

Charity for rare cancer calls for flexibility to allow ‘game changing’ cancer treatments to be made available in the UK

Press release – embargoed until 00.01am, 17.01.20

Sarcoma UK is calling on the National Institute for Health and Care Excellence (NICE), NHS England, and pharmaceutical companies to have flexibility so that cancer patients in England with few treatment options can access the latest treatments as soon as possible.

National bone and soft tissue cancer charity, Sarcoma UK, was disappointed to see that the first of an exciting new class of cancer medicines, with scope to treat range of cancers, will not be made available to cancer patients in England through the Cancer Drugs Fund.

An interim decision - published today by NICE - gave an initial negative verdict for one drug - larotrectinib (Vitrakvi, Bayer) - saying that it does not show plausible potential for cost-effectiveness.

The drug was being appraised for treatment in adults and children who have no effective treatment options for their cancer. It is the first ‘histology-independent’ drug to be licenced for use in Europe and shows real promise for cancer patients with few treatment options, like sarcoma patients.

Unlike traditional therapies, which treat tumours based on location (such as breast or lung cancer), this drug works by targeting tumours with specific genomic mutations. This means it can treat multiple tumours at once and those which develop in hard to treat areas of the body. [1]

So far, as many as 20 cancer types, including sarcoma, breast and renal, have been shown to have the specific genomic mutation that larotrectinib targets, which leads to the development of advanced neurotrophic tyrosine receptor kinase (NTRK) fusion-positive solid tumours. [2]

For people with rarer cancers, such as sarcoma, chronic lack of awareness has led to a treatment vacuum. The interim decision that larotrectinib will not yet be made available due to cost is incredibly disappointing.

Richard Davidson, Chief Executive of Sarcoma UK, said:

‘It’s incredibly disappointing that sarcoma patients will not have access to this exciting new type of cancer treatment though the drug larotrectinib. For cancers like sarcoma, where the number of drugs and treatment options are already incredibly limited, we cannot afford for patients to wait for potentially game-changing options.’

Sarcoma UK is calling for collaboration and flexibility from NICE, NHS England, and the pharmaceutical companies involved, to ensure that cancer patients are able to access to these promising treatments as soon as possible.’

Sarcoma is an uncommon cancer that can affect any part of the body, on the inside or outside, including the soft tissues, such as muscles, tendons, blood vessels and fatty tissues, or the bone. Sarcoma accounts for 1.3% of all cancers in the UK and approximately 15 people are diagnosed every

day. Currently, because of the lack of effective treatment options, only 55% of people survive beyond five years.

Another histology independent treatment, entrectinib (Rozlytrek, Roche), is also being appraised by NICE, and has not yet received marketing authorisation from the European Medicines Agency (EMA).

Sarcoma UK is committed to helping people with sarcoma access the most effective treatments for their cancer and represented the views of sarcoma patients throughout the review process for both larotrectinib and entrectinib.

For more information about histology independent treatments, please consult your clinician or contact the Sarcoma UK [Support Line](tel:08088010401) on 0808 801 0401.

~Notes to editors~

Contact

The press office at Sarcoma UK can be contacted by emailing Catherine Bennett , Communications Officer at Sarcoma UK on catherine.bennett@sarcoma.org.uk or calling 020 7250 8271. All contacts should be made through the Sarcoma UK press office, please do not contact any third parties quoted or referenced in this release.

About sarcoma:

- Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues.
- 15 people are diagnosed with sarcoma every day in the UK. That's about 5300 people a year.
- There are around 100 different sub-types of sarcoma.

About Sarcoma UK:

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma and campaigns for better treatments. It is now one of the biggest funders of sarcoma research in the UK, having invested more than £3 million to 52 research projects to date (as of November 2019). Sarcoma UK's Support Line has helped more than 1,700 individuals through 6,200 calls and emails and texts since 2016. sarcoma.org.uk

Please include after article:

*Sarcoma UK Support Line nurses and occupational therapist are here for every person affected by sarcoma. **Talk to us** or **email** for information and support.*

Phone: 0808 801 0401

Email: supportline@sarcoma.org.uk

References

[1] Sarcoma UK, [The Loneliest Cancer](#), December 2019. Page 9

[2] Cocco, Scaltriti, Drilon, [NTRK fusion-positive cancers and TRK inhibitor therapy](#), Nature Reviews Clinical Oncology, 15, 731-747 2018