



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



Rare Disease Day

Programme of events

Royal Holloway
University of London



Rare Disease Day



Rare Disease Day®

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 Yáñez and Professor George Dickson,
School of Biological Sciences,
Royal Holloway, University of London.

Sponsors

- Ark Therapeutics
- Royal Holloway Alumni Development Fund



Exhibitors

- Muscular Dystrophy Campaign
- Bio Science Society
- The Jennifer Trust
- Action Duchenne
- Genetic Alliance UK
- Rare Disease UK
- AKU Society
- DEBRA
- Sparks
- Tuberous Sclerosis Association
- Ciliopathy Alliance
- PKD Charity
- Ehlers-Danlos Support UK
- Myasthenia Gravis Association
- Ichthyosis Support Group
- The Educational Support Office, Royal Holloway
- BHD Foundation
- Samantha Dickson Brain Tumour Trust



Registration and Exhibition

Picture Gallery, 10am-1pm

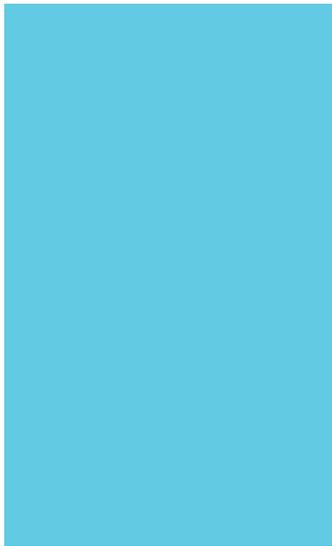
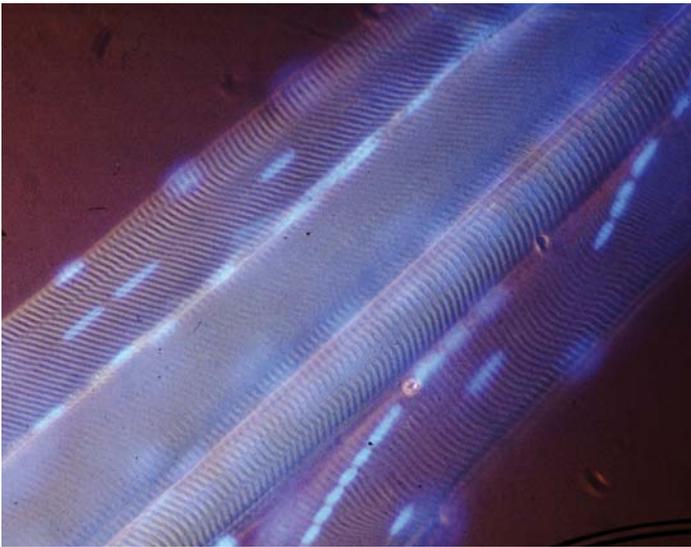
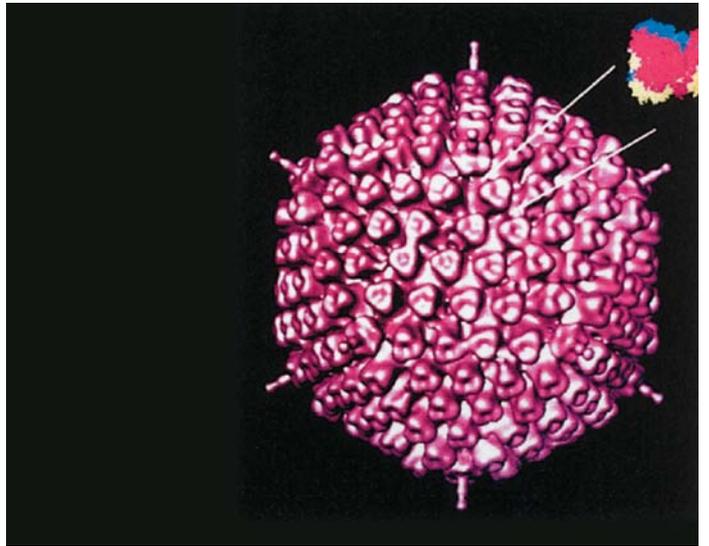
- **Exhibitor Stands**
15 charities will be present to discuss the various causes they work hard to support. Please see our exhibitor list on page 2 for further information or visit www.rhul.ac.uk/rarediseaseday.
- **Mentored Poster Competition**
Come and view the posters prepared by the children of 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).





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