

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 67 June 2015

Copacabana cast present Malcolm with a large cheque!



Cromer and Sheringham Operatic and Dramatic Society put on a production of the musical Copacabana at the Cromer Pier Pavilion Theatre. Throughout the week of 23-30 May 2015 there were nine performances including evening shows and matinées. Andrew Payne, Chairman of CSODS, wrote, 'one of the main purposes of the Society is to raise funds for charity'. They have chosen to support the Norwich and Waveney Branch of the MNDA as their 2015 charity; one of their member's family has been affected by the condition and had spoken highly of the work of the Association. The programme included a page highlighting the work of the MND Association. Malcolm represented the branch at the final performance on Saturday 30 May, where he was invited to say a few words about the work of the charity, and was presented with a cheque for £1,825.50.

Bucket collections were held in the foyer as the audience left the theatre. Some friends and committee members were able to enjoy the show and hold buckets after a few of the performances. We were stunned by the range of musical and acting talent; the energy needed must have been immense, yet no matter how tired the cast may have been after a long week it was good to see they were all still smiling at the end! We were very grateful for the support of the front of house staff who were happy to help with the collections. They were also kind enough to count the money. This was no small task as they raised the magnificent total of £2,288.16 once the final collection was included. Thank you to everyone who took part, supported or attended.



Alex goes for a walk. On 9 May, Alex Georgescu (shown on the final straight with 'support crew') completed a 40km sponsored walk in support of the MND Association – Norwich and Waveney Branch. Alex and her walking buddy made it all the way round the course in approximately 10 hours. They had been hoping to be a bit quicker, but unanticipated stops for fixing a camelpack (water bag) and changing socks/treating blisters, plus the impact of the blisters themselves, meant it took them a little longer to hobble home than they'd intended. They were really pleased to have made it and to have raised £460.03, increased to £553.79 by gift aid.



We echo Alex's thanks to all who supported, encouraged and sponsored her.

AGM at Eaton: It was good to see so many people at the branch Annual General Meeting on Sunday 26 April. We were delighted that 43 members and friends were able to attend, including Dr David Dick, Senior Consultant Neurologist at NNUH, who became the Branch Patron (pictured on the right).

We have long felt the need for more people to join the committee, so it was particularly pleasing that Shirley expressed her willingness to get involved. She has written a short piece to introduce herself – reproduced in full.

'My name is Shirley Basey-Fisher and I have been elected onto our Norwich and Waveney Branch committee at the AGM in April this year having been approached by Malcolm Chubbock.



My interest in MND came about when my husband Ian developed symptoms of the disease in 2003 and sadly passed away 10 years later. Because I am aware of the difficulties around managing the symptoms of this condition on a day to day basis and the lack of treatments available, having been the main carer for my husband, I feel very passionate about raising the awareness of MND and help to improve the lives of those living with the disease, as well raising funds towards research into treatments towards a cure.

I have two children; a daughter Holly who is 30 and was married to Carl last year and a son James who is 26 and is currently working in New Zealand. Motor Neurone Disease has had a major impact on our lives

and together, with the help of lots of friends, we were able to host two successful fundraising events at our home. We were also overwhelmed by the response of friends and family with last year's ice bucket challenge.

I work as a community nurse supporting people with long term conditions, including those with neurological conditions such as MND and helping them to manage their symptoms, making choices about their care. However, I know from experience that those who have lived with MND have a greater understanding of its effects on patients and their families and I feel passionate about improving lives for those with MND and continuing to fund raise towards finding a cure.

I look forward to being part of the Norfolk and Waveney MNDA Branch committee in continuing to raise funds and awareness.”

Victoria Edwards, Advanced Speech and Language Therapist at the MND Care Centre at Addenbrookes Hospital, gave an informative and interesting presentation on alternative and augmentative communication in MND. Her power point presentation can be viewed both from www.mndnorwichandwaveney.org.uk and our branch page on www.mndassociation.org.

Victoria began by noting common difficulties experienced by people living with MND.

- Slurring of speech due to weakness of tongue and lip muscles
- “People think I'm drunk”
- Changes in voice due to reduced breath support
- Speech intelligibility will deteriorate – speed of decline varies

She then defined Alternative and Augmentative Communication (AAC) as the term used to describe various methods of communication that can 'add-on' to speech and are used to get around problems with ordinary speech. AAC includes simple systems such as pictures, gestures and pointing; slightly more advanced techniques include pen and paper, alphabet charts and picture charts. As technology is advancing rapidly the equipment available is becoming more sophisticated. Initially the MND Association supplied SL 35 Lightwriters. These are text-to-speech devices - the user types a message on a keyboard which is then displayed twice, one display facing the user and a second facing outwards for others to read. A speech synthesiser is used to provide speech output. A more recent model, the SL40, has a SIM card allowing text messaging.

More recently people have begun using tablets – either iPads or Android – as they are often already in use and are familiar; they are more cost effective, portable and provide a wider range of uses. Apps are available for both systems.

iPad/iPhone

- ClaroCom
- Speak it!
- Predictable
- Proloquo2go

Android

- Type & Speak
- Speech Assistant
- Let Me Talk

Some people may need switch access and use a scanning method; the switch can be activated by hand/feet/head/knee/face.... Sadly it is much slower than typing. Eye gaze technology is also available. There are a number of different devices, however, whilst some find it easy to use others find it tiring and high costs can be involved with some systems. Examples include:

- Speakbook <http://www.speakbook.org>

- Megabee <http://www.proxtalker.com/megabee>
- E-Tran frame <http://www.communicationmatters.org.uk/page/e-tran-frames>

Victoria spoke about current provision and plans for the future. Provision was inconsistent so NHS England provided £15 million for AAC, some of which was earmarked for environmental controls. There was no specialised service in the East of England. Addenbrooke's have submitted a business case to act as a specialist hub. Representatives from all 6 counties have attended meetings at Addenbrooke's and are in support. The proposed service is a hub and spoke model. The service will consist of a multi-disciplinary team which will include the staff from most or all of the following professions: Speech and Language Therapists; Clinical Scientists; Clinical Technologists; Occupational Therapists; Specialist Teachers; Physiotherapists and Psychologists where necessary.

Only the complex top 10% of those needing AAC will be assessed by the specialist centres who will fund the equipment. The other 90% will still be assessed by their local therapists and funding for equipment should ideally come from the Clinical Commissioning Groups.

What is the top 10%?

- An individual
 - In need of a complex assessment (but not necessarily complex equipment);
 - Able to understand the purpose of the communication aid;
 - With communication technology needs beyond the competence of the local AAC service.
- In addition they may have/be some or all of the following:
 - Severe physical disability especially of the upper limbs;
 - Sensory impairment which is additional to the communication impairment;
 - In need of specialist switch access, which may need to be bespoke;
 - In need of a device that integrates spoken and written communication as well as environment control;
 - Multiple disabilities which in combination impact on the individual's ability to communicate;
 - Experience of using low tech AAC which is insufficient to enable them to realise their communicative potential.

The process:

- Referral made by the local therapist to the specialist hub;
- Referral acknowledged within 10 days of receiving it;
- Assessments should be carried out typically within 6 weeks;
- Equipment will be available for use within 12 weeks of the assessment;
- There may be potential to have a loan of the equipment whilst waiting;
- The local therapist will support the on-going use of the equipment.

Priority should be given to patients with conditions such as MND and efforts will be made to ensure these patients are assessed and/or provided with equipment as soon as is practically possible.

Training – it will be the role of the specialist hub to educate and up-skill local therapists; the plan includes a sub-hub somewhere else in the region – staff will have to be recruited and trained.

As a branch we are very aware of the difficulties facing people needing anything other than the basic equipment. The changes to AAC provision in the region will mean a significant improvement on what is currently in existence, but they won't solve everything.

Cliff Park High School, Gorleston, 19 April, 2015: Malcolm attended a charity football match organised by Ann-Marie Doggett. The proceeds were to be divided between the MND Association and an orphanage in Ukraine. So far £300 has been raised, with a further £76.33 raised by Richard Dunne on his Just Giving page.

Cherry Lane Garden Centre coffee morning, 29 April, 2015: Everyone looks so happy; we hope you will feel encouraged to join us at one of our informal gatherings. The photo shows Ronald & Janet Rackham, Peter & Doris Burgess Biggerstaff, Judy Burns-Thomson (AV), Linda, Ann Franklin, Colleen Alp (AV) and Jean Lindsay (neuro nurse). Thank you to Ann for arranging the photo and Judy for sending it to me.



30th Norfolk Palliative Care Conference, 13 May, 2015: Judy Burns-Thomson and Sue Kitson held an information table at the conference held at the John Innes Centre, Norwich. It was attended by 150 hospital and community based health and social care delegates. The programme included topics such as Dementia, Mindfulness and Deprivation of Liberty Safeguards. There was considerable interest in the MND Association stand and the information literature on display. Judy and Sue spoke to numerous delegates, including GPs, palliative care nurses and nursing home staff.

Volunteering Fund Showcase: On Wednesday 3 June, our Royal Patron, Her Royal Highness The Princess Royal attended our Volunteering Fund project showcase at the Royal College of Nursing in London. The event celebrated the Volunteering Fund project achievements since 2013. The Volunteering Fund project, funded by the Department of Health, aims to support work on improvements in services for people living with MND in the East of England region.



Volunteers, supporters and staff of the MND Association were in attendance alongside national partners. Judy Burns-Thomson, Shirley Basey-Fisher and Sue Heal (pictured with HRH The Princess Royal) attended to represent the branch. Also in attendance were Care Service Navigators Isobel McCarthy and Jo-Ann Dawson, who work directly with people affected by MND in our area, and support them to navigate services to ensure their specialist and complex needs are met. Regional Care Development Advisers, Liz Cooper and Lindsay Goward were also there together with several of the neurological nurse specialists from Norfolk. Most importantly it was good to see some branch members with MND together with their carers. We were all particularly impressed that HRH The Princess Royal took time to speak with everyone present and, from her replies, was clearly well aware of the work that we are doing and still need to do!



By using technology more effectively, the Volunteering Fund project has created new ways of providing accessible information to people affected by MND, as we have heard when Pauline Matheson has spoken at our open meetings about the Support Portal <http://mndsupport.org>.

HRH The Princess Royal also unveiled a plaque for our Investing in Volunteers Quality Standard, recognising the excellent work that the association does with volunteers.

Downing Street Charter Presentation & Parliamentary Reception 16 June, 2015: We smashed our target with 33,630 signatures in support of our MND Charter. Thank you to everyone who signed and promoted it! We have been collecting signatures since the Charter was launched 3 years ago, calling for the right care, in the right place, at the right time for all people with MND and their carers. We have now stopped collecting signatures having handed the MND Charter to 10 Downing Street. It was presented by a group of committed campaigners, Association Patron and ITV presenter Charlotte Hawkins, and the MND Association's Chief Executive Sally Light. Cilla Godfrey, our Campaigns Representative, and Sue Kitson, our Secretary, were there to represent the branch.

Following the Charter presentation, there was a reception for volunteers and MPs in Westminster. Over 300 supporters travelled to Westminster from across England, Wales and Northern Ireland and were joined by 78 parliamentarians. This is a record number for an MND event; sadly, although we are grateful to everyone who took our e-action encouraging their MP to attend, there were no MPs from Norfolk in attendance. We shall have to invite them to our open meetings instead!! It is really important that we continue to engage with newly elected MPs so that they understand MND, and how they can support local people affected by MND in their constituency. The MND Association has created '*Motor Neurone Disease: a guide for MPs*' to help us talk to our MPs about MND, and the issues affecting people living with the disease. You can download this guide, and learn other tips to help you engage with your MP at <http://www.mndassociation.org/wp-content/uploads/2015/05/FINAL-MP-guide.pdf>.

The Association will be building on the success of the event, and continuing to raise awareness of MND amongst parliamentarians so that the vision outlined in the MND Charter can be realised.

You can read more about the event at <http://www.mndassociation.org/news-and-events/latest-news/our-charter-is-delivered-to-downing-street/> Speeches by Sally Light, David Setter and Charlotte Hawkins will appear on the branch website soon.

Future events in aid of the MNDA

Charity Classic Car Show Saturday and Sunday 15th & 16th August 2015: Yes, it's that time of year again! We are hosting a stand for both days of the show, but this year it will be a little different. We aim to have a large area for awareness and also two fund raising activities. One day we plan to have guess the name of the dog and on the other guess the name of the giant teddy. This will be primarily aimed at children.

To generate as much income as possible for the branch from the weekend we are also having over the two days a chance for people to win a bottle of wine. These will be wrapped in newspaper and placed in amongst wine bottles that have been filled with water also wrapped in newspaper.

We have been very lucky in having a number of bottles of wine donated for this occasion, but if anyone would like to donate a bottle then please contact Cilla (number below) or bring a bottle to the open meeting at Upton.

And now Cilla comes to that crunch – we cannot do these fund raising events without people to man the stand so PLEASE PLEASE TRY AND SPARE SOME TIME TO HELP. Contact Cilla and let her know if you can help and on which day and for how long. The days run from 10am-4pm so help between 9am-5pm would be fantastic.

We are hoping to put the gazebo up on Friday 14th so if any one can help please let Cilla know. Contact details: Cilla Godfrey 01362 637580; there is an answer phone so please leave a message and Cilla will call back.

Sprowston Family Fun Day and Charity Football Match Sunday 30 August, 2015: Last year Amie Godfrey and family organised their first Family Fun Day and Charity Football Match in memory of Noel Godfrey. It was the first time they had ever done anything on this scale, and it was a great success raising almost £2000 for the Norwich and Waveney Branch of the MNDA. In the light of their success they were nominated to attend a royal drinks reception, where they had the pleasure of meeting Her Royal Highness the Princess Royal, patron of the MND Association. As a family they are trying to raise as much awareness and money for the charity as they can.

Everyone is invited to join them. The event starts at 12:00 noon at the Sprowston Sports and Social Club. So far they have a bouncy castle, face painting and more – including a football match, Mr Frosty's Ice Cream, Big Pete's burger van and lots of stalls too. There will also be an appearance by the Sprowston Fire Department and the local police. They still have lots of attendees yet to confirm! We can confirm that the branch will be there to help raise awareness of the nature of Motor Neurone Disease and the work of the Association. All we need now is good weather!

Cards for Good Causes is a joint charity initiative operating a national network of charity Christmas card shops during the Christmas trading period. The aim of Cards for Good Causes is to make a wide selection of charity Christmas cards easily available to the public and at the same time secure the highest possible return for the charities it represents.

We are expecting to be asked soon to join them in The Forum in Norwich. Would you be willing to volunteer two mornings or two afternoons a week throughout the sales period (early October to mid December)? Roles include: operating a simple electronic till for which training is given; re-stocking the card boxes; keeping the card boxes and Christmas goods tidy.

Take a Bow — *thanks to the following for donations received by the branch*

Donations and fundraising

- SMT Motors, collection Box - £58.58
- Marks & Spencer - £1,189.52
- Dr S Godfrey, sale of Christmas cards - £18.75
- Raffle at Eaton AGM - £117
- Naval & Military Lodge fundraising activities - £270
- Wroxham & Hoveton Lions Club, monthly prize from charity shop draw nominated by Mrs Hatcher of Horning - £100
- Mrs T. Gadding collection box - £229
- Mary King, sale of Hagstones - £146.50
- Judy's friend's Teddybear fund - £30

Donations in memory of

- Keith James Bass - £388.65
- Richard Moys - £150
- Jenwyn Lucy King - £400

Internal transfers

- Interest - £45.94
- Charities Trust - £27.26

My apologies to those who have made donations but whose names have not appeared, these figures will appear in the next edition.

News from National Office

Awareness Month: Our national poster campaign has run throughout June on London's underground stations and across the national rail network – sadly there is no poster in Norwich. Two of the posters include people living with MND and the impact of the Ice Bucket Challenge on them. The third poster shows a bucket and a garden chair with a headline recognising the achievement of those who took part in the challenge and a poignant reminder that we have lost some good friends to MND over the years. This year the campaign is called 'Silence Speaks'.

Wheelchair Project: The MND Association has appointed the Institute of Health and Wellbeing at the University of Northampton to conduct an evaluation of the Wheelchair Project. As part of this evaluation they are seeking feedback from wheelchair users or carers on their experiences of mobility assessment and wheelchair provision from their local wheelchair service. This will take the form of a questionnaire which should take 10-15 minutes to complete. We would like as many wheelchair users as possible to participate in the survey as it will be of great value not only to our evaluation, but also to gain more information on wheelchair provision in general.

The following is a link to the questionnaire: <https://survey.northampton.ac.uk/wheelchairprovisiononlinesurvey/> For more about the Wheelchair Project see:

<http://www.mndassociation.org/wheelchair-service> For queries about wheelchair provision, please email: wheelchairqueries@mndassociation.org

Interestingly the BBC reported recently on delays to wheelchair provision; their article, which can be found at <http://www.bbc.co.uk/news/blogs-ouch-32718615> featured (amongst others) Liam Dwyer who is living with MND.

Launch of redeveloped information sheets:

11: PEG and tube feeding – Making the decision

12: Oral hygiene

16: MND care centre programme

You can download publications from www.mndassociation.org/publications or ask your AV.

The Introduction to MND is now available in 10 languages other than English in A4 sheet format. The current options are based on common languages in the UK: Arabic, Bengali, Gujarati, Mandarin, Polish, Punjabi, Tamil, Turkish, Urdu and Welsh. These can be printed when needed or sent by email in PDF format. For general enquiries about translation requests, please contact MND Connect.

TONiC study enters the next phase: part funded by the Association, the Trajectories of Outcome in Neurological Conditions (TONiC) study is the largest study of its kind in the world. The study aims to examine factors that influence quality of life in patients with neurological conditions, including MND.

The MND Association is funding Prof Carolyn Young, to continue this essential healthcare project and take it to the next level. This means she needs to recruit a large number of people living with MND to take part to help establish a 'tool kit' for quality of life with MND.

During MND clinic visits, neurologists use a physical tool kit to look at factors that have a physical impact on people living with MND, such as assessing breathing and muscle strength. However, currently there is no standardised kit for assessing quality of life in MND – TONiC aims to change this.

The researchers hope that by recruiting more people living with MND to take part they can use the results from TONiC to create a national quality of life tool kit, to be used alongside the physical measurements, for assessing quality of life in the MND clinic.

So far 200 people with MND have already sent back the questionnaire pack as reported in the Spring edition of Thumbprint. The large-scale extension to the TONiC study is now being rolled out and is inviting people living with MND to take part. Participants will need to consent to take part in the study before they complete a questionnaire pack of mainly 'tick-box' type questions.

Visit the website www.mndassociation.org/tonic. Alternatively telephone 0151 529 5446/5666 or email tonic@thewaltoncentre.nhs.uk to contact the TONiC team.

TBK1: Research published in *Nature Neuroscience* has identified mutations in the TBK1 gene as a cause of both inherited MND and frontotemporal dementia.

Dr. Brian Dickie, our Director of Research Development, said “Dr Weishaupt and colleagues have identified TBK1 as a cause of inherited MND and frontotemporal dementia in Germany and Sweden. The next step would be to find out whether this gene mutation is present in other populations, like the UK – as we know this is not always the case – and to develop models to study TBK1 in detail.”

ProGas (Prospective Gastrostomy) study results on gastrostomy in MND were published in the *Lancet Neurology*, and posted on the research blog in May 2015 by Dr. Samantha Price.

Funded by the Association, the Prospective Gastrostomy (ProGas) study aimed to develop evidence-based guidelines to identify the most appropriate method and timing of gastrostomy in people living with MND in the UK. This study is the first large-scale nationwide study on gastrostomy in MND. The team worked with 24 MND care centres and multidisciplinary clinics across the UK and recruited 345 people living with MND to take part.

In some people living with MND, the muscles involved in swallowing can become slow, weak and/or uncoordinated. This can cause difficulty when eating and drinking, resulting in slower meal times and insufficient intake of nutrients. This can cause weight loss and an increased burden for carers.

To ease these problems alternative feeding methods such as gastrostomy can help. Feeding by gastrostomy is where a tube is inserted directly into the stomach through the abdomen. There are three main types of gastrostomy, percutaneous endoscopic gastrostomy (PEG), radiological inserted gastrostomy (RIG) and post oral image-guided gastrostomy (PIG), which is a ‘hybrid’ of the previous two methods.

Of those who underwent gastrostomy (323), the researchers found that all three methods of gastrostomy tested appeared to be as safe as each other, with no evidence of a difference in survival.

The researchers found that people who had less than 10% weight loss since diagnosis and before gastrostomy benefited most from the procedure and had an increase in survival compared to those who had 10% or greater weight loss before undergoing gastrostomy. This led the researchers to recommend that people living with MND should undergo early gastrostomy.

Although there was no difference in survival between the three gastrostomy methods, the study findings indicate that PEG may be the best method, before respiratory problems arise, due to the ease of post-insertion tube management. Dr McDermott said: “PEG is the preferred method of gastrostomy, when someone has good respiratory function and is able to lie flat and be sedated for the procedure, or PIG/RIG when there is significant compromise of respiratory function.” Dr McDermott also highlighted that the main findings from the study are that the timing of gastrostomy is recommended when someone with MND has lost around 5% of their body weight.

Director of Research Development, Dr Brian Dickie commented: “The findings can also be presented to the National Institute for Health and Care Excellence (NICE), which is currently in the process of creating broader, multidisciplinary Clinical Guidelines for the Assessment and Management of MND, due to be published next year.”

MIROCALS - new MND clinical trial announced: This article has been taken from the news section of the National Office website with additional material from the research blog. The MND Association is backing a new clinical trial, known as MIROCALS, which will aim to start recruiting 216 people living with MND in the UK and France in **autumn 2016**.

The Modifying Immune Response and Outcomes in Amyotrophic Lateral Sclerosis (MIROCALS) study will aim to investigate existing drug interleukin-2 as a potential new treatment for MND.

It is a joint clinical trial between France and the UK, supported by an award of €6million from the European Commission, with additional funding of €0.5million from the French government and a further €0.5million currently under consideration from the MND Association.

High dose interleukin-2 has been used for many years to treat cancer. However, it has been proposed that at much lower doses it may have benefit in treating a number of immunological conditions. Changes to the immune system have been linked with the speed of disease progression in MND, so if an altered immune system does play a damaging role, then restoring this imbalance could be beneficial.

Prof Nigel Leigh (Brighton and Sussex Medical School) and Dr Gilbert Bensimon (Hôpital Pitié-Salpêtrière, Paris) are the scientists behind this project. Both were involved in the development of Riluzole and, along with other leading MND researchers, make up the MIROCALS Consortium. Prof Leigh and Dr Bensimon will begin working on the essential groundwork from September 2015, including a small pilot study in France, before the main trial can begin recruiting participants in autumn 2016.

More information is available at <https://mndresearch.wordpress.com/2015/06/26/mirocals-episode-mnd/>.

European Network for a Cure of ALS (ENCALS) met from 21-23 May, 2015 in Dublin: Dr. Jakub Scaber (Medical Research Council/MND Association Lady Edith Wolfson Clinical Fellow) reported back from the event summarising the TDP-43 session. This is the protein that

accumulates in the brain of people living with MND and has been linked to the development of the disease. Abnormal forms of this protein can be found in 98% of cases.

He summarised five presentations, each highlighting a different aspect showing how TDP-43 fits into the MND picture. As TDP-43 is found in the majority of cases of MND, understanding its contribution gives a promise for finding a targeted treatment. More information can be found on the research blog at <https://mndresearch.wordpress.com/2015/06/19/an-insight-into-tdp-43-an-encals-2015-meeting-report/>

Oxidation Resistance 1 – tackling oxidative stress: What causes MND? In most cases it is a combination of subtle genetics, lifestyle and environmental factors, quite how they work is a harder question to answer. We have previously included posts from the research blog showing possible mechanisms such as build up of toxic waste.

MND Association-funded researchers, Prof Dame Kay Davies and Dr Peter Oliver, both based at the University of Oxford, have identified the oxidation resistance 1 gene as a neuroprotective factor in MND. They wrote, “One of the key questions in MND research is why certain cells in the nervous system, motor neurons, are susceptible to degeneration over time, while other cell types are not. Oxidative stress has been implicated in MND as one of the early signs of this selective degeneration.”

“We have already shown that the gene oxidation resistance 1 (OXR1) can protect neurons from oxidative stress, and that loss of this gene renders cells more susceptible to a range of insults. We have now tested whether expressing more OXR1 in neurons could be protective in a mouse model of inherited MND. We were excited to discover that OXR1 could delay the motor deficits and motor neuron degeneration in a mouse MND model, as well as improve survival by up to 20%.”

“This significant result suggests that OXR1 may be a valuable neuroprotective target for the future. We are currently working hard to understand the function of OXR1, with recent funding from the MND Association, to investigate how the gene can be regulated pharmacologically for future therapeutic benefit.”

More information is available on <https://mndresearch.wordpress.com/2015/06/10/%EF%BB%BFoxidation-resistance-1-tackling-oxidative-stress/>

Writing a will: National Office has asked us to place a mention in our newsletter to highlight the importance of legacies to the work of the Association.

Since the Association was founded in 1979 it has grown significantly, yet shares the same vision to achieve a world free from MND, whilst also providing the best possible care and support for people living with MND, their families and carers. To achieve this we must continue to raise the necessary substantial income required to meet the costs involved.

The Association relies on voluntary donations, of which legacies are a vital element. Over the past decade legacies have provided around a third of the total income. This reflects the generosity of our supporters and comprises gifts of all sizes – each is gratefully received. Such income is vital in helping maintain our investment in research, contributing to funding the extensive range of care and support services, campaigning and raising awareness initiatives.

It is not a source that can be taken for granted. We are well aware of the financial pressures facing the majority of people in the UK. This is why, despite our constant need for funds to fight MND, we always ask people to consider leaving a legacy to the Association only after family and friends have been looked after. There is a Legacy Information Pack to make the

process of leaving a legacy to the Association as easy as possible. This explains more about the importance of and preparation of wills and legacies, illustrates our plans for achieving our vision and shows the progress that we are making towards our goal.

To receive your free Legacy Information Pack call Stephen May on 01604 611865 or email stephen.may@mndassociation.org or visit www.mndassociation.org/legacies.

Important note: When it comes to leaving a legacy we always advise people to consult a solicitor – the legacy pages of the national website feature a link to the Law Society's website which provides details of solicitors in a local area.

Ice Bucket Challenge anniversary: We are approaching the anniversary of last summer's Ice Bucket Challenge. The ALS Association in America plan for August to become Ice Bucket Month. They will shortly release teaser videos featuring celebrities doing the challenge, which those of you on social media might start to see filter through to your news feeds. These will be followed up with an event by the originators of the challenge at the end of July to kick start the anniversary month.

The Association plans to use the anniversary as an opportunity to thank again everyone who took part, highlight what we are spending the money on and emphasise that there is still no cure. However, if anyone wishes to mark the anniversary by doing the challenge again in August, or by doing a different challenge, then National Office (NO) will provide materials and resources to support this – watch the NO website. They will continue to promote the #lastsummer campaign.

Children and Young People: It was agreed to use part of the Ice Bucket Challenge income to fund a one year post to look at what support we offer for children and young people in families affected by MND. James Kitchener has joined the Association to develop our proposals, in conjunction with affected families.

James will be seeking opportunities to meet with people with MND, their families, children and young people (aged under 25). Initially he has asked the branch to consider their demographics and how many people in our area would be willing to talk with him.

Miscellaneous: The **shower seat** pictured on the right has been offered free to a good home! If you are interested please contact Judy Burns-Thomson. As always, we would suggest talking with your occupational therapist about the suitability of this seat, and would draw your attention to our disclaimer.

Record me now: I have received an email from Liz Cooper regarding an app currently available for Windows or Mac: <http://www.recordmenow.org/>. It can be used to record your life, through a series of questions. You need a webcam so it will record you talking. You can save the work as you go along until you've finished and then burn it to a DVD.



The research: Between 2007-2012, 100 volunteers, who lost one or both parents before the age of 16, were interviewed. They were asked questions regarding their loss, their prior knowledge and their subsequent educational, social and professional development. They were also asked what questions they wished they could have had answered from or about the parent who died. The RecordMeNow app is the culmination of this research.

There is a pull down list of questions, for example 'How did you choose your child's name?'

Branch News

Next Open Meeting: Sunday 2 August 2015, 12:30 for 1:00pm – 4:00pm. Upton Village Hall, NR13 6AU

Advanced notice of the final Open Meeting for 2015: Sunday 18 October 2015, open meeting at Wortwell Community Centre, IP20 0HS

Coffee mornings

At Notcutts coffee shop: The next coffee morning will be held on Wednesday 15 July from 11:00am to 1:00pm. As usual we are hoping that many who are caring for, or who have previously cared for, people with MND will be able to attend an informal get together. Of course people living with MND are always welcome. Refreshments can be purchased in the coffee shop.

Advance notice of dates for Notcutts, Daniels Road, Norwich, NR4 6QP

Wednesday 16 September

Wednesday 18 November

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 29 July between 11:00am and 12:00 noon. It is an informal gathering for people with MND and their carers.

Advance notice of dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

Wednesday 26 August

Wednesday 30 September

Wednesday 28 October

Wednesday 25 November

Taxi companies: Mary Smith, a branch member, has recommended Loyal Taxis 01603 619619. They do not have wheelchair accessible vehicles, but are able to fold a wheelchair to put in the boot of the taxi – best to tell them when you book a taxi. (See disclaimer).

Website: www.mndnorwichandwaveney.org.uk We are always happy to add information about events you are planning in support of the Norwich and Waveney Branch of the MNDA (and would welcome content from the Suffolk Fundraising Group).

Newsletter Editor: Thank you to all who have sent photos and stories for inclusion in our newsletter. The next deadline for receipt of articles is 20 August for the September 2015 edition.

Useful Numbers

Regional Care Development Advisers share an email address

eastangliarcda@mndassociation.org

Norfolk – Lindsay Goward 08453 751829. Lindsay works Tuesday, Wednesday and Thursday

Suffolk – Liz Cooper 08453 751827. Liz works Monday, Wednesday and Friday

Care Service Navigators

Isobel McCarthy 07714 077671 email isobel.mccarthy@mndassociation.org

Jo-Ann Dawson 07872 161747 email jo-ann.dawson@mndassociation.org

Please pass this newsletter on to people who may be interested and together we will fight for our vision of a world free of MND.

Disclaimer. The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact sue.kitson2@btinternet.com, or write to her at the address given on the back page or write to Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR

If you would like to talk to someone about MND please contact our MND Connect team on 0345 626262 or email mndconnect@mndassociation.org
Visit our online forum <http://forum.mndassociation.org/>
Website: www.mndassociation.org
Registered Charity no. 294354
Registered Address: Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR
MND National Office 01604 250505