Wilson's Disease Support Group UK

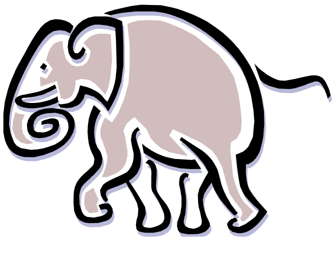
NEWSLETTER , VOLUME 3, ISSUE 2 NOVEMBER 2002

WELCOME !

The Wilson's Disease Support Group UK {WDSG-UK} is an all volunteer organisation which strives to promote the well-being of patients with Wilson's Disease and their families and friends. The organisation aims to provide informative articles about the nature of the disease, articles written by patients, families and friends about their experiences of the disease, recent progress in treatment and much more, by way of a biannual newsletter. The organisation also aims to promote networking of WD patients and their families by helping and encouraging them to correspond with each other. Finally, the organisation strives to generate a wider awareness of Wilson's Disease and its diagnosis within the medical profession.

Our Search For A Patron.

Dr J M Walshe.



WDSG - UK

At the September gathering of the Wilson's Disease Support Group, I told you briefly of our plans to ask Miss Ann Widdecombe to be our Patron and that she had expressed interest, and that Caroline Simms and myself planned to see her in October, and so we did.

On October the 14th we met up at Kings Cross station and took a taxi to her office at the corner of Whitehall and Parliament Square. We managed to persuade the security at the door that we were not terrorists, heavily disguised, and were let in. We were about a quarter of an hour early but after only a very brief wait we were ushered into her very comfortable reception room.

Miss Widdecombe was friendly but businesslike and to the point. We gave her a very brief account of the nature of the illness and your needs, particularly the justice of giving you all free prescriptions and possibly help in persuading insurance companies that you wont all drop dead as soon as taking out a policy!, but I'm not sure how she can help there. Miss Widdecombe kindly agreed to take on the patronage for a few years until we get established, but not indefinitely. She promised to let us have in writing her agreement, so until we have this we cannot officially claim her patronage.

Security being what it was, we had to be escorted out of the building. The young man deputised to this hazardous task seemed friendly, so I asked him where we could get a reasonable snack lunch, the reply was "sorry I'm new here, but the staff canteens are excellent." We wandered up Whitehall and looked in a couple of seedy pubs, as we got to the top, Caroline had her first glance of Trafalgar Square and Nelson's Column. I pointed out the National Gallery on the north side of the square and Caroline very astutely suggested that they would have as good a restaurant where we could get a snack. Entry now being free, we went in to see what fare they had to offer. Well Don't. It was very disappointing. From experience I can safely say that the Royal Academy is, or perhaps is it a long time since I have been there, much better. After which we taxied back to our respective stations and returned about our lawful occasions.

Wilson's Disease Support Group -UK, Volume 3, Issue 2

SCANDISHAKE MIX— NUTRITIONAL SUPPLEMENTS.

Caroline Simms.

It is commonly known for Wilson's Disease patients to have problems in being able to gain weight, particularly when in the situation of being newly diagnosed and symptomatic. It is a common question as to which nutritional supplements would be suitable for gaining weight, which may have been lost during the disease process (bearing in mind they should be low in copper or copper free).

Quite recently it has been brought to my attention that the product, SCANDISHAKE MIX, seems to be very suitable for weight gain!.

Scandishake has no added copper, other products seem to contain copper in the ingredients. The product comes in various flavours, including strawberry and banana, it is mixed with milk and taken as an addition to a diet avoiding high copper containing foods.

If you are interested in finding out more about this diet, please get in touch with a hospital dietician, or write to; SHS and Nutricia N.V SHS International Ltd, 100 Wavertree Boulevard, Liverpool, L7 9PT.

Do not fear going forward
slowly,

Fear only to stand still .

Belinda gets Packing at ASDA

Shortly after being diagnosed with Wilson's Disease, I found out about WDSG UK and became a member. I started writing to Linda who has been a great help to me. This was when I decided that I would do something to help the group in some way.

I came up with the idea of a bag pack at the supermarket where I work, but the next thing I needed was help to do it. My son is a member of the Local Air Cadets in St Helens where we live and so I thought I would ask them if they could help . They eagerly came to the rescue. Between us we organised a day to do it.

The fundraiser took place on Saturday May 11th 2002 and Officer Commanding Flt/Lt. Jon Baker said " It was a great pleasure to help such a worthwhile cause. Thanks must go to the staff at ASDA, St Helens for their support also."

W
D
S
G
-
U
K

This is me telling Ginny, one of my colleague's, all about Wilson's Disease.

"This was a great day: I was able to spread the word about Wilson's Disease and to collect the fantastic amount of £689 by just giving one day of my time. I am sure that most of us could give a little time to do some fund raising for the group and to spread the word to make people more aware of this illness."

"This is me and Joanne, the customer services manager, at ASDA St Helens, along with Officer Commanding of 969 squadron, FLT/LT. Jon Baker and the cadets, who gave up their time that Saturday morning to help the W.D.S.G.– U.K".

RED WINE OF NOVEMBER

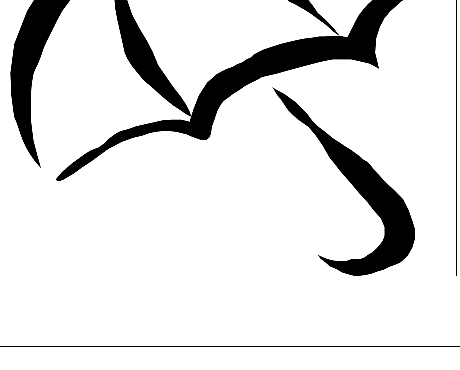
Poem by Steve Plowright

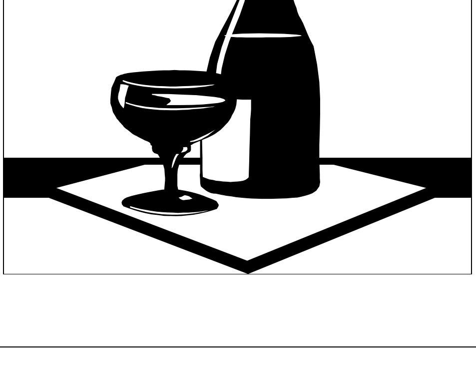
Come mist- laden days of decaying November
And burn on your bonfire old Autumn's last embers,
Enshrouded melancholic month to remember,
Pour out all your grief, let us share all you send us.

Damp, sodden squelching of composting leaves,
Drippings from overhead, tears of your grief,
Your days ever shortening, signifying retreat,
Like an aged old warrior, dignified in defeat.

Your days slowly turn towards the end of the year,
Nervous November now your dark days appear,
Can you kindle a glow through a tryst with the sun,
And give us a glimpse of a battle you’ve won.

All is not lost you have beauty indeed,
Though scanty with jollity, you’re not bitter with greed,
There’s a depth to your feelings when you let the sun shine,
Cold heart of November– you’re a fine old red wine.





WDSG-UK is an all volunteer organisation run by patients. Please direct questions you may have to Caroline Simms by post, e mail or phone, to the address on page 12.

WDSG-UK will do its best to answer your questions promptly or if we don't know, we will endeavour to put you in touch with someone who does!

We encourage you all to get involved with the group;
Write a story/article for the newsletter…..
Come to the meetings….
Tell your family/friends/Dr's about WDSG-UK

DONATIONS TO WDSG-UK

(above £25 are acknowledged in the newsletter)

Thank you to Joan Smith for £45 donation received in memory of her late father, Mr Harry Harrop.
At the family's request, any donations received in lieu of flowers were to be given to the Wilson's Disease Support Group.

* * *

Thank you to the family of Peter Bull, for £100 donation, in memory of Peter, who passed away on the 8th of October 2002

* * *

We would like to thank everyone for support of the group, in terms of membership monies and donations. All membership monies and donations go towards newsletter production and distribution of information.

WDSG-UK would also like to express sincere thanks to Anstead International, for their continued support and sponsorship of our newsletter.

If anyone would like a copy of the patients and family correspondence list, please drop a line to Linda at the address on page 12. We have around 50 people on the list, who would like to be in touch with other patients and families.

WENDY'S JOURNAL

Nearly ten years ago I was in the drum core of Morpeth Pipe band and we had just returned from playing in a music festival in Holland. I had been sick on and off fainting and occasionally having nose bleeds. It was all put down to puberty as I didn't feel ill. It was just that every now and again every three weeks I would throw up, have a nose bleed and then possibly feel faint. Then I started to get the nose bleeds more often, and I started to feel sick, really tired, I can remember thinking it was a lot like flu but without the blocked up feeling. So my mum took me to see my doctor and he said I probably picked up a virus on my travels, possibly a mild case of hepatitis. So he arranged to get my bloods checked and I went home with a comic, a bar of chocolate and a sore arm!

Over the next two days I got a lot worse. I couldn't stand up without getting dizzy or blacking out, then my mum noticed my eyes were bright yellow. She said "It's like something out of one of those horror movies" Thanks mum! So I went to bed and the doctor was called out, more blood was taken and sent off. My mum and dad were both advised that I could be 'highly infectious'. The doc went and returned with in two hours to take me to hospital. My blood count was 8 and was the reason for my tiredness and fainting and the nosebleeds. The doctor told me I had hepatitis B a very highly infectious disease I was 15 at the time and couldn't understand how I got it! So off I went to Ashington Hospital where the interrogation was to begin.

I was taken to casualty, where I was examined and even more blood was taken. I was asked the basic questions about sex, alcohol and smoking, I told them I hadn't done any of those things, but they kept on asking them again and again.

After I was admitted I was told that I was to be 'barrier nursed', which means I would be in a room by myself and anyone who came into the room had to wash and disinfect themselves before they came in and after they went out. They also had to wear gowns and masks. I also remember a rather horrid consultant, who ordered them to disinfect casualty department as I would have infected it. They then repeated all the questions about sex, drugs, and alcohol. They told my mum that I was pregnant I had a drug problem and I was an alcoholic. I had always been told to show respect for the medical profession but really this was the last straw. I told them if I was pregnant to call the Pope. I screamed at them that if they thought I was a drug addict then God help the other patients! What hope had they. I was barrier nursed for three days before they gave me a blood transfusion, my blood count was now 3 and I couldn't even lift my head without blacking out.

They finally admitted that I did not have Hep. B or any other viral hepatitis. They also admitted that they didn't have any idea what was causing my blood count to be so low. All they knew was my red blood cells were dying. They decided to see how I went on over the next few days. My Liver function tests were abnormal. I was still bright yellow but not dizzy. Tired and annoyed ,I went home. We travelled back and forth from the hospital, having blood tests and monitoring my progress.

continued on page 6

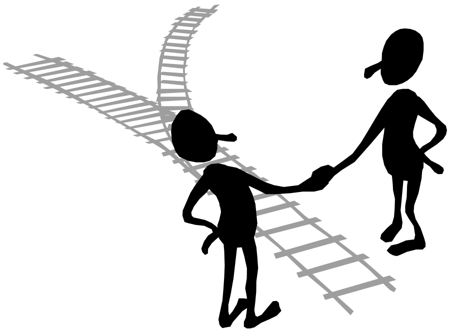
The only thing they found was my liver and spleen were enlarged, and oh, I had a few gallstones, which they thought unusual for a 15 year old.

Well! After three months of going round in circles and being tested for everything from lead poisoning to weird exotic diseases. The jaundice was barely noticeable on my skin but my eyes were still a pale yellow My then consultant took my case to a meeting at the Freeman Hospital where unusual cases were presented and discussed A question from the floor was asked.
"Has this girl been tested for Wilson's Disease"

So I went to the Freeman where I was to be tested for this 'new' disease. On arriving I didn't know a lot about it. I knew I was to get something called a 'liver biopsy' to see if I had too much copper, but other than that I knew very little. I had my eyes checked for KF rings. I had none. They repeated scans for liver damage, both ultra sounds and Ct scans.
I then had the dreaded liver biopsy. (I can completely sympathise with anyone who hates these!) They told me I had to wait for about 3 weeks for the results to come back. In the meantime I was to complete a 24hr urine collection. After this I was started on Penicillamine only a small dose then a few days later I had another 24 hour collection. Before I left hospital I had been unofficially diagnosed with Wilson's Disease and started the Penicillamine and Pyridoxine(B6) both in small quantities. So three weeks to the day the results came back from the labs that I had huge copper deposits in my liver and the diagnosis was confirmed. Over the next two months my dose increased to 4 x 250mg of Penicillamine and 50mg of Pyridoxine(B6) I have been on this dose ever since.

I still get angry at the original medical team for not listening to or believing me. That's probably why I am so brash with doctors now.! I lost my faith in them. That's one of the many reasons why I tried to find out more about Wilson's Disease by myself. I discovered the presence of this group. I had so many questions unanswered. Until 3 years ago I had never communicated with another WD patient.
"Alone" is such a small word that describes such a big feeling. I started to communicate via e-mail across the world to other patients and doctors and I slowly started to learn more about the Disease and how many different forms of it that there are, but most importantly I learnt how lucky I have been. I have fairly mild case. My liver has now recovered and my blood results are normal I have very minimal fibrosis. I have no psychological/ neurological symptoms. All in all I feel that I am very lucky. This August marks the 10th year since I was first taken to hospital and life is good

REMEMBER: The most important thing about a support group is communication amongst us. Passing on our experiences really does help. Not just bad experiences but the good ones too. More often we need reminding that ahead of us is not doom and gloom.



I heard from a lady in her mid 60's who is a retired nurse who trained here at Newcastle RVI.
Her message to me was quite simple. "Enjoy it!" It's taken a long time for me to come to terms with what I have and what my individual circumstances mean to me but it wasn't until I found others like me that I started to fully understand what it means to have WD and what that means in real terms.

By Wendy Craig. W.D. patient.

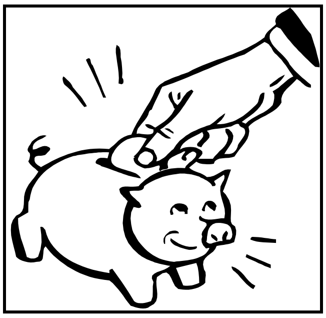
BRAINBOX TEASER

FINISHED FILES ARE THE RESULTS OF YEARS OF SCIENTIFIC STUDY COMBINED WITH THE EXPERIENCE OF YEARS.

1. READ THE SENTENCE IN THE BOX. Read it to yourself as many times as you like.
2. NOW COUNT ALOUD THE F'S IN THE BOX. Only once-and no going back .
3. NOW YOU'VE GOT YOUR TOTAL. Turn to page 12 to see how you fared.

COST OF PRESCRIPTIONS

A yearly paid prescription could save you money.
Do you know, you can pay your prescription charges for a year.
It's a standard charge, instead of £6.95 per item.
It is valid for the year, and can be used in any chemist or pharmacy.
So ask at your pharmacy,
you may get a pleasant surprise.



Wilson's Disease Support Group -UK, Volume 3 , Issue 2 .

A GOOD DAY OUT

Linda Hart

September 21st, a beautiful, sunny, late summer day, and the fourth meeting of the Wilson's Disease support group.

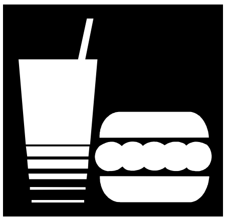
Once again a very enjoyable and productive day, many thanks to all who attended, to help make the day a success.

It was good to see quite a number of new faces as well as old friends.

Unfortunately Caroline and I were a little late arriving this year. This I must admit, was due to my navigational skills, which deserted me at 10.45 that morning! I normally cycle around the university campus, and have no trouble at all getting from A to B. This year we were driven by Calum, Caroline's long suffering partner, and we went in to the university by the North entrance, which completely threw me. We then spent the next 15 minutes driving around in circles, bumping into new students who were also lost!

Next year, as someone suggested, we will make every effort to ensure signs are put out near to the venue, enough said.

Tea and coffee was available on arrival. Many people had introduced themselves and were busily chatting, lunch was served from 12.30, and very nice it was too, not as much spicy food as last year, lots of sandwiches, sausages, quiche's and fresh fruit.



Afterwards Dr Walshe had a few words about our search for a patron.

The raffle was drawn, three super prizes this year, the 'Wilson's' lemon cookies in the hamper amused a few people!.

Dr Walshe attended the meeting, along with Kay Gibbs, who many of you will remember from Addenbrookes, and Dr Rupert Purchase, we were delighted to welcome them all again. Also this year we were pleased to welcome Dr Hal Dixon, a Biochemist from Cambridge, and academic colleague of Dr Walshe for many years. We were also delighted to welcome Pauline Davies, representing Anstead International, the makers of Trientine. Thank you all for your support.

It is always quite an informal and sociable gathering, and we hope everyone who attended gained something from the day. Many people have said to me that since they joined the group and / or have come to meetings, they have not felt so isolated. I know many people now keep in touch, which is very encouraging.

From experience, I know how difficult it is not to know anyone else with WD, who understands your problems and with whom you can compare notes. So just from that point I feel that the group is a success, and we can only go on to better things…...

We sincerely hope to see you all again next year, and many new friends too.

So until then I hope you all stay cold and flu free through the winter.

Photos from the 4th WDSG-UK meeting

Kay, Helen, Joan and her daughter Ruth.

The Vaughn family, Jay, Kevin and Sandra, along with Caroline.

FOOD FOR THOUGHT

By Wendy Craig , WD Patient.

When I was first diagnosed in November 1992 one of the first things I remember being told was about avoiding a high copper diet. At the time I had a large box of Malteasers next to my bed and my Consultant proceeded to hand my chocs to the medical Students as he told me they were HIGH in copper and it was in my best interest. I was very sceptical about this at the time and thought he was just having a bit of a joke, giving a treat to the medical students who had gathered over previous days to see the strange and interesting case in Cubicle 5. Well, as I became more aware that this was indeed true (i.e. about high copper content foods) the questions started to roll in. What foods were 'high in Copper?' Could I indeed have a copper free diet?"

I am what my mum calls a 'good eater' and when I was told the list my heart sank, as many of the items on the list were some of my favourite foods Mushrooms, in particular, are a great favourite of mine. To look on the brighter side at least now I had a good excuse never to eat nuts again!

Many of you out there will have faced the same scenarios as I but maybe some of will have encountered a completely different scenario, perhaps difficulties with food allergies or even diabetes. Are you a Vegetarian who's trying to live with WD? If you are then I would like to hear from you. I would like to know how you overcame your problem how did you overcome the temptation of eating stuffed garlic mushrooms as a light snack. What would have helped me overcome my fears of never being able to eat another mushroom, in case of it caused my liver to explode, would have been to have had a good book that explained things and gave me examples.

So I would like to collect and document as many recipes as possible maybe your favourite meal de-coppered. All kinds will be acceptable starters, main courses, sweets, snacks, FUN STUFF in fact anything to do with food! The pet things you hated when you were first diagnosed. Even if its two waffles and a burger I want to know!

The book will help newly diagnosed patients come to terms with the impact food has on the disease. The book will introduce helpful advice and guidance from the people who know and are respected in their field.

So please send any recipes to: Wendy Craig, 2 Bamburgh Drive, Pegswood, Morpeth, Northumberland, NE61 6TT , or email : w.l.craig@freeuk.com

Wilsons Disease Support Group UK

For membership, correspondance, and information

Contact : Dr Caroline Simms (group chairperson and coordinator, newsletter production, information and awareness)
36, Sunningdale Drive, Woodborough, Nottingham. NG14 6EQ.
e.mail : wdsguk@ hotmail.com

If you would like to be put in touch with others with WD

Contact : Linda Hart (patient and family corresspondance coordinator, newsletter production)
36, Audley Drive, Lenton Abbey, Beeston, Nottingham. NG9 2SF.

Mrs Valerie Wheater (Coordinator and group liason, interest in genealogy)
38, Grantchester Road, Cambridge. CB3 9ED.

Ann Widecombe M.P. - group patron
Dr John Walshe - honorary president, medical expert and world authority on Wilson's Disease
Dr Godfrey Gillett - group advisor, honorary member
Dr Alan Stevens - group advisor
Dr Jim Lowe - group advisor

WILSONS DISEASE SUPPORT GROUP UK

W
D
S
G
U
K

Tell others about the WDSG-UK

Please tell others who you may know who have WD, who might benefit from the support group and what we are doing.

Inform your family, friends, consultant physicians, GP surgery, local MP's about WDSG-UK

The more people who know about us , the more we can promote a better awareness of Wilson's Disease within the community and the better the chance of early diagnosis of WD for future WD patients.

If more copies of this newsletter are required, please contact:
Dr Caroline Simms
36, Sunningdale Drive, Woodborough,
Nottingham. NG14 6EQ.
e.mail : wdsguk@hotmail.com

BRAINBOX TEASER– HOW DID YOU DO?
There are SIX F's in the sentence. On average most people find three,
If you got 4, you're smarter than average.
If you got 5, a real brain box.
Got all 6? You're the sort of genius who shouldn't be wasting time on such nonsense!