

Welcome!

The Wilson's Disease Support Group UK (WDSG-UK) is an all volunteer organisation which strives to promote the wellbeing of patients with Wilson's Disease, their families and friends. The organisation aims to provide informative articles about the nature of the disease, articles written by patients, families and friends about their experiences of the disease, recent progress in treatment and much more by way of 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 generate a wider awareness of Wilson's Disease within the medical profession. If you have any questions regarding any aspects of Wilson's Disease please contact WDSG-UK at c/o 36, Sunningdale Drive, Woodborough, Nottingham. NG14 6EQ. We will do our very best to answer them as swiftly as possible.

WILSON'S DISEASE SUPPORT GROUP - UK

May 2002

Volume 3, Issue 1

WDSG - UK

WE NEED YOUR HELP!

Plans to do a poster, information leaflet, newsletter distribution to Hospital Clinics GP surgeries and Libraries UK wide

In order to spread a greater awareness of WD within the general community across the UK we the organising committee are distributing the 6th edition of the WDSG - UK newsletter to hospital outpatient clinics (hepatology, neurology and gastroenterology) UK wide. This is an **ambitious goal for WDSG -UK to achieve** given our limited funds but we feel it **will be well worthwhile for the**

future of WD sufferers. If we can generate a greater awareness then perhaps people born with this condition will be diagnosed earlier. Perhaps when you have mentioned WD to people you hear the common response is "Whats that?" Or "I've not heard of that before."

Meanwhile we have included a copy of the WDSG-UK pamphlet and a poster with this newsletter. **Next time you go to your GP, hospital clinic and if you have a local library please take one with you.** Ask the clinic receptionist/

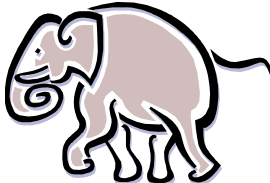


Spread information to increase awareness

secretary/administrator, library administrator to display a poster/pamphlet on public notice board! And **feel free to make more copies** of these to distribute to friends/relatives if they can help too!). **By doing this you can help us spread the word!**

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 ★ **A date for your diary!**
 ★ The next WDSG-UK event will be on
 ★ Saturday 21st September, 2002
 ★ At Nottingham University Staff Club
 ★ 11am to 3pm (details on page 4!)
 ★ *****



WDSG - UK

The Bioartificial Liver

by Prof. H.J.F. Hodgson, Centre of Hepatology, Royal Free Hospital, London.

The 20th Century saw huge advances in medical care, particularly in artificial organs. The artificial kidney was invented in the 1950s and has been progressively improved. The heart-lung machine was also invented in the 1950s. Why is an artificial liver taking so long? The answer is of course that the liver is much more complicated than those other organs. Each of the others is concentrating on performing one function. The kidney is a filter; the heart is a pump. The liver is much more complex. It is a chemical factory, making hundreds of different substances. It processes our food, and keeps our body energy supplies stable by breaking down and converting fats and sugars. It processes toxins; those made outside the body and those that we eat, to make them safe. Nobody has ever counted the number of different processes that the liver can perform, but it must be well over 1,000.



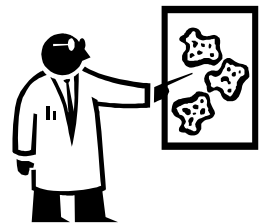
As a result nobody has yet successfully designed a machine to replace all those functions. Some workers have tried very simple machines to replace some of the functions, for example removing simple toxins, but they were not effective. The sheer complexity persuaded most people that if a liver machine were to be effective, it would have to contain living cells. In other words, only liver cells can replace liver function.

So in principle a liver machine is straightforward. A few - or rather thousands of millions of liver cells - growing in a culture vessel. Some of the blood from a patient with severe liver disease will be passed via plastic tubes into the culture vessel; the liver cells would purify the blood, just as they do in the body. The improved blood would return through the tubes to the patient.

If the idea is so simple - what is so difficult? The answer is unfortunately - lots of things. It is quite difficult to get liver cells to survive in culture, and particularly difficult to get them to continue to

function as well in culture as they do in the body. It is difficult to get liver cells to grow in appropriate numbers in culture - and that is going to be essential to make the machine a reality. The thousands of millions of liver cells have got to be packed at high density, so that the machine is compact enough to be connected to a patient's circulation. So there are a whole set of bioengineering designs.

Who would benefit from such a machine? Initially there are two main groups of patients who might benefit. The first is the patient with such severe acute hepatitis that currently transplantation is the only option. If a liver machine could temporarily replace the function of the liver, this might allow time for the damaged liver to regenerate. If that would be successful, it would be a marvelous achievement, as the severely damaged liver, given time, is capable of complete recovery to normality.



The second situation is when a patient is awaiting a transplant and the function of the liver, either suddenly or as in a complication of cirrhosis, deteriorates further. In that case if a donor organ was not available immediately, the artificial liver could again buy time until one was.

A number of groups internationally are working on the problem, but no one has come up with a practical machine. However, so much more is now known about what makes liver cells grow and what keeps them functioning properly, that at long-last the goal is beginning to appear close. In particular the approaches that Professor Hodgson's team are investigating include new techniques to grow liver cells compactly, in a system that keeps the liver cells in normal shape, based on culturing liver cells in droplets of a jelly-like substance called Alginate. This, together with a set of liver cells developed by collaborators in Canada, are producing valuable information which should contribute to what has been described as the "holy grail" of liver research.

I'm Not a Natural Driver ! - by Caroline Simms

Well after putting off learning to drive for too long , my friends finally convinced me that I should have a go at learning. Lets just say some people should not be allowed on the roads! OK I managed to get through 7 years at Uni studying Chemistry (which most people think is a difficult subject!) but driving is quite different to academic Chemistry. Driving is a very practical task (some assume easy..... not me!) and is quite different to having your head in a textbook of

abstract chemical formulae. My previous instructor despaired when I reversed round a corner in 4th gear (I didn't even realise!). I am now looking for a new instructor because I have moved to Loughborough. And I shall not let this difficult task beat me, despite driving being made more difficult by having WD.



To renew your membership for this year:

Send dues to Linda Hart
 36, Audley Drive,
 Lenton Abbey,
 Beeston,
 Nottingham. NG9 2SF.

Never give in the fight!
 Put one foot forward and you can reach for the stars.



Membership Renewal Form 2002

I still wish to receive the WDSG-UK biannual Newsletter

Name:.....

Address:.....

Email:.....

UK Membership: I enclose a check/postal order of £5 for my annual membership

USA/Canada membership: \$10 (Please note we cannot accept non-UK cheques but can accept IMO's (International Money Orders) or \$10 bills by registered post.

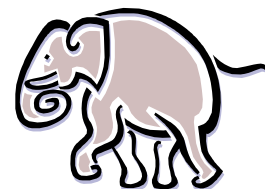
I wish to donate £ To WDSG-UK

(All cheques/postal orders should be made payable to Wilsons Disease Support Group-UK

N.B. Those of you who have already paid your 2002 subscription may ignore this form

Please note if you have not renewed your membership for this year we regret that we will not be able to send you future newsletters unless you complete and return this form before September.

A DATE FOR YOUR DIARY — don't miss it !!!
4th WDSG-UK Meeting, 21st September 2002



WDSG - UK

We are holding another event in Nottingham on 21st September 2002.

Event Details:

Venue :Nottingham University Staff Club, Nottingham.

Date : Saturday 21st September 2002

Time : 11am till 3pm *(Please note that we have to vacate the club at 3pm prompt!)*

Cost : £5 per person *(to cover buffet and room hire cost)*

Important: If you would like to attend please return cheque (£5 per person) in advance along completed form (name, address and stating clearly no of people coming) . Unfortunately we can only book you a place if payment is received in advance.

Maps and final details of itinerary will be sent 3 weeks prior to the event date.

If you've not been before the day is quite informal. People usually get a lot out of the event. It's a chance to meet others make contacts, friends, ask questions.

We hope that Dr Walshe and Dr Gillett will attend again.

We look forward to seeing many of you there !!!



I / we are coming to the 4th WDSG-UK Meeting in Nottingham
 Please book me place/places in advance

Please **find enclosed a cheque** for £ **(made payable to WDSG-UK)** for Person / people
 for **tickets in advance.**

Name :.....

Address :.....

Delete as appropriate:

We will be travelling by car / train / coach

Please send / do not send details of hotel accomodation in Nottingham

Please complete and cut out this form (membership renewal is on the other side!) and **return to :**
Linda Hart at 36, Audley Drive, Lenton Abbey, Beeston, Nottingham. NG9 2SF.

Winter Blues

By Linda Hart

Hello everyone! I hope the year is treating you all well. I've not much of any great interest to report because I've not been on any seek and destroy missions of late..

I tend to get a little glum in November and it usually lasts till February Caroline informs me its me that SAD disorder exists (Seasonal Adjustment Disorder), its apparently due to lack of sunlight (do scientists have an answer for everything?). So on the plus side an upturn is immanent because its now March!

John and I both managed to catch the Flu virus that was doing the rounds at Christmas. Why are nasty colds always called "viruses" nowadays, like shampoos being known as hair care systems—very irritating ! It (the virus) very nicely arrived the day before Christmas eve and needless to say put a complete KYBOSH on all festive plans. We both felt truly lousy. However a bright spot came on Christmas eve which cheered us both. I opened the back door for a breath of fresh air where (to my astonishment) standing on the doormat was a 3ft Santa surrounded by carrier bags! Inside the bags I found tins of soup, fresh fruit, bread, chocolate, Kleenex tissues (the posh ones with Balsam), paracetamol tablets, bubble bath and all manner of goodies! Whilst still puzzling as to where these gifts had come from I received a text message, telling me to open the back door—Caroline !!!

I should have known but it was a terrific present and a total surprise also proving extremely useful because we were both too ill to go shopping. I didn't ask too many questions about where Caroline had acquired the 3ft Santa Clause , but I have a good idea I heard a rumour that a certain Santa had gone AWOL in the region of West Yorkshire!

Though both John and I were a bit dubious about the Haggis Broth we ate it anyway



(perhaps the bonus of having a bad cold is that the sense of taste disappears!).

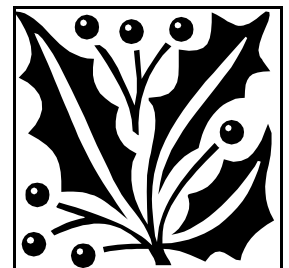
Needless to say Christmas came and went , and we survived, fortified by all the above. On New years Eve we went out our local folk club and made the most of the celebrations. I have vague recollections of trying to play the spoons and a sad attempt to sing Whisky in the Jar, a good time was had by all..

I took my book-keeping exam in January, no results as yet (mid March I

think we get them). I found the course quite challenging and most people in the class had a knowledge of the subject and were there mainly to get their certificate in book-keeping rather than for the sheer hell of it!

The course tutor went off sick a month before Christmas with **STRESS!!!** This unsettled me.

During the exam I felt so nervous I almost choked to death on an extra strong mint, Having a coughing fit during an exam is not the best way to gain popularity. Oh well, not to worry, if I've failed it's back to the drawing board to resit the exam later this year. I'm especially looking forward to the next WDSG-UK meeting in September. It's always nice to meet old friends and to make some new ones. So I hope to see you there. Enjoy the Spring and Summer !



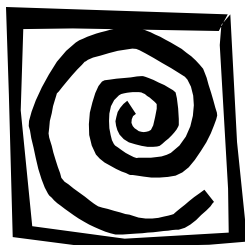
DONATIONS TO WDSG - UK (above £25 are acknowledged in the newsletter)

Maureen Adams - £25 Donation in memory of her father, who passed away in late September 2001

Peggy Mace - £60 Donation

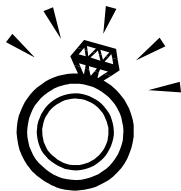
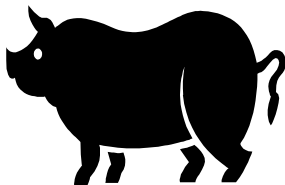
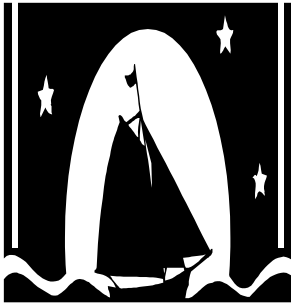
Isabel Smith - for numerous donations to and many kind words in support of WDSG-UK

Deepa and Sonny Sharma - £50 Donation



The spiral of life is never-ending...

We would like to thank everyone for support of the group in terms of membership monies and donations. All memberships and donations go towards newsletter production and distribution of information. WDSG-UK is an all volunteer organisation.



The Owl and the Pussy-Cat

The Owl and the Pussy-Cat
Went to sea
In a beautiful pea-green boat:
They took some honey,
And plenty of money
Wrapped up in a five-pound note

The Owl looked up to the stars above,
And sang to a small guitar,
“Oh lovely Pussy, Oh pussy, my love,
What a beautiful Pussy you are,
You are,
You are!
What a beautiful Pussy you are!”

Pussy said to the Owl,
“You elegant fowl,
How charmingly sweet you sing!
Oh let us be married;
Too long we have tarried:
But what shall we do for a ring?”

They sailed away, for a year and a day,
To the land where the bong-tree grows;
And there in a wood a piggy-wig stood,
With a ring at the end of his nose,
His nose,
His nose!
With a ring at the end of his nose.

“Dear pig are you willing to sell for one shilling
Your ring?” Said the Piggy, “I will.”
So they took it away,
and were married next day

By the turkey who lives on the hill.
They dined on mince and slices of quince,
Which they ate with a runcible spoon;

And hand in hand on the edge of the sand
They danced by the light of the moon,
The moon
The moon!
They danced by the light of the moon.

**WILSON'S DISEASE
SUPPORT GROUP - UK**

c/o 36, Sunningdale Drive
Woodborough
Nottingham
NG14 6EQ

Phone: 07870 636370 (7 - 9p.m.)
Email: carolinesimms@hotmail.com

Working towards a better awareness

WDSG-UK is an all volunteer organisation run by patients. Please direct questions you may have to Caroline Simms by post, email or phone.

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 our meeting on September 21st 2002

Tell your family/friends/Dr's about WDSG-UK

Wilson's Disease Support Group UK

For membership, correspondence, and information

Contact : **Dr Caroline Simms** (group chairperson and coordinator, membership coordination)
36, Sunningdale Drive, Woodborough, Nottingham. NG14 6EQ.
e.mail : carolinesimms@ hotmail.com

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

Contact : **Ms Linda Hart** (membership secretary, patient and family correspondence coordinator)

Ms Ursula Mott (Group coordinator and contact for London and the South of England)
4, Holders Hill Parade, Holders Hill Road, London. NW7.

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

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

Professor Jim Lowe - webmaster

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