A Life Under Damocles’ Sword
Migraine Trust Supporter Brett Gooden shares his story

Remember a Charity Week
Consider making room for The Migraine Trust in your Will

Film Hack
Find out about our new, hard hitting video
Dear Readers

I recently travelled to Boston for the International Headache Congress and enjoyed presentations from the leading clinicians and researchers who are working on migraine and headache. It was good to hear of new advances and potential new treatments that are going to be made available to patients. It was an excellent congress and also gave me the opportunity to meet new patient organisations and to extend our reach into the international headache community.

This Migraine Awareness Week (1-7 September) we are running a campaign which is called ‘more than just a headache’. We are running a series of activities to highlight the reality of migraine to those who do not suffer themselves.

The campaign encourages everyone affected by migraine in the UK to talk about their own condition and the reality of how it affects their lives. As an existing supporter of ours, you will be sent a letter and a card. On it, we would like you to write down just a few words – as much or as little as you feel you want to share – about what migraine means to you. We are going to collect all of these cards and present them to the government and the more we have the bigger statement it will be.

The funding climate for charities is always tough, but now it is more difficult than ever so you will also find a donation form attached to the letter and we would be hugely grateful for any additional support you are able to send us.

Again, I would like to extend my personal thanks to you. As a supporter of The Migraine Trust, you know only too well the pain and misery that migraine can bring and it is only with your support that we are able to drive forward our pioneering research programme. Without your support, migraine research will stop. With your support — we will find a cure.

With best wishes,

Wendy

Wendy Thomas
Chief Executive
Postcode lottery leaves children with health conditions without support in schools

Many of Britain's 800,000 schoolchildren who suffer from migraine are seeing their education damaged through poor support for their condition.

Pupils are denied access to medication amid a migraine attack, lack help to catch up on missed work when unable to join lessons, and face unfair disciplinary measures. Sanctions include monitoring their absence and detention for the failure to meet homework deadlines, as well as exclusion from school trips and activities because of low attendance records.

The Children and Families Bill, which is currently before Parliament, aims to simplify and strengthen existing systems to support children and their families. The Migraine Trust is a member of the Health Conditions in Schools Alliance which represents the needs of children and young people with health needs. We are working closely with other members of the alliance to call for the Bill to be strengthened to give children with health needs the statutory support and protection they need.

Methysergide may be withdrawn

The Committee for Medicinal Products for Human Use (CHMP) is reviewing the use of methysergide in the treatment of migraine and may decide to discontinue its use. Studies have shown that the use of methysergide is effective for some migraine and cluster headache patients who have not responded to other prophylactic (preventative) treatment options.

A statement from the British Association of the Study of Headache said “We feel strongly that such an effective drug that has been the lifeline for many intractable migraine and cluster headache sufferers should remain available to neurologists and headache specialists". To read the full statement visit www.migrainetrust.org/news.

If you have been prescribed methysergide and are unable to get a repeat prescription from your pharmacy please speak to your GP or neurologist about alternative treatments.
Botox remains unavailable in Scotland

The Scottish Medicines Consortium (SMC), the body that assesses and accepts newly licensed drugs for NHS use in Scotland, has decided not to recommend Botox® as a prophylactic treatment for chronic migraine. This is the second time that the SMC has considered the use of Botox® for the treatment of chronic migraine. The treatment was first assessed by the SMC in 2011 and received a negative decision. The SMC did not recommend botulinum toxin type A (Botox®) for use because “the balance of costs and benefits meant that it was not considered to offer value for money”. For more information visit the SMC website www.scottishmedicines.org.uk

The Prescription Charges Coalition

On 1 April 2013 prescription charges in England were increased by 20p to £7.85 per item. The Migraine Trust believes that this is unfair for people living with migraine and other long-term health conditions, forcing them to pay more to stay well.

We have joined the Prescription Charges Coalition to campaign to abolish prescription charges for people with long-term health conditions. In the current system some health conditions qualify for exemption whilst others do not. Prescriptions are free in Scotland, Wales and Northern Ireland. The Migraine Trust believes it is time for a fair and consistent system to be put in place.

For more information please visit www.migrainetrust.org/policy
Working in Parliament

The All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) met in March 2013, during Brain Awareness Week. The All-Party group heard from top neurological experts on the barriers to establishing research into primary headache disorders and the implications for the UK if essential funding to underpin research developments is not made available. At this meeting it was revealed that Britain spends less than £1 million a year on research into migraine – under 12.5p for each migraine sufferer. This forum, held in the House of Commons, Westminster, was attended by parliamentarians, representatives from leading headache charities, including The Migraine Trust and other key stakeholders in the research and clinical treatment of headache disorders; and the public.

Charities urge action on ‘haphazard’ neurology services

The Migraine Trust, as a member of the Neurological Alliance, has been working closely with its colleagues to raise awareness of the need for improved neurological services. The Neurological Alliance has warned that a "legacy of neglect" is preventing an estimated 12 million people living with neurological conditions in the UK from gaining vital treatment and that current neurological services will fail unless there are swift improvements and investments.

Regarding the situation for people with migraine and other primary headache disorders specifically, Wendy Thomas, Chief Executive of The Migraine Trust, said: "The UK has a lack of suitably qualified health professionals with a special interest in headache disorders, and as a result services are patchy and inconsistent. The impact of this is that many migraine and headache patients are unable to receive an accurate diagnosis and suitable treatment, worsening the detrimental effect on their quality of life. Recognition of the scale of the problem and investment into cost-effective headache services will be a step in the right direction to limiting the burden of headache and migraine in the UK."

Obituary

Dr Marcia Wilkinson

Dr Marcia Wilkinson, the first medical director of The City of London Migraine Clinic (now known as The National Migraine Centre) died peacefully in her sleep on 4 February 2013. Throughout her life Dr Wilkinson was committed to helping migraine sufferers through her work in the field of medical research as well as her involvement with The Migraine Trust and other patient organisations. A full obituary is available on our website at migrainetrust.org/news

The Migraine Trust supports AllTrials campaign

The Migraine Trust is calling for transparency in all clinical trials and has signed up to support the AllTrials Registered / All Results Reported campaign. The Migraine Trust strongly supports the need for evidence based medicine and believes that migraine sufferers should have access to information about the condition and suitable treatments that are based on the best available clinical evidence. The AllTrials initiative is a collaboration of Sense About Science and a network of high profile organisations and individuals calling for the publication of the results (that is, full clinical study reports) from all clinical trials – past, present and future – on all treatments currently being used.

You can find out more about the AllTrials campaign and lend your support to the petition by visiting www.alltrials.net

Medicine & Me: Living with Migraine

Thank you to everyone who attended "Medicine & Me: Living with Migraine" organised by the Royal Society of Medicine in association with The Migraine Trust in April. We hope you found the event informative and interesting.

For those who were unable to attend the event, or if you would like a refresher, videos of three of the presentations are now available to watch online. The available presentations are What is migraine and why do I get it; Migraine: how to get help and where from; and Hormones in migraine: Periods, the pill and pregnancy. You can watch the videos at www.rsmvideos.com

Changes to the NHS in England

The government has reformed the National Health Service (NHS) affecting the way that healthcare is paid for and provided across England. The changes to the structure of the NHS came into force on 1st April 2013 although it may continue to be some time until all the changes are fully implemented. The changes will not affect the way that healthcare is delivered in Wales, Scotland and Northern Ireland.

For more information about the changes and how they may affect you visit www.nhs.uk
Remember A Charity is a coalition of charities working together to show how everyone can help the work of charities live on through leaving a gift to charity in their will. The week after Migraine Awareness Week is Remember A Charity in your Will Week, a time when we would like to encourage you to reflect on the need to think of friends, family and a charity when writing your will.

It’s a common myth that you have to be wealthy to leave a gift in your Will to help us, but nothing could be further from the truth. After taking care of family and friends, you’ll be amazed at what one final gift, no matter how big or small, can do. Like most charities a large proportion of our annual income comes from the generous donations people have bequest to us in their Wills. Without these legacies we would not be able to fund as much research; hold as many events across the UK; or help as many individual sufferers via our Information & Enquiry and Advocacy Services as we do today.

Of course, we don’t expect you to update your Will right now. Instead, we only ask that you take a moment in Remember A Charity in your Will week to consider making room for The Migraine Trust in your Will. Keep an eye on our Facebook page www.facebook/themigrainetrust and Twitter @MigraineTrust to find out more and get involved.

If you would like to write or update your Will, it’s easier than you think. Remember A Charity has teamed up with The Co-operative Legal Services who can give you free advice and support. Just call 0844 252 9965 and quote RACWILLS01. Or visit rememberacharity.org.uk to find your nearest solicitor or Will writer.

If you would like an information pack or to talk to a member of our fundraising team about leaving a gift in your will please get in touch on 020 7631 6977 or email fundraising@migrainetrust.org.
Migraine Trust supporter Brett Gooden is both a migraine sufferer as well as a retired medical researcher. Australian by birth, Brett has spent time working in America and here in the UK. Here Brett shares his experience of migraine as a patient and scientist. The second part of Brett's story will be published in a future issue of Migraine News.

In a Greek legend Damocles was a courtier of a tyrant king Dionysius. Damocles coveted the king's apparent good fortune, so the king sat Damocles in his throne with a sword hanging above his head held by only a single hair of a horse's tail. Under such a persistent threat of doom, Damocles begged to be released and concluded that he no longer wished to be so fortunate as Dionysius. Enveloped by the excited chatter of my little friends we streamed out of the local picture theatre following the Saturday afternoon matinee with images of Hopalong Cassidy and Tom and Jerry still flashing through our minds. Suddenly I was aware of the intense light from the vast blue dome of the Australian summer sky. I felt somehow different. I walked home the one and a half miles with the gaggle of friends progressively dwindling as they peeled off to their homes. When I reached our garden path I still did not feel "right". What was it? What was happening to me? No one had ever told me about a thing called "a headache". This odd feeling was my first "bad headache" as my mother euphemistically described them. I had watched my mother vomit into the toilet as I held her hand. She called this "a migraine" for which she took tablets. But when the migraine was really severe nothing seemed to help her, only time lying in a darkened room. Later I learnt that my maternal grandmother had also been stricken by the same condition. She lived in the Stygian gloom of an old Victorian house with the heavy window drapes perpetually drawn.

At the age of ten I moved to another school which entailed a 30 minute trip on an electric bus. Previously I had walked to school. One or two times a year I would develop a headache in the afternoon at school and by the time I took the bus home I would feel nauseated. I spent the trip hoping that I would not disgrace myself on the bus. Simple analgesics would relieve the pain.

As a first year medical student at the University of Adelaide I would sometimes develop a headache in afternoon practical classes but managed to carry on despite the pain. I learnt to endure the headaches and tried as much as possible to ignore them. This approach worked for some years. As a junior medical House Officer I would lie down in the on-call room at lunchtime and work with the pain in the afternoon. Incredibly it was only at this time, with my medical training, that I faced the reality that I was having migraine headaches. Up to this time I still thought of them as simply "bad headaches". Once I made this mental adjustment I realised I should be using oral ergotamine for the severe headaches and this usually resulted in resolution of the pain.

I decided that I wanted to go into medical research and since I enjoyed my time in physiology as an undergraduate, I approached the Professor of Human Physiology and Pharmacology, Robert F. Whelan. I received a small grant and was put to work elucidating the cardiovascular responses in human subjects to breath-hold diving. A large swimming pool was erected in a laboratory and along with two Bachelor of Medical Science students,
I embarked on a fascinating study of the diving response in humans. During the course of this research, I performed, out of curiosity, two simple experiments on myself during migraine headaches. One day as a headache nagged me, I performed a simulated breath-hold dive by immersing my face in a bowl of water for 60 seconds and was surprised to find that the pain of my migraine headache was alleviated during this procedure (Figure 3 – “Dive” in bowl). During another diving study I was testing oxygen equipment and noticed that breathing pure oxygen for a few minutes also appeared to alleviate the pain of migraine. Did these random observations mean anything? I shall discuss these matters further in Part 2.

In 1972 I travelled to the USA as a Fulbright Scholar where I worked in Pennsylvania and Texas with Dr. Stewart Wolf. Stewart had performed some intriguing studies some years earlier on the diving response in humans which had raised the question of whether this response was an oxygen-conserving mechanism in humans as it was in naturally diving mammals, for example seals. Stewart had collaborated with the legendary Dr. Harold G. Wolff on pain studies in the 1940s. In 1948 Harold Wolff published his famous book *Headache and Other Pain*.

In this book Wolff included a crucial experiment, first reported by him in 1937, in which he had demonstrated that ergotamine reduced the pulsation of the temporal artery in a patient suffering a migraine and simultaneously the headache stopped (Figure 4 – Wolf’s experiment). Knowing that ergotamine predominantly constricts arteries, Wolff concluded not unreasonably that a migraine headache was a phenomenon related to an abnormal dilatation of the cranial arteries in migraine sufferers. There is no doubt that the extent of peripheral arterial blood flow varies in association with a migraine headache. My wife often remarked that my face became “ashen” just before a migraine headache presumably due to the constriction in arteries supplying the skin of the face.

During my research in the United States I was invited by Professor David Greenfield to apply for a lectureship in physiology in the newly established Medical School in Nottingham, which in 1977 became part of the Queen’s Medical Centre. I arrived in Nottingham in 1973 to take up this post. I decided to focus my attention on blood flow regulation in a diving and non-diving animal. I chose the duck and the hen. My choice was predominantly influenced by the fact that the original work on the diving response had been done in the 1870s on these two species of bird by the eminent French physiologist, Paul Bert, who was also the founder of the discipline we now call aerospace medicine (Figure 5 – Dabbling duck). I proceeded to examine the responses of arteries from the
In intestine of the duck and hen, in particular the affect produced by the stimulation of their nerve supply and to a chemical called noradrenaline. Noradrenaline is a chemical messenger which is released from the endings of nerves supplying arteries and attaches to receptors on the arteries causing them to constrict.

At the end of September 1974 I took the train down to London with a colleague from the Biochemistry Department to attend the Sixth Migraine Symposium. It was held jointly by The Migraine Trust and the Scandinavian Migraine Society. Twenty six nations were represented. Two trials were presented involving the use of propranolol, a drug used initially in the treatment of blood pressure, as a possible preventative drug in migraine. Shortly after my return to Nottingham I was asked to present a review of the papers presented at the Migraine Symposium. I titled my seminar “From Chocolate to Dysnoception – Some comments on the Sixth Migraine Symposium”. This title derived from two papers which not only showed the diversity of topics covered at the Symposium but also highlighted presentations that had particularly interested me. A blind trial suggested that chocolate could be a triggering food-factor for migraines in some people. The other paper that I found particularly interesting was presented by Federigo Sicutell. He suggested that there might be an abnormality in the way migraineurs perceived pain. Dysnoception simply means an abnormality in the perception of a painful stimulus. For me this paper represented an important shift away from the thinking of researchers like Harold Wolff, who believed that migraine was a problem centred on blood vessels, towards it being a problem mainly involving nerves possibly in the brain.

“Here I was working with a technique for examining the response of arteries to nerve stimulation and chemical agents. Why could I not compare the reaction of arteries from migraineurs and non-migraineurs?”

My attendance at the Sixth Migraine Symposium had set me thinking. Here I was working with a technique for examining the response of arteries to nerve stimulation and chemical agents. Why could I not compare the reaction of arteries from migraineurs and non-migraineurs? I put together a proposal to examine the reaction of human intestinal arteries using tissue that would be discarded following certain types of abdominal surgery. I approached surgeons with the idea but was unable to elicit any interest. A pity as such a study may well have added something to our knowledge of migraine even if it did not show any difference in the reaction of arteries from migraine and non-migraine patients.

My earlier work in Australia on breath-hold diving had broadened into other areas relating to asphyxia in general such as during the burrowing activity of echidnas (spiny anteaters) (Figure 6 – Echidna in the bush). On my return to Australia from England I went on a field trip to Queensland with my long time friend and colleague the echidna expert Dr Michael Augee. We found that the echidna in its natural environment, like its cousin the platypus, uses electrical receptors on the end of its snout to help it locate its prey. Huge trigeminal nerves relay this information to its brain. About two weeks after returning from this field trip I developed viral encephalitis possibly from being infected by a mosquito bite. Over the years I had had migraine headaches on both sides of my head, not simultaneously of course, but either on the left or right side with roughly equal frequency. However, much to my surprise, upon recovering from the acute brain inflammation of the encephalitis, I found...
that my migraines only occurred on the right side of my head. I never suffered another migraine on the left side of my head again.

By this time I was using oral ergotamine in a rather hap-hazard fashion. Vomiting the medication was also a problem. I had tried all of the standard preventative medications without success. Under the direction of my neurologist I started using rectal ergotamine. This avoided the problem of loss of the medication due to vomiting and also meant that I could measure the amount of ergotamine quite precisely by carefully slicing the suppositories into small pieces. Having years of experience in titrating chemicals in my research, I decided to try to find the minimum dose of ergotamine that I could use to prevent my migraines rather than to treat each acute attack. I discovered that a regular daily dose of less than one milligram of ergotamine was adequate to provide me with some stability in my life and allowed me to continue to work. I still had an occasional severe migraine but only two or three per year which was a great improvement. I did not become tolerant to the ergotamine and the daily dose hardly changed over 25 years. However I continued to experiment to see if I could reduce the dose further but the headaches simply returned if the dose fell below this threshold dose.

Ergotamine had become my life-line which allowed me to work effectively. Then out of the blue I was advised that ergotamine would no longer be available commercially in either the tablet or the suppository form. Drugs called triptans were now used routinely for acute migraine. Their use as preventive agents was contentious and the cost of daily use would have been prohibitively expensive. In addition it was not given rectally. The thought of having to endure unrelenting excruciating pain was too much for me. I could see no escape from Damocles Sword. In the space of two weeks I entered a very dark place called exogenous depression. I had never experienced such a state before despite all my battles with migraine over 50 years. I had learnt how to endure a migraine headache. However severe the pain and however ill I felt, I knew that eventually I would recover. But now I could see no light at the end of the tunnel. I became acutely fearful of even the simplest activity. It became agony filling in the time between one hour and the next. I was house bound and dreading being alone. I had no pleasure in anything. Damocles Sword swung above my head by a wisp.

The Australian aborigines had a custom called “pointing the bone” or Kurraltcha. They believed so strongly that if “the bone”, the kundela, was pointed at them they would surely die. These victims were admitted to hospital but they refused food and water and died. I understand Kurraltcha now.

One day my astute GP suggested that I try a relatively new antidepressant medication called escitalopram to treat...
"At this time I didn't believe that anything would work but I agreed. It was a miracle."

my profound depression. At this time I did not believe that anything would work but I agreed. It was a miracle - after only a few milligrams of escitalopram each day for a week I began to feel my personality returning and after two weeks I was almost "me" again.

This was a wonderful release but more was in store. By accident I became aware that my daily dose of ergotamine could be reduced by a small amount without a migraine ensuing. Very slowly over many weeks I continued to reduce the dose of ergotamine. I could not believe it. "Just wait", I thought, "it will strike again just when you think you have escaped." But no, Damocles Sword did not fall as it always had previously when I tried to reduce the dose. Finally after six months I was off ergotamine completely. Forty years on ergotamine had ended and I was headache free. I felt like a new person. I could do whatever I liked. I could travel and enjoy a full life again. I remain on a small dose of escitalopram each day and I have not had a migraine for two years.

In Part 2 I shall discuss some interesting matters about the possible mechanisms underlying migraine headaches. How our ideas have changed radically over the years and how some of the drugs we use today to prevent and treat migraine may work. I shall attempt to explain what I think happened in my brain that led to my release from severe depression and a lifetime under Damocles Sword.

The Migraine Trust would like to emphasise that individual responses of migraine sufferers to medicines vary considerably and there is no strong evidence for the use of escitalopram in the preventive treatment of migraine.

References

9. Seminar notice, Department of Physiology, Nottingham Medical School, Dr Bratt Gooden "From chocolate to dynoacception - Some comments on the Sixth Migraine Symposium. Talk given on Wednesday, 23 October, 1974. Author's archives.

Figures

Figure 1 – Painting of Damocles, King Dionysius and the famous Sword (Oil painting by Richard Westall, 1812. See Wikipedia – no limits on reproduction).

Figure 2 – Simulated diving by total immersion. We measured blood pressure, heart rate and upper and lower limb blood flow. Our heart and blood vessels respond like naturally diving animals, for example ducks, but to a lesser degree (© Gooden, 1969).

Figure 3 – The cardiovascular response to diving can be simulated most easily by simple face immersion in a bowl of water. We found that the trigeminal nerve played a central role in the diving response as we believe it also does in migraine. (© Gooden, 1970).

Figure 4 – Wolff's original experiment showing the effect of intravenous ergotamine on temporal artery pulsation and a migraine headache (Modified from Graham & Wolff, 1937).

Figure 5 – A dabbling duck. In 1870 the famous French physiologist Paul Bert placed his hand on the breast of a "dived" duck and noted that its heart rate slowed profoundly. In so doing he initiated the study of the diving response which continues to this day (Gooden personal archive).

Figure 6 – The reclusive little echidna has most remarkable physiology - a great diver, it if it has to, and Australia's largest hibernator; it possesses electrical detectors in its snout like its cousin the platypus. This ancient mammal probably co-existed with dinosaurs. It never ceases to amaze us (© Augee, Gooden & Muser, 2006).
User Group

The Migraine Trust User Group is a group of migraine sufferers from across the UK who use their individual skills and experience of living with the condition to support the work that we do.

We asked Claire Horton, a member of the User Group since 2011 to explain more about her experience of the group:

Why did you join The Migraine Trust User Group?

I joined The Migraine Trust User Group because I wanted to use my experience of almost 25 years of migraine to inform the organisation and to support the valuable work that it does to be as effective as possible. I am also very aware of the benefits that volunteers can bring and thought that I had other knowledge and experience from my work and home life that could help the charity.

What does membership of the User Group involve?

Membership of the User Group involves attending three meetings a year in London, commenting on documents and ideas by email, and thinking about how the charity can best support people with migraine in the UK.

Do you think that the User Group is fulfilling its aims of acting as a critical friend to The Migraine Trust by ensuring its work is informed by, and relevant to the need of migraine sufferers in the UK? – Please give an example(s) of how this has been successful.

I do think that the User Group is fulfilling its aims of acting as a critical friend. I believe that members of the group are developing good relationships with staff and trustees and are able to have open and honest conversations about the work of The Migraine Trust. A practical example of the kind of thing that we have helped with is the development of the Patient Advocacy Toolkit. Members of the User Group read the toolkit before it was finalised and printed, making suggestions about changes to help it to be as user-friendly and relevant as possible for migraine sufferers. I think giving this perspective can be really helpful to staff.

How do you see the User Group developing in the future?

I see the User Group getting stronger as it becomes more embedded within the organisation, I hope that we enhance the charity not only by giving our views and experiences as migraine sufferers, but by contributing our other skills and knowledge to supplement the small team that run the organisation on a day to day basis.

Do you have anything else to add?

Unfortunately, since joining the User Group my seven year old daughter Holly has been diagnosed with migraine. This does mean that I now also contribute a parent’s perspective and can ask her what she thinks from a child’s point of view. It also means that I’m more determined than ever to help to raise the profile of migraine and the need for further research, to try and avoid her having the same kind of experience of living with the condition that I have and that my late mum did.

If you are interested in joining the User Group or finding out more please contact Hannah Verghese hverghese@migrainetrust.org 020 7631 6973
Film Hack

The Migraine Trust was delighted to be chosen by YouTube to work with them as part of ‘YouTube Film Hack 2013’. Partnering with such a high profile company has increased our online reach exponentially. As a result, we are able to reach more migraine sufferers and support more people in need.

What is the YouTube Film Hack?

YouTube and the Moving Picture Company hosted the “YouTube Film Hack” to challenge the creative industry to use YouTube as tool for storytelling.

The project brought together multidisciplinary teams from seven creative agencies to bring their storytelling skills to a brief from the Migraine Trust. The teams partnered with popular YouTube Partners who brought their expertise in developing original content for the platform and how to reach the YouTube audience.

The teams had one week to come up with their creative idea and one day to film it in the YouTube Creator Space, a top of the line facility usually reserved for YouTube Partners. The output was twofold: a piece of content judged on how it fits the YouTube platform – for example, how interactive and responsive it is. Plus a live YouTube “Skippable” ad that was scored on how long it can compel the viewer to watch.

The Migraine Trust was delighted with the winning video, an original piece of content created by Saatchi and Saatchi and featuring Migraine Trust supporters and beneficiaries which really showcased the horror of living with migraine.

You can view the winning video here: http://bit.ly/1crQlLi
Fundraising round-up
If you would like to fundraise for us please contact our Fundraising team on 020 7631 6977 or email fundraising@migrainetrust.org.
To see what fundraising opportunities are coming up visit www.migrainetrust.org/fundraising

London Marathon

Everyone at The Migraine Trust would like to say a big thank you to everyone who ran the London Marathon in April. Together Harriet, Matthew, Nick, Olly, Sarah, Sham and Simon raised over £11,000 for The Migraine Trust, which will help us to continue our vital work.

If you would like to take on this challenge in 2014 Please visit www.migrainetrust.org/running to find out how to apply.

Lent

This year our Senior Fundraising Officer Eleanor and supporter Ruth both gave up very different things for Lent to raise money for The Migraine Trust. Eleanor gave up her love of chocolate whilst Ruth gave up swearing for 40 days and 40 nights. They both managed to avoid temptation and between them raised £531 for The Migraine Trust! If you'd like to take on a challenge for Lent next year get in touch.

Turn Pennies into Pounds with Ploink!

Ploink! is a great new website offering you the chance to donate small amounts of change to The Migraine Trust. You can put in as little or as much as you like – just like dropping your spare change into a collecting tin. Once a piggy bank has at least 99p in it you’re able to donate the money to your charity. Every penny will make a difference to The Migraine Trust, helping us continue to support migraine sufferers across the UK and fund more research into this complex condition.

You can start your virtual piggy bank by visiting www.ploink.co.uk/charity/the-migraine-trust

Christmas cards

A great selection of cards and other items. Every purchase supports The Migraine Trust.
Visit www.migrainetrustshop.org
All Roads Lead to Rome

The weekend after the new Pope, Francis I, was elected, supporter Jamie took to the streets of Rome to run the Rome Marathon for The Migraine Trust. Rome is famous for being the city of seven hills making this marathon particularly challenging. Jamie completed this gruelling challenge and raised an amazing £800 – thank you Jamie!

BNP Paribas Fundraising

Staff at Arval office in Swindon nominated The Migraine Trust as their charity of the month for May 2013. Staff used the month to fundraise by holding cake sales and selling Migraine Trust key fobs as well as having a stand of Migraine information for colleagues and managers to learn more about the condition. Arval staff raised over £400 – thank you! If you would like to know more about fundraising in the workplace contact our fundraising team.

The Trans Pennine Challenge

Could you walk from Manchester to Sheffield? Migraine Trust supporter Gareth got halfway there! On 22nd June he walked the 50km trek to raise money for The Migraine Trust and raised over £100 towards our work. Thank you Gareth for the effort you put into fundraising and training for this gruelling challenge.

Café de Mort

Café de Mort was Remember A Charity’s most recent awareness-rasing campaign that featured a pop-up restaurant opening its doors for just two nights in London in February 2013. Launched by television presenter and food expert Gregg Wallace, Café de Mort served a range of deadly delicacies as part of Remember A Charity’s campaign to encourage more people to leave a gift to charity in their Will. Two of The Migraine Trust’s staff members, Eleanor Francis and Hannah Vergheese (above), dined at the restaurant to help promote the importance of charitable legacies to the work of The Migraine Trust. Both Hannah and Eleanor survived the deadly menu, including Fugu, a potentially fatal dish which must be prepared by a specially trained chef, and Ghost Chili; the world’s hottest chilli which is being studied for use in chemical warfare.

Edinburgh Half Marathon

A big thank you to Christie (top left) who, despite suffering from a nasty cold, ran the Edinburgh Half Marathon in the fantastic time of 1 hour 58 minutes. Before the race Christie said “I’m sure anyone who knows me will know how migraines can affect your life so raising money for The Migraine Trust is especially important to me. Running a half marathon is a bit of a challenge and a great excuse to raise some money – let’s hope I don’t have a migraine on the day!!” Christie raised over £450 in sponsorship, which will help us continue our vital work.

British 10K 2013

This year a team of five runners took part in the British 10K on one of the hottest days of the year! Together our team raised over £1,000 for The Migraine Trust with sponsorship still coming in, so we’d like to say a massive thank you to our team: Faye, Diane, Trevor, Graham (above), and Neha; for all the hard work they put into their training and fundraising.

Wilmslow Half Marathon

Nicky, son of our Chairman of Trustees Ian Watmore has also been fundraising for The Migraine Trust in 2013. Back in March Nicky ran the Wilmslow Half Marathon to raise funds for The Migraine Trust and awareness of migraine. We could never have imagined the reaction from Nicky’s friends and family and his sponsorship total stands at a formidable £9,736! Everyone here at The Migraine Trust would like to thank Nicky for the hard work he put into fundraising and training.

Ian’s in memorium skydive

As we go to print Ian is preparing to do a sponsored skydive to raise funds in memory of his mother, Karen. Ian says “I am raising money for The Migraine Trust as I feel this is a charity that isn’t recognised enough and seeing my mum suffer over the years makes me want to help raise money to find a cure or better medication for migraine sufferers.” Ian’s skydive took place on 24th August but you can still sponsor him via his JustGiving page: www.justgiving.com/Ian-Pinchback
Is migraine a disability?

It may be – the answer depends upon your own individual circumstances. As a migraine sufferer, you are likely to be classified as disabled if your migraines have a long term and substantial effect on your ability to carry out normal day-to-day activities. This will usually mean that you have suffered from migraines for 12 months or more and your migraine attacks prevent you from doing normal everyday tasks such as attending work, concentrating on certain tasks and driving.

Whether or not you have a disability will normally depend on the frequency and impact of your migraine attacks. If you suffer from a migraine attack once a year, you are much less likely to be classified as disabled than someone who suffers from weekly attacks. The key is the impact of the attacks on your everyday life.

If you are classified as disabled, your employer is not allowed to discriminate against you because you suffer from migraines. In addition, your employer has a duty to make "reasonable adjustments" to make sure you are not disadvantaged due to your migraine attacks. This could include allowing you reasonable time off for medical appointments or allowing you to sit in a dark room if you feel an attack coming on. You can also be protected from discrimination even if you are not technically classified as "disabled" but someone (such as your employer) perceives that you are disabled due to the severity or frequency of your migraine attacks.

Am I legally allowed to drive with migraine?

There are two issues to consider here. First, can you drive if you suffer from migraines? Secondly, is being a migraine sufferer something that you have to notify to the DVLA?

Being someone who suffers from migraines does not on its own prevent you from driving. The condition does not create any safety concerns, unless you drive during a migraine attack or whilst taking medications that affect your ability to drive safely.

The symptoms of migraine can cause complete impairment. Some sufferers experience visual disturbances, dizziness and difficulty concentrating. These symptoms could make you vulnerable to driving errors and place you and others at risk of accidents and injury. If you do experience an attack whilst driving you should stop your car and immediately treat your migraine. You should not resume driving until you feel better and you are sure that your medications will not interfere with your ability to drive.

You must notify the DVLA (in writing) if you think that your migraine attacks are likely to be a source of danger to the public. If you have notified the DVLA and your migraines become worse than previously disclosed to the DVLA you should contact them again.
September

1st: Migraine Trust Christmas Cards go on sale


Our London Evening Series of events offers a small group size, providing a great opportunity to meet other sufferers and ask questions. This session will focus on how to manage and treat migraine.

8th: Run to the Beat, powered by Nike+, London

This great half marathon is returning London’s O2 arena and docklands. The course passes multiple stages featuring today’s best musical talent. Contact The Migraine Trust to apply for a place.

12th: Oxford Headache Centre Launch Event

Come and join us to celebrate the launch of the new Oxford Headache Centre.

14th: Thames Path Challenge

Take on this epic walking challenge and raise money for The Migraine Trust.

October

12th: Managing Your Migraine, Edinburgh

These information days for people living with, or who have an interest in, migraine include presentations by migraine experts, with the chance to ask your questions.

25th: Halloween Moonride 2013

You don’t have to be a runner to take on a challenge for The Migraine Trust! Contact The Migraine Trust if you’re interested in getting on your bike and raising funds.

26th: Managing Your Migraine, Newport

These information days for people living with, or who have an interest in, migraine include presentations by migraine experts, with the chance to ask your questions.

November

TBC: The Migraine Trust London Evening Series: Women and Migraine

Our London Evening Series of events offers a small group size, providing a great opportunity to meet other sufferers and ask questions. This session will focus on women and migraine.

For more information about any of the events below please visit www.migrainetrust.org/events, emailevents@migrainetrust.org or call 020 7631 6976.
The Migraine Trust is the health and medical research charity for migraine in the United Kingdom. The Migraine Trust is committed to supporting all those affected by migraine and disabling headache. We seek to raise awareness of migraine and headache as a serious public health problem. The Migraine Trust funds and promotes research into migraine and disabling headache for the purposes of better understanding, improved diagnosis and treatment and, ultimately, to find a cure for these debilitating conditions.

**Information and Enquiry Service:** we can help with questions you may have about migraine, other headaches and their management. All our information is based on the best available evidence.

**Telephone:** 020 7631 6975 please leave a message if necessary and we will get back to you or Email: info@migrainetrust.org

**Advocacy Service:** We can provide advocacy support to empower migraine sufferers to assert their rights and claim their entitlements in the areas of healthcare, employment and education. (See website for further details and resources).

**Telephone:** 020 7631 6973

**Email:** advocacy@migrainetrust.org

**Events:** throughout the year we organise a variety of educational events around the UK that cater for both health professionals and the public. (See website for details of upcoming events).

**Website:** information about migraine and headache is available at our website including downloadable fact sheets and packs. You can also subscribe to The Migraine Trust’s ebulletin. The Migraine Trust is a registered charity funded entirely by voluntary donations from individuals, charitable trusts and corporate supporters. Without your support we would be unable to continue our work. Please give your support by making a donation or become a regular supporter and receive our journal Migraine News.

Find us on Facebook, Twitter and Justgiving.com

**Telephone:** 020 7631 6970

**Fax:** 020 7436 2886

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A company limited by guarantee incorporated in

England no.3996448

A registered charity in England and Wales (no.1081300) and Scotland (no.SCO42911)

Design: SteersMcGillanEves Design Ltd