Wilson's Disease Support Group-UK

NEWSLETTER, FEBRUARY 2007

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 an annual 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.

WDSG - UK

Hello…..and wishing you all a somewhat belated Happy New Year! I hope you'll enjoy reading the latest edition of our newsletter. Many thanks to all our contributors. Subscriptions are now due for 2007 (see enclosed form).

We have significant funds in our Group account, thanks to your generous fundraising efforts and donations over the past 6 years. We have been in touch with Dr Gillett about how to put some of our money to good use. He suggested we pay for the production of the electronic archive of Dr Walshe's papers printed since the 1950s, which will be a useful resource for patients and the medical profession alike (see Dr Purchase's article on page 10) and we have agreed to do this.

He has also suggested the name of a company that would be prepared to run our website and we are considering this at the moment. We are grateful to him for his continued interest in the Group.

Meanwhile, we will let you know as soon as we have confirmation of a venue, date and time for our next meeting.

Linda

The Best Laid Plans………………………………..

Having this winter taken up walking in Derbyshire, I am very much looking forward to spending more time in the Peak District, when the weather is 'fairer'. Hopefully, my map and compass reading skills will have improved by then, for on a recent walk on Stanton Moor, visiting the *Nine Ladies Stone Circle* with a friend, we got hopelessly lost! Despite insisting that I knew exactly which direction we needed to walk in, we spent two hours walking around in circles, with the mist descending around us, soaked to the skin and with no signal on my mobile phone, before we eventually managed to find our way back to Bakewell!

A hot pie from the *Bakewell Tart shop* and a stiff drink in front of a roaring fire at *The Pheasant* revived our spirits and made the whole experience worthwhile!

Linda

IN THIS ISSUE……

OUR MEETING AT KING'S COLLEGE, CAMBRIDGE - JUNE 2006

The 6th Meeting of The Support Group took place in the Beves Room, King's College, Cambridge, on June 3rd last year. This was the same venue as we had used for our meeting two years' earlier. Around 60 people attended including "old" and "new" patients, their families and friends, Dr Walshe and Kay, Dr Gillett from the Northern General in Sheffield and also the Middlesex in London, Dr Bill Griffiths from Addenbrooke's, Dr Rupert Purchase and Dr Hal Dixon, a Fellow of King's College and former collaborator with Dr Walshe. Hal again organised the hiring of the room.

Light refreshments were available on our arrival and we chatted informally during the morning, catching up on news from patients who have been involved with the Group since its inauguration in 2000 and also meeting new patients, whom we were delighted to welcome on their first visit. After a light luncheon, Dr Walshe gave us a talk on the history of Wilson's Disease and answered questions from the floor. Later, James Beckett, talked about the WDSG website which he had taken over some years earlier and asked us what improvements we wanted to see.

The raffle, which made £90 towards Group funds, was drawn before the meeting closed at around 3.00, with Barry and Belinda Diggles then organising a group photo outside. For the intrepid, Hal kindly took us on a tour of the Chapel, followed by a tour of the recently renovated Fellows' rooms opposite the college on historic King's Parade.

A most enjoyable day was had by all!. **Valerie**

A few of 'us' with Drs Walshe Purchase & Gillett & Kay

What a terrific raffle!

A beautiful view of King's College Chapel

The Beves Room and time for a chat

“ Oh!   We do like to be beside the seaside………………”

After a very busy year for both of us, Linda and I managed to spend a few days together in October last year on the Lincolnshire coast. This is an area familiar to Linda, living in Nottingham, but one that I had never explored before.

We met, appropriately enough, in Boston at ‘The Stump’ like the Puritans had done four hundred years earlier before setting sail for America! However, unlike the Puritans, our journey was a relatively short one up the coast to our holiday destination at Sutton-on-Sea! The tourist season was officially over, the fun fairs, alas, all closed, but the weather was reasonably warm and Linda was only too happy to show me the sights. In the short time that we were there, we visited the historic Georgian market towns of Louth, Spilsby and Alford, we toured the Wolds (*that meet the sky*) and explored the coastal resorts of Skegness and wonderful- sounding Mablethorpe and Cleethorpes.

I had a really great time. My overriding memories are of the beaches with their long expanses of golden sand; of waking up early enough to see the sun rise over the sea, which was beautiful; of discovering that Louth was divided in half by the Greenwich Meridian line (perfect material for quizzes); going into shops in Skegness, the likes of which I’d never been in before; and discovering that my namesake had arrived in Cleethorpes ahead of me and had set up a café in my name, the exact moment of which was captured by Linda in the photograph below!

This year I’m hoping that Linda will introduce me to the delights of the Derbyshire Peak District……….

Valerie

Well I never!

The pier at Cleethorpes

Meeting the local bird life

PRESCRIPTION CHARGES

Jane Kaill

I expect that the WDSG has already been "round the block" a few times over the years on the subject of prescription charges.

However, it does seem that the Government is taking a new look at the issue of medical exemptions from prescription charges. Apparently, in Wales, prescription charges are being phased out altogether from April '07.

When my daughter was diagnosed with WD in 2004 I looked into the list of medical exemptions from prescription charges and found, as many of you will already know, that the list is very limited.

It includes:

- Permanent Fistula
- Forms of hypoardrenalism
- Diabetes
- Hypoparathyroidism (Under-active thyroid)
- Epilepsy requiring continuous anti convulsive therapy

The list has not been changed since it was agreed in 1968.

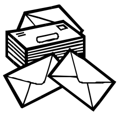
Earlier this year I got in touch with my MP, Sandra Gidley, about this. As an ex-pharmacist and recent Lib. Dem Health Spokesperson, she seemed a good contact. After meeting with my daughter and me in March '06, Mrs Gidley wrote to the then Health Secretary, Jane Kennedy, about the possibility of adding Wilson's Disease to the list of exemptions from prescription charges. Mrs Kennedy's reply was not particularly encouraging, but did mention that prescription charges were being looked at by the House of Commons' Health Select Committee as part of its inquiry into NHS charges.

The Select Committee reported in July last year. It recognised that the exemptions list was inconsistent and anomalous. One of its recommendations was that the Government should undertake a major review to assess the costs and benefits of completely revising the medical exemptions to the prescription charge.

So more reviews and enquiries!

Revision or modernisation of the exemptions list is potentially a problematic business for a Government. Perhaps they will decide it will be easier (if not cheaper!) to follow the Welsh example and abolish them altogether.

However, if it is decided to keep and modernise the exemptions list, then let's make sure that Wilson's Disease is on it.



FREE PRECRIPTIONS
FOR PATIENTS WITH WILSON'S DISEASE?

Dr J. M. Walshe

Most patients with Wilson's Disease must wonder why they do not automatically qualify for free prescriptions. **Well I do too.** I have waged a long and fruitless battle with successive Ministers of Health for this injustice to be rectified.

Prescription charges were first introduced in the early 1950s. Later, when Harold Wilson was Prime Minister, I first attempted to have a parliamentary question asked by my MP, David Renton (now Lord Renton, probably the oldest active member of the Upper House). Not surprisingly, when he asked for free medicines for patients with Wilson's Disease, Members of the House thought this hugely funny, not realising that it was a serious question.
The answer he passed on to me showed the appalling ignorance of the Ministers' medical advisers. The reply was that there was no treatment for this disease so there was no point in giving any treatment! When I pointed out to the Minister that his advisers were hopelessly out of date the correspondence came to a grinding halt. It was clearly a mistake to show up the failure of a Government Department - First round to the DoH

I have tried to raise the question on many occasions subsequently, sometimes directly to the Minister, sometimes through my MP, who at one time was John Major when he was Prime Minister. These later questions all elicited the same answer. "We give free prescriptions to A,B,C and D, aren't we generous? Hard luck your patients. We have no intention of reviewing the list!" The reply was so predictable that they must have got it out of the same file kept handy for re-use. The last attempt was through our patron, Ann Widdecombe, who again gave the standard answer. The only thing likely to embarrass the DoH is bad publicity in the national press. To this end I have tried to enlist the help of Dr le Fanu, medical correspondent of the *Daily Telegraph* and *Sunday Telegraph*. Although he has promised to do so, he has not over several years fulfilled this promise. The actual list of illnesses which qualify for free medication is short and quite bizarre (as mentioned by Jane Kaill opposite). It must have been drawn up by a couple of out-of-date endocrinologists and bears no relation to modern medicine. It can be found on the Royal Pharmaceutical Society of Great Britain web site,
Http:/www.patient.co.uk/showdoc/23069022/
If you want to be disillusioned, have a look at it.

However, DO NOT GIVE UP HOPE.
In a recent issue of *BMA News* there was a short article saying that the DoH was about to review the list of situations and diseases which will qualify for free prescriptions: now is, therefore, the time for us to try again.
I have written to Miss Widdecombe to this effect. Being of a cynical turn of mind, I suspect that the Parliamentary review will be an attempt to reduce the number of occasions on which free prescriptions are issued, so as to save money and so that dear Mr Brown will be able to squander it on some ill-thought out computer scheme which will probably never work!

It is now up to you, the patients, to take up the cudgel.

Write to your MP pointing out the injustice that you with a potentially fatal, inherited disease, who need medication for life, are not given free medicines; send a copy to Ann Widdecombe as well.
The address to write to is;
The House of Commons,
London,
SW1 0AA.

Since writing this article Dr Walshe has received a further communication from Ann Widdecombe that said:
" The Minister, Lord Warner, replied to the effect that the Government is reviewing the whole free prescription situation with the following options:
1. Amend the list
2. Introduce a flat rate with no exemptions
3. Base charges on income only."
Dr Walshe urges you to write promptly to your MP before any disastrous changes are made.

ACUPUNCTURE: a brief view

Matthew McGuire MBAcC

As a friend of Linda’s, I have been asked to write an article about my profession as an Acupuncturist.

People are becoming much more familiar with the practice of acupuncture these days (although I still have relatives who continue to ask me how the aqua-puncture is going!) I first experienced acupuncture because I wanted to try a form of treatment that was different from that offered by my GP.
A friend recommended I see an acupuncturist, and I was immediately impressed.

As an acupuncturist, myself, now, most patients I see have come either because they have found out that it can help with a specific problem or because someone they know has recommended it to them. It’s rarely as a result of wishing to experience the natural sciences of an old culture from the Orient! So, although I find people’s interest is mainly pragmatic, I thought I would write a few words explaining the practice.

Firstly, there are two professional bodies representing acupuncturists in the UK: The British Acupuncture Council (www.acupuncture.org.uk) and the British Medical Acupuncture Society (www.medical-acupuncture.co.uk). The latter group mostly represents family doctors and hospital specialists who practise acupuncture, whilst the former group represents people, like myself, who have chosen acupuncture as a specific career. Both websites will contain lists of registered practitioners and information on what treatment is available. Acupuncture is becoming more popular in the UK and the two bodies compete on some levels. It is members of the Council who are more likely to use traditional Chinese diagnostic methods, as their accredited colleges have stronger links to China.. Their training does, however, have to include the biomedical sciences appropriate to the practice of acupuncture.

Simply put, acupuncture does what it says on the tin! It involves the accurate insertion of needles into the body. The practice originated in China around 5000 years ago and was a well-structured medical intervention by the time it was first documented between 300-100BC. There are a lot of myths about how it first started including emperors receiving arrow wounds which cured long-standing illnesses! I read a more plausible story by a Japanese acupuncturist, who thought that it was the presence of silk in China and the use of needles in sewing it, that gave rise to the early development of fine needles and he theorised that perhaps a hard-working seamstress with aching shoulders had discovered that inserting needles into the painful areas had provided her with pain relief! Today, rest assured that all needles are sterilized and only used once.

Acupuncture became more sophisticated as people realised that the needling at one point could affect distant areas and the functioning of organs. Modern research into the effect of needling certain points and a growing knowledge into the ways in which the body communicates within itself concurs with ancient beliefs.

Most of the commonly used points are below the knee or elbow (which is why a patient usually does not have to disrobe too much), the flow of Qi (pronounced “chee”) in the meridians is used to explain this. The concepts that underline traditional Chinese medicine come from the philosophies and natural sciences of the time, but the landscape they evolved to describe i.e. the human body, remains similar which is why it can successfully relate signs and symptoms of disease to prescriptions which are clinically effective. When learning about the internal organs in traditional Chinese theory, I was taught to see them as functional systems rather than anatomical entities. This functional thinking is obviously no help to the surgeon, but does correspond to what patients experience. Also (in my opinion) it avoids some classic mind/body problems. Whilst the core of Chinese medical theory had developed over 2000 years ago , it would be incorrect to suggest it has not been subject to criticism and change. Neither has it been unfailingly popular in China. The latest growth and modernisation in acupuncture was probably concurrent with Mao Zedong distancing himself from the Soviet Union.

I want to cut the theory short here apart from to say something about 'holistic' medicine. It can be an advantage to look at all aspects of someone's life to make a diagnosis and offer treatment, taking into consideration their diet, lifestyle, emotions, environment, traumatic events, etc. This being so, we can say that patients may present differently despite having a similar disease and conversely present similarly with a different disease. I think this is an important principle.

What then is acupuncture good for? It was developed as a complete system of medicine and as such its scope is huge, but of course for many things there are now more effective treatments. In my experience it is best known for treatment of musculoskeletal pain including arthritis and back pain. It is also common for patients to get benefit for specific conditions such as high blood pressure, skin conditions, asthma, circulatory problems, headaches, menstrual irregularities, many digestive and intestinal problems, anxiety states and also depression and addictions. It can also support patients with chronic conditions and in post-operative recovery. I think that although acupuncture evolved to treat a largely agrarian and short-lived population, it has a capacity to treat the complicated late onset diseases that have become more common as we live longer with more stressful and less physically demanding lives.

So what does treatment involve? After an initial consultation, the practitioner should suggest a treatment plan (how often and for how long) and seek your consent for this. Treatment involves very fine needles (around 0.22mm diameter) usually of stainless steel being inserted into certain points of the body. They can be removed in a matter of seconds or left for around 15 minutes. An average amount of needles would be between 5 and 20.

What does it feel like? Well it differs from person to person, point to point and also time to time. Common sensations are of tingling or of a dull ache or a feeling of warmth. The treatment should not be painful. It is helpful if the patient is relaxed and many patients gain a feeling of relaxation with treatment. Obviously it is not for everybody, even in China. Acupressure, a form of massage using finger pressure on points, can be used effectively as an alternative.

With specific reference to Wilson's Disease, I think this is a prime example of the success of modern medicine and there is no complimentary medical alternative to taking the required medication.

If you are receiving treatment for a condition from your GP and wish to try acupuncture as well, I would strongly recommend that you do first consult your doctor.

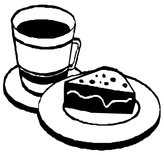
MEMOIRS OF AN S.E.N.

Vicky Morrill (S.) E.N.

At the end of summer 1968 I had just started on my first ward, Thackeray, as a pupil nurse, training to be a State Enrolled Nurse. It was at Old Addenbrookes Hospital, a beautiful old Victorian hospital, full of enchantment and character.

Thackeray Ward was not so enchanting, and on one of the beds amongst the very ill patients, sat this rather small, bubbly, cheeky thirteen year old girl, who was under the care of Dr Walshe, and was obviously very bored! It was Linda Hart.

With Sister's permission I started to take Linda to tea rooms and the cinema in my "off duty." We have been friends ever since, and have enjoyed meeting up on the many occasions that Linda has visited Cambridge.



Those nursing days, when I met Linda, and for a long time after, were the days when the presence of Matron had you almost curtseying. It certainly kept us on our toes. We wore REAL uniforms, with starched white aprons and caps, and were never to be seen in our uniform out of hospital, unless we wore our outdoor rain Mac and cap. Lockers and beds were cleaned by nurses, and sluices kept spotless. Urine was tested by the dropper system, temperatures taken by thermometers in the mouth or underarm, and blood pressure manually. But, we still had time for four hourly turns, bed baths, dressings, medications, feeding and many a comforting word.

Of course there was fun too. I can remember climbing over the Nurses Home gates, late at night because they were locked at 10.30 pm!., I think Sister in charge of the home knew, because we were often given an evil look in the morning!.

Many a party was 'gate crashed': one in particular where I met my wonderful husband. We had four children and now two grandchildren, all of whom share our friendship with Linda.

State Enrolled Nurses and State Registered Nurses worked well together, and personally, I think it was a great mistake and insult to stop the training of the former. They've even taken the 'State' out of our title! The training of State Enrolled Nurses came into being at the end of the Second World War, because of the courage and capability of the Red Cross nurses. What more could a National Health Service want. These were and still are practical and capable nurses and they are cheaper to employ too!

Perhaps the only way forwards is backwards.

MARATHON MAN

Philip Hawkins

When I first decided in September 2004 to fulfil a long cherished dream and run a marathon, it wasn't difficult to decide at the same time to try and raise a bit of money for Wilson's. My daughter was diagnosed a few years ago; and I know that because it is such a rare condition it doesn't get much attention or financial support. So, I contacted Dr Gillett and he kindly put me on to Oliver Bandmann who is doing research at Sheffield University.

Eventually I was able to send him a cheque for a reasonable sum; friends and family were very generous. And, in fact, I was sponsored by a much larger circle of friends and acquaintances (many in Turkey as my wife is Turkish) who contributed large amounts of money to various children's charities as well.

That's the serious bit! I did actually run my first marathon in Rome in March 2005. My wife and I went with a group of medical friends, so I was tempted to insist they ran behind me just in case! As it was, most of them were very good amateur runners, as doctors often are, and ran well ahead of me.

I had trained for about 6 months in the countryside around our home outside Oxford. There is something seriously and spiritually uplifting about setting off early on a Sunday morning, whatever the weather, to find oneself alert to every sight, sound and smell of the country. Despite the noise of my own gasping, all was peace!

So the marathon was quite a shock, albeit a pleasant and exciting one; lots of people, a number of bands along the way and then, of course, the wonderful sights of Rome. This wasn't Rome in a day, but in 4 hours 20 minutes .

We set off from the Colosseum and crossed the finishing line there as well. It struck me very forcibly, the contrast between how that wonderful arena had been used in its gory past and how now it was witnessing 15,000 people enjoying one of the simplest human activities. Tulin, my wife, and daughter, Isik, ended up helping out at one of the water stops.

So, for a time I was addicted. In September of the same year I ran in the Berlin marathon, which was altogether a much bigger affair: in fact the second largest marathon in the world, with 60,000 runners and a **million** spectators. However, I almost felt a veteran, though I was quite a bit slower. Nevertheless, I enjoyed it every bit as much; and Tulin cleverly managed to spot me at several key stages.

So, as if going into another battlefield, we found ourselves in Prague last April; with Tulin also taking part in the half marathon. But I must confess, after another half marathon locally, the body,especially the knees, are beginning to feel the strain. So it's time for a rest. However, I do have my hopes set on a marathon when I'm sixty, about five years from now. And we are thinking of a walk along the Pyrenees, so we may be asking you for sponsorship soon!

Finally, I am faced with the difficult task of finding a marathon photo to accompany this article that doesn't show me looking too downcast or with too much of a stomach, or both!.

J. M. WALSHE ELECTRONIC ARCHIVE

Among his many achievements, Dr John Walshe belongs to that select group of scientists and clinicians whose publications have contributed to the scientific and medical literature over a 50 year time span. One of his earliest papers was published in the *Biochemical journal* in 1951, (*Biochem.* J.,1951, **48** (1), xiii):

PROCEEDINGS OF THE BIOCHEMICAL SOCIETY

The **290th meeting** *of the Biochemical Society was held at the National Institute for Medical Research, The Ridgeway, Mill Hill, London, N W 7, on Friday, 20th October 1950, when the following papers were read:*

COMMUNICATIONS

Ethanolaminuria, An Obscure Metabolic Defect Associated with a Case of Primary Hepatoma.
By C. E. Dent, D. I. Fowler and J. M. Walshe. *(Medical Unit, University College Hospital, London W.C.1)*

Many of Dr Walshe's papers, which preceded the landmark 1956 *American Journal of Medicine* paper on the use of D-Penicillamine for treating Wilson's disease, were concerned with diseases of the liver, and are recognised as pioneering contributions. For example,

" The seminal observations of John Walshe on the use of glutamic acid in hepatic encephalopathy are the pharmacological basis of the use of ornithine-aspartate." (R Jalan et al, The Lancet, 2005, **365,** 1385.

However, it is his work on the treatment and management of Wilson's Disease that has earned Dr Walshe international recognition.

At the last WD Support Group UK meeting held in Cambridge in June 2006, Dr Godfrey Gillett came up with the useful suggestion of whether we could produce an 'electronic archive' of all Dr Walshe's publications from 1950 onwards. Such an archive would be a unique resource on the literature of Wilson's disease, and allow access *via* the internet to many papers (and book chapters), which are not readily available nowadays in their original printed versions, even in specialist libraries.

Investigation into the costs and logistics of producing an electronic archive has been fruitful. The cost of electronically journals and producing pdf files (the preferred format for looking at documents on a computer screen) is comparable with the cost of photocopying, and a specialist company who carry out this work has been located in West Sussex. There will be around 200 papers and book chapters to scan.

There is one obstacle to overcome before we can start, and that is whether there are any copyright issues in scanning some of Dr Walshe's published output. However, we hope to overcome this hurdle and arrange to begin scanning within the next few months. Once Dr Walshe's papers have been scanned and the archive rearranged in some sort of logical order, then it is hoped that it can be made available electronically to members of the Wilson's Disease Support Group UK.

Rupert Purchase
January 2007

MY FRIEND

To make a day and give it to a friend,
To open up one's heart in a poem that is penned.
To fear its loss with a sense of remorse,
Not knowing if I can stay the course.
You are my friend and difficult to find,
Not measured in teaspoons but in the quality of time.
Time has no meter except to be true,
But friendship is a burden and I might be so for you.
You're kind and considerate - the things you said so fine,
But you know I complain and here I draw the line.
The test is long and one cannot carry two,
Do you get the impression I want this for you?
You would not let it happen - I know -
And now I am clear.
For you to think this of me is what I really fear.
I value your friendship - not to be abused,
You know, I'm not really moaning - only
Always a little confused

Wilsons Disease Support Group UK

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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 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 MPs 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 patients & 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