A YEAR OF GREAT PROGRESS!!

OUR CHARITY IIH UK enables support and research for all those who suffer from Idiopathic Intracranial Hypertension. We became a national charity (No.1143522) on 24th August 2011.

This serious impairment is suffered by around 30,000 people in the UK and many more worldwide. No-one yet knows what causes IIH but the debilitating symptoms come from an excess of pressure on the brain and spine generated by cerebrospinal fluid. This can cause dreadful headaches, hearing problems, fainting and hallucination, blindness and life-threatening adverse movement of the brain.

The impairment affects men, women and children: around 25% of men go blind – twice as many as women.

In the short space of a year we have made remarkable progress as a charity.

Important Milestones:

IN DECEMBER 2011 we made formal links with the Astronaut Medical Programme Director (Jennifer Fogarty PhD) at NASA Johnson Space Centre in USA and the NASA Human Health Programme. NASA have seven astronauts who are suffering eye problems and hallucination and other IIH-like symptoms and we are passing key information to them.

A major study of the biochemical mechanisms which might cause IIH and which also might be linked to obesity was approved for funding during early January 2012, led by Dr Alexandra Sinclair MBCb (Hons) MRCP PhD the NIHR Clinician Scientist in Neurology and Honorary Neurology Consultant at University of Birmingham and University Hospitals Birmingham NHS Foundation Trust.
First Medical Conference!

OUR FIRST medical conference was held on 27th June 2012 at Addenbrooke’s Hospital and was hosted by Cambridge University with the help of our Patron, Professor John Pickard, Professor of Neurosurgery MChir, FRCS, FRCSEd, FMedSci at Cambridge University and Addenbrooke’s Hospital. He is also the Director of the Wolfson Brain Imaging Centre. The conference was attended by some of the most eminent doctors, consultants, research nurses and sociologists in the UK and it established a five-year plan for research into IIH.

News

♦ ON 1ST AUGUST 2012, the Department for Work and Pensions listed IIH as being an impairment requiring special medical evaluation in relation to the payment of disability benefits and DWP staff have been most helpful in clarifying the details of IIH to benefit decision-makers.

♦ A NATIONAL DATABASE of all IIH patients was approved for funding on 2nd August 2012 and will begin in May 2013 and this will be linked to the UK Shunt Registry operated by Professor Pickard’s team.

♦ A meeting with a Shadow Minister of the WELSH ASSEMBLY took place at Holywell in Deeside on 20th August 2012.

RNC ‘Have a Go’ taster weekend
Saturday, 20th - Sunday, 21st October

If you are thinking about going to College next year or the year after, but aren’t sure what you want to study why not try this free ‘taster’ weekend at the Royal National College for the Blind. Join in a weekend of fun and experience:

- Sport and Recreation
- Media and Music Technology
- Performing Arts
- Art, Design and Ceramics
- Massage and Complementary Therapy
- Business
- Living away from home, developing independence

The event is free to all young people with sight loss, aged 14-16, with en-suite accommodation, activities, food, refreshments, 24 hour support. Free accommodation is also available for an accompanying adult. To book your place go to http://www.rncb.ac.uk/calendar-detail-29

On 18th July 2012 IIH UK became a registered charity in Scotland! (No. SCO43294)

Genetics Study

FOLLOWING A MEETING WITH IIH UK on 23rd July 2012 at Addenbrooke’s Hospital in Cambridge, we are pleased to announce that a genetic study of 1,000 people across the UK suffering from IIH is being evaluated by Dr Sadaf Farooqi, Wellcome Trust Senior Clinical Fellow Professor of Metabolism and Medicine at Cambridge University’s Department of Clinical Biochemistry.

We continue to appeal for funds to help us continue the support of individuals and families affected. www.iih.org.uk
DONATIONS and fundraising play a vital part in any charity. Without it many charitable projects could not happen. We all know that funds are used for things like research and raising awareness, but what about what goes on behind the scenes. The medical conferences, to enable vital research. The daily cost of telephone calls, stamps, printing etc. to enable contact with sufferer, supporter, medical professionals and business organisations. The yearly AGMs that bring you all together to discuss what a charity has done, what you want to see happen and how a charity will move forward. And the list goes on...

IIH UK is very grateful to all fundraisers for their efforts and continued support and is amazed at the brilliant and wacky activities they do to support us. You never seem to run out of ideas.

Coming up with novel fundraising not only helps to bring in much needed cash but more importantly raise awareness. IIH, IH or BIH.

So we are going to give you some ideas for fundraising.

### Summer Fete/School or Church group events

- **Bake Sale Stall** – Make cupcakes, buns etc. and sell them on a stall or from home
- **Tombola** – Everybody loves a tombola stall
- **Popcorn stall** – A little tricky if you don’t have a kitchen close by
- **Craft stall** – Show off your skills and sell your homemade goods
- **Coconut shy/ Sponge throwing** – Great fun with little outlay
- **Count the sweets** – Guess how many sweets are in a jar, nearest guess wins the sweets
- **Trash & treasure /White elephant stall** - Gather those unwanted bits & bobs and sell on
- **Welly Wanging** – Pay a fee, throw the welly, furthest throw at the end of the day wins

### Larger Scale

- **Teddy bears picnic** - Great for pre-school & playgroups. Enjoyed with singing & clapping games
- **Supermarket bag pack** - Pack shopper’s bags at your local shop……make sure you have a charity pot close by
- **Sandcastle competition** - Great for all ages. If you have enough entrants you can do several categories
- **Sponsored head shave** - make sure you’re 100% sure before you start gathering those sponsors
- **Sponsored events** – i.e. bike ride, silence, swim, marathon etc.

### Adrenaline Junkie

- **Bungee Jump** – Definitely not for the faint hearted
- **Parachute jump or Sky dive** – You’re going to love it or hate it!
- **Charity Abseil** – Make sure you have a head for heights!

### Seasonal ideas

- **Carol singing** – Safer if in a group. Ask at your local supermarket etc. and sing in the foyer.
- **Gift wrap station** – Perfect for Christmas fetes. Offer to wrap gifts in exchange for a fee or donation
- **Valentine Romantics** – Make cards, cupcakes in Valentine theme and sell at events
- **Easter egg hunt** – Charge a fee to supply a map & hints on where to find an egg
- **Easter bonnet parade** – Kids love this. Pay to enter and winner wins a prize
First 2012 20 Week Weight Loss Challenge

By Karen Smith - Liaison Officer

After the success of the £ for lbs challenge of 2011, which lasted 40 weeks, Mark Walden suggested that we should run two 20 weeks Weightloss Challenges in 2012. The first starting on Monday 9th January 2012.

We set up a web site and advertised the challenge to IIH members, their family and friends, as well as anyone else who wanted to join us. We managed to get 39 people to join the challenge, but sadly only 23 managed to see it through to the end. Some had to leave because of illness or surgery, one of our ladies found out she was expecting a baby!

“Collectively our challengers lost a whopping 529 lbs”

To add a little more excitement we had a prize for the ‘Biggest Loser’. Melissa Naylor lost 48lbs and was runner up, Lilias Gardiner came in second at 52lbs lost The Winner, was Louise Peet losing 53lbs. Hayley Simpkins kindly donated a beautiful Body Shop Hamper for the winner’s prize and Lilias and Melissa received a gift from the IIH UK online shop.

Of course the main aim of all this hard work was to raise funds for IIH UK, and to date we have raised the fantastic SUM OF £2320

We have the new Weight Loss Challenge underway now! Heidi Hemmingway and I, with the help of Holly Mattock and Melissa Naylor assisting us on the Challenge Facebook Group page, we hope to raise even more for the charity.

Details of the new challenge can be found on the website here: http://www.iihukwchallenge.moonfruit.com

My journey on the 20 week weight loss challenge

By Sabrina Hazelden

I decided to take part in the challenge as I needed to lose some weight and I thought what better way to do it in the support of other sufferers and their families whilst raising much needed funds for IIH UK.

I chose to follow the Slimming world plan as I know that is a good diet and you can eat most foods without it seeming like a diet. My 20 weeks were not too bad; I found the diet not too bad to stick to, the hardest days were when I was in a lot of pain. Alongside the diet itself I was walking my dogs for near on a mile everyday; again the hardest days were when I was in pain as I couldn’t get out. Overall though I enjoyed the challenge and I managed to lose 2 stone and half a pound and raised £292. I recommend everyone to take part in future challenges they are brilliant.

Football team fundraise for IIH UK

By Sandra Doughty-Fundraising Officer

Joining the fundraisers this year is a youth football team AFC Alsager Diamonds from Alsager in Staffordshire.

Out of the blue, I received an email from Ben Chamberlain, assistant manager to the team. He told me that his sister suffered from IIH and that the team would like to raise money for us over the next year.

“Super” - I thought! The email got more exciting as I read further.

He asked if they could display the IIH UK logo on the team shirts and, in exchange, would hold a series of fundraising events for IIH UK. I thought I would be cheeky and ask (after he mentioned they had a web page) if they could create a link to the IIH UK website and also if we could have a team photo in their kit.

Ben promised to send a photo which we will share with you, hopefully, in the next newsletter! Ben was also offered an IIH UK quiz pack to help with the fundraising – he said that quiz nights always went down well. So if you live in the area and have some free time, pop to a match and cheer them on!

The email has made me itself gave me some food for thought… do you know anyone who runs a team, be it football, netball, darts or hockey - the list is endless? Could they raise money for us and wear the IIH UK logo? It is a great way of raising awareness through free advertising and raising much needed funds.

If you would like any help, ideas or information regarding fundraising, please contact fundraising@iih.org.uk
Fundraising Quiz packs
by Sandra Doughty

Hello everyone,

After recently being voted in as a Liaison Officer for IIH UK, I volunteered to take over the role as Fundraising Officer.

It was in at the deep end for me! Being an IIH sufferer it was a struggle at first to get all the information I had in some kind of order; it's still work in progress now! The Trustees and especially Natalie Trinity have been very patient with my endless questions.

I have lots of Fundraising ideas and will be sharing them with you over the coming months. I have recently created a quiz pack, which includes questions, an answer sheet, poster and tie breaker etc. In fact, all you need to run your own Fundraising Quiz Night! You can make the event as big or small as you wish.

I am going to be holding a quiz night dinner party soon. My plan is to invite 10 couples and charge them £10 per couple, so £100 will be raised for IIH UK on the night. I will provide an easy buffet dinner and ask guests to bring a bottle, and I intend to buy a toy cup for the winning team! I enjoy socialising and cooking, and I know my friends will be happy to part with a tenant, as the money is going to such a good cause.

If you or your family are a member of any clubs, or visit a local pub, a quiz night is a great fun and brings out the competitive spirit in many! IIH UK can help raise the profile of your event by providing collection pots, sashes, flags and stickers. We can also help with the promotion too!

If you would like a quiz pack, or if I can help in any other way with your fundraising ideas please email me at fundraising@iih.org.uk or contact me through the link on the IIH UK website http://www.iih.org.uk/

Easy, quick & hassle free donating

If you want to help with raising funds, but time proves difficult, you can do your bit in a very simple, quick and easy way. You can make a one off donation at:

www.justgiving.com/iihuk/donate

You can set up a monthly Direct Debit via Just Giving and donate as little or as much as you want.
Get involved!!

KAT CURTIS is raising money for IIH UK by shaving off her hair to support her wife LEEANN CURTIS who will be having her head shaved for her 8th operation soon - a VP Shunt.

DAVE & NEIL SHEPHERD are undertaking a 110 mile cycle ride from Glasgow to Edinburgh to raise money for IIH UK. Dave’s daughter (Neil’s sister) KAREN was diagnosed with IIH in 2011, both Dave & Neil want to raise money to enable IIH UK to continue to support sufferers, raise awareness and help towards research.

SAM MEEHAN’S mum WENDY is undertaking a sponsored slim to raise money for IIH UK.

Brain Facts

....the Human Brain......

1) Is approximately 3 lbs in weight
2) Is made up of about 75% water
3) Is the fattest organ in the body and may consist of at least 60% fat
4) At birth, is almost the same size as an adult brain and contains most of the brain cells for your whole life
5) Is unable to grow after the age 18
6) Requires a yawn in order to send more oxygen to the brain, therefore working to cool it down and wake it up
7) Won’t allow you to tickle yourself because it distinguishes between unexpected external touch and your own touch
8) May not remember your dreams but it doesn’t mean you don’t dream. Everyone dreams!
9) Requires activity in five different areas of your brain when laughing at a joke: it is no simple task
10) Is believed to experience on average 70,000 thoughts each day
11) After the age of 30, shrinks a quarter of a percent (0.25%) in mass each year
12) Can feel no pain
13) Is so soft you could cut it with a butter knife
14) Is only just bigger than your two fists
Katie in the Press
By Michelle Williamson

A few weeks ago I liaised with a reporter named James Johnston at North East Press. We discussed doing a piece for the Sunderland Echo about Katie’s chance to get her ‘Moment to Shine’ as I had nominated her back in November last year to carry the Olympic Flame when it arrived in Sunderland on June 16th 2012.

James took an interest in Katie, her illness, her achievements, her work as Youth Rep of IIH UK and suggested that he would like to write an ‘IIH Awareness Raising’ piece for our local newspaper. Katie first appeared in the Sunderland Echo on May 10th. We were very surprised to find that her story was front page news which was continued inside the newspaper. Initially we were quite shocked by the headline but after reading the article soon realised that such a headline was a great way to raise awareness of IIH. Her story was continued on page 4 of the paper and on page 26 were the reporters comments.

Well you can imagine how pleased we were with the article, then to our surprise on May 23rd appeared another article about Katie. This time a whole page feature full of facts about IIH and IIHUK and they had included comments that Katie had made in an email to the reporter.

NHS Trust
By Sabrina Hazelden

I just thought I would update you with I have been busy doing recently as IIH UK Publicity Officer. I have written to 154 NHS trusts in England to get our leaflets approved for display in each of the hospitals. The benefit of this is once they are approved they can be delivered in bulk for distribution across the hospital especially Neurology, Neurosurgery, Neuro-ophthalmology departments and any other departments that they feel would fit in. I am currently waiting replies from them.

Next on the agenda is to contact all the NHS trusts / Health Boards across Scotland and then followed by Wales.

If anybody has any queries or questions on this do not hesitate to contact publicity@iih.org.uk
AGM Meeting and Me

By Victoria Davies

IIH UK HAS BEEN there as a support to me since being diagnosed with the condition, as soon as I heard there was going to be an official get together along with the AGM meeting for IIH UK I was eager to know more information.

It worked out nicely, the 2012 weekend was on a date that allowed my mum to come with me. It was right in the middle of the UK therefore allowing lots of people to attend. For those who wanted to stay overnight a meal, (which was lovely) and pool facilities were also included in the price. We chose to stay 2 nights and enjoyed every moment.

The conference day was excellent, it started at 10am with welcome drinks so everyone's IIH heads weren't too bad. The room was set up with a main area, an IIH UK shop, (which I enjoyed buying lots of nice things from) and a children area, as everyone was made to feel welcome to join the weekender.

First we were given a talk by our chair David, who explained the history of IIH, disclosed some informative statistics and gave us some background into what IIH UK has been doing the past year, which was a lot. Not only do the team work on keeping us all in contact via Facebook as well as on the forum, but they have also set up the new website.

The IIH UK team have been sharing information with NASA, securing funds for research, consulting with different medical professionals about research, investigating how to get guidelines set for all medial staff to follow when performing LPs, creating the new Sarah Hibberd conference for medical staff to learn about IIH and the list goes on.

Next to the floor was Dr Lim a friendly Paediatric Neurologist, although his studies were based on children I found the information really informative and felt I learned more about the condition. Everyone threw a lot of questions his way but he kept going and answered all that he could. I even think it was interesting for him to hear patients views and I hope he attends again at future weekenders.

The formality of voting in officials was quick, as forms had already been completed. We had a fun quiz, a raffle and a few donations were made which made a nice day even better.

In the evenings we sat in the bar area till late talking to different people about our experiences with IIH and having a general natter. From this side it was really good to meet other people facing similar challenges and share tips on what helps make the day a little easier.

Mum found speaking to other parents reassuring and has been able to cope with my condition better since attending the weekend.

Both myself and mum met too many nice people to mention by name so thank you to everyone who attended.

Jokes by Lana-Mae Garrett

Q. What runs but never walks? A. A tap!
Q. How do mountains hear? A. With mountaineers!
Q. How do you weigh a fish? A. With it’s scales!
Q. How did the Pirate get his eye patch half price? A. It was in the sails!
I have been busy spreading awareness of IIH... Our dedicated information stand has spent some time being positioned, in the foyer, of one of the Midlands largest and busiest hospitals, the University Hospital of Coventry and Warwick. The stand contains copies of our leaflets and other awareness information, as well as providing patients and their families the opportunity to come and meet us, in person, should they wish. The stand has proved to be a huge success. We will be based at the University Hospital of Coventry and Warwick again for the period covering 10th September 2012 – 21st September 2012, should anyone wish to pay us a visit.

I am busy contacting other hospitals, around the UK, to see if we can visit them and I will keep you all updated with my progress.

IIH UK—Working in Wales
By David Dennis

As part of our plan for regional development and support for IIH sufferers, our Chair – David Dennis, met with Mark Isherwood AM - Shadow Minister for Communities and Housing (see photo) and Joseph Carter – MS Society Policy, Press and Campaigns Manager – Wales at Holywell, N. Wales on Monday 20th August.

As a result, IIH UK has joined the Welsh Neurological Alliance (WNA) and will receive invitations to conferences and have an opportunity to address conferences about our aims. They have formed a cross-party committee on Neurology in Wales chaired by the minister.

The aims of this powerful cross-party Welsh Committee, which has the support of Labour and the Coalition – are:

- to engage and work in partnership with people affected by neurological conditions
- to raise awareness of those conditions and their impact on individuals and their communities
- to inform and influence policy makers about the needs of people with these conditions
- to support and promote research.

During the meeting, David was given the contact details of many organisations in Wales who wish to help us, including the Neuroscience Network Board, Health Challenge Wales, the All Wales Medicines Strategy Group, the Welsh Health Specialised Services Committee, the Neuroscience Committee for North Wales, Wales Reablement Alliance and the Wales Advocacy Service. David was also given the names and programmes of the doctors and surgeons in North Wales and of the Head Surgery and Spinal Surgery Committee chaired by Dr P Birch who is also the Medical Director of the N Wales NHS Trust.

The minister is now in possession of all the facts concerning IIH and our charity and David was very much encouraged about the way the IIH UK and the Cross Party Committee can work together.

This was a very successful meeting and the minister is keen to help us as much as possible. Around 40 people who live in Wales and have IIH are known to us. However based on the population of Wales we would expectation around 570 people with IIH in Wales.

So - please, if you live in Wales and know someone with IIH, ask them to get in touch with us. Next year in May our medical team will be opening the UK- wide national database of IIH patients and so it is important to identify as many IIH sufferers as possible. The database will be fully confidential. It has been funded by the Department of Health.

IIH UK Charity Market Stall
By Sarah Newton

On Saturday 18th August, we held our first, of many, charity stalls on Hinckley market. A super, fun day was had by all and we raised £104.56!

Our 2nd stall will be held on 3rd September, with others in the pipeline, as well as a great big Christmas stall!

A huge thank you to my Mum, Dad and wonderful children, Jack and Holly for helping to make this stall possible.
IIH is a rare disease but is becoming increasingly prevalent. Our members and forum users have been concerned to find that they have been turned down for disability benefits even though they thought they had a legitimate case. An investigation showed that there could be three main reasons:

a. Disability Benefit evaluators were either ignorant, poorly trained or unprofessional in their attitude to rare diseases. For example, they turned down applications because they mistakenly interpreted the word ‘hypertension’ in the IIH name – Idiopathic Intracranial Hypertension – as being connected to high blood pressure not high cerebrospinal fluid pressure.

b. Disability Benefit evaluators were failing to adhere to Department for Work and Pensions guidelines based on the Disability section of the Equality Act 2010 in that they turned down applicants with IIH because IIH was ‘not listed’ on the DWP website either internally or externally as a known impairment. This, despite being specifically and repeatedly told by DWP Ministers to make judgements only on the facts of cases – the effect of symptoms on people not just the name of their impairment.

c. The effect of IIH on particular patients was not sufficiently impairing to warrant payment because the symptoms did not have a significant long-term effect on their ability to live their lives at home or to go to work, as specified by the Equality Act 2010.

An investigation by the Chair of IIH UK found that a. and b. were unfortunately true.

Senior official Norman McCormack at DWP has been extremely helpful in immediately listing IIH as Idiopathic Intracranial Hypertension on DWP staff internal and public external lists – but also cross-refering it to the older medical names of Benign Intracranial Hypertension and Pseudotumor Cerebi with the help of his colleague June Jenkinson who gives DWP advice to ATOS.

All disability evaluators must now refer anyone with IIH to DWP medical staff and not make judgements themselves based on faulty assumptions.

When thanked for his help, Norman McCormack said:

‘I think the important message for everyone working in an organisation such as the DWP is this.

We are all in a position to make a difference and if we are to improve the perception of DWP amongst the general public, it is vital that individuals within the organisation take responsibility for trying to effect positive change.

If I’ve managed to do this in some small way, then I’m satisfied.’

A letter about our concerns at IIH UK about poor work by ATOS Healthcare staff and incorrect judgements at DWP Tribunals, including some possible breaches of human rights was sent to Secretary of State Iain Duncan Smith MP and Disability Minister Maria Miller MP.

Some IIH sufferers who had given up trying to obtain disability benefits have now been contacted by DWP to request that they resubmit their claims. Some IIH sufferers who have been turned down have now had those decisions reversed.

As far as c. above is concerned – DWP will not pay out if the effects of the symptoms upon home or work life are not sufficiently severe or impairing. Each person who applies must show clearly that not only do they have IIH but also that its effects are debilitating. We will continue to work on your behalf in this matter to ensure that both you and DWP have maximum information.
Programmable Shunt Valves and Magnetic Influence

By Natalie Garrett

Many people with shunts will know the name of their programmable valve and the manufacturer of that valve. However, not many may know that everyday magnets can have an influence over the setting of their valve.

Programmable valves are adjusted using magnets. This picture is of my daughter having her old programmable LP valve checked and adjusted to 2.5.

The device is held just above the skin so the adjustment is totally non-invasive and painless.

Recently there has been talk of how the new Apple iPad®2 Smart Cover has been having a negative effect on adjustable valves. The smart cover has a very strong magnet and if held too close to a programmable valve can change the setting. A paper was written after testing tablet computers against programmable valves:

Programmable shunt valve affected by exposure to a tablet computer.

http://theins.org/doi/full/10.3171/2012.3.PEDS1211?prevSearch=ipad&searchHistoryKey=

This paper showed that after 100 exposures at distances between 0 and 1 cm, 58% of valves had different settings following exposure.

At distances greater than 1 cm but less than 2.5 cm, 5% of valves in 100 exposures had setting changes.

Only a single setting change was noted in 100 exposures at distances greater than 2.5 cm but less than 5 cm.

No setting changes were noted at distances greater than 5 cm, including 100 exposures between 5 and 10 cm, and 100 exposures of more than 10 cm.

For the 30 valve exposures to the tablet without a cover, 20 valve performance-level changes (67%) were noted.

Laboratory investigation, Jennifer Strahle, M.D.*, Béla J. Selzer, N.P., Karin M. Muraszko, M.D., Hugh J. L. Garton, M.D., M.H.Sc., and Cormac O. Maher, M.D.
Department of Neurosurgery, University of Michigan, Ann Arbor, Michigan

* Drs. Strahle and Selzer contributed equally to this work.
Address correspondence to: Cormac O. Maher, M.D., Department of Neurosurgery, University of Michigan, 1500 East Medical Center Drive, Room 3552 Taubman Center, Ann Arbor, Michigan 48109-5338. email: cmaher@med.umich.edu.

IIH UK received a leaflet from Medtronic who manufacture shunts and valves. The table of magnetic influences is pictured here. The full leaflet is available on our website here: http://www.iih.org.uk/resources

In conclusion: If you have a programmable valve it is very important that any strong magnet does not get closer to it than 2.5cm in order that it doesn’t change the setting of your valve.

If you think your valve setting may have been changed due to close proximity to a magnet – get it checked as soon as possible!
Food that can raise intracranial pressure (ICP):

**Oily Fish:**
- Sardines
- Salmon
- Mackerel
- Trout
- Herring
- Pilchards
- Anchovies
- Fresh Tuna
- White Bait
- Shellfish

**Dairy:**
- Cheese
- Eggs
- Muller Light Cherry
- Muller Light Blueberry
- Muller Light Raspberry
- Muller Light Banana And Custard
- Danone Activia Cherry
- Weight Watchers Fromage Frais
- Weight Watchers Toffee And Vanilla

**Vegetables:**
- Carrots
- Broccoli Leaves
- Kale
- Sweet Potato
- Broad Beans

**Salad:**
- Tomatoes

**Meat:**
- Liver
- Salami
- Pepperoni

**Citrus Fruit:**
- Tangerine
- Satsuma
- Orange
- Clementine
- Grapefruit
- Kumquat
- Lemon
- Lime

**Crisps:**
- Walkers Prawn Cocktail
- Walkers Sensations Thai Sweet Chilli

**Spices**
**Sweets And Treats:**
- Chocolate
- Liquorice
- Wrigley’s Airwaves (All Varieties)
- Wrigley’s Orbit (All Varieties)
- Wrigley’s Extra (All Varieties)

**Other:**
- Uncle Bens Sweet And Sour Light
- Pickled Food
- Nuts
- Olives

**Drinks that can raise ICP:**

**Contains Aspartame:**
- Robinsons Orange Squash
- Robinsons No Added Sugar Range
- Ribena Really Light (All Varieties)
- Oasis Citrus Punch
- Oasis Summer Fruits Extra Light
- Dr Pepper Zero
- Fanta Orange
- Fanta Zero (All Varieties)
- Schweppes Slimline Drinks (All Varieties)
- Lucozade Sport (All Varieties)
- 7UP (All Varieties)
- Tango No Added Sugar (All Varieties)
- Tango (All Varieties)
- Sprite Zero (All Varieties)
- Lilt Zero (All Varieties)
- Diet Irn Bru (All Varieties)
- Pepsi Max (All Varieties)
- Diet Pepsi (All Varieties)
- Coke Zero (All Varieties)
- Diet Coke (All Varieties)
- Caffeine:
  - Tea
  - Coffee

**Alcoholic:**
- Beer
- Wine

**Drink Powders:**
- Options Hot Chocolate (All Varieties)
- Cadbury’s Highlights (All Varieties)

**Medicines that can raise ICP:**

**Alternative Medicines:**
- HRT
- Multi Vitamins
- Cod Liver Oil
- Ginseng
- Gingko Bilbao
- Hawthorne
- Tetracycline Anti Biotic:
- Tetracycline
- Ox tetracycline
- Demeclocycline
- Doxycycline
- Minocycline

**Contraceptive:**
- Any Contraceptive That’s Oestro-
gen Based

**Cold And Flu Remedies:**
(Avoid anything with ingredient Phenylephrine Hydrochloride)
- Nyal Decongestant Nasal Spray
- Panadol Flu Strength Day & Night PE
- Demazin PE
- Cordal Cold & Flu
- Excedrin Sinus Headache
- Benadryl Allergy & Sinus Head-
ache
- Theraflu
- Dristan
- Robitussin CF, Tylenol Sinus
- DayQuil Capsules
- Sudafed PE Non-Drowsy Nasal Decongestant
- Alka-Seltzer Cold Effervescent
Formula
- Benelyn Cold And Flu Day And
Night
- Beechams Flu Plus

**Hayfever And Allergy:**
(Avoid Anything Containing Corticos-
teroids)
- Nasonex
- Flonase
- Rhinocort
- Nasacort AQ
- Nasarel
The following leaflet has been taken from UKTis website. We wanted all to see it as not all Drs are advising women about the possible dangers of taking Acetazolamide and pregnancy. Please make sure you read this and if possible share it with your GP and medical team if you are taking Acetazolamide and hope to become pregnant or are already trying. You can report possible pregnancy exposure to Acetazolamide via the uktis website here: www.uktis.org/

USE OF ACETAZOLAMIDE IN PREGNANCY

SUMMARY: Acetazolamide is a carbonic anhydrase inhibitor used in the treatment of glaucoma, idiopathic intracranial hypertension, some forms of epilepsy, and as a diuretic.

There are limited data on which to base an assessment of the safety of acetazolamide in human pregnancy. Preclinical studies have demonstrated teratogenic risk, however available data from human pregnancies do not suggest a significantly increased risk of congenital malformations or spontaneous abortion following exposure, however are too limited to exclude any increase in risk.

Use of acetazolamide in late pregnancy has been associated with neonatal electrolyte imbalance and metabolic acidosis. Following exposure, monitoring of the neonatal electrolytes is recommended.

The use of acetazolamide should be reserved for appropriate indications where no suitable alternative treatment is available. Exposure to acetazolamide at any stage of pregnancy would not usually be regarded as medical grounds for termination of pregnancy or any additional fetal monitoring.

If you are pregnant and require advice regarding exposure to acetazolamide please contact your health care professional who can contact UKTIS on your behalf.

If you have a patient with exposure to acetazolamide and require assistance in making a patient-specific risk assessment, please telephone UKTIS on 0844 892 8909 to discuss the case with a teratology specialist.

If you would like to report a pregnancy where exposure to acetazolamide has occurred, please click here to download our pregnancy reporting form.

Disclaimer: Every effort has been made to ensure that this monograph is accurate and up-to-date. However it cannot cover every eventuality and the information provided cannot be held responsible for any adverse outcomes of the measures recommended. There is a background incidence of congenital malformations (2-3%) and spontaneous abortions (10-20%) irrespective of any drug or chemical exposure. The final decision regarding which treatment is used for an individual patient remains the clinical responsibility of the prescriber. This material may be freely reproduced for education and not for profit purposes within the UK National Health Service, however no linking to this website or reproduction by or for commercial organisations is permitted without the express written permission of this service.

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Gluten-free muffins!

These little cakes are incredibly simple to make, they're also gluten-free and because of the almonds very moist. You will need muffin cases and a tin to bake them on (I use a 6-hole cake tin which the filled cases drop nicely into the spaces) I have converted the quantities to be able to use equipment readily available to most of us.

**Method**

1. Pre-heat oven to gas 3/4
2. Measure the oil into the bowl/jug and whisk the eggs in one at a time (don't go mad it should just form a batter)
3. Mix in the sugar, the mug of almonds and baking powder with the whisk.
4. Now add your flavourings if desired:- one dessert spoon of cocoa for chocolate, 2 dessert spoons blueberries or raisins etc. (chopped banana, raspberries or strawberries also work)
5. Fill the cases with the batter and bake for 25 minutes. (I turn the tin round after 15 to even the colour).

When baked, place on cooling rack and when cool - Enjoy!

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**Ingredients**

- 4 dessert spoons oil
- 3 eggs
- 4 dessert spoons sugar
- 1 mug ground almonds (a normal mug is half pint)
- half tspn baking powder
- Flavourings

**Equipment needed**

- 6-space tin with muffin cases
- bowl or jug large enough for mixing (about one and a half pt)
- hand whisk
- dessert spoon and teaspoon

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**The pain in my head, drives me insane.**

**It's always there, it won’t leave me alone.**

I wish it would go. Nothing I do will stop it. Why? Why? Why?
I want it to stop, the constant ache, like people trampling on my head.
I can’t do anything; go to school, socialise. I feel so lonely.
I don’t know what to do.

Poem By Vicky Kimber
Olympic themed word search

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Words to find:

Hint: Look up and down!

Gold Silver
Bronze
London
Heptathlon
Tennis
Rowing
Sprint
Cycling
Swimming

Spot the difference!

Find and circle SEVEN differences between the two pictures
This September IIH UK hopes to raise as much awareness of Idiopathic Intracranial Hypertension and its sufferers as possible! So far this month we have the following Fundraisers:

Here at IIH UK, we are determined to make as loud a noise as possible to raise awareness for those with IIH.

We thought it would be great to have as many fundraisers as possible in one month so if you have any ideas please don’t hesitate to tell us about them or - ask our fundraising team for help to organise them. You can email fundraising@iih.org.uk with any ideas or questions and we will do our best to help you.

We have flags, stickers and sashes available for fundraisers. So please - if you have an idea for September to raise awareness for IIH let us know!

The 2nd IIH UK Weight loss Challengers have raised £1078.50 in sponsorship via their JustGiving pages so far! To date they have lost a combined weight of 110lbs, there are 12 weeks left of the challenge.

We have an IIH September Awareness Twibbon for Twitter and Facebook. The Twibbon is available here: http://twibbon.com/Search?searchQuery=iih+uk
News updates will be released to the press and advertisements will be taken out in National newspapers.
Leaflets and posters will be printed and distributed to as many hospitals, GP surgeries and public places as possible!

Lance Clifton is running the Kent Coastal Marathon on the 2nd September 2012 for his daughter Lauren an IIH Sufferer and IIH UK Youth Represenative. You can support Lance here: http://www.justgiving.com/Lance-Clifton

9th September 2012 Karen Orchard’s Father Dave and her Brother Neil are taking part in the 110mile cycle as part of the Pedal for Scotland Challenge. Starting in Glasgow and cycling via Kilmarnock then through the Southern Uplands to the finish in Edinburgh. You can donate via their fundraising page here: http://www.justgiving.com/Dave-Neil-Shepherd

Natalie Markham has done a sponsored Sky Dive for her friend Lisa who suffers with IIH. The event was on the 26th August 2012, Sibson Airfield at 12.30pm. Please sponsor Natalie via her JustGiving page: http://www.justgiving.com/Natalie-Markham

Lizzie Stuart ran the Birmingham 5k Fun Run from Cannon Hill Park on the 19th August 2012. You can still sponsor Lizzie via her JustGiving Page here: http://www.justgiving.com/lizzieiih

Show your support and help Lizzie to get a great sponsored total!
September 2012 is IIH Awareness Month

Let's work together to relieve the pressure!

www.iih.org.uk
www.iihsupport.org

Registered Charity in England and Wales 1143522 & Scotland SCO43294

Kayleigh Johnstone has organised a night of live music at The Bumper, Harman Street, Liverpool. £5 entry and raffle tickets for sale on the night. Contact Kayleigh on Kayleigh21@hotmail.co.uk for more information and tickets.
Huge thanks to all who fundraise for IIH UK it is greatly appreciated and allows us to carry on sending information advice to those who need it most, print & distribute leaflets and posters to hospitals and anyone who will take them! The money pays for the upkeep of our websites, enabling people to find help and support they never knew was there.

Over the last few months many people have fundraised for us, either putting their spare change in to a pot in their kitchen or organising amazing days and nights out. Every little really does help!

Jess Gawn held a Family Fun day at the pub on with an evening of live music and cocktails. Jess and friends also clubbed together and got sponsored to have the IIH Awareness ribbon tattooed. All in all Jess and friends and family raised a truly wonderful £563.81!

Louise Husband presented a PowerPoint presentation to the children of All Saints School, Waddington. The School also held a non uniform day and raised £323.87!

Mark Walden and his family held a bowling night in memory of Mark’s Sister Karen Sherlock. The evening was enjoyed by all and the £420 raised was split equally between IIH UK and Diabetes's UK. At the end of the evening the family released Diabetes's UK balloons with 'In memory of Karen Sherlock' notes attached. Thank you Mark.

Holly Mattock and her family and friends held a fundraiser in her Aunt’s garden with plants, cakes, books and more for sale and raised a wonderful £400!

Stephen Pooley ran the London 10K for his sister Karen who suffers with IIH. He has raised an amazing £865!! Thank you Stephen!

Sainsbury’s Bag Pack on 16th May Michelle Williamson, her daughter Katie and family undertook a bag pack at Sainsbury’s in Shiremoor. A big thank you to Sainsbury’s for giving IIH UK the opportunity to fundraise and a bigger THANK YOU goes to Sainsbury’s customers for their generosity. We were there for 4 hours and raised £241.13.

Sunday 22nd July was the Great North 10K Run. Taking part for IIH UK are Helen Williamson, Nikki Dodds as well as two of Sainsbury’s staff from the Sainsbury’s Northumberland Park Store in Shiremoor, Newcastle Upon Tyne. Many thanks to the Sainsbury’s staff who presented IIH UK with a sponsor money cheque for £220.50.