

## List of Contacts

Our new telephone/email contact scheme has now begun. The updated list is as follows:



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# FSH-MD Support Group

Newsletter 12  
December 2008

## Welcome

Hello again, here is the Winter edition of your newsletter. Please do write in with your letters, hints or stories. By writing articles based on your experiences in coping with life you can really help others with the condition.

The deadline for the next edition is **May 12th 2009**. I look forward to hearing from you.

Wishing You All  
A Very Happy  
Christmas.

*Gill*

Please email your contributions to:

[gilldmanning@hotmail.com](mailto:gilldmanning@hotmail.com)

Thank you.

*Gill Manning*

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## FSH Conference

The FSH Annual General Meeting was held in Birmingham on 27th September 2008 as part of MDC's Annual Conference. An account of this day is to be found on page 2.

## Spring Get Together

We are holding a Spring Get Together in April—full details to be found on page 9.

**Come and join us!**

## FSH SUPPORT GROUP MEETING

The annual Conference took place on 27th September and the FSH Group Meeting was part of this. Here is a summary of our Meeting:

Professor Jane Hewitt, from Nottingham University, spoke about recent developments in understanding and research into FSH, both within her team and also worldwide, particularly in the United States. A copy of her presentation is available on the FSH website at <http://www.fsh-group.org/>

### *Activities in the group over the last year*

#### Joint Working with MDC

In October 2007 the group decided to work more closely with MDC, so that all members of the FSH Support Group are automatically members of MDC, and that MDC should manage the membership details for the support group. However members of the group felt it was important to have a written agreement between the FSH Support Group and MDC and a draft

Memorandum of Understanding (MoU) was presented to the meeting.

### *Outstanding matters in MoU*

Finance: at present the group has a bank account with just over £5,000 and relatively small outgoings. However, as the FSH group is not a registered charity this money is a private account, not subject to audit, etc. It was suggested that this money should be transferred to MDC where it would be held in a ring fenced account for FSH, and any donations could then attract Gift Aid. The view of the meeting was that the FSH Support Group should close its existing bank account and transfer its fund to MDC where the FSH Support Group fund would be run as an individual cost centre. The role of the FSH treasurer would change, from having to do the banking and financial reporting, to monitoring the account within MDC and making recommendations to the FSH group about expenditure.

**It was important to have a written agreement**

## Internet Car Insurance

**We have all seen the TV adverts** saying how easy it is to get a car insurance quotation over the internet. However, is this really the easiest way to get a quote?

Quotation websites often refuse to give or confirm a quote for disabled drivers or those with a pre-existing medical condition. It's quite hard to get an online quote for anyone who does not fit the 'average' profile set by the automated risk assessment system that such websites use.

Many insurers will request further information about your disability or your vehicle before quoting. Most companies will offer to phone you back so that you can speak to a consultant. It may be more straightforward, therefore, to telephone an insurance company direct for a quotation. If they refuse to give you a quotation then they are being discriminatory. If an

unrestricted licence has been granted by the DVLA then you must not be penalised for your disability.

There are companies that specialise in policies for disabled drivers, such as Fish Insurance and Chartwell Insurance.

It is important to ensure that your medical condition has been fully disclosed or a future claim may be invalidated. Also any adaptations to your car should be covered and if you use a scooter/



wheelchair they too should be covered by either the car insurance or another policy. It is also important to ensure that a suitable courtesy car will be provided if your car has to be repaired, or that the insurance company will pay for taxi fares.

*Adapted from an article in 'Mobilise' October 2008.*

## FSH - Should I Have My Children Tested?

Fibromyalgia but he gets on with his life and is in a relationship, both he and his partner have decided to have genetic testing if and when they decide to start a family.

My eldest daughter is twenty four, she's a nurse, and has recently been diagnosed with severe asthma which has proved difficult to get under control, but it hasn't stopped her doing cross country mountain biking, swimming, abseiling or any other daredevil thing she and her partner come up with.

My youngest daughter was tested for FSH when she was around twelve as she was having joint problems and it needed to be ruled out, her test came back negative for FSH, which was a great relief.

When she was seventeen she was the diagnosed with a condition called Woolf Parkinson White which is quite dangerous as it can without warning cause the heart to stop beating, she had to undergo heart surgery to correct this. Less than six

months later she had a gap year and took herself off to New Zealand and Australia for six months. I guess what I'm trying to say is, I don't think you should rush into genetic testing if your child isn't displaying any symptoms, in our case all three have developed other conditions equally unpleasant and debilitating and they didn't need the extra burden of an FSH diagnosis as well. Obviously if children do show symptoms it's a totally different matter, they should have a diagnosis to enable them to get help and support to keep them independent.

With the advances of modern technology all my children have decided to use genetic testing when they themselves decide they want to have children.

At least today there is more information and support available for parents who find themselves in the same position of making decisions which can affect their children for the rest of their lives.

*Karen Bayliss*

## Support Group Meeting cont.d....

Review: it was suggested that the MoU should be reviewed after two years. The group was supportive of the Memorandum of Understanding and Sheila Hawkins and Lyn Inman indicated that they expected to agree the MoU by Christmas.

*(This has now been signed. Ed)*

### **Other activities and comments**

Members of the group felt that it was important to have some meetings independently of MDC as it made for a more informal atmosphere and enabled people with FSH to meet up with each other more quickly than at the larger MDC event. It was agreed that the next meeting would be separate from MDC.

The group welcomed the award of £120k made by MDC to support FSH research. Given the high

level of reserves in its account (see above) it was agreed to contribute approx £3k to the FSH research fund, leaving a balance of £2k in the Support Group fund. The group may decide to contribute more money to the FSH research fund, depending on future finances. With the proposed financial changes (see above), anyone donating money to MDC could specify that it should go to the FSH Support Group, or FSH research, or MDC's general funds.

### **Telephone Support Group**

This went 'live' on 2<sup>nd</sup> June, following training earlier in the year. There were now eight individuals around the country who were prepared to take phone calls and e-mails from local members, particularly people who were newly diagnosed.

**The group welcomed the award of £120k for research**

### Support Group Meeting cont.d....

Individuals have had up to 3 calls in the first three months, showing that there is some need for the service and that it is useful.

#### ***MDC lobbying and campaigning:***

Members of the group had responded to MDC questionnaires about the services they received, which had contributed to the report showing the inconsistent services available to people with MD across the country, and which MDC will use as a campaigning tool.

Janet Neilson had taken part in a lobby of the Welsh Assembly and Karen Bayliss had taken part in the Panel Discussion the previous evening, as part of the publicity by MDC about services in the West Midlands.

#### **Officers of the Group**

Gill Manning has taken on both the role of Newsletter Editor and Secretary to the group, and was thanked in her absence for all the work she has done over the last year.

The meeting thanked Norman Jonas for his work over the years as treasurer, and would be pleased if he would continue as treasurer. If Norman no longer wished to carry out this changed role Moira Finlay would be prepared to act as treasurer for the group.

Sheila Hawkins informed the meeting that she intended to stand down as Chair of the group in the next year, and would be happy to discuss the role informally with anyone who was interested in standing for the position.

\* \* \* \* \*

#### ***UP-DATE***

Moira Finlay is our new Treasurer as Norman Jonas has stepped down from this role. As MDC now holds our money for us, the Treasurer's role will be to take an overview, monitoring income and expenditure rather than to do the banking. Many thanks to Norman for all his hard work over the years.

*Sheila Hawkins*

**There is  
some need  
for the  
service**

### FSH - Should I Have My Children Tested?

children were aged two, five and seven, genetic testing was available and we were asked if we wanted the children tested, it was something we had to think long and hard about. My consultant arranged for the children to see a paediatric consultant who had them doing all the usual neurological tests, puckering the lips, rocking on their heels and checking how tight could they shut their eyes. He couldn't find any clinical evidence that they were displaying any symptoms but that could change as they got older the only way to be sure was to have the tests done.

After much thought we decided against testing, if they had shown any symptoms we would have had the tests done but as they weren't we thought it best not to because once you are given a label it can dramatically affect you emotionally and practically for the rest of your life.

We did not want the children to think they couldn't achieve their full potential because at the back of their minds there would always be "I can't/ shouldn't do this because I have FSH." I didn't want them to be different from their friends, it's so easy to make excuses not to do things when you are told you have something wrong, and practically, it could affect the chances of getting life insurance, a mortgage, etc when they were older.

We were always open with the children about my condition and they were aware it was hereditary but we didn't dwell on it, and although they were very aware of my decline it never prevented them from getting on with their lives.

I'm sure in retrospect we made the right decision. My son is twenty seven, and a physics teacher, he does have a very painful condition called

**We made  
the right  
decision**

## FSH - Should I Have My Children Tested?

When I was originally diagnosed it was difficult to take in all the possible consequences of having FSH. I remember talking to my mum about the implications and was very shocked when she confided how badly my Dad had taken the news, he was quite guilt ridden that he had passed on something so dreadful and he was very angry that his father had passed it on to him, his thinking being that his father must have known that he had something that wasn't quite right and the fact he went on to have seventeen children truly angered my Dad.

I remember talking to my Dad and said that he shouldn't be angry with his father or himself because muscular dystrophy wasn't known about way back then let alone FSH, and just as his father hadn't known that he had FSH, my

Dad hadn't known either so he shouldn't blame himself, because I certainly didn't blame him, as far as I was concerned it was just one of those things.

Out of seventeen brothers and sisters my Dad had drawn the short straw, none of my uncle, aunts or cousins have shown any symptoms to date.

I have a younger sister who is now forty five and luckily seems to have missed out on the faulty gene. I also have a half sister who must be a carrier as she has a son affected, but her other children seem ok.

All this made me think about my own children who had been born before I knew that I had FSH. I'd always believed that I had arthritis so had never had any concerns that I could pass on anything so serious. At the time of my diagnosis my

Out of  
seventeen  
brothers and  
sisters

## I Think I must Be Getting Old.....

One of my passions has always been reading and my idea of heaven is to spend a couple of hours in my local library working my way through the shelves in the detective section or biographies and historical non fiction department.

I'm a huge fan of Agatha Christie's Poirot and Miss Marple. I've always thought I was born in the wrong decade I love the elegance of the twenties and thirties.

So when my mobility declined and I found it more difficult to get to the library I just assumed that it was just one more interest that I would have to forgo. I happened to mention it to a friend of mine and she told me that our local Library ran a scheme

called "Library Services At Home" for people with disabilities. I gave them a call and 'hey presto' I now have a monthly delivery of books which keeps me going through the dark winter nights we are having at the moment and it doesn't stop with books, I have had Videos, DVDs, and CDs. They also do a monthly magazine with book reviews, recipes and news about what's new in my local area.

I would thoroughly recommend it, ring your local library to see if they offer the same service.

.....Oh yes, I also receive a copy of "Mature Times" in my box of books..... I don't feel that old!

*Karen Bayliss*



## Karen's FSH Journey

From an early age I always knew I was different. At school I never looked the same as any of my friends, they could all wear trousers, skirts and pretty dresses. I always had a pot belly that made me look like a refugee from a third world African country!

I got used to the stares and nudges when the other kids would poke fun and call me fish lips because I could never remember to make a conscious effort to keep my lips together and school photographs were a nightmare, my face always looked lopsided and I never seemed to smile although I thought I was at the time.

....When I hit my mid teens that was when the pain started, so bad I just wanted to hit my head against a wall. I was find-

ing it difficult to lift my arms and that along with the pain, and needing to be on my feet for long periods of time, meant I had to give up my chosen career as a hairdresser.

I was in pain and fell over frequently but that was me, everyone knew it was Karen's thing; I'd always got scabby knees and bruises.

I met my husband and got married when I was twenty and still I didn't have any idea what was wrong with me. Five years and three children later the pain had spread to my hips and legs and walking was getting a real problem. I saw a consultant neurologist who decided to do tests and finally a muscle biopsy.

Two days later I was told I had Facioscapulo-humeral Muscular

I had to  
give up my  
chosen  
career

## Adult Self Management Packs

Following its publication in July this year, MDC have already distributed over 500 of free Adult Self-Management packs, containing information for people who have an adult-onset muscle disease. We know that there are still many more people to reach, so if you know someone who would benefit from this information please do let them know about this ground breaking publication.

The pack contains 36 factsheets covering topics ranging from exercise to hospital admission to holidays, a diary and a medical alert card. To order your copy call freephone **0800 652 6352** or email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org).

## The Joseph Patrick Trust (JPT)

continues to help promote mobility and independence for children and adults by providing vital financial support towards specialist equipment, such as wheelchairs, adapted computers and beds.

The JPT panel is meeting to confirm grants on 4 February 2009 (deadline for applications 28 January).

If you would like to apply for help towards a piece of equipment, you can find further information, application forms and guidelines online through: [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) (Care & Support Grants)

## Benefits Information.....from 'Contact a Family'

### Urgent call for families with disabled children to get advice on their benefits and tax credits entitlements.

Contact a Family has identified that some families with disabled children could lose out on vital income due to changes in benefit rules.

From 27 October 2008 Incapacity Benefit and Income Support for people with health problems was replaced by Employment Support Allowance (ESA). Some families will be worse off on the new ESA depending on individual circumstances.

Sarah Rush, Head of Advice at Contact a Family, said: "We know that families with disabled children face enormous financial challenges with more than half living in poverty. It is therefore vitally important that families get advice to find out how these benefits' changes will affect them".

The Contact a Family freephone helpline – 0808 808 3555 - is staffed by benefits experts and trained parent advisers who can help to maximise a family's income.

Contact a Family, working with HM Revenue and Customs (HMRC), has also identified there are 28,000 families in the UK who are missing out on much needed extra income through additional tax credits. Families who have not informed HMRC that they receive Disability Living Allowance could be missing out on this additional income, which is paid in addition to existing tax credits they may already receive. If you feel you might be affected by either of these issues or simply want to check that you are getting all the money you are entitled to, telephone the Contact a Family helpline – 0808 808 3555.

## Karen's FSH Journey cont.d..

Dystrophy. Once the shock had worn off and I realized things hadn't really changed I was still the same person with the same problems. I just had a fancy name for it, though at the time I didn't actually understand the long term consequences.

**I consider  
myself  
lucky**

Having FSH has made me the person I am today. I can't say it's much fun having FSH, it's a truly frustrating, devastating and a soul destroying condition, there are days when I sink into the depths of despair. I carry the guilt that I may have unknowingly passed it on to my children and future generations. I feel anger when I can't do something, I hate my dependence on others, and want to scream at

the very people that I love most deeply, that they don't understand how I'm feeling. I worry what will happen to me in the future, who will look after me, will I be able to cope if I can't feed or wash myself or have to suffer the final indignities of having others to do the most personal things that I can't manage myself.

I consider myself lucky in that I have three amazing children of whom I'm so very proud. They give me the will to carry on. We've all had to get through so much over the years, not just the practical problems of living with FSH and all that it entails, but also the emotional roller coaster that we've been on which has left its mark on all of us.

*This is a shortened version—the full article can be found at [karensfshjourney.blogspot.com](http://karensfshjourney.blogspot.com)*

**Do you live in Birmingham  
or surrounding areas?  
Would you like to meet up with fellow  
FSH'ers  
for relaxed informal get togethers?  
If the answer is yes then contact Karen  
at  
[Karen-fsh@hotmail.com](mailto:Karen-fsh@hotmail.com) or call  
07912680552**

### SPRING GET TOGETHER

This is an informal event, aiming to bring people together to socialize, make friends and to encourage greater participation in the support group, with a view to possibly organizing more get togethers and outings in the future and hopefully to form smaller local groups.

I'm also looking at various suitable alternative therapies such as reflexology, etc I'm open to any suggestions from anyone who has tried anything and found it beneficial.

Please contact Karen on [Karen-fsh@hotmail.com](mailto:Karen-fsh@hotmail.com) or call 07912680552 if you have any suggestions.

### Carol's Bus Adventure cont.d....

the problem. As we sat at one of the tables outside the coffee shop, he opened a note-pad attached to the clip board he had been carrying and asked if I would like to make a formal complaint to the bus company? Well... there won't be any improvements if one doesn't, right..? He took my name and address, details of my journey which included the number and destination of the bus and times of travel. As we sipped our cappuccinos he told me his name was Jeff and that he was familiar with disability after meeting and marrying a lady with multiple sclerosis. Jeff explained that his wife was not able to differentiate temperatures and made light of when she told him his bath was ready and he found she had filled it with scalding hot water. Gosh...life isn't easy is it?

Jeff asked if I needed to contact anyone at home and offered me the use of his mobile phone. I hadn't told anyone I was going out or where for that matter, but thankfully, I had remembered to bring my mobile phone. I thought it might be useful to have in an emergency, so hopefully I could remember how to use it. I declined his kind offer and brought it out of my bag. I rang my sister's number and was

relieved to hear her voice. Trying to make myself heard over the noise of the traffic I replied "Guess where I am?"..

Jeff made sure the next bus to leave the depot had a ramp fitted and in working order before seeing me safely on board. We smiled and waved our goodbyes.

An hour later I arrived back in my village and although I felt a bit weary after the events of the day I gave myself a BIG pat on the back for my achievement. It was at this point I suddenly caught sight of the forgotten duck-toed footrest and laughed. Now in high spirits I headed in the direction of the local Chinese takeaway which would be the yummiest way to end the day.

After receiving a letter of apology from the bus company a few days later, I asked if it would be an idea to inform them in advance of the date and times of my travelling, as they were unable to guarantee the bus would have a ramp fitted, let alone it being in working order.

Okay wheelies, don't become disheartened, let's venture onto the train... watch this space!!

*Carol Lawson*

**Guess  
where I  
am?**

### Carol's Bus Adventure cont.d....

Laughing and rubbing my hand tingling from the encounter I entered a bustling Department Store.

I took the lift to ladies fashions on the first floor. As I wandered around the designer labels I noticed the meticulously made-up sales ladies, some of whom looked as if they had eaten pickled gherkins for lunch. Oh dear, not a lot of happiness going on here! Trying to keep a straight face I quickly finished browsing and made my way up to the second floor. While I was there I paid a visit to the disabled loo. Unfortunately, due to this facility being misused, it is now kept locked and those entitled to use it have to have their own key. Luckily, I had purchased mine from one of the stands at the Disability North Exhibition together with a handy little booklet of where these facilities are situated around the UK.

After making a few small purchases I left the store. I made my way through town making mental notes of access into various buildings and places of interest. After a while, I looked at my watch and realised I had spent over three hours leisurely wandering around so I decided it was time to head back to the bus stop in time to catch the thirty-eight minutes

past back home. I arrived just as the bus was pulling up at the bus stop and was congratulating myself for timing it just right when I saw "IT" again. I couldn't believe it! Here I was trying to get back home on the bus I couldn't get on in the first place! There "IT" was taped in the window "RAMP NOT WORKING"

Rather than wait for half an hour I decided to spend the time taking in the sights and sounds of the town before arriving back and joined in the conversation of putting the world to rights with fellow travellers waiting in the queue. As the bus came into view I was dismayed that no familiar yellow wheelchair logo was on display, which meant the bus wasn't wheelchair accessible. Feeling frustrated and isolated I watched as my fellow travellers disappeared one by one onto the bus and wondered what I should do? It was at this point I heard a voice behind me asking if I needed assistance. I turned to see a nice looking chap dressed in a dark suit and wearing a tie with a Company logo. He was a bus inspector!

After explaining my dilemma, I declined his offer to drive me home (not in this chair sunshine..!) However, I did accept his invitation to go for a coffee while he sorted out

### *FSH Support Group UK*

Are pleased to announce their first

"Spring Get Together"



Saturday 4<sup>th</sup> April 2009

10am-4pm

At

Rowheath Pavillions

Bournville

Birmingham

Cost £12 per person (includes a buffet Lunch)

The Theme will be

"Keeping Well With FSH"

With guest speakers, demonstrations, workshops  
plus lots more.

We look forward to seeing you.

Keep an eye on your post, we'll be sending you a  
"Spring Get Together" pack soon.

## Carol's Bus Adventure

After learning the local bus service had adapted their vehicles to accommodate wheelchair users I had to give this a try! Well, nothing tried, nothing gained, right...?

It was a bright sunny day when I found myself at the bus stop which is conveniently about five minutes walk, or in my case about three minutes wheel from where I live. I hadn't told anyone in particular I was going out and without further thought, I hot-wheeled it to the bus stop. While I waited, I wondered where I had summoned up the courage to go on this venture alone as I usually go out shopping with one of my sisters. However, this was different! This was going to be the start of my new found independence.

As the bus came into view I noticed the familiar yellow wheelchair logo displayed on the front next to the number and destination. I felt a surge of excitement as I took my place in the queue; after all I hadn't used public transport for years! As the bus pulled up at the stop I suddenly saw "IT"!! "IT" was a Notice

displayed in the nearside window which read "RAMP NOT WORKING".

My excitement soon turned to disappointment as I wheeled myself out of the queue. The driver apologised and assured me the next bus was due in thirty minutes. But would the ramp be working I wondered? Was this a sign telling me I should go back home? I sighed, and told myself this was just another hurdle to get over, so I decided to carry on and wait for the next bus.

The bus came along on time and I watched cautiously as the driver lowered the ramp while still sitting inside his cab. The ramp emerged automatically from a concealed area just below the doors of the bus and lowered onto the pavement. It was just the right size to accommodate my wheelchair and I was able to ascend easily onto the platform. Once on the bus I carefully manoeuvred my chair into the narrow designated space, however I somehow managed to bump one of my footrests in the process. When I looked down I was horrified to discover it was turned inwards giving the impression I was

**It was a  
bright sunny  
day**

## Carol's Bus Adventure contd.....

duck-toed! I bent down to straighten it but it was determined to stay put so I decided to put up with the impression until I got off the bus. As I lifted my head my face slowly reddened and I realised I was facing an audience of passengers who had all witnessed my dilemma! It felt a bit strange travelling in the opposite direction of everyone else and my gaze wandered aimlessly around. I shook off my inhibitions and settled down to enjoy the journey by taking in some sight-seeing, and from the corner of my eye, a bit of people watching too.

The bus travelled quickly along the bus lanes; and I did think the driver was a little enthusiastic when he sped around the roundabout at the Angel of the North on two wheels! I immediately followed suit when I realised I hadn't applied the brakes to my wheelchair! Talk about being on the waltzer!

The journey of fifty minutes had passed quickly as we arrived in town. I waited until the bus stopped before manoeuvring out of the narrow space and descended the ramp onto the pavement. It was busy with people bustling back and forth and I looked around for a familiar face. There wasn't one of course, and a strange feeling came over me. Was this what independence felt like? Or was I feeling a little vulnerable?

Fond memories of growing up and working in this town came to mind. I knew the streets like the back of my hand. How good was it to be back? It was magic! My heart was pounding as I made my way up the busy street bustling with shoppers. Just ahead, I saw a fellow wheelchair user coming towards me. I noticed he was dressed head to foot in black leathers and displayed an array of piercings from ear to ear. I cringed, and I recalled the dreaded day when I had my ears pierced. I had celebrated my birthday the day before and received a gift of a small pair of earrings. It wasn't until I took them out of the tiny box I realised I would have to have my ears pierced to wear them. Being terrified of needles I asked a friend to accompany me to the jewellers where I asked if the procedure would be carried out under local anaesthetic? The lady smiled and assured me it wasn't necessary as it was very quick and quite painless. To summon up a bit of Dutch courage however, I insisted on having a couple of wine spritzer's beforehand. And here today, as I watched this guy coming towards me it crossed my mind that he must have had a couple of bottles going by the amount of his array. He came up to me smiling like a long lost friend, held up his hand and shouted, "Gimme five Honey!" as the palm of one of our hands smacked together in comradeship.