

## Useful Contacts

### Group Leader

Andrew Lane  
portsmouth@mndassociation.org

### Campaigns Contact

Helen Warren

### Newsletter Editor

Melanie Nicholls, mel\_hunt@hotmail.com

### Volunteer Fundraiser

Sammy Clarke

### Publicity Officer

Judi Ammari, judi.ammari@harvestpr.co.uk

### RCDA South Central

Louise Rickenbach, 08453 751831

### Regional Fundraiser – SE

Pamela Fry, 01202 849151

### Volunteering Development Coordinator

Claire Tuckett,  
volunteering@mndassociation.org

### MND Connect

03457 626262

Do you have any stories, information or fundraising events you want to share? Please let us know for the next issue by 8th January 2016



## Fundraising Update

The biggest contribution to our funds this quarter was from the charity golf day we reported on in our last edition. Many thanks to all involved in it, and of course to all our other tireless fundraisers.

July 2015 - Cams Hall golf day donation £2300.00

August 2015 - Mrs J Mouland donation £10.00

September 2015 - Monty Long, London Marathon £440.00

To find out how you can organise your own fundraiser or to make a donation please contact Pamela Fry (details above) for more information or visit: [www.mndassociation.org/get\\_involved/fundraising](http://www.mndassociation.org/get_involved/fundraising)

### Motor Neurone Disease Association, Registered Charity No 294354

PO Box 246, Northampton NN1 2PR, Tel 01604 250505, Fax 01604 624726/638289  
enquiries@mndassociation.org, www.mndassociation.org

Registered Office: David Niven House, 10-15 Notre Dame Mews, Northampton NN1 2BG

Registered in England. Company Limited by Guarantee No 2007023, © MND Association 200



PortsouthGroup  
support. awareness. fundraising

## Newsletter

Autumn 2015

Winter is slowly creeping up on us, but let's not dwell on that! Time instead to celebrate some of the wonderful achievements our Group has accomplished over the summer months. People have been busy raising money for the MND by cycling, swimming, running and singing, and you can find out about all of these inside.

We have a few changes in our Group membership to report on, and Andrew Lane has written about a very interesting-sounding talk he and others in the Group attended to find out about the current state of research into MND. I hope you enjoy reading about it and let me know what you think!

Melanie Nicholls, mel\_hunt@hotmail.com

To find out how to get involved in our Group, see our website:

[www.mndportsmouth.org/](http://www.mndportsmouth.org/)

We're also on Twitter: @MNDPortsouth & Facebook

## Coffee Mornings



Here are the dates for the upcoming coffee mornings. Coffee mornings are held at the Rowans Hospice in Purbrook from 10.30 to 12.15 pm. We hope to see lots of you there!

Monday 7th December

Monday 4th January

Monday 1st February

Monday 7th March



## Volunteer Focus

**Name:** Annie Fitzpatrick

**Role:** Helper at the MNDa coffee mornings held at the Rowans.

**What do you do in 'real life'?** I help as a volunteer at the Theatre Royal, Portsmouth.

**How did you get involved with the MNDa?:** I answered an advertisement in the local press. I went to a meeting of the Portsmouth MNDa and then went to a coffee morning at Anne Chilcott's house at North Hayling where I met Anne for the first time. Anne had MND and could not speak but walked a little. To my surprise I found that I was able to communicate with Anne despite her disability. Thereafter I became a 'Visitor' and remained an AV for 8 years, most of the time operating as a team with another AV, Heather Grant. After that I have stayed in contact with one or two members of the Group.

**What do you like best about volunteering for the MNDa?** I enjoy helping at the monthly coffee mornings and am pleased that I can make them a happy sociable event for those who come to experience a change in environment and a friendly chat.

**What is your favourite pastime?** I like supporting the Theatre and being involved with my family

We are currently recruiting volunteers to help organise fundraising and support activities for local people living with MND.

**Group Finance Officer:** Could you give 2-4 hours a month to bank donations, thank donors, receive and check financial reports, oversee the Group's financial records and attend a monthly meeting?

**Group Correspondent:** Could you attend a monthly meeting, organise lifts to coffee mornings and provide admin support for your local Group?

**Association Visitors:** AVs provide one to one support to people living with MND, their families and carers. They visit, email or phone people with MND and get training and support to carry out this vital role.

To find out more please contact Claire Tuckett on [07831 349382](tel:07831349382) or [emailvolunteering@mndassociation.org](mailto:emailvolunteering@mndassociation.org)

## MND Research Talk

However we are affected by MND, we all have reasons to be interested in the research that is going on into finding a cure for the disease. As we all know, MND is very complex and affects each person differently. Recently several of us had the opportunity of attending a talk by Dr Brian Dickie, Director of Research Development for the MND Association.

Brian's responsibilities include raising the Association's profile within the biomedical and care research communities, increasing the quantity and quality of Association-sponsored and collaborative research and communicating advances in MND research to lay and specialist audiences. His friendly and informative manner, with plenty of inoffensive humour, was perfect for this audience of interested but non-expert people.

Brian shared with us the aims and goals of the Association-funded research, which include:

- identifying causes and the mechanisms that trigger and alter the progression of MND
- delivering new disease models to the research community to test new therapies
- contributing to the identification and validation of MND 'fingerprints' to speed up diagnosis
- strengthening the basic and clinical research base throughout the UK, through the increased number of quality researchers and specialist centres involved in MND research

The Association also aims to be a leading authority in MND research, and it is invited to shape the optimum conditions for MND research to be carried out in the UK and beyond – and it was good to hear that it is recognised as such by other countries. Experts are confident a cure for MND will be found – it is clear this can only come about through joined-up research involving the best people available. I for one came away from Brian's talk very confident and happy that the best people are very much on the case and that the journey is progressing to its vital conclusion.

**Andrew Lane**

## Portsmouth Group News

### New Group Leader and a farewell

As many of you know, our Group has been without a Leader for a while, but Andrew Lane – who was Leader until he stepped down eighteen months due to work commitments – is taking on the role once more from the beginning of December. Many of you know Andrew from the Coffee Mornings, and he would love to hear from you – especially if you would like to join the committee or have ideas about how we can improve our support for people affected by MND. We are all extremely sad to say goodbye to Graham Turner, who has been an AV and very efficient Group treasurer for many years. For personal reasons he has decided he can no longer commit to the group; we will all miss him terribly.

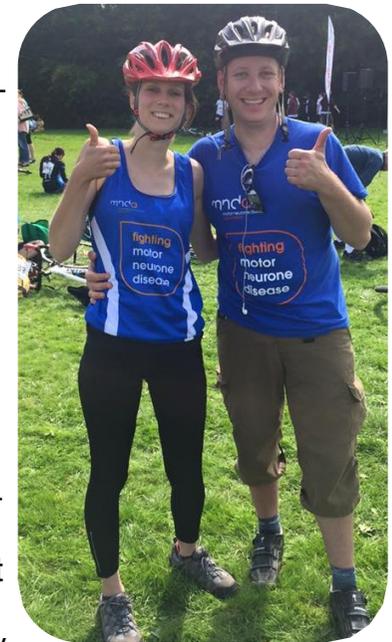
### Fundraising Facebook site

Our Fundraising Volunteer Sammy Clarke has been hard at work putting together a newsletter to celebrate all the fundraising events that goes on across the South of England. She has recently set this up on Facebook to reach more people and let them know about fundraising events and any awareness work that people have done as well as promoting any upcoming events. This is a different page to the Portsmouth one we already have, and you can find it at <https://www.facebook.com/Southern-Fundraising-MND-1806052712955169/>, or search for 'Southern Fundraising MND'. Please find a moment to like the page and share it to spread the word.

To find out how to get involved in our group, see our website: <http://www.mndportsmouth.org/>  
We're also on Twitter: @MNDPortsmouth & Facebook, 'MND - Portsmouth and SE Hampshire Group'

## London to Brighton Bike Ride

In September my Boyfriend and I completed the London to Brighton bike ride in aid of the Motor Neurone Disease Association raising an amazing £2253. In January I purchased a bike and went out for a short 4 mile ride which I found exhausting, the thought of cycling another 50 miles at this point was very daunting. And so training began, months of long bike rides, intense spinning classes and swimming many lengths of the pool and before we knew it the day we had been training for arrived. The sun was shining and the conditions were perfect. It was a hard day and my training was put to the test but it all paid off as we rode over the finish line after six and a half hours greeted by wonderful family and friends.



**Sammy Clarke, Volunteer Fundraiser**

## Campaign Network Meetings

Helen Warren, our Campaigns Contact, recently attended the Wessex local delivery team meeting and the Wessex forum meetings in Eastleigh. The next ones will be in February 2016 and are well worth attending if you can. One of the items raised was about encouraging people to join the Campaign Network. It is very quick to join online; sadly there are only nine people joined up in the Wessex area so we want to try to get to 100! You will get updates on campaigning issues and details of how to help if you wish. It would be great if you could join up yourself and encourage others to also. The link is;

<http://www.mndassociation.org/get-involved/campaigning-influencing/campaign-network/>

## Solent Swim Success

Despite the weather with five cancelled crossings, the third Ian Pratt Motor Neurone Disease Challenge (Solent Swim 2015) managed to raise a staggering £30,000 for MNDA and more importantly, raise awareness for the disease. The team led by Tony Bray, managed three crossings with 37 swimmers plus supporting kayakers and safety boats making the journey. They carried 160 MND Angels and Warriors (wrist bands) with them.



The event started two years ago with four people swimming from Ryde on the Isle of Wight to Southsea. In 2014 22 swimmers took part. It is named after Ian Pratt who is living with MND. He says: "It is people like Tony who have the dedication, commitment and ability to raise awareness in the wider community. It is through his determination that more and more people know about this disease. I am very fortunate to be able to call Tony one of my closest friends when he called me to ask whether he could make the Solent Swim an annual event, and name it after me, I was so honoured."



**Judi Ammari, Publicity Officer**

## Ellie Randall's Fundraising Quest

Running in memory of her dear late uncle, Kim Manns ( a MND Angel) Ellie pledged at the beginning of this year to run in the following 15 events:

- 28th March - 5k Night Run Portsmouth
- 25th April - 5k Foam Fest, Portsmouth
- 26th April - 10k, Southampton
- 10th May - Half Marathon, Hereford
- 7th June - Half Marathon Ramathon, Derby
- 5th July - 5k Summer Solace, Southampton
- 12th July - 10 London Run
- 18th July - 5k Mud Run, Portsmouth
- 6th September - Spit Fire 10k, London
- 13th September - Great North Run
- 27th September - Robin Hood Half Marathon, Nottingham
- 4th October - 5k Fuddy Mud Sucker, Southampton
- 11th October - 10k Mud Monster Run
- 25th October - Great South Run, Portsmouth
- 20th December - Portsmouth Coastal Half Marathon

To date she has managed to raise over £2,000 and has been interviewed by the media on numerous occasions and has enthusiastically supported other charity raisers too. An inspiration to us all, not least to her family who are so proud of her. Our Group would like to say a special thank you to Ellie. Keep up the good work. In your words "No finish line, until there's a cure."



### Chords for a Cure

In July Sammy Clarke, Portsmouth Group Fundraiser, organised a charity gig in aid of the Motor Neurone Disease Association and the Alzheimer's Society at the Festing Pub in Southsea. Four fantastic local bands and musicians played throughout the night to a sold out venue. There was also a raffle with prizes donated from both large and small businesses. The night was a huge success raising over £700 which was shared between the two charities.

