



## Julie Power (Vasculitis Ireland Awareness)

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“In 2005 I was diagnosed with Wegener’s Granulomatosis Vasculitis. Treatment involves the use of toxic drugs with substantial side effects which in turn need to be managed, and the implications of long term use are still unknown.”

“I quickly progressed through the range of drugs available and came to the stage where I had no alternatives left and this has fuelled my interest in research.”

“I believe knowledge is power and that patient involvement throughout the entire research process is mutually beneficial to the researchers, clinicians and patients.”

### Expertise / Areas of interest

- EUPATI fellow
- I am a EUPATI Fellow and am founder and Chairperson of Vasculitis Ireland Awareness. I have presented to Health Committees in both Stormont and the Dáil about improving services for those affected by Vasculitis.
- I have written articles for the Vasculitis Foundation and Vasculitis UK circulars, about our work in Ireland. I am both organiser of (and occasionally speaker at) regional support group meetings and annual all Ireland Vasculitis Conferences.
- In 2016, I am speaking at the Northern Ireland Rare Disease Day Conference on Patient Innovation.
- Prior to diagnosis, I had 17 years working as an Occupational Therapist specialising in Neurology and Palliative Care.

### Patient involvement experience

- Founder and Chairperson of Vasculitis Ireland Awareness, an all Ireland support group for those affected by any of the Vasculitis diseases.
- Patient representative in Rare Kidney Disease Registry Steering Committee,
- Patient Support Group representative in VINE (Vasculitis Ireland Network),
- Irish patient support contact for Vasculitis Foundation and Vasculitis UK.
- Member of the Northern Ireland Rare Disease Partnership Board of Directors.
- Patient representative in pilot Northern Ireland Vasculitis service.