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Major concerns over the future of adult neuromuscular care in Northern Ireland

- Patient advocacy and support organisations join forces to raise concerns of people living with muscle wasting and weakening conditions
- Disruption in access to treatment could have ‘catastrophic’ implications on those living with a neuromuscular condition
- Changes at the Belfast Health and Social Care Trust leave patients on ‘ticking time’ bomb

Muscular Dystrophy UK, Spinal Muscular Atrophy UK (SMA UK) and Pathfinders Neuromuscular Alliance have joined forces to raise concerns of people living with muscle wasting and weakening conditions as a result of potential significant changes at the Belfast Health and Social Care Trust adult neuromuscular service in the coming weeks.

Patients have been informed that the current lead consultant will be leaving at the end of March and there has been no communication about any arrangements in place for the continuation of care beyond this date.

The news raises major concerns about the access and availability of treatments including risdiplam, a treatment currently available to eligible adults living with Spinal Muscular Atrophy (SMA) through a Managed Access Agreement (MAA) for the Northern Ireland community.

The Trust is the sole provider of this treatment in Northern Ireland, and with the departure of the lead consultant, no prescriptions will be able to be signed for. Those patients currently taking the medication are on a ‘ticking time bomb’ with only weeks left of access to a life-changing drug.

The organisations are also concerned about the potential implications for access to other treatments, including Spinraza, a second SMA treatment, and the Duchenne muscular dystrophy treatment Translarna.

For patients with SMA or Duchenne muscular dystrophy, treatments aim to halt progression of the condition so that it does not get worse. A worsening of the condition could mean a loss of the use of muscles for swallowing or breathing, which represents a significant risk to the patients’ lives and their quality of life.



Michaela Hollywood MBE, 33, from Co-Down, who is Deputy Chief Executive of Pathfinders was diagnosed with SMA in 1991 at eight months old. She was first prescribed risdiplam in March 2021 and described it as ‘liquid gold’ and has seen a noticeable positive impact.

There was a 48-hour period where she was without access, which had a detrimental effect. In the first three hours she had a heavy sensation down her arms and fingers and within just 12 hours she couldn’t swallow.

With rapid changes evident in such a short space of time, Michaela is concerned that this could have dangerous results for her and many others currently using the drug if they were to stop, even temporarily.

Michaela predicts that she currently has around nine weeks of supplies left in what she describes as being ‘92 doses safe’. She said: “Too many people fought too hard to get this drug to be giving it up too easily. It’s a frustrating situation as there has been a lack of communication about the next steps, which could have a catastrophic impact on the lives of those living with SMA and their families too. Without access to treatment, and not because there’s a lack of drugs, this could see a rise in hospital admittance, so we’re hoping to get answers. At the moment patients are being kept in the dark.”

Director of Campaign, Care and Support, Rob Burley, at Muscular Dystrophy UK, the leading charity for more than 110,000 children and adults in the UK living with one of over 60 muscle wasting and weakening conditions, said: “We’ve heard from a number of people and their families who are understandably extremely worried about the current situation, and we share their concerns. We’ll do all we can do help resolve this and can’t express enough the urgency to get some answers and clear information from the trust.”

Giles Lomax, CEO of SMA UK added: “It’s really important that everyone across the UK has equal access to treatment and we will advocate as strongly and as quickly as possible to ensure that there is a clear and immediate plan in place to continue with the Risdiplam service within the Belfast trust.”



Muscular Dystrophy UK, Spinal Muscular Atrophy UK (SMA UK) and Pathfinders Neuromuscular Alliance have written to the Belfast Health and Social Care Trust expressing their concerns and as yet have not received a clear response on the future of the adult neuromuscular service.

For more information about Muscular Dystrophy UK visit muscular dystrophyuk.org or call our free helpline on 0800 652 6352 (open Mon – Thu 10am – 2pm).

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For more information, photos, or interviews, please contact: Heather Fanning, PR Manager at pressoffice@muscular dystrophyuk.org

About muscle-wasting conditions

- Living with a muscle wasting and weakening condition can be exhausting, stressful and lonely. With endless medical appointments, physiotherapy, treatments, and respiratory support.
- Progressive conditions get worse over time. They can cause difficulty walking. Trouble swallowing. Breathing complications. Pain. Heart problems and failure. Life can be more challenging. Or cut short.

About Muscular Dystrophy UK

- We're the leading charity for over 110,000 people in the UK living with one of over 60 muscle wasting and weakening conditions
- We share expert advice and support to people living with muscle wasting and muscle weakening conditions so they can live well now.
- We fund groundbreaking research to understand the different conditions better and to lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.
- We've already made advances that would have been unthinkable just 10 years ago, and we're determined to go even further and faster.
- We support people with muscle weakening and wasting conditions through every stage of their life. From the point of diagnosis to living the best life possible.
- Together we are stronger. Together we are Muscular Dystrophy UK. Join us.
- For more information or to help support our work, visit muscular dystrophyuk.org or call our free helpline on 0800 652 6352 (open Mon – Thu 10am – 2pm)

About Spinal Muscular Atrophy UK

- At SMA UK our vision is that everyone affected by SMA will have access to the best care, support and treatment and there will be no barriers preventing full inclusion in society.
- At SMA UK our outreach team provides personalised practical and emotional support for all those affected by and living with SMA.
- We provide health information accredited by the Patient information forum to the SMA community, health care professionals and those affected by SMA.
- We advocate on behalf of the SMA community across the UK to authorities that regulate access to drug treatments, care and services.

About Pathfinders Neuromuscular Alliance

- We are the only user-led charity supporting people living with a muscle weakening condition across the UK.



- Our staff and trustee board bring together our lived experience to provide and promote choice, control and quality of life for individuals living with muscle weakening conditions.
- Our UpLift project supports young people aged 18-30 as they learn to navigate adult life with the condition through training, resources and peer support
- Our PA and PA Employer Training supports Personal Assistants and their employers to deliver high quality, person centred care and equips employers with the knowledge they need to support their employees.
- We campaign and advocate for better care, support and accessibility across all areas of life in the UK.
- We believe in a future where every individual with a muscle weakening condition has autonomy over their own lives and are able to reach their dreams throughout their lives without barriers.