MIGRAINE NEWS

ISSUE 110 | September 2014

The Journal of

Research Update from The Migraine Trust’s Fellow

The All-Party Parliamentary Group on Primary Headache Disorders Publishes Findings

Asking for Evidence with Sense About Science

I have been (it is am pleasing to say) exceptionally busy since the last issue of Migraine News. I have chaired the last three Migraine Trust public meetings in York, Belfast and, most recently, Keele University. The All-Party Parliamentary Group on Primary Headache Disorders report into Headache Services in England, organised by The Migraine Trust, was launched at Portcullis House. This provided an excellent opportunity to meet parliamentarians, pharmaceutical and device companies, medical colleagues and our supporters.

At all of these events I met people who are living with the grim reality of migraine: a condition which is truly awful and utterly debilitating and yet seen by most people in the UK (including, sadly, some in the medical profession) as just another type of headache.

Migraine sufferers ask me all sorts of things at these events, but the question I hear perhaps the most often is simply: “Will we ever find a cure for migraine?”

My answer is always in two parts. “Yes!” then, I have to add, “But we just don’t know when.” There is a solution and there will be a cure: and this will come through dedicated research. Medical research has delivered cures and effective treatments for many conditions and diseases that were thought to be insoluble just a few decades ago.

Within the migraine community, we have seen in the last year alone the evolution of new stimulation treatments which are already proving to have positive benefits to many migraine sufferers. These new techniques came from research and I am confident that – if we continue to fund future research – we will be able to make major breakthroughs within a generation.

There is currently no government or NHS funding available at all for this research. That is why, during Migraine Awareness Week 2014, we are launching an urgent fundraising appeal to raise the funds we need to increase our meagre research budget. The cure is out there, but we will only be able to find it if we can increase the number of research projects we can fund. To do that, we must have the active support of all those who understand the daily reality of migraine. Please take a moment to read the article on page 7 to see how far we have already come – but how important it is that we increase our research funding in the future.

So, I have my own question to pose now to all those who ask me about a cure. How quickly would you like us to find a cure? Because every donation we receive moves us closer to that day.

Best wishes and good health.

Wendy Thomas
Chief Executive

Thank you to everyone who attended our Managing Your Migraine events

In the past six months, we have held three of our Managing Your Migraine events. We visited York during March, Belfast in May and we were at Keele University in June. We wanted to say a huge thank you to everyone who attended and we hope you found it useful. If you haven’t done so already then please fill out your impact questionnaires as without feedback we can’t improve. We are currently busy planning our next events so have a look at the calendar on the inside back cover for more information. If you have any questions about events then please email events@migrainetrust.org.

Curelator focus groups

On Monday 21st July a group of sixteen volunteers came to The Migraine Trust office to help healthcare company Curelator trial their new product, Curelator Headache™, a new website and mobile app which people with migraine can use to enter information about their daily behaviours, migraine attacks and other headaches, in a simple and quick way. To find out which triggers could be causing migraine attacks and help them manage these to reduce the number of attacks, this information is then analysed by a set of advanced, proprietary statistical techniques. Participants were asked to take part in a short, computer based training game, matching questions about migraine and its triggers with relevant picture symbols. They were then given the opportunity to try out both the website and the mobile app and asked to give feedback via a questionnaire and short discussion. We would like to thank everyone involved for their time and we will keep you updated with the progress of Curelator Headache™.

Migraine in the News

On Tuesday 17 June, The Migraine Trust attended a reception in Parliament that marked the launch of a new report by the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD). The report, ‘Headache Services in England’, calls for urgent reforms to headache services in England and follows an inquiry that began in October 2013 to examine whether opportunities exist to improve patient care. As a result of the report, migraine received a lot of attention in the press with articles being featured in The Express, The Times and several prominent online publications. Our trustee, Professor Peter Goadsby, was interviewed on ITV’s Good Morning Britain along with chairman of the APPG Jim Fitzpatrick MP and two migraine sufferers, Vicky Probyn and Hilary Hoad. For more information on the APPG report please see page 12.
First ever neurological dataset for England launched

Following years of campaigning by the neurological community, the first ever neurological dataset for England was published on 29th March 2014. The Neurological Alliance, of which The Migraine Trust is a member, has been instrumental in bringing about this essential change for the future of neurological services. For over a decade, there has been recognition all the way up to the most senior levels of the NHS that neurological services will only be able to improve if the health service can measure what is currently happening on the ground. Despite this knowledge and the growing impact that neurological conditions are having on our health and social care services, up until now very little information has been nationally collated and published on how services for people with neurological conditions are performing. Without such data the NHS cannot accurately define service priorities or capture progress. The publication of the neurological dataset, which is available on the Health and Social Care Information Centre website, is a huge first step in addressing this lack of information. For the first time we will be able to shine a light on what is happening for people with migraine, headache and other neurological conditions in England and start to pinpoint where problems may exist and how they can be addressed.

Help others with migraine by displaying a poster

Can you help us to raise the profile of The Migraine Trust by displaying a poster? Our new poster is aimed at people with migraine who may not be aware of The Migraine Trust and that we offer free information that could help them understand and manage their condition. We hope to get our poster displayed in as many GP surgeries, community venues (libraries, etc.) and workplaces as possible, but need your help. Visit www.migrainetrust.org/posters to request a poster to be sent to you.

Public Health England and NHS England launch the first Neurology Intelligence Network

The Rt Hon Norman Lamb, Minister of State for Care Services, launched the new neurology intelligence network in June. Sponsored by Public Health England, in partnership with NHS England, and supported by the Department of Health, the Neurology Intelligence Network is one of only five Health Intelligence Networks being developed during 2014-15. The Neurology Intelligence Network website provides information on emergency admissions to hospital for 12 neurological conditions, including headache and migraine, across all the Clinical Commissioning Groups in England.

The Neurology Intelligence Network website provides information on emergency admissions to hospital for 12 neurological conditions, including headache and migraine, across all the Clinical Commissioning Groups in England.

The Network will:
• Promote efficient and effective data collection throughout the neurology journey
• Provide a common national repository for neurology datasets
• Produce expert analyses, to monitor patterns of neurology care
• Enable use of neurology information to support audit and research programmes
• Use information to drive improvements in neurology care and clinical outcomes

Care and Support Minister, Norman Lamb, said: “Time and again we’ve seen that better information leads to better care. These Networks will be hugely important to help providers use data and intelligence in ways that will help improve services. It will also be an invaluable assistance to commissioners.”

You can view and comment on the Neurology Intelligence Network, and tell commissioners what information is needed to commission effective neurological services at www.ypho.org.uk/mhdnln.

New rules to improve support to children with medical conditions in school

New statutory guidance for schools on the support they should give children with medical conditions such as Type 1 diabetes, asthma, epilepsy and heart conditions has been published by the Government.

The guidance sets out the practical support schools will be expected to provide to support children with medical conditions, such as making sure they have individual healthcare plans in place and providing training and support for school staff. Children with migraine take on average between 32 days and 3 months off from school due to their migraine compared to the general population who take between 3-13 days off (Abu-Arafeh 2010). This can have a knock-on effect on a young sufferer’s educational attainment, confidence, behavioural problems and their ability to make friends. It is vital that these children have the support they need at school, and that teachers and school staff understand the condition and its impact.

The change comes following a long campaign by a group of health charities, including The Migraine Trust. The charities, working collectively as The Health Conditions in Schools Alliance, called for this legal protection because under the previous system there was no consistency in the support that children with migraine and other health conditions received. Whilst we know that many schools provided excellent support to sufferers, there are too many examples where children do not achieve their full academic potential due to migraine, and experience avoidable ill health, bullying and stigma at school.

The guidance gives examples of the type of support that schools should give, including:
• Training and support for school staff
• Information and training for parents
• Access to a named contact

You can view and comment on the guidance on the Government’s website www.gov.uk.

Wendy Thomas, Chief Executive at The Migraine Trust, said: “The Government’s new guidance is excellent news for pupils with migraine and other health conditions. We welcome this much needed change, which provides clarity on the responsibilities of schools, local authorities and health services for parents. We do not underestimate the challenge that schools face in supporting the millions of children with a medical condition. The task now is to ensure that the guidance is properly implemented across the country, and that school staff and nurses have access to the condition specific information and training they need to fulfil their role.”

The guidance, “Supporting pupils at school with medical conditions” is available to download from the Government’s website www.gov.uk.
The fourth European Headache and Migraine Trust International Congress (EHMTIC) will take place 18-21 September 2014 in Copenhagen, Denmark. EHMTIC is a biennial research conference organised jointly by The Migraine Trust and the European Headache Federation.

EHMTIC has become known as a premier international event for neurologists, physicians, scientists, researchers, international experts and healthcare professionals with an interest in migraine and headache disorders. EHMTIC 2014 offers a four day programme covering the latest research, therapies and developments from internationally recognised leaders in the field.

The aim of this conference is to provide a better understanding of migraine, trigeminal autonomic cephalalgias, particularly cluster headache, tension-type headache and other headache disorders as well as trigeminal pain, and to share new scientific evidence and understanding for improving diagnosis and treatment for patients.

Representatives of The Migraine Trust, including Professor Peter Goadsby, Drs Fayyaz Ahmed, Brendan Davies, Mark Weatherall and other trustees, our Chief Executive Wendy Thomas and Research Fellow Dr Anna Andreou, will be travelling to Copenhagen later this month to attend EHMTIC. As with EHMTIC 2012 in London, EHMTIC 2014 will feature an event specifically organised for members of the public to attend as part of our commitment to disseminating information to those personally affected by migraine and headache disorders.

In the next issue of our Migraine News journal we will share with you a roundup of key news from EHMTIC 2014.

**Migraine Trust research programme**

Many in the headache and migraine community, including The Migraine Trust, have been frustrated and disappointed in recent years to see the research base for migraine in the UK rapidly diminishing with less than £1 million invested in 2012. Despite the plethora of facts in circulation which demonstrate the prevalence, impact and financial cost of migraine, we continue to fight the stigma and disinterest surrounding migraine.

The Migraine Trust was established as a charity in 1963 with a strong focus on promoting and funding migraine research, something that we passionately believe is vital to understanding migraine and finding a cure. We are proud of our continued commitment to research and pleased that we were able to re-establish our migraine research programme in 2012 by funding a three-year project led by Dr Anna Andreou, Migraine Trust Research Fellow (read on for an update on Dr Andreou’s work).

We are pleased to announce that The Migraine Trust recently awarded a Clinical Training Fellowship attached to Professor Peter Goadsby at the NIHR-Welcome Trust Clinical Research Facility, King’s College Hospital, London. Our dedicated research programme is the only one of its kind in the UK and we are extremely grateful to all those who make it possible through donations and legacies to The Migraine Trust. It costs £35,63 to fund one hour of migraine research and we need to continue seeking the money needed to fund research in the UK. We must ensure migraine research continues so we can make significant advances in our understanding of migraine.

Research funded by The Migraine Trust (Research Fellowship programme) was presented at the 55th American Headache Society meeting, held in Los Angeles in June 2014, by Dr Anna Andreou, Imperial College London.

The study aimed to investigate whether nitric oxide, a known trigger of migraine attacks, may alter the neuronal activity of a specific subnucleus of the brain area called the hypothalamus. In migraine patients, the molecule nitric oxide has been shown to trigger a migraine attack with all associated symptoms, including premonitory symptoms, i.e. symptoms that patients experience before the actual migraine headache starts, such as yawning, neck stiffness, dizziness, etc. A recent study in migraine patients, demonstrated that during the premonitory phase of migraine attacks induced by nitric oxide, there are blood flow changes in the region of the hypothalamus, suggesting the involvement of this brain area in the development of symptoms, and possibly in the initiation of the attack.

However, brain imaging techniques are limited in the information they can provide. The techniques cannot suggest the exact hypothalamic subnuclei that are involved. As a number of hypothalamic subnuclei with different neurotransmitter properties exist in the brain, it is essential to identify more specifically potential subnuclei that may be involved in this process. Additionally, the brain imaging techniques used in humans cannot offer any direct information on the actual changes of the neuronal activity in the affected areas.

The study identified the specific hypothalamic subnucleus, the A11, as an important subnucleus affected by nitric acid. This area expresses the neurotransmitter dopamine, and has previously been shown to be involved in migraine pathophysiology. The physiological function of this subnucleus following its activation, is to suppress neuronal activity evoked by painful stimulation that is used to model migraine head pain. In the study presented at the AHS meeting, nitric oxide was found to reduce the activity of the A11, suggesting that this subnucleus, under the influence of nitric oxide, may no longer suppress painful signals in the brain.

This is the first study to identify a specific hypothalamic subnucleus, the neuronal activity of which, can be negatively altered by the migraine attack trigger, nitric oxide. This data offer important insights into the pharmacological targets that can be used to block these actions of nitric oxide with a significant potential for pain relief, or even for preventing the initiation of a migraine attack.

The project was selected for an oral presentation at the AHS meeting, and further investigations on potential pharmacological targets that can benefit patients will be investigated in future experimental work. The Migraine Trust is grateful to all its private donors and the Rosetrees Trust for supporting this important research.
For almost 50 years, The Migraine Trust has been working to eradicate the pain and misery of migraine from people’s lives. We have come a very long way in that time and we are now able to support hundreds of thousands of migraine sufferers every year through our information and advocacy support services and our public events. All of these are vital tools in allowing migraine sufferers to lessen the number and severity of their attacks.

But, all these services simply disseminate the knowledge we already have – they do not move us any closer to a cure. Our ultimate goal at The Migraine Trust – the reason for our existence as a charity – is to find a full, permanent cure for migraine. We fund two Research Fellows, whose work is absolutely at the cutting edge of new migraine research (and it’s the only work being done in the UK).

It’s progress: but it’s not enough. Finding a cure for migraine is like looking for a needle in a haystack: we know it’s there, but it’s incredibly difficult to find. The simple truth is that the more researchers we have looking, the sooner we’ll find it.

So, this Migraine Awareness Week, we are asking everyone in the migraine community to support our research fundraising appeal. We can not promise overnight success, but we can guarantee two things. Firstly, that every penny donated towards our research work will bring the day we find a cure closer. Secondly, that The Migraine Trust will continue to work tirelessly to support everyone in the migraine community – by providing free support and information to help to reduce the impact migraine has on their lives.

But, we can only fund more research if people who understand migraine and its horrible effects support us with donations. We will get no support at all from the government or the NHS for this work (although we have tried and continue to push). We are on our own. A cure for migraine will only be found through the support of migraine sufferers.

At the moment, our research spending is limited to just £356 per day. That’s a total of £130,000 per year – or the equivalent of only 1.6 pence per year for every migraine sufferer in the UK.

This is the research that will – one day – find a cure. But while we are only able to invest this tiny amount in new research that day will remain very far off. Without a significant increase in funding, we will consign further generations of young migraineurs to a life with the burden of migraine.

No one outside the migraine community will help. The cure for migraine will only be found by migraine sufferers themselves.

We have seen in recent months the huge leaps forward that have been made in the understanding of Alzheimer’s disease. This has been delivered through exactly the same kind of research in which The Migraine Trust is currently engaged. So, we ask all who know and understand the reality of migraine to take action today. Support our Research Appeal today and help us to find the cure sooner.

You can make a donation now online at www.justgiving.org.uk/migrainetrust/Donate/ or by calling our Fundraising Team on 020 7631 6976.

“I’ve suffered from migraine for over 50 years. It ruined my young adult life and has shaped my whole life since. Research led to the discovery of Triptans, which I first took in 1991 and have allowed me to take control of my migraine. We still need more research. It might not help me now, but there’s a generation of young people right now who simply can’t be allowed to go through the pain and misery I experienced.”

Valda Walker

“2015 will be the 50th anniversary of The Migraine Trust. We have created ‘migraine heads’ and we will be using them in online and offline activity to demonstrate the reality of migraine for those who suffer with the condition – and the hope for the future we all have. You can take part today by going to www.migrainetrust.org/migraine-heads.

We would like people to use the grey head to show what it’s like to be affected by migraine – using words, illustrations or pictures. The blue head is to show no one outside the migraine community will help. The cure for migraine will only be found by migraine sufferers themselves.

We have seen in recent months the huge leaps forward that have been made in the understanding of Alzheimer’s disease. This has been delivered through exactly the same kind of research in which The Migraine Trust is currently engaged. So, we ask all who know and understand the reality of migraine to take action today. Support our Research Appeal today and help us to find the cure sooner.

You can make a donation now online at www.justgiving.org.uk/migrainetrust/Donate/ or by calling our Fundraising Team on 020 7631 6976.

“My mum had migraine, I have it and now my 8-year old daughter Holly has it too. It’s heartbreaking to see her going through an attack, I feel upset, angry and guilty all at the same time. We have to invest in research – today – to make sure that we can break this vicious cycle. Not just for Holly, but for every family going through this nightmare.”

Claire Horton

We would like people to use the grey head to show what it’s like to be affected by migraine – using words, illustrations or pictures. The blue head is to show what it would be like to be completely free of migraine.

Valda Walker

“My mum had migraine, I have it and now my 8-year old daughter Holly has it too. It’s heartbreaking to see her going through an attack, I feel upset, angry and guilty all at the same time. We have to invest in research – today – to make sure that we can break this vicious cycle. Not just for Holly, but for every family going through this nightmare.”

Claire Horton
In October 2013 the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) launched an inquiry to investigate the current delivery of headache care. The aim was to examine whether opportunities exist to prevent spending wastage, make better use of NHS resources and to improve the experiences of headache sufferers in England. The APPGPHD is a cross party group of MPs and members of the House of Lords who have a particular interest in primary headache disorders.

The inquiry panel, led by the APPGPHD’s chair Jim Fitzpatrick MP for Poplar & Limehouse, received over 70 evidence submissions following their call for evidence. Commissioners, academics, health professionals, patient groups, stakeholder organisations, patients and their families were all given the opportunity to provide written evidence on their experiences of existing service provision and the opportunities that exist to improve these. The APPGPHD invited key witnesses to address the panel at two oral evidence sessions, held in the House of Commons. Wendy Thomas, Chief Executive at The Migraine Trust submitted oral evidence alongside a number of patients, representatives from the Organisation for the Understanding of Cluster Headache in the UK (OUCH UK), Trigeminal Neuralgia Association, the British Association for the Study of Headache (BASH) and specialist health professionals including The Migraine Trust’s medical trustees, Professor Peter Goadsby, Dr Fayyaz Ahmed and Dr Brendan Davies.

The final report reveals that headache disorders, including migraine, are poorly managed and under prioritised. The report stresses that greater value for money and a reduction in NHS resource wastage can be achieved by strengthening services for headache and migraine patients at primary care level. Despite the fact that the majority of cases can be treated in primary care, headache accounts for 33% of all new referrals to neurology and is the most common neurological reason for an attendance. The group also warned that failure to address poor public awareness of headache disorders, inadequate education of health professionals, and to prioritise neurology services undermines the ability of the NHS to effectively commission, design and deliver high quality services.

The APPGPHD make 10 clear recommendations in the report intended to address inconsistencies in service provision of services and support available to headache disorder patients. We have a significant way to go before the provision of services and support is sufficient to address the burden of primary headache disorders across England. The inquiry highlighted the huge breadth of factors and complex considerations that affect the provision of high quality care and the experience of headache disorder patients. We have a significant way to go before the provision of services and support is sufficient to address the burden of primary headache disorders across England. To read a copy of the report visit www.migrainetrust.org/parliament To read more information about the inquiry, including summaries of the written evidence, oral evidence sessions and the reception visit www.headacheuk.org

Here’s what people had to say about the APPG’s report:

Vicky Quashe, Headache Nurse Specialist, Hull Royal Infirmary: “I would gladly welcome the development of more specialist headache services and the creation of additional headache specialist nurse posts within these services as recommended in the report. This would ensure all headache sufferers are able to access specialist evidence-based headache management, advice and support when they need it, as close to their home as possible. It is welcome news that the impact of the headache specialist nursing role is now slowly gaining recognition as a crucial, cost-effective component of healthcare delivery, in addition to the recognition we already receive from the patients we see within our own clinical practise.”

Hannah Verghese, Advocacy & Policy Manager, The Migraine Trust: “Despite the huge impact that migraine and other headache disorders have on the NHS, the economy, society, and on sufferers’ lives, it is all too often overlooked as ‘just a headache’. We welcome the report and fully support the 10 recommendations made by the APPG. We are committed to working with the MPs, Peers and stakeholders involved to drive forward these priorities.”

We want as many MPs as possible to know about the report and take action locally and in parliament. MPs are more likely to take note if they are contacted by a constituent. Please consider contacting your MP:

• A template letter is available on our website
• Write or email your MP about the report and ask them to take action.
• Tweet your MP using the hashtags #APPGPHD #migraine
• Find out if your MP is on twitter at www.tweetminster.co.uk/mps
• www.migrainetrust.org/news-headache-services-in-england-18589
Q&A

“Do chocolate and cheese cause migraine? Is it true that taking painkillers makes migraine worse? Would many years of severe migraine attacks cause brain damage in later life? There are a lot of myths about migraine, and it is only with evidence based information that people with migraine can make informed choices about managing their health condition.”

Susan Haydon, The Migraine Trust

Back in 2012, we introduced Migraine News readers to a campaign The Migraine Trust was backing called ‘Ask for Evidence’. Science education charity Sense About Science launched the campaign to encourage people to ask for the evidence behind scientific and medical claims to counter a tide of misinformation and to get us all asking advertisers, companies, government bodies and others to set out the evidence for their claims.

For more information visit www.senseaboutscience.org/a4e.

A key focus of our work has always been to promote and disseminate evidence based information to aid migraine sufferers in their decision making, so we were happy to be involved with the ‘Ask for Evidence’ campaign’s recent focus on migraine related claims.

Here is a selection of the questions asked, with answers provided by The Migraine Trust’s Susan Haydon. You can read additional Q&As at www.senseaboutscience.org/pages/ask-for-evidence-on-migraine-claims.html.

Amy asked for evidence about the Cefaly® neurostimulation device that claims to be able to relieve the symptoms of migraine.

Q: “Cefaly seems like an interesting drug-free alternative for some migraine sufferers. Peripheral nerve stimulation (PNS) has shown promising preventive properties in episodic and chronic migraine. The intervention caught my attention as I have successfully used an electric acupuncture system for years after a head injury and chronic cluster migraines and this operates by similar principles.”

A: Neurostimulation devices have been of increasing interest for the treatment of primary headaches in recent years. Several new minimally invasive and non-invasive devices are being tested for migraine and other primary headaches. Two different approaches are currently being developed in the United Kingdom: single pulse transcranial magnetic stimulation (tMS), and vagal nerve stimulation (VNS). Whilst the evidence base for the use of TMS and VNS devices in headache disorders is still sparse, early indications suggest that they may in time become helpful additions to the armamentarium of headache specialists in the UK.

The National Institute for Health and Care Excellence (NICE) has recently reviewed the use of sTMS both as an acute treatment (at the start of a migraine attack), and as a preventative treatment lused regularly with the aim of reducing the frequency and/or severity of attacks. Based on this trial, and on the results of subsequent audits of its use in real-world practice, NICE has recommended that the device may be used in an NHS setting only under the direction of doctors specialising in managing headaches. They have further recommended that patients should be told that the procedure is not intended to cure migraine and reduction in migraine symptoms may be moderate, and that more research on magnetic stimulation of the brain for treating and preventing migraine is needed.

Information from the National Institute for Health and Care Excellence (NICE) about transcranial magnetic stimulation for migraine can be read on the NICE website (www.nice.org.uk).

Data from a multi-centre, double-blind, randomised, sham-controlled trial including 67 patients analysing the efficacy of a transcutaneous supraorbital nerve stimulator (tSNS), the Cefaly® device, for the prophylactic treatment of migraine have been presented. The results show a reduction of monthly migraine days and drug intake while no adverse events were observed. Therefore the results indicate that tSNS may offer an effective prophylactic migraine treatment. However, larger trials are needed to clarify its potential efficacy.

Regular tea drinker Dan wanted to know whether his tea-free weekends were the cause of his migraine.

Q: “I suffer from fairly regular headaches over the weekends. I’m not sure if they can be classed as migraine or not, although they are very unpleasant. I recently read an article that suggested caffeine may be the cause of my headaches – or at least the absence of caffeine. During my working week I’m fuelled by a regular supply of tea in the office. At the weekend I hardly drink it at all. Are my headaches a sign of caffeine withdrawal and is this a well-known situation? I’ve asked for the evidence behind these claims from the authors of the article but I would like to hear from The Migraine Trust about what research has been done in this area.”

A: “Abandoning regular high dose caffeine can trigger headache. Caffeine may have some value in treating migraine symptoms. Some headache experts advise no caffeine at all, which can be worth trying, though most allow moderate caffeine intake.

People with migraine who work from Monday to Friday often report that their migraine is more likely to occur at the weekend. This pattern may result from a gradual build-up of triggers during the week, culminating in additional triggers at the weekend. For example, a person may feel more relaxed after a stressful week, go to bed late on Friday night after an evening out, sleep in on Saturday morning and change their eating patterns, often with a late breakfast. Caffeine withdrawal, following a reduced caffeine intake at weekends compared with the working week, has been blamed for migraine at the weekend, however there may also be other triggers involved.”

Rob asked for the evidence behind claims regarding the efficacy of acupuncture and acupuncture for treating migraines.

Q: “While not a regular sufferer of migraines myself, the few that I have experienced have been unpleasant enough to make me very interested in any treatments on offer. So I was intrigued by the range of treatments being advocated on the Remedy’s Health Centre’s website. While many treatments were suggested, the ones that particularly caught my eye were the recommendation of acupuncture and acupuncture. Acupuncture, it claims, ‘can balance underlying hormonal deficiencies, tone the gastrointestinal system, and calm reactive blood vessels’. In order to assess the validity of these claims, and their relevance to migraine treatment, I contacted the website, and asked them if they could provide any links to the sources and evidence behind their claims. I am awaiting a response.”

A: “There does seem to be some evidence for the use of acupuncture for migraine and headache prophylaxis (preventive treatment). However the evidence is difficult to evaluate as ‘ sham’ acupuncture seems to be as effective as ‘real’ acupuncture for headache and migraine in trials. It may be that there is a powerful placebo effect in relation to acupuncture for migraine. Some trials have looked at acupuncture in addition to usual treatment for migraine, which also provided some evidence for effectiveness.

NICE have published guidelines for migraine treatment which include acupuncture, in that up to 10 sessions of acupuncture may be offered for the prophylactic treatment of migraine by the NHS if other medicines do not work. However it is not really known how acupuncture may work in migraine. It is not thought to be in relation to underlying hormonal deficiencies, problems with the gastrointestinal system or calming reactive blood vessels, rather, a powerful placebo effect has been suggested.”
Meet Wendy Thomas,
Chief Executive of The Migraine Trust

1. What first motivated you to join The Migraine Trust?
I think that I've always been interested in migraine because I started to have migraines when I was at university and also my eldest son and my daughter, so two of my three children, developed migraine. My eldest son in particular has suffered a great deal.

I have always worked in the voluntary sector, always in health, in sexual health for many years both in the UK and internationally. So when this job, which was an interim job at the time, became available, I was very interested. I had previously had some information from The Migraine Trust, for my eldest son and thought their information was very good and so I applied for it. I then discovered, as I've learnt more about migraine over the years, I did actually know more than I thought I did as there is a lot of cross over with sexual health.

2. What are the key developments you've seen for the migraine community in your time here?
I think one of the biggest things to have changed, in the last few years in particular, have been related to social media with the growing use of Facebook and Twitter, etc. There are many more people now that have heard of The Migraine Trust. It's an ongoing problem trying to make sure people know about us. It is always a disappointment when we have a 'Managing Your Migraine' event, for example, and somebody says 'I've had migraine all my life and I've only just found out about you.' We always have to continuously try to extend our reach and, no matter what you do, you can never do enough to reach out to people but social media has been very good for that. Now there is a different group of people saying 'yes, I've got migraine.' I think a lot of people feel stigmatised by getting migraine and don't like to tell people about it. They don't want to be seen as unreliable in work situations, or also in social situations, so they're reluctant to admit they've got it but now there's a new group of people now saying 'yes I've got it and why is there not more being done about it, why am I not getting a better service, why am I not getting better help?'

In terms of the migraine and headache community working together, we have done a lot of work in supporting the All-Party Parliamentary Group on Primary Headache Disorders (APPCHD) which means that we have been able to bring a lot of people together – health professionals, clinicians, patients, groups, and Parliamentarians. This community has grown with a lot of input from The Migraine Trust.

3. If you could go back in time and change one thing since you joined The Migraine Trust, what would it be?
That's quite a difficult question. I really can't think of anything I would change dramatically actually, apart from getting the research programme up and running earlier than we did but it was lack of funds that prevented this. Lack of funds dictates our strategy unfortunately.

4. You're also involved with several other organisations, what roles do you have there and how do those relationships help the work of The Migraine Trust?
I am a director of the European Headache and Migraine Trust International Congress (EHMTIC) from the Migraine Trust side, as well as two of our trustees, Professor Peter Goadsby and Dr Fayyaz Ahmed. We have meetings every two years and that does require quite a lot of my time. We have professional congress organisers but it stills requires a lot of input to see how everything is progressing. The next meeting is in Copenhagen in September and we're hoping for some good science and a lot of delegates because the profits from these congresses go into the research pot. The following meeting will be held in Glasgow in 2016.

I'm also a council member of the British Association for the Study of Headache (BASH). I was elected in 2011 for 2 years and then re-elected in 2013. That is actually very interesting and useful as I am able to bring my expertise in charity law and governance to BASH, which is also a charity. We work closely with clinicians on how to improve treatments and how to help patients find access to treatments. We also always ask local BASH members to help us when we put on our 'Managing Your Migraine' events around the country. Patients very much appreciate the opportunity to listen to experts talking about acute and preventative treatments and, of course, the latest research. They also value the chance to meet and talk to others with the same condition.

As well as this, I have been the treasurer for the International Headache Society (IHS) since 2010 and I find it extremely helpful to be able to understand how migraine is treated in different communities across the world. The International Headache Congress is held every 2 years so it is always a good opportunity to meet and discuss areas of concern, new developments and funding opportunities, as I do at EHMTIC.

5. Looking forward, what developments do you think we'll see in the next five years and what are you most excited about?
I'm personally most excited by the prospect of future research. I think migraine is getting a higher profile and we mustn't lose momentum. I think, especially with Professor Goadsby as the Director of the NIH-Wellcome Trust Clinical Research Facility at King's College Hospital London, there must be more support for headache research forthcoming.

I also think that because of the genetic component in migraine, I'm starting to see more people who are concerned not just about their children but their grandchildren, as I am, and are quite focused on trying to finding a cure. If there is more research on the condition then that will help us to gain a better understanding. Whether there will be a cure in my lifetime I don't know, but I do think that there is a lot of competition for funding, especially for research against other conditions which are life threatening. Migraine continues to be under resourced but considering that there are an estimated eight million people with migraine in the UK then we should get a little bit more of the action.

"Migraine continues to be under resourced but considering that there are an estimated eight million people with migraine in the UK then we should get a little bit more of the action."
Charity of the Year
As well as people taking on specific challenge events for us, we have also been elected Charity of the Year twice over. Nicki Vincent, Lady Captain of the Bognor Regis Golf Club and Karen Spicer, Lady Captain of the Lindfield Golf Club, have both elected to raise money for The Migraine Trust throughout 2014. Between the two clubs there have been a whole host of fundraising activities from raffles and fun days through to golfers playing four rounds of golf in one day! A huge thanks to Nicki and Karen who chose The Migraine Trust as their charity of the year.

Plymouth Half Marathon
Last May saw a family effort to raise money with Allan, his wife Liz, daughter Hannah and son-in-law Tom taking to the streets to run the Plymouth Half Marathon. Between them they managed to raise over £1000 and we’re incredibly grateful for all the work they put in!

Open Gardens
If you have green fingers and are proud of your garden, however big or small, why not use your hobby to raise money for The Migraine Trust next summer? This year we had two supporters open their gardens for us – Valda in March and then Kathy in July – and between them they managed to raise over £500 and were featured in the local press.

You can organise your own open garden event, publicise locally and collect donations from visitors, refreshments and small fundraising events. Our Fundraising Team will be able to provide you with all the help and support you need to plan your event and make it a success.

If you are interested in independently opening your garden get in touch with us on 020 7631 6976 or email fundraising@migrainetrust.org.

Isle of Wight Challenge
On Saturday 23rd August, husband and wife team Cat and Dan took on the epic challenge of walking 56KM around the Isle of Wight. Cat suffers from chronic migraine and took the challenge on as she knows ‘first-hand the difficulties living with an invisible illness and the importance of new research into preventative therapies, the support of a network of migraine specialists and raising awareness of the realities of migraine disease.’ Between them they raised over £500 with sponsorship money still coming in. Congratulations on completing this ambitious walk!

Inverness Half Marathon
In March, Jill took part in the Inverness Half Marathon on behalf of everyone like her who suffers from migraine. Jill said, ‘I have been a migraine sufferer since the age of 10. For the past 11 years, I have been frequently bothered by these exruciating migraine attacks. These migraines put your life on hold and have caused me to miss numerous days of school and work. I envy every individual who has never suffered a migraine. They are not “just a headache”. A migraine is sheer pain throughout your whole body that can last up to 3 days. As well as experiencing a throbbing headache, there is also the aura (no vision), nausea and tingling sensation throughout your body. The worst part is that a migraine can occur at any time of the day.’

All of Jill’s efforts led to her not only finishing the half marathon in just over two and a half hours, but also raising over £600 for The Migraine Trust. Thanks Jill!

London Marathon 2014
On Sunday 13th April, our amazing team ran a gruelling 26.2 miles to raise money to help beat migraine. Despite having a fundraising target of £9,000 between them, Alex, Becky, John, Natasha, Simon and Sreejesh managed to raise over £16,000 – a huge achievement which we’re very proud of! Everyone here would like to say a massive thank you to the 2014 Marathon Team for all their hard work, both training and fundraising!

If you would like to take on this challenge in 2015 please visit www.migrainetrust.org/running to find out how to apply. Applications close on September 30th.

In July, our team of runners joined 25,000 people filling the streets of the nation’s capital for the British 10K London Run. They enjoyed the unique chance to run past many of the country’s greatest landmarks including Big Ben, the London Eye, St Paul’s Cathedral, Trafalgar Square and Westminster Abbey. Between them Anna, Damon, Charlie, Ellie, Daniel, Javid and Iain managed to raise over £1000 for The Migraine Trust and we’d like to say a huge thank you for all the hard work they put into training and fundraising.

London Bupa 10,000
In May, Naomi took part in the London Bupa 10,000 to raise money for migraine to support her friend, Amanda. Naomi raised a staggering £1,340 and everyone here at The Migraine Trust would like to say a big thank you for all her hard work!

Chester Half Marathon
The spring of 2014 saw Sian take on the Chester Half Marathon. Sian, who suffers from migraine herself, said she chose to run for The Migraine Trust because it is a charity she ‘really cares about’ and because ‘migraine research is “desperately underfunded”.’ She raised the fantastic total of £138 and we really appreciate all the work she put in.

If you would like to fundraise for us please contact our Fundraising Team on 020 7631 6976 or email fundraising@migrainetrust.org. To see what fundraising opportunities we have coming up, visit www.migrainetrust.org/fundraising.

If you have green fingers and are proud of your garden, however big or small, why not use your hobby to raise money for The Migraine Trust next summer? This year we had two supporters open their gardens for us – Valda in March and then Kathy in July – and between them they managed to raise over £500 and were featured in the local press.

You can organise your own open garden event, publicise locally and collect donations from visitors, refreshments and small fundraising events. Our Fundraising Team will be able to provide you with all the help and support you need to plan your event and make it a success.

If you are interested in independently opening your garden get in touch with us on 020 7631 6976 or email fundraising@migrainetrust.org.
CALENDAR OF EVENTS

If you have any questions regarding events, please email events@migrainetrust.org or call 020 7631 6976.

September
7 – 13: Migraine Awareness Week
A national campaign to increase public awareness of migraine. Visit www.migrainetrust.org/migraine-awareness-week for details and how you can get involved.

9: Twitter Q&A with Dr Mark Weatherall
Consultant Neurologist and Trustee of The Migraine Trust Dr Mark Weatherall will be answering your migraine related questions on Twitter from 2-3pm. Use hashtag #AskMigraine.

13: Thames Path Challenge
Join supporter Anna in taking on this epic walking challenge and raise money for The Migraine Trust. For more information go to www.migrainetrust.org/events.

18 – 21: EHMATIC
The fourth European Headache and Migraine Trust International Congress (EHMATIC) will take place in Copenhagen, Denmark, offering a four day programme covering the latest research, therapies and developments from internationally recognised leaders in the field.

30 – Virgin Money London Marathon
Application Closing Date
Please make sure you get your application for the London Marathon to our Fundraising Team by 30th September if you would like to be considered for one of our guaranteed places for 2015. Email fundraising@migrainetrust.org.

October
11 – Managing Your Migraine, Newcastle
Come and join us in Newcastle for an information day for people living with migraine in association with British Association for the Study of Headache. The event includes presentations by migraine experts with the chance to ask questions.

November
1 November – 24 December
Don’t forget to order your Migraine Trust Christmas Cards. Cards are available through our online shop (www.migrainetrustshop.org) or by getting in touch with our Fundraising Team: please email fundraising@migrainetrust.org or call 020 7631 6976.

Christmas time...

Christmas time...

Our Christmas cards are available to buy from www.migrainetrustshop.org or by calling 020 7631 6976.

Everything we do for migraine sufferers across the UK is funded by voluntary donations. Please, give what you can today and help us to continue our vital work.

- £32.60, which will pay for two hours’ information support, making sure we can answer the telephone helpline when it rings.
- £20, which would cover the costs of two information packs sent to migraine sufferers who have contacted us for the first time.
- £285, which would pay for a full day of dedicated migraine research – bringing us one day closer to better treatments and ultimately a cure.

My own preferred gift amount of: £___

I enclose a cheque payable to The Migraine Trust OR Please debit my credit/debit card
Card type: Maestro Visa Mastercard Delta CAF
Card holder’s name: ____________________________
Card number: ____________________________
Valid from: / Expiry date: / 3 digit security number: ____________________________
Issue number (Maestro only): ____________________________
Signature(s): ____________________________ Date: ____________________________

Please treat as Gift Aid Donations all qualifying gifts of money made:
- Today
- In the past four years
- In the future (Please tick all that apply)

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Signature: ____________________________ Date: ____________________________

The Migraine Trust will keep your name and contact details on our database and use this information to inform you about events, news or ways to support The Migraine Trust that might be of interest to you. If you do not wish for your details to be used in this way please tick the box.

Funds raised will be used in accordance with the aims of the charity as set out in its governing document, namely to help improve the lives of people with migraine in the UK, and work towards our vision of a world where people can live free of the condition.

Please use the freepost envelope provided or return to: Freepost RSRB-ZYSK-GGCC, The Migraine Trust, 52-53 Russell Square, London WC1B 4HP

Thank you
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.)

Telephone: 020 7631 6973

Email: info@migrainetrust.org

Website: information about migraine and headache is available at our website including downloadable factsheets and packs. You can also subscribe to The Migraine Trust’s bulletin. The Migraine Trust is a registered charity funded entirely by voluntary donations from individuals, charitable trusts and corporate sponsors. 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

Email: info@migrainetrust.org

Website: www.migrainetrust.org

The Migraine Trust, 52-53 Russell Square, London, WC1B 4HP

A company limited by guarantee incorporated in England no.3996448

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