

Bernadette Gilroy

Phenylketonuria (PKU) is a rare metabolic condition that is complex and very often misunderstood. I got involved in patient advocacy to highlight the significant challenges and unmet needs of the PKU community. One of my coping strategies for living with PKU is "Control the Controllables" and for me advocacy is just that. Participation in the IPPOSI Patient Education Programme was essential to enable me to engage with and to navigate our healthcare system more effectively. It facilitates opportunities for more meaningful engagement amongst all stakeholders supporting a holistic approach to healthcare and promotes longevity in the roles of advocates. I am so grateful for the most amazing journey with so many inspirational advocates from whom I have learned so much, working tirelessly across Ireland to enhance our healthcare system.