Wilson's Disease Support Group-UK

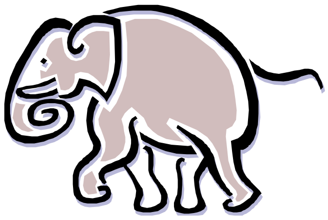
Newsletter, volume 5, issue 2 March 2005

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 36 Sunningdale Drive, Woodborough, Nottingham NG5 7DL. We will do our very best to answer them as swiftly as possible

AT LAST!



WDSG - UK

But better late than never, welcome to the 10th edition of our newsletter.
Over the next few months we shall be making major changes to the organisation and day to day running of the support group and hope that you will bear with us during this time, we will of course keep our members informed of what is happening.
Over the last year we have received two major donations, one from a sponsored walk by the Southport Lions, organised by Barry Diggles, story and photographs on pages 6 and 7.The second a large donation of £500 from fundraising by the Catenian Association in Accrington Lancashire forwarded to us by Mrs M Wilson, these have given an enormous boost to our funds and we would like to offer our sincere thanks to all concerned for their tremendous efforts.
Enjoy reading the newsletter and a belated Happy New Year to everyone, hope you all have a brilliant one.
Some words of wisdom I read recently I would like to leave you with…

Do not always follow where the path may lead,
Go, instead,
Where there is no path
And leave a trail.

Linda

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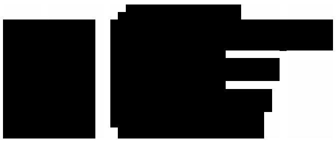
Your support group needs



YOU

As mentioned on page one the support group is undergoing changes.
We need your help, your skills, your talents!
Anything anyone out there can do from origami, to recipes to organising skills, writing funny stories, your own stories anything at all, please get in touch.
To keep running as a support group and running well, we need your input and support.

SO COME ON YOU TALENTED BUNCH
LETS HEAR FROM YOU!

We still have T shirts available to buy.
They are in black or white good quality cotton, with our logo front and back, (as modelled so well by Barry-see page 6!)
sizes S.M. or L at £10 each

WILSON’S DISEASE

My story by Sue Boysons

My story began in April 1983 when I was working as a midwife at Watford General Hospital. I was 26 years old and had been married to Chris for three years, when I woke up jaundiced one weekend. Prior to this I had been feeling very tired, seemed to have permanent indigestion and been losing weight which I had blamed on night duty.

At the time Chris was working in the Shetland Islands and we were due to go on holiday to Crete in a couple of days time. Initially everyone, including myself, thought I had infectious hepatitis and because I was working in the special care baby unit there was quite a fuss at work. Chris came home we cancelled the holiday and to cut a long story short after six months of investigations Wilson’s Disease was diagnosed by the Royal Free Hospital in November 1993.

I can remember the day quite vividly because I had been an inpatient for two weeks undergoing various tests and been told that I had chronic active liver cirrhosis so had realised that my number was up. My consultant had sent me to the ophthalmic department to have my eyes examined and the registrar was so excited when he looked into my eyes he exclaimed “Mrs Boysons you are a very lucky lady you are not going to die from liver disease, you have Wilson’s Disease”.

I was none the wiser.

He explained that he could see the Kayser Fleischer rings in my eyes and that with regular medication my illness would be controlled. He had never seen these rings before and was so excited he called in other people to view my eyes. I can remember going back to the ward in a sort of daze and phoning my husband and parents who like me had never heard of Wison’s Disease

In 2002 with improving computer skills I discovered the Wilson's Disease support group on the internet and never having met anyone else with this disease, attended my first meeting.

I began taking D-Penicillamine in gradually increasing doses, avoided copper in my diet and began it feel stronger and healthier than I had felt in years. Initially I was told that I would never have children and felt I had let my husband down. I read all the information I could find about Wilson’s disease, which in 1983 with no internet was not much, and wrongly I assumed I would get all the possible side effects of Wilson’s disease .

I can remember asking my husband for a divorce as I felt he was too young to have a sickly wife. He told me marriage was for life, in sickness and health and here we are 21 years later enjoying life to the full.

We moved to Thailand the following year with my husbands work and a 12 month’s supply of D-Penicillamine! I sent my monthly blood results back to the UK and resisted all the lovely seafood so high in copper in Thailand. After a year I returned to the UK for another liver biopsy which confirmed that my copper levels were reducing nicely, and I was told that my liver was now strong enough to try for a family. We waited until we knew we were returning to the UK and in November 1986 I had my first son at the Royal Free Hospital.

continued over

We moved to the Bahamas in 1998 for a couple of years and in November 1990 our second son was born.

Over the last 20 years I have had 10 liver biopsies to determine the copper level in my liver and subsequent treatment changes.

In 2002 with improving computer skills I discovered the Wilson's disease support group on the internet and never having met anyone else with this disease attended my first meeting. It was a great relief to me to discover that there were other people out there who understood what the disease was and discuss how the disease affected them.

After speaking with Dr Walshe I discovered that it was not necessary to have any more liver biopsies and have had my medication reduced even further.

Since 1996 I have been working as a community nurse and in September 2002 went to university to study for a BSc in Specialist Community Nursing which I completed in July 2003. I commenced my new post as a district nurse in St Albans in September 2003 and feel very fortunate to have achieved this at my age. I feel extremely well and apart from tiredness can honestly say that the disease hardly affects my life.

* * *

NICCOLO MACHIAVELLI

1469-1527

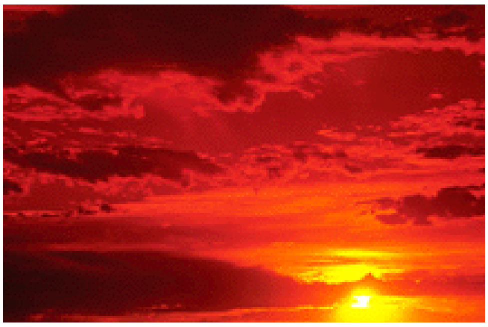
What you may ask, has Machiavelli to do with Wilson's disease. Well, nothing is the answer, but he did have something to say, nearly 500 years ago, which is strictly relevant today. Machiavelli might be described as the Alistair Cambell of his day. From 1498, for the next 14 years, he was involved in a number of important diplomatic missions for the council of ten which governed Florence after the exile of the Medici.

After their return in 1512 he was sent into exile, and that it was after this that he wrote his famous or infamous, treatise on government, "The Prince" in which he proposed the hypothesis that governments may do evil if they believe that good will come of it; what most governments are still prepared to do, though none would admit it. In the Prince Machiavelli wrote "*As the doctor says of a wasting disease, to start with it is easy to cure but difficult to diagnose; after a time, unless it has been diagnosed and treated at the outset, it becomes easy to diagnose but difficult to cure*". How sad, but how very true.

Sent by Dr Walshe.

Most of what I really needed to know about
how to live, and what to do, I learned in
kindergarten...
These things I learned. Share everything.
Play fair.
Don't injure people. Put things back where
you found them. Clean up your own mess.
Don't take things that aren't yours.
Say you're sorry when you hurt someone.
Wash your hands before you eat.
Learn some and think some; draw and paint,
Sing and dance; play and work some
When you go out into the outside world,
Watch out for traffic.
Be aware of the sense of wonder....
The Golden Rule is Love....
Think of what a better world it would be if
we all had a basic policy for our nations and
other nations
To always put things back where we found
them
And clean up our own mess.

Robert Fulghum.



Wilson's Disease Charity Walk 16th May 2004
Halsall to Maghull– 10 Miles

The following is a letter we received from Barry Diggles last summer.
We would sincerely like to thank Barry and his friends and colleagues for their help friendship and enormous support.

I just thought I would write to give the Wilson’s Disease Support Group UK a bit of good news.

On the 16th of May, myself and my work colleagues decided to take part in a sponsored 10 mile walk along the Leeds/Liverpool canal from Hallsall to Maghull, which is annually run by Southport Lions, as a result of a lot of friendly banter within our office about who could and couldn't do it!
However we needed to organise a charity to raise the money for, and immediately I mentioned the Wilson’s disease support group, due to Belinda and the work that you and the rest of the people do and again to raise the profile.
All the organisation and drive for the walk was done by Miss Christine Pilon, with help from Mrs Sue Lyon who both did a fantastic job in planning the day and making sure everyone turned up and had lifts to the start line.
The walk was a great success, and the day was hot and glorious, with a couple of little stops at some nice watering holes along the way but with everyone enjoying the walk and finishing in three hours and fifty minutes, [I have attached a photo for you.]
The people who did the walk were; Dave & Linda Ring, Kevin Sanderson & Christine Pilon, Lorraine & Bill Salmon, Amanda Callery & Chris Walker,
Sue & Mike Lyon , Ayessa and finally yours truly wearing the T shirt!!!
Now for the good news, as a result of the sponsorship from all our friends and colleagues at Pilkington Automotive European Technical Centre at Lathom and other sites in the group, we managed to raise in total **£630.00** for the Wilson’s Disease Support Group UK, for which I enclose a cheque.
I hope this amount will help in some way, as I know I have certainly spread the word here and was asked loads of questions on what Wilson’s disease is both before and during the walk and how the money would help you.
Hope to see you when we go to the next meeting.

Yours Faithfully
Barry Diggles.

Wilsons Disease Support Group UK

For membership, correspondence, and information
Contact : Dr Caroline Simms (group chairperson and coordinator, newsletter production, information and awareness)
36 Sunningdale Drive, Woodborough, Nottingham. NG14 6EQ

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 liason, 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 James Dooley - group adviser, honorary member
James Beckett - web master, honorary member

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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:
Linda Hart
36, Audley Drive, Lenton Abbey, Beeston, Nottingham. NG9 2SF.

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