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The
dystonia
society

Dystonia *matters!*

Issue 70 ● Winter 2010

On top of the world



Also in this issue...

Parents conference
page 27

Physiotherapy trial page 13

Research advances page 24

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Printing is supported by an
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Issue 70 ● Winter 2010

PHYSIOTHERAPY
SPECIAL ISSUE

THE DYSTONIA SOCIETY

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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: Leanne Donellan
who raised over £3,500 taking
part in the Artic Challenge.*

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.

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Members news

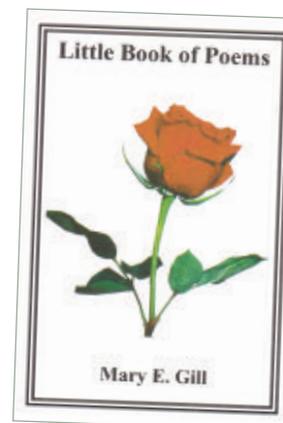
Oxford is the business

Group coordinators, Lorraine Jackson and Carol Powell, organised an excellent 'Living with Dystonia' day at the Said Business School in Oxford last September.

Two medical presentations about dystonia treatments were followed in the afternoon by four workshops on complementary therapies which were very well received.

Poetry please

A charming booklet of poetry has been produced by its author, Mary E. Gill. Mary has kindly donated a number of the booklets to the Society. If you would like a copy, please call UK office. The booklets are free but any donations will be gratefully accepted.



Talking of iPhone Apps...

Karl McEvoy, now 21 years old, developed dystonia at 4 years of age resulting in him being unable to communicate verbally with many people apart from his family. However, his life has changed since his father, Hugh McEvoy, developed an app called 'TalkforMe' for the iPhone. The cost of the new app is €4.99. For more information please contact Hugh at info@talkforme.ie



● Organisers Lorraine Jackson (left) and Carol Powell

Book Review

Member, Barry Fagg, has compiled a personal choice of books about living with dystonia that he believes other members will find of interest. The full list can be requested from UK Office – email or paper versions. Particularly recommended is: *Living Well with Dystonia: A Patient Guide* at a cost of around £18.

Prayer chain

A few years ago a prayer chain was organised in Northern England. Yvonne Coram would like to start it up again. If you are interested in knowing more, please email or call the UK office to be put in contact with Yvonne.



Welcome to the Winter newsletter

Goodbye and thanks for all your support...

This has been a particularly exciting few months as a number of important projects have come to fruition, for instance, the preliminary findings of the clinical trial into physiotherapy for cervical dystonia were announced at the Annual Conference (page 13). The Society also staged its first conference in a decade, specifically for parents and youngsters affected by dystonia (page 27). Very heartening too, has been the response from GPs to a special web-based training module developed in conjunction with BMJ Learning (see page 4). On top of that, we had our best attended Annual Conference ever...

Behind an excellent staff team who 'get things done', there is a strong team of trustees who make the decisions about our priorities. There are now vacancies on the Board. Why don't you think about bringing your skills and interests to that Board? (see Fiona's article on page 7).

I will be leaving the Society very shortly for health reasons. I have been saying that this job has been the great 'love affair' of my working life – and I mean it! It has been a great privilege to be Chief Executive over the past six years. I am sure that with the staff team we have, and with Paul King at the helm, the Society is well placed to achieve even more in the future.

Philip Eckstein *Chief Executive*

Society news

Primary care progress

GPs and healthcare professionals throughout the UK now have an important new web-based source of information about dystonia, following a collaboration between the Society and BMJ Learning. Part of the BMJ Group, BMJ Learning delivers high quality medical information worldwide.

The web-based learning module called *Dystonia – a guide to assessment and management* was especially developed to help GPs and other primary care professionals throughout the UK to recognise the tell-tale signs of dystonia and then understand the importance of referring their patients to neurological specialists. The module includes video and multiple choice questions. We are very grateful to Drs Mark Edwards and Tom Warner for the time they gave to the project.

Originally the target we set was for 500 medics to complete the one hour module within the first six months. However, the excellent news is that since the site went live on 20 October, seven weeks ago, we have already had more than 500 medical professionals complete the module! We are also delighted by the many comments that GPs are leaving on completion of the module – they show the module is clearly providing new information for GPs, in a way that they find useful. Just a few of the many comments: "An excellent review, thanks!" Dr Richard Shiggins "Very good review of a subject I have previously given little thought to..." Dr Lindsey Elliott "An excellent review, I particularly enjoyed the videoclip." Dr Brendan O'Colmain

Donations in memory

We offer our sincere condolences and grateful thanks for the many donations received in memory of loved ones:

- * Gladys Wright
- * Donald Hadden
- * Diana Tripp
- * Sheila Hopgood
- * Margaret Cannell
- * Barbara Coombes
- * Audrey Albon
- * Lesley Whatling
- * Charles Wilkins
- * Gwen Edwards
- * Bill White



Anyone can register onto BMJ Learning to undertake the dystonia learning module – even you! Go to the website <http://learning.bmj.com> (no www. in the address) and register – see the box on the right.

Great memories

On a personal note, I was diagnosed with MS a couple of years ago and travelling to London from Brighton is getting a bit difficult for me. So I am now planning a quieter life, based at home as a maths tutor! (I have always liked mathematics and I am looking forward to it.) I really do appreciate the nice comments and cards, thank you so much.

It has been the contact with members and the work with volunteers that has made the job such a delight. All the very best to you and the Society in the future.

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



● Paul King

Society news

New Chief Executive

The Society's new Chief Executive, Paul King, starts on 4 January 2011. He has already attended the Annual Conference and met a number of members there. He writes:

I am delighted to have been offered the position of Chief Executive at the Dystonia Society and am really looking forward to starting in the new year.

I have been really impressed by everything I have seen of the organisation so far but I am also aware that there are some major challenges especially relating to concerns around funding of treatment by Primary Care Trusts.

My background is that, for the last five years, I have been Chief Executive of Hammersmith and Fulham Mind which is an independent charity affiliated to the network lead by Mind, the mental health campaigning organisation. Prior to this I worked in the private sector. I have experience both in running charities and influencing government health policy that I can use to support the interests of the members of the Dystonia Society.

Annual Conference

The Annual Dystonia Society Conference took place on 6 November in central London. Over 220 members attended the event (a record attendance!) to hear leading clinicians and researchers speak about research developments for dystonia. Complimenting these presentations were a series of workshops focusing on practical options including support for carers, the Alexander Technique, physiotherapy and self-management techniques.

● Right: Conference photos



Facebook

We now have an official Facebook page where you can keep up to date with all that's happening and let us know about your own events and fundraising. If you are on Facebook just search 'The Dystonia Society UK' and join us!

Society news

Grants available

The Society is able to make small financial grants to those affected by dystonia.

The grants panel are especially keen to hear from those looking for a contribution towards a respite break, holiday or a piece of specialised equipment (not wheelchairs). Grants will not usually exceed £300, but in some circumstances a higher amount can be considered. The endorsement of a health or social care professional is required as part of the process.

In order to ensure that our limited funds reach those most in need, applications are only considered once all other reasonable sources of support have been explored such as Social Services, NHS, local education grants and any other charitable sources of funds for which you may qualify. The selection process also takes into account the weekly income of the household involved and also the amount of savings held.

Please do call the Helpline on 0845 458 6322 if you would like more information on the scheme or you would like an application form.

Website forum



On the Society's website there is now a 'forum' enabling members to post messages and respond to others who have posted a comment. You do not need to register to view the conversations. Just log on to our website www.dystonia.org.uk and click the forum tab at the top.

Helpcards...

The Helpline team has developed a selection of 'helpcards' covering the most common forms of dystonia.

They provide a very succinct summary of your condition and are credit card sized, designed to be carried easily in pockets and handbags.

They were produced in response to requests about how useful it would be to have a simple card to give to a member of the public when the situation demanded. Cards have been produced for cervical, blepharospasm, generalised, laryngeal, oromandibular, focal dystonia of the hand (writer's cramp), tardive, paroxysmal, myoclonus, hemi-facial spasm and dopa-responsive dystonia plus a general one for dystonia. Anyone wishing to request some of these cards, please ring the Helpline on 0845 458 6322. This is a pilot project and there will be no charge for the cards.

Who wants to be... ...a trustee?

Fiona Ross, Chairman of the Society, writes:

Could you spare some time to join the Board and help the Society? We're looking for volunteers. Do you have a special skill that we could put to good use? What we really need are people with fund-raising experience, or who have a background in communications, but you may have something else to offer in a specific area such as computers, medicine or science. Are you a good organiser? Do you know your way round the complex benefits system? Everyone has a skill – could we use yours?



● Fiona Ross, Chairman

Many people who are living with dystonia have become experts at managing the condition – patients, parents, and partners – that could be your skill. Whether you have direct experience of dystonia or not, what we need are people with basic common sense! We also want to represent the whole of the UK. At present most of our trustees are from England... where are the Welsh, Northern Irish and the Scots?

The Dystonia Society is run by a Board of Trustees like the directors of a company, although we're not paid. We are all volunteers, with different backgrounds and experiences. In short, we're ordinary people, just like you. What binds us together is we have a common interest in dystonia and want to help others.

We meet, in London, six times a year. Each meeting lasts about three to four hours, and travel expenses are reimbursed. It is the responsibility of the Board to ensure the Dystonia Society is an efficient professional organisation, which complies with all the various aspects of the law, and delivers what our members require. This means over-seeing the finances, and planning for the future. We decide the policy and strategy of the Society – the CEO and staff carry it out, although in practice we work as a team.

Each trustee is expected to sit on at least one sub-committee dealing with such areas as communications, fund-raising, awareness, research, support and welfare. These meetings are usually held at the office in London but can also be dealt with by telephone conferences, and by email.

A trustee is elected for a term of three years during which time, as well as attending meetings, he or she is effectively an ambassador for the Society.

It is not as daunting as it sounds, and all new trustees are given an induction course explaining how the Society operates. Elections are held, by postal ballot, early in the New Year in time for the first Board meeting of our financial year in May. There are nine elected trustees at the moment. Several of them are due to stand for re-election, and so we have four spaces to fill on the Board. Why not throw your hat in the ring?

The process is very straightforward, it's a bit like applying for a job, but much more informal. Contact me by Friday 7 January 2011 via the office in London. You can phone, write or email geraldine@dystonia.org.uk and you will be sent an application pack. A small group of the existing trustees will go through the applications and draw up a short-list of those to be interviewed – although it's more of a chat than a grilling!

Assuming you get through that process, your name will go on the ballot paper for the members to vote. You'll be asked to submit a photograph and 200 words explaining who you are and why members should elect you. As with most other charities, if elected, you will have to undergo the standard security checks – by the Criminal Records Bureau in England and Wales, Disclosure Scotland in Scotland and by the DHSSPS in Northern Ireland.

If you've read this far, you must be interested! It's your Society. Come on, get involved!



● Trustees left to right: Roger, Shona, Joanna, Fiona, Penny, Mike, Sue and Nirma (absent: Maureen and Alan)

Physiotherapy and dystonia

A personal perspective

Joanne Day works for the Society as its Information Officer and Web developer. Remarkably, she also has a Masters degree in physiotherapy at the same time as living with the challenges of generalised dystonia! In this article Joanne responds to frequently asked questions about physiotherapy.



● Joanne Day

What activities are involved?

In some people's opinions, physiotherapists are simply concerned with providing a list of exercises to work on at home. In fact, there is much more in the physiotherapists' armoury than such lists. Depending on circumstances, the physio may suggest massage, use of hot or cold packs, acupuncture tapping, fitting a splint, TENS equipment, stretching exercises or proprioceptive neurofacilitation (an advanced form of flexibility training) to name but a few.

How is physiotherapy helpful?

In dystonia, some muscles contract, spasm and therefore shorten, which conversely means that the opposing muscles are being lengthened and weakened. Physiotherapy can address these imbalances. Muscles kept in a shortened position that are not gently stretched, will gradually become permanently shortened, resulting in contractures. Physiotherapy will aid in training you to stretch the affected areas and to undertake gentle movement exercises to compensate for deficits caused by the dystonia.

At your first physiotherapy session, the level of your disability will be reviewed at a thorough examination to give you and your therapist a pre-physio assessment baseline. A treatment plan will then be drawn up, which will consist of a mix of muscle 're-education' exercises and perhaps some of the various techniques listed above. At subsequent sessions you will be assessed again and this will be compared to the baseline to identify improvements. Interventions may focus on muscle 're-education'. For instance in the case of cervical dystonia, patients may 'lose' a sense of where their midpoint is due to their neck being constantly pulled to

one side. Knowing the position of your true symmetric midpoint is important for balance, walking and a pain-free spine. A physiotherapist may use 'mirror therapy' to help the patient rediscover where their midpoint is, as well as providing exercises and advice to help alleviate the problems that have arisen due to their imbalanced posture.

There have recently been a number of studies investigating the effects of physiotherapy on dystonia and they are showing promising results. More and more medics are now in little doubt that physiotherapy may be helpful in managing some symptoms of dystonia (see Dr Grosset's article on p13).

Types of dystonia helped

Physiotherapy may well be able to help in controlling the symptoms of a number of types of dystonia. These include generalised, cervical, writer's cramp, hemi- and lower limb dystonia.

For focal dystonias found in the hand/arm, physiotherapy will very likely focus on a 're-learning' approach (see later article on re-learning techniques for musicians). The rehabilitation of hand movements associated with writing focuses on performing exercises to improve independence and precision of fingers and wrist movements.

Must it be a neuro-physiotherapist?

'To wait to see a neuro-physiotherapist or accept an appointment with a general outpatient physiotherapist?', is a commonly expressed dilemma. There are different opinions on this matter but from my experience, I would indeed advise seeing a specialist neuro-physiotherapist wherever possible. These professionals are used to treating conditions such as stroke, head injuries and multiple sclerosis, which share symptoms with dystonia.

Neuro-physiotherapists are used to being patient and taking small steps. In contrast, the work of physiotherapists working in outpatient departments will focus much more on dealing with broken bones and sprains so that results usually occur at a quicker pace. Another advantage of seeing a neuro-physiotherapist is that they are often assigned to Rehabilitation Units and can get to know patients better as they are referred back for 'top up' treatments.

When is the best time to start?

The best time to start physiotherapy is early after diagnosis; this should minimise any problems. Physiotherapy aims to prevent the formation of

Physiotherapy and dystonia

A personal perspective (continued)

soft tissue shortening as happens when muscles are kept in a permanently shortened position by dystonia. Once these contractures are formed, physiotherapy cannot help significantly. However, if you are having pain or other problems that are not being addressed by other treatments, it can be beneficial to see a physiotherapist who can offer help or advice. Unless your dystonia is fixed in a rigid position, physiotherapy could well help.

How to ensure the benefits are maximised

To maximise any benefits of physiotherapy, do what your physio advises – even if you feel it makes no difference! Progress may be slow or you may not notice a drastic improvement, but it will be worth it, I promise. When your physio advises you how to do your exercises and how frequently to do them, he/she aims to empower you to take charge of your condition. But to take charge of matters, you will need to be committed to the treatment techniques.

How does a member find a physiotherapist?

Referral to an NHS physio can be done through your GP, Consultant, specialist nurse, or in some cases by self-referral. However, as self-referral is still a relatively new concept within the NHS, you should contact your local primary care trust (PCT) to check whether it is available in your area. Don't forget to ask to see a neuro-physiotherapist.

If you are receiving botulinum toxin injections, the hospital in which you receive them will most likely have a neuro-physiotherapy unit, so ask your Consultant to refer you. In England, many physiotherapists work in the private sector. If you decide to visit a private physiotherapist, you will have to pay for any treatment you receive.

You can make sure any private physiotherapist is properly qualified by ensuring they are a member of a recognised body such as the Chartered Society of Physiotherapy (CSP) www.csp.org.uk Only practitioners who are registered with the Health Professions Council (HPC) are allowed to use the title 'physiotherapist'. Before seeing a physiotherapist, you can check that they are registered with the HPC, by going to their website www.hpc-uk.org Private physiotherapists can also be located through the specialist group *Physio First* www.physiofirst.org.uk

Me and my treatment

Indian head massage

Mike Stephens, member from East Sussex, has found his life hugely improved since he discovered Indian head massage, a technique that uses traditional massage strokes such as rubbing and stroking. Mike who is 60, was born with dystonic cerebral palsy. He finds it difficult to walk and suffers from muscle pain. In March he undertook a course of six sessions in Indian Head massage. Here is his log for the last session:



● Having a massage

Before the session

My neck spasms are worse than ever. My botulinum toxin is not working. But my stress levels are not too bad. I am very happy with life.

During the treatment

My head and neck went into spasm during the back, shoulder and neck massage but I had no pain. There were not too many knots and the massage was very comfortable. I felt so much better when my head was massaged – the best so far. My spasms stopped and I had a lovely relaxing feeling as my head was supported. Her fingers and hands flow from one movement to another in a smooth, wave motion. Great.

Writing a week after treatment

I still feel full of life and relaxed at the same time. No other treatment has had this effect on me. I am tired in the evening and the spasms are just as bad, but there is no pain! In addition to focusing on the head, the technique also targets the upper back, shoulders and neck area – the significant places in the body where we store tension. The techniques are apparently easy to learn and can be self-applied too! It has a reputation for being effective in dealing with a range of complaints, especially those that are stress related.

The massage is administered by district nurse, Alison Gow. Recently, Mike was pleased to help her eight year old niece who requires 24 hour care by raising over £4,000 in a sponsored parachute jump to buy her new equipment. For more information, please contact Mike via our UK office.

Physiotherapy and dystonia

Clinical trial results

Can physiotherapy help people with cervical dystonia? Is one type of physiotherapy more effective than another? A major clinical trial in Scotland has studied these questions, and initial results are now available.



● Fiona & Dr Grosset

Funded by the Dystonia Society, the trial was started in 2008 and is now in its final stages as the detailed statistical analysis nears completion. However, Society members got a preview of the findings at a presentation by Dr Donald Grosset to a packed auditorium at the Society's annual conference in London on 6 November. Dr Donald Grosset, Consultant Neurologist at the Institute of Neurological Sciences, Glasgow, is one of the project's two lead researchers.

Dr Grosset highlighted how the trial had compared two types of physiotherapy, one based on standard practice in the UK and the other based around the 'specialised' type devised by Dr Jean-Pierre Bleton, who works at the Centre Raymond Garcin, Hôpital Sainte-Anne in Paris. Initially 105 patients were recruited to the trial which ran across two centres in Glasgow and Aberdeen. Two physiotherapists, Hazel Sinclair (Glasgow) and Jillian Fowlie (Aberdeen), received training in Paris in specialised techniques. They administered one of the two techniques to trial participants on a weekly/fortnightly basis over six months. The trial had a PROBE design (prospective, open, blinded evaluation) which means that at the start of the trial, patients were assigned randomly to one style of physiotherapy or the other. While the physiotherapists knew which style of physiotherapy was to be administered, the patients were not aware in which group they had been placed. The independent experts who made the final assessment of the outcomes of the physiotherapy for each patient, were also unaware which type of treatment they had had. Assessments were made via three widely used dystonia rating scales known as TWSTR, CDIP-58 and EQ5D. Between them, the scales not only took into account measurements on the patients' head/neck movements

at one, six and twelve months but also focused on patients' reports on the quality of their lives at these milestones. While the final assessment of results is still being undertaken by experts at the Robertson Centre for Biostatistics and the Glasgow Clinical Trials Unit, the broad outcomes are now clear. Dr Grosset summarised them as follows:

1. The improvement over time is (at least in part) likely to be due to participation in the study.
2. There was no overall difference between the two different types of physiotherapy that were administered.
3. Both forms of physiotherapy were 'well tolerated' which meant there had been very few 'adverse events' (side-effects) and only a small number of patients who had had to drop out of the trial (largely due to neck discomfort or pain).

Commenting on the results, Dr Grosset said: "The results of this trial are helpful. Although no particular type of physiotherapy was shown to be more effective than the other, the trial has shown that physiotherapy can be applied in many people with cervical dystonia". Dr Grosset also hoped that the trial would reassure clinicians throughout the UK who until now may have had concerns about proposing physiotherapy as an appropriate treatment for their patients with torticollis. "I believe that the results of the trial will provide clinicians with some reassurance that physiotherapy can be administered to patients with neck dystonia. The trial will hopefully ensure that there is no reason now to believe that physiotherapy will necessarily exacerbate the problems associated with prolonged dystonic postures", Dr Grosset said.

Philip Eckstein, CEO of the Dystonia Society said: "This was the largest piece of medical research that the Society has ever supported and the results are important. We are very grateful to many members and organisations in Scotland and throughout the UK for all their efforts to raise the £150,000 required for the project. Particular thanks also to the RS Macdonald Charitable Trust and the Foyle Foundation. Finally, thanks are due from everyone at the Society to the researchers, physiotherapists and the many members who took part, without whose involvement the trial could never have taken place," he said.

Physiotherapy and dystonia

Hitting the right note

This article describes a research study carried out with eight musicians affected by focal hand dystonia (FHD) to test a technique to help them regain control of fine hand movements.

Focal hand dystonia, which affects musicians, is characterised by an involuntary loss of control and loss of coordination of finger movements. Musicians report a range of symptoms including muscle spasms, cramping sensations, abnormal hand posture, finger curling, loss of control of finger movements while playing the instrument. It most often involves the 3rd, 4th and 5th fingers of the hand, and is thought to be related to the intense and prolonged practice of rapid and highly precise finger movement patterns. The condition can be disabling enough to curtail a professional career.

A lot of scientific research has been carried out on focal hand dystonia in recent years, and research findings have shown abnormal processing of sensory and motor information in several parts of the brain. This would explain the abnormal muscle contractions and spasms observed in focal hand dystonia. The management of FHD remains imperfect and uncertain, and to date there is no cure. However, with the recent advances of research on the brain, new therapy interventions have emerged. The aim of this study was to investigate the effects of a specific exercise therapy over twelve months. The participants were tested every two months during this period.

Constraint-Induced Therapy

This therapy involved immobilising the wrist and a specific finger with a splint. Generally, fingers which were causing excessive muscle contractions or spasms were splinted. The aim of the splint was to reduce the number of spasms affecting the hand, and therefore to retrain the adjacent fingers to move more freely in order to regain normal movement patterns. The musicians had to practise specific finger movements on their instrument, at slow speed, with the splint in situ. The splints were made of a thermo-plastic material that could be moulded to the musician's hand while holding a normal playing posture. The first week of retraining was very



● Dystonia 4th finger

intensive. The musicians had to practise their finger exercises while playing for two hours every day. After the first week, they were asked to practise these finger sequences daily with their splints for thirty to sixty minutes.

Motor Control Retraining

After completion of the first week of intensive constraint-induced therapy, a second type of exercise therapy was started. This did not involve splints. The participants selected two pieces of music (an easy piece and a more challenging one).

For each piece, using a metronome, the musicians were asked to play at a very slow speed that made it possible for them to play with a minimum of abnormal muscle spasms in the hand. This was done in order to encourage normal rhythm and normal movement patterns. Musicians were allowed to increase the metronome speed as long as they could manage to play with minimal abnormal movements at the new speed. They were asked to practise this type of retraining for thirty minutes per day, in addition to the thirty to sixty minutes of constraint-induced therapy.

Results

To assess progress, a three minute video recording of each subject was taken for each piece at regular intervals. In order to measure progress, the number of abnormal movements occurring over the three minute video was counted for each finger affected by muscle spasms. Results revealed that the number of abnormal movements per second of instrumental playing decreased significantly over the twelve month period. These results demonstrated that this type of specific exercise protocol could help musicians affected by focal hand dystonia towards recovery of normal fine motor control while playing their musical instrument. More information about the study can be found on this website: www.musicianshealth.co.uk

Article by Patrice Berque BSc(Hons) MCSP HPC
email: patrice.berque@btinternet.com



● Playing with splints

Physiotherapy and dystonia

Further perspectives

Rachel Atkins, senior physiotherapist at the National Hospital for Neurology in London, has seen physiotherapy make a real difference to the life quality of people with dystonia.



● Rachel Atkins

She highlights three areas in which it can have a beneficial effect:

- Improving the range of movements available to a patient
- Improving posture and balance
- Lessening the strength of spasms and any pain associated

The initial assessment by the physiotherapist of the patient's current posture is the key to identifying the optimum exercises or treatment required. The physiotherapist may also spend time with the patient advising on postural 're-education' ie. about how posture can be optimised for function.

An important aim of physiotherapy is to build the patients 'core stability'. This involves ensuring all the muscles in and around the abdomen (the 'core') remain strong yet mobile. The understandable reluctance of people with dystonia to exercise and 'get out and about' as they used to, can easily mean the core muscles along with all other muscles become de-conditioned. Using a gym ball is one effective way of reversing the trend. An important aspect of postural management also relates to ensuring that seating and wheelchairs provide optimal positioning throughout the day.

In addition, in cases of cervical dystonia, exercises will be identified that focus on strengthening weakened groups of neck muscles. These are the under-used muscles that oppose the over-active muscles caused by dystonia on the opposite side of the neck. Exercises may also aim to counteract the on-going effects of any contractures (muscles or tendons that have been too tight for too long, thus becoming shorter and so limit natural movement). The physiotherapist will work with the patient's timetable of botulinum toxin injections. Rachel said: "The two week window after botulinum toxin injections, can be very helpful to the

Two styles: The physiotherapists who administered the two styles of physiotherapy treatment compared in the clinical trial discussed on page 13, were Jillian Fowlie (Aberdeen) and Hazel Sinclair (Glasgow). The Society is very grateful to them both for their enthusiasm and hard work over the period of the trial.



● Jillian Fowlie



● Hazel Sinclair

physiotherapist. The effects of the toxin have then started and can make tense and spasming muscles more responsive. This can be especially helpful at the assessment stage." The physiotherapist can also provide advice on issues relating to ergonomics. It is especially important for people with cervical dystonia to ensure their desk is arranged in the optimum position. The location of a computer or the siting of a light for reading, should encourage a corrected head position. The same applies to the placement of visitors and friends. The layout of tables and chairs should ensure they sit on the side that 'corrects' a person's head position.

Rachel feels that for the physiotherapy to be as successful as possible it is important for professionals to work together as a team. So at the National Hospital, there is regular 'interdisciplinary working' ie. liaison between occupational therapists, speech & language therapists, doctors, nurses and even the psychologists.

Writer's Cramp

*Judith Turner had writer's cramp for about 7 years which prevented her using her right hand to write as she normally would have. In 2000, Judith then changed careers, retraining as a physiotherapist. She experimented with several physiotherapy techniques. One of these, tracking the facet joints at the neck so that the median nerve was not adversely affected, appeared to abolish her writers' cramp. She can now write normally with her right hand. Judith is happy to talk to anyone who may be interested in knowing more about her journey and the treatment she undertook. However, **Dystonia matters!** stresses that the treatment has not been assessed independently to substantiate whether it readily works for others. If you are interested in contacting Judith, please do so via our UK office.*

Dystonia Society Groups

Local Groups offering friendly, informal support. See reverse side for key.

Any general queries about groups or new groups, please contact Una Rennard on: 0845 458 6334 or una@dystonia.org.uk



Dystonia Society *Group meetings*

*Not all meetings are shown – please call contact person for details.
All 0845 numbers are charged at local call rates only.*

 GROUP	 <i>Meetings</i>	CONTACT	TEL NO.
1	Blepharospasm ● 13 Feb, 3pm, meeting at Littlehampton	Cathy Palmer	0845 899 7112
2	Bristol, Glos & Somerset ● 21 Jan, Annual Buffet	Keith Jones	0845 899 7113
3	Cardiff	Viv Adams	0845 899 7110
4	Easington ● 14 Jan ● 11 Feb ● 11 March, 11am – 1pm, meeting in Crows Nest pub, Seaham	Tom & Joan Donkin	0845 899 7114
5	Furness & South Lakes ● Christmas events TBC ● 20 Jan, 7.15pm, Lisdoonie Hotel, Barrow	Harry & Gill Jepson	0845 899 7115
6	Kendal	Una Rennard	0845 458 6334
7	East Sussex ● Post Christmas get together TBC ● 12 March, meeting	Kay Frost	0845 899 7149
8	Essex ● 30 Dec, 10.30am ● 27 Jan ● 24 Feb, Hadleigh Baptist Church, Essex	Molly Perry	0845 899 7117
9	Plymouth & South Devon ● 19 Feb, meeting	Janet Chaston	0845 899 7108
10	Hampshire (West) ● 26 Feb, speaker Sarah Chave, Body Talk Practitioner Greyfriars Centre, Ringwood	Martin & Val Cross	0845 899 7119
11	Hampshire (East) ● 29 Jan, 2.30pm, St Nicholas Church, Wickham	Peter Cole	0845 899 7120
12	Hertfordshire	Sue Smith Jonquil Everett	0845 899 7121 0845 899 7103
13	Kent ● 15 Jan, meeting in Orpington	Dave Ward	0845 899 7122

13	Kent ● 15 Jan, meeting in Orpington	Dave Ward	0845 899 7122
14	Lancashire & Fylde ● 31 March, meeting	Carolann Curley	0845 899 7123
16	Lincolnshire ● 10 Feb, New Year lunch	Janet McMillan Anne Alderton	0845 899 7125 0845 899 7150
17	Liverpool & Merseyside ● 29 Jan, 1 – 2pm, Bring & Buy	Margie Hughes	0845 899 7126
18	London ● 15 Jan, 1pm, Post Christmas lunch	Ian Boddington	0845 899 7127
20	London SE ● 22 Jan, 12.30 – 3.30pm, Post Christmas lunch ● 19 Feb, meeting, Salvation Army Lodge, Upper Norwood	Bridget Davis	0845 899 7129
21	London SW	Ian Boddington	0845 899 7130
22	Manchester ● Christmas event TBC, please phone for details	Mike Smith	0845 899 7131
23	Mansfld, Chesterfld, Wksop ● 1 March, 10.30 – 1pm, meeting in Mansfield	Richard Cantrill	0845 899 7132
24	Oxford ● Christmas lunch date TBC ● 8 Jan, 2 – 5pm ● 12 March, AGM 2 – 5pm, John Radcliffe Hospital, Headley Way, Headington	Lorraine Jackson	0845 899 7134
25	Bournemouth	Lynn Preston Una Rennard	lynn.preston@rbch.nhs.uk 0845 458 6334
26	Staffs & Shropshire	Sue Day	0845 899 7135
27	Surrey	Linda Barns	0845 899 7136
28	West Midlands	Anne Tingle	0845 899 7137
29	West Sussex	Graham Ashdown	0845 899 7138
30	Worcestershire ● 23 Feb, 10.30 – 12 noon, Stourport Manor Hotel	Frances & Don Pitt	0845 899 7139

Dystonia Society *Group meetings*

 GROUP ● <i>Meetings</i>	CONTACT	TEL NO.
31 Hull & East Riding ● <i>Meetings are twice a year (usually Jan & July, please call for details)</i>	Thelma Bayram	0845 899 7140
32 Glasgow ● <i>22 Feb, main group meeting</i> ● <i>20 Dec ● 17 Jan ● 21 Feb ● 21 March, 2 – 3.30pm</i> <i>Informal meetings, 3rd Monday of month, at John Lewis Place to Eat</i>	Dorothy Chisholm	0845 803 1006
33 Aberdeen	Christine Graham	0845 899 7141
34 Perth / Dundee	Peter Meager	0845 803 1005
36 West Calder	Lorraine McDaid	0845 899 7107
37 Airdrie ● <i>Meet every other Wednesday, dates TBC, Weavers Cottage, Airdrie</i>	Ruby or Jim	0845 899 7142
38 South Yorkshire	Keith Hall	0845 899 7143
39 West Yorkshire ● <i>5 March, 2pm, Speaker Nurse Practitioner, Shipley Library</i>	Denis Colman	0845 899 7144
42 Inverness	Muriel Falconer	0845 899 7109
43 Norfolk & Suffolk ● <i>15 Jan, meeting at Bury St Edmonds</i>	Sarah Sayer	0845 899 7133
45 Berkshire ● <i>26 Feb, meeting</i>	Carol Powell	0845 899 7148
47 Cambridge ● <i>15 Jan, meeting</i>	Bettina Starke	0845 899 7106
48 Cornwall ● <i>19 March, Trelander Community Hall, Truro</i>	John Beckett	0845 899 7104
49 Torbay & Exeter ● <i>8 Jan ● 12 Feb ● 12 March, 1 – 3pm, Paignton Library</i>	Debbie Skerrett	0845 899 7105
50 Belfast ● <i>This is a new group please contact for details</i>	Neil & Barbara Stacey	0845 899 7100

Research advances

Brain plasticity

Current research into brain plasticity is giving scientists important new insights into the mechanisms behind dystonia. At the Society's Annual Conference in November, delegates were fortunate to hear a presentation by one of the leading researchers in this field, Professor John Rothwell of the Institute of Neurology, London. Below is a summary of his presentation:

The cells of the brain, known as neurones, are connected by thousands of synapses which send messages between the neurones. Astonishingly, each cell has around 10,000 connections. There are two types of these connections – excitatory and inhibitory. An excitatory input causes the cell receiving it to become 'excited' so the information flow continues across neurones. Similarly, with inhibitory connections, the synapse 'turns off' the recipient cells, reducing the information flow. You can think of them like an accelerator (excitatory) and a brake (inhibitory).

It is a remarkable fact that in people with dystonia, the inhibitory connections do not seem to work as strongly as those in people who do not have dystonia. This, of course, makes sense, as one naturally thinks about dystonic muscles (which are controlled by motor neurones) as having too much activity. Professor Rothwell suggested that there might be something happening in the synapses (the junctions that permit neurones to pass an electrical or chemical signal to one another) of the inhibitory connections that turns down the normal level of activity.

However there are clearly other factors involved too, as recent research into the brain connections of people who have dystonia affecting one arm and not the other, show that the brain was equally different from normal on both sides: there was the same lack of sensitivity to inhibition on both sides. So the question naturally arises: why does the dystonia not affect both arms? In a small proportion of people with writer's cramp in one arm, the condition goes on to develop in the other arm. This is leading researchers to believe that a lack of inhibition predisposes people to dystonia.

Research advances (continued)

Brain plasticity

This is where plasticity comes in. We know that the synapse can either be excitatory or inhibitory, but, in addition, the number of incoming connections to a neurone can grow, with new connections being formed, so as to increase their strength. Recent research has upturned the accepted view that these connections are fixed in youth and simply decline in later years. The latest results show just how variable and changeable these connections are. We have hundreds of millions of synapses in our brain and these connections are constantly changing, at all ages. The way these connections are formed can vary from day to day, hour to hour!

The system is very flexible, and this is what we term 'plasticity' – the variability of the connections between the neurones within short periods of time. Every day we lose 5% of these connections (synapses), and every day we grow around 5% of new ones – there is a constant turnover of synapses. When you learn something new, a burst of extra connections is formed or strengthened. Over time they get 'pruned off' until only the most important of these connections remain. We are left with the 'real memory' from the small number of the new synapses which are not pruned off.

This process has been clearly demonstrated in mice which have been trained to carry out a task over a couple of weeks. The connections in their brains have been studied and researchers are able to see an increase in the connections, which are then pruned down over a few days to get the 'real' skill.

So how does this link to dystonia in humans? Scientists have been able to stimulate human brains using TMS (Transcranial Magnetic Stimulation) which applies a magnetic field above the brain to induce (painlessly) an electric current into the brain which then stimulates neurones. If researchers stimulate the part of the brain that controls the hands, then the hand will twitch and size of the 'twitch' can be measured electronically. This enables us to measure how effective the connections are in the brain.

Subjects are then given training in a new movement skill to see how the size of the induced movement varies. This gives some idea of how easily the connections change between one cell and another in the brain. If the response gets bigger, we have increased the effectiveness of the connections in the brain, if it gets smaller we will have made them less effective.

The brains of people with dystonia appear to find it easier to change these connections than people who don't have dystonia. In other words, the dystonia brain is 'better' than a typical brain at starting the learning process... but there does not seem to be the usual process of trimming down the connections. In the mouse brains studied, the mouse made lots of extra connections initially, but these were pruned down as the mouse learned the task. Perhaps in dystonia, after the proliferation of connections made initially, these connections are not properly trimmed down leaving a surplus of new connections that involve too many motor neurones (ie. too much excess plasticity).

We know that an increase in plasticity can be a good thing. Most professional musicians have similar plasticity to people with dystonia, however their inhibitory synapses work well too. In other words both groups can learn new muscle movements relatively quickly, but only the musicians without dystonia were able to automatically trim down the connections not needed. In short, to learn anything you need the plasticity in your brain to make the new synapse connections, but if your brain fails to trim these connections you are left with too many of them and could end up with too much (inappropriate) movement.

So, we are now starting to view dystonia as a problem of either a deficit of brain inhibition and plasticity (insufficient pruning of new connections). At the moment we believe some forms of dystonia are the result of over-learning or over-practice (in cases of writing or practising music), while other forms can be caused by excess plasticity.



● Prof. John Rothwell

Childhood dystonia

Parents and Carers Conference

In October, the Society held a conference for parents and carers of youngsters with dystonia. Staged at the Wellcome Centre in London, the eighty people who attended were treated to a varied day that included presentations from leading clinicians and key support organisations as well as candid reports from parents.

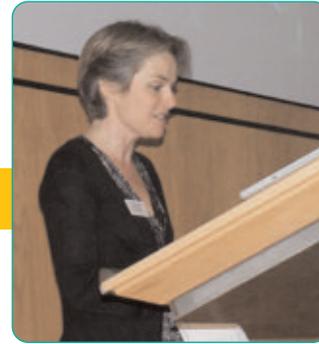


● Dr Jean-Pierre Lin

What is dystonia? was the subject of Dr Jean-Pierre Lin's talk. A consultant paediatric neurologist at Evelina Children's Hospital, Dr Lin drew attention to an intriguing similarity between the movements that we all see in very young children and those of an adult with dystonia. As babies develop, they go through a range of abnormal postures which require the use of all their muscles. This process is part of developing the economical movements and fine motor skills of later life.

Dr Lin suggested that, in developing dystonia, the brain may again act as if it has too many options. Instead of choosing one option for muscle control it wants them all, resulting in a 'pile up of motor strategies'. The brain seems to revert to the child's earliest state, with all muscles turned on, resulting in the postures and movements that we see in dystonia.

Dr Lucinda Carr, consultant paediatric neurologist at Great Ormond Street Hospital, presented the Robert Surtees Memorial Lecture, and discussed treatments for childhood dystonia. She drew attention to the big question concerning clinicians: *How (if at all) should you treat the dystonia?* Doctors try to balance the positives and negatives of each treatment and consider the daily impact that dystonia has on the child; what having the treatment will mean for the family; whether there are any side effects to consider, and the time and cost implications of treatments. Only by considering how the condition affects the child's overall quality of life, taking note of particular problems, say with



● Dr Lucinda Carr



● Hortensia Gimeno

communications, education or other medical conditions, can the clinician be confident they have come up with the best combination of answers.

Hortensia Gimeno, Senior Occupational Therapist Team at the Evelina Children's Hospital talked about the importance of enabling children with dystonia to develop and learn the life skills that others take for granted. Otherwise they face the double disadvantage of living with the symptoms and lacking the opportunities to develop skills and confidence.

Children learn through their everyday experiences and opportunities and children with dystonia often do not get opportunities to 'learn through doing'. Occupational Therapists will now try and empower children by providing the family with equipment and strategies to develop independence and life skills. This may be by providing equipment, or by modifying tasks to make them more accessible. She stated that one of the most important things a parent can do is to set up a daily activity that is accessible to the child.

Before lunch there were especially poignant contributions from two parents of youngsters with dystonia as well as from Amy-Belle, 18, who was diagnosed with dystonia aged 4.

Ruth King spoke about her son, Mattie, now 14, who has been severely disabled since birth, with dystonic atheroid cerebral palsy. A couple of years ago, Mattie was told he would need rods put in his back due to problems with his spine; however the severity of his dystonia meant this surgery would not be possible. Mattie was put forward for an Intrathecal Baclofen pump to help reduce his dystonia spasms and this has had a positive impact on Mattie's quality of life – he is now in less pain, happier, more communicative and his personality has blossomed.

Childhood dystonia (continued)

Parents and Carers Conference



● Ellie Logue



● Mattie King

Jackie Logue's daughter Ellie is 16 and has had a severe form of dystonia since birth. Ellie uses a communication aid and is totally care dependent; however, she has full cognitive ability. Jackie talked about the importance in seeing Ellie as a child first – she is given every opportunity to enjoy life, going on holidays and pop concerts like any 16 year old. She

emphasises the importance in having fun with your children and not letting a medical label overshadow their lives. "You need to think about what your child can do, not what they can't," she said.

Amy-Belle was 4 when she found she couldn't lift her right arm. She had DBS surgery earlier this year. Before the DBS her arm was moving uncontrollably, which she found incredibly frustrating. Although she says it was a difficult decision to have the DBS surgery, the surgery was very successful and she said that she would recommend it to anybody.

In the afternoon there were very informative presentations from representatives of four leading support organisations that provide support for children with health conditions: *Contact a family*, *Parent Partnership* and *Abilitynet*. Those who attended the event were enthusiastic, as comments on the evaluation forms showed: "It was incredible. I had thought I was alone – meeting other parents helps me to see the future and understand there are people who have been through it and can help me get some answers"; "I really enjoyed the talks from the professionals and the parents/individuals" and "which part did I find most useful? – All of it!"

Conference for parents of children with dystonia
Saturday, 9th October 2010, London

Location: Wellcome Conference Centre, London NW1 2BE (2 minutes walk from Euston station)
You are invited to a FREE conference for parents of children with dystonia.

The special conference offers:

- Presentations from leading paediatric neurology specialists
- Workshops from leading organisations
- Other parents and children talk about their experiences
- A chance for you to find answers and meet other parents

There will be a supervised programme of activities (age appropriate) for children/teenagers during the day. Places may be limited.

Morning session 10.30 – 12.30

- **Dystonia – what is it?**
Dr Jean-Pierre Lin, Evelina Children's Hospital
- **Treatments – what are the options?**
Robert Surtees Memorial Lecture
Dr Lucinda Carr, Great Ormond Street Hospital
- **Life options – putting you in charge**
Hortensia Gimeno, Evelina Children's Hospital
- **Lessons learned**
Other parents and youngsters speak honestly about their journeys

Lunch 12.30 – 14.00

Afternoon session 14.00 – 16.30

- **A choice of workshops from each group:**
- GROUP 1
 - Where do I get support?
 - Mobility matters
 - Wheelchair / mobility expert
- GROUP 2
 - The educational statement
 - Adapting computers to change lives

Representative from: Contact a family
Representative from: Abilitynet

Finish 16.30

For children/teenagers with dystonia...
A programme of activities is planned in adjoining rooms with supervision.

Fundraising Preview

Awareness Fun Day

● Ready to cycle

For our 2011 Awareness Week we will stage a brand new event at the Queen Elizabeth Country Park, Portsmouth on Saturday 7 May 2011.

This sponsored cycle or walk offers members a great opportunity to get together in a beautiful setting, which features a nature reserve, a café parking, toilets and a visitor centre. Dogs are also permitted on leads. See our website for more information or call Ann to offer a helping hand.



Marathon places 2011

We have two remaining places for the **Brighton Marathon** on 10 April and also several for the **Silverstone Half Marathon** on 6 March. Judging from feedback from our 2010 runners, these are fantastic events! There are eleven runners in the Brighton marathon to-date, so if you would like to join them or start with the Silverstone half marathon, please contact Ann.



Tom McCartney and Stephen Lawrence (above) are two of our London Marathon runners. They both have the Society's interest close to heart as Tom's girlfriend has recently been diagnosed with dystonia as has Stephen's mum. Their training has started and we look forward to following their progress.

Great Wall of China

Jayne Thomas is training for her trek along the Great Wall of China in April 2011. She is a keen musician and is taking part in many concerts, see photo below, to raise funds and awareness before the event. Keep up with Jayne on her *Justgiving* fundraising page.



For more information on any of these events please contact Ann Dedman: 0845 803 1004 or email: ann@dystonia.org.uk



Walking for Lee

A sponsored walk in fond memory of Lee Heath took place in Coventry (photo below). Organised by his father Ray, more than twenty people with their dogs took part, walking along the canal. Ray is especially keen to raise awareness of dystonia; he contacted three local newspapers who covered the event and included a really nice photograph of Lee in the articles. The event raised over £1,000.



Further funds of over £400 were raised by Lee's partner, Rebecca, who organised another walk in Leicestershire. Rebecca walked with her and Lee's baby daughter, Gracie-Lee and was also joined by many friends for the day.

Fundraising news

Eight wheels, four W's?

Roger Key was joined by three other cyclists, Simon, Geoff and Matt for a cycle ride, aptly named 'The Four W's'. Starting in Watford, it went via Windsor and Winchester before finishing at Warsash.

Roger Key and the Brotherhood have been mapping out cycle routes for many years to raise funds and awareness. This event raised **£450**. As Roger and Simon couldn't make Rutland this year because of holiday dates, they travelled from their



● *The Brotherhood Team* home in Hampshire to Scotland to take part in the Falkirk Wheel Bike Ride which was held a week earlier. What true supporters they are!

Editor: Where will it be next year Roger? We hope to see you at the Society's 2011 Awareness week cycle ride at the Queen Elizabeth park in Portsmouth, of course!

Waitrose

The Stafford and Shropshire group are the latest group to gain Waitrose Green Disc support. Sue & Joanne Day are pictured right, gratefully receiving the cheque. A fantastic **£290** was raised.



Fundraising news

Frosty Challenge

Leanne Donellan (front cover photo) took part in the gruelling Arctic Challenge, raising over £3,500 for the Society. Leanne's mother has been a sufferer of dystonia for many years.

Leanne said: "I wanted to do something to help the Society which has helped her. My mother has had a difficult time with the condition." Commenting on the Challenge, she said: "The terrain was very changeable; for some of the journey we travelled through forests or careered across frozen lakes, and some areas were very barren and desolate. However towards the end of the week long trip we finally came to the mountains. I have never seen such a sight before! Not a soul as far as the eye could see. Everything was so very still. It was just us and the sound of our sleds gliding across the ice and snow. And I must admit, as I held on tight to the back of that sled I thought how lucky I was to be undertaking such an amazing challenge, for such a worthy cause and how I would never forget this as long as I lived."

Golf Club Success

Roger Richards was the Captain of the Theydon Bois Golf Club for 2010. The Society was his chosen charity as his daughter Alison has dystonia. Roger organised many events throughout the year and presented the Dystonia Society with funds of over **£2,600**.



Peak at 40!

Annabel Evans, below, achieved her goal of climbing Kilimanjaro on her 40th Birthday and exceeded her target of raising over £500. In fact, she raised over £1,500 with the help of her employer, AON. Her mother has dystonia so I am sure that she was the driving force when the going got tough.



Fundraising news

Adidas Hyde 5k Park

The Society had quite a presence at the Adidas 5K event in Hyde Park in September.

With 36 walkers made up from volunteers, staff and good weather on the day, a great time was had by all. *Fundraiser, Ann Dedman said: "Thank you to all for participating and wearing the t-shirt for dystonia – we definitely had a high profile! Best of all we raised £3,300. Congratulations to everyone who attended!"*

Footie Fundraising



● Chris & Sharon

Sharon Slack was able to present a cheque for **£140** to Chris Yarrington at the Lancashire and Fylde Group meeting in September. The funds were raised by entry donation to the Burnley V Blackburn Football Club and this was organised by Martin Heys, Sharon's son.

Raising the Stakes...

Tony Goddard organised a fundraising evening at West Horndon Bridge Club. In total, **£420** was raised, so many thanks for all your great effort!



● Our fantastic 5K walkers!

Cheese & Wine

Gilly Marshall organised a spur of the moment cheese & wine event with the help of her very special Mum, Sheila Bates. Pictured below, Gilly said: "It was a spur of the moment idea and everyone turned up. It was a great evening, Mum's bungalow was absolutely bulging!"

Thank you Gilly, Sheila and guests for raising a wonderful £450 for the Society.



Dystonia is a neurological movement condition. It is not rare – it affects at least 70,000 people in the UK.



Fundraising news

Running for dystonia

We are very grateful to all our fundraisers for entering running events countrywide...

Fraser Russell ran the Glasgow Half Marathon, Kimberley Anne ran the Hinkley 5k event, Nick Parsons took part in South Coast Run while Daniel Wilkinson completed the 10k North Run and has his name on a place for Silverstone Half Marathon. Debbie Belcher ran the New Forest Half Marathon and will also be one of our Brighton runners in April. Together they raised a fantastic total of **£1,428**.

Skydiving for dystonia

Zoe Bush a sixth form student from Taunton School is raising funds by participating in a 10,000 feet skydive in April 2011. Good luck Zoe! To make her fellow students aware of dystonia, Society members Derek White and Kate Forsythe kindly gave presentations to the students in November.

Annual Conference Raffle

We are sincerely grateful to the following organisations for donating prizes for the Annual Conference raffle: Tuckenhay Mill (for the superb first prize) Premier inn, Lush, and Whyte & Mackay. We raised **£310**.

Faye's Peddling Power

Faye Nash took part in a sponsored Sky Ride in Birmingham and raised over **£300**. Faye raised funds for the Society because her partner's mum, Doreen Beesley, has dystonia. Thank you very much Faye.



Scottish Ceilidh

Thanks to Harry and Sandra Jeffrey who ran a very successful Ceilidh on 16 October at Glen Douglas. The event raised £1,006 and the music was provided by Jock Borthwick.



● Zoe Bush with Kate Forsythe

Legacies

Make a Will, Make a Difference

To help answer members' questions about writing and updating their Wills, we are very grateful to Michelle Gavin of law firm, Martineau, for an article that sets the matter straight.

Why make a Will?

In the 18th century, Benjamin Franklin famously said that there were two certainties in life – death and taxes.

By making a Will you decide who inherits your assets on your death and you potentially take steps to reduce any tax payable. If you don't have a valid Will in place then there are fixed rules (known as the Intestacy Rules) that dictate which family members inherit your assets and when. Don't leave matters to chance. Take control of your affairs and make a Will, as without a Will your loved ones may not be provided for and could be left in financial hardship.

Take control, keep your Will up to date!

Life has a habit of changing, often when you least expect it. So, it is vital that you keep your Will up to date particularly in the light of changes to your personal and family relationships as well as changes to your personal wealth. Many people do not realise that if you marry or enter into a civil partnership, then any Will you had in place prior to this, is automatically cancelled by law, unless the Will expressly provides for it to continue after the marriage or civil partnership. Updating your Will is easy. Simple changes such as a change in the Executors or adding a gift (known as a legacy) can be done by simple Codicil. More substantive changes can be done by making a completely new Will.

Why should I leave a legacy to a charity in my Will?

Leaving a legacy to a charity in your Will can benefit both the charity and your estate. Wills are the main source of income for most charities and are currently worth around £1.3 billion per year!¹ This sounds like a lot but once you consider that there are 185,000 charities in the UK² these legacies do not stretch far. Charities rely on your donations to keep up their good work. Inheritance tax is payable on the value of your assets above £325,000 (2010-11) at a rate of 40%.

By leaving a legacy to a charitable organisation in your Will you can help to reduce the amount of inheritance tax payable on your death, as gifts to charity are exempt from inheritance tax.

How can I benefit a charity in my Will?

There are many different ways in which you can benefit a charity in your Will. You could choose to leave gifts of money, specific assets or even the remainder of your estate once family and loved ones have been provided for.

Where do I go to make a Will or Codicil?

It is essential that your Will or Codicil is drawn up professionally by a lawyer who specialises in this area of law and is a member of an established organisation such as the ones below:

- *The Law Society*
tel: 0207 242 1222 www.lawsociety.org.uk
- *The Society of Trusts and Estate Practitioners (STEP)*
tel: 0207 7340 0500 www.step.org
- *Solicitors for the Elderly (SFE)*
tel: 0844 567 6173 www.solicitorsfortheelderly.com

Making or updating your Will gives you peace of mind that you have put your affairs in order and provided for the persons that mean the most to you. It gives you the opportunity to make a charitable donation that could make a difference for many years after you have gone – what a wonderful lasting legacy to your memory.

¹ figures taken from www.rememberacharity.org.uk

² statistics taken from www.charity-commission.gov.uk

Michelle Gavin is an Associate at Martineau, Birmingham
tel: 0870 763 1468

We are enormously grateful to those who remember the Society in their Wills. All the new projects we have undertaken recently have only been possible due to income from legacies. The same goes for most of our funding of medical research. Codicil forms are available from the UK office or on the website.



● Michelle Gavin



A day in the life... *In good hands*

Bernie McMahon started as the Society's Administrator in April. Here she describes some of the many sides of her role:

● *Bernie McMahon*

My day starts by dealing with the telephone and email messages that have come in overnight. There are sometimes poignant emails from people looking for information about dystonia and treatments. I ensure these messages are passed on to the Helpline, pleased that they will get some constructive support. In addition, there may be messages from people calling their local group 'after hours' as they are redirected to the office. I ensure the Group coordinators get the messages quickly.

Another rewarding aspect of the role is the administration of our welfare grants scheme. I read the completed application forms through with an eagle eye, to ensure that applicants have included all the information the committee will need for their decision-making. When the decision is made to grant the request I send out the good news to the applicant – and the cheque!

At the moment opening the post is exciting. The raffle tickets are flooding back. It is nice to think that amongst all the envelopes I open there will be some winners. Membership renewals, letters back from charitable trusts and our fundraisers can also provide nice surprises.

I mostly get out of making the tea for the team (who are all keen tea/coffee drinkers) because I don't drink it! Coke is my drink!

I enjoy all the preparation for our conferences such as dealing with the incoming reply forms and helping members if they ring with transport concerns. Then there are the badges to produce and all the work on the day of the event. Now I am going to get my chance to be involved in the organisation of a conference from scratch, as we prepare for our next living with dystonia day in the South West in May.

Out of work I am a Doctor Who fan, collecting memorabilia and going to shows and exhibitions. Roll on the Christmas Special!

Dystonia Society *Christmas gifts*



With the festive season nearly upon us, now is the time to think about gifts for family and friends.

The Society has produced a limited run of teddy bears, book marks, shopping bags and lapel badges. Not only with they make lovely gifts – perfect for a Christmas stocking – but they will raise awareness of dystonia too. The bookmarks include two magnetised strips to ensure they stay snug within your book.

How to order

Send the completed form on the back cover to the UK Office, enclosing your cheque. Or you can phone us on: **0845 458 6211** or email: **info@dystonia.org.uk**

All items will be sent to you on the day the order is received.

Hurry while stocks last!



Dystonia
affects men,
women and
children...



● *Please give me a new loving home!*