

ISSUE NO:- 05/ 2017

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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NEWS UPDATE

Freda Morton

On Monday the 1st May we received the sad news that Freda had died. It was a shock to all of us when she was diagnosed with a tumour on her lung. She was so determined and head strong that she would recover quickly and start getting on with her life again, and we all hoped that this would be the case for her. Unfortunately she was constantly being hit with setbacks and infections since the operation to remove her lung, meaning long stays in hospital and a recuperation period in a care home in Yarm to help build her back up again.

She had helped out at the Drop-In for over 20 years, not only looking after us all making our cups of tea and coffee, but also joining in with our conversations and laughter, she was one of us. She was someone who could be relied on to turn up every week and help out, even when we used to meet on Thursdays when others went on holiday.

I'm sure we all enjoyed her company and her conversations over the years. It will be strange not having her around us, busying about and pampering after us all. She has left us with lots of memories, all good, and I'm sure we are all grateful that she chose to share her free time and company with us for all those years.

A wonderful lady with a huge heart, R.I.P. Freda.

Susan O'Neill

www.bbc.co.uk 13 April 2017

The truth about the miracle cure that promises to treat everything:

Stem cells are known for their remarkable healing powers. But while they work for many, others have been left unaffected by treatment.

Zoe Derrick was diagnosed with multiple sclerosis after the birth of her second son, Freddie, in January 2012.

'At first, I thought breastfeeding was the reason I was so, so tired all the time,' she says. 'It was so bad that Paul, my husband, was having to help me up the stairs.

'I kept tripping on the pavement when I was pushing the pram, then I trapped my hand in the car door. It was very bruised and swollen, but I couldn't feel a thing. I should have been in agony.'

An MRI scan that night revealed patches of damage all over her brain. Zoe, with her medical training as an NHS midwife, knew what it meant.

'I wondered how I could be alive, let alone speak.'

Multiple sclerosis (MS) is a neurological condition in which the immune system destroys the vital protective sheaths around nerves, causing damage that can have a devastating and paralysing effect on functions including movement, sight and speech.

Over the next two years, Zoe failed to respond to three drugs she was prescribed and became 'weaker and weaker'; she had lost her peripheral vision and soon couldn't walk.

If I wanted to go anywhere, I had to use a mobility scooter,' she says. 'I cut down work to alternate days but even then I was off sick a lot, I was just exhausted.

'I couldn't cook a meal, bathe my baby or do anything. My balance and speech were affected. I felt and looked drunk all the time.'

Zoe was given another drug, 'but the side-effects were unbearable: the most excruciating burning sensation throughout my body. I was only 36 but I felt that my life was ending.'

She desperately looked for other options and last year came across stem cell treatment. Stem cells are capable of turning into all kinds of other cells the body needs.

The treatment for MS involves completely destroying the malfunctioning immune system using chemotherapy, then healthy stem cells, harvested from the patient's bone marrow, are returned to the body to re-grow a healthy immune system.

Cancer specialists have already successfully treated blood cancers using stem cells from bone marrow and, in 2012, specialists at the Royal Hallamshire Hospital in Sheffield and King's College Hospital in London, began testing the technique on a handful of MS patients with good results.

Stem cell treatment looked like the only option,' says Zoe, 'but I was turned down for the trial because they said my MS wasn't actively advancing.'

Zoe decided to go abroad for the treatment. Her NHS consultant 'pleaded with me not to, saying it would be a highway to death because it was untested and unregulated, and treatment would be available here in five years. I said I didn't have five years'.

As a young mother, Zoe should surely have been given access to the best available healthcare. Instead, she had to spend £38,000 to go to Mexico for the treatment and now faces selling her home to repay the loan.

ONLY A FEW HAVE BENEFITED

It is more than 35 years since the biologist Professor Sir Martin Evans first identified stem cells in mice at Cardiff University in 1981.

He won a Nobel prize for his work, and stem cells have been hailed ever since for their ability to provide a 'master repair kit' for all of us, with the promise of curing MS, spinal injuries, heart failure and even age-related macular degeneration, the most common cause of blindness.

Breakthroughs continue to be made. Last month, for instance, researchers at Bristol University announced they had found a way to use stem cells to make limitless quantities of red blood cells, which could mean human blood donors will no longer be needed.

Ultimately, stem cells could treat diabetes (by regenerating insulin-producing cells) and be used to repair cartilage (to treat arthritis), the liver, the brain and virtually any other sort of soft tissue, according to Professor Brendon Noble, a spokesman for the UK Stem Cell Foundation.

Yet so far, only a small number of patients in the UK have been given the treatment.

Global progress on research was initially limited because ethical concerns about using stem cells from early embryos led President George W. Bush to declare a moratorium on stem cell work in 2001, which continued until 2009.

The value of stem cell treatment for MS is now 'established', according to the latest European Society for Blood and Marrow Transplantation annual report.

One of the few NHS patients who has benefited from the treatment is 43-year-old Steve Storey, a former management consultant and marathon runner from Sheffield. Though he is still confined to a wheelchair, Steve, a father of two, says the treatment has given him a new lease of life.

'Within 18 months of MS being diagnosed in 2013, I was pretty much paralysed and needed 24-hour care,' he says. 'The next stage was respiratory failure. I didn't think my life expectancy was more than a year or two.'

Nine days after his transplant in October 2014, he could move a previously paralysed toe.

Within four weeks, he could stand up, and ten months later, he competed in a one-mile open-water swimming race in the Lake District.

'I'm continuing to improve. I'm still in a wheelchair but I don't need 24-hour care,' he says. 'Who knows what the future holds?'

WHEN IT'S GONE HORRIBLY WRONG

Professor John Snowden, who is leading the work at the Royal Hallamshire, has said there is 'an increasing evidence base' to support the use of stem cells in treating MS particularly, but also connective tissue diseases and Crohn's disease.

This all suggests that more MS patients should be offered the treatment — but Paolo Muraro, a senior neuroscientist at Imperial College London, says that between only 50 and 75 MS patients in Britain have so far received stem cell transplants.

Across Europe, more than 1,000 patients have been treated.

'It is vastly underfunded,' Dr Muraro told Good Health. 'Thousands could benefit from this, but the NHS is not proactive in adopting innovations.'

'I read that \$600 million [£469 million] was invested in developing the new MS drug ocrelizumab — stem cell therapy gets a fraction of that investment.'

One stem cell transplant operation costs about £30,000, which is the same as a year's supply of one of these drugs.

'If we received the money for more trials that show it is safe and effective, we could save many years of treatment costs.'

Or, as Zoe puts it: 'Stem cell treatment is a one-off cost. Why would you want to go on shoving expensive drugs into people when it doesn't stop the progression of the disease?'

But stem cell transplants can go wrong. Last year, the New England Journal of Medicine reported the horrific case of a stroke patient from San Diego, California, who ended up with a 'strange, sticky fibrous mass' growing aggressively in his spine after having injections of foetal stem-cell tissue in Argentina, China and Mexico.

Another report, in 2009, described a child from the U.S. who developed a brain tumour after his parents had taken him to Russia for foetal cell injections.

And treatment may not work. Gregg Burgess-Salisbury has spent more than a decade fighting the advance of MS after being diagnosed within days of his 30th birthday.

Gregg, a former IT engineer from Twyford, Berkshire, was offered stem cell treatment two years ago, but it didn't work and he is still confined to a wheelchair, hoping a different form of the treatment, or something else, will transform his life.

'It's disappointing, but you have to be stoical about it,' he says.

'I am no worse now than I was before, and I believe the disease would certainly have progressed if I hadn't had the treatment. I would still recommend that any MS sufferer goes ahead with it.'

Similarly, stem cell treatment for conditions such as liver disease has brought mixed results.

In 2011, Professor Anil Dhawan, of King's College Hospital, used the treatment on 18 children with acute liver failure. One child, Iyaad Syed, then two months old, was snatched from the jaws of death and six years later is healthy.

'About half the children did really well,' says Professor Dhawan.

The use of stem cells to treat paralysis still seems a long-term hope. A breakthrough was achieved in 2014, though, when nasal stem cells engineered in Britain were used in an operation in Poland to allow a 40-year-old man to walk after his spinal column was severed in a knife attack.

David Nicholls, whose charity, the Nicholls Spinal Injury Foundation, part-funded the operation, said it would help only 2 to 3 per cent of patients whose spinal columns were wholly severed.

Mr Nicholls, a leading hotel chef, set up the charity when his son, Daniel, then 18, was left paralysed after he dived into shallow water during a gap-year trip to Australia in 2003.

His father has raised more than £1 million for stem cell research.

'When I started on this, people said I was wasting my time — paralysis would never be treatable. Look how far we've come,' he says. 'Even a 10 per cent improvement in nerve function would make a huge difference to Dan.'

Predictions of stem-cell treatments for age-related macular degeneration, a common cause of blindness, have also proved premature. There is still no such treatment available.

Current hopes are focused on Cell Cure Neurosciences, of Israel, which has developed an injectable type of stem cell derived from human embryonic stem cells.

LIMITED TO HEARTS AND MS

Recently, scientists in the U.S. published a claim that stem cells had been programmed to grow new cartilage on a worn-out hip joint, and that this new cartilage would release anti-inflammatory molecules to ward off the return of arthritis.

The proposal was dismissed by Professor Justin Cobb, an orthopaedic surgeon at Imperial College London.

'The simple problem is that with at least three times your bodyweight going down through your hip joint, even if you got the cells in they would immediately be completely mashed,' he says. Indeed, apart from MS, the only condition in which regenerative cells have so far produced results in UK patients is heart disease.

In studies at St Bartholomew's Hospital in London, 250 patients have been enrolled in stem cell treatment for heart failure, a condition that affects 900,000 people in Britain.

Gordon Foster, 59, a former welder from Bridlington in East Yorkshire, suffered from heart failure for many years and has no doubt that he owes his life to stem cell therapy.

'My consultant put me forward for a trial at Barts five years ago,' he says. 'I started really going downhill afterwards and found out I had been given a placebo.'

'They contacted the hospital and I was given stem cell treatment last September on compassionate grounds, because I had already volunteered for the trial.'

Gordon is convinced that the treatment has worked.

I wouldn't have made it to this year without these brilliant people. I was in constant pain and going upstairs on my hands and knees because I couldn't get a breath. Now my family haven't got that worried look on their faces and I'm getting better and better.'

Yet the lead clinician, cardiologist Anthony Mathur, admits the programme is going nowhere without more charitable funding. 'Unless there is an obvious route to profit, no one is interested in funding the studies,' he says. 'We need another £6 million to £7 million.'

Professor Noble told Good Health: 'I think we are on the cusp of something huge. There is evidence that stem cells can treat spinal injury, eyesight loss, all our biggest health problems.'

'Medicine is like that. You get nothing for years, then you get penicillin or organ transplants.'

'We just have to make sure we get it right, because if we get it wrong, it will set us back years.'

www.bbc.co.uk 14 April 2017

Disability benefits: PIPs assessment firms 'to get extra £200m'

Two private firms that assess people claiming disability benefits will get nearly £200m more than officials had originally expected, figures suggest.

The UK government had estimated that Atos and Capita would earn £512m for Personal Independence Payments (PIPs) assessments between 2013 and 2017.

But analysis by the Press Association suggests they will actually get £700m. Labour said the deals were "rewarding failure", but the government said effective assessments were vital.

PIPs are payments for people aged between 16 and 64 who have ill health or a disability, and since 2013 have been **gradually replacing the Disability Living Allowance**.

Money is allocated according to a points system and a person's eligibility is kept under regular review.

'Operational problems'

Atos and Capita assess PIPs in England, Scotland and Wales, with tests devolved in Northern Ireland.

Payments averaged £19m a month in the past two years, according to monthly spending data from the Department for Work and Pensions (DWP).

If kept at current levels, this could land the DWP with a total bill of more than £700m.

Former Work and Pensions Secretary Stephen Crabb, made a **U-turn on plans to cut PIPs payments** when in office in 2016, said officials had underestimated the number of claimants and therefore the cost of the contracts.

"I think that is probably a fair criticism that could be levelled at the DWP," he told BBC Radio 4's Today programme. "It hasn't been very good at getting its forecasts right."

He added that there had been "operational problems" with the way the contracts were carried out.

'Best value'

Shadow work and pensions secretary Debbie Abrahams said: "It is beyond belief that this Tory government is rewarding failure.

"The PIP process is in disarray and these private companies are receiving huge payouts in a time of extreme austerity. It is clear that these costs are spiralling out of control."

A DWP spokeswoman said the department worked to ensure disability payments offered "best value" for taxpayers.

She said: "We routinely review our work to make sure that we focus our resources on the most viable options and deliver the most effective support for the most vulnerable in society."

Capita said it had been selected to carry out the tests via a "rigorous procurement process".

"We are paid according to the number of quality controlled assessments we complete for DWP," a spokeswoman said.

www.bbc.co.uk 15 April 2017

Trying to avoid care home fees? Think twice, consumers told

Care from the NHS is free, but if you need social care because you're physically or mentally frail, you have to pay for it yourself.

And it is not cheap.

The latest figures show a place in a residential care home in the UK costs, on average, more than £30,000 a year. A nursing home costs more than £40,000 a year. In the South East, it is £10,000 a year more than that, according to consultants LaingBuisson.

There is financial help from local authorities, but it is strictly means-tested.

You only qualify if your home, savings and investments are together worth less than £23,250. If you are worth more than that, you have to pay the full cost of your care - during your lifetime and, if necessary, from your estate after you have died. It may not leave much for your family to inherit. Which is why marketing leaflets from a will-writing firm called Universal Wealth Preservation are eye-catching. The leaflet claims that 45,000 families are forced to sell their homes every year, to pay for care.

'He thought it was a good thing'

In 2015, one of Universal's leaflets dropped through the letterbox of retired teachers Susan and Don Steer. Don had just been diagnosed with a terminal cancer.

Since the Steers owned their home near Hull outright, and had savings as well, they would not qualify for council support.

"Don thought that if he had to go into a care home or nursing home that we would have to pay and we could lose the house," Susan recalls. "Universal said they could protect the house from care home fees, and he thought that would be a good thing to do."

So, after a home consultation with a Universal representative, the Steers signed up, paying Universal a fee of almost £4,000.

Universal's scheme works by transferring the ownership of assets like a home or savings into what it calls a "Wealth Preservation Trust".

Trusts are legal devices designed to hold assets on behalf of named beneficiaries - often children.

With a trust owning the assets, the theory is those assets will no longer be counted in the means test. That should make it more likely that the individual will qualify for local authority help. But there's a big catch.

Trusts

According to Bridgette Shilton, chair of the National Association of Financial Assessment Officers, if avoiding care fees is a substantial motive for putting assets into a trust, then a local authority can challenge it as "deliberate deprivation".

"If people are trying to protect their house in the avoidance of care fees then that's not allowed; that is a clear deprivation of assets. It doesn't work," Ms Shilton says.

"As soon as we find out a property has been transferred we will be looking into the motivation, we will be asking questions."

If trusts are genuinely set up for reasons other than avoiding care fees, Mary Butler, the senior partner of solicitors Bell Buxton, says they may succeed in avoiding care fees as well.

"I'm not saying that these products would not in certain circumstances work, if you were seeking to part with ownership of a property when you're fit and healthy, when there's no prospect whatever that you're going to go into a home."

But with the financial squeeze on local authorities growing, Mary Butler says, it's getting harder to slip such trusts under the radar.

"We've got a social care crisis on our hands now, a local authority funding crisis, so they're using every possible means to get money in. The people who are looking at these forms are wise to the stunts that people pull."

Don Steer died last year. He never did pay care fees because his treatment was covered by the NHS.

Care cap

Universal says its representative wasn't told the Steers' main goal was protecting the family home from care fees. It says it wasn't told that Don's cancer was terminal and would have provided different advice if it had been.

Surprisingly, while care fee protection is prominent on Universal's marketing fliers, the company told the BBC: "We deny that we offer strategies to avoid paying care fees."

We wanted to explore what lies behind this apparent contradiction, but Universal did not take up the BBC's offer of an interview.

Potential customers might therefore be wise to ask searching questions of their own, or to take advice from a solicitor before signing up.

Universal is one of a number of firms offering such services. Almost all are unregulated, so customers have nowhere to complain if things go wrong.

In 2013, Chris Grayling, then Lord Chancellor, turned down a recommendation from the legal industry and consumer groups that will-writing should be regulated.

And the government has delayed the introduction of a £72,000 cap on the amount anyone has to pay towards their care. Originally scheduled for April last year, it's now postponed to April 2020.

Financial catastrophe

Economist Andrew Dilnot, the chair of the commission that first proposed the care fee cap in 2011, says a cap would remove the fear generated by a means test he describes as the "most pernicious" in Britain.

He says a £72,000 cap would also reduce the incentive for people to try to avoid paying them altogether.

"If we could get the cap in place, the worst case is that you'd be liable up to the cap. So you're taking away the catastrophic element and I think then the avoidance industry would find things much tougher."

Removal of the fear of the financial catastrophe would also reduce the moral dilemma care fees now pose for people like Susan Steer.

"I'm torn about what I feel," she says. "I don't like the rule about having to sell to pay for care home fees. On the other hand, I've got socialist views so it sounds ludicrous, but it's human nature to not want to sell the house."

www.bbc.co.uk 2 May 2017

'Why I went to court for my disability payments'

The number of people going to court to try to win back a key disability benefit is expected to continue to rise this year, a leaked letter seen by the BBC suggests. We follow one woman who took her case to tribunal.

Debbie Neal was diagnosed with a rare kidney disease 10 years ago. She takes dozens of pills each morning to manage her symptoms - sickness, high blood pressure and seizures.

She may well need a transplant in future.

For the moment, she has to empty excess fluid from a tube attached to her stomach, and replace it with new liquid from a bag, five times a day.

"It is a burden," she tells the **BBC's Victoria Derbyshire programme**. "They say, 'Don't let it affect your life,' but you can only live your life to a point.

"I can't even remember what it was like not doing it."

Debbie lives on her own, and works part-time as a cleaner. For years, she has relied on disability living allowance (DLA) benefit payments - worth £80 a week - to help pay the bills.

But last year a letter came in the post, saying her payments had been stopped completely.

DLA is being replaced by another disability benefit scheme - the personal independence payment (Pip).

Debbie's case had been reassessed by a private company and it was decided she did not need the payments.

"I was scared. I thought, 'Why are they doing it?'" she explains.

"You sort of judge yourself differently. You think, 'Well [my condition] can't be that bad then.'

"But they can't be right when I'm doing this all the time," she says, sitting connected to the bag of fluids.

"I mean, do they have to do it? How much would it disrupt their life?"

The government says overall it is spending more on disability benefits, and that Pip is a better system based on individual need than the "outdated" DLA scheme it replaced.

Official figures show more than 250,000 people have lost money in the switch from DLA, some with incurable diseases.

Debbie had been given an indefinite, or "life", payment under the old system.

After failing to get her case reviewed, she decided to go to a tribunal - in court - to ask a judge to overturn the decision.

'Assessors are rushed'

The number of people taking the government to court over Pip has risen sharply in recent years as more people were switched to the new benefit.

The Victoria Derbyshire programme has seen a leaked letter to tribunal judges - from a senior judge working on benefit tribunals - suggesting the number is expected to increase again this summer.

Around 65% of people who take their case to tribunal are successful, higher than for most other types of benefit.

When Debbie's case was heard at Kidderminster Magistrates' Court, she was questioned for around an hour in front of a panel including a judge, a doctor and a disability specialist.

Debbie was awarded the standard daily living element of Pip for 10 years - an unusually long period of time without reassessment. Any money she had lost was backdated.

New figures seen by the Victoria Derbyshire programme suggest the amount of public money spent on Pip tribunals stands at around £1m a week.

Judges and others who sit on tribunals can lose their jobs if they speak to the media, but some were prepared to talk on the condition of anonymity.

"As a tribunal member we often have to start again when it comes to appeals," said one.

"We often see people who get nothing at all in the first assessment. Then we end up giving the maximum award possible and just can't understand [the original decision].

"It's pretty obvious assessors are rushed and they are just copying and pasting answers.

"Sometimes they don't even change the pronouns, so you get a woman being described as 'he' in the assessment document.

"Not all are like that but the problem is, if some can't be trusted, then it taints the whole system."

'Great sense of injustice'

The government says since Pip was introduced, more than 2 million decisions have been made - of these 7% of cases have been appealed against and 3% overturned.

A spokeswoman for the Department for Work and Pensions said: "We constantly review our processes to make sure they are working in the best way possible."

For Debbie, the whole experience was stressful and nerve-racking, as she puts it, but ultimately she feels it was worthwhile.

"For people who are out there, who are honest and who need the help, just don't give up," she says.

DISCLAIMER

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

YOUR JOKES

A single guy was living at home with his father and working in the family business. When he found out he was going to inherit a fortune when his sickly father died, he decided he needed to find a wife with whom to share his fortune. One evening, at an investment meeting, he spotted the most beautiful woman he had ever seen. Her natural beauty took his breath away. "I may look like just an ordinary guy," he said to her, "but in just a few short years, my father will die and I will inherit \$200 million." Impressed the woman asked for his business card and three days later, she became his stepmother. Women are so much better at financial planning than men.

Mick and Paddy had promised their Uncle Seamus, who had been a seaman all his life, to bury him at sea when he died. Of course, in due time, he did pass away and the boys kept their promise. They set off with Uncle Seamus all stitched up in a burial bag and loaded onto their row boat. After a while Mick says, 'Do yer tink dis is fer enuff out, Paddy?' Without a word Paddy slips over the side only to find himself standing in water up to his knees. 'Dis'll never do, Mick. Let's row some more.' After a bit more rowing Paddy slips over the side again but the water is only up to his belly, so they row on. Again Mick asks Paddy, 'Do yer tink dis is fer enuff out Paddy?' Once again Paddy slips over the side and almost immediately says, 'No dis'll neva do.' The water was only up to his chest. So on they row and row and row and finally Paddy slips over the side and disappears. Quite a bit of time goes by and poor Mick is really getting himself into a state when suddenly Paddy breaks the surface gasping for breath. 'Well is it deep enuff yet, Paddy?' 'Aye 'tis, NOW hand me dat shovel.'

Two young businessmen in Chadstone were sitting down for a break in their soon-to-be new store in the shopping mall. As yet, the store's merchandise wasn't in -- only a few shelves and display racks set up. One said to the other, "I'll bet that any minute now some senior is going to walk by, put his face to the window, and ask what we're selling." Sure enough, just a moment later, a curious senior gentleman walked up to the window, looked around intensely and rapped on the glass, then in a loud voice asked, "What are you selling here?" One of the men replied sarcastically, "We're selling arse-holes." Without skipping a beat, the old timer said, "You must be doing well. Only two left."

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!

Name the song from the following lyrics

- 1/ I got my first real six string. Bought it at the 5 and dime.
- 2/ It's 9 o'clock on a Saturday, the regular crowd shuffles in.
- 3/ Hello darkness my old friend, I've come to talk with you again.
- 4/ Sitting in the morning sun, I'll be sitting when the evening comes.
- 5/ Young teacher, the subject of schoolgirl fantasy.
- 6/ Is this the real life, or is this just fantasy.
- 7/ People try to put us down, just because we get around.
- 8/ I've got sunshine on a cloudy day.
- 9/ On a dark desert highway, cool wind in my hair.
- 10/ Turn around. Every now and then I get a little bit lonely.

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/ Dom Perignon 2/ Lake Superior 3/ The Moon 4/ A Farrier 5/ A Mackintosh 6/ A Sword
7/ String 8/ Dictionary 9/ Uranus 10/ Louis Pasteur