# Headway Sefton News



## Happy New Year

## it's time to talk about our heroes!

People who have experienced something as traumatic as a brain injury, be it survivor or their family; often have a greater understanding of the value of people around them.

Next month is my 7th brain surgery anniversary. I am lucky enough to live in Liverpool; home The Walton Centre.

Many of us will have someone who stands out in their own journey, and Dr Udo Weishmann fills that role for me. It spans from my initial brain tumour diagnosis in November 2011, right the way through to my treatment as an outpatient. Throughout that time he was clear, supportive and to be fair, very entertaining in a thoroughly professional manner. He also encouraged me to get back to work and that was a really important part of my recovery.

Sadly, we don't always get the same positive experiences. Good and bad encounters with medical professionals should always be acknowledged and recorded. Each hospital in the UK should have a feedback system known as a **Friends & Family Test**, to let them know

how you feel about their services. If you want to let a hospital or surgery to know how you feel about them, ask at the reception desk for details how to access theirs.

You can also contact **The Patient Advice** and Liaison Service (PALS) who offer confidential advice, support and information on how to make a complaint.

Healthwatch also carry out a similar role in each borough of the UK. They are an independent service for people who use health and social care services to make sure that those running services, and the government, put people at the heart of care.

Back to the positive feedback. Sometimes it's enough to just say thank you directly to that person; so Thank You Dr Weishmann, and to all the team involved in my treatment, care and recovery!

By Emma Seasman

Brain News amazing breakthrough on detecting brain injury on newborn babies Pg 2

Tell us YOUR story We need to hear your tales about your journey Pg 4

K.I.T Weekly Support. What's involved and where to go Pg 4

Who's to blame?
Many brain injuries
happen due to an
illness; however
some as result of
taking risks. Is blame
a reasonable
response to the
choice of another
Brain Injury
Survivor? Pg 5 & 6

Fundraising Ideas
We need you to get
involved and create
some fun,
motivating and
entertaining
fundraising ideas
Pg 9



**Dr Udo Weishmann** 







## THE WRIGHT WAY \* WELFARE BENEFITS NEWS

During the most recent budget The Chancellor announced that the move to universal credit for those on existing benefits, what's known as *managed migration*; would be made a bit easier.

Last October, Chancellor announced a package of changes to Universal Credit (UC) following growing concerns that the system is leaving people in hardship and not working as well as it should. The changes are welcome, but there are concerns that they do not go far enough to deal with the many problems that currently exist in the UC system.

People claiming Universal Credit will stile able to receive some of their existing benefits for a couple of weeks after they claim. This starts in July 2020. If they have debts the maximum amount that can be reclaimed will be lowered, this aims to reduce the risk of hardship.

The managed migration schedule will now begin in July 2019 rather than January 2019 and is due to be completed by December 2023....we will see!



**Researchers in Cork** have identified two biomarkers or biochemical signals that can be used to aid the detection of a lack of oxygen to the brain in newborn babies.

The discovery is the first step in the development of a test to help doctors diagnose brain injury at birth to speed up intervention and treatment. It focuses on lack of oxygen to the brain at birth. This is condition known as Hypoxic Ischaemic Encephalopathy or HIE that affects around 200 babies in Ireland alone each year. HIE results in death or disability in more than two million babies worldwide.

A team of researchers from the INFANT Research Centre in Cork under Professor of Paediatrics Deirdre Murray have made a breakthrough; as they have discovered that levels of two biomarkers in the blood of newborn babies with HIE are significantly decreased.

Doctors hope that a test for these biomarkers, which are small strands of genetic code, may provide the first clue that significant brain injury has occurred, allowing for earlier intervention and treatment. The results of the ten-year study have been published in the Journal of the American Medical Association. The team at the INFANT centre have said their work is not finished yet and will go on until further knowledge is gained to enable doctors to save the lives of many children in the future.





## The Brain

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EG0 LEARN CEREBRUM CEREBELLUM CRANIUM VENTRICLE INTELLECT BRAIN INTELLIGENCE THINK **PSYCHE** GENIUS STEM MEDULLA NERVE MENTALITY **FREUD** LOBES CORTEX

There are a few interesting tests on the site below. It measures brain age, but that won't include the impact of brain injury on the findings. Despite that, they're still challenging and helpful games to play - <a href="mailto:freebrainagegames.com">freebrainagegames.com</a>



## Tell us Your Story:

You can email Emma Seasman at **vbc@swanwomenscentre.org** to let us know your story; or simply chat to her at the next groups attends!

- Name:
- Why do you come to Headway Sefton meetings?
- How is your life affected by brain injury?
- Are there any tips you could give to anyone new to their experience of brain injury?
- What positive things have come from your experience of Brain Injury?
- What would people in a similar situation to yourself get from attending Headway Sefton monthly meetings and/or K.I.T?



# Sharing your story can help folks new to BI to find comfort and learn new coping skills

## Our Headway Sefton K.I.T (Keep In Touch) Group meetings are every Wednesday from 10am-12pm at Wetherspoons on South Rd Crosby

Headway Sefton's K.I.T Group (Keep In Touch) is a peer led social group that's been created outside of the main groups' monthly meeting. The aim is to improve the social life of the group and to improve the lives of brain injury survivors.

NOTE: The group doesn't run on the second Wednesday of each month as that's when we have our main support group.









## **Do Risk Takers Deserve Their Fate?**

# I have met many people who have a TBI or ABI.

I'm lucky to attend Sefton Headway's main group most months; where I have listened to remarkable stories and heard a vast array of causes for brain injury.

Many stories are simple to justify. There would be not judgement on a person for being hit by a speeding car or victim to a brain tumour.

# Sadly, that's not the same for all survivors of brain injury.

Media can have a huge impact on how person is perceived in times of trauma. Taking personal risk can be seen as an a heroic accolade, or as a selfish act that deserves it's outcome.

In our previous issue we looked at a number of celebrities who have brain injuries with causes as varied as those of the members of our support group.

If we reflect back on the words media use to describe people living with ABI; it is easy to see how society also has levels of judgement. This is demonstrated in medical treatment, relationships, employment and welfare benefits for people with brain injuries.

I'm in the 'innocent' category of ABI. I had a squatter in my brain, also known as a brain tumour. That's the cause of my brain injury. I get flattering accolades of bravery as I deal with my thoroughly irritating broken brain. I also get empathy and sometimes nauseating pity from those who know no better.

If we ask the general public what they think of Ozzy Osbourne, would they be as supportive?

In 2014, The Black Sabbath frontman revealed he is suffering from various health problems

including brain and liver damage as a result of his battle with alcohol and drug addiction.

He told The Times newspaper, "Your liver can repair itself with time. I told my therapist last week, 'My short-term memory is destroyed. Do you think I have brain damage?'





I doubt the therapist involved,replied by saying "Duh! What do you think?" However, it would be an understandable reaction.

If we take drugs out of the picture and look at the legal side of his substance misuse, maybe that can help us to see above our own judgement. Let's start by looking at alcohol.

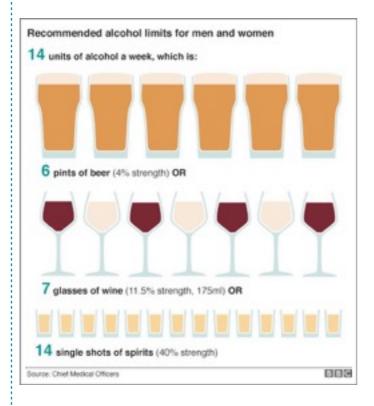
Alcohol related brain damage (ARBD) is an increasing challenge for older people and adults.

ARBD has a complex origin, making support and treatment for people with ARBD difficult. This is further complicated by social issues around the misuse of alcohol and society's attitude towards alcohol consumption.

It's not just rock stars who like a bevvie. We have a relaxed attitude towards alcohol consumption in Britain and as a result the UK's Chief Health Officers changed the guidelines for consumption in 2016.

# The 2016 guidelines issued on alcohol, cut recommended drinking limits and said there is no such thing as a safe level of drinking.

The new advice says men and women who drink regularly should consume no more than 14 units a week equivalent to six pints of beer or seven glasses of wine.



# Anyone drinking above the recommended consumption limits would be rather hypocritical to furrow their brow at the likes of Ozzy.

Alzheimer's Society UK say that alcohol-related brain damage (ARBD) is a brain disorder caused by regularly drinking too much alcohol over several years. The term ARBD covers several different conditions including Wernicke-Korsakoff syndrome and alcoholic dementia. None of these are actually a dementia, but they may share similar symptoms. However, in contrast to common causes of dementia such as Alzheimer's disease, most people with ARBD who receive good support and remain alcohol-free make a full or partial recovery. In addition, there is a good possibility that their condition will not worsen.

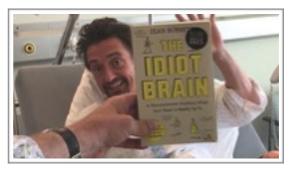
#### www.alzheimers.org.uk



## Then we have heroes, speed freaks and extreme sports enthusiasts.

## How does the press & media treat those who take risks for kicks?

When Richard Hammond, of Top Gear fame flipped over in his jet-powered dragster in 2006; his survival was hailed as a medical miracle and he was the resilient hero at the centre of an adventure. He had chosen take a serious risk by attempting to break the British land speed record. The car had reached 314mph when a tyre burst, flipped and scraped the presenters head across the ground.



Despite almost losing his life, and being subject to severe brain injury; he chose to continue his speedy lifestyle. In 2017 he was airlifted to hospital in Switzerland after being involved in a car crash while filming the first series of Amazon's Grand Tour. The 47 year old had to be pulled from the wreckage of a supercar worth £2m, that later burst into flames.

# So what's the difference between burning rubber and burning the candles at both ends?

I don't think there's any difference between the actions of either celebrity. I don't believe taking risks should lead to judgement about who is worthy of empathy when we hear their brain injury tale.

We all make choices that risk our health. Judging either star is unfair. I would rather see what lessons can be gained from people with such high profiles.

Richard Hammond has is now vice-president of The Children's Trust, which works to care for and rehabilitate children with acquired brain injuries and complex health needs. A famous bloke paying back to help kids.

As for Ozzy? Well he's a 70 year old man, still touring the world singing to the fans he's delivered to for decades. As a fellow ABI survivor, that shows me that many of us can keep going regardless of who's banging the gavel at the reasons why our neurones are jumbled.

By Emma Seasman

## **Group Meetings 2019**

## 11am - 1pm on the 2<sup>nd</sup> Wednesday of every month

### **Wednesday 13th February**

February is Raynaud's Awareness Month - www.sruk.co.uk

### **Wednesday 13th March**

11th - 17th March is BRAIN AWARENESS WEEK



## Wednesday 10th April

April is STRESS AWARENESS MONTH



### Wednesday 8th May

May has National Epilepsy week from 18 - 24<sup>th</sup> May ₩

### Wednesday 12th June

June celebrates National Picnic Week from 11 - 19th June ₩



#### Wednesday 9th July

No pressure, but it's WORLD CHOCOLATE DAY on 7th July!!





**Sefton Headway Newsletter** 



Thank you to Carpenters Solicitors for sponsoring our work; and also giving Carol Hopwood time away from her professional role. She's a cracking lass, with a devotion to people with Brain Injuries in her professional and personal life. She understands the impact of BI on the person along with their friends and family.





## **Easyfundraising**

Easy fundraising is free to use, all you have to do is register with them and use their link to shop at thousands of internet retailers. A percentage of each spend goes straight into Headway's Sefton's account. That might may you feel a bit less guilty about your latest shopping spree. It was for charitable reasons after all!

Got to the website below to find out how to register.

www.easyfundraising.org.uk

## **Fundraising**

#### TYPO APOLOGY:

Many, many thanks to Angie & MICHAEL for their generous donation last year. We renamed Michael and gave him the title Michelle in our DECEMBER edition. Your efforts help unto continue support the fabulous people attending our monthly support group and our extended services a K.I.T each week.

## Fundraising Ideas?







Do you have any creative ideas for fundraising? Could we invent the Sefton version of

'Ice Bucket Challenge' or 'Movember'

Have a good gab about it and pass ideas on to Headway Sefton Volunteers

If you would like to feature in next month's issue or find out more details about Headway Sefton; call Cath Johnson on 07866367886 or email cathyjohnston22@gmail.com.