# Curriculum Vitae

Kay Parkinson LLB (hons) Dip. Legal Practice

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An entrepreneurial parent of two children with an ultra-rare disease, I am highly motivated and innovative, able to develop and deliver sustainable projects from lived experience of un-met need. I like to work hard and can develop highly motivated management teams.

1995 LLB (Hons) Degree Exeter University
1996 Diploma in Legal Practice
1997 Grant Officer- National Lottery Charities Board
1998 Founder Alstrom Syndrome UK Charity
2007 Gained NHS Highly Specialised Funding for multi-disciplinary clinics for Alstrom Syndrome
2013 Awarded EURORDIS Patient organisation of the Year 2013
2013 Founded Alstrom Syndrome Europe
2015 Founder and CEO of Cambridge Rare Disease Network
2017 Awarded “Champion of Hope Award” Genetic Disorders UK

Published Papers
:

High quality, patient centred and coordinated care for Alstrom syndrome: a model of care for an ultra-rare disease

Rare disorders presenting in the diabetic clinic: An example using audit of the NSCT adult Alström clinics- Wolfram syndrome: natural history and genotype-phenotype correlation based on EURO-WABB registry show gender differences in disease severity

Working with the NHS to develop the Alström multi-disciplinary clinic service

Dispelling myths about rare disease registry system development.

EURO-WABB: An EU rare diseases registry for Wolfram syndrome, Alström syndrome and Bardet-Biedl syndrome

http://www.euro-wabb.org: an EU Register for Alstrom, Bardet Biedl and other rare syndromes

Rare disorders presenting in the diabetic clinic: An example using audit of the NSCT adult Alström clinics

https://www.researchgate.net/publication/257881421_The_involvement_of_patients_in_developing_clinical_guidelines?ev=srch_pub