We are another gene closer…
Mutations in ANXA11 gene takes us closer to understanding MND

A new research paper has been published in the Science Translational Medicine journal, describing a new gene implicated in developing MND.

Dr. Bradley Smith and his colleagues from King’s College London found that mutations in ANXA11 gene are associated with the development of amyotrophic lateral sclerosis (ALS), the most common form of Motor Neurone Disease (MND).

The function of the ANXA11 gene is to form small fluid-filled sacks that have the ability to transport cargoes within and between motor neurones. Its mutations cause the associated protein – annexin A11 – to reduce its ability to bind to a protein called calcyclin, affecting internal structure of annexin A11.

These findings provide a new insight into the mechanism of MND, which will now be further investigated by the lab.

If you want to read more about the findings and what they mean, you can find a more in-depth article at www.mndassociation.org
ANNUAL GENERAL MEETING: 22nd March, 2017

The Annual General Meeting was held at Hemingford Abbots Village Hall in the presence of the Mayor of Cambridge City, Cllr Jeremy Benstead and Andrew, Lord Lansley. Forty members and friends of the Branch also attended.

Cynthia George (Branch Chair) welcomed all to the meeting and thanked the Village Hall Committee for allowing the use of the delightful hall for the AGM. She hoped it would be an interesting day and that everyone would enjoy the presentation by Andrew, Lord Lansley, and the delicious buffet lunch provided by Christine and Andrew Norton and Marion Taylor.

The Minutes of the 2016 AGM were adopted and agreed as a true record.

Chair’s report

Cynthia George reported on her first year as Chair which had been an interesting and busy one. It had been a pleasure and privilege to try in some small way to help people living with MND come to terms with the devastating diagnosis of MND. Cynthia’s first priority has and always will remain, helping in whatever way she can to make the lives of those living with this fatal and progressive illness a little easier and knowing the Branch and Association are here to help. It goes without saying that this includes the spouse, carer and family.

There has been a lot of change in recent times, with a never-ending mass of new projects and ideas coming out of David Niven House. Research is a priority for the MND Association. We all hope that in the not too distant future a cure is found for this cruel and at present fatal illness. All this creates a lot of reading for everyone which sometimes overwhelms us with the vast amount of information to digest and understand!

Cynthia gave little bit of background on the Association as follows:

The MND Association

- was founded in 1979
- has 9,000 members
- has 7,000 people who volunteer their time
- includes over 300 Association Visitors
- 180 paid staff
- 89 volunteer-led branches and groups

Cambridgeshire Branch

- founded in 1987
- covers the whole of Cambridgeshire and can offer support to those living just over the county boundaries
- has 10 committee members, 6 AVs/CSNs, 1 Campaigns Volunteer - some volunteers undertake a dual role

The Branch represents the MND Association at a local level and focusses on providing support to those living with MND and their families/carers by way of: monthly social afternoons, fundraising, raising awareness, campaigning.

All the work would not be possible without the enormous effort put in by our branch committee members, AVs and CSNs. We are all volunteers giving up a tremendous amount of our time. We do this because we WANT to but Cynthia thanked all of them for their devotion which enables the branch to run like clockwork and makes her position as Chair that much easier. Cynthia’s aim is that we all work as one team.

The Branch Committee and members are of course supported by locally based staff from the Association.
**News Hot off the press**

Not officially in the year we are reporting on but nevertheless - we have two newly trained AVs who will be joining the team in the very near future. They have both finished their training and once officially signed-off or rather “on” they will be on board to assist the existing AV team. This is great news for all of us in Cambridgeshire.

**New Campaigns Volunteer**

Towards the end of 2016 the Association appointed Daniel Emery to work in this area. Daniel's first task for us was to attend the MNDA Parliamentary Reception in October. See more in 'News of campaigning' below.

In May we were selected by the Mayor of Peterborough as one of his three charities during his year in office. See more in ‘Fundraising’ below.

The fundraising that Simon and many of you are involved with enables us to continue to help support requests from people with MND or their families for items not available on the NHS, or to buy or hire equipment to make their lives that much easier. Without these funds we would not be able to support as many of you living in the county with these extras which hopefully help in part to allow you to have a better quality of life.

We hold regular monthly Get-Togethers at three venues across the county. The Cambridge venue at Scotsdales Garden Centre site in Great Shelford continues to be the most popular. These are for you to come and chat and enjoy a relaxing afternoon. We sometimes have a speaker on a related topic or completely “off-piste”; varied subjects included:

- Life in the Police Force by Simon Crooke;
- Demos/Focus Group sign off by Pauline Matheson;
- Talk on Counselling by Marian George;
- Canine Partners with OJ (dog) and his handler;
- Garden/Travel by Robert Bletsoe

We ended the year with a Christmas-themed afternoon, indulging ourselves with Christmas goodies: hot mulled non-alcoholic punch on arrival gets the afternoon off on the right foot.

**Two awards**

Pam Wilkie received a Volunteers Award in 2016 from the Peterborough Volunteers Council. This was in recognition of her devotion and tireless work and was particularly appropriate as she stepped down as Chair at the 2016 AGM. Pam remains a committed branch committee member and AV.

The MND Association rewards volunteers when they have given a certain number of years of continuous service. This year a five-year award was received by Brenda Parkes who has devoted her time as an AV and took on the role of a CSN in the original pilot scheme so now carries out a dual role. The Mayor of Cambridge City Council, Councillor Jeremy Benstead, presented Brenda with her certificate.

Cynthia thanked the branch committee, National Office staff and everyone else for supporting her over the last year.

**Presentation of accounts**

Income for the last financial year was £23,609.12 with expenditure amounting to £37,757.18. The last financial year was shortened to 11 months, due to the changes made by DNH. Fundraising activities and sponsored events made up a huge portion of our income this year. Expenditure on “Care and Support” was 67% of the overall total spend and included payments for such things as bio-bidets, stair-lifts, hoists, respite care, house adaptations and counselling.

The year-end restricted fund balances total £25,541.47 and expenditure from the restricted funds was £16,121.58 and is included in the above total expenditure.
Our year-end balance is £6,000 in our Branch General Fund to start this current financial year. We fortunately have good reserves in the Restricted Fund balances to assist with payment of Funding Requests. Without the generous fundraising donations, and the restricted funds, it is quite clear that we would struggle to cope with the financial requests that we receive. The Accounts were agreed and adopted.

**Election of Branch Committee**

The Committee were re-elected en bloc and are listed below:

**Officers**: Cynthia George (Chair and Branch Contact), John Morren (Vice-Chair), Maire Collins (Secretary), Melanie White (Treasurer).

**Committee**: Veronica Angus (Support), Simon Crooke (Fundraising Coordinator and Financial Support Coordinator), Anthony Flynn (Newsletter Editor), Chris Glover (AV and Support), David Griffiths (Webmaster), Pam Wilkie (AV and Support).

**Fundraising**

Simon Crooke said that 2016 had been a busy year for the branch. There have been musical events ranging from ukuleles in Pam Wilkie’s garden, followed by a lovely evening of music in Hilton Village Hall. Other musical events included the Massed Brass Bands concert held in Cambridge and Dances (Salsa nights).

Thanks to the five railway stations (Cambridge, Ely, Huntingdon, Peterborough St Neots) that allowed us to hold bucket collections at their station entrance halls. Also thanks to Peterborough Football Club for allowing us to collect at the ground on New Year’s Eve.

Thanks to all the people of Cambridgeshire who held coffee and cake parties.

We had two Walks to D’feet last year, one was the very successful Grafham Water walk and the other was a walk at Hadrian’s Wall which five walkers managed over the August bank holiday.

On top of all this activity we were chosen as one of the Mayor of Peterborough’s three charities for May 2016 to May 2017. It has been a busy time for all concerned and has ranged from meet and greets with the Mayor, to dances and balls and evenings with famous Peterborough people.

**Cottenham Fundraising Group**: Andrew Norton reported that the Cottenham Fundraising Group composed of Andrew and Christine Norton, Maire Collins, Marion Taylor, Rosemary Scarborough, Debbie Love and Cynthia George, have worked diligently throughout the last year. It is with great sadness that we note that Maire and Marion’s sister Rosemary, passed away during 2016 and the group appreciated all her efforts over the past years for MND Cambridgeshire Branch, starting with her part in our epic trip across America on Route 66 and going on through many events until very recently. She is greatly missed.

Andrew and Christine have worked throughout the year making and selling our unique brand of cards for all occasions especially Christmas and Easter, with help from the others at sales in Addenbrooke’s Hospital Outpatients Hall and other locations. At Christmas we made and sold hundreds of cards and Xmas favours for the Branch, and with help from Barclays through Debbie Love, we managed to generate almost £2000 in sales with the addition of the Barclays £ for £ scheme. For Easter this year we produced the little chicks with a Cadbury Crème Egg inside.

We held a successful Grafham Water Walk in 2016 with almost 40 walkers and raised a substantial sum.

There was also a lunch event organised by the group which is an annual event for the older residents in Cottenham. We have a raffle and the day generates about £300 for the group.
The group presented the branch with a cheque for £3000 as a result of our activities and there will be more to come in 2017.

Simon Crooke stressed his thanks to all our Fundraisers for all they do. Every penny that is raised goes to help all those living with MND and their carers.

News of Campaigning

Daniel Emery who has personal knowledge of MND was appointed by National Office last Autumn as our Branch Campaigns Volunteer. Daniel had been working with councillors from Peterborough City Council with the aim of persuading the Council to adopt the MND Charter. He has been very successful with this and the Charter was signed in March. He was to meet with the Health and Wellbeing Board on 23 March in order to keep the momentum going and to ensure that the Charter does not end up in someone’s drawer with no action being taken. The next item on his agenda is to try to do the same with the Cambridge Councils.

Presentation

Andrew, Lord Lansley presented ‘The challenges of commissioning high quality services and bringing new therapies to patients’.

Andrew was Health Minister between 2003 and 2013 and had been involved in many health issues. His particular interest in MND is because he has had two friends who have passed away with the disease. He said that knowing people with the disease is very important as it helps to understand the problems of the illness. The NHS budget was very constrained from 2010-2015 but they had managed to save £15m in the latter part. It is now clear that the NHS needs significant increases in the near future. One reason for the pressure is an increase in the drugs bill as new treatments agreed by NICE are very expensive. New treatment should be available through the NHS and most patients have access to necessary drugs. It is clear that pharmaceutical companies do need to charge affordable prices giving a consistency in available medicine. There is a clear quality standard through the NICE Guidelines. The MNDA should be looking at the Fibrosis System where payments are made for a specific service.

Andrew was impressed by the Research MNDA has done and the Ice Bucket Challenge had made a huge difference to money available for Research. There should be a consistency in Continuing Health Care where people should have access to personal budgets/direct payments around the needs of individual patients.

At the end of Andrew’s presentation there were a few questions which were mostly on the same theme ‘access to these services does not get through to the patients’. Another question was: is there a possibility of Disability Grants becoming non-means tested? Andrew’s answer was that this was ‘unlikely’.

Vote of thanks: John Morren gave a vote of thanks to Andrew for giving up his time to come and give us such an interesting presentation.
Association Visitors and Care Service Navigators

Following the article in the last newsletter about the valuable and caring work carried out by our Association Visitors and Care Service Navigators, this photograph puts names to faces.

Below from left to right: Chris Glover, Brenda Parkes, Ann Porter, Pam Wilkie and Sue Hallifax.

Peterborough Mayor’s Reception
MNDA Charter

On Monday 10th April committee members of the Cambridgeshire Branch, Association Visitors and people affected by MND met with the Mayor of Peterborough, David Sanders, and other councillors for a reception and a light lunch in the Mayors' Parlour.

This meeting, arranged by Cllr Dowson, followed the efforts of Daniel Emery who is our branch Campaigns Volunteer to get the Peterborough City Council to adopt the MND Charter last month.

We are asking local authorities to sign the charter to raise awareness of MND and to show their respect and support for people with MND and to work to improve their services. At the meeting we highlighted the need for the right care, in the right place, at the right time. Peterborough City Council is responsible for many services which people with MND rely on, such as Social Care, Children's services, housing and adaptations, transport and carers' support. They are also in a position to help us influence local community health services as we stressed the importance of joined up services. The Mayor and an influential councillor agreed to help us progress the work to improve services in the area and we have arranged a follow up meeting. Ultimately our aim in the area would be to have a specialist MNDA co-ordinator working across health and social care.

We would like to ensure that Cambridgeshire County Council also signs up to the charter to give an opportunity to work to improve services across the whole county. If you would like to contact your councillor we have advice on www.mndassociation.org/mndcharter or contact Daniel our campaigns volunteer for advice.

We would like to thank Cllr Dowson for organising the event and for giving us the opportunity to raise awareness of MND.

Lindsay Goward  Regional Care Development Advisor
Future Fundraising Events:

**Mayor of Peterborough’s Charity**

There are a few of these events still to come. For information please check the Branch website at: [www.mndassociation.org](http://www.mndassociation.org) or Simon Crooke: simoncrooke@aol.com, Tel: 01733 725797.

**Strictly Come Dancing in Peterborough Cathedral** Friday 19th May

**Mayor’s Farewell Ball** Saturday 13th May

**Other Future Fundraising:**

**Insane Terrain**

Racing waist-deep through mud and other extreme athletic activities led Max Flintoft, from Peterborough, to raising more than £1000 for the branch.

He completed “Insane Terrain” events over last summer in Peterborough, Ipswich and Cambridge, each involving a 10-mile assault course over a variety of obstacles, winning three medals.

Max raised the money in memory of his aunt, Mrs Pauline Sharman, of Whittlesey, who died from Motor Neurone Disease.

Accompanied by members of his family, including his aunt’s husband, Anthony, Max presented the four-figure cheque to branch officials when they met at the Brampton Garden Centre.

Max said: “I really hope these funds help out. I know it’s not much but I know it will be used very well. Everyone is doing a fantastic job in the area to help support and battle MND.”

**Coast to Coast Cycle ride** Thanks to Sarah Bates great idea, we have 13 people cycling the ‘Way of the Roses’ route on the last May bank holiday weekend.

**Bucket Collections** A bucket collection has been confirmed at the following rail station:

- Peterborough – 30 May to 2 June.
- Huntingdon – 8 to 9 June.
- St Neots – 15 to 16 June.
- Cambridge – 22 to 23 June.
- Ely – 29 to 30 June.

**Three Peaks 24hr challenge, May 2018**

We are in the process of organising this challenge but we need as many as possible to walk Ben Nevis, Scafell Pike and Snowden. If you know anyone that might be interested please ask them to contact Simon Crooke.

**Strawberries and Cream Musical Afternoon**

This will be held in the garden of Pam Wilkie on Sunday 2 July at 2pm. Her ukulele Group will be playing again as it was much appreciated by all last year. For further information please contact Simon Crooke.
DUBLIN GIRLS!

We had the opportunity to attend the International MND Symposium in Dublin in December 2016. This was a chance for us to gain new clinical knowledge about the latest studies and research. It was also an opportunity to network with other health professionals from across the world. The Care Centre team presented posters on the Care Centre audit and Gastrostomy audit which were very well received.

A lot was covered in the three-day conference but we thought it would be interesting to summarise some of the presentations and posters we found very interesting.

ALS Untangled www.alsuntangled.com
This website reviews alternative treatments for people with MND to allow them to make more informed decisions. You can read about topics such as Vitamin D, Hyper Immune Goat Serum for people with MND, Investigating stem cell transplants at the Hospital San Jose Tecnologico de Monterrey. You can read about the studies completed and those still under review.

Meditation Training for people with ALS/MND
This study looked at meditation training (based on the original mindfulness-based stress reduction programmed and tailored for people with MND). 100 people took part in the study and were randomly assigned to two groups. They had 8 weekly 1.5 hour sessions. Significant differences between groups over time were found in quality of life, anxiety, depression, negative emotions, and interaction with care givers.

Canals study
This looked at the use of a cannabis extract oral spray to improve spasticity. There was a positive trend for improvement of all outcome measures in the group having the drug rather than the placebo. It was identified that further study was needed although findings suggested it could be a valuable option for spasticity management. It may have additional beneficial effects such as pain relief.

There were several presentations on cognitive assessments in MND. Many of them used the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) tool which has been designed specifically as a first step in assessing the presence of cognitive change in MND. The tool is designed to take 20 minutes to complete by any health or social care professional, including non-neuropsychologists. It can be used to screen people to see whether they would benefit from a full neuropsychological assessment.

There were some interesting presentations on nutritional management and metabolic changes in MND. One study examined the eating behaviour, calorie intake and body mass index and survival across the spectrum of MND with and without cognitive impairment. The greatest behavioural changes in terms of increase fat, carbohydrate and food intake were observed in MND patients with cognitive impairment and these changes were associated with an improved survival (3-fold...
decreased risk of dying).

Weight loss has been shown in several studies to be an important prognostic factor in MND. One study examined the benefit of percutaneous endoscopic gastrostomy on survival in patients with weight loss without dysphagia. The results showed that in patients with preserved bulbar function weight loss of ≥5% was negatively associated with survival. PEG in these patients did not improve survival.

We had an opportunity to present an audit on gastrostomy placement in patients known to the Cambridge MND Care Centre. We also evaluated a novel technique; Nasal Unsedated seated PEG (NuPEG), which was introduced as an option for all patients who required gastrostomy placement at the Cambridge MND Care Centre in 2013. We compared the outcomes for patients who underwent NuPEG with the outcomes in those patients who previously underwent Radiologically inserted gastrostomy (RIG). Our results showed that NuPEG was a well-tolerated procedure with low complication rate and is a viable alternative to RIG placement, particularly in patients living with MND with features of respiratory compromise, who are unable to lie flat, and where the use of sedation is felt to be high-risk.

We thoroughly enjoyed this learning experience and hope to attend, and possibly present at future symposiums. To read about more of the topics presented visit the MNDA website. www.mndassociation.org/research/international-symposium/abstracts-online

Victoria Edwards (MND Care Coordinator) & Artika Datta (MND Dietitian)

Thank you to the branch for the funding to support our attendance.
Peterborough Cathedral and the Mayor of Peterborough present

Strictly Cathedral

with Louis Smith & Cassidy Little

Friday 19th May 2017
from 7.00pm to 10.00pm
Peterborough Cathedral Nave

An evening with BBC Strictly Come Dancing winners, Louis Smith MBE and Lance Corporal Cassidy Little.

- Prosecco reception
- Tu Danse Studios masterclass
- Q&A with Louis Smith and Cassidy Little
- Take to the dance floor

Tickets: £25 per person
Book online or call Peterborough Information Centre
peterborough-cathedral.org.uk
01733 452 336

All proceeds to the Mayor’s Charities and the Peterborough 100 Campaign
Registered charity number: 1165640
Afternoon Get Togethers

Huntingdon MS Therapy Centre

Our first social afternoon Get Together for this year was at Huntingdon MS Therapy Centre on Wednesday 18th January.

We welcomed old and new friends who spent a very pleasant afternoon chatting and exchanging news and ideas.

We had our usual light refreshments with the highlight being Polish cream cakes provided very kindly by our member, Max Jarmolowicz, who regrettably wasn’t able to be with us. A big thank you to Max for thinking of us and our best wishes to him. What great cakes - not good for the waistline!

David Rayner Building, Scotsdales Garden Centre, Cambridge

Thursday 16th February

We had a lively and exceptionally well-attended afternoon; even the weather was good for a February day!

Doctor Rhys Roberts, Consultant Neurologist and Director of the Cambridge Care Centre at Addenbrookes Hospital, and a colleague, Doctor Dirk Baumer, along with Victoria Edwards and Louise Boardman, Care Centre Co-Ordinators joined us for the afternoon. Doctors Rhys Roberts and Dirk Baumer gave an overview of their individual roles and what is happening at the Care Centre and answered questions from the floor. They then mingled and had a personal chat with those there.

They are all happy to be contacted at mndcare.centre@nhs.net

As many of you will know, in a few weeks the Care Centre is moving from the Addenbrooke's site to the Arthur Rank Hospice, which is located in new purpose-built premises at Shelford Bottom next to the Babraham Park and Ride site.

During the rest of the afternoon teas and coffees were enjoyed by many of you. Veronica Angus and her two grandchildren, Tonde and Tanaka, had been baking and brought along some cupcakes which were delicious. This was a very kind thought and thanks to all three.

Peterborough Salvation Army Centre

Wednesday 19th April

We met again at the Salvation Army Centre for our social afternoon in Peterborough. It was a gorgeous sunny afternoon which always helps lift spirits.

We welcomed past, present and new members, some of whom we hadn’t seen for a while, with a number of the branch committee members coming along as well. We all chatted and mingled over a cup of tea/coffee with our usual bits and pieces of savoury/sweet snacks for everyone to enjoy.

This was an afternoon to chat and catch-up, exchange ideas in a relaxing atmosphere. The conversation flowed and before we knew it was time to go home.

Cynthia George
Cambridgeshire branch contacts

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Northampton
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Registered charity number 294354

**Find out more about the Cambridgeshire Branch**
Visit www.mndassociation.org/cambridgeshire where you can discover more about what we do and the support available. There’s information on meetings, fundraising, contacts and the latest news about what’s happening in our county.

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**Future Get-Togethers…**

**Dates of Get-Togethers in 2017**

- **May 17**
  - Huntingdon
- **Jun 15**
  - Great Shelford
- **Jul 19**
  - Peterborough
- **Sept 13**
  - Huntingdon
- **Oct 19**
  - Great Shelford
- **Nov 15**
  - Peterborough
- **Dec 7**
  - Great Shelford