



## Wendy Costello (Irish Children's Arthritis Network—iCAN)

---

Thanks to the IPPOSI patient education programme I have a better understanding of what my role is as a patient advocate, and it is a vital one. Setting up a charity is something I am hugely proud of and raising awareness of Juvenile Idiopathic Arthritis (JIA) is my primary goal. Early intervention is the key to better outcomes. I am involved in various research projects but of prime importance to me is the voice of the family, parents, siblings and the child living with JIA. This chronic condition has a huge effect on the whole family. Another area of interest is transition of care from the paediatric to adult settings. This is something we could do better and we need to learn from other countries and share best practice.

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

- Raising awareness of Juvenile Idiopathic Arthritis (JIA)
- Transition for JIA patients from paediatric to adult services
- Working with researchers on JIA projects
- Facilitating workshops on giving the young person living with JIA a voice
- Running educational weekends for JIA families

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

- Member of the UCD Centre of Arthritis Research steering group committee
- Board member of European Network of Children with Arthritis (ENCA)
- Chairperson of iCAN (Irish Children's Arthritis Network)
- Board member of Autoinflammatory Rare Disease Council
- ENCA representative on the Paediatric Rheumatology European Society (PREs) council