

## Annual Parliamentary Reception 2016 for MNDa

More than 100 volunteers travelled to Westminster from across England, Wales and Northern Ireland for the Association's annual parliamentary reception.

They had the chance to share their experiences of issues that affect people living with MND, their families and carers.

They also raised the issue of the proposed changes to Attendance Allowance (a benefit for people aged over 65) with MPs – over 55 came on the day.

They heard from Chief Executive Sally Light, author and first wife of our Patron Prof Stephen Hawking, Dr Jane Hawking, and award-winning volunteer and artist Sarah Ezekiel, who is living with MND. They encouraged the politicians to ensure that people living with MND, and their carers, can access the financial support they are entitled to through the benefits system.

Sally Light said:

'It was wonderful to see so many of our amazing volunteers gathered together and for them to have the opportunity to share their personal experience of MND with MPs and peers present'.

Attendees also heard from Penny Mordaunt MP, Minister for Disabled People, Work and Health who said:

It's incredibly important for members of Parliament whether we're ministers or whether we're backbenchers to hear your stories. It helps us make better policy. The anecdotes and stories you tell us, we can talk about on the floor of the House of Commons and in the House of Lords. And it really does help us tremendously make better laws, make better policy and get you what you need.'



Dr Jane Hawking, Penny Mordaunt and Dr Sally Light

## Better than a hole in one!

We have recently heard that Belfairs Golf Club has chosen MND as its Charity for the coming year.

The current captain takes over as president at the end of November. The lady captain has also chosen us which I understand is rare as it is usually two separate charities so we are very lucky

They are putting on a year's worth of events for us and

anticipate raising a whole heap of money

They are both managers of Morrison's and they are going to be asking Morrison's to get involved with fund matching the amount they raise together with their own fundraising and to give us the opportunity of bucket rattling.

For more great fundraising news turn to page 2.

# Fundraising news

## Running team!

Clark Summers and his wife have both secured places in the London marathon and will be running to raise funds for us. Over the next few weeks we will be featuring them on our Facebook page. Well done and good luck to you both!

## Welcome Matthew!

We also welcome on board Matthew Daly a young man who has chosen us to volunteer with for his Duke of Edinburgh award.

He is currently researching news and info for us and has come up with a huge list of fundraising ideas.

It's great to have some young views and ideas and it's wonderful he has chosen us to work with. Thanks Matt!

## Pinney Talfourd

Pinney Talfourd, solicitors in Upminster continue to raise funds for us – we have been nominated as their charity of the year. Already one of the partners has undertaken a 100 mile sponsored cycle ride around London and another of the lawyers has swum the equivalent of the English channel with her son. How fantastic and energetic! Well done to those involved.

Dress down days, bake offs and a raffle for a day's annual leave have already been popular and the total is steadily rising. To have a look at how much they have raised have a look at their website [www.pinneytalfourd.co.uk](http://www.pinneytalfourd.co.uk) – charity of the year

Going forward they have some amazing events coming up. Six members of staff are taking part in the Brentwood half marathon and Sebastian, one of the family lawyers is determined to top this and is cycling from London to Paris! Full details of his training and journey will be posted on our facebook page and website in due course

In December they will be hosting the annual and very popular Christmas carol concert at the Queens theatre in Hornchurch. Tickets for this event sell out quickly but we have 20 tickets for this event which generally raises tons of money which is split between the charity of the year – us – and the Queens theatre itself. Again more details will be on the website and facebook page. It would be lovely if some of us can attend and show support to his wonderful company who are doing wonderful things for us.

## DONATIONS & FUNDRAISING

### Donations

Gillian Trevelyan .....	£10.00
Michael Sheville .....	£45.00
Christine Dartnell .....	£160.01
L A Bennett .....	£40.46
ZB News .....	£45.24

### In memoriam

D E Noble .....	£20.00
Hilary Barry .....	£40.00
Terry Shabi .....	£145.00

### Tribute Funds

Beverley Storey .....	£111.00
P A Stubbs .....	£10.00

Grateful thanks to all donors and fundraisers

## Aims of the Association

- To provide care and support for people living with MND
- To promote scientific research and provide funding to specialists seeking to find treatments and ultimately a cure for this disease
- To speak on behalf of people with MND, demanding the best possible standards of care and campaigning locally and nationally
- To increase awareness of this disease

# News from National Office



Calling all young artists! If you are under 18 why not get creative and help design a Christmas card for the MND Association?

The winning design will be published as one of the official Christmas cards for next winter, 2017. All proceeds from the sale of the card will be used to help people with or affected by MND.

Entrants can draw, colour or paint in any way they wish, but must remember to put their name and age on the back of the picture, and include a contact telephone number or email address. There are terms and conditions online on how to send in your entry.

The Association hopes to feature as many pictures as possible in the online gallery!

Enter online at [www.mndassociation.org/for-carers/young-carers-hub/christmas-card-competition/christmas-card-competition-entry-form](http://www.mndassociation.org/for-carers/young-carers-hub/christmas-card-competition/christmas-card-competition-entry-form) or phone MND Connect 0808-8026262 for more information.

## Counting down to the International Symposium

The world's leading MND clinicians and researchers will visit Dublin between 7-9 December to attend the MND Association's 27th International Symposium on ALS/MND.

Over the years, the worldwide MND community has used the conference as a focal point and a range of other meetings have developed alongside it, including the annual meeting of the International Alliance of ALS/MND Associations, the Allied Professionals Forum and of course the Symposium itself.

Each year the Symposium, which attracts around 900 delegates, is held in a different place, making it possible for local researchers to attend the meeting and to hear from the global research and clinical community.

"We can't wait to explore and engage with our international colleagues on upcoming advances that might help us realise our collective ambition of achieving a world free from MND."

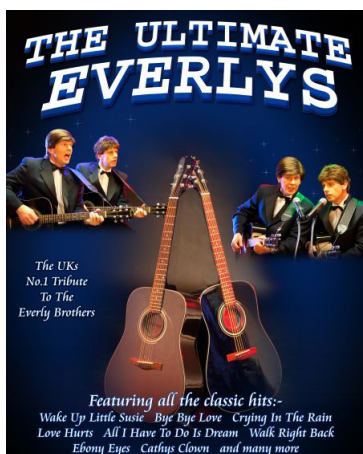
A meeting of health and social care professionals from across the world will take place prior to the start of the Symposium on 6 December.

'By fostering good relations and hearing more about the day-to-day experiences of professionals caring for people living with MND around the world we can implement any

necessary changes to the way we work and offer the very highest standards of care possible.' The MND Association's Children and Young People Development Manager, Karen Welsenaer will be among those speaking the conference.

She will be describing a new way of working to encourage professionals to consider the needs of the whole family when planning care for a parent or guardian living with MND. Karen said: 'It's a great opportunity to get adult health and social care professionals to rethink their approach and consider everyone's needs. This should help families with children to get better support more quickly.' To find out more about the work of the Forum visit [www.mndassociation.org/alliedprofessionals-forum](http://www.mndassociation.org/alliedprofessionals-forum)

For those who cannot travel to Dublin, our Symposium Live page on the MND Association's website will give everyone the chance to get closer to the action, wherever they are in the world. The page will include videos, photos and links to the MND Association's research blog to find out more about the science behind the Symposium. In addition, those wishing to find out more can follow the action on Twitter using the hashtag #alssymp



## A night of music for MNDA

A forthcoming charity night is to be held at Hadleigh Conservative Club, 24, High Street, Hadleigh, SS7 2PB (car park at rear)

21st January 2017, 7-30pm-Midnight.

Entertainment by the Ultimate Everlys Tribute, also live music from the 60s-90s by Tricks of The Trade.

There will also be a raffle with all proceeds going to the Association. Tickets are priced at £7. Please contact Valerie on 07743-281171.

# Events, news and contacts

## Dates for your diary

### 2016

\*\*Change of date\*\*

Please note the next meeting at Fair Havens will be on

**November 25**

November 21..... 8-10pm open meeting  
St Luke's  
November 25..... 2.30-4pm drop-in  
Fair Havens

### 2017

January 2 ..... 2-3.30pm drop-in  
Thurrock Garden Centre  
January 1 ..... 8-10pm open meeting,  
St Luke's  
February 3 ..... 2.30-4pm drop-in  
Fair Havens  
March 7 ..... 2-3.30pm drop-in  
Thurrock Garden Centre  
March 8 ..... AGM  
(details in next newsletter)  
April 7 ..... 2.30-4pm drop-in  
April 25 ..... Chinese evening  
Zen City, Westcliff  
May 2 ..... 2-3.30pm drop-in  
Thurrock Garden Centre  
May 15 ..... 8-10pm open meeting  
St Luke's  
May 21 ..... Walk to d'Feet

Fair Havens Day Room  
Stuart House, Second Avenue  
Westcliff-on-Sea SS0 8HZ

St Luke's Hospice Day Room  
Nethermayne, Basildon SS16 5NJ

Thurrock Garden Centre  
South Ockendon RM15 6DU

Zen City  
Hamlet Court Road,  
Westcliff-on-Sea SS0 7EW

### ACKNOWLEDGEMENTS

- The health and social care professionals who work with our people with MND
- The many donors and supporters of the Branch
- Mike Searle, for our website [www.mndsouthessex.org](http://www.mndsouthessex.org)
- St Luke's and Fair Havens hospices for their continuing care and hospitality
- Grant Flashman for printing and folding our newsletter

**mndconnect**  
**0808 8026262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### WHO'S WHO IN THE BRANCH

#### THE COMMITTEE

CHAIR ..... SUE NASH  
VICE CHAIR ..... SANDY LAMBERT  
SECRETARY ..... SHARON CLARK  
TREASURER ..... ROWAN HARVEY  
PUBLICITY ..... KEVIN WATTS

#### ASSOCIATION VISITORS:

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MON – FRI. 9.00 AM – 5.00 PM AND  
7.00 PM – 10.30 PM

[WWW.FACEBOOK.COM/MNDASOUTHESSEX](http://WWW.FACEBOOK.COM/MNDASOUTHESSEX)

TWITTER: @MNDASSOC