



PRESS RELEASE

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Petition calling for cancer drug Vidaza to be made available on the NHS presented to the Prime Minister today

London, 17 May 2010 – The MDS UK Patient Support Group and the healthcare professional body, the UK MDS Forum, is to present a 688-signature petition to the Prime Minister today (13.00 hours) asking for the same standard of care for UK patients with bone marrow diseases as that available throughout most of Europe. The petition was sparked by the decision by the National Institute for Health and Clinical Excellence (NICE) not to make Vidaza (azacitidine) available through the NHS to patients with a range of life-threatening bone marrow diseases.

Approximately four in 100,000 people in the UK have myelodysplastic syndrome (MDS), a group of debilitating bone marrow diseases that lead to complications such as recurrent or life-threatening infections or bleeding. Most MDS patients have to rely on frequent blood transfusions to manage anaemia and extreme fatigue. While the average survival of patients with MDS is about twenty months, nearly a third (30%) progress to acute myeloid leukaemia (AML), a very aggressive and resistant form of leukaemia with an average survival period of a few months only.

In its decision, NICE recognised that azacitidine was clinically effective and that it should be seen as a life-extending end-of-life treatment, but decided that it should not be provided through the NHS on cost-effectiveness grounds.

Petition organiser, Dr Dominic Culligan, from the UK MDS Forum, a body representing blood cancer consultants, said: “As members of the UK MDS Forum, we strive to ensure all of our patients receive the best possible care and we consider azacitidine to be a very valuable resource. Our patients include people who have experienced over seven years survival benefit as a result of receiving this treatment. In addition, we have undertaken groundbreaking trials here in the UK which have brought significant advances in standards of care for people experiencing MDS. If we are denied access to this treatment in future, it will make continuing high quality research here in the UK much more difficult.”

David Hall, Chairman of the MDS UK Patient Support Group and MDS patient said: “For the sake of all UK patients with this cruel and debilitating disease, we cannot accept the NICE guidance on azacitidine which is currently the only licenced drug available to treat MDS specifically. We hope the prime minister will share our view – and the view of everyone who signed the petition –

that it is unacceptable to deny life-extending treatment when no other option is available to patients with MDS.”

IN supporting the petition, Alastair Kent, Chair of Rare Disease UK commented: “This is another example of the difficulties therapies for rare conditions face in satisfying NICE’s criteria. Due to the small market to recoup the significant research and development costs and the difficulty in collecting data on effectiveness, therapies for rare conditions are often expensive and at the high end or beyond what NICE considers to be cost effective using the ICER/QALY analysis. We believe the Department of Health and NICE need to work with patients to ensure the technology appraisal system can judge rare therapies which fall outside the threshold fairly.”

This petition is the second petition to be presented this year asking for azacitidine to be made available to UK patients. An earlier petition set up by leukaemia patient Donald Facey collected 525 signatures. Mr Facey called on the Prime Minister to overturn the NICE decision on azacitidine to “help all people who suffer from acute myeloid leukaemia to have the right to live”.

On 1 June the MDS UK Patient Group will be one of eight organisations appealing against the NICE decision on azacitidine. It is appealing jointly with two other patient groups, the Rarer Cancer Forum and the Leukaemia Society. Healthcare professional bodies, the National Cancer Research Institute Haematological Oncology Clinical Studies Group and the Royal College of Physicians’ Medical Oncology Joint Special Committee have lodged a joint appeal. Celgene Ltd, the manufacturer of Vidaza (azacitidine) and the Royal College of Pathologists and the British Society for Haematology are also appealing.

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Notes to Editors:

1. The NICE press release announcing the organisation’s Final Appraisal Determination on azacitidine can be found at the NICE website: <http://guidance.nice.org.uk/TA/Wave18/19>
2. Information on Vidaza (azacitidine), which is manufactured by Celgene Ltd, can be found at <http://emc.medicines.org.uk/medicine/21645/PIL/Vidaza+25+mg+ml+powder+for+suspension+for+injection/>
3. Published survival data includes: Fenaux P; Mufti GJ; Hellstrom-Lindberg E et al. Efficacy of azacitidine compared with that of conventional care regimens in the treatment of higher-risk myelodysplastic syndromes: a randomised, open-label, phase III study. *Lancet Oncol.* 2009 Mar;10(3):223-32. Epub 2009 Feb 21.

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