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London

PRESS RELEASE

FOR IMMEDIATE RELEASE

BONE MARROW TRANSPLANT DAY SEES PATIENTS SHARE EXPERIENCES

London, 12 April 2013 - London hosted the 7th annual EBMT Patient and Family Day on Saturday 6th April as part of the 39th annual meeting of the European Group for Blood and Marrow Transplantation (EBMT).

Organised by a team from Imperial College, London, EBMT and Anthony Nolan, the event gave people with blood cancers and disorders the chance to meet other patients, talk to medical experts and hear about the latest developments in blood and marrow transplantation.

Professor Jane Apperley, EBMT 2013 Congress President and Chair of the Department of Haematology at Imperial College, set the tone for the day when she said: 'Patients are our focus as they are at the heart of what we do.' Her talk focused on the importance of patients and families for informing the work of the EBMT and of educating patients to help them cope with the challenges ahead.

A wide range of patients at different stages in their recovery attended the day: those who recently had a transplant and even one lady who shared her experiences, saying: '30 years ago, I didn't think that I would see my children grow up. Now I have seven grandchildren, which is just amazing. I live every day to its fullest and love spending time with all of my family.'

Leading international experts presented on topics including life after transplant, what's new in transplantation, state of the art treatment for late effects and how do we find the right donor at the right time.

Jodie McGauley from Folkstone, Kent, attended the day. She was diagnosed with MDS in October 2011 and received her transplant in December. Jodie said: "Even though I've had a transplant already, I've learnt a lot more about the whole process: no one ever sat us down and explained how it all works. It was great to hear other people ask the questions that we wanted to ask but



never had the courage to. It was also reassuring to hear that all of my experiences and feelings about the bone marrow transplant were normal and that other people had had similar experiences to me."

Jayne Snell from York gave a presentation about her experiences, particularly about how her family dynamics were affected by her diagnosis with AML and resulting transplant in July 2012. She said: "I hope that by talking about my experiences, I am able to give people hope for the future. It was great to see so many patients and families relating to each others' experiences in a very positive and supportive way."

The day came soon after the announcement by the WMDA (the World Marrow Donor Association) of the 1 millionth transplant worldwide, a testament to the growing success of blood and marrow transplantation as a potential cure for many diseases. Last year alone, UK charity and donor register Anthony Nolan gave 1,000 people the chance of life through unrelated bone marrow matches.

Ends

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About Anthony Nolan

Anthony Nolan is a pioneering charity which helps save the lives of people with blood cancer. Every day we use our register to match individuals willing to donate their bone marrow to patients in desperate need of a lifesaving transplant. For more information about our work or to sign up online, please visit www.anthonynolan.org.

About the European Group for Blood and Marrow Transplantation (EBMT)

The EBMT is a non-profit organisation that was established in 1974 to allow scientists and physicians involved in clinical bone marrow transplantation to share their experience and develop co-operative studies. The EBMT aims to promote all aspects associated with the transplantation of



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haematopoietic stem cells from all donor sources and donor types including basic and clinical research, education, standardisation, quality control and accreditation for transplant procedures. For further information about the EBMT, please visit the website: www.ebmt.org

About the Imperial College

Imperial College, London is a science-based institution with a reputation for excellence in teaching and research that is consistently rated amongst the world's best universities. The Centre for Haematology at the College and the associated clinical department at Imperial College Healthcare NHS Trust is internationally renowned for its research and clinical management of patients with blood disorders. They have performed more than 2000 transplants since the first procedure 1977 and have a long-standing commitment to improving transplant outcome through excellence in clinical care, research and education.

Notes to editors

Key messages

- The efforts of the EBMT have resulted in the compilation of the largest transplant registry in the world (450,110 transplants were registered in the EBMT Registry at the end of the year 2012)
- Anthony Nolan uses its register to match potential bone marrow donors to blood cancer patients in desperate need of a bone marrow transplant.
- We need more young men aged 16-30 to sign up, as they account for 80% of bone marrow donations yet make up just 12% of our register.
- We urgently need people from Black, Asian and other Ethnic Minority backgrounds to sign up, as they are currently under-represented on the register.

Key statistics

- Every 20 minutes someone in the UK is diagnosed with a blood cancer.
- There are around 1700 people in the UK in need of a bone marrow, or blood stem cell, transplant. This is usually their last chance of survival.
- 70% of patients will not find a matching donor from within their families; instead they turn to us to find them an unrelated donor.
- We can only find a suitable donor for around half the people who need a lifesaving bone marrow transplant.
- White Northern Europeans have a 90% chance of finding a bone marrow donor. This falls to just 40% for people from Black, Asian, and Ethnic Minority backgrounds.
- We particularly need young men aged 16-30 to join the register, as they are the most likely to be chosen as donors.
- 90% of donations take place via PBSC (peripheral blood stem cell collection). This is an outpatient appointment and is similar to donating blood.
- To join the register, you must be aged between 16 and 30, weigh more than 8 stone (51kg) and be in general good health.