

My EUPATI Story

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Me

- New Zealander (& British!)
- Diagnosis – 1998
- Law
- London – 2001
- Drug therapy – 2012
- EUPATI – 2014/2015
- Imperial College/UCLPartners - AHSN

PNIH

S U P P O R T

- 2014 - need for independent patient group
 - information
 - support network
 - mandated platform
- EUPATI
- Charitable Incorporated Organisation (CIO) -1 May 2015
- England, Wales & N.I.
- Constitution with voting members (28), 3 Trustees

Why EUPATI?

- Novel opportunity (and free!)
- Address my unanswered questions
- Explore the unknown

How EUPATI has impacted my advocacy work

- Power of the patient voice
- Working with stakeholders
- Importance of alliances and collaboration
- Education & language
- Peer network

Aspirations for the future

- Research cycle
- Pre submission/submission/post submission
- True partnership