

## [FSH CONTACT LIST](#)

If you would like a chat with a fellow fsher the contact list is as follows:



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**Muscular  
Dystrophy  
Campaign**



**FSH-MD Support  
Group**

Newsletter 13

Summer 2009



### **Welcome**

Hello again,

Summer is almost here at last. A lot has been happening with the FSH Group. We had a very successful Spring Get Together Day in April which has given us some ideas for the future of our group. A full report of the day can be found inside on pages 4 – 7.

A group of us met on May 9<sup>th</sup> to form a committee in order to formalise and structure the group

as we now have over 500 members. Read about this on page 3.

Members are interested in reading life stories or holiday tales—good or bad - so please send them to me at the address below. You may also have health tips to pass on to others too.

Thank you for your contributions. The deadline for the next edition is **November 15<sup>th</sup> 2009**. I look forward to hearing from you.

*Gill*

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*Please email your contributions to:*

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

Or post to: 3 Gleneley Court, Third Avenue,  
Frinton on Sea, Essex CO13 9EA.

## Letter From The Chair

This is an exciting time for the FSH Support Group – we had a very successful Spring Get Together in Birmingham in April with almost eighty people attending, we have formed a new committee and are planning a programme of events over the next year, recognising that different members have different interests and priorities and if we are to be successful as a group we need to offer a range of activities. We've also agreed a new strapline:

### **Support – Information – Encouragement**

which we hope reflects what we can provide to members.

One thing that I know concerns most members of the FSH Support Group is the post code lottery in terms of the services we receive around the country. The Muscular Dystrophy Campaign are well aware of this – it applies to most other MD Conditions – and are keen to work with us to address this.

Nic Bungay from the MDC Campaigns Team will be attending our **Autumn Get Together** to talk about their work and how FSH members can help, by attending meetings with NHS Commissioners to talk about their experience of accessing services. I hope we'll see you there on **October 17th** – more details on the diary dates page.

We have also developed links with FSH Groups in other countries – both in Europe and in the USA – and are exploring ways in which we can support each other.

Sheila Hawkins

Chair of the FSH Support Group

An exciting  
time for the  
FSH  
Support  
Group

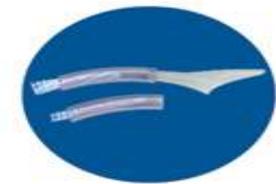
## Something for the Ladies

For those of us who have difficulty using a conventional toilet when out or are unable to stand from a sitting position then the **Shewee** may be the answer.

**Shewee** is a moulded plastic funnel that provides women with a simple, private and hygienic method of urinating without removing clothing! You can shewee whilst sitting or standing, meaning no more crossed legs or uncomfortable squatting. Shewee lets you stand up to avoid dirty loo seats. Combine with a Shewee extension pipe to direct urine flow when seated.



Shewee



Extra length outlet pipe for extreme sports or bulky clothing

### **Absorbent Pouch**

Suitable for use with or without a Shewee these handy absorbent pouches contain a special lining that rapidly converts fluid into a non-drip, odourless gel. Ideal for keeping in the car for those traffic jam emergencies! The pouch can absorb up to 400ml of fluid which means that each one can usually be used 2-3 times (depending on how much you've had to drink!). After use simply peel off the tape and seal ready for disposal.



For more information [www.reallyusefulthings.com](http://www.reallyusefulthings.com)

[www.shewee.com](http://www.shewee.com)

## PRODUCT REVIEWS from K Bayliss

It has to be said it's sometimes the little things that make life easier here are a selection of ideas seen at the recent Naidex Exhibition. If anyone has anymore products big or small that they have found useful and would like to share send them in for inclusion in the next newsletter.

If you have problems knocking over drinks then these three ideas could be really useful.

### Tip Topz Drink Covers

Latex drink covers that stretch over the glass. Drinks are sipped through the straw without the risk of spills, even when in a lying position.



### L'il Sucker Cup Holder

Looking for a simple solution to hold your drink steady? L'il Sucker is really easy to use: simply pop your glass into the cup holder and suction will hold it steady on any smooth, non-porous surface, and at any speed! No more knocking drinks flying across the table! Gently lifting the edge of the ring releases the suction. Lil Sucker Cup Holders remain attached to the surface so you can remove your glass easily, and your drink will be secured every time you replace it.



### L'il Sucker Ring

L'il Sucker rings work in the same way as the L'il Sucker Cup Holders, but attach to your glass instead, so you can put your drink down anywhere on your smooth surface and it will be secured. L'il Sucker rings stretch over objects up to 3 inches (7.6cm) in diameter and are ideal for use with glasses, bottles, jars and cans.



Available in 6 different colours.

## New Committee for FSH Group

Since the last Newsletter there has been an exciting new development for our group. On May 9th twelve members of the group met at the Holiday Inn, Peterborough with the intention of forming a committee structure in order to take the FSH Group forward on a stronger footing with more members being involved in the management and development of the group.

The aim of the group is to provide 'Support, Information and Encouragement' and to support the MDC and its research.

It was thought that in order for these aims to be fully realized it was necessary to 'spread the load' of the work involved in administering the group rather than it being the responsibility of three or four people. Those present also agreed that it was important for

the group to take over the management of our finances from MDC. This gives us more control as to how we plan the future of the group.

Listed here are the agreed committee roles until our first AGM in the Autumn when group members can elect a new committee for the year ahead.

The AGM will just be a short part of our next group 'get together', further details to follow.

Sheila intends to stand down as Chair at the AGM after five years in the role and would be happy to talk to anyone who may be interested in 'stepping into her

shoes'. Her email is **Sheila-fsh@hotmail.co.uk** The group wants to reach out to as many people as possible and feels that a strong committee structure will be the best way forward.

Chair	Sheila Hawkins
Vice Chair	Andy Findlay
Treasurer	Moira Findlay
Email Secretary	Traceyanne Pilato
Minute Secretary	Shona Crump
Publicity & Events	Co-ordinator Karen Bayliss
Newsletter Editor	Gill Manning
Young Persons	
Co-ordinator	Laura Bayliss
European Rep	Stuart Watt
Research	
Co-ordinator	Colin Lucas
Members Rep	Margot Keats
Members Rep	Cynthia Hale
Members Rep	Geoff Manning

## Spring Get Together..by Karen Bayliss

The first support group "Spring Get Together" was held on Saturday 4th April in Birmingham. In a move away from our usual conferences it was decided that the aim of the day would be to bring people together in an informal setting to encourage members to chat and make friends. We received eighty one bookings which were nearly double the usual numbers that have attended some past events.



and Sonia Day from Mediacotech Ltd who demonstrated the Thera range of passive exercise cycles. We also had our three "Here to help" volunteers Louise, Laura and Alison. They were available to help members and to keep the day running smoothly.

The day commenced with a welcome from our chairman Sheila Hawkins who expressed her delight at seeing so many new faces and hoped that everyone would find the day helpful and informative.

Our first speaker Carolyn Evans talked about her position as a specialist Neuromuscular Nurse. She explained that many patients have a wide range of problems. As well as the more obvious ones that having a neuromuscular condition brings, there are often hidden problems that patients often find difficult to discuss. Carolyn regularly finds herself dealing with many issues ranging from help with walking aids, personal care or form filling for benefits, right through to helping people considering Scapular Fixation procedures.

The theme for the day was "Keeping Well with FSH". To help us achieve this we were pleased to welcome our guest speakers for the day: Nick Emery Head of Physiotherapy at the Neuromuscular Centre, Winsford, Cheshire; Carolyn Evans Specialist Neuromuscular nurse who is part of Dr Ros Quinlivan's team at the RJAH Orthopaedic Hospital, Oswestry; Jane Stein Regional Care Advisor for the MDC based in Oxfordshire, and group member Stuart Watt, who covered international co-operation in research into FSH.

As well as our speakers we were joined by Shukri Manseur

There are often hidden problems

## Dates for your Diary

### 12<sup>th</sup> September 09

#### Muscular Dystrophy Campaign

Scottish Annual Conference & AGM

Glasgow

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### 17<sup>th</sup> October 09

#### FSH Autumn Gathering

The venue (in South of England) to be confirmed, so watch the MDC Care Events Calendar for further information at

[http://www.muscular-dystrophy.org/how we help you/care events](http://www.muscular-dystrophy.org/how_we_help_you/care_events)

### 26<sup>th</sup> November 09

#### Kidz Up North

Reebok Stadium

Bolton

[www.kidzsouth.co.uk](http://www.kidzsouth.co.uk)

### Volunteers needed for MDC AGM

We'd like to have an Information stall at the MDC annual conference and AGM on 5<sup>th</sup> September in Bradford and the Scottish conference on 12<sup>th</sup> September.

If you'd be prepared to do this – sit by a table with some leaflets and tell people about the FSH Support Group to encourage new members and collect ideas, please contact me at:

[sheila-fsh@hotmail.co.uk](mailto:sheila-fsh@hotmail.co.uk)

## Dates for your Diary

**4<sup>th</sup>-6<sup>th</sup> June 09**

### **Mobility Road Show**

Kemble Airfield,  
Gloucestershire

Free Admission & Parking

[www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)

**18<sup>th</sup> June 09**

### **Kidz South Exhibition**

"Dedicated to children,  
their families and the  
Professionals that look  
after them".

Rivermead Leisure  
Complex

Reading, Berkshire.

[www.kidzsouth.co.uk](http://www.kidzsouth.co.uk)

**25<sup>th</sup> June 09**

### **Neuromuscular Centre, OPEN DAY**

Winsford

Tel: 01606 860911

for details

[www.nmcentre.com](http://www.nmcentre.com)

**4<sup>th</sup> & 5<sup>th</sup> July 09**

### **Beyond Boundaries**

"The UK's most exciting  
event for Disabled people"

Farnborough FIVE

Showcentre

[www.beyondboundarieslive.co.uk](http://www.beyondboundarieslive.co.uk)

**12<sup>th</sup> July 09**

### **Disability Awareness Day**

Promoting Independence  
throughout Life and Work

Walton Hall Gardens

Warrington

[www.disabilityawarenessday.org.uk](http://www.disabilityawarenessday.org.uk)

**5<sup>th</sup> September 09**

### **Muscular Dystrophy Campaign**

Annual Conference & AGM

Bradford

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

## Spring Get Together cont.d....

She also explained that Dr Quinlivan's clinics are able to offer a wide range of services including physiotherapy, orthotics, gait clinics and surgical procedures all under one roof. This means that patients are often able to access several departments in one day so avoiding the need of waiting for or travelling to different appointments.

Our next speaker Nick Emery, explained his role and that of the Neuro-muscular Centre in relation to clients with neuromuscular

conditions. His presentation covered the benefits of physiotherapy, exercise, diet and nutrition along with complimentary therapies.

Nick explained that clients first have an assessment, and as well as covering their individual physical problems, consideration is given to other problems the client may be having such as the use of equipment to maintain mobility. He stressed that everyone is treated on an individual basis and treatment is tailored to

individual specific need.

The importance of keeping active was discussed and it was stressed that it was important to maintain mobility for as long as possible. By having physiotherapy on a regular basis constrictors of the muscles could be alleviated and muscle tone maintained to enable some form of mobility to continue.



This is achieved by using various methods including passive stretches, assisted standing, active exercise gait training and hydrotherapy.

FSH -MD is the only MD that causes pain that varies from person to person in intensity; some pain can be alleviated with physiotherapy.

A good diet is essential as with reduced mobility come problems that face many, as eating more calories than our bodies burn off causes weight to increase, adding more stress to already weakened muscles.

Nick then moved on to complementary therapies although there was no evidence that

**A good  
diet is  
essential**

## Spring Get Together cont.d....

any of them worked, his advice was "if they made you feel better then carry on using them".

Nick then explained the procedure for attending the NMC. All that is required is a referral from your GP or consultant. After your initial assessment you may be offered a range of treatments including physiotherapy, if you decide to go ahead the centre will contact your local PCT who will usually fund your treatment, if they don't the centre will cover the cost of treatment at no cost to you.

Patients travel from all over the country to attend and once you have attended you are on their books for good and should you stop going for what ever reason you can always return at a later date without a doctors referral letter.

Nick's PowerPoint presentation can be viewed online at [www.fsh-group.org](http://www.fsh-group.org)

After the morning coffee break we welcomed Jane Stein. Jane is co-author of the new "Adult Self Management" pack recently produced by the MDC, for adults with

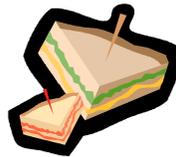
one of the many adult onset neuromuscular conditions.

The packs cover all aspects of living with a neuromuscular condition, and to answer all those questions you wanted to ask but never knew where to go to get the answers. They are packed with fact sheets and information and include a diary to keep records of hospital appointments, etc.

Unfortunately it wasn't possible logistically to have them available on the day but there were cards in the welcome pack, so members could send off for their own copy.

Members enjoyed a two course buffet lunch and still had time to chat with fellow members or try out the passive exercise equipment that was demonstrated by the staff from Medicotech Ltd which proved very popular.

The afternoon commenced with workshops with either Carolyn "Your Questions Answered" or with Nick "Keep It Moving" members split into two smaller groups and alternated between workshops.



**You may be offered a range of treatments**

## SALES CALLS & JUNK MAIL

*Commissioning Group to take forward proposals for a thorough review of the gaps in current service provision – in which the Muscle Group would play a key part.*

*In the South West local campaigning has already had a fantastic impact – through working with local NHS commissioners the South West Muscle Group has secured a £1 million investment in local neuromuscular services.*

*The West Midlands Muscle group will work to achieve the same kind of result for the 5,000 people living with muscle disease and their families in the West Midlands."*

I've been invited to join the West Midland Muscle Group Committee, so I will keep you all updated on any news or progress made. If anyone would like more information or if you have any thoughts on the subject please feel free to email me at:

[Karen-fsh@hotmail.com](mailto:Karen-fsh@hotmail.com)

Karen Bayliss

If you receive too much junk mail or annoying phone calls from companies trying to sell you something or telling you, that you are the 'lucky winner' of a cruise etc. (usually a scam) there are two services to help you.

The Mailing Preference Service and the Telephone Preference Service are free services and once you have registered with them you should not receive any personally addressed junk mail or annoying phone calls. However, it will be up to you to ensure that your favourite charities still keep you on their records. The websites are [www.mpsonline.org.uk](http://www.mpsonline.org.uk) and [www.tpsonline.org.uk](http://www.tpsonline.org.uk)

If you receive 'silent' phone calls generated by automated systems, register with Silent Callguard to reduce the number of these calls. Just ring 0844 372 2325 and type in your phone number when prompted.

## West Midlands Muscle Group

On Wednesday 22<sup>nd</sup> April I attended the first meeting of the newly formed West Midlands Muscle group. It was a real eye opener as to what services are not available to people with a neuromuscular condition, the meeting was well attended with a good sprinkling of fellow fsh'ers.

After the success of a similar campaign in the South West it's hoped that services can be improved and standardized in the West Midlands as opposed to the present postcode lottery which is unacceptable to everyone who suffers the frustration and indignities that having a neuromuscular condition brings.

*"The Muscle Group will be a coalition of local families and health*

*professionals, working together to improve services and provide peer support in the fight against muscle disease. The group will meet quarterly, at locations across the West Midlands.*

*At the group's first meeting a new report about services in the West Midlands will be launched which shows that too many families in the West Midlands are being denied essential services – such as ongoing specialist physiotherapy and the support of a Care Advisor.*

*The Muscle Group will have a unique opportunity to help secure improvements in current services. Already in the West Midlands the Muscular Dystrophy Campaign are working with the NHS Specialised*



## Spring Get Together cont.d....

During the afternoon coffee break the numbers were drawn for our Easter egg raffle the lucky ten winners all received a Cadbury Easter egg, we raised £75 which has been sent to the Neuromuscular Centre Cheshire.



The final presentation of the day was from Stuart Watt who as well as being a group member is also a member of the European Steering Group. He attends conferences with other European FSHD organisations with the aim to increase funding, care and research while promoting the sharing of information, Stuart began by telling us the aims of FSHD Europe, which include; being proactive and involved to stimulate finding a cure, raising the profile through increased awareness, developing extra funding sources, and lobbying more effectively to the EU.

At present Belgium, Italy, Netherlands, France, Denmark, Slovenia and the UK are members but more are being invited.

Stuart went on to discuss how FSHD Europe planned to achieve these aims including:

To stimulate collaboration and accelerate translational research pathways in FSHD

To improve quality of life, promote interests of FSHD patients in health policy, raise public awareness, and promote best practices

Plus

To facilitate interactions between people involved with FSHD (patients, clinicians, researchers, agencies, industry).

We looked at care and social integration across Europe and the standards of care proved to be very varied.

Stuart has kindly made his powerpoint slides available online at [www.fsh-group.org](http://www.fsh-group.org)

If anyone would like to contact Stuart to discuss his work, please email him at

[stuartjmwatt@hotmail.co.uk](mailto:stuartjmwatt@hotmail.co.uk)

Members then had time to chat and discuss the day's activities and there was also a last chance to speak with the guest speakers.

The day finished at 4pm and special thanks were given to the guest speakers who had made such a valuable and informative contribution to the day.

# Muscular Dystrophy Campaign



***Moving forward – Understanding what goes wrong in the muscle.***

***Dr. Marita Pohlschmidt, Director of Research Muscular Dystrophy Campaign***

This year the Muscular Dystrophy Campaign is marking its 50<sup>th</sup> anniversary. The charity was originally set up to fund research into Duchenne muscular dystrophy and has grown since then to support more than 60 neuromuscular conditions. As well as funding world class research into these conditions, we provide free care and support for families, campaign to raise awareness and bring about change, and provide grants towards specialist equipment, such as powered wheelchairs.

In the last 50 years we have invested more than £50m into high-calibre research to find treatments and cures for muscle disease. Thanks to investment in research in the UK and around the world we now have a much better understanding of how muscles work and the underlying causes of muscle disease.

## ***Does the Muscular Dystrophy Campaign fund research into FSHD?***

Yes – in 2008 Professor Jane Hewitt at the University of Nottingham was awarded a grant that provides funding for a PhD student to investigate the mechanisms that cause the muscle weakness associated with FSHD.

FSHD is the second most prevalent muscular dystrophy in adults affecting approximately 1 in 20,000 people in the UK. The condition is characterized by progressive weakness and wasting of facial, shoulder and upper-arm muscles. It is a highly variable type of muscular dystrophy with symptoms appearing any time from early infancy to late life but typically in the second decade of life.

FSHD is commonly caused by a deletion in the DNA of affected

**£50m into high-calibre research**

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

his own curiosity then for any medical purpose. His advice was..... Don't have children!! .... If I didn't have children then there would be no way of passing FSH on and the condition would die with me.

I chose not to take his advice. I really wanted children, if they had FSH then I would have to explain to them that I had wanted them so much I was prepared to take that risk and that I hoped they would never hold that decision against me.

As to what impact the pregnancy would have on me personally I wouldn't know until I went through it.

Luckily I sailed through my pregnancies. I was given no special treatment, no extra checks and ended up with two beautiful sons.

It was quite hard when they were little, silly things like not being able to lift them if they

fell or carry them upstairs to bed but where there's a will there's a way and we muddled through as a family. My boys are now in their 20's, both seem fit and healthy and have as yet not been tested for FSH, their choice entirely. I am also a very proud grandma of a beautiful little girl.

My FSH is obviously getting worse but it's just made me more determined to do what I can while I can. The last year or so has seen me going around a race track at high speeds in a Lotus, taking the controls in a Cherokee airplane and in a



few weeks I shall be doing a paraglide and hopefully raising some much needed funds for the Neuromuscular Centre in Winsford.

*Life is an adventure and one that needs living so that is exactly what I intend on doing.*

Traceyanne Pilato  
Copyright May 2009

## It's My Story cont.d...

I also had to give up playing the violin. Not such a hardship as I didn't particularly enjoy it. I was unable to keep my violin up and it made the orchestra look untidy according to our pompous Music Teacher.

One other rather ironic incident at school was in one of my more rebellious moments I etched my initials over an equals sign with the initials of my boyfriend ... later to be my husband... underneath. I have always been very conscious about my mouth and as far back as I can remember I've been picked on for it... not quite so these days...( thank goodness for Angelina Jolie and her fuller lips that's all I can say). Anyway my initials at the time were "T C" and my boyfriends "L P". The next time I went into that classroom some someone had inserted an "I" between the "L & P" and added an "s"..... T C = LIPS.

I spent the whole of that lesson scratching it out and fighting back the tears. I

grew to hate school and was really glad when it was time to leave.

While I was at school I had a part time job at our local Supermarket. It just seemed so easy to slip into the full time job when I left school. I worked on the checkouts and at that time there weren't conveyor belts you had to lift the shopping from one trolley to the next. With my shoulders getting weaker I was struggling with some of the larger items... 10lb bag of potatoes etc... I dreaded Christmas because of the fat turkeys I had to lift .

I got married at 20 and wanted to start a family at some point so I went to seek advice from my doctor who arranged for me to see a consultant. This was the first person I had seen in relation to FSH since my diagnosis. He hadn't got a clue about FSH and had never met anyone with FSH. I had to explain what I knew, which to be frank wasn't really that much at that stage. He examined me in a fashion, far more for

In one of  
my more  
rebellious  
moments

individuals in an area on chromosome 4 that is of a highly repetitive nature. Generally individuals carry between 11-100 copies of the same DNA repeat that is called **D4Z4**. People with FSHD have a deletion at this location and the number of copies is reduced to only one-ten copies. The remaining number of repeats varies between people with FSHD and the extent of the deletion determines the severity of the symptoms.

Although the mutation was first described 15 years ago, the scientific community is still in debate about the function of the DNA repeat and how the deletion of these repeats causes FSHD. Some researchers have found evidence that it regulates the activity of neighbouring genes without being a gene itself, others have found evidence for the presence of a gene within the repeat that actually produces a protein.

Professor Jane Hewitt's award is based on recently published results by her team which revealed that the repeat is present in other species including mice, rats and elephants. Which means that the DNA repeat has been conserved in this unusual form during millions of years of evolution which is generally only the case for

areas in the DNA that contain genes. Her findings support the idea of the presence of genes within the repeat and her theory is that it produces a protein that then regulates the activity levels of neighbouring genes.

During this project, funded by the Muscular Dystrophy Campaign, Professor Jane Hewitt plans to provide proof for the presence of a gene within this repeat. In order to confirm her theory she will test whether the deletion in people with FSHD leads to a reduction of the protein thought to be produced by the repeat. Her second aim is to identify the genes that are altered in their activity levels and produce more or less protein compared to people unaffected by FSHD. Her final interest is to investigate how this knowledge can be used to establish a mouse model of FSHD - an animal model would enable researchers to study the condition in more detail and to test the potential of possible approaches to treat this form of muscular dystrophy.

### *How does the Muscular Dystrophy Campaign allocate funding for research?*

The Muscular Dystrophy Campaign invests approximately £1.7 million into neuromuscular research each year. This research falls into four

## MDC Moving Forward cont.d..

year. This research falls into four main categories:

- Basic research, which seeks to understand muscle cell biology and what goes wrong in muscle disease.
- The development and testing of new therapeutic approaches in the laboratory.
- Clinical management projects, which aim to find the best way to manage the symptoms of muscle disease, for example with exercise therapy.
- Clinical trials to test promising new treatments in patients.

Researchers are invited to submit grant applications for research into any of the more than 60 different types of muscle disease that we support. Grants are awarded based on a strict international peer review system to ensure that only the best and most relevant research is funded and the impact of investment is maximised. Each grant application is scrutinised by either two or three independent reviewers who are experts in the field. Our own panel of experts (the Medical

Research Committee) consider the reviewers' comments and in turn recommend to the Board of Trustees which research to fund. We support project grants for up to three years and we have recently extended this to PhD studentships to encourage young scientists to enter the field of muscle research.

For more information about the Muscular Dystrophy Campaign's research programme please:

Call: [020 7803 4813](tel:02078034813),  
Email: [research@muscular-dystrophy.org](mailto:research@muscular-dystrophy.org)

Or visit our website at:  
[www.muscular-dystrophy.org/research](http://www.muscular-dystrophy.org/research)

## It's My Story... Tracey Anne Pilato

*By the age of 10* there were signs that not everything was as it should be. I had poor posture, was rather clumsy and tended to breathe through my mouth. During a medical at school my mum raised her concerns. I was then sent along to the local clinic once a week to do exercises which would hopefully improve my posture and breathing. Apparently I was just being lazy. I attended these classes for over a year. I hated them and felt really singled out.



When I was 12 my mum asked me to carry on painting a ceiling for her while she just checked on something. I just suddenly found myself saying "I can't, I can't raise my arms". After a trip to the doctors I was booked into hospital, where I had numerous tests ending with a muscle biopsy... then the diagnosis. I then spent a few days more in hospital being poked and prodded and feeling like the proverbial guinea pig. After the diagnosis my mum and I joined the local MD group. No one in the family had been

diagnosed with FSH before so I knew nothing about it and did not know what to expect. The only people I had contact with at the MD group were a few lads with DMD which of course made me really fear for what lay ahead.

My school were not informed which meant I had to attend PE lessons just like everyone else. I really began to struggle and was always the last to be chosen when teams were picked so I started to skip lessons. One day I got caught and was sent to the head mistress. When she asked why, I told her I had MD and couldn't keep up. I never had to attend another PE class.

Another incident at school was in an English lesson. I wasn't paying attention and the teacher shouted "Hey you, stop looking so gormless and pay attention"... because I breathed through my mouth people did tend to think I was a little gormless but to have him shout it out in front of a whole class was mortifying.