

CHit CHat

Official Newsletter of OUCH (UK) - The Organisation for the Understanding of Cluster Headache

Spring 2014



Welcome

to the latest edition of CHit CHat.

There has been a huge amount going on for OUCH (UK) of late - the majority of which is outlined in this newsletter.

We do hope that you

find the stories of interest. We also have a fair few meeting scheduled, so please, ensure you book your space as soon as possible.

As always, we welcome any stories, tips, hints and experiences that you wish to share with other sufferers and supporters, please see the contact details below should you wish to submit anything for considered inclusion in other editions of CHit CHat.

Regards,

Karen.

YOUR CONTACTS

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MEETINGS, MEETINGS, MEETINGS!



Dig out your diary and make a note of that on Sunday April 6, 2014, there will be an OUCH meeting at the Lords Hill Hotel, Shrewsbury. Confirmed speakers so far are Professor Peter Goadsby, (our patron) keynote speaker; Dr Brendan Davies, headache lead, University of North Staffs Hospital, Stoke on Trent; member and Trustee, Peter May. There will also be the popular workshop sessions on four different topics, so that you can take part in the meeting, instead of being talked at all day. You will have an opportunity to ask questions of the best in the headache

world, talk to a Trustee, and talk with sufferers and supporters. Booking is now available on the events page of the main OUCH website. As always OUCH is subsidising the cost to members, so that as many people as possible are able to attend. Tickets: members, £12.50 each includes lunch and coffee/tea.

Then in July we all head north of the border to Scotland on July 20th for a meeting in the Edinburgh area, details will appear later on the OUCH website and everyone will receive an e-mail alert. This will be OUCH's first visit to east Scotland.

And the autumn brings us to London for a meeting at St Thomas Hospital with the headache group there – date to be announced and details to follow on the OUCH website. So a busy year for us and we look forward to seeing you at one of the venues.

Enquiries to info@ouchuk.org

RECYCLING FOR OUCH (UK)

Starting with the Scotland meeting, OUCH will have recycling boxes for old and unwanted mobile phones at regional meetings, doesn't matter if they are locked or broken, all are welcome! The Royal Mail don't like lithium batteries being sent in the post, so we'll bring the boxes to the meetings, you bring your old phones. The recycling company will then collect the box by courier from Val and OUCH will receive a percentage of the auction value of the phones. We are also investigating boxes for print cartridges, both inkjet and laser, more about that on our website.

LONDON MEETING

Returning to London after a 2 year absence the London OUCH meeting was held in Learning Centre for the Institute of Neurology Queens Square. On Sunday August 11, 2013, nearly 100 members and supporters attended the meeting on what turned out to be a particularly warm day.

As at York our opening presentation was carried out by 2 sufferers Andrya Barnet, Scott Bruce and our stalwart supporter Sandra McDowell who offered their presentation from the sufferers (both episodic and chronic) and supporters viewpoint of CH All 3 of the speakers offer up their free time to work on the helpline. As it did in York, the presentation struck a chord with the audience with many commenting that our stories exactly reflected their own.

Next up was OUCH's own Peter May who presented the early and encouraging results of the Ultra High Flow Oxygen Therapy trial which is being co-ordinated via OUCH (UK)

Our first medical speakers was Dr Anish Bahra who gave her presentation on CH, it's diagnosis and treatment and what your neurologist can do to help. Dr Bahra is from the Headache Group at the National Hospital for Neurology and Neurosurgery in London and also at Whipps Cross Hospital.

The final presentation of the morning was given by Dr Alex Nesbitt, Research Fellow University of Surrey and Dr Juana Marin, Research Fellow to our patron Professor Peter Goadsby at the Royal Free Hospital. Both Dr Nesbitt and Dr Marin have been of great support to sufferers. Both doctors updated us on various trials they have underway including Dr Nesbitt's studies into sleep and neurological conditions and Dr Marin's studies including the work with the Gamma-core device.

The afternoon saw the return of the popular group workshops on four different topics. Each attendee could pick two from the list of available subjects which were: oxygen and the demand valve; a supporters information exchange for those who live with a sufferer; frequently asked questions, (i.e. how do I get oxygen, how do I get a referral); and OUCH (UK). Each workshop was facilitated by a trustee or officer of OUCH; Chairman Mike Pollock facilitated the OUCH (UK) discussions, with Steve Hathaway from BPR Medical and Andrya Barnet leading the Oxygen workshop. Colin Allen and Andy McDowell fielded the FAQs; and Scott Bruce and Sandra MacDowell led the supporters workshop. The workshops were well attended by all and sufferers and supporters alike benefited greatly, not only from interaction with the trustees and officers, but also by gaining tips and tricks from each other.

With the demand valve on show, several sufferers who were struck down with an attack were able to treat their attacks and were painfree within minutes. (For more details on the trial of the demand valve, e-mail info@ouchuk.org).

Our final speaker of the day was Professor Peter Goadsby, now of Kings College Hospital his presentation on cluster headaches their treatment and management, touched on all the current trials and a few possible areas of future study. The Professors presentation was, as always, very well received by the attendees.

The day ended with a question and answer session with all the speakers taking part and a very successful day was brought to a close in the late afternoon. OUCH hopes to return to London in Autumn 2014.

The Trustees and members of OUCH are very grateful to Dr Nesbitt, Dr Marin, Dr Bahra and Professor Goadsby for having given up their precious free time to come and speak to us and for their valuable assistance throughout the day.

The next meeting will be in Shrewsbury, on Sunday April 6, details elsewhere in this issue. See you there!

TRUSTEE APPOINTMENTS

The Board of OUCH (UK) is delighted to announce the appointment of four new Trustees.

Sandie Bissett – from London - is a non-sufferer who is a great supporter of OUCH and has great liaison with the NHS and Department of Health, her organisational skills on the medical front will be greatly appreciated by all!

Scott Bruce – from Perth - has been a member since 2003[?], joined the helpline team in 2006 and has provided stalwart support to sufferers both on the helpline and at regional meetings and conferences. His input both on the helpline and at meetings is invaluable. Steve Hathaway works in the medical equipment manufacture field; a non-sufferer he has supported OUCH for the last four years attending meetings and assisting with queries regarding oxygen therapy. He has also assisted in the ongoing demand valve trial that OUCH has fostered.

Dorothy Chapman has worked tirelessly in fundraising for OUCH and her whole family supports OUCH – one of her children is a firefighter and he and his mates in a group called 'Banned Again' have raised funds for us at events local to Dorothy in Sunderland. The Board feels that these appointments have widened and improved the skillset of the Board enabling them to better serve the members, their families and supporters.

OUCH NEEDS YOU!

Once again we need your assistance on behalf of CH sufferers throughout the UK. As you know, we are conducting a small trial on Ultra High Flow Oxygen therapy for the treatment of the pain of CH. For this treatment to be accepted the Department of Health and the NHS need to be made aware not only of the efficacy of the treatment, but also the huge potential saving to the taxpayer if this treatment is approved.

Recently our chairman, Mike Pollock spoke at a meeting of the All Party Parliamentary Group on Headache disorders [APPGHD]. OUCH is a member of an umbrella organisation of headache charities, Headache UK which gives headache sufferers a voice in Parliament through the APPGHD. Mike was asked to address the meeting on 'Whether opportunities exist in the new NHS system to save money and improve patient care.' Amongst the items which Mike identified was a huge potential cost saving of £23million pounds if UHF oxygen therapy was approved as a standard treatment for cluster headache – that's a saving of 79% on the annual spend on cluster headache prescribing.

We need you to download this letter and attachment here insert the name of your MP, sign it yourself and ensure your address is there for a reply and send it to your MP, either by e-mail or snail-mail. Your MPs name followed by 'House of Commons, London SW1A OAA, will find him or her and e-mail addresses should be available on your MP's website. If you live in Scotland or Wales, please also send the e-mail/letter to your Member of Scottish Parliament / Welsh Assembly Member.

The treatment is of proven benefit to sufferers and if we can ensure that as many MPs as possible join in the fight to get this treatment approved, they will fight with a will if they can show money can be saved to the taxpayer.

C'mon guys – get those letters over the net or in the post!

HELPLINE SNAPSHOT- by Colin Allen, Trustee

I thought you may be interested to see a few facts and figures about the helpline and, in particular, the nature of the calls we receive on a daily basis. Trawling through the calls we have received over the past three months, there are a few facts which may interest you. Far and away the most frequent calls (70%) related to diagnosis, medications and better treatment. Many of the calls relating to medications are from individuals who are unhappy with the medications prescribed and/or the insufficient amounts (particularly Imigran injection) prescribed. We still have difficulty with some GPs confusing cluster headache with migraine – hence the incorrect medications being prescribed – although there are signs that the situation is slowly improving.

Sourcing the right medications in the correct dosage also continues to be problematic. Some GPs are reluctant to prescribe sumatriptan injections (ie 2 per day) probably due to their comparatively high cost and some GPs don't realise that they are able to prescribe oxygen from their own surgery rather than send the patient to see a specialist – unless it's ambulatory (portable) cylinders that are needed, of course. Of the percentage of all calls relating to medications, 26% related to the sourcing of oxygen and it's best use and 19% of all calls received were enquiries about referrals to a TAC (trigeminal autonomic cephalalgia) specialist. GPs are not generally well informed about neurologists who specialise in headache, and most calls are from people who have been disappointed with their first referral. Remember, in England, you are entitled to select the consultant of your choice under the NHS 'Choose & Book,' scheme and you are also entitled to a second opinion referral under the NHS . You choose the expert and hospital – provided that the hospital is a foundation trust. The helpline team has an up-to-date list of neurologists around the UK who OUCH(UK) consider to be expert in the field of TACs. In Wales, Scotland and Northern Ireland it's a case of persuading your GP to refer you out of area.

11% of all calls related to employment and benefit issues. Many employers baulk at the amount of sick leave taken by TAC sufferers. Cluster headache is a listed disease for the purposes of the Disability Discrimination Act and employers are obliged to make reasonable adjustments to accommodate your illness. Your employer should record absences for CH separately to those of other illnesses Sadly, quite a number of our people are forced to leave work due to the disabling nature of the disease. Because of this, OUCH(UK) retains the services of Neurosupport in Liverpool. Neurosupport is the only organisation of it's kind in the UK, offering support to sufferers and their families who suffer with a neurological illness. They are able to give advice on all employment issues, including benefit advice. Please feel free to contact Gerry Tyrrell or any member of his team on 0151 2983288,or email gerry@neurosupport.org. Perhaps the most surprising tatistic of all is the gender ratio. For the first time since OUCH(UK) began it's helpline service, female sufferers have outnumbered their male counterparts by nearly 2-1 (63% F - 37% M). I have taken into account the ladies who ring on behalf of their menfolk (yes,chaps,we are still more reluctant to call than the ladies) and removed them from the final figure. I have long since held the opinion that the gender ratio has been skewed by the misdiagnosis of female patients in particular. As diagnosis of the disease improves, my own feeling is that women will shortly outnumber men.

The helpline service is available 7 days a week. Please call 01646 651979 and leave a brief message together with your contact number. Calls will be returned between the hours of 10am and 2pm. Alternatively you can email to helpline@ouchuk.org or visit our F acebook page - *Colin Allen - Helpline Manager*

THE UNTOUCHABLES

District attorney Chee sat in the courtroom contemplating the trial ahead of him. He had worked tirelessly for years, collecting evidence, grilling witnesses and was often called upon as a last resort when some unsuspecting citizen was attacked by a member of C.L.U.S.T.A.

C.L.U.S.T.A. was a worldwide terrorist organisation with cells in countries all over the word. They held individuals hostage with savage attacks, which often came in waves, or clusters.

C.L.U.S.T.A.'s aims and motives were completely unknown. No demands had ever been received, but here at last in this courtroom history was about to be made. The brains behind the operation had been caught by an undercover agent sent in by the top secret British counter terrorism group known simply as Q.S.

The agent (code name O.N.S.I.) had infiltrated C.L.U.S.T.A. and had successfully disrupted their activities and had managed, with great heroism and skill to free a small group of hostages. O.N.S.I. had also delivered the head of the organisation to D.A. Chee. His name was Encep. Falagia. and it was his work that had given the authorities such a headache over so many years. Now D. A. Chee had his best chance, a once in a lifetime opportunity to bring down C.L.U.S.T.A. for good.

D.A. Chee looked at the notes he had prepared and pondered his preparations. He had, with some difficulty, established a fast flow from O2, that vast tented arena in London, which was ostensibly a venue for pop concerts, but was in reality the home and nerve centre of the U.K's fight against C.L.U.S.T.A.

He had also managed to liaise with those shadowy characters at Q.S., an establishment which reminded the D.A. of Bletchley Park, where the Enigma code had been broken during the second world war. He knew that if anyone understood C.L.U.S.T.A. it was these secretive men and women who worked tirelessly round the clock to defeat this menace.

D. A. Chee had scoured the globe to find experts in their field and had assembled a formidable team. He looked at them now. By his side sat Vera Permil. She was a tall, elegant red head, who could quell attacks caused by C.L.U.S.T.A. The D. A. had secretly been in love with her since the moment they had met, but she had been unable to commit. He often thought back to that night in Paris. He had been thrilled when she agreed to join his team and he had held her lovingly in his arms when they met again after the arrest of Encep Falagia.

Next to Vera sat the exotic Pria Gabahlin. She had flown in from Mumbai a week earlier. She sat wearing a blue sari. With her dark eyes and black hair, which fell softly down her back no one would guess what a formidable opponent she was. On hearing about Encep she had quickly contacted her mentor Gabi Pentin, the Australian who was often first on the scene after an attack had been called in. It was really reassuring to have these two on the team.

The D.A.'s confidence was, however shaken when he saw Falagia's defence team. At the next table sat Mia Graine. She was almost as feared as C.L.U.S.T.A. its self and had ground many stalwart defenders down with her vicious attacks, which could go on unrelentingly for days on end. The D. A. was worried. The jury could easily be swayed as she had a certain aura about her that many would find irresistible. Also on the defence team was an anonymous member of that vicious cell, which hid behind a cloud of obscurity - S.U.N.C.T.!

The D.A. had been called in on several S.U.N.C.T cases, but was seldom able to help.

He brought himself back to the case in hand and was quietly reassured. He had managed to contact "The Tripan Family". The Family had been countering attacks for many years, and had sometimes been over used, but still they plugged away, such was their hatred of C.L.U.S.T.A. From the eldest, Suma, who could be relied upon to inject doubt and confusion in C.L.U.S.T.A.'s work to the strong and powerful Ele. Even the moderate Alma could be called upon day and night. Frova The dog had been specially trained to attack and even kill if needed.

D.A. Chee opened his Apple Mac. Contacted O2 and established a fast flow. The link with Q.S. was in place. He could do no more.

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To be continued.

MalcolmC

NEW WEBSITE, FORUM AND DATABASE!



At the end of November 2013, the OUCH website suffered a severe hack, severe enough to bring down the website and forum altogether. For several months prior to that the Trustees and Officers and our IT supporters, Turtle Reality had been working on building a new website. It was almost complete and within hours of the loss of the website the new one was up and running. However, the forum was not operational as the new database was in the process of creation.

The process is now complete and went live on February 26th. By now, all online members will all have received e-mails with instructions for how to log in with your one-time only password to access both the forum and your own account. The changeover went very smoothly, Turtle Reality made it a relatively painfree process!

The forum is, as always, password protected and you can only post there if you are a paid up member. Any queries regarding the changeover can be sent to info@ouchuk.org. Each member can look at their account and update their personal and contact details

OUCH WILL NOT keep a record of any passwords. If you do forget and can't remember where the safe place is you put your password, there will be a 'forgot your password?' button available on the log-in page. With the database now linked to the forum, members will have the opportunity to update their personal details, contact details and add notes to their account – for instance if you have specific skills that you think OUCH might benefit from, or you want to volunteer for research etc.

The online payment facility will also be operational from that date too and we have switched to PayPal, a much safer and trusted payment means. You will be able to pay for regional meetings, make donations, send sponsorship donations etc. So, lots been going on behind the scenes, and our grateful thanks go to Turtle Reality and to Peter May (Trustee) who has offered invaluable help in the database processes. See you on the forum!

REPORT....YORK MEETING

The first ever north-east regional meeting of OUCH was held in York at The Monkbar Hotel in the shadow of York Minster. On Sunday April 14, 2013, 75 members and supporters attended and the meeting was significant not only as the first in that region, but two new innovations were introduced to the meeting format. At previous meetings the speakers have nearly always been health professionals, but Scott Bruce, Sandra and Andy McDowell felt it was time we heard from the sufferers and supporters about their view of CH from three standpoints, the sufferer, the supporter and the helpline. Andy is our helpline manager and is a sufferer; his wife Sandra is his supporter and Scott, also a sufferer, is one of the helpline volunteers. Their presentation was lively and had very in tune with the experiences of the audience in relation to CH and living with it. Done with humour and understanding, the presentation was a great hit with all attending. More about the new innovations later.

Our two principal speakers were Dr Juana Marin, Research Fellow to our patron Professor Peter Goadsby at the Royal Free Hospital who gave us an update on the very successful Gammacore hand held device which has brought relief to sufferers whose CH has previously been intractable to any other treatment.

Dr Anish Bahra gave her presentation on CH, it's diagnosis and treatment and what your neurologist can do to help. Dr Bahra is from the Headache Group at the National Hospital for Neurology and Neurosurgery in London and also at Whipps Cross Hospital. OUCH is grateful to both Dr Marin and Dr Bahra for having given up their precious free time to come and speak to us and chairman Mike Pollock presented Dr Marin with the OUCH Achievement Award for her work with the Gammacore device and assisting CH sufferers.

The afternoon session saw the second of the new innovations; workshops on four different topics, each attendee could pick two from the list of available subjects which were: oxygen and the demand valve; work and benefits advice for sufferers; frequently asked questions, (i.e: how do I get oxygen, how do I get a referral); and ONSI and DBS - what are they, what are the criteria for acceptance for treatment etc. Each workshop was facilitated by a trustee or officer of OUCH; Chairman Mike Pollock facilitated the oxygen and demand valve discussion with Steve Hathaway from BPR Medical who manufacture the demand valve. Gerry Tyrrell from Neurosupport (a national charity supporting sufferers of all neurological disease with advice on benefits, employment rights, re-training, assistance with living at home etc.); Colin Allen and Andy McDowell fielded the FAQs; and Val Hobbs and Michala Hollands explained ONSI and DBS and took questions. Of all the workshops perhaps the oxygen and demand valve was the session that provoked most interest and during the day, three sufferers tried the device to treat their attacks and all three were painfree within minutes. (For more details on the trial of the demand valve, e-mail info@ouchuk.org). The day ended with a question and answer session with all the speakers taking part and a very successful day was brought to a close in the late afternoon. We'll be back in the north-east in a couple of years.

HOW TO GET YOUR GP TO PRESCRIBE OXYGEN AND IMIGRAN



We've visited this subject before, but it does bear repeating as there are changes and more to come. These notes pre-suppose you have a confirmed diagnosis of cluster headache.

At present to get oxygen in England and Wales, a Part A Home Oxygen Order Form needs to be submitted to an oxygen supply company by a GP practice and the patient is then contacted by the oxygen supply company to arrange delivery.

As a patient, what you need to do is to go to the Downloads section of the OUCH website and download the Part A Hoof Form, which is part completed ready for a CH sufferer. Take this form to your GP and he should complete your details and the surgery details and the surgery then fax off the form to the oxygen supply company and, as above, they contact you direct to arrange delivery.

If your GP is reluctant to prescribe the oxygen, you can first of all point out to him that cluster headache is listed as one of the conditions (on the reverse of the Part A form) as being suitable for prescribing of oxygen. Further, every surgery has a copy of the Home Oxygen Therapy Service specification which states GPs can prescribe oxygen for the relief of pain in conditions such as cluster headache. The BNF (British National Formulary – the prescribing bible for health professionals) lists oxygen as a treatment for cluster headache, section 4.7.4.3. If your GP still refuses to prescribe, then in England, you could complain to the prescriptions adviser at your local CCG – Clinical Commissioning Group which replaced the Primary CareTrusts - (list online here: http://www.england.nhs.uk/resources/ccg-directory/) and they will also be listed in your local telephone directory. In Wales, you would need to contact the prescriptions adviser at your Local Health Board, listed here: http://www.wales.nhs. uk/ourservices/directory/LocalHealthBoards . You can tell the prescriptions adviser that your GP is refusing to prescribe high flow oxygen, which is listed in the BNF as being an appropriate treatment for CH.

In Scotland however, you will need to see a secondary clinician, i.e a consultant neurologist, for prescription of oxygen. So it is even more important that you seek a referral to a headache neurologist. Fortunately the Scots neurologists of our acquaintance are well up to speed on oxygen prescription with a SHOOF form which only the consultants have. All the cylinders supplied have integral high flow regulators, but the number of cylinders delivered varies from region to region, check with your neurologist on prescription. Be aware that in Scotland if you are a smoker, then the standard practice is to refuse oxygen prescription.

To get Imigran/Sun Pharma sumatriptan injections, again this treatment is listed in the BNF as a licensed treatment for the pain of CH. Some GPs baulk at the cost of the injections and will try to prescribe the nasal sprays or the tablets. The nasal sprays don't work as fast as the injections and sometimes don't work at all, they have to hit a 'sweet spot' at the back of the nose to work properly. The tablets won't have any effect at all, they are just not strong enough to knock out the pain of CH. Again, you can complain to the prescriptions adviser at your CCG/LHB as above. If you do not yet have a confirmed diagnosis of cluster headache, then it does make getting the above problematic; so if your GP hasn't diagnosed you, then ask for referral to a headache specialist neurologist so you have a confirmed diagnosis of the headache condition you have. Call the helpline or e-mail helpline@ouchuk.org to find the nearest headache neuro to you; he/she may be out of area, but in England the patient can choose which consultant they would like to see under an NHS Scheme 'Choose and Book – Choice at Referral', provided the consultant's clinic is at a hospital which is a foundation trust (and most of them are). Once you have a confirmed diagnosis, it's more difficult for the GP to wriggle out of correct prescribing and the consultant will, in any case, write to the GP with his treatment recommendations. There are suggested consultants in Wales and Scotland (who are OUCH friendly too!), so call the helpline for further info or e-mail helpline@ouchuk.org

ALCOHOL AND CLUSTER HEADACHE

As most people know the vast majority of cluster headache sufferers, when in cycle, will avoid any alcohol at all costs. Drinking alcohol can cause an attack within one hour amongst most CH sufferers, unlike migraineurs who generally have a headache some hours after a drink. Also, some CH sufferers can even have an attack triggered by very small amounts of alcohol in food, so watch out for that innocuous looking sherry trifle! However, alcohol does not usually trigger an attack during a period of pain-free remission, and anecdotal evidence suggests that there may be different individual responses to different types of alcoholic drink.

Alcohol as a trigger is an interesting one and has become a perennial theme amongst many CH sufferers. The professionals still do not fully understand why it triggers an attack in cluster headache, particularly amongst episodic sufferers and perhaps less so in chronic cluster headache, but it may be something to do with an endogenous substance called nitric oxide. Nitric oxide (NO) is an important (gaseous) signalling molecule in our bodies and



amongst other things is responsible for neurotransmission, modulation of the hair growth cycle and even penile erections! NO that originates from the vascular endothelium, neurons and macrophages (inflammatory cells) is also an important mediator of physiological vasodilation.

Vasodilators such as nitroglycerine (GTN) are converted to NO, which may be why they almost ubiquitously trigger an attack in CH when sufferers are in cycle. Alcohol also increases NO in the short term suggesting a similar triggering mechanism, but long term alcohol consumption can markedly reduce NO levels, which may help explain its potential as a prophylactic amongst some sufferers (although not recommended for obvious reasons). An alcohol induced attack can also be notoriously difficult to treat, but strangely enough, there have been reports over the years of alcohol being used successfully as an abortive agent, again perhaps suggesting suppression of NO release in the longer term.

Why only certain types of alcoholic drinks trigger attacks for some sufferers remains a mystery but it obviously suggests that some other mechanism or even multifactorial mechanisms may be involved. For example, red wine is almost always a trigger for many types of primary headache, and although most white wines also behave similarly, some varieties of grape seem to be worse than others.

One possible explanation could be the higher levels of sulphites in some white wines compared to others, but this theory is at best spurious. Most red wines also have high levels of naturally occurring sulphites, but white wines tend to have more added sulphites (as a preservative). Unfortunately, the now mandatory labelling of added sulphites on wine packaging doesn't mean they have to specify how much has been added. Of course it could just be the varying levels of tannins in wine too, which may boost production of the brain chemical serotonin, a neurotransmitter that has often been implicated in triggering headache.

Another possibility is that the higher levels of procyanidins in some red wine (the stuff responsible for making it good for your heart) may also affect some people's attack patterns. Procyanidins suppress the synthesis of a peptide called endothelin-1 that constricts blood vessels, but whether this is associated with headache is unclear.

Whatever the mechanism, most CH sufferers agree that it is not worth experimenting with different types of drink when in bout. However, given the relatively high proportion of us who enjoy the odd tipple, if someone out there can develop an alcoholic beverage that is guaranteed to be "trigger-free", there may be some. CHeers!

Lee Scoresby

ST MARY'S SCHOOL - DONATION TO OUCH (UK)

OUCH has received a donation of £186.49 from St Mary's School in Gerrards Cross, among other things they had a non-uniform day and a cake sale. Our grateful thanks to the staff and pupils at St Marys and we hope they had fun while raising funds for us.