
MNDA Summer Newsletter | From Your New Editor

Hello and Welcome!

I'm **Rona Stephens-Hill**, your new newsletter editor, and I'm delighted to step into this role. I'll be keeping you updated on all things **MNDA and fundraising**, continuing the fantastic work of our former editor, **Ellie Seymour**, whose dedication has been invaluable. Let's all give her a heartfelt thank you!

This newsletter provides updates, inspiring stories, and opportunities for meaningful engagement. MNDA's mission is close to many of our hearts, and I'm excited to share this journey with you.

Thank you for being part of our community. Let's keep the momentum going!

MNDA News Update

Complementary Therapies Webinar

A new pre-recorded webinar launching on 26 August will explore how complementary therapies can help improve wellbeing for people living with MND.

Register in advance to receive access upon release.

Exclusive Q&A with Professor Nigel Leigh: MIROCALS Research Revealed

Exciting news! Back in 2014, the East Sussex Branch supported Professor Nigel Leigh in launching the MIROCALS research project, a collaboration with French researchers, funded by the EU and the MND Association. The results have now been published, and you may have seen Professor Leigh discussing them on BBC Breakfast TV.

To share insights from this research, Professor Leigh has kindly agreed to host a Q&A session for us at Ringmer Village Hall on Wednesday, **16 July at 2 PM**. His past sessions have been incredibly informative, and this one promises to be just as engaging.

We'd love for you to join us! Please let me know **in advance** if you plan to attend. **Tea and biscuits will be provided**, and the session will last approximately **two hours**.

To RSVP, reply to this email or contact Sharon at **07484 657310** or email sharon.bass@mndassociation.org

Looking forward to seeing you there!

Mark Your Calendar!

You're invited to a *fantastic* fundraising event that you won't want to miss. This year's concert at The Big Beach Café in Hove is happening on Saturday, **5 July, from 2 PM**.

Expect an afternoon filled with live music, great company, and the chance to support a meaningful cause. We'd love to see you there!

Looking forward to sharing this special event with you.

Omaze House Draw – Win a £4M Sussex Home + £250K

Support MNDA and enter to win a luxurious **beachfront home in Sussex** and **£250,000 in cash**, guaranteed **£1 million donation** to MNDA from ticket proceeds.

Enter by:

- **Online:** June 29
- **By Post:** July 1

Enter here: omaze.co.uk/sussex-house-draw



Nick Deane's Remarkable Fundraising Journey

When **Nick Deane** was diagnosed with **Motor Neurone Disease (MND)** in late 2023, he could have focused inward. Instead, he turned outward, rallying **friends, family, and the community** to raise an astonishing **£88,000** in just a few months for **MND research and support**.

Nick's journey began with the **MND Association's "Run 26 Miles in December" challenge**, where he completed all **26 miles**, raising **£11,500** and proving that **positive action** is possible even in the face of adversity.

Building on this momentum, **Nick and 38 supporters** took on the **Three Peaks Challenge**, conquering the tallest mountains in **England, Scotland, and Wales—Snowdon, Scafell Pike, and Ben Nevis**. This gruelling climb raised **over £54,000**, reflecting not just the challenge of the climb but the power of a united community.

By **spring 2024**, Nick's fundraising total had surpassed **£65,000**, and the highlight of his journey came in **April**, with a **gala dinner at Shrewsbury Town Football Club**. The black-tie evening drew over a hundred supporters, with a charity auction featuring standout items like a **signed**

England rugby shirt and a coaching session from **rugby legend Jonny Wilkinson**. By the night's end, the event raised **£23,000**, bringing Nick's total to approximately **£88,000**.

Now, as Nick prepares to **relocate from Shropshire to East Sussex this October**, he brings the same passion and drive, eager to **connect with the local MND community**, continue raising awareness, and inspire new fundraising efforts.

Nick's story is a powerful reminder that **one person's determination** can spark a ripple effect of **generosity, hope, and action**. From solo runs to mountain climbs to packed banquet halls, he has proven that **even in the most challenging times, a united community can achieve incredible things**. His journey continues to **inspire**, lighting the way for others to follow.

May Fundraising Events: A Huge Success!

We're delighted to share that we've had **two successful fundraising events** this month in support of **MNDA East Sussex**, raising a fantastic, combined total of **£4,767**.

Comedy Night – May 8

Held at **Mid Sussex Golf Club**, the night was a **sold-out** success, full of laughs, fun, and generous giving. Thanks to the incredible support of attendees, this event raised **£2,410** for MNDA. The response was so fantastic that we've already been invited back for follow-up events in **October and December!**

Community Fundraiser – May 25

Hosted at **Eastbourne Football Club**, this event featured a **charity football match, family activities, and an exciting raffle**. Through ticket sales, donations, and the generosity of local businesses, we raised **£2,357** to support those affected by MND in our local area. We are deeply grateful to everyone who participated and contributed.

Upcoming Comedy Nights:

- **Roedean College – Aug 22 & Dec (TBC)**
- **Brighton College – Dates TBC**
- **Mid Sussex Golf Club – Oct & Dec**

Help Us Grow MNDA Comedy!

Know an incredible **venue** or a **generous business** willing to **sponsor an event**? Let us know!

Get in touch at rona.stephens-hill@mndassociation.org

Help Us Grow MNDA Comedy!

- **Know a great venue?**
Golf clubs, village halls, sports clubs — let us know!
- **Know a generous business?**
We're seeking event sponsors and donors. Every lead helps make our events bigger and better.

We're expanding and need **your recommendations**:

Inspiring Stories – We Want Yours!

Do you have a story to share? Whether it's about a personal journey, a local hero, or an uplifting act of kindness, we'd love to feature it.

- A career milestone
- A child's achievement
- A business making a difference
- An MND warrior's journey

Submit stories to: rona.stephens-hill@mndassociation.org

Let's inspire hope together.

We honour those we've lost to MND. Their strength, courage, and love remain a guiding light in

Together, we remember.

Wendy Ridley
Adrian Stewart Hill
Indira Pillay
Amanda Simmonds
Samantha Whittaker
Stuart Macabe
Diane Howarth (Krissie)
Stephen Richardson
Kevin Carias
Stephen Moles
Jackie Kulkarni
Lyn Taylor
John Maslem
Mick Defries
Lee Driver
Andrew McEvoy

Thank you for reading and supporting MNDA. We couldn't do it without you.

Stay connected,
Rona Stephens-Hill
MNDA Newsletter Editor

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