

Creating a National Network for Medical Students who Dare to Think Rare



LSD PATIENT COLLABORATIVE

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Background

- 1 in 17 people in the UK will be affected by a rare disease in their lifetime (1)
- One of the main challenges is reaching a diagnosis
- Over 50% of medical students become GPs (2), the first contact for most patients, so it is critical that they recognise the signs of rare diseases
- The current undergraduate curriculum has limited teaching on when to suspect a rare disease
- Barts and The London School of Medicine and Dentistry, QMUL, formed the first Society for Rare Diseases in October 2011
- The success of the society inspired them to spread their model across other medical schools

Methodology

- Aim to encourage medical students to develop an **understanding and awareness** of rare conditions to reduce time to diagnoses
- Establish a national society that **supports medical students** to create their own Societies for Rare Diseases across all the medical schools in the UK
- Provide a **variety of speakers** including clinicians, patients and advocates
- Design a **website** to provide key information about the society and events
- Continue to hold an annual national symposium
- Collaborate globally via **social media**
- Appoint a **co-ordinator** as a single point of access for interested students

Conclusion

- The project has **raised awareness** of rare diseases to **future generations of clinicians**
- Positive feedback from medical students attending events has validated the success of our events
- To date rare disease societies have been fully established in **3 London medical schools**
- New societies are emerging at Southampton and Liverpool
- Students are accessing resources via the **website**
- S4RD aims to encourage all UK Medical Schools to **adopt this model**
- Twitter (>250 followers) and Facebook provide access to a wider audience

Results

Students4RareDiseases (S4RD) is a national organisation supported by the UK LSD Collaborative patient advocacy group.

UK LSD Collaborative winning the prestigious Genzyme Patient Advocacy Leadership Award has enabled us to extend the concept to other medical schools.

April 2014

Second National Symposium held at the Royal Society of Medicine in collaboration with the Medical Genetics Section

- Attended by over 50 delegates
- Topics: MPS, primary lymphoedema & SCID

February 2015

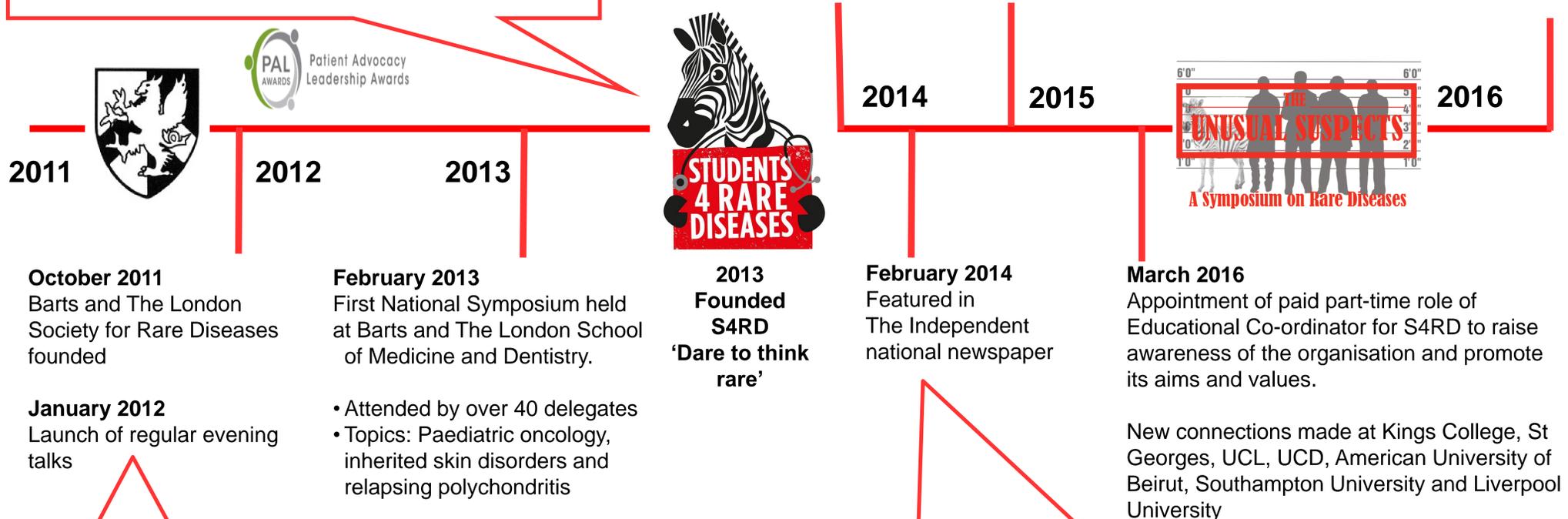
Third National Symposium hosted by the Royal Society of Medicine.

Topics: Pompe Disease, disorders prevalent in Ashkenazi Jews including Tay-Sachs, The 100,000 Genome Project & disorders of sex determination

May 2016

Fourth National Symposium to be held at the Royal Society of Medicine

Topics: Niemann Pick, hyperphosphatasia, achondroplasia & inherited skin diseases



- Topics have included:
- Ehlers-Danlos syndrome
 - Paraneoplastic syndromes
 - Fabry Disease
 - Newborn Screening and Krabbe
 - Retinoblastoma
 - Batten Disease

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NEWS

Training a future generation of doctors to diagnose rare diseases

A unique collaboration between a group of medical students and a of Medicine in London on 2 April. There will be speakers who are world renowned spe- the personal side as well as the clinical signs and the two compliment each other. We are

“Rare diseases exist as well – if you don’t learn to think outside the box you’ll never consider them in your diagnoses”

References

1. RDUK - a voluntary sector group representing people with rare diseases and their supporters – www.rarediseases.org.uk
2. Department of Health. Delivering high quality, effective, compassionate care: developing the right people with the right skills and the right values. A mandate from the Government to Health Education England: April 2013 to March 2015