



Tom

LIVING WITH PHENYLKETONURIA (PKU)

One of the first generation to have been diagnosed at birth who has maintained a strict diet for the entirety of my lifetime.

“Living with PKU forces me to avoid social situations – eating out & general socialising as most of these activities revolve around food, and as I am unable to eat up to 85% of food served, which is incredibly restrictive for me.”

Growing up Tom experienced difficulties with the strict PKU dietary therapy during his teenage years. This had an adverse knock on effect and consequences in other areas of his life as a result. Without being able to stay on diet, Tom suffered from severe difficulty concentrating in school and struggled academically for many years, even though classified as “clever” by his school.

Over 800 Irish people (1: 4,500 people), live with the challenging rare disease Phenylketonuria, commonly known as PKU in Ireland today, one of the highest and incidences in Europe. This genetic lifelong disease, diagnosed at birth by the heel prick test, affects a person’s metabolism - impacting their ability to breakdown protein.

Phenylketonuria requires daily treatment from the individual living with PKU or the person caring for them, in managing the strict, daily dietary therapy (“diet for life”),

to prevent devastating neurological consequences.

Tom also had an unfortunate medical incident in 2011 - suffering a stroke quite out of the blue, whilst working in Galway. Tom was admitted to University College, Galway. When medical staff learned that I had PKU, communication was made to the Mater Dietetic unit to ascertain if my diet contributed to the stroke, To this day, no-one can say whether or not my PKU condition was a cause.

Tom added “Living with PKU forces me to avoid social situations – eating out & general socialising as most of these activities revolve around food, and as I am unable to eat up to 85% of food served, which is incredibly restrictive for me, I find myself opting out and self-isolating”

I am one of the first generation to have been diagnosed at birth who has maintained a strict diet for the entirety of my lifetime, but I am obviously concerned about my future from a medical perspective given my experience to date.

The PKUAI & PKU community hope to raise awareness of the severe daily challenges experienced by people living with PKU through sharing of lived experiences, such as Tom's . The PKUAI mission is to strive to improve the quality of life for people living with PKU in Ireland.

For more information please visit - pku.ie.
The support we have all been shown is absolutely incredible.....