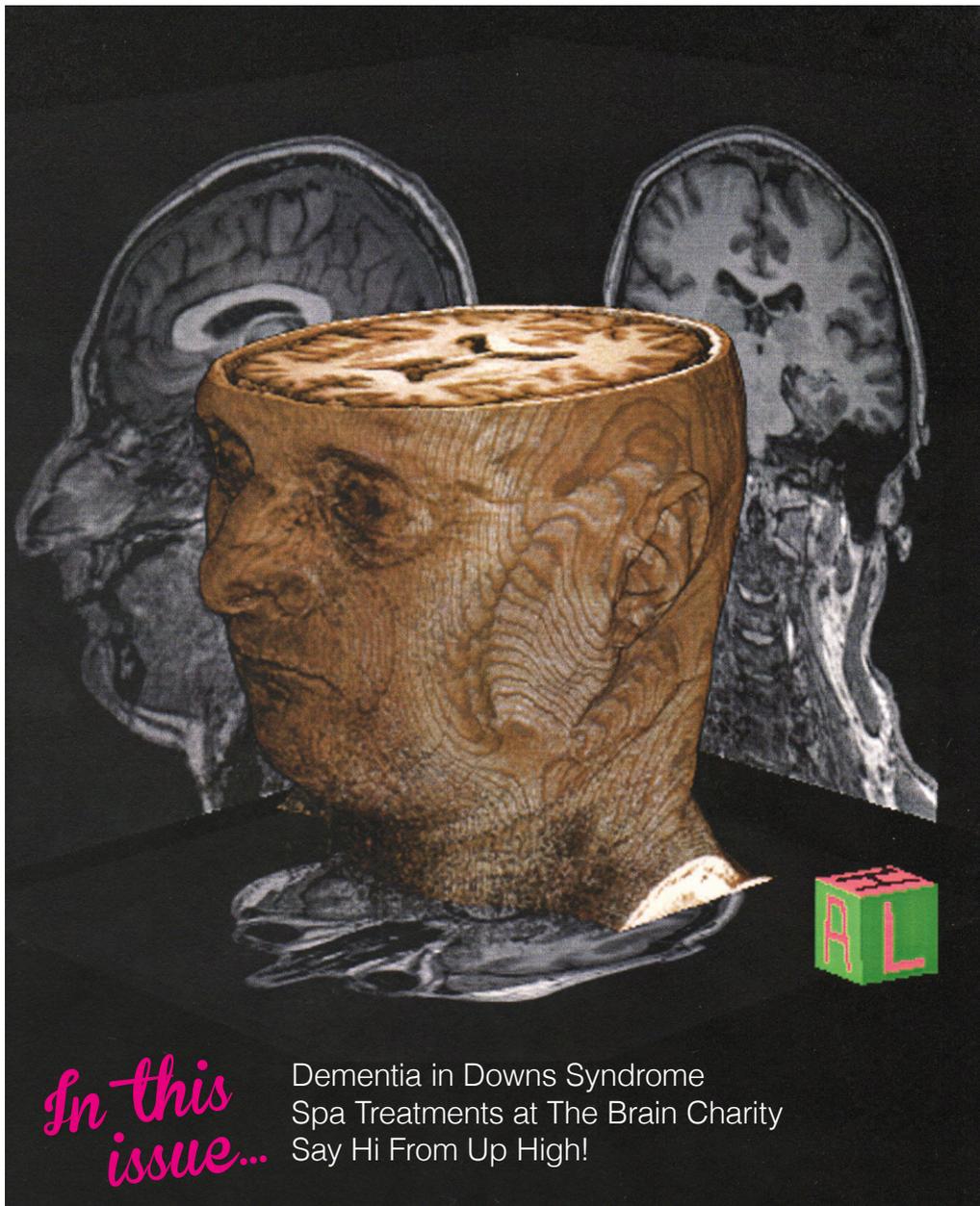


Glance



National support for all neurological conditions

February/March 2017



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Dementia in Downs Syndrome

Hello, my name is Jonathan Hurley and I am Downs Syndrome.

About five or six years ago I got involved with the University of Cambridge on the '**Defeat Dementia in Downs Syndrome**' project.

I joined this program because Downs Syndrome people can get dementia at quite an early age, mid-thirties onwards.

The studies that are being made are all about finding new information about dementia in Downs Syndrome, and finding new methods for showing signs of dementia, which will hopefully lead to finding early markers which can be used to treat and monitor treatments of dementia.

I first attended the Wolfson Brain Imaging Centre, which is based at Addenbrooke's Hospital in Cambridge, I had a magnetic resonance imaging (MRI) scan lasting about one hour. This scan looks at the structure of the brain.



I then had a positron emission tomography scan (a PET scan), which took about two and a half hours. This scan maps the brain and shows if there is a substance called amyloid in it; this substance is associated with dementia.

I also had blood tests and a range of tests to assess my memory. All these tests were then repeated three years later and are still being evaluated to see what, if any, are the difference between the two.

I had a number of other studies done including a Mitochondria study to measure my energy levels and a DEXA scan which measures body fat and muscle content and gives a print out of what you look like on the inside.

I had an EEG study too, which used a cap to look at brain activity and played a range of noises and images to see how my brain interpreted the information and whether this was different from people who are not Downs Syndrome.

I also took part in an eye study, which looked at the retina for signs of dementia related changes.

I took part in all these studies because I hope they will help, not only myself, but all people who are born Downs Syndrome to have a more secure and healthy life.

I hope this gives all my peers confidence that we are not forgotten and people are thinking about us.

If anyone wants any more information you can contact Maddie (Madeleine Walpert. She is a PhD student and part of the research team based at Department of Psychiatry University of Cambridge.) Maddie can be contacted on 01233 746172 email: mjw208@medschi.cam.ac.uk

*" Instead of worrying,
I deal with things "*

Laura, 28, tells us how counselling helped her feel better about her future

After being diagnosed with epilepsy, Laura's mum advised her to visit The Brain Charity. That was over twelve years ago. Last year, Laura felt she needed a bit of extra support in the shape of our counselling service.

"I was feeling very low about myself, how my conditions affect me and decided to take action. I have three neurological conditions: epilepsy, autism and dyspraxia and felt I was on the edge of falling into depression and didn't want to go there."

Laura asked to be referred to The Brain Charity's counselling service and started having sessions with Joan, one of our volunteer counsellors. With Joan's help, Laura was able to find some coping mechanisms to help her.

"I went into the first session feeling that things were hopeless but came out feeling great and couldn't wait for the next session. I thought I was living a normal life before counselling. Now, instead of worrying, I deal with things. Instead of stressing and shouting I deal with it."

Laura had a total of nine sessions with Joan, and felt that it was enough to help her feel better about herself and her future.

"I would advise anybody to go for counselling if they are feeling low. The experience was amazing and I use the coping strategies I have learnt every day."



Spa Treatments at The Brain Charity

Having a neurological condition can make you feel stressed, tense and just not really 'yourself'. Here at The Brain Charity we think that being able to relax and feel better about yourself is a really important part of living with any condition.

This is why we are very pleased to announce that we will be providing FREE spa treatments for clients of The Brain Charity this year! These treatments will be provided by our new starter Natasha, who is a qualified beauty and relaxation therapist.

There is plenty of evidence to suggest that massage therapy and other therapies designed to boost relaxation, confidence and self-esteem are hugely beneficial for people who have a neurological condition. The benefits to having spa treatments are numerous and include things like improved self-esteem and joint movement; reduced anxiety, stress and chronic pain; and an overall improvement in quality of life. One particularly beneficial treatment is massage and we will be including massage in all of our treatments for this reason.

To begin with, we will be offering manicures with arm and hand massage. You can decide on a coloured polish or just to have your nails shaped and buffed – so no need to be afraid, gentlemen! We will then be offering pedicures and manicures with GelColor polish, Indian head massage, and a variety of aromatherapy massages. We are very excited at this opportunity and can't wait for you to come and enjoy some time at The Brain Charity Spa!

Just call us on 0151 298 2999 and ask for Natasha, or email natasha@thebraincharity.org.uk to book an appointment today.



The C-App website has been designed to tell people what they need to know about the process of applying for the disability related benefits Personal Independence Payment (PIP) and Employment and Support Allowance (ESA).

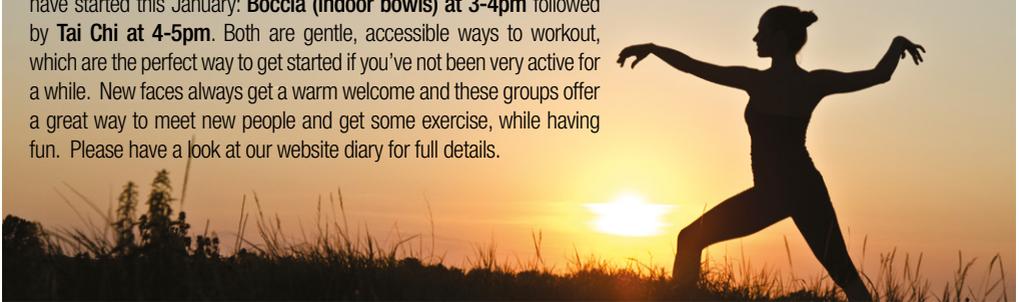
It's packed with help and guidance on the application and assessment process, advice on how to answer the questions in the assessment to accurately describe the impact of conditions and information about a person's rights in the assessment.

Most importantly, the site offers practice questions like the ones people can expect in their face-to-face assessment. It can then identify a list of the key issues that it will be important to mention at the assessment, which will often be vital to getting a fair result.

To give it a try visit: www.c-app.org.uk

GET MOVING WITH THE BRAIN CHARITY

If you promised yourself you'd be more active this New Year, Thursday afternoons at The Brain Charity are for you! Two new FREE activities have started this January: **Boccia (indoor bowls) at 3-4pm** followed by **Tai Chi at 4-5pm**. Both are gentle, accessible ways to workout, which are the perfect way to get started if you've not been very active for a while. New faces always get a warm welcome and these groups offer a great way to meet new people and get some exercise, while having fun. Please have a look at our website diary for full details.



The
Brain
Charity

0151 298 2999

E: meetings@thebraincharity.org.uk

The income from our room hire directly funds our charity work, supporting people with neurological conditions

**MEETING AND CONFERENCE
FACILITIES FOR HIRE**

For 2-100 people



www.thebraincharity.org.uk

Say

Hi!

From Up High!

This Brain Awareness Week, The Brain Charity will be saying **#HiFromUpHigh** to raise awareness of the invisible effects that a neurological condition can have on mobility, energy levels, and pain.

Taking the lift is just one example of the small adjustments that many of the 12.5 million people in England affected by a neurological condition may have to make to create a big impact on their independence, ultimately enabling them to stay in employment, carry out their daily activities, and live their lives to the full.

By tackling the staircases of the some of the most iconic (and tallest!) buildings in Liverpool all in one day, Alice Biggar, successful candidate for The Nicest Job in Britain, hopes to raise awareness of the issues facing people with an invisible disability. Comprising of hundreds of flights of stairs, this will be no easy task! Show your support by donating £5* by texting **HFUH17 £5** to 70070.

Stay tuned to our social media on **Thursday 16th March** to see how she gets on!

HOW TO GET INVOLVED

This Brain Awareness Week, from Monday 13th to Sunday 19th March, The Brain Charity is asking you to say **#HiFromUpHigh** to show support and raise awareness for those that are living with the invisible effects of a neurological condition.

No matter how you get there, snap a photo from up high and post it to your social media platforms with the hashtag **#HiFromUpHigh**. Donate £5* to The Brain Charity by texting **HFUH17 £5** to 70070 and inspire your followers to do the same!

You can also make a donation online at www.bit.ly/glHFUH17

*For full JustTextGiving terms and conditions visit: www.justgiving.co.uk



HEAD MATTERS 2017

A TREAT FOR THE SENSES

Brain Awareness Week is an international campaign to share what's new in brain research. So from 13th-19th March this year The Brain Charity will be joining with others around the world to let our communities know about all things brain-related as well as how we can help them or a loved one.

The highlight of the week will be our Head Matters Tea Party on **Wednesday 15th March, from 11am-4pm**, at our base on Norton Street. This year's party has a theme: 'The Senses', so there will be plenty going on to excite our senses of taste, touch, sight, smell and hearing – the five sources that our brains use to understand the world.

As well as giving you the chance to tickle your senses, lots of groups covering a wide range of neurological conditions will be on hand to answer your questions and provide advice. We will also have a series of talks by leading doctors and brain science researchers taking place through the day - details will be announced on our website and social media channels soon.

Of course, it wouldn't be a tea party without tea! We'll also be offering the chance to freely sample our unique new range of teas, each of which have been hand blended by local company Lady Liver Teas with a health benefit in mind. So come and relax, meet other people who understand what you're going through and make new friends with a chat over a nice cuppa. We hope you will all be able to find some time to drop in and see what's happening during the day.

Finally, here's a heads up: We will be celebrating the brain with our ever-popular funny hat competition on the day. Perhaps you could make your own special hat to dazzle the judges and win a prize this year?



Astonishing new **STEM CELL** **THERAPY** for MS

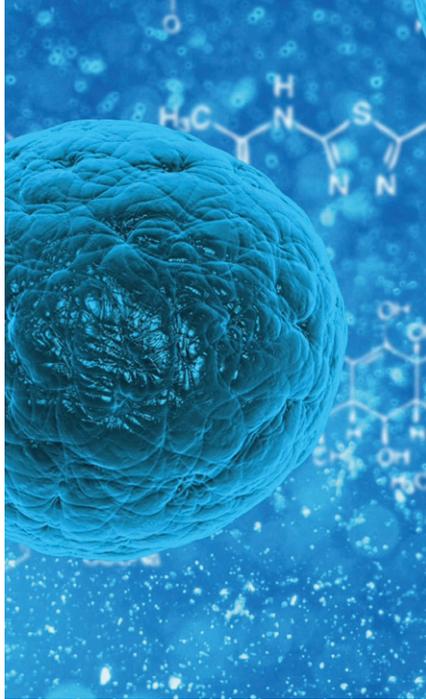
Stem cells are different from your body's ordinary cells because they can repair themselves, and they can even produce other types of cells. This means they could be used to help treat multiple sclerosis (MS) and other conditions, using treatments known as 'stem cell therapy'.

Recent research looks promising for the treatment of people who have the 'recurring-relmitting' form of MS. This is one of the main forms of MS, where a 'relapse' means the sudden development of a new symptom, or the sudden re-appearance of an old symptom. Other symptoms like fatigue are common, long-term, problems in recurring-relmitting MS.

The clinical trial of the pioneering new treatment meant that the existing faulty cells were removed and replaced. This was done first by using chemotherapy to treat the immune system. It is the immune system itself which looks like the culprit for attacking the brain and nervous system, causing the symptoms of MS.

Then the new treatment used stem cells taken from the patients' own blood to rebuild new, healthy cells.

Patients effectively had the progress of the disease brought to a halt.



Read more about stem cell therapy:

www.bit.ly/GLMSscell

MS Society: Emerging areas of research:
Stem cells

www.bit.ly/GLMSsc2

MS Trust: Stem cell therapy

www.bit.ly/GLMSsc3

International Society for Stem Cell Research:
Patient handbook on stem cell therapies

HOLD YOUR OWN TEA PARTY

The Brain Charity helps people from all over the country, so we know not everyone will be able to make it to our Head Matters Tea Party on **Wednesday 15th March**.

However, we hope you can still help us to celebrate Brain Awareness Week and raise awareness of the charity by hosting your own Head Matters Tea Party at home, at work or anywhere else where people meet in your community. We've put together a free tea party pack with lots of ideas, recipes and inspiration to help you get started.

Download our tea party pack here: www.bit.ly/GLTEA



THE BRAIN CHARITY CALENDAR

February 2017

March 2017

Wed 1st	Walking Group, 1.30-3pm Merseyside Spinal Injury Group, 2.30-4.30pm O.C.D. Support Group, 5-7pm
Thurs 2nd	Indoor bowls, weekly till 16th, 3-4pm Tai Chi, weekly, 4-5pm
Frid 3rd	Parkinson's Support Group, 2-4pm Advice drop in, weekly, 1-4pm
Sat 4th	Ataxia NW Support Group, 11am-3pm
Mon 6th	Tea, Coffee & Company Morning, 10:30am – 12pm Aphasia Support Group, weekly, 1-3pm Alzheimer's Society Support Group, 2-4pm Choir, weekly, 5-6pm
Tue 7th	Craft Club, weekly, 10.30am – 12pm
Wed 8th	Walking Group, 1.30-3pm
Fri 10th	Migraine Peer Support Group, 1-3pm Advice drop in, weekly, 1-4pm
Tue 21st	Tuberous Sclerosis Support Group, 10.30am-12.30pm
Thurs 23rd	Epilepsy Action Coffee and chat, 11am-12.30pm Tai Chi, weekly, 4-5pm
Mon 27th	Brain Tumour Support Group, 1-3pm

Wed 1st	Merseyside Spinal Injury Group, 2.30-4.30pm O.C.D. Support Group, 5-7pm
Thurs 2nd	Craft Club, weekly, 10.30am-12.00pm Tai Chi, final session, 4-5pm
Fri 3rd	Parkinson's Support Group, 1-4pm Advice drop in, weekly, 1-4pm
Sat 4th	Ataxia NW Support Group, 11am-3pm
Mon 6th	Tea, Coffee & Company Morning, 10.30am-12pm Aphasia Support Group, weekly, 1-3pm Alzheimer's Society Support Group, 2-4pm Choir, weekly, 5-6pm
Tue 7th	Craft Club, weekly, 10.30am – 12pm
Fri 10th	Migraine Peer Support Group, 1-3pm Advice drop in, 1-4pm
Wed 15th	Head Matters Tea Party, 11 am-4pm
Mon 27th	Brain Tumour Support Group, 1-3pm Aphasia Support Group, weekly, 1-3pm Choir, 5-6pm
Thurs 30th	Epilepsy Action, coffee and chat drop in, 11am-12.30pm

ABOUT THE BRAIN CHARITY

The Brain Charity offers practical and emotional support to people with neurological conditions and to their families, friends and carers. For more information contact the Centre or visit our website: www.thebraincharity.org.uk

Get Social with us:



thebraincharity



thebraincharity You can also find us on:



Instagram



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Email: info@thebraincharity.org.uk

The Brain Charity is registered as a charity (No: 1114999) and a company limited by guarantee in England and Wales (No: 5741930) Glance is available in large text or braille on request.

Glance is available on The Brain Charity website: www.thebraincharity.org.uk

If you wish to be added to the Glance mailing list, please contact our Information and Advice Officer using the telephone number or email above.



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