# Scottish Muscle Network (SMN)
# ANNUAL REPORT 2023/24

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## Introduction

The Scottish Muscle Network (SMN) was established in 2004 to ensure that equitable, evidence based, patient centred care is provided for all children and adults with neuromuscular conditions, at each point of their care pathway. This is provided through the development and implementation of clinical guidelines, patient pathways, clinical standards, and information resources.

Neuromuscular conditions include muscular dystrophies, myopathies, mitochondrial diseases, peripheral neuropathies, and disorders of the neuromuscular junction such as myasthenia gravis. Although much progress has been made in the diagnosis and management of these diseases, neuromuscular conditions are largely progressive, debilitating and can frequently be life shortening. Patients commonly require complex and long-term management.

Services for those affected by neuromuscular conditions are delivered across Scotland through a collaborative network approach. Care is routinely delivered as locally as possible, but travel may be necessary for diagnosis and to access specialist expertise or specialist facilities.

## Current Position

21/23 (91%) Business as Usual objectives were achieved by the network. Of the two not achieved, one related to the delay in updating five patient information leaflets which were due for review in March 2024.This was delayed due to clinical capacity and the leaflets will be updated in April 2024. The other was that a summer newsletter was not issued due to service pressures.

7/8 (87%) Service Delivery objectives were achieved by the network, the objective unachieved was outwith the networks control. The SMA Core Dataset, agreed by the network and IMS and sent to CAS Developers in 2021/22. The aim was to capture data that could be used to identify demographics, current therapies, specific disease rating scores and likely trajectories for the Scottish services. Due to pressures within CAS Development Team, there has been continuous delay in progressing this. An alternative solution has now been identified and this will be progressed in 2024/25.

## Lead Clinician Reflection

During the year 2023/24, The Scottish Muscle Network has continued to deliver on key objectives to improve care for patients with neuromuscular disease. This activity is centred around development and implementation of clinical guidelines, patient pathways, clinical standards and our information resources which are available via our website.

We have several guidelines in place which are regularly reviewed and updated. This year we have collectively decided to adopt the DMD Care UK Guidelines which are peer reviewed and accepted as good practice across the UK. Adoption of these Guidelines has been welcomed and audit of care in the context of these guidelines can be planned.

Our website has been updated as part of a roll-out across the Managed Clinical Networks. Governance of MCN websites has been updated and now that the new system for approval of content has been in place for several months, we are confident that updates can be made in a timely manner.

The project to develop the database for care and management of our patients with Myotonic Dystrophy has been ongoing and delays have crept in due to staffing issues within IMS and CAS Developers. This has meant that we have not been able to complete our biannual audit of our Care Standards as planned but the changes to the system continue so that we anticipate this will be able to be completed for the period 2025-2026.

Educational events have continued to be very successful, with an annual conference in September 2023 that was well attended and evaluated. Our guest speakers were very much appreciated by attendees both in the room, and those attending virtually. A new addition for us was our 'Great Debate', which we took off-line, but it was thought provoking and our evaluation responses indicated that it was the highlight of the day with respondents reflecting that they were very pleased to be given the opportunity to consider the nuance around research discussions with patients and their families.

Another activity has been to reorganise some of our subgroups to focus more on certain areas of development. This is discussed further below.

Moving into 2024/25, we plan to meet in June 2024 to develop our workplan for the next 3-5 years, to look at opportunities for further development and how to focus work within the Scottish Muscle Network to continue improvement for our patients in Scotland with neuromuscular disease.

# Highlights

## Effective Network Structure and Governance

SMN reviewed and changed its subgroup structure and representation to ensure they meet the network objectives. Terms of Reference developed and agreed by all subgroups as well as for the steering group. Myotonic Dystrophy and the Drugs and Therapeutic Intervention Group (DATIG) subgroups remained unchanged, Education subgroup representation refreshed, and new subgroups formed for Patient Engagement, Research and Genetics Diagnostics.

## Service Development and Delivery

### Service Planning

Following the development of a vision for neuromuscular services and the gathering of service data to identify gaps, in 2023/34 the network continued to have discussions with health boards on implementation.
One of the most challenging needs highlighted in this report was additional resources to meet both current and future demands on adult neuromuscular services. With limited specialist neurology resource in adult services in Scotland and no national specialist provision, the network is exploring options for sharing and developing expertise across the country. One option that is being explored is the establishment of a complex case discussion forum.

### Guidelines/Protocols/Pathways

During 2023/24, the Network continued to develop and review guidelines and care pathways in accordance with NNMS guidance. As such, two guidelines and two care pathways were reviewed and updated. SMN had planned to develop a DMD MDT Care Pathway but collectively agreed to adopt the DMD Care UK Pathway which was recently completed. SMN placed a link to this pathway on the SMN website at http://www.smn.scot.nhs.uk together with all network updated documents.

### Genetics Diagnostics

The main aim of this new subgroup is to develop and audit neuromuscular diagnostic pathways across Scotland to ensure that all Scottish patients have equitable access to NHS diagnostic services, and national and international research projects.
The group membership contains the network's four genetics consultants representing each tertiary centre in Scotland. The group met twice during the year with the following outputs.

- Agreed a document about the genetic investigation of RYR1 variants which would be piloted for a year among the group members only.

- Developed guidance for Geneticists on DMD gene variants which was available on the SMN website.
- An audit was completed on the investigation of rhabdomyolysis gene panel from across Scotland, and the analysis was being finalised.
- A draft patient information leaflet for adults on “finding a genetic cause for your neuromuscular condition” would be shared at the forthcoming patient engagement session for patients / families to comment.
- Agreed some minor changes to the Scottish Genomic Test Directory.
- Discussed with the SSNGM about the NSCT testing sent to England which should continue for the foreseeable with no requirement to repatriate that to Scotland.

**Research**
This subgroup will operate virtually with the objective to understand what research was taking place in Scotland in neuromuscular disease and what was on the horizon. Dr Joseph has written a comprehensive summary of what research was underway in paediatrics and has posted this on the SMN newsletter and website. Dr Farrugia will produce a summary of research in adults for the winter 2024. This process will continue going forward, with the aim of establishing a directory of the latest research on the SMN website. The purpose will be to facilitate patients across the country getting more consistent access to research studies as well as informing professionals. The network plans to measure impact through monitoring website views and through feedback from the Glasgow Paediatric Neuromuscular Centre on family/patient access to clinical trials.

## Stakeholder Communication and Engagement

**Strategy**
The networks Communication and Engagement Strategy for 2024-26 was reviewed and signed off at the March 2024 Steering Group meeting. The plan going forward will be to align this strategy with the new NSS template.

**Website/Newsletter**
The website moved to a new platform during the year making it easier to navigate with the aim of increasing use by stakeholders. The network has continued to monitor content to ensure it is kept updated with relevant and appropriate content for network stakeholders relevant to NNMS website guidance. A winter newsletter was also produced and placed on the website. https://www.nn.nhs.scot/smn/news-and-events/news/

**Patient Engagement**
The new subgroup aims are to **e**ngage with patients and their families and the voluntary sector organisations to ensure their needs, preferences, values, and views are captured and inform the networks workplan. A patient engagement meeting was organised and held virtually with three patients/parents. Good feedback was captured. Providing a roadmap of how best to get clinical support in times of need was their priority due to variability that patients had experienced. The network agreed to take this forward. Participants were also sent two patient information leaflets to review, and feedback would be looked at by the network. The subgroup plan to continue this process throughout 2024/25.

**Stakeholder Survey**
A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. The survey was shared with 144 stakeholders and 25 responses were received (17% response rate).

While the number of responses was disappointing, a large amount of positive feedback was received and highlights the value added by the network:

- 92% responses ‘strongly agreed’ or ‘agreed’ that the network provided a structure to make service improvements in neuromuscular care.

- 92% responses ‘strongly agreed’ or ‘agreed’ that the networks service development activity adds value to neuromuscular care.
- 100% responses ‘strongly agreed’ or ‘agreed’ that the networks education offering adds value to neuromuscular care.
- 76% responses ‘strongly agreed’ or ‘agreed’ that the networks audit and continuous quality improvement activity adds value to neuromuscular care.

This table includes a summary of all survey responses. However, it is acknowledged that some response views may not be relevant to the role and or remit of the National Managed Clinical Network.

| Strengths | Areas for Improvement |
|---|---|
| • Many respondents noted the network key strength was group of highly committed professionals who want to deliver the best possible care to their patients cross-specialty working.<br>• Good communication and collaborative working<br>• the overarching badging up of national guidance for clinicians across Scotland to adhere to.<br>• Truly has multidisciplinary representation. Stakeholders genuinely motivated to deliver excellent care for families great go-to for information for professionals and families.<br>• Adds value through service development by developing/reviewing pathways and guidelines.<br>• Adds value by providing specialist information.<br>• Adds value through facilitating connections and collaboration with colleagues.<br>• Adds value through high quality education events, providing peer support for those working with people affected by rare muscle conditions, which can be quite isolating.<br>• Adds value by providing evidence through data collection to inform practice and identify improvement. | • Continue to Develop a Scottish database.<br>• More targeted meetings. Less duplication (as what tends to happen in Steering group meetings).<br>• Getting back to F2F meetings<br>• Financial constraints<br>• Better IT support for gathering data. Funding for the limited number of in-person meetings we aim to have.<br>• Linking with other UK muscle meetings/organisations for peer review of complex cases on annual /biannual basis could help(being trialled soon).<br>• Services for patients with neuromuscular services across Scotland are seriously limited compared to other areas of the NHS. There are significant staffing issues and a national approach to workforce planning is needed, especially with the advent of new therapies on the horizon. Currently patients do not have the clinician time and support that is afforded to their counterparts in areas on NHSE and this is before new therapies place additional stress on services. The SMN is well placed to gather the data to plan for what is needed. |
| **Suggested Future Priorities (3-5 years)** | **Network Challenges/Threats** |
| • Completion of current workstreams - publication of guidance/pathways.<br>• Transition<br>• Discussion on how to improve manpower and skills of people belonging to the network, to allow more dedicated clinics throughout Scotland and the delivery of specialist treatments to different patient groups. Ongoing discussion with the different health | • money and time. the new wave of therapies will be expensive to buy, very costly in staff time to administer and to monitor treatment efficacy that will be required to justify ongoing treatment costs.<br>• therapeutics in muscle conditions will evolve quickly in the coming years, professionals will be inundated and will |

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|---|---|
| boards and Scottish government on how to improve services for patients with muscle conditions pan-Scotland wide.<br>• New developments in translational research, clinical trials and new therapies will pose a significant challenge which we should prepare t<br>• Continued support for MIG<br>• facilitate clinical trials and deliver the upcoming wave of transformational therapies.<br>• Taking time to engage with patients and explore the impact of new therapies and how they would like to see this work.<br>• Robust data collection. Continued education events to keep clinicians up to date with the quickly changing research landscape in muscle disorders. Providing guidance on standards of care, with a focus on transition to adult healthcare, to ensure equity of service across the country.<br>• Approval and implementation of Scottish Newborn screening for treatable neuromuscular disorders due to strong evidence of preventative treatment e.g. SMA. Network key driver for this vital need. | be more compromised in contributing sensibly to the network.<br>• Lack of financial backing and increasing reliance on clinicians participating in their own time - leading to loss of engagement<br>• Ongoing new treatment developments that threaten clinical capacity to implement and maintain-more staffing/posts across all disciplines -e.g. genetics/neuro/physiotherapy already becoming necessary. SMN network really helpful and NB in advocacy for staffing and patient care as a national combined voice.<br>• Workload to run the various subgroups may cause problems for already stretched professionals across Scotland. Financial.<br>• The recent cancellation of support for a learning event that requires to be face to face is a huge loss to our networks education provision. The way this was done will have alienated the external speaker - these events have proven excellent in building clinical links that facilitate better diagnostic and research opportunities for patients and so this is now threatened |

The feedback received will be considered by the SMN Steering Group and an action plan to support areas for improvement will be developed.

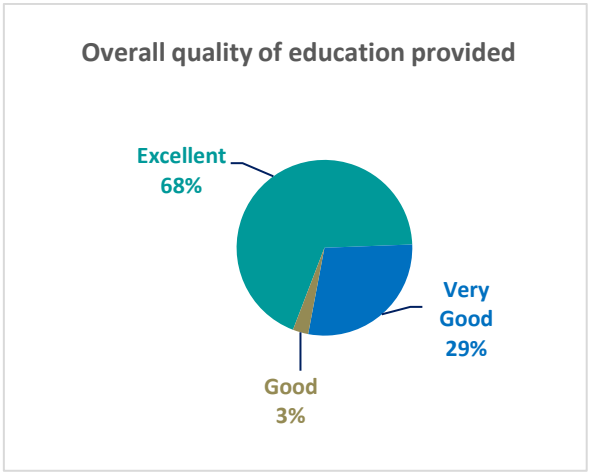
## Education

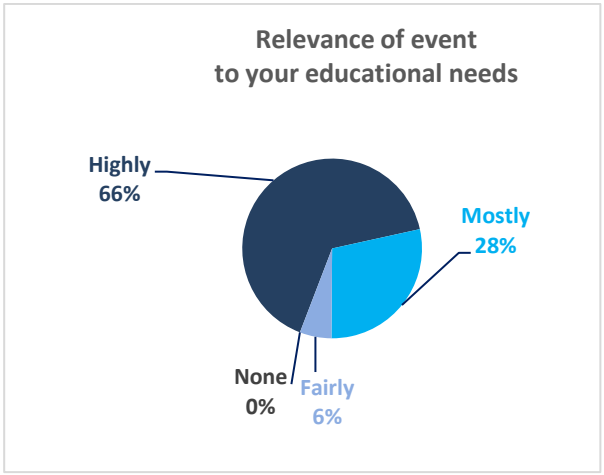
Focus remained on the delivery and implementation of the SMN Education Strategy that reflects and meets stakeholders needs: The strategy for 2024-26 was reviewed and signed-off at the March 2024 steering group meeting. Again, this will be aligned with the new NSS template-SMN has continued to deliver the strategy through the following: -

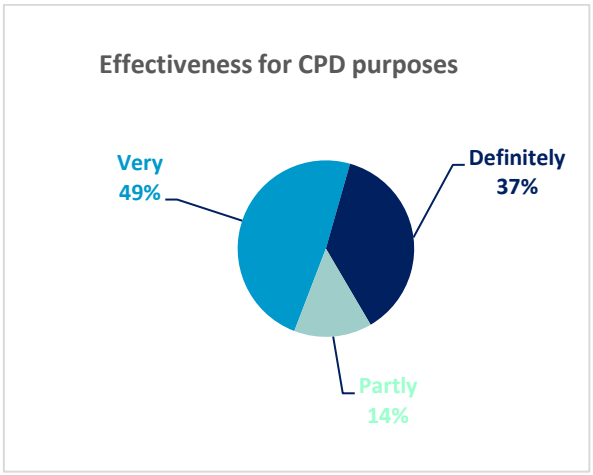
**Annual Conference**
The annual conference was held in September 2023 at Ninewells Hospital, Dundee. This was a hybrid event with 43 delegates attending in person, and 19 on-line using MS Teams. Delegate feedback response rate was 56%. 97% felt the quality of education was excellent or very good, 94% identified the event as relevant for their education needs and impacted on keeping them informed about neuromuscular conditions. 86% said it was relevant for CPD purposes whilst 94% said it would impact clinical practice going forward. Graphics below show results. Themes identified regarding impact on clincial practice were as follows:

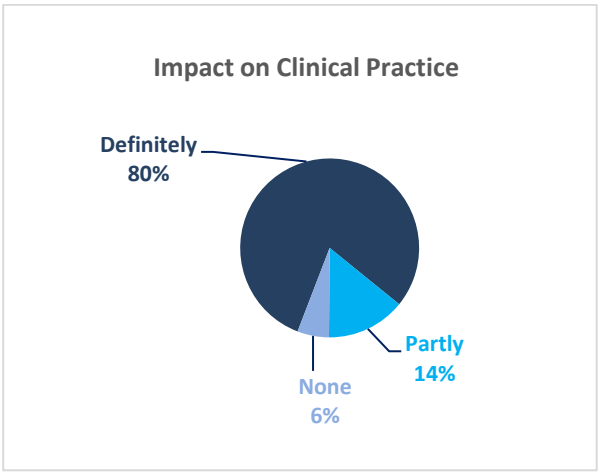
- better understanding of clinical trials and the onus on families
- thinking about an unusual form of genetic muscle disease when examining development delayed children early on

- more client led discussions allowing plenty of time to discuss what's meaningful to them and their families.
- more proactive in leading anticipatory care planning discussions early on
- informative and knowledge gained empowers conversations with families to signpost them and support them appropriately.
- importance of holistic care in clinic time to achieve improved outcomes.
- addressing difficult conversations prior to transition



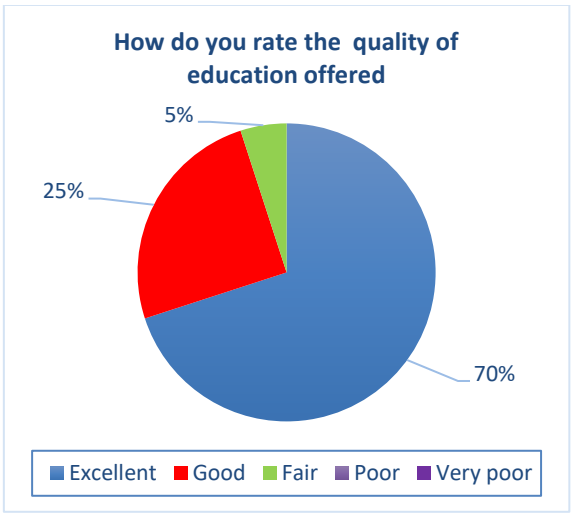



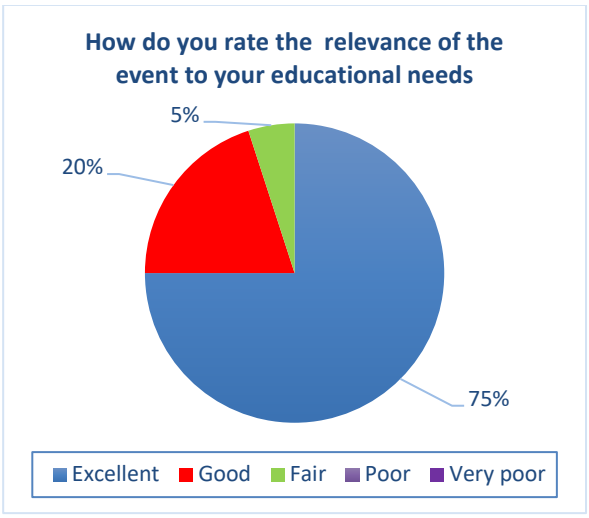



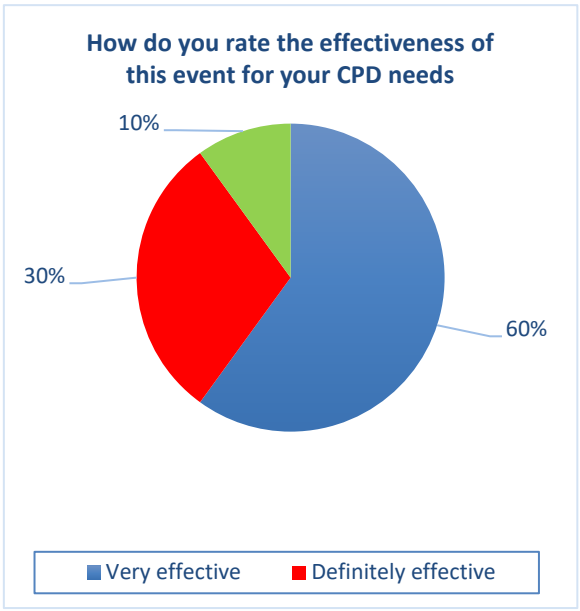

**Muscle Interest Group (MIG) Meetings**

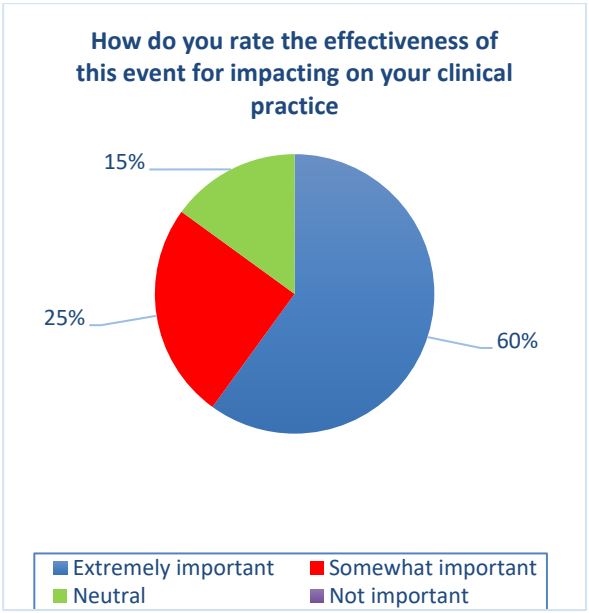
The network again held two MIG's in May and November 2023. Both were hybrid events. The former had fifteen in person and eight virtual, the latter thirteen in person and eight virtual. The aim of these meetings is to provide a forum for discussion of challenging neuromuscular cases, professional peer support, and dissemination of medical knowledge. Combining the two meetings, evaluation response rate was 46% with 95% rating the education provided effective and the same percentage rating the quality of education as excellent or very good. 90% of responders also said the education was relevant to their CPD, whilst 85% planned to modify their clinical practice because of the education provided. Benefits of attending the meeting included:

- meeting other clinicians and hearing expert opinion about complex cases
- made a clinical diagnosis in a complex patient.
- updated understanding on FSHD
- I have learnt difficult cases of neuromuscular disease. Role of muscle MRI is taking over the role of neurophysiology, but it is still useful somewhere. As I am still in the training stage, it is good to learn cases.




**Plans in place for 2024/25**

- Organising the Annual Conference and Muscle Interest Group meetings for 2024/25
- Developing a Learning Needs Analysis for AHP's and Nurses
- Creating an education channel on MS Teams for resources for professional stakeholders

## Audit and Continuous Quality Improvement

The network recently developed its Quality Improvement Strategy focusing on the following:

**Myotonic Dystrophy (DM1)**

The subgroup continues to focus on maintenance and audit of Management of DM1 in Adults Care Standards.

The network previously worked with IMS and the CAS developers in finalising the Myotonic Dystrophy (DM1) database, the system successfully went live on March 31st, 2022. This system is critical to providing reporting structure to support this audit as it will allow data to be collected more efficiently across the four Regional Genetic Services (Aberdeen, Dundee, Edinburgh, and Glasgow) which will help ensure DM1 patients across Scotland receive equitable, optimal care. Users have over the past two years identified continuous problems in both using the system and its functionality. A short life working group (SLWG) was formed over the past year, led by Dr Richard Petty and Dr Mark Hamilton who looked the key issues including reporting functionality

data collection, practical uses in clinic (letters/forms etc.) and an updated version has been released for testing.

The audit is reported biannually and for period August 2022-August 2023, given the challenges with the new system, it has been decided to reschedule this until developments have been concluded and it has been robustly tested.

## Climate Sustainability

The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

## Looking forward

Priorities for the network in the coming year include:

- Development of a Strategic Plan for 2024-2027. The network is planning to meet on June 13th, 2024, hopefully face-to face to focus on what workstreams the network wants to prioritise going forward over the next 3 years.
- Test and continue to populate the updated DM1 database with a view to using it to audit against Management of DM1 in Adults Care Standards in the future.
- Collate information on current research.
- Develop a mechanism to capture agreed data for people with SMA to inform planning.
- Continuing to collaborate with colleagues from genetics and NBS laboratories to gather evidence to inform consideration for SMA Newborn Screening. The NSS Pregnancy and Newborn Screening Board Research and Innovation Group approved SMN's proposed research study in September 2022. The network will aim to align any pilot with the work NHSE is planning to support the gathering of evidence as recommended by National Screening Committee Inservice Evaluation (ISE). Funding and ethics approval has still to be finalised.

## Finance

A previous project undertaken by SMN to maximise the number of patients with Myotonic Dystrophy are carrying a medical alert, identified keyrings as the method that they were most consistently able to produce. This is critical information to support emergency care for this patient group and the keyring directs clinicians providing it to important information on the SMN website. The keyring was designed and continues to be supplied through the network to take advantage of economies of scale.

| **Item** | **Spend** |
|---|---|
| Venue Hire/Catering for Annual Event and two Muscle Interest Group meetings. | 3,058.80 |
| Travel costs for speakers at Annual Conference and MIG | 270.60 |

| | |
|---|---|
| 1000 keyrings for DMI patients | 1,014.00 |
| **TOTAL SPEND** | **4,343.40** |

## Risks & Issues

- The recent cancellation of support for a learning event that requires to be face to face is a huge loss to our network's education provision. These events have proven excellent in building clinical links that facilitate better diagnostic and research opportunities for patients.
- The network needs to meet face to face to develop a strategic work plan for the Network, make shared decisions regarding priorities and how we can support neuromuscular patients. This would be very challenging to do on Teams and the Steering Group feel, at this time, a face-to-face meeting is the best way to make progress with this task.