Wilson's Disease Support Group-UK

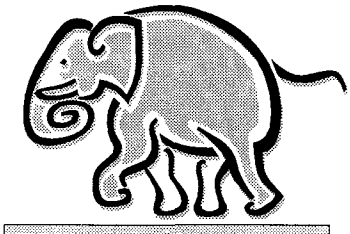
NEWSLETTER, VOLUME 4, ISSUE 2 DECEMBER 2003

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, 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 one another. The organisation also strives to promote a wider awareness of Wilson's Disease within the medical profession If you have any questions regarding any aspect of WD please contact WDSG-UK at 33, Cavendish Street, Arnold, Nottingham NG5 7DL. We will do our very best to answer them as swiftly as possible

THE FIRST WORD.....



WDSG - UK

To our disappointment, the 5th meeting of the Wilson's Disease Support Group U.K had to be cancelled. The reason for this was the lack of interest in attending from the majority of our members. Previous events have been very successful and people who attended generally enjoyed the day. Though we appreciate that there may be several reasons why people find it difficult to get to the meetings, please do not forget that these meetings are organised for you. As patients, family or friends it is vital that we continue to work together and WDSG-UK feel that your attendance at such meetings allows the network to continue so that we can all help the cause which is so close to all of us and affects us in some way. We are hoping to organise the next "get together" in spring 2004 and hope many of you will make the special effort to attend.

Those of you who have been to previous events will remember that they are very informal and give you the opportunity to meet old friends and make new ones, ask questions and put your ideas for the support group forward. Your ideas are very welcome. So, we look forward to seeing you in the Spring.

On a further note WDSG have noticed that there has been a significant decline in the renewal of memberships this year, this is concerning! We need your continuing support to keep WDSG-UK alive! If you want to be involved in some way and care to help future generations cope with living with Wilson's Disease then...at least renew your memberships so we can send you the newsletter and keep you informed.

Wilson's Disease Support Group-UK, Volume 4 Issue 2

MY STORY BY JANE RIDLEY

I was born an only child in 1957, but it all began sometime back in 1978. I had been to London with friends to see the television recording of Top of the Pops, we decided to stay overnight. We stayed at the Great Northern Hotel at Kings Cross. What a dive, I would not recommend it. Anyway I had eaten a packet of peanuts and got a bit stuck in my tooth, I tried to get it out with my tongue when my jaw locked. I was rushed to a dental hospital close by, where they put it back into place. When it happened I thought that was the end for me, I could not talk or move my mouth for about three hours and my jaw seemed to be getting tighter and stiffer. What a relief when they unlocked it.

After that is when all my problems started. In those days I worked in Woolworths in a town called Holbeach in Lincolnshire, I used to stack shelves and work on the till. I noticed, soon after my jaw had locked, that I was making a lot of saliva and I could not control it. I started to dribble like babies do when they are teething, it got to a stage where it became embarrassing. Customers used to stare and snigger. I went to see my GP who gave me some tablets to try and dry the saliva up, but they did not work, so I went back to him, I recall going back a couple of times, and then he decided to admit me to the Pilgrim Hospital in Boston for tests. I was in hospital for about ten days, then they sent me home because they could not find anything wrong. They said it was all in my mind and that I was to pull myself together. My mum was not very happy with this, so we went back to the GP and my mum asked for a second opinion. He sent me to see a psychiatrist. I explained to him what was happening. He gave me an injection in my bottom and told me to go back and see him a month later, which I did. He asked me if the injection, which was meant to dry up the saliva, had worked. It had for a while but every time I went back to see him I was dribbling again. I saw him for about five months then he said that he didn't know what was wrong and that he wanted to send me to Addenbrookes to see a doctor there higher than himself, I think his name was Dr Yearlands

I had to wait a couple of months for an appointment and we went along to see him. He took some blood to test and asked us to wait for the results, which would take a couple of hours. When he got the results he referred me to Dr Walshe and I was told that I had Wilson's Disease.

I was diagnosed on the 14th April 1979, and admitted to Addenbrookes for tests, blood tests, brain scans, 24hr urine collection etc: I had lovely kayser fleischer rings in my eyes at the time and was very ill, I had lost a lot of weight I went down to just under five stones and got so weak that I could not walk.(I have since packed the weight back on, I call it middle aged spread!) I could not walk or talk properly, because of the saliva my speech was slurred, and people could not understand what I said, Dr Walshe lent me a communicating machine, so that I typed out what I wanted to say.

I was in hospital for a very long time. Everyone thought I was going to die. I was put on Trientine, (it was a high dose and it made me anaemic). I had a blood transfusion and was then put on Distamine.

I cannot remember exactly when it happened, it seemed to happen overnight, my left hand started to bend down, my wrist twisted round, my finger bent down and my knuckles went down into the palm of my hand, all due to Wilson's Disease. While I was in hospital I could not cut my food, I asked the nurse's and matron if they would cut my food for me, they said I was to try myself or I would never get better. The matron on the ward was horrible, when Dr Walshe found out he would come up to the ward at meal times to cut my food up or take the Clingfilm off my sandwiches. After about six weeks of being in hospital I started to pull through and get a bit better. I was sent over to the rehab. Department to do exercises on my legs and my left hand, also I went to speech therapy. Eventually my speech came back but I think it has left my speech a bit abnormal. I also began to walk again. The only thing that has never got better to this day is my left hand, I have a deformed left hand and I can only move my thumb, I have had my wrist operated on and the doctors have taken the moving ball joint out and fixed my wrist so I am permanenently disabled. I have not worked since being diagnosed all those years ago.

I am now 45 years old, I got married for the second time on July 4th 1987 in Bow, East London. My first marriage broke up when I was very ill. I had a daughter on May 21st 1988 she is doing her GCSE's, she is very pretty and has escaped the dreaded disease, thank God. I was brought up in Lincolnshire, lived in Poplar, East London for ten years and moved to Peterborough five years ago.

It will be 25 years this coming April since I was diagnosed and I'm back on the Trientine capsules now. My health has not been very great and I've been in and out of hospital quite a few times, and got better. I hope that I've got a good few years left in me to come. I have adapted to my disability

I would like to say a big THANK YOU to Dr Walshe and Kay for getting me better. If it was not for them I would not be here today to tell my story.

I have made some new friends who, like me, have Wilson's Disease. I keep in touch with two of them by writing regularly. If anyone else would like to write to me, you can get my address from Linda Hart, it would be lovely to hear from you!

I class myself as one of the lucky ones.

DONATIONS

Special thanks to the following members:

Philip and Tulin Hawkins— £40
Anjeli Karandikar—£25

Please send your questions, articles, stories to Linda at WDSG-UK (see address p8)

We welcome these for publication in future editions of our newsletter and thank those of you who have already sent items for publication ... keep 'em coming!!!

The Umbrella's Invention

Under a toadstool crept a wee elf,
out of the rain to shelter himself,
under the toadstool sound asleep
sat a big dormouse, all in a heap,
trembled the wee elf, frightened and yet
fearing to fly lest he got wet,
he tugged 'till the toadstool toppled in two,
holding it over him gaily he flew.
Soon he was home, safe and dry as could be,
then woke the dormouse, good gracious me,
Where is my toadstool loud he lamented,
and that's how umbrella's
First were invented.

FATTY LIVER

British Liver Trust– Information Service.

What is fatty liver?

Fatty liver is not a liver disease as such. It simply means there is more fat in the liver than normal. A person with a fatty liver is not necessarily ill.

What causes fatty liver?

Fatty liver can be caused by certain chemical compounds and by nutritional and endocrine disorders. Drugs or poisons that can cause fatty liver include alcohol, tetracycline, cortisone, phosphorus and carbon tetrachloride. Of these alcohol is by far the most common cause.

Nutritional causes of fatty liver are starvation, obesity, protein malnutrition and intestinal bypass operations for obesity. In obesity the fatty deposits are occasionally accompanied by some inflammatory changes and scarring of the liver. The endocrine disorder diabetes mellitus often leads to fatty liver. In juvenile diabetes the fat may be rapidly deposited leading to tenderness in the upper right of the abdomen.

Fatty liver of pregnancy is a serious condition occurring near term. Premature termination of pregnancy may be necessary . Delivery of the baby by Caesarian section may be a life-saving measure.

What are the symptoms?

Uncomplicated fatty liver does not usually produce symptoms because fat accumulates slowly. A doctor may be able to detect that the liver is enlarged by palpation (an examination by touch). When the fat content is increased rapidly the liver expands, stretching its covering, and pain results.

In fatty liver of pregnancy there may be nausea, vomiting, abdominal pain and jaundice.

How does fat get into the liver?

Fat enters the liver from the intestines and from the tissues. Under normal conditions, fat from the liver is metabolized by the liver and other tissues. If the amount exceeds what is required by the body it is stored. In obesity some of the fat accumulates in the liver.

Can fatty liver lead to other liver disease?

Fatty liver in people who drink too much alcohol is sometimes followed by more serious liver damage in the form of alcoholic hepatitis. Serious liver damage is less common in diabetes and obese people who don't drink but it does sometimes occur.

How is fatty liver treated?

Treatment of fatty liver is related to the cause. Underlying conditions such as diabetes require treatment. Fat is decreased by removal of any drugs or other chemical compounds thought to be responsible. Nutritional causes are treated by altering the availability of fat coming into the liver. This is accomplished by providing available carbohydrates or by adding protein to overcome a complete or large deficiency in protein needed to make lipoproteins

(proteins linked to fat and not capable of being dissolved in water).

How can I avoid fatty liver?

Do not drink to excess: alcohol can decrease the rate of metabolism and secretion of fat, leading to fatty liver. Overweight patients may have fatty liver, and are also at risk for several more serious conditions such as high blood pressure, stroke, diabetes and heart disease.

It is a good idea to watch your diet : starvation, excess dieting and protein malnutrition can also result in fatty liver.

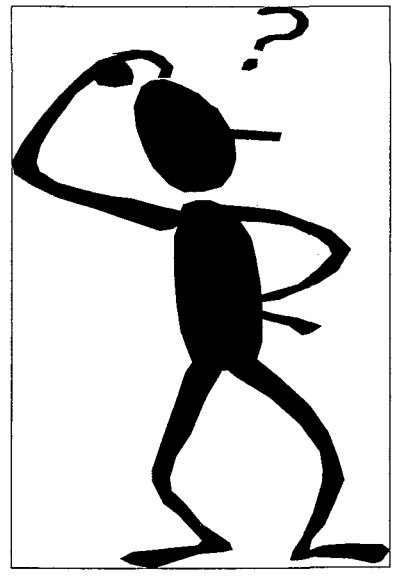
The British Liver Trust is the only national charity in this country dedicated to fighting all adult liver diseases through research and education. Experts estimate that more than half of all liver diseases could be prevented if people acted upon the knowledge we already have

PAST, PRESENT and FUTURE....

Written by Caroline

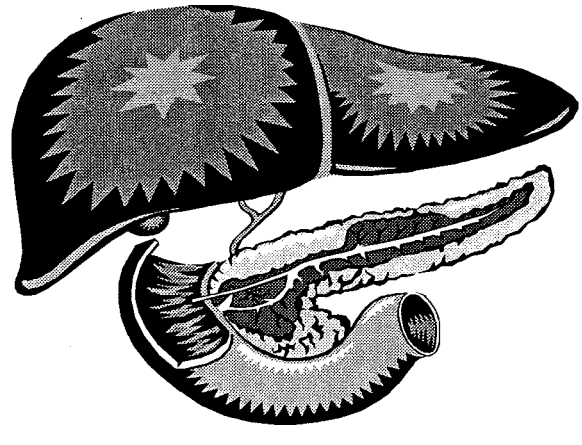
It has been 12 years now since I was told my liver was in bad shape. Bad shape for me means Chronic Cirrhosis and portal hypertension (pressure at the liver). Though the frequency of my endoscopies is far less than it was, (annually in December) I have numerous other complications, all liver related, and caused by Wilson's Disease and the damage the copper did before my diagnosis in 1987. Major concerns include a very low platelet count, hyperspleenism, varicies, gall stones, chronic tiredness, memory loss. From a personal point of view I would say that the tiredness and memory loss are the biggest frustration.

At 30 years old there is so much I want to do but can't because I always feel so tired. And the biological clock is ticking away! Though having children is not a major consideration for having a transplant but it would be nice to have the option. In my present condition this is not a viable possibility.



So after 12 years of worry and 5 years deliberation on Liver Transplant, I have come to the decision that my time is now. I was 30 years old in July and feel this was a real turning point in terms of my health and my future. Yes, sure I could wait as my liver gets steadily worse over the ensuing years, but the fact remains my liver will not get better, only steadily worse.

So with this in mind I have made the choice to have my transplant and hopefully have a much better quality of life, a quality of life I have forgotten. After all it has been near 20 years since I first fell ill with WD.



Questions and answers

Q/Am I scared?
A/Yes. Who in their right might wouldn't be. In fact I am terrified. The way I overcome the fear is by focusing on what I will have afterwards. A second chance, energy, etc...

Q/Will the Transplant be successful?
A/I am told 95% success after 1 year (that means 95% of transplant recipients are alive after 1 year). To me that it pretty successful odds!!!!!

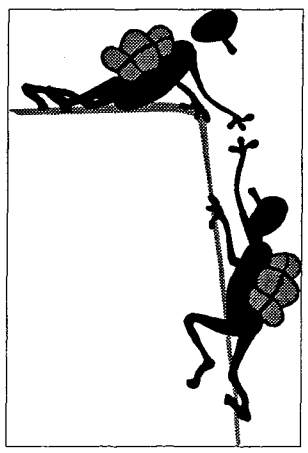
Q/How long is the operation?
A/In the region of 6 to 10 hours usually

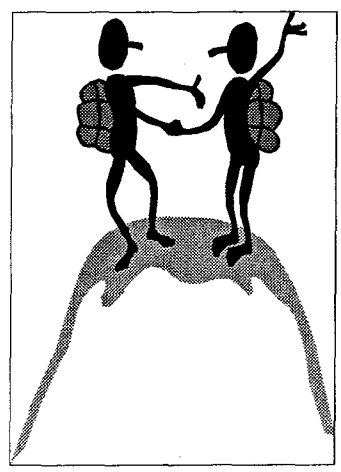
Q/How long is the recovery period?
A/This could be weeks to months. Depends on any complications which may occur and patients attitude (mind over matter kind of thing.....)

Q/Will I still have WD?
A/Physically no. Genetically yes. Neurological symptoms I still have may also remain post transplant.

This will not be easy journey, but I also know that I will come through it with support from the people closest to me. I have met people who have had their TX and they give me the hope and strength to go through it. Most of these people say that the only regret they have is "they didn't decide to go for TX sooner".
To receive a donor organ is a great gift, possibly the greatest gift someone could give, particularly because organ donation can only happen when someone else's life is lost. If I am given such a gift I shall be grateful for my second chance I shall live a life which I would not have known without it.

I will go on the active list for Liver Transplant in January 2004





Wilsons Disease Support Group UK

For membership, correspondence, and information

Contact : Dr Caroline Simms (group chairperson and coordinator, newsletter production, information and awareness)
33, Cavendish Street, Arnold, Nottingham. NG5 8DL

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

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

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

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

Tell others about the WDSG-UK

Please tell others who you may know have WD, and 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 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:
Linda Hart
36, Audley Drive, Lenton Abbey, Beeston, Nottingham. NG9 2SF.

W D S G U K

We're on the web
www.wilsons-disease.org.uk