MND Association | Leicestershire and Rutland

Branch Newsletter

SPRING / SUMMER 2026

Dear Friends

In May 1986 a small group of people affected by MND attended an initial meeting in Leicester to discuss setting up a local branch of the MND Association. Thanks to them, and all the many kind and generous people who've since become involved, the branch is now marking 40 years of providing support to local people affected by MND as well as helping to raise funds and greater awareness of the disease in the community

Included in this newsletter is our Annual Report which is intended to give an overview of the branch's activities and expenditure during 2025. Of course, none of this could happen without the support of our amazing team of volunteers. A huge thank you, then, to all those who've made this work possible since 1986 by making donations, organising fundraising events or giving their time to help with branch meetings and activities. And of course, we must also recognise the many dedicated volunteers who, over the years, have taken on all the essential and unseen tasks such as responding to phone calls, managing the accounts, acknowledging donations and keeping everyone in touch, whether by post, email or social media.

Do come and join us as we mark our 40th anniversary with a Strawberry Tea in the beautiful surroundings of Ulverscroft Manor on Sunday 14 June. Whether you're new to the branch or a long-standing friend or supporter, we'd love to welcome you to this special occasion!

Best wishes

Janet McMillan

(Branch Chair)

MND Association | Leicestershire and Rutland

40th Anniversary
1986 - 2026

You're invited to our 40th anniversary

Strawberry Tea



Sunday June 14th 2.00pm – 4.00pm

Do come and join us on this special occasion to mark the branch's 40th anniversary at the

Shuttlewood Clarke Foundation Activity Centre
Ulverscroft Manor, Priory Lane, Markfield, LE67 9PH

An open invitation to all our friends, supporters, volunteers and anyone affected by Motor Neurone Disease

For more information or to RSVP please contact Janet at
janet.mcmillan@mndassociation.org / 01509 880577

FESTIVE FUNDRAISERS!

Beautiful baubles by Rufus



We all know that just before Christmas is a very busy time for everyone, so well done to 9-year-old **Rufus Oliver** from Clarendon Park, Leicester who made time before Christmas to buy some plain Christmas baubles and then paint and decorate them. By selling them to family and friends and splitting all the money received, he was able to donate **£137.98** to our branch funds as well as his own rugby club, Oadby Wyggeston.

Congratulations, Rufus - Kev would be proud of you!

Calendar girls (and boys!)

Many thanks to **John, Jill and all the team at Bridge 67 Butchers of Kibworth** who created a Calendar Girls-type calendar featuring all the staff in some light-hearted cheeky poses which raised **£2,000** for the branch as well as for "Yellow Wellies", the farm safety charity.



We're also very grateful to **Vanessa Wood** who produced another set of beautiful calendars for 2026 which raised an amazing **£1089** for the branch. This year they featured her own specially-created wildlife paintings including these delightful blue-tits.



MND Association | Leicestershire and Rutland

Dates for your Diary

MND Support Group Meetings at LOROS



Working in partnership with the MND team at LOROS, the **MNDA Leicestershire and Rutland Branch** holds monthly meetings for the MND Support Group in Seminar Room 1 at LOROS. The meetings are open to anyone living with MND, families affected by MND and those who have been bereaved by MND. From 10am - 12.30pm our friendly team of volunteers, including **Kath** and **Verene** *(pictured left),* will have a warm drink and piece of cake for you and are available to give support if needed. Although these meetings coincide with the MND clinic dates, you don't need a clinic appointment to attend. If you are at clinic that day, do feel free to pop in before or after your appointment. If you're just coming along to the Support Group, please be aware that the MND nurses have full clinics on those days and won't be available so any clinical queries should be addressed in the usual way.

Support Group Dates 2026

LOROS - Seminar Room 1

5 May 2 June 14 July 11 August
8 September 6 October 3 November 1 December

As well as our monthly **MND Support Group Meetings** at **LOROS** regular meetings of the **Rutland Drop-In Support Group** are now being held in Oakham on the 4th Tuesday of the month. Just call in at **the Old Buttercross Inn** between 2pm and 4pm on the dates shown – tea, coffee and soft drinks will be provided! The LOROS and Rutland Support Group meetings are both informal drop-in events to which those living with and affected by MND are warmly invited.

Family and Friends Meetings

The branch also holds regular **Family and Friends Meetings** at the **Heathley Park** in Leicester, especially for MND carers and family members. So, if you would welcome a friendly and supportive chat about living with or caring for someone with MND, why not drop in for an opportunity to meet other carers and family members and a chance to discuss any issues with them and our MNDA Association Visitors.

2pm - 4pm at the Heathley Park Pub and Grill
Groby Rd. Leicester LE3 9QE

Next meetings: June 24 August 26

Tea, coffee and soft drinks will be provided
Carers, family and friends all welcome!
For more information contact Goff Tearle at: rafgoff@gmail.com

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The Rutland Drop-In Support Group

Meets on the 4th Tuesday of the month 2pm - 4pm

May 26 June 23 July 28 August 25
Sept 22 October 27 November 24 December 22

at The Old Buttercross, Panniers Way
Oakham LE15 7US

For more information contact Anne Anderson at:

anne.anderson@mndassociation.org

NEWS FROM LOROS

The LOROS MND Team



Patients who are diagnosed with MND in our area are referred for ongoing support with the **LOROS MND** team of 3 specialist nurses and a healthcare assistant. Their role is to arrange regular reviews either at home or in clinic with patients, co-ordinating support from the wider MND team including dietitians, ventilation specialists, therapists, social workers and the medical team. The team works very closely with our MNDA branch volunteers and pictured left are (L-R) **Katie, Omina, Louise & Helene.**

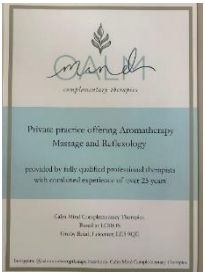
Welcome to Amy



Hi, I'm Amy the new MND nurse specialist covering for Katie's maternity leave. I am married with 4 children and 2 granddaughters! I live in Chesterfield and commute to LOROS 4 days a week. My background and passion is palliative care. I have worked in hospice care as a nurse, onto a Community Palliative Care Nurse and most recently as a Dementia Specialist Palliative Care Nurse. I started here at the beginning of February and have had a really lovely welcome to the team and to LOROS. I am looking forward to meeting more teams and our wonderful MND patients.

Amy Lyons

Complementary therapy Services



LOROS, like many hospices, is experiencing a challenging time due to a decline in income at a time of increased demand for its vital services. Sadly, this has resulted in a reduction in the range of services it provides, including free complementary therapy sessions. However, **Alison** and **Mani,** whose complementary therapy treatments at LOROS have been much appreciated by MND patients and their carers, have now set up a private practice using LOROS premises and can also offer home visits. The **Leicestershire and Rutland Branch** is able to provide wellbeing grants for a course of complementary therapy so, for more information about the services available locally and how to access them, do speak to the MND clinical team or one of our AV's.



Wheelchair Service Satellite Clinic at LOROS

Members of the **Leicester Wheelchair Service** clinical team are continuing to holding their satellite clinics at **LOROS** every other Tuesday alongside the MND clinics. This unique service gives patients the opportunity to drop in for postural assessments, wheelchair assessments and any alterations that may be needed

For more information about the wheelchair service contact:

Claire Harrison - Clinical Lead Occupational Therapist
(Leicester, Leicestershire and Rutland Wheelchair Service)

Working Days: Monday & Tuesday 8am-2pm, Wednesday & Thursday 8am-4.30pm

Referral forms can be located at **https://opcare.co.uk/clinic/leicester/** .
Please email these to **opcare.wheelchairservices@nhs.net.** For any other queries, or if you wish to be seen in the clinic at LOROS, please contact the admin team on **0116 296 8400.**

MND Association | Leicestershire and Rutland

How we can help



Our **Branch Association Visitors (AVs)** work closely with the MND team at LOROS to ensure local MND patients and their families receive appropriate help and support when needed. AVs are specially trained volunteers who are able to visit people with MND and their carers at home or keep in touch with them by telephone or email. Their aim is to offer friendly, informed support to people with MND and their families by advising them about the support and services provided by the MND Association and by signposting them to other appropriate sources of help. They also support the work of the MND multi-disciplinary clinic based at LOROS. Many of you will know **Jenny and Kath** (pictured here with **MND Nurses Omina and Katie**) who are regularly on hand to welcome patients at LOROS on clinic days. Our branch AVs are also able to provide information about the support available from MNDA as well as other clinical and therapeutic services such as complementary therapy and counselling.

If you would welcome telephone contact or a visit from one of our team of volunteer visitors, do get in touch directly with our AV coordinator, Jenny Holmes-Shuttlewood or speak to one of the MND team at LOROS.

MNDA Support Funds These funds not only help to provide practical aids and adaptations but also aim to improve the general well-being of people living with MND, their families and carers through such experiences as holidays and complementary therapy. To find out more about MNDA Support Funds, please contact one of our Association Visitors or talk to the MND team at LOROS. Information is also available on the financial support webpages at **www.mndassociation.org**

MND Connect 0808 802 6262 This is the MND Association's helpline which is currently available on **Monday - Friday from 9am - 4pm**. It provides advice on all aspects of MND as well as information about the work of the Association and the support available.

MNDA Benefits Advice Service Call for free on **0808 801 0620**

An opportunity to participate in MND research



Researchers are looking for local volunteers to take part in a new study which is investigating muscle changes in the ALS version of Motor Neurone Disease, as explained below by Gemma Brownbill from Loughborough University

*"Researchers at **Loughborough University** are running a study called **MONITOR ALS**, funded by the **Darby Rimmer MND Foundation**. In ALS, the nerve cells responsible for controlling movement are progressively lost, but we currently have limited ways to track this process non-invasively. **MONITOR ALS** aims to identify biomarkers of this nerve cell loss that could be detected using simple electrical recordings from the skin. These biomarkers could ultimately help with earlier and quicker diagnosis, and with tracking how the disease progresses.*

The study is open to people who have received a confirmed ALS diagnosis within the past 3 years, are aged 18–90 and are not reliant on ventilation support for more than 20 hours a day. We are also looking for healthy volunteers (aged 18–90, no neurological conditions and in general good health) to take part as comparison participants.

*Participating involves 3 visits to Loughborough University, each around 3 months apart. During each visit, you would be asked to perform some gentle, low-effort movements of the ankle and fingers while small electrode pads are placed on the skin overlying the muscles. There are no injections or invasive procedures. Each visit lasts approximately 2–3 hours and travel expenses are available. This study has been approved by an **NHS Research Ethics Committee**. "*

If you are interested or would like more information, please don't hesitate to get in touch with Gemma Brownbill at g.brownbill@lboro.ac.uk.

Care and Support Activities

Thanks to the support of the management and MND clinical team at LOROS, we continued to hold monthly meetings of the LOROS MND Support Group in Seminar Room 1 on clinic days. As well as being available to welcome those attending clinic, our specially trained volunteers host these informal meetings to offer refreshments, a friendly chat and support, if needed, to anyone living with MND, families affected by MND and those bereaved by MND. The introduction of the Rutland Support Group arranged by our MNDA Community Support Coordinator (CSC) has been very popular, demonstrating the need for a support group in the Rutland area. As a result, a programme of regular monthly meetings has now been established in Oakham.

Other activities arranged by the branch include the Strawberry Tea in June and the Christmas Social in November which were both held at the Wycliffe Rooms in Lutterworth. The branch also introduced regular "Family and Friends" drop-in meetings in Leicester which aim to provide family members and carers with an opportunity to meet others in a supportive and informal setting. In addition to hosting these support meetings, our team of Association Visitors (AVs) are also able to keep in touch with individuals and families affected by MND, visiting them at home where invited. Branch volunteers not only delivered Easter eggs to all the children of local people with living with MND but also arranged for to over 90 local people living with MND to receive a Christmas card and festive biscuit tin.

In 2025 the branch contributed over £33,000 towards the cost of more than 80 MNDA Care and Support Grants for local people affected by MND. This represents a 60% rise in the number of grant applications supported by the branch compared with 2024, reflecting the national trend for increasing numbers of people seeking financial aid from the Association. These grants provide or contribute to the cost of aids, services and equipment that are not provided by statutory services such as riser-recliner chairs, bathroom adaptations and complementary therapy treatments. Also included in this

figure were several grants specifically aimed at supporting family members of those living with MND i.e. carers and young people.

LOROS partnership

The branch has continued to work closely with clinicians and other professional colleagues at LOROS. Our branch AV Co-ordinator attends the regular MND Multi-Disciplinary Team (MDT) meetings where any issues or concerns about MND patients can be raised with clinicians in a confidential forum. The MND nurses also liaise directly with MNDA's Support Services and branch AVs regarding any applications for MNDA Care and Support funding. Branch representatives also met with members of the LOROS MND Supportive and Palliative Care Group to share information and discuss any general issues relating to the provision of services to around 90 local MND patients.

Fundraising

As in previous years, the branch is very grateful to the many local donors and fundraisers who raised most of the income received by the branch in 2025. Thanks to their support and generosity the branch received a total of £17,229.72 from corporate, individual or "in memoriam" donations. In addition, the branch received a total of £21,650.69 as a result of fundraising events organised by individuals, families and various organisations such as Charnwood Forest Golf Club and Morrisons Supermarket. Fundraising activities organised by the branch raised an additional £1,297. 62. The branch is keen to develop and promote more opportunities for branch and community fundraising so committee member Paul Wilcock has agreed to lead on this vital area of work, supported by Alistair Laing, our MND Association Community Fundraising Coordinator.

Branch Finances

The total income for the year ending 31 December 2025 was £41,148.63 which was a slight reduction on the previous year. During 2025 the branch spent £34,670.26 on direct support for local families affected by MND including contributions to MNDA support grants and AV expenses. Administration costs i.e. meetings, newsletters, postage and IT services totalled £3,175.50. The total remaining in the branch account at the year-end was £21,747.50 so, in line with Association policy, the branch

transferred 50% of this sum (£10,873.80) to support MNDA's national care and research activities.

Branch Management

The day-to-day work of the branch is managed and coordinated by members of the branch committee who are supported by the AV team and other volunteers. Regular committee meetings are held and the wider team of volunteers and friends of the branch are kept informed and involved as appropriate through the use of specific WhatsApp groups. As well as circulating 2 branch newsletters to nearly 150 local contacts, branch volunteers also kept the wider community in touch with MND Association news and local events through social media accounts. (**Facebook - @Leicestershiremnd** and on **X - @MNDA_Leics)** The branch website (**www.mndaleicester.org.uk**) is also maintained by volunteers with technical support provided by Caged Fish Ltd.

The branch committee is fortunate to be able to call upon many enthusiastic, capable and committed volunteers to support its work in the local community. The MND Association provides appropriate training and the branch is very grateful to our MNDA Community Support Coordinator Anne Anderson for her invaluable advice and involvement in branch activities. The committee would like to pay tribute to Yvonne Minifie, our long-serving committee member who sadly died in December 2025, having supported the work of the branch in many ways, including the role of Branch Secretary. We would also like to formally acknowledge the contribution made by Jane de Zilva who has now stepped down from the committee having done so much to organise many successful branch events and activities as well as co-ordinating our growing team of volunteers.

Once again, the Leicestershire and Rutland branch is hugely grateful to all those who have helped us to continue supporting people affected by Motor Neurone Disease.

"Because, with MND, every day matters."

Janet McMillan

Chair, Leicestershire and Rutland Branch

Come and join the local team!

MNDA's Leicestershire and Rutland Branch is made up of a group of friendly, dedicated volunteers who all contribute different skills and interests to our work in the local community. As well as organising and helping out at meetings and events, our team of local volunteers are also responsible for the day-to-day running of the branch such as dealing with correspondence, managing the accounts and keeping people informed through social media and newsletters etc.



We would love to hear from anyone who would like to help in any way, whether as an occasional volunteer or a member of the branch committee**.** In particular, we really need some **extra support with our branch administration, eg. updating the branch website, helping to produce and mail our newsletters or organising activities and events.** These tasks can all be done at home at any convenient time so are ideally suited to anyone with access to a computer who'd like to make a contribution to the work of the branch.

All **MND Association** volunteers receive appropriate training from the Association, both in person and through on-line learning and, of course, our branch committee and other volunteers would be delighted to offer their support and welcome them to the Leicestershire and Rutland team!

For more information, please contact:-

Branch Chair - Janet McMillan ***janet.mcmillan@mndassociation.org***

or

MNDA Community Support Co-ordinator - Anne Anderson

anne.anderson@mndassociation.org

Are you a member?

MNDA's quarterly magazine **Thumbprint** is full of interesting articles and information for members, including the latest news in care, research and campaigning as well as features on fundraising and living with MND. Membership of the **MND Association** is free to people living with MND and their carer so, if you've not already joined and would like to receive regular copies, just log on to: **www.mndassociation.org** or see the **"Get Involved"** page on the branch website at **www.mndaleicester.org.uk**

Find us on Socials!

You can find out more about local branch events and MNDA news on

Facebook - @Leicestershiremnd

Twitter / X - @MNDA_Leics

DONATIONS TO THE BRANCH

In memory of Stephen and Carl Symes-Goodman	£70
In memory of Clive Jones	£500
In memory of Michael Webb	£20
In memory of John Vann	£1300
In memory of Peter Wood – Bob Millar Golf Day	£400
In memory of Michael and Guy Holmes	£100
In memory of Guy Holmes	£20
In memory of Yvonne Minifie	£167.90
In memory of Tony Edwards	£150
In memory of Mick Porter	£100
In memory of Colin Robinson	£20
In memory of Simon Wood	£100
Johnson Astills Solicitors	£140
Sue and Steve Rees – Cake in the Garden	£40
Steve and Audrey Guiney	£250

MNDA Raffle	£90
K N Shopfitters	£250
Narborough Elect	£250
Pub collections	£356.11
N & K Bannister	£35
Norma Hodges	£20
Lynn Bosworth-Payne	£100
Derek Vasey – Pub collections	£295.07
Vanessa Wood – Sale of calendars	£1547
Martin Wigmore – Fishing event	£501.60
Judith – Christmas stall	£100
Syston RFC Charity Boxing Day rugby match	£522.85
Birstall Friends	£35
MNDA Christmas raffle	£335
Edith and Archie Christmas Social stall	£12.50
Jane De Zilva	£407.62
Marge Thrift	£20
Rufus Oliver – sale of hand decorated baubles	£137.98
Bridge 67 Butchers	£2000
Rebecca Pearce – Skydive Elizabeth Hubbard tribute fund	£90
In memory of Percy Sarkari	£1000
Ashby Show - Charity donation	£2000
City Rooms Ball Nov 25 – Raffle	£3500
Wolfson School of Mechanical, Electrical and Manufacturing, Loughborough University – Staff Christmas lunch collection in memory of Professor Bucur Novac	£911.53

Many thanks to all our generous donors and fundraisers

If you are planning to raise funds specifically for the **Leicestershire and Rutland Branch** please make this clear on all publicity about the event, Just Giving pages etc. Donations to the branch can be made via Bacs or sent directly to the Branch.

For more advice/ information please contact our Branch Treasurer at rebekah.grycuk @mndassociation.org

Leicestershire and Rutland Branch Contacts

Chair: Janet McMillan 01509 880577 *janet.mcmillan@mndassociation.org*

Vice-Chair: Ruth Johnson 0116 2478279 *ruth.johnson@mndassociation.org*

Treasurer: Rebekah Grycuk *rebekah.grycuk@mndassociation.org*

Branch Fundraising Co-ordinator: Paul Wilcock 07725 509 508

Branch Association Visitor Co-ordinator
Jenny Holmes-Shuttlewood 07973 478358
jenny.holmes-shuttlewood@mndassociation.org

Branch website – www.mndaleicester.org.uk

MND Association

Registered charity no. 294354

National Office

MND Association, Francis Crick House,
6 Summerhouse Rd, Moulton Park, Northampton NN3 6BJ

www.mndassociation.org

MNDA Community Support Co-ordinator - Anne Anderson
anne.anderson@mndassociation.org

Connect (MND Association Helpline)

0808 8026262 Open weekdays 10.00am - 4.00pm

Please let us know if you no longer wish to receive the branch newsletter, would prefer to receive it by email or have changed your address.