

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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www.mailonline.co.uk 18 September 2017

Breakthrough study offers new hope for multiple sclerosis patients as research finds a way to stop condition worsening through stem cell therapy

For patients with the incurable nerve condition multiple sclerosis (MS), there is often little hope. In the early stages, symptoms such as muscle weakness, fatigue, pain and even depression come and go.

As the disease progresses, patients lose their ability to walk and are often consigned to a wheelchair, facing an early death.

Medication can ease discomfort and improve physical problems but at present there is nothing that will stop the march of the illness.

But now, remarkable results from an NHS study into groundbreaking stem cell therapy has led experts to cautiously suggest it may halt MS from worsening, and in some cases lead to long-lasting remission.

The disease, which affects 100,000 Britons, occurs when the immune system turns on the body, attacking healthy nerve tissue. The stem cell procedure effectively resets the body and stops this process from occurring, experts claim.

About 60 patients have now been treated as part of the ongoing study at London's King's College Hospital and Imperial College Healthcare and doctors say that the effect has been dramatic for some.

At a cost of £35,000 per patient, the price is comparable to a single year of MS drugs.

One of the first patients to benefit, former pilot Sarah Brown, has revealed how the therapy has transformed her health. Once a keen marathon runner, Sarah was diagnosed in 2009, and her condition deteriorated rapidly. Two years ago the pain in her legs and hips was making walking for more than a few yards impossible.

The 42-year-old from Cheltenham said: 'If it wasn't for stem cell therapy, I may well have been in a wheelchair by now.

'I've recovered sufficiently to go back to work, which is something I thought I would never be able to do. I won't run marathons again but I've regained my independence. It has turned my life around.'

The procedure, hematopoietic stem cell transplantation (HSCT), is similar to the one used to treat leukaemia, and was once known as a bone marrow transplant.

After Sarah's husband Bob, 47, came across the UK study while researching treatments online, her neurologist in Bristol agreed to refer her to haematologist Dr Majid Kazmi at King's College Hospital, an expert in the field.

Dr Kazmi said: 'We have known for some time that patients with multiple sclerosis who also develop leukaemia seem to experience remission from their MS symptoms after HSCT. Treating the cancer meant the MS got better too.

'Immune system cells are made in the bone marrow, and during HSCT the patient's existing bone marrow is killed off with powerful drugs then replaced with a transfusion of stem cells.

'After the procedure, we have seen the immune system return to a more normal state.'

'One of our first patients was treated in 2009. His MS was so bad that he would not have been expected to live more than a few years, but he is still alive today.'

HSCT is carried out in stages. First, patients are given low-dose chemotherapy drugs and medication to stimulate the bone marrow to secrete stem cells into the blood.

About six ounces of blood is taken and then processed in a laboratory machine to extract the stem cells, which are frozen and stored. Once this has happened, the patient is given more powerful chemotherapy, which kills off existing bone marrow, over a week.

As this knocks out the immune system, the patient must be kept in isolation as even a minor infection can be fatal.

Finally, the stem cells are defrosted and reintroduced via a blood transfusion.

These cells find their way through the circulation back into the bone marrow, where they reproduce and create new, healthy tissue.

'We aim to give patients about two to three million stem cells per kilogram of body weight,' explained Dr Kazmi. 'In most cases, the small amount of blood we take gives us far more than we need.'

The patient remains in isolation for a further two to three weeks as their bone marrow begins to create immune system cells. 'The main aim of this treatment is to halt further damage caused by MS,' added Dr Kazmi. 'For those with significant disability, we don't expect a dramatic transformation.

'If they are in wheelchair, they are likely to stay in one. But they may not get worse. And there have been very good results with patients with earlier-stage MS.'

Researchers from Imperial College London published results last year from HSCT trials in 25 centres in 13 countries. Out of 281 people who had the treatment, nearly half benefited for as long as five years, according to their paper in the Journal Of The American Medical Association. Roy Palmer, 43, is about to embark on the second stage of his HSCT treatment after having his first round of chemotherapy. Next week he will have more chemotherapy, followed by his stem cell infusion and five weeks' isolation.

The father-of-two from Quedgeley, Gloucestershire, has spent a decade in a wheelchair and has a form of the disease that will get steadily worse.

He said: 'My daughter Aby, who is 12, was just a toddler when I went into my chair and she doesn't remember her dad when he could walk. To be able to walk out of my front door would mean the world.'

www.the guardian.com 21 September 2017

Pregabalin, known as 'new valium', to be made class C drug after deaths

A prescription drug described as the "new valium" is to be classified as a class C controlled substance after it was linked to a growing number of UK deaths.

Pregabalin – a substance used to treat nerve pain, epilepsy and anxiety – is increasingly being handed out too readily and being used recreationally, according to doctors and pharmacists.

They say that when it is mixed with other substances it can lead to overdose. Deaths connected to pregabalin have risen from four in 2012 to 111 last year, according to the Office for National Statistics.

Data provided by NHS Digital shows that prescriptions for pregabalin have shot up more than 11-fold in the last decade, from 476,102 in 2006 to 5,547,560 last year. The government has now accepted in principle that pregabalin should be reclassified as a class C controlled substance, which would mean patients could not obtain a repeat prescription.

Yasir Abbasi, a consultant psychiatrist and clinical director for addiction services at Mersey Care NHS foundation trust, said the rising prescription numbers were worrying as, if used inappropriately, pregabalin could be hazardous.

“Doctors need to be cautious about who they are giving it to and be aware of the potential of the drug to be misused and the fact it could be addictive because there is not much information at the moment. The drug was approved for medical use in 2004 and we need more robust evidence,” Abbasi said.

Addaction, the largest drug and alcohol charity, is calling for GPs to be given guidance about how to prescribe pregabalin, particularly to people with substance misuse history. The charity noted that deaths linked to the drug had risen more quickly than those linked to new psychoactive substances.

Rachel Britton, Addaction’s lead pharmacist, said: “The deaths linked to it – that will be people taking a cocktail of substances that affect the central nervous system eg heroin, pregabalin and benzodiazepines. It eventually depresses respiration, controlled by the brain, and people who take these cocktails die.”

Those who use pregabalin recreationally call it “Budweiser” because it induces a state similar to drunkenness. It makes users feel relaxed and euphoric in a similar way to tranquilisers. It can also enhance the euphoric effects of other drugs, such as opiates, and is likely to increase the risks when taken in this way.

Abbasi said that those misusing pregabalin included people who took it on top of other drugs but also those who were prescribed it who, without talking to their doctor, then started taking a higher dose.

Testimony from doctors, pharmacists and drug counsellors, who were responding to a Guardian callout, suggests abuse of the drug is widespread.

A family doctor working in Scotland, who also asked for anonymity, said: “Pregabalin is overprescribed by GPs and other doctors for all types of pain despite it only being licensed for neuropathic pain and generalised anxiety disorder. Others easily access it off the internet. It is used by drug users in order to enhance the effects of other drugs they are taking ... This is only going to increase as the prescription of both continues to increase.”

Another anonymous respondent, who works in a hostel, said: “Pregabalin has been the cause of several residents overdosing after using this with other substances. In this environment we suspect residents who are prescribed Pregabalin for anxiety and pain of dealing it to other residents ... Over the last six months paramedics have been called out over half a dozen times due to these incidents and it is only through pure luck no one has died and feels only a matter of time before this happens.”

Pharmacists were originally advised not to accept requests for cheaper, generic versions of the drug, but this changed in July, when Pfizer’s patent expired. There are concerns that this has prompted a further rise in the drug’s misuse.

A statement from Pfizer said: “When prescribed and administered appropriately, pregabalin is an important and effective treatment option for many adults living with chronic neuropathic pain, generalised anxiety disorder and epilepsy.”

Earlier this year the British Medical Association (BMA) called for the drug to be made a controlled substance in the UK in the same class as steroids and valium. Last year the Advisory Council on the Misuse of Drugs wrote a letter to the government making the same recommendation. It would mean the drug could not be repeat-dispensed and prescriptions would only be valid for one month. The letter warned of the risk of addiction for both pregabalin and a similar drug called gabapentin.

The minister for crime, safeguarding and vulnerability, Sarah Newton, said: “Any death related to misuse of drugs is a tragedy and that is why we have published a comprehensive new drugs strategy to tackle the illicit drug trade, protect the most vulnerable and help those with drug dependency to recover and turn their lives around.

“We have accepted the Advisory Council on the Misuse of Drugs advice to control pregabalin and gabapentin as class C drugs in principle, subject to the outcome of a public consultation to assess the impact on the healthcare sector. We will launch the consultation shortly.”

www.mdedge.com 25 October 2017

Are Bladder Dysfunction and Falls Related in MS?

Urinary urgency with incontinence is associated with recurrent falls in people with relapsing-remitting multiple sclerosis (MS) with mild to moderate disability, according to data published in the July–August issue of *International Journal of MS Care*. Urinary urgency with incontinence often responds to physical, behavioral, and pharmaceutical interventions, and neurologists should ask patients with MS about bladder symptoms and fall history, according to the authors. Bladder dysfunction and falls are highly prevalent among people with MS, and bladder dysfunction is associated with falls in older adults. Studies of the association between bladder dysfunction and falls in people with MS, however, are limited and have produced mixed results. Jaime E. Zelaya, PhD, a doctoral student at Oregon Health and Science University in Portland, and colleagues conducted a longitudinal observational cohort study to clarify the possible association between baseline urinary symptoms and future falls.

Participants Prospectively Recorded Falls

The investigators recruited participants from outpatient MS clinics in the Veterans Affairs Portland Health Care System, Oregon Health and Science University MS clinics, and the surrounding community. Eligible participants had a diagnosis of relapsing-remitting MS, mild to moderate MS-related disability, and no relapse within 30 days of baseline. Patients with another condition that affected their balance or gait were excluded from the study. At baseline, Dr. Zelaya and colleagues asked participants whether they had urinary incontinence, urinary frequency, or urinary urgency. Participants then prospectively recorded their number of falls each day using fall calendars. They were asked to return their calendars to the investigators at the end of each month. The researchers defined four patient categories based on the number of falls during three months. Recurrent fallers fell two or more times, nonrecurrent fallers fell once or not at all, fallers had one fall or more, and nonfallers did not fall. The investigators analyzed the data using age, sex, and disability as potential confounders.

Most Patients Fell at Least Once

The final analysis included 51 participants (37 women). Mean age was 40, and median Expanded Disability Status Scale (EDSS) score was 3.0. In all, 15 participants (29%) were recurrent fallers, and 36 (71%) were nonrecurrent fallers. Furthermore, 32 (63%) participants were fallers, and 19 (37%) were nonfallers.

Urinary dysfunction was more prevalent in fallers and recurrent fallers than in nonrecurrent fallers or nonfallers. In the adjusted analyses, urinary urgency with incontinence was significantly associated with recurrent falls (odds ratio [OR], 57.57). The researchers did not find a significant association between urinary urgency without incontinence and recurrent falls, or between urinary frequency and recurrent falls. They also did not find significant associations between urinary urgency with incontinence, urinary urgency without incontinence, or urinary frequency and sustaining one or more falls.

The high prevalence of falls and bladder dysfunction in this population and previous studies “suggests that both falls and bladder dysfunction are common, early, and persistent symptoms in MS,” said the authors. The findings suggest that fall-prevention programs “should particularly be considered for reducing fall risk in recurrent fallers, and that such programs should include strategies for managing urinary urgency with incontinence,” they concluded.

People with disabilities 'humiliated' by taxi refusals

Some taxi services in Wales are refusing to pick up passengers who use wheelchairs or assistance dogs, a campaign group has claimed.

Disability Wales said people are being ignored and refused cab journeys leaving them "stranded and humiliated".

It wants the Welsh Government to **use new powers over transport** to ensure they are treated fairly by cab drivers.

The Welsh Government said it plans to introduce new national standards "to drive out poor practice".

The Equality Act 2010 means it is illegal for a private hire vehicle to refuse to take a person with disabilities, unless they have a medical exemption from the licensing authority.

But wheelchair users and people with sight loss claim they have been refused transport.

Glyn Furnival-Jones, from Cardiff, is living with multiple sclerosis and uses a wheelchair and scooter.

He claims some drivers do not want to take people with disabilities because they think they will not want to travel far and are too difficult to deal with.

"It's scary because very often on a Saturday night at a rank there are lots of people who are drunk queuing up, so you're having discussion after discussion with the taxi drivers," he said.

"You have to take a deep breath when you're going to go to find a taxi because you know it's not going to be easy."

Nicki Cockburn, from Cardiff, who is blind, said she has been overcharged and refused a fare for having her assistance dog James with her.

"When people refuse to take me it makes me feel like an outcast because the only thing I can't do is see," she said.

Councils have the power to suspend or revoke taxi drivers' licences and they can be fined up to £1,000 if they break the law and refuse to take fares, but very few people with disabilities make complaints.

Ruth Nortey, from Disability Wales, said she wants to see the Welsh Government "make stronger laws and strengthen the laws against discriminating against disabled people".

"We would like to see all taxis and private hire vehicle drivers undertake disability equality training so this would give taxi drivers the confidence to be able to support disabled passengers who are wanting to use their taxis," she said.

Keith Shackell, from the Taxi Drivers of Cardiff group, said all of its licensed drivers have undertaken disability awareness training, adding: "There is never an excuse for a taxi driver to refuse to take a passenger with any disability."

The Welsh Local Government Association stressed councils work alongside the taxi trade in Wales "to ensure that the rights of passengers are understood".

The Welsh Government has recently finished a consultation on the future of taxi licensing.

Economy and Infrastructure Secretary Ken Skates said: "I want to make sure that we get a far higher standard of service, that we embrace the good that we see but that we also push out bad practice."

DISCLAIMER

Articles in this Bulletin are meant for the sole purpose of information only and do not necessarily reflect the views of the committee.

Antihistamine Shows Evidence of Stimulating Myelin Repair in Small Phase II MS Study - More studies needed before benefits and risks are verified

Summary

- In a small, phase II clinical trial, the oral antihistamine clemastine modestly improved the transmission of electrical signals in the optic nerve in participants with MS who had optic nerve damage.
- The improved transmission indicates that nerve-insulating myelin was repaired along the nerve pathways.
- Clemastine is an over-the-counter allergy medication. Doses in this trial exceeded the maximum recommended for over-the-counter use. Clemastine affects a range of targets in the body, and involves the risk for side effects, particularly at increased dosages.
- More studies are needed before the full benefits and risks of this approach can be verified. This team is conducting an additional trial in people with optic neuritis to further determine the safety and effectiveness of clemastine, as well as studies to identify compounds that may enhance myelin repair and cause fewer side effects.
- Clemastine was identified as having possible myelin-repairing properties through innovative preclinical research conducted by National MS Society-funded Jonah Chan, PhD, who went on to become **first recipient of the Barancik Prize** for Innovation in MS Research for this pioneering work.
- UPDATE: The full results of the study, led by Ari Green, MD (University of California, San Francisco), **have now been published in The Lancet**. (Preliminary results were previously presented at the annual meeting of the American Academy of Neurology in April 2016.)

Background: In MS, the immune system attacks and destroys myelin, the fatty substance that surrounds and protects the nerve fibers, and the nerve fibers can also be damaged. Current therapies are largely aimed at dampening the immune attacks. However, a therapy that repairs damage to myelin and nerve fibers is also necessary.

A team at the University of California, San Francisco led by National MS Society-funded Harry Weaver Neuroscience Scholar Jonah Chan, PhD, invented a new micropillar technology to rapidly identify compounds that stimulate the regrowth of myelin. The team **initiated a screen** using this technology, testing a library of 1000 drugs already approved by the FDA for other conditions for their ability to promote the development of myelin-making cells and wrapping of myelin around the micropillars. Clemastine, an oral antihistamine used to treat allergy symptoms, was identified through this process. Dr. Chan was the **first recipient of the Barancik Prize** for Innovation in MS Research for this pioneering work.

The Clinical Trial: Ari Green, MD, led the team conducting the clinical trial. They administered oral clemastine or inactive placebo twice daily to 50 people with MS and optic nerve damage for 150 days. For the first three months of the study, people were given either clemastine or a placebo, and for the second two months, those initially given clemastine received the placebo and vice-versa. Tests were performed before and after treatment that measured visual evoked potentials. Visual evoked potentials measure transmission of electric signals along optic nerve pathways in response to stimulation. Delays in this transmission occur when the myelin is damaged and if these delays are reduced, it is an indication that myelin repair is occurring along the nerve pathways. (Participants had significant delays in transmission in at least one eye.)

UPDATE: The full results of the study, led by Ari Green, MD (University of California, San Francisco), **have now been published in The Lancet**. (Preliminary results were previously presented at the annual meeting of the American Academy of Neurology in April 2016.) The trial met its primary endpoint, reducing delays in visual evoked potential by 1.7 milliseconds per eye, a statistically significant result. The results hinted at a reduction in vision impairment as well, but it did not reach statistical significance. Fatigue increased mildly in participants taking clemastine.

Clemastine is an over-the-counter allergy medication. Doses in this trial exceeded the maximum recommended for over-the-counter use. Also, clemastine affects a range of targets in the body, and involves the risk for side effects, particularly at increased dosages.

Dr. Green cautions that more research with larger numbers of people is needed before doctors can recommend clemastine as a treatment for people with MS. This team is conducting an additional trial in people with optic neuritis to further determine the safety and effectiveness of clemastine, as well as studies to identify compounds that may enhance myelin repair and cause fewer side effects.

Drs. Green and Chan both received Society funding to launch their early careers as independent researchers focused on MS, including Harry Weaver Neuroscience Scholar Awards.

Comment: “This is a significant step forward in one of many different approaches being taken to find a way to repair the nervous system damage caused by MS,” said Bruce Bebo, PhD, Executive Vice President, Research at the National MS Society. “Research to restore function to people with MS is a very high priority.”

www.neurologyadvisor.com 2 October 2017

Multiple Sclerosis Not Tied to High Dietary Sodium Intake

High sodium intake is not associated with an increased risk for multiple sclerosis (MS), according to a prospective cohort study published in *Neurology*.

Researchers evaluated food frequency questionnaires completed by 80,920 women from the Nurses' Health Study and 94,511 women from the Nurses' Health Study II over a span of 3,096,959 person-years to determine whether dietary sodium intake increased the risk for MS. A total of 479 MS cases were reported during follow-up.

The investigators found no significant association between dietary sodium and MS risk (multivariable hazard ratio [HR]_{pooled} for 100 mg/day increases in sodium = 1.00; 95% CI, 0.96-1.03). At baseline, total **sodium intake** showed no association with higher risk for MS (HR_{pooled} 0.98; 95% CI, 0.74-1.30; $P < .75$). Additionally, no association between cumulative average sodium intake and MS risk during follow-up was observed (HR_{pooled} 1.02; 95% CI, 0.76-1.37; $P < .76$).

To provide a more comprehensive analysis, the investigators suggest that future research should evaluate whether dietary sodium intake increases **MS risk** across both genders. More than 95% of the women in the current study were white, and the authors suggest that future research should examine whether a risk exists among other ethnic groups. Food frequency questionnaires, which were used in this study, often lead to underestimation of sodium consumption and may not have provided truly accurate insight into dietary patterns among these 2 cohorts.

Despite the study's conclusion that dietary sodium intake does not increase risk for MS, the investigators believe moderating sodium intake “is nevertheless favorable with regard to the prevention of cardiovascular disease.”

Make A Wish Campaign

Once again we have registered with the Evening Gazette for their Make A Wish Campaign.

The first tokens appeared in the Gazette on Monday 11th October 2016, and the last tokens will appear on Saturday 7th January 2017.

Could you please encourage all your friends and family who buy the Evening Gazette to save the tokens to help raise much needed funds for the group.

Thank you

MEMBERSHIP FEES

The yearly membership subscription of £5 is now due.

Payments can be made at the Drop-In, Social Evening or sent by post. All cheques made payable to Stockton MS Group please.

Payments by post can be sent to:-

Mr D Henderson
74 Windermere Road
Stockton-on-Tees TS18 4LY

YOUR JOKES

There once was an Indian who had only one testicle And whose given name was 'Onestone'. He hated that name and asked everyone not to call him Onestone. After years and years of torment, Onestone finally cracked and said,

If anyone calls me Onestone again I will kill them!

The word got around and nobody called him that any more.

Then one day a young woman named Blue Bird forgot and said,

'Good morning, Onestone.'

He jumped up, grabbed her and took her deep into the forest where he made love to her all day and all night. He made love to her all the next day, Until Blue Bird died from exhaustion.

The word got around that Onestone meant what he promised he would do.

Years went by and no one dared call him by his given name until

A woman named Yellow Bird returned to the village after being away.

Yellow Bird, who was Blue Bird's cousin, was overjoyed when she saw Onestone.

She hugged him and said, 'Good to see you, Onestone.'

Onestone grabbed her, took her deep into the forest, Then he made love to her all day,

Made love to her all night, Made love to her all the next day, Made love to her all the next night, but Yellow Bird wouldn't die!

Why ???

Everyone knows..You can't kill Two Birds With Onestone

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/ The asterisk * appears above which number on a keyboard?
- 2/ The Scottish city of Glasgow is situated on which river?
- 3/ Affenpinscher, French Brittany, and Grand Griffon Vendéen are breeds of which animal?
- 4/ Julian Assange, founder of Wikileaks, was born in which country?
- 5/ Which USA TV 'cop' sang Silver Lady in 1977?
- 6/ 'Loss swirl' is an anagram of which dessert?
- 7/ In French cuisine, what is fougasse?
- 8/ Real Madrid beat which Italian club 4-1 in final of the 2017 UEFA Champions League?
- 9/ Who was the Greek god of time?
a) Eros b) Cronos c) Hypnos
- 10/ Which European river flows through 4 capitals and forms some of the borders of 10 countries?

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/ Spiders 2/ A Murder 3/ Sumatra 4/ A Sea Bird 5/ 4-5kg 6/ The Americas North & South
7/ Eating 8/ Black Mamba 9/ Blue Whale 10/ Antelope