PRESS RELEASE
Embargoed until 00.01 17 February 2011

MDS patients achieve access to vital new treatment option
National Institute for Health and Clinical Excellence recommend azacitidine is available through the NHS

London, 17 February 2011 – The National Institute for Health and Clinical Excellence (NICE) announced today that Vidaza (azacitidine), the only licensed drug available specifically to treat myelodysplastic syndromes (MDS) - a range of life-threatening bone marrow disorders - will be available through the NHS. The MDS UK Patient Support Group, which has been in consultation with NICE during the approval process and campaigned on behalf and in conjunction with MDS patients across the UK, welcomes this announcement.

There are nearly 3,000 new cases of MDS in the UK each year and many people newly diagnosed with MDS have not heard of this disorder before. A person with MDS will suffer from chronic tiredness and weakness due to the often extremely low levels of haemoglobin, owing to a malfunction in the bone marrow in producing the correct quantity and quality of blood cells. This is debilitating in itself and often requires regular blood transfusions.

Azacitidine is an anticancer drug that is thought to work by re-establishing cells’ natural mechanisms to control abnormal growth. The final appraisal determination by NICE recommends the use of azacitidine for the treatment of MDS, chronic myelomonocytic leukaemia (CMML) and acute myeloid leukaemia (AML) following a revision to the patient access scheme provided by Celgene (the manufacturers of azacitidine). Rodney Taylor, Deputy Chairman of MDS UK Patient Support Group said, "I am delighted to hear of NICE’s decision to recommend azacitidine for these patient groups which can benefit from this form of treatment. Having been on azacitidine myself, I know how effective it can be in promoting a good quality of life, giving independence from blood transfusions and allowing patients to lead a normal family life. Azacitidine is the only specific treatment for MDS that improves quality of life, prolongs survival and delays disease progression. It is great news that many more patients will now be able to benefit from it."
While the announcement is good news for MDS patients in England and Wales, MDS UK Patient Support Group is concerned that access to this vital new treatment is still denied to MDS patients in Scotland, as azacitidine has yet to be re-submitted to The Scottish Medicines Consortium (SMC) following a rejection in April 2010. We urge all concerned to apply both maximum effort and the highest priority to bring azacitidine to Scotland, in line with England and Wales. “Clearly I am delighted that NICE has approved azacitidine for use in England and Wales in conjunction with the associated patient access scheme,” said Dominic Culligan, Consultant Haematologist, Aberdeen Royal Infirmary, Scotland. “I hope that Celgene will re-submit azacitidine to the SMC as a matter of urgency, so that further consideration can be given to making this important treatment for high risk MDS and some patients with AML available in Scotland.”

It is a distressing reality that, during the protracted evaluation process attendant to the successful outcome of this appraisal, some MDS patients have progressed to AML, and some did not survive, in the absence of azacitidine. MDS UK Patient Support Group are aware of the complex financial constraints and cost effectiveness criteria attendant to the adoption of new drugs, and ask only that even more effort is applied in reaching speedier positive conclusions in critical, end of life situations such as MDS.

- Ends -

Notes to Editors:

About MDS UK Patient Support Group

The MDS UK Patient Support Group is affiliated with the MDS Forum, the foremost UK organisation focused upon MDS, providing information and advice on the status and progress with MDS treatment in the UK. The MDS UK Patient Support Group is also supported by major pharmaceutical companies.

The MDS UK Patient Support Group is affiliated with the MDS Foundation Inc., a multidisciplinary international organisation dedicated to sharing and improving MDS information and awareness between patients, globally. For further information on MDS and the MDS UK Patient Support Group please visit http://www.mdspatientsupport.org.uk

Contacts:

For more information or to arrange interviews with an MDS UK Patient Support Group spokesperson or patient case study please contact:

Jonathan Kearney at jonathan.kearney@gmail.com or on 07946 373 500.