Migraine at work
Great Ormond Street Hospital’s Headache Team
What is it like to take part in a clinical trial?
I think I should start by telling you all that after ten years as Chief Executive of The Migraine Trust I am retiring this month after the 5th European Headache and Migraine Trust International Congress (EHMTIC) in Glasgow.

It has been an eventful and mainly enjoyable experience and I have been lucky to have worked with such excellent colleagues and trustees over the years. The commitment that everyone has to improving the lives of those who suffer from migraine is simply unparalleled.

Looking back over our 50th celebration last year, I realised just how many changes there have been over the last ten years. Some of the times have been tough, especially after the financial crisis in 2008. Financial support dropped as many people realised that they just had to cut their monthly outgoings. Since then I am pleased to say that many have reinstated their donations and we have been fortunate that device developers and pharmaceutical companies have thought that supporting a patient focused, research driven charity is vital.

We have attracted more individual donors as well as extending our reach via Facebook and Twitter.

Supporters and their families continue to remember us in their wills. Legacies are so important to us as they enable us to continue our research into migraine as well as providing the best evidence based information and advocacy services to people who are suffering from this condition. We are always grateful for this act of remembrance.

I am pleased to tell you all that preparations for EHMTIC are going well. We will have some excellent speakers and be able to hear about the latest research and the emerging treatments for migraine. The Public Session will be held on Sunday 18th September in the afternoon and there will be a write up of the Congress in Migraine News early next year.

Thank you for all your help and trust in me over the years. I do intend to keep in contact with The Migraine Trust, as well as spending more time with my hens. I wish my successor good luck and feel assured that I am leaving the Trust in her very capable hands along with those of the staff and trustees.

Wendy Thomas
Chief Executive
Research update

Update from our Chairman, Ian Watmore

The Chair of any organisation wants to have a great Chief Executive, and when they have one, dreads the day when they leave or retire. I have been filled with such dread ever since Wendy told me she wanted to retire after EHMTIC 2016.

Wendy has truly been a great Chief Executive for the Trust. She came for a year and stayed for a decade. She has been a source of wisdom and inspiration for us all. She has steered us through the dark days of the financial crash and was rewarded by hosting our 50th anniversary in 2015. She has led a team which has funded research, served sufferers and raised awareness of this dreadful condition. Most of all she has helped give migraine sufferers and their loved ones support and hope at their lowest ebb. EHMTIC 2016 will be a fitting climax for her tenure and we are all grateful for her leadership.

Secondly, we have appointed an outstanding new Chief Executive, Arlene Wilkie, who starts on 1 October 2016, and will be in attendance at EHMTIC before then. Arlene is a scientist by background who then moved into the charitable sector with the Breast Cancer Campaign. From there she became Chief Executive of the Neurological Alliance, and now joins us after her unanimous selection by our Board of Trustees. Science, charity, neurological and CEO experience is a dream combination of skills for us and we are very lucky to have her. Welcome Arlene.

“Arlene is joining the Trust at an exciting time for migraine research and support.”

But despite her retirement, I have good news on two fronts. First, after she has taken a well earned rest, Wendy has kindly agreed to become a Trustee in 2017, thus helping the Trust to have continuity and access to her contacts and experience.

“Arlene is joining the Trust at an exciting time for migraine research and support. Our medical trustees are genuinely excited by some of the emerging research into calcitonin gene-related peptide neurotransmitters – long words that may unlock a cure for migraine. The device and pharmaceutical companies are investing and innovating to provide relief and remission for sufferers. Employers are becoming more aware of the cost to their business from migraine induced lost or low productivity days. And we continue to press Government and the NHS to improve public investment and practitioner training.

But all this takes money to invest in research, patient support, employer advocacy and public affairs. We have an outstanding team of dedicated professionals which needs to be funded, and PhD and other research posts likewise. So thank you to everyone reading this who already donates to us, and to everyone else please contact us via migrainetrust.org to help us help sufferers.

In conclusion, let me thank Wendy once again for all she has done, and welcome Arlene for the next chapter in our story to defeat this dreadful condition.
News

Neurology focus packs for Clinical Commissioning Groups (CCGs): England

NHS England’s Right Care programme has released ‘neurology focus packs’ for each CCG in England with detailed spending and activity data for a range of neurological conditions including headache and migraine. The new focus packs are intended to encourage commissioners to identify opportunities to improve the quality and value of neurology services locally. All commissioning packs can be accessed from the NHS England website.

Supporting learners with healthcare needs: Wales

The Migraine Trust responded to a consultation by the Welsh Government on their guidance for schools on supporting learners with healthcare needs. Poor and inconsistent support from schools can have a negative effect on young sufferers’ attendance, educational attainment, confidence, behavioural problems and their ability to make friends. We welcomed the opportunity to respond to the consultation and work with colleagues from a number of health charities to inform the Welsh Government on these issues. For updates please visit our website.

The Government responds to the Public Accounts Committee: England

The Department of Health has responded to the recommendations put forward by the Public Accounts Committee (PAC) in their progress review report on neurology. The PAC warned that neurological conditions are not a priority for the Department of Health and NHS England, and expressed that positive progress risks not being sustained. Despite this, the Government’s response rejected a number of the recommendations including retaining the role of the National Clinical Director and instead cut the post in April 2016. The Migraine Trust, neurological charities and patient and professional bodies across the sector have expressed concern and disappointment with the Government’s response and will continue to work together to campaign for better services for people with neurological conditions.

NICE Multimorbidities Consultation

The National Institute for Health and Care Excellence (NICE) are producing a clinical guideline on the assessment and management of multimorbidities. The guidance, aimed at health professionals, patients and their families and carers, covers optimising care for people with two or more long-term health conditions (multimorbidity) by focusing on individual needs, preferences for treatments and health priorities. The Migraine Trust has submitted a response to the stakeholder consultation. The final guidance is expected to be published in September 2016. For updates please visit our website.

Give with confidence

Following the recent scrutiny of the conduct of some charities, we would like to reassure our supporters and donors that The Migraine Trust is committed to best practice, honesty and accountability with regards to our fundraising and data protection policies. We do not sell on personal details and do not participate in fundraising activities that bombard people or take advantage of the vulnerable. We are registered with the Information Commissioner’s Office and are members of leading fundraising bodies and comply willingly with their regulations and policies so that people can give with confidence to support our work.

For more news, visit our website: www.migrainetrust.org/news/
Leave a gift in your Will

Support migraine understanding and awareness long into the future

After taking care of your loved ones, please consider leaving a gift to The Migraine Trust in your Will.

A gift of just 1% will make a real difference to supporting our charitable work.

Most of The Migraine Trust’s work is funded by individuals – people just like you – and our most vital income comes from people leaving gifts in Wills. We couldn’t do what we do without them.

You don’t have to be wealthy to leave a gift in your Will to help us, nor do you need to exclude loved ones. Whatever the amount – big or small – we’re extremely grateful for any gift that is left to The Migraine Trust, after you have looked after family and friends.

Your gift will help us to continue supporting the millions of people in the UK who suffer from migraine, educating the public and health professionals, as well as funding research to improve treatment and find a cure.

More information can be found at www.migrainetrust.org/legacy or you can call us on 020 7631 6977.
What is it like to take part in a clinical trial?

By Elka Giemza, Unit Manager at the NIHR/Wellcome Trust King’s Clinical Research Facility

Taking part in a clinical trial or study can be daunting, but at the same time extremely rewarding. However, without patients helping us with our research, we would not improve the care and treatments we can give.

I have been asked to write a few words to tell you about clinical trials and what is involved. Here is a little information on several aspects, including finding out about clinical trials, advantages and disadvantages of taking part and what happens when you are in the trial. I go on to discuss the process of giving your permission to do the trial and if you do, the options you have to discontinue the study if you want.

In the UK, we have an organisation called the National Institute for Health Research (NIHR), which is the NHS branch of research. The mission of the NIHR is to maintain a health research system in which the NHS supports outstanding individual working in world class facilities, conducting leading edge research focused on the needs of patients and public. They fund a great deal of research and training for professionals wishing to enter this field of medicine. A clinical trial is any research study that allocates human volunteers or groups of people to one or more health-related interventions to measure and assess the effects on health. Clinical trials are sometimes called interventional trials. Interventions include pharmaceutical drugs but also include cells and other biological products, surgical procedures, radiologic procedures (like x-rays and scans), devices (like a blood glucose monitoring device), behavioural treatments (like psychological therapy), and preventive care, etc. This definition also includes Phase I to Phase IV trials.

“We run trials to increase our understanding of how to treat a particular disease or condition, which may benefit you, the participant, or others like you, in the future.”

We run trials to increase our understanding of how to treat a particular disease or condition, which may benefit you, the participant, or others like you, in the future. You might learn more about your disorder by attending and having more opportunity and time to discuss your condition with your doctor. You may, or may not, be the first to benefit from taking part in a trial.

If you are unwell and interested in taking part in a clinical trial, your doctor or other healthcare professionals may know of research being carried out that may be right for you. However, the most convenient way to find out more is to use the Internet. You can find information on the online registers of clinical
trials, such as the World Health Organization’s International Clinical Trials Registry Platform (ICTRP) or at www.nhs.uk/Conditions/Clinical-trials/. These sites collect information from different registers to provide a central database of clinical trials.

Several charities also keep details about trials for specific conditions. For example, The Migraine Trust works closely with Professor Goadsby, who runs several migraine trials. Further information about these trials can be found on The Migraine Trust website (www.migrainetrust.orgfinding-a-cure). Other health charities also have user-friendly information about some clinical trials. Some charities may not formally publish lists of clinical trials, but may know of some that are relevant to patients with particular conditions.

There are advantages and disadvantages of taking part in a clinical trial. The main reason for carrying out trials is to assess whether one treatment is better than another. During the trial, your treatment and progress may be monitored more closely than if you were receiving the usual treatment. Trials are very important in helping find better treatments. By being involved in a trial, you will obtain information and evidence that may be helpful to you in the future, as well as helping to provide others with the best possible health care.

One of the disadvantages of being in a trial is that, as with any treatment, you can’t be sure of the outcome. You may be given a new treatment that turns out not to be as effective as the standard treatment. It is possible you will experience unexpected side effects. You may have to visit your place of treatment more often, or have more tests, treatments or monitoring than you would if you were receiving the standard treatment in usual care. You will, however, be informed of all the visits you would be required to make, before you agree to take part.

It is important that you fully understand what is involved before joining a trial. If you are asked to take part in a trial you are free to say yes or no. For people under the age of eighteen, a parent or guardian may have to give permission. The doctor or nurse organising your treatment will talk to you about being involved. They should explain the possible risks and benefits. If you take part, you should make sure you understand and receive all the information you want before you give your permission. This may mean taking some time to think about it and talk it over with family or friends, unless a decision is needed urgently because of your medical condition. If you decide to take part, you will be asked to sign a form to say you agree to take part in the trial and have understood what it involves. This is called giving your informed consent.

Sometimes it may not be possible for you to be involved in a particular trial. For example: your condition may need to be at a particular stage; you may not be allowed to receive another treatment at the same time; some trials seek people with certain illnesses and conditions, while others need healthy people; some trials need people of a certain age; there may already be enough people in a particular category who have joined the trial.

Before you join a trial, you may need to have tests to see if you can take part. This is generally known as a screening or baseline visit. This will give the researchers more information about your health before you start treatment, which will allow them to tell whether there has been an improvement at the end of the trial. During the trial, you may have more tests to see whether the treatment is working. It may be possible for the tests to be carried out as part of your routine care, or you may have to make more visits than usual to your GP or hospital.

Whilst being on the trial you may wish to stop taking part if, for example, your condition is getting worse, but you can also choose to leave at any time without giving a reason and without it affecting the care you receive. Alternatively, if there are signs that the treatment in a trial could be unsafe, the research team or the regulators will stop the trial.

I hope this explains a little about taking part in a trial and what is involved. If you would like more information you are welcome to email our research facility at King’s College Hospital at kingscrf@kcl.ac.uk

“During the trial, your treatment and progress may be monitored more closely than if you were receiving the usual treatment.”
Living with migraine

Managing the impact of migraine at work

By Hannah Verghese – Advocacy, Policy and Campaigns Manager at The Migraine Trust

Migraine is most common amongst adults of working age. For the vast majority of migraineurs their condition should not be a barrier to finding and retaining employment. However, from time to time it may have an unavoidable impact at work and this article outlines some general considerations for migraineurs that are employed.

Whether you are starting a new job or have been in your role for a while, taking the following steps may help to manage the impact of your migraine in the workplace:

Tell your employer

Some migraineurs experience attacks once or twice a year, whereas for others they may occur much more regularly. The frequency and severity of attacks, as well as the symptoms experienced, can vary at different times and amongst migraineurs. Telling your employer can seem like a daunting thing to do, especially since there is so much misunderstanding and stigma surrounding the condition. Employers are less able to provide support and understand the condition if they do not know that you experience migraine attacks. Formally disclosing your condition means that it will be on your personnel file should there be any changes to management in the future. Your GP may also be able to write to your employer to confirm your diagnosis and any important considerations based on your personal circumstances.

Check your company sickness policies

At times migraine attacks can necessitate taking time off from employment. Since migraine attacks typically last between 4 to 72 hours, migraineurs are more likely to take short-term sickness absence due to their condition. Your company’s sickness policy and absence management procedure should outline your employer’s approach to managing sickness absence, in particular short-term absences, how they will support you and what to expect if you take absence. It is important to familiarise yourself with these policies and you may also want to read your company’s Equality and Diversity, and Health and Safety policies since these may also be relevant. If you are concerned about how your migraine related sickness absence is managed you are entitled to discuss this with your manager or HR. Information from your GP or neurologist and The Migraine Trust’s Advocacy Service can support these discussions.
Take steps to tackle work-related stress

The pressures of an increasingly demanding work culture can result in significant work-related stress for many employees. Depending on the nature of your work this may be consistent or vary across months, years or even throughout your working life. Stress can have a detrimental effect on sleep, eating habits and general wellbeing which can all be potential triggers for migraine attacks. Clear demands, clarity of role and objectives, regular supervision and support through change should all be adopted into management systems to effectively deal with stress in the workplace. Many employers have additional offerings in place to promote staff wellbeing. These can range from flexible working policies, employee assistant programs, gym memberships and mentoring programs. Familiarise yourself with your company’s polices on managing stress at work and what you are entitled to in your workplace. If you feel that you have specific needs as a migraineur then you can discuss this with your employer. The Health and Safety Executive has a body of excellent information and resources on work-related stress, including the Management Standards for work-related stress which helps employers to support their workforce. Visit their website for more information.

Address any health and safety issues in your work environment

Depending on your role and the nature of your work environment there may be additional environmental factors to consider in relation to your migraine. These may concern managing triggers, providing the correct equipment or even avoiding particular activities. All employers have a duty to manage the health and safety of their staff at work. However, you don’t need to wait for your employer to raise these considerations with you. If you have concerns check the company policy and approach your employer directly to request a meeting.

Keep your manager informed

Migraine is a fluctuating and episodic condition and its impact on you at work may vary. Keeping your employer informed of any relevant changes to your condition or treatment can help them to provide you with the necessary support that you need. Your GP, neurologist and Occupational Health (if your employer has one) can support you in this process. You may also want to provide your employer with The Migraine Trust’s website and information resources to help debunk any misconceptions or confusion about the condition.

Keep a paper trail

Whether you are disclosing your condition to your employer, requesting time off for a migraine related medical appointment, informing them of sickness absence etc., it is a good idea to record this in writing. This may mean emailing HR or your manager even as a follow up to a face to face or phone conversation and requesting written minutes and outcomes of any meetings held to discuss your condition. You might consider keeping a diary and copies of any correspondence related to your migraine in your personal email account if you have particular concerns. In the event that any problems occur or circumstances change e.g. company restructure, change of management etc. these may be useful to refer to.

The impact of migraine on employment is a huge issue for people with migraine and The Migraine Trust. We understand that even with a supportive employer and the above in place, difficulties at work because of migraine may still occur. If you are faced with a problem at work our Advocacy Service is here to support you. Our Employment Advocacy Toolkit has information, resources and tools to inform and support you to exercise your rights at work. You can also contact our Advocacy Officer to discuss your circumstances in more detail and the support that is available to you. Find out more at www.migrainetrust.org/asking-for-support

“We do not provide legal advice and the employment toolkit is not a substitute for legal advice. If you are concerned that your job is at risk please contact a legal professional.”

“Since migraine attacks typically last between 4 to 72 hours, migraineurs are more likely to take short-term sickness absence due to their condition.”

Since migraine attacks typically last between 4 to 72 hours, migraineurs are more likely to take short-term sickness absence due to their condition.
Meet Jo Mortimer, Clinical Nurse Specialist, and Dr Hayley Bullock, Clinical Psychologist, from the Headache Team at Great Ormond Street Hospital for Children

The Great Ormond Street Hospital for Children (GOSH) headache clinic has quite a unique way of supporting children and young people with migraine and headache. Can you tell us how this works?

JM: The approach taken is very much a team approach and we stress the importance of the young person and family acknowledging the dual pronged approach of medicine with psychological support. For children and young people with chronic headache difficulty, we find that outcomes are optimised when they are open to a range of treatment options and support.

At an initial extended, new appointment Dr. Prabhakar, Paediatric Neurologist and Headache Specialist, will spend time taking a detailed history of the child or young person’s general medical and headache history. Then a full neurological examination takes place and any scans or investigations completed are reviewed. Additionally current medication and medication tried are discussed.

At this appointment I will try to be present to introduce myself and the support I can provide as the Headache Service Clinical Nurse Specialist. Often Dr. Hayley Bullock, Clinical Psychologist will also attend the clinic to explain her role.

As Clinical Nurse Specialist, as well as attending clinic, I support with arranging some investigations and procedures. I will visit inpatients to ensure that they are informed of what is happening and to offer support.

A large proportion of my role is to support young people and their families in managing their headache and symptoms from home. Young people and their carers can call or email me for advice and guidance and I act as a link between the patient and Dr. Prabhakar when I am unable to answer questions directly. School is often an area where there may have been difficulties, for example with poor attendance or lack of understanding of the headache condition. In these instances I can liaise with the school to provide information and guidance.

Parents often call or email when the headache, or symptoms, have been particularly difficult for a period and they firstly need someone who understands the condition to listen to them and secondly they are looking for advice about alternative treatments or reassurance that they are doing all that they can.

What difference does having a psychologist make for your patients?

JM: Having a psychologist is imperative to the Headache Service patients’ care. Before reaching Great Ormond Street Hospital for Children, a lot of the children and young people we see have spent a long time struggling with this chronic headache problem. The stress and strain of dealing with other’s lack of understanding about the potentially debilitating nature of chronic headache is a common theme that comes up in the initial clinic consultation. Many of the young people say that they have had some psychology or counselling input previously, but felt that this was because professionals had assessed the headache as being psychological in origin, rather than having the psychological support for more constructive reasons. Often young people are therefore sceptical, until we explain the kind of support that Dr. Bullock and her team provide.
HB: One aspect of the service that we offer here is a group for young people. Through the group sessions we consider the challenging cycles that can develop for young people experiencing migraine. For example, often young people miss school as a result of migraine, which can lead to falling behind, work accumulating and feeling less connected to peers. This can result in increased stress or anxiety on returning to school and also trying to do as much as possible on a good day, which may then trigger further bad days, missing school and so on. During the sessions we consider different strategies that can be helpful in breaking these cycles and reducing the impact of migraine on a young person’s life. The group is also particularly important in enabling young people to meet others who have similar experiences to them, to share the challenges of living with migraine and the different management strategies they find helpful. Many young people have not had the opportunity to do this before.

What’s the most rewarding part of your job?

JM: The most rewarding part of my job is when children, young people and their families express feeling empowered to manage the headache problem, with the collection of resources that the Headache Service have provided. This can take some time, but gives the reassurance that the young person and family will manage effectively, even when no longer under our care.

What do you think are the biggest challenges for children/young people with headache and migraine?

JM: I think the two biggest challenges are coping with the headache pain (and accompanying symptoms) and also the loss to general function. A large proportion of patient or parent calls and emails are about pain or symptom management and this is closely followed by children and young adults missing lots of school days and social events due to their symptoms. They are looking for support to help them to optimise functioning with symptoms still present often.

HB: The impact upon functioning can be very challenging for young people and their families, often in terms of school but also friendships and family life. I also frequently hear about the challenge of helping others to understand their condition and the impact it is having.

How do you see the service developing in the future?

JM: We have had parents and carers express a wish for a parent group, where they would have the opportunity to meet other families going through similar experiences. We are currently gauging opinion, as patients are seen by our service, as to whether an ‘open clinic’ may work, where families attend for a morning or an afternoon, with the opportunity to meet with Dr. Prabhakar, Dr. Hayley Bullock and myself; as well as meeting other families. It is anticipated that this would initiate links and therefore support between families.

HB: It would be really positive to be able to offer the opportunity for parents and carers to meet, as the young people who attend the group consistently feedback that they find meeting each other particularly helpful.
In the 10 years I worked as a GP I had heard of but never came across chronic migraine. It was to become the diagnosis that would devastate three of our children’s lives and have a huge irreversible impact on all of us.

Chronic migraine is a genetically inherited primary brain disorder, diagnosed when more than 15 days in the month are dominated by migrainous headache. Heartbreakingly for our three children, the headache free days are rare.

William (19), Isabel (15) and Katie (13) are all under, or have been under, the care of Dr. Prabhakar at Great Ormond Street Hospital (GOSH) and his excellent team in the headache clinic. However, our route to GOSH and a clear diagnosis was long and arduous.

In 2011 William was 14, enjoying school, playing rugby and leading an active social life. An unremarkable vomiting virus hit both William and his brother James. James missed only a few days of school, whilst William complained of persistent headaches and nausea. So began a cycle of multiple appointments, tests and propositions as to the cause. We were grilled on stress issues in his life and ours, leaving us bemused and frustrated. Few believed us, many criticised our son, our parenting or both. ‘Was William under pressure?’ ‘Had we
thought about his diet? ‘Was our marriage OK?’ and ‘don’t you understand all teenagers find it hard to get up in the morning?’ Meanwhile, William remained white, with rings around his eyes, struggling to eat and his school attendance dropped radically. It was a year before we met an excellent paediatric neurologist, Dr. Kinali, who recognised the condition and started appropriate treatment. However, William’s headaches and nausea remained resistant to treatment and we were referred to Dr. Prabhakar.

Little did we imagine that a year later Isabel, after several years of atypical attacks, would experience her migraine transforming into a chronic condition when she hit puberty. She ended up in the same clinic as her brother. Then a year later their younger sister Katie joined them.

The past five years have been an extraordinarily painful journey for us all, but as Christians we believe that God is sustaining us and we thank Him for providing the expertise of the GOSH team. The clinic has helped the children learn to live with migraine, with Dr. Prabhakar gently and consistently saying he cannot take it away. This has been so very hard to hear but helpful in adjusting to the ‘new norm’.

Awareness of chronic migraine is extremely limited. We have received lots of advice and criticism from well-meaning but ill-informed doctors, teachers, friends and family. The sense of isolation and loneliness has been overwhelming at times. In a world of huge medical advances we struggle with the reality that no one can take our children’s headaches away.

GOSH has proven such an oasis of understanding and wisdom. I have lost count of the number of times I have walked through the doors with tears streaming down my face with relief of being in a place of understanding and encouragement. The invaluable peer groups allowed William and Katie to feel reassured that they were not ‘going mad’ by meeting others going through similar experiences.

Migraine has a massive impact on the whole family. We have seven children (five by birth, two adopted). It has been very painful for the two birth children who don’t have migraine to watch their siblings’ lives change so drastically. Both have struggled with the guilt of living a ‘normal’ teenage life, with frustration at being unable to help.

Our five-year journey has been like bereavement. We have lost the family life we had. We have passed through seasons of shock, denial, anger, depression, adjustment. Sometimes as a couple we have been in different stages at different times, and with different children, as well as trying to make normal life happen for the others. It has been vital to find protected time to talk, listen, support, pray with and love each other throughout.

Life today is at best challenging, at worst a relentless cycle of heartbreak often unremitting for several months at a time. There are many late or broken nights. Days divide into good and bad headache days for each child. The GOSH clinic has helped us think of chronic migraine as a centre in the brain that operates with a ‘dimmer switch’ rather than ‘on/off’ – it’s always on, varying in intensity. A good day is one where the child can sit, eat and chat despite nausea, and is able to get to school for however short a time, despite exhaustion and nagging headaches. The bad days are hard to describe, a mesh of cancelled arrangements, a child, or two, or three in miserable distress, pain, overwhelming nausea, vomiting, a mother’s broken heart. I have often wanted to run out of the house screaming ‘this isn’t ok, somebody needs to do something’.

I have learned to be willing to set aside my own plans to be with whichever children are struggling that day. Friends have become used to me cancelling at the last minute. We have learnt not to look too much into the future but to trust that God will powerfully work in them to enable them to live fruitful, purposeful lives whatever the restrictions.

William has now left home and is enjoying a part-time apprenticeship. He is learning well how to live life as an adult within the inevitable restrictions of migraine. Isabel attends mainstream school 50-60% of the time. Katie has attended a hospital school for two years. She has an excellent head teacher, but no peers her age and a constantly changing register of children. We are currently appealing for an assessment to seek more appropriate long-term schooling.

It is hugely reassuring for us living with a condition so widely misunderstood to be in a worldwide centre of excellence where research is part of the hospital culture, and treatment is evidence-based. One of our children has cystic fibrosis; with tremendous advances in treatment his life expectancy is far better than it would have been 50 years ago. In the same way we hope and pray that funding for research into headache disorders will improve the quality of life and prognosis for people with these debilitating conditions.

“A good day is one where the child can sit, eat and chat despite nausea, and is able to get to school for however short a time, despite exhaustion and nagging headaches.”

“It is hugely reassuring for us living with a condition so widely misunderstood to be in a worldwide centre of excellence.”
Q: Is there a link between migraine and Ehlers-Danlos or hypermobility syndrome?

A: Ehlers-Danlos and hypermobility syndrome form part of a spectrum of disorders called “connective tissue disorders” (CTD). These cause symptoms such as joint and skin laxity and musculoskeletal pain. Some people consider hypermobility syndrome to be separate to Ehlers-Danlos and hypermobility syndrome alone is more common. These conditions are more common amongst females (as is migraine). There have been a few studies showing that headache and migraine, in particular, is two to three times more common in CTD than in the general population. Two of these studies suggested that the frequency of migraine attacks and level of disability was also higher in the CTD group although it must be noted that these two studies involved a relatively small number of patients (28 and 33) from selected clinics so may not be applicable to the general population.

It is likely that migraine and hypermobility are comorbid conditions meaning they occur more frequently together but this does not mean that one causes the other or that they necessarily have a common cause. Other examples of comorbid conditions are migraine and depression. Although the treatment for people with migraine and hypermobility remains the same as for those without it, there may be some migraine preventatives (e.g. amitriptyline) which can also help with other pains and it is important to try to avoid regular codeine based analgesics.

References:

Q: I’ve come across a number of sites online that suggest gluten sensitivity causes migraine – is this true? I’ve also read about avoiding various foods and additives to help migraine. Is there any evidence for this and is there a migraine diet?

A: Celiac disease is an autoimmune disease where the body produces an immune response to gluten resulting in gastrointestinal and other symptoms. It can be tested for by detection of various antibodies in the blood e.g. Anti-
gliadin antibodies (AGA). Non-celiac gluten sensitivity is a more controversial diagnosis. Antibodies in the blood are often negative but up to 50% of such patients presenting to gastroenterologists have detectable AGA circulating levels in one study. There is evidence that it is a separate disorder but it is often over-diagnosed and there is likely to be an overlap with irritable bowel syndrome.

Headaches may be part of a large number of symptoms which are listed as being associated with gluten-sensitivity but there is no evidence that gluten-sensitivity causes migraine. Two published studies investigating the prevalence of headache in adults with celiac disease from Italy showed different results: Cicarelli et al reported 32 percent prevalence of migraine in celiac disease compared with only 5.6 percent reported by Briani et al. Another study found headaches were more prevalent in celiac patients from a celiac clinic compared to controls although they had fewer females in their control group and migraine is more common in females. Interestingly, they also reported a similar prevalence amongst the irritable bowel group who did not have celiac disease.

There is no good evidence to suggest a gluten-free diet has an effect on migraine. In the aforementioned study only eight of the 188 celiac patients reported an improvement although the study wasn’t specifically looking at this. It also showed that the duration of gluten-free diet did not correlate with migraine severity. There was a paper in 2001 of ten celiac disease patients with migraine, most with other neurological problems as well. It was stated that a gluten-free diet resolved the migraine in seven of these but it does not state for how long and no details of the migraine history or treatment were given in the report.

Other diets have been tried but the studies are usually open-label so the participants know what they are eating which may mean the results could be influenced by the placebo effect. Also they often involve only a small number of participants or a short duration. There have been two such studies suggesting the benefits of a ketogenic diet over a four week period but better studies are needed to validate these findings.

There have also been some small studies suggesting eliminating individualised food allergens. One study involving thirty migraineurs looked at headache days over a six week diet period and had positive results but a larger randomised, controlled study of 167 participants where half were given a sham diet for twelve weeks was negative. It may be the case that in a small number of people allergens may be a trigger but there is no evidence to suggest that this is the case in the majority of migraine sufferers.

Another popular myth suggests that chocolate can trigger migraine. The evidence does not support this. The myth may have arisen because of cravings which can form part of the prodrome or premonitory phase of migraine, so when the chocolate is eaten during this phase the migraine has actually already begun.

In conclusion, there is no migraine diet but it is clear that missing meals is a well established migraine trigger so eating a healthy diet at regular mealtimes is advisable. If you are concerned about gluten sensitivity or a specific food allergy it is advisable to consult with your GP.

References:

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- Dimitrova et al. Prevalence of Migraine in Patients with Celiac Disease and Inflammatory Bowel Disease. Headache 2013; 53:2 (344-55)
- Orr S. Cephalalgia, 2015
- Alpay K et al. Diet restriction in migraine, based on IgG against foods: a clinical double-blind, randomised, cross-over trial. Cephalalgia 2010 Jul; 30(7):829-37

“Headaches may be part of a large number of symptoms which are listed as being associated with gluten-sensitivity but there is no evidence that gluten-sensitivity causes migraine.”
Fundraising review

London Marathon

On Sunday 24th April 2016 staff from The Migraine Trust went along to mile 14 of the iconic London Marathon route to support this year’s team of runners. David, Neil, Dora and Michael all rose to the challenge not only of the 26.2 mile run but also to raise as much money as they could to help beat migraine. Between them they have raised over £8,500. We would like to say a huge thank you to them for the months of effort they put in to fundraising and training and for this epic challenge.

If you would like to apply for one our places in the 2017 Virgin Money London Marathon please visit our website to download an application form

Great East Anglia Run

In May 2016 Tamara took on the Great East Anglia Run for us. Tamara, who suffers from New Daily Persistent Headache, said “The Migraine Trust is a lifeline. It provides information about getting help to make sure you get the support you need as quickly as possible, works with other organisations to promote awareness in an intolerant world for an invisible disability, actively seeks to gain understanding through research to better provide care, and ultimately aims to find a way to cure it for good. Isn’t that a beautiful thought? That one day we might be able to offer hope to the hopeless and save lives with the definitive knowledge that it WILL get better. Because right now we don’t have that.” She has raised an amazing £305 for us and we really appreciate her support, thanks Tamara!

Knysna Half Marathon

In July 2016 Heather travelled all the way to Knysna in South Africa to take on their forest half marathon despite suffering from exercise-induced migraine. When asked why she wanted to support us she said “The advice from The Migraine Trust has been so valuable to me and with more research they will be able to provide better medicines and target advice for migraine sufferers.” Thank you to Heather for choosing to support us and for raising a fantastic £410.
Thank you to all our fundraisers who have raised money for us over the past six months. We really appreciate all the hard work and effort you’ve put in. If you would like to fundraise for us there are many ways to get involved from challenge events through to dress down days. If you’re looking for inspiration or would like to get in touch with our Fundraising Team please go to www.migrainetrust.org/fundraising

Defeating Worm’s Head

We would like to thank dedicated supporter Lewis who, over the course of the past six months, has taken on a number of endeavours to raise both funds and awareness for us. He started by distributing our posters and leaflets before placing a collection tin in the Glenn Social and Sports Club. He then organised a non-uniform and fundraising day at his former school, the Francis Combe Academy, on 27th May raising £609.58. As if this wasn't enough he travelled to Rhossili in South Wales in July to defeat Worm’s Head raising a further £360, smashing his target within 24 hours! When asked why he wanted to raise money for us he said ‘The Migraine Trust has helped me understand there are many more sufferers just like me out there. The Migraine Trust do so much for us therefore, I decided to give something back.’

A battle against chronic migraine

Since October the wonderful Graham has taken up the fundraising mantle for us. We asked him to explain in his own words how he has fundraised and why he is supporting us.

“I am keen to raise money for The Migraine Trust as I get great support from the information that it shares with people such as myself, a chronic migraine sufferer. Migraines took away my ability to work but raising funds gave me a purpose in life and allowed me to raise awareness of the effect it has on the sufferers and their loved ones.

I found comfort in the information and other sufferers stories that I read on The Migraine Trust website. I was compelled to share my story too. I was putting on weight and wanted to change that, so I set up a JustGiving page to get donations to spur me on and raise money. Donations gave me personal support and also a purpose, I felt I was doing something positive and realised how negative my existence had become.

I achieved my weight loss goal by the end of December 2015. I set myself a challenge to refrain from any alcoholic drinks for the whole of January 2016. I found this easy and extended the challenge for another month. At the end of February I set myself a new challenge to refrain from alcoholic drinks until my daughter’s 18th birthday, 24th April. On this day I had my first sip of alcohol with Hannah and I had raised £425.

On 20th April I had surgery to replace a disc in my neck with a prosthetic one due to nerve pain radiating down my left side. As I lay in hospital, recovering, I received a few more donations including one from the landlady of The Wheatsheaf & Pigeon, who offered to host a charity night including karaoke and a raffle to raise additional funds. This was held on 16th July and raised £207.86.”

We would like to thank Graham for everything he has done and for the £632.87 he has raised in total, as well as thanking the team at the Wheatsheaf and Pigeon for getting involved.

Vitality British 10K London Run 2016

A huge congratulations to Amelia who completed this year’s British 10K on Sunday 10th July. She took to the streets of London raising over £220 as well as vital awareness for us by wearing her Migraine Trust vest. Thanks for all your hard work!
## Calendar of events

For more information about any of the events below please visit [www.migrainetrust.org/events](http://www.migrainetrust.org/events)

### September

**4–10: Migraine Awareness Week**  
An annual campaign to draw attention to migraine, educate the public and reduce stigma.

**15–18: EHMTIC**  
The fifth European Headache and Migraine Trust International Congress (EHMTIC) will take place in Glasgow offering a four day programme covering the latest available research, therapies and developments from internationally recognised leaders in the field.

**18: EHMTIC Public Session**  
As part of EHMTIC we are holding a public information event in Glasgow for migraine sufferers and their families. Come along to hear expert presentations on the latest migraine research and to have the opportunity to ask your questions. Advance booking required.

**30: Virgin Money London Marathon Application Closing Date**  
Please make sure you get your application for the London Marathon 2017 to our Fundraising Team by 30th September if you would like to be considered for one of our guaranteed places.

### November

**12: Managing Your Migraine, Staffordshire (Date TBC)**  
Come along to meet migraine experts, staff from The Migraine Trust and learn more about migraine, its management and latest research developments.

### January

**21: Managing Your Migraine, Hull**  
Come and join us in Hull 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 your questions.
Yes, I want to help The Migraine Trust invest in crucial research and find a cure for migraine. Please find enclosed a donation of:

- **£20.68**, which could pay for an hour of specialist migraine research by our pioneering neuroscientists.
- **£62.03**, which is enough to pay for half a day of research into headache disorders.
- **£144.74**, which could pay for an entire day of dedicated migraine research.
- My own preferred gift amount of: **£___________**

I enclose a cheque/CAF voucher 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: __________________________ Date: ______

Your details

Telephone: 

Email: 

I am happy for The Migraine Trust to contact me by email [ ]

For every donation we receive, we send a letter acknowledging receipt and thanking the giver. We are delighted to do this, but if you would prefer us to not send an acknowledgment, please tick the box [ ].

Please return to

Freepost RSRB-ZYSK-GGCC, The Migraine Trust, 52-53 Russell Square, London, WC1B 4HP

Gift Aid declaration. Please treat as Gift Aid donations all qualifying gifts of money made. (Please tick all boxes you wish to apply)

□ In the past 4 years

□ Today and in the future

Signature: __________________________________________

Date: __________________________

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 25p of tax on every £1 that I give.

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 migraine.

The Migraine Trust will keep your name and contact details on our database and use this information to inform you about events, news (such as our journal Migraine News) or ways to support The Migraine Trust that might be of interest to you. We will never sell or pass on your details. If you do not wish to receive further communications from The Migraine Trust please tick this box. [ ]
The Migraine Trust was founded in 1965 primarily to promote medical research into migraine.

Currently The Migraine Trust:

• Provides a comprehensive information service to the general public, health professionals, employers and the media. We have a comprehensive website and produce a journal called Migraine News
• Holds workshops and courses for GPs, nurses, health professionals and the general public
• Jointly holds the European Headache and Migraine Trust International Congress (EHMTIC) every two years for leading experts in migraine from all over the world to meet and exchange research results and ideas
• Funds research, fellowships and studentships in hospitals and universities.

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