Our 2016 exhibitors

We warmly welcome the following partners to our Rare Disease Day
AKU Society
ALD Life
Ashford and St Peter’s Hospitals NHS
DEBRA
Ehlers-Danlos Support UK
Rare Disease UK
Spinal Muscular Atrophy Support UK
The Batten Disease Family Association
The British Society for Gene and Cell Therapy
The Fragile X Society
The Haemochromatosis Society
The SMA Trust
UK Thalassaemia Society

Useful links

Rare Disease Day:
royalholloway.ac.uk/rarediseaseday
School of Biological Sciences:
royalholloway.ac.uk/biologicalsciences
Advanced Gene and Cell Therapy Laboratory (AGCTlab): http://agctlab.org
Twitter @RHULScience

Rare Disease Day
Patient Voice: Join us in making the voice of rare diseases heard
Monday 29 February 2016
A day of talks, activities and exhibitions
Introduction

This special day aims to draw attention to rare diseases and the millions of people who are affected by them, and highlight the need for more research and funding to help sufferers and their families. The theme for 2016 is ‘Patient Voice: Join us in making the voice of rare diseases heard.’

In Europe, a rare disease is defined as one with an incidence of less than 1 in 2,000 people. While each of them is rare, there are more than 7,000 rare diseases, which together affect 24 million (6%) people in Europe and take 20% of all health care costs. Rare diseases are a serious public health concern and an international priority but unfortunately often very little is known about them by health professionals and the public alike.

3,000,000 people in England will be affected by a rare disease in their lifetime. They will mostly receive symptomatic and palliative care, because there are hardly any curative treatments. And we have not started talking about the relatives who will have to stop working and become full-time carers.

Rare Disease Day encourages us to continue finding ways to work together to provide the different kinds of care that people living with a rare disease need.

Rare disease research at Royal Holloway

Royal Holloway is a leading institution in the development of novel therapies for rare diseases, including Spinal muscular atrophy, Duchenne muscular dystrophy, Motor neurone disease and Severe Combined Immunodeficiency (referred to as ‘child in a bubble’ disease). Our scientists are at the forefront in developing innovative techniques in gene based therapy.

Today’s Organisers

Dr Rafael J. Yáñez, Reader in Advanced Therapy, Centre for Biomedical Sciences is a member of the Board of the British Society for Gene and Cell Therapy and a trustee of the Genetic Alliance UK; and Professor George Dickson (Co-Organiser), Chair of Molecular Cell Biology, School of Biological Sciences, is a founder member of the British Society for Gene and Cell Therapy.

School of Biological Sciences

The School of Biological Sciences at Royal Holloway has earned an international reputation for the world-class quality of our research which is at the forefront of scientific discovery. We offer an exciting range of undergraduate degree programmes and research opportunities ranging from gene therapy, tropical diseases, GM technology, vaccine technology and neuroscience to animal behaviour, conservation, ecology and biodiversity.

The School places a strong emphasis on practical teaching, with state-of-the-art equipment, and an exceptionally supportive environment for all students.

Life Sciences at Royal Holloway is ranked 18th in UK and 88th in the world in the Times Higher Education World University Top 100 for 2015-16. For more information visit royalholloway.ac.uk/biologicalsciences

Programme

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Our Speakers

Welcome
Professor Paul Hogg, Vice-Principal and Dean of Science, Royal Holloway

Introduction to Rare Disease Day
Dr Rafael Yáñez, Centre for Biomedical Sciences, School of Biological Sciences

Developing novel gene therapies for Motor Neurone Disease
Dr Philip Chen, Lecturer in Biomedical Sciences

New therapies for Duchenne muscular dystrophy
Professor George Dickson, Professor of Molecular Cell Biology

All undergraduate degrees offered in the School of Biological Sciences are accredited by the Royal Society of Biology.