerie attended the 10th meeting of the LPG and ODT in London on 17 July. It was reported that the number of organ transplants had increased to around 1600 in the past year and the average waiting time for elective transplants was 99 days for adults. New techniques of keeping the liver viable are working well with Cambridge and Edinburgh leading on machine perfusion For further more detailed information of NHSBT's work, please visit https://www.odt.nhs.uk

This year England has followed Wales by introducing a 'deemed consent/opt-out system' for organ donation meaning that unless you specifically register your wish not to donate your organs, it will be tacitly accepted that you have given your consent.

Drug Trials—Alexion/Medicys Ltd

We were asked by a medical market research company to find 8 patients willing to be interviewed by telephone about their experience of living with Wilson's disease, which we did and each patient received an honorarium for their trouble. If this is something that might appeal to you, please let Valerie know.

Wilson's Disease—HK

Sam Ho, who co-founded the Hong Kong Wilson's Disease Support Group has been studying in Manchester over the past year and is keen to forge links with patients in the UK. He and Valerie had an introductory meeting in November.

WDSG-UK Management Committee Meetings

During 2019-20 the WDSG-UK management committee met three times in May, October and February. Our annual Support Group Meeting and 9th AGM was held in Cambridge in July 2019 (please see report overleaf).

WDSG-UK 10th Annual General Meeting

The 10th AGM was to be held immediately before Dr Walshe's planned birthday party at the beginning of May. It is now our intention to delay this until July. Because of current uncertainties due to Covid-19, we have decided to hold a virtual AGM on **Sunday, 26 July** at **1100** a.m. This will be held via ZOOM and details will be sent to members beforehand. However, enclosed with the newsletter is a formal notification of the meeting, a copy of the final accounts for 2019-20 (that have now been audited) and an invitation for you to submit any questions you may have in advance. Election of officers and members of the WDSG-UK Management Committee for 2020-21 will take place then. All members of the current committee, **Mary Fortune, Liz Wood, Caroline Simms** and **Valerie Wheater,** who I thank for their commitment this year, have submitted their names for re-election for the coming year.

Next WDSG-UK Meeting

WDSG-UK has no plans to host a social gathering until we are sure that Covid-19 no longer poses a risk to our patients. Details of any future meetings will be sent to you immediately we have them.

Wilson's Disease Support Group Meeting & 9th AGM

Sunday 21 July 2019

WDSG-UK's 2019 annual gathering and 9th AGM took place in the *Turnstone Suite* of the Cambridge Rugby Union Football Club on Sunday, 21 July. After meeting here for the past 12 out of the WDSG-UK's 19 year history, with its easy access to the M11, ample free parking and disabled facilities, it is now considered to be our favoured venue! There was an excellent turn out again with patients, their families and friends and representatives from the medical profession and Public Health England (PHE) in attendance.

View from The Turnstone Suite towards Cambridge

We were delighted to welcome our regular members together with some new faces including those of **Ashley, David, Peter, Sheina** and **Ursula**. We were also delighted to welcome **Dr John Walshe,** our President and World Authority on Wilson's disease, **James Kinnier Wilson**, who lives locally and is the son of Samuel Kinnier Wilson who first documented Wilson's disease in 1912, **Dr Godfrey Gillett,** who succeeded Dr Walshe and who has been a staunch supporter and adviser to the Group since it was formed in 2000, **Dr Bill Griffiths**, a consultant hepatologist from Addenbrooke's, **Dr Sam Shribman** a neurologist from University College Hospitals London and **Maggie Burrows**, his assistant in the CROWD Study, **Jeanette Aston** from Public Health England (PHE), **Simone Hermans** from Univar and our speaker for the day, **Dr Jake Mann**.

Dr Jake Mann

For those who have never attended an annual meeting, the programme for the day is balanced. Refreshments are served on arrival, while people get their bearings, choose where to base themselves for the day and then catch up with friends old and new. At noon, the chairman opens the meeting with a formal welcome and gives a short resumé of the committee's achievements over the past year. He then hands over to the speaker, who this year was Dr Jake Mann from the Genetics Department of Cambridge University, who spoke to us about a Study he had been part of in which the prevalence of Wilson's disease was estimated using a large genetic database of healthy volunteers (see ***p10***).

Sam, Maggie and Godfrey

Attendees

We had an update from Sam Shribman on how the CROWD Study was going (see *p14*). Many current members of the Group are involved in it and the Group has given a grant of £5,000 towards accommodation and travel expenses of patients taking part. Jeanette Aston reported on the progress of the National Congenital Anomaly and Rare Disease Registration Service's (NCARDRS) Pilot Study which is setting out to establish the number of people in England living with Wilson's disease (see *p15*). The ultimate goal of the Pilot Study is to help improve overall care for patients.

In-house caterers provided a delicious buffet luncheon, throughout which our new patient committee member, **Liz Wood**, continued the selling of raffle tickets for the draw. The draw took place later in the day and raised an astounding **£200** for the Group. Thank you to everybody who donated prizes and bought tickets and thanks to Liz and her husband for running the event!

The AGM, which our constitution requires us to hold each year, took place immediately after lunch. **Jerry Tucker**, our chair, enthused about the aims of the recently convened WD Special Interest Group (SIG) run by the British Association for the Study of the Liver (BASL) which is bringing all medical specialities with an interest in WD together under one roof. Sadly, Jerry, who has been on our committee since it was formed in 2010, first as its vice-chair and most recently as its chair, has now stood down. He was presented with a book token by fellow committee member, **Mary Fortune**. We should formally like to thank Jerry through this column for his tireless hard work and dedication to the WDSG-UK cause. His contribution has been enormous and he will certainly be sadly missed.

Finally, our thanks go to **Anusha Joseph** who once again was our official photographer for the day, a selection of her outstanding photographs appearing here and on the WDSG-UK Facebook page. The date for our next meeting is yet to be announced due to the uncertainties that Covid-19 presents.

Carlie, Anusha and Katie

James Kinnier Wilson—praising Sam!

Denise, Emma and Lesley collecting their raffle prizes

The Group Photograph: Dr John Walshe standing (front row) with many former patients *Anusha Joseph*

Fundraising 2019-20

Valerie

AFC Rushden & Diamonds Football Club —Youth Section

For the third consecutive season, AFC Rushden & Diamonds Youth Section, chaired by **Mark Cullen,** has kindly raised funds for WDSG-UK. **Sam Fitzgerald**, a Wilson's disease patient, was an outstanding junior player at the Club before Wilson's disease took its toll on him in 2015. The Club has supported Sam and his family ever since. The season culminates in the very popular Ladies' Football match, which took place last year on Sunday, 18th May 2019. Because of the uncharacteristically warm weather on the day, a record crowd turned out to watch the "*Red Super **Sharp** Shooters*" gain victory over their "***Stephen's** Blue Hat-trick Swayze*" rivals! To mark the annual event, the Club has commissioned a silver cup which will be presented to the winners each year. We were thrilled that they have named the cup "*The Wilson's Cup*". After the match, **Tracy Stephen,** head of fundraising, kindly presented WDSG-UK with a cheque for **£500,** which Valerie happily accepted. We thank everybody involved - the players, supporters, organisers and sponsors—for their overwhelming generosity and we wish all sections of the Club great success in the future.

The newly commissioned "Wilson's Cup" competed for by the Ladies!

The Burravoe Carnival—Island of Yell—June '19

Gemma Anderson and friends took part in the Barravoe Carnival in June 2019. She writes, "Every year the Burravoe Carnival takes place on the island of Yell, the second most northerly island in Shetland. It is run by the local community and the first, second and third prize floats get a cash donation to give to a charity of their choice.

Gemma, the yellow-haired Smurfette (back left) with friends and family on the float

Laura (whose story appears on pages 12-13 of the newsletter) and I are both primary school teachers and when I moved to the village where she lives, we became close friends. We are very similar in looks and people often used to mistake us for one another! We have been members of the same float since the very first carnival, 10 years ago, during which time we have dressed up as rock stars, and characters from Indiana Jones, Star Wars and the Flintstones! It's always good fun and this year we were Smurfs! Unfortunately, Laura was in hospital at the time of the Carnival, so we had to go ahead without her. We won third prize and thought it only fitting to donate our **£25** winnings to your charity, which we know is supporting Laura through her illness."

Samantha's Sale of WD Wristbands

Samantha Ryan Panchal had the idea in June 2017 to commission and sell blue silicon wristbands raising awareness of Wilson's disease and raising funds for the Group. Sam's own brother, **Ben,** has been badly affected by neuro Wilson's disease since his diagnosis in August 2016 when he was 28 years old. He has been hospitalised since December 2016 and is currently being cared for in a Leonard Cheshire Home in Garstang, Lancashire.

While most of her friends have already bought wristbands, she still managed to credit Group funds with a further **£100** this year, taking the total raised so far to **£850.** Many thanks to Sam for her tireless work and to everybody who supports her. If any members of the Group would like to make a purchase, please get in touch with Valerie.

Lyndsay Kelly and Maria's Ben Nevis Ascent

Lyndsay and her mum, Maria at the summit of Ben Nevis on 8 August 2019

Lyndsay works and has become close friends with Lynn Martin, whose 26 year old son, Jonathan, was diagnosed with Wilson's disease eleven years ago. It has taken its toll on the whole family and Lyndsay felt that she wanted to do something to help. As she had never heard of Wilson's disease before, she thought it would be a good idea to raise its profile among the wider community by choosing a challenge for which she could get sponsored. After much thought, she decided she would attempt to climb Ben Nevis. There were organised events with guides which were quite costly to join, so as a former soldier she decided that she would do it by herself. Her mother, however, decided it was too dangerous to do alone and insisted on doing it with her!

What an achievement! Lyndsay holding a certificate to prove she did it!

Lyndsay says, "We set off from Gateshead on Friday, 8th August and after a five and a half hour drive arrived at our accommodation in the *Sheradon Studios* in Fort William. The following morning, we set off early to take the ten minute drive to the base of Ben Nevis. We started the ascent at 7.30am—just me and my mam. I was in the army when I was 16 years old so I made sure that we were fully prepared. The weather was forecast to change, but in fact remained absolutely boiling hot throughout.

Ben Nevis is the highest mountain in Britain and it was a constant, rough climb over rocks and rock pools all the way up. The views, however, were gorgeous and it was an amazing feeling when we actually reached the top. The decline was even tougher and was very scary! Mam lost her footing and fell three times, the first time being the worst when she hurt her wrist quite badly. I slipped numerous times, too, and ended up with bruised toes. Some of the people who we had overtaken on the way up still hadn't reached the summit as we were coming back down! In total it was a 10 mile round trip and took us 6 hrs 20 mins to complete."

Together Lyndsay and Maria raised a staggering **£641.61** for the Group through Virgin Money Giving and we should like to thank them for taking on the challenge and choosing to raise funds for us. We should also like to thank all of their supporters for their very generous sponsorship.

Valerie's Demon Dingbats

Dr Walshe drawing the Winning 2019 Entry

For the fourth year in a row, Valerie dreamt up some more Dingbats to tax members of the Group (free with their newsletter) and also the wider community around where she lives (who paid **£2** per copy). The theme for 2019 was *Countries of the World* and more participants competed than ever before. Out of the 250 copies distributed, 43 were returned for marking. Of those there were 5 all correct answer sheets including that belonging to Liz Wood (who incidentally found **blom** one of the easiest clues!)

The all correct answer sheets were placed in a hat and during one of my lunches with Dr Walshe in his local community café, he drew the winning entry. It belonged to the Catton Family of Cherry Hinton, Cambridge, who received a cash prize of **£25.00.**

Thank you to everybody who took part. The total raised was a very respectable **£450.** For those of you who are still waiting for the answers, these are available on our website www.wilsonsdisease.org.uk. I had planned to take a year off, but with all this time on my hands during lockdown, I have managed to produce another one. It is themed *Capital Cities of the World:* I hope you enjoy solving it.

A Brother's Legacy

by David Chiswell

Mark, David and Paul Xmas 1968

We had just celebrated our 6th birthdays, school had broken up and we had set off on our summer holiday to Margate with our parents and older brother, **Mark**. Shortly after arriving there, Mark had become seriously ill and mum's sister, Auntie Edna, was summoned to take Paul and me back home to Leicester. Mark was 9 at the time and had been rushed to Great Ormond Street Hospital (GOSH). It was July 1969. We never saw him again.

By 1973, when I was also 9, I became violently ill one Sunday night. I was sick and had a crashing migraine. This became a regular occurrence, mostly on Sunday nights, and the doctor suggested it was probably to do with school the following morning. It seemed strange to my mother because I loved school whereas Paul, my identical twin, who showed no signs of illness, didn't like it at all! Getting nowhere with the GP and having lost one son already, my mother contacted Dr Young, a consultant paediatrician at the Leicester Royal Infirmary and pleaded with him to see me straight away.

Dr Young agreed and I was taken into hospital one Monday morning. Mark had died from "jaundice" and Dr Young suspected there was something wrong with my liver, too. Various blood tests were done, X-rays were taken and a barium meal given. I also had a liver biopsy. While my mother was sitting in the waiting room one day, she picked up a copy of the *Readers Digest* in which there was an article called "A Brother's Legacy" all about a rare liver condition called Wilson's disease. She mentioned it to Dr Young, who knowing of only one specialist in the condition at that time, picked up the phone and rang Addenbrooke's Hospital in Cambridge. I was later discharged to await the next stage of my journey.

It came on the Sunday afternoon. Paul and I were bundled into the back of a green van, where we bounced around for two hours, catching glimpses of the passing countryside through the small panes of glass in the rear doors. When we arrived at Addenbrooke's, somewhat confused and exhausted, we were ushered into a side room and rewarded for our good behaviour with a chocolate finger. A tall man in a white overall then peered round the door, introduced himself and proceeded to hold an instrument up to our eyes. He took the chocolate fingers out of our hands and offered us a cup of orange cordial instead. He then put his hand in his pocket, removed some penicillamine, unwrapped it and said, "Take these!" before turning to my mother and saying "You're right: They appear to have Wilson's disease!"

This was our first of many encounters with Dr Walshe. We were admitted to the Children's Ward at Addenbrooke's for two weeks, repeating some of the tests I had had at Leicester and undertaking others. I knew what to expect but Paul didn't and besides as far as he was concerned there was nothing wrong with him! Mum and dad went home, as was customary in those days, and Dr Walshe's assistant, Kay, became our surrogate mother. She thought we were "lovely little boys," but unlike mum could seldom tell us apart! The most exciting part of our annual visits was getting hold of the large syringes after Dr Walshe had taken our blood, and running around the ward using them as water pistols on anybody or anything that moved!

Our appetite for combative behaviour remained with us throughout adolescence and we decided when we left school we'd like to join the Army. However, because of our Wilson's disease, we couldn't, so instead Paul and I joined the Army Cadets for three years in our teens. When we were 21, we returned as adult instructors for a further 36 and 20 years respectively, during which time we also served in the TA; Paul for 7 years in R.E.M.E and I for 4 years in the Parachute Regiment.

We have remained on penicillamine ever since. After our diagnosis, our mother wouldn't rest until Mark's death certificate was altered to reflect the true cause of his death. This she eventually achieved and her mind was put to rest.

Katie's Story

by Katie Dale

Katie today

I am David's daughter, Katie. In 1996, when I was 8, dad was contacted by Genetics at Leicester Royal Infirmary asking him if he wanted his children to take part in a genetics study they were doing into Wilson's disease. Happy to oblige, dad took my older sister, Carlie, and me to the hospital to get tested. The results came back that we each had one faulty ATP7B gene, which as dad has Wilson's disease, was no surprise at all!

I'd always been in excellent health. As a child, I was very active. I loved playing outdoors and at school I was a promising swimmer and gymnast. I had my first child in 2011 when I was 23 and sailed through my pregnancy without any problems at all. However, four years later I embarked on a second pregnancy and things didn't go quite so well. I was diagnosed with gestational diabetes and was closely monitored after that. The baby was delivered at 40 weeks and all seemed to be well again apart from my iron levels which were low and for which I was given tablets. I had put on a lot of weight during the pregnancy and didn't seem to be losing it afterwards, as I had done in the previous pregnancy. In fact, by the time the baby was nine months old I was heavier than I was at the end of the pregnancy and I noticed that my ankles were ballooning up and down! By March, when the baby was 1, I was completely exhausted and had put on a further 3½ stone, in just a couple of months.

My husband, Peter, came home one Sunday evening and found me very confused. I was lying on the bed and asking him to fetch something from out of the window that was normally kept in a cupboard downstairs! Alarmed to say the least, he called 111 for help. A paramedic arrived first, assessed the situation and called immediately for an ambulance. I was taken to the Leicester Royal, where over the following two days tests including a CT scan were run and a heart monitor was fitted. Nobody knew what was going on until Pete happened to mention to the doctor that my dad had Wilson's disease and asked if my condition might be connected. The doctors immediately contacted dad and asked for his medical history. Dad told them that I had been tested 21 years earlier and he had been told that I was just a carrier.

> *"I lost over 7 stone in just a matter of weeks!"*

My condition deteriorated further and in the early hours of Wednesday morning, I was transferred on *blues and twos* to the Queen Elizabeth Hospital, Birmingham and admitted to Critical Care. More tests followed. I didn't appear to be jaundiced, but doctors visited in droves and Kayser-Fleischer rings were detected and my kidneys were found to be failing. Dr Armstrong, the lead transplant surgeon, put me to the top of the list and within two days I had received a liver transplant. I remained in critical care for a further 5 days and then spent 2 days on the high dependency unit. Luckily for me the liver was a perfect match and I am on the lowest dose of anti-rejection drugs possible. My kidneys have since recovered and I lost over 7 stone in weight in just a matter of weeks!

Katie awaiting a transplant

My diagnosis of Wilson's disease lasted just under a week! With a new liver, I don't technically have it any more. As a result of my experience, my three siblings were tested and Carlie was confirmed as just being a carrier whereas my younger brother, Robert, who didn't take part in the Study in 1996, was diagnosed with the condition. He was immediately started on meds. but the strange thing is after liver scans, brain scans, blood tests and copper collections the doctors still can't find any evidence of copper in him at all. He remains on zinc while they keep looking!

Meanwhile, I am happy to report that I am back to normal again, living life to the full with my husband and our two lovely children. I am told that recent research suggests that the incidence of WD carriers in the population is 1:40. It's just a shame that my mum happens to be that 1 and more to the point, that she passed her abnormal gene on to me and my brother!

Estimating the prevalence of Wilson Disease using genetics

Back in 2016 I was having a discussion with one of my supervisors who mentioned to me that no-one really knew how common Wilson disease (WD) was. This struck me as strange particularly for a well-known condition that was described a long time ago.

I did some reading and in almost every text book it says that WD affects 1 in 30,000 people, however this comes from some very old evidence, even before the WD gene had been found. So, three of us (Jiali, Simon, and I) decided to try and use freely available genetics data from the internet along with published papers to try and improve the estimate for how common WD is.

The principle behind this research is that WD is caused by inheriting two copies of a faulty gene (called *ATP7B*, or just the WD gene) and people who have one faulty copy don't have WD (Figure, *left*). Then, if we can figure out how common it is to have just one faulty copy of the WD gene in healthy people then we can estimate how likely it is to get two faulty copies.

There are big databases freely available on the internet that have combined data from having sequenced all the genes in a large number of healthy people. This let us calculate how common it was to inherit one faulty copy of the WD gene, then did our calculations to . We also looked at other previous research where people had tried to estimate the prevalence of WD by counting numbers of people diagnosed with WD ('clinical' estimate). This let us compare the original number (1 in 30,000), the 'clinical' estimate (about 1 in 72,000), and our genetic estimate which was 1 in 7,500 (Figure, *right*).

We were also able to estimate whether people from different ancestries might be at higher or lower genetic risk of WD. We found that people of African or black American origin are probably less likely to get WD, whilst East Asians are slightly more likely to have WD. This is because some WD gene mutations are more or less common in some ancestries.

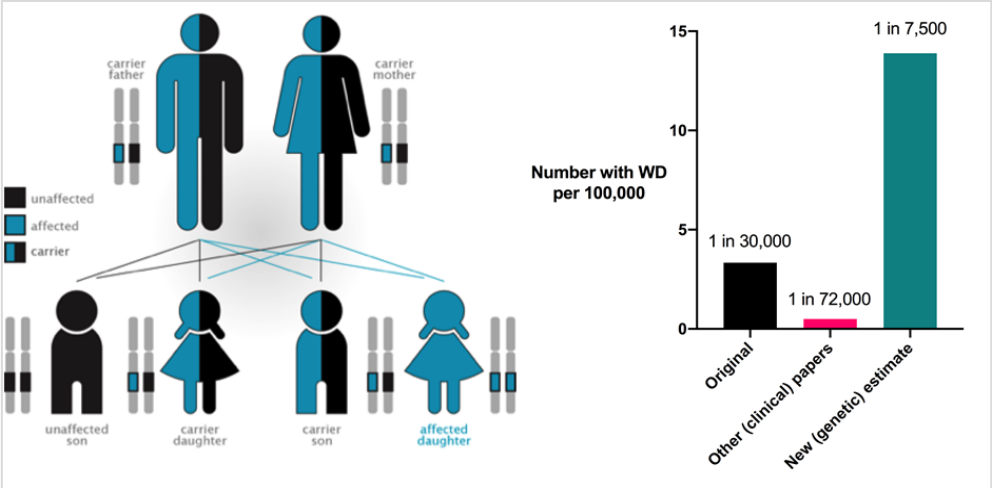


***Figure**. Using genetics to estimate the prevalence of WD. This research used the principle that WD is caused by inheriting two faulty copies of the WD gene (left). Therefore, we calculated the prevalence of the faulty WD gene in carriers and used this to calculate the prevalence of WD (right).*

The difference in numbers could be for several reasons, but most likely that there are some mutations (faulty gene changes) in the WD gene that we would expect to cause WD but don't always cause it. This is similar to how some people have different types and symptoms of WD despite them both having the same faulty gene.

It could also be explained that there are some people with very mild forms of WD who don't know they have it, but we don't think that would explain all the difference.

Interestingly, since we did our research, two other groups have done very similar research but have done their calculations in slightly different ways. They found the estimated prevalence to be higher than 1 in 30,000 but lower than ours. So the true value is probably somewhere between all of them.

Whilst our research unfortunately doesn't directly help to treat, cure, or prevent WD we think that it is still important and will make a small contribution to the understanding of the condition.

Our paper can be found here: https://www.repository.cam.ac.uk/handle/1810/285352

The other papers doing similar research are:

https://doi.org/10.1101/499285 and https://pubs.acs.org/doi/abs/10.1021/acs.jcim.9b00852

Jake Mann is a paediatric registrar at Addenbrooke's hospital in Cambridge. He is currently doing a PhD studying the genetics of metabolism and hopes to do research into metabolic liver disease long-term.

THE WILSON'S DISEASE SPECIAL INTEREST GROUP (WDSIG)

Through the British Association of the Study of the Liver (**BASL**) a number of Special Interest Groups (**SIGs**) has been established in certain areas of liver disease in order to bring relevant expertise together from around the UK. The **WDSIG** was one of the first to get going and had its first meeting in December 2017. Wilson's disease lends itself well to this new initiative, being a rare disease that has several types of clinician involved in its care. Sitting in the Group are hepatologists, neurologists, clinical chemists, paediatricians and psychiatrists as well as research scientists and representatives from WDSG-UK and Public Health England (**PHE**). Over 100 individuals from across the UK are registered on the WDSIG database.

4th WDSIG meeting—29 November 2019—National Hospital for Neurology and Neurosurgery, Queen Square,

The SIG approved 3 new specialist WD Centres (Nottingham, Oxford and Bristol) bringing the total number of adult centres across England to 15. NHS England has been updated with these changes. A standards document to which Centres of Excellence should adhere was agreed and is now up on the BASL website under the relevant section www.basl.org.uk. All patients on trientine in England should have an annual review via one of these Centres, if they are otherwise being looked after elsewhere. In terms of specialised commissioning of WD services, at present NHS England (via the relevant clinical reference group) is not planning to take this on though this may change in the future.

PHE (specifically NCARDRS which is the national congenital anomaly and rare disease registration service) is gathering pace with its work on Wilson's disease. Dr Osob Mohamed, Hepatology clinical fellow based at the Royal Surrey Hospital, has been recruited to take on the work started by Michelle Camarata before she went on maternity leave and back into clinical Hepatology training. There are a number of strands of data collection including clinical information from Centres, hospital episode statistics, prescription data, mortality data, genetic and copper results. By cross-referencing these data sources the aim is to build up a comprehensive database and answer certain questions about prevalence, long term outcome and variation in WD treatment. Preliminary results have been submitted in abstract form to the European liver congress. By linking in with the CROWD study the hope is to better understand why patients with certain gene mutations present differently. It is also hoped that NHS Wales and NHS Scotland will be involved in due course.

The clinical session covered primary care awareness, screening for liver cancer (thought to be very rare) and a very interesting session on Deep Brain Stimulation (DBS) where Mr Ian Low a Neurosurgeon based at the Queen's hospital in Romford spoke of his experience. It seems that very selected patients with neurological WD might benefit from DBS and this is going to be taken forward by the movement disorder group of the Association of British Neurologists. It is recognised that more could be done to educate GPs in the early signs of WD and the group is hoping to publish a review aimed at primary care.

Research progress is a key remit of the SIG. The CROWD study has successfully recruited and is now generating data. Nottingham reported on a study which identified a higher prevalence of WD in their surrounding area than previously recognised, potentially diagnosing new cases and bringing existing patients under Specialist review. Some interesting work presented at the American liver congress was presented and an update on Pharma trials given. Many other research projects are ongoing and in development.

The meeting concluded with a discussion about the different formulations of trientine and about laboratory measurement of copper. There are some differences between the dihydro- and tetrahydro- forms of trientine which mean dose comparisons are not straightforward. In terms of copper measurement, this remains a fine art but progress is being made towards a more accurate way of calculating 'free' copper. There remains quite wide variation in how patients with WD are monitored and the SIG intends to audit this.

Full minutes of the meeting are available via the BASL website (www.basl.org.uk). The next meeting of the SIG is scheduled for 20th November 2020. More detailed information about the remit of WDSIG can be found on *p16* of the 2019 WDSG-UK newsletter (www.wilsonsdisease.org.uk)

Finally, BASL recently paid tribute on its website to Dr John Walshe on his 100th birthday with a photo and link to a specially written biography.

Bill Griffiths,
Consultant Hepatologist at Addenbrooke's Hospital, Cambridge, and WDSIG lead.

Laura's Story

Hello everybody. I'm **Laura**; I'm 31 years old and I live in Shetland. Shetland is the most northerly group of islands in the British Isles and has a population of approximately 22,000. I was born in the capital, Lerwick, and brought up in the small village of Aith on the west coast. I had a very normal, happy and healthy childhood, the eldest of three sisters, and did well at school. I went away to study Primary Teaching in Glasgow for 4 years, graduating in 2011. In 2014, I got married.

In 2015 I had a temporary numbness in my leg that was investigated with an MRI and lumbar puncture. It happened again in 2016 and multiple sclerosis was considered. The numbness disappeared and the tests weren't repeated.

During our marriage we suffered three miscarriages and in April 2017 I had a psychotic episode which resulted in me being flown to hospital in Aberdeen. I was put on antipsychotic medication and was then referred to the mental health team back in Lerwick. I saw a community psychiatric nurse weekly and was prescribed antidepressant medication and also medication to help me sleep. I was very confused, anxious and unable to understand what was happening to me.

In July 2017 a tremor started in my left hand, then in my arm. It also started in my legs and then my head. When walking, my balance was affected, my gait was different and I had poor coordination. The tremor in my hand made it very difficult to eat and drink and I got special utensils to help. Writing became very difficult, as did performing everyday chores, and eventually my husband and family had to feed me. I became increasingly worried I had Parkinson's disease like my grandmother, as our symptoms were very similar. I mentioned it to the consultant, but he reassured me that I hadn't. By now I had stopped driving as I found my leg tremor made it difficult to control the clutch.

My temporary teaching contract came to an end in April 2018, by which time I was very low emotionally. I saw a clinical psychologist for 10 weeks and he concluded I had anxiety issues and told me to continue with CBT (Cognitive Behavioural Therapy) and medication. My local GP practice had various locum doctors, which meant I didn't have much continuity of care. It seemed nobody was taking my symptoms seriously. I tried several different private therapies; acupuncture, a private chiropractor and also energy healing sessions. None of them made any difference but I felt I had to try something.

By June 2018 we were extremely concerned about my worsening tremor and my mental health. I had been on mental health medication for over a year, but it didn't seem to be helping at all and might be causing the tremor. We asked for it to be stopped. It made no difference to the tremor, but I was glad to be off the medication as I felt more in control and could think more clearly. In July 2018 I was finally offered a CT scan, but the results showed no abnormality and the consultant therefore said there was no need to go to Aberdeen for an MRI. He diagnosed me with FND (Functional Neurological Disorder), as there was no structural problem with any part of my body, brain or nerves. It was a 'malfunction of how the nervous system was working' which was causing my tremor.

It was suggested I look on the FND website for information and help. I had monthly physiotherapy appointments which initially seemed to help, but it wasn't sustained and by December 2018 I was extremely poorly. We insisted on seeing the consultant again and he asked the neurologist in Aberdeen to refer me for an MRI scan. By this stage, I needed assistance with everything and borrowed chairs, stools and aids from occupational therapy to help me around the house.

> *"It was a malfunction of how the nervous system was working...which was causing my tremor…"*

In January 2019 I had a video conference with the neurologist in Aberdeen who mentioned that the symptoms I was displaying—severe tremor in hands, arms, leg and neck and loss of balance—could possibly be a condition called Wilson's disease. My new local GP agreed. I was told that it was very rare, but that a blood test could be done to confirm it. A caeruloplasmin blood test was ordered and the result was so low, the laboratory in Shetland thought there must have been an error. The test was repeated with the same results. At last I had a possible diagnosis. I was relieved, but a bit worried at the same time.

I attended the Aberdeen Royal Infirmary (ARI) under the care of the neurologist, Dr Duncan, and from an MRI scan, slit lamp test, further blood tests and 24hr urine copper collection, he confirmed the diagnosis of Wilson's disease. It was 28 February 2019 and Dr Gillett was contacted and medication begun. I started with 125mg of penicillamine, doubling to 250 mg two weeks later when I was back home in Shetland. I was warned that my symptoms could worsen. Indeed over the next three months, they did. My right arm and hand became very dystonic and unusable. The tremor in my legs was terrible. I could hardly walk and needed two people to shower and dress me. My speech became faint and slurred and I had swallowing issues. I couldn't sleep at night because my arm was so painful and I needed somebody with me at all times. I could virtually do nothing for myself. The local rehabilitation support team was very good, helping me every morning to get up, showered and dressed.

On 15 May I flew down to London with my husband and mother to see Drs Gillett and Shribman at their clinic in Queen Square. Travel was difficult and I had to use a wheelchair, but I was so glad to meet them both so they could see my condition. I had another MRI scan and was given a botox injection in my right arm and hand to relax the dystonia and help relieve the pain. On my return to Shetland two days later, things deteriorated further and I was admitted to hospital. A gastro nose tube was fitted so that I could be fed and given my medication. From there they sent me back to Aberdeen by air ambulance. By now, I could do nothing for myself, not even push the hospital buzzer for help. Dr Duncan could see the extent of my deterioration and contacted Dr Gillett again, who advised acquiring dimercaprol injections from the US. They aren't licensed in the UK, so we had to wait four weeks for them to arrive.

My recollection of the next 8 weeks is hazy. I remember having a peg feed tube fitted in my stomach for my food, drink and medication. Special low copper feeds were arranged. I had casts made for my legs, which had also become dystonic. My tongue became dystonic and I could no longer speak—only grunt. My neck was affected, my mouth gaped wide open and I stared blankly into space. I had regular suctioning in my mouth and I lost nearly 2 stone in weight. The Dimercaprol injections were started on 22nd June and were administered into the muscle, alternating the injection sites between my upper arms and buttocks. They were very painful! I had 1 injection each weekday and none at the weekend. On Saturdays and Sundays I had to give my body a rest! The first batch lasted 6 weeks, followed by a 2 week break, then another batch was ordered for a further 6 weeks.

This routine continued until the end of October. It seems that once the injections started, so my health gradually improved. I had no complications or side effects from them. I was getting more movement in my arm, which ironically became overflexed requiring a splint to correct it. I was referred to a psychiatrist, and had help from speech and language therapists, occupational therapists, physiotherapists and dieticians. I spent my 31st birthday in hospital. In mid-July my husband walked away from the situation leaving me in the care of my mum, dad and two sisters, who took it in turns to stay in a flat nearby so that they could visit me every day in hospital.

The staff in Ward 205 at ARI were amazing and my spirits and health improved as various friends and family from Shetland came down to see me. My speech slowly started coming back at the end of July, the dystonia became less and my mobility improved. I started to get out of bed to sit in a chair, then I was able to stand with a zimmer and eventually I was able to walk with a stick. By the end of August I was eating normal food. I was transferred from the ARI to Woodend Neuro-Rehabilitation Hospital in Aberdeen, where I remained for the month of September receiving further specialist help from the various disciplines. I flew home to Shetland on 2 October 2019.

My dosage of penicillamine was increased to 1000mg when I started dimercaprol and I remained on this dose until December 2019. By then I had noticed my legs were quite swollen (because of nephrotic syndrome when penicillamine causes the kidneys to lose protein), so I was changed to trientine. I have been on this ever since and have had no side effects or problems from changing medication.

It's now February 2020 and I am driving again, doing voluntary work and have just started working back in local schools. I go to a variety of classes at the leisure centre several times a week and my fitness has never been better! My diet is varied and good; I just stay away from high copper foods and avoid alcohol altogether. My tremor has virtually disappeared and my right hand, which received the botox, is very much improved, possibly because of all the embroidery I have been doing recently!

The separation from my husband has been heartbreaking but I am so grateful to be here enjoying the littlest things of life. I am also grateful to Dr Duncan and Dr Gillett, Dr Russell in Shetland and to all the staff both at ARI Ward 205 and Woodend Hospital for their help, care, advice and support. I also thank Val Wheater and WDSG-UK for keeping in touch and, of course, my mum, dad and my sisters who stayed by my side throughout.

WDSG-UK Notices & Updates

Research

UCL Queen Square Institute of Neurology, London

An update on the CROWD study: A UK-wide research study on Wilson's disease

Dr Sam Shribman writes, "Further to our update in last year's newsletter, I should like to report that it has been a busy year for the research team at University College London. We have been making significant progress with both parts of the Cohort Research On Wilson's Disease (CROWD) study and are incredibly grateful to all those taking part and to WDSG-UK for their contribution of £5,000 towards the travel and accommodation costs of patients.

In the first part of the study, participants are completing an online questionnaire and sending us saliva samples for genetic research to understand why Wilson's disease affects the brain in some people but not others. We are delighted that at least 108 participants have signed up so far and more people are signing up each week. We are still looking for more people who might be interested in completing our online questionnaire but are temporarily stopping saliva sample collection due to the COVID-19 epidemic. More information about this part of the study is available at www.thecrowdstudy.com for those who are interested.

In the second part, we are studying how to monitor the effects of Wilson's disease on the brain. We have now completed the baseline visits for this part of the study. This involved 40 participants attending the National Hospital for Neurology and Neurosurgery for clinical assessments, urine and blood tests and an MRI scan of the brain. Several patients have also had lumbar punctures and/or skin biopsies. We are delaying the start of the follow up visits due to the COVID-19 lockdown and are now in the process of analysing the data we have collected so far. We will keep you posted on our progress through the Wilson Disease Support Group—UK.

Separate to the CROWD study, we have been continuing to raise awareness about Wilson's disease among doctors across the UK through presentations at the annual meeting of the Association of British Neurologists and at the Neuropsychiatry faculty at the Royal College of Psychiatrists. Our group has also published two academic papers on Wilson's disease in medical journals since the last newsletter:

The first paper, 'Clinical presentations of Wilson disease', is a review article that was published in a special edition of the *Annals of Translational Medicine* in collaboration with Dr James Dooley. We cover the initial neurological and hepatic symptoms of Wilson's disease in order to help clinicians identify it earlier. We explain some of the reasons why the diagnosis is often missed or delayed and provide some clinical hints and tips on how this can be avoided. For those who wish to read the full article it is available here: http://atm.amegroups.com/article/view/25358/pdf

The second paper, 'Liver transplantation for late-onset acute liver failure in Wilson's disease: the UK experience', was recently published in *JHEP Reports* in collaboration with Dr Bill Griffiths and the team from Cambridge. In the paper we describe the case of a 62-year-old male who developed acute liver failure and was successfully treated with urgent liver transplantation. We then discuss the outcomes of other late-onset cases of acute liver failure due to Wilson's disease in the literature and provide additional data from the UK Transplant Registry. For those who wish to read the full article it is available here: https://doi.org/10.1016/j.jhepr.2020.100096

Please do not hesitate to get in touch if you have any queries about our work. You can email us at crowd@ucl.ac.uk or call on 07739 751200."

University of Sheffield, Dept of Neuroscience

Prof. Oliver Bandmann and his team continue their work investigating mitochondrial biomarkers in Parkinson's disease and other neurodegenerative diseases, including Wilson's disease. He writes,

"We enormously appreciate the generous support of WDSG-UK for our research. The aim of our study will be to undertake cutting-edge brain imaging in patients with neurological WD and compare this to patients with hepatic WD. We predict that there will be a more marked impairment of the cell batteries, the mitochondria, in the brains of patients with neurological WD. The scan is called "31Phosphor Magnetic Resonance Spectroscopy (31P-MRS)". Unfortunately, the Covid-19 crisis has made it impossible for us to actually scan any patients! However, we have already approached quite a few patients who have all agreed to participate. Furthermore, the clinical fellow Dr Tom Payne has been using the lockdown time to analyse the many 31P-MRS scans which we have already done in Parkinson's disease patients and age-matched controls. This has helped us a great deal to optimise the analysis strategy. We are desperate to now also scan patients with Wilson's but we certainly don't want to put patients or staff at risk. We just all have to be patient."

Public Health England (PHE) —Wilson's Disease Pilot Study—Update

As mentioned in Bill Griffith's report on the last BASL WDSIG meeting (*p11*), **Mary Bythell,** Head of the **National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), Jeanette Aston** and **Osob Mohamed** are continuing to work together on PHE's pilot study to identify the number of patients with Wilson's disease living in England. At the same time, they are collecting information about diagnosis and treatment to help commissioners make the right healthcare decisions and improve patient care. So far they have identified over 400 patients being treated in England through information provided by 26 Trusts across NHS England. Some Trusts have not yet responded and we appeal to them to do so as soon as possible. Patients are identified through their NHS number so that the same patient, being seen by a number of different specialists, is only included on the Registry once. Further details about the Registry and how cases can be reported to NCARDRS can be obtained through Jeanette at Jeanette.aston@phe.gov.uk or by emailing Mary at phe.ncardrsd@nhs.net

Drug Trial — Birmingham, Cambridge and Guildford

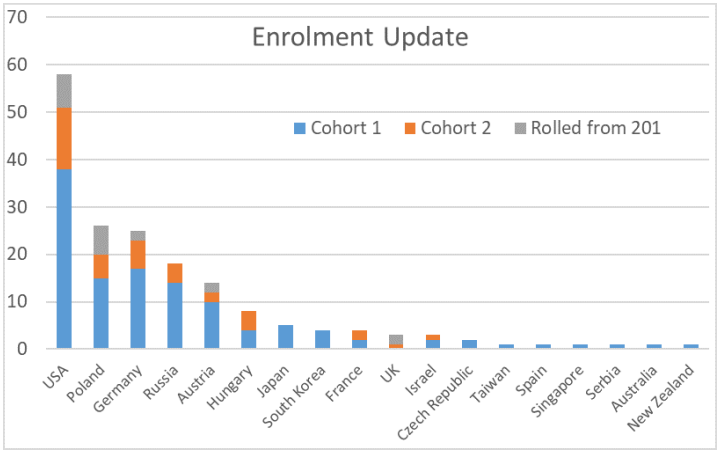
Efficacy and Safety of WTX101-301 Administered for 48 Weeks Versus Standard of Care in Wilson Disease Subjects

The WTX101-301 study, being run by Alexion Pharmaceuticals stopped recruiting in February of this year as they had reached their target. (For a background to this drug trial, please refer to our previous 3 newsletters). Bill Griffiths writes:

"The original plan was to recruit around 100 adult WD subjects worldwide and randomise them to the tetrathiolmolybdate study drug (ALXN1840) vs standard of care in 2 cohorts. The larger cohort 1 consisted of patients who were established on treatment, whereas the smaller cohort 2 consisted of 'treatment naïve' patients, i.e. newly diagnosed patients. By December 2019, 172 patients had been recruited worldwide and the graph below shows how many patients have been recruited in each country and into which cohort these patients fall. A few patients taking part in this study (and the majority of patients put forward by the UK) were already enrolled in the forerunner to this Study (WTX201) back in 2017 and continued taking their assigned medication uninterrupted. The researchers will be collecting and analysing the data.

There are also two onward studies being planned, using the same drug; one which will assess de-coppering through serial liver biopsies and non-invasive imaging and a second study which aims to enrol children. We hope to keep you informed of progress in subsequent newsletters."

Chart Showing the Countries taking part in the Alexion WTX101-301 Study



Supply of Penicillamine in the UK (May 2020)

We understand that there are two pharmaceutical companies in the UK that normally supply penicillamine: **Mylan** and **Kent Pharmaceuticals**. Mylan experienced "manufacturing issues" with both their **125mg** and **250mg** tablets over Autumn and Winter, but we are assured that both are now back with their wholesalers. Kent Pharmaceuticals only manufactures **250mg** tablets and they are also currently having problems with manufacturing. They have no stocks and have made no promises about availability in the future.

Supply of Trientine dihydrochloride (trientine—Univar Ltd) in the UK (May 2020)

Univar continues to hold many months of stock within the UK to safeguard against any shortages in availability, so do not anticipate any problems. Despite the logistical difficulties created by Covid-19, their supply partners in the UK have been able to deliver on time to pharmacies, hospitals and patients who have their meds sent direct. If you are having difficulty getting hold of your meds, please contact Valerie direct.

Trientine tetrahydrochloride (Cuprior®, GMP-Orphan UK Ltd)

For patients in the UK taking trientine, it may be of interest to you to learn that an alternative trientine preparation, trientine tetrahydrochloride (Cuprior) has been licensed in certain parts of the UK. It does not need to be refrigerated.

A Glimpse into my life

Hello! My name is Ambuja Sabharwal and I am 29 years old. My friends and family call me Amby. I currently reside in Gurugram, which we moved to when I was 10 and which is about 20 kms away from Alaknanda in the heart of New Delhi, where I was born. Gurugram was just becoming popular when we moved and today is buzzing with metro connectivity, shopping complexes and IT offices—a proper concrete jungle! I like hanging out at the various cafes and restaurants nearby, especially the ones that serve Italian food!

Even though I have lived in Gurugram for almost 20 years now, I distinctly remember the Alaknanda days when I was growing up, for it was then that the symptoms of Wilsons' Disease started showing up. I was around 9 at the time and started experiencing quite an odd and disturbing sensation in my feet - of 'pins and needles' as I would often describe it. At first it did not seem like a major issue, but this sensation persisted for about 2 months. There were times when the pain would be simply unbearable and this ended up causing a limp in my walk. This was soon accompanied by various other effects like darker complexion and frequent joint pain. There were even bouts of aggression. Apart from the constant feeling of pain, I found myself confused, often wondering what was happening to me.

All of this made me extremely sad and depressed. My family soon realised that this was an extremely worrying situation. My father, being a doctor, swiftly figured out the various testing procedures I had to then undergo, in addition to consulting other doctors in specialised fields. After having consulted many doctors, from Orthopaedics, Microbiology and Psychiatry and having conducted various tests like blood tests, X-rays, bone density scans, it was found that no clear diagnosis emerged. This was an even more worrying sign. As a last measure, a full body MRI scan was done including that of the brain.

> *"They would make fun of my slightly odd walk"*

Through the process of differential diagnosis my father had developed a reasonable understanding that my diagnosis could result in Wilson's disease. My parents wanted to be absolutely sure about these initial suspicions. Now what I am about to describe is again a very vivid memory for me. At 2.00 a.m, in the dead of the night, my parents woke me up so that we could go to my Mamu's house (My mother's elder brother; an

Ophthalmologist) where I would be checked for the presence of Kayser-Fleischer rings. It turned out that I had them. Even though suspicions were there, they were all completely shocked to find conclusive proof of me actually having Wilson's disease. In search of more information about this disease I travelled with my father to Europe and attended an International WD conference in Leipzig, Germany in 2001, where I met Linda Hart and Caroline Simms and also Drs John Walshe, Godfrey Gillett and James Dooley.

After all this, regular life finally caught up, with much negativity. I distinctly remember feeling completely isolated from the other kids at school. They would make fun of me for my slightly odd walk and did not gel with my supposedly odd personality as well. I remember instances where people would just move away and ignored me as I tried to approach them. As a little girl in school, this was heartbreaking for me. We all long for friends in school, but this was a time where I had none. Because of the disease affecting my ability to concentrate and focus on academia, my performance fell drastically from the 6th grade onwards. Prior to that I had maintained top grades. The isolation I had been subjected to, actually made me feel that there was something majorly wrong with me. What resulted from such negative thoughts was a low self-esteem and depressive thoughts. When I look back rather painfully at my school days, it brings back quite a lot of those bad feelings, even now.

When I was around 11 years old I was advised to have Syprine as medication since penicillamine did not particularly suit me. This medicine has been quite effective. Over a period of 3 years, my neurological Wilson's symptoms like limping and ataxia started to disappear. However I must add that despite that, some of the hepatic effects of Wilson's disease remained and showed up occasionally; fluid build up on the legs, muscle stiffness, fatigue, problems with physical coordination, depression and clumsy gait.

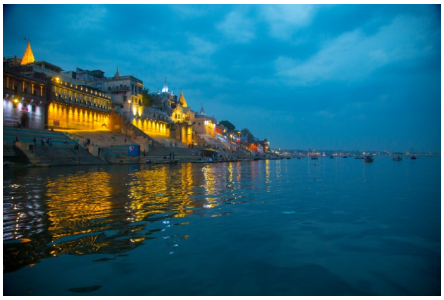
As I grew older, I diligently took the proper medication and even ensured a good, healthy diet. My overall condition gradually improved and I had become largely asymptomatic. With a growing confidence and a slow return to normality, I stopped my medication for a while (secretly). However, I remember that this action was met with stern counselling from my parents who informed me that even a minor slip in medication could cause major problems. That is when I grasped the gravity of the situation. It took me a while to actually realise that Wilson's disease is a cause of serious concern and that without medication and proper care my condition would deteriorate significantly. Coming to grips with the fact that I had to live with a disease that caused me so many medical problems, restricted my life in so many ways, drove people away and would probably never be cured was difficult.

A recent jolt I faced because of this disease is that of a heartbreak. I was dating a decent guy and it was going pretty well until I found out that many of his family and friends could not accept me because I had this disease. Without a doubt, this has caused immense emotional pain. Moreover, having to deal with life while even fighting a constant battle with the disease, from the medical aspect, is certainly hard.

Even today, despite the fact that Syprine is managing to keep most of the symptoms at bay, I do face an ever increasing threat of liver cirrhosis. My most recent discussions with the doctors suggested that I might need a liver transplant soon enough. I will admit that the prospect of coming to the stage of needing a liver transplant does scare me quite a lot. However, I do get some comfort from the fact that my family is standing by me every step of the way.

However, I have never been defeated, despite the isolation, rejection, pain and medical problems I have gone through because of this disease. I must say that despite all the problems, I feel blessed to have a very loving family and some very caring friends in my life. They have always encouraged me to work, study, learn and to strive to push my professional boundaries.

When Wilson's Disease tried to erode my confidence, I was encouraged to believe that I should accept it and tackle it head on. I learned that everyone can be good at something and despite the shackles that this disease put on me, I firmly stuck to that idea. Upon some soul searching and introspection, I realised the urge to add value to myself by developing professional skills like photography, sketching and other forms of art. The pain and suffering that Wilson's causes are eased when I see the things I create. I now believe that our struggles and suffering are meant to transform us into the strongest versions of ourselves. Yes, Wilson's disease has made me strong and resilient and I will not let it ruin my relationships, my work and my life.



Here are some photographs I took of Varanasi, recently. Varanasi is on the banks of the River Ganges in northern India and has been a cultural centre and major centre for Hindu pilgrimage for several thousand years.

Dr Walshe's 100th Birthday

After twenty years of publishing newsletters, I rather suspect it is no longer necessary for us to introduce our President, Dr John Walshe! If you are one of his 320 former patients or have been associated with WDSG-UK in the past or if you are a Facebook member of the Group living anywhere in the world, you will have heard that it was his 100th birthday on 24th April 2020. You will also have been invited to write a personal message to him to be included in a special commemorative book that luckily we were able to get printed during lockdown and present him with (responsibly in the circumstances) on the doorstep of his home in Hemingford Grey on his actual birthday! Here he is, sitting in his back garden shortly afterwards, reading the many fond tributes paid to him, interspersed with original artwork, original poems and trips down memory lane. He has asked me to pass on his best wishes to you all as follows:

"I am sorry that because of coronavirus the special party that you had arranged for me has had to be postponed. I was looking forward to it very much. However, I had much pleasure in reading through the pages of tributes that you have kindly taken the trouble to write, which I am humbled by and which have rekindled fond memories of the time when many of you were my patients. It was also gratifying to read messages from patients and their families whom I have never met but who have benefited from the drug therapies that I have developed. In particular, it was lovely to see photographs of so many of you who appear to be leading healthy and happy lives and I wish you all good health for the future, particularly in these difficult times."

Many other special birthday tributes were paid to Dr Walshe in local newspapers, the local parish magazine, on the British Liver Trust and BASL websites and at his alma mater, Trinity Hall College, Cambridge. In addition, he received nearly 100 birthday cards, floral tributes, birthday cakes and presents from family, patients and friends with the villagers forming a choir in the afternoon outside his house and regaling him with a verse of "Happy Birthday" followed by a rendition of "Nelly the Elephant" in deference to his love of and association with such animals! To have waited 100 years for an occasion which was all but ruined by Covid-19 restrictions, was tough. However, he is still with us thank goodness and we shall just have to wait a little longer to celebrate it with him.

For those of you who are keen to see the book, this will be available to thumb through at our next meeting. Because the messages written within it are all personal, we think it inappropriate to have the book on general release. However, may I take this opportunity of thanking everybody who responded to my request to contribute. With the permission of her parents, I would like to share the first message in the book, written by the lovely Olivia, accompanied by a photograph of her writing it and a picture that she painted especially for his birthday!

"This can't be happening to Olivia!" were the first words my parents cried when they found out I had Wilson's disease in Korea one scorching, summer day in **2012**. I was only an adorable 2 year old child (that was 8 years ago though) when this happened! My parents were depressed for a short time after they found out, but they were lucky to find out at an early stage and I was lucky to have your medicine.

How did you invent this medicine? You must have worked arduously and have never given up which gave you the result of saving a multitude of lives—including mine! I would do anything to thank you! You're the best hero I have ever known!

The final thing I want to say to you is…

HAPPY 100TH BIRTHDAY!!!

You are the first person I know to be a 3 digit number!

Have a special day, Dr Walshe!

From *Olivia Jeon*—aged 10

Members' News 2019-20

Dr Walshe wasn't the only one to have a significant birthday this year. Here are four others:

First of all**, Anusha Joseph** was **40** on 3rd December 2019 and her parents and sister hosted a surprise birthday party for her at her favourite restaurant near her home in Harrow. Family members attended from afar including her uncle from Norway and her cousin from Canada.

Her sister, Navasha, organised a fun quiz for the occasion to test which table knew Anusha best! We now know her favourite colour, animal, food, coffee shop, film, book and tv programme not to mention that she shares her birthday with Andy Williams and Ozzy Osbourne! Anusha thanked everybody for attending and said,

> ***"I have been quick to learn that all things in life slowly begin to fade, though the important things that continue to shine in my world are the true connections and relationships I have formed with my family and friends."***

More recently, **Allie Johnston** from Edinburgh celebrated her **50th** birthday on 23rd April, the day before Dr Walshe's 100th! In fact the day she was born, Dr Walshe would have been looking forward to his own 50th birthday!

Had Covid-19 not come to plague us all, she and her mum would have been on holiday in Vienna. However, it wasn't to be and instead Allie was in lockdown at home making the most of a difficult situation! Her sister went to a lot of trouble to mark the occasion, supplying special party *glasses* and a tiara, streamers and balloons, as well as baking a cake and getting her children, Michael and Suzanne, to sing "Happy Birthday" to her via a videolink.

All is not lost, however, and Allie and her mum have now booked a cruise to the Baltic next summer, sailing up the Norwegian Fjords and visiting the Hermitage Museum in St Petersburg. Meanwhile, once lockdown is lifted, they will enjoy having all the family round for a high tea party in the garden.

Joan Smith reached a milestone on Monday, 4th May, when she celebrated her **70th** birthday. She says that during lockdown she has done a fair bit of reading. She lives in the same house as her daughter and nine year old grandson, but because she had a liver transplant in 2004, she is having to shield herself from them.

It was another lovely day on her birthday and when the sun came round in the afternoon, she was able to throw open her windows and cycle a few more kilometres on her exercise bike—in the fresh air. In so doing, she was able to shed enough calories to compensate for the excesses of a special birthday tea! Her family bought her a new tablet computer for her birthday and her grandson, who is learning computer programming, composed a special Happy Birthday jingle which he sang to her that morning. When lockdown is over, they intend going out for a slap-up birthday meal!

And finally, last Sunday on 24th May, **Gill Ford** from Watford also celebrated her **70th** birthday. Gill was diagnosed with WD in Reading in 1976, and with her husband, Peter, has attended our last two meetings in Cambridge. Together with Eric their dog, they managed to sneak in an early birthday tea in Canterbury just before lockdown restrictions were put in place. On her actual birthday Peter organised a Zoom houseparty session to which her son, Graeme, and daughter, Lucy, were invited together with several of her friends. The Italian holiday they had booked this summer has had to be postponed, but hopefully it will take place at the same time next year. Meanwhile, she has decided to take advantage of her time at home by teaching herself Italian and we wish her well! Buono!

Liz Wood joined our committee in 2018. She writes: "Hello everybody. I thought I'd let you know what I'm doing during this lockdown time. In normal times I am a singing and piano teacher and run two choirs. Obviously I am currently not able to see any of my students face-to-face so have been teaching them virtually via Zoom, which is challenging but I'm managing to make it work. At the end of this term I am planning to have a virtual Zoom concert so that my students can all sing and play to each other and their families. They are all looking forward to having something to it.

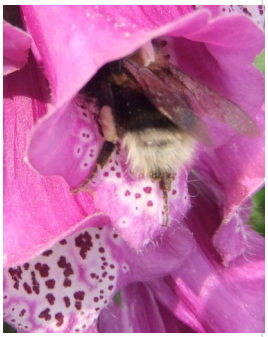
I am also continuing to 'see' my ladies' choir every Wednesday evening at our usual time. Whilst it is nothing like singing together in the same room, they are really enjoying meeting up each week and keeping some semblance of normality to their week. In the photo, you can see me in the top left playing the piano and singing along. The choir all have to keep their microphones on mute, otherwise we have a great cacophony of sound, due to the time lag being different for everybody. It's very strange for them as they are effectively singing a duet with me rather than singing as a choir. We've managed 7 weeks of 'rehearsals' like this now and sadly I think it will be a long time before people are allowed to sing together so it might continue for some months to come."

Caroline Simms writes, "Hi all, this is a living nightmare for me and my partner Eamon. He has ulcerative colitis and takes azothiaprine. I had a liver tx 16 years ago due to Wilson disease and take cyclosporin. It's certainly a test of a relationship. He has a very dry sense of humour and I am super sensitive. Anyway we stay busy: he is furloughed and I am working from home. I work for the NHS, but not on the front line thank goodness—in research and innovation. We go out and clap for the wonderful work the care workers and NHS do with respect to tackling this war. And it is a war as so many lives have been lost including a friend of mine. We need to focus on staying safe. When the evil was let out of Pandora's box, there was hope. We wish you all well and I'm sending a picture of *Wilson* who my nanna gave to me in 1987 when I was first diagnosed with the disease."

Linda Hart says, "Hello everyone! I hope you're all faring as well as you can in these unprecedented and sad times. I'm so grateful for my home, small garden and cat! I think that one blessing in these enforced periods of isolation is that many of us are taking stock of ourselves and our way of life and maybe we'll make changes, see what's most important and separate the wheat from the chaff, so to speak.

Judging by the amount of time I'm spending in my garden, by August it really should look like Kew! Last summer my vegetable plot ran wild with self seeded sunflowers and hollyhocks— spectacular though, but very few vegetables! This year, however, I've got my act together and hope to be self sufficient in vegetables. I'm helped in my endeavour at slug and snail control by hedgehogs. I've had a hibernation box behind my shed for a few years and it's wonderful to see it being used and them emerging in the Spring. I feed them nightly and one youngster is bold enough to just wander over my feet on its way to feed. I also love these bright mornings and am up uncharacteristically early having my morning cuppa in the garden and watching the bees at work and the many varieties of birds coming to my feeders.

I do, of course, miss seeing my friends and family and going out to my weekly drumming group, and Tai Chi and Yin Yoga classes. But I have at least mastered video calls. I've joined in my Yoga via Zoom, which is a tad awkward to say the least as I don't have a lap top or I-pad so I have my 'phone balanced on a chair, and either it falls off or the cat strolls in and sits on it! All part of the fun...or so I'm told. I've had a tin whistle and instruction book for years which I'd forgotten about so that has resurfaced too…though I'm mindful of my neighbours as I'm sure they value their hearing!!



Times will change, this will pass and I hope you will all remain healthy, positive and forward looking. I'll look forward to seeing you all when we have our next get –together."

Ashok Pandit, a 29 year old patient from Nepal with whom we have close connections, is also affected by the restrictions of coronavirus. Although not confined to the house, the country is in lockdown and people have to observe social distance when they meet.

After 4 years of studying digital marketing (2015-19), he now works freelance as the Fb marketer for two Nepalese companies. Having overseen the rebuilding of the family home after it was destroyed in the 2015 earthquake, he is now working on his professional dreams.

At school, he had originally wanted to become a doctor, but the dystonia in his hands made it difficult for him to write and keep up with his studies. Instead, he graduated from high school in management, taking computer science as an optional subject and his love and passion for Information Technology came to the fore. He came top of his class. Since then he has specialised in digital marketing and is earning a good salary each month. His domain name is https://digitalmarketingnepal.net. Do visit it and also follow him on his blog https://gadgetslist.com

Aliceanne Devine is a regular contributor to our Facebook Group and lives in Wishaw, Lanarkshire, just outside Glasgow. She and her brother were diagnosed with Wilson's disease in 2004 and she narrowly escaped a liver transplant. She has been fine since and recently married the love of her life.

She has taken full advantage of lockdown by binning all the unnecessary stuff that's been kept in her house "just in case!" She's also cut 4" off her hair and dyed it pink; she's taken up doing yoga exercises every day in her living room; she's attempting to teach herself guitar, is dabbling with adult colouring-in books and for an intellectual challenge she is following some free open university courses on television. In fact, she's never been busier!

Helen Lothian Khan isn't enjoying lockdown at all! First of all her fridge freezer broke down just four days before and she had to race to get a replacement. Then the monitor on her computer broke and there were no cheap replacements as people working from home had already snapped them up. And then, to cap it all, her mobile started playing up and she was forced to get a new one with just one day to spare. At least it is a smart phone and she can now use Skype and What's App to keep in touch with her family while she's stuck at home, self-isolating.

Even the warm weather hasn't brought her any comfort. Sitting in her back garden, she is irritated by the people living on one side of her with Asian music blaring out and on the other side is a Moldovian family playing Russian music loudly. The English chap living two doors along plays thump, thump, bang, bang music all day long and opposite is the Turkish man with the volume turned up on his belly dancing music! "They'd all better be careful", she says. "I was brought up in Glasgow and am tempted to retaliate with the bagpipes!" Can anybody help?

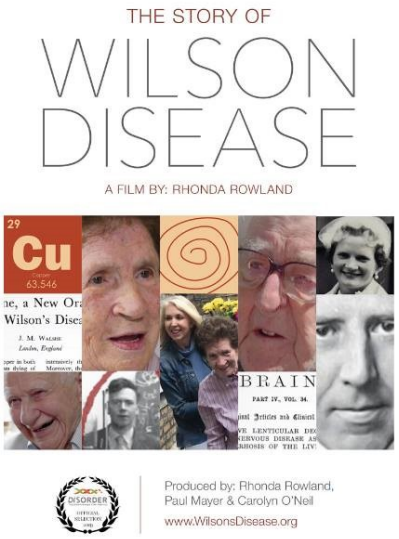
And finally, **Linda Asher** takes the biscuit as far as being creative! She is also enjoying the wonderful home cooking of her Dulwich daughter-in-law Robyn, which is left on her doorstep with all her shopping during these difficult times!

Linda desperately misses family, including her two sons and four gorgeous grandchildren, but she has distracted herself by drawing this lovely painting on her I-pad and at the same time has spent many hours making a clay sculpture of a Spanish dancer. All she needs now is for her modelling class, nicknamed "The Crackpots," to re-open so she can use the kiln and have her dancer fired!

Other News 2019-20

The Story of Wilson Disease—A Film by Rhonda Rowland

You may recall my mentioning on Fb last year and in last year's newsletter that Rhonda Rowland, a Wilson's disease patient from America and also former medical correspondent on CNN, had visited the UK in August 2018 to interview Dr John Walshe, James Kinnier Wilson and Dr Walshe's first ever patient, Shirley Wylie. She had organised for her visit and interviews to be filmed by a contact here in Cambridge, Paul Mayer, and when she returned to the States they worked together on a 10 minute documentary called "The Story of Wilson Disease."



Last summer Rhonda then entered the documentary in the US Rare Disease Film Festival and it was well received. She wrote, "The Film Festival went well! There are no awards - just the opportunity to share among the rare disease and filmmaking community, and provide a platform for releasing the documentary to a wider audience." Later, at Rupert Purchase's suggestion, she submitted the film to Rare Disease—UK's own Film Festival, which was held in London on 10 February 2020. Not being able to attend herself, she asked Paul and me to attend on her behalf. The film was shortlisted in the category of Best Aspiring Filmmaker—Voluntary Group Collaboration and a clip from it was shown, although sadly it did not win.

Rhonda had initially set out to write a book of patients' stories which she is hoping to get published in the near future. She has travelled all over the States interviewing people and of course wasted no opportunity in interviewing me while she was over here. We shall look forward to hearing whether her endeavour to find a publisher has been successful and I will keep you updated of the outcome via Facebook. For anybody wishing to view the video footage, please refer to Rhonda's Fb page https://www.facebook.com/RhondaRowlandR2/videos/598110020615574/ It's well worth a visit.

Dr Alan Stevens—Obituary

It is with great personal sadness that I report the death of Dr Alan Stevens on 10 April 2019. Steve, as he liked to be known, was a lifetime supporter of WDSG-UK. A retired consultant pathologist at Queen's Medical Centre in Nottingham, he had been a friend of mine through my late husband for thirty-five years. Living in Nottingham, he made himself known to Caroline and Linda when in 2000 they first began the Group. In the early years he arranged and hosted Support Group meetings at the University Staff Club there, and more recently he wrote several articles for the newsletter about the effects of Wilson's disease on the body, drawing on many years' experience of writing medical textbooks for students. He was a master of clarity making even the most difficult of subjects easily understood. He had a huge intellect, but was the most modest of men and detested pomposity in others.

Steve could speak for hours on any subject you like! And he did! I am frequently reminded of the time I bought my first telephone with an answering machine. It was the late 1990s and it caught him by surprise. He was so affronted to get through to a *modern piece of technology* and not to me that he decided to push it to its limits in the hope that he would annihilate it! He proceeded to deliver a 30 minute monologue on Creutzfeldt-Jakob disease aka bovine spongiform encephalopathy — without hesitation, repetition or deviation! He talked about Scrapie in sheep and how in Papua New Guinea eating one's ancestors' brains was commonplace. After playing the tape many, many times, our family became well versed in the ins and outs of Mad Cow Disease at a time when everybody was worried about catching it! I wonder what Steve would have made of Covid-19 today? We'll never know, but what I am absolutely certain of is that he will be delighted that Graeme Alexander has gallantly stepped forward to carry on where he left off…

A Date for your Diary 2020-21

Date	Time	Event
Sunday, 26 July 2020	**1100**	**WDSG-UK 10th AGM – Zoom Virtual Meeting — Details to follow**

WILSON'S DISEASE MULTIDISCIPLINARY CLINICS

The Birmingham WD Clinic

Dr Andrew Holt (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 Cheryl.Scandrett@uhb.nhs.uk. She is the WD Clinic Coordinator at Queen Elizabeth Hospital, Mindelsohn Way, Edgbaston, Birmingham, B15 2WB

The Cambridge WD Clinic

Dr Bill Griffiths (Consultant Hepatologist) and **Dr Paul Worth** (Consultant Neurologist) run a joint clinic every 6 months for patients with neurological manifestations of Wilson's disease at Addenbrooke's Hospital in Cambridge. Dr Griffiths sees a number of patients with hepatic-only disease separately in his adult genetic liver clinic. Both clinics run on Wednesday mornings. Referrals from clinicians can be made to Dr Griffiths at the Liver Unit, Box 210, Cambridge University Hospitals, Hills Road, Cambridge CB2 0QQ.

The Leeds WD Clinic

Dr Joanna Moore (Consultant Hepatologist) and **Dr Jeremy Cosgrove** (Consultant Neurologist) run a joint clinic for patients with Wilson's Disease at St James's University Hospital, Leeds. This currently runs on a Thursday morning. Referrals from clinicians can be made to Dr Moore at the Leeds Liver Unit, Merville Building, Beckett Street, Leeds LS9 7TF or Dr Cosgrove at Department of Neurology, F Floor, Martin Wing, Leeds General Infirmary, LS1 3EX.

The National Hospital Wilson's Clinic, Queen Square, London

A dedicated Wilson's disease clinic has been held at University College Hospitals for the past 30 years. It was set up in 1987 by Dr John Walshe after his retirement from Addenbrooke's Hospital, Cambridge and at the invitation of Dr Gerald Stern. **Dr Godfrey Gillett** started to attend in the mid-1990s and has continued the clinic under the kind auspices of Dr Robin Lachmann at the National Hospital for Neurology and Neurosurgery, Queen Square. The clinic is held on the third Friday of the month with the close involvement of **Professor Tom Warner, Dr Sam Shribman** and **Mrs Maggie Burrows**. There are currently 58 patients. Referrals from across the UK are welcome, addressed to Dr GT Gillett, Laboratory Medicine, Northern General Hospital, Sheffield Teaching Hospitals NHSFT, Herries Rd, Sheffield, S5 7AU or to Dr GT Gillett, Charles Dent Metabolic Unit, Internal Mailbox 92, NHNN, Queen Square, London WC1N 3BG.

The Sheffield WD Clinic

The Sheffield clinic is jointly run by **Prof Oliver Bandmann** (Consultant Neurologist), **Dr Godfrey Gillett** (Consultant in Clinical Biochemistry, Inherited Metabolic Disease, and Adviser to WDSG-UK) and **Dr Barbara Hoeroldt** (Consultant Hepatologist). 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 clinic.

** Royal Surrey County Hospital NHS Foundation Trust & University of Surrey, Guildford*

*The **Royal Surrey County Hospital** (RSCH) hosts regular multidisciplinary clinics to assess and manage patients with Wilson's disease. The team includes established consultant experts in Wilson's disease with focus on liver (**Prof. Ala**) and movement disorder (**Dr Jan Coeberg**), and has access to international clinical trials and patient registry programmes. Referrals should be addressed to the Centre Clinical Director, Professor Aftab Ala, Dept. of Gastroenterology and Hepatology, Royal Surrey County Hospital, Egerton Road, Guildford, Surrey GU2 7XX, email aftabala@nhs.net.*

*** Not confirmed at time of going to the printers'.**

Wilson's

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Dr John Walshe Honorary President, World Authority on Wilson's disease
Dr Godfrey Gillett Group Adviser, Honorary Member
Linda Hart: Group Co-Founder
Rupert Purchase, DPhil Group Adviser on trientine
Webmaster: **Blackcat Websites**

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 an early diagnosis.

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

We're on the web
www.wilsonsdisease.org.uk