Muscular Dystrophy
Support Centre
inspiring independence

IMPACT REPORT

2018-19

Welcome

Welcome to our Impact Report for 2018-19.

Reflecting on the last year, it continues to be a challenging yet exciting and rewarding time to be part of Muscular Dystrophy Support Centre as we strengthen and build on our foundations.

This year has seen the charity develop significantly, and we have focused our efforts both on meeting growing demand, and on looking strategically ahead, to shape the future of our services for people with muscular dystrophy.

We provided over 2,000 hours of therapy during the year, an increase of more than 30%, from three established sites, namely our Centre at Hereward College in Coventry, our Birmingham satellite clinic, and our outreach clinic at Droitwich Spa Osteopaths. To help us grow our services, we recruited two additional therapists, who have fast become part of the MD Support Centre family.

As well as our primary objective to provide physical therapy, we have been involved in some exciting projects this year. We actively participated in a number of external forums and events to promote improvements in care and choice for people with MD and to raise the profile of wider issues affecting our community. We embarked upon a project to create training videos for physiotherapists working with muscle-wasting conditions. And with the support and participation of our service users, we began measuring outcomes in our therapy programme, with the support of our service users, to gather information that will monitor the trajectory of MD and analyse the impact of regular therapy.

It was lovely to see over 70 guests at our open day in June 2019 which was held on the theme of "Health and Wellbeing". The event included therapy taster sessions, guest speakers, and an Arts Therapy class ran by Birmingham Centre for Art Therapy, as well as our AGM. We had a great day and were pleased that feedback from the event showed that you enjoyed it, too!

Our open day also marked the end of our service user survey (more details on p6). The survey gave some really encouraging results, including 91% of service users reporting that the MD Support Centre helps "slow or prevent deterioration of my condition".

As our charity grows in reputation and reach, referrals to our services have more than doubled this year from 60 to 128. We are thrilled that more people are becoming aware of us and are seeking out our support, but we are aware that there is still a great unmet need across the Midlands region and demand for our services will continue to increase for the foreseeable future. It really drives home the message that we are the sole provider of regular physiotherapy for people with MD in our region, and it is essential that we continue to meet increasing demand.

It is timely then that we have turned our efforts to creating a plan for the future. We want to transform our service to be able to meet the needs of all people with MD across the Midlands who need it. We will do this by expanding our team and opening several additional satellite clinics over the next five years.

Through collaboration with the people who use our services, we want people with MD to be as involved as possible as we grow the charity to ensure our service continues to meet the needs of those in our community. People with MD are represented at all levels of our organisation from the Board of Trustees to our Fundraising and Awareness Groups and among our staff and volunteers. Our five-year strategy will include more opportunities for people with MD to get involved in the governance of the organisation and have a say in our decision-making.

Of course as we grow our services, we will need to increase our income. We continue to be indebted to our tireless supporters who go above and beyond to raise funds for us in their local communities, running golf days, pub quizzes and a huge range of other activities to help keep funds coming in. Our regular donors continue to help by providing vital cash donations, and we are also grateful to a number of charitable trusts and foundations for their generous contributions. And as ever, we are endlessly grateful to our many volunteers who selflessly provide skills, time and support and to our team members, who work tirelessly to help people with MD.

On behalf of the Board of Trustees, thank you to everyone who has contributed to the very real difference Muscular Dystrophy Support Centre makes to the lives of the people with muscular dystrophy and their families. Our work is only possible thanks to you.

Ruth Hereford
Chair of Trustees

Who we are

About us

Muscular Dystrophy Support Centre was set up and is led by people with muscular dystrophy (MD) and their families. Our Board of Trustees has seven members, all of whom either have MD themselves or have a family member with muscular dystrophy. We have been providing therapies since January 2013.

Operating from our Centre in Coventry, and with primary satellite clinics in Birmingham and Loughborough (to be launched in 2019), we support people primarily by providing specialist physiotherapy on a long-term basis. We are the only organisation in the Midlands region to do so, and one of only two in the UK. The majority of our referrals currently come from GPs and specialist Consultants in hospitals across the Midlands.

Need

Muscular dystrophy is a life-long, progressive condition that affects around 70,000 people nationwide. There are more than 60 different sub-types of muscular dystrophy and related neuromuscular conditions which cause the muscles to weaken over time and waste away. Their severity and how they affect the individual varies from person to person. Some conditions begin in childhood and are ultimately life-limiting while others are diagnosed in adulthood.

As the person's muscle strength deteriorates, life can become extremely challenging, especially as most people lack access to regular physiotherapy that is central to preservation of strength and effective management of the condition.

Regular physiotherapy can help improve muscle usage, reduce pain and slow down muscle deterioration, enabling people to better manage their condition and retain greater functionality and independence. Around 11,000 people with muscular dystrophy live in the Midlands.

But current provision of appropriate therapy is very poor, and falls behind other long term conditions. For example, there are 100,000 people in the UK with another degenerative condition - Multiple Sclerosis - and over 50 therapy centres to serve their needs. For the 70,000 people with MD however, there are just 2 therapy centres. This leaves over 8,000 adults in the Midlands alone unable to access the therapy they need.

Our aim as an organisation is to transform access to therapy for everyone with MD in the Midlands region who needs it.

Our approach

Our goal is "inspiring independence". There is currently no cure for MD, but evidence from our work shows that regular physical therapies can help reduce pain and slow down muscle deterioration, enabling people to take control of their condition and retain greater functionality and independence. Key to our approach is its long-term nature – we never discharge service users once registered. This year, 91% of respondents to our annual survey said our support slowed or prevented deterioration of their condition, and 88% said it helped them to manage pain. 97% said they found our therapies beneficial to their wellbeing.

We are:

Committed – We don't discharge service users once registered so they can rely on us to help them manage their condition long-term and access our therapies/support as needed. Some service users attend therapy fortnightly or monthly, others less frequently.

Specialised – As MD conditions are rare, many GPs and community physiotherapists have had little exposure to it. This matters because with muscular dystrophy, the muscles do not rebuild or respond in the way they would with other patients. Our staff are specialist neurological physios with concentrated experience of working with muscular dystrophy. Treatment from our physios includes hands-on muscle manipulation, work on the core, and use of assisted exercise equipment as well as exercises to carry out at home.

Preventative – When someone begins to lose muscle function in one area, they may compensate by over-using another muscle which can start a downward spiral. Regular therapy helps identify these progressions quickly, focussing on efficient muscle use and retaining the best possible overall condition. With early intervention, many people see an improvement in their muscle function after a few months' therapy. The subsequent decline typical of muscular dystrophy can be slowed down or lessened accordingly.

Multi-disciplinary – Every newly referred person has a detailed assessment with a physiotherapist at their first appointment. Then, depending on their needs and wishes, they may use any of our services: physio, osteopathy, hydrotherapy, complementary therapies, or group classes such as Seated Pilates.

Our progress this year

We received 128 new referrals, more than double the 60 we received the previous year.

During the year, registered service users grew to 375. We provided 2,058 hours of therapy, an increase of 32% on the previous year. Despite significant growth, our waiting list has grown to 9 months, as we are now receiving 10+ referrals per month, up from around 5 the previous year. Growth in demand is partly due to increased knowledge of our service among NHS Consultants and partly due to the success of our satellite clinics which lead to referrals for more people living in these locations.

Our satellite clinic in Birmingham, formerly a pilot project, has become part of our core programme. Held at Acorns Children's Hospice in Selly Oak, we now provide 13 hours of therapy per month in Birmingham, which will increase in 2020. This clinic is the blueprint for our second satellite, in partnership with Rainbows Hospice, which we launched later in 2019 to begin addressing the need for local provision in the East Midlands.

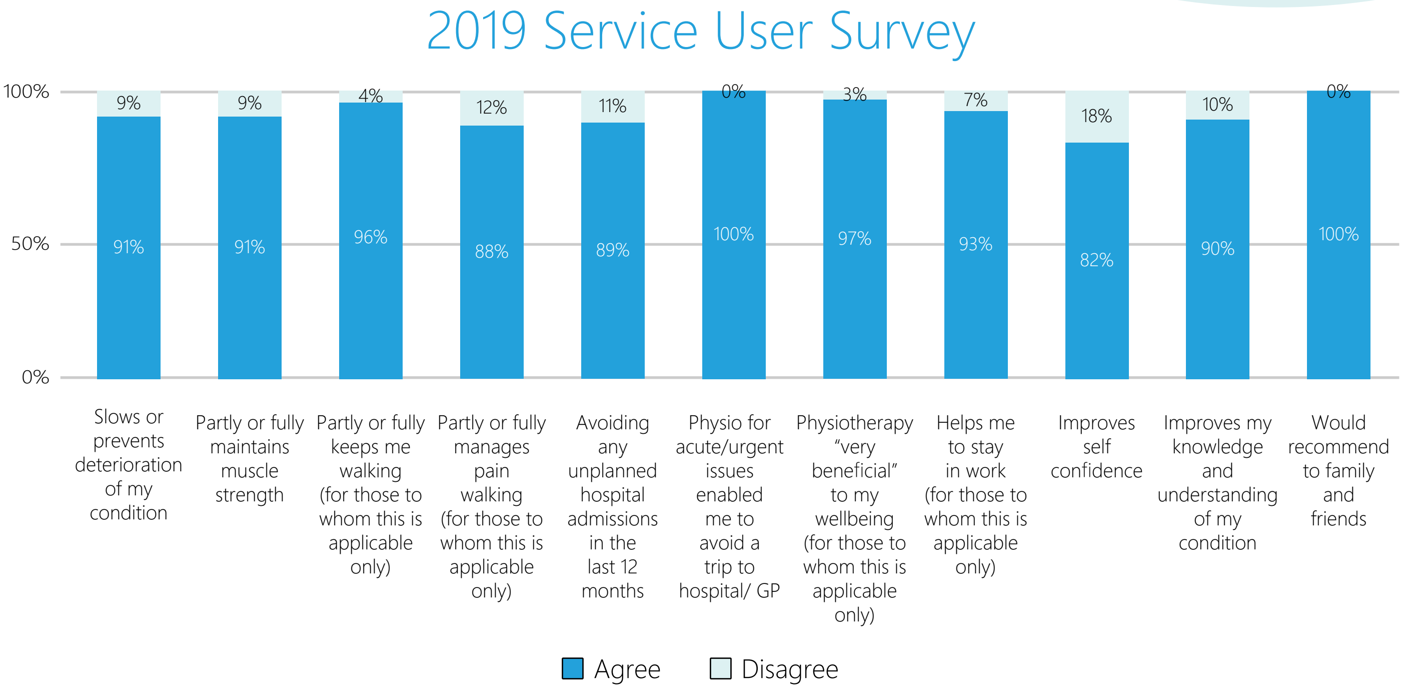
Two more part-time physios have joined our team over the past year. We now have 6 neurological specialist physios, 3 osteopaths and 2 complementary therapists in our therapy team, as well as a volunteer physio helper who is herself a retired neuro physio.

85% of available therapy hours were filled compared to 86% the previous year so there has been very little change. Our administration team works hard to refill cancelled sessions as they are in such high demand, but some last-minute cancellations, especially due to illness, are to be expected.

As a charity we began measuring outcomes at set intervals in physiotherapy for each service user (participation is voluntary). The aim is to compile data which will help inform interested parties of the trajectory of the condition of individuals receiving physiotherapy over time. This project is in its infancy and will develop further.

We held our annual Open Day in June 2019, which featured guest speaker Martyn Sibley of Disability Horizons. The theme was "health and wellbeing", and the day included therapy taster sessions, an arts therapy workshop led by Birmingham Centre for Art Therapy, a wellbeing workshop and our AGM. 70 people attended the day.

Service user survey



We are pleased to be able to present the results from our 2019 Service User survey.

Health

100% say their therapy partly or fully keeps their joints flexible

97% say their therapy partly or fully maintains muscle strength

96% say their therapy partly or fully keeps them walking (of those to whom this applies)

93% say their therapy partly or fully keeps them in work (of those to whom this applies)

92% say their therapy partly or fully prevents falls or accidents

88% say their therapy partly or fully enables them to manage pain

100% say their therapy partly or fully keeps them out of hospital (of those to whom this applies)

97% of service users said the MD Support Centre slows or prevents deterioration of their condition.

Therapies - Of those who receive Physiotherapy, Osteopathy and Hydrotherapy, 100% said it was either somewhat or very beneficial. 89% of people receiving Hydrotherapy and Complementary therapies found them somewhat or very beneficial.

Wellbeing - When asked about the impact the MD Support Centre has on wellbeing, people responded positively, 85% of service users said it improves their self-confidence and 91% said it helps them to understand and manage their condition confidently.

Healthcare - Only 12% of those surveyed had unplanned hospital admissions in the past 12 months 100% of those who received our physiotherapy when they had acute or urgent issues said this avoided a trip to their GP/ hospital/ other NHS department.

When asked 'Which professional do you feel plays the primary role in helping you manage your condition?' 61% responded by saying MDSC therapist.

Friends and family test - 100% of respondents would be likely or extremely likely to recommend us to friends and family if they needed similar treatment.

What we can change - the main feedback we received was on difficulties travelling to the centre, we are working to address this by expanding our satellite provision.

We also asked people what other services they would be interested in accessing, of these the most popular were: yoga, a neuromuscular advisor, advocacy and counselling. We will look into all of these.

Feedback from service users and professionals

We continually collect feedback from service users through the Annual Survey and via service user testimonials. We also receive feedback and testimonials from professionals working in the neuromuscular field. Full details can be found in our Impact Report which is available on our website or on request. Examples of feedback this year include:

> They picked me up when I was down, they showed me it's ok to be frightened and said how I can overcome what the condition throws at me. But most importantly they have instilled hope in me. Their fantastic range of therapies - including physiotherapy and osteopathy - is crucial to help people like me to lead a fulfilling life.

Jay, service user

> If you put in the work, you can make a difference to your condition. You can take control. When I go on the exercise bike, in order to stay balanced you have to keep moving, and I find this movement really empowering. It's what you can do that really counts.

Sanah, service user

> The support that the Muscular Dystrophy Support Centre is able to give patients is phenomenal. The patients that I have spoken to have all praised the depth and breadth of knowledge that the service providers at the MD Support Centre have been able to offer and they feel that the treatment they receive is complimentary to the treatment that they receive from the NHS services.

Alice Roe, Neuromuscular Clinical Nurse Specialist, Queen Elizabeth Hospital Birmingham

> The Loughborough satellite clinic will be of great benefit to the patients that access it. Specialist, timely and ongoing physiotherapy plays an essential role by helping to maintain function, participation and well-being for as long as possible. More patients will access a local service, as previously the difficulties of travelling a distance has been a barrier.

Yvonne Julien, Specialist Care Advisor, University Hospitals of Leicester

Sharing our skills

Working with people with MD with new members of our team and with physiotherapists working in other settings. We created a series of four videos demonstrating different approaches to treating people with muscular dystrophy. This is accompanied by a 50 page practice guide which details our approach to assessment, treatment and review.

We will be monitoring uptake of the new materials among professionals in the field and collecting feedback on their use and possible development in future.

Our partnerships

We work in partnership with **Hereward College**, a college for young people with complex disabilities and learning difficulties. Hereward is our landlord, from whom we have rented our Centre space since our inception in 2012, and we share their physiotherapy suite. The two physio teams share best practice, knowledge and skills, and we are forever grateful to everyone at Hereward College for this partnership.

Acorns Children's Hospice is the partner organisation for our Birmingham satellite clinic, and **Rainbows Children's Hospice** in Loughborough is the home of our East Midlands satellite clinic.

We are steadily working to build relationships with local CCGs to continue to grow this area as a source of income.

We regularly signpost service users to **Muscular Dystrophy UK**'s advocacy service for support with areas such as benefit entitlements and care packages. They signpost to us for physiotherapy on their website. We also attend their national conference and play an active role in their East and West Midlands Muscle Groups, and we hold a range of their printed materials in the Centre including their Alert Cards.

We were pleased to host a visit by Catherine Woodhead, Chief Executive and Rob Burley, Director of Campaigns, Care and Support of **MDUK** to the Centre during the year, and additionally MDUK published an article on our Centre in their Target MD magazine.

We are in regular contact with other relevant parties such as the **NeuroMuscular Centre**, the only other therapy centre like ours in the UK. We are in talks with **Coventry University** to explore physiotherapy research partnerships. We utilise **MDUK** information and research findings in our fundraising literature.

In addition we were represented by our Chair, Trustees and volunteers at many different external forums throughout the year, including the West Midlands Neuromuscular Clinical Network, the National Neurological Alliance, and MDUK's National Conference.

Overcoming challenges with muscular dystrophy

One of our service users shares his story:

"You may end up a wheelchair and there is nothing we can do," those are the devastating words said to me as I sat in Queen Elizabeth's Hospital.

Being told you have FSHD, a muscle-wasting condition that affects around 1 in 25,000 people, is a traumatic and terrifying experience for anyone to go through.

But at 23, in a successful job as a journalist and loving life, it hit me hard.

My dreams of growing old, enjoying my retirement and living my life a strong and happy person crumbled before my eyes as I sat vacantly staring at the doctor.

Each of his dreadful outcomes - including not even being able to smile properly - ripped through me like a knife.

My world went black, my visions of the future disappeared and was replaced with sheer terror - something I wouldn't wish on my worst enemy.

With no cure, no medication - only to medicate pain - and no positive outlook, I was sent from the hospital with nothing but a phone number to call.

My family broke down in tears as I announced the devastating news over the phone, alone in a multi-storey car park.

Months turned into years, and life with a condition that cannot be cured slowly grinded on - I remained frightened.

FSHD has continued to affect my body, as the doctor said it would.

I am unable to lift my arms over my head - due to my winged scapulas - I have foot drop in my right leg and my right thigh has severe muscle wastage.

Despite all the weakening of my muscles, my brain has continued to get stronger.

My mindset and determination is not only because my friends family and loved ones - it's because of a special charity called Muscular Dystrophy Support Centre based in Coventry.

They picked me up when I was down, they showed me it's ok to be frightened and said how I can overcome what the condition throws at me.

But most importantly they have instilled hope in me, which is something that can't be said for the NHS.

Their fantastic range of therapies - including physiotherapy and osteopathy - is crucial to help people like me to lead a fulfilling life.

Without their talented team, and amazing work they do, I would be a shadow of myself today.

And now at 26, I've learned to cope, to overcome and take on challenges that most able-bodied people would struggle with.

I have summited two of the three highest peaks in the UK, with the third planned in 2019, I can still bike for more than 30 miles and I enjoy an active life.

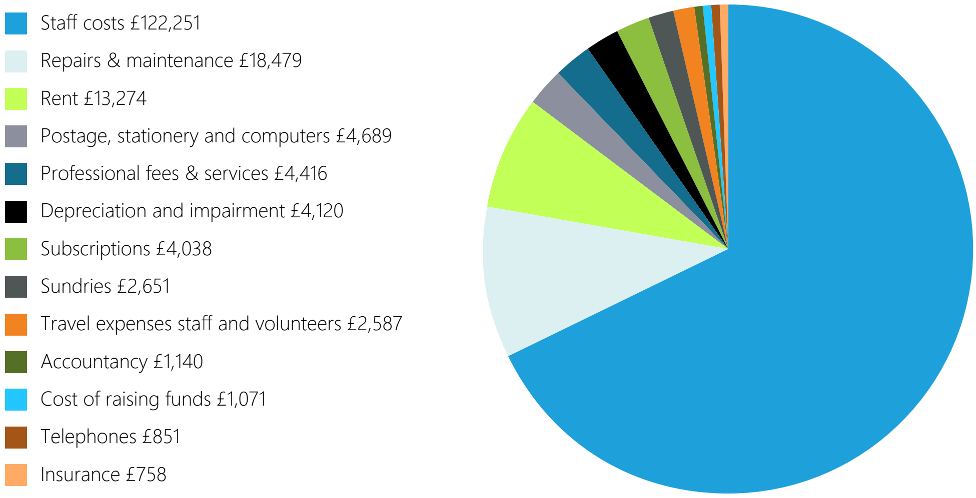
This condition will NOT beat me.

Financial update

Expenditure

We increased our expenditure in 2018/19 to £180,325, up from £137,885 the previous year.

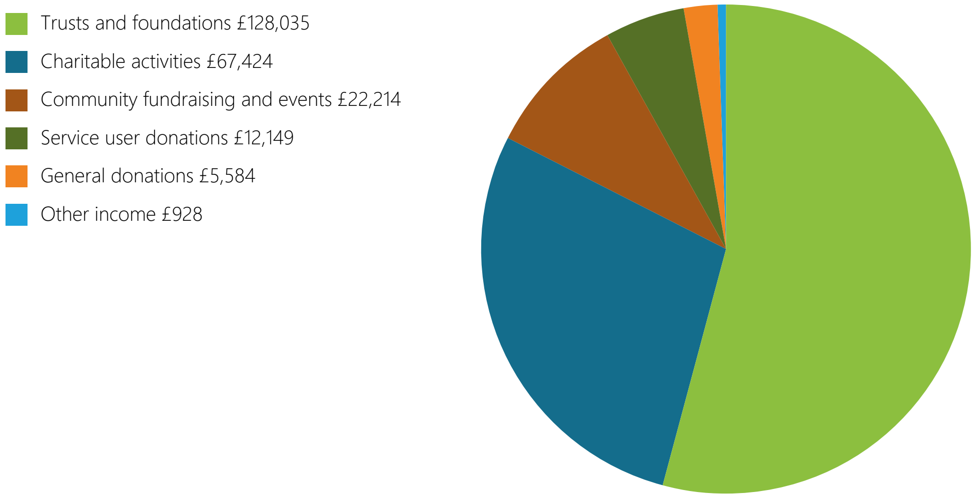
What is the breakdown of our expenditure?



Income

We had a strong year for income growth in 2018/19. Total income was £237,065, up from £201,945 the previous year.

What is the breakdown of our income?



Fundraising efficiency: For every £1 we invested in fundraising, we generated £4.05.

Our plans for the future

Increasing demand for our service is a challenge for the charity. We are committed to meeting the needs of people with muscular dystrophy and are seeing a steady increase in referrals month by month which has subsequently increased our waiting list for new assessments. There are no other providers of this service in the Midlands region and it is incumbent upon us to have a strategy in place for our long-term sustainability and growth.

The rapid growth of our therapy services in order to meet the needs of people with muscular dystrophy is something the whole team is immensely proud of, but it has also created challenges to which the charity must respond. To date, the charity has been run with significant involvement of volunteers, most notably being managed on a day-to-day basis by the Chair of Trustees, Ruth Hereford. The organisation has now reached a point where its size and complexity necessitate a professional team, which will be a priority over the coming period. This will ensure the organisation remains sustainable in the long-term.

In 2020 we will begin a five-year capacity-building project, Transforming Access to Therapies. This project is being supported by a grant from the National Lottery Community Fund.

The aim of this project is to help our charity grow sustainably in order that we can provide therapies for people across the Midlands who are in need. This will improve the ability of people with muscular dystrophy to live well with their condition by growing our capacity, scope, reach, and relevance to younger people with MD.

By 2025, we will be providing over 1,100 people with regular therapy as well as providing numerous new volunteering and peer support opportunities for people in the muscular dystrophy community. This is a complete step change in enabling people to access therapies that improve their lives and help them retain their independence.

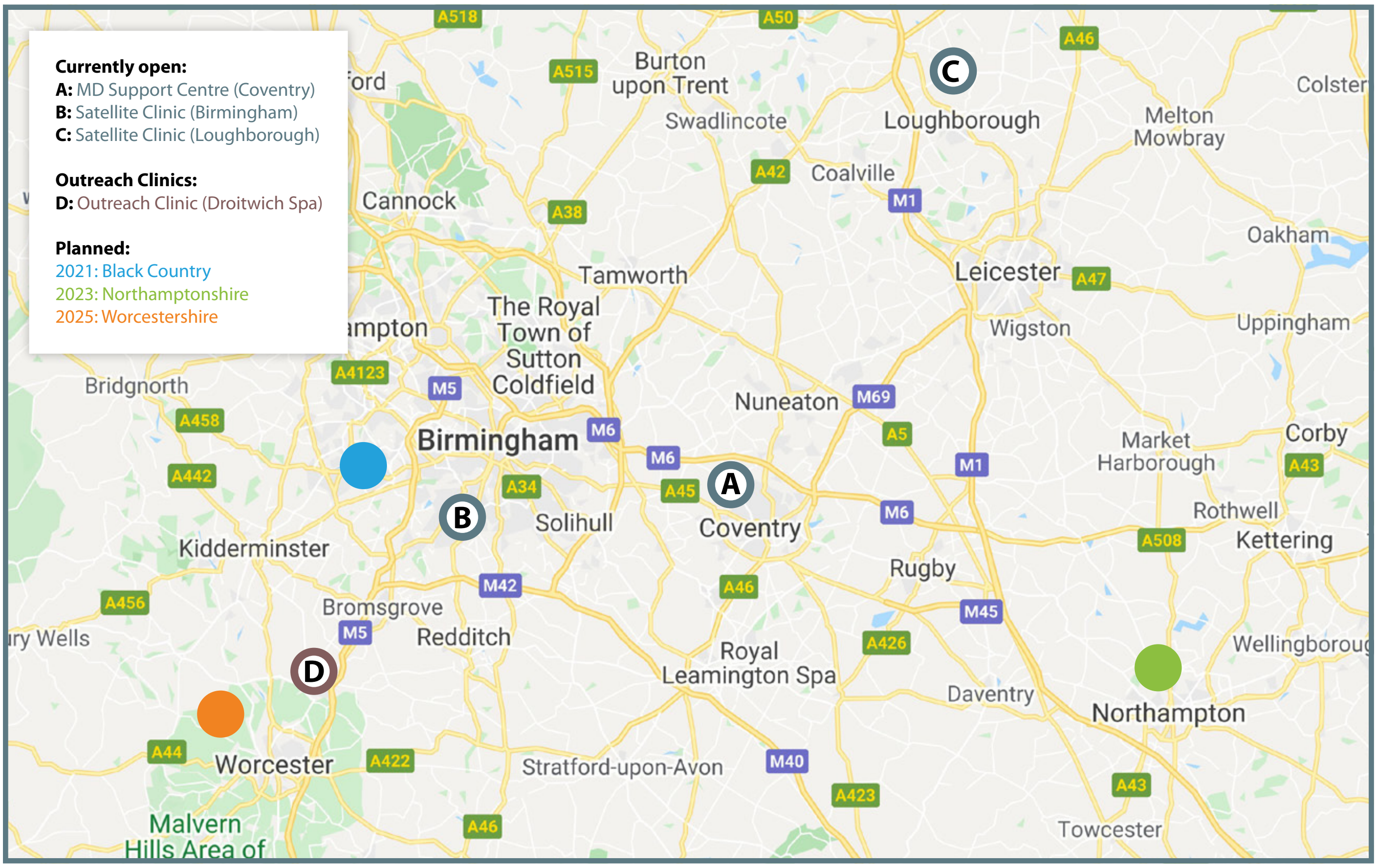
This will include three new satellite clinics with partner organisations in the Black Country, Northamptonshire and Worcestershire.

At the heart of this growth strategy is the requirement to be led by people with MD. We are very grateful for our active community of service users and their families and will be creating a number of new opportunities to get involved in the charity's development via satellite clinic steering groups, a project board, and additional Fundraising & Awareness Groups.

We are very grateful to the National Lottery Community Fund for supporting this project. Their grant of almost £300,000 over five years will cover around a third of the total cost. As a charity we will need to raise the remaining two thirds of the income.

In order to ensure we grow sustainably, we will diversify income streams and improve the charity's communications and marketing, securing our ability to serve people with muscular dystrophy for the long-term.

Our locations plan



Meet the team in 2018/19

Ulrike Uta	Lead Physiotherapist
Lynn Ward	Lead Physiotherapist
Chandni Patel	Physiotherapist
Kate Andrejevas	Physiotherapist
Taher Dhuliawala	Physiotherapist
France Quirin	Osteopath
Jane Field	Osteopath
Liz McGirl	Osteopath
Marie Claire Dalmar	Complementary Therapist
Alison Sheff	Complementary Therapist
Natasha Sweet	Philanthropy Manager
Corrina Jacob	Reception and Administrative Coordinator
Louise Meadows	Reception and Administrative Assistant
Debbie Meadows	Reception and Administrative Volunteer
Vicki McGeown	Reception and Administrative Assistant
Tao Cosnett	Reception and Administrative Volunteer
Bryan Gould	Engagement Officer
Anna Walker	Project Manager
Terry McDonagh	Administrative Volunteer
Linda Hill	Volunteer Safeguarding and Clinical Team Support
Adriana Bustillo	Fundraising Intern / Fundraising Officer

Our Trustees

Thank you...

We continue to value the incredible generosity of all the individuals, community groups, companies, charitable trusts and foundations that support the Muscular Dystrophy Support Centre. Although it's not possible to thank every single person or organisation who has supported us here, we'd like to give special thanks to:

29th May 1961 Charitable Trust
Armson Electrical
Gayle Armson
Baxi Heating Charitable Trust
Mark Birch
Birmingham Hospital Saturday Fund
Andy Collins
Anthony Corbett
Cotton Trust
DMF Ellis Charitable Trust
Douglas Heath Eves Charitable Trust
D'Oyly Carte Charitable Trust
Duke of Devonshire Charitable Trust
Dumbreck Charity
Edgar E Lawley Foundation
Edith Murphy Foundation
Edward Cadbury Charitable Trust
Edward Gostling Foundation
Eric Stanton- Northampton Trust
Eric W Vincent Trust Fund
The Evans family
Roger Flemming
G J W Turner Trust
Garfield Weston Foundation
General Charity, Coventry
Geoff Hill Charitable Trust
George Fentham Birmingham Charity
Elizabeth Goodman
Gordon Trust
Grand Lodge of Warwickshire
Caren Hands
Sheila Hawkins
Heart of England Community Foundation
Hearth Foundation
Henry James Sayer Charity
Jarman Charitable Trust
JC Seccombe Trust
John Avins Trust
John Lewis Partnership
Paul Jorden
JT Matthews Building Supplies
Keith Coombs Charitable Trust
Leamington Spa Community Fund
Lillie Johnson Charitable Trust
Mezei Design
Michael Guest Charitable Foundation
MK Rose Charitable Trust
The National Lottery Community Fund
Nicoleta Mezei Photography
Elizabeth Norman
The Nuneaton & Hinckley Fundraising and Awareness Team
Phillips and Rubens Charitable Trust
Private Physiotherapy Educational Foundation
Provincial Grand Lodge of Warwickshire
Ratcliff Foundation
Richard Kilcuppe Charity
The Rotary Club of Meriden
The Rotary Club of Wolverhampton
Rugby Group Benevolent Fund
David and Lesley Salt
Schroder Charity Trust
SHIRE Community Grants
Simon Cooper Foundation
Sir Jules Thorn Charitable Trust
Souter Charitable Trust
Stratford Town Trust
Theo Paphitis Charitable Trust
The Thompson family
W.E.Dunn Charitable Trust
Warburtons Trust
Warwickshire Mark Benevolent Fund
Judy Wellby
William Dudley Trust

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The Muscular Dystrophy Support Centre is a working name of NMC Midlands, registered charity number 1148855 and registered company limited by guarantee 08132198.