Six Steps to Fight Muscle Disease in Wales

Local patients living with neuromuscular conditions and their families – backed by the Muscular Dystrophy Campaign – are calling on you, as an Assembly candidate, to join the fight against muscle disease.

If elected on 5 May 2011, we are asking that you support the following six key pledges:

1. If I am elected on the 5 May, I will join the Cross Party Group on Muscular Dystrophy.

The Cross Party Group (CPG) on Muscular Dystrophy brings together Assembly Members (AMs) from across the parties to discuss developments of neuromuscular services required across Wales. We want to raise awareness of the key issues that affect people with muscular dystrophy and related neuromuscular conditions. These meetings are held quarterly.

Lynne Taylor from Cardiff is mum to 16 year old Ross who has Duchenne muscular dystrophy. She says:

“Giving evidence to the CPG on Muscular Dystrophy gave me a chance to tell Assembly Members about the reality of living with muscle disease. I call on every AM to join the CPG on behalf of families like mine.”

2. If I am elected on the 5 May, I will sign up to the recommendations put forward in the Thomas Report.

Specialist neuromuscular services in Wales must be urgently brought inline with services in the UK. The CPG and the Muscular Dystrophy Campaign are calling on the Welsh Assembly Government to act on the Thomas Report’s recommendations.

Ray Thomas had two sons, Robert and Leighton, who were affected by Becker muscular dystrophy. His sons were denied the vital specialist care that could have drastically improved their quality of life. He says:

“It is essential that urgent action is taken to ensure the recommendations in the Thomas Report are implemented so that people living with muscle disease across the whole of Wales receive the specialist care and support they are entitled to.”

3. If I am elected on the 5 May, I will meet with the Wales Muscle Group to discuss the gaps in services in their local area.

The Wales Muscle Group which meets quarterly has been established for patients, clinicians and health professionals to share experiences and to campaign for improvements in local health and social care services.

Janet Neilson, who has FSH muscular dystrophy, says:

“Through the muscle group and campaigning for better services with the CPG, we feel that progress is being made and that improvements to neuromuscular services are beginning to take place. We need local AMs to support us in the fight for better services.”
If I am elected on the 5 May, I will meet with young campaigners involved in the Trailblazers network from across Wales and work with them in the fight to improve access to local transport, education and leisure facilities.

The Trailblazers have published hard-hitting reports about access to transport, education, leisure facilities, employment and tourism and are calling on service providers to ensure that people with mobility difficulties can access these essential services.

Lauren West, a Trailblazer from Cardiff, says:
“I have met politicians to bring to their attention the obstacles in accessing vital services for young disabled people. I hope that AMs will make it a priority to address the issues that the Trailblazers have highlighted.”

If I am elected on the 5 May, I will meet with local Health Boards and local authorities to discuss with them what action they are taking to ensure that specialist care provision is accessible for all people living with muscle disease in Wales.

Health Boards and Councils play a vital role in ensuring high quality standards of care for people with neuromuscular conditions.

Chris George from Cardiff, whose son has Duchenne muscular dystrophy, says:
“It is vital that AMs in contact with and meet the key decision makers who can make a real difference for people like me and other families who are living with muscle disease. The care and support available from new Cardiff Care Advisor, Rachel Salmon, is having such a beneficial impact for families.”

If I am elected on the 5 May, I will work with the Muscular Dystrophy Campaign to ensure vital funding for infrastructure so that patients benefit from new treatments as soon as they are available.

As research for new treatments and therapies develops, it is essential that the NHS ensures that these are available to patients living with muscle disease.

John Burke from Cardiff, whose son Seth has Duchenne muscular dystrophy, says:
“There are no effective therapies available for any of these muscle diseases – but we are getting closer than ever before. We need AMs to ensure that the NHS has the infrastructure for a speedy bench-to-bedside transfer of promising new technology and that new treatments reach our families as soon as they are available.”

Make sure you are signed up to the Muscular Dystrophy Campaign’s Manifesto for Muscle by sending your name, and prospective constituency in an email to campaigns@muscular-dystrophy.org We will then publish your name on our website.

For more information about the Muscular Dystrophy Campaign please visit: www.muscular–dystrophy.org
For more information about Trailblazers please visit: www.mdctrailblazers.org