Our patron Helene Raynsford, Paralympic Champion. Helene has the rare disease Ehlers-Danlos Syndrome.

Rare Disease Day
Wednesday 29 February 2012
Together we are strong

Programme of events

Royal Holloway
University of London
Together we are strong
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.

The aim of Rare Disease Day is to highlight the need for more research and funding to help sufferers and their families and to draw attention to rare diseases and the millions of people who are affected by them.

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.

Visit our Rare Disease Day website at www.rhul.ac.uk/rarediseaseday/

Organisers
Dr Rafael Yañez and Professor George Dickson, School of Biological Sciences, Royal Holloway, University of London.

Sponsors
- Ark Therapeutics
- Royal Holloway Alumni Development Fund
- Ciliopathy Alliance
- PKD Charity
- Ehlers-Danlos Support UK
- Myasthenia Gravis Association
- Ichthysis Support Group
- Action Duchenne
- Genetic Alliance UK
- Rare Disease UK
- AKU Society
- DEBRA
- Sparks
- Tuberous Sclerosis Association
- BHD Foundation
- Samantha Dickson Brain Tumour Trust
- The Jennifer Trust
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Exhibitors
- Muscular Dystrophy Campaign
- Bio Science Society
- The Jennifer Trust
- Action Duchenne
- Genetic Alliance UK
- Rare Disease UK
- AKU Society
- DEBRA
- Sparks
Registration and Exhibition

Picture Gallery, 10am-1pm

- Exhibitor Stands
  15 charities will be present to discuss the various causes they work hard to support. Please see our exhibitor list on page 2 for further information or visit www.rhul.ac.uk/rarediseaseday.

- Mentored Poster Competition
  Come and view the posters prepared by the children of local schools involved in Rare Disease Day.

- DNA Origami
  Take part in fun and games building DNA models with beads and paper!

- Lab Visits
  Come and take a tour around our scientists’ labs, where we work on cures for rare diseases. Please note you need to book on arrival for this popular activity.

- Purify human DNA!
  Watch our young scientists purify DNA from human cells, measure how much they get using spectrophotometry and take a picture at the end!

- PC Lab Activity: Researching Rare Diseases Online
  Let our final year students guide you to rare disease information on the internet and complete a fun question and answer game. Please note you need to book on arrival for this popular activity.

- Screening of BBC Horizon: ‘A Decade of the Human Genome’
  Watch how gene therapy can make a difference, plus mice that cannot help but get tipsy!

Presentations

Windsor Auditorium, 1.15-3pm

- 1.15pm  Welcome Address
  Paul Layzell, Principal

- 1.20pm  An Introduction to Rare Disease Day
  Dr Rafael J. Yáñez, from our School of Biological Sciences

- 1.30pm  Research into treatments for Muscular Dystrophy
  Prof George Dickson, from our School of Biological Sciences

- 1.45pm  Living with Duchenne - perspectives from families
  Diana Ribeiro, Action Duchenne

- 1.55pm  Zombie Science presentation

- 2.10pm  Keynote Address
  Helene Raynsford, Paralympics Champion with a rare disease

- 2.30pm  Question and answer session

- 2.45pm  Closing Address
  Phillip Beesley, Vice Principal (Research).