Our 2015 exhibitors

We warmly welcome the following partners to our Rare Disease Day:

AKU Society
Ataxia–Telangiectasia Society
The Fragile X Society
Brittle Bone Society
DEBRA
Findacure: the Fundamental Diseases Partnership
Genetics Disorders UK
The British Society for Gene and Cell Therapy
Spinal Muscular Atrophy Support UK
Rare Disease UK
Muscular Dystrophy Campaign
Ashford and St Peter’s Hospitals NHS

Royal Holloway exhibitors:

History Department
Computer Science Department
Educational Support Office
BioSoc and Medicine Society

Useful links

Rare Disease Day:
royalholloway.ac.uk/rarediseaseday

School of Biological Sciences:
royalholloway.ac.uk/biologicalsciences
royalholloway.ac.uk/research/researchthemes/
health, the human body and behaviour/

Advanced Gene and Cell Therapy Laboratory (AGCTlab): http://agctlab.org

Twitter @RHULScience

Rare Disease Day
Living with a rare disease – day-by-day, hand-in-hand!

Friday 27 February 2015

A day of talks, activities and exhibitions
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 2015 is ‘Living with a rare disease – day-by-day, hand-in-hand.’

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 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, Senior Lecturer, Centre for Biomedical Sciences (Organiser) and Professor George Dickson (Co-Organiser), Chair of Molecular Cell Biology, School of Biological Sciences.

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.

For more information visit royalholloway.ac.uk/biologicalsciences

A message from George Freeman MP, Minister for Life Science
About 350 million people on our planet have a rare disease and we owe every single one of them the promise that we will improve their lives and those of people who care for them. Science, research, genomics and technology are at the forefront of this and they are developing fast. Rare diseases are part of the project to sequence 100,000 genomes – the first ever project like this in the world. The UK is also a respected leader of research into Rare Disease. Both will change healthcare, research and science for generations to come. They are providing us with new possibilities and new opportunities that mean it’s an exciting time to be involved.

I hope you have a fascinating day. It will be one that gives you not only a valuable insight into the opportunities there are to make a difference, but also a look into the reality of what it means to have a rare disease.

Programme

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<td>Speed dating</td>
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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, Royal Holloway
Inspiring Women campaign and Rare Disease Day – Ms Miriam González Durántez, International Lawyer
Research into treatments for Duchenne muscular dystrophy – Dr Linda Popplewell, Research Officer, School of Biological Sciences, Royal Holloway
Clinical translation of Rare Disease research – Professor Rosalind Smyth, Director of the UCL Institute of Child Health, Non-Executive Director of Great Ormond Street Hospital NHS Foundation Trust