# motor neurone disease association



# NEWSLETTER

## New clinical trial launched

MND-Smart is a new generation of clinical trial in which multiple treatments are evaluated simultaneously.

The trial is led by a team of researchers based in Edinburgh and will test potential new treatments for MND as well as looking at whether existing treatments for other conditions could have some benefit.

Typical clinical trials focus on a single drug – patients receiving the active drug are compared with those who receive an inactive substance, known as the placebo. MND-SMART will allow more than one treatment to be tested against a shared placebo group so that patients have a higher likelihood of receiving an active treatment.

People with MND are invited to register interest in the trial at www.mnd-smart.org. The first participants will be seen in Edinburgh with other clinics across the UK joining during 2020.

It's good news for people with MND and we're delighted people will be recruited to the trials through MND Association funded care centres.

MND-SMART is supported by the Euan MacDonald Centre, substantial private donations, MND Scotland and the My Name'5 Doddie Foundation.

For more information www.mnd-smart.org

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## **Social Afternoon Get Togethers**

#### Wednesday 6<sup>th</sup> November 2019 Ely Community Centre

We were back for our second visit of the year to this venue. Those of you who managed to come along had a lively afternoon. Everyone was able to join in and chat which is a useful way of exchanging ideas and suggestions of how to deal with any issues.

#### Thursday 5<sup>th</sup> December 2019 David Rayner Centre, Gt Shelford, Scotsdales Garden Centre, Cambridge "The Christmas Spectacular"

Our Christmas-themed festivities were on offer at this afternoon which brought to a close our social calendar for another year.

Warm non-alcoholic mulled punch got the afternoon off well. The tables were decorated with festive goodies, crackers and party poppers.

To enhance all this we welcomed Sue and John back to entertain us. Sue Hallifax, as many of you will know is one of our Association Visitors and John is her partner. Their singing and guitar playing lifted the afternoon. Words were provided for some of the songs so anyone could sing-along.

Geoff and Chris Glover had set a quiz – a lighthearted part of the afternoon but it always brings out the competitive side!



Home made cakes and cheese biscuits along with mince pies and lots more were enjoyed, washed down with either more of the mulled punch or a cup of tea.

On leaving, our members living with MND were given a "mystery" gift and poinsettia. You are such an inspiration to us all. Your branch committee feels this is a very small way in which we hopefully create a light-hearted, bright, lively and special afternoon for you.







Wednesday 15<sup>th</sup> January 2020 Hemingford Abbots Village Hall

This was our first social afternoon of 2020 where we were back at this really great, light and airy venue. This building is easily accessible with onsite parking, a large hall with facilities all on one level. We were also lucky with the weather that afternoon!

We were pleased to welcome our "regular" members and some new ones with a number of the branch committee members and association visitor there on hand.

The usual tea and coffee and goodies were enjoyed.



#### 2020 Social Afternoon Gatherings

Many of you will have seen from the 2020 Events Diary that we will be at four venues for these social afternoon gatherings this year.

We return, of course, to Cambridge, to the David Rayner Centre on the Scotsdales Garden Centre, and the Peterborough venue will be at the Salvation Army Centre. We have already had our first afternoon at the Huntingdon location, the Hemingford Abbots Village Hall. We have found a new centre for the Ely afternoons as felt the facilities at the Community Centre were not adequate for our needs. We did a lot of research and with the help of one of our members we have decided upon the Methodist Church Hall. There is easy access through a gate in St Mary's Public Car Park. It is free parking (as at the time of writing this article) for 2 hours maximum. This is the reason these afternoons (only the Ely ones) will be restricted to 1<sup>1</sup>/<sub>2</sub> hours.

Our monthly gatherings offer a social afternoon and are held for you, our members, to get to know each other over a chat and cup of tea. This is an ideal way of picking up hints and exchanging ideas and tips in an informal way or just to come and have a relaxing afternoon. Family members, carer, or friend are welcome to come with you. We may have a speaker to give a talk on an interesting subject or someone from the MND staff.

We can help with travel to get to any of the venues by arranging transport (wheelchair friendly if needed).

If you would to know more about these afternoons then please get in touch. Do come along and join in, you will be made very welcome.

Cynthia George Tel: 01954 202095/07515 534430 Email: c.i.george@icloud.com

## **Volunteering for Cambridgeshire Branch**

"Being a Motor Neurone Disease Association volunteer is a very rewarding role. It gives me a boost when I have made a difference for someone living with MND".

Do you enjoy listening to and helping people? Do you have skills which you could share to help support the work of your local branch? Are you looking for a volunteering role which fits in around your family, work, studies and other commitments?

The Cambridgeshire Branch of the MND Association is currently looking for volunteers to support its work. Roles available include:

## Care Support Volunteers

#### **Association Visitor**

By giving just two to four hours a week, Association Visitors can have a huge impact by offering confidential emotional support. As an Association Visitor you would maintain contact with people with MND, their families and carers by phone, email or face to face visits.

#### **Care Service Navigator**

By offering support, accurate information and help to access the right services and equipment, you can enable people affected by MND to live their life more easily and to make informed choices.

These roles are challenging but rewarding. Full training and induction is provided.

For more information about Association Visitor or Care Service Navigator roles please contact Liz Cooper our Area Support Coordinator on 0345 375 1827 or e-mail Liz.Cooper@mndassociation.org

#### Branch Roles:

#### **Branch Treasurer**

This is an important position within the branch where the requirement is to keep accurate spreadsheets of branch finances. Guidelines are set out by our National Association. Branch committee meetings are held bi-monthly where the Treasurer provides up-to-date financial information.

#### **Fundraising Officer**

The Branch is looking for someone to arrange events to raise funds and awareness to support local families.

#### General Branch Support

The Branch would appreciate support with general duties such as helping set up the venue for local Get-Togethers, admin, bucket shaking and other duties to raise funds. If you have limited time any one of the above would be appreciated.

Support and induction provided by branch committee members for any of these roles.

For more information about the branch roles please contact Chair, Cynthia George by e-mail c.i.george@icloud.com or telephone on 01954 202095/07515 534430.

You can find out more about MND and our volunteering opportunities and express an interest online at: www.mndassociation.org/get-involved/volunteering/become-a-volunteer/

## Could you or someone you know become a Trustee?

Do you know any members of the MND Association who have the skills needed to become a Trustee?

Our trustees are volunteers responsible for ensuring that the mission and long-term aims of the Association are met. This challenging but rewarding role means taking a national perspective to meet the needs of people affected by MND. Trustees have the ultimate legal responsibility for directing the affairs of the charity, ensuring it is solvent, well-run and continues to meet the needs of people living with MND.

You may have seen in the December edition of the Volunteer News or the Winter Thumbprint that we are holding a trustee information day to enable people to find out more about the role of a trustee and to get an overview of the structure and nature of the Association.

This event is being held from 12:30 to 3:00pm at our offices in Northampton on Thursday 19th March 2020. There will also be an opportunity to join by video conference.

Anyone who might be interested in finding out more information or who would like to book a place at theinformation day can email governance@mndassociation.org or telephone 01604 611 844.

Richard Coleman Chair of Board of Trustees MND Association

## Items for Sale:

**Kia Sedona** (pictured) Manual drop down ramp at rear. Drive in with power chair and secured with harness and floor straps. Seats four plus chair.

#### **Motorised Scooter**

For use over all-terrain.

Both available in the local area.

If interested, enquiries in the first instance to: Brenda Parkes, Care Service Navigator brenda.parkes@mndassociation.org 01832 281052



Please note all transactions will be arranged privately between the buyer and seller, the MND Association/Cambridgeshire Branch is not endorsing or affiliated with any of the above items.

## EARTH, SEA 5 SPACE



## SATURDAY 14<sup>th</sup> MARCH 2020 7:30pm

Wesley Methodist Church Christ's Pieces Cambridge CB1 1LG

Includes music from: Alan Silvestri -Back to the Future

Johann Strauss -Thunder and Lightning Polka

James Horner -Apollo 13

Richard Strauss -Also Sprach Zarathustra (2001: A Space Odyssey)

AND MORE!

**Conductor: Suzanne Dexter-Mills** 

Tickets: £10 each Coffee/tea during interval break



APOLLO 13



CCO Charity No.: 263524

## Further information and to book tickets please contact:



Simon Crooke, Branch Fundraising Co-Ordinator Email: cambridge@mndassociation.org - 07551 575752 or

Cynthia George, Branch Chair Email: c.i.george@icloud.com - 01954 202095/07515 534430

## MOTOR NEURONE DISEASE ASSOCIATION

## **CAMBRIDGESHIRE BRANCH**

## AGM

This year's AGM will be held at

Hemingford Abbots Village Hall

on Wednesday 18th March

### at 12.30pm

We look forward to seeing you there.



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Dates of Get-Togethers in 2020		
Weds 8th April	Ely	
Thurs 14th May	Great Shelford, Cambridge	
Weds 10th June	Peterborough	
Thurs 9th July	Great Shelford, Cambridge	
Weds 16th Sept	Hemmingford Abbots	
Thurs 15th Oct	Great Shelford, Cambridge	
Weds 11th Nov	Ely	
Thurs 3rd Dec	Great Shelford, Cambridge	

To find out more about the Cambridgeshire Branch visit www.mndassociation.org/cambridgeshire www.facebook.com/cambridegshireMNDA

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Mrs Maire Collins (contact details above)