



Sharon Thompson (Unaffiliated)

“Our only daughter Victoria developed a rare disease at three months old. Grieving, with little sleep or knowledge, we had a lot to overcome in the short six months she battled with her terminal illness. Victoria had no nerve insulation. Yet we were forced home, many miles from the hospital that knew her, with no proper medical supports. Thankfully we found LauraLynn, Ireland’s children’s hospice. Victoria had a safe death cradled in memories and love.”

“I want families to have the same care. I became interested in families having information on rare diseases/palliative care. I want them to have access to gentle support and advocacy. I feel passionate about the need for children’s palliative care services for all.”

“When investigating research opportunities and discovering EUPATI, I couldn’t quite understand that patient involvement was in its infancy. My wish is for ‘meaningful’ patient involvement to become a respected, accepted and usual element of the entire R&D process.”

Expertise / Areas of interest

- EUPATI fellow
- Interested in childhood rare diseases, children’s palliative care and advocacy services.
- BEd (ex-primary-school, teaching principal), Diploma in copywriting & counselling.

Advocacy

- Presented poster at Ireland’s Children’s Palliative Care conference – own research project and abstract on the role of advocacy in children’s palliative care.
- Member of parent groups for very ill children.
- Member of AIHPC committee for the palliative hub website project. #pallhub
- Wrote two leaflets published on the website for parents.
- Spoken in national/local media and in Leinster House on service provisions and funding for children’s palliative care.
- Blog at remembervictoria9.wordpress.com.
- Tweet @sharontwriter & @Victoriabttrfly
- Fundraised for LauraLynn, Ireland’s only children’s hospice. (RTE documentary ‘No Time to Die’.) Wrote pieces for their website and promotion.
- Member of Save Babies UK (leukodystrophies and new born screening charity).

Patient involvement experience

- Presented at Letterkenny training event for medical professionals, through Crumlin Hospital.
- Presented with my husband in NUIG Galway to student nurses as part of their palliative training.
- Prompted and helped in the development of a day: workshop for parents of Life-limited children in rural Donegal. (First of its kind).