

Guinness World Breaking Record Attempt



On Sunday 10th February, Phil Rossall who has Motor Neurone Disease, Marcus Green and Nick di Paolo attempted to break the Guinness World Record for the fastest wheelchair push around a half marathon course at the Worthing Half Marathon. Raising awareness for Motor Neurone Disease Association, Phil put his trust in Marcus to push him around the course at average speeds of over 14kmh with Nick di Paolo running alongside with a spare ventilator.

The previous record stood at 1 hour 35 minutes 6 seconds and Phil, Marcus and Nick crossed the finish line in 1 hour 29 minutes 38 seconds - shaving off over 5 minutes and 28 seconds! They were supported by the West Sussex South Branch of the MND Association who helped organise an independent witness, who will be crucial in ratifying the record attempt. The team now have a nervous wait to see whether Guinness World Records will officially recognise the attempt and announce them as world record holders.



In the run up to the attempt, on the day itself and in the aftermath, it was clear that Phil's bravery and positive attitude to life has had a massive impact on other people. If you are interested in hearing more of Phil's story and enjoying his humour, visit his blog at <https://livingwithmotorneuronedisease.thefunbits.home.blog/>.



Our very own super-runner Sue Acaster also competed in this race, running for the branch, and beat her personal best by 3 minutes. Well Done Sue!

NEW BLUEBELL WALK

Sunday 28 April 2019

The Dover, Dover Lane, Arundel BN18 9PX

By kind permission of Nigel Clutton

Tickets £13 to include Lunch + Wine

(accompanied children under 8 free)

Walks start at 10am & 11am Lunch 12.15

Please see Valerie or Alastair for tickets



GRUFFS MALE VOICE CHOIR

Friday 31 May 2019



7 pm Bohunt School

65a Broadwater Road

Worthing BN14 8AH



BRANCH NEWS AND EVENTS



Our Christmas party seems a long time ago now but we would like to thank everyone who attended for making our Christmas Branch Party such a fun evening.

We had a fantastic raffle, Christmas card sales and Lin's designer bags which all brought in much needed funds for the branch. The Sundown



Ukulele Band once again gave a very enthusiastic and enjoyable performance all free of charge, so a big thank you to them.

Thank you Steve and Anita

Steve Goulding, Worshipful Master of the Masonic Lodge of Union in Chichester and his wife Anita presented Sandy, our co-Chairman, with an amazingly generous Cheque of £983.50 raised at their Gala Event they held in October and then a White Table sale at Christmas.

The Branch is very grateful to Steve and Anita for all the hours and hard work they put into raising funds for our Branch.

The Sussex Provincial Grand Lodge also gave a generous extra £600.



We were very fortunate to have Tony and Frances Lambert come along to the February Branch meeting to talk about their life in China. The talk was titled **China - A Land of Contradictions** (Tony has summarised his talk below):

I first went to China in 1973, and was stationed at our embassy in Beijing 1976-79. From 1982 onwards my wife and I have worked to help China's growing Christian church, and were based in Hong Kong for 10 years.

China under Mao at the tail end of the Cultural Revolution was a backward and poverty-stricken country. Fast forward 40 years and China has been transformed into the world's economic power-house and has become a political superpower rivalling America. Across the river in Shanghai the modern area of Pudong with its

skyscrapers and TV tower was just paddy fields 40 years ago. In those few decades China has lifted hundreds of millions of people from dire poverty to relative prosperity and seen a mass emigration from the countryside to the cities of hundreds of millions of people. A vast industrial revolution which has transformed the country has been telescoped into a few decades compared to over a century in the UK.

Yet poverty and inequality still exist in rural areas in the north and west particularly. Moreover the spectacular rise in living standards for many has come at a huge cost – nearly all China's rivers and lakes are badly polluted. Air pollution is very bad – when I was in China last year a pollution cloud covered several provinces – an area larger than the UK. Deforestation and the shrinking of arable land go on apace, too. Although a campaign against corruption continues, 60 years of one-Party rule mean that corruption is endemic. Poor people are routinely expelled from their homes by greedy developers and Party officials.

Mao destroyed much of China's ancient culture. But now all the old crafts – painting, calligraphy, Beijing opera and traditional folk music are flourishing. Confucianism, which he hated in particular, has made a spectacular comeback with Confucius' own works receiving the official approval of no less a leader than President Xi Jinping himself. The Party still clings to 'Marxism-Leninism-Mao Zedong Thought' as a thin cloak for rampant capitalism and consumerism, but everywhere ancient beliefs and religions have made a spectacular come-back. Buddhist and Daoist temples are crowded at festivals and have become rich on worshippers' offerings.

More surprisingly, Christianity which has been frowned on as an import of Western imperialism has made sweeping gains. When Mao seized power in 1949 there were 3 million Roman Catholics and 1 million Protestants. Today there are about 12-15 million Catholics and 70-100 million Protestants. China has the largest Bible-printing factory in the world and the explosion of Christian belief has brought renewed persecution in the last 2 years. Islam which has millions of followers in Xinjiang in the north-west is at present being savagely persecuted under the pretext of terrorist prevention: a million or so Muslim Uygurs have been or are currently imprisoned in 're-education' (read: concentration) camps for long periods – about 10% of the Uygur population. While outwardly China thrives in material terms, the regime is increasingly repressive with crack-downs on intellectuals, human-rights lawyers, religious believers and political dissidents and a sinister reliance on state-of-the art surveillance technology to track citizens' every move, as well as draconian censorship of the press and the internet. But through it all Chinese people have learnt to survive and prosper, like bamboo bending in the wind. *Tony*

Brighton Day Out For Visitors



Association Visitors updated their knowledge at Sussex MND Care & Research Network day on Wednesday 6th February 2019.

Association Visitors Sue, Anne, Pru and Sandy attended the event at Brighton University. Rachel Thomson, Sussex MND Care and Research Coordinator assisted by Jane Giles our (RCDA) Regional Care Development Advisor presented the day.



Professor Nigel Leigh, Director of Sussex MND Care & Research Network welcomed everyone. There were 80 delegates including several people with MND, Health Professionals and Volunteers from from West Sussex, East Sussex, and Surrey Branches.

The day covered presentations and discussions on Local Care and future opportunities. Dr Claire Troakes, Brain Bank Coordinator at the London Neurodegenerative Disease Brain Bank gave a talk about how a donation is made and how the tissue is used in research.

After a finger buffet lunch Professor Nigel Leigh and the Sussex network team gave a presentation on Sussex MND Research updates and discussed the next steps. The Professionals gave a talk on 'Education and how and how it impacts on care'.

Rachel concluded a very good informative day with an important appeal for us all to encourage people we visit to complete the MND Register.

Birthday Celebrations

A special celebration was held on Monday, 11th March during the Chichester Support Group meeting at Manor Nurseries. Anne and Kate, who are both committee members in the branch, while Anne is also an Association visitor, were both celebrating significant birthdays during the week, so we took the opportunity to have a cake with our tea and to wish them both a very special week.



Save the Date! Friday 21st June 2019 – time TBC but provisionally 11.00 am to 3.00 pm. Boughton House, Kettering, Northamptonshire.

To mark the Association's 40th Anniversary, and to coincide with Global MND Awareness Day, we are planning a free event for supporters in our local stately home Boughton House (by kind permission of The Duke of Buccleuch).

The house – known as “The English Versailles” – is not often open to the public, and is surrounded by rolling parkland and formal gardens,

including contemporary art installations and the stunning 21st Century Garden. The day will include an opportunity to tour part of the house, visit the gardens, learn more about the Association (past and present), reminisce with our Founders, meet our Chief Executive Sally Light and directors, ask questions of leading MND scientists and researchers, watch interviews with celebrity guests



who support our work... and enjoy entertainment, refreshments and conversation!

Two tickets will be available to each Branch and Group – please see Sandy if you would like to attend. If we have a lot of interest in our 2 tickets we will enter names into a draw.

Professional football and MND – looking at the evidence

Last year professional football players, Len Johnrose and Stephen Darby, announced they'd been diagnosed with MND. This follows previous announcements from other prominent footballers in this country and across the world in recent years. Is it the case that professional football players are more prone to developing MND than the general population? Or is this just the impression created by the high-profile nature of these professionals and the corresponding media coverage these cases bring? What does the science suggest?

A 2007 study looked at the **use of permitted drugs in Italian professional soccer players**. Of the 743 players questioned, nearly 93% reported use of oral anti-inflammatory products in the previous year and most of these were current users. 36% of players reported current use of analgesics and almost 83% reported current use of supplements and vitamins. Therefore, although medicine use has been speculated as a possible cause of MND in footballers it should be remembered that professional athletes from other sports probably use the same compounds. There is therefore still no clear evidence of a specific link between the use of medicinal drugs in football and MND. **Pesticides** A distinctive feature of football players is the continuous contact with grass treated with organophosphates, a common pesticide. This is a potential environmental exposure that links them to farmers, another population group which has an increased risk for MND (**Merwin and colleagues, 2017**). Organophosphates work by damaging an enzyme in the body called acetylcholinesterase, which helps to break down the neurotransmitter acetylcholine, potentially resulting in neurological damage. However, there have been no studies that show a direct link between pesticides and an increased risk of MND among football players, and other professional athletes are equally exposed to grass treated with pesticides.

A **2016 review** by Bozzoni and colleagues, 'Amyotrophic lateral sclerosis and environmental factors', looked at the links between physical activity, football and MND. The authors reviewed several studies, including the two Italian studies (see full article on website), and concluded that the literature would suggest there may be an increased risk of MND in football players, which isn't seen in other sports professionals. There does not seem to be a single risk factor associated with the disease. However, a number of risk factors acting together cannot be ruled out in football players. The researchers also reviewed several studies in which no association between playing football and developing MND could be identified. More studies are needed that use matched groups of professional sports people from different countries, together with control groups, to confirm this suggested association.

MND has already claimed the lives of Tony Hopper (who died in October last year), Jimmy Johnstone, Don Revie and Willie Maddren. Fernando Ricksen is currently living with the disease. There are also many footballers affected by other neurodegenerative conditions such as Alzheimer's Disease, or chronic traumatic encephalopathy (brain damage). The apparent high rate of neurological illnesses found in footballers has spurred on the **FIELD study** (Football's Influence on Lifelong Health and Dementia) which will compare the physical and mental health, including risk of neurodegenerative disease, of approximately 15,000 former professional footballers with the wider population. It is hoped this, along with the work being carried out by the **Drake Foundation** (which aims to improve understanding of concussion in sport and its effects on long-term brain health), will help us understand any association between brain injury and neurodegeneration.

It is clear that more work is needed to understand the causes of MND, the biology of the disease and the interaction between genetics, lifestyle and environment. Only then will we be able to tackle these perceived issues and finally defeat MND.

For more information on this subject please go to the MND Association website and click on Research Blog.

FUNDRAISING



Gruffs Male Voice Choir Concert, Friday 31st May, 2019

A date for your diaries, Friday 31st May. We have provisionally reserved the Hall at Bohunt School Broadwater, Worthing. The Gruffs Male Voice Choir are giving their time free in support of MND West Sussex South Branch to raise money for local people and their families who have been diagnosed with MND. One of the reasons for their generosity is to support a friend who has MND. There will be a tea and coffee bar and maybe even a wine bar. Please see any member of the committee for more information and tickets.



Following on from our successful March bucket collection at Tesco Bognor, Lin has arranged another one. This time at Tesco Chichester for Friday 17th May. If you can spare an hour or so to help Lin, and even better if you have a nice calm dog as well you could bring along, she will be really grateful for your help.

Lin has also registered our branch with Easy Fundraising. Its very simple. All you have to do is go to their website look for Motor Neurone Disease Association West Sussex South and register. Then every time you shop online go to their website first and click on the company you would like to shop with. They get a commission which they turn into a donation. It won't cost you a penny extra.

Raise funds for
Motor Neurone Disease Association West Sussex South

every time you shop online

Find us on easyfundraising to start:
<https://www.easyfundraising.org.uk/causes/mndwss/>

Shop with over 3,500 online stores

amazon.co.uk John Lewis ebay M&S
Argos Booking.com Boden Next
Debenhams GAP Viking Sainsbury's
Screwfix Just Eat Monopkg OSOS

Recycle for the Branch

We are now also able to recycle most ink cartridges the exception being Epsom. So if you have any of these items lying around then please bring them along to any branch meeting or give to any committee member and we will turn them into much needed cash for the branch.

Jewellery

- Unwanted gold and silver including damaged items.
- Costume Jewellery.
- Watches.

Stamps

- Loose / single stamps.
- Albums.
- First Day covers/ presentation packs.
- Collections.
- Postcard collections.

Currencies & Coins

- Banknotes and coins. Any currency UK or foreign of any age. Even outdated / unchangeable currency.

Mobile Phones, Cameras & Gadgets (including broken or damaged)

- Mobile Phones.
- Video cameras.
- Old film cameras, SLR's and lenses.
- Digital cameras.
- Sat Navs.
- Game consoles, games and accessories.
- Ipods.
- MP3 Players.
- Laptops.
- Tablet computers.

NEW—Ink Cartridges (not Epsom)

For Sale



New home wanted for unused, boxed AKW Medi care 4000 Shower Seat - Wall mounted, fold up moulded seat with padded back and arms. Cost £600 will accept £300 ovno. Tel: Sandy 07711 987671



WEST SUSSEX SOUTH ON LINE

www.mndwestsussexsouth.co.uk

Do visit our website. There's a facility to contact us.
If you have a story you would like to put online please
contact Sue at s.krueger@tiscali.co.uk

NEW FREEPHONE NUMBER FOR MND CONNECT

mndconnect
0808 802 6262
mndconnect@mndassociation.org

Email: mndconnect@mndassociation.org

The MND Connect helpline offers advice, practical and emotional support and signposting to other services and agencies. MND Connect is for people living with MND, carers and family members, Health and Social Care professionals and Association staff and volunteers who support people living with MND.

Tel: 0808 802 6262
Mon to Fri 9.00am – 5.00pm.
And 7.00pm to 10.30pm

SUNDAY 28 APRIL

NEW BLUEBELL WALK & LUNCH
The Barn The Dover
Dover Lane Arundel BN18 9PX
Walks start at 10am and 11am
Lunch 12.15—Food by Posh Spuds
Inc vegetarian and vegan options plus
Glass of wine. Tickets £13
(accompanied children under 8 free)

MONDAY 29 APRIL

Refreshments provided

BRANCH AGM MEETING 7PM
With guest speaker Chris James
The Laurels Sheepfold Avenue
Rustington BN16 3SQ

FRIDAY 31 MAY

GRUFFS MALE VOICE CHOIR 7PM
Bohunt School
65a Broadwater Road
Worthing BN14 8AH

Please can you take a moment to visit the *Latest News* page of our website and subscribe to the 'blog' – it is a free service. Simply go to the *Latest News* page and click on 'subscribe to Blog' at the top right (just underneath the 'Contact Us' link), then add your name and email address and that's it – you will receive all our latest news and information when we add it to the website



Rachel is doing a fantastic job tweeting about all our branch news. Please follow her on twitter and catch up with our news as it happens at [@MNDWestSxSouth](https://twitter.com/MNDWestSxSouth)



Find us on:
facebook

The branch Facebook page:
Motor Neurone Disease
West Sussex South

Please let us know via the website if you would prefer to receive your newsletter and/or invitations via email
www.mndwestsussexsouth.co.uk

The Thumbs Up Club First prize at each monthly draw is currently £15, and second prize is £7. There are 26 chances to win in any one year! The more subscriptions, the more money to help the Branch and the more paid out as prize money! To book your chance to win, please speak to Alastair Sharp at any Branch Meeting. Call him on **01903 856397** or e-mail mnda.wss.treasurer@chattan.plus.com

THUMBS UP CLUB
Winning Numbers



XMAS
1st 40 2nd 13
3rd 11 4th 24

JAN
1st 57
2nd 43

FEB
1st 15
2nd 48

WEST SUSSEX SOUTH BRANCH

www.mndwestsussexsouth.co.uk

President: Dr Robert Clifford-Jones **Vice President:** Kate Pottinger

Branch Patrons: Nick Gibb MP Althea Gifford Kay Glendinning MBE

Branch Officers & Committee Members: 2018 - 2019

Joint Chairman: Johanne Stimson 07920 290917 and Sandy Barrett 07711 987611

Secretary: Lin Crompton 01243 781850 Email: lindijb@btinternet.com

Treasurer: Alastair Sharp 01903 856397 Email: mnda.wss.treasurer@chattan.plus.com

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