



# NEWSLETTER



Unite to find a cure

## WORLD FSHD DAY

20th June 2016

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World FSHD Day 20th June.

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Attached: Booking form for FSH-MD Support Group Get Together Saturday 3rd September 2016

## Well Done Abigail.

Here is Abigail Stephen who decided to raise funds for Action on FSH. Abigail along with her best friend made Loom Band Bracelets and bookmarks to sell at her school to raise money



and awareness for her condition. Abigail and her friend raised £106 in total. What amazing young ladies!

Thank you from everyone at the FSH-MD Support Group. Action on FSH Appeal is a fund held by the Muscular Dystrophy UK to channel money directly towards research into FSH and to maintain the FSHD Registry UK.

For more information about Action on FSH and how to raise funds please follow this link:

[Action on FSH Appeal](#)

Or contact Muscular Dystrophy UK Tel: 020 7803 4800  
Email: [info@muscular dystrophyuk.org](mailto:info@muscular dystrophyuk.org)

# PIP transition from DLA. My experience.

by **Liz Williams**

As those of you currently receiving Disability Living Allowance (DLA) are probably aware DLA is ending for people who were born after 8 April 1948 and are 16 or over. This change started in 2015 for those already receiving DLA and everyone born after 8 April 1948 will be contacted and invited to apply for the new benefit Personal Independence Payment (PIP).

Like most of us I was dreading the brown envelope advising me that I would be hearing soon that my DLA claim (Indefinite Award) would be ending and that I should expect a further letter letting me know how to proceed.

In December 2015 I received a letter informing me to expect a letter about moving over from PIP to DLA. I received the further letter advising me that I needed to apply for PIP on the 8th January 2016. I suspect they sent it to arrive on a Friday, giving the whole weekend to worry about it. You have 2 weeks to ring them and apply for PIP. If you do nothing your DLA will end.

I rang the Department for Work and Pensions on the following Monday. They ask you the question "So you are sure you want to apply for PIP?" or words to that effect. They asked for the details of any medical professionals involved in my care. I gave my Consultant Neurologist's details. I had to supply the hospital address and postcode and any other health professional I was happy for them to contact.

They also wanted my bank account details. I think the phone call takes about 20 minutes.

They asked if I wanted them to take my previous DLA application into consideration. As I was on indefinite award and that was over 12 years ago, I said no as I had deteriorated significantly since my application for DLA. I received high rate mobility and middle rate care under DLA back in 2004 and at that time was given an indefinite award.

Over a week later I received the PIP Form. I used the Disability Rights website ([disabilityrights.org](http://disabilityrights.org)) to help with the questions and this really did help. (link below)

Disability Rights PIP

With very specific descriptors about my condition, outlining how certain tasks are a risk and my limitations I filled out the form without help. I sent the form for their assessment and included 5 years

of clinic letters from my Consultant Neurologist as evidence.

On 10th February 2016 I was telephoned at home by a Nurse from the claims team PIP. She stated she wanted to ask me some questions and that I would not be assessed in person. The Nurse stated that this was a purely paper assessment. I was asked some questions, which I know I had answered quite thoroughly in the application but asked me about my ability to drive. I stated I could drive with powered steering. My driving licence states this as a condition and I wasn't sure why she was asking as my ability to drive wouldn't have anything to do with receiving the enhanced rate for mobility. I was then asked how I use a toilet. I went through how I have to place both hands on the floor in front of me and climb up the seat and cistern to stand.

When home alone I use a urination device that allows me to stand and wee as I am female, this would not be usual. If I am out of my home, I cannot use a disabled toilet independently, my partner has to lift me from the toilet. I cannot transfer from my wheelchair independently. The Nurse gave no reasoning for these questions so this led to her coming to a conclusion about my ability to use aids for daily living that wasn't actually true.

She then went on to question me about the distance I can walk. I stated that if I am out of the home I would have to stop every few steps to look around to make sure it was safe for me to keep walking as I HAVE to look at the floor to move. My brain has to tell my feet where the floor is and judge the distance as I cannot do this automatically due to the lack of muscle reflex. If I cannot see the floor I will basically fall down if the ground is uneven. However, I can stop once I am balanced to look around. Changing direction in an emergency or avoiding an oncoming car would be impossible if it were not to stop. I could not jump out of the way. The most likely outcome would be to fall. I cannot use crossings safely now as I take too long to cross the road and the bobbles on the pavement surface to aid those with impaired vision unbalance me. I have got my feet stuck on these in the past and have been unable to move. I have to be committed to the direction of travel. This is really difficult to get across to someone who has full physical faculties.

At the end of the conversation she informed me I should hear within 4 weeks.

4 weeks later, Friday 4th March 2016, I received a letter stating there had been a delay in gathering the information and that I would hear my decision soon.

Cont/

A week later, Friday 11th March 2016, I received the decision.

I remained on effectively middle rate care now as I scored 11 points which is standard rate care for PIP and scored 12 points for the mobility component which achieves enhanced rate (Formerly high rate mobility under DLA)

The mystery of the question about my ability to drive was to do with gripping the steering wheel. They decided that as my grip was sufficient to drive then my grip was sufficient to use aids for daily living. It isn't quite that simple with an arm weakness and core weakness. With hindsight I should have informed her that I can only drive as the back rest helps me hold my arms up and driving with your arms lower than the 10-2 position would be a reasonable adjustment. I push against the backrest with my back and shoulders which provides me with the resistance that enables me to turn the steering wheel. They also decided that I could use a stool to cook with (I have a severe core weakness so if I lean forward slightly unsupported I will lose balance and effectively face plant into a work surface, not to mention I would not be able to get off a stool unaided, nor could I lift a lid off a pan or stir from a sitting position.

I am still mulling over whether to appeal the decision as the comment made in my outcome letter about using a stool to cook with is false.

## PIP TIPS

1. Get as much evidence as possible. If you have a Consultant Neuromuscular Specialist I would ask if you could have a copy of the clinic letters they send to your GP. They may well document your gradual deterioration and in my case these were invaluable as they gave evidence of my increasing wheelchair use and the adaptations I have made around the home. Do not presume they will contact your Health Care Professional. In my experience they did not contact my Consultant, Physiotherapist or my GP. My claim was based purely on the evidence I provided. If the DWP contact your Health Care Professional they will most likely incur a fee and the transition is a cost cutting exercise so they will not do this unless absolutely necessary.

2. Remember it is important to get this right first time if you currently have a Motability car. If they downgrade your claim the car will be taken back 2 weeks after your claim has been processed and the decision made. Even if you Appeal the decision the car will be taken back until the time of the Appeal decision. I don't want to be negative but it is a very real prospect. If I hadn't have been able to get

across how I walk and how unsafe I am they may have deemed me safe and given me standard rate Mobility.

4. Don't hesitate to seek help with filling in the form. I am happy to go through my experience with anyone who would like to discuss it. I can be contacted by email in the first instance at [fshgroup@hotmail.com](mailto:fshgroup@hotmail.com). The Advocacy Team at Muscular Dystrophy UK can certainly help too.

5. One other thing to take into consideration is that they may change the pay date of the benefit. So be aware to keep an eye on your bank account. They do notify you when you will be paid and when your last payment for DLA is so you will have warning.

Muscular Dystrophy UK Tel: 020 7803 4800

## Useful Links:

### Government Website:

<https://www.gov.uk/pip/overview>

<https://www.gov.uk/pip-checker>

### Disability Rights PIP Information:

PIP

<http://www.disabilityrightsuk.org/personal-independence-payment-pip>

### Citizens Advice:

<https://www.citizensadvice.org.uk/resources-and-tools/search-navigation-tools/Search/?q=PIP>

### Muscular Dystrophy UK:

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

see Also Summer's Story:

### [Summer's Story](#)

### [turn2us.org.uk:](#)

<https://www.turn2us.org.uk/Benefit-guides/Personal-Independence-Payment/How-much-Personal-Independence-Payment-will-I-get>

**I hope sharing my experience helps.  
Liz Williams**

## Scapula Fixation Update

You may remember in the Spring issue 2015 that two of our members had undergone the scapula fixation operation.

### What is scapular fixation?

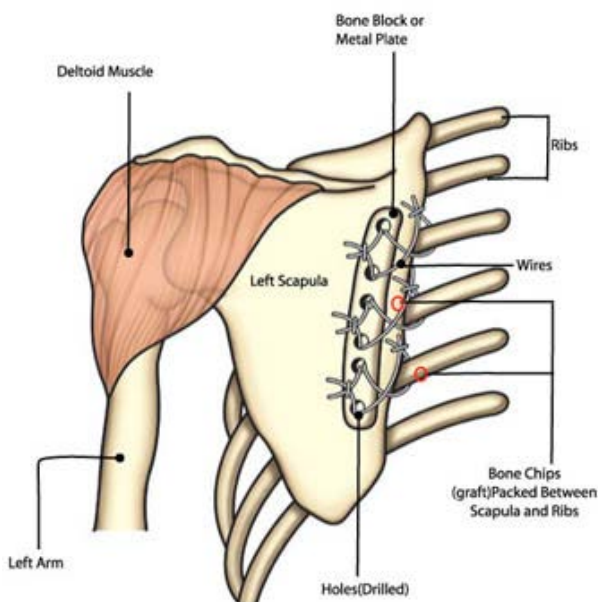
Scapular fixation is a surgical procedure performed under general anaesthetic that stabilises the scapular (shoulder blade) by attaching it to the rib cage.

### Why is it done?

One of the characteristic problems of FSH-MD is the 'winged' effect of the shoulder blades, caused by a weakness in the muscles that hold the scapular in place. As a result of this muscle weakness some people with FSH-MD can have significant loss of ability to raise their arm above their shoulder which can cause problems when eating, drinking, lifting, reaching etc. Surgery to stabilise the scapular should improve functional ability of the shoulders, however movement in some directions will be restricted.

### Is it always a success?

Unfortunately no. Deciding on the surgery is not an easy decision, not everyone who have had surgery are pleased with the result. Some people who have had both shoulders operated on can be pleased with the result of one shoulder but not the other.



Terri has kindly given an update of her progress from her operation last year.

## Terri's experience post op

The first few weeks were quite tough. I'm 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 quickly 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 actually 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.

## Terri's experience one year on

It's been 12 months exactly since I had my Scap Operation.

As hard going as the first 6 months were I would definitely have it done again if I need to. It now seems like a lifetime ago.

To make things easier I've just compiled a list of things I have observed in recovery.

1) It's very easy to put on weight and over eat during the recovery period. I put on around a stone and a half. Make sure you eat what you need to save ballooning. Now I'm back working out and it's coming off gradually.

2) Access to physiotherapy was an issue at first until I was seen by the NMC centre in Winsford. They worked wonders and I would recommend making the effort to go.

3) Yes you will be bored and reliant on others for a while, but enjoy the convalescing. You'll soon be back in the swing of exhausting day to day life!

4) As with any procedure it's not an instant cure. It takes time and effort to regain strength.

5) The plates they put in the shoulder may be uncomfortable at times but it beats the constant aches I used to have. Mine does clink and click at times but that doesn't hurt.

6) The scars are barely noticeable.

7) I'm pretty much back to normal life and much more appreciative of it.

8) As long as you don't go crazy, use the shoulder, don't be afraid of using it. I've been diving, hiking, rocking and rolling since the 8 month mark. It's been fine.

On the whole I'm glad I've had the op. As well as transform my shoulder into a sturdy joint it's given me the chance to change my lifestyle to one that's kinder on me. I gave up my backbreaking job and found a new one in medical research. This allows me the energy to go to the gym after work to exercise in a controlled manner.

I hope this helps others come to a decision that is right for them. Terri.

#### Useful links:

FSH-MD Support Group UK's information regarding Scapula Fixation:

[fsh-group.org](http://fsh-group.org)

See Newsletters Tab and download issue 25

or click here:

[FSH Scapula Fixation Data](#)

For other stories regarding scapula fixation please go to [fsh-group.org](http://fsh-group.org) and click the about FSH-MD tab and click What is Scapula Fixation.

Also, Sam's Story below:

<http://www.fsh-group.org/samstory.pdf>

Other Links:

FSH Society:

[https://www.fshsociety.org/assets/pdf/FSHSocietyPatientIPRN2010\\_Curl.pdf](https://www.fshsociety.org/assets/pdf/FSHSocietyPatientIPRN2010_Curl.pdf)

The Neuromuscular Centre, Winsford Cheshire:

<http://www.nmcentre.com>

The Neuromuscular Centre, Midlands:

<http://nmc-midlands.co.uk>

For further signposting please contact the FSH-MD Support Group UK

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

Or Join our Facebook Group by searching [FSH-MD Support Group UK](#) in the Facebook search box for peer to peer support.

Muscular Dystrophy UK:

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



Unite to find a cure

## World FSHD Day 20th June 2016

Many countries have organisations, associations, and/or support groups working to support those with FSH and those working towards a cure and treatment. Greater benefits can be obtained by working more collaboratively. The two groups outlined below are ones that the FSH-Support Group has links with, either directly through a representative of the Committee on the Board, as with [FSHD-Europe](#) more indirectly through a representative of [Muscular Dystrophy UK](#) with the FSHD Champions. A brief overview of these associations is given by Gill Penny of the FSH Support Group and Andrew Graham of [Muscular Dystrophy UK](#) for FSHD-EUROPE and the FSHD Champions respectively.

### **FSHD-Europe**

FSHD-EUROPE is an organisation representing the needs of adults and children with FSHD and their families at a European level. Its members are drawn from a range of European countries including France, Germany, Italy, the Netherlands, and the UK. It has several objectives:

- To raise awareness, understanding and knowledge of FSHD by sharing best practice in the care, welfare, support and diagnosis for people with FSHD and their families
- As the voice of patients, to augment and sustain the multiple efforts of key FSHD scientists and clinicians working on one common project in order to accelerate the achievement of a cure

- To raise funds for FSHD research and appropriate care and support programmes.
- 

It aims to achieve this in a number of ways including through:

- The stimulation of a Europe wide patient registry based on key parameters in order to prepare the ground for future clinical trials.
- Steering a project with a cohesive group of scientists and researchers working to a common goal to improve the well being of those with FSHD.
- Targeting relevant EU Committees in Brussels and private companies in the field of pharmaceuticals to promote FSHD-related research and funding of FSHD projects.
- Extending the scope of the organisation to other potential European associates outside those currently involved.

It also has links worldwide with other FSHD organisations working to promote the well-being of those with FSHD and their representatives meet in the global [FSHD Champions](#). A recent outcome of this group was the decision to designate and promote an annual World FSHD Day on June 20<sup>th</sup> to raise awareness of the disease and bring it to the greater attention of the public. FSHD-EUROPE has been working actively with the national MD/FSHD organisations in Europe to ensure coverage of the FSHD Day and its promotion within their own countries.

### **FSHD Champions**

The FSHD Champions group was created as a collaboration of FSHD and broader MD charities around the world, over 2 years ago.

The Purpose was to form a voluntary, informal federation of all national and international organisations funding FSHD research.

The mission is to ensure researchers funded by each organisation communicate and collaborate together. Where appropriate to jointly fund projects and to promote funding of FSHD through government organisations.

The group has no overall Governance structure but will form working groups for time to time such as for the creation of the world FSHD day.

**Initial activities**

- Preparation and publication of a white paper, defining FSHD.
- Taking inventory of past and current funded projects.
- Preparing a list of the most important areas for research to focus on.
- Sharing project application forms.

**Potential areas for future cooperation**

- Co-funding of research projects.
- Agreeing on a plan to make better use of the scarce funding resources.
- Create a network of patient registries adhering to a minimum set of fully harmonised measures.
- Sharing good practice in fundraising. Possible cooperation in fundraising.
- FSHD Advocacy and lobbying.
- Ensuring the establishment of internationally harmonised standards of care, outcome measures.
- Ensuring an internationally acceptable way to establish trial readiness.
- Paving the way to reimbursement and availability of an FSHD effective treatment worldwide, and to ensure that a treatment that has a positive effect will receive a broad label.

**Useful links:**

FSHD Champions: [fshdchampions.org](http://fshdchampions.org)

Muscular Dystrophy UK on Facebook  
[Muscular Dystrophy UK](#)

or website: [muscular dystrophyuk.org](http://muscular dystrophyuk.org)

You can find friends of FSH Research on Facebook [Friends of FSH Research](#)

[FSHD-Europe](#)

**Upcoming Events**

**21st June 2016**

**Muscular Dystrophy UK**

**Muscle Group Meeting Cambridge**  
 1pm to 3pm at Holiday Inn Express  
 Cambridge, Coldhams Business Park, Norman  
 Way, Cambridge CB1 3LH

For more information contact  
 Shivani Handa on 020 7803 4808 or  
 email: [s.handa@muscular dystrophyuk.org](mailto:s.handa@muscular dystrophyuk.org)

**3rd September 2016**

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

**Snowzone, Xscape, 602 Marlborough Gate,  
 Milton Keynes, Buckinghamshire MK9 3XS**  
 Registration 9:15 am to 10 am  
 10 am - 4 pm  
 £20 per person, includes refreshments and  
 lunch.

Booking form attached and on our website  
[fsh-group.org](http://fsh-group.org) or telephone Liz Williams  
 01280 840456

**1 October 2016**

**Muscular Dystrophy UK National Conference  
 and AGM Muscular Dystrophy UK National  
 Conference and AGM**

**Park Plaza Victoria Hotel, London**  
**Registration fee**  
**£5 to £35**

Registration fee:  
 £5 Child  
 £15 Adult  
 £35 Family ticket

[Click here for more information](#)