
Approval of sarcoma drug by NICE offers hope to hundreds diagnosed with the most common type of sarcoma

For immediate release

People with GIST, the most common type of sarcoma cancer, now have access to a life-extending cancer drug through the NHS in England following close to four years of campaigning by the charity Sarcoma UK.

The announcement marks the end of years of uncertainty of whether the drug would be available for those already living with the disease as well as the 900 or so people diagnosed with GIST (gastrointestinal stromal tumour) every year in the UK.¹

The approval by NICE (The National Institute for Health and Care Excellence) of regorafenib provides a vital additional treatment option for people in England who would otherwise have no further treatments available to them.

Regorafenib has been approved in England for people living with GIST where their tumour cannot be removed through an operation. It can also be used where the GIST has spread to more than one place in the body, or if two other drugs typically used to treat GIST - Imatinib and Sunitinib – prove ineffective or cause bad side effects.

Crucially, as a drug with relatively few side effects when compared to many other treatments for sarcoma, regorafenib offers people with GIST a chance to maintain a high quality of life.

GIST is a type of soft tissue sarcoma that occurs in the digestive system, most often in the wall of the stomach.

Regorafenib is a targeted cancer drug that can shrink the cancer or stop it growing for a period of time. It is a type of protein kinase inhibitor (TKI) or cancer growth blocker that hinders particular proteins called kinases in cancer cells that encourage the tumour to grow. Regorafenib also stops the cancer cells from developing the blood vessels that they need to grow.

The drug is now the second in 2017 approved by NICE for the treatment of sarcoma. Olaratumab, used to treat soft tissue sarcomas, was approved by NICE in June 2017 for use in England and was the first new treatment since 2010 to be approved by NICE. Previously, regorafenib was available on the NHS through the Cancer Drugs Fund before being withdrawn from the fund in 2015 then reinstated after four appeals and subsequently put through NICE's technical appraisal process.

Professor Ian Judson, Trustee at Sarcoma UK and former Head of the Sarcoma Unit at the Royal Marsden Hospital, says: "This announcement by NICE is tremendous news for patients living with GIST in England, some of whom were facing the daunting prospect of having no other treatments available to them where surgery is not an option or they develop resistance to the usual treatments..

¹ According to NICE: [/www.nice.org.uk/news/article/new-treatment-option-for-people-with-gastrointestinal-cancer](http://www.nice.org.uk/news/article/new-treatment-option-for-people-with-gastrointestinal-cancer)

“It draws a line under the uncertainty faced by the hundreds diagnosed each year with GIST as well as those already undergoing treatment, giving the vital reassurance that, should they need it, regorafenib is a viable treatment option available through the NHS.

“Alongside GIST Support UK, we’ve worked hard to provide evidence and challenge negative decisions since 2014. I’m delighted we have secured this crucial decision that offers hope to those currently living with GIST.”

Sarcoma UK is the only cancer charity in the UK focusing on all types of sarcoma. Its mission is to drive awareness of sarcoma, promote early diagnosis and improve patient experience. The charity offers support to those affected by sarcoma and has funded more than £1.7 million in sarcoma research to date. To find out more visit sarcoma.org.uk

Notes to editors

For further information, please contact Bevis Man, Communications Director at Sarcoma UK: bevis.man@sarcoma.org.uk or 07931 254 697.

- Sarcoma is cancer of the bone and soft tissue. It can develop anywhere in the body.
- A key symptom of sarcoma is a lump that is increasing in size, often quickly.
- About 3,800 new cases of sarcoma are diagnosed each year in the UK, making up approximately 1% of all cancer diagnoses.
- Sarcoma is one of the hardest cancers to diagnose. People visit their GP more times than those with any other form of cancer before being diagnosed with sarcoma.
- Early diagnosis could increase survival by 20%.
- Sarcoma is usually the size of a baked bean tin when diagnosed. If sarcoma is diagnosed when it is smaller than a golf ball, it would increase the chance of survival by at least 20%.
- People with sarcoma tend to be younger than most people with cancer. 16% of sarcomas are diagnosed in people under 30, compared to only 2% of all other cancers.
- In **Northern Ireland**, the Department of Health, Social Services and Public Safety (DHSPSS) usually reviews NICE guidance within three months of publication.
- The All Wales Medicines Strategy Group (AWMSG) has approved regorafenib to treat people with unresectable or metastatic GIST **in Wales**.
- In **Scotland**, The Scottish Medicines Consortium (SMC) approved regorafenib in 2015 for the treatment of adult patients with unresectable or metastatic GIST.

¹ According to NICE: [/www.nice.org.uk/news/article/new-treatment-option-for-people-with-gastrointestinal-cancer](http://www.nice.org.uk/news/article/new-treatment-option-for-people-with-gastrointestinal-cancer)