NICE approves first new drug for Giant Cell Arteritis in 70 years - and patients are delighted

Thursday 8 March, 2018

PMRGCAuk is delighted to announce that:

NICE, the National Institute for Health and Clinical Excellence, has approved the use of Tocilizumab for cases of Giant Cell Arteritis. There has not been a new drug for this disease since steroids were first used 70 years ago. Thousands of patients have had no option up to now but to take high doses of steroids for several years.

Giant Cell Arteritis is an inflammatory illness that strikes people over 50. It causes the walls of arteries to become so inflamed that the blood supply to the head and other parts of the body can become completely blocked. In about 25% of cases, when GCA isn't caught in time, the patient loses some or all of their vision irreversibly because of lack of blood supply to the optic nerve. High doses of steroids can treat the inflammation and get the blood flowing again. But patients find themselves on steroids for years on end, and many either relapse or find that the steroid treatment doesn't work for them.

Unlike other inflammatory diseases such as Rheumatoid Arthritis, research has not come up with effective alternatives to steroids in GCA. Until now.

Tocilizumab, patented by Roche as 'Actemra' is one of a new generation of 'biologic' drugs that treat the inflammation causing the disease rather than just the symptoms, as steroids do. Trials have shown that patients taking this drug end up taking a much lower overall dose of steroids, thereby avoiding relapses and the dangers of high doses of steroids over long periods. These dangers include diabetes and osteoporosis.

Kate Gilbert, spokesperson for PMRGCAuk, says

"In its first report, issued in December, NICE rejected Tocilizumab for use in the NHS, despite its having been approved in the USA and Australia. Interested parties were given just four weeks to respond, four weeks that included Christmas and New Year. PMRGCAuk worked tirelessly over the holiday season to mobilise patients and rheumatology experts. Nineteen patients, and a carer, registered with NICE so that they could make individual submissions. The British Society for Rheumatology also lent their weight with a compelling argument for a new drug for GCA. This is a great example of patients, charities and the medical profession all pulling together to improve outcomes for patients.

New evidence demonstrated cost-effectiveness for the drug when used for just a year with a very specific group of patients who are not helped by steroids".

Now people with repeated relapses, or those who don't respond to steroids, will be able to have TCZ for up to a year on the National Health. This is not only good news for them. .but also ushers in a new dawn for Giant Cell Arteritis. We hope to see more new treatments developed, so that GCA, with its pain, its limited treatment options, and danger of blindness, comes out of the shadows for good.

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