

Useful Contacts

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Do you have any stories, information or fundraising events you want to share? Please let us know for the next issue by 25th July 2014



Fundraising Update

Thanks to all the hard work of all our fundraisers. Don't forget that you can access these funds if you are affected by MND; contact your AV to find out how. Here's a round-up of the funds raised this spring.

February 2014:

Hayling Golf Club Veterans Section Donation £1500

Mr E Tambling Donation £40

Margaret, Friend of Mrs S Stevens Donation £10

March 2013:

Mrs J Blake Donation £60

April 2014

Mrs G Lane Donation £100

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/getinvolved/fundraising

Motor Neurone Disease Association, Registered Charity No 294354

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PortsmouthGroup
support. awareness. fundraising

Newsletter

Spring / Summer 2014

A lot has been happening in MND in the Portsmouth area over the last few months, and this edition of your newsletter is packed with news of all the fundraising and other activities everyone has been up to. There are lots of inspiring fundraisers, who have recently completed, or are about to attempt some amazing feats; you can read about runners, abseilers, amazing swimmers, and pub-goers inside, and we've included details for you to sponsor whoever inspires you the most!

Our little group continues to grow, with several new members who are already busy at work; see Andrew's article on page 7. If you would like to become more involved, please get in touch, you'll be very welcome!

Melanie Nicholls, Editor

Coffee Mornings

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



Monday 2nd June

Monday 7th July

Monday 4th August



bakeit!
and help make MND history

Penny Sheppard, one of our new Group members, is organising a 'Bake It' event and Bring & Buy on the 12th July in the Parish Rooms, Titchfield, from 10am—1pm. Some of us will be baking (yum yum), and we hope to see lots of you there. There is wheelchair access.

Volunteer Focus

Name: Helen Warren

Role: Campaigns Coordinator

What do you do in 'real life'?: I am a Pilates teacher, I run 9 classes a week locally and have been for about 18 months. I did a charity Pilates night last year raising money for MND and plan to do another later this year.



How did you get involved with the

MNDA?: I came to my first meeting in July 2013 and found everyone so welcoming, I was quite nervous but now I look forward to the meetings. I became involved because my dad (pictured with me above) had MND from around Jan to Sept 2011.

What do you like best about volunteering for the MNDA?:

Meeting new people who are caring and understand how devastating the disease is. Learning new skills such as Twitter(!) and hopefully making a difference by raising awareness & funds. In my campaigning role getting a reply from a councillor or MP is rewarding.

What is your favourite pastime?: Fitness, I love going to classes at my local gym. I love boats, one of my favourite places to be is on my dad's boat as it is now mine and my brother's, it can be bittersweet but we are doing our best to make it a fun place to be, as it always was!

Join Us as we Walk to D'Feet MND!



Once again this year we are planning to hold a Walk to D'Feet at Manor Farm Country Park. If you took part last year you'll remember it was a very wet day, which reduced numbers. Nevertheless, we raised over £1,000. Our aim is to do even better this year, no matter what the weather, raising both sponsorship money and awareness. The course will again be about a mile, and the fitter ones amongst us can do as many laps as they wish. The paths are suitable for wheelchairs. We plan to hold the Walk on Sunday 21st September. Please make a note in your diary to be there and join us for a leisurely but important stroll through glorious surroundings.

Your Group Still Needs You!

I wrote in the last newsletter about our efforts to recruit new volunteers for our Group. I'm very pleased to let you know that we have grown – but we still need more people!

One of our weak points was that we had no-one to look after publicity – vital if we are going to succeed in raising awareness and funds. We were very lucky to be joined by Judi Ammari, who is a very experienced public relations executive. Judi has already been working hard raising our profile by gaining coverage in the local press. She was also persuaded to join us for the St George's Day Quiz at The Rose in June, with her partner Ian, and helped us to second place!

Many of you will know Penny Sheppard and her husband Tony. I'm delighted to say Penny finally gave in to my pleas and joined us at the same time as Judi. Penny has lots of contacts through her nursing career, and lots of experience organising events. I know her experience will be very valuable.

Two other great pieces of news:

Helen Warren has kindly agreed to become Deputy Chair, standing in for me if I am unable to attend meetings and generally helping keep a watchful eye on things. Helen is already doing a terrific job as our Campaigns Co-Ordinator, working hard to ensure our voice is heard by politicians and other decision-makers locally and nationally.

My wife Gill, who has always been very supportive of my work with the Group, has agreed to join us as a volunteer. Now I just have to find something for the cats to do!

I hope the Group will continue growing so that we can organise more events and have a louder voice shouting about MND to those that know little or nothing about it. I know you will join me in thanking our wonderful team of volunteers for their time and hard work – why not come and join us?

Andrew Lane, Portsmouth Group Leader

To find out how to get involved in our group, see our website: www.mndassociation.org
We're also on Twitter: [@MNDPortsmouth](https://twitter.com/MNDPortsmouth) & Facebook

Abseiling for MND

Publicity-shy Winston from Portsmouth is a Royal Navy veteran and a member of HMS Ganges Association who meet at HMS Excellent on Whale Island where he trained as a seaman gunner in 1958. Last year he took part in Portsmouth's MND's "Walk to D'Feet" event and helped raise a sizeable sum for the MNDA. This year he has set his sights on the Spinnaker Tower.

Despite having recently had a knee replacement, Winston is keen to give something to the community, and those suffering from MND in particular. He is due to abseil from the Spinnaker Tower on Saturday 23 August at 1pm. He has already raised £200 from family and friends; if you would like to support him you can visit his Just Giving page at: www.justgiving.com/winstonsabseil



Great News from CTruk Boats

You will know from the volunteer focus that my dad had MND and is the reason I know about and got involved with the Association. He was a naval architect and one of his designs was being built whilst he was ill. The company called CTruk Boats is owned by a lovely man who had known my dad for a long time and was devastated by his illness and passing. In the summer of 2012 my brother and I were invited to go to the naming ceremony of the boat our dad designed and I got to name her and smash the champagne!

The owner said that every subsequent boat they built they would donate £20,000 to MNDA! And this month we found out that they have built a second one and it is out in operation. They have produced a press release which talks about the boat, MND and my dad. They have also set up a Just Giving page to encourage their suppliers, customers etc. to donate: www.justgiving.com/CTruk



Helen Warren

Special Thanks to Portsmouth's 'The Rose in June' Pub



The publican and landlord have been strong supporters of MNDA over many years and we would like to show our appreciation and support for their sterling efforts in raising funds for the Portsmouth branch.

St George's Day Quiz Night

On 22 April their Tuesday night quiz was in aid of MNDA and other charities and raised over £200. We had a small team there on the night and managed to come second (see photo below). This was a significant improvement to our last ranking so we were very pleased. The pub was packed and each team member paid £4.00 to participate in the quiz and there was a raffle and free food!

Come to their Beer Fest in June

On the last weekend of June (Friday 27-Sunday 29 June) the pub are holding their Seventh Annual Charity Folk and Beer Fests in their magnificent garden and will have a marquee with 30 real ales and 6 ciders on offer. With free entry from noon each day it is set to be a fun-packed weekend with lots of stalls and entertainment.

Friday is taster's day and on Saturday 28 June the line-up includes clog dancers, morris dancers and folk music with a jam session for everyone in the evening. On Sunday the folk music continues and just for the children there will be a traditional Punch and Judy and a bouncy castle. For food, the BBQ will be busy throughout each day providing burgers and other such tasty fare.

All proceeds are donated to the Motor Neuron Disease Association (MNDA) for research and support. This is a very important event for us and raises much needed funds. We urge everyone to go to the pub over this weekend to say thanks to Paul, Caroline, Paul and Mary.

THE ROSE IN JUNE
102 Milton Road, Portsmouth
Tel: 023 9282 4191
www.theroseinjune.co.uk



MNDA Charter

Last edition we highlighted the MNDA Charter and how you can sign online. Helen Warren has been working on the Local Council Elections Campaign (calling on candidates standing in the local elections and existing councillors to sign our MND Charter and pledge to listen to people with MND and their carers.) and has written to 84 councillors. She has had 7 replies so far; one has signed the Charter, the other said he would not sign the Charter but did make a donation of £25. The link for this campaign is www.mndcampaigns.org/2014elections

If you would like to encourage our councillors further to sign the charter then the website (<http://www.mndassociation.org/>) you will find a link and a pre written letter you can send to your local MP asking him/her to sign the Charter, as well as signing it yourself.

MNDA Portsmouth on Facebook

Please “Like” our Facebook Page

For you facebookers out there please take time to look at the Portsmouth and SE Hants Group brand new page and make sure you click on “Like” at the very top. At the moment the page has 69 likes but we want to make it over 100.



Facebook is a highly visual medium and we hope to add lots of photographs and news of our local fund-raising activities and topics of interest. The next date for your diary is The Rose in Hand Pub’s Charity Folk and Beer Fest in aid of MNDA at the end of June.

Like our page and keep up to date on our news.

<https://www.facebook.com/pages/MND-Portsmouth-and-SE-Hampshire/486058304850776?code=81694>

If you would like to add anything to our Facebook page which you think would be of interest to others, please email our Publicity Officer Judi Ammari and she will be very happy to help publicise your event/efforts. Email Judi on judi.ammari@ntlworld.com

Fundraisers this Spring/Summer

Solent Swim

Tony Bray of the IOW branch, together with a large team of others, will be swimming across the Solent on Monday 21st July in aid of MNDA. The Maritime Volunteer Service in Portsmouth will be providing 2 boats, most welcome and essential in adhering to the Royal Harbour Portsmouth Health & Safety regulations. The swim is scheduled to leave Ryde Sands at around 1:00pm, it is anticipated the last swimmers should arrive at Southsea beach at approximately 3:30pm. Pamela Fry (our Regional Fundraiser), her partner David and family will be there on ribs and kayacks so come along and give them a wave! You can donate to at the following website: www.swimmingthesolent4mnd.com/2014-swim/2014-swimmers/



Marathon Fundraiser

Matt, son of our very own Peter and Gill Crosse, will be running for MND in the San Francisco Marathon. In America MND is known as ALS or Lou Gehrig's Disease, so named after the brilliant baseball player for New York Yankees who died in 1941 aged 37. Matt will be running in the San Francisco Marathon for MNDA Portsmouth on Sunday 27th July. To support him visit his Just Giving page: www.justgiving.com/Judi-Ammari1



Generous Townswomen’s Guild

“My life has changed in two ways recently. As well as caring more for my husband Tony, who is living with MND I have lost my monthly meeting with friends at Waterlooville Townswomen's Guild. Unfortunately our numbers have dwindled in the fifty years it has been in existence and no-one had the time to commit to running the group. Our treasurer wanted to donate any leftover cash in our kitty to two charities, one for animals that she favoured and I asked if the other could be the MNDA. I was delighted when I heard she had sent a cheque to MNDA for £66.08. Not only was it nice to donate but it also drew the ladies attention to the disease which is affecting my husband, who is known to many of them.”

Helen Beeson