Having lost family to brain aneurysms and having undergone brain surgery herself, Rebecca founded Hereditary Brain Aneurysm Support last year as a patient-centred organization supporting families and individuals living with familial brain aneurysm syndrome, raising awareness of the genetic condition and research into its genetic cause.

Rebecca is a committed patient advocate and is a founding member of the Participant Panel at Genomics England, where she sits as its Vice-Chair for Rare Disease. The independent Panel advises the Genomics England Board and actively engages in decision-making, playing a vital role in keeping participants' interests at the heart of everything.

Rebecca is also involved in the Newborns Genomes Programme steering committee as well as chairing a key working group of the study that aims to sequence the genomes of over 100,000 newborns. The programme will evaluate the feasibility, and impact on the NHS of offering WGS for all newborns.

As a PR and Communications Director with over 20 years of international experience, Rebecca also brings her strategic view and experience to her work, as well as her lived experience as an adult rare disease patient.

Twitter:
@RebeccaMiddle16

LinkedIn:
linkedin.com/in/rebeccamiddleton1

Websites:
Hereditary Brain Aneurysms - HBA Support For Families
The Participant Panel | Genomics England