

## **NICE's final ruling on Velcade made public early - joint statement from charities in response to the decision**

Too expensive was the reason given by the National Institute for Health and Clinical Excellence (NICE), the drugs watch dog for England, Wales and Northern Ireland, for rejecting a vital treatment for the bone marrow cancer, myeloma, despite it being the only treatment to be licensed for patients in over ten years. NICE's final guidance was issued on Friday 20th October, after English newspapers leaked the content of the report.

Although acknowledging the clear clinical effectiveness of bortezomib (Velcade), both in terms of increasing survival and enhancing the quality of life of patients, NICE have deemed it not to be cost effective. Myeloma is a less common cancer, affecting around 20,000 people in the UK at any one time and although it is sadly incurable, bortezomib (Velcade) can offer precious extra time to patients.

Responding to the news, **Myeloma UK, Cancerbackup, Leukaemia Care and Leukaemia Research**, leading UK cancer charities, all expressed their extreme disappointment at the decision, stating that as bortezomib (Velcade) is a proven and licensed treatment, no myeloma patient in the UK should die without having access to it.

The UK ranks as one of the top European countries for the availability of direct cancer research funding, yet perversely it lags behind other EU countries in terms of the ability of cancer patients to access new cancer drugs. The Velcade decision will help to push the UK closer to the bottom of the league in terms of cancer survival.

"This represents probably the single biggest set back in the history of the treatment of myeloma in the UK, and the entire myeloma community is devastated about the decision", said Eric Low, Chief Executive of Myeloma UK. "NICE are explicit in their final guidance that bortezomib (Velcade) is clinically effective and recognise the lack of an alternative. The fact that the drug works is not up for dispute; rather, this is an unmistakable instance of where the cost of treatment is seen as more important than peoples' lives.

"We are calling on the UK Secretary of State for Health, Patricia Hewitt, to urgently revise NICE's scope to enable it to better evaluate treatments for less common cancers. Account needs to be taken of the fact that development costs for novel drugs in smaller cancers are inevitably higher than for treatments for more common illnesses. Also, NICE do not seem to place any value on treatments that can extend life – they only seem equipped to assess curative treatments.

"In NICE's assessment of bortezomib (Velcade), it was compared against a licensed, but very low cost, standard treatment that represents a poor standard of care. In rejecting bortezomib (Velcade), NICE did not offer an alternative.

"We must therefore try to look for solutions for the myeloma community. We do not want to see a two tier health care system emerge, where those who can afford to dig deep in their pockets can access this important treatment privately whilst those being treated on the NHS cannot. The charities involved in the appraisal, along with their stakeholders, will urgently review its position with a view to appealing against the decision."

- To see NICE's response to UK newspaper reports on the Velcade ruling:  
<http://www.nice.org.uk/page.aspx?o=377719>