

Newsletter

West Sussex County Council adopts MND Charter

Written by Dr. Steve Dyer, President of West Sussex North Branch

September 6th was a day to celebrate as West Sussex County Council formally adopted the MND Charter. At last I hear you say!

The occasion was a reception at County Hall, Chichester, hosted by Cabinet Member for Adults and Health, Amanda Jupp. Councillor Jupp welcomed the Charter and recognised the commitment of many that had led to this important day.

By signing the Charter the Council will actively strive to ensure its services are fully compliant for the needs of those living with MND and their carers.

Representing the MND were Jane Giles, Regional Care Development Adviser for Surrey & West Sussex MND and Rachel Martin-Smith, Campaigns Manager (South). Specialist nursing in MND and Palliative Care were also represented. Lee Millard and David Setters together with his Carer extraordinaire, Helen, represented local people living with MND. The Horsham based Neuro Rehabilitation team sent two delegates and our sister Branch Chair and AV completed our group.

It was my privilege to introduce the signing and I highlighted the partnering of those attending together with the Council in training and equipping services in West Sussex to provide excellence in helping those challenged by MND and of course their carers.



Above: (L-R) Alison Moorey- CEO St Wilfrid's, Jane Giles, Sandra Holden- MND nurse Worthing Community Trust, Dr Steve Dyer, Councillor Amanda Jupp, Brian Turner - Chair of W. Sussex Council Adult and Health Round Table, Rachel Martin-Smith, David Setters, Helen Setters and Lee Millard.

David Setters gave an excellent speech in response, saying how important this public commitment by the Council means to those challenged by living with MND in the area.

The photo shows the signed Charter and most of those present.

A fruitful light reception followed with good bridge building for future working.

Radio Sussex covered the event and it was featured on their Drive Time program in the evening.



Above: (L-R) Steve, Dave Setters, Helen Setters and Councillor Amanda Jupp.

Revolutionary new neck collar now available on NHS

A revolutionary neck collar designed to ease pain and make everyday tasks such as eating and communicating much easier for people with motor neurone disease is now available to patients in the NHS and across the world.

The Head Up collar, which was funded by NIHR's Invention for Innovation (i4i) programme and the Motor Neurone Association, has been brought to market as a result of an innovative five-year project by the University of Sheffield, Sheffield Hallam University and the NIHR Devices for Dignity MedTech Co-operative.

The neck support collar is now being used with suitable patients at 25 NHS Trusts (although please note patients have to be referred by their health care professional and/or MND nurse). It can also be purchased privately.

A frequent problem caused by motor neurone disease is the loss of strength

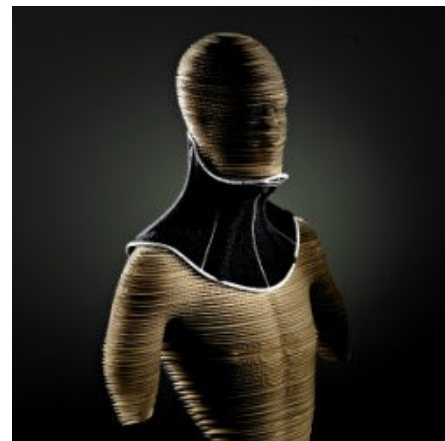
in the neck, causing patients' heads to droop to the side or the front. Until now, many head supports available to patients resemble the restrictive braces used after a trauma – such as a car crash.

The unique Head Up collar, which was designed with the help of patients with motor neurone disease, offers personalised support to the collection of small muscles in the neck that are particularly vulnerable to the wasting effects of the disease.

The neck support collar was trialled by more than 100 patients in 10 sites across the UK and Ireland, 80% of whom felt the collar helped them and wanted to carry on using the collar after the trial.

Clinical Director of the NIHR Devices for Dignity MedTech Co-operative, Professor Wendy Tindale, said: "Devices for Dignity has been a real catalyst in

enabling the Head Up collar to be developed and made accessible to patients. Gathering the evidence about how it has helped people with motor neuron disease has been a really important part of the journey and has helped in ensuring the product got to market."



October Branch Social: 14th at The Ark

We look forward to seeing you on October 14th for our next Branch social at The Ark in Turners Hill.

There are lots of things for you to look forward to. Firstly, we have Margaret Watson the Harpist back to entertain us all.

Secondly, you will be able to purchase Christmas cards on the day.

See you there!



Currency left over from holiday? Donate it to us!



Have some currency left over from your summer holiday? Well rather than popping it in a draw and forgetting about it, you can give it to us.

Not only will you be donating money to us, but we can exchange it to sterling and

receive an additional 5% of the currency we convert as we are a charity.

This is all through a scheme run by leftovercurrency.com

So don't forget to bring your currency to the next social for us to exchange.

Charity Quiz Night at Haywards Heath Golf Club

Join us on Friday 9th November for a light supper and quiz. Doors open at 7.30pm for an 8pm start. £12 per person for a team of 6.

Contact julie@mndwestsussexnorth.com to book your place.



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Treasurer's List of Monies Received & Spent

Thank you to everyone for their contributions. The below are the cleared funds received for the second quarter 2018.

(All information was the best available at time of going to press).

MONEY RECEIVED

Money from activities:

Horsham Rock Choir - Concert	£850
Hairworks Cuckfield - Open Evening	£715
Sirus Taghan & Amir Salehi - London to Brighton Bike Ride 2017	£283
Creative Medical Research - Participation in Research Trial	£100
Horsham Street Collection	£1,206
David Shepard - Brighton Marathon (grand total to date £775)	£390
Haywards Heath Golf Club (Al & Ben Turner - London to Brighton Bike Ride 2018)	£1,065
Amanda Wilkens - Simply Treasures - Sale of Handiwork at The Ark	£15
The Ark - Sale of Teas and Cakes	£10
AGM - Sale of Teas and Cakes	£16

Box Collections:

St Francis Social & Sport Club	£39
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Donations and Gifts:

June Hewins, Joan Crompton & Ann Wyatt £50

Donations and gifts in memoriam:

In memoriam Andy Spriggs (Horsham Rotary Club)	£500
In memoriam Douglas Grove (Funeral and other personal donations)	£130
Sue Charman Tribute Fund (M. Blake-Dyke)	£30

Other income:

Bank Interest	£85
Gift Aid	£98

MONEY SPENT

Financial Support for members & carers:

Lightweight Wheelchair	£476
Quality of Life Grant (x2)	£1,500
Carers Grant (x4)	£1,900
Young Persons Grant (x2)	£500
Contribution to Members Lunch	£47

Expenses:

Visitors - Travel Allowance	£244
Room Hire - Burgess Hill	£29
AGM	£50

PUBLISHED BY: West Sussex North Branch of the MND Association.

The views expressed in this newsletter are not necessarily those of the MND Association. If products and services are mentioned, these should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

We would like to keep in contact with you about the important work we do. If you do not wish to receive further information please contact a member of the Committee.

MND Connect

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