

ISSUE NO:- 01/ 2019

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.bbc.co.uk 31 December 2018

Councils 'failing' to prosecute blue badge abusers

A disability charity says it is "disgraceful" councils are failing to take action against people misusing blue-badge parking permits.

Analysis by the Press Association found 94 out of 152 (62%) local authorities in England did not pursue anyone for abusing the scheme in 2017-18.

Phil Talbot, from charity Scope, said thefts of disabled permits were rising.

The Local Government Association said councils had to take "tough decisions" on enforcement with limited resources.

Mr Talbot added: "Stealing blue badges isn't a crime without consequences. They are a vital lifeline for those who genuinely need them."

The analysis of the Department of Transport data showed the number of blue badges reported stolen totalled 4,246.

Zero prosecutions

It found 31 councils did not catch anyone despite claiming to have a policy for prosecuting offenders.

Local authorities in Nottingham, Middlesbrough, Shropshire, Luton, Milton Keynes, Bournemouth and Reading were among those to record zero prosecutions.

Martin Tett, transport spokesman for the Local Government Association, said gathering evidence and mounting a prosecution could be "time-consuming and expensive".

About 2.4 million disabled people in England have **blue badges**, which are issued by councils. Almost every case involving the 1,215 prosecutions across the country involved drivers using someone else's blue badge.

The permits allow holders to park for free in pay and display bays and for up to three hours on yellow lines, except for where there are restrictions. Blue badge holders can register for **100% discount from the London congestion charge**.

The largest number of prosecutions were made by the London boroughs of Hammersmith and Fulham (137) and Newham (88), with Leeds (78) in third place.

Mr Tett claimed the disparity in enforcement levels across England was likely to reflect "different levels of pressures on available parking".

www.bbc.co.uk 5 January 2019

Universal credit: Vote to extend benefit to three million delayed

The next stage of the universal credit rollout is to be scaled back amid concerns about the controversial new benefits system.

MPs were due to vote on whether to move three million benefit claimants onto universal credit in the next few weeks.

But this vote has been pushed back and Parliament will instead be asked to vote on transferring just 10,000 people to the new benefits system.

Labour said ministers should halt the rollout "as a matter of urgency".

But the government says all claimants will be on universal credit by 2023 as planned.

Universal credit works by **merging six different benefits** for working age people into one monthly payment.

The single payment is paid directly into claimants' bank accounts, covering the benefits for which they are eligible.

Supporters of the welfare reform, which is being introduced in stages across the UK, say it helps simplify the old complicated benefits system.

The Department for Work and Pensions has said that, under universal credit people are moving into work faster and staying in work longer.

2.2 million families are expected to gain under the system, with an average increase in income of £41 a week according to analysis by the Resolution Foundation think tank.

However the same analysis found that 3.2 million households could lose an average of £48 per week.

Some people already claiming universal credit say it has forced them into destitution and **in some cases prostitution**. Others say they have been left to **rely on foodbanks**.

The rollout has also faced criticism for running over budget and is currently years behind schedule.

More than one million people are currently in receipt of universal credit - either new claimants for benefits or those who have had a change in circumstances, perhaps by moving house.

The government's plan is for almost seven million people to be on universal credit by 2023.

Ministers were due to seek Parliamentary approval to move three million existing welfare claimants onto the new benefit.

But now Work and Pensions Secretary Amber Rudd will seek approval for just 10,000 people to be moved onto universal credit in the summer.

That process will then be assessed and further Parliamentary approval sought before every other existing welfare claimant is moved.

A source close to Ms Rudd said the pause was the right thing to do, and should reassure Parliament that she was listening to MPs' concerns.

Prime Minister Theresa May told the BBC's Andrew Marr Show the new benefits system would be fully rolled out by 2023, as intended.

She said the government was taking its time "to get this right", insisting that universal credit is a better system than the one it replaces.

She added: "The legacy system we inherited from the Labour Party had nearly 1.4 million people left on benefits for almost a decade.

"Helping people into work, giving them the dignity of being in work, the ability to support their families, that's what universal credit is about."

The news that the government was pushing back the vote **was first reported in the Observer on Sunday** which quoted a Whitehall source as saying Ms Rudd wants a "fresh Parliamentary mandate" for the reform.

Ms Rudd, speaking when she was first given the job of work and pensions secretary in November last year, said she would listen "very carefully" to concerns over universal credit and admitted the system "can be better".

She added that she would "learn from errors" and "adjust" the system, which she said had problems, where needed.

Labour's shadow work and pensions secretary Margaret Greenwood described universal credit as "deeply flawed" and called on the government to halt the rollout "as a matter of urgency".

Former Labour MP Frank Field, work and pensions select committee chairman, told the Observer he welcomed Ms Rudd's decision to revisit the plans.

He said: "The government seems finally to have woken up to the human catastrophe that was waiting to happen under its ill-formed plans for moving people on to universal credit."

The government should proceed with "managed migration" of people to universal credit "only once it has proved to parliament that it will not push more vulnerable people to the brink of destitution", Mr Field added.

The government has agreed on several occasions to slow the pace at which universal credit is extended across the UK.

Ms Rudd's predecessor, Esther McVey, had **promised** claimants would be given more time to switch to the new benefit and they would not have to wait as long for their money.

And in the 2018 Autumn Budget last month, Chancellor Philip Hammond pledged an extra £1bn over five years to help those moving to the new payments and a £1,000 increase in the amount people can earn before losing benefits, at a cost of up to £1.7bn a year.

www.bbc.co.uk 8 January 2019

Breaking Bad star defends playing disabled character

Bryan Cranston has defended playing a disabled character in his latest film, saying his casting as a man with quadriplegia was "a business decision."

In *The Upside*, the US actor plays a wheelchair-using billionaire who hires a former criminal, played by comedian Kevin Hart, to be his live-in carer.

"As actors we're asked to play other people," said the *Breaking Bad* star.

Cranston said the subject was "worthy for debate" and there should be "more opportunities" for disabled actors.

Yet he maintained he was entitled to play characters whose attributes and abilities differed from his own.

"If I, as a straight, older person, and I'm wealthy, I'm very fortunate, does that mean I can't play a person who is not wealthy, does that mean I can't play a homosexual?" he mused.

"I don't know, where does the restriction apply, where is the line for that?" he told the Press Association.

Jake Gyllenhaal and Dwayne Johnson are among others who have faced criticism for playing disabled characters.

Gyllenhaal's 2017 film *Stronger*, about a man who lost both legs in the Boston Marathon bombings, was criticised for not casting a disabled actor in the role.

Last year, meanwhile, Johnson was censured for calling for more disabled actors on screen while also playing a man with a prosthetic leg in action film *Skyscraper*.

Cranston's comments come in the wake of ongoing debate over whether it is appropriate for straight actors to play gay or transgender roles or for white actors to play characters associated with ethnic minorities.

Scarlett Johansson, Tilda Swinton, Jack Whitehall and Ed Skrein are among those who have faced criticism for accepting certain roles. Some have gone on to withdraw from projects following a backlash.

Last month Darren Criss said he would **no longer accept LGBT scripts** because he did not want to be "another straight boy taking a gay man's role".

The *Glee* actor played a gay serial killer in *American Crime Story: The Assassination of Gianni Versace* - a performance that won him an Emmy in December and a Golden Globe on Sunday.

Hart, meanwhile, believes there are always positives to discussions about diversity and inclusion.

"I think having a conversation started is always a good thing," he said.

"In this particular case, bringing awareness to the fact that hey, we would love to see more disabled people given the opportunities to participate in the entertainment world, and potentially grow."

The comedian turned actor faced renewed criticism himself recently for comments he made in 2010 about his fears that his son might grow up gay.

Criticism of his remarks led to him **stepping down as host** of next month's Oscars ceremony and apologising to the LGBTQ community for his "insensitive words". Hart apologised again this week on his SiriusXM radio show, saying he was "now aware" of how his words had made members of the LGBTQ community feel. "I think that in the times that we're living in, we have to be understanding and accepting of people and change," **he told his listeners**. Britain's Ben Whishaw expressed similar sentiments to Cranston's on Sunday after winning a Golden Globe for playing a gay man in *A Very English Scandal*. "I really believe that actors can embody and portray anything and we shouldn't be defined only by what we are," said the openly gay actor. "On the other hand, I think there needs to be greater equality," he continued. "I would like to see more gay actors playing straight roles." "It should be an even playing field for everybody. That would be my ideal."

www.msra.org.au 12 December 2018

AUSTRALIAN AHSCT TRIAL RESULTS RELEASED

- The results of an observational study of 35 people with relapsing-remitting and secondary progressive MS who received the treatment in Sydney have just been released.
- Autologous haematopoietic stem cell therapy (AHSCT) uses a combination of chemotherapy and reinfusion of blood stem cells to rebuild and reset the immune system.
- In this study, 60% showed no evidence of disease activity for three years after the treatment and 13 participants showed improvements in their disability scores. 8 people had continued disability progression during the follow-up period.
- Immune cell analysis showed that after one year, attacking immune cells were still wiped out by AHSCT but cells that regulate the immune system were restored.

A Sydney team have published results from their study of Autologous Haematopoietic Stem Cell Therapy (AHSCT) in people with relapsing-remitting and secondary progressive MS.

AHSCT has been under investigation, worldwide and in Australia, as a treatment option for MS using different protocols and in different types of MS. Good results have been seen for many people with relapsing MS however, it is also a treatment with high risks and international clinical trials and studies have shown that it is not effective or suitable for everyone with MS.

AHSCT aims to reset the immune system using chemotherapy to wipe out most or all the immune cells and then the individual's own blood stem cells are reinfused to rebuild the immune system. The hope is that the treatment puts MS into remission.

Researchers and clinicians at St Vincent's Hospital in Sydney have been conducting a study of the treatment since 2010. Their results have been published in the *Journal of Neurology, Neurosurgery and Psychiatry*. The study included 20 people with relapsing-remitting MS and 15 people with secondary progressive MS, who have now been followed for an average of 3 years following the treatment.

This study used the "BEAM" chemotherapy protocol, which completely removes the immune system and is the one most commonly used in people with MS around the world, but with limited published clinical trial results.

Participants in this study had levels of disability that ranged from low to moderately severe (disability scores between 2 and 7 as measured by the expanded disability status score (EDSS)) and had failed to respond to at least two previous therapies for MS, including two thirds who had failed on natalizumab, a high potency MS medication.

The researchers tracked evidence of disease activity via relapses, brain lesions on magnetic resonance imaging (MRI) and disability progression. In this group of people with MS, 60% showed no evidence of disease activity for up to three years after the treatment. In the people with relapsing-remitting MS, the result was higher, with 70% showing no disease activity. 73% of participants had no disability progression during the follow-up period. In fact, 13 participants had improvements in their EDSS disability score of an average of 1.4 points – all but one of these had relapsing-remitting MS. However, eight participants had their disease continue to progress during the follow-up period, two with relapsing-remitting MS and six with secondary progressive MS. 83% of participants had no new or enlarging lesions at their last MRI scan and 96% showed no active lesions.

Participants experienced the expected side effects of high dose chemotherapy, including ulcers in the digestive tract, nausea and hair loss. One third required red blood cell transfusions and a half required platelet transfusions during their hospital stay. No-one died as a result of the treatment in this study which is in keeping with recent international AHSCT outcomes for people with MS receiving medium intensity chemotherapy where the treatment is provided at an experienced hospital centre.

An important part of this study was the work conducted by MS Research Australia-funded PhD Student and clinician, Dr Jennifer Massey, who looked at the profile of immune cells in patients following the treatment. This work showed that the attacking types of T immune cell were still wiped out and that there was a sustained rise in other immune cells that work to calm and regulate the immune system. By comparison, these changes were not seen in patients who received the same AHSCT for lymphoma. This suggests that in people with MS, AHSCT may work by turning off the attacks as well as restoring the immune system's ability to regulate itself. These results may help us work out how to better treat MS without needing to use intensive chemotherapy treatments.

This study shows that AHSCT can provide good outcomes for people with relapsing MS who do not respond to other types of MS treatments. The results are similar to those seen in other international studies and confirm that people with relapsing-remitting MS respond better to AHSCT than those with secondary progressive MS.

Each person's situation is unique and decisions about any MS treatments, taking into consideration the potential benefits, risks and side effects, should be made in careful consultation with your medical team. A small number of Australian hospitals are currently providing this treatment for people with MS, but can only do so for patients who have failed to respond to other MS therapies and with a referral from a neurologist.

www.mstrust.co.uk 10 December 2018

Ocrevus (ocrelizumab) approved for relapsing remitting MS in Scotland

The Scottish Medicines Consortium (SMC) has approved Ocrevus([link is external](#)) (ocrelizumab) as an NHS treatment for relapsing remitting multiple sclerosis in Scotland.

SMC has recommended that Ocrevus can be prescribed for relapsing remitting MS if: you are experiencing relapses or have MRI evidence of new areas of MS activity, and

- you are unable or unwilling to take Lemtrada (alemtuzumab)

This reverses SMC's decision earlier this year that it did not recommend Ocrevus for relapsing MS.

This is really welcome news for people with relapsing MS in Scotland, as it gives them access to a proven treatment alongside people in the rest of the UK. We are also hopeful that ocrelizumab will be made available for those with early primary progressive MS across the UK in the near future. There are currently no treatments that can slow the progression of this form of the disease, in which disability accumulates significantly faster than for those with the relapsing form.

- Linden Muirhead, Director, Information and Engagement, MS Trust

NICE has paused the decision to reject Ocrevus as an NHS treatment for primary progressive MS (PPMS) in England and Wales. This is to allow time for additional discussions to take place between the drug company and NHS England. No timeframes have yet been published, and the outcome is obviously unknown, but we will continue to campaign for equitable access to effective care options for everyone living with MS. We will update you as and when further information becomes available. SMC has not scheduled a review of Ocrevus as an NHS treatment for primary progressive MS in Scotland at the present time.

multiplesclerosisnewstoday.com 19 December 2018

Ampyra Significantly Improves Walking Ability As Reported by MS Patients,

Phase 3 Trial Shows

Treatment with Ampyra (dalfampridine) for 24 weeks leads to sustained and clinically meaningful improvements in walking ability as reported by multiple sclerosis (MS) patients with gait difficulties, according to a study analyzing results from a Phase 3 trial.

The study, "Assessment of Clinically Meaningful Improvements in Self-Reported Walking Ability in Participants with Multiple Sclerosis: Results from the Randomized, Double-Blind, Phase III ENHANCE Trial of Prolonged-Release Fampridine" was published in the journal *CNS Drugs*. More than 90 percent of MS patients have difficulty walking, which reduces their independence and negatively affects their quality of life and productivity.

Ampyra (prolonged-release dalfampridine tablets) is an approved MS medication marketed by Acorda Therapeutics in the U.S. It is the first therapy specifically approved to help improve walking in adults with MS. A generic version of Ampyra was made available this year in the U.S. by Mylan. In Europe, the medicine is approved under the brand name Fampyra, being marketed by Biogen.

An international group of researchers involved in the clinical trial ENHANCE — a large study evaluating Ampyra's efficacy — conducted the present study to see whether the therapy could improve, in a clinically meaningful way, the walking ability of MS patients based on data from the trial.

ENHANCE was a multinational, randomized, placebo-controlled, Phase 3 study (NCT02219932) to assess whether Ampyra given over a 24-week period could reduce the walking difficulties of MS patients. The study was carried out at several centers in 10 European countries, the U.S., and Russia, and included patients with different MS subtypes.

In total, 636 MS participants, ages 18-70 and with walking difficulties, were randomized to be given either Ampyra tablets 10 mg twice a day (317 patients), or matched placebo (319 patients) for 24 weeks.

The primary endpoint of the trial was the proportion of participants exceeding an eight-point improvement (the predefined threshold for clinically meaningful improvement) on the Multiple Sclerosis Walking Scale (MSWS-12) following the 24 weeks of treatment. MSWS-12 is a patient self-assessment survey based on walking limitations because of MS.

Other outcome metrics included changes in mobility scores (Timed Up and Go speed), in the physical impact of MS (MSIS-29 physical subscale), body balance (Berg Balance Scale), and manual ability (ABILHAND).

Results showed that after the 24-week treatment, a higher proportion of Ampyra-treated patients (136 out of 315; 43.2%) had a clinically meaningful improvement in walking ability as measured by MSWS-12, compared with those given a placebo (107 out of 318; 33.6%).

This translated into an estimated 61% higher odds of patients under treatment with Ampyra getting relief from their walking difficulties.

Ampyra also led to more patients being able to move faster, as measured by TUG scores, and reporting fewer physical limitations as assessed by the MSIS-29 physical scale. Improvements in body balance and manual ability were also seen in patients receiving Ampyra, but they were not statistically significant.

The most common adverse events associated with Ampyra were urinary infection and insomnia. Based on the results, the researchers concluded that treatment with Ampyra “was associated with a greater likelihood of walking-impaired participants with MS experiencing clinically meaningful improvements in self-reported walking ability over 24 weeks.”

But researchers caution that while one of Ampyra’s benefits is its rapid action, those effects are lost when treatment stops. “This means that patients must be watchful” when stopping Ampyra “as their functioning can worsen soon after,” they stated.

Ocrelizumab Reduces Progression of Upper Extremity Impairment in Primary Progressive MS

For patients with multiple sclerosis (MS), upper extremity (UE) impairment is not uncommon. Although patients across MS types report impaired UE function, patients with primary progressive MS (PPMS) tend to have a higher prevalence of UE dysfunction and greater impairment.

A new study compared ocrelizumab with placebo in patients with PPMS to examine the effects of the therapy on confirmed progression and confirmed improvement in UE impairment. The results were published in the *Multiple Sclerosis Journal*.

UE impairment can affect patients’ independence and quality of life, and UE dysfunction can also be associated with unemployment. “Therefore, objective quantitative assessment of UE functionality is critical for monitoring overall MS disease progression and evaluating the benefit of MS therapy,” the authors explained.

The researchers used the Nine-Hole Peg Test (9HPT), a component of the Multiple Sclerosis Functional Composite, to understand UE function. The 9HPT was administered at baseline and every 12 weeks until the end of the study and researchers tested both hands twice to determine the time it took to complete the test.

Patients were randomized 2:1 to receive either ocrelizumab 600 mg (administered as two 300-mg intravenous infusions given 14 days apart) or placebo every 24 weeks for at least 120 weeks. The analysis included an intention-to-treat population and subgroups stratified by their baseline 9HPT time.

Among the intention-to-treat population, ocrelizumab significantly reduced the risk of 12- and 24-week confirmed progression of $\geq 20\%$ on the 9HPT versus placebo in both hands. During the baseline test, one hand was identified as the better hand and the other as the worse hand, and there were reductions with ocrelizumab for both, although the effects were less pronounced in the worse hand. “In a chronic disease like PPMS that is typically diagnosed during the most productive years of a patient’s life span, preservation of UE function is an important therapeutic goal,” the authors wrote. They added, “Findings from this analysis showed that ocrelizumab mitigated progression of UE impairment in patients with PPMS using the 9HPT.”

YOUR JOKES

(from my dad jokes)

To whoever stole my antidepressants,
I hope you're happy.

My buddy went bald years ago but still
carries an old comb with him,
he just can't part with it.

What country's capital is the fastest growing?
Ireland, everyday it's Dublin.

An invisible man married an invisible woman
The kids were nothing to look at either.

My doctor wrote me a prescription for daily sex
My girlfriend insists it says 'dyslexia'
But what does she know.

What do you call a zombie who doesn't
joke around,
Dead serious.

I'm pretty sure the hotel receptionist was
checking me out.

I told my girlfriend she was drawing her
eyebrows too high,
She looked surprised.

My wife said if I got her another stupid
Gift this Christmas she would burn it,
So I bought her a candle.

How does a butcher introduce his wife?
Meat Patty.

My wife and I laugh about how competitive
we are,
But I laugh more.

I went to a zoo and saw a baguette in
a cage,
The zoo keeper said it was bread in captivity.

My wife ran off with guy next door
I'm really starting to miss him.

A man was found guilty of overusing
commas. The Judge told him to expect
a long sentence.

What do you call a constipated detective
No-shit Sherlock

I gave my date a bottle of tonic water
Schwepped her off her feet.

My boss hates it when I shorten his
name to Dick,
especially when his name's Steve.

Three weeks ago I sent my hearing aids
in for repair,
I've heard nothing since.

We all know Albert Einstein was a genius
but his brother Frank was a monster.

A sperm donor, a carpenter and Julius
Caesar all walked into a bar.
He came, He saw, He conquered.

I have this weird talent that I can identify
what's inside a wrapped present,
It's a gift.

What do you call a bulletproof Irish man?
Rick O'Shea.

I used to date a girl who worked at a
brewery,
She was in charge of the hops.

My wife told me to put down the toilet seat
I don't know why I was carrying it around
anyway.

DISCLAIMER

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

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 name for which type of building or construction stems from both the French and Latin word for butterfly?
- 2/ The largest known spider in the world is named after which biblical character?
- 3/ Which Paul McCartney and Wings album title is also the name of a famous painting by Sandro Botticelli?
- 4/ According to Forbes magazine, who is the wealthiest monarch in the world?
- 5/ Which two bands had a hit with the song 'Dandy' in the 1960s?
- 6/ What is the largest lake in the Tropics?
- 7/ In which country is the southernmost inhabited community in the world?
- 8/ Which two footballers have been sent off twice while playing for England?
- 9/ Which US city is the gin soaked bar room queen from in the song 'Honky Tonk Woman'?
- 10/ Which well known Order have been coined 'The Bankers of the Middle Ages'?

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/ Bolshoi 2/ Knight Industries Two Thousand 3/ Sand or dust storm 4/ Yellow sea, South China sea, Sea of Japan 5/ Abide with me 6/ Microwave Oven 7/ Finger Nail 8/ China 9/ Bjorn Borg 10/ He ain't heavy