



FSH-MD Support Group UK

Newsletter 15: Summer 2010

25th Anniversary Edition

A word from the chair....



Welcome to our special 25th anniversary edition. My thanks to Martin Fielden for taking on the role of news editor.

The last twelve months have been very busy for our group; we have had the Autumn Get together in Oxford which saw eighty five members in attendance, and the recent "Mega Spring Get Together" held at the Holiday Inn, Haydock. This was our first full weekend venture but proved to be very popular with forty two members staying over for the whole weekend and twenty five more joining us for the Saturday day event and our 25th Anniversary evening dinner.

We now have two regional groups in the West and East Midlands, with further groups in the pipeline, and we've been invited to visit Northern Ireland and Scotland. Our membership has grown over the last twelve months and enquiries for information have increased significantly both from individuals and professionals dealing with FSH-MD. This is very gratifying and justifies our makeover and the cost of providing new promotional literature.

We will be having our usual stand at the MDC conferences in Birmingham and Glasgow so do please come over and say "Hello" It's the best part of being chair of the group, I do get to meet so very many nice people and it's great to be able to share your experiences of living with FSH-MD.

Enjoy the summer and I look forward to seeing you at the Autumn Get Together

Best Wishes
Karen

Our New Honourary Presidents

On Sunday 6th June we held a special lunch to recognize the work of our



founders Norman and Lorraine Jonas who set up the group twenty five years ago.

Along with their daughter Lisa, previous chairs and some of the first ever members, we presented Norman and Lorraine with engraved glassware and flowers on behalf of the group. Norman and Lorraine laid the foundations so that today we are able to continue to offer *Support-Information-Encouragement*

The early days

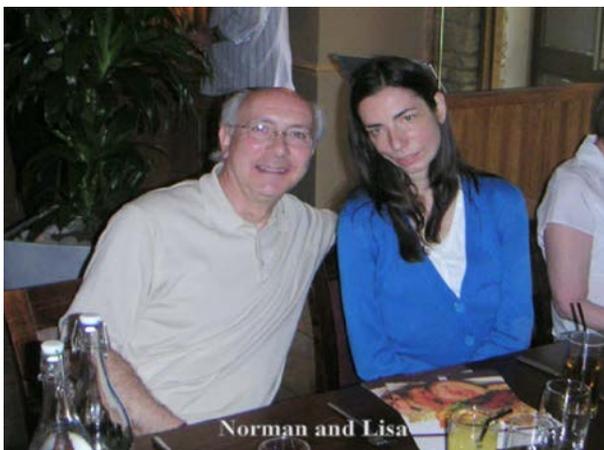
The seeds of the support group were established by Norman and Lorraine Jonas in the 1980's after their eldest daughter Lisa was diagnosed with FSH-MD in her teens. With no other known members of either Lorraine's or Norman's families showing any signs or symptoms of FSH-MD, the diagnosis came as a big shock.

At the time of diagnosis, Lisa was finding it extremely difficult to lift her arms above her head; she was unable to close her eyes tightly or use her face muscles to smile.

....."The only information handed to me at the time of diagnosis was a small article from a very old medical journal" Lorraine.

The group was setup with the aim to enable people with FSH-MD and their families to meet and share experiences, to find out more about research into this Particular type of muscular dystrophy and to help people come to terms with a diagnosis of FSH-MD and also to publicize the group so that others with FSH-MD know that they could contact us for support.

...."I wanted to find out more about this condition and help Lisa to meet other people with FSH-MD, I felt the best way to go about this was to start a support group". Lorraine



Present and Future.....

Although Norman and Lorraine have now retired from the running of the support group they still keep in touch to stay up to date with latest happenings.

In July 2009 the group underwent a major makeover to bring it up to date and to widen its appeal. Armed with a new logo, promotional material, a re-launched newsletter and website the group continues to offer:

Support - Information - Encouragement

September 2009 saw the launch of the West Midlands local group set up and run by members who meet up for social occasions and outings. This was followed by the East Midlands group who met for the first time in April 2010

In February 2010 the committee produced the group's first constitution May 2010 saw our second Spring Get Together at the Holiday Inn, Haydock, Merseyside this was our first weekend event. The aim was to give members more time to socialize and allow a greater range of topics over the two days. The weekend also included our special 25th Anniversary dinner.

With requests to help set up groups in Northern Ireland and Scotland the support that our groups offers seems to be in more demand than ever so here's to the next 25 years

"We have a shared belief that we are stronger through working together"

(From MDC memorandum of understanding)

Spring Mega Weekend Get Together Haydock May 2010

“Yes, it was the Spring Get Together And 25th Anniversary Dinner”

If you weren't there the chances are you may have thought “Spring Mega Weekend Get Together”, that's setting the bar pretty high. However, I was there with my wife Gill and I can report that the imaginary bar was well and truly cleared. The whole weekend was excellent with a very varied programme, something for everyone really. The Holiday Inn venue in Haydock seemed to suit everybody's needs very well and it was handy being so near to an M6 junction.

The weekend had a relaxed, unhurried feel which suited this particular FSH'er very well! Having the event spread over the weekend gave us all more time to get to know each other. For me personally, this was probably the highlight of the Get Together, having the time to chat to others, find out how they are coping with their lives and exchanging tips, thoughts, feelings, etc. The feeling of positivity that came from everyone I found very inspiring and I certainly took that away with me, it will help me in my own life.

The balance of activities was 'spot on'. Useful information from Nic Bungay on MD campaigning, telling us how successful it has been and how we can all 'get involved' in the future – fancy being a media star? Now's your chance! Matthew Lanham from the Neuromuscular Centre in Winsford gave us the low-down on what goes on there.

Gill and I made a visit last year; it is an excellent facility and well worth at least one visit. It was interesting to hear that the biggest number of referrals to the NMC come from us FSH'ers.

Claire Kelleher from MDC gave us the opportunity to take 'The Wheel of Life' which showed us which areas of our lives we might want to address.

Image Consultant, Martine Alexander who advises 'the stars', gave us a fun presentation entitled 'Look Good & Feel Good'. This gave both females and male's tips on how to dress according to their particular body shape, to look and feel good about themselves. I now know what spanx are!

Sue Manning (great surname!) a Specialist Neuromuscular Care Adviser with MDC, gave a very interesting, informative and thought provoking presentation on her role.

Outside of the main meeting room it was possible to view a range of wheelchairs, presented by Jennifer from Permobil, and a range of Active and Passive Therapy Exercise Equipment, presented by Pete from Medicotech.



Andy Findlay – Vice Chairman

Spring Mega Weekend cont....

On the Saturday evening we had our special 25th Anniversary Dinner, yes our Support Group has been going for 25 years, since being first set up by Norman and Lorraine Jonas.



The evening was great fun with good food, wine, conversation, raffle, silent auction, and live music from the very talented Robin Surgeoner and Georgie Edwards.



Georgie Edwards

I can't thank Karen and the FSH Group Committee enough for arranging this weekend, especially at such a good value for money cost to each attendee, also a big thank you to Louise Bayliss who did such a great job as MC for the weekend and kept us all smiling.

I shall look forward to attending another 'Mega Weekend' some time in the future.

Geoff Manning

New East Midlands Group



The East Midlands Regional group met for the first time on Saturday 12th April at the "Old Vicarage" Public house, Whetstone, Leicester. Fifteen members enjoyed the warm sunny spring day. They were treated to fine food and excellent company. For further information on future events or to join the group email Sheila-fsh@hotmail.co.uk

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 FSH-MD 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

Our Thanks to:

Alan Young Who cycled from Edinburgh to Gibraltar, Alan raised over £1000 to be divided between us and the MDC

Elle Browne organized a non uniform day at her school and raised £500

Our Thanks also to

Manchester United Football Club

Who kindly donated a signed shirt which we auctioned at the anniversary dinner and raised £95.



Margot goes to Parliament in Fight over patient care

Courtesy of This is Derbyshire
Thursday, January 14, 2010,

A MUSCULAR dystrophy patient from Derby will visit the Houses of Parliament to demand more local services for people with the condition. Margot Keats has been invited to give evidence to a group of MPs on Tuesday about care available in the East Midlands. The same group of MPs published a report in August last year, which raised a number of concerns about regional NHS services for people with the muscle disease. Now the All-Party Parliamentary Group on Muscular Dystrophy wants to know whether improvements have been made.

Mrs. Keats gave evidence to the MPs last year and the group also heard evidence from her brother, Andy Findlay, of Stoneyhurst Court, Shelton Lock. The Derby Telegraph reported in October that Mr Findlay was calling for a specialist muscle centre in the East Midlands. Mrs. Keats said that would be one of the issues she raised at next week's meeting.

She said she would call for more spending on preventative care to ensure that fewer people needed to be taken into hospital for emergency treatment. Prevention would be cheaper than emergency care, she said.

The 62-year-old, of Evans Avenue, Allestree, said: "I'll be calling for a muscle centre with specialists who know about the condition and could offer information and diagnosis."

Representatives of the East Midlands Specialized Commissioning Group, which pays for specialist NHS services in the region, will also be at the meeting.

Nobody from the group was available for comment. Last summer's report called for an urgent review of services for people with muscle conditions across the East Midlands and for an NHS staff member to be responsible for the development of services. The call came after MPs found children in Derby with muscular dystrophy faced an average six-month wait for powered wheelchairs.

They also learned the East Midlands only had one regional care adviser to support muscle-condition patients – a post paid for by charity The Muscular Dystrophy Campaign. Last summer the charity warned it could not afford to continue funding it.

Nic Bungay, head of policy and campaigns at the charity, said some improvements had been made but argued that more were needed.

He said: "The NHS has agreed to fund the post of the regional care adviser. But having one care adviser simply isn't enough. The south west, which has a similar size population, has five. Our evidence is that provision of powered wheelchairs hasn't improved."



It's My Story - My Scapula Fixation



Hey! I'm James Morrison, born 9th December 1987 in Florida, USA. I grew up in Peterborough,

Cambridgeshire. I first noticed obvious signs of FSH when I was 16/17 years old when I was beginning to lose a lot of muscle mass despite doing intense weight training. I was finally diagnosed with FSH muscular dystrophy in the summer of 2008 when I was 20 years old. It was a big shock as there is no family history. I am currently at the University of Bristol studying dentistry.

My symptoms are relatively mild. Scapular winging is the only thing that affects my everyday life. In February 2009 I had just begun dental clinical training which is when I noticed the scapular winging was becoming a problem with regards to dentistry. I found it quite difficult to work for long hours with my arms raised. I made the decision to suspend my studies for a year and began looking for a surgeon who could perform scapular fixation.

Being a dental student I am medically minded and I have thoroughly researched scapular fixation and the science behind FSH since I was diagnosed in 2008. I did not need any persuasion when deciding to go ahead with scapular fixation, I knew what it was about and I definitely wanted to get it done. After attending the FSH spring get together on 4th April 2009 I was put in contact with an experienced orthopaedic surgeon.

I met the surgeon in May. He explained to me the procedure, recovery process and possible risks involved.

The surgeon understood that I had been looking into the surgery for a long time and I already knew what I was getting myself in for so we got straight into signing the paperwork.

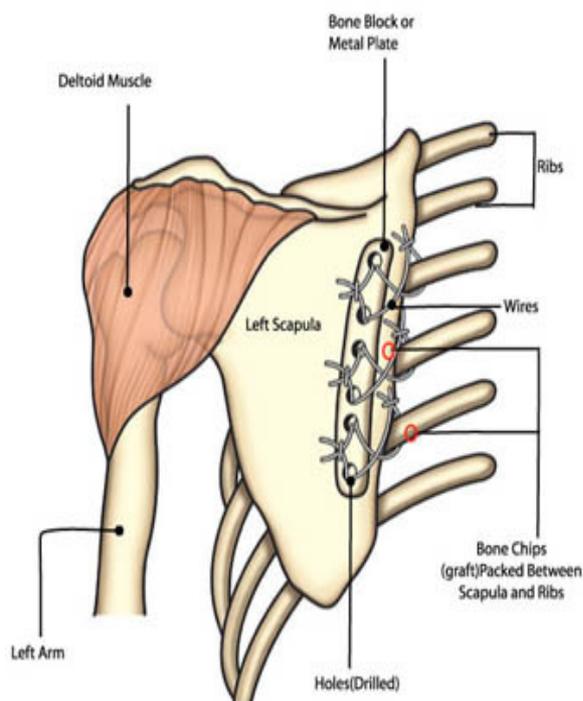
I had the first operation on my left shoulder on the 21st July 2009. My recovery was relatively painless, though I do have a very high threshold to pain, similar to my Dad and my Brother. The hospital looked after me with all the necessary pain killers. I spent 3 days in hospital. On the 2nd day I was put in the upper body spica cast that would keep my operated arm at 90 degrees to my side for 7- 8 weeks. At first it was a little weird and uncomfortable. I felt smothered and restricted but over time you just get used to it. I left hospital on the 3rd day after my surgery.

Whilst at home I spent most of my time on the sofa. The spica cast makes it very difficult to sleep in bed on your back so I decided to just sleep on the sofa up right with my feet up. Now and again I would walk around just to loosen up and get a change of scenery but the sofa very much be-came my home. The week after my surgery the pain was bearable; I was taking less pain killers by then. If I coughed or made a sudden movement I felt a sharp pain. The weird thing is the pain is in the ribs on the side rather than the scapula at the back.

It's My Story Cont.....

You will need someone there for you just to help with odd things. Getting up the stairs, cutting your food, putting on clothes, is all very difficult when you're in a spica cast with only one arm accessible. Unfortunately I had complications with the surgery. A week after my surgery I had to go back into hospital after getting pneumonia (infection) in my left lung. Because I am diabetic I am more at risk of getting an infection. It meant I would be in hospital for 5 weeks having chest drains and antibiotics. The infection developed into an Empyema (collection of pus in the pleural cavity of the lung) which meant I had to undergo decortication surgery on my lung in Leicester at the start of September. This meant that my spica had to be removed 2 weeks early. I was only in hospital for 3 days after the decortication. The surgery solved my lung problem completely and I was back to good health!

When the cast was removed I could barely move my arm at all. My brain wasn't connecting with my arm. At first I was quite worried that I wouldn't get the mobility that I hoped for. I then had a week of intense physio. I didn't enjoy the 8.30am starts but the physio was absolutely amazing! I did sessions in the hydro pool and in the gym. Day by day my arm was moving better. By the end of the week of physio I could move my arm above my head, which I could never do before my surgery. It was a great feeling to move my arm so freely with no restriction.



After the physio I continued to do the exercises for my shoulder. The shoulder doesn't feel painful when moving my arm above my head. It did ache after days involving a lot of movement though. This is understandable as the arm is getting used to physical activity. After a couple weeks out of cast the shoulder was painless with no aching. The shoulder blade looks a lot better as it is flat to my back now. My scapula doesn't dig into the back of chairs or stick out through my t-shirts so I am happy with the way it looks.

It's My Story (cont).....

The scar is quite big though, but it doesn't bother me. I also have a scar on my lower back where the surgeon took a bone graft from my hip.

Overall I am extremely happy about the results. I am planning to get my right shoulder done in January 2010. I was very unlucky to have the complications with my lung. Having diabetes puts me more at risk of infection. If you have a condition such as diabetes this is something to consider but I hope I haven't put anyone off, I was just very unlucky! Despite the complications the recovery was relatively painless and not as bad as I imagined it to be, though people are very different when dealing with trauma. I recommend the surgery to anyone considering it.

When considering the surgery you should take your time with the decision and not rush into it. I spent a long time researching the operation and I always had it in the back of my mind that I wanted to get it done. When I noticed the scapular winging affected my ability to perform in dental clinics that just enforced upon my decision to get it done. The ability to perform overhead activities is not an essential thing in life but reaching up to tall cupboards, holding my phone to my ear, washing my hair etc are all things I want to do, as does everyone. On top of this my career would be greatly improved by the operation. Also the way the shoulder blade looks when it wings out is not nice and has a big impact on my confidence.

I'm sure a lot of people considering the operation (especially girls who wear backless tops) share this opinion.

With all of these reasons combined I was 99.9% sure I wanted to get this done and I don't regret a single thing about my decision. Even if you just have one small reason I would still strongly consider the surgery if it will give you what you want in life.

I hope this article has been useful for people making decisions regarding scapular fixation. I understand it is very difficult to get people's opinions about this operation as it is rare. If you have any further questions feel free to email me:

morrisonusa@hotmail.com

I'd like to thank the medical team at Oswestry for their hard work and support. They were absolutely fantastic and I couldn't have asked for better medical care.

James Morrison



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

The “Seat to Stand” lifting device

For those of us still able to walk (albeit with limitations), but who struggle to stand up from a seated position, I have found an adaptation which I find particularly useful/essential. The ‘seat to stand’ lifting device has helped me get out of the car and allows me to stand-up in the house.

Initially I had a demonstration of the car version by the manufacturer KC Mobility of Keighly near Leeds. Although it took a little getting used to, I was soon able to transfer onto the small platform then rise to a standing position. This significantly extended my period of independence, the biggest problem had been the effort required to get upright. The fitting in the car is very discrete and can easily be removed when you happen to change cars (although new fitting brackets would be required for a different model of car). I soon realised this same device would be useful in the house where I was having similar problems standing up. Existing ‘riser’ chairs were no use to me as they just pushed me up and forward but did not allow me to lock my knees. The KC Mobility version is different in that the lifting platform remains flat and lifts to whatever height is needed to lock the knees (some form of handle or post or person may be needed to help get straight - the riser leaves you upright but very slightly leaning back). KC Mobility normally only supply this device for the car but after a short discussion they agreed to customize one for use in the house.

(supply only, but it only needed bolting to a solid wall and plugging in) – it’s surprisingly compact.

I also fitted a couple of handles to help my stability and to pull me vertical. So far it has been a great success, without it I would now be off my feet. The only downside is I only have one! It is fitted in the bedroom, so I have to move back through the house on my garden stool, I then transfer to the platform and it lifts me to a standing position. The costs for both the car and house versions were about £1,300 (the car version included fitting). I would strongly recommend both versions, KC Mobility have their own web-site and it is well worth having a discussion with them. www.kcmobility.co.uk

Ian Walker



South West Neuromuscular Network

South West Neuromuscular Network

Do you live in Isles of Scilly, Cornwall, Devon, Dorset, Somerset, Wiltshire, Gloucestershire, Bristol, Bath or North East Somerset? If so the new neuromuscular network set up by the South West NHS Specialized Commissioning Group could be of interest to you. The aim of the network is to improve the level of medical and social care offered to people living with a neuromuscular condition and to work in partnership with them, their families and local professionals. The new network is developing regional clinics run by specialist neuromuscular consultants supported by physiotherapists and a team of Neuromuscular Advisors (Tamsin Coade, Louise Gethin, Carla Spreadbury, Jan Smith and Jane Stein).

The Neuromuscular Advisors are also able to visit families at home to discuss practical and social issues, and can liaise with local professionals where appropriate. The network is managed by Jennie Shine, a nurse with over 30 years experience. If you would like to be included on the database of neuromuscular patients and be part of the new network or if you have any queries please contact Jennie Shine on 01173302597 or email jennieshine@nhs.net



Editors note.

All published articles reflect the views and opinions of the contributors and not the FSH-SG committee. The editor welcomes contributions (in Word format) and photographs (in jpeg format) which should be sent to:- martin-fsh@hotmail.co.uk as soon as they are available. Editing takes time!

Martin

Dates for Your Diary 2010

July

1st, 2nd, 3rd **The Motability Road show**
East of England Showground Peterborough

September

18th **MDC 2010 Annual Conference**
Hilton Birmingham Metropole NEC

October

2nd **MDC 2010 Scottish Conference,**
Beardmore Hotel, Glasgow.

October

23rd **Autumn Get Together**
Holiday Inn Gloucester/Cheltenham
(Please see enclosed booking/info pack or download a booking form from our website)

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