



# FSH-MD Support Group UK

MDC Support Group of the Year 2010/11

Newsletter 16: Winter 2010

## FSH Autumn Get Together

A Members view.....

Attending the FSH Autumn Get Together in Gloucester was something I had really been looking forward to, not just because it was an opportunity to meet others with FSH and to hopefully learn something I may not already know about the condition but also to meet friends I had made online but had not yet met in person, and where better to do that but in the hotel bar!



Liz & Phil Orme with Sarah & Stacey Crabtree

This was the first Get Together I had attended and I'm glad I decided to stay at the hotel the night before the conference as it gave me the opportunity to chat with some members of the group in a sociable environment. Taking part in a fun quiz also gave me the chance to create a team with others who I may not have otherwise had the chance to chat to and being part of the winning team was pretty good too!

The conference itself was very informative and well organised. It was good to hear about the latest research from Dr Marita Pohlsmidt and Dr Kristina Elvidge. We were all well aware of the latest government announcement about changes to the mobility component of DLA and it was obviously of great concern to us all. Alexandra Crompton, MDC Senior Policy and Campaigns Officer reassured us that this change would currently only affect those in residential care but the MDC would be campaigning against this decision. We also visited the display area; I had a go on one of the passive cycle machines from Medioctech. Ltd,

I wasn't sure I would be able to do it, but I did after a little persuasion from Peter their demonstrator. Who said I would probably be pleasantly, surprised which I was. The machines will either gently exercise you or you can put a bit of power in yourself. The only problem now is, I want one!! I can easily see myself cycling either my upper or lower body, from my wheelchair whilst watching Corrie!

I attended one of the workshops by Gordon McClurg, from Care Management Services about Independent Living. It was interesting and certainly gave me thought for the future. It is also good to know that there is a service there which can advise you with all aspects of independent living present and for the future. Gordon is certainly an inspiration.

It was also a pleasure to be present for the award given to Jet, Les Sutton's canine best friend, an award extremely well deserved. It just goes to show how important is to provide dogs like Jet to people like ourselves, they can literally be lifesavers. We could all do with a best friend like Jet. I'll have to get him to give my border collie, Lucy some tips!!



Dr Kristine Elvidge - FSH Research update

Being at the Get Together showed me that we are all at varying stages of FSH, all uncertain of what the future holds. However, being together shows that we are not alone. We can talk about our worries and sometimes overcome them. The FSH Support Group is a fantastic source of support, corny I know but true!

**Stacey Crabtree**

## A word from the chair.....

Hello & Welcome,

to our Winter Edition. I hope you like our new full colour format. I would like to thank Les Sutton Head of Roxburgh UK, for his very generous offer to sponsor our newsletter and also covering the cost of printing.

This has been a special year for us, as well as Celebrating Twenty Five years as a Support Group, we have seen our membership grow along with an increase in enquiries and requests for support and information. We again had a presence this year at both the MDC National Conference in Birmingham and the MDC Scottish conference held in Glasgow.

We are also pleased to announce that we plan to have a Scottish Regional Group in place in the New Year.

Our Autumn Get Together in Gloucester went exceedingly well and I would like to thank all our guest speakers for giving up their time to be with us. As ever they were interesting, thought provoking and very informative.

I'd also like to thank my daughter Louise for all her help and support and making sure everything ran smoothly and without any hitches.

To crown our year we are pleased and proud to be the Muscular Dystrophy Campaign Support Group of the year 2010. The award was accepted by our deputy chair Andy Findlay and myself on behalf of all our members who make our group the success it is today. So thank you all for your continuing support.

I look forward to meeting up with many more of you at our next event. Which will be a "Summer Get Together" held in June. The support group committee have decided to have just one event this year given the current economical climate and the expense incurred when organising these events. More details will follow once we have confirmed a date and venue.

Seasons Greetings to you all  
Karen Bayliss  
Chair

# WANTED!

## Your Email Addresses

Please let us know if you change your email address or if you prefer us to send future newsletters and updates by email. It keeps our costs down and is much easier for us to keep in contact with you  
Email [fshgroup@hotmail.com](mailto:fshgroup@hotmail.com)

## MDC Launch Appeal to Raise Funds For A New West Midlands Neuromuscular Centre

The Muscular Dystrophy Campaign launched their latest fundraising Appeal on Friday 17th September to raise funds for a Neuromuscular Centre in Birmingham. It will be first Neuromuscular Treatment Centre in the West Midlands and only the second such centre in the UK

The centre will benefit people living with muscle disease across the West Midlands and beyond who often have to travel long distances for specialised physiotherapy and hydrotherapy or even go without them altogether.



The Lord & Lady Mayoress with the WM NMC Project Group Members

The Lord Mayor and Lady Mayoress of Birmingham and the MDC Chief Executive Robert Meadowcroft joined local people and members of the West Midlands Muscle Group for the launch event. The centre is particularly necessary in the West Midlands where millions of pounds - £6.6m in one year – is being wasted on avoidable, unplanned emergency admissions for patients with muscle disease. These admissions cause huge distress to patients and their families and can be incredibly damaging to their health, and a huge and unnecessary cost to the taxpayer.

Courses in graphic design and basic IT skills for people with neuromuscular conditions will be offered at the centre. It will also build its own social enterprise design and print company, providing employment opportunities. The new centre will also offer support, information and advice to individuals, carers and families. The centre will have a cafe area for people to meet up socially. The project has been made possible by the generosity of the Patrick family who, in March 2010, offered a vacant building to the Muscular Dystrophy Campaign for use as a Neuromuscular Centre.

If you would like to find out more about the centre or would like to be involved with fundraising please contact the Muscular Dystrophy Campaign. Tel: 0800 652 6352

## Sheila's Bungalow diaries – September 2010

I've had FSH for over twenty years and while it's been a nuisance it's only in the last five years that it's started to seriously slow me down. It's harder and harder to climb stairs and I can no longer carry anything upstairs, such as basket of washing or a cup of tea. With this in mind it seemed worth thinking about future housing rather than reaching a point when I could no longer get upstairs to use the loo. We live in an Edwardian villa house, with steep stairs, long narrow corridors, and no off road parking. We've done a lot of work on it and have nice neighbours so in many ways I'd like to stay put. I'd already got a disabled parking permit and a disabled bus pass so approached Leicester City Council to ask for advice on whether the house could be adapted for wheelchair use, to be told they wouldn't do that until I needed a wheelchair as that time might never come. Well, yes, but I know enough people with FSH whom I have seen become less mobile over the years, so think there's a strong probability that I could be in a wheelchair at some point. So I took the measurements of some other FSHer's in wheelchairs, measured our doorways and corridors and decided it wouldn't be possible to adapt this house, however much I'd like to stay.

I'm lucky in that I'm still working and have unusual technical skills so should be able to stay employable for a while – certainly as long as I can use a computer, phone and get to some meetings. I'd also done well on the property market so we had a very small mortgage on the current house and some savings. My husband, Paul, has good practical skills, we'd found a reliable plumber, electrician, plasterer etc from work on our current house, and we know that between us we're good at managing these kind of projects, including specifying the work and setting and managing budgets and timetables. With this in mind we started looking for bungalows nearby that we could renovate and make disabled friendly. I signed up to [Rightmove.co.uk](http://Rightmove.co.uk) which sends regular e-mails alerting you to properties according to your particular search requirement, so I requested bungalows within 3 miles of our postcode. Bungalow seems an elastic term, as I did receive lots of dormer bungalows, and some with basements, but it's free and provided lots of suggestions. Some I was able to dismiss from the pictures those which showed steep steps to the property, or the price, or the area – what I really didn't want was to live in bungalow land where we were the youngest people by twenty years.

Finally, in April this year we found the property we had been looking for. It was a three bedroom bungalow about a mile from where we live, and was on the market because the previous owner had died, having lived there since it was built in the early 1960s. He'd really cared for it but in the last few years things had obviously slipped and we immediately knew it would need re-wiring, re-plumbing etc.



Unlike all the people on the TV property programmes we did invest in a full survey (approx £500) which was well worth it for peace of mind, knowing the internal cracks were not serious and could be repaired. We also discovered that the Co-operative Bank, with whom we both banked, would not lend us a mortgage on a property that we were not going to move into within 28 days. This was a bit tricky as on the one hand we had a good reason in that we wanted to do it up and adapt it for my disability, but on the other hand I wanted them to think that I could continue to pay the mortgage. In the end we financed the purchase by extending the mortgage on our current house, and on 10th June 2010 it finally became ours.



## Bungalow Diaries Cont.....

Paul immediately started looking at the technical aspects of the building whereas I started seeking advice. I had discovered that the Red Cross Disabled Living Advisor would give general pre-emptive advice so invited her round straightaway. It transpired that the bathroom that we thought was fine wouldn't fit in a wheelchair and she gave us some very helpful advice on layout, turning circles etc, as well as loads of information re suppliers etc.



I also decided to have a party, partly so our friends would appreciate the final result but also to encourage suggestions about what to do with the house. The party was good fun but I'm not sure about the suggestions – one friend, a keen gardener, was horrified to see we had mares tail (a particularly nasty perennial weed) and suggested we should have sought a further reduction in price. However another one friend did suggest putting French windows in the kitchen and we're still mulling that one over.



**By late June** we had decided to move several internal walls, to enlarge the bathroom and create a better shaped kitchen and living room. Paul started stripping the house to see what was there, including lots of odd bits of wiring and plumbing, and we submitted our plans to Leicester City Building Control. Their role is to approve the fitness or building works, and they are a really useful source of impartial advice about how to do things properly, compared to a builder who is quoting for a job.

Because the purpose of the renovation was to make adaptations for disabled access we didn't have to pay a registration fee (usually about £95), and they very quickly gave us the go ahead, asking us to inform them when certain pieces of work were due to take place. We also met our immediate neighbours who seemed pleasant and ok about access and disruption, so let's hope we can keep them happy.

### August

We got a tree surgeon in to remove the conifers which took them two whole days with two people working full time. Once it was done the whole place seemed much larger and lighter, and the garden went back another six feet. And we met another neighbour who had moved to one of the bungalows across the road because his son had Becker MD. Sadly his son had died a year earlier, aged sixteen, and he and his wife were still grieving for him. He obviously knew a lot about buildings so he and Paul discussed the strange gutters these bungalows have, and we decided to spend money now to get them fixed for all time, and resolve the internal cracks at the same time. We have found a specialist firm who start work next week....

### September - October

The gutters are done, so that we now have light modern gutters which won't need much maintenance. We toyed with the idea of using the rainwater for grey water, to flush the toilet, but in the end we have set them up so they will provide water for the garden and greenhouse rather than just going down the drain. Paul has strengthened the roof, putting in additional bracing in the roof space, as a preliminary to moving internal walls. However he has been delayed. He's a self employed gardener and by this time of year his work has usually slowed down, but for some reason he still has a lot of paid work. So earning money obviously takes a priority, especially as we're going to spend a lot over the next few months.....

*(to be continued in the next edition)*



**Sheila Hawkins**

### **Jet's Special Award**

They say every dog has its day; in this case the dog in question was the very gorgeous and very clever canine partner Jet.

Jet belongs to group member Les Sutton; they have become totally inseparable since they were matched together by Canine Partners just over twelve months ago. We were very pleased to make this special award to Jet for saving Les's life. Unfortunately Les had an accident while home alone which rendered him unconscious with a life threatening injury causing him massive blood loss. Jet sprang into action and covered Les with a blanket and lay close to him as trained to keep Les warm. When Les finally regained consciousness some hours later he was able to instruct Jet to get his phone so Les could call for help. Les was duly taken to hospital.



Karen Presenting Les and Jet with a special Award

Thankfully he has made a speedy recovery. Les and Jet were able to join us for the recent Autumn Get Together in Gloucester where we were very pleased to acknowledge Jet's heroism and outstanding loyalty.

### **Contacting others with FSH-MD**

We often get enquiries from members wishing to contact or meet up with others with FSH. Although we are at present trying to set up local groups it is taking a while to cover all the regions, the ones we do have are possibly too far for you to travel. However the Muscular Dystrophy Campaign has recently launched MD Links which aims to bring people with the same neuromuscular condition together. Peter Lawson talked about the new project at the recent Autumn Get Together and we included a leaflet on how to join in the info packs, to date we have had eighteen of our members join. Obviously the more of us who sign up the greater the chance of finding someone local to chat and make friends with. If you would like to join MD Links or get more information on how it works please contact MDC Tel: 0800 652 6352

### **MDC Support Group of the Year 2010**

The Muscular Dystrophy Campaigns held their National Conference on Saturday 18<sup>th</sup> September at the Birmingham Metropole Hotel. The conference was very well attended with close to two hundred people in attendance. The highlight of the day was the Presidents Awards usually presented by the MDC President Sue Barker. Unfortunately due to filming commitments Sue was unable to attend but did send a video message with her apologies and her good wishes to all those nominated for awards. Standing in for Sue were Baroness Celia Thomas and Sarah Kelly one of the founders of the NMC Cheshire



Liz, Tracy, Juliet, Traceyanne, Margot, Cynthia, Andy, Moira & Karen with our award at our display stand.

We are very pleased to report that the [FSH-MD Support Group UK](#) is the Muscular Dystrophy Campaign Support Group of the Year 2010. The award was accepted on the group's behalf by Chair Karen Bayliss and Vice Chair Andy Findlay.

### **Donations and Fund Raising**

We're very grateful to receive donations from members, often in memory of loved ones or from fundraising events. This helps us to cover the groups running costs and subsidize events. You can also specify if you would prefer to donate to our FSHMD Research Fund. All donations can now be sent to us direct, please include your name and address so that we can acknowledge your donation and send to:

**[FSH-MD Support Group UK](#)**  
**[10 Stoneyhurst Court, Shelton Lock, Derby](#)**  
**[DE24 9JZ](#)**

---

### **Gordon Nutter 1935-2010**

Many of you may remember Gordon Nutter who was a chairman of the FSH Support Group for several years. Sadly Gordon passed away on 27<sup>th</sup> July 2010 after a short illness. We extend our deepest sympathy to Wendy and to both their Son and daughter.

## It's My Story.....

I wonder how many people with muscular dystrophy have been misdiagnosed. In my late teens, I went to see a consultant about my protruding shoulder blades, after examination, he asked if I could remember perhaps falling out of a tree, when younger. Then, even more worryingly, and I have to say my confidence in the consultant was beginning to wane, he said it looked similar to a rugby injury! I assure everyone I didn't attend that appointment in shorts and carrying a spherical ball!!

He thought an operation would be beneficial and would correct the line of my shoulder blades. Thank heavens I didn't accept this offer. Several years later, I was sent to the Rheumatology clinic and then on to see a Consultant, who had trainee doctors with him. That was uncomfortable, a bit like being on show. He emphatically told me it was not genetic, but never what he thought the condition was.

A little about myself; after leaving school at 16, I started to train as a draughtswoman, went on to work at the Land Registry, at Nottingham, but came back to Derby to work at the Telephone Managers Office, doing admin work. Fortunately, I then had the chance to work in the research drawing office at British Rail, which meant I was able to use my technical drawing skills. The drawing boards were on stands and you were able to move them up or down. I always found it more comfortable to stand up to work, rather than raise my arms to draw. Of course, I now know why. I found longer hair easier to manage, rather than blow drying it, or putting rollers in a shorter hair style. I didn't have to keep my arms up for too long. Also to take a jumper off, I would bend forward, instead of standing upright and raising my arms above my head.

Now I have shorter hair, and with the availability of self-holding hair rollers, I can use one arm, supported by the other, to put them in, or sit down, lean over and put the back ones in, with both hands. I've got that off to a fine art now! Another tip; I spent so much time and money on trying to find a bra, where the straps didn't slip down over the top of my arms, really frustrating. I discovered sloggi sports bras. Some of their prettier bras seem to work for me too. I've always been fairly active and from the age of 17 played club hockey and stopped playing when about 38 years of age. I played this sport to a fair standard and actually found it easier running with a stick and ball, than without! After taking my son for swimming lessons, I decided to join an adult class, which I still attend, 20 plus years later.

Around 25 years ago, my brother went to see a consultant neurologist about problems with his foot and he was told he had FSH MD. I was also referred to him and was given the same diagnosis. We were told it was genetic. I'll always remember him calling a colleague in and showing him the 'text book' signs of FSH in my face, how humiliating is sitting there, a specimen not a person. No real empathy, no signposting on, I never saw him again. I did ask my GP about physiotherapy, she wrote to the consultant and his answer; 'there was no point to exercise'.

My husband and I had genetic counselling and were told that there was a 50/50 chance of any offspring inheriting FSH. At that time a research project was being run by Dr Lunt for MDC and he took blood samples from as many of our immediate family members as possible. My mother was found to have FSH MD, which put the affected gene as coming through her side of the family. We took the decision to have no more children, something I often regret, even now, but there was so little information at that time.

I met a regional care adviser at an MDC event and she advised me to be referred by my doctor to a Dr Edwards, at a hospital at Oswestry. I attended his and, subsequently, Dr Quinlivan's clinics and even though it was a heck of a drive there from Derby, it was worth it, especially their positive view of exercise. The experience and knowledge was a complete contrast to anywhere else. One of the registrars there was a Dr Margaret Phillips who is now a consultant in the Medical Rehabilitation Department at Derby City Royal and I transferred there.

I am sometimes asked to be a volunteer patient for doctors and consultants final exams, which is a way to highlight MD. I would suggest if you have the opportunity to do the same. The condition now affects me in certain everyday tasks, but again I learn to compensate and tackle whatever it is in a different way, as far as I can. I attend Pilate's classes and adapt the movements to suit my level of attainment, as well as asking to be referred to physiotherapy when I feel I need it. I broke my leg about 3 years ago and told the hospital staff I had MD, because of which anaesthetic I'd need. It was also decided to give me an epidural. Before the operation, the head Anaesthetist came to see me. "I thought your condition only affected males" he said..... Continued on next page

## It's My Story..... Continued

I know one cannot know everything, but I must admit I was slightly apprehensive being in hospital and apparently no-one had accurate knowledge of Muscular Dystrophy.

Compared to others I have been fortunate with the slow deterioration of my condition. However, I believe that exercise, determination to access appropriate help and knowledge of FSH MD has also been a large factor in where I am today. The more we can educate the health and social professionals about Muscular Dystrophy, the better, and to keep campaigning for better muscle services in our regions.

Take care everyone and look forward to seeing you at the next FSH/MDC event.

## Margot Keats

### **FSH-MD SUPPORT GROUP AT THE MDC SCOTTISH CONFERENCE GLASGOW**

2nd October 2010

Once again intrepid members of the support group travelled up to Glasgow to the MDC Scottish Conference, held at the lovely Beardmore Hotel

It was a long tiring journey, but as usual at our journey's end, we were made very welcome by the staff and by those attending the conference. It was lovely to chat with everyone – people seemed so pleased we had made the effort to travel so far to join them. We met up with friends old and new and caught up with the latest campaign, care and research news. We were particularly pleased to meet up with our 'Face book' friend Natalie, and her two girls Helen and Jane, and with Chris, and his two little girls, Gillian and Helen. It was the first time Natalie had been to a conference, and although she lives in Scotland it took her just as long to travel from her home in Inverness to Glasgow as it took us to travel from the Midlands. It was very relaxed, we were able to sit and chat about our shared experiences and concerns.



Moira, Andy, Natalie, Traceyanne, Cynthia

Natalie was able to tackle Nicola Sturgeon MSP (Deputy First Minister) about the lack of facilities in her area, and got an assurance from the minister that she would look into Natalie's concerns personally. There was a lot of interest shown in our stand and Andy, Moria and Louise happily chatted to everyone and answered questions about the group all day. They also managed to sell our mugs and Christmas cards! As you can see from the photo's Louise did her usual job of making our display board and table really tell 'our story'



FSH Group Stand @Glasgow

Andy and Lou led a workshop to encourage people to get together and start a Scottish local 'Meet and Eat' group and to do this as a way of giving a real source of support and friendship. Linda Sturtevant is very interested in getting a 'Meet and Eat' group up and running in her area, and will be contacting people in the new year who might be interested in meeting up. We came away from Glasgow tired but pleased with all the contacts we had made, the discussions we had had, and most importantly, the friendships we had forged.

## Cynthia Hale

### **Editors note.**

The **FSH Support group UK** are not responsible for the content and accuracy of articles, external websites or the suitability of products or advice given in this newsletter.

We welcome contributions (in Word format) and photographs (in jpeg format) which should be sent to- [fshgroup@hotmail.com](mailto:fshgroup@hotmail.com)  
The next edition is due out April; deadline for articles is 25<sup>th</sup> March 2011

**Accompanying this Newsletter you will find a members questionnaire please spare a few minutes to complete and return to us at the address given, this will enable us to improve our events and services- Thank You**

## **Social Care Personalisation Agenda**

At the recent FSH Get Together in Gloucester, Roxburgh UK gave a presentation on the 'Personalisation Agenda' and discussed what people in receipt of social services support, or those who may need support in the future, might expect. It became apparent that although there were people currently in receipts of services, few knew of or had heard of the changes in social care. We have therefore written this brief outline of the agenda and some processes.

The Government has told Local Authorities to personalise the way services are delivered and to have a minimum of 30% of services delivered in this way by March 2011.

The term 'Personalisation' is also referred to as 'transforming social care' and is about giving people who are eligible for social care funding more choice and control over their lives.

The starting point is seeing the person as an individual with their own strengths, preferences and aspirations.

The person is always at the centre of the process of identifying their own needs and making choices about how and when they are supported to live their lives – simply put choice and control – Independence.

For those who have been using direct payments personalisation may appear very similar, the main difference is that once the personal budget has been agreed the funds can be used much more widely to achieve an individual's desired outcomes.

### **Assessment**

The assessment process for personalisation is very different to previous community care assessments, it focuses on self-assessment with or without support from a social worker. The self-assessment will list multiple choice questions about your abilities and you tick the answer which best describes you. Each question and answer will have a numerical value which once completed will provide an overall numerical value; this is then translated by a matrix which social services have developed into a financial figure, this is your indicative personal budget to be used to meet your needs.

Traditionally adult social services have decided what care services to develop and make available, in other words a 'commission led' approach. This approach has more often than not, meant that people have little real choice in which services they receive, and have therefore been unable to shape the kind of support they

feel would best support their 'self identified' need(s). The use of personal budgets will change this because each individual will be able to shape and commission the services that are available to suit their need(s).

### **Support Plans and Self Directed Support**

Support Plans give the person who has been awarded a personal budget the opportunity to determine how best that budget will be spent, and spent in such a way as to ensure it best meets their individual needs.

The whole assessment process can be seen as 'Self Direct Support' in the sense that the individual makes his or her own choices.

However, I personally consider the Support Plan to be the more liberating of the processes as it gives the individual control of their own resources, control over how and where those resources are best used, and most importantly, they ensure the individuals desired outcomes are achieved. Each individual can decide how involved they want to be in arranging the support and management of their personal budget.

The entire budget or part of it can be paid as direct payments so that you have control of the monies; purchase services; and, employ your own staff. Those people that do not wish to do this, can have services arranged in the more traditional manner through social services; this is called a Virtual Personal Budget

The important thing is that your personal budget gives you: -

- Greater control over your life;
- The chance to maintain or increase your independence
- More choice on how you live your life;
- The opportunity to be more creative, Imaginative and flexible services to meet your needs and achieve your own outcomes.

**Les Sutton**



**01926 888987**

**[www.roxburghuk.com](http://www.roxburghuk.com)**

**[mail@roxburghuk.com](mailto:mail@roxburghuk.com)**