2014 exhibitors

We warmly welcome the following partners to our Rare Disease Day

AKU Society
Ashford and St Peter's Hospitals NHS
DEBRA
Ehlers-Danlos Support UK
Findacure: the Fundamental Diseases Partnership
Genetics Disorders UK
Ichthyosis Support Group
Muscular Dystrophy Campaign
Royal Holloway Department of History and College Curator
Society of Biology
The British Society for Gene and Cell Therapy
The Jennifer Trust for Spinal Muscular Atrophy
The SMA Trust
Tuberous Sclerosis Association
Royal Holloway Biosciences Society
Royal Holloway Medicine 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

Join together for better care

Friday 28 February 2014

A day of talks, activities and exhibitions

Rare Disease Day

Royal Holloway, University of London
Egham, Surrey, TW20 0EX
T: +44 (0)1784 434455
royalholloway.ac.uk

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Introduction

Rare Disease Day 2014 focuses on care and encourages everyone in the rare disease community to join together for better care.

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. 20% of the Health budget will go to look after them, mostly providing 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 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 (Lead Organiser), Senior Lecturer in the Centre for Biomedical Sciences, School of Biological Sciences and Professor J George Dickson (Co-Organiser), Chair of Molecular Cell Biology, School of Biological Sciences.

School of Biological Sciences

Ranked 1st in the University of London for research at the forefront of scientific discovery, the School of Biological Sciences at Royal Holloway offers an exciting range of undergraduate degree programmes and research opportunities in fields 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, hosts state-of-the-art equipment, and offers an exceptionally supportive environment for all students.

90% of the School's graduates are in employment or further study within six months of graduation. For more information visit **royalholloway.ac.uk/biologicalsciences**

Programme

09.45-10.15	Arrival and registration, Windsor Building
10.15-11.00	Rotating activities
	Exhibition area, Windsor foyer
	Campus Tour
11.00-11.15	Break
11.15-12.00	Rotating activities
	Exhibition area, Windsor foyer
	Campus Tour
12.00-12.45	Lunch
12.45-13.45	Rotating activities
	Postgraduate Research Posters
	Hands on Lab activities
13.45-14.00	Changeover time
14.00-15.00	Talks on Rare Diseases Moore Building Lecture Theatre
Speakers: Dr Rafael Yáñez An introduction to Rare Disease Day Dr Clare Robinson, DEBRA Living with epidermolysis bullosa – a patient's perspective and new hope for a cure Professor George Dickson Research into treatments for muscular dystrophy	
15.00	End

Rare Disease Day

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