

MESSAGE FROM YOUR CHAIRMAN



Mention is made later of this being the 40th year of our Association's existence. Quite co-incidentally I was in fact a work colleague of one of the founders (Martin Anderson) at a Nottingham company before departing for Northern regions in 1976, and what pride he and his 'team' must have in looking back on what has been achieved in those 40 years. This is underlined by the fact that 'around £15.5 million is invested in global research' - quite staggering! And the subject of research leads me to add my personal congratulations to Brain Dickie for the award recognising his unstinting 22 years of devotion to that very subject which one day we trust will provide the breakthrough for which we all pray will emerge before too long. I have known Brian over those 22 years and he has talked to the

Branch on several occasions always with tremendous enthusiasm and determination.

Continuing with the research theme, one of the projects undergone at Sheffield has been funded by your Branch and we are thrilled that Dr Tennore Ramesh has found time to join us on Sunday 17th March for tea and cake(s) and for us to hear all about the project (which, if you remember, is all about the trial use of zebra fish) and he will talk about the stage it has reached, results achieved and other interesting side issues.



So I do ask that as many of you as possible will join us on that afternoon in support of Dr Ramesh but also, I can assure you, for some 'exceedingly good' cakes!

This is the last edition of Chatter before committee elections are upon us and we really do need some more 'hands on deck'. Please do let us know if you have a few hours to spend which you could give to us – you don't have to join the committee as such but help behind the scenes with such as publicity, promotion, awareness-making etc would be invaluable additions to what we already manage to achieve.

Do get in touch, and you will see from the photos which follow later that we are quite a sociable lot! So, as they say, just pick up the 'phone!

Peter Thompson

DATES FOR YOUR DIARY

On the **first Tuesday** in the month don't forget our monthly get-togethers (2pm – 4pm) which are held at "**The Barrows**" (previously known as Christians) in Crimble Hall on Leeds Road just outside Harrogate.

The next **Lunch** will be held on 27 March 2019 at the Old Spring Well

AGM Sunday 17th March 2019, 2 pm for 2.30, papers will be sent out soon

Swing into Spring– 6th April 2019 in Pannal Village Hall,

Tickets on sale soon – please let us know if you want to attend



A FEW SNIPPETS FROM THE NATIONAL WEBSITE

Iconic Wheelchair nets windfall for the Association - One of Professor Stephen Hawking's wheelchairs has provided a massive cash boost for the MND Association after smashing through its estimated sale price at auction selling for £296,750, making it the third most valuable lot sold in a Christie's online auction this year. It was described in the auction catalogue as 'Professor Hawking's wheelchair....from which his mind voyaged to the outer reaches of space-time, making it literally and figuratively one of the most-travelled wheelchairs in history'. The money raised will be split equally between the MND Association and the Stephen Hawking Foundation.

Scrap 6 Months - Over the last few months, many supporters and campaigners have taken action on our Scrap 6 Months campaign to help make benefits more accessible for people with MND and other terminal illnesses. Madeleine Moon MP's Private Members Bill to help all people with a terminal illness easily access the benefits they need was due to have its Second Reading on 23 November but was unfortunately delayed. The Association (and also the Marie Curie Charity) will continue to keep the pressure on and demonstrate to the Government that there is strong support to change the law. Please sign the new petition calling for a change in the law so everyone living with a terminal illness can use the Special Rules for Terminal Illness (SRTI) fast-track process. Here is a link <https://e-activist.com/page/33936/petition/1#>

International Alliance awards Director of Research Development – The Association's own Dr Brian Dickie, Director of Research Development, has been awarded the International Alliance Humanitarian Award. The Humanitarian Award recognises individuals or groups whose work makes a contribution of international significance for people affected by MND. This prestigious honour has been awarded to Brian in recognition of his tireless work in progressing research into MND over the past 22 years and it is fitting that he received the award at the 29th International Symposium in Glasgow, the city in which he studied for his Bachelor of Science Degree.

MND Register - The MND Register of England, Wales and Northern Ireland is a research study funded by the MND Association, and led by Professor Ammar Al-Chalabi at King's College London and Professor Kevin Talbot at University of Oxford. It will collect information about every person living with MND which affects about 5000 people in the UK at any one time. However the true figure is not known as there is no single source of information about who is affected. The information will help plan the care for people living with MND and tell researchers more about what might be causing the disease. For example, counting every person with MND will enable a calculation of the number of people diagnosed with MND per year, how many people currently have the disease and how this is changing with time. Information such as gender and ethnicity can be used to look for characteristics of people more likely to develop MND. People with MND can take part in the study via the project website www.mndregister.ac.uk. They may also be invited to take part during an appointment at their MND clinic. The Association is grateful for funding from the Betty Messenger Charitable Foundation and a family trust that wishes to remain anonymous.

Launch of jointly funded Study aimed at improving the quality of care received by people with MND - Together with the terminal illness charity Marie Curie a new study, led by Dr Sally Wheelwright at the University of Southampton, will develop and pilot a web-based decision aid for people with MND considering a gastrostomy. Many people with MND have problems swallowing. One way of managing this is to have a feeding tube fitted into the stomach. Currently it's not known if being fed in this way improves either nutrition or quality of life for people with MND and some people have concerns about having a feeding tube fitted. The project will develop a web-based decision aid to help people living with MND decide whether to have a PEG tube fitted. It will present accurate and reliable information, clearly explain risks and benefits and check users' understanding of the material presented. Crucially, it will also help people understand what is most important to them so supporting personal choice. The decision aid will be developed with the help of people with MND, carers and clinicians to make sure the information included is relevant, useful and presented in the best way possible.

40th Anniversary - The MND Association was established in 1979 by a group of families affected by the disease (see the latest issue of Thumbprint). With little information, co-ordinated care or support available they felt 'isolated' and utterly 'helpless'. They were 'in the dark' and aimed to fill the void of care and support and encourage research into the disease. The Association will mark 2019 with a relentless commitment to people living with MND, underpinned by a fresh optimism that together we will deliver our vision of a world free from MND. We know so much more about MND today and invest around £15.5 million in a global research effort to discover causes, potential new treatments and ultimately a cure and our research focus now is to take that knowledge gained globally into clinics, to find potential new treatments. We have enclosed a copy of a wonderful infographic created by the Association.

CHRISTMAS LUNCH

The usual seasonal celebrations took place at Millstones Restaurant in December and here are a few photos of folk enjoying themselves!



INFORMATION FROM OPEN COUNTRY

Open Country began in 1990 and has developed into a small charity with huge aims! On an average week they run up to fifteen countryside activities, catering for a range of abilities. They know how difficult it can be for people with disabilities and their carers to obtain information about visiting the countryside so they have produced a series of Directories to help people discover accessible places to visit, clubs to join and things to do. Their Directories cover the four counties of Yorkshire, Teesside, County Durham, Lancashire and Wakefield.



To find out more then visit their website <http://www.opencountry.org.uk/countryside-access-directories/> and click on the appropriate directory. If you don't have web access they will send you a print copy or let Yorkshire Dales Branch know and we will obtain copies for you.

This photo is from their website, taken at Buckden in the Yorkshire Dales.

Their aim is to keep the directories up to date so if anyone has any comments, additions, up-dates or suggestions as to how we may improve them please let them know by contacting them by the form on their website or telephone 01423 507227

FUNDRAISING NEWS

In December we were delighted to receive a very generous donation from High Trees Adventure in Keighley - they had held a comedy night – something they do regularly - and had chosen us as their charity for the event!! Here is BMC member Veronica (in the middle) collecting the cheque for £789.01



And if you are in Waitrose Harrogate before the end of January then please get a Green token and put it in our box, we'll let you know in the next Chatter how much we get!!

WINNERS OF RECENT 100 CLUB DRAWS

Recent winners include:

November 2018 – Harris Eggleston
December 2018 – Liz Burnley
January 2019 – Rebecca Shuler

Well done everyone and thank you for taking part, information about renewing Membership will be sent out with the AGM papers.



BRANCH WEBSITE AND OTHER INFORMATION

Please let us know if you would like to publish something on either our facebook page <https://www.facebook.com/MNDYorkshiredales> or our website www.mndyorkshiredales.co.uk . Or perhaps you might like to contribute to Chatter? It would be lovely to publish something from one of our members - just send your article to Ruth Pridmore

Can you help us save money by sending you paperwork by email instead of the Royal Mail?
If you have an email address just let Ruth know and she will add it to the database.

Branch Contacts

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
Treasurer, Geoff Catley - 01423 870143 treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com

National Contact Information

www.mndassociation.org

MND Connect – 0808 8026262