

Rare Disease UK & the Welsh Rare Disease Patient network: Empowering patients to take part in the policy process

Angela M Burgess¹, Rhian R Morgan¹, Emma L Hughes²

¹Wales Gene Park, ²Genetic Alliance UK

Rare Disease UK (RDUK) is a national campaign for people with rare diseases and all who support them. RDUK provides a unified voice for the rare disease community, capturing the experiences of patients and families and raising the profile of rare diseases across the UK. In Wales, the campaign aims to influence the development and implementation of the UK Strategy for Rare Disease in Wales, ensure rare diseases are viewed as a public health priority by the Welsh Government and the NHS, and bring together and mobilise the rare disease community.



In 2014, workshops were held to support network members and the rare disease community across Wales in making consultation responses to the draft Welsh Implementation Plan. In total, over 100 people attended. Evaluation of the events showed that 100% of those who gave feedback agreed that the stakeholder events helped them to better understand the details of the rare disease plan under consultation.



Through a programme of public affairs, policy and campaigning activities, there has been increased awareness, shared knowledge and political interest for rare diseases in Wales. Building a strong rare disease community of patients, patient groups, researchers, clinicians and industry, RDUK generated a comprehensive and compelling campaign to ensure Welsh Government acted on their responsibility to implement the UK Strategy for Rare Diseases. In February 2015, the Welsh Implementation Plan for Rare Diseases was launched at our parliamentary event, hosted by Vaughan Gething AM, Deputy Minister for Health at the Welsh Government.



In collaboration with the Wales Gene Park, RDUK established the Welsh Rare Disease Patient Network to engage patients, families and patient organisations to ensure the patient voice is properly informed of, and effectively represented in the discussion and development of the implementation of the UK Strategy for Rare Diseases. The network was launched in October 2015. Over 80 people attended the launch and signed up to the network. Contact is maintained with network members through email and a twice yearly newsletter keeping them informed of latest news, advances and initiatives. Patient involvement in events such as Rare Disease Day, Patient Pledge Campaign & a Twitter Takeover has been enhanced by using network contacts. The network continues to grow with over 140 members at present.



'Working collaboratively with other groups as part of the rare disease patient network provides a united voice for campaigning to improve rare disease provision for patients and families across Wales.'

Kayleigh Old, Public Affairs Officer, Cystic Fibrosis Trust