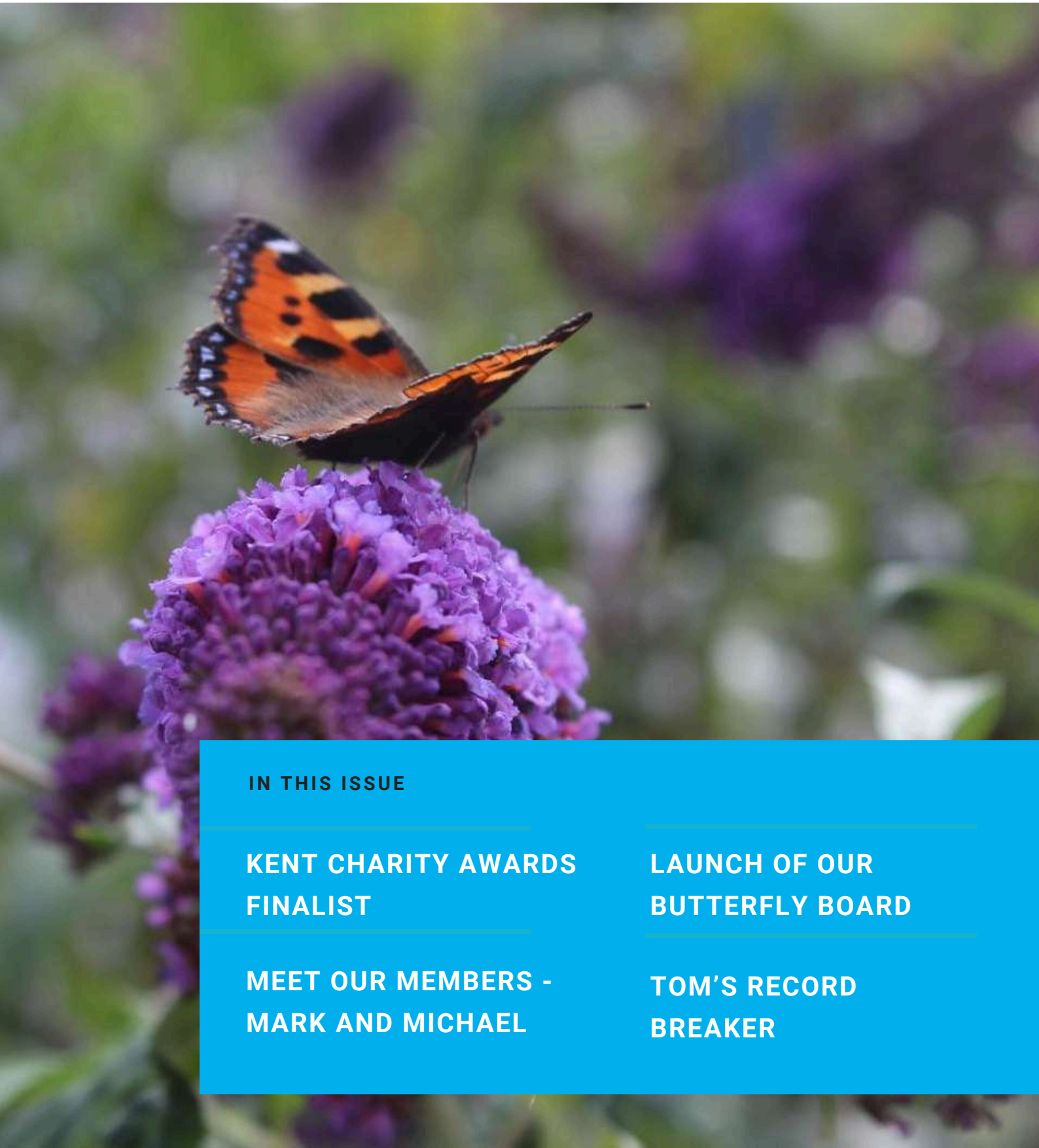
KMSTC | SUMMER 2025

VOL. 14

IN TOUCH

The Kent MS Therapy Centre's Quarterly Newsletter



IN THIS ISSUE

KENT CHARITY AWARDS FINALIST

LAUNCH OF OUR BUTTERFLY BOARD

MEET OUR MEMBERS - MARK AND MICHAEL

TOM'S RECORD BREAKER

Celebrating our community!

I hope this message finds you well and that you've been able to enjoy the beautiful weather when possible. I know that, for some, the heat can be challenging, so I do hope you're managing to stay cool and comfortable.

It's been a jam-packed start to the summer here at KMSTC, as you'll see throughout this newsletter. We've enjoyed a lovely afternoon tea, followed by a hugely successful golf day and our annual summer fayre. Thank you to everyone who supported or attended these events. They mean so much to our community and play a vital role in enabling us to continue providing our services to members.

I'm also delighted to share some exciting news: KMSTC has been shortlisted for the Kent Charity Awards 2025 in the Community Charity of the Year category. Being shortlisted is a fantastic achievement, and we now look forward to September, when the winners will be announced. A heartfelt thank you to everyone who has contributed to the growth of our charity within the community – this recognition is thanks to you.

Sadly, we've also experienced a time of loss in recent months. We've had to say goodbye to several long-standing members of our community: Tony Vera Cruz, Sue Friend, Simon Slinn and Christine McGarrick. Their passing has been deeply felt, and our thoughts are with their families at this time.

With warmest wishes,

Heidi

Chief Executive

We welcomed the Enterprise and Engagement Department from Canterbury Christ Church University for a volunteering day!

In May we held a wonderful gala featuring our members Catherine Futcher and Naomi Honour as well as many local schools.

We are hugely grateful to Kent Construction Consultants who organised to replace our tiles with fresh tarmac and make our entrance safer for all.

KENT CHARITY AWARDS 2025 FINALIST

Thanks to SPAR London Road, Dover and Ashford 5 A Side Darts League for the kind donations.

Incredible effort by the Smith family completing the Yorkshire 3 Peaks in memory of Alida and raising over £2,600!

We had so much support from the local community for our afternoon tea including baking and serving from Leo Lounge in Faversham, strawberries from Tesco Whitstable, cake stands from Butterfly Garden Tea Parties, sponsorship from CSIS and Shadwell and Wright and of course help from our wonderful volunteers!

Fantastic support by the local business community at our Bat and Trap event including Verum Financial, Jenner Constructors and Digital Lookout!

Another super fun evening organised by our wonderful volunteer Debbie for her Stars in their Eyes night.

KENT CHARITY AWARDS 2025 FINALIST

Andy Joyce raised over £300 at his annual car run in June.

We are delighted to be one of Burgess Hodgson's chosen charity partners for this year!

Dan Hyder completed the 3 Peaks Challenge in memory of his dad Martin and raised over £1,000 for our Centre.

Our summer fayre was supported by our wonderful community including Rotary Canterbury Sunrise who donated their time and giant footdarts, so many of our brilliant volunteers who helped and ALE Business Machines for sponsoring the event.

My story with MS

by Mark Barleycorn

Mark Barleycorn was just 26 when he experienced the first signs of something being wrong. While away for the weekend with his wife, he struggled to walk up a bank - an unusual difficulty that led him to visit the doctor upon returning home. There, electrodes were attached to his head, and he received the diagnosis of Multiple Sclerosis. His early symptoms included numbness on his left side and problems walking. Diagnosed with relapsing and remitting MS, his symptoms initially eased within a month or two, allowing him to return to a sense of normality.

At 30, after finally undergoing an MRI scan, the diagnosis was confirmed. The scan revealed the lesions affecting his body. **Steroids helped manage the symptoms during flare-ups**, but over time those episodes began lasting longer.

He has been taking 8000mg a day of evening primrose oil for the last 30 years and credits it with helping his mood and symptoms.

As he moved into his 40s, **Mark found himself struggling with depression**, something he later realised was connected to how he had shelved the diagnosis and not dealt with it emotionally. He began talking therapy, which helped. Still, outside of his close family, he didn't speak openly about his MS. He once visited the Centre when it was still just a shed over the road but he couldn't bring himself to go inside and instead drove away.

Despite the condition, Mark remained active in his working life, **finding roles that allowed for flexibility and understanding**. Over the years, he has worked as a funeral director, with the NHS, and as a salesman - always making sure the job fit around his MS.

A lover of sports, he was encouraged to try

walking football after he retired but found it too physically demanding due to the quick turns, even when playing in goal. Instead, he found peace in gardening, which became a new source of joy.

Mark remained mobile into his 50s, **using a stick to aid with walking**. At this stage, he finally began coming to terms with his diagnosis. His wife had grown tired of him breaking crockery and glasses due to the lack of sensation in his left side! Now living with secondary progressive MS, that side is still usable but numb, and he lacks dexterity, forcing him to adapt to new ways of doing everyday tasks like buttoning clothes.

Mark has also faced challenges with the benefits system. Initially awarded medium banding for PIP, he was denied it four years later, ironically, because he had driven himself to the assessment and got out of his car unaided. Thankfully, he has since regained access to it and continues to value the independence that driving gives him.

After retiring in 2017, Mark felt it was time to revisit the Centre, this time at the recommendation of his NHS Physio.

"Once I walked in the doors, I was greeted by the friendly crew at Reception and instantly felt at home here."

He now regularly attends the Centre, using **oxygen therapy** every three weeks. It helps **regulate his sleep**, something he can feel deteriorating when he's due for another session.

Exercise has become a vital part of his routine. For the past four years, Mark has taken part in classes at the Centre, including **Balance Warrior** on Mondays where he sees **real improvement in his stability** and enjoys the "penguin waddle" exercise. He also does HIIT (high intensity interval training) classes with Vanessa on Fridays.

Family has always been central to Mark's journey. When he had his first MS attack, he had four children, two stepchildren aged twelve and nine and his two daughters were just four and six years old. Unsure how to explain the diagnosis, he and his wife found a children's book about MS, leaving it around the house. Gradually, the girls asked questions and learned about their father's condition.

Now a grandfather, Mark's grandchildren are also beginning to understand MS and the limitations it brings such as not being able to play football with them for long periods. Still, they motivate him to stay active and mobile.

"I count myself as very lucky and have never let my MS hold me back," Mark shares. **"Some days you have to rest and some days you don't. You need to know your limits and adapt."**

You can find out more about our gym classes and physical therapies on our website.

We want to hear from you...

We have introduced a feedback box at the sign-in desk. This provides an opportunity for you to share your thoughts and experiences of KMSTC. You can also give feedback online using our form here. Please do take a moment to engage with this if you can - it's so important for us to know how we're doing and where we can improve.

Neuro physiotherapy at KMSTC

"I have only started coming to the MS Centre recently, but found it very welcoming and friendly. The physios give me good exercises and ideas to help my condition. It's a great asset to the local community."

We offer specialist neurological physiotherapists dedicated to supporting individuals living with a range of neurological conditions. Our experienced physiotherapy team provides thorough initial assessments and creates tailored treatment plans to help members achieve their personal goals.

The Centre is fully equipped with specialist facilities to ensure accessibility for members with mobility needs. We also have a hydrotherapy pool, maintained at a constant temperature of 33°C. This creates an ideal environment for relaxing muscles, improving balance, and allowing greater freedom of movement than is possible on land. We also have a purpose-built gym, specially designed for neurological rehabilitation.

Therapy available to those living with...

Multiple Sclerosis

Physiotherapy plays a vital role in managing MS symptoms. Tailored sessions can help improve balance, posture, strength, and mobility, while also reducing fatigue, stiffness, and muscle spasms. Our team also offers practical advice and strategies to support daily living and promote independence.

Parkinson's

For people with Parkinson's, physiotherapy is essential to maintain independence, prevent falls, manage pain, and improve endurance and cognitive function.

Hydrotherapy is especially beneficial for people with Parkinson's.

Stroke

Recovering from a stroke can be challenging, often leading to weakness, loss of sensation and mobility issues. Our specialist physiotherapy programmes are designed to help stroke survivors regain strength, improve balance and reduce pain and spasticity, supporting a return to independence in daily life.

The above graphic is taken from our 2024 Member Impact Survey, it shows the symptoms that our members have seen an improvement with using the therapies listed.

If you are yet to have a physio assessment at the Centre, please do talk to our team at Reception on 01227 470876.

Tom's record breaking attempt

On 15 June, 26-year-old Tom Mears achieved his goal of becoming the fastest person living with Multiple Sclerosis (MS) to run a half marathon, an extraordinary feat made even more powerful by his deeply personal connection to the condition.

Not only does Tom live with MS himself, but both his sister and father also have the condition, a family occurrence so rare it's almost unheard of.

Diagnosed in his early twenties, Tom's journey began with a numb foot he initially dismissed as a trapped nerve. He was told he had MS in a two minute appointment at his GP Surgery who then followed up months later to discuss treatments and confirm his relapsing remitting diagnosis. The process included a painful lumbar puncture requiring six attempts. He then began Ocrevus treatment and committed himself to staying active.

"Running is one of the only things that eases the heaviness in my legs," says Tom. "When I run, I feel like I'm taking control - not just of the pain, but of the condition itself."

Fatigue, brain fog, and slurred speech are daily challenges, but Tom has found strength in a disciplined training regime, pushing his body further than ever before.

The emotional weight of the challenge is equally intense. Tom's older sister has lived with progressive MS for nearly 20 years, diagnosed as a teenager. His father was only recently diagnosed with relapsing remitting MS.
"We only speak about it positively," says Tom. "This run was for them too. I want people to see that it's not over after diagnosis, far from it. How you care for your body can help make all the difference."

Tom has raised over £1,445 for our Centre with plans to raise more at his next record attempt in October at a Hyrox event. "This charity helped my sister when she was younger, and they've been a big part of our journey as a family," he explains. "It's about giving back, but also about showing people that community and care matter."

Even with an intense training schedule, fatigue can hit him harder than others, and recovery takes longer due to his condition.

Tom's message to others living with MS is simple but powerful: "I firmly believe that exercise and nutrition are some of biggest factors in living with MS. It's a small part that you can play in your own MS journey that could make a massive difference in the long run."

In memorium

As many of you know, we have experienced a time of loss within the KMSTC family in recent months. We've sadly said goodbye to several long-standing members: Tony Vera Cruz, Sue Friend, Simon Slinn and Christine McGarrick. Their passing has been deeply felt by us all and the Centre feels quieter without them. It is always incredibly sad to lose members of our community, and we have all felt their absence.

The families have expressed how grateful they are for the support and kindness shown by the KMSTC community and I want to thank you all for that compassion. We would also like to extend our heartfelt thanks to the families for nominating KMSTC to receive donations in memory of their loved ones and to everyone who has given so generously. Your contributions make a real difference and help ensure we can continue to support others in their journey.

What follows is a reading shared by **Chris Betts** at Tony's funeral. It beautifully captures the experiences many of our members face following an MS diagnosis and reflects the vital role that charities like ours play - not only for those living with long-term health conditions, but for their immediate carers and families too.

> **I work at the Multiple Sclerosis (MS) Therapy Centre as a Therapist, and over the years, I've had the privilege of becoming a close friend to Tony and Kathryn.** I feel truly honoured to be here today to represent the Centre and to speak on behalf of Kathryn as we celebrate and remember Tony - a man who touched so many of us with his quiet strength, resilience, and warmth.

On 24 January 2015, Tony was diagnosed with MS and life changed in ways no-one could have imagined. Tony and Kathryn had been married for just six months, with dreams and plans stretching far into the future. That diagnosis brought everything to a sudden halt. It was a difficult and painful journey - one filled with challenges, change, and constant adaptation. But it was also a journey of unwavering love, deep loyalty, and moments of courage that speak volumes about the kind of man Tony was. Through all the ups and downs, the MS nurse Sylvie was there, walking with them both. Her support has meant a great deal.

MS is a complex and often cruel disease - unpredictable, relentless and deeply impacting, not just the individual but everyone around them. Watching someone you love change in ways you never imagined is heartbreaking, but within that heartbreak, Kathryn and Tony found new ways to hold on to each other, to adapt and to carry on.

Yet, through it all, their journey was not without light. It wasn't all negative. In fact, there were so many blessings along the way. They watched their family blossom. Andrew joined the family, and it brought great joy to see David settled. They were blessed by Emma and Dean with four wonderful grandchildren - Jacob, Poppy, Elsie, and Reginald - each one a source of love and laughter. The wider family grew too, with great-nieces and nephews born, and relatives moving closer, offering incredible support. Every helping hand, every shared moment of care, made a difference.

Tony and Kathryn moved house several times, finally finding their “now home” six years ago. One memory Kathryn holds close is of Tony sitting calmly, watching TV, completely unfazed, as total chaos - a building site - unfolded around him. That image sums up something essential about Tony: steady, centred, taking things as they came.

At the MS Therapy Centre, they found a community. A refuge. A place of understanding, friendship and joy. From their first visit, welcomed by Karen and Geoff, they became part of the Wednesday gang. Tony took part in gym sessions, massage, reflexology and seated yoga.

These therapies helped his symptoms, but the laughter, connection, and companionship were just as important. Kathryn also found support - among carers, those unsung heroes who share so much behind the scenes.

Tony had a way about him - quiet but present, observant and kind. He didn’t seek the spotlight, but his presence made an impact. Without him, the Centre feels different. His table feels empty - but his spirit and the love he shared with Kathryn, remain part of the fabric of the place. Kathryn, our door is always open to you and your family. It is not the same without you.

This past year has brought tremendous heartbreak. But even through those painful months, there were rays of love and light. The grandchildren brought Tony joy with their stories and smiles. David’s practical support - and that unforgettable trip to the dentist - meant so much. Andrew, Tony always enjoyed your stories and hearing about your work. Dean, he asked for you often, and your presence comforted him.

And Emma - “Chardonnay” - what can be said? You gave Tony, or “Mr T,” exceptional professional care and fierce advocacy. The way you fought to ensure he received what he needed was a true act of love. Tony and your mum are so very proud of you.

Tony and Kathryn's journey together ended on 10 June. Tony passed away peacefully with Kathryn and Emma by his side. Tony's physical presence may have left us but his legacy - of love, family, friendship, and quiet strength - lives on.

To Sylvie, the MS Nurses, the staff at the Therapy Centre, and the Hospice Nurses - **thank you. Your compassion, your skill, and your unwavering presence have made an enormous difference.** Special thanks to the hospice team - for making those final days not just bearable, but full of love and laughter.

The work of the MS Therapy Centre continues, and I thank you all for your generous donations in Tony’s memory. They help us continue to provide hope, support and strength to others on similar paths.

Today, we say goodbye to Tony - but we also say thank you. Thank you for the memories, the humour, the courage and the love. You will be missed deeply, but never forgotten.

Student placements: supporting the workplace of the future

Our partnership with **Canterbury Christ Church University** continues to thrive. In addition to our shared research interests, we were pleased to welcome several **physiotherapy and occupational therapy students** during the first half of the year. These placements offer students the chance to immerse themselves in a unique clinical environment and apply their developing knowledge and skills in real-world settings.

At KMSTC, students gain valuable experience working alongside our expert multi-disciplinary team, with exposure to specialist areas such as neurophysiology and aquatic physiotherapy - disciplines that are often under-represented in traditional training.

We'd like to thank Canterbury Christ Church University for providing the opportunity, the students who have joined us so far and extend our gratitude to our members for warmly welcoming them. **It's a real privilege to support the development of the next generation of health professionals.**

Trusts and foundations update

Behind the scenes at the Kent MS Therapy Centre, our fundraising work continues to grow and we're thrilled to share some exciting developments this month.

We're delighted to have received continued support from the **Frank Brake Charitable Trust**, their second grant to us this year and to welcome new funding from the **Roger De Haan Charitable Trust**, **Canterbury City Council** and the **Souter Charitable Trust.** These generous contributions will help us deliver therapies, maintain our facilities, and keep the Centre running for everyone who depends on it.

To make sure we're always improving our fundraising efforts, I recently attended **Embracing the Future, a conference hosted by Stronger Kent Communities**. With inspiring speakers from the **National Lottery Community Fund** and **Kent Community Foundation** - including their new CEO, Catherine Glover - the event was a great opportunity to connect and learn. I've also had one-to-one support this month from **Funding for All, Canterbury City Council**, and the **National Lottery**, all helping to sharpen our strategy and skills so we can secure even more support for Kent MSTC.

"As always, if you know of a trust or foundation we should be applying to or if you'd like to support our fundraising in any way, please do get in touch. We'd love to hear from you." - Sally at staylor@kentmstc.org

What a brilliant golf day at Canterbury Golf Club in June! A huge thank you to all who came, supported, played and volunteered. These events are a perfect way to showcase what we do to new audiences and share stories of how our services help improve the lives of people living in Kent with a neurological condition.
We're pleased to share that we raised £10,000. We couldn't have done this without the help of our generous supporters including Square One Padel Club.

A look at our events...

We held our first Wings of Memory event in June to launch our Butterfly Board. It was a truly special and heartfelt occasion, sharing stories and memories with loved ones.

Oxygen for diabetes

Did you know we work with the **Paula Carr Diabetes Trust**?

If you have diabetes and would like to try oxygen therapy, please speak to Jemma in person or email jpask@kentmstc.org as the Paula Carr Diabetes Trust may be able to fund the oxygen sessions for you.

"My blood sugar levels have come right down and are now stable." - Quote from Katie who has diabetes and uses oxygen.

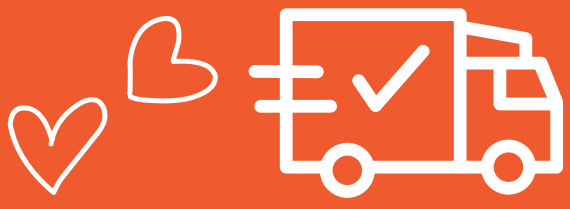
Oxygen is now available on Thursday evenings until 8pm!

Kindness delivered

Our Thera Trainer, one of our key pieces of gym equipment, broke down a few months ago. It's a vital tool for helping our members improve their mobility and overall fitness.

A replacement was generously donated by Abi but needed collecting from Dartford. We put out a plea to our community for help and were thrilled that Wendy Reid and her husband stepped in to offer their help.

Thanks to our wonderful community!



A journey of strength and hope: Michael's story at the Kent MS Therapy Centre

From surgery to stroke: a life transformed

Michael's journey to the Kent MS Centre is one that began with excitement and optimism, only to take an unexpected and challenging turn. After years of waiting, Michael was thrilled to finally have his long-awaited double hernia surgery at the beginning of September 2024. Little did he know, this would mark the start of an even longer and more difficult journey. Following the surgery, Michael's recovery didn't go as planned. His wound began leaking, and he became breathless. He worryingly said, "I've never felt so ill." The cause, however, was not the surgery as initially thought - it was heart failure, but his symptoms were mistakenly treated as a chest infection.

A call for help and the turning point

One day, after a long day at work, I (his daughter) was feeling tired and contemplating heading home. But something told me to visit my dad. When I walked in, I found my sister (Alison) and dad's partner (Maureen) desperately calling for help from upstairs. It was clear his condition had worsened. In a flurry of panic, we rushed him to William Harvey Hospital, where things took a dramatic turn.

Despite presenting clear symptoms of a stroke - facial drooping and slurred speech - initially, the doctors missed the signs. After persistent requests from the family, a CT scan was carried out, and by 1:30 a.m, Michael was admitted to the ICU. The stroke diagnosis was finally confirmed, and he began receiving the proper treatment.

After a week in ICU and multiple ward transfers, Michael was eventually moved to Canterbury in October for rehabilitation, where he began his journey of recovery.

Rehabilitation and recovery: a new beginning

Thanks to the incredible team at Harbledown and Kingston Wards, Michael's progress started. His rehabilitation was slow but steady: from feeding tubes and pureed foods to solid meals, with physio sessions helping him regain strength. He couldn't walk initially, but his determination was unmatched.

He was then transferred to Westbrook House, a specialist stroke unit, where his journey continued. However, another major setback - sepsis - threatened his progress. Yet, Michael, being the fighter that he is, overcame this and returned to Westbrook for further recovery. After five long months in hospital, he was finally able to return home in January.

A new hope at the Kent MS Therapy Centre

As Michael settled back, the next chapter of his recovery began. My family and I knew that hydrotherapy would be beneficial, but we had no idea where to turn. A bit of online research led us to the Kent MS Centre. To our delight, not only did they offer the hydrotherapy Michael needed, but

they also accepted stroke patients - a revelation that brought us immense relief.

Since February, Michael has been attending the MS Centre regularly, and the results have been nothing short of incredible. The hydrotherapy sessions have helped him regain mobility, and he is now able to walk with the use of a walking stick - something we once thought was impossible.

Michael's twice-weekly gym visits, although met with a bit of moaning, have provided him with a sense of purpose and determination to continue his recovery. He has also found camaraderie with fellow stroke survivors, like Stephen, whose stories inspire Michael and give him hope for the future.

Looking ahead: oxygen therapy and gratitude

"We're also encouraging dad to embrace oxygen therapy and to that end, my sister's husband, Halim, is currently testing it out for him…!" The MS Centre's support has been invaluable, and we can't express how grateful we are for the team there.

The MS Centre has given Michael a sense of purpose again. For the family, it's a chance to enjoy a cup of tea and a slice of cake while watching Michael take important steps toward recovery. The warmth, care, and community at the Kent MS Centre have been life-changing for our family, and we couldn't be more thankful.

A place of purpose and possibilities

Michael's journey has been filled with challenges, but through his courage and the support of the Kent MS Centre, there is hope on the horizon. It's not just about treatment - it's about finding purpose and a renewed sense of determination, and for that, we will forever be grateful.

Written by Julia Woodcock, daughter of Michael

Staff training

On Friday 16 May, staff took part in Manual Handling of People. This training is crucial for preventing injuries, promoting safety, and ensuring compliance with health and safety regulations, particularly in healthcare and other manual labor settings. It equips individuals with the knowledge and skills to safely move and handle loads, including people, minimising the risk of musculoskeletal disorders and other related injuries.

Staff will also be doing Evac Chair Training which is due to happen Tuesday 29 July. Proper training equips people with the knowledge and skills to respond effectively during emergencies, minimising panic, preventing injuries and facilitating a swift and organised evacuation.

Sponsored by Pocock's Solicitors of Whitstable

Christmas Ball

Saturday 6 December | 6pm - 12am

Darwin Conference Suite, University of Kent

Includes a three-course meal. Live entertainment from Whiskey & Wine and our fantastic MC Dave Fulton.

Tickets are £70pp or £700 for table of 10.

Registered with FR Fundraising Regulator