

BULLETIN



EVENTS

Drop-In:-

Greens Lane Methodist Church, Hartburn. We meet here 1pm to 4pm on a Tuesday. Alternative therapy is available for those who enjoy or would like to try Shiatsu.

Social Evenings:

These are held at the Orthoptic Supplies, 176 Belasis Avenue, Billingham, TS23 1EY, on the last Wednesday of every month at 7pm.

Shopping Online????

Buy items or book holidays through the Stockton MS Group web site and we will receive a donation. There are over 100 top retailers to choose from. It all helps raise funds for the group.

Monthly Bulletin

"If you would like to receive this bulletin by email, then just send a request to news@stocktonmsgroup.org.uk.

Remember if you change your email address to let us know by sending a message to news@stocktonmsgroup.org.uk"

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Early MS scans 'can predict long-term prognosis'

Scans carried out when someone is first diagnosed with multiple sclerosis can predict their long-term prognosis, research has shown.

Magnetic resonance imaging (MRI) scans are already a key part of the diagnosis and management of MS.

But a 15-year study of people with clinically isolated syndrome (CIS), who can go on to develop MS, suggests they can also predict future disability.

The MS Society said more information would help patients' treatment choices.

The organisation, which funded the study in the journal Brain, added that knowing more about their condition would also reduce uncertainty for patients.

'You can live your life'

Dr Susan Kohlhass, director of research at the MS society, said: "For someone newly diagnosed, who gets a list of 14 treatments, who has no information about how their MS might develop, it's really complicated.

"We know the earlier you get treatment the better the long-term outcomes.

"So knowing early what type and what kind of disability you might have is really helpful in making decisions about treatment and lifestyle choices."

Melanie Ellis took part in the study, but not because it was going to tell her more about her own prognosis.

"I'd lost my vision in one eye and they asked me to take part - at the time I didn't even know I had MS. My view is if you can help and it isn't going to cause you any pain, go for it," she said.

Mrs Ellis, 53, from north London, was later diagnosed with relapsing/remitting MS.

She said if the long-term prognosis had been available, she would have wanted to know.

"Not everyone will want to know how their MS is going to turn out, but I'm the sort of person who likes to know.

"If you know what's going on you can at least deal with it, rather than sitting waiting for something awful to happen.

"If someone can tell you 'well this is the likely impact', it means you can live your life and plan for the future."

'More effective treatment'

More than 100,000 people in the UK live with MS. The condition affects everyday activities like walking, talking and eating, though everyone's condition develops differently and to differing degrees.

MRIs are already used to show if there is damage to the myelin sheath, the layer surrounding nerves in the brain and spinal cord.

In this study, specialists followed 164 people diagnosed with CIS - neurological symptoms which can, but do not always, develop into MS - for an average of 15 years.

Scans were also carried out one and three years after the CIS episode.

Prognosis was worst for those who had both inflammation in the brain and spinal cord damage. And early spinal cord damage was also an indication that a patient would go on to develop the secondary progressive form of MS, which currently has no treatment and is where disability gets steadily worse.

However, early treatment can reduce the risk of developing secondary progressive MS.

Dr Wallace Brownlee, from the UCL Institute of Neurology, which carried out the research, said it showed that standard MRIs - available in every hospital - could help those newly diagnosed with MS make better informed choices about treatment.

"The way we treat MS right now is we put people on treatment and consider escalating or trying a more intensive treatment if it's not working.

"But with this, we might be able to identify people at the beginning which might mean a more effective treatment at the outset."

www.theheartysoul.com 23 July 2019

Meet the Cambridge Scientist on Verge of Curing Multiple Sclerosis

Multiple sclerosis (MS) is an inflammatory disease of the central nervous system, affecting 2.3 million people in our world. MS is as an immune-mediated disease, where the immune system attacks the protective myelin sheath which covers nerve fibers, causing communication issues between your brain and the rest of your body.

Eventually, the disease can cause nerves to deteriorate or become permanently damaged. Currently there is no cure for MS, however Dr. Su Metcalfe and her company, LIFNano are hoping to change that.

Since there is no cure for the autoimmune-like disease, the method of action for people with MS is to suppress the immune system with pharmaceuticals. Since the brain cannot be repaired, such as other vital organs, and the high price tag on MS drugs also come with a list of side effects, Su is working to find a solution.

The Potential Cure

After discovering a small binary switch which regulates inside the immune cells. Su is now working with a stem-cell particle called LIF, which has the potential to control the cell and ensure it doesn't attack healthy bodily tissues, while still protecting us and releasing an attack when needed. LIF stem-cell particles are a form of regenerative medicine, playing a role in tissue repair while keeping the brain and spinal cord healthy.

Su's approach is what she calls a "double whammy", she's finding a way to reverse the autoimmunity, and also repair the damage caused in the brain."

After celebrating her discovery, she hit a snag, she found that LIF could only survive for 20-minutes before being broken down by the body, meaning there would not be enough time for the therapeutic actions to deploy. This is where the technology of nanoparticles came in.

The Role of Nanoparticles

A combination of LIF and nanoparticles are compatible with the body, and they slowly dissolve like soluble stitches. The nanoparticles become the delivery device which administers the LIF over a period of five days.

As Su states "the nanoparticle itself is a protective environment, and the enzymes that break it down can't access it. You can also decorate the surface of the particles with antibodies, so it becomes a homing device that can target specific parts of the brain. So you get the right dose, in the right place, and at the right time."

The particles themselves were developed at Yale University, but LIFNano has the worldwide license to deploy them, and Su believes we are on the verge of some groundbreaking medicine.

How Nano-Medicine is Helping

She says: "Nano-medicine is a new era, and big pharma has already entered this space to deliver drugs while trying to avoid the side effects. The quantum leap is to actually go into biologics and tap into the natural pathways of the body.

"We're not using any drugs, we're simply switching on the body's own systems of self-tolerance and repair. There aren't any side effects because all we're doing is tipping the balance.

Auto-immunity happens when that balance has gone awry slightly, and we simply reset that.

Once you've done that, it becomes self-sustaining and you don't have to keep giving therapy, because the body has its balance back."

LIFNano has already attracted two major funding awards, from drug firm Merck and the Government's Innovate UK agency. Su hopes to attract more investment in her work, with the aim of starting clinical trials in 2020.

"We've got everything we need in place to make the nanoparticles in a clinically compliant manner, it's just a case of flicking the switch when we have the money. We're looking at VCs and big pharma because they have a strong interest in this area. We're doing all our pre-clinical work concurrently while bringing in the major funds the company needs to go forward in its own right."

Working with immune cells has been a big part of Su's career, she is passionate about the subject. "The immune cell is the only single cell in the body that is its own unity, so it functions alone.

It's probably one of the most powerful cells in the body because it can kill you, and if you haven't got it you die because you haven't got it."

While MS is her focus at the moment, this work will "lead into other major autoimmune disease areas."

I think we're all looking forward to the future with Su and her works with LIFNano. She also states that "Psoriasis is high up on our list, and diabetes is another.

Downstream from there are all the dementias since LIF is a major health factor for the brain – if we can get it into the brain we can start protecting against dementia."

Her research is significant and inspiring.

www.bbc.co.uk 2 August 2019

Carers bullied by government, MPs say

The Work and Pensions Select Committee says ministers are harassing people who have made honest mistakes when receiving carer's allowance.

Long-standing problems within the Department for Work and Pensions (DWP) led to a failure to spot overpayments.

The government says while it has a duty to the taxpayer to recover the money, "safeguards are in place to protect claimants from financial hardship".

The MPs have urged the government to review, on a case by case basis, whether overpayments are worth pursuing, given the Department of Work and Pensions' culpability and the cost of recouping them.

"Bullying carers is no way to recognise, much less support, the invaluable contribution they make to our society and the people they care for," said Frank Field, who chairs the committee.

George's story

"The DWP and the courts are not listening," George Henderson, from Leyland, Lancashire, says.

He is being pursued for an overpayment of more than £19,000 of carer's allowance by the DWP - and has had to put his house up for sale.

The 59-year-old first started receiving the benefit in 2010 while caring for his son John, who has mental health problems and is a heroin user.

He applied for carer's allowance and stopped his son receiving an alternative benefit, as John's drug dealer "actually had his bank card".

"He knew when he got paid, he went and got his money out of the machine, gave him the drugs and that was it," George says.

George admits he made a "mistake" when he applied, stating he was unemployed when he was actually working for a taxi company.

In 2017, the DWP contacted him to say he was not eligible for the benefit.

He was convicted of fraud, given a 32-week suspended sentence and electronically tagged for 16 weeks.

The DWP then used a proceeds of crime order to make George to sell his home.

Over seven years, George is estimated to have received about £100 more than his son would have been paid if he had continued to receive the benefit he was on.

"The impact has been immense," he says.

"There was no money to be made.

"If I'd known that I was earning too much money, obviously I'm not going to claim carer's allowance, take money off my son to give it back to him on a daily basis, and then get myself done for fraud.

"I mean it's just ludicrous. It's laughable."

For years, the Department for Work and Pensions ignored a whistleblower's concerns they were failing to spot overpayments to thousands of carers as they had cut the number of staff working on the benefit.

HM Revenue & Customs was providing earnings data to the department that should have highlighted the overpayments, while the confusing nature of the benefit meant many people were unaware they were no longer eligible.

In April, the National Audit Office said about two-thirds of carers with debts for earnings-related overpayments over £2,500 would have had their overpayments stopped earlier if the DWP had put in place sufficient staff.

Carer's benefit is paid to people who provide at least 35 hours a week of care.

The government says 850,000 people receive the allowance, with millions of payments made each year.

It is currently worth £66.15 per week and the recipient is allowed to earn up to £123 per week and still receive carer's allowance, though their earnings can be higher if they have childcare costs - but the moment they earn a penny more, they immediately become ineligible and have to repay any benefit they may have received.

The National Audit Office found the DWP was aiming to recoup overpayments from 80,000 people, worth about £150m.

Most debts are for less than £1,000 but some people owe more than £20,000.

BBC News has discovered the DWP and the Crown Prosecution Service, who take the cases to court, are not routinely telling judges the department could have spotted the errors earlier.

A Crown Prosecution Service spokesman said every case was "carefully considered" but it did not have a duty to disclose "publicly available government reports that do not relate to specific cases".

Welfare experts told BBC News, however, it was unrealistic to expect judges or magistrates to be aware of the changing circumstances around any individual benefit.

Emily Holzhausen, director of policy and public affairs at Carers UK, said many people who have been impacted by overpayments were already struggling financially and are experiencing considerable stress and anxiety.

"The department must urgently consider writing off overpayments where its administrative failures have allowed them to accrue," she added.

Shadow work and pensions secretary Margaret Greenwood said carers are "paying the price for a rigid system that is poorly explained".

The DWP said decisions to prosecute were not taken lightly and were generally reserved for overpayments of more than £5,000.

"It is a condition of receiving carer's allowance that people tell DWP if their circumstances change and we work extremely hard to make claimants aware of their responsibility to provide correct information," a spokeswoman said.

www.bbc.co.uk 16 August 2019

'Hundreds' seek private clinics for medical cannabis

Hundreds of people in the UK are turning to private clinics for medical cannabis, BBC News has been told.

Since its legalisation in November 2018, there have been very few, if any, prescriptions for medical cannabis containing THC on the NHS.

And this has led some patients, with conditions such as epilepsy and MS, to pay up to £800 a month privately.

The government said it sympathised with families "dealing so courageously with challenging conditions".

Cheryl Keen has been trying to get medical cannabis on the NHS for her daughter Charlotte - who has brain damage and epilepsy - but has been refused twice.

And she had been told it was too expensive and she had not yet tried all the other available options, she said.

"Nothing has happened, nothing has changed [since the legalisation]," Ms Keen told BBC Two's Victoria Derbyshire programme.

"It's absolutely disgusting that anyone is having to pay to go private," she added - something she cannot afford to do.

Campaign groups say by not prescribing cannabis medicines with THC, the NHS is limiting treatment options for patients.

A **review earlier this month by NHS England**, however, highlighted a lack of evidence about the long-term safety and effectiveness of medical cannabis.

NICE said it was unable to make a recommendation about the use of cannabis-based medicines for severe treatment-resistant epilepsy "because there was a lack of clear evidence that these treatments provide any benefits".

And this has led to the introduction of private clinics.

Grow Biotech, which handles about three-quarters of all medical cannabis imported into the UK, said as of July it had received more than 100 requests for private prescriptions - of which about 60 had been fulfilled.

The new London branch of The Medical Cannabis Clinics has not yet opened but said it had 162 patients on its waiting list - with conditions such as epilepsy, Parkinson's, post-traumatic stress disorder (PTSD) and fibromyalgia.

"Everyone can get an appointment to come here but not everyone leaves with a prescription for cannabis," its director, Prof Mike Barnes, said.

"There are some conditions for which there is good evidence for cannabis to be useful, so you'd have to have one of those conditions - like pain, anxiety, or nausea and sickness in chemotherapy or epilepsy."

The clinic says consultations are carried out to ensure prospective patients have tried all reasonable licensed medication for their conditions and reached "the end of the road for treatment".

Prof Barnes described the service as a "lifeline for patients in need".

Prescriptions cost between £600 and £800 a month but Prof Mike Barnes rejected any suggestion the clinic was exploiting patients.

"This is the only way patients who are in significant need can get access to this medicine," he said.

Government 'failing patients'

A report last month by the Health and Social Care Committee said the hopes of patients and families had been unfairly raised when doctors were allowed to prescribe cannabis.

Labour MP Ben Bradshaw, who sits on the committee, told BBC News the government was "failing patients".

"If anything [since its legalisation], it's become more difficult for people to obtain it," he said.

"[The government] now has to put this right, by delivering on the promises that it's made to the patients."

The Department of Health said in a statement: "To support doctors prescribing these products, we have asked the National Institute of Health and Care Excellence (NICE) to develop additional clinical guidelines and are working with Health Education England to provide additional training.

"The decision to prescribe unlicensed cannabis-based products for medicinal use is a clinical decision for specialist hospital doctors, made with patients and their families, taking into account clinical guidance."

www.bbc.co.uk 5 August 2019

Brighton Pride sorry over lack of disabled access to Kylie's show

Brighton Pride has apologised after some disabled people were unable to watch Kylie Minogue's performance.

It said its accessibility platform was at "full capacity" by the time its main act took to the stage on Saturday.

Jenny Skelton says her 22-year-old daughter Charlie - who has severe learning disabilities - was "crying inconsolably" when they were told to stay in a tent without a view of Kylie during her performance.

She says up to 20 people were involved.

Brighton Pride said the platform had a fixed capacity and access was on a "first come, first serve basis".

"We had the correct wristbands and then we were told no," Jenny tells Radio 1 Newsbeat.

"My issue is just simply that they didn't have sufficient space for disabled people and that's wrong."

Jenny says that most of the people kept in the tent left Pride before the end of Kylie's performance because their only option was to remain where they were or join the crowd, where they didn't feel safe.

But eventually - and after requests from those who remained - security staff were allowed to let disabled guests and their friends and family take empty spaces on a VIP viewing platform.

"Charlie was crying inconsolably for much of it," says Jenny, "but then when we went onto the VIP area, in the end she loved it.

"She was dancing and she had an absolutely fantastic time, it's just such a shame it was spoiled by waiting for an hour and a half trying to explain to her why she wouldn't be able to see Kylie." Jenny says she had only had positive experiences at Brighton Pride, partly because of the involvement of Brighton and Hove community safety forum, who had in previous years helped with disabled access.

Jenny also shared a video of her experience on Twitter.

She was joined in the disabled tent with no view of Kylie by Liam Hackett and his mum, who's an amputee, and gran, who uses a wheelchair.

"My grandma was recently given a terminal diagnosis with cancer and on her bucket list was to come to her first ever Pride. It really meant a lot to us," Liam tells Newsbeat.

In a video posted on Twitter, he said around 10-15 people were left stuck in a tent without a view of the stage because there were no free seats on the platform.

Other people who were at the event also shared their "awful" experiences of disabled access at Brighton Pride on Twitter.

Brighton Pride said 275 people applied and used its range of access services at Preston Park - where the event was held.

It denies claims that any people were prevented from leaving the access tent.

Becky Stevens, head of operations said: "Our aim is that all Pride-goers are able to enjoy what Brighton Pride has to offer. We work hard with our provider Tiger Tea to create safe, accessible spaces throughout the festival.

"Over 100 people with accessibility requirements enjoyed the main stage shows on the accessible viewing platform, on a first-come, first-serve basis.

"We encouraged people with accessibility requirements to contact us after purchasing tickets, so that we could help to make their day as inclusive and enjoyable as possible.

"We are sorry if some Pride-goers were unable to be accommodated at the viewing platform later on Saturday night."

But Liam wants a refund for the cost of tickets for himself, his mum and his gran.

"I think the statement Pride put out was absolutely ridiculous and I haven't seen any ownership," he says.

"I think Pride have made a lot of errors in this."

Your Jokes

An atheist was taking a walk through the woods. What majestic trees! What powerful rivers! What beautiful animals!" he said to himself. As he was walking alongside the river he heard a rustling in the bushes behind him. He turned to look. He saw a 7 foot grizzly charge towards him. He ran as fast as he could up the path. He looked over his shoulder and saw that the bear was closing in on him. He looked over his shoulder again and the bear was even closer. He tripped and fell on the ground. He rolled over to pick himself up but saw the bear right on top of him, reaching for him with his left paw and raising his right paw to strike him.

At that instant the Atheist cried out: "Oh my God!..." Time stopped. The bear froze. The forest was silent.

As a bright light shone upon the man, a voice came out of the sky: "You deny my existence for all of these years, teach others I don't exist, even credit creation to a cosmic accident. Do you expect me to help you out of this predicament? Am I to count you as a believer?"

The atheist looked directly into the light, "It would be hypocritical of me to suddenly ask You to treat me as a Christian now, but perhaps could you make the BEAR a Christian?"

"Very well," said the voice. The light went out. The sounds of the forest resumed.

And then the bear dropped his right paw, brought both paws together and bowed his head and spoke:

"Lord, bless this food, which I am about to receive from thy bounty through Christ our Lord, Amen."

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you do not answer all the questions, send in those you have answered – you could still win!

- 1/ What colour is a Polar Bears skin?
- 2/ Which nail grows fastest?
- 3/ What Spanish artist said he would eat his wife when she died?
- 4/ What did the crocodile swallow in Peter Pan?
- 5/ Which German city is famous for the perfume it produces?
- 6/ What year did the Spanish Civil War end?
- 7/ Where is the smallest bone in the body?
- 8/ What does the roman numeral C represent?
- 9/ What nationality was Chopin?
- 10/ Which is the only mammal that can't jump?

Name:

Address:

Send Completed Forms To:
Mr D Henderson
74 Windermere Road
Stockton-on-Tees
Cleveland TS18 4LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

- 1/ Seven Seas of Rhye 2/ Killer Queen 3/ Your my best friend 4/ Radio Ga Ga 5/ One Vision
6/ Innuendo 7/ The Miracle 8/ These are the best days of our lives 9/ Bohemian Rhapsody
10/ We are the Champions