

**The Mackie Report:**

Access to specialist neuromuscular care  
and social care in Scotland

*Cross Party Group  
in the Scottish Parliament  
on Muscular Dystrophy*

September 2010

# The Mackie Report: Access to specialist neuromuscular care and social care in Scotland

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## Foreword

The evidence published in *The Mackie Report* emphasises the need for the Scottish Government and NHS Scotland to take urgent action to address the significant gaps and inequalities in the provision of specialist neuromuscular care and social care highlighted by expert witnesses.

The Cross Party Group's Inquiry was conducted alongside the neuromuscular services review commissioned by the Scottish Government in September 2009 and undertaken by the Scottish Muscle Network. The Cross Party Group recognises the excellent work done by the Scottish Muscle Network. The evidence received demonstrated that, while there are strong aspects of specialist care, there are clear disparities in the existence and quality of service provision in both health and social care.

The lack of structure and organisation between many parts of health and social care that was reported to the Cross Party Group is unacceptable. It is essential that neuromuscular Care Advisor posts are funded by and embedded within the NHS with an increased capacity as part of the specialist multi-disciplinary team and that more appointments are made to meet the needs of people with neuromuscular conditions across Scotland.

The overall impression conveyed by the evidence is that there is a postcode lottery of services depending on whether there is access to specialist care and social care. There is also a very real concern shared by patients, families and health professionals that economic uncertainty and financial restrictions will have a devastating impact on the level and quality of service. It is therefore important to remember, as highlighted in one of the evidence sessions by Dr Martin Hepworth, whose son has Becker muscular dystrophy, that patients' needs must still be met. Investing in services will create savings as unplanned emergency admissions to hospital for people with neuromuscular conditions, which cost an estimated £6.7million per year according to the Muscular Dystrophy Campaign, will be greatly reduced.

I would like to place on record my thanks to 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 MSP colleagues for their interest and contributions in supporting the work of this Inquiry from April 2010 to September 2010. 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 Reg Mackie, whose son Alex had Duchenne muscular dystrophy and passed away in 1970. Reg has been a devoted supporter of the Muscular Dystrophy Campaign for 50 years. His many distinguished roles at the charity included being a founding member and first Chairman of the Muscular Dystrophy Campaign's Scottish Council and a Vice Chairman of the Muscular Dystrophy Campaign. In recognition of his selfless commitment, determination and continued support, the Cross Party Group is very pleased to name this report *The Mackie Report*.

**Jackie Baillie, MSP for Dumbarton**



**Chair**

**Cross Party Group in the Scottish Parliament on Muscular Dystrophy**



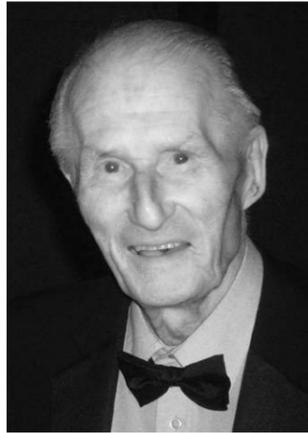
## About Reg Mackie

Reg Mackie has been one of the Muscular Dystrophy Campaign's most devoted supporters for 50 years. Reg, whose son Alex was diagnosed with Duchenne muscular dystrophy in 1960 and passed away in 1970, has worked tirelessly in support and fundraising for the Muscular Dystrophy Campaign.

Reg has held many distinguished roles at the charity included being a founding member and was first Chairman of the Muscular Dystrophy Campaign's Scottish Council from 1975 to 1986 and then elected a Vice Chairman of the Muscular Dystrophy Campaign.

In 1979, Lord Attenborough, an Honorary Life President of the Muscular Dystrophy Campaign, sent these words to Reg, in a personal letter,

*"Your family has been an inspiration to many of us over the years. While people such as yourself continue to serve the Group with such loving devotion, I am certain that not only is our future safe, but that ultimately we must achieve our objectives."*



## The Cross Party Group on Muscular Dystrophy

The Cross Party Group in the Scottish Parliament on Muscular Dystrophy is chaired by Jackie Baillie MSP and is made up of a cross party group of Members of the Scottish Parliament (MSPs). It aims to ensure that the needs of people living with muscular dystrophy are highlighted in the Scottish Parliament and to press for improvements to essential services for families across Scotland. The secretariat of the group is provided by the Muscular Dystrophy Campaign.

## Acknowledgements

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

## The Cross Party Group's Members of the Scottish Parliament are:

Jackie Baillie MSP (*Labour, Dumbarton*) (*Chair*)

Malcolm Chisholm MSP (*Labour, Edinburgh North and Leith*)

Cathy Craigie MSP (*Labour, Cumbernauld and Kilsyth*)

Rhoda Grant MSP (*Labour, Highlands and Islands*)

Robin Harper MSP (*Green, Lothians*)

Hugh Henry MSP (*Labour, Paisley South*)

Cathy Jamieson MSP (*Carrick, Cumnock and Doon Valley*)

Tom McCabe MSP (*Labour, Hamilton South*)

Michael McMahon MSP (*Labour, Hamilton North and Bellshill*)

Hugh O'Donnell MSP (*Liberal Democrat, Central Scotland*)

Cathy Peattie MSP (*Labour, Falkirk East*)

Mary Scanlon MSP (*Conservative and Unionist, Highlands and Islands*)

Elaine Smith MSP (*Labour, Coatbridge and Chryston*)

John Wilson MSP (*Scottish National Party, Central Scotland*)

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

## Executive Summary

The Cross Party Group (CPG) in the Scottish Parliament on Muscular Dystrophy launched its Inquiry into access to specialist neuromuscular care and social care in Scotland in April 2010 alongside the hard work and extensive research carried out by the Scottish Muscle Network.

The Inquiry showed that patients in Scotland affected by neuromuscular conditions experience a patchy and sometimes non-existent level of service from diagnosis onwards and that there is an alarming reduction in services when moving from paediatric to adult services, such as the provision of physiotherapy and hydrotherapy, which are essential parts of specialist multi-disciplinary care.

To make improvements to the current provision and give patients with neuromuscular conditions the service they deserve it is imperative that the Scottish Government ensures that Care Advisor posts are embedded within the NHS. Patients, families and health professionals time and again stressed the importance of these roles as part of the specialist multi-disciplinary team. The existing Care Advisor posts are currently funded 50:50 by the Muscular Dystrophy Campaign and the NHS, with an agreement for full NHS funding from April 2011. These posts need to be increased in capacity and added to with appointments covering a wider area in Scotland.

We learned that there are pockets of good practice in social care provision, and there are people who can join the services up. Children's services are relatively good but action needs to be taken to improve the transition to adult services as well as adult services themselves. The support provided to families, with personal interaction to help somebody through the maze of benefits, is either excellent or non-existent. It is vital that services are more integrated, and that there is a balanced mix between self-directed support and services provided.

The CPG and the Muscular Dystrophy Campaign are calling on the Scottish Government to act on the following recommendations.

## Recommendations

1. The Scottish Government and NHS Scotland define and fully recognise neuromuscular services as specialist services.
2. NHS Boards and the Scottish Government hold discussions with the Scottish Muscle Network and Muscular Dystrophy Campaign to discuss further specific areas of investment to prevent unplanned emergency admissions and reduce related costs.
3. NHS Boards create a structure of accountability and responsibility for neuromuscular care; key areas of specialist multi-disciplinary neuromuscular care such as physiotherapy, respiratory care and cardiac care require urgent service development.
4. The Scottish Government takes steps to make sure that existing vital neuromuscular Care Advisor posts are secured long-term within the NHS, with increased capacity, and creates more of these posts, which provide the best possible support and advice and reduce unplanned emergency admissions by investing small amounts to save more in the long-term.
5. NHS Boards appoint transition workers to facilitate patients' transition from paediatric to adult services.
6. NHS Boards and NHS Trusts implement measures to ensure that the unacceptable disparity between paediatric and adult services is reduced.
7. The Scottish Government addresses the inequalities of wheelchair service provision so that there is consistency and that people with neuromuscular conditions are not forced to resort to private purchase of a suitable wheelchair.
8. The Scottish Government ensures that Specialist Nurses are retained in the specialist multi-disciplinary team for people with neuromuscular conditions and are not transferred from these specialist duties to acute wards.
9. The Scottish Government, in conjunction with NHS Scotland, improves the level of recognition and knowledge of neuromuscular conditions at GP level.
10. The Scottish Government implements a structured long-term succession planning system for key neuromuscular posts to address the alarming potential gaps in future service provision.
11. The Scottish Government reviews the situation regarding the unequal treatment of the small number of patients with Pompe disease living in Scotland. While some patients are currently receiving enzyme replacement therapy, others are being refused this treatment. In England all patients are able to access this treatment.
12. NHS Boards and Scottish Councils develop structured joint planning provision so that there is a seamless transition and co-ordination between health and social care services.
13. The Scottish Government, in conjunction with the Scottish Councils, learns from the examples of good social care provision highlighted in this Inquiry to provide a high standard of care for all people with neuromuscular conditions.

14. Scottish Councils ensure that there are an adequate number of welfare benefits advisors to assist people with neuromuscular conditions through the complexities of the benefits system so that they receive the help that they are entitled to.
15. Scottish Councils increase their co-operation across boundaries so that people with neuromuscular conditions receive the most appropriate and most effective care.
16. The Scottish Government implements the Scottish Muscle Network Review and Cross Party Group Inquiry's recommendations.
17. The Scottish Government ensures that the Scottish Muscle Network's excellent work has the required support to improve the specialist care provision for patients with neuromuscular conditions.

## Background to the Inquiry

The Cross Party Group in the Scottish Parliament on Muscular Dystrophy decided to launch an Inquiry into access to specialist care in Scotland to highlight developments in services in Scotland for people with muscular dystrophy and related neuromuscular conditions that need to be addressed and to identify areas of best practice.

The Inquiry was conducted alongside the neuromuscular services review commissioned by the Scottish Government in September 2009 and undertaken by the Scottish Muscle Network.

The Inquiry heard the views of people in Scotland who are affected by neuromuscular conditions, and those clinicians and health professionals who have a direct interest in the provision of services for this group of patients. The Inquiry also sought the perspective of those people who are responsible for the commissioning of these services in Scotland and representatives of local authorities in Scotland about the social care provision for people living with neuromuscular conditions.

The Muscular Dystrophy Campaign's *Building on the Foundations in Scotland: Improving Specialist Care, Support and Independence* report published in September 2008 was welcomed by Minister for Public Health, Shona Robison MSP, who was made aware of the urgent improvements to access to specialist care required and the need for a review of neuromuscular services in Scotland.

In September 2009 Deputy First Minister, Nicola Sturgeon MSP, announced a thorough review of neuromuscular services across Scotland to be undertaken by the Scottish Muscle Network. This commitment by the Scottish Government was welcomed by the Muscular Dystrophy Campaign, families living with neuromuscular conditions in Scotland and health professionals.

The formation of the Cross Party Group in the Scottish Parliament on Muscular Dystrophy was a significant step forward in giving neuromuscular conditions a prominent and powerful voice in the Scottish Parliament to press for essential improvements to neuromuscular services.

There are encouraging signs that the patchy level of specialist care and social care in Scotland may be rectified and that there are positive moves to ensure high quality standards of care in the NHS and in the social care setting. Firm action is now needed to implement the recommendations in this report to ensure all people living with neuromuscular conditions in Scotland have the same access to specialist services and social care as others in the UK.

## What is muscular dystrophy?

There are more than 60 different types of muscular dystrophy and related neuromuscular conditions. It is accepted that, for every million people in the UK, just over 1,000 children and adults are affected by muscle-wasting neuromuscular diseases. It is therefore estimated that some 6,000 people are affected by a neuromuscular condition in Scotland.

Many neuromuscular conditions are low-incidence, orphan conditions, with some regarded as very rare and ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the 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 under way 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 all neuromuscular conditions and is dedicated to improving the lives of all people affected by these conditions. Founded in 1959, the Muscular Dystrophy Campaign funds vital research, provides and supports care services and also gives information, advice and direct help to individuals living with these conditions.

The Muscular Dystrophy Campaign has set up a Scotland Muscle Group which works closely with the Cross Party Group to campaign for better neuromuscular services in Scotland.

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

## Section 1

### Evidence Summary

#### Living with muscle disease

Oral evidence was provided by:

Eileen McCallum – *Edinburgh, grandmother of two boys with Duchenne muscular dystrophy*

Eileen Stewart – *Glasgow, living with limb girdle muscular dystrophy*

Robbie Warner – *Dumbarton, father of young man with Duchenne muscular dystrophy*

1. We received thorough and detailed accounts of patients' and families' experiences of the significant inequalities in the provision of specialist multi-disciplinary care across Scotland.
2. We were deeply concerned that the quality and delivery of diagnosis and subsequent support for people with neuromuscular conditions has been markedly different. We were shocked by the lack of recognition and knowledge of neuromuscular conditions at GP level, which appears to hamper a quick diagnosis process. Eileen Stewart, who has limb girdle muscular dystrophy, described to us the drawn out process and the ordeal she faced with her diagnosis:

*"I was 13 when I was diagnosed with limb girdle muscular dystrophy. It took nine years in total – it is a hard time as you're growing up. You can't even put a name to why you can't climb stairs and can't do sports. It was a horrible diagnosis process. Being put on the steroids when I shouldn't have been led to bullying at school. That was a really hard time and psychologically really harmful. It didn't make me stronger."*

3. However, Robbie Warner, whose son Eoghan has Duchenne muscular dystrophy, related a more straightforward diagnosis process. He outlined the treatment and support that Eoghan receives:

*"Eoghan sees a variety of people throughout the year, mostly at Yorkhill Hospital, such as Dr Horrocks, once a year. He will also have his heart checked once a year and breathing checked at least once a year. That essentially is it – he doesn't go to the GP. He sees a local physio from the local Acorn centre – she actually comes to the house every two or three weeks. That essentially is the amount of people he sees from a medical point of view. Educationally he has a package that is put together. He is not seen as one with special needs within that because he doesn't need to be as such. There are meetings within the school on a yearly basis. He has an Occupational Therapist (OT) from the social work department and he has a social worker."*

4. We received evidence that paediatric services were comparatively better than adult services, and a worrying lack of dedicated services was brought to our attention in the transition period between paediatric and adult services. Eileen Stewart emphasised in her evidence the unacceptable lack of care and support in adult services and the effect that ongoing physiotherapy has in managing the condition:

*"When you go into the adult services, you are just left and don't get these things; whereas when you are at Yorkhill and in the children's services, it is much more apparent that you get physio more often. That is something that is really important. There is no cure for muscular dystrophy right now, but at least prevention from getting weaker as quickly can be helped by physio."*

5. Eileen Stewart went into further detail about the detrimental effect of a lack of physiotherapy and hydrotherapy and the deterioration she has experienced:

*"I see Dr Richard Petty at the Southern General Hospital in Glasgow once a year but every six months I go back to get my heart checked over. Other than that I don't get any physiotherapy or hydrotherapy. I don't get any care at home – my mum and my brother are my carers if I ever need help. They are the ones who have to do it all."*

*"A few weeks ago I caught a virus and since then I have felt a big deterioration coming on. I would like to stay out of a wheelchair as long as I can but if things go on the same way, it will be six months from now. If I was getting physio and being shown how to do the stretches, if I had access to that, it won't make me stronger but it will keep me out of a wheelchair for longer and keep my independence. Hydrotherapy has never been mentioned to me, even things like splints for my feet – when I am in bed, my feet are completely flat in that my calf muscles are starting to tighten up. When I was at Yorkhill, splints had been mentioned, and then I transferred over, and it hasn't been brought up since."*

6. Margaret Nicol, in her written evidence, highlighted the need for significant improvements to the specialist physiotherapy service for people with neuromuscular conditions.
7. We heard compelling evidence of the crucial importance of the Care Advisor to provide support and alleviate the burden on patients and families. Eileen McCallum, who recently visited Denmark for a BBC documentary, illustrated the difficulties of coping with home adaptations without advice and support from a neuromuscular Care Advisor:

*"In Denmark, as soon as a diagnosis was made for a little boy the same age as Milo, a health representative was assigned to them, took care of everything and there were no arguments with the council. We had such a struggle sorting out our home adaptations and the help given was so grudging at that point – it is better now. We should have applied on behalf of Milo and then Daniel, but because they knew there were two boys, they said that you've had the grant for this house, and we had only done a quarter of the work – it has been a hard struggle. The presence of a health representative would have calmed the waters and sorted it."*

8. Eileen McCallum was particularly impressed by the way young people were cared for in Denmark and called for a mindset change to improve services in Scotland:

*"When I went to Denmark, I was so struck by the carers, particularly in the house with four young men doing university degrees. The house was buzzing with at least a dozen young people of their age. I thought they must be well trained and well paid – it must be an attractive profession to go into. It's the same with all nursing but I think it's very important that it's their peers that are looking after them. It needs a whole mindset change. People I spoke to there who are nothing to do with the programme, like the driver and someone in a café, and they were asking what we were doing, their jaws dropped and didn't seem to understand why there was a difference."*

9. We were alarmed by the patchy provision of wheelchair services across Scotland and noted with concern the variety of individual circumstances, particularly in adult services. Several examples of privately purchased wheelchairs were brought to our attention. Kim Kemp told us about her unsatisfactory experiences:

*"I was given a battery operated wheelchair and I couldn't get out of it. They said they would have to re-refer me again. I said I couldn't understand why they had given me a chair I can't get out of and I suggested putting cushions on it. They said that was against health and safety. The reason for having the new chair is to get out of my new house. The chair is now sitting in the cupboard at home until I am re-referred and somebody comes back to me. I have a chair at work which rises but I can't take that out of the workplace."*

10. We received evidence throughout the Inquiry about the significant impact that good quality social care could have on the day-to-day life of both patients and families and the anxiety that a minimal amount of care causes. Eileen McCallum highlighted her concerns for her daughter and grandsons, and the need for adequate respite care:

*"I personally am worried about my daughter coping with the two boys and receiving four hours care per week. I would love to see the care coming as part of the care provided by different people without going through the over stressed Muirhouse social work department."*

*"Care is uppermost in my mind at the moment. More care should be provided to keep the pressure off, particularly the single parent, and also some form of respite care provided."*

11. Dr Martin Hepworth, whose son David has Becker muscular dystrophy, expressed his frustrations about the obstacles and the bureaucracy of social services that he and the health professionals have encountered:

*"David is trapped inside his own house; his electric wheelchair is not satisfactory and has needed several modifications; the single gene nurse is trying to get him a home care package, but is struggling with this. We are struggling with bureaucracies – anybody who works in the health service knows it is riddled with bureaucracy and lack of funding and resources. I'm sure social services are not being deliberately bad over this. This is a result of lack of resources and funding – the same applies for the single gene nurse and Care Advisors."*

12. We received deeply concerning evidence about the decline in the quality of care packages in recent years. Katrina Sweeney informed us about the restrictive nature of care packages currently set up:

*"The lack of resources is a big factor. The criteria for what people get are completely different now. My package set up nine years ago was a 24/7 package. I get good support but if I was trying to get one set up now, I would find things very different and I can't imagine what my life would have to be like to fit in. The criteria have changed so much that you would be restricted to basics."*

13. We heard evidence from Robbie Warner about the good quality personal care from the social worker for his son Eoghan which makes a real difference and this demonstrated an example of care which could be aspired to where levels of social care are unacceptably sub-standard. Robbie Warner told us:

*"The new social worker for Eoghan, who herself has a disability, is very well tuned into everything, and it makes a big difference. I think Sharon, the social worker, has already raised the issue with Eoghan of potential respite and going somewhere. It was actually her who convinced him that carers coming in the morning to get him ready would not be a bad idea rather than me doing it all the time."*

14. We received powerful evidence that psychological support can be extremely beneficial to both patients and families. Eileen Stewart highlighted to us the importance of having the option of psychological support available:

*"Psychological support could be really helpful. I have a fantastic family network as well, but sometimes having somebody that is completely separate and not involved in your life, who isn't a member of your family or a friend – that could be really helpful, especially for me right now. It is hard growing up, coming to terms with being an adult and that muscular dystrophy isn't going away. It shouldn't be compulsory but it would be really helpful to have the option of somebody to talk to. It is something I have thought about in the past but I would need to pay for it."*

15. We heard from Robbie Warner how planning and advanced acknowledgement of service changes are extremely helpful for patients and families to ensure that they have the care and support they deserve. Robbie Warner expressed his hopes for service improvements:

*"I would want advice available for people living with muscular dystrophy, and I would want the planning to be done and for people to acknowledge it. I would want the whole system streamlined in such a way that you don't have to fight to get everything, because if you get it at the end of the fight, you wonder whether all that energy was wasted in terms of them resisting it. I would like to see a change of attitude that would say that you need it and you plan for it, and get into a working relationship. The big thing for me is the wheelchair provision and the home adaptations, aside from psychologically coming to terms with it."*

## Section 2

### Evidence Summary

#### What constitutes specialist multi-disciplinary care?

Oral evidence was provided by:

Dr Stephen Banham – Consultant Respiratory Physician, Glasgow

Janette Barrie – Nurse Consultant for Long Term Conditions, NHS Lanarkshire

Alex Davidson – Chair, Scottish Muscle Network

Dr Ian Grant – Home Ventilation Service, Edinburgh

Prof Alex McMahon – Deputy Director of Strategic Planning and Modernisation, NHS Lothian

Dr Robert McWilliam – Consultant Paediatric Neurologist, Glasgow

16. We received very helpful evidence from the Scottish Muscle Network, which uncovered alarming widespread disparities across many aspects of specialist care during its review of neuromuscular services. Alex Davidson outlined some of the key findings of the review:

*“The headlines are the difficulties with data of numbers of people with neuromuscular conditions; services with funding which has been short-term or temporary – such as specialist nurse and Care Advisor posts – adult neurology; paediatric and adult psychotherapy, and respiratory services were all consistently mentioned by staff across all areas as being most in need of development; and also the need to encourage more professionals to have a specialist interest in neuromuscular conditions in neurology and physiotherapy. Adult services are patchier than paediatric services. Transition came up in discussions a lot. There is need for more contact with patients as some have been out of touch with specialist services for many years. There needs to be better end of life care. There are real issues around wheelchairs, equipment, adaptations and social care issues.”*

17. We were deeply concerned by the cost cutting of vital services by NHS managers, which Dr Robert McWilliam outlined to us:

*“Many services are potentially at risk because our managers are looking for cost cutting wherever they can find it. The specific thing is Care Advisor funding, which has been funded by the Muscular Dystrophy Campaign, and we are struggling to get that transferred to the NHS, and in this climate that will be a real struggle.”*

18. We received alarming written evidence from Marina di Marco about the disparities in specialist physiotherapy provision and the need for a more cohesive service across Scotland:

*“A specialist adult physio is required for the adult services as the current neuromuscular physio service cannot input into adults over the age of 40 and those who have been diagnosed in the adult service. There is also no specialist physiotherapy service to the myotonic dystrophy patient population in the West of Scotland. We thus have an inequitable neuromuscular physiotherapy service in the West of Scotland as well as a different service to the east and north. This service requires a more cohesive approach with one overall therapist to pull everything together and further develop the role of physio in neuromuscular disorders.”*

19. We welcomed the discussions during the evidence gathering sessions on the cost of unplanned emergency admissions, which is an estimated £6.7million per year, and the potential savings that can be made by investing in specialist services. Dr Stephen Banham, following a discussion on the importance of setting up adequate care packages, told us:

*“The other point that goes on is one that the Muscular Dystrophy Campaign is looking at in terms of the unplanned emergency admissions and the cost of that, and there is of course the cost of keeping these people, who are entirely well to go home, in very expensive medical facilities.”*

20. We were extremely alarmed by reports of specialist nurses being taken off specialist duties and put on acute wards. Health professionals expressed their potential concerns at this practice and Dr McWilliam warned us that this is already happening:

*“That is already a reality in paediatrics. The specialist nurse in neurological disorders – we don't have a specialist nurse in neuromuscular disease, we have a regional Care Advisor – they are already taken to acute wards for tasks which they are not well trained for and it is not a good use of their time. It is being done to save money.”*

21. We were left in no doubt of the vital role played by the Care Advisors and specialist nurse in providing essential care, support and advice as part of the specialist multi-disciplinary team. Dr Banham gave us an insight into the caseload of the specialist nurse:

*“I never walk into the specialist nurse's office without there being a phone call from a patient or family, often about a piece of equipment or something else.”*

22. Dr McWilliam highlighted to us the wide variety of skills of the Care Advisor and the geographical area that Wilma Stewart, the Care Advisor based in Glasgow, covers:

*“The diversity of her task and geographical immensity of it means we would be very concerned if we lost her – that is a huge skill in terms of counselling, practical advice, troubleshooting, enabling and advocacy. It is also a big part of the transition process.”*

23. Wilma Stewart described to us in her written evidence the broad remit of her role, the difficulties in providing an equitable service and the lack of succession planning:

*“The role of the Regional Care Advisor is diverse, demanding and varied – however a huge part of the role is about emotional and psychological support to families at crucial times in their respective journeys, i.e. when diagnosed. considering genetic issues, dealing with loss, losing mobility, becoming increasingly dependant, considering spinal surgery, moving home and pre-bereavement issues to name but a few.”*

*“We not only support children with muscular dystrophy but adults also – combining adults and children makes this a huge post and is severely under-represented across Scotland. The service we deliver is highly valued but we believe we are unable to provide an equitable service due to the geographical area we cover and the demands made on our service on a regular basis.”*

24. We also discovered how specialist nurses can be an invaluable part of the multi-disciplinary in freeing up consultant time. Janette Barrie told us:

*“Another thing the specialist nurses can do is run review clinics and free up consultant time, which is absolutely crucial. Putting a figure on that can really strengthen the case for specialist nurses.”*

**25. We were told about comparisons with services in other parts of Europe which the Scottish Muscle Network is looking at in detail. Dr Banham described how attempts to reach a gold standard service need fundamental services to be in place first:**

*"Anywhere in the world that has achieved the best outcomes in this field are not all the same model but they have invested in long-term respiratory support services and some sort of social care infrastructure to have arrangements whereby care can be delivered. In Denmark they have a lot more hostels and intermediate care for young adults, and elsewhere in Scandinavia. In Spain and Portugal it is different but they certainly have a system that enables them to offer supported long-term respiratory care at home in a way that has been much more patchy in the UK. So you have to have something on the respiratory side and something to underpin that care in the community. In the Scottish Muscle Network, we are interested in looking at different models from around Europe which might be most easily transferrable and perhaps even mix and match to some extent for the Scottish situation."*

**26. We were keen to establish the level of succession planning for key posts in the specialist multi-disciplinary team. Dr McWilliam shared his concerns about planning both in terms of who would succeed him and how the role would evolve:**

*"I have a colleague who will be the succession on my retirement. However, that's not very secure and that will be one person for paediatric neuromuscular disease in the whole of Scotland. That doesn't feel comfortable for me, particularly as it takes quite a long time to have enough experience with the conditions that you only see once in every 30 or 40 years. You do need to plan ahead but my biggest concern is that when I retire, my job will be left and my patients will be picked up by someone else, because that is the way the financial situation is in the health service at the moment."*

**27. We were deeply concerned to hear of the lack of specialist equipment such as cough assist machines. Dr Banham told us about his struggle to manage the small number of machines:**

*"Getting the number you need as the service develops and there are more and more people where weak cough is a particular issue. We are paying about half the £8,000, but nevertheless that is still as much as a pretty good multi-purpose home ventilator. So in terms of a piece of equipment which only has one purpose, it is quite expensive relative to other stuff. In Glasgow, where it has grown over years, I do not at least have a great difficulty in maintaining supply of the ventilator equipment. Other pieces of equipment like this are roughly the same sort of price – that is hard and so I only have a fraction of the cough assist machines that we could do. I have only got half a dozen whereas I could do with at least three times that without being ridiculously over the top."*

**28. We held in-depth discussions on the essential need for joint health and social care planning. Professor Alex McMahon told us of his plans to discuss how to reduce gaps in services with local authorities in the NHS Lothian area:**

*"If there isn't a joined up discussion, the chances are that people will fall into the service gaps because of a lack of planning and financial planning alongside that. From an NHS Lothian point of view, the Finance Director and I have agreed to go around all the local authorities in Lothian and have a discussion about all the plans that have been made about services in order that we can reduce the gaps. I would turn this round and say that it is an opportunity to be creative if you can do some service re-design and clever partnerships and joint-funding."*

**29. Professor McMahon outlined, in subsequent written evidence, NHS Lothian's partnerships to achieve improvements in access to services:**

*"The Lothian Physical and Complex Disability Strategy (PCDS) is working with colleagues across the four local authority and Community Health (Care) Partnerships (CH(C)P) areas to influence service redesign to respond to the views of service users and carers and apply a hub and spoke model to service delivery. The ambition, in line with national policy directives, is to deliver services more locally wherever appropriate, and in partnership with both local authorities and voluntary organisations so that there are more cohesive relationships across services and straightforward access to and journey through these services for the service user."*

**30. We were shocked by the constant battle to set up care packages and the unacceptably longer stays in hospital than are necessary. Dr Ian Grant shared his dismay at the situation:**

*"Every single care package set up is a constant battle between social work and local health authorities. Direct Payments are often resisted although under pressure, they have yielded. The situation is bad with these care packages and it may get worse for somebody with an allied condition. One person has been waiting in hospital for four months having been fit for discharge. This person had a care package before going into hospital. We added non-invasive ventilation and the immediately local authorities said that they can't do anything to do with that. So this person has been in hospital for four months while we try to re-negotiate the care package. That is unacceptable and sheer incompetence, but some of it will get worse with the potential cuts."*

**31. We were deeply concerned about the Independent Living Fund (ILF) being tied in with care packages. The fall in number of the packages results in a huge drop in care, as Mr Davidson outlined to us:**

*"In Scotland, we have done relatively better in gaining ILF across the board because it is built into the care packages. You get ILF because you get a care package. Given that care packages have fallen, it means that there is a huge drop in care."*

**32. We heard evidence from Dr Grant of how the lack of social care infrastructure appears to have contributed to commissioning decisions:**

*"As far as the National Services Division was concerned from the submission of the business case 10 years ago, they took a long time to make up their mind not to get involved in neuromuscular disease and ventilation, the final straw was the implications it was going to have for social work and social support, and that there wasn't a national framework at that time linking social work departments. If we made a big deal about a medical national service for home ventilation for neuromuscular disease, it left a whole lot of financial and other implications hanging in the air and I think that is why they said no."*

## Section 3

### Evidence Summary

#### Importance of social care provision

Oral evidence was provided by:

Eddie Fraser – *Head of Service: Community Care, East Ayrshire Council*

Elsbeth Milne – *Team Manager: Occupational Therapy, East Dunbartonshire Council*

Kath Barclay – *Team Manager: Children with Disabilities, East Dunbartonshire Council*

Morag O’Dwyer – *Team Manager: Children with Disabilities, Falkirk Council*

Patricia Finlay – *Manager: Community Care, Falkirk Council*

Iona Colvin – *Corporate Director (Social Services and Health), North Ayrshire Council*

Colin Johnston – *Housing and Community Care Service Manager, Perth and Kinross Council*

Jill Derby – *Service Development Officer, West Lothian Council*

33. We received the views and opinions of Council representatives from across Scotland on the crucial issues relating to social care provision for people living with neuromuscular conditions.

34. We heard about the role of a Council in setting up care packages and how this varies in different parts of Scotland and the different types of care that are provided. We are concerned about the increasing pressures that Councils will face with further budget constraints. Eddie Fraser outlined to us the role of the Council in providing the care package:

*“There is sometimes a different focus between the support to children and adults. We will look at people’s individual and personal needs. The role is often about how we support the parents, and that changes as we move through transition, and the aspirations for the person change. The focus of the care package changes.”*

35. We welcome the increased influence that people with neuromuscular conditions have in setting up self-directed support but we are alarmed about the possibility of the over-reliance that Councils might be placing on personalisation of care in the current economic climate. Iona Colvin told us:

*“The personalisation agenda is developing quite quickly and is centred on that. The danger is seeing it as a solution in the current economic position, and a lot of savings are being predicated around it. It offers a lot of really good solutions if it is done well. We do set up a really good service within children’s services by and large. We have planning in North Ayrshire which starts at the age of 15. In Glasgow it starts at 17. The set of services in adult services are just not there.”*

36. Alison Couston, listening to the comments by Council representatives, emphasised the struggle that her daughter Eilean has in securing a care package and the obstacles she faces:

*“She has had many problems with independent living. Eilean is trying to manage on her own as a young person and there is lots of bureaucratic obstruction. There is no care package at all and no personalisation. Life is really hard for a young disabled person and there is no advocacy.”*

37. We received evidence about the vital need to frequently review care packages to ensure that people living with neuromuscular conditions and their families have access to the care and support that they require. Jill Derby explained to us:

*“It is not just about setting up the packages but ensuring that the packages are reviewed frequently and the provision for families, because needs can change, not just for the individual but also for the wider family.”*

38. We heard about the vital importance of strong links between social care and health care as well as co-operation between local authorities and the further areas of improvement needed. Iona Colvin emphasised to us:

*“There is a definite need to work across boundaries. We need to look at what children and young people and families require, in terms of care management and proper ongoing assessment. We are doing quite well in some places but it is going to be patchy. The number of days that children stay in hospital has reduced but there has never been any transfer of that into communities. The transfer into primary care is as important as the transfer into social care but there has never been a planned programme around children’s services.”*

39. Kath Barclay drew our attention to the benefits of strong working relationships between social care and health care:

*“If we have issues with what health services are doing, we have good working relationships with senior managers in the local NHS. We have not had huge issues in something not being addressed or picked up and we can work on specifics when they arise. It is one of the benefits of working in a small authority.”*

40. We received evidence about the difficulty that many young people have in accessing information and care and support services. Alex Davidson outlined this to us, and emphasised the importance of the expert support and advice provided by the neuromuscular Care Advisor:

*“The damage is done in the way that people find the lack of access to information and services very difficult. I have supported young people who I know are stuck in trying to find Direct Payments, equipment and adaptations. There are very real issues around transition across Scotland and the different ways health services, education, schools and social care services work together at the different stages of the process.”*

*“The users and carers in the Network emphasise the lack of contact, and the posts that they most value are those supported by the Muscular Dystrophy Campaign at the moment [to be fully funded by the NHS from April 2011] – the Care Advisor of which there are currently only two across the whole of Scotland. It is that day-to-day reference point where you get that care management support. People would describe that as disappearing when you become an adult, and you don’t have that day-to-day contact with a care manager. It is not managed like in children’s services, with specialist support wrapped around it.”*

41. We also heard evidence about the crucial role that welfare benefits advisors play in some local authorities to assist families in negotiating their way through the complexities of the benefits system.

42. We learned that respite care takes on different forms across the local authorities. We were alarmed that the important respite care arrangements that local authorities try to set up encounter bureaucratic obstacles. Eddie Fraser explained to us:

*"In terms of adult services, we certainly recognise that adults with long-term conditions don't fit the traditional respite model. There are organisational difficulties. We took a house and we wanted to use it as a respite facility but the Care Commission said it had to be of the standard of a care home. We want to set up a house for respite care and one that gives people a break but we were prevented from doing it. Also, what is the definition of respite and what is the role and involvement of the carer?"*

43. We received evidence about the need for flexibility between services and to work with families so that appropriate provision is planned for. Robbie Warner told us about the joint approach:

*"That is done by a partnership. We had a social worker quickly who had little to do at the beginning. My view was that I stressed the need for my son to be known about in five years time, so become aware of him now. By and large people are willing to do that. There seems to be a rigid line between child care and community care, which starts at 18."*

## Appendix

### The Cross Party Group Inquiry

The Inquiry was launched in April 2010 to carry out an in-depth investigation of access to specialist, multi-disciplinary care and social care provision for people living with neuromuscular conditions. This arose from the concerns of the Cross Party Group that people living with muscle disease were not receiving the specialist care and social care provision that they are entitled to.

The Cross Party Group Inquiry has received both written and oral evidence that underlines the need for urgent action to improve and strengthen multi-disciplinary health care for this vulnerable group of patients living with rare and very rare conditions.

### Witnesses

The Group would like to thank all the expert witnesses, both from a patient and professional perspective, who gave oral evidence and submitted written evidence describing and analysing a wide range of key issues. The CPG 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:

#### **27 April 2010 – "Living with muscle disease"**

Eileen McCallum – *Edinburgh, grandmother of two boys with Duchenne muscular dystrophy*

Eilean Stewart – *Glasgow, living with limb girdle muscular dystrophy*

Robbie Warner – *Dumbarton, father of young man with Duchenne muscular dystrophy*

#### **30 June 2010 – "What constitutes a specialist neuromuscular service?"**

Dr Stephen Banham – *Consultant Respiratory Physician, Glasgow*

Janette Barrie – *Nurse Consultant for Long Term Conditions, NHS Lanarkshire*

Alex Davidson – *Chair, Scottish Muscle Network*

Dr Ian Grant – *Home Ventilation Service, Edinburgh*

Prof Alex McMahon – *Deputy Director of Strategic Planning and Modernisation, NHS Lothian*

Dr Robert McWilliam – *Consultant Paediatric Neurologist, Glasgow*

#### **7 September 2010 – "Importance of social care provision"**

Eddie Fraser – *Head of Service: Community Care, East Ayrshire Council*

Elsbeth Milne – *Team Manager: Occupational Therapy, East Dunbartonshire Council*

Kath Barclay – *Team Manager: Children with Disabilities, East Dunbartonshire Council*

Morag O'Dwyer – *Team Manager: Children with Disabilities, Falkirk Council*

Patricia Finlay – *Manager: Community Care, Falkirk Council*

Iona Colvin – *Corporate Director (Social Services and Health), North Ayrshire Council*

Colin Johnston – *Housing and Community Care Service Manager, Perth and Kinross Council*

Jill Derby – *Service Development Officer, West Lothian Council*

## Terms of Reference

The formal Terms of Reference for the Inquiry are:

*“To determine the current provision and quality of specialist services in Scotland for people with muscular dystrophy and related neuromuscular conditions; to highlight areas of best practice and 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

*Acute/emergency admissions April 2009 to end of March 2010 for neuromuscular patients*

Dr Ros Quinlivan, Consultant in Paediatrics and Neuromuscular Disorders, Robert Jones and Agnes Hospital, Oswestry, June 2010

*Building on the Foundations: Focus on Physio*

Muscular Dystrophy Campaign, May 2008

*Building on the Foundations: State of the Nation – The 2008 National Survey*

Muscular Dystrophy Campaign, September 2008

*Building on the Foundations: State of the Nation – The 2010 National Survey*

Muscular Dystrophy Campaign, August 2010

*Building on the Foundations in Scotland: Improving Specialist Care, Support and Independence*

Muscular Dystrophy Campaign, September 2008

*Care Advisors* Wilma Stewart, June 2010

*Duchenne Muscular Dystrophy and Spinal Muscular Atrophy standards of care guidelines*

Treat-NMD, June 2010

*Joint Health and Social Care*

Prof Alex McMahon, Acting Director of Strategic Planning and Modernisation, NHS Lothian, August 2010

*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

*Physiotherapy provision* Marina di Marco, Clinical Specialist in Physiotherapy of Neuromuscular Conditions,

NHS Greater Glasgow and Clyde, June 2010

*Scotland Muscle Group* Falkirk, February 2010

*Scotland Muscle Group* Clydebank, August 2010

*Scottish Muscle Network Review* September 2009 – September 2010

*Eileen’s Boys*: BBC Documentary on Eileen McCallum as she juggles her busy filming schedule with helping her daughter, Sarah, look after her children BBC 2009

### **Muscular Dystrophy Campaign contributions at Inquiry evidence sessions provided by:**

Robert Meadowcroft – *Acting Chief Executive*

Nic Bungay – *Head of Policy and Campaigns*

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

Mark Chapman, *Edinburgh*

Callum Couston, *Glasgow*

Mary Gray, *Crieff*

Kim Kemp, *Glasgow*

Alan Noble, *Glenrothes*

Katrina Sweeney, *Edinburgh*

Emma White, *Edinburgh*

Alison Couston, *Glasgow*

Alex Davidson, Chair, Scottish Muscle Network

Martin and Kay Hepworth, Newport on Tay

Margaret Nicol, *Kelty*

Sharon Sutherland, *Parkinson’s Specialist Nurse, NHS Highland*

Robbie Warner, *Dumbarton*

**The Mackie Report:**  
Access to specialist neuromuscular care and social care in Scotland  
*Cross Party Group in the Scottish Parliament on Muscular Dystrophy*

September 2010