



## Nuala Ryan

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Thanks to the IPPOSI Patient Education Programme I was given the learning and tools to become a better patient advocate. Throughout the course and after, I was able to network with many like-minded, enthusiastic patient representatives. This course, my own personal experience as a cancer patient and a mother of a child with a rare genetic syndrome, combined with my clinical research background gives me a unique perspective, seeing and understanding both sides of the process. I believe strongly in the power of the patient voice in providing meaningful input into all aspects of the lifecycle of a medicine: from clinical trial conduct; drug safety evaluation and tracking; regulatory approval and health technology assessment.

### **Experience/Areas of Interest**

- Awareness raising on the importance of genetic research in early diagnosis and treatment of rare disease.
- Advocate for research into Nicolaides-Baraitser syndrome (NCBRS)
- Advocate for the development of an integrated Irish E-Health Patient Record
- Involving patients in clinical research planning/design and patient outcome measures
- Graduate 2019 IPPOSI Patient Education Programme
- Science graduate/Clinical research background

### **Patient Involvement and Experience:**

- HPRA patient advisory committee member
- Member HIQA Steering Committee for public engagement on use of Health information
- Patient advisor on DASSL committee - research project related to health information system
- Member of HSE Research and Development (R&D), Patient and Public Involvement (PPI) in Research Advisory Panel
- Member of IEHG-UCD Working Group on Incidental Findings.
- Panellist on multiple patient panel discussions
- Member EUPATI National Platform, Ireland