

Hertfordshire Branch Newsletter

July 2023



Neil and Carl Rutherford who presented the Gala, with Councillor Steve Buck, Mayor of Stotfold and Councillor Myla Arceno Mayor of Stevenage, who joined us for the evening

The National Office Helpline is 0808 8026262
Motor Neurone Disease Association - Registered Charity No. 294354
Branch Patron: Dr Viv Lucas

A Message from the Chair

Hi everyone,

Recently, Grant Cameron, Sue and I attended the MND EnCouRage conference. It highlighted presentations, discussion and networking with early career researchers on various aspects of the continuous research effort on specific projects into many aspects of MND.

There were more than 20 active research studies explained, with some international presenters and ample opportunity for us to ask specific questions and have informal discussions with the scientists/clinicians/speakers.

We came away with a strong sense of being cared about and also quite impressed with the broad range of study being progressed in the UK. I was also very pleased to meet face to face with other people with MND.

The whole experience helped me feel relevant, heard and cared about. I laughed with others, had fun conversations during breaks, lunch and dinner and made some new friends to keep in touch with. My wife Sue also met other spouses, carers and researchers to discuss her specific interests, concerns and feelings.

I encourage you to get involved with any of the ongoing MND projects, events and discussions available to you. I strongly believe the more information, connections and resources we interact with, will bring us helpful practical, emotional and energetic benefits at every stage of our lives.

Kent

Grant Cameron's Report

MNDA host an annual research conference where Early Career Researchers (ECRs), many funded solely by MNDA, get to meet one another. The goals of the meeting are for the ECRs to build networks within the MND research community and to present their work, in lay terms in three-minute presentations to a mixed audience of fellow researchers, people living with MND and others involved with the Association.

The core of the meeting was 22 presentations from PhD students and post-doctoral researchers. The topics presented ranged from the development of practical support guidance for improved cough and secretions management to the use of Artificial Intelligence (AI) to better predict disease progression from its early stages to the use of genetic and protein technologies to identify potential targets for drug discovery.

The work, with follow on discussions was enlightening and above all showed the multiple approaches being taken within the research community all aimed at improving the outcomes for people living with MND. Some topics will, of course,

bear fruit earlier than others. I was particularly impressed with the range of skills demonstrated by the ECRs and the enthusiasm and dedication shown by them. They said that it was incredibly motivating and important to meet and talk to people living with MND. On a day-to-day basis they are in their laboratories and offices so this was a critical reminder of why they are doing the work, how important that work is and what the real world impact their projects could have. I think the future of MND research looks to be in very good hands.

Grant

Finance Report – May and June 2023

May and June have been bumper months for donations. We have received donations via Just Giving, totalling £2,513, from Daniel Hoaran and Adrian Spanna who have both run the London Marathon on our behalf. In early June Neil & Carl Rutherford held their 3rd Gala at the Gordon Craig Theatre, proceeds were shared equally between MND Scotland and our branch and we were very grateful to receive £4,910. We have also received several smaller donations over the last 2 months which have added up to a further £1,212 plus Gift Aid amounting to £308.

These wonderful donations both large and small have enabled us to fund a washer/dryer toilet, an ironing service, a carer's spa break and 2 taxi rides in a wheelchair accessible vehicle.

Thank you to everyone for your continued support.

Heather

Fundraising

Gala Sunday 4th June

The West End Cast Charity Gala organised by Neil and Carl Rutherford was a wonderful evening filled with beautiful songs, music, laughter and memories. The orchestra lead by Neil and Simon Beck were outstanding and the Mountview choir from the Mountview school, where Neil is the Industry Liason Manager were amazing.

Oliver Gordon, who is 11, sang Giants in the Sky from Into the Woods. What a great performance. Oliver is from Welwyn Garden City and will be performing in the latest BBC show of The Greatest Dancer. We wish him well for the forthcoming show.

Nathania Ong who is appearing as Eponine in Les Miserables, performed On my Own from the show, it was absolutely stunning.

Neil was brilliant as Fagan, performing Reviewing the Situation from Oliver with interruptions by solo violinist Jonathan Hill. Carl was equally brilliant performing One for my Baby from The Sky's the Limit.

I am very proud to mention my daughter Nicola, who having written a poem last time was asked to write a song, she felt very honoured to be asked and wrote the words for

Close to You, sung by Niall Sheehy and the choir. Niall is currently appearing in Glory Ride in the West End. There were also great performances by Kelly Price, Chumisa Dornford-May and Ben Cutler.

The show was hosted by Hayley Tamaddon who shared several funny stories with us from her time in Coronation Street, Emmerdale and Dancing on Ice.

There was a fantastic ending to the show with the whole company and audience singing You Can't Stop the Beat from Hairspray.

Thanks to everyone who supported the Gala and bought so many raffle tickets for the amazing prizes. A big thank you to the Mountview choir for help in selling the tickets and programmes.

What can you say! It was a truly memorable evening, many many thanks to Neil, Carl, the great orchestra, the wonderful choir and all the fabulous stars that gave their time to perform to raise funds and awareness for MND Scotland and the Hertfordshire Branch. The amount raised was an outstanding £9.819.84 shared equally between the Hertfordshire branch and the Scottish MNDA. Chris



A message from Richard Long who is a member of our Branch

I was asked by the MND Association to speak at the Care Showcase at Boughton House, Kettering on Tuesday 6th June 2023. This was an event for major MNDA supporters with charities and corporates attending. Boughton House is the home of Richard Scott, 10th Duke of Buccleuch who is known as Duke Richard and who was also in attendance.

I was asked to talk about my MND journey and how the MNDA has helped me with grants for things such as stairlift, levelling our lounge, my original electric wheelchair, a washer dryer toilet, wet room, my second wheelchair and the vehicle locking system.

I wasn't sure what to expect from this event, but I was really hoping that I could help the MND Association by sharing how expensive having MND is. People living with MND get wonderful support from the Association, but the charity can't provide all of the support due to limited funds. I hope that the organisations who were in attendance were inspired to continue to support the MND Association financially after hearing my story.

HRH The Princess Royal sat with us and spoke after me. She cut a cake and was given a bouquet of flowers and then left. However after cutting the cake, she asked me if I was able to eat any. I replied 'Medically or matrimonially?' hence the smiles on our faces.



Future events for your diary



Britain's MND Veterans Group Needs You

Please join us on August 18th at 3pm

We would like to welcome all veterans to join us for a different type of support. Not just about MND but about you and your background and some common interests.
A safe place to talk with like-minded people.
Please let me know if you would like to join us and I will send you a Zoom link to join.

Please contact:
Dawn.pond@mndassociation.org

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www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
| Registered charity no. 294354 | Created in RightMarket - 6/6/2023 - 11:24:00

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**FUNDRAISING
REGULATOR**

Folk by the Tree - Orange Tree pub – Baldock – **Sunday 27th August**

The annual Folk around the Tree organised by the Baldock Folk Club, will once again be raising money for the Hertfordshire Branch of the MNDA.

Folk around the Tree will take place at the Orange Tree Pub in Baldock on Sunday 27th August from 1.30pm featuring various artists including our very own patron Viv Lucas. The event takes place in the pub garden until 7.30pm when it moves inside.

Further details will be available on the Baldock Folk Club Facebook page and on the Hertfordshire MNDA Branch Facebook page and website.

Variety Express show - St Francis Theatre – Letchworth **Thursday to Sunday - 26th - 29th October**

Pirates – A family musical adventure. A swashbuckling tale, action, romance, song and magic on the high seas. Tickets online at varietyexpress.org.uk

FUTURE MEETINGS FOR YOUR DIARY

Hertfordshire Branch Meetings – Face to Face – The Three Horseshoes
Hooks Cross, Watton at Stone, Herts SG14 3RY - 01920 830391 - **11am**
Monday - 31st July - August no meeting - Monday 25th September - Monday 30th
October

Get Togethers - Box Moor Trust Centre, London Road, Hemel Hempstead HP1 2RE
For those living with MND their family and carers - First Wednesday of each month -
2pm 2nd August - 6th September - 4th October - 1st November - 6th December

For more information contact - Lesley Ralston - leshenhouse@gmail.com

Daytime Group - Zoom - 3rd Tuesday of every month - **11am to 12.30pm**

15th August - 19th September - 17th October - 21st November - 19th December

For more information contact - Dawn.Pond@mndassociation.org

South East Carers Coffee & Chat - Zoom - Carers only - First Tuesday of each
month - **11am** - 1st August - 5th September - 3rd October - 7th November - 5th
December

For more information contact - lisa.burnard@mndassociation.org

Evening Carers Group - Zoom - Carers only - Last Wednesday of each month-
6.30pm
26th July - 30th August - 27th September - 25th October - 29th November - 20th
December at 6.30pm

For more information contact - justine.cox@mndassociation.org

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MNDA HERTFORDSHIRE BRANCH WEBSITE

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TWITTER

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THE MND HELPLINE – Tel 0808 8026262

mndconnect@mndassociation.org

Our MND Connect helpline offers advice, practical and emotional support
and directing to other services and agencies.

Mon - Fri 9.00am - 5.00pm and 7.00pm - 10.30pm.