



PRESS RELEASE

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Rare cancer charity very disappointed by SMC decision not to fund life-extending treatment for patients with advanced cancer of soft tissue (sarcoma)

Sarcoma UK is very disappointed by the news today that the Scottish Medicines Consortium has not accepted trabectedin for use in NHS Scotland, despite approval for use in England by the National Institute for Health and Clinical Excellence.

Trabectedin is a new anticancer medicine for patients with a rare and often devastating form of advanced cancer of soft tissue called sarcoma. In Scotland, it is estimated that around 180 new cases of soft tissue sarcoma are diagnosed each year, with a total sarcoma incidence of around 280 cases. Whilst not suitable for every sarcoma patient, trabectedin may have helped around 30 Scottish patients with advanced cancer to live longer and have a better quality of life.

Until the development of this treatment, there had been no advances in drug treatment for metastatic soft tissue disease in the last quarter century in Scotland. This is in contrast with more common cancers where survival rates have improved, dramatically in many instances, through the introduction of new treatments. Trabectedin offered a new route through this dilemma. It offered extended survival (with stable disease) and a generally high quality of life, a need which has been unmet for years.

Trabectedin was turned down by the Scottish Medicines Consortium on economic and cost grounds. It is of great concern to Sarcoma UK that new treatments for rare cancers are evaluated in the same way and using the same economics as treatments for common cancers where there are high numbers of patients able to take part in studies. The process actively discriminates

against patients with rarer cancers. The effectiveness of trabectedin is proven and the patient benefits from this treatment are highly valued, illustrated by NICE approval for its use in England. Sarcoma UK is very disappointed that Scottish patients with advanced soft tissue sarcoma will not have access to this treatment.

Ends

Notes to Editors:

- Sarcoma UK is the main charity in the UK dealing with all types of sarcomas.
- Sarcomas are rare cancers that develop in the supporting or connective tissues of the body such as muscle, bone, nerves, cartilage, blood vessels and fat.
- There are around 70 different sub-types of sarcoma.
- There are around 3200 new cases of sarcoma diagnosed each year in the UK. In Scotland, it is estimated that around 180 new cases of soft tissue sarcoma are diagnosed each year, with a total sarcoma incidence of around 280 cases in Scotland.
- Sarcomas are some of the commonest childhood cancers.
- Sarcoma UK's aim is to achieve the best possible standard of treatment and care for patients with sarcoma. It does this through:
 - Funding scientific and medical research into causes and treatments;
 - Delivering a range of support and information services covering all aspects of sarcoma;
 - Raising awareness of sarcoma amongst the public, healthcare professionals and policy makers;
 - Campaigning on behalf of sarcoma patients for improved treatment and care.
- Sarcoma UK relies on voluntary donations and fundraising activities to fund its work.
- Sarcoma UK works collaboratively with doctors, nurses, researchers, and other cancer charities.
- For further information please contact Lindsey Bennister, Chief Executive, Sarcoma UK (lindsey.bennister@sarcoma.org.uk) or 020 7250 8271 or 07825 701329
- Further information about sarcoma and Sarcoma UK is available at www.sarcoma.org.uk.