Mid Kent Matters

motor neurone disease

Spring 2025

DATES FOR YOUR DIARY

Support Group Meetings

Heart of Kent Hospice : 1st and 3rd Fridays in each month 3rd & 17th January; 7th & 21st February; 7th & 21st March; 4th & ?? April; 9th & 23rd May, 6th & 20th June

Wisdom Hospice : Every other Wednesday of each month 8th & 22nd January; 5th & 19th February; 5th & 19th March; 16th & 30th April; 14th & 28th May; 11th & 25th June

OPEN SUPPORT MEETINGS

Saturday 18th January 2025 and Saturday 22nd March, 2pm – 4pm Wisdom Hospice Therapy Centre, High Bank, Rochester ME1 2NU See inside for more details

Carers Meetings

1st Monday of alternate months **Monday 3rd February, 7th April and 2nd June** Contact Sue Copping <u>s.copping@sky.com</u> for full details and to be included on mailing list.

FUTURE LOCAL EVENTS

Quiz Evening with Shaun Wallace – Saturday 26th April Booking essential –Ring Joan on 01634 686685 or 07930675991 Branch Meeting and Afternoon Tea 17th May, Bower Grove School. Annual walk to D'Feet, Sunday 7th September, 10am

Contact Jen Sanders 07726122268

Christmas Bazaar : 22nd November, Princes Hall, Rochester Medway Neuro Tech Fair –Stalls and Speakers, 4th September, Pilkington Building (UKC) 48 North Road Chatham ME4 4EL

More details later



FROM THE CHAIR



I do hope everyone has had a lovely Christmas and my very best wishes for 2025.

A huge thank you to so many of you who have supported the branch over the last year whether through volunteering, fundraising, attending meetings or just sharing your friendship – 2024 was a good year for us and between us we have achieved so much.

As you will see from the diary and the Branch Information Card which is enclosed with this newsletter we have plenty of activities planned for the coming year and hopefully we will get to meet every one of you at some stage in 2025. If there is anything that you would like to do or something that we could put on that would be of interest to you please don't hesitate to let one of us know.

For people that have more recently joined the branch, please do not purchase any equipment without checking with one of us first – we have a lot of items donated and we would much prefer them to be helping someone rather than sitting in a store.

As I write this the wind is howling outside and the rain is lashing down – but the good news is that Spring is on the way! My best wishes to everyone for 2025 Annette

RECOMMENCEMENT OF "OPEN MEETINGS" IN THE NEW YEAR

We are grateful to the Wisdom Hospice for a venue to offer once again in addition to regular support meetings an Open meeting to support both those living with MND and their family members and carers. They will be held on a Saturday afternoon so that that those unable to attend a weekday session have an opportunity to come along and meet us. We plan to hold the meetings once every two months and the inaugural one will be on **Saturday 18th January 2025 2pm - 4pm**, with a second booked for Saturday March 22nd. Hopefully when the weather allows over the Spring and Summer period we will be able to gather at outdoor venues such as Leeds Castle, or Aylesford Priory.

Meanwhile the initial meetings, subject to response, will be held at the **Therapy Centre, Wisdom Hospice, High Bank (off St Williams Way) Rochester ME1 2NU.** Please come along and join us for friendship, support and information over a cuppa and cake. We look forward to seeing you in January. Sheila

TREASURERS REPORT



Welcome to 2025

With a big **Thank You** to everyone for supporting Mid Kent MNDA in 2024. The start of a new year gives us the chance to look back and see how much we have achieved in the last 12 months. December 31st is the end of our financial year, so I am pleased to give you a full summary of the past year. We were most grateful to receive a generous legacy in August and this together with other generous donations and endless fundraising, meant that we raised £65000 more than we did in 2023! A fantastic achievement and at every fundraising and social event we have helped raise awareness of MND too! This boost to our income has provided much needed reserves which we may draw upon to support the costs

of providing our specialist nurses in the future. Our expenditure, at £87750 was almost £15000 more than in the previous year, and helped us support people affected by Motor Neurone Disease with the provision of equipment, therapies, quality of life grants and much needed social support. I want to take the opportunity to say how lovely it was to see so many people at the Christmas Bazaar in November and meet with new people at the Christmas Social event in December, these events make the role of treasurer all the more rewarding. I also want to thank the committee for their support in 2024 and also Wendy who stood in as treasurer whilst I enjoyed a lovely cruise in November! Now to the figures!

During 2024 our general and "in Memoriam" donations were £11350 and from fundraising events we raised a fantastic £27509! We have gratefully £8358 received from corporate donations, and grants of £2000 to support people in the cost of living crisis, and to help cover costs of the Support Group days. (As already mentioned) we received a wonderful legacy of £90000 in August, which will be used to help cover the costs of providing the specialist nurses and the Support Group days; our total income for the year was a fabulous £146329!

Our thanks go to :- Jane Judd and Tasha for their Wing Walks, Sheerness Freemasons, Beryl Wilson and Friends (afternoon Tea), Time Savers Drycleaners, Dave Sheridan and Jennifer Saunders for the Brenda Sheridan Walk to D'Feet. General Gordon Masonic Lodge, Sturdee Gillingham Bowls Club, Woodham Cards and Gifts, Rachel Fuller, Lynne for the 60 mile run in August, Aiden O'Reilly, Mr & Mrs Nichols, Annette's brother for the Ashford Cattle Market sale proceeds, Lois for book sales, Leybourne Convenience Stores, WH

Smiths Post Office Maidstone, The estate of Tony Tracey, Leybourne Convenience Stores. The fabulous committee members for the Newington Fete, Doddington Fete, Ryarsh Xmas fete, raffles and Christmas Bazaar, Annette & co for book sales, Jean for quiz sheets, Joyce for Plant sales, Sue for 100 Club, and of course to everyone for your support and general donations. Special thanks to those who donate regularly via standing order, use Easyfundraising for their online purchases, and thanks also go to everyone who has gift aided their donations, we raised £1750 through Gift aid in 2024! Over the course of the year, we have

spent £63063 to support people affected by MND; £42176 of which has been on care, and £20886 on Our equipment. 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 installations and rental of stairlifts, ramps and Bio Bidets. We have purchased wheelchairs, handrails, radar keys, a suction unit. robotic Neater Eater and helped with the cost of a power-chair, hoist, electric chair and various home From the adaptations. Maidstone Borough Council Grant we have supported people with grants to help with some of the increases in household bills. We have also covered the annual clean, maintenance and repair costs, delivery and collection of equipment. In addition, we continue to cover the costs of the MND support days at both the Heart of Kent Hospice and Wisdom Hospice.

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. As always we commit to using every penny raised or donated, to support others diagnosed with MND. Your donations will help us to continue to provide support to people with MND. Lynne

AN UPDATE FROM ONE OF OUR SPECIALIST MND NURSES

Hello Everyone, My name is Maria Marshall and I am the Motor Neurone Disease (MND) Specialist Care Coordinator for the Maidstone area.

My post began in August 2023 and I am based at The Coxheath Clinic in Coxheath. where I live with the Community Neuro Rehab Team (CNRT)! I am lucky enough to work with these fantastic therapists, and I am sure many of you are familiar with some members of this team such as the Physio's, Occupational Therapists, Speech and Language Therapists and Therapy Assistants.

I am also supported by the MNDA Mid Kent Branch, who also generously fund any study days and conferences that you may benefit from my attendance at. Our local branch is very passionate, pro- active and knowledgeable so please do not hesitate to ask myself or them any questions or queries no matter how small, we would love to help.

My role is to provide person centred care, to be a single point of contact and to coordinate with the multi professional teams associated with people living with MND both locally and in specialist centres such as Kings College Hospital, London. To provide referrals and liaison along a recognised Care Pathway for MND. This includes the MNDA locally and nationally, CNRT, community nurses, local and regional hospitals, Kent Social Services, and GP's. I attend The Heart of Kent Hospice for the Maidstone area MND support group on the first and third Friday of every month between 10am and 2pm. I am available there during these times in a drop-in clinic for people living with MND, and carers and family.

The role is varied, with home visits, visiting people with MND and liaising with ward staff when they are in hospital if necessary, providing educational support to Health Professionals and attending meetings.

People living with MND are discussed at a Multi-Disciplinary Team meeting every two months which I chair, and at a CNRT Clinical Meeting once a month which I attend. This is to make sure we are delivering a high standard of support and ensuring Best Practice.

The MNDA nationally produce and facilitate a vast amount of excellent training and resources and I recently attended the annual St Christopher's Hospice and Kings College Hospital MND Conference. The speakers were able to update us on the latest developments. It was excellent.

I am very proud to be your Coordinator for the Maidstone area, and thank you all for making me feel so welcome and embraced.

Please do not hesitate to contact me for anything specific or just for a catch up! My contact details are: mobile 07816 088666, email <u>m.marshall22@nhs.net</u>, CNRT office: 0300 123 4145

TESCO BLUE TOKENS SCHEME

The Tesco Blue Token scheme is running in Lunsford Park Tesco and Tesco Express in the Esso Garage Larkfield and we are up against "Space to be me" and a school Neurodiversity Project. I have shared on my personal Facebook account. Please share this information far and wide and encourage people to pop their Blue tokens in the MNDA slot! EXTENDED SUPPORT GROUP & PICNIC AT LEEDS CASTLE



On a glorious Saturday in late September we had a picnic in the grounds of Leeds Castle. We settled in large groups on the cricket field, and taking care to watch out for loose balls, set up the deck chairs and got sociable. As well as enjoying our own picnics, a lot of sampling and sharing went on – Bob's scrummy cheese bics and other delicacies were passed around for all to enjoy. Ideas and experiences were exchanged – AND we've booked **June 21**st in 2025,

Which happens to be MND Awareness Day! THANK YOU LEEDS CASTLE





FORTY YEARS OF THE WISDOM HOSPICE

The Wisdom Hospice celebrated its 40th Anniversary in October and to mark the event, they held a Thanksgiving Service which included a Recognition Awards Ceremony.

Our Support Group volunteer, Pat Cameron received one of these awards for her continuing and dedicated service to the care of patients at the Wisdom Hospice, both as a professional at the Wisdom and after retirement as a loyal volunteer for the Hospice and especially latterly for those affected by MND at our regular Support Group sessions. Congratulations from us all Pat, on this well-deserved recognition for your years of service.



Concentration - and collaboration as Pat gives us some brain teasers at a recent meeting ...



And the answers are ...

WALK TO D'FEET MND 2024





I just wanted to say thank you so much for you time and support on Sunday - wasn't it good!! The books were so popular and we smashed last years amount.

We appreciate it so much and the books were such a success! We are still counting donations but since Sunday we have had a bit more come through so I have asked Lynne to give us a final count over the next day or so.

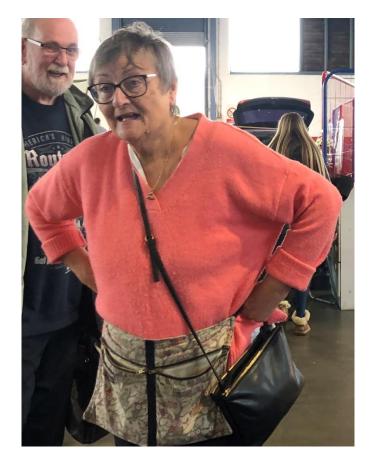
We are already planning next year! Sunday 7th September - registration from 10am same place. Brilliant result – Well Done Team Brenda!

Jen

ASHFORD MARKET STALL IS GENEROUS ONCE AGAIN



Joyce and I were happy to make our regular biannual trip to Ashford Market in late September to collect one of their generous cheques from Ray Scott. I will never cease to be amazed at the source of their income – at the end of each market day, they accept any left-over goods from stall holders, and the lady below and her helpers sorts and checks them all ready for resale at the next market. In this way they are able to present cheques worth a total of £20,000 to a range of charities every other year.



WISDOM HOSPICE SUPPORT GROUP CHRISTMAS MEETING





Teresa Murray (Deputy Leader of Medway Council) talking to David and some of our patients at Wisdom Support Group Christmas meeting

Cllr Murray has always been very approachable and interested in what we do and spoke for us some years ago when Medway Council adopted the MND charter. When I met her at an event sometime last year, I invited her along to meet us at a Support Group which she was pleased to accept. During her visit she made a point of speaking with all patients and volunteers. She even brought us a box of sweets which we put into our raffle!

After the meeting I received positive feedback from our members about her visit in that those who met Teresa felt she had a genuine interest and is supportive to needs of people with MND making them feel confident that they can contact her on any issues they encounter. Sheila

CHRISTMAS TEA 2025



My apologies for decapitating you Sam (can't get the staff!), especially as it also truncated your matching family Christmas jumper. I heard from someone who sat at this table that they enjoyed hearing about your experience helping the actors in "Coronation Street" get a better understanding of MND.



Another chatty scene from our Christmas Tea at the Masonic Hall in Maidstone. As well as exercising our tongues, we enjoyed a raffle, bought some last minute MND Christmas cards, exercised our brains with some light quizzing and enjoyed a variety of savouries and cakes with a cup of tea!

CHRISTMAS SING-ALONG



We were so lucky to be able to welcome Sarah back to the Maidstone December Support Group session. She certainly helped us to catch some Christmas Spirit as we sang along with her.



PRESENTATION AT HOKSG

Andrew, Anne, and Paul joined Linda and Terry at a recent HoK Support Group meeting when Molly presented Mid Kent with a cheque in memory of her husband Brian.

BEST DECORATED CHRISTMAS TREE AT HEADCORN



Headcorn church challenged its friends to decorate Christmas Trees in their churchyard and Pete Hills and his family took up the challenge. They decorated their tree with MNDA colours. Pete, Pauline and friends went to look at it – Pete's blue scooter is a good colour match too – but unless you go to our webpage, you'll have to take my word for that! I hope he didn't have to leave it there all the time!



SOME SCENES FROM OUR 2024 CHRISTMAS BAZAAR Another successful, if exhausting Day under the Clock!



FC and Douglas Hamandishe, Deputy Mayor of Medway, who talked to customers and stall holders and has expressed an interest in attending a future Support Group Meeting.



Who could resist this array of home baking? Well done to Dorinda and all her bakers



I think Sue and Amy got a sale out of this lady

RIVERS OF THE WORLD



John wrote "Is "Orinoco" forty four? That lovely Womble I adore I'm sure he's grey, I think he's fat But as for greasy –was he that?" John T And I replied Oh No –no no that's not so The answer is Kipling's Lim-po-po!

This has proved a popular quiz topic – it would certainly have been good for armchair travel. Sixty sheets have been returned so far and the answers are:-

- 1. Exe
- 2. Medway
- 3. Thames
- 4. Avon
- 5. Test
- 6. Tyne
- 7. Swale
- 8. Severn
- 9. Wear
- 10. Orwell
- 11. Forth
- 12. Tees
- 13. Cam
- 14. Trent
- 15. Ouse
- 16. Dee
- 17. Clyde
- 18. Dart
- 19. Teign
- 20. Mersey
- 21. Wye
- 22. Axe
- 23. Shannon
- 24. Isis
- 25. Derwent
- 26. Humber
- 27. Don
- 28. Yare
- 29. Waveney
- 30. Nene 31. Great Ouse
- 32. Welland
- 33. Tamar
- 34. Usk
- 35. Tweed

36. Liffey 37. Ganges 38. Volga 39. Seine 40. Danube 41. ROAN 42. Yangtse 43. Hudson 44. Limpopo 45. Congo 46. Neisse 47. Rhine 48. Mississipi 49. Amazon 50. Loire 51. Nile 52. Zambesi 53. Moselle

- 54. Oder
- 55. Jordan

Moving on to the next quiz, you will need to match the clues to girls' names, old and new. I have covered this topic before but hope that the answers have been forgotten. Jean

100 CLUB DRAW



Sept 24	1st	97	Anna Richards
	2nd	28	Dave Sheridan
Oct 24	1st	30	Kathy Hales
	2nd	61	Leanne Prettyjohns
Nov 24	1st	69	Grace Pathberiya
	2nd	10	Harry Futrell
Dec 24	1st	58	Karen Lee
	2nd 88		Claire Richards

Sue Copping

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-mnd-association</u>

Bank Transfer – Please contact our Treasurer for further information: <u>lynne.eldred@mndassociation.org</u>

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 in the 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 lynne.eldred@mndassociation.org 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 the Easyfundraising website 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 <u>www.midkentmnda.org</u>

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 : All 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