

**The McCollum Report:**

Access to specialist neuromuscular care  
in Northern Ireland

All Party Group on Muscular Dystrophy  
in the Northern Ireland Assembly

July 2012



# **The McCollum Report:** Access to specialist neuromuscular care in Northern Ireland

## **Contents**

<b>Foreword</b>	<b>1</b>
<b>Gerry, Geraldine and Christopher McCollum</b>	<b>2-3</b>
<b>The All Party Group on Muscular Dystrophy</b>	<b>4</b>
<b>Executive summary</b>	<b>5</b>
<b>Recommendations</b>	<b>6</b>
<b>Background to the Inquiry</b>	<b>8</b>
<b>What is muscular dystrophy?</b>	<b>9</b>
<b>Muscular Dystrophy Campaign</b>	<b>9</b>
<b>Evidence summaries</b>	
1) Living with muscular dystrophy and related neuromuscular conditions	10
2) What constitutes specialist multidisciplinary care?	16
3) Commissioning, planning and delivery of specialist services	20
<b>Appendix</b>	
The All Party Group on Muscular Dystrophy Inquiry	28
Witnesses	28
Terms of reference	29
Written evidence and additional evidence provided to the Inquiry	30-31
<b>References</b>	<b>31</b>

## Foreword



The evidence published in *The McCollum Report* highlights the need for the Northern Ireland Executive and the Health and Social Care in Northern Ireland (HSC) to take urgent action to address the significant gaps in the provision of specialist neuromuscular care identified by expert witnesses.

The evidence received by the All Party Group demonstrated that, while there are excellent expert health professionals in Northern Ireland, there are clear shortfalls in the co-ordination of neuromuscular service provision.

The All Party Group expects action to be taken to consider additional specialist care advisor posts to meet the needs of people with muscular dystrophy and related neuromuscular conditions across Northern Ireland, following the commitment to a timeframe for recruitment and appointment of the vacant care advisor post. The sudden departure of the previous post-holder and the absence of essential support and advice for the 2,000 people with these rare conditions in Northern Ireland highlight the significant caseload and the need for stronger back-up and succession planning for these vital roles.

The overall impression which can be drawn from the evidence is that people with muscular dystrophy and related neuromuscular conditions in Northern Ireland are experiencing gaps in many aspects of specialist care provision which may potentially shorten lives and reduce quality of life. There is also a very real concern shared by patients, families and health professionals that investment in much-needed service improvements will be constrained by budgetary demands. However, unplanned emergency admissions to hospital for people with muscular dystrophy and related neuromuscular conditions in Northern Ireland currently cost £2.27million per year. Based on figures in the Muscular Dystrophy Campaign's *Invest to Save* report, an estimated £908,000 is being wasted on unnecessary admissions<sup>1</sup>; investment amounting to a fraction of those costs would make a significant impact not only in improving services across Northern Ireland for people with these conditions but also in reducing these costs.

I would like to thank all those who have participated in the Inquiry by giving oral evidence, submitting written evidence and attending the evidence sessions. I also want to thank my MLA [Members of the Legislative Assembly] colleagues for their involvement and incisive contributions in supporting the work of this Inquiry from December 2011 to June 2012. I also wish to thank the Muscular Dystrophy Campaign for its hard work and efficiency in providing the Secretariat to the Inquiry.

Finally, I would like to pay tribute to Gerry and Geraldine McCollum, whose son Christopher had Duchenne muscular dystrophy and passed away in 2001. Dedicated supporters of the Muscular Dystrophy Campaign, Gerry and Geraldine set up the Christopher McCollum Fund to provide funds to help purchase wheelchairs, or other equipment, for young people aged 18 or under who have a disability or illness which may be life-limiting. In honour of Christopher, and also in recognition of Gerry and Geraldine's dedicated support to pressing for improvements to services in Northern Ireland, the All Party Group is very pleased to name this report *The McCollum Report*.

**Conall McDevitt, MLA for South Belfast**  
**Chair, All Party Group on Muscular Dystrophy in the Northern Ireland Assembly**

## Gerry, Geraldine and Christopher McCollum



Gerry and Geraldine McCollum from Bangor have been dedicated supporters of the Muscular Dystrophy Campaign for many years. Their son, Christopher, was diagnosed with Duchenne muscular dystrophy in 1989 at the age of five, and passed away in 2001. They have remained at the forefront of the Muscular Dystrophy Campaign's efforts to secure service improvements in Northern Ireland.

Gerry and Geraldine wrote to the All Party Group about Christopher's experiences:

"While general support and care for Christopher were good, he did have a horrific period from 1998 to 2000, with a delay in wheelchair provision at a very critical time in his life. After his spine operation, it took 18 months to get a suitable powered wheelchair for him. This was mainly because of lack of funds and it was made more difficult given that he had a progressive, life-limiting disability, which was not recognised in the procedure at all. He was considered no different from someone aged 50 who, while needing a wheelchair, may not have had a progressive or life-limiting disability.

On one occasion, we were interviewed as to why Christopher deserved a new manual wheelchair as against two others, both adults. We were told there were insufficient funds for all three. Christopher was granted his manual wheelchair, which cost £2,000. The trust official said she 'recognised he had a life-limiting condition and deserved every support he could have'. That was a profound statement. We realised such a view must be embedded into the system to help others make decisions in the future. Sadly it took eight months to adapt his wheelchair; it arrived a short time before he died.

The delay had a huge impact on his quality of life. He suffered severe pressure sores, which took months to heal; a tilt to his neck because he had no firm head support, and loss of weight. It also cost the NHS thousands of pounds to treat these problems. Because of his poor health at that time, the MRSA superbug opened the scar on his back which, over 14 months, cost thousands of pounds to treat. All of these problems could have been avoided. We also believe similar problems could arise today.

We are currently aware of a 15-year-old boy with Duchenne muscular dystrophy who needs a new head support but has had to wait a year for an occupational therapy (OT) assessment. This is an example which has the potential to incur the NHS unnecessary costs. If a specialist centre was in place, set up by government, that where possible it would treat each person as a priority, also to save on NHS funds, then that would help that OT justify arranging an appointment immediately rather than a year ahead.

In 2008, we set up our own charity to help provide funds for equipment for young people 18 and under. Last year we were approached by a family whose son, aged six, had Duchenne muscular dystrophy. He had been using a child's buggy for two years and urgently needed his first lightweight, customised, manual wheelchair. He was assessed for this but then he was put on a waiting list. Our charity obtained a wheelchair in three weeks. It is totally unacceptable that the NHS cannot always provide a six-year-old with his first manual wheelchair."

## **Christopher McCollum**

“Despite his disability, Christopher was always a happy boy with a wonderful smile. His courage and determination were an inspiration to everyone. He did not deserve what he had to endure for 18 months. Young disabled people who are born with a condition inspire and teach us all so much. Everyone with a disability should be provided with the best care and support and should get the equipment they need as soon as possible.

In 1998 we started to campaign for better provision, and we met the Health Minister in 2000. Sadly in 2001, Christopher experienced further delays. We planned again to meet the Health Minister. One day Christopher said he would go along to meet him, to say how he felt. He died a week later and never got the opportunity. We knew then, as in 1998, that we had to continue to campaign to improve care and support for everyone with a neuromuscular condition.

We welcome the All Party Group Inquiry. It is a great achievement, ten years after Christopher died, to see these issues now being debated within government. The Muscular Dystrophy Campaign should be applauded for supporting everyone in Northern Ireland with neuromuscular conditions.”

## **The All Party Group on Muscular Dystrophy**

The All Party Group on Muscular Dystrophy in the Northern Ireland Assembly is chaired by Conall McDevitt MLA and is made up of an all party group of Members of the Legislative Assembly (MLAs). It aims to ensure that the needs of people living with muscular dystrophy and related neuromuscular conditions are highlighted in the Northern Ireland Assembly and to press for improvements to essential services for families across Northern Ireland. The Secretariat for the Group is provided by the Muscular Dystrophy Campaign.

### **Acknowledgements**

The All Party Group on Muscular Dystrophy wishes to thank the Muscular Dystrophy Campaign for its administrative support in the organising and staging of evidence sessions, in the gathering of written evidence, and in producing this report.

### **The Cross Party Group's Assembly Members are:**

Conall McDevitt MLA (*SDLP, South Belfast*) (*Chair*)  
Robin Swann MLA (*UUP, North Antrim*) (*Vice Chair*)  
Kieran McCarthy MLA (*Alliance Party, Strangford*) (*Secretary*)  
Roy Beggs MLA (*UUP, East Antrim*)  
Paula Bradley MLA (*DUP, North Belfast*)  
Mickey Brady MLA (*Sinn Fein, Newry and Armagh*)  
Pam Brown MLA (*DUP, South Antrim*)  
Ian McCrea MLA (*DUP, Mid Ulster*)  
Karen McKeivitt MLA (*SDLP, South Down*)  
Peter Weir MLA (*DUP, North Down*)  
Jim Wells MLA (*DUP, South Down*)

**A full note of the witnesses who gave oral evidence to the Inquiry is attached in the Appendix, together with a note of the additional evidence submissions.**

## **Executive summary**

The All Party Group (APG) on Muscular Dystrophy in the Northern Ireland Assembly launched its Inquiry into access to specialist neuromuscular care in Northern Ireland in December 2011.

The Inquiry shows that patients in Northern Ireland affected by muscular dystrophy and related neuromuscular conditions experience inconsistent standards of care from diagnosis onwards. There is also an alarming reduction in services when moving from paediatric to adult services, such as the provision of physiotherapy and respiratory services, which are essential parts of specialist multidisciplinary care.

The general consensus of discussions during the Inquiry was that additional specialist care advisor support is urgently required in order to provide the best possible care and support for people with muscular dystrophy and related neuromuscular conditions and to ensure long-term security for this vital part of service provision. The process of advertising and recruiting the much-needed neuromuscular care advisor post by the Belfast Health and Social Care Trust has been protracted and has caused much frustration for people affected by muscular dystrophy and related neuromuscular conditions. The appointment of a neuromuscular care advisor should be seen as the first step to increasing care advisor support and not the conclusion of service development in this area.

We acknowledge that there are expert, dedicated health professionals in Northern Ireland who are providing a high standard of service in the time allowed to them. However, it is evident that the limited amount of clinical time that they are able to devote to neuromuscular services is an area of significant concern. The overall pattern of more comprehensive support in paediatric services, compared to adult services, is exemplified by the incorporation of increased network support in paediatric services. The APG has concerns about the imbalance of co-ordination of solely paediatric services, and will be encouraging inclusion of adult services here as well.

It is essential that the complex nature of muscular dystrophy and related neuromuscular conditions is recognised and not just generically grouped with neurological conditions or long-term conditions. Other specialisms are also needed for these rare and very rare conditions, such as genetic, respiratory, rehabilitation and cardiac support.

The APG and the Muscular Dystrophy Campaign are calling on the Northern Ireland Executive and HSC to act on the following recommendations.

The APG will expect to receive regular reports on progress from the Minister, the Northern Ireland Executive and HSC.

## Recommendations

1. A lead for muscular dystrophy and related neuromuscular conditions is appointed from within Health and Social Care in Northern Ireland (HSC) to take overall control and be accountable for identifying and fixing the gaps in specialist multidisciplinary neuromuscular care, which require urgent service development.
2. The Northern Ireland Executive and HSC define and fully recognise neuromuscular services as specialist services in order to distinguish the complex muscular dystrophy and related neuromuscular conditions as requiring specialist support, which includes different specialisms.
3. The Northern Ireland Executive ensures that the care advisor post in Northern Ireland is secured long-term within HSC, and takes urgent steps to create more of these posts. These steps will provide the best possible support and advice for people with muscular dystrophy and related neuromuscular conditions and will reduce unplanned emergency admissions by investing small amounts to save a large amount in the long term.
4. Health and Social Care Board and the Northern Ireland Executive create a steering group for developing specialised neuromuscular services which incorporates the views of people affected by muscular dystrophy and related neuromuscular conditions, health professionals, commissioners and the Muscular Dystrophy Campaign.
5. Health and Social Care Board initiates steps to ensure that a network approach for muscular dystrophy and related neuromuscular conditions is formally developed for adult services, following the announcement of increased co-ordination of paediatric services.
6. Health and Social Care Board and Health and Social Care Trusts use the specialist expertise within Belfast Health and Social Care Trust to develop further a 'hub and spoke' model of service provision, with Belfast Trust at the centre of the set-up at which core specialists are located.
7. Health and Social Care Trusts appoint transition workers to facilitate patients' transition from paediatric to adult services.
8. Health and Social Care Board and Health and Social Care Trusts develop a more streamlined and efficient genetic testing system to reduce delays.
9. Health and Social Care Trusts address the need to increase clinical time dedicated specifically to specialist neuromuscular care.
10. The Health and Social Care Board develops a neuromuscular registry for both the paediatric and the adult services in Northern Ireland to ensure the most efficient delivery of specialist care.

11. The *Duchenne Standards of Care* guidelines are made widely available to those commissioning, planning and delivering services so that high-quality standards of care are achieved in a multidisciplinary approach for all neuromuscular conditions. As new guidelines emerge for other neuromuscular conditions, these should also be made widely available so that commissioning, planning and delivery of these services can also be improved.
12. The Northern Ireland Executive addresses the inequalities of wheelchair service provision so that there is consistency and that people with muscular dystrophy and related neuromuscular conditions are not forced to resort to private purchases of suitable wheelchairs.
13. The Northern Ireland Executive, in conjunction with HSC, improves the level of recognition and knowledge of muscular dystrophy and related neuromuscular conditions at GP level.
14. The Health and Social Care Board implements a structured long-term succession planning system so that key neuromuscular posts are recruited for and appointed quickly to prevent a detrimental gap in services for people with muscular dystrophy and related neuromuscular conditions.
15. Health Trusts and Northern Ireland Councils develop structured joint planning provision so that there is a seamless transition and co-ordination between health and social care services.

## Background to the Inquiry

The APG on Muscular Dystrophy in the Northern Ireland Assembly decided to launch an Inquiry into access to specialist neuromuscular care in Northern Ireland in December 2011.

The purpose of the Inquiry was to highlight gaps in services in Northern Ireland for people with muscular dystrophy and related neuromuscular conditions that need to be addressed urgently. The Inquiry aimed also to identify areas of best practice and to acknowledge the expertise of specialist health professionals in the neuromuscular field in Northern Ireland.

The Inquiry heard the views of people in Northern Ireland who are affected by muscular dystrophy and related neuromuscular conditions, and those clinicians and health professionals involved in the provision of services for this group of patients. The Inquiry also sought the perspective of representatives of the bodies and organisations responsible for the commissioning of these services in Northern Ireland.

The Muscular Dystrophy Campaign's *Building on the Foundations in Northern Ireland: Improving Specialist Care, Support and Independence* report was published in February 2009 to draw the Northern Ireland Executive's attention to the gaps in access to specialist care in Northern Ireland and to the need to fix these urgently.

The subsequent recruitment of a paediatric neurologist was a welcome step in addressing the need to develop specialist care, but clearly many aspects of service provision remain under-strength.

The formation of the APG on Muscular Dystrophy in the Northern Ireland Assembly was also a crucial step forward in consistently involving MLAs in the concerns of people with muscular dystrophy and related neuromuscular conditions about accessing the necessary services.

Edwin Poots MLA, Minister for Health, Social Services and Public Safety in the Northern Ireland Executive told the BBC's *In Your Corner* programme, which ran a feature on the Inquiry in February 2012: "I receive infinite demands, but I have finite resources."

There are positive signs that HSC is appreciating the severe impact that gaps in services have on the daily lives of people with muscular dystrophy and related neuromuscular conditions. It is hoped that the recruitment and appointment of a care advisor by Belfast Health and Social Care Trust will be the beginning of an increase in specialist support for people with these conditions.

Decisive action is now needed to implement the recommendations in this report. All people in Northern Ireland with muscular dystrophy and related neuromuscular conditions, regardless of their age, condition and location, need to have equal access to specialist services which are also currently more developed in many parts of the UK.

## **What is muscular dystrophy?**

Muscular dystrophy is a condition – of which there are 60 different types, including more aggressive types such as Duchenne muscular dystrophy – that causes muscles to weaken and waste over time, leading to increasing disability. The conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy.

It is accepted that for every million people in the UK, just over 1,000 children and adults are affected by one of these muscle-wasting conditions. It is therefore estimated that some 2,000 people are affected by muscular dystrophy or a neuromuscular condition in Northern Ireland.

Many neuromuscular conditions are low-incidence, orphan<sup>2</sup> conditions, with some regarded as very rare and ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the rare exception of a couple of acquired conditions, there are currently no known effective treatments or cures.

Clinical trials in some forms of muscular dystrophy are now underway and it is hoped that these will lead to the introduction of new treatments that can slow or arrest the progressive nature of these often devastating conditions. There is a pressing need to develop the clinical trials infrastructure with additional trial centres in the UK to enable more patients to participate in them and, in turn, help to hasten the development and introduction of new treatments.

## **Muscular Dystrophy Campaign**

The Muscular Dystrophy Campaign is the leading UK charity focusing on muscular dystrophy and related neuromuscular conditions and is dedicated to beating these conditions by finding treatments and cures and by improving the lives of everyone affected by them. Founded in 1959, the Muscular Dystrophy Campaign takes the lead in investing in world-class research to find treatments and cures. People rely on the charity to provide expert information, advocacy and community support, and to signpost them to effective specialist services.

The Muscular Dystrophy Campaign has set up a Northern Ireland Muscle Group, comprising families affected by a muscle-wasting condition, clinicians and supported by MLAs, which has played an invaluable role in the APG to campaign for better neuromuscular services in Northern Ireland.

The charity also campaigns and works with parliamentarians and clinicians across the UK to ensure all people living with neuromuscular conditions have equal access to high-quality health and social care services.

## Section 1

### Evidence summary

#### Living with muscular dystrophy and related neuromuscular conditions

##### Oral evidence from the panel was provided by:

*Dr Janet Bailie, whose son Andrew has Duchenne muscular dystrophy*

*Margaret Casey, whose son Brendan has Duchenne muscular dystrophy*

*Michaela Hollywood, who has spinal muscular atrophy*

*Marina Lupari, whose son Marc has Duchenne muscular dystrophy*

*Gerry McCollum, whose son Christopher had Duchenne muscular dystrophy and passed away in 2001*

*Dr Amy Jayne McKnight, whose father Barry has spinal muscular atrophy*

*Other contributions were received and taken on board from people affected by muscular dystrophy and related neuromuscular conditions in every oral evidence session.*

1. We received thorough and detailed accounts of patients' and families' experiences of the significant inequalities in the provision of specialist multidisciplinary neuromuscular care across Northern Ireland.
2. We were extremely concerned about the impact that the lack of a dedicated neuromuscular care advisor has had, since the previous post-holder left in November 2011. Dr Janet Bailie summed up the wide-ranging importance of the post:

*"If we're going to be going through the experiences that people have with living with diagnosis and living with neuromuscular disease, and there are several points at which you really need psychological support, as well as clinical support, what we particularly need from the care advisor is someone to co-ordinate the interface with so many clinical people that you come across as a patient; you need someone to co-ordinate that."*

3. The delays in recruiting for a new care advisor have been unacceptable. Gerry McCollum said that people living with muscular dystrophy and related neuromuscular conditions simply cannot believe that it has taken so long to replace the role:

*"Obviously we're in this position because the care advisor left; it's not that it's a new post in a sense. If she'd never left, I presume everything would have gone on as it was and they would have continued to pay for the post and the job she was doing."*

4. We heard about the central role that the care advisor plays in the specialist multidisciplinary care for people with muscular dystrophy and related neuromuscular conditions. Gerry and Geraldine McCollum highlighted this to us in written evidence:

“Northern Ireland must have at least one care advisor. We believe this is probably ‘the single most important person’, being the link between families and health departments. Their knowledge, experience and knowing in advance what may be necessary can help save the health service considerable funds in the long term. Many difficult situations can arise which sometimes make people, especially young people, feel neglected. For them to know they can turn to their care advisor when things are difficult is a very vital support to them.

“The Muscular Dystrophy Campaign report, *Invest to Save*<sup>3</sup>, proved that nearly £2.5 million per year is wasted in Northern Ireland because of unnecessary hospital admissions and unnecessary treatments, most of which could be avoided. A care advisor can play a vital role in avoiding such wastage.”

5. We established during evidence sessions that one care advisor would not be enough to shoulder the caseload of the estimated 2,000 people across Northern Ireland. Margaret Casey raised the issue of gaps in the service:

“I would like to reiterate the importance of this vital role being split over two posts to avoid gaps in support during periods of absence.”

6. We were shocked by the lack of continuity in support following diagnosis. Gary Stevenson told us about how support decreases after initial diagnosis:

“You’re putting more pressure on the health service and it’s not getting any better, it’s getting worse. I had faith in the system when we first came in but once you’re told, and for about six months after, you are cared for; after that you’re in the wilderness.”

7. We received alarming evidence about the length of time that patients and families have to wait after testing is carried out. Mary Loughran told us:

“From initially going to the muscle clinic and having a muscle biopsy done, no definite result had been sent off. Blood then was taken from myself and my daughter, and it was two years later before we got the result. There were various issues in that; I 100 percent support what Gary [Stevenson] was saying. Our son was seen in June, and was then to be seen in six months time, but we still haven’t got an appointment. And since Dr Tirupathi took the position – and I’m not saying it’s her fault – I’ve had to ring each time to get an appointment. There doesn’t seem to be a system where you’re continually called. So I feel, as a parent, we are managing the condition; if we get into great difficulty we’ve got to come to Belfast.”

8. We heard that it is often the persistence of family members that ensures that a correct diagnosis is made. Dr Amy Jayne McKnight said about her father's diagnosis:

"So he was disabled from birth and in a wheelchair when he was eight. He had four different diagnoses. The only reason he was actually correctly diagnosed was that I formally asked for a genetic test. I had to request that. Now that was 11 years ago and since then he's seen a neurologist twice."

9. We realised that there is much work to be done in educating and training health professionals about identifying muscular dystrophy and related neuromuscular conditions. Michaela Hollywood emphasised this to us:

"It's a matter of ignorance almost; I think the doctors were happy to think it's a lazy child. You go to the GP with a child that's six months old and can't sit up or just lift their eyes up like I did, and they just think it's a lazy child and that's a problem."

10. Michaela also told us an extremely shocking situation that she experienced recently:

"I had a massive anaphylactic shock in November and, as a result, I stopped breathing. Now, had my mum and dad not been there, I may not be sitting here today. But this is something which I think needs to be learned from. I had a really good doctor but he didn't know about neuromuscular conditions all that well, and that's worrying and something that needs to be learned from. So basically what happened was that I needed oxygen. They were wondering if I was oxygen-sensitive and whether or not I was allowed oxygen to begin with, and we went with the oxygen anyway. Separately, there was more oxygen put on my life-support machine; only the doctor didn't know that my life-support machine was a life-support machine, so there was stuff like that going on. I think doctors need to be learning a little bit more about neuromuscular conditions."

11. We were alarmed at the paucity of specialists in the neuromuscular field and that neuromuscular conditions are often put in the neurological category, when in fact these conditions are more complex and cut across different specialisms. Dr Janet Bailie said:

"The fourth consultant has been appointed but unfortunately her main focus is neuro-disability, which does not exactly fit with the needs of neuromuscular disease although, ironically, the person they have picked does have experience with neuromuscular disease. However the consultant that we have presently, her specialty was epilepsy and the learning that she has about neuromuscular disease is subsequent to her accepting that post in 2009."

12. Michaela Hollywood illustrated the ideal scenario for people with muscular dystrophy and related neuromuscular conditions:

“There’s physiotherapy and hydrotherapy, trying just to cover everything. I do receive physiotherapy but it’s a tricky issue because when you’re under 18, with a neuromuscular condition, you have respiratory physio in the community; when you’re over 18 and in the community, with a neuromuscular condition, you’re with disability physios, even though you’re deemed as having a respiratory problem. So that I think is something that is a prime example of the disjointed care that we’re receiving. If we have one specialist multidisciplinary team, as was mentioned earlier, that would make things so much easier. If we had a physio that concentrated on neuromuscular diseases but also had experience within respiratory areas, that would make things easier. Also, if we had a cardiologist who pretty much had a good knowledge all round, that would help too.”

13. Marina Lupari compared the services in Northern Ireland with the specialist care experienced in Newcastle:

“Once we attended Newcastle. What you actually get there is a very detailed report with regards to what it is they’ve found, what their suggestions are and what the recommendations are for follow-up. Our big challenge then is that when we come back to Northern Ireland, we have to fight to get what Newcastle says we need, and that’s where we have our biggest challenges.”

14. Gerry and Geraldine McCollum clarified in their written evidence that a relatively small amount of investment would save a lot in the long term:

“We believe a specialist neuromuscular centre should, in the long term, be established in Northern Ireland. Why? Because it will save the NHS millions of pounds. Every person with a condition should be registered. The fact that people born with a progressive condition that is predictable must be an advantage to the NHS, as it can be known in advance what each person may require over their lifetime. Being registered would also highlight that all care and support for such a person should, where possible, be treated as a priority as it will save money in the long term.”

15. We received powerful evidence about the need to establish specialist multidisciplinary support in Northern Ireland. Dr Amy Jayne McKnight said:

“He [my father] was only offered respiratory care after he ended up in ICU and that was the first time he was ever seen by a respiratory consultant, and again he has seen that person twice over the last four years. Definitely push the comprehensive multidisciplinary approach. The important thing for muscular dystrophy is that, yes, there are fabulous centres in the UK, but one of the main problems with this condition is that it’s respiratory. Children and adults can’t fly when they have respiratory complications. So a comprehensive multidisciplinary approach that’s based in Northern Ireland, building on the expertise we have in Belfast, is exactly where we need to go.”

16. Marina Lupari told us how delays in actually delivering the care at the right time had a negative impact on the care that her son, Marc, received:

“At one point in time, Marc had 28 professionals involved in his care, but what he had was 28 professionals who didn’t deliver, who made promises, who assessed his needs but by the time things were actually delivered, Marc had gone past the point of needing that. And I have letter after letter that gives it to you. There’s the letter where we made the decision about the orthopaedic surgery; we have the letter that for his scoliosis surgery he would be seen as quickly as possible but by the time we got the appointment it was too late; there’s a letter with regards to the muscle clinic; there’s what it is that Marc should actually have in terms of multidisciplinary care.

“The truth is, rather than just being disadvantaged, things like this have an adverse effect on people’s health. When Marc didn’t have that wheelchair, that had a really adverse effect on his musculature and on his scoliosis; it’s worse than being disadvantaged.

“Before Christmas, because of the wheelchair, he ended up with three pressure sores. A boy of 15 who is doing his GCSEs, who is getting A\* and A because he’s so committed to it and he ends up with three pressure sores because of his chair; this isn’t right.

“The services do not join up and you can’t get basic things. Marc’s having things when it’s too late, all the time.”

17. We heard how the lack of clinical time for neuromuscular conditions is so difficult to access for people living with muscular dystrophy and related neuromuscular conditions. Angela Rogan reported in written evidence:

“I was in contact with the muscle clinic at the City Hospital today as Jamie [her son] is due his six month review in February. They offered us a cancellation for this Thursday but when I said it was too short notice and my husband [Davy] couldn’t get out of work, they told me the next appointment they could give Jamie would be April, i.e. two months later. I questioned why this is the case and was horrified to hear that there are only 10 appointments per month for Dr Tirupathi. The clinic only operates fortnightly and even less often when she is on leave.”

18. We heard evidence about the critical importance of supporting people with muscular dystrophy and related neuromuscular conditions through the transition from paediatric services to adult services, which often appears to be poorly managed. Michaela Hollywood said:

“The main big issue for everyone is transition – I started when I was 14 and I’m now 21 and still in transition, so that’s another huge barrier that people with neuromuscular conditions face. If you’re in transition for seven years, it’s such a big problem to bridge. You’ve got your education, then you have your health service, you have your transition from paediatric to adult, you have all of that going on at one time. It’s not co-ordinated; it’s a little bit ad hoc. It is annoying that the occupational therapist takes you off the books, which is my biggest problem, until you phone up with a problem.”

19. Michaela Hollywood highlighted the invaluable role that respite care plays for both the individual with the condition, and the carers:

“Respite in terms of the hospice is brilliant. I get a break from my Mum and Dad and my Mum and Dad get a break from me. So that’s one thing that I think should be widened. And indeed the hospice is not so much a hospice but a regular home. If anyone hasn’t been, then you should go up and visit; it’s completely different from what you perceive it to be. So the hospice is there and you can go and hang out and visit them, it’s a completely different vibe to what you would perceive. In terms of home, it was a bit of a battle. My Dad had a heart attack about four years ago and until that point we really didn’t get that much help at home. It took Dad to have a heart attack and nearly die on us, to get any help.”

20. The evidence which we received pointed to an alarming lack of specialist care available for people with muscular dystrophy and related neuromuscular conditions in Northern Ireland. The comprehensive specialist multidisciplinary approach is not an unrealistic objective and can be achieved with minimal investment and an improved co-ordinated network approach.

## Section 2

### Evidence summary

#### What constitutes specialist multidisciplinary care?

##### Oral evidence was provided by:

*Dr John McConville, Consultant Neurologist, Belfast*

*Dr Brian Herron, Consultant Neuropathologist, Belfast*

21. We received very helpful evidence from a cross-section of health professionals describing the importance of the component parts of specialist multidisciplinary care for people with muscular dystrophy and related neuromuscular conditions.
22. We heard about delays to the diagnostic process, which causes frustration both for patients and health professionals. Dr Brian Herron gave us an insight into the assessment of the biopsy:

“Now, in the past – and this is maybe something we can work on here – there has been a significant delay at this stage because we are outside the loop even though these are national referral centres. So if you are in Wales, or Scotland, or London, the biopsy gets sent there. I have to find funding; it’s not a problem as the funding will always come. I have to put in requisitions. Can I arrange the transport for the biopsy because it has to be sent frozen and that’s several hundred pounds, and that can cause a delay of several weeks as well? So there are delays at every stage. You’ve got a family wanting to know if their child has a life-limiting condition; it’s desperately frustrating for everybody. So I think from a neuropathological point of view, if the delay could be shortened by having some kind of centralisation of funding for diagnostic neuropathological services. That would be very helpful.”

23. Dr John McConville outlined the clinical time which is necessary for arranging the genetic testing:

“Current waiting time for neurophysiological tests in Northern Ireland is about 12 to 14 months for your first test. So it may involve genetic testing for common disorders; that is straightforward. For uncommon disorders, we have no direct commissioning arrangements, so for each individual case I have to write to the Board via the Trust, the Trust has to sign off and say ‘that’s ok, you can do that genetic test’. The Board has to decide whether that test can be done, then it comes back to me, then I can make the request for the funding for that individual genetic test to go. So that’s hours of admin time for us, and it takes maybe six months for a single genetic test, which, if it was available locally, you would just write at the bottom of the form ‘FSH Gene Test’ and it would just be done.”

24. We received evidence about the importance of the diagnosis, both in terms of the management of the condition and also in planning for the future. Dr McConville said:

“You say, ‘well what’s the point of making a diagnosis with some of the disorders?’ Well the point is, of course, that the disorders are different. They have different propensity to affect your heart for example, so we know if you need to see a cardiologist for a cardiomyopathy. Your breathing muscles, they have different prognostic outcomes. Not just your knowledge and information about your genetics and what the chances of your offspring getting the disorder might be, and the impact if you’re an adult, but also the focused management is very different when you know what’s wrong with somebody, rather than if you don’t. It makes an enormous difference to people and an enormous difference to clinicians.”

25. Dr Herron re-iterated the family planning aspect of making an early diagnosis and the consequences of this:

“A lot of the people are young children, very young children, and one of the times when speed is important is when the families are planning a second child or another child. And to know if this is an inherited condition – a one in four chance, one in two, one in a million chance – is very important for the families in those situations.”

26. We received written evidence from Professor Patrick Morrison about the sustainability of the genetic service. He told us:

“To sustain what we have at present, I contribute time equivalent to 2.0 consultants per annum to attend muscle clinics twice per month and the associated follow-up of seeing and testing and managing further at-risk or affected family members. We would also need a sum of around 1.5 per annum of genetic counsellor/nurse time to allow further outreach to other family members and consolidating the diagnosis of muscular dystrophy and related neuromuscular conditions in families. Currently, if I’m on leave, even though it’s not directly funded, I do have colleagues who will cover telephone calls etc. so at least families with muscular dystrophy get continuous genetic advice.”

27. We heard that it is vitally important for the care advisor post to be comprehensive and to cover all the responsibilities that other care advisors across the UK take on, which incorporates provision for both children and adults. Dr McConville highlighted this in his evidence to the Inquiry:

“They have to balance up those clinical nurse-led positions with how much is counselling support, transition support, information giver, and sign-poster. Those things are very useful too. So from the Trust position, that’s not straightforward, there isn’t enough service. And remember there are an estimated 2,000 people with a neuromuscular condition in Northern Ireland; there are certainly 500 to 600 people in the province with quite disabling neuromuscular disorders and most of those are adults, actually. So we need some structures in place to make sure that those people get some support as well.”

28. The need for greater education and training for health professionals, as well as a service constructed around the specialist team, was exemplified by Dr McConville's evidence:

"So it's your local GP, it's the generic services that are there. And these people usually are not knowledgeable about muscle disorders. It's exceptional for them to be knowledgeable about muscle disorders. So there is a shortfall, and absolutely, this is a huge vulnerability generally with support services for rare disorders, that if you put a single individual there, you are extremely vulnerable and you don't have a complete service."

29. We were encouraged to hear from Dr McConville that there is greater importance placed on the vital role of respiratory care but were concerned to hear that respiratory care for adults is lacking when compared with paediatric services:

"The emphasis on respiratory care has really changed quite a lot in the last decade or so, because we know that there is certainly an enormous difference in people's quality of life, and there is good evidence to suggest that it extends people's quality of life for quite some time.

"So there has been a huge change in the emphasis and it should be that every young person with a condition, for example, like Duchenne muscular dystrophy, who is prone to respiratory failure, is referred to a respiratory physician early in the course of the disorder.

"One of the things which always perplexes me is how the framework gets drawn up which sets standards of care and allows us to commission services. So there was a respiratory framework document which specifically dealt with long-term ventilation and that set out standards of care for assessment and allowed commissioning of services for that. But, actually, long-term ventilation is only commissioned for children and young people. So adults are not covered by that document and despite my commenting on that many, many times as part of the scrutiny, and telling them, 'you can't have a service for this child but not for when they get to 19'; that just doesn't work."

30. We received written evidence from Siobhan MacAuley, Clinical Specialist in Neurophysiotherapy, about the need for comprehensive specialist neuromuscular physiotherapy to be an integral part of a co-ordinated specialist multidisciplinary service:

"There is no provision for annual leave, succession planning or sick leave. When on secondment three years ago, the post was left empty, and again was empty when I was on leave for three weeks.

"There needs to be a linkage between the physios that work with paediatrics/adults/respiratory as, at the moment, the services tend to work separately. There also needs to be some linkage on a regional basis rather than coming from the Belfast Trust.

“As the children progress into adult services, they move from their school service to community provision, which is sadly lacking and under extreme pressure. The adult provision will be by musculo-skeletal and community physios who don’t have specialist knowledge of neuromuscular conditions and this may actually have a deleterious effect.”

31. Dr McConville summed up the urgent need to co-ordinate the specialist services already in existence:

“So the principal feeling, I think, is a lack of co-ordinated capacity planning – a lack of facilitation – to make the generic services work for individuals by having appropriate levels of specialism. But that means you need a specialist neuromuscular person, you need specialist nurse support, counselling services and psychological services, and you need individuals within each of those areas who’ve got the interest and capacity to do it. I think we have those individuals, they’d be keen to do it; what we don’t have is this really being facilitated. So we’re miles away – and not too far away – from having a service.”

32. It is evident that specialist health professionals do an excellent job in providing the best possible service they can for people with muscular dystrophy and related neuromuscular conditions, but they require increased support in terms of additional posts and clinical time within the specialist multidisciplinary team set-up.

## Section 3

### Evidence summary

#### Commissioning, planning and delivery of specialist services

##### Evidence was provided by:

*Donna Curley, Head of Community Services for Adults with a Physical Disability, Southern Health and Social Care Trust*

*Dr Colette Donaghy, Consultant Neurologist, Western Health and Social Care Trust*

*Karin Jackson, Co-Director Child Health and Dental Services, Belfast Health and Social Care Trust*

*Dr Sandya Tirupathi, Paediatric Neurologist, Belfast Health and Social Care Trust*

33. We received evidence on the significant commissioning and planning developments which are required to improve the neuromuscular service provision in Northern Ireland and the importance of incorporating different parts of the service into the specialist multidisciplinary team context.
34. After many months of delay, we were pleased to hear commitments to advertising for, recruiting and appointing the long-awaited care advisor post and we express the hope that there are no further delays. Karin Jackson informed us:

“We should be in a position where that post will be advertised towards the end of this month [May]. There is another phase of consultation because we had endeavoured that we would speak to Dr Bailie about that when we put the post through grading. We will do that and the job will be out before the end of May, with the view that the post will be recruited before the end of June, the start of July.”
35. Karin Jackson, confirming that the post would cover paediatric and adult services, outlined the structure and funding of the role:

“We have part-funding for one post from the Health and Social Board and we have identified resource from our existing budget. The Muscular Dystrophy Campaign funding ended in March 2011<sup>4</sup>. We have created one post, which is a neuromuscular specialist nurse post, which will work in conjunction with other neurology specialist nurses. If you have a full-time employee, they have about seven weeks of the year for annual leave and study leave. By incorporating this post with other specialist nurses, there will always be somebody at the other end of the phone.”

36. We heard alarming evidence from Dr Sandya Tirupathi about the lack of co-ordination and the lack of named leadership for different vital components in the specialist multidisciplinary team:

“On therapeutics, as and when a patient comes, you start off the diagnostic process but you also do the referral for physiotherapy, occupational therapy, speech and language therapy, social work, all these aspects. They all go simultaneously so they are linked in; but we do not have a named physiotherapist who could lead the neuromuscular service, we do not have a named occupational therapist who could lead the service, or a psychology service, which is really important because diagnosis of a neuromuscular condition has a huge psychological impact on the family, so that aspect is lacking.”

37. We were deeply concerned about the transition from children’s services to adult services and the inconsistencies of service provision. Donna Curley told us:

“Sometimes in the area of transition, where people are moving from children’s services to adult services, there can be gaps in service and it isn’t as smooth as we would like it to be. Also, when moving into adult teams, there maybe isn’t the number of identified therapists available with the expertise needed on the ground. That is something the Trusts are going to have to address.”

38. We were encouraged by the steps taken to develop networks of services in Northern Ireland but are concerned about a potential imbalance between children’s services and adult services. Karin Jackson said in her evidence:

“We are looking to develop networks in Northern Ireland where we are providing services with a base and outreach. Sandya [Tirupathi] is already doing that in other aspects of her work and we are doing that with paediatric services.”

39. We heard evidence from Robert Meadowcroft, Chief Executive of the Muscular Dystrophy Campaign, about the need for commissioning leadership for services in Northern Ireland. He told us:

“I am afraid that Northern Ireland has been going backwards and is inferior to the rest of the UK in the commissioning of specialist healthcare services. *The Thomas Report* in Wales identified the need for a Lead Commissioning Officer and that is what is necessary in Northern Ireland to drive forward service improvements which are urgently required. We need additional care advisor support in place and more clinical time made available. The ‘invest to save’ case has been made – investment not only to prevent unplanned emergency admissions to hospital for people with muscular dystrophy and related neuromuscular conditions but also to reduce costs.”

40. We received written evidence from Aidan Cosgrove, Clinical Lead for Paediatric Orthopaedics, that there is a need to plan and sustain crucial input into the service provision:

“We have had a problem in that the orthopaedic provision has always been ad hoc to this clinic, without the orthopaedic presence at the muscle clinic being funded, and was provided on an additional basis by the clinician. With the modern emphasis by the trusts on job planning, it has not been possible to sustain this. We believe that there ideally should be a resourced commitment by an orthopaedic surgeon to the clinic, probably ideally on a monthly basis.”

41. We were deeply concerned by the lack of education and development of health professionals in the neuromuscular field. Dr Colette Donaghy, who subsequently informed us that the Health and Social Care Board is setting up a ‘Neurological Conditions sub-group’, told us:

“Neurology needs organising. Unless there is a specific interest, clinicians have to develop the knowledge themselves.”

42. The Chartered Society of Physiotherapy Northern Ireland submitted very helpful evidence in setting out its concerns for specialist physiotherapy provision for muscular dystrophy and related neuromuscular conditions and explaining the improvements that could be made with investment in services:

“The Chartered Society of Physiotherapy is concerned that currently patients with these conditions do not receive continuous specialist physiotherapy and that those who live in rural areas are particularly disadvantaged. The Chartered Society of Physiotherapy is particularly concerned that there is no dedicated funding for the specialist neuro- and respiratory physiotherapy services in Northern Ireland. In addition, the provision of specialist physiotherapy services is constrained by a lack of succession planning and dedicated funding for the specialist role. There is an urgent need to address this shortfall and ensure that patients have access to specialist physiotherapy as part of a multidisciplinary team.

“Arrangements should be developed to ensure that patients with muscular dystrophy can receive ongoing and timely physiotherapy interventions. Investment in specialist neuromuscular physiotherapy services is clinically effective and will save money by saving consultants’ time, reducing emergency admissions and re-admissions, reducing hospital stays and providing better co-ordination of care locally.”

43. We welcomed the detailed analysis from the College of Occupational Therapists on the current provision of occupational therapy for muscular dystrophy and related neuromuscular conditions in Northern Ireland. The written evidence submission informed us:

“There is a regional variance with regards to delivery of occupational therapy provision for people with muscular dystrophy, with reports of services with good practice but also of gaps in provision. Occupational therapy is delivered in special schools (with some services limited owing to staffing issues) or by community-based paediatric occupational therapists, if children attend mainstream schools.

“To date, there is no specialist occupational therapy with dedicated funding for occupational therapy input within the neuromuscular team that we are aware of.

“There is an occupational therapist post in the City Hospital, and the post-holder is on a bleep [paging] system to respond to referrals from the Muscle Clinic. The post is not covered at present.

“It would seem essential that, at a minimum, there should be a specialist/consultant occupational therapist post within the Muscle Clinic – specialist multidisciplinary team – that can provide specialist advice and support to occupational therapists regionally as well as advise on very complex cases, ensuring a high quality of care. In addition, this service-user group requires prompt and timely input and, owing to existing waiting lists and pressures on existing services, they generally need to wait for occupational therapy input at present.”

44. We approached the Health and Social Care Board for a response to the questions considered at the session on commissioning, planning and delivery of neuromuscular services. We received the following response:

**Q1) Northern Ireland is currently the only part of the UK without a neuromuscular care advisor. Can you update us on the recruitment process for a new care advisor, as families have been left without access to specialist care, support and advice since the previous post-holder resigned in November 2011?**

45. For a three-year period up until 31 March 2011, the Muscular Dystrophy Care Advisor post was funded by the Muscular Dystrophy Campaign. At the request of the Muscular Dystrophy Campaign, Belfast Trust was asked to fund this post from April 2011, as the charity was unable to continue with its funding. This post was funded from within Belfast Trust’s budget.

46. Unfortunately, owing to health reasons, the post-holder resigned from the post in November 2011 and, following this, the Belfast Trust reviewed the role in collaboration with clinicians involved in the service. It was agreed that replacing the care advisor post with a neuromuscular nurse specialist post would provide patients and their families with an improved service, incorporating many of the functions carried out by the care advisor, with specialist clinical knowledge and skills.

47. Belfast Trust has shared the job description for the neuromuscular nurse specialist post with individual parents and carers for comment, and is currently considering the responses received. In addition, the Muscular Dystrophy Campaign is also providing comments on behalf of parents, carers and patients. It is hoped that this post will be appointed in the coming months.
- Q2) Can you give me the named point of contact for families urgently seeking care and support at the present time in Northern Ireland?**
48. All parents are able to make direct contact with the paediatric neurologist who specialises in neuromuscular disease (NMD) within the Royal Belfast Hospital for Sick Children, which is part of the Belfast Trust. In addition, all children have a named community paediatrician and social worker.
- Q3) Unplanned emergency admissions to hospital for people with neuromuscular conditions in Northern Ireland currently cost £2.27million per year. Care advisors are a vitally important part of the specialist multidisciplinary care to reduce unplanned admissions for patients with these conditions. Therefore, what action is being taken to invest in specialist neuromuscular care in order to save money?**
49. Please see update on care advisor post detailed in Q1. The neuromuscular nurse specialist will have expertise in clinical aspects of NMD, which will support families and provide support to other health professionals including general practitioners who are involved in the child's care. It is anticipated that the clinical focus of this role will be more responsive to patients' clinical needs and will allow more care, for example reviews and patient assessment, to be carried out at the patient's home as well as in hospital.
- Q4) Can you identify the services which are at risk? What neuromuscular service improvements can be made in Northern Ireland?**
50. The development of clinical networks with specialist centres in other parts of Great Britain is a priority for specialist children's services in Northern Ireland. Over the next six to twelve months, formal networks with highly specialist centres in other parts of the UK will be further developed. This will include formalising links with a specialist neuromuscular service so that clinicians can develop expertise in neuromuscular conditions, and experts from the specialist centres can provide input into the service in Belfast.
51. The Health and Social Care Board has recently agreed three-year funding for a fixed-term clinical network manager post. This role will be to develop and formalise network arrangements at a local, regional and national level. Neuromuscular patients will be one of the patient groups covered within this role.
52. The development of a formal clinical network for neuromuscular conditions will mean that clinicians specialising in neuromuscular conditions, who are based in Northern Ireland, will be able to link with specialist centres in other parts of the UK. Part of this arrangement will be for a consultant from a national centre to visit the Royal Belfast Hospital for Sick Children three to four times a year to support the care of children within this group and to help develop the neuromuscular service in Northern Ireland.

53. The post-holder will also help strengthen links between Royal Belfast Hospital for Sick Children and local services closer to patients' homes.
54. The clinical network manager post has been advertised and interviews are scheduled for the end of May.
- Q5) Can you tell us about succession planning that is in place for key specialist multidisciplinary care posts in Northern Ireland? What action do you think needs to be taken to ensure appropriate succession planning for neuromuscular services in Northern Ireland?**
55. Every effort is made to ensure effective succession planning for doctors across a range of specialities. Generally, where possible, medical posts where the post-holder is approaching retirement age are highlighted and identified to the Northern Ireland Medical and Dental Training Agency in order for them to allocate a junior doctor to a specialist training programme. Similarly, where it is apparent that a specialist nurse is approaching retirement, steps can be taken to begin to train staff who have generic skills.
56. However, as specialist medical training can take up to five years and retirement age is not fixed, it can prove challenging to co-ordinate the completion of training with the retirement of a senior consultant in specialties where the number of consultants is very low. Both the Health and Social Care Board and the Trust are aware of these challenges and aim to address them via advanced planning where possible.
57. As outlined above, establishing formal network arrangements will also greatly assist in developing the Northern Ireland service.
- Q6) Do you think that all people with muscular dystrophy and related neuromuscular conditions in Northern Ireland currently receive comprehensive multidisciplinary care? If not, what needs to be done to achieve this? Are new specialist posts required, and if so, why?**
58. Yes, multidisciplinary care is available for people in Northern Ireland with these conditions.
59. There is a neuromuscular clinic held twice monthly in Belfast City Hospital. This is led by an adult neurologist and a paediatric neurologist with an interest in neuromuscular conditions. The clinic is also attended by a clinical geneticist, neuro-physiotherapist and an orthotist, and has input from an occupational therapist. The consultants working in the clinic make referrals to and have close working relationships with cardiology, orthopaedics and respiratory colleagues.
60. There have been preliminary discussions in the Belfast Trust about the possibility of developing a one-stop-shop clinic with the other specialists present. The Health and Social Care Board and the Public Health Agency will work with the Trust to explore if a one-stop-shop clinic for neuromuscular conditions can be put in place.

**Q7) Can you describe the respiratory care and ventilatory support that patients with neuromuscular conditions receive in Northern Ireland? What are the referral practices for respiratory care?**

61. There have been significant developments in the respiratory service for patients with neuromuscular conditions over the past six to twelve months. An important part of this has been the appointment of a specialist physiotherapist with expertise in the management of the respiratory complications of neuromuscular conditions.
62. There is appropriate service provision for long-term ventilation in paediatrics. This service, which consists of a respiratory physician, specialist nurse and respiratory physiologist, is a regional service which also provides respiratory support to local services.
63. The Public Health Agency and the Health and Social Care Board are in the process of setting up a regional group to consider the provision of non-invasive ventilation in the community for adults affected by a number of diseases, including muscular dystrophy.

**Q8) How do specialised services link in with community-based services and social care?**

64. As outlined above, all patients have access to a named community paediatrician and social worker.

**Q9) What assurances can you give us that specialist neuromuscular knowledge and training at tertiary level is disseminated to primary and secondary care, where there is often minimal or no expertise, nor awareness, of neuromuscular conditions?**

65. The appointment of a clinical network manager will help develop a neuromuscular network. Part of this will be the development of and formalising links with local services.
66. The neuromuscular nurse specialist will also have a role in liaising with services at a local level.

**Q10) What actions will you be prioritising for improving services, following today's discussions?**

67. The main priorities will be to work closely with Belfast Trust to ensure that the specialist nurse post is progressed and appointed as soon as possible and to explore formal network links in order to develop the Northern Ireland service further.

**All Party Group on Muscular Dystrophy’s response to the evidence submitted by the Health and Social Care Board**

- 68. We are reassured by the comments from the Health and Social Care Board about the commitment to the recruitment of the care advisor post, which has been vacant for several months. We would encourage the Health and Social Care Board to consider the next steps for additional care advisor support.
- 69. We welcome the development of a clinical network for children’s services incorporating neuromuscular services in Northern Ireland. However, to prevent uneven standards of care for people with muscular dystrophy and related neuromuscular conditions, urgent action must be taken to ensure that adults with these conditions receive the same level of care as children.

**Costings data**

- 70. Based on NHS data in English regions gathered from the Muscular Dystrophy Campaign’s *Invest to Save* report<sup>5</sup>, we have calculated that, for the estimated 1,992 people in Northern Ireland who have muscular dystrophy and related neuromuscular conditions, there would be 787 emergency hospital admissions each year at a total cost of £2.27 million. We believe that access to high-quality, specialist multidisciplinary care would significantly reduce these unplanned hospital admissions and, consequently, reduce the considerable costs involved.
- 71. The following table illustrates the recommended posts necessary for patients living with muscular dystrophy and related neuromuscular conditions across Northern Ireland to prevent the service from collapsing:

<b>Posts required</b>	<b>£s recurring</b>
1 WTE consultant neurologist (inc. secretarial support) specialising in neuromuscular conditions	£130,000
1 additional WTE care advisor (band 7 – mid range)	£43,012
1 WTE specialist physiotherapist (band 7 – mid range)	£43,012
0.5 WTE psychologist (mid grade band 8a)	£25,533
0.5 WTE occupational therapist (band 7 – mid range)	£21,506
1 network manager (band 7 – mid range)	£43,012
0.5 WTE administrator (band 5 – mid range)	£14,591
<b>Total investment required (full-year cost)</b>	<b>£320,666</b>

- 72. The cost per patient per year would be just £160.98, or £13.41 per month.
- 73. We have expressed our alarm elsewhere in this report at the lack of succession planning in recruiting for and appointing a care advisor post, following the previous post-holder’s departure in November 2011. We believe that the current shortage of clinical time which can be dedicated to neuromuscular services, along with the lack of named leads for different parts of the specialist service required, are having a detrimental effect on care and support for people with muscular dystrophy and related neuromuscular conditions in Northern Ireland.

## **Appendix**

### **The All Party Group on Muscular Dystrophy Inquiry**

The Inquiry was launched in December 2011 as an in-depth investigation of access to specialist multidisciplinary care for people living with muscular dystrophy and related neuromuscular conditions in Northern Ireland. This arose from the concerns of the All Party Group that people living with these conditions were not receiving the specialist care provision that they are entitled to.

The All Party Group Inquiry has received both written and oral evidence that underlines the need for urgent action to improve and strengthen multidisciplinary healthcare for this vulnerable group of patients living with rare and very rare conditions.

### **Witnesses**

The Group would like to thank all the expert witnesses, from both a patient and a professional perspective, who gave oral evidence and submitted written evidence describing and analysing a wide range of key issues. The All Party Group greatly appreciates the very useful and informative evidence which it can now take forward through the recommendations in this report.

Below is a list of the witnesses who provided oral evidence for the Inquiry:

#### **5 December 2011 – What constitutes specialist multidisciplinary care?**

*Dr John McConville, Consultant Neurologist, Belfast*

*Dr Brian Herron, Consultant Neuropathologist, Belfast*

#### **7 February 2012 – Living with muscular dystrophy and related neuromuscular conditions**

*Dr Janet Bailie, whose son Andrew has Duchenne muscular dystrophy*

*Margaret Casey, whose son Brendan has Duchenne muscular dystrophy*

*Michaela Hollywood, who has spinal muscular atrophy*

*Marina Lupari, whose son Marc has Duchenne muscular dystrophy*

*Gerry McCollum, whose son Christopher had Duchenne muscular dystrophy and passed away in 2001*

*Dr Amy Jayne McKnight, whose father Barry has spinal muscular atrophy*

*In every oral evidence session, other contributions were received and taken on board from people affected by muscular dystrophy and related neuromuscular conditions.*

### **30 April 2012 – Commissioning, planning and delivery of specialist services**

*Donna Curley, Head of Community Services for Adults with a Physical Disability,  
Southern Health and Social Care Trust*

*Dr Colette Donaghy, Consultant Neurologist, Western Health and Social Care Trust*

*Karin Jackson, Co-Director Child Health and Dental Services, Belfast Health and  
Social Care Trust*

*Dr Sandya Tirupathi, Paediatric Neurologist, Belfast Health and Social Care Trust*

### **Terms of reference**

The formal Terms of reference for the Inquiry are:

*“To determine the current provision and quality of specialist services in Northern Ireland for people with muscular dystrophy and related neuromuscular conditions; to highlight areas of best practice and to recommend possible solutions where improvements are necessary.”*

## **Written evidence and additional evidence provided to the Inquiry:**

*Access to Specialist Neuromuscular Care: The Walton Report*  
All Party Parliamentary Group for Muscular Dystrophy, August 2009

*Building on the Foundations: Focus on Physio*  
Muscular Dystrophy Campaign, May 2008

*Building on the Foundations: State of the Nation – The 2010 National Survey*  
Muscular Dystrophy Campaign, August 2010

*Building on the Foundations: Invest to Save – Improving services and reducing costs*  
Muscular Dystrophy Campaign, May 2011

*Building on the Foundations in Northern Ireland: Improving Specialist Care, Support and Independence*  
Muscular Dystrophy Campaign, February 2009

Chartered Society of Physiotherapy Northern Ireland response, May 2012

College of Occupational Therapists response, May 2012

*Duchenne Standards of Care guidelines*  
Treat-NMD, June 2010

Health and Social Care Board response, May 2012

*Muscle disease: The Impact, Incidence and Prevalence of Neuromuscular Conditions in the UK*  
Muscular Dystrophy Campaign, January 2010

*National Patient Survey 2010*  
Muscular Dystrophy Campaign, August 2010

*Spinal muscular atrophy Standards of Care guidelines*  
Treat-NMD

### **Additional evidence provided by:**

Dr Janet Bailie  
Roy Bailie  
Aidan Cosgrove  
Dr Colette Donaghy  
Sean Fitzsimons  
Barry Headley  
Dr Brian Herron  
Mary Loughran  
Marina Lupari  
Siobhan MacAuley  
Andrew and Yvette McClean  
Gerry and Geraldine McCollum  
David McDonald  
Sean McKinney  
Dr Amy Jayne McKnight  
Robert Meadowcroft  
Professor Patrick Morrison  
Marie Mulholland  
Davy and Angela Rogan  
Professor Michael Shields  
Cathy Smyth  
Gary and Bev Stevenson  
David and Beth Watson  
Dean Widd

### **References**

1. Calculation based on Muscular Dystrophy Campaign's *Invest to Save* report (2011) in which it is estimated that £31million is being wasted on unnecessary emergency admissions across the UK out of a total of £81million
2. 'orphan conditions' is a term used for rare conditions
3. Muscular Dystrophy Campaign's *Invest to Save* report (2011)
4. See p.23 for the response to Q1 by the Health and Social Care Board
5. Muscular Dystrophy Campaign's *Invest to Save* report (2011)



**The McCollum Report:**

Access to specialist neuromuscular care in Northern Ireland

All Party Group on Muscular Dystrophy in the Northern Ireland Assembly

July 2012