Wilson's Disease Support Group-UK

Newsletter, volume 6, issue 1 March 2006

Welcome!

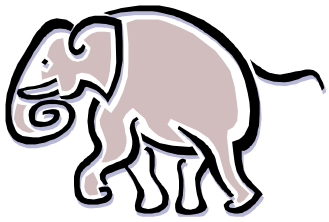
The Wilson's Disease Support group UK (WDSG-UK) is an all volunteer organisation which strives to promote the well being of patients with Wilson's Disease, their families and friends.

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 Wilson's Disease 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.

Your support made a difference



WDSG-UK

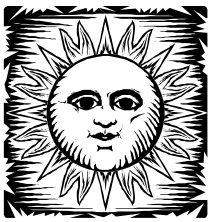
I received the following from Mrs Lesley Collcott Shortly after Christmas along with information about the cinema association card, which you will find inside the newsletter.

I would like to thank the members for their cards, presents and letters of good wishes and support, to my daughter Emma. It was very interesting hearing some of your stories and experiences. They helped cheer her up immensely at a time when she was feeling very low.

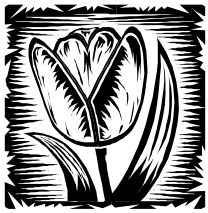
She has regained her drive and determination and is making good progress in her speech and movement in her arms.

THANK YOU ALL FOR YOUR SUPPORT

Lesley Collcott



ALMOST SPRING!



Wilson's Disease Support Group-UK, Volume 6 Issue 1

FIRST WORD

Hello everybody! I hope the year is treating you kindly so far.

It is with regret that I have to inform you that Caroline has now decided to resign as chairperson of the Group. She is recovering well from her liver transplant and feels she now needs to concentrate on getting her life back on track, returning to work and fully restoring her health. I an sure you will wish to join me in thanking her for all the hard work she put into the Group since its inauguration in 2000 and we look forward to her continued advice and help in the future.

Valerie and I are hoping to carry the Group on: writing the newsletter, arranging the meetings and dealing with any queries you may have. We welcome fresh ideas and articles for our newsletter. However, above all, we rely on your continued support through your annual subscription, without which we would be unable to sustain the every day running of the Group. **SO PLEASE RENEW NOW (form enclosed)**

Linda

The Cinema Exhibitors' Association Card

This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema.

Http:/www.ceacard.co.uk/

To apply for the card you will need to meet one or more of the following criteria.

1) Be in receipt of the disability living allowance or attendance allowance

2) Be a registered blind person

3) Be a holder of a disabled person's rail card

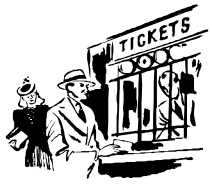
The card is valid for three years from the date of issue
Application forms are available from cinemas across the UK supporting this card.
Alternatively - download the form .

If you have any difficulty, contact the address below.

A processing fee of five pounds is chargeable per card. This is to be sent along with the completed application.

The card network,
The Technology Centre,
Rossmore Business Park,
Ellsmere Port,
Cheshire. CH65 3EN.

Tel: 0151 348 8020
Fax: 0151 348 8021
email:
info@ceacard.co.uk



Donations & support

Our thanks again go to Belinda Diggles for her fund raising; selling Christmas Puddings. She made and marketed them herself and raised £75 for us. You're a star Belinda! (as, of course, is husband, Barry)

Thanks to Mr R.J Haycock for his very kind donation of £20 to the Support Group; much appreciated Robert.

Thank you to everyone for their donations and help over the last year or two while the Group has been a **tad** disorganised!, I am especially grateful to James Beckett for maintaining the web site and not visibly tiring of my inane questions, to my partner John for his help and encouragement, and to Maureen Adams and Jane Ridley, for their friendship and support. Jane seems to know exactly when a joke is needed and usually supplies one!.

HOW I CAME TO LIVE IN CAMBRIDGE

by Valerie

One day in June 1968 I was going about my normal business in Manchester (school in my case) and the following day my brother, John, and I had taken up beds at (Old) Addenbrooke's in Cambridge. I was 15 then, and my older brother, who was 18, had just been diagnosed with Wilson's Disease. (He was 11 when my parents first noticed neurological changes and, although his condition got progressively worse over the next seven years, until then nobody had known what was the matter with him.) Through a blood test I had had at Manchester Royal Infirmary the previous week, I was apparently found to have got it too, though I was lucky enough not to have any neurological symptoms. In those days Dr Walshe, being the World Authority on the illness and being based in Cambridge had patients from all over the world. Not that there were many of us; it was an elite club and took a very clever doctor, indeed, to suspect the diagnosis and add to our number.

Anyway, it was all rather an adventure for me.
I was young and Cambridge seemed a really attractive place after the grey suburbs of Manchester. The fact that I was having needles stuck into me like a pin cushion, I was weeing into large plastic bottles, being injected with radio isotopes, having my knees and elbows jerked on a regular basis, popping penicillamine capsules before my meals and being a bit of a curiosity for visiting doctors was nothing more than a minor irritation! On the plus side, when being allowed out, I couldn't help noticing that there were many more men around than women (the student ratio in those days was about 11:1), I had no parental supervision after the first few days, I was missing my end of year exams and, to put the icing on the cake, while I was there Manchester United won the European cup! So how lucky was that.

My stay lasted only a fortnight before I returned home, but I had already decided that Cambridge was where I wanted to live at the earliest opportunity. Unfortunately, my brother died in the August. Making me an only child. It was hard on my parents, but I did come back to live and work in Cambridge in 1971. And here I have stayed: I have been married twice, have three grown-up children and am now in my seventeenth year of widowhood! But, I am happy. Yes, I do miss the cosiness and nosiness of the north, the surrounding countryside, the trips to the Lake District and the beaches of North Wales, not to mention the rain; and **not enough** to go back! I am a complex little "sunflower" and Wilson's Disease has had more of a psychological than physical effect on me. Addenbrooke's is my security: until **it** moves, **I'm** going nowhere fast!

BELINDA'S WD WORLDWIDE FRIENDSHIP CLUB

In 2001 I was diagnosed with Wilson disease; I went through all the emotions of why me, have my sons got it and what changes I would have to make to my life.

Firstly, my sons are o.k., and as to what changes have happened, well to tell the truth, not that much, the only thing is I now take drugs every day, and have to make sure this is before I eat, and go to the hospital every 4 months to see a doctor and have some blood taken and pick up my drugs for the next 4 months.

The best change has been all my new friends I have made, first there was Linda, who helped when I first found out I had WD, and who was a great help and still is, then I found this list based in USA but it has members all over the world, so I joined this list and made friends who know what its like to have Wilson's Disease. We then booked a holiday for June 2003 to go to Orlando, and found that one of the members of the list lived there called Karen, so we arranged to meet up when we got there but what a surprise when we went to pick up our luggage and Karen and Tommy (her partner) met us at the air-port in Orlando. Well anyone who knows me, knows how much I can talk, so after some time we exchanged presents and arranged to meet up again, which we did on 4th July, going out for a meals and watch the fireworks and have kept in touch ever since.

The following year we decide to travel to Washington, Philadelphia and New England, and we then found that someone else on the list was not far from us, so again we arranged to meet up, this time with Dvora and Paul who are another great couple. We again went for a meal, in which we sampled the unusual delights of Afghan cuisine which was totally different but enjoyable, but as they had two boys, one of which was very young, they could not stay out late and had to leave early, but never the less, a good time was had by all anyway.

The following year resulted in Dvora and Paul coming over to England on Holiday and us travelled up to Lake District to meet them and have a meal and meet there youngest son, and again a very good but late night!!

Then in 2005 came a very special event for Me and Husband Barry, as it was our Silver Wedding Anniversary, and we always said we would love to go to Australia, and by now I have friends all over the world,
and as soon as I say we are thinking of going to Australia, we got an offer from Belinda (Yes, the Aussie version of me and she can talk as much as me too!) in Cairns to meet up, and yes we did we meet up, watching a street parade and fireworks and then arranging to meet again the next day.
Belinda is married to Glenn, and they have two very lively young boys, and we were going to meet them at the local sports club to watch a big live televised rugby game, but instead, they invited us to there house for a few cold ones or “Tinnies” (That’s Beers to those not familiar with Aus. Speak!) to watch the footy (I mean Rugby League) and have a BBQ, and yet again a great time was had by all.

It was great to talk to yet another fellow WD sufferer and for my Husband Barry to talk to Belinda’s Husband Glen and learn and share each other’s experiences.

As any one can see from the pictures, we all had a good time, but no doubt some of you are already thinking after reading this article, who will she meet this year??
Well holiday is booked, but as yet no plans to meet up with any one yet (I Think!!)

WHICH DRUG?

Dr John Walshe

Some weeks ago I promised Linda an article for the next number of the Newsletter. Last week Linda rang to remind me. Unlike the elephant I had forgotten. What was it I was going to write about, heaven only knows. So I thought about what would be helpful and I decided to say something about the various treatment options which are available and why any particular one is chosen. I am sure most of you want to know 'which is the best for me', why did my doctor make the choice he did? very reasonable questions.

Let me begin at the beginning, Humpty Dumpty recommended this approach.

Up until 1948 the cause of Wilson's disease was unknown, there was no treatment and all sufferers died. A grim diagnosis to make. In 1948 Professor Cumings proved that all patients had an excess of copper deposited in the brain and liver. He suggested that it might be possible to stop the inevitable progress of the disease by giving a course of a drug with the chemical name 2,3 dimercaptopropanol to remove the excess copper. The compound had been designed by professor Peters and his team in Oxford when they were searching for an antidote to the wartime gas Lewisite a compound of arsenic which it was feared Hitler might use to attack the civilian population. The drug was named, by the Americans, British Antilewisite or, more popularly, BAL. Professor Cumings was able to show that BAL did indeed help. The problem was that it had to be given by injection into the buttocks, was painful, had a lot of side effects and ceased to work after a few courses of injections. It was so active that the body learned to take the molecule apart. But this was a start and pointed the way to future developments.

In 1955 I suggested that penicillamine, a breakdown product of penicillin, had the correct chemical formula to mobilize copper and tests showed that it did indeed do so very effectively. This had the great advantage over BAL that it could be taken by mouth - nobody wants to have painful injections for life. Penicillamine became the treatment of choice and it was some ten years before the side effects became apparent - in this respect it must be remembered that all active drugs will have side effects in a small percentage of people to whom they are given. In the early 1960's a Dutch neurologist, Dr Schouwink, pointed out that zinc salts blocked the absorption of copper from the gut and might be used to treat Wilson's disease and in Holland this is still widely used, but zinc does not actively mobilize copper so it is not an ideal starting treatment and in many patients it causes abdominal discomfort and nausea. By the late 1960's a number of patients were seen who could not tolerate penicillamine so a new drug had to be found and with the suggestion of Dr Hal Dixon I tried using a new copper binding compound, triethylene tertamine, now known as Trientine and we were able to show that this also worked very well to treat Wilson's disease. It seems to have fewer side effects than other drugs but is rather more expensive. About the same timee the first liver transplant was done in the US for a patient with advanced liver damage and this is now a routine procedure for such patients.

Finally in the 1980's I tried yet another compound, tetrathiomolybdate for a patient who could not tolerate any of the other forms of treatment then available. This also worked. Molybdate has two actions, first like zinc it blocks absorption of copper, but it also has another action, it forms a compound with copper already present in the body making it chemically non-toxic. The problem with molybdate is that it is still not available as a licensed drug and is very hard to get hold of. It also has two side effects, it can damage the bone marrow, though this is readily reversible if the drug is stopped, and in animals it has been shown seriously to damage growing bone, making it dangerous to use, except for a very short period, in children.

So, when your doctor sees you for the first time he has a wide choice of available drugs to choose from. Which is the best for you?

Well BAL is not a good first choice though sometimes it works when all else has failed and is a valuable fall back, but no one wants to give or to receive injections for life if it can be avoided; also it is very, very expensive.

Penicillamine is the drug with which there is there most experience and this works very well in the majority of cases, but it may make things seem worse before improvement sets in, always worrying.

Zinc salts are not a good starting treatment though they may work well for long term maintenance, personally I have not been impressed .

Trientine is a good drug, it is rather more expensive than penicillamine. It has usually been used for patients who have developed penicillamine intolerance, so there is less experience with this for a starting treatment; it has very few side effects.

Liver transplantation is life saving for patients who have developed liver failure, but not for routine use.

Finally molybdate, very difficult to get hold of, at the present.

I believe it is not available in this country. The Department of Health have been approached but they have a genius for 'keeping the ball in the air' for as long as possible. It is still up there at the moment! If experience is anything to go by it will be there for a very long time.

MOVING MEDITATION

By Linda

Doing T'ai Chi has remarkable benefits with recent research revealing that the ancient Chinese art can help with balance, flexibility, strength and even the heart.

Gentle, smooth and flowing, as far removed from the sweat and grind of the gym as can be imagined. Yet for all it's gentleness, the ancient Chinese art of T'ai Chi can offer as many health benefits as more vigorous forms of exercise.

In China, where it has been practised for thousands of years, it is estimated that more than 200 million people incorporate Tai Chi into their lives. In the UK many people are discovering the ancient art.

Many are being attracted by the stress-busting and relaxing and vitalising effects of the 108 postures that make up the Tai Chi form. The words themselves mean "supreme unity" of body and mind, each of the movements aims to restore balance between the body's opposing energy forces, the yin and yang.

Although it is traditionally a martial art, it is non-violent and often practised alone.

There are different styles of Tai Chi each with slightly different postures and rhythms, but all aim to restore the natural flow of energy or chi around the body. In classes there are elements of breathing, posture and calming and focusing the mind. The underlying purpose is to learn how to generate conserve and channel chi for health and well-being, it is about getting mind and body to work together to produce harmony.

Over the years I have tried many forms of exercise classes etc, in my quest for some reasonable level of fitness, the worst by far being aerobics (I still have bad dreams!) I couldn't stand it, but tortured myself with it for over a year; sure, I got fit, but what a price, all that manic jumping around and awful music!.

I started Tai Chi three years ago and took to it almost immediately. It was very different from anything else I had done.

Our class lasts for an hour and a half. The first fifteen minutes are spent drinking tea and chatting! We then do gentle warming up exercises, before going through the form, (as the three sections of Tai Chi are called), this can take 15 to 30 minutes, depending on the speed, the slower the better. We then refine and brush up our technique, I particularly like the "winding down" breathing and standing postures alternatively we will often sit in a circle doing relaxation exercises.

The beauty of Tai Chi is that it can be practiced by all ages and abilities. It is very beneficial to older people as it increases mobility and suppleness.

I have found that since starting Tai Chi my posture has improved, I am far calmer in my way of dealing with things, concentrate better and generally have a more relaxed approach to life in general, (so that has to be good), and it is something I have stuck at, which is even better - for me, I find people at the classes are very friendly and pleasant and we all help one another as we aren't in competition, I have made many new friends, I can happily say it's the best thing I've done in years.

Wilsons Disease Support Group UK

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Anne 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

WDSGUK

Tell others about the WDSG-UK

Please tell others whom 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 or patient's & families correspondence list 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