

# 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](mailto:news@stocktonmsgroup.org.uk).

Remember if you change your email address to let us know by sending a message to [news@stocktonmsgroup.org.uk](mailto:news@stocktonmsgroup.org.uk)"

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# NEWS UPDATE

June 2017

## Family Fun Day

Can you please note the date of the cricket club field day at Stockton cricket club has now changed.

It will now be held on Sunday 30th July 2017.

We continue to look for prizes for the tombola stall if anybody can donate something.

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www.multiple sclerosisnewstoday.com 19 May 2017

## Phase 3 Study of High-Dose Biotin, MD1003, in Treating Primary and Secondary MS Patients Underway

A Phase 3 clinical trial has been launched by [MedDay Pharmaceuticals](#) to investigate whether treatment with high-dose biotin ([MD1003](#)) may ease disability and improve mobility in non-relapsing primary or secondary progressive MS patients. The study is recruiting participants across the U.S., Canada and Europe.

Biotin is a form of vitamin B, and it plays an important role in energy production within cells. Researchers believe the compound has no anti-inflammatory action, and thus no effect on relapses, but that it treats disability by tackling neuronal loss.

Eligible patients must be 18 to 65 years old, and can maintain existing disease-modifying therapies, if treatment has been stable for at least three months before enrollment. A list of U.S. cities with testing sites can be viewed [here](#).

This randomized and double-blinded trial, called SPI2 ([NCT02936037](#)), is expected to enroll 600 MS patients, especially those with gait impairment, who will be assigned to receive either a capsule of [MD1003](#) (100 mg) or a placebo three times a day for 15 months. Results are expected to be known by mid-2019.

“An interesting point with biotin is that it doesn’t seem to work in the short term,” Frédéric Sedel, MedDay’s CEO and co-founder, said in a recent [interview](#) with *Multiple Sclerosis Today*. “When we start the drug, we start to see an effect after at least nine months of treatment.”

Following the trial’s randomization phase, patients will be allowed to enter an open-label extension study in which all will receive treatment with MD1003 (100 mg) for an additional 12 months.

The study’s main objective is to assess improvements in mobility and changes in disability, as measured on the Expanded Disability Status Scale (EDSS) or a timed test of walking 25 feet. Researchers will also analyze other clinical parameters, such as cognitive function, quality of life, and disease activity as captured on magnetic resonance imaging (MRI) scans.

Results of an earlier Phase 3 clinical trial ([NCT02220933](#)) of MD1003 in 154 patients with primary or secondary progressive MS in France, published in the *Multiple Sclerosis Journal* in 2016, found eased disability progression and improved mobility in 12.6 percent of treated patients, compared to those taking a placebo. The treatment was well-tolerated and no serious side effects were reported.

“What we observed in patients was progressive improvement, which was very unusual, as you know — patients with progressive MS, as with other neurodegenerative diseases, are not supposed to really improve,” Sedel said in the interview. About 5,000 MS patients in France are also taking MD1003 outside of the earlier and ongoing clinical study, under a temporary license, known as an ATU, granted the treatment by French regulatory authorities, Sedel said.

www.bbc.co.uk 17 May 2017

## **MS patient defers plan ending his life**

A man who planned to end his own life in a clinic in Switzerland has deferred his decision after being encouraged to seek more support.

Colin Campbell, of Inverness, has primary progressive multiple sclerosis and told BBC Scotland last month that **his health had rapidly deteriorated**.

He has now said he may not attend the Swiss clinic after another MS patient encouraged him to press for more help.

NHS Highland said support was tailored to individual patients' needs.

Assisted suicide is unlawful in Scotland. A move to change the law was defeated in a vote in the Scottish Parliament in 2015.

Mr Campbell, 56, who was booked to go to a clinic in Basel next month, was first diagnosed with MS when he was 34, but had previously suspected he had a health condition because of a deterioration in his ability to play sports.

He told BBC Scotland that he has deferred his decision to explore his options of better support and the possibility of stem cell treatment.

### **Mobility scooter**

He told the BBC earlier: "How people should be looking at this is 'Colin is worn out with having had this incredible progressive illness'.

"His death will give him release."

Mr Campbell uses a walking frame to move around his flat and a wheelchair when travelling outside his home.

He formerly worked in IT, still has use of his hands and plays the guitar.

However, he fears he will reach a point where he can no longer use his hands and will be unable to feed himself.

Since expressing his intention to end his life, Mr Campbell has been contacted by fellow MS patient Rona Tynan.

She has offered to help him seek appropriate help to improve his quality of life.

She said: "It was extremely important that I made contact with Colin and I'm so glad I saw him on the television.

"What alarmed me about Colin was, I felt he was more able than myself.

"I was very, very concerned that he'd made his decision when it was maybe horrible weather. The winters are long when you've got MS."

### **Specialist nurses**

Among the practical measures Ms Tynan has helped Mr Campbell with has been a test drive on a mobility scooter.

It is one of the things he said had prompted him to look again at his plans.

He said: "This has given me some kind of optimism which I definitely didn't have - so I owe that to Rona.

"There are a lot of people that are forgotten who need a lot of help and are unaware that there is help.

"That's when people like me think they're off to Switzerland."

A spokesman for NHS Highland said: "After diagnosis the support provided to our patients is tailored to suit their individual needs and is very much driven by them.

"Once MS is confirmed, each patient is contacted by one of our MS specialist nurses who goes through options and details the wider support that is available to them in the community."

www.theguardian.com 29 May 2017

## How I learned to love my walking stick

If you want to learn about life, get a walking stick. I did, when, after a period of denial, I reluctantly accepted that multiple sclerosis was causing me to become unsteady. I felt as if my legs were being operated by somebody else; somebody who wasn't paying attention.

My GP booked me an appointment with a physiotherapist, who observed me walking to assess what was required, suggested a simple stick, and guided me on its correct use. So as not to place undue strain on elbows and shoulders, the arm should be straight, the handle reaching the end of the arm. For me, an ergonomic handle (which lessens callouses) was the way to go. I was then given a lesson in stick wrangling. Users are advised to carry their stick when climbing stairs, relying on stable bannisters instead. So much for those "spot the fraud" exposés, where people spotted climbing flights of stairs, stick in hand, are deemed skivers. That is what you are supposed to do. I was then taught how to stand up properly (push yourself up without using your stick). Also, if you have one dodgy leg, the stick is held against the good leg. Those films where a disabled cop wobbles with one bad leg against a stick are just plain wrong.

Maintenance, too, is important: a metal telescopic stick should make a pleasing hollow thud. If it doesn't, it is wearing out and needs replacing. All this is free, locally provided by the NHS.

It can take a while to get into your stride, but walking soon becomes natural – the knack is to treat your stick like an extra leg, rather like this scene from *Delicatessen*, albeit without maracas. It is also teaching me a lot about people. My walking stick is a visible declaration that I am weaker than others, which occasionally makes me feel vulnerable – but I also enjoy quiet fantasies of being a cyborg with an additional metal leg.

The action of walking in public regularly reveals the unspoken hierarchy as we move along within that notional bubble of personal space that surrounds us all. If oncoming entwined couples threaten to sweep me aside, a pointed tap on the pavement usually alerts them. People with two sticks prevail, a wheelchair has right of way, a mobility scooter and everyone scatters. But I dread cyclists on pavements. Please don't do this; you can't see my limitations and I am slow to get out of your way.

An artist added a skull and rose to Anderson's stick.

I have also encountered a fresh and dangerous level of manspreading. This simple neologism takes on a sinister meaning when your stick is knocked out from beneath you by a burly man striding proudly, wide and long. And no, he didn't so much as look back, let alone apologise, despite my remonstrations (swearing).

Then there are the people who wince with shame on realising they have just barged into a person with a walking stick. They shouldn't be barging into, and potentially knocking over, anyone in the first place, let alone a woman with a visible disability.

While happy to lose my debilitating wobble, I now struggle to hold a bag full of heavy shopping as well as a handbag, while reaching for keys, maybe pulling on gloves, answering my phone and maintaining an upright posture. Then down comes the rain and I scramble for an unwieldy umbrella. That stick is an additional complication.

Mobility issues had already limited my choice of shoes. Never keen on vertiginous heels, I surrendered to flats some years back. I also had to re-evaluate my handbags. I was never fond of clutch bags; mercifully, as they are now utterly impractical. I need a bag directly on my shoulder, not low-slung as before. I have jettisoned bulkier bags so I can hold the stick properly, close to my side. I suppose the fact that my jaywalking days are over is a good thing: no more speedily scuttling across roads. Journeys will now always take longer. My nemesis are amber-light-gambling taxi drivers who deem my transit too slow, and drive menacingly towards me as a warning.

But I have also learned that people are usually very kind. Drivers slow down to let me cross, people pick up my stick if I drop it, and also open gates. However, they are occasionally callous, slamming doors, glaring in an accusing fashion when I can't reciprocate to hold the entrance open in return, or bumping in to me without looking, usually while texting.

I am now obsessed with bespoke carved wooden sticks, currently on my wishlist. Regulation NHS sticks are uniform and grim. It is important to me as an individual to stamp my identity on to an item that is now an unalterable part of my life. So, bored of regulation black sticks, and encouraged by the physiotherapist, I decided to customise mine. Glitter paint was mentioned, but I'm not a nine-year old girl. Someone else suggested ribbons, which are bit too Morris-dancer. Fortunately, I know some very kind and talented artists, who spent time carefully decorating my black stick, creating excellent art using gold paint.

Ross Sinclair spent hours painting his signature statement Real Life, Alan Campbell added a lovely abstract crow, Kate V Robertson provided a hand clutching the stick, and Fiona Wilson a tattoo-style skull and rose. I feel so much better about using a walking aid since it was so beautifully personalised. Now when I set out, I reach for my keys, phone and stick. I am still me, a person who uses a stick but is not defined by it. It just holds me upright. Which is all you can ask of a walking stick.

www.bbc.co.uk 4 May 2017

## **Mat Fraser on playing Richard III and TV's 'pathetic' disabled casting**

Mat Fraser is the first disabled actor to play Shakespeare's twisted anti-hero Richard III - and he's relishing the political incorrectness of the Bard's script. But British TV channels are "pathetic" at giving such juicy roles to disabled actors, he says.

At the end of our interview, Fraser gives me a bit of advice about how to make his quotes suitable for publication.

"Whenever I swear, just put 'hell' or 'damn' instead," he suggests.

That tip comes just after he has been talking about progress with casting disabled actors on TV. Two minutes earlier: "In terms of opportunity for disabled people, there are four more people on telly than there were 20 years ago. Excuse me for not having a party."

Fraser and other disabled actors "clearly have the experience", he says. "I mean if I didn't have the experience, I wouldn't be asked to be doing damned Richard III, you know?"

"If people didn't think I could act, no-one would let me near the role. But can I get a look-in in any of the BBC dramas? Can I hell."

Fraser has the experience - although recently, US TV executives have been the most willing to let him use it.

He played Paul the Illustrated Seal Boy in American Horror Story: Freak Show, and will soon be part of an addicts' self-help group in a new TV comedy by Dumb And Dumber co-creator Peter Farrelly.

He has been in bits on Channel 4 and the BBC, has been a regular on stage and played drums with Coldplay during the London 2012 Paralympic closing ceremony.

He is easily recognisable - he was born with underdeveloped arms as a result of his mum being prescribed the morning sickness drug Thalidomide during pregnancy.

Ten minutes earlier in the interview, Fraser is not yet as exasperated as he will get by being asked to talk about the opportunities on TV for disabled actors. More of that later.

For now, he's talking about playing Richard III for the Northern Broadsides Theatre Company at Hull Truck as part of Hull's 2017 City of Culture events.

He describes Richard with relish as a "wonderfully evil character who has no redeeming qualities at all".

Unlike most actors who have played the scheming monarch, when Fraser steps on stage to deliver the famous opening speech, he won't have a pillow strapped to his back or a walking stick to demonstrate a physical ailment.

"I don't have to start performing my own impairments," Fraser says. "I can just be, in my body.

"I don't have to make any flourishy hand movements to show my wonderfully crippled hand, or prance about on a stick or anything to illustrate the point.

"I can just stand there and be, and I feel be more direct and honest."

"I can be as horrible as possible and infer it's in part due to my disability and I can relax and enjoy that."

In the opening speech, Richard describes himself as "rudely stamp'd", and "cheated of feature by dissembling nature, deformed, unfinish'd". He is so bitter about his condition and how he's been treated that he is "determined to prove a villain".

Among the blunt insults that come his way, he's called a "poisonous hunchback'd toad" and a "lump of foul deformity".

Rather than having a problem with the way Richard is described, Fraser says Shakespeare's words are liberating in an age when most modern disabled characters are portrayed with the utmost sensitivity.

"It's very freeing, precisely because I don't have to worry about any political correctness or [think] 'Hmmm it's my responsibility as a disabled person to imbue this disabled character with as much sensitive understanding as possible'," he says.

"Au contraire with Richard III. It's literally my job to make him as horrible as possible."

Richard III is directed by Barrie Rutter, who founded Northern Broadsides in Hull 25 years ago Fraser says he feels he has to act as an ambassador for disabled people when playing "most characters if they're in the contemporary setting".

But with Richard, he explains: "I can be as horrible as possible and infer it's in part due to my disability and I can relax and enjoy that."

Perhaps Adam Hills, the host of Channel 4's The Last Leg, was referring to the sensitivity - maybe oversensitivity - around portraying disability when **he told a recent panel discussion** there should be more disabled villains on TV.

"Why are disabled people on TV always portrayed as being nice all the time?" he asked.

### **'Too politically correct'**

"Nice" is not a word that could be applied to Richard III. Fraser responds to Hills' comments by saying: "Disabled people are where black people were in the '80s.

"They can't be baddies. People [in the TV industry] are too politically correct. But they're not ready to give us the hero role yet. So we get no role.

"And for anyone on Channel 4 to have a go about what characters should and shouldn't be with disabled... How about having some damned disabled actors who actually are damned characters for some of their damned dramas, yeah?"

"BBC are all right. ITV are OK. I mean it's minimal and pathetic. But they have something. Something I can hold on to."

He lists Liz Carr in Silent Witness, Lisa Hammond in EastEnders and Cherylee Houston in Coronation Street.

"What have I got on Channel 4? Some damned lad who's on The Last Leg. Woo. Doesn't impress me, mate."

"And as for those panels - I've been doing panels since 1996 about trying to get disabled actors in. I'm just done with panels. Jobs not panels."

### **'Nothing's changed'**

We're back where we started, and Fraser's exasperation is growing. He stresses he's "not having a go at Adam Hills".

"But if people want to talk to me about roles for dramas, the conversation should be, 'We'd like you to audition for...' Any other conversation is going to get short shrift from me."

How does the conversation normally go?

"It's the same as it has since 1996. 'Do you think there should be more disabled actors in different roles and what are the barriers that prevent them?'

"Yes I do. Attitudinal barriers and the fact that commissioning editors didn't go to school with disabled people."

"The questions and the answers have not changed in 21 years."

"But what has changed is my tolerance for the conversation."

www.racingpost.com 16 June 2017

## **Racing should be doing all it can to assist wheelchair users**

In the last few weeks I have been making some of my first trips to racecourses in my wheelchair and the reception I have had at the likes of Newmarket and York has been wonderful.

Unfortunately, it seems not all wheelchair-using racegoers have had such a positive experience.

I was recently introduced to Mo Charge, who has been forced into a wheelchair in recent years by hereditary spastic paraplegia. Mo, 58, is the former owner of Sports Bookmakers, a passionate racing fan and has owned a number of horses down the years, including Greed Is Good, who I rode for him back in 2013.

Mo has reached out to the Racing Post after taking what he describes as the "heartbreaking" decision to give up owning horses, because he finds going to watch them run at many of Britain's racecourses too much hassle in his wheelchair.

Having been in his chair for longer than I have, Mo has experienced more than me but is already making me aware of certain things I may encounter as I visit more courses in the years to come and, unfortunately, he does not paint a pretty picture.

"As sporting venues go, horseracing is absolutely and utterly at the bottom of the pile," Mo told me, and two examples highlight some of the reasons for this.

## **Inaccessible viewing area**

On a day out at Doncaster in 2013, Mo was originally frustrated by the disabled parking being on grass, something that makes pushing yourself along in your chair extremely difficult. Things did not improve once inside the course, with staff unable to point him in the direction of lifts he could use to access the disabled viewing area in the grandstand. Having worked out where that area was himself, he had to make his way through a restaurant, between tables of diners, to reach it.

"Why put it in such an inaccessible place?" Mo asks. "They've ticked the box saying there is a designated area but the practicality and reality of it wouldn't encourage anybody to go back there because of the embarrassment and annoyance factor."

Mo had another bad day when he went to Windsor to watch his Mystic And Artist run on June 22, 2015. A toilet marked as being for disabled racegoers turned out to be too small for Mo to wheel himself in and transfer on to the lavatory. "That really highlights the problem," said Mo. "Who on Earth thought of having a disabled toilet where you can't take in the wheelchair and sit on the lavatory?"

Asked to respond to both of these incidents, Arc's Sam Cone confirmed a lift that allows access to Doncaster's disabled viewing area without having to go through the restaurant has now been repaired, while at Windsor, he explained there are disabled toilets near the grandstand big enough to accommodate a motorised wheelchair. Cone also said all Arc courses have accessibility statements on their websites.

"We want to make sure wheelchair users are able to enjoy their experience at an Arc racecourse in line with all customers and we have, over the years, worked to make adjustments to facilities to help achieve this," Cone said. "That is not to say there is not room for improvement, however, and such considerations are high up the agenda of any new development or refurbishment of our racecourses.

"We are happy to receive feedback on this issue and listen to any concerns customers have to see if we can improve."

## **Better toilet facilities at all courses a must**

The size of disabled toilets is not the only problem Mo has highlighted, with the lack of National Key Scheme (formerly Radar Key) facilities available at British courses a real issue.

The purpose of the NKS is to provide disabled people with public toilets they can trust will be available when they need them and will be in a usable condition. I have one of these keys and, as with so many issues like this, nobody can fully appreciate their significance until they have the misfortune of finding themselves in a wheelchair.

Mo is calling for every racecourse in Britain to be fitted with such toilets and this is something I am happy to support. He rightly said: "It's peanuts in terms of cost in the big scheme of things but it's a must."

Doncaster and Windsor are by no means the only two courses Mo has had problems with and nor are his issues confined to venues owned by Arc, but the bottom line is a valuable supporter of our sport has been all but forced away by the circumstances.

Will Aitkenhead of the Racecourse Association has expressed his disappointment at hearing of Mo's decision but said he welcomed the opportunity to look again at accessibility on racecourses.

Aitkenhead points out that all courses in Britain are assessed every year by Visit England, Visit Wales and Visit Scotland, with Goodwood and Aintree having undergone significant improvements in recent months, including the resurfacing of car parks at the former and modification of toilets at the latter.

He also notes a recent House of Commons report on accessibility of sports stadia openly criticised many sports but made no mention of horseracing, although he added: "That's not to say we are complacent and first-hand experiences such as Mo's are invaluable in helping us improve the raceday experience for disabled guests."

"We would very much welcome the opportunity to work with Mo and anybody else who felt they could help us improve accessibility on racecourses."

Arc and the RCA's openness is good to hear and hopefully things will continue to improve, but the fact is Mo will now visit only Huntingdon racecourse, where he has a box and where NKS toilets are available. That he feels the need to seek refuge in a box, as he did at many other courses in recent years, has to be a concern.

Such facilities come at considerably greater expense than a general admission ticket and it is wrong that a wheelchair user feels he cannot get the same experience from a day racing with a general admission ticket than an able-bodied visitor would.

If somebody like Mo, who eats, sleeps and drinks racing, feels he has no choice but to step away from ownership then the question has to be asked: how does racing expect to attract wheelchair users who do not have that emotional link to get involved?

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## YOUR JOKES

This morning I was sitting on a park bench next to a homeless man. I started a conversation by asking him how he ended up this way.

He said, "Up until last week, I had it all. I had plenty to eat, my clothes were washed and pressed, I had a roof over my head, I had TV and Internet, and I went to the gym, the pool, and the library. I was working on my MBA online. I had no bills and no debt. I even had full medical coverage."

I felt sorry for him, so I asked, "What happened? Drugs? Alcohol? Divorce?"

"Oh no, nothing like that," he said. "No, no. I got out of prison."

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Two Tasmanians were sitting around talking one afternoon over a cold beer.

After a while the first Tasmanian says to the second, "If I was to sneak over to your house and make love to your wife while you was off fishing', and she got pregnant and had a baby, would that make us related?"

The second Tasmanian crooked his head sideways for a minute, scratched his head, and squinted his eyes, thinking real hard about the question.

Finally, he says, "Well, I don't know about related, but I reckon it'd make us even."

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### EXERCISE FOR PEOPLE OVER \*\* ( a certain age ! )

Begin by standing on a comfortable surface, where you have plenty of room at each side.

With a 5-kg potato sack in each hand, extend your arms straight out from your sides and hold them there as long as you can. Try to reach a full minute, and then relax.

Each day you'll find that you can hold this position for just a bit longer.

After a couple of weeks, move up to 10-kg potato sacks.

Then try 25-kg potato sacks and then eventually try to get to where you can lift a 50-kg potato sack in each hand and hold your arms straight for more than a full minute. (I'm at this level.)

After you feel confident at that level, put a potato in each sack.

## 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/ Which of Henry VIII's wives is buried alongside him in St. George's chapel in Windsor Castle? .....
- 2/ Which is the most southerly city in the UK? .....
- 3/ The Battle of Goose Green was fought during which war? .....
- 4/ The New Shekel is the currency of which country? .....
- 5/ In which year did Princess Diana die following a car crash in Paris. ....
- 6/ Name the bassist in the original line-up of the band Queen. ....
- 7/ Who was the first ever queen to rule England in her own right? .....
- 8/ "The course of true love never did run smooth." are words from which play? .....
- 9/ A 'Finnish Spitz' is a rare breed of which animal? .....
- 10/ To Kill A Mockingbird – by Harper Lee was predominantly set in which country? .....

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/ Summer of 69 - Bryan Adams 2/ Piano Man – Billy Joel 3/ Sound of Silence – Simon & Garfunkel 4/ Dock of the Bay- Otis Redding 5/ Don't stand so close to me – The Police 6/ Bohemian Rhapsody - Queen 7/ My Generation – The Who 8/ My Girl – The Temptations 9/ Hotel California – The Eagles 10/ Total Eclipse of the Heart – Bonnie Tyler