



NEWSLETTER

Spring 2015

Issue 25

A MESSAGE FROM THE CHAIR

IN THIS ISSUE

Liz Williams, Chair FSH-MD
Support Group



Dear Members, this issue focuses particularly on Scapular Fixation with articles from 2 members who have recently undergone the procedure. There will also be an update on their progress in the next issue. This is a must read for anyone considering the procedure, there is also data available from the UK FSHD registry. If anyone would like to share their post-operative experience in the next issue, please contact me via email: fshgroup@hotmail.com.

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FSH-MD Support Group Facebook page

Scapular Fixation

Note from Liz Williams, Chair FSH-MD Support Group UK.

This issue of the newsletter focuses on the procedure for scapula fixation. The FSHD patient registry for the UK is able to translate the data given by participants and Libby Wood, Curator of the FSH patient registry has very kindly written an article for us along with 2 support group members who have recently undergone the procedure. This may be particularly useful if it something you are considering, to enable you to make an informed decision about the procedure together with advice from your Neurologist and Surgeon. As Libby Wood states in her article, all information should be treated with caution, we cannot advise this is the right decision for you, it is entirely a decision to be made by the

individual and there is no absolute guarantee that a scapular fixation will improve your quality of life.

I must take this opportunity to thank everyone who has given of their time and been so generous with their experiences to enable us to get this information out there. There are also other articles on our website fsh-group.org from members who underwent the procedure. We are not Medical Professionals, just a means of getting information out to our members so please bear that in mind when reading our articles. There are members who have found the scapular fixation procedure to be beneficial there are some who have not. This topic is here entirely to inform members of the enormity of the procedure, the post-operative experiences and documented eventual outcomes. We will have updates from our two contributors with regard how they feel the operation went in our next issue in the Autumn.

Please also see:

www.fshd-registry.eu/org

www.fsh-group.org

<https://www.fshd-registry.org/uk/>

FSHD-registry

Scapular Fixation Data

Article from Libby Wood, Curator FSHD Registry (UK)

The UK FSHD patient registry is a tool to help research. It is a database of information about people living with FSHD in the UK; anyone with a genetic diagnosis can sign up online and complete a number of questionnaires. This includes information about how FSHD affects you along with some more specific questions about pain and quality of life. We hope the registry will be useful to help researchers plan and recruit into clinical trials in the future.

The registry can also be used to collect and feedback information. One of the areas we are interested in doing this is around scapular fixation. Scapular fixation is a surgical procedure which fixes the scapular (or shoulder blade) using wires or screws. This is often performed when the muscles that normally keep the shoulder blade in place have become weak.

Many doctors find it difficult to provide advice on this procedure because some people benefit and others experience a lot of side effects. As part of the registry we have asked people who have had the operation about their experiences and this has been completed by 38 people. Twenty six people reported they were happy with the

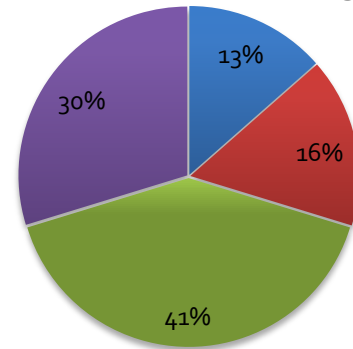
outcome and 24 would recommend the procedure to others. A number of side effects were reported including an increase in muscle wasting and experiencing sensory loss particularly in the hands and fingers.

Overall there was an improvement in the ability to raise the arm which was sustained one year after the surgery and on average 15 years later. Little change in rotational ability was reported within the first year but this seems to decrease over time.

It is important to note the data mentioned here should be treated with caution. Everybody completing the questionnaire has had a different experience, some having the procedure over 30 years ago. The best advice to anyone considering the procedure is to discuss with a neuromuscular consultant and find a surgeon who is experienced in performing scapular fixation.

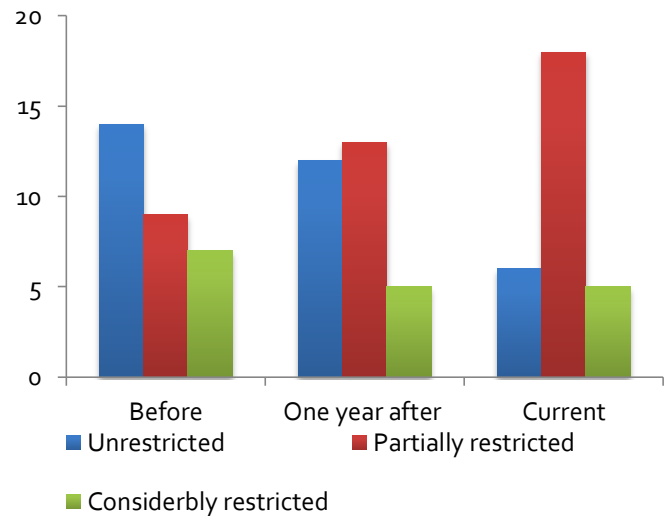
You can find out more about the registry and take part at

Are you happy you underwent scapular fixation surgery?

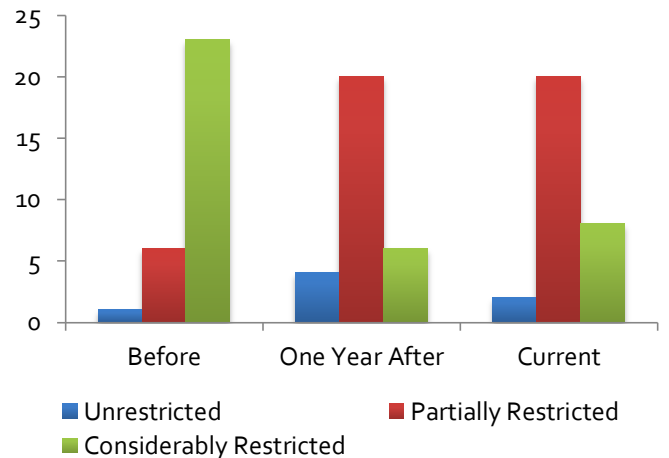


■ Very Unhappy ■ Unhappy ■ Very Happy ■ Happy

How would you describe your ability to rotate/twist your upper body?



How would you describe your ability to raise your arm above shoulder height?



My Scapular Fixation Story with a Sling.

By Anonymous

I was diagnosed with FSHD in my mid-twenties. I had initially presented with winging of the scapula on my dominant side. Up until this point I was very active and had no other problems (apart from the usual tell-tale signs in retrospect).

After the initial shock of diagnosis and a whirlwind of appointments, I decided that scapula fixation was definitely an option for me. I was finding things like reaching for a cup in the cupboard an ordeal, my bra straps kept falling down and I found the shoulder unsightly. All of these annoyances added up and grated on me. It was certainly not how I wanted to live. My Neurologist referred me to a surgeon in the Northwest who had trained under Dr Levy at the Reading Shoulder Unit.

I had some reservations. One of my questions was whether I should wait until it was an absolute necessity as it was a large operation. However, the Surgeon asked "why not experience the benefit now rather than struggle on for another 5-10 years?". He also believed whilst I had restrictions, the mobility of the joint was very good and it would be easier to manoeuvre into the correct position. If I waited I may develop stiffness causing the fixation to become trickier.

He performed a quick test by holding my shoulder blade in place and then asking me to lift my arm. I almost hit the ceiling with complete ease and this was a very good sign that it would be worth it. I was sold and signed the consent forms.

8 weeks later I was being admitted for surgery. I was chatting away in the anaesthetic room and before I could count to ten I awoke in recovery. I was attached to an on demand morphine pump as planned and although I was drowsy and very thirsty I was comfortable.

The procedure I had involved wires, plates and bone graft from my hip. For immobilisation I didn't have a spica cast as many seem to have but what I can be described as two duvet sets up my arm and then a sling (see photo). These would gradually be removed over the next 6 weeks. I had a few hiccups in my recovery over the next couple of days. I had a sensitivity to the morphine and so had to be put on a restriction for a short while, which was very uncomfortable. I was on a manual bed with no bed rails and therefore trying to mobilise with one arm and a hip wound was near enough impossible. I also didn't think through my choices of clothing properly.

I had to stay in hospital over the weekend and was eventually released after having made adjustments to

painkillers by Monday. I went straight to my sister's house where I would be looked after.

The first week was a slight blur. I said goodbye to my social life and set up camp in front of Netflix. I tried to read however my concentration was pants due to the painkillers!

The first few weeks were quite tough. I am a person who is used to being constantly active and being restricted was a big adjustment. Doing something as simple as having a wash became a tiring ordeal for the first week at least. It quietly started to get easier and now 5 weeks in I'm pretty much independent apart from hair straightening and cooking:/.

The pain I had seemed to be related to the hip and the ribs rather than the actual shoulder wound. I was worried about sleeping on my back but I slept well. Now the pain is minimal I have to remind myself not to throw myself all over the bed. Unfortunately, I had a setback with the pain when I got a cold and coughing was not pleasant but that has resolved.

So all in all I'm doing pretty well, I start physiotherapy next week and I'll start swimming to get myself back into shape.

Has it been worth it so far?

Hard to say so soon but one thing I noticed straight away is that I look much better! The "ache" has disappeared. It's also a great confidence booster when people mention that even though I'm in a sling my posture looks much better.

I start physiotherapy soon so I guess we shall know then, and I will update my progress in the next Newsletter in the Autumn.

My new accessory:



My top tips things to consider are:

1. **Ladies, Step in boob tubes and strapless bras**
2. **Ask whether the hospital will be able to provide you an electric bed or bedrails at a minimum**
3. **Make a pain management plan with your anaesthetist**

4. **Remember it isn't just your shoulder affected; it's your hip as well so make sure you'll get some decent support at home or if this is lacking let the hospital team/GP know.**
5. **Get the Surgeon's secretary's telephone number before you leave the hospital, just in case there are any issues that may arise post-discharge, it is unlikely your GP will have the knowledge required.**
6. **Relax and don't try and do too much in the first few weeks. Things will tire you quite easily. On the other hand do try and mobilise often for short bursts. I found walking around the house every hour stopped me getting stiff and sore.**
7. **If you watch a comedy or you have comedie company, position yourself against a hard surface because laughing hurts in the first 2 weeks!**
8. **Not an issue for me but smoking massively delays bone healing. So quit prior if you can.**
9. **I booked a holiday with friends the night before surgery to keep me looking forward and positive, make plans to do something you love!**
10. **If possible try and have the surgery early in the week Monday-Wednesday, any later and you risk getting trapped over the weekend with inexperienced On-call doctors (For this type of surgery at least)**

To be continued....Autumn 2015.

My Scapular Fixation Story with a Body Spica

By Rashmi Makwana

Hi my name is Rashmi Makwana and I was diagnosed with FSHD in 2007. The symptoms started slowly, just tripping up and having falls. After visiting a number of consultants the doctors at the National Hospital, Queens Square, London confirmed the condition. The progression at the start was relatively slow but then it picked up with more and more muscles becoming wasted and fatigue increasing. I was medically retired because things just got too much. I started getting a lot of pain in my left shoulder and it became very difficult to raise the arm. After some consultations with the consultants and Dr Higgs (who is superb) at the National Orthopaedic Hospital in Stanmore, we came to the conclusion that the

shoulder blade had started 'winging' and an operation would be necessary. I did not know what I was really letting myself in for but agreed to go ahead with the surgery and had my left shoulder fixed to my rib cage in 2013. However, this became a bit of a learning curve for me and there were a number of issues we had after the operation that should have been put into place before the operation so when I had my second operation I had learned my lesson and this was my experience:

When they operated on my right shoulder I had opted for a full body Spica which was made two weeks before the operation. This Spica was made of a fibreglass sort of material and very rigid, it also weighs about 7-8 kilos, it does not flex and you are not allowed to take it off for at least three months.

The Body Spica

As mentioned the weight is around 7 kilos and you have to bear in mind that this becomes part of your body for three months. You have to walk and sleep in it so you have to be fully prepared for it. You have to consider your level of strength and your fatigue levels and would make it a lot easier if you are in a wheelchair. For me, even though I have an electric chair when going out, I was almost housebound because even moving around in it makes you tired. When you have the Spica made you have to ensure that you tell the specialists if the Spica is a comfortable fit and to ensure that it is not rubbing against your skin as it will become hard to alter once made and they put the cast on whilst you are sedated.

Consultation and Physiotherapy

Ensure that you discuss all the details with your consultants before the operation so that you are fully prepared for what is to come. The main discussion has to be Physiotherapy. I had a number of problems with my first operation so this time around I made sure the this was discussed. We had agreed a plan that I would get physiotherapy soon after my operation. If you notice on the attached photos



the top part of the Spica on the arm comes off and I think it is important to have deep tissue massage done, this will ensure that the arm does not get too stiff. I had also got in touch with my Community Physiotherapist and this was done in advance so that they were aware of my requirements and the dates of when the operation was scheduled. So as soon as I was discharged from the hospital I had a Community Physiotherapy Team come around at least twice a week. I think I have been very lucky to receive this level of service but that has been a great help. After the Spica was removed the Physiotherapist at the National Orthopaedic Hospital got in touch with the Community Physiotherapist and a plan of action was agreed. I still get the local Physiotherapy Team come around and they have been working my arm and I have a got a good range of movement already. However, I feel the key to the rate of recovery is dependent on how the FSHD has already affected you. The bicep in my right arm considerably wasted and added to that the arm had not been moving for three months I have a great deal of difficulty in bending my arm at the elbow and this is something I feel that you should discuss with the consultants so that you are prepared.

House Adaptions

Just before my operation I had some major adaptations made to the house which included a through the floor lift. Both toilets converted to wash and dry bidets. As soon as I came out of hospital I was able to move more freely around the house. I would not have been able to climb the stairs and would not have been able to go to the bathroom to have a wash. This is another thing that you need to be aware of because of the Spica you can only have a strip wash and you will be dependent on someone else helping you. In my case I have a carer but you have to be prepared to lose part of your dignity. The two toilets also made a difference because after the operation I have not been able to reach round to my back hence the electric bidets have been brilliant. These adaptations do not come cheap and if you can get some help with funding these (I didn't) try getting this sorted out before your op. You also have to consider whether you are right or left handed because this will have a major impact on your day to day activities if it is the dominant arm that is being operated upon.

To summarise you may think that reading this it is all doom and gloom, but regardless of all the above I think I made the right decision of having a fixed Spica. I am the sort of person who cannot sit still and if it had not been for the Spica I would have had a tendency to

move my arm around and that could have impacted on the recovery. You also have to remember that this is a major operation and by having the Spica I believe it gave my back a good chance to heal and for the fusion to take place. Regardless of all the negative points I think I made the right decision but you just have to be prepared for what's in store. I would also like to say a big thank you to all the staff at the Royal Orthopaedic Hospital at Stanmore and my Community Physiotherapy Team who have been working with me.

I do hope this article has helped but if you require further information you can contact me via the fshgoup@hotmail.com and mark emails for the attention of Rashmi.

FSH Registry Update

As our facebook users will be aware we intermittently remind our members to sign up to the FSHD Registry UK. The number of people registered has now reached the milestone of 500 and I know that Libby Wood, Muscular Dystrophy UK and ourselves are incredibly grateful to everyone who has taken the time to complete the online questionnaire.

Again, we would encourage you to register your details if you have not already done so. If you can please follow this link or cut and paste to your browser: <https://www.fshd-registry.org/uk/>

There is no other definitive way of knowing how many people there are with the condition diagnosed so all this data is incredibly helpful for many many reasons.

Liz Williams

FSHD REGISTRY | THE NETWORK

UK FSHD Patient Registry

To help advance the research and development of treatment, therapies and care for all those diagnosed with FSHD.

[Register now](#) [Login](#)

- More information for participants and their families
- More information for professional users

There are currently 500 patients registered in this database.

The registry is funded by the **Muscular Dystrophy Campaign** with support from the **TREAT-NMD Alliance** and **MRC Centre for Neuromuscular Disease**.

Muscular Dystrophy Campaign | MRC Centre for Neuromuscular Disease

FSHD Teens/Young Adults (& other MD friends)

Below is an article from Nicky Williams Dexter who has set up a facebook group for Teens and Young Adults living with FSH. FSH-MD Support Group UK has links with other Groups within the facebook community worldwide. If you are a teen or young adult and would like to get in touch with others then the FSH-MD Support Group UK would encourage you to join FSHD Teens and Young Adults on facebook. Here is Nicky who lives in America to explain how the Group came about and why.



When the groups on Facebook were just starting and there were only a couple, FSH-MD Support Group UK and FSH Friends, the topic of other possible groups came up in conversation. Every time I would say the same thing, "I don't want to be a moderator, nor make a separate group. The only other group I believe should be made is a teen and young adult group. But a young person needs to be the one to start it." I would say this over and over and do nothing about it. Then one day Carden Wyckoff decided she would go ahead and make this group I had been advocating for, and added me to help her start to fill the group.

At first I held back, never saying anything, just trying to collect the youth. Then one day I just decided I was going to do everything I could to help these amazing young FSHers to connect and share their story with one another. Even if they weren't ready to talk, or share, I wanted them to have that sense of community by just going down the list of members and seeing teens and young adults just like them with FSHD.

You might ask me why it was so important to me; a 37 year old woman with FSHD to encourage the youth to make a teen and young adult group for younger FSHers, and help them connect with one another. And I would tell you that unless you had progression during your school years you will probably not understand why it makes a difference. Why it is a completely different experience than someone getting weakness in adulthood and middle age. When you are a teen in middle school and high school dealing with all the average stuff you have to deal with, and then on top of

that figuring out your way through your disorder, it is a hard place to be in.

I grew up in a family that has had FSHD for generations, but still felt no one could relate. It was a different time and I was different. Even though my aunt struggled in school, it was not the same. Her experiences did not connect with mine. I remember waiting on the Quest Magazine every time it came in the mail hoping there was someone in there like me wanting a pen pal (pre internet). During this time the Quest was the only time we would see experiences we could relate to, and they were very limited.

Even though I had people around me that could relate to the FSHD, I still felt lost. No one really knew ME. Not my friends, not my family; they all just got a little piece of me, but no one really knew what it meant to be 16 and using a wheelchair and planning a future that was more vast and unknown than any of my peers. They could all guess at what that meant, but no one ever knew.

I always felt, if I had just one person that was my age and knew what it meant to have FSHD I would be so happy. And now, because of this group, so many young FSHers have that opportunity. I have tried so hard to look far and wide to help bring the young FSHers all together. And that was no easy task. A lot of young people look to other social media for an outlet other than Facebook, so I have tried to find them everywhere from Youtube to Tumblr to Twitter & Instagram. I have tried to help bring people in little by little, or leave posts on other M.D. groups or sites, to allow them to find us.

We have been a group for two years now, and finally have over 100 members. The members range from 13 yrs old to 28 years old. But it seems the average is 15-24. The group talks about trying to stay active, difficulties on college campuses, how to deal with large books and the best book bag options. This is why it's important for the youth to have their own place to talk about the issues that affect their lives, which are completely different from what is discussed in the other groups. I'm so glad I decided to help build and grow this group, and now finally it can stand on its own! It makes me feel great to know if there is one young person out there that doesn't feel alone, the group is doing what it is supposed to do. If you would like to join us, please look for a closed group on Facebook entitled:

FSHD Teens and Young Adults (& other MD friends)

By Nicky Williams Dexter.

Find FSHD Teens and Young Adults (& other MD friends) on



FSHD Teens/Young Adults (& other MD friends)

Article from Ricky, FSHD Teens/Young Adults

Hi my name's Ricky, I'm 26 years old and suffer from FSH muscular dystrophy. I was diagnosed at around age 15. It came as quite a shock as I had blood tests as a child and they came back negative. FSH runs in my family so in some respects it didn't come as a surprise. I had real difficulties dealing with my diagnosis, I was a skateboarder and the prospect of not being able to skate when I get older really got me down. I had scapular fusion when I left school aged 16 and then again at 17. After having it done I never really picked up skateboarding again as I never felt safe riding it, I still did it up until I was about 18-19 but I never pushed myself to try new tricks.

It was around this age that I began to notice deterioration in my legs. I found this harder to deal with than my surgery. It felt like my freedom was being taken away from me. I found it hard to explain to mates that I couldn't do the things I used to but after a while they began to understand. Having good understanding friends is one of the things I've really appreciated since my progression with FSH sped up. For the next 5-6 years I began to slip into depression, I was always worried about the future and what it would hold for me. I was worried about my life getting worse and couldn't stand the thought that life would get worse than it currently was.

It was around this time that I found various groups on facebook that had other people with my condition in, these include living with FSH, FSH friends and FSHD for young teens and adults. It was in the FSH for young teens and adults that I found people I could relate with, even though I'm no

spring chicken anymore. I asked any questions I wanted and could talk about anything I liked as the group was closed to outsiders. This meant I could discuss private matters that I wouldn't want to discuss with my regular friends, even though they are very understanding and always have time for me there is just some things that they don't understand

One of the questions I'm really glad I asked was how they dealt with depression and the fear of the future. The answers I received have changed me as a person. A lot of it is mind of matter and it's best to try to remain positive and optimistic. Obviously this is easier said than done but it takes more energy to be negative than it does to be positive. I began to count my blessings in life. I look at life and think it can always be worse and that there are always people worse off than yourself. I noticed this in the group as there are some people who are younger than me and their condition has progressed quicker than mine. Now 18 months on I have a new outlook on life, I live for the now and make the most of my time on this earth. Life has its ups and downs but if you can remain positive it will make life much easier.

Ricky.

Thank you to Ricky and Nicky for the articles regarding the facebook group aimed at teens and young adults. The FSH-MD Support Group UK has links with various groups within the facebook community. I honestly learn something every day popping in and out of the groups. There are some truly wonderful people online who take the time to share their experiences in the hope that it will help others in some way. We can only cram so much information into a newsletter, so to keep up to date with events and various meetings and exhibitions, or just "lurk" and read how others cope and live with the condition I can thoroughly recommend interaction on the facebook platform. If you require information regarding anything from holidays, to accessing services then a quick question on the group most suited to your personal circumstances or preferences will usually procure advice from those who understand best. Liz Williams

FSHD-Europe

By Gill Penny, Secretary FSH-MD Support Group UK

On the 21st April I flew out of Luton to take part in a 2-day strategy meeting of FSHD-Europe. I was excited but a little nervous as this was the first opportunity I'd had to meet other members of the Board since I'd joined as the committee representative of FSH-MD Support Group last Autumn. Previously, I'd only communicated with them via telephone meetings but this time I was meeting them face-to-face. What would they be like? I needn't have worried – everybody was very welcoming to me as the newcomer, and despite the variety of languages spoken including Dutch, French, German, and Italian, the meeting was held in English with members translating as necessary. I have come away with a much greater understanding of the organisation, its aims and objectives and of those involved.

But let me start at the beginning. As its name suggests, FSHD-Europe is a pan-European organisation established to improve the quality of life of those with FSHD. It was set up in August 2010 at the initiation of Kees van der Graaf, director of Stichting FSHD in the Netherlands and Ria Broekgaarden, staff member of the Dutch Neuromuscular Diseases Association [VSN] in August 2010. In summary, its objectives are to raise awareness and understanding of FSHD; to share and promote best practice in the care and support of those with FSHD, to encourage research into a cure for FSHD and to work with national and international FSHD/MD organisations and governments to achieve these objectives. Currently European member organisations include FSHD related ones in Italy, France, the Netherlands, Germany as well as the UK. It would seem that organisations to support those with FSHD are limited in many European countries and part of the remit of FSHD-Europe is to make contact and promote the establishment of such groups. As they do so, they will be encouraged to join with FSHD-Europe to provide a cohesive voice for those with FSHD.

This 2-day meeting hosted by Kees in Marbella, Spain, and led by himself and Chairwoman Fabiola Bertinotti, was to review progress in achieving the initial objectives and to review and refine strategy for the future. All nine participants had an intimate knowledge of FSHD with either themselves or a family member having the disease, which gave a particular focus to the discussions that covered a variety of issues. Links had been made with international FSHD organisations in Australia, Canada and America. Developments in

research that provided an understanding of the mechanisms of the disease and suggested avenues for effecting a cure were reviewed. A report on Facio Therapies, a company established to take advantage of potential drug therapies within a social responsibility framework – i.e. for the benefit of patients rather than large profits for the drug companies – was considered. Information on FSHD related research, rehabilitation and therapies, and the development of clinical registries in the various countries was shared. Discussions centred around how FSHD-Europe could best support those with FSHD given all these developments and where its main focus should be. The final afternoon concluded with a refinement of the objectives and an action plan involving an improvement in its current website as a matter of urgency and the development of a knowledge database bringing together scientific findings in FSHD research, approaches to and developments in therapeutic interventions, and greater understanding of patient and carers' experiences that might lead to further understanding of the disorder. In addition, it would promote the development of FSHD associations for the benefit of those with the disease and their carers across Europe. It would also advocate and support the development of patient registries with a common structure across European countries to ensure the community is ready for implementing clinical trials as they become available. To achieve this, as a matter of priority it would raise funding, for example, by applying for European funds from Brussels under existing frameworks where appropriate.

This was an intensive but very interesting, informative and positive meeting. I came away with a great respect for members of the group and admiration for their efforts and energy devoted to the development of this association. It was very heartening to hear people talking of potential therapeutic advances based on recent research findings. They may not happen immediately, and undoubtedly there will be many problems and disappointments along the way, but there has been so much progress in understanding FSHD that even reputable scientists are considering potential avenues for treatment, a situation unimaginable a decade or so ago. Supporting the development of and bringing together existing FSHD related national organisations to ensure that the FSHD community has a significant voice in Europe at this critical time, seems to me to be a highly worthwhile development and I look forward to working with FSHD-Europe to help achieve its aims and objectives. I also look forward to reporting back to you on its progress.

GILL PENNY
FSH-MD Support Group Committee Secretary and
FSHD-Europe representative.

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Upcoming Events

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



National Conference

FORTHCOMING MUSCLE GROUP WORKSHOPS

Muscle Group meetings are a great opportunity for people living with muscle-wasting conditions, as well as their family and friends, to meet others affected and share advice and support.

These forthcoming meetings will be focused on access to equipment; for example wheelchairs, other mobility aids and cough assist machines. This will be your chance to find out more about accessing equipment that meets your needs, as well as sharing advice on your own experiences of going through this process.

To join us at one of our workshops and for more information, please contact:

Peter Sutton on 020 7803 4838 or at p.sutton@muscular-dystrophy.org

Muscle Group	Date Summer 2015	Time and Venue
Ipswich	Thursday 4 th June	1pm – 3pm, Holiday Inn, London Road, Ipswich
Nottingham	Friday 5 th June	1pm-3pm, Novotel, Long Eaton
Milton Keynes	Friday 5 th June	11 am-1 pm, Holiday Inn Express, Milton Keynes
Chelmsford	Monday 15 th June	1pm-3pm, Chelmsford Museum
Crawley	Thursday 18 th June	1pm-3pm, Holiday Inn, London Gatwick, Worth
York	Friday 19 th June	1:30pm-3:30pm, Acomb Energise Centre, York
Reading	Saturday 27 th June	1pm-3pm, Holiday Inn, Reading South
Birmingham	Wednesday 1 st July	7pm-8:30pm, Holiday Inn Express, Birmingham
St Helens	Friday 3 rd July	1pm-3pm, Thistle Hotel, Haydock
Southampton	Tuesday 7 th July	1pm-3pm Holiday Inn Express, Southampton M27 J7
Ashford	Monday 13 th July	1pm-3pm, Holiday Inn, Ashford
Blackburn	Monday 20 th July	1pm-3pm, Blackburn Enterprise Centre

Join Muscular Dystrophy UK at the 2015 National Conference and AGM, Saturday 26 September 2015 at the Holiday Inn London, Kensington Forum, 9:30 am to 4:30 pm



Don't miss out on this year's National Conference. We're moving venues to coincide with the World Muscle Conference, to give you the opportunity to hear the latest in research from the world-renowned researchers. You'll also be able to meet other families living with muscle-wasting conditions, take part in numerous workshops and find out about other work we are doing. Our president, Sue Barker will be presenting or Presidents Awards.

The tickets costs include lunch, morning and afternoon refreshments.

There will be a crèche available for children up to the age of 16 years.

There are disabled parking bays at the front of the hotel, which will be reserved for delegates using large adapted vehicles. Further parking is available and subsidized by Muscular Dystrophy UK at a cost of £5 for the full day.

For further information email: Maureen Winslade or call

Tel: 0207 803 4800

Website: <http://www.muscular-dystrophyuk.org/>

Muscular Dystrophy UK support the FSH-MD Support Group UK by mailing our Newsletters, providing speakers for our Get Togethers and Advocacy Support to name but a few. We are very grateful for their help in reaching out to our Members and Members of Muscular Dystrophy UK.



**Annual Get Together
The Beacon
Newcastle upon Tyne
5th September
2015**

The FSH-MD Support Group is happy to announce the Annual Get Together will be held at the Beacon, Westgate Road, Newcastle upon Tyne NE4 9PQ.

This will be the first time we have visited the North East so we would love for you to join us.

We will have speakers from the team at Newcastle upon Tyne, including Professor Hanns Lochmuller and Libby Wood, curator of the FSHD Registry UK. Also Professor George Dickson regarding his research project into drug therapy for FSH-MD funded by the Rosetrees Trust. Muscular Dystrophy UK will also be supporting the event.

We are really excited to bring the Get Together to the North East and hope it will be supported. Please see our booking form for further details and booking information.

Our format will be

9:15 am -10:00 am registration

10:00 am Speakers

11:15 am – 11:30 am refreshments

11:30 am – 1:00 pm Speakers

1:00pm – 2:00pm Lunch

2:00pm- 3:15 pm refreshments

3:15 – 4:30pm speakers and close

There are 50 car parking spaces on site with further overflow parking at a reduced rate at the Newcastle General Hospital car park over the road.

There are many hotels in the area but we do offer a guaranteed price when you book with the Holiday Inn Express Newcastle, prior to 31 July 2015. All details are on the booking form sent with this newsletter so please refer to this when booking. This is on a first come first served basis.

We really hope as many people as possible can attend however, numbers are restricted so please book early to avoid disappointment.

For further information please contact:

Liz Williams

Tel: 01280 840456

Mobile: 07801 785903

**FSH-MD Support Group UK Annual
Get Together**

Saturday 5th September 2015

The Beacon

Westgate Road

Newcastle upon Tyne

NE4 9PQ.

Booking Form Attached

***Please book early to avoid
disappointment***

Limit places available

Contact: Liz Williams

Tel: 01280 840456

Mob: 07801 785903

Fundraising for The FSH-MD Support Group UK

Christopher Finister, my partner of 24 years has entered in the Iron Man Lanzarote challenge.

As you know the FSH-MD Support Group is entirely run by volunteers either with FSH-MD, their carers or family members. The funds will ensure the Group can continue to provide Annual Conferences in the long term and the website fsh-group.org. We do not charge a membership fee as we do not wish to exclude anyone from accessing information that may help anyone living day to day with the condition.

Many thanks for listening and to those who have already donated a huge thank you it means a great deal to me and the Committee.

Details of his immense challenge are below as are details of how to donate if you feel you can:

Liz Williams, Chair, FSH-MD Support Group UK

Chris Finister is competing in Ironman Lanzarote on 23 May 2015. Ironman consists of a 2.4 mile swim, 112 mile bike ride and a 26 mile run.

Chris is raising funds for the FSH-MD Support Group UK. Chris has funded the entry, travel and accommodation himself. All funds raised will go to the FSH-MD Support Group UK to ensure the continuation of Annual Conferences and administration costs for the Group. Funds raised already are helping to subsidise the cost to members of the Annual Get Together and we would hope we could continue to provide these events at a realistic cost to our members

If you would like to sponsor Chris please could you make cheques payable to:

FSH-MD Support Group UK

and send to:



**FSH-MD Support Group
UK**

27 Lawyers Close

Evenley

NN13 5SJ

Website: fsh-group.org



Alternatively you can donate online via this link:

<http://www.gofundme.com/fshsupportgroupuk>

I will update with photographs of Chris' challenge in the Autumn Newsletter.

Thank you, Liz Williams, Chair, FSH-MD Support Group UK.

New Be Able Travel Website

Mandy Altoft

Be Able Travel was created in 2015 by myself, a wheelchair user with FSH Muscular Dystrophy and a vision impaired person who has been blind since shortly after birth.

We found that despite our best research, what was classed as accessible by websites or other people's reviews, in reality wasn't always the case.

I recently wanted to meet up with friends for a drink at a local pub (bar) and called ahead to check if it was accessible. A member of staff assured me I would be fine in my wheelchair so off I went.

Upon arrival, the pub did indeed have a ramped entrance, great start! Unfortunately, I couldn't get to the bar to order as it had 5 steps up to it, and sadly, the toilets were the same!

Something as simple as meeting friends for a drink had, suddenly, become impossible without having to rely on others for assistance.

With Be Able Travel we hope to achieve a comprehensive database of reviews from all over the world to enable disabled people to be informed without having to rely on the venues for information.

Who knows, maybe together we can change accessibility for the better, one review at a time!

Please show your support and like our facebook page Be Able Travel or follow us on

Twitter (@Beabletravel) or leave a review at

www.beabletravel.co.uk

FSH-MD Support Group UK on facebook

Liz Williams

Again, I would like to recommend for instant information our members register on our facebook Group. We can only cram so much information into a Newsletter and there really is a lot going on in the facebook community.

Please search FSH-MD Support Group UK once you have logged on to facebook and we will add you.

If you are experiencing any problems with day to day living there is a wealth of information available asking your fellow members. I, have recently solved my dilemma of using loos outside the home with a female urination device recommended, which enables me to stand up, negating my issue with low toilets if I am walking to a venue. It means I am not worrying about being away from home and needing the loo. I have not only been stuck on a low loo, but fallen trying to get up from one. More than once have I been sat in someone else's wee after slipping when trying to stand from a disabled loo.

Also recommended were home kettles that do not require tipping, these are water decanting machines that heat the amount you need to make a cup of tea or coffee. Filling them with cold water is far less dangerous than tipping a boiled kettle. My new kettle truly changed my life much to the relief of my family and Consultant. Please do not hesitate to contact me directly if facebook isn't your thing. We are here to help and honestly, I would hate to think anyone was struggling with something we might be able to help with.

So please find us on facebook (FSH-MD Support Group UK) or alternatively email us:

fshgroup@hotmail.com

Tel: 01280 840456

Liz Williams, Chair

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a dark blue rectangular background.