



Thalassaemia
International
Federation

PRESS RELEASE

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For immediate release

Pioneering postgraduate degree course addresses global education need for improved care of patients with neglected genetic diseases

The first e-MSc course in Haemoglobinopathies uses a virtual classroom, videoconferencing and other innovative internet-based technologies to provide specialist postgraduate qualification to students anywhere in the world.

Haemoglobinopathies are genetic red blood cell disorders, mainly thalassaemia and sickle cell disorder. They are highly prevalent in formerly malaria-endemic regions of the world such as Asia, Middle East, Africa, South America and West Pacific. An estimated 7% of the global population carries an abnormal haemoglobin gene, and some 500,000 affected children are born each year. Haemoglobinopathies lead to severe illness and death if not diagnosed early and managed appropriately. The first-ever postgraduate degree course in haemoglobinopathies has now been developed jointly by University College London (UCL) and a Cyprus-based patient organisation, the Thalassaemia International Federation. The course, launched on 8 June 2009, is supported by the AG Leventis Foundation and offers medical students and health professionals from around the world a unique opportunity to pursue a specialist qualification. To provide an accessible study option for health professionals from lower-resource countries for developing the expertise needed in order to provide optimal treatment to patients locally, the course is presented through an innovative online distance-learning format. It is taught by a faculty of internationally recognised experts and covers all aspects of the prevention and holistic care of thalassaemia and sickle cell disease. Students have the choice between a full MSc degree, a postgraduate diploma or a certificate, which can be completed on a full-time or part-time basis.

With the first students already enrolled in the programme since April 2009, a formal launch reception took place on 8 June in the grounds of UCL in London. Course staff, academics and patient representatives were present, and speakers included Prof. Michael Worton, Vice-Provost Academic and International, and Prof. Ed Byrne, Vice-Provost Health, as well as Dr Ratna Chatterjee, Course Director. Prof. Worton welcomed the guests and expressed his satisfaction with the successful outcome of the partnership between UCL and TIF and the very high quality of the course, due to the contribution of a number of international authorities representing a wide range of medical and scientific specialities. He also stressed the value of using innovative online technologies, which allows postgraduate study at less cost and with minimal interruption to professional and personal life.

The President of TIF, Panos Englezos, emphasised in his speech: "This course aims to increase awareness and knowledge of haemoglobinopathies, their treatment and effective prevention. We hope it will make a real and sustainable difference to the children and adults living with haemoglobinopathies, by educating local clinicians and researchers, and thus helping to further the mission of TIF to improve the medical care and quality of life of thalassaemia patients all over the world."

TIF Executive Director, Dr Androulla Eleftheriou, who is also an Assistant Director of the course, said: "We are particularly proud of this course, as it forms a milestone in TIF's quest to promote education of medical professionals and equal access to quality treatment for patients with thalassaemia."

Interested candidates can apply now to start in September 2009. Contact the UCL Course Administrator (msc_haemoglobinopathy@ucl.ac.uk) or TIF (thalassaemia@cytanet.com.cy).

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Information for editors

About thalassaemia and other haemoglobinopathies

Haemoglobinopathies, which mainly include thalassaemia and sickle cell anaemia, are among the most common hereditary diseases worldwide: around 7% of the global population carry an abnormal haemoglobin gene, and more than half a million affected children are born each year. Patients with β -thalassaemia major – the most severe type of thalassaemia – cannot make normal red blood cells and do not produce enough haemoglobin. This leads to severe anaemia with consequences such as retarded growth, bone deformities, reduced energy – and ultimately death at a young age if appropriate medical care is not given. Today, thalassaemia is a treatable though chronic condition, and with the right care patients

can grow up to lead almost normal lives. The treatment of thalassaemia is lifelong, complex and costly, requiring specialist expertise and a multi-disciplinary approach.

About the Thalassaemia International Federation

The Thalassaemia International Federation (TIF) is a non-profit non-governmental organisation established in 1986 by patients and parents, mainly from the Mediterranean countries, the UK and USA to coordinate the struggle against thalassaemia on a worldwide basis. Since 1996, TIF has been in official relations with WHO and is today considered the international reference organisation for thalassaemia.

TIF's mission is to obtain equal access to quality health care for every patient with thalassaemia. Its activities focus on supporting national patient associations and establishing new ones; and supporting national health authorities in their efforts to develop effective national control strategies. A major focus of activities is TIF's international educational programme, aimed at spreading information and awareness about thalassaemia prevention, management and cure. The Federation organises regular conferences, workshops and seminars, and publishes an extensive range of educational materials. For further information see www.thalassaemia.org.cy

About UCL (University College London)

Founded in 1826, UCL was the first English university established after Oxford and Cambridge, the first to admit students regardless of race, class, religion or gender, and the first to provide systematic teaching of law, architecture and medicine. UCL is the seventh-ranked university in the 2008 THES-QS World University Rankings, and the third-ranked UK university in the 2008 league table of the top 500 world universities produced by the Shanghai Jiao Tong University. UCL alumni include Marie Stopes, Jonathan Dimbleby, Lord Woolf, Alexander Graham Bell, and members of the band Coldplay. UCL currently has over 12,000 undergraduate and 8,000 postgraduate students. Its annual income is over £600 million. For further information see: www.ucl.ac.uk