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I was delighted and honoured to join The Migraine Trust as its Chief Executive in February. It is a wonderful charity that has achieved a lot but there is much more we need to do.

When applying for the role I was truly shocked that ten million people in the UK alone live with migraine. And on reading personal stories and speaking with people affected, I was taken aback by the significant and widespread impact migraine has on all ages and aspects of life including school, work and personal relationships. I want to ensure The Migraine Trust is there for greater numbers of people affected in the way they want us to be, to increase its influence and impact at a policy level to ensure the best treatment and care is available, to see greater understanding and awareness of migraine and for the inequity that surrounds migraine to be reduced.

I plan to spend the coming weeks speaking and meeting to as many people and organisations as possible, not to just build my personal learning and understanding of how people feel about the charity, but to better understand the wider picture, issues, challenges, opportunities and what collaborations can be developed.

I am excited at the impact the charity can have over the coming years and I know people look to us to improve on how things look right now. Be assured that I and my colleagues will be working harder than ever to achieve this. I look forward to working with you in helping us do this.

Rob Music
We ran our first virtual Managing Your Migraine event in January. It included talks about new migraine treatments, vestibular migraine, and migraine and hormones. We will be holding more events over the year, check migrainetrust.org/events for details.

There has been very positive news about erenumab (Aimovig), a medication that is used to treat migraine.

Last year the National Institute for Health and Care Excellence (NICE) decided not to approve it as a treatment for migraine within the NHS in England. Following an appeal, the NICE Appraisal Committee has issued a Final Appraisal Document recommending that erenumab be used to prevent both episodic and chronic migraine. This can be used as the basis for NICE’s guidance on whether erenumab can be used to treat migraine in the NHS in England.

This provides another treatment option to prevent migraine, and one that has proved effective to many people with migraine. Significantly, this would be a treatment option of a medication that was designed specifically to prevent migraine, and one of the new calcitonin gene-related peptide (CGRP) class of drugs.

We are delighted to congratulate our trustee Professor Peter Goadsby for winning this year’s The Brain Prize. Professor Goadsby is one of four neuroscientists who won the prize for their discovery of a key mechanism that causes migraine which has led to ground-breaking new migraine treatments. These are calcitonin gene-related peptide (CGRP) monoclonal antibodies (MABs), which are the first preventive medicines specifically developed for the treatment of migraine.

The announcement was made by the Lundbeck Foundation, who grant the annual prize. The Brain Prize will be awarded at a ceremony in Copenhagen in October that will be presided over by His Royal Highness, The Crown Prince of Denmark.
Susan was an expert on migraine and dedicated to giving people accurate and evidence-based information about it. She was also a champion of other people developing a professional understanding of migraine that would enable them to help people with the condition. The bursary is a tribute to her commitment to helping people with migraine.

This will be an annual award as we want to support the development of migraine professionals. It builds on our biennial symposium that brings together people working in the area of migraine to share their latest research and learning. Teaching sessions for migraine professionals are an important part of the symposium.

The bursary gives up to £1,000 to someone who is studying for a Master’s degree or as part of their professional development. For those studying for a Master’s degree, they would have to undertake a dissertation on a migraine related topic. For those looking to improve their knowledge and understanding of migraine via Continuing Professional Development, the bursary can be used to attend an event, training course or study day.

Congratulations to Dr Joseph Lloyd on being awarded a PhD for his migraine research. Joseph was granted a Migraine Trust PhD Studentship in 2016 which he completed in February 2021. His research has furthered the understanding of what happens in the brain that leads to migraine attacks, and neuromodulation as a migraine treatment.

In his thesis, supervised by Dr Anna Andreou at King’s College London, Joseph investigated the mechanisms of action of three different neuromodulation techniques. These being; transcranial magnetic stimulation (TMS), spinal cord stimulation (SCS) and occipital nerve stimulation (ONS). Through his studies, he shed more light on the neuromodulation mechanisms needed to treat and prevent migraine attacks.

This research was only possible because of the donations from supporters and hard work of people who fundraise for us. Thank you to everyone who has made this possible.
It’s been an exciting few months with Calcitonin Gene-Related Peptide (CGRP) monoclonal antibodies (MABs) receiving approval across the UK. However, we know in some areas there are issues with accessing them. We’re aware that some delays and issues are due to the unprecedented demands of Covid-19 on the NHS and services are working hard to continue to provide support and care to people with migraine. However, it also highlights more general issues with access to specialist headache services, and gaps in provision across the country.

What are CGRPs?

CGRP is a protein that has been associated with migraine. During a migraine attack the cerebral nerves and blood vessels release CGRP. Researchers and doctors believe CGRP is an important factor in generating and maintaining the headache associated with migraine. The new treatments aim to deactivate the CGRP molecule to prevent migraine developing.

CGRP MABs are an exciting new treatment option. However, they are not suitable or appropriate for everyone. People should always have a review with their doctor to discuss treatment options and what is most suitable for them.

England and Wales

In England, when the National Institute for Health and Care Excellence (NICE) approves a new treatment, Clinical Commissioning Groups (CCGs) and NHS England have three months to comply. The NHS in Wales should usually provide funding and resources within two months of the first publication of the final appraisal document.

- Fremanezumab (Ajovy) is available for people with chronic migraine who have failed three preventive treatments.
- Galcanezumab (Emgality) is available for people with episodic or chronic migraine who have failed three preventive treatments.
- Erenumab (Aimovig) is available for people with episodic or chronic migraine who have failed three preventive treatments.
If you think you are suitable for CGRP treatment, you should speak to your doctor. Currently, they are only available via a Headache Specialist or (in some areas) a consultant neurologist. If you’re not currently being seen by a specialist - discuss a referral with your GP.

Where there are issues with access, speak to your specialist and the local Patient and Liaison Service (PALS) to discuss why it’s not available and what options you have. They should be able to advise whether it’s been added to the local formulary (list of available medicines) and support you in asking the relevant committee if it hasn’t.

If it has been added to the local formulary, PALS should be able to advise who has been identified as the local prescribers. You can ask for a referral to them (if different from your existing consultant). If no-one has been identified or there are no services available it may be necessary to contact whoever is in charge of neurology services locally (most likely the local hospital Trust) and ask them why there are no specialist headache services, and how to access appropriate treatment.

You could also consider a complaint about not having access, PALS can help with this and you can speak to your consultant. You can also contact the charity Healthwatch to ask about independent NHS complaints support in your area.

**Scotland**

- Erenumab (Aimovig) is available for people with chronic migraine who have failed three preventive treatments.
- Fremanezumab (Ajovy) is available for people with episodic or chronic migraine and who have failed three preventive treatments.
- Galcanezumab (Emgality) is due to be reviewed by the Scottish Medicines Consortium (SMC) in Spring 2021.

The CGRP MABs should be available from local headache or neurology services. If you are having difficulties accessing treatment speak to your Headache Specialist or neurologist. If you think you meet the criteria for a CGRP MAB and are not currently under a Headache Specialist or neurologist -
speak to your GP about a referral.

You can also contact the Patient Advice and Support Service (PASS) for more information around accessing treatment. They can also help with complaints.

**Northern Ireland**

In Northern Ireland the Department of Health has accepted the NICE approvals for both fremanezumab (Ajovy) and galcanezumab (Emgality). However, each individual Trust makes its own decisions around funding and services.

If you think you're suitable for a CGRP MAB you should speak to your specialist. If you’re not under a specialist, you can discuss a referral with your GP.

If you're unable to access a specialist or appropriate treatment you can contact your local Community Advice agency for guidance and support. You can also put in a complaint. Your local Health and Social Care Trust will have a complaints procedure and should be able to advise you on the process.

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**Are you struggling to access CGRP monoclonal antibody medication?**

Join our campaign for greater access to CGRP monoclonal antibody medication! Find out what we are going for Migraine Awareness Week on pages 12 and 13.
MANAGING MIGRAINE THROUGHOUT MY EDUCATION

BY EMMA PARKS

Back in September 2017, when I was starting my second year of college, I first developed chronic migraine. It had a big impact on my work because I started to take lots of time off and miss lessons.

Being in education and studying is already stressful enough as it is, and it was a very difficult time for me because I didn’t know what was wrong with me and was very stressed about how my attendance and education were suffering.

At the time I hadn’t been diagnosed and was making regular trips to the doctor and coming back with painkillers that didn’t work, later finding out that they were giving me rebound headaches. All of this made it very difficult mentally and I struggled to concentrate on my education.

Managing after my diagnosis

After my diagnosis a few months later my migraine had become less frequent.

I was able to do research into migraine and tried to figure out what my triggers were.

I was also able to work with my tutors to make everything a bit more flexible and in the end I was able to finish the course and moved onto the next level.

This is how I managed

When it comes to studying it can be very difficult. Spending lots of time sat in front of a screen, reading, writing, staying up late and focusing can all get very stressful and straining. I found that those things made me more susceptible to my migraine, which would cause me to struggle to find the motivation.

When it came to studying I found it best to stick to a shorter time slot, setting myself a limit of two hours; more than that in one go would be pushing it for me.

I would make sure that I didn’t leave it too late at night either because studying when tired meant it was more likely that a migraine attack would be triggered. These things didn’t always help but they did make a difference.

I am now currently studying for my NVQ and working. I still make sure that any studying I do is at a time that suits me and doesn’t cause me to push myself too much - I have found that this works better for me as I minimise my chance of triggering a migraine attack, allowing me to work better.
MY ADVICE FOR STUDYING IF YOU HAVE MIGRAINE

1. The first thing I would recommend is to talk to your doctor, as they will be able to help you.

2. Ask your GP for any leaflets or booklets about migraine and look online as there are many helpful resources with great advice on triggers and what can help you - hopefully then you can find what works for you.

3. Talk to your teachers and tutors and hopefully it will allow them to understand and help you to work around your migraine too. Everyone suffers differently with migraine and triggers can vary: stress, lack of sleep, eye strain, travelling, poor posture and not drinking enough water were a few common triggers that I noticed while I was in education.

4. Please remember that you are not alone and there is plenty of help and support available if you need it.
Migraine and headache are common in children.

Frequent and chronic migraine attacks can have a serious impact on a child’s quality of life. This can significantly affect their attendance and performance in school. Chronic migraine attacks also can disrupt a child’s ability to carry on with their home learning or go to school.

A child should not have to miss out on their learning or school due to their migraine.

Migraine in children

The symptoms of migraine in children differ from an adult's symptoms. Migraine in people over the age of 16 include throbbing headache, nausea, vomiting and sensitivity to bright lights. Migraine symptoms in children include feeling sick and abdominal pains. A child’s migraine episode may last for a short period.

This provides an opportunity for the child to recover in school rather than sending the child home. Recovery in school allows the child to benefit from the remainder of the school day as they can return to classes after the attack. If the child is learning remotely they are able to take medication and rest, and work flexibly to do as much work as they are able to complete for the day.

Supporting schoolchildren with migraine

Migraine is protected under the law so if a child’s migraine recurs over a period of a year, and negatively impacts their ability to carry out their normal day-to-day activities, they may be classed ‘disabled’ under the Equality Act 2010. This puts an obligation on schools to make reasonable adjustments for a disabled child to ensure that they are not put at a major disadvantage.

The Children and Family Act 2014 also puts the duty on maintained schools and academies to support children who have medical conditions in school. A child’s doctor can advise whether a child is likely to be classed disabled in accordance with the Act.

Ways to support schoolchildren with migraine

If migraine is having a negative impact on your child at school, you can ask the school to make adjustments for your child. A child’s parent/carer and school can devise an Individual Health Care Plan to set out the needs and support for the child.

There are many common adjustments that schools can make to support a child with migraine. These include
providing materials to catch up on work missed, extra tuition, online or distance learning, giving extended timescales for completion of coursework, giving additional time in exams, giving them access to medication, allowing access to a quiet dark room, and opportunities to drink frequently.

During the Covid-19 pandemic, most children are learning remotely from home and spend lots of time on screen and have deadlines to meet. This may create stress that could trigger a child’s migraine. A parent can help their child to manage this by ensuring that they take frequent breaks from the computer screen and ask the school for extended time to submit their coursework. Reasonable adjustments are not a ‘one size fits all’ solution and a child’s doctor can help to recommend suitable adjustments for them.

You can find further examples of reasonable adjustments in our Help in school toolkit available online at migrainetrust.org/help-in-school

Managing migraine in higher education

Migraine can also impact on the education of young people in higher education institutions. A student whose migraine meets the definition under the Equality Act 2010 may be classed as disabled and entitled to support from their education provider. The student’s doctor can help to advise whether a person is likely to be covered under the Act and recommend adjustments that suits the person. If a student is disabled by their migraine they can speak to their Disability Support Adviser in their university or institution to help them get support.

It is important for a student to tell their institution about their migraine early in the application process, speak to their doctor, familiarise themselves with the institution’s policies, and register with the disability support services in their institution. Disability support can provide information and support such as help with claiming welfare benefits or accessing funding and grants.

You can find out more information about your rights in our Help in further and higher education toolkit online at migrainetrust.org/help-higher-education

If you have questions about getting help you can contact The Migraine Trust’s Support Services by telephone 0203 9510 150 or complete an enquiry form online via our website migrainetrust.org
This is unacceptable. People living with migraine have had to wait a long time for a preventive medication that was developed specifically to treat migraine. They have taken medication that was often ineffective and that had a range of unpleasant side-effects.

Finally, a medication has been developed that has proved effective to many, and is often described as ‘life-changing’.

It was first approved by the European Medicines Agency, which meant people could access it privately before it was approved by NICE for NHS use. This created a division between who could and couldn’t afford it. We know some people struggled to afford to pay for it, spending all of their money on it until they couldn’t afford it anymore, thereby stopping medication that was giving them their life back.

It was therefore wonderful when drugs from this new class of migraine medication started to be approved for use on the NHS. People who were eligible for this drug would no longer be divided between who could and couldn’t afford it.

**Postcode lottery**

Now, another division has emerged. A postcode lottery where people living with migraine can access this medication in one area but not another. Our research has found that there are entire regions where there is very little access to this medication, with Clinical Commissioning Groups (CCGs) having not added any of these drugs to their list of drugs that people in their area can be prescribed.

We have also found that there are flash-points where a particular hospital Trust, despite their CCG adding one or several of these drugs to their list of drugs that they can prescribe, not prescribing them anyhow. There also appears to be a reluctance by individual neurologists to prescribe these drugs, even when they are allowed to by their CCG and Trust.

**Barriers to access**

While there are clearly issues with a lack of neurologists that are Headache Specialists throughout the UK, as well as long waits for appointments with either, people with migraine should not face a barrier to accessing this medication when they are eligible for it.

There appears to be a lack of will to give migraine the priority it deserves. It seems that too many people don’t recognise this serious impact that migraine has on people’s lives. Too many don’t seem to understand how migraine affects so many parts of a person’s life and how much time it steals.

When they do, migraine is treated with the seriousness it deserves. So, while there is a problem with accessing CGRP MABs in certain areas, many are now prescribing it. We are hearing from people who have been prescribed one of these drugs and how it has transformed their life. It is not only wonderful for them, their friends and family, but everyone who is involved in their treatment.
Prioritising migraine

This needs to change and we are working to do that.

We have been contacting CCGs and Trusts, talking to our colleagues in the migraine community, and crucially, migraine patients. This has helped us fully understand the situation throughout the UK, and has also allowed us to form a group to campaign for change.

We will campaign on this until everyone who is eligible for this medication has access to it, but we want to use this year’s Migraine Awareness Week (5-11 September) to gain national attention for this issue.

We will be running a media campaign and lobbying politicians, and working with people from across the migraine community to draw attention to this inequity.

We invite you to join our campaign!

How you can help

1. Share your experience
Wherever you’re based in the UK, if you’re having difficulties accessing CGRP MABs, appropriate treatment or specialist services, we’d like to hear from you. You can contact us via info@migrainetrust.org with information about your situation and the difficulties you’re having.

2. Tell your MP
You can also write to your MP, and Scotland, Wales and Northern Ireland residents can also contact their MSP (Scotland), AM (Wales) or MLA (Northern Ireland) in your regional parliament. We have letter templates that you can download at migrainetrust.org/migraine-awareness-week

3. Write to your local newspaper
We will be running a media campaign that will focus on national and local media which you can support by writing a letter to your local newspaper. We have letter templates that you can download at migrainetrust.org/migraine-awareness-week

4. Sign up to our ebulletin
The best way to stay up to date with the campaign is by subscribing to our ebulletin at migrainetrust.org
Return of my migraine attacks

It wasn't until around two years ago that they returned with a vengeance. Vision loss, inability to speak or think properly, exhaustion to the point of collapse, nausea, vomiting and a thumping head, so painful that it must surely be something more serious than "just a migraine".

My life was governed by the constant fear something I did would set one off. Bad attacks could last seven days or longer, while battling through working life.

Getting into running

I had major surgery two years ago, which left me unable to exercise. It has been a mountain to climb to get back to fitness and I started running, unable to continue for more than 30 seconds.

I turned 40 last September and I wanted to celebrate with a positive event, to show how far I have come, so I committed to running 100km in a month.

I chose to support The Migraine Trust because, at my darkest point, I found the website and it led me to the right people who helped me see that I could start to try to regain control. Migraine ruins lives. Millions of people's lives. And yet so many people really know so little about them.

A balancing act

Eighteen months after starting, I regularly run 20 miles or more a week. It's a constant balancing act between the exercise helping to stave off the migraine and getting the hydration/nutrition wrong and triggering an attack but, as I get stronger and learn how my body responds, I'm getting better at managing it.

The impact on my life has been incredible. My attacks are less frequent and shorter. I don't take any preventive medication and, if I get an attack, I can normally get by with strategic use of basic painkillers. If I have more than a couple of rest days it can kick an attack off.

Running keeps me on an even keel. I have built up very slowly to allow my body to adapt - initially I got a migraine after most runs - but 18 months ago I never would have thought I could manage my migraine enough to achieve something like this. And I have!
My top tips for running if you’re living with migraine

• Take it very slowly. Ignore what everyone else is doing. Allow your body the time it needs to adapt and accept it might take a while.

• Play around with fuel to find out what your body needs. I take in some electrolytes before a longer run and have found I need some carbohydrates/sugars earlier than other runners might. I always take water if I’m going more than four miles.

• Listen to your body. I can feel now when a gentle run will help a migraine and when I need a complete rest.

• Invest in decent sunglasses, sunscreen and a good hat.
HOW YOU CAN HELP PEOPLE WITH MIGRAINE
Gift in Wills
Thanks to generous supporters and those who leave us gifts in their Wills, we’re able to continue our vital work. Because of them, our dedicated migraine researchers, support service and campaigners continue to support people living with migraine.

We have partnered with the organisation FareWill so our supporters can write their Will free of charge. It’s private, simple and quick, taking as little as 15 minutes. To write your free Will online please visit FareWill and enter the voucher code at the check-out. The code is: TMT-online

Become a corporate partner
It is estimated that the UK population loses 25 million days from work or school each year because of migraine. With the help of our corporate partners, we can change this together. There are many ways you can partner with The Migraine Trust including:

- Charity of the Year partnership
- Do your own fundraising
- One-off donations
- Give as you Earn
- Matched funding
- Sponsorship
- Pro bono support

You can find more information about these ways to become a corporate partner by emailing us at fundraising@migrainetrust.org or at migrainetrust.org/askyour-employer-to-fundraise-for-us/

Donate in memory of someone you love
Giving a gift in loving memory is a very special way to remember your loved one and their life. There is a range of ways you can give in memory of your loved one including: creating an online tribute fund, collecting donations at the funeral or memorial service or fundraising in memory of a loved one. You can find out more at migrainetrust.org/raise-money-in-memory-of-a-loved-one/

Shop and donate
Did you know that whenever you buy anything online – from your weekly shop to your annual holiday – you could be raising free donations for The Migraine Trust? We have partnered with easyfundraising and AmazonSmile so you can shop and donate at no extra cost to you. You can find out how to do this and sign up at migrainetrust.org/get-involved/shop/easyfundraising/

Taking on a challenge event
We have a range of challenge events that you can take on in support of The Migraine Trust. Ranging from running a marathon, walking 100k or skydiving. To find your challenge event please visit migrainetrust.org/events/
THANK YOU FOR YOUR SUPPORT!

Christmas Appeal
A massive thank you to everyone who donated to our Christmas Appeal. We have now raised over £9,000 to help fund The Migraine Trust’s valuable work.

Ella’s October run
Congratulations and thank you to Ella Bryant who ran 120km over October and raised an amazing £1,193 to help people with migraine.

“I have suffered from chronic migraine for the past seven years. Having lived through the debilitating effects of migraine, I can truly express that there is not enough support and awareness out there for people with migraine. The Migraine Trust has been a great resource for me, helping me cope and understand my migraine better, but needs funds to help others like myself who are in desperate need of support and advice.”

Kate’s long run
A huge congratulations and thank you to Kate Wertheimer who ran over 100k in September to raise funds to help people with migraine! She shares her story of why and how she took on the challenge on pages 14 and 15.

Climbing for migraine
Congratulations to everyone who completed the Virtual Everest Challenge, climbing the equivalent of Everest (8,848 metres in height) over 12 weeks for The Migraine Trust! Together you raised over £560.

Jon’s Ironman challenge
A huge thanks and well done to Jon Park who has raised £370 to help people with migraine by doing an Ironman challenge. Since the Ironman 70.3 Weymouth was cancelled, Jon undertook a homemade triathlon in Sidmouth – ‘The Sidman 70.3’! He completed a 1.9km sea swim, 90km bike ride and 21.1km run all in just under 7 hours. What an achievement, Jon! Thank you!

He did this because, “unfortunately my wife has bad migraine. About half the month is affected by migraine for her and our family. It has now been seven years for us living with this. Some of the medicines have helped a bit, but what has helped the most is learning to adapt and to live with the effect that migraine has. Looking at positive ways to manage it has been the best medicine!”

Monthly donors
A huge thank you to the 590 people who give a regular direct debit or standing order donation every month to The Migraine Trust. This regular income is essential to The Migraine Trust and helps us to plan our activities over a number of years more effectively.
Together we can beat migraine
Please support us and help improve the lives of people living with migraine.

Your details
Title: __________________________ Surname: __________________________
Address: __________________________ __________________________
Postcode: __________________________
Email: __________________________ Telephone: __________________________

Your donation
I wish to make a single gift of £ __________________________
I enclose a cheque/CAF voucher made payable to The Migraine Trust OR
Please debit my credit/debit card Complete details below
Card type: Maestro Visa Mastercard Delta CAF
Card holder’s name: _______________________________________________________________________
Card number: ____________ ____________ ____________ ____________ ____________ ____________
Valid from: ____________ / ________ Expiry date: ____________ / ________ Security number: _______
Issue number (Maestro cards): ____________ ____________ ____________ ____________ ____________
Signature: ____________________________________________________________________________ Date: ____________

I wish to make a regular gift of £ __________________________ a month/a year Please delete as necessary.
(Please note that to receive our journal Migraine News we request a minimum Direct Debit donation of £30 a year, £2.50 a month, to help cover costs.)

Instruction to your bank or building society to pay by Direct Debit
Service User Number: 838322
Please pay The Migraine Trust Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction will remain with The Migraine Trust and details will be passed electronically to my bank/building society.
Bank/Building Society name: ___________________________________________________________________
Bank/Building Society address: ___________________________________________________________________
Name of account holder(s): ___________________________________________________________________
Account number: ____________________________________________________________________________ Account Sort Code: __________________________________________________________________
Signature(s): __________________________________________________________________________ Date: ____________

The Migraine Trust is a registered charity in England and Wales (1081300) and Scotland (SC042911)
March 2021
continues overleaf>
Staying in touch

Please let us know how you would like to hear from us?

We would like to send you news about our work, fundraising activities and ways to get involved.

Would you like to receive updates from us?

Email  Yes  No
Post  Yes  No

We will look after your details carefully and won’t share your details with any other organisation without your consent.

You can change your mind at any time by contacting us at supportercare@migrainetrust.org or on 0203 9510 150.

For more information on our privacy policy, please visit migrainetrust.org/privacy-policy.

To find out more about The Migraine Trust, and to support our work, visit www.migrainetrust.org/support-us.

Please return this form to: Freepost RUAE-EGGG-KXKG, The Migraine Trust, Mitre House, 44-46 Fleet Street, London EC4Y 1BN.