Mid Kent Matters

motor neurone disease

AUTUMN 2024

DATES FOR YOUR DIARY

Face to Face Support Group Meetings Heart of Kent Hospice : 1st and 3rd Fridays of each month 6th & 20th September; 4th & 18th October; 1st & 15th November; 6th December; 3rd & 17th January

Wisdom Hospice : Every other Wednesday of each month 4th & 18th September; 2nd, 16th & 30th October; 13th & 27th November; 11th December; 8th & 22nd January

> Carers Meetings 1st Monday of alternate months 2nd October; 4th December; 5th February Contact : Sue Copping, s.copping@sky.com

*** SPECIAL EVENT: Family Picnic at Leeds Castle Saturday September 21st 11.00am – 1.00pm Look inside MKM for full details

***REMINDERS: Annual Walk to D'Feet, Sunday Sept. 1st at Shorne Country Park Registration from 9.30am, Contact: Jen Sanders 07726122268

Mid Kent Christmas Bazaar Princes Hall, High Street, Rochester ME1 1LS, Saturday, November, 9.30 – 2.30



PICNIC at LEEDS CASTLE on Saturday 21st September 11.00am



Leeds castle have very generously allowed us to hold our next outdoor Support Group meeting in the castle grounds. For those of you who have not joined us at a previous outdoor meeting, we generally spend an hour or so just chatting and catching up or making new friends. Many people bring a picnic whilst others chose to go off exploring and eating out – the choice is yours! The Castle passes we have been given last for the whole day so you can stay for as long or as little time as you like.

If you are able to join us you will need to park in the main carpark – there are some disabled parking bays but it is pot luck whether you can get one. Then make your way to the reception area for about 11.00am, where one of the branch committee members will meet you and get your pass sorted out.

We will be meeting up on the Rose Lawn which is next to the pavilion but there will be people to guide you to the right place – just look out for the blue tshirts. If you are able to bring a lightweight folding chair that may be useful as seating is limited (except for the grass!) but not if you are going to have to carry it around all day!

For those people with electric wheelchairs or scooters there is a 10 minute walk/drive to the Rose Lawn along the tarmac road but for those able to get on the minibus or little train you can get a lift to a drop off point close to the meeting place.

As this is a Saturday we are hoping that people not usually able to join us on a

week day may be free to come. If you are able to let me or your AV know if you are planning to join us that would be helpful as we can make sure we reserve a big enough meeting place. If you need any additional information please don't hesitate to contact me or your AV.

I have requested good weather but if that isn't granted, and the weather is poor we will have to cancel as there is no shelter available.

If you are in any doubt about the weather, contact me on 07746623292, Sheila on 07787191920 or Dave on 07798723848.

Looking forward to seeing you. Annette

DECEMBER AFTERNOON TEA Saturday 7th December 2 - 4pm



We have arranged a special Christmas Afternoon Tea in The Cornwallis Suite at Maidstone Masonic Centre, Off Courtney Road, Maidstone ME15 6LF on Saturday 7th December. This is open to all branch members and it's great to see old and new friends. As we have to provide numbers to the caterers please let me know by 18th November if you would able ioin are to us. Annette.scott4@btinternet.com 01622 820719

TREASURER'S REPORT

Well the summer is almost over and it seems everyone has been busy fitting in lots of different fundraising and social activities. I know a couple of our brave supporters have completed Wing Walks at Headcorn Aerodrome this summer...whilst I have instead preferred to keep both feet on the ground by running 60 miles in August for MND! However you have been fundraising this summer, selling books, sponsored walks, quizzes, summer fairs or garden tea parties...thank you for your continued support.

Alongside all the wonderful fundraising events we have also received in memoriam. tribute and legacy donations totalling £92485 during the last three months, with £90000 of this coming from a legacy specifically left to our branch so that we may continue to support people affected by MND in the Mid Kent area. We are most grateful for these donations and legacies and would like to use this platform to thank the donors, families and friends for their generous gifts to help us continue our commitment to help people with and affected by Motor Neurone Disease.

Over the last few months our branch fundraising and third party fundraising events have all been very well supported and helped us to raise almost £5000 as well as raising awareness for MND too. We have received over £500 from corporate donations and another £500 from gift aid claims since my last report; if you are able to gift aid your donations we are most grateful. Thank you also to the committee members for their hard work and to everyone who helps organise, run and support fundraising events for Mid Kent. In total our income so far this year is £118725!

Our thanks go to Sturdee Bowls Club, Linda and her Ladies Group, Eden for his Treadmill Challenge, Smarden Community Store, Lin and Lynne (not me another Lynne!) for their Hadrian's Wall Walk, Leftovercurrency for the exchange of our foreign coins, General Gordon Masonic Lodge, Leybourne Scout Group, Woodham Cards & Gifts, Leybourne Convenience Stores, Allison Thompson for her marathon

fundraising, Post Office Maidstone and everyone who has donated in memory of Rob Burrow. We also thank the fabulous committee members for the raffles at the AGM/afternoon tea and Aylesford Priory, book sales,100 club, quiz sheets and plant sales and of course to everyone for your support and general donations. Special thanks to those who donate regularly via standing order and thanks also go to everyone who uses Easyfundraising and who Gift Aid their donations.

Over the last few months, we have spent £10533 to support people affected by MND. Our care costs have included quality of life grants, carers grants and therapies for people with MND and their carers. We have made contributions towards the installation and rental of stairlifts and ramps, helped with the costs of wheelchairs, home adaptations and handrails and covered the costs of repairs, deliveries and collections of equipment. In addition, we continue to cover the costs of the MND Support Groups at both the Heart of Kent and Wisdom hospices.

Thank you to everyone who has continued to support us with online donations via our justgiving and tribute pages, by standing orders or bank transfers direct to our account. Please get in touch if you wish to gift aid any donations that are made directly to our account, we receive an extra 25p for every £1 donated via gift aid which really does make a difference to our funds. We commit to using every penny raised to support others diagnosed with MND so no one feels alone. Your donations will help us to continue to provide support to people with MND. Lynne Eldred

CAMPAIGNS & FUNDRAISING UPDATE

FUNDRAISING

Lynne and I have completed and submitted the Tesco application and we've got a couple of other ideas between us that we're looking at. who did the Sarah. sianina at Rochester Cathedral and had her head shaved, is keen to do another fundraiser for the Kent Branches and Groups. Her current idea is to climb the rigging of the Cutty Sark, (ooh! That'll make some lovely photos! Jean) and Alison from NW Kent will probably be joining her. We haven't looked into it in detail yet but if anyone else wants to give it a go, get in touch!

CAMPAIGNS

This is likely to be my last Campaigns Update. I'm taking a step back from formal campaigning, as I'd like to focus on local issues and links rather than committing time to wider, national campaigns. We made some useful contacts at the Roundtable and I think it's more important to pursue these, with help from all of you, obviously. I'll still be part of the circulation list for campaigns and will keep an eye out for anything relevant or useful to Mid-Kent that comes out from the Policy and Campaigns Team, but I won't be part of the "official" network.

MND GUARANTEE

Thanks to all of those who contacted their candidates – nationally, around 500 pledged to support people living with MND. Of these, 85 were elected. We have several new MPs in the Mid-Kent area and although I don't yet know which ones signed the Guarantee, it is certainly worth approaching any or all of them to establish contact. It can just be a quick email to introduce yourself and the work of the Branch, and it would also be useful to invite them to one of the Support Groups. If anyone is interested in arranging a face-to-face surgery meeting with their MP, I'm happy to help with this, so just let me know.

STATISTICS

A while ago, I asked the P&C Team if they had numbers of plwMND by constituency (which would be useful to know when contacting MPs), but due to the recent boundary changes they can't supply this at the moment. However, they did provide these statistics by postcode:

BR - 26 CT - 36 DA - 35 ME - 56 TN - 46

Elaine Coates

A FLOCK OF BIRDS

Ornithologists have this Hobby Of looking for that little brown jobby They also like those birds of prev Like Hawks and Owls as well as Osprey. John Townsend

This has been one of the most popular guizzes for a long time - there are obviously a lot of keen ornithologists on my list! The answers are:-

- 1. Albatross
- 2. Dove
- 3. Heron
- 4. Herring gull
- 5. Curlew
- 6. Osprev
- 7. Pheasant
- 8. Owl
- 9. Wren
- 10. Sparrow
- 11.Swift
- 12.Ruff
- 13. Eagle
- 14. Dipper
- 15.Jay
- 16. Hobby
- 17.Merlin
- 18. Kingfisher
- 19. Chaffinch
- 20. Plover
- 21.Knot
- 22. Robin
- 23. Shaq
- 24. Lapwing
- 25. Partridge
- 26. Grouse
- 27. Nightingale
- 28. Hooded crow
- 29. Turnstone
- 30. Spoonbill
- 31.Kestrel
- 32. Stork
- 33. Goldcrest
- 34. Gannet
- 35. Capercaillie 36. Buzzard
- 37. Cuckoo 38. Kittiwake
- 39. Fieldfare
- 40. Skua

- 41. Starling
- 42.Tern
- 43. Woodpecker
- 44. Bustard
- 45. Cormorant
- 46. Nuthatch
- 47. Puffin
- 48. Swan
- 49. Sparrow hawk
- 50. Snipe
- 51.Rook
- 52. Pigeon
- 53. Blackbird
- 54. Marsh Harrier
- 55. Barnacle goose

I am writing this before the closing date, but there have already been more than 10 sheets with every answer the same as mine. After September 14th I will gather them all up into a mistnet and pull out the winner.

The next sheet is Rivers of the World, so be prepared for some intellectual flooding! Jean

100 CLUB RESULTS



JUNE	-	
1 st	85	L. Jones
2 nd	65	Barbara Brown
JULY	,	
1 st	63	Michael Barber
2 nd	79	Wendy Gardner
AUG	UST	
1 ST	25	Alison Leigh
2 nd	110	Karen Taylor

IL IN IT

Please remember - if you wish to continue having the chance to win some prize money, you need to send Sue Copping your renewal subscription - which has not risen and is still £25 for the whole year.

Ring Sue on 01634 815467 or email on s.copping@sky.com for further details.

MND GLOBAL AWARENESS DAY IN CANTERBURY



They made it happen!

They entertained!

Well it all came together on the day! The Roundtable in the afternoon was very successful and well-attended. Representatives from most of the clinical/professional disciplines involved in the care and support of people in Kent & Medway living with MND were there. Tanya Curry (CEO), Usman Khan (Chair) attended, as did Charlotte Roy from the Research Team. Charlotte gave a brief overview of current research progress and there were also a number of other speakers who shared their experiences. In particular, Sam Hayden-Harler and David Grzywacz spoke movingly and passionately about their experiences of living with MND, whilst Katy Styles provided the carers' perspective. The structured table discussions were very productive with valuable links being forged and we hope these can be built on for the future. We're compiling a report on the Roundtable for circulation to those who attended (and some who didn't) – if you'd like to see a copy please contact <u>elaine.coates@mndassociation.org</u>

The concert in the evening by the Canterbury and Bexleyheath Rock Choirs was an uplifting and joyous end to the day – the audience was certainly appreciative! We also raised over £470 from a bucket collection afterwards.



It really was a ROUND TABLE discussion!

PROFITABLE AND HAPPY BIRTHDAY CELEBRATIONS



Marilyn presented her cheque at a Wisdom Hospice Support Group Meeting

Marilyn Milligan was diagnosed with MND in 2020, and did not think she would live to see 70. But as the 1st of February 2024 loomed closer, she decided to have a party to celebrate. The Bridgewood Manor Hotel was the chosen venue and a room was booked for the 4th February. Being non-verbal, she used her eye-gaze machine to contact those who she wanted to see at her party, and she also let them know that no presents were needed, but that she would appreciate donations to the local MND Mid Kent branch.

On the day, there were guests who she had been in the RAF with 53 years ago, workplace colleagues from BT and Royal Mail, as well as members of the bowls club and walking groups she had been involved with. There were guests from the local area, Scotland, Spain, Stockport and her cousin from Sandwich – that is Sandwich in Cape Cod, USA, not Thanet! And her family, of course, who have been very supportive. Thank you, Nigel and Julie, god daughter Sophie, who brought her band "Alright on the night" and god son Dan, who organised background music using Marilyn's play list.

With music, dancing and an excellent buffet, everyone enjoyed the day and by them giving generously, Marilyn raised £1500 for the local branch and she presented the proceeds to the branch at a Wednesday Support Group meeting.

Allan Milligan

A TRIP DOWN THE RIVER MEDWAY – JULY 2024



How lucky were we? In spite of everyone having a weather App forecasting rain, we enjoyed a lovely sunny day. At last we made the trip south, down through Teston and Farleigh locks and into Maidstone which was a very different and interesting trip. We were again lucky enough to get sightings of two kingfishers and also a cormorant. As always a delicious picnic lunch was enjoyed by all. A special mention must go to Lincoln, Peter's grandson who safely helped us through the locks. Annette



...JUST ONE DAY LATER

SOME OF US WEREN'T SO LUCKY!

Joyce and I spent a showery morning selling and singing in the rain at a Borstal Table-Top Sale. However, thanks to some super healthy and floriferous plants we managed to reach three figures and several Borstal inhabitants went home wet but happy and with something to plant when the rain stopped!

FOOT TAPPING AND HAND CLAPPING ENTERTAINMENT



Thank you so much to Sarah Starkey for an amazing concert at the Heart of Kent Support Day. Sarah sang so many hits from the 60's and 70's and as you can guess we remembered them all! It was a super start to our Friday Support Day and we look forward to a repeat at Christmas.



TONGUES BEING EXERCISED AT WISDOM SUPPORT GROUP



The noise level is amazing!

TRAVELLING IN STYLE or Useful Information learned at HoK Support Group meeting



Derrick gives a double thumbs up – it must have been good!

This was the first time we had tried Assisted Travel at the airport and Derrick was a bit apprehensive but we were very impressed and would **definitely recommend** anyone with health or mobility issues to use the facility. When we arrived at Departures at Gatwick we had to ring a number and a member of staff brought a wheelchair for Derrick which took us straight through assisted fast track where they booked our cases in and then took him by wheelchair through to the Assisted Travel Lounge in Departures. We were given a buzzer to inform us when we would be picked up by a buggy which would take us to the departure gate and from there, straight to the plane. All the staff were so pleasant and helpful. It was the same on the return we would definitely use it again as it took all the stress out of travelling.

Sitting beside Derrick is another member of the family group, who has a pace-maker and that meant that on this occasion, she wasn't held up at Security. Sandra Tobin **TO FIND OUT MORE PUT "ASSISTED TRAVEL" INTO YOUR SEARCH ENGINE OF CHOICE**





Another glorious sunny day for an Aylesford picnic The baking was up to the usual high standard and the ices were cool as usual!

HORTICULTURAL THERAPY AT THE WISDOM SUPPORT GROUP



Laura's gloves gave them blue fingers, but they gave her their full attention.

Laura Daniels came to the Support Group meeting at the Wisdom Hospice with rosemary, sage, lavender and mint. She had come to show us how to take cuttings for free. Every one squeezed the leaves and the room was filled with wonderful scents which made for a happy hour before lunch.

Laura carried us along with her enthusiasm and confidence and soon everyone was at work. We mixed cutting compost with grit –all wearing gloves- filled the pots with the chosen cuttings and put them into a paper bag to take home to be nurtured. I am sure the successes will be reported – and there may even be photographic evidence in the next MKM!

No pressure though - Remember even Monty Don doesn't get every cutting to root!



Some end products

A STROLL! ALONG HADRIAN'S WALL



At the end of May we walked the Hadrian's Wall path over six days to raise money for MND. Walking west to east, our first day began with a sunny morning at Bowness-On-Solway where we had magnificent views across the water to Scotland. We continued our walk following the wall, passing through many villages and stopping at tea rooms (even playing afternoon bingo in one!). The rugged and remote middle section was a tough two days with many steep climbs, but we were rewarded with spectacular 360-degree views. It would be true to say that the end point of Wallsend was a very welcome sight on Day 6, but the next day we continued walking on to Tynemouth and completed the coast-to-coast walk! We walked 104 miles in total, met lots of lovely and very generous people along the way, were very lucky with the weather, had a real adventure AND came home with a suntan!

Lin Barnes and Lynne Spear



Lynne and Lin with some of Newcastle's many bridges behind them

WING WALKS ARE ALL THE RAGE



On Monday 12th August, on the hottest day of the year, a small group of us met up at Headcorn Aerodrome to witness Jane Judd go off on one of her bucket list "Before I am 70" activities." And I can testify that she was smiling when she went off and still smiling when she got back - I thought it looked horrendous! Thank you to Jane and all her family and friends who raised over £1000 for Mid Kent branch.

A week earlier on August 4th,

Natasha Rayner also did a wing walk at Headcorn Airfield and she said "Five years ago, after a long struggle with MND, my uncle Stanley Campbell died. During his illness your charity were a great help and support to both my uncle and aunt. Stanley was a great character, loved by all his family. I thought we could do something in his memory hence the "Wing Walk" sponsorship. We hope that the £1275 raised will go some way towards helping other MND patients as you helped my family," Her Mum and aunt Geraldine, and young family members brought photos of Stan to watch her land safely.





ALLI THOMPSON'S MARATHON PROGRESS

Alli's training is progressing well and, along the way, she is continuing to fundraise for the Mid-Kent Branch and East Kent Group. Recently she held an "Open House" providing a tasty lunch of soup and savouries, as well as tea, coffee and cakes. Several people from Doddington and around came along, including members of "Lowering the Tone", the local sea shanty men's singing group, who can be seen in the photo tucking into soup and sausage rolls!



On August 3rd it was the village Ukefest where Alli not only performed, but also found time to sell some books. She is the one in the middle with fair hair and sunglasses and her son and daughter-in-law are also in the group. During the afternoon Alli's friend, Sue, on whose behalf she's been doing all this, sadly died at the Pilgrim's Hospice in Canterbury, but I know she would have been delighted to know that £265 was raised on that day alone. This will be added to the £1250 (plus Gift Aid) on Alli's Justgiving page.



WAYS TO DONATE TO MNDA MID KENT BRANCH

JustGiving - you can donate via our JustGiving page <u>https://www.justgiving.com/fundraising/mid-kent-branch-emergency-appeal</u>

Bank Transfer – Please contact our Treasurer for further information lynne.eldred@mndassociation.org

Standing Order –. Please contact our Treasurer for further information <u>lynne.eldred@mndassociation.org</u> Please add something to the reference if you wish this to be a general donation or in memory of someone. If you wish to gift aid your donation, please complete the form (link below) and email to our treasurer

Gift Aid – if you wish to gift aid any donation please complete the form (see the link below or contact our treasurer for a form) and email to our treasurer <u>lynne.eldred@mndassociation.org</u> https://www.mndassociation.org/sites/default/files/2023-01/mnda-gift-aid-form_0.pdf

Easyfundraising - This is an excellent way to raise funds for the Branch, every time you shop online, without it costing you a single penny more. Simply <u>register on</u> the Easyfundraising website <u>Motor Neurone Disease - Mid Kent Branch</u> <u>Fundraising | Easyfundraising</u> and remember to shop via the website and you can earn funds for the Branch.

Text - you can donate via text message - you can donate £5 by texting MND4MIDKENT to 70085 (costs £5 plus one standard rate message). £5 is the Default value for the text but if you wish to donate more, simply add that value after MND4MIDKENT (eg MND4MIDKENT 10 to donate £10)

Old Coins- we can exchange your old British coins or foreign currencies (notes and coins). Just pass them on to our treasurer or any committee member or you can choose our charity at leftovercurrency.com <u>Leftover Currency - Donations to MNDA</u> <u>Mid Kent Branch</u>

USEFUL INFORMATION

Motor Neurone Disease (MND) is the name given to a group of related, but widely varying, diseases affecting the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells that control muscles; hence their degeneration causes weakness and muscle wasting.

MND is usually regarded as progressive but the rate of progression varies greatly from person to person and between the three main types of disease. In the UK it is believed that there are about 6,000 people suffering from MND at any one time.

WE MAY BE ABLE TO HELP YOU! BEFORE YOU SPEND MONEY ON A PIECE OF EQUIPMENT, CHECK WITH THE APPROPRIATE PROFESSIONAL. IF IT IS SOMETHING THEY DO NOT PROVIDE, SPEAK TO YOUR ASSOCIATION VISITOR or ANNETTE SCOTT.

> Mid Kent Branch covers the ME postcode area except ME13, and includes DA11-13 Mid Kent MNDA website (details TBC)

BRANCH OFFICERS

PRESIDENT: Professor David Oliver VICE PRESIDENT: Mr Colin Thompson, <u>colinwthompson@btopenworld.com</u> CHAIRMAN : Miss Annette Scott, <u>annette.scott4@btinternet.com</u> SECRETARY : Mrs Joan Simpson, <u>joansimpson@ic24.net</u> TREASURER : Mrs Lynne Eldred, <u>lynne.eldred@mndassociation.org</u>

CAMPAIGNS : Mrs Elaine Coates, <u>elaine.coates@mndassociation.org</u> LOCAL CONTACT : Mrs Joan Simpson, <u>joansimpson@ic24.net</u> FUND RAISING : DIGITAL SUPPORT: Mr David Smart, <u>david.smart@mndassociation.org</u> MKM : Miss Jean Lear, <u>jeanlear@btinternet.com</u> MND Specialist Nurses : Maria Marshall <u>m.marshall22@nhs.net</u> Kelly Chubb <u>kelly.chubb1@nhs.net</u> AREA SUPPORT CO-ORDINATOR : Sarah Smith 01604 800651 sarah.smith1@mndassociation.org



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease