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## **The City of London Migraine Clinic Newsletter**

# **MARCH 2011**

Welcome to all new subscribers to the Newsletter. We start this month with an event that we feel is very important for the future of the clinic, so please help us spread the word if you can. Following this is a heartfelt letter from a patient who found the support provided by the Clinic changed her life after many years of suffering in silence. Receiving letters like this make us feel all the hard work is worthwhile. I'm sure her story will strike a chord with some of you.

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### **1. WE'RE TELLING THE NHS HOW TO SOLVE YOUR HEADACHES**

We all know that the NHS is under immense pressure to provide care of a high standard within a tight budget, and we believe that our 30 years of experience could prove a valuable resource. At a one-off Master Class event on March 17th we will let them know how to provide treatment quickly, cost effectively, with high quality outcomes. With the current government reshuffle of the NHS, giving GPs in England control over how funds are spent, we feel that this is the ideal time to promote our service.

This event is primarily aimed at GP Commissioning groups, Public Health doctors and Pharmaceutical Advisors. If you happen to know of any relevant PCT contacts that we should be inviting, please forward their details to [rebecca.sterry@migraineclinic.org.uk](mailto:rebecca.sterry@migraineclinic.org.uk).

### **2. WHAT THE MIGRAINE CLINIC HAS DONE FOR ME**

I had my first migraine when I was 16. It struck while I was sitting in a history 'A' level lesson trying to follow the teacher and write down notes. I suffered what I now know is a

migraine with aura which meant I couldn't see properly; everything was just a confusing, bewildering blur. It was very distressing. I left the class and just managed to see clearly enough to walk across the school grounds to the nurse's office. By the time my dad came to collect me I was convinced I was dying and felt very frightened. Once safely home lying in a dark room made a difference but offered no relief to the insufferable pain in my head, so I just hoped the end would come soon. Only later on did I learn this was a migraine.

I suffered another migraine later that summer. I remember it was a bright sunny day and we were on holiday by the sea. I remember the piercing flashes of the bright sun and lying down in the middle of the promenade, embarrassing my parents but feeling unable to move, again wanting just to give in to the pain of it all.

So began my relationship with migraines which I have suffered with on and off ever since, during the worst phases suffering nearly every week. One of the rare but longest experiences was during a three day episode while working in the Far East. As well as the headache pain I felt very weak and generally ill. When I visited the local doctor he asked if I had recently travelled anywhere 'remote', suspecting malaria (which felt plausible given how wretched I was feeling). It didn't help the eventual diagnosis of migraine that I had just returned from climbing Mount Krakatoa on a remote island in Indonesia!

Some years later, after one particularly bad spell of weekly interruptions, my doctor prescribed the daily preventative medication Pizotifen. The outbreaks were being caused by a particularly stressful job which brought with it other stress-related illnesses including depression. The medication was meant to prevent the headaches but didn't help much once the headaches had set in and I did not like the idea of being on daily medication, so after a while I came off it. Changing jobs eventually helped.

In the years that followed I continued to struggle with migraines, from time to time switching to the latest off the shelf products as recommended by friends and television adverts, but nothing really seemed to work. I resigned myself to living with migraine and concluded it was just part of me and who I am. I also got used to suffering in silence. No one really wants to hear about what they perceive to be just a headache, especially if telling them means mentioning it so regularly.

A year ago, now aged 46, I began to feel decidedly cheesed off with migraines and started thinking again about doing something about it. I still hadn't really got round to acting on this good intention (denial and despondency as ever playing their part), but the seed had been sown by the time I heard Professor Anne McGregor speaking on Woman's Hour about her work and studies at the Migraine Clinic. I learned that it is the only independent, charitable clinic in the world entirely focused on headaches and migraine. I began contemplating a visit and mentioning it to one or two people as a way of committing myself to action.

Then I mentioned it to the guy who was plastering my house after he happened to say he was recovering from a migraine. It transpired that he was a regular sufferer, like me generally in silence. Having found a rare kindred spirit we both offloaded at length about the pain, frustration, misunderstanding and ultimate loneliness of dealing with the condition in isolation; what a relief to find someone else who understood! By the end of it I realised what a huge effect migraine was having on my life, and hearing someone else describe the debilitation it causes prompted me to follow through my intention to see if anything could be done.

When I first visited the Migraine Clinic I was struck by the warm welcome of the staff and the relaxed and supportive environment captured in the open door logo of the Clinic. The physical environment and ambiance of the place meant it did not feel like a 'clinic' at all. In complete contrast to my imagined cold, sterile, hospital environment, the Clinic is based in a multi-storey Georgian house located in charming Charterhouse Square, an impressive and picturesque set of buildings in a cobbled square surrounded by Grade II listed cast-iron gates and railings. Once inside I was immediately made to feel welcome and instantly knew I was being supported. The sense of failure for not having tackled and beaten my migraines thus far began to wane.

During my visit I was invited and agreed to participate in a clinical trial that was about to start testing a new drug for menstrual migraine. Participation involved a series of monthly visits for seven months and keeping a simple diary recording medications, headaches and other treatments. Alongside this I completed the Clinic's own diaries which have helped me record the triggers, patterns and symptoms associated with my headaches.

I am now at the end of participation in the trial. As a by-product to participation the whole experience has made me proactive about monitoring, recording and taking active steps to manage my migraines. In particular keeping a diary has highlighted for me the role of denial in my treating symptoms early at the onset of a headache and the importance of eating and drinking regularly. I have learnt that while I suffer from menstrual migraines (which means I now have more control in predicting and managing those headaches) there are other pre-disposing triggers too which I am now reviewing and seeking to manage. Just as importantly I am now able to talk about my experiences of migraine with my family and close friends, which in itself pays a part in my feeling supported and active in dealing with the headaches.

My visits to the Clinic are also now coming to an end but I will be keeping in touch with the staff there and the newsletters will remain part of my ongoing education and support network. There is still more trial and error to come in identifying and managing my individual experience and management of migraine. I have learned that there may be no instant miracle cure for me, an important fact about migraine and a piece of self-awareness which is also helping me to be realistic about my own self-expectation and self-judgment. Most significantly I feel more in control and further along the road to addressing causes and symptoms. I am no longer trying to cope with migraine by running away and keeping myself in the dark- literally! There is also the satisfaction of having contributed to pioneering research which may help other sufferers in the future.

I have decided that another useful outcome of my association with the Clinic is to keep talking about migraine with other sufferers and those fortunate others who do not suffer but need to understand as the starting point for supporting those of us who do. Being listened to, exploring options and not settling for an unsettled life is the best way to beat migraine. I am very grateful and would like to thank everyone at the Migraine Clinic for their help and support of people like me.

*Anne*

### **3. NEWS**

In the past month 'migraine' has been hitting news with a number of celebrities being revealed as sufferers. Holly Willoughby from 'This Morning' suffered a severe migraine last week whilst heavily pregnant that meant she was unable to present on Dancing on Ice and her breakfast show. Across the pond, big news was that US TV presenter Serene Branson

spoke what was described as "gibberish" when broadcasting at the Grammy Awards. Headlines stated "Grammy reporter had Migraine not Stroke."



It is often the case that high-profile people do not admit to being sufferers as they feel that it will impact on their work. It is a shame, as these are the people that could get the subject of Migraine the press and recognition that it needs in order to make the public aware of the extent of the problem. This could in turn increase funding for treatment and research so that people, like our patient Anne, receive the right treatment immediately rather than suffering for years unnecessarily.

#### **4. FUNDRAISING**

##### **Hurry! We get more from your donations before April**

Until 5 April 2011, the government is chipping in an extra 3p in gift aid per £1 donated in a 'transitional tax relief', to make up for the cut in basic rate tax from 22% to 20% in 2008. 3p may not sound a lot, but it is going to mean a significant loss of earnings for us at a time when we need it most.

This means if you have already decided to donate, we will benefit more if you can afford to do it now! Thank you.

*giftaid it*

##### **Easy fundraising**

We have raised £286 since becoming a member of online shopping site 'Easy Fundraising' and £74 alone was raised between Oct and December just by people using the site as a search engine to forward them onto their favourite shopping sites.

Please remember to keep using the site, especially when buying large items, or ongoing payments such as insurance and phone contracts. We get up to 15% of your total purchase price at over 2000 of the UK's favourite retailers. See [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk) to see what it's all about.

#### **5. RESEARCH**

##### **New Studies**

If you haven't already been in touch, do let us know if you are interested in having your name on our research database. You will be the first to hear when we need people for new

studies! Alison Frith our Clinical Research Sister can be contacted via email at [research@migraineclinic.org.uk](mailto:research@migraineclinic.org.uk) or telephone her direct line 020 7251 8094.

### **Is the cure for menstrual migraine in our genes?**

Our genetics research is ongoing. We are still looking for women who have menstrual migraine (with three months of diaries showing migraine and periods) and also women who are lucky enough not to have migraine at all. Contact Alison by email if you think you can help. This is a simple study which only involves visiting the Clinic to complete a questionnaire and provide a saliva sample. We can help with travel expenses if required.

## **6. FAREWELL**

We would like to take this opportunity to thank Ciara Seymour, our intern of 3 months from Manchester. We're not sure how we would have coped without her in the snow of last year, when she battled in every day to keep reception running ship-shape. We are pleased that the experience gained with us has led to an exciting new job, and we wish her all the best with it. We now welcome two new interns to share the role of reception, Megan Hook-Child and John Sterry, and hope that they too find the experience valuable.



## **7. OBITUARY**

### **Carolyn Bedford**

General practitioner; former Clinical Assistant, the City of London Migraine Clinic (b 1950; q University of Birmingham 1974; MB ChB) d 15 December 2010.

Caro was a lifelong migraine sufferer but never let the condition affect her tremendous optimism, drive and love of life. Trained in General Practice, she came to work at the Clinic in January 1999 to pursue a specialist interest in headache. With her empathetic approach and sensible advice, she was much loved by patients and highly respected by her colleagues. She continued to work in primary care but this increasingly demanded more of her time. As a consequence, and with much reluctance, Caro left the Clinic in 2005 but remained in close contact.



Caro enjoyed good health and had just moved to a new home in Bath that she was looking forward to renovating. Sadly, she died suddenly and unexpectedly from a ruptured aortic aneurysm. She is survived by her husband, Jack Steenstra, and her two children Abigail, a doctor, and Henry, a Chemistry undergraduate.

*Anne MacGregor January 2011*