BPSU - Rare Disease Day activities

The BPSU hosts an annual Rare Disease Day tea party - an informal networking event that brings together patients and carers, healthcare professionals, researchers and policy makers.

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About Rare Disease Day

Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008. Rare Disease Day takes place on the last day of February each year.

The main objective of is to raise awareness among the general public and decision-makers about rare diseases and their impact on patients' lives. The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

2017 event

The theme was ‘research’. Rare disease research is crucial to providing patients with the answers and solutions they need, whether it’s a treatment, cure or improved care.

Highlights:

- Called upon researchers, universities, students, companies, policy makers and clinicians to do more research and to make them aware of the importance of research for the rare disease community
- Raised awareness of rare diseases through thousands of events all over the world
- Recognised the crucial role that patients play in research, ensuring it is better targeted to the needs of patients. Patients no longer solely reap the benefits of research; they are empowered and valued partners from the beginning to the end of the research process
2016 event

The theme was ‘Patient Voice’. It recognised the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers.

Our slogan ‘Join us in making the voice of rare diseases heard’. It appealed to a wider audience, those that are not living with or directly affected by a rare disease, to join the rare disease community in making known the impact of rare diseases. People living with a rare disease and their families are often isolated. The wider community can help to bring them out of this isolation.

The young people of Alstrom Syndrome UK, Hear my Voice Youth Forum (HMV) presented their newly designed transition resources. The resources known as T-KASH (Transition-Knowledge And Skills in Health) are aimed at young people/families and professionals. They consist of ten logos and a visual map, which can be used in any setting e.g. Hospital, GP, Health Centre to signify that adolescent health care is more than just a consultation about a medical condition/s. The message is that young people, with long term health conditions, have full and active lives.

They also expect healthcare professionals to be able to have wider discussions about areas such as vocational choices, confidentiality or how to develop life skills. The logos draw attention to ten knowledge and skill areas that these young people say they should be competent in by the time they transfer to adult health care. Developmentally appropriate adolescent health and lifestyle competencies are what the young people want to emphasize. The logos can also be given a tactile/braille finish so that visually impaired users can read them too.

It is hoped that the resources are used to underpin transition across adolescent health.

The BPSU Rare Disease Day tea party 2016 was supported by Dirunal.
2015 event

This was hosted in collaboration with the RCPCH Youth Advisory Panel and Rare Disease UK.

Earl Howe congratulated the BPSU on its thirtieth birthday. He highlighted the importance the government gives to delivery on the UK rare disease strategy, particularly in responding to the need for speedy diagnosis.

Presentations were given by Professor Timothy Cox of University of Cambridge and Daniel Lewi from the CATS Foundation on Tay-Sachs disease, they emphasised the importance of research and collaborative working between patients/carer, health professionals and patient organisations. Professor Timothy Barrett presented the work of the newly established NIHR Translational Research Collaboration. Dr Nick Sireau, CEO of Findacure spoke on the parent’s perspective of rare disease and the importance of actively engaging with patient groups in order to develop treatments.

Thines Ganeshamoorthy from the RCPCH Youth Advisory Panel communicated his experience of living with a rare disease. Finally, Professor John Newton, the Chief Knowledge Officer from Public Health England rounded proceedings off with a presentation on the National Congenital Anomaly and Rare Disease Registration Service.

2014 event

Our first event looked at the UK plan for implementing the UK strategy for rare disease.

Over 70 people attended the event including patients and carers, healthcare professionals, researchers and policy-makers. All were united by the theme of the day ‘Joining together for better care’.

This podcast was unveiled by the Youth Advisory Panel on living with a rare disease, and introduced by Earl Howe.

Presentations were received from Alastair Kent on implementing the UK strategy for rare disease; Dr Christopher Verity on undertaking rare disease research and surveillance; and Miriam Evans on patient involvement in rare disease research.

Downloads
Rare Disease Day 2017 - Programme 414.38 KB
Rare Disease Day 2015 - Programme 479.69 KB