

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 65 January 2015

Open Meeting at Wortwell on 19 October 2014



The open meeting was attended by 48 people – most of whom appear in the photo! It was a lively meeting with lots of chat, everyone appeared to enjoy the hot lunch prepared and served by John Groom Catering which included a choice from three main courses and a variety of desserts. Once again it was good to see people from Norfolk and Suffolk, and particularly to welcome Janet Oliver who together with Janine Vince does so much for the Suffolk fundraising group. Phillip Laurier presented our treasurer Trish Bates with a cheque for £30 raised when he ran the Baxters Loch Ness marathon. Donna Andrews from Tennis for Life came with three young people to present a cheque for £220. The picture on the right shows Liz Cooper receiving the cheque on behalf of the branch. Donna agreed that if the young people raised £100 she would take the Ice Bucket Challenge, they did and the result was another £120 raised from her Ice Bucket Challenge.



Our guest speakers were Suzanne Godfrey, Clinical Director and Francesca Ray, beauty therapist from the **Multiple Sclerosis Therapy Centre Norfolk** (MSTCN). Francesca gave massages after the talk to those who wanted to try the service. Suzanne and Francesca made it clear that despite the name their aim is to meet the needs of people affected by all neurological conditions; they offer the appropriate services to support, sustain, and actively encourage independence. The community based multi-disciplinary team (MDT) includes physiotherapists and assistants, a continence advisor, a neurological specialist nurse, occupational therapist, counsellor and benefits advisors. In addition they offer a full range of holistic therapies that include podiatry, yoga, pilates, Indian head massage, reflexology and a range of beauty therapies. Referrals are accepted from NHS Norfolk, Norfolk Adult Social Services, Consultants and GPs; people may also refer themselves to the MDT. The team is also able to refer patients to other services including the wheelchair service and other relevant departments. The comprehensive community based services provided at the centre offer assessment, treatment, practical advice and on-going support and equipment to those living with a condition as well as family members and carers.

MSTCN is a membership organisation. The charge to each individual ranges from £8 to £60 which enables members to access all the facilities and services that they provide – and facilitates a discount when using their complementary therapies. To join the organisation contact MSTCN Unit 1 Icen Court, Delft Way, Norwich NR6 6BB Telephone 01603 485933 or email info@mstcn.org.uk. More information can be found on their website www.mstcn.org.uk

Pauline Matheson, with support from Liz Cooper, gave a presentation to update us on the work of the Volunteering Fund Project during its pilot stage.

The Volunteering Fund Project

Following a detailed application process to the Department of Health Volunteering Fund the MND Association was awarded over £500,000 of funding to support work on improvements in services for people living with MND in the East of England region.

As part of this project new volunteers known as Care Services Navigators (CSN) are working directly with people affected by MND to further empower them to become involved in care decisions and service design to ensure their specialist and complex needs are met.

This is quite a different role to that of our Association Visitor (AV) as the CSN will only be involved with a person with MND and their carer long enough to ensure they can find their way through the health and social care system and will refer for ongoing AV support where available for more long term support and information.

Where we were last year (Oct. 2013)	Where we are now (Oct. 2014)
3 Care Service Navigators	7 Care Service Navigators
21 people with MND supported	79 people with MND supported
226 hours volunteered	840 hours volunteered
3666 miles covered	13948 miles covered

By using technology more effectively the project will create new ways of providing accessible information to people affected by MND through an interactive, web-based portal. The portal is based on the ‘Living with MND guide’ produced by the Association and provides a wealth of information on health and social care services in Peterborough, Cambridgeshire, Norfolk, Suffolk and West Essex.

To ensure that the content remains up to date six new volunteers have been recruited specifically to:

- Gather information
- Test the web portal links
- Report issues

The web-based portal was launched on Sunday 19 October at the open meeting and can be accessed at <http://mndsupport.org/>

Your feedback is extremely important as this will enable us to develop the portal further so please share you thoughts good or bad with Melanie Smith, Forum & Support Site Coordinator at melanie.smith@mndassociation.org

If you would like any more information on the project please contact Pauline Matheson pauline.matheson@mndassociation.org

Celebrating events in aid of the MNDA

Pen-y-ghent 9th September 2014: The weather on the day of the walk was ideal. The walk went well and took Emily O'Flaherty and her father, Peter Smith, about 6 hours. Annette commented that it was a real physical achievement for both of them. Including Gift Aid they raised £840.

Chris O'Flaherty and Annette Smith were there as support and waited for their safe return. Prior to the walk Emily and Chris were interviewed by Look East and Mustard TV and appeared on their programmes raising awareness of MND.

Thank you to Emily and Chris, Annette and Peter, and all who supported them.

4th Annual memorial golf day

Sue Fretter and her son Darren Fretter-Hall once again organised a very successful charity golf day in memory of her late husband Brian who died from Motor Neurone Disease in 2010.

This year they included an auction, organised golf days and had donations of bouquets which together enabled them to raise £1,300. Pictured on the right are Sue, Paul Heath, who won the longest drive trophy, Roger Marshall who won the award for being nearest the pin and Darren. Our thanks to Sue and Darren, and to all who supported them.

Sue hopes that the funds raised will help in the search to find a cure for MND.



North Elmham Young Farmers 1st October 2014 invited Cilla and me to join them at one of their weekly meetings to give a talk on the work of the Norwich and Waveney Branch of the MND Association and to receive a presentation cheque for £4,588.96, much of the money had already been received by the branch, we have also been sent a real cheque for £3,546.56.

Rebecca Vick, their Charity Fundraising Officer for 2014, lost her father to MND when she was



10. The Young Farmers have spent this year raising as much money as they could for the Motor Neurone Disease Association to help all the people living with MND have the best life they can and hopefully attain the ultimate goal of finding a cure for this cruel disease. Over the past year we have featured some of their events, now we have some photos of some truly brave fundraisers. Rebecca (on the left) and three friends took part in a sponsored skydive!



And safely down!

Thank you all.

Christmas Charities Fair Sunday 2nd November 2014. The Norwich and Waveney Branch of the MNDA is grateful to Greenacres Woodlands Burials Park, Colney for inviting us to host a stall at their Christmas Charities Fair, and to the management for agreeing to match fund £100. Sue K., Cilla and Sue H. sold Christmas cards and other MNDA merchandise, and held a 'water and wine' lucky dip. Business was brisk in the morning, but slowed after lunch; perhaps the heavy rain deterred people from venturing out. We were pleased to raise £191.35, giving us a total of £291.35 for use by the branch in support of people living with motor neurone disease. As in previous years it was a good opportunity to raise awareness of MND and to collect signatures for the MND Association Charter. Thank you to those who attended and supported us.

The Thetford Society was established to promote high standards of planning and architecture, to educate the public in the geography, history, natural history and architecture of Thetford and its environs and to secure the preservation, protection, development and improvement of features of historic or public interest.

We were pleased to be invited by Pat Smith to join them at their meeting of 4th November 2014. Pat and Wendy Raphael, joint activity co-ordinators, presented Malcolm with a cheque for £300. The money was raised when they held a quiz night on 4 October in aid of the Motor Neurone Disease Association.



Ice bucket challenge: In the last edition of Fightback we reported on Chloe Smith's Ice Bucket Challenge in which she nominated Jeremy Goss as one of the three people who she would like to take the challenge. We are pleased to report that he did!! Although he is a fundraiser for the Norfolk & Norwich Association for the Blind, as is clear from the photo, they expressed great respect for the work that we and other charities undertake. Our thanks to Donna Minto, NNAB Fundraiser, for providing the photo.

Future events in aid of the MNDA

Cards for Good Causes: Some months ago the branch was asked if they could provide volunteers to help sell cards and Christmas merchandise in The Forum in Norwich for Cards for Good Causes. They stock MNDA cards and give at least 70p in every pound from their card sales. This year Judy and I agreed to help, though I think we both felt a little nervous and could not commit to helping for the full 11 week season. The people we worked with were extremely friendly and made us feel very welcome and part of the team. We were relieved to find that using the credit card machine was not as hard as we feared. This is a really early request for volunteers for 2015 – the volunteer coordinator starts to put together her team in August. If anyone feels that they would like to be part of this next year either for the whole season or just for a few sessions please let us know – it would be good to have an MNDA team that could cover one shift each week – typically they need around 60 volunteers to staff the stall.

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

Donations and fundraising

- Lorraine Law – Ice Bucket Challenge -£5
- Mrs B. Ford – Ice Bucket Challenge by Millie Ewing & Richard Ford - £20
- Jamie & Niki Fowler - Ice Bucket Challenge - £50
- Chloe Smith – Ice Bucket Challenge - £25
- Judy Burns-Thomson – Ice Bucket Challenge - £50
- Pam Challand – Ice Bucket Challenge from friends - £20
- Damien & Lori Baker – Ice Bucket Challenge - £60
- Carol Powell's cousin's Ice Bucket Challenge in memory of Colin - £25
- Mrs N. E. C. Eaton - £20
- Wendy Brown – Coffee & cake afternoon at Hemsby - £330
- Mary King – Sale of Hagstones £185
- Mary King – Sale of fruit and vegetables - £485
- Beth Chubbock – Marathon & £1,000 from Beth's employers - £2,030
- Sales - £58
- Wedding, a relative of Mr. Burgess-Bickerstaff donated - £30.34
- Collection Box Norfolk & Norwich University Hospital Pharmacy - £63.02
- Sprowston Family Fun Day in memory of Noel Godfrey - £2,135.76
- Marks & Spencer Norwich - £4,117.90 in memory of Noel Godfrey

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

New resource for Accident and Emergency: National Office is creating a new information resource for staff working in A&E departments about how to treat someone with MND, if they have to go into hospital. They are looking for thoughts on:

- What are the most important things for A&E staff to know about MND?
- Is there anything in particular A&E staff should know when treating someone with MND?

If you have any thoughts or an experience of being in A&E that you are willing to share please contact Bev Goodman, Professional Information Developer, on 01604 611866 or email beverley.goodman@mndassociation.org

- Ruth Rudd – Pub crawl in memory of Carol Kumar - £1,427.00
- Raffle at Wortwell Open Meeting - £134
- Nicola Gladstone - £20
- Norfolk County Women's Bowls - £14
- Mrs A. Braithwaite - £20
- Mr Brian Claxton - £10
- Clive Gladding – Collection Box - £195.14
- June and John Garrett – West End Waiters Concerts - £525
- Julie Grimmer – Jesters of Bungay - £100
- Norwich Petanque Club – Tournament and Raffle - £111
- Mary Shutt – Donation from UCM Dereham Foundation - £100
- Goodies Farm Shop - Collection Box - £60
- MND Association Christmas Sales - £449.15

Donations in memory of

- Ian Bassey-Fisher - £5
- Barry Norman - £7
- Noel Gerard Godfrey - £355
- Anthony Aldrich - £741.75
- Mrs Pauline Savill - £335
- Leonard Herbert Barnard - £465

Internal transfers

- Interest - £68.69
- Charities Trust - £250 money from Aviva in £ match
- Charities Trust - £90.89

New era for our DNA Bank: The UK MND DNA Bank was set up to find out more about the causes of MND, using DNA from donated samples. Now MND researchers are able to use white blood cells to create cell models of MND; creating motor neurones from blood cells was unimaginable when the DNA bank was first created in 2003. These models will be used to further understanding of MND in the lab, but the samples will not be given to patients.

The bank has made the decision to allow researchers to use the samples more widely, but recognise that some people may not wish for their samples to be used outside of genetic research. If you gave a sample but would NOT like it to be used in this way or you would like more information, please contact the research team on 01604 611880 or research@mndassociation.org.

Charter signatures keep on rising: Thanks to the General Election campaign, and the amazing support following the ice bucket challenge, we are happy to announce that over 24,000 people have now signed our MND Charter; helping to raise awareness and understanding of good care for people with MND. Our aim is to get 25,000+ signatures before it is presented to 10 Downing Street after the General Election. The more signatures we have the greater the impact we will make. Please help achieve this – make sure all of your family and friends have signed by sharing this link www.mndassociation.org/charter

2015 General Election campaign: Thank you to those who have already supported the General Election campaign, 'Don't let me die without a voice'. We are asking candidates standing in the next General Election to commit to working with us, if elected, to ensure that the communication challenges of people living with MND are met. Over 800 candidates nationally have already been contacted via the online e-action.

Please join the campaign and strengthen our voice. It will only take a few minutes for you to take part. <http://www.mndassociation.org/get-involved/campaigning-influencing/general-election-campaign-2015>

Surprise discovery – Researcher Dr Adrian Isaacs and his team at University College, London, have identified that the toxic proteins made by C9orf72 are the main cause of motor neurone death in inherited MND and frontotemporal dementia caused by the C9orf72 mutation.

Most cases of MND are thought to be caused by a combination of environmental, lifestyle and subtle genetic factors. However, approximately 5-10% of all cases of MND are inherited. This means that they are characterised by a strong family history and the disease is caused directly by a mistake in a specific gene.

C9orf72 was first identified in 2011 as being the most common cause of inherited MND and the related neurodegenerative disease, frontotemporal dementia. It is caused by a mistake in the gene where a segment of DNA is wrongly repeated thousands of times. Since then, researchers have been continually trying to understand more about this gene and how it causes both MND and frontotemporal dementia.

Dr Isaacs said, *“We previously believed that the C9orf72 mutation produced a toxic type of RNA, but our research has shown that the RNA on its own is not toxic to motor neurones, but the proteins are.”* He went on to say, *“Finding out that the proteins produced by the C9orf72 mutation were toxic was a complete surprise, as we didn't expect this at the start. Our next steps are to find out exactly how these toxic proteins cause the motor neurones to die and go on to try to develop drugs that stop their production.”* However, this does not completely rule out Ribonucleic Acid (RNA) toxicity.

New inherited MND-causing gene identified – An international team of researchers, led by Association-funded researchers based at King's College London, have identified the TUBA4A gene as a new cause of the rare inherited form of MND. It causes the cell's structure, or skeleton, to break down – resulting in the cell being unable to transport molecules from one end of the cell to the other.

The researchers identified TUBA4A by looking for rare genetic changes in 363 inherited MND cases from six countries (including samples from the UK MND DNA Bank). They also checked that TUBA4A was specific for MND by comparing this with over 13,000 healthy controls.

Dr Bradley Smith, who led the research said, *“This gene is essential for forming the physical architecture of a neuron. With experiments we proved that mutations destabilise the neuronal structure and stop the building blocks of the framework coming together.”*

New research newsletter – Our Research Development Team has launched a new quarterly newsletter – 'What's happening in MND research?' It provides the latest research news, conference reports, updates on Association-funded projects and current opportunities to take part in research. To receive the newsletter, contact the Research Development Team on 01604 611880 or research@mndassociation.org. Alternatively the newsletter can be viewed online at <http://www.mndassociation.org/Resources/MNDA/Research/Documents/online-layout-summer-14.pdf>

The Research Blog: Provides updates on these and many other stories, including those presented at the 25th International Symposium on ALS/MND held in Brussels from 5-7 December 2014.

A recent article on the blog by Dr Robin Highley from the Sheffield Institute of Translational Neuroscience highlighted the value of tissue donation. He is a pathologist who spent many months dissecting out motor neurones from spinal cord, kindly donated by people who had died from MND. His team extracted Ribonucleic Acid (RNA – a sort of molecular message that conveys instructions from genes in the DNA to the machinery that makes protein). They concluded that a key issue in MND was the processing of RNA which they published in 2014 – they also uploaded the entire data from the research onto a publicly available website, making it freely available to scientists anywhere in the world.

He took the opportunity to thank the MND Association and its supporters, as well as those people who agree to donating their tissues to autopsy studies on MND. The research these donations generate is a valuable legacy. The researchers need healthy 'control' tissue as well as MND tissue. If you are interested in finding out more about tissue donation and how it can be used in research look on the website for the Association's information sheet or request a copy from National Office. My late husband donated his brain and spinal cord; it gives me great comfort to know that he achieved his wish to be part of research into the causes of MND – it is worth considering.

Care information: The following information sheets have been updated and relaunched:

- 19 – Advanced Decisions to Refuse Treatment (ADRT). The sheet now includes a sample completed form and a blank form to fill in, if wished. An interactive version of the form is also available on the MNDA website.
- 22B – Direct payments and personalisation
- 22E – Work and MND

The sheets can be downloaded from the MNDA website or ordered from mndconnect@mndassociation.org

Branch News

Next Open Meeting: Sunday 1 February 2015 from 12.30 – 4.00pm. Swanton Morley Village Hall

Advanced notice of Open Meetings for 2015:

Sunday 26 April our AGM will be held at St. Andrew's Church Hall, Eaton.

Sunday 2 August open meeting at Upton Village Hall

Sunday 18 October open meeting at Wortwell Community Centre

Coffee mornings

At Notcutts coffee shop, Daniels Road, Norwich: The first coffee morning in 2015 will be held on Wednesday 21 January from 11am to 1pm. As usual we are hoping that many who are currently caring for, or who have previously cared for, people with MND will be able to attend an informal get together. The morning will provide opportunity to sit and chat. Of course people living with MND are always welcome. Refreshments can be purchased in the coffee shop. Let us know if you are hoping to attend, but do not worry if on the day things don't go to plan and you are unable to make it – we understand!

Advance notice of dates for Notcutts 2015

Wednesday 18 March

Wednesday 20 May

Wednesday 15 July

Wednesday 16 September

Wednesday 18 November

At the Cherry Lane Garden Centre, Beccles Road, Fritton: A coffee morning for people living with MND and their carers between 11am and 12 noon will take place on the last Wednesday of every month throughout 2015. There is no agenda.

“The Princess and The Baron” based on a piece sent by Brian Cloke

He writes, “all good stories have a beautiful princess and a hero in them”. In this story the princess is Diana, and the hero is Group Captain Leonard Cheshire, later Baron Cheshire, holder of the Victoria Cross, and a man who lived with Motor Neurone Disease for the last few years of his life. The connection between them is Park House Hotel on the Sandringham Estate close to the Queen’s home. Princess Diana was born there when her father was an equerry to the Queen and he and his family were living there. Some years later Leonard Cheshire was looking for a large house for the Cheshire Foundation to set up an hotel that catered for disabled people with twenty four hour care available if required. The Queen made this very large house available to the Cheshire Foundation to set up such a hotel.

Brian visited Park House Hotel recently when one of his brothers-in-law was staying there. Whilst visiting he was able to talk to the chef and learn how she caters for all sorts of diets and requests; he found the food served very good! In the case of his brother-in-law the chef provided a birthday cake with candles at an evening dinner! His sister-in-law was enthusiastic about the standard of attention given behind the scenes and, having opted for an extra care package, she told him that the staff arrived promptly if called and were more than willing to help.

One lady had brought her husband and his sister all the way from Burham on Sea in Somerset by taxi. Both were in wheelchairs. This lady told him that she could find nowhere else in England that was able to match the service and twenty four hour care given at Park House Hotel.

Park House Hotel gives the impression of being a very calm and welcoming place to stay. More details can be found on www.parkhousehotel.org.uk/

Thank you: The branch is very fortunate in receiving so much help raising money to fund research, campaigning (lobbying for better services) and to help support people living with MND in the Norwich and Waveney area. Isobel McCarthy, one of our Care Service Navigators, has been working with Daniel, who was kind enough to write the following piece for us to publish.

“I am very pleased with my new fitted bedroom furniture which I have been able to purchase thanks to a grant from Norwich and Waveney MND Association. The fitted furniture means that I can maximise all the space in my bedroom, providing storage for all my clothes and equipment and enough room to use my wheelchair when necessary. Importantly as the units are firmly fixed to the walls there is no danger of an accident if I need to use them for support!

Since September this year I have founded a charity 'The marshmallow challenge' all money raised will go to palliative care services at Priscilla Bacon Lodge and will be focussed on helping people with communication problems.” More details can be found at <https://www.facebook.com/Marshmallowchallenge>

Of course the branch was not able to fund the full cost of the furniture, but rather to provide some help towards its purchase. We are pleased that Daniel is also helping to sell MNDA merchandise on our behalf.



MND Association AGM Saturday 13 September: Cilla and Sue H. attended this year's AGM and Annual Conference at the Radisson Blu East Midlands Airport. It was a very interesting experience providing an opportunity to speak with people from other branches as well as with members of the National Office team. We also had the chance to see the new wheelchairs that were developed by the suppliers who worked with the Association. The neuro wheelchairs are designed to meet the needs of people with MND and other similar neurological conditions. This work has been possible through a Department of Health grant and the specification was produced following meetings with people with MND, Department of Health, wheelchair service managers, therapists, rehab engineers and other charities. The new models are now available for wheelchair services to prescribe, they are high specification chairs at an optimum cost with features that would normally be an additional cost, provided as a standard within the price. Significantly the manufacturers have agreed these will be available on short lead times, in view of the potential for rapid progression of MND. The MND Association is encouraging Wheelchair Services to procure these chairs. Concerns relating to wheelchair provision can be emailed to wheelchairqueries@mndassociation.org

I attended the Care and Support workshop. It focused on two questions. Do we provide enough support for people bereaved as a result of MND? Can we improve care and support for people with MND, their families and carers with a particular focus on the needs of young carers and children? A Young Persons grant is now available, up to a maximum of £250 per person per year. Requests must go through David Niven House though in the first instance they would come to the branch.

Cilla attended the Campaigning workshop, as a result of which she volunteered to become our branch lead on campaigning. The workshop gave a taste of what was to come in November!

The theme for the day was 'One Organisation'. The Autumn edition of Thumbprint contains an article on the conference. The AGM began with a presentation by Mark Todd, the outgoing chair of the association's trustees – this role has now passed to Alun Owen. He spoke of the work of the association over the previous year which included 7,383 calls to MND Connect, where people were seeking help on a range of issues; 2,500 people affected by MND supporting one another on the online forum, where they share experiences; 3,500 people with MND helped by our Regional Care Development Advisers bridging gaps in provision or addressing issues of quality of service in health or social care - they often put people in touch with the places where they can receive the help they need; and finally noted that 883 people received specialist equipment. Mark also spoke of the 2013 International Symposium in Milan where over 950 of the best minds in research met together to share knowledge and ideas. The symposium was established and is organised by the MNDA. He also expressed thanks to the 3,000 volunteers and thousands more who donate regularly, for the 150 legacies the association received and the support of trusts and companies who together donate time, money and intellectual energy.

The main speaker was Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics and Director of King's MND Care and Research Centre at King's College Hospital, London. His talk was entitled: Nature, nurture, age and chance.

He began by describing motor neurones as cells much like any others – something like a box – but where they differ is in having a very long wire that enables it to talk to another nerve cell that lives in the brain stem or spinal cord. We have a very simple system for movement whose great strength is that it gives us significant dexterity, the downside is that if there is a problem we cannot replace a cell and grow round the problem. The first nerve in the chain is called the upper motor neuron and the second is called the lower motor neuron, regardless of whether they are going to the upper limbs or the lower limbs. Damage to an upper motor neuron causes weakness, stiffness and brisk reflexes. Damage to a lower motor neuron causes a different pattern of problems including weakness again, also wasting, twitching and loss of reflexes.

A common question people ask is whether there are 'clusters' of cases of MND and Prof Al-Chalabi showed how careful we need to be, as these apparent links can often be logically explained. For example, more cases of MND around the coast of South East England could be due to people retiring to the seaside (people of retirement age are statistically more likely to develop MND wherever they live) rather than there being an environmental cause linked to the coast. However, he explained there is some evidence to show that smoking, exercise and heavy metals may be factors.

He also referred to hearing people say MND is very rare, but went on to suggest that is isn't – it affects 1 in 300 people and is as common as Multiple Sclerosis. The difference is that the life expectancy with MND is typically shorter than life expectancy with MS. He suggests that MND is the commonest neurodegenerative disease of mid-life. At least 3 people are diagnosed per day in the UK, though many GPs see few cases during their working life and it frequently takes up to a year to get a diagnosis. The risk increases with age – the peak age of onset is 50-70.

He suggests that neurologists classify different features of MND through clinical experience – the list used at King's University Hospital is Bulbar Palsy; Limb onset ALS; Flail arm syndrome; Primary Lateral Sclerosis; Progressive muscular atrophy. However if the symptoms are given to a computer they are much better at classification and predicting survival rates.

Where neurologists observe the later stages of life – disease to death – as they only see people after diagnosis they are left to guess what happened prior to that.

This led him to ask, 'Why do some people develop MND?' is it nature, nurture, age or chance? He then went on to talk about what we can examine

- MND pathology – the process of the disease
- Genes – the blue print of how our bodies are made
- Lifestyle and environmental exposures
- Relationship with age

He explained that it is very difficult to study lifestyle and exposure because you would need to ask about every single exposure for your entire lifetime – by the time you are 60 you cannot remember what happened when aged 3 or 4! There are many studies, some are too small, some are poorly designed, but some have been replicated or have interesting results.

Studies of exercise are inconclusive though they suggest a risk factor. Anecdotal experience of neurologists show exercise might be a factor, but being fit people might live longer and hence appear more likely to develop MND since age is a factor.

It has been suggested that footballers have an increased risk – Italian professional players are often cited in this context where 6.5 times more players are diagnosed than might be expected again suggesting exercise might be a factor, but when the results were analysed differently it could be shown that exercise might actually have been protective.

He cited three friends who grew up in the same village in Kent, played amateur football several times a year for 12-28 years, two on the same team and same pitches, all were diagnosed with MND at the same time. Two died on the same weekend – yet, they shared other potential risk factors – smoking, electric shocks, trauma and exercise – two were electricians and one a builder. The point is that it is difficult to draw firm conclusions. To summarise there appear to be some geographical clusters, but it is not clear why, smoking is probably a risk factor, exercise maybe.

Prof. Al-Chalabi went on to look at the problem of genes. He described DNA as being a bit like a barcode with more than a metre per cell! Coils upon coils of DNA become chromosomes of which there are 23 pairs – and he explained how they replicate and mistakes creep in. However, the real question was is there a genetic component to MND? People ask is there a risk to relatives? He answered essentially no; there is no great change in risks for people with no family history of MND. The background risk shows 99.7% chance of **NOT** developing MND, the risk for relatives is about 98% for **NOT** developing MND – he felt the difference to be irrelevant, people are overwhelmingly likely to die from something else – heart disease, stroke or cancer. Genetics gives a clue to increased risk but does not mean you 'will' develop MND.

To summarise he said,

- Genetics technology is mature and well funded. We are beginning to understand nature and MND.
- Environmental studies are currently less well funded and difficult to perform. It is vitally important that nurture and MND are studied further
- Nature, nurture, age and chance all play a part in determining who will develop MND.

A simple model of risk would suggest we are all born with a genetic load, this is followed by environmental exposure and at some point a burden of disease causing factors may push a person to develop MND. Knowing causes may help to design treatments perhaps through gene therapy, intervention in biological pathways or in finding ways to stop the disease.

Introduction to Campaigning workshop, Norwich 21st November 2014.

Three committee members plus Ann Franklin and Barry Burgess attended the course presented by Alice Fuller and Emma Yorke. The day generated some excellent discussion and ideas, which



we hope might be developed locally over the coming months. Hopefully we will be able to share some of the ideas and videos shown on the day. In the meantime for anyone interested it is possible to sign up to the **MND Campaign Network**, so that you receive campaigning news and actions. You can sign up at www.mndassociation.org/get-involved/campaigning-influencing/campaign-network or at the same time as taking the **Don't Let Me Die Without A Voice** campaign e-action (if you've not already).

Alice and Emma showed the following videos which you may like to view if you have access to a computer.

- Campaigns Contact film www.mndassociation.org/campaignwithus (5m30)
- MND Charter promotional film www.youtube.com/watch?v=Fp10FoARYVo (1m30)
- Our director Chris James on campaigning and raising awareness <https://vimeo.com/101386991> (4m)

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 February for the March 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

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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.

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