RICHARD WEST

PATIENT ADVOCATE

Behcets UK https://behcetsuk.org/ Over the last 20 years, I have been a member, Trustee and Vice Chair of the Patient Society who help people living with Behcets. For the last 25 years I have lived with Behcets a rare, complex and life-long disease.

In 2012, the Society led a successful NHS bid (Only the second time this has occurred) supported by three Clinicians to establish 3 Centres of Excellence in England for Behcets. Awarded £20 million in funding to set up a multi-disciplinary, holistic world class service for Behcets patients covering physical health and mental well-being with psychological support to learn how to live with the disease.

European Advocate for Behcets Disease - Elected to be Patient representative of Rita European Reference Network (Primary Immunodeficiencies, Auto inflammatory disorders and Auto Immune diseases - https://ern-rita.org/ – one of 25 European Reference Networks for Rare Diseases.

Invited to Zurich to be one of two patient representatives for updating the International guidelines for the management of Behcets. 2018 update of the EULAR recommendations for the management of Behçet's syndrome https://ard.bmj.com/content/77/6/808

2020/21 Ongoing.

Invited to be one of two patient representatives for first UK Guidelines for Behcets Treatment - Conducted by British Association of Dermatologist / British Society of Rheumatology.

Eurordis (European Charity for Rare Diseases)Award - 2019 Awardee: Richard West

For his admirable commitment of over 20 years as a dedicated advocate of rare disease issues on behalf of the Behçet's community and his longstanding supportive partnership with EURORDIS particularly as one of our representatives at the Patient and Consumer Working Party at the European Medicines Agency. His actions on off-label use of medicines in rare diseases - whilst also advocating on behalf of Behçet's Syndrome, is testament to Richard's drive and dedication to improving the lives of people living with a rare disease.

The PCWP, established in 2006, has enabled the Agency to build upon its existing interactions with patients and consumers. It provides recommendations to EMA and its human scientific committees on all matters of interest in relation to medicines.