

Client: Justine Rawlins PR Yellow News
Source: Sunday Express
Date: 16/07/2017
Page: 32
Reach: 335772
Value: 40095.25

“I’ve never felt better”

Taking part in a drug trial for a debilitating condition gave one woman a new lease of life By Christine Fieldhouse

Carol Howell, 65, is a retired dental surgeon and she lives with her husband Mark, 68, in Bournemouth, Dorset.

Carol says: “When my mum Audrey and I are power walking at 10-kilometre events along the seafront, I have to remind myself of how far I’ve come. Only a few years ago, I couldn’t get out of bed, and some days I even struggled to get out of a chair. I was also at risk of losing my sight.

I always used to be very fit, doing a half-a-mile swim or a ballet session before or after work. But that all changed one morning in the summer of 2011 when I woke up feeling as if I had caught the flu. I was so achy and stiff, I was unable to get out of my bed.

After a week, I paid a very rare visit to my GP, Dr Stephen Kidman, who said he thought I might have a condition called polymyalgia rheumatica (PMR). I’d heard of it because a relative had it. The treatment was steroids, and he started me off on 5mg a day.

The stiffness with PMR is worse in the morning and it wears off as the day goes on. But about 10 days later, I woke up with the most blinding headache. I couldn’t even move my jaw to eat my breakfast. Opening my mouth was agony. This time Dr Kidman gave me a diagnosis I’d never heard of – giant cell arteritis, which is linked to PMR.

‘It won’t kill you, but you’re not going to like the treatment because you’ll put on weight,’ Dr Kidman told me. ‘You have to take it because if you don’t, you risk losing your sight. They say as

a GP, you will diagnose this once in your lifetime, and this is my once.’

After a series of tests, including a colonoscopy, an endoscopy, an echocardiogram and a brain scan at Bournemouth University Hospital, I was reassured there was nothing else wrong with me.

But an artery biopsy taken from the right side of my face, just in front of my ear, confirmed I had GCA. The vascular surgeon showed me a healthy vessel, which was like a little thread. Mine was abnormal, swollen like a piece of jelly baby.

I was devastated at the thought I might go blind and have to give up my two big loves – patchwork and sewing.

‘If that happened, all I could do is sing,’ I woefully told my husband, as I religiously took my steroids – now up to 80mg a day.

I’d never been a person who got headaches, but those GCA headaches felt as if somebody was sticking knives into my head. My scalp was so sensitive I couldn’t touch it. Even combing my hair was agony. I managed to stay at work for another year, then I took the chance to retire early. Around that time, my leg buckled in a ballet class so I made an excuse and left and never went back. My old life was fading away. It felt like old age and illness were beckoning.

Because steroids have side effects, like diabetes and osteoporosis, we tried to reduce the dosage and I started taking other drugs, even chemotherapy ones, but none made a difference to my PMR/GCA. They just gave me diarrhoea,

Client: Justine Rawlins PR Yellow News
Source: Sunday Express
Date: 16/07/2017
Page: 32
Reach: 335772
Value: 40095.25

liver inflammation and a stomach ulcer.

The only thing that eased my joint stiffness and temple soreness was the steroids, which I started having injected every month. But a scan showed I already had osteoporosis in my spine. I was taking 16 tablets a day and my face was getting increasingly rounder from the steroids.

Luckily, my husband Mark took up the challenge and his research led him to Professor Bhaskar Dasgupta, a consultant rheumatologist at Southend University Hospital in Essex. When I saw Professor Dasgupta in 2013, he told me I needed a drug called tocilizumab, which had been used to treat arthritis. But he explained tocilizumab wasn't yet licensed to treat PMR and GCA, and it might be hard to get.

How right he was. The application that we put forward for the drug was turned down because it was expensive and there was no proof it would work. I felt as if I was back to square one. When I saw a new consultant, I explained how I felt that I had gone full circle.

'At least you haven't had a stroke or gone blind,' he told me glibly.

Mark was fuming.

'We're going to go back to see Professor Dasgupta and ask if there are any trials you could take part in,' he said.

It's funny how things happen. Within seconds of sitting down with Professor Dasgupta in January 2015, he asked if I'd be interested in taking part in a trial to test tocilizumab.

'Don't raise your hopes,' he warned. 'There are a lot of criteria and you may not fulfil them.'

I know some people see drugs trials as a gamble, but I have a medical background and I was willing to give anything a try. I have faith in trials. Besides, Mark would have gone to the ends of the Earth to ease my pain.

Luckily, I was accepted on to the trial. I started in February 2015 and we did the 400-mile trip from Bournemouth to Southend every month. It was a double blind trial, so I didn't know if I was in the group taking tocilizumab or a placebo medication. At the same time, my steroids were being reduced.

But within weeks, we suspected I was on the placebo because my PMR stiffness started to come back. Luckily, the GCA headaches stayed away. It was frustrating, especially considering we were doing such a long journey to get the tablets. But Professor Bhaskar had promised I would get the tocilizumab at the end of the

year if I didn't get it in the trial. That was my prize, so I kept going.

By now, everything was an effort. I love gardening, but my pain meant I could only manage 10 minutes in the garden. I'd have a cup of tea with my best friend Millie and struggle to get up out of her chair. I still walked my two miniature dachshunds, Coco and Mopsy, but it was hard work.

By February 2016, I'd done a year on the placebo. When I was given my tocilizumab, it was like getting treasure and I couldn't wait to start. The dose was 160mg to be injected

into the fleshy part of my abdomen once a week. I was monitored for the first few weeks to check for adverse reactions. Then I was taught to do it myself.

Within five weeks, I looked 10 years younger and I had such amazing energy again. My stiffness and aches vanished. Sometimes, you don't realise how horrible you felt until you're feeling better. I went back to swimming, I did a yoga class three times a week and I signed up to do ballroom dancing. Mark joked that I was wearing him out.

I took tocilizumab for a year until January this year, without any symptoms or side effects, as part of the study. I'm no longer on it but if my symptoms return, I'll be entitled to it for another 12 months. My steroids are down to 1mg a day, which I'm reassured won't do me any harm.

I've no regrets about taking part in a drugs trial. I didn't feel like a guinea pig. I was treated like a private patient. If I hadn't taken part, my life would have carried on at a rather painful rate. I've since met other sufferers who have lost sight in one eye or their faces are blown-up by steroids. That could easily have been me.

Now, I have a new lease of life. My 86-year-old mum and I power walk together while runners jog by, and Mark and I have received medals for ballroom dancing.

I long for the day when tocilizumab is licensed to treat PMR and GCA because I was one of the lucky ones. I just wish that it could be the same for everyone." 🌟

PMR and GCA – the facts

- Polymyalgia rheumatica (PMR) and giant cell arteritis (GCA) are rheumatic conditions, which can strike separately or together.
- PMR causes pain, tenderness and stiffness in the large muscles around the shoulders, hips and back, while GCA is an inflammation

Client: Justine Rawlins PR Yellow News
Source: Sunday Express
Date: 16/07/2017
Page: 32
Reach: 335772
Value: 40095.25

of the arteries in the head and neck and can lead to blindness if left untreated.

- Symptoms include sudden headaches, scalp tenderness and pain in the tongue or jaw when chewing or talking.
 - PMR and GCA tend to affect those over 60 and there are thought to be 250,000 people with the conditions.
 - The international trial of tocilizumab found more than half the patients with GCA were able to come off steroids after 12 months.
- Visit the support group at pmrgca.co.uk or call the helpline on 0300 111 5090.*

Client: Justine Rawlins PR Yellow News
Source: Sunday Express
Date: 16/07/2017
Page: 32
Reach: 335772
Value: 40095.25



HAMISH MITCHELL