Christmas cards *for 2009...*

- **Over Bethlehem**
  Actual size: 137 x 137mm
  (shown right)
- **Festive Poinsettia**
  Actual size: 121 x 121mm
  (shown below)

The message inside both cards reads:

"With Best Wishes for Christmas and the New Year"

Cards are available in packs of 10 at £3.50 per pack, including postage and packaging.

Please use the order form inside this cover.

Registered Charity No. 1062595

The dystonia society

Dystonia*matters!*

Issue 65 • Autumn 2009

Joe's walking tall...

Also in this issue...

IPSEN Innovation for patient care

Printing is supported by an unrestricted grant from Ipsen Ltd

GENERALISED DYSTONIA *SPECIAL ISSUE*

Issue 65 • Autumn 2009

THE DYSTONIA SOCIETY

Registered Charity No. 1062595
Company limited by guarantee No. 3309777

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Newsletter published at end of:
February, May, August, November
We welcome new ideas for the newsletter, please call the Editor to discuss your ideas. Items intended for publication should be submitted to the Editor, eight weeks before publication.

Cover shot:
Joe Doliczny, a teenager from Chippenham, Wiltshire, made a remarkable recovery following his DBS surgery.

The Dystonia Society exists to support people who have any form of the neurological movement disorder known as dystonia, and their families, through the promotion of awareness, research and welfare.

Society news

Essay Prize winners

The winner of the Society's fourth 'Jackie Deakin' biennial essay prize for 3rd, 4th and 5th year medical students has just been announced.

Thirty one essays were received by the closing date in April. Philip Eckstein, CEO, said: "It is very encouraging to have had such a good response from busy medical students. I feel sure a number of entrants will be interested in following up this early interest in movement disorders in their later careers – which can only be good for our members". The winning entry will be published in the next issue of Dystonia*matters!* and entries will be available to view shortly on our website.

The selection of the winners was difficult due to the high standard of all submitted essays and we are very grateful to Dr Peter Moore, chairman of the marking panel, and to the other five neurologists who so willingly gave their time. Congratulations to the prize winners: **Chris Mansi** (1st prize), **Alex Tsui** (2nd prize), and **Connie Han, Shehab Jabir, Reuban Pratheepan, Christopher Deutsch,** and **Sangeeta Chaal** (joint 3rd prize).

Help wanted **We have been approached by an important UK charity which is looking for three volunteers living outside London to join one of several panels to provide a voice for dystonia. Any member interested should contact Val Wells on 0845 458 6299 or email val@dystonia.org.uk**

The future of care...

*The Department of Health recently launched a green paper **'Shaping the Future of Care Together'** which aims to deliver care more equitably and to remove the postcode lottery that currently exists. However there will be no more money available to do this so the government is looking at different ways of using existing resources. Our concern is that the Attendance Allowance benefit may be modified. We are very aware that many of you have fought hard to get the benefits and care you need and we would encourage you to use the opportunity (until 13 Nov) to make your views known.*

*Please go to the website **www.dh.gov.uk** or call 0845 702 3474. The Society will also be making representations of its own.*

Report & Accounts

You can find a copy of the full report and accounts for the year ended 31 March 2009 on our website, or obtain a printed copy from the UK office.

We are very grateful to Ipsen Ltd for their generosity in providing a significant, unrestricted grant to support the newsletter.

Welcome *to the Autumn newsletter*

I do hope you will consider attending our annual conference which takes place on 7 November at the Wellcome Conference Centre in London. Not only is it a chance for you to meet the trustees of the Society and have your say about how it should develop, it is an opportunity for members and professionals to meet in a relaxed environment. We have four eminent speakers who will cover the latest developments in research, as well dystonia in childhood and dystonia and the mind. It is going to make for a very interesting programme.

We know from the many letters we receive following each of our regional *Living with Dystonia* conferences, how useful our members find them. We are therefore pleased that we are able to stage three further regional conferences this year, to take place in Norwich, Stafford and Northern Ireland. I hope we will see you there too!

I am very grateful to the 100 or so young people affected by dystonia and their parents and carers for responding to a recent questionnaire. The results have just been collated and make for humbling reading about the obstacles and challenges faced by many families on a daily basis. The trustees will very shortly be considering how the Society can better support young people affected by dystonia and their families. I look forward to reporting back in the next issue of the newsletter.

Philip Eckstein *Chief Executive*

Society news

Where's the AGM?

We hope to see you at the Society's annual conference on Saturday, 7 November. It is no longer known as the 'AGM' because following the adoption of the new Articles of Association last year, a formal Annual General Meeting is no longer required.

The trustees are insistent, however, that a regular annual meeting continues to enable members to meet with and discuss issues with the Board of trustees. There may be times in the future when a general meeting of members is still required (when, for instance, there is a legal matter which requires a vote of the members, such as the adoption of the new Memorandum of Association this year).

Scotland training success

The Long Term Conditions Alliance Scotland has just awarded the Society a grant of **£22,105** over two years to develop a specially tailored course for Scottish members to help them better manage their dystonia. As a result there is now an exciting opportunity for two volunteers with dystonia to undertake the prestigious Stanford self-management trainers course. (This course has been the basis of the highly successful *Expert Patient programme* in England). The volunteers will then use the funding to run six courses in various parts of Scotland for up to 72 people with dystonia.

Anyone who is interested in knowing more about the project, please contact Scotland Manager, Peter Meager on 0845 458 1005.

Living with dystonia days planned...

Three 'Living with dystonia' conferences are planned as follows:

- **Norwich** *19 September*
- **Stafford** *17 October*
- **Belfast** *28 November*

Members living in each region will be mailed information about these events some weeks before each event. If you are interested in knowing more about any of them , please contact UK Office.

- *Peter Meager*

Society news

Almost a year...

It will be one year in October since the Devon and Cornwall Dystonia Support group held its first exploratory meeting.

Now the group has 31 members and "most importantly we have made new friends and enjoyed our times together", says coordinator, Janet Chaston. "We held our **Lions summer event** at the end of May, followed by our first garden party at the end of June. Unfortunately, when we had the **Alexandra Rose Day** collection in June, the weather was atrocious and we only collected **£23.47** but every penny counts!"

More calls than ever!

During the last 6 months the Society's Helpline has taken 1,808 calls which represents 6,476 minutes of calls. This is a 10% increase on the same period last year!

Registration in Scotland

Under the Charities and Trustee Investment (Scotland) Act 2005, bodies which represent themselves as charities in Scotland are required to register with the Office of the Scottish Charity Regulator (OSCR). This requirement includes bodies which are established and/or registered as charities in other legal jurisdictions, such as England and Wales.

The effect of this requirement on the Dystonia Society has been that we will not be able to apply for funding to most of the Scottish charitable trusts and foundations until we have completed our registration with OSCR. The trustees are keen to do this as soon as possible. The Society's existing constitution meets the Scottish Regulator's guidelines apart from a definition of "charitable" which is set out as Clause 8 in the draft Memorandum. The change must be adopted formally by the members and it is hoped that this may achieved at an Extraordinary General Meeting at the beginning of the annual conference on 7 November 2009. Page 6 is the formal notice of the meeting, together with the draft Memorandum enclosed with this mailing which incorporates the required amendment at Clause 8. Please contact Geraldine Isherwood at UK Office if you wish to make any comments.

NOTICE OF EXTRAORDINARY GENERAL MEETING

Notice is hereby given that an Extraordinary General Meeting of The Dystonia Society will be held at the Conference Centre, Wellcome Collection, 183 Euston Road, London NW1 2BE at 11.30am on 7 November 2009 at which the following resolution will be proposed for passing by members:

1. THAT the memorandum of association in the form presented to the meeting and enclosed with this Notice be and is hereby adopted as the memorandum of association of the Charity.

By order of the Board

Geraldine Isherwood
Company Secretary

The Dystonia Society
89 Albert Embankment,
London, SE1 7TP

31 August 2009

Appointment of proxies

As a member of the Company, you are entitled to appoint a proxy to exercise all or any of your rights to attend, speak and vote at the Meeting. Full details regarding appointment of proxies will be sent upon request by email or post if received before 23 October 2009.

Primary Generalised dystonia

Early-onset dystonia

This issue of **Dystonia***matters!* *highlights primary generalised or 'early onset' dystonia – a rare form of dystonia that begins in childhood or early teens. Typically, the condition starts with involuntary spasms that occur in a foot or leg and then progress to include other limbs and the trunk. The most common age of onset is around nine years old and onset of symptoms with this condition after the mid-twenties, is highly unusual.*

Initial symptoms will often spread over a number of months, usually up to two years, to lead to a 'generalised' form of dystonia. However, some patients may only develop dystonia in one or two body areas (focal/segmental dystonia respectively). Symptoms will then typically plateau, although they may wax and wane. Symptoms may include:

- Muscle spasm with or without pain
- Twisted postures of the limbs or trunk
- Abnormal fixed postures of the limbs or trunk
- Turning in of the foot and/or leg and/or arm
- Rapid jerking movements
- Unusual walking with bending and twisting of the torso

Generalised dystonia is sometimes still known by previously used names of 'Oppenheim's dystonia' and 'primary torsion dystonia'. In this "primary" form of dystonia there is no identifiable cause other than genetic factors, in contrast to secondary or degenerative dystonia which results from an independent neurological condition caused, for example, by a stroke or use of certain drugs, or an underlying condition causing degeneration of the brain over time.

In cases of early-onset primary dystonia there is a 50–60% likelihood that the person affected will have a genetic mutation known as DYT1 (the first gene identified for dystonia). The DYT1 mutation occurs in all ethnic groups but is 3 – 5 times more common in Ashkenazi Jews compared to other populations. Testing for DYT1 is technically easy and widely commercially available.

Dr Mark Edwards

DYT1 dystonia is inherited in an autosomal dominant fashion but has a markedly reduced penetrance. This means that although the gene mutation can be passed to the child by just one parent who is a carrier (ie. each child has a 50% chance of inheriting the abnormal gene), the reduced penetrance of the condition means that only 30% of carriers of the abnormal gene actually get any symptoms of dystonia during their lifetime.

Furthermore, the penetrance is age dependent: if a carrier of the mutation reaches 25 without developing symptoms of generalised dystonia, these individuals are unlikely ever to develop dystonia. However, even if symptoms of dystonia develop, there is great variability in the range and severity of the symptoms that result. For instance, while some patients develop severe generalised dystonia, others may just have mild focal dystonia in the limbs. Once the condition has plateaued, further progression is highly unusual.

While genetic counselling is available for those undergoing a test for the DYT1 gene, the psychological and social implications of a disorder with markedly reduced penetrance and very variable expression, are complicated. Patients and their families will need time to review their situation and to consider their options.

As well as DYT1, there are other genetic forms of young onset dystonia. For instance, dopa-responsive dystonia (DRD) which is responsible for 5% of cases of primary young onset dystonia, is caused by a mutation in gene DYT5. This form of dystonia usually starts in childhood and affects the lower limbs. There is often a strong diurnal (daily) variation (ie. the child can seem unaffected in the morning and then their movements become progressively worse throughout the day). This condition can respond dramatically to daily treatment by the drug called levodopa. Because of the positive effect of the drug, most physicians will now suggest that all children presenting with dystonic symptoms where the cause is not clear should be tried on a course of levodopa to see if there is any improvement. There is also a newly indentified genetic form of generalised dystonia – DYT6 – which typically affects teenagers in their neck or larynx.

In cases where a young patient is not a DYT1 gene carrier and has not responded to a simple course of levodopa, the physician will want to explore whether the dystonia is 'secondary' ie is the result of other

Primary Generalised dystonia

Early-onset dystonia (continued)

progressive or degenerative conditions. "Secondary dystonia is quite common in children," says Dr Mark Edwards, Clinical Scientist at the Institute of Neurology, Queen Square. "As far as possible, it is important to establish the underlying neurological condition, as specific treatments may be available". These further examinations will involve an MRI scan of the brain as well as testing for other rare conditions such as Wilson's disease (a rare but treatable genetic condition in which the body does not process copper properly) or neuronal brain iron accumulation syndrome (NBIA – a genetic degenerative condition in which iron is deposited in the basal ganglia).

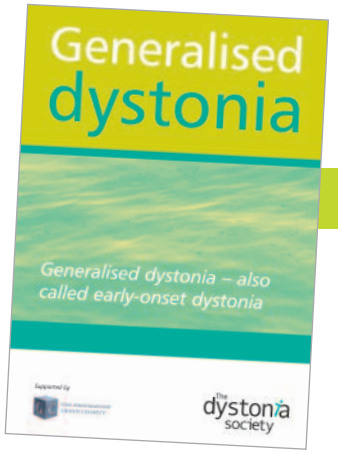
Getting a Diagnosis

Although descriptions of dystonia have appeared in medical literature since the early part of this century, getting an accurate and prompt diagnosis has been more unusual than typical for too many people. The usual clinical tests come up negative, so doctors can sometimes be as mystified as the patient. Getting referred to a neurologist who specialises in movement disorders is often the only way an accurate diagnosis can be reliably found.

How is generalised dystonia treated?

Although there is no cure for dystonia at present, there are a number of treatment options which can be highly effective. "As every person's dystonia is unique, treatment will need to be tailored to each individual; no single solution is appropriate for every person," says Dr Edwards. "However, the primary intention of all treatment is to help reduce the effects of muscle spasm and the awkward postures with the goal of ensuring the maximum quality of life of everyone affected".

Oral medications will generally be the first type of treatment tried. A trial of levodopa is appropriate in all young patients with early-onset primary dystonia to exclude the possibility of dopa-responsive dystonia. Generally a course of the drug will be tried for at least two months before the effectiveness is judged. If, as is unfortunately usually the case, levodopa is ineffective, an anti-cholinergic drug such as trihexyphenidyl will often be tried which can often be very helpful in controlling muscle spasms and tremor. In some cases, second line treatments will be tried which may include clonazepam (a strong muscle relaxant), tetrabenazine (helps to control tremor and involuntary spasm) or baclofen (an effective muscle relaxant). A combination of medications is often advised by a neurologist. These drugs can have side effects which you should discuss with your doctor. Botulinum toxin injections are the most common and effective treatment for the thousands of adults with focal dystonia. These too can have a role for people with generalised dystonia. For instance their use in specific areas with troublesome spasms, such as the jaw, hands, feet, leg or even back, can be very helpful.



A surgical technique known as deep brain stimulation (DBS) has recently been shown to provide remarkable and sustained benefit for selected individuals. It works by inserting fine electrodes in the brain that stimulate areas of the globus pallidus to damp down the spurious signals causing the muscle spasms. Selection of patients for surgery is done carefully after an extensive series of tests at a movement disorder clinic in order to ensure the patient's condition is likely to benefit from the surgery. "This has turned out to be a very important treatment for primary generalised dystonia and in many cases bringing about improvements of 50–70%," says Dr Edwards. "However, recent research has shown that patients with primary dystonia respond much better to DBS in general than those with secondary dystonia."

In contrast to the complex technical treatments, it is important not to underestimate the benefits that basic therapeutic support can bring through properly adjusted seating or appropriate adaptations to the home. A consequence of unsuitable seating and support can result in patients picking up secondary problems caused by pressure on the nerves of the neck as well as long-term wear and tear of muscle and bone structures. "The importance of getting the physical adaptations right should not be underestimated," says Dr Edwards. "Unfortunately, I see too many patients whose wheelchairs have too little cushioning and inappropriate support for their type of movements," he says, "and this can lead to secondary consequences that can cause patients long-term difficulties in the future."

If any members are having trouble with sourcing appropriate equipment or aids, please call Val Wells on 0845 458 6299.

Case study
Baclofen and dystonia

While DBS has become widely recognised as a significant surgical treatment for dystonia, there is another surgical intervention that is also proving to be effective in controlling the symptoms of dystonia: intrathecally administered baclofen. This refers to baclofen administered as an injection into the spinal canal (the intrathecal space surrounding the spinal cord).

Baclofen (one of the 'gaba agonist' family of drugs) is a muscle relaxant and is widely used to treat conditions which cause the muscles to spasm, cramp or tighten such as dystonia, multiple sclerosis and cerebral palsy. Baclofen relaxes the muscles thereby preventing spasms and reducing pain and discomfort. It is available in tablet, oral liquid and injection form.

Dystonia*matters!* *talked to Mr Michael Vloeberghs, Professor of Paediatric Neurosurgery at Nottingham University Hospital, who is a European expert in the use of intrathecal baclofen. He conducts courses on behalf of the European Continuing Medical Training organisation on the surgical techniques involved.*

"Baclofen is definitely very effective in the management of dystonia," says Mr Vloeberghs. "Baclofen delivered intrathecally provides a completely different treatment option to that taken in oral form". Intrathecal baclofen is delivered through an intrathecal pump implanted just below the skin of the stomach with a tube connected directly to the base of the spine, where it bathes the appropriate nerves using a dose about one thousand times smaller than that required by orally-administered baclofen. Intrathecal baclofen also carries none of the side effects, such as sleepiness, that typically occur with oral baclofen. "The doses required to relieve some cases of dystonia may just not be achievable with oral baclofen without severe side effects", says Mr Vloeberghs. "That is where the intrathecial delivery is important".

Before the baclofen pump is inserted into a patient, a test procedure is undertaken. The test involves insertion of a fine catheter or tube under a general anaesthetic. The results of the test will establish whether treatment works for the patient and, if so, will determine the optimum doses needed in the future. The patient can go home after the test dose and is then readmitted a week or two later for insertion of the long-term device.

To implant the small pump, a short incision is made into the abdomen where it is positioned just under the skin near the waistline. Another small incision is made in the back for the catheter to be positioned in the spinal canal. Mr Vloeberghs prefers to use a general anaesthetic as it can be less stressful for the patient. There is also less likelihood of the patient spasming.

Once the pump has been implanted it requires regular refills every 8 – 12 weeks. These are dependent on dosage and are done by trained professionals. It is important to highlight that intrathecal baclofen is still a rare treatment for either adults or children in cases where dystonic symptoms predominate. It is used principally in cases of spasticity. Worldwide, there are thousands of people who have had pumps successfully implanted.

All surgery has small risks associated with it but there are usually few problems or long term detrimental effects with intrathecal baclofen, according to Mr Vloeberghs. Newer models of pump mean that pump failure is now rare. In addition, the current generation of pumps do not need to be replaced for 7 years.

Unfortunately, getting funding for the operation can be difficult in certain regions, confirms Mr Vloebergh, even in the case of children for whom it can sometimes have a dramatic and positive impact on their lives.

If you want more information about intrathecal baclofen you should first of all contact the Helpline who have basic information. We would then suggest you discuss this option with your neurologist to see if you may be suitable.

Joe Doliczny

My story

Now looking forward...

"It was the most miraculous change I had ever experienced as my body returned to the same state before the dystonia had begun..."

The first signs of Joe Doliczny's generalised dystonia began before Christmas 2003, when he was twelve. As Joe, who lives in Chippenham, Wiltshire now explains, it started with constantly jerking spasms in his right arm before eventually progressing into his neck, most of his upper body and to his other arm, until even sitting down became a difficult task.

This worsening condition had a huge impact on my confidence and education – as the spasms became so obvious, it was clear that people were noticing and I had a hard time at school. Also as I was right handed, I found it impossible to write. This was clearly a problem, so I taught myself to write with my left hand which meant I could still attend school.

A year of tests and treatments later, involving a range of drugs, botulinum toxin injections and MRI brain scans, led to me originally being misdiagnosed with Niemman Pic Type C, which is a terminal degenerative brain disease.

This pushed me into a state of depression as my spasms became worse. I stopped attending school and spent the majority of my time confined to my room. Although the relief that I did not have the terminal disease was indescribable, I became frustrated that there was still no explanation as to why I was unable to control my body.

The day finally came in June 2005 when I was diagnosed with dystonia and I spent a long time with the doctor who explained the illness to me. I was told that I would have to undergo an operation called deep brain stimulation.

It would be a lie to say that, on the day of my main surgery, I did not feel incredibly nervous when going into the operating room but the actual operation was apparently straightforward, even though I now have a battery pack in my chest that is powered through leads into my brain. Coming out of the operating room and later waking up to see the Bristol Club Football team at the end of my bed was confusing to say the least but I also felt a new sense of hope as I believed I could finally follow the road to recovery.

Sadly, it was not as I hoped. Far from being the equivalent to flicking a light switch and going back to my previous self, the device in my brain had to be tuned in to send the right signals to my body. As everyone's brain is different it became a matter of hit and miss as to what settings would improve my dystonia. This continued through another painful year of disappointing trips to the hospital to fiddle with my device which also included a dangerous reaction to certain drugs leading to the High Dependency Unit because my brain experienced too much trauma.

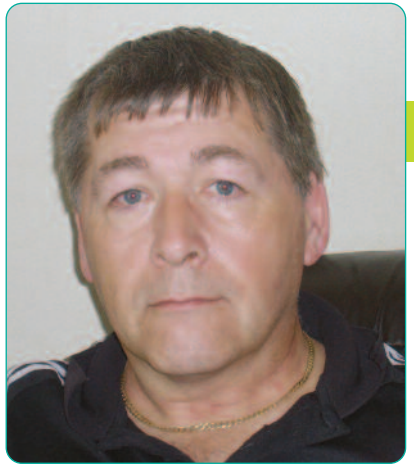
As a result of my dystonia, I did not want to return to school until my spasms were totally under control. I think the major problem was that there is a very low awareness level to what dystonia actually is, or how it affects people and this has a psychological impact on people with dystonia. It had a massive impact on me as my dystonia developed so suddenly, therefore it is very hard to explain when this change occurs after so many years of being without the illness.

At the end of 2006, once the device had been tuned to the correct settings, my spasms stopped and no longer appear to exist. It was the most miraculous change I had ever experienced as my body returned to the same state before the dystonia had begun. I returned to school and my friends and have now just finished my A levels at college and obtained a B and two C's. Six years ago I would not have believed that my dystonia could be controlled completely but after the support of my family, especially from my mum, my friends and the hospital, I overcame dystonia and am now looking at universities and hoping to pass my driving test."

My story

What a difference!

Following the intervention of the Dystonia Society, Alan Jones from Rugeley, Staffordshire finally won funding from his local Primary Care Trust. This funding was for his DBS operation, which has enabled him to start to cope with decades of distress and suffering which was brought about by generalised dystonia.



● Alan Jones

At the age of four I had a slight limp in my right foot which was very painful. At the time it was said I was too idle to exercise, which was a familiar story. My doctor sent me for physiotherapy, which did more harm than good. I couldn't explain the amount of pain I had in all my joints, particularly in my back. This continued for about 17 years until my condition got worse. I suffered memory loss and had problems with remembering where I had left things. Also, at the time, my mum and dad divorced – looking back, I put this down to thinking it was my fault for having this condition.

My school years were the worst. The kids at school took every opportunity to call me names and push me around, just because they felt I was different. After leaving school, I started as a welder in a local firm but this had to finish when I was told that my disability may cause harm to myself or others. My hands had started to shake slightly when the job required me to keep still all the time.

As time went by I began to get used to being a recluse. I did venture out after a day of feeling really sorry for myself and that's when my world took a turn for the better because I met my wife. A year or so after that first meeting I explained what I felt was wrong with me but she said she didn't care as it was me she wanted. So we got married in 1979. Two years later, my wife gave birth to our daughter, who is now 28 years old.

"The Dystonia Society got involved after my wife contacted them and, after two years, the PCT finally agreed to fund the operation."

In 1984 I was sent to London to see Professor Marsden who diagnosed generalised dystonia. To have answers about the cause of my pain and movements was in some ways a relief for my wife and me. But we had a daughter now and suddenly we were being told that she might have the gene that caused my condition. At that time there was a 50% chance of having the gene and, thankfully, tests showed my daughter didn't have it, but we didn't want to take any further risks so I decided to have a vasectomy.

Following this, my wife and I went through a rocky patch in our marriage. Looking back, I realised it was my fault. However, rather than her having had enough of me, it had the opposite effect and she helped lift the dark cloud that hung over me.

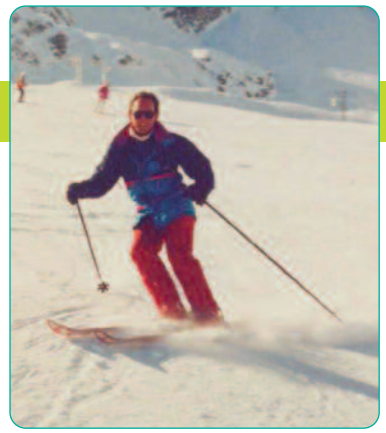
We decided to move home to sort our lives out. Now we have an extended family with my son-in-law and grandchildren, aged eight and three and they keep us all busy.

Three years ago, we heard about deep brain stimulation and went to see Professor Aziz at Oxford, who thought I could benefit from this type of surgery. An application was made to the PCT for funding but they turned me down. This was despite the fact I was often taking higher than the recommended dose of drugs to control my spasm and pain. My generalised dystonia affected my speech, neck, back and legs, causing involuntary movement and painful spasms.

The Dystonia Society got involved after my wife contacted them and, after two years, the PCT finally agreed to fund the operation. Thanks to the Dystonia Society and my wife (yes, we still are married!) I was admitted to the John Radcliffe Hospital on the 7 April and had the operation the day after.

Wow, what a difference! No more pain. I am able to stand upright for the first time in over 20 years. The movement is just magical. You cannot imagine how my life has changed. To cap it all, I have enrolled for an IT course at my local college, which starts in September.

My story
Mike Newbigin



● In complete control...

When Mike Newbigin was eventually diagnosed with generalised dystonia in his early twenties, the chances of surviving past his 30th birthday weren't considered very likely. Now some thirty years later with a loving and sympathetic wife, together with two sons and a daughter, Mike leads the sort of life that most able-bodied men would envy.

Mike has never seen his condition as a drawback. He holds a BSc in microbiology and virology and is qualified as a chartered accountant. Not only is Mike honorary treasurer of the Dystonia Society but as a trustee also helps to plan the future development of the Society. He is also involved with several other charities including Comic Relief.

"I started to walk on the toes of my left foot when I was aged nine which led to me undergoing an orthopaedic operation. I clearly remember being in plaster for a fortnight and that I was screaming for most of that time! I had another operation when aged 12 to lengthen my left foot tendons. I was in plaster for six months on that occasion. Although I can't say my life has been easy, I didn't seem to have any difficulty in passing examinations. Apart from my BSc degree from Warwick University, I managed to gain 11 O levels and 3 A levels at school.

I was also determined to stay active and as fit as possible. When I lived in Bath, I cycled everywhere. As I had only 4 gears, I often had to use all my effort to push my bike uphill. I had lots of sprained ankles but my left leg was getting stronger. By the time I was 16, I felt very fit and even walked unaided six miles on the Isle of Lundy from the south to the north, and back.

"I know I am a prime candidate for DBS. However, having been through 13 operations, I really don't welcome another one..."

● Mike & AnnMarie

After university I came to London and worked for a firm of chartered accountants. It was at that time I ended up by accident living in the same flat as three recently qualified medical students. One of my housemates was dating a Professor of Neurology. One day at breakfast my housemate said: 'We think we know what your problem is. Come to the Royal Free Hospital for some tests'. I was diagnosed with spinal muscular atrophy and was referred to a neurologist. Eventually I was finally diagnosed by Dr Stern at University College Hospital when I was 22 years of age with Generalised Torsion dystonia.

One of my hobbies for 20 years (up to 1998) has been skiing. My theory of why skiing has helped me is that it's controlled falling! A former girlfriend of mine became a chalet girl at the resort of Val D'Isere where I met Jean-Claude Killy who promised that he would lend me his equipment free of charge for as long as I was trying to ski! Within two weeks I finished with the nursery slopes and was attempting the more difficult blue runs.

I know I am a prime candidate for DBS. However, having been through 13 operations, I really do not welcome another one. Also I do not feel I really need it at the moment – I can still drive, walk, get around, do the shopping and socialise. If I really could not control my movements, then I would have to think about it but I have no plans to at the moment.

With generalised dystonia, I always try and avoid infections because our bodies have enough to cope with rather than trying to fight other bugs. I always have a flu jab and so far have managed to avoid the virus.

Whatever time is left to me I will try and enjoy myself as much as possible. I have a very full and active life. Being busy helps keep my brain active and I still feel I have much to contribute to the Dystonia Society."

Review of 2008-09
Reflections and projections

Our last financial year (Mar 08 – Mar 09) was a busy and productive year with progress made in improving access to treatment services: enhancing support and information for those affected by dystonia, funding and encouraging the advance of research, and raising awareness of the condition – particularly among healthcare professionals.

The trustees believe that the funding of research is of paramount importance. To this end, we awarded £50,000 in prize money and grants to Dr Hardev Pall of the University of Birmingham, and Dr Tom Warner of the Royal Free Hospital in London for their respective research into vital aspects of dystonia. Working with medical professionals at all levels has, and continues to be, a priority.

The study underway at hospitals in Glasgow and Aberdeen to examine two forms of physiotherapy for those with cervical dystonia, also made progress. The results are expected early next year. At the same time, the trial of a device aimed at helping those with blepharospasm also progressed. We now have a scheduled start date of October 2009.

Forums have been held nationwide as part of our ongoing programme to improve access to treatment, and those healthcare professionals who participated found them to be useful and effective. The Society has also helped members who had difficulty in accessing appropriate treatment; opening doors that had hitherto remained closed to them. Improving support and information saw volunteers man our 'One To One' support service, offering telephone advice and understanding to 'fellow dystonians' if you will. Early results have been most encouraging and there are plans in the pipeline to expand this service. Another successful project was the staging of 'Living with Dystonia' days in Crawley, Nottingham, Liverpool and Bristol. These events focussed on practical management of dystonia, with special sessions on alternative therapies and new approaches to living successfully with the condition. The positive feedback received from those in attendance led us to plan similar conferences in Southampton, Norwich and Stafford.

"The most valued component of our Society is of course you, our membership..."

● Fiona Ross, OBE

Our quarterly newsletter continues to attract entertaining and informative feedback. Work was also underway to launch a new website which, when fully developed, will feature maps of all UK treatment centres: vital contact information, special areas dedicated to healthcare professionals, and an opportunity for all members to communicate with one another. It should be 'live' by the end of August 2009.

There is, however, no such thing as a free launch. The setting up of the Society's website, and all of the aforementioned activities, cost money. We the trustees are therefore immensely grateful to the many individuals and organisations who made voluntary donations throughout the year. In particular, the Society wishes to thank the John Ellerman Foundation, Eisai Ltd and the Sydney & Phyllis Goldberg Memorial Charitable Trust.

The coming year will present fresh challenges which the Society will meet with enthusiasm. Together with our many ongoing projects we will strengthen our efforts to promote and to fund research into dystonia. In these harsh economic times we are acutely aware of the need to augment our income generating activities.

The most valued component of our Society is of course you, our membership. Without your support, encouragement and feedback we would be unable to make the kind of progress we have seen during the past year. In response to a mid-2008 questionnaire soliciting feedback on key issues affecting your lives, the majority of respondents expressed satisfaction with the Society's services: conferences, Helpline, quarterly newsletter, local groups, and of course our new website. More than 90% of you found our services to be 'helpful' or 'very helpful'.

Since, according to Shelley, 'Nothing wilts faster than laurels that have been rested upon', we promise to aim for 100% satisfaction in the year ahead!

The Dystonia Society

Statement of Financial Activities for the 13 months ended 31 March 2009
(Incorporating an Income and Expenditure account)

	RESTRICTED	UNRESTRICTED			12 months to 29 February
		Designated	General	2009	2008
	£	£	£	£	£
INCOMING RESOURCES					
INCOMING RESOURCES FROM GENERATED FUNDS:					
Voluntary income:					
• Donations, grants and subscriptions	**309,612**	**-**	**247,809**	**557,421**	560,559
• Legacies	**-**	**-**	**136,986**	**136,986**	11,248
	309,612	**-**	**384,795**	**694,407**	571,807
Activities for generating funds:					
• Sales of goods and literature	**-**	**-**	**4,114**	**4,114**	5,611
• Investment income	**8,053**	**-**	**14,425**	**22,478**	21,126
TOTAL INCOMING RESOURCES	**317,665**	**-**	**403,334**	**720,999**	598,544
RESOURCES EXPENDED					
COSTS OF GENERATING VOLUNTARY INCOME:	**-**	**-**	**121,356**	**121,356**	84,390
CHARITABLE ACTIVITIES					
• Raising awareness	**41,137**	**-**	**56,283**	**97,420**	43,255
• Improving access to treatment	**35,559**	**-**	**12,428**	**47,987**	35,278
• Providing support and information	**216,927**	**28,613**	**76,088**	**321,628**	235,544
• Research	**99,728**	**-**	**-**	**99,728**	66,573
	393,351	**28,613**	**144,799**	**566,763**	380,650
GOVERNANCE COSTS	**-**	**-**	**52,505**	**52,505**	27,295
TOTAL RESOURCES EXPENDED	**393,351**	**28,613**	**318,660**	**740,624**	492,335
NET INCOMING/(OUTGOING) RESOURCES FOR THE YEAR, BEING NET INCOME/(EXPENDITURE) FOR THE YEAR	**(75,686)**	**(28,613)**	**84,674**	**(19,625)**	106,209
FUNDS AT THE START OF THE PERIOD	**224,354**	**61,613**	**272,796**	**558,763**	452,554
FUNDS AT THE END OF THE PERIOD	**148,668**	**33,000**	**357,470**	**539,138**	558,763

All of the above results are derived from continuing activities.
There were no other recognised gains or losses other than those stated above.

The Dystonia Society

Balance Sheet as at 31 March 2009

	31 March 2009	29 February 2008
	£	£
FIXED ASSETS		
Tangible assets	–	–
CURRENT ASSETS		
Debtors	**65,902**	19,686
Cash invested at bank and in hand	**540,309**	600,631
	606,211	620,317
Creditors: amounts falling due within one year	**(67,073)**	(61,554)
NET CURRENT ASSETS, BEING NET ASSETS	**539,138**	558,763
Represented by:		
UNRESTRICTED FUNDS:		
• General funds	**357,470**	272,796
• Designated funds	**33,000**	61,613
TOTAL UNRESTRICTED FUNDS	**390,470**	334,409
RESTRICTED FUNDS	**148,668**	224,354
TOTAL FUNDS	**539,138**	558,763

Trustees' Statement in respect of The Dystonia Society

The summarised financial statements have been agreed by our auditors, Chantrey Vellacott DFK LLP, as being consistent with the full financial statements for the period ended 31 March 2009. These were prepared in accordance with the Statement of Recommended Practice "Accounting and Reporting by Charities" 2005, and the Companies Act 1985, and received an unqualified audit opinion.

These summarised financial statements are not the full statutory financial statements and therefore may not contain sufficient information to enable a full understanding of the financial affairs of the Dystonia Society. For further information, the full Annual Report and Accounts, and the Independent Auditor's report should be consulted. Copies of these can be obtained from the registered office. The full financial statements were approved by the Board of trustees on 24 June 2009 and have been submitted to the Charity Commission and the Registrar of Companies.

Independent Auditor's statement to the trustees of The Dystonia Society

We have examined the summarised financial statements set out on pages 21– 24.

Respective responsibilities of the trustees and Auditor

The trustees are responsible for the preparation of the summarised financial statements in accordance with United Kingdom law and in accordance with the recommendations of the charities SORP.

Our responsibility is to report to you our opinion on the consistency of the summary financial statements with the full report and annual financial statements, upon which we gave an unqualified opinion on 24 June 2009. We also read the other information contained in the summarised annual report and consider the implications for our report if we become aware of any apparent miss-statements or material inconsistencies with the summarised financial statements.

Basis of opinion

We conducted our work in accordance with Bulletin 1999/6 'The auditors' statement on the summary financial statement' issued by the Auditing Practices Board. Our report on the Society's full annual financial statements describes the basis of our audit opinion on those financial statements.

Opinion

In our opinion, the summarised financial statements are consistent with the full financial statements and the Annual Report of the Dystonia Society for the period ended 31 March 2009.

Chantrey Vellacott DFK LLP *Registered Auditor* Date: 31 August 2009

Fundraising preview

Team Spirit!

The staff of the Dystonia Society, UK office are looking forward to joining members in Hyde Park for the 5K Women's Challenge on 6 September to raise funds and awareness...

Check out our page on the JustGiving website at: **www.justgiving.com**

● *UK office!*

Moving on together

The Norfolk & Suffolk Group want to raise funds and awareness of dystonia with a fundraising relay and they are hoping that other local groups will join in. Read more about their efforts on their fundraising page on the **JustGiving** site. Or for more details about how you can get involved, contact Sarah Sayer on 0845 899 7133 or email her at **sarahjane.sayer@virgin.net**

AWARENESS WEEK BIKE RIDES

Scotland will be hosting their first bike ride on the 8 May 2010, to launch Awareness Week, whilst the ever popular Rutland Bike Ride will be on 15 May. So... get booked in or perhaps you know somebody else who can ride! Both rides have a fantastic location. For more information please call the office on 0207 7933659 or email ann@dystonia.org.uk

Cycling Mania & London Marathon 2010

Cycling events have been happening all over the country this summer in aid of the Society. Details and photographs will follow in the next edition of **Dystonia*matters!*** Also, Ian Gordon and Steve Mackenzie are our men taking part in the next London marathon so watch this space!

Brighton Marathon places...

Phil Taylor's running in the very first Brighton Marathon for the Society! We've booked five places – two are still remaining, so if you would like one or know someone else that would, please contact Ann Dedman at UK office.

When celebrating a special occasion why not ask guests to make a gift to the Society? Plus Every Click Counts! Please use www.everyclick.com as your search engine to raise money for the Dystonia Society.

Fundraising preview *(continued)*

More Miles for Mark

● *Mark Hurren*

After Mark's achievement with the London marathon, he is off to take up the challenge of the Berlin marathon. Good Luck!

Eleanor's Hat Trick...

Eleanor Chadwick (who is the Granddaughter of Ivy Black) ran the London 10k recently. She will also be taking part in the adidas 5k Challenge and hopefully be doing a half marathon in September. Thank you Eleanor!

Great North Run

Aaron Haigh and Ben Barley will be running in this year's Great North Run. Hope the weather is as kind as your sponsors! We look forward to following all your progress, good luck!

Your Questions *& Answers...*

With thanks to Dr Tom Warner, the Dystonia Society's Medical Adviser

HELPLINE: 0845 458 6322

Q. What is hemi-dystonia and how is it different to segmental or generalised dystonia?

● Hemidystonia refers to an unusual type of dystonia that affects just one side of the body (for instance leg, arm and sometimes face on one side). In the great majority of cases this form of dystonia is a 'secondary' dystonia which means that the dystonic symptoms are the result of an underlying neurological condition that has affected one side of the brain (actually the opposite side to that on which the dystonic symptoms are manifest). Such conditions could include a stroke or a tumour affecting one side of the brain. The basal ganglia area of the brain controls our physical movements and is particularly susceptible to loss of oxygen caused by a stroke. Anyone presenting with this type of dystonia is likely to undergo various investigations to identify the underlying neurological cause. Testing will almost certainly involve an MRI brain scan.

As regards alleviating the dystonic symptoms, the accepted treatments involving drugs or botulinum toxin injections are likely to have a role to play. Unfortunately, research to date indicates that deep brain stimulation (DBS) is generally much less effective in cases of secondary than primary dystonia.

Q. I have dystonia. If I get swine flu is it going to cause me problems?

● There is no reason that having dystonia should mean you are at a higher risk of incurring more serious flu symptoms or any other complications than the rest of the population. However, people with dystonia often report that an infection can make their symptoms of dystonia more uncomfortable for the duration of the infection.

Q. It worries me that health professionals and others don't seem to know a lot about dystonia. What can I do to help change this?

● The good news is that responses from our members to the survey last year showed that the average time for diagnosis has come down dramatically over the past 20 years. However, as you suggest, there is still much to be done. The Society already runs a programme of regional forums for local healthcare professionals such as nurses and physiotherapists which inform them about the condition, its management and treatment. The trustees see this as a crucial area to develop in the future – so expect news of an expanded range of educational activities for healthcare professionals in the future.

It is very pleasing when individual members want to get involved in raising awareness of the condition and Society locally. We have posters and leaflets available from the Society that are suitable for your GP's surgery or your treatment centre, as well as local libraries and other information centres. Please do call the office (tel: 0845 458 6211) to request free leaflets and posters. PS: A big thank you to all of you who are already disseminating information about dystonia and the Society, it is a great help.

Q. Why don't the managers who are involved in planning local services know more about dystonia?

Questions *& Answers...* *(continued)*

● This is a good question and while we are making progress, there is still much to do. This is also an area in which members can increasingly become involved. Most local NHS trusts are committed to involving patients, carers and the public in the planning and decision making process around the services they purchase and provide. They are increasingly looking for local people of all ages who are users of their services (or carers of such people) to air their views about the types of and standards of services available. In a growing number of areas there are opportunities for service users to become involved on significant committees or by taking up opportunities to visit NHS premises to monitoring services or perhaps to become involved on 'reader panels' for patient information. Do make enquiries of your local NHS trust about such opportunities. Their websites are often a good place to start. Your involvement can be as little or as much as you want and by being involved you can help shape future local NHS services.

You can also join other local action groups such as local Neurological Alliance groups and Disability Awareness groups. In some cases, training is provided and you will be reimbursed your travel expenses. If you are interested and want to get involved then please contact the Patients and Public Involvement Team at your local NHS provider.

If you just want to know more about how you can get involved then contact Val Wells at the Society's office on 0845 458 6299.

Q. I take a lot of medicines which have been prescribed by my GP and also others from different doctors I see at the hospital. I am worried about how many different tablets I am taking and I am not sure if I still need to take them all.

● You are right to want to be reassured about this matter. We suggest that you start by making a list of all the medicines you are taking – not only the ones that have been prescribed for you by the doctors but also any vitamin or mineral supplements; homeopathic or herbal remedies that you yourself have decided to take. Make an appointment to see your GP and take the list with you and discuss the medicines and your concerns. Your GP will be able to check what you are taking and refer to your medical records and letters from your hospital doctors. If your GP decides you shouldn't take some medicines anymore then you can always take these redundant medicines along to your local pharmacist who can dispose of them safely for you.

Q. I have been in a lot of pain with my dystonia and have been advised that I might benefit from cognitive behavioural therapy but I cannot see how therapy can help me with my pain?

● Feedback from a number of our members has shown that cognitive behavioural therapy, or CBT as it is often known, can actually be very helpful in helping members with their pain management in three ways. Firstly it helps patients understand that cognitions (thoughts) and behaviour can affect the pain experience and it emphasises the role the person in pain can play in controlling their own pain. Secondly, CBT teaches coping skills and strategies such as progressive relaxation and cue-controlled brief relaxation exercises to decrease muscle tension, reduce emotional distress, and divert attention from pain. Activity pacing and pleasant activity scheduling are used to help patients increase the level and range of their activities. Also, training in distraction techniques such as pleasant imagery, counting methods, and use of a focal point, can help patients learn to divert attention away from severe pain episodes. Cognitive restructuring is used to help patients identify and challenge overly negative pain-related thoughts and to replace these thoughts with more adaptive, coping thoughts.

Thirdly, CBT involves the application and maintenance of learned coping skills. During this phase of treatment, patients are encouraged to apply their coping skills to a progressively wider range of daily situations. Patients are taught problem solving methods that enable them to analyze and develop plans for dealing with pain flares and other challenging situations. Self-monitoring and behavioural contracting methods also are used to prompt and reinforce frequent coping skills practice. CBT for pain management is typically carried out in small group sessions of 4 to 8 patients that are held weekly for 8 to 10 weeks. The groups are typically led by a psychologist or psychologist-nurse educator team.

Research update

Neuroplasticity

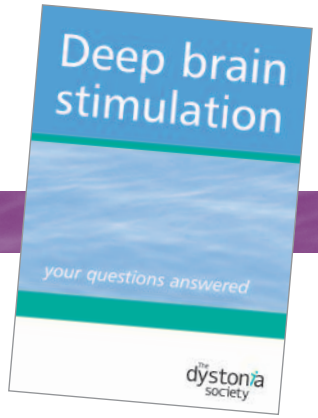
● *Dr Diane Ruge*

The 'hot' topic in the world of dystonia research at the moment is the subject of 'neuronal plasticity' (neuroplasticity) and the role it may play in dystonia. Neuroplasticity refers to the changes in the structure and properties of networks of neurones due to the 'past experiences' of those neurones. Clues that neuroplasticity may be a significant issue in dystonia have come as researchers study the mechanisms of deep brain stimulation (DBS) therapy. DBS is, of course, one of the most important surgical treatments for complex cases of dystonia.

The Institute of Neurology in Queen Square, London is a leading UK establishment in dystonia research. In this article researcher Dr Diane Ruge explains how their research is developing.

Although injections of botulinum toxin are a good treatment for individuals whose dystonia affects only one part of the body, ie. the eyes (blepharospasm) or hand (writer's cramp), therapies for more widespread dystonia have in the past been much more limited. Recently deep brain stimulation (DBS) has emerged as an effective treatment in some of these cases.

DBS is a treatment that uses high frequency electrical stimulation to suppress the function of a part of the brain that seems to be operating abnormally in dystonia. It requires a neurosurgical operation to place wire electrodes in a region called the internal globus pallidus. These electrodes are connected to a device called the internal pulse generator (IPG) which is similar to a cardiac pacemaker and is implanted under the skin below the collarbone. When switched on and programmed by a neurologist or a neurosurgeon, the IPG provides continuous electrical stimulation that interferes with function of the target area in the brain. Because any form of surgery carries a small risk of adverse effects, this procedure is usually limited to individuals who suffer from severe motor disability, and potential candidates undergo a detailed evaluation before the decision is made about treatment.



Although DBS can work well, we still understand little about how it affects the brain. In the Sobell Department in the Institute of Neurology in London, some of our work focuses on exploring the mechanisms of a successful DBS treatment for dystonia patients.

One feature that is of particular interest is that the effect of DBS on dystonia is usually not immediate – it often takes several weeks or even months before peak benefit is reached. Strangely enough, after this peak has been reached, the response to subsequent turning the stimulator off or on, is very quick. Symptoms reappear within a few minutes if the stimulator is off and then disappear just as rapidly when it is turned back on.

Our hypothesis is that there might be two key components of dystonia that explain this pattern. The first component is the main cause of dystonia which occurs when the brain sends abnormal signals through the internal globus pallidus that interfere with normal movement. This is exacerbated by a second problem in which the brain develops a better than normal memory of any previous movements that have been performed. Normally this sort of 'movement memory' might be what helps us remember how to ride a bicycle or drive a car. Being better than normal in dystonia means that it forms a particularly good memory of the abnormal movement patterns that have been experienced in the past.

When a DBS stimulator is implanted it interferes immediately with the transmission of abnormal signals through the internal globus pallidus. However, this does not restore good movement immediately because of the strong memory of previous dystonic movement patterns. It takes time for these to be forgotten and replaced with new and better patterns, and this is why DBS takes so long to reach peak benefit. When this peak is reached, and the 'bad patterns' have been replaced, then we see the effects of DBS very quickly.

Research update (continued)

Neuroplasticity

So far, this is just a hypothesis and not fact. However, we are beginning to test it using a technique called transcranial magnetic stimulation (TMS), which is a way of stimulating the brain through the scalp without the need for a neurosurgical operation. It works on the principle of electromagnetic induction and uses a brief but very strong pulse of magnetism to induce a short lasting electrical current in the brain. This technique cannot be used instead of DBS because it can only stimulate the surface of the brain. However, it is useful way of probing and comparing how the movement control system works in people with and without dystonia.

In our preliminary work we have been able to test how well the movement control system can remember previous patterns of activity. As expected, we found that the system actually works better in dystonia than normal. More recently we have tried to follow how this memory system changes before and after implantation of DBS. We find that immediately after implanting DBS, the excess memory formation is abolished, and only gradually recovers towards normal over several weeks. We think that this allows the abnormal memory patterns that have been stored to be replaced by more natural patterns that lead to clinical improvement. To help prove this we need to study more individuals, particularly testing how they respond to turning off and on DBS after several years of treatment. We also need to use brain imaging systems like fMRI to complement our TMS results. These should show us how the whole motor system changes gradually over time after DBS is started.

We hope that by understanding how DBS works, and why it takes so long to act, we can begin in the future to predict who might benefit most from DBS.

Our research is funded by Action Medical Research and the Dystonia Medical Research Foundation. Researchers involved in the project include: Diane Ruge, Steven Tisch, Patricia Limousin, Marwan Hariz, Ludvic Zrinzo, Kailash Bhatia, Neil Quinn, Marjan Jahanshahi and John Rothwell.

Research update

Projects funded by Dystonia Society

Oxford Blepharospasm project

Following the completion of a lengthy approval process, the Oxford Eye Hospital is now moving forward with the final stages of preparation to start the trial that will test a simple plastic attachment to spectacles. It is hoped that the device will make a significant difference to some people living with blepharospasm. Currently 100 samples of the device are being manufactured for the trial which is due to start in October 2009.

Physiotherapy project

The project to compare two different types of physiotherapy for people with cervical dystonia to see if one is better than the other, is well underway and proceeding on schedule. Half of the 102 participants are receiving a personalised physiotherapy programme whilst the other half are receiving the standard physiotherapy advice. Results of the trial are expected during the first six months of 2010.

Biochemistry of DYT1 dystonia

The winner of the 25th anniversary prize for £25,000 to support innovative research into dystonia (awarded November 2008) was a project from Dr Hardev Pall, University of Birmingham to examine the biochemical changes in DYT1 dystonia. The project is currently being assessed by the relevant ethics panels. We are hoping that this will be completed by the end of this year.

Hand dystonia – potential new project

The Society is currently seeking funding for an innovative project to develop and pilot a therapy for focal hand dystonia. Currently a number of funding bids are out with potential funders for this project which will be undertaken by Dr Mark Edwards at the National Hospital, London. Fingers crossed! If we are successful we hope the project can be started in Q4 of 2010. Focal hand dystonia (also known as writer's cramp, musician's cramp and occupational dystonia) is a relatively common form of dystonia affecting approximately 10,000 people in the UK. The proposed research project therapy will combine motor and sensory retraining techniques and will be delivered combined with botulinum toxin treatment.

Hannah Jackson at the finish line...

A GREAT South Run

Daniel Tomkinson (from the Plymouth & South Devon group) took part in the Great South Run and raised £450 for the Dystonia Society

Daniel Tomkinson with some of his supporters

Fundraising news

Stockholm Success for Hannah...

Heroic Hannah Jackson ran the Stockholm Marathon and raised a whopping £3,500. She completed the marathon in just over 4 hours, on the hottest day of the year!

"My mother suffers from spasmodic torticollis and finds great support from the Dystonia Society, particularly as so few people are aware of the disease. During my run I was really struggling because of the heat, but the thought of the money I'd raised going to such a good cause kept me going." A big thank you Hannah, for all your effort and support!

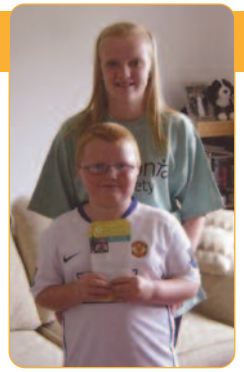
10k... no problem for our runners!

- *Ladan Mirzadeh and Marvin Hong* (left) were sponsored to a fantastic sum of £642. Well done for a great achievement.
- *Daniel Wilkinson* from the armed forces did extremely well running the course (must be his training) and raised £64 for dystonia.

GREAT MANCHESTER RUN – GREAT RESULT!
Lynda and Robert Holdsworth raised £634 in sponsorship – another great achievement!

Fundraising news

Coffee for coffers!



- *Mollie & Billy*

The Marshall Family don't mind rolling their sleeves up for a good cause. They organised a coffee morning and set up stalls selling all sorts of goodies along with a raffle, raising a whopping £450.

Their intention was to hold it in the garden but yes the weather decided to do it's thing so… everyone inside! Mollie (age 11yrs) and Billy (age 9yrs) got really involved with helping out on the day. Ben Barley who is a very sporty member of the Marshall family, will be running in the Great North Run in September.

- *Paula Mulooly and Angela Bedwell* (below) Sharon Cattermole was there to support them and said: "We waited eagerly for the girls, ears pounding from the drumbeat of feet and eyes dancing with flashes of colour. Then at 10.40, I spotted a hand above the crowd and another dystonia t-shirt! Their finish time was 1 hour, 35 minutes, a great achievement for their first 10K, together with the £710 for dystonia."

Brian's amazing challenge

Brian McGregor completed the Three Peaks Challenge with cycling in-between. He achieved a total climb of 3,400 meters and a cycle of 510 miles, all in less than six days. The total amount raised was £1,310. For some great close up footage of his intrepid tour, go to www.youtube.com

Celebrations with donations

- *Joan Nicholson invited her friends from the Emmanuel Women's Guild to a special lunch in order to celebrate her 90th birthday. She chose donations for the Society in lieu of gifts.*
- *Pat Oak celebrated her 80th Birthday in style! She's pictured below with her sons John & Peter. In total, an amazing £585 was donated to the Society.*

- *Pam Simpson enjoyed her 70th Birthday Party and also asked friends to donate to the Society instead of presents.*

- *Pam celebrating in style!*

Fundraising news

Artful collecting

Bruce Glasser held another successful Art exhibition in June and collected over £73 in the collecting box.

He was able to raise awareness of dystonia by displaying leaflets and information to many visitors. A group of doctors attending a seminar at the centre also visited and were very interested in the information available on the table.

Raising awareness in Sussex

The East Sussex group held a stall at the **Uckfield Festival** on 11 July to act as an information point for the Dystonia Society aswell as for the local branch. We had many conversations with members of the public, and hope to be able to meet some new members at our next meeting on 11 July.

175 happy years celebrated...

Mr & Mrs Springett celebrated their **Diamond wedding anniversary**. Congratulations on celebrating 60 years of marriage! Mr & Mrs Phipps honoured their **Golden wedding anniversary** by holding a special lunch for their family. There were **Ruby wedding celebrations** for Mr & Mrs Williams and a **Silver wedding anniversary** for Marion & Wallace Frew, who celebrated in June. Thank you all for thinking of the Dystonia Society on your Special Day! Over **£12,000** has been donated with money still rolling in!

Fundraising news

Lunch with a view

The Blepharospasm Group held their summer lunch at Jill and Tony Haynes lovely home in Lewes, East Sussex.

The weather was kind (hooray!) and the group were able to enjoy their lunch on the terrace with wonderful views over the South Downs. Cathy Palmer managed to capture a lovely moment at the end of the afternoon.

Grateful for gazebo's

A garden party which was held at Molly and Tony Perry's home was enjoyed by a huge crowd, who managed to raise **£343** between them. The gazebo's they purchased with their **Alexandra Rose Grant** were put to good use!

A test of stamina!

Thanks go to David Keene who's raised over **£2,000** in sponsorship. "My wife Rosanna developed Blepharospasm over two years ago and has not been able to work since March 2008. We joined the Oxford Branch of the Dystonia Society and have become actively involved as joint secretaries – Rosanna does the talking and I take the minutes! I wanted to do more to support the Society and make more people aware of dystonia, therefore I decided to do a sponsored walk on 12 June this year to raise funds," he said.

Congratulations

...to all our fantastic cyclists! The Rutland Bike Ride bought in a grand total of £8,000. Hope to see you at the same time and place next year. The date for your diary is 15 May 2010 so secure your place asap!

- *The Drewery Team*

Una Rennard

A day in the life...
Una Rennard

Group Support and Development

Although I have been employed with the Society for some years now, it was only in June this year that I started my new role. One initiative soon to be introduced is a region by region page on the revamped website...

One of the most rewarding aspects of my job is supporting the development of new groups and getting existing groups active again. I love the enthusiasm and drive brought to the process by volunteers with fresh ideas and a desire to support others. The Society has been quite successful in obtaining funds for new groups during the first year or two. This helps with the cost of the venue, printing and refreshments at meetings. We're particularly keen to get groups going in Wales and Northern Ireland – so get in touch if you think you could help!

One of the things I am determined to do is support groups establishing links with each other and get them to think about new activities. I'm in the process of finalising a handbook for groups that should help them to identify other groups they would like to talk to. One of my new tasks is helping to keep groups informed and give them new ideas by introducing a regular bulletin aimed just at them.

There is an ideal opportunity for groups to get together on Sunday 8 November, following the annual conference, at the Annual Groups' Forum (now in its 4th successful year – how time flies!). It would be great if as many as possible could attend as it will give us all an opportunity of getting to know each other a little better.

I am also in the process of updating the group pack which is something I have been really proud to be involved with. I hope it becomes a 'living document' and used as a reference by groups on an almost daily basis.

You can contact me on 0845 458 6334 / email: **groups@dystonia.org.uk**

Letter from America
From Ms Rogers Hartmann

www.lifewithdystonia.com

Ms Rogers Hartmann

Despite my rather unique name, I am a 38 year old woman who was diagnosed in June last year with dystonia/spasmodic torticollis. I knew what I had because my brother has a milder version of it but it took me months to get a doctor to agree with me.

Soon thereafter I began writing a blog on the internet. A few months later the famous American talk show hostess, Oprah Winfrey, took an interest after reading about my story and I was invited to appear on her show along with actor Michael J. Fox who has Parkinson's disease along with dystonic symptoms. That same week I was asked to appear on NBC's *Today Show* in New York and was interviewed by Meredith Vieira. She is very well respected on TV and has dealt with chronic illness affecting her own life as her husband has multiple sclerosis.

I have become 100% dedicated to help the misdiagnosed, the un-diagnosed and those without any proper treatment or support. I have worked with a number of patients in the UK and will continue to do so. Part of my family resides in London so I hope to come for a visit to see them, as well as meeting as many support groups as possible.

We are all united in this quest for relief from the pain and, even more so, the big quest for a cure. I wholeheartedly believe that we can each find ways to heal. Dystonia is complex disorder, as we all know. What works for one may not work for another but I do know that one thing that will work for ALL OF US is cultivating a positive attitude. I find comfort in knowing that we have a community that can really support one another. It takes bravery to leave one's home. Reach out to your friends and family. Reach out to me, if you like. I am not aligned with any US dystonia foundations or drug companies. I have chosen to remain independent. God bless to all.

Beatrice's legacy

A kind, Christian lady

● Buzz at home

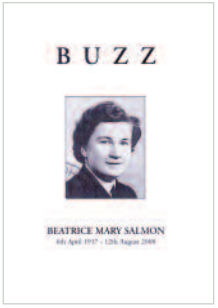
The Society has only been able to make the progress it has over the past few years thanks to several generous financial gifts bequeathed to the Society as part of a legacy.

It is such a shame the Society cannot say a personal thank you to those special individuals who have helped the Society in this wonderful way. However, we are delighted to be able to honour the memory of Miss Beatrice Salmon with this short appreciation.

Beatrice Salmon, or 'Buzz' as she was know to her family and friends, never married but left a substantial estate after her death at 91 in August to twenty one good causes including the Dystonia Society. Buzz did not have dystonia herself and her executors are not sure of exactly how she ever heard of the condition!

"Buzz was just a very kind, Christian lady who was very generous," said Patricia Wilson, wife of Buzz' nephew, David Wilson. "I remember her as a remarkable woman and always very active. She painted birds and played golf and bowls," said Patricia. "She was one of the old breed who just got on with life despite the ups and downs."

We are also grateful to Jenny Foale, who was Buzz's god-daughter for filling in more details. "Buzz lived in Harpenden until after she retired and went to Welwyn Garden City to be near her sister. In the Second World War, she was an officer in the Wrens and, after coming out of the service, she worked for the School Meals Service. By the time Buzz retired, she was responsible for the provision of 18,500 school meals a day in Hertfordshire." Buzz' love of nature and marvellous creativity were reflected in her meticulously observed and exquisite paintings of birds and flowers. Buzz was a powerful individual whose inner strength and generosity of spirit never deserted her. She is remembered with love and admiration by all who knew her.



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