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Mark Samson, with Gail and daughter Cheryl
View from the Chair

Welcome to the Winter issue of your newsletter. Christmas will soon be upon us, so I hope your preparations are going better than mine!

Every person with MND is special, but I hope you will forgive me just this once for singling out one of our MND family who is no longer with us. Mark Samson and his family had to face the realities of MND soon after moving here from South Africa, so being in a relatively strange land must have added to the load. We hope that their many new friends in the UK made their MND ‘journey’ a little easier.

Mark decided straight away that he would use his time profitably for the MND cause, and did everything he could to raise awareness, initially by helping us to revise our website, and start the Facebook page. He was of course featured in many of the Association’s publications, especially in the ‘Voice’ campaign last year.

It is fitting that Mark, Gail and Cheryl are pictured on our new banner, which will be in evidence at our future meetings. He would be pleased to be continuing his work into the future, and his family have given their enthusiastic blessing.

Cheryl has started an appeal in her father’s name, the proceeds of which will be shared between this branch and the Phyllis Tuckwell Hospice, which cared for Mark. If you or anyone you know would like to contribute, visit: https://www.justgiving.com/msamson4

Donations on this page will come to this branch. (To donate to the Hospice, substitute a 3 for the 4 in the address).

On a happier note, may I take this opportunity to wish you a Happy Christmas, and all the best for 2016.

Best Wishes,

Bob

Please read (1)

Important change to the December Branch meeting . . .

Apparently there was a ‘clerical error’ in the Cathedral admin recently, and they double-booked the Education Centre!! They’ve found somewhere else for us, so on this occasion, we’ll be meeting in

The Chapter House

This is at the far (Eastern) end of the Cathedral itself. We are also meeting a little earlier; i.e.

1.30 to 3.30 pm

as the next booking is from 4.00 pm. The date remains the same; Wednesday 16th December.

Sorry about this, but this problem appeared very recently, out of the blue!

Please read (2)

Many thanks to all who have returned the survey form in the last newsletter.

However, quite a few members haven’t yet got round to it. If you’re one of them, could you let Alison Husanndee know your intentions as soon as possible please?

We need to know who wants to change to digital newsletters (to save the Branch LOTS of money!) or if you no longer require them.

This will be the last reminder, so as from the 31st January, we’ll have to start removing members’ names from the list.

Contact Alison on 01483 723645, or via any committee member.

We don’t want to lose you, but the clock is ticking . . !!
News

Saturday 12th Sept: **MNDA National AGM**
Radisson Blu Hotel, East Midlands Airport

This was a great opportunity to meet other members and compare notes. It was encouraging to hear how seriously the Association was taking the task of identifying the most worthwhile uses for the amazing £7.2 million windfall produced by the Ice Bucket Challenge last year. The workshops were useful and informative, and the keynote address by Prof Nigel Leigh fascinating.

We also did a quick ‘Tea4MND’ photoshoot - result below. Your Branch reps are in there somewhere!

The ‘Don’t Let Me Die Without a Voice’ campaign, which co-starred our late member Mark Samson, has been short-listed in the category ‘Voluntary Sector Campaign of the Year’ in The Public Affairs Awards. The winners will be announced at a Black Tie event on 10th December.

The Chancellor’s **Spending Review and Autumn Statement** on 25th November had changes relevant to those living with MND. The MND Association has issued its response, which you can find on: http://www.mndassociation.org/news-and-events/latest-news/our-response-to-the-spending-review/

which includes a link to a more detailed paper.

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CEO’s Appeal

This year the Branch is contributing £8000 to the Appeal, to be split as follows:

- £4000 to Research (in the form of PhD grants)
- £2000 to Carers’ Grants (so carers can get a much-needed break occasionally)
- £2000 to MND Connect running costs

This is in addition to our normal contribution to National Office at the end of each financial year, which is half of our remaining balance after reserves.

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Street Collections

The programme for our street collections next year has been finalised, and we’re adding a new venue as an experiment. On 10th September, we’ll be invading Staines-on-Thames. Since we spread north from our old stamping grounds, Staines is now a large and important centre in our expanded territory, so deserves a visit from us. Let’s hope the natives are generous!

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The **26th International Symposium on ALS/MND**
- is being held in December in Orlando, Florida. Our Association’s scientists will be meeting their opposite numbers from around the world, and we can follow the discussions via:

  http://www.mndassociation.org/
Sunday 27th Sept:  

**Windsor Half Marathon**

Emma Mason ran all 13 miles round Windsor Great Park, and has almost got her breath back!

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On the way round, they met a familiar face . . . (It’s Chris Evans, if you didn’t recognise him under the hat!)

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Emma with her running partner, David Hodgson

- tired, but triumphant!

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Well done Mummy!

To date, she has raised a magnificent £1576.50 for us, but she would love some more! You can still help her by going to:

https://www.justgiving.com/Emma-Mason11

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**‘SelfT’4MND Campaign**

We’ve all noticed the craze for taking pictures of yourself at arm’s length and posting them on social media. You can even buy a special stick thing to extend your arm; a ‘Selfie-stick’. (Include it in your letter to Santa if you’ve got everything else!)

This can make money for the Association - just take a selfie of yourself drinking a cup of tea, post it on Facebook or other social medium, then text ‘TMND55 £5’ to 70070. £5 is just a suggested amount - more would be better, but every little helps!

We might even make the next Branch meeting a ‘SelfTea Party’ . . .
We are very grateful to all those who run events to support us. Here is a selection of recent events:

Our esteemed Hon Treasurer Alvin Hale took a stroll along the Grand Union Canal recently (well, 25 km of it), and put £150 in Branch coffers as a result. Thanks, Alvin!

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We were fortunate to be nominated as the beneficiaries of a raffle held by the London United Busways company, and are now a magnificent £1450 better off!

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Soroptimists International (Woking branch) held a Cheese & Wine event and donated proceeds of £450 to us. We are their nominated charity for next year.

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Sheila Green raised a fantastic £620 for us by holding a Supper Party. What generous guests!

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Saturday 14th November:

Haslemere Charities Fair

Once again, Lucia was in charge of our presence at this event, and she and her band of helpers raised nearly £200 for us.

****

Wednesday 18th November:

Federation of Small Businesses
(Surrey and W. Sussex region)

Awards Evening at Mercedes World, Brooklands

We were kindly nominated to receive the proceeds of the raffle at this event, and the result was a wonderful £875 to help our work along!

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Sunday 22nd November:

Christmas Charities Fair at the Guildhall, Guildford

We don’t make a fortune at this event each year, but it’s an opportunity to wave the flag, and we also meet local councillors and the mayor, so can make sure they know all about MND on their patch, and what they can do to help.

(Right) Mary is distracted by the new addition this year - a string band right behind our stall!

Thumbs Up Club winners

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<thead>
<tr>
<th>Month</th>
<th>Name</th>
<th>Number</th>
<th>Amount</th>
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<tr>
<td>Sept</td>
<td>J Blake</td>
<td>(129)</td>
<td>£50.00</td>
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<td></td>
<td>M Bayley</td>
<td>(291)</td>
<td>£30.00</td>
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<td></td>
<td>A Carpenter</td>
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<td></td>
<td>L Woodward</td>
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<tr>
<td>Oct</td>
<td>A Shepherd</td>
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<td>A Husaunndee</td>
<td>(243)</td>
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<td>M Dean</td>
<td>(182)</td>
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<td></td>
<td>P Corver</td>
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<td>Nov</td>
<td>C Jackson</td>
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If you would like to participate in the Thumbs Up Club, please contact Sallie on 01483 274337 for a share number form.

Each share is £12 per year by cheque payable to MNDA Cranleigh Thumbs Up Club, or by STO.
Do retroviruses contribute to the common, sporadic form of MND?

by Belinda Cupid

Head of Research, MND Association.

New research from scientists at the American National Institute of Neurological Disorders and Stroke in Bethesda suggest that they might. In a research paper published in ‘Science Translational Medicine’ yesterday, Li, Nath and colleagues proposed that sporadic MND may be linked to an endogenous retrovirus called ‘HERV-K’. So they conducted a series of experiments to investigate their ideas further.

What are endogenous retroviruses?

These are viruses that are our body’s equivalent of fossil – a left over from our evolution many thousands of years ago. Everyone has them but they are normally in an inactive state.

They are a bit like a family heirloom, lets say a vase. You might walk past the vase every day without really noticing it until one day the cat knocks it off and it smashes onto the floor in front of you.

What did the researchers do?

First, they compared brain tissue of 10 people who died from the sporadic form of MND to brain tissue of 10 people who died from Alzheimer’s Disease. They found proteins made by the virus in MND brain tissue but not in Alzheimer’s Disease brain tissue. Next, studying one of these proteins (called ‘env’) in more detail, they found it was toxic to motor neurones.

Li and colleagues then took a step back and asked ‘what triggered HERV-K to become active in the first place?’. (In other words, going back to my analogy, what caused the vase to fall on to the floor?). They found that the trigger was activation by a protein called ‘TDP-43’ – and this protein is already linked MND.

So what does this really mean?

In a comment article giving a wider perspective on the research study, Professors Bob Brown and MND Association grantee Ammar Al-Chalabi concluded:

“...the exciting observations of Li, Nath and colleagues will provoke further follow up studies that will illuminate the interplay between the biology of endogenous retroviruses and seemingly impenetrable neurodegenerative disorders like ALS”.

So while this study in itself might not give us the answer, it’s an exciting step forward in understanding the most common form of MND, that other researchers around the world will build on.

A new three-year project to study the detailed structure of SOD1 and TDP43 proteins began in October at the University of Liverpool.

These proteins become damaged in MND, forming deposits within the motor neurones that cause the cells to become sick and die. Why this happens is not yet understood.

This project aims to study the SOD1 and TDP43 proteins in exquisite detail using X-ray scattering and X-ray crystallography to produce a 3D picture of their structure. Better understanding of these proteins may help with identifying potential drug targets within the nerve cells.

Coming up

Saturday 12th December at 7.30 pm

Christmas Concert

The Waverley Singers

St Andrews Church, Farnham

This will be a great evening of carols; both interesting ones for the choir, and traditional for the rest of us to have a go at!

One of our Drop-in friends, Mayonne Coldicott, sings in the choir, and has kindly organised for our branch to benefit from the collection at their next Easter concert, which will be a performance of the St John Passion, by J.S. Bach.

Wednesday 16th December, and 16th March 2016:

Branch Open Meetings & AGM

Details on back page

Could you please bring a Raffle prize to the December meeting - thanks!

Tuesday 2nd February 2016:

We will be giving a talk about MND and the Association to the Soroptimists International branch at Woking. The year’s President, Jan Perrot, kindly selected us as her Charity of the Year, and we have already benefited from their generosity.
Can you help?

We always need more Super-people to help us to improve what we do, especially with fundraising. (Anything legal considered!)

If you have ideas and energy, and want to make a difference to people with MND now and in the future, please get in touch with anyone on the ‘Who's Who’ list opposite.

By bus: There are no public bus routes that come right up to the Cathedral; however, there are several routes that stop at the bottom of Stag Hill, leaving a 5 minute walk up the hill to the Cathedral. Get off at the top of The Chase.

Are you living with MND?

. . Or do you know someone who is? Are they feeling a little solitary?

Informal 'Drop-in' meetings are held every month in the Cathedral Refectory, specifically for anyone with MND and their family. You are very welcome to come along to share your experiences, ups and downs, or just chat to friends over a cup of tea. First Wednesday of every month at 2.00 pm.

Open Meetings

Wednesday 16th December:

Guildford Cathedral Chapter House
1.30 to 3.30 pm
‘Putting the Fun into Fundraising'
by Pam Fry (MNDA Regional Fundraiser)
plus . .
Christmas Nibbles and Wine

Wednesday 16th March 2016:

Guildford Cathedral Education Centre
2.00 to 4.00 pm
Branch AGM

plus . .
‘Medicine on the Edge’
by Prof Colin Connolly

How to find us

By car: Stag Hill, Guildford, GU2 7UP
Adequate free parking
By train: 10 min walk from Guildford Station