

Beverley Power

CDH UK – The Congenital Diaphragmatic Hernia
Charity

Registered in England & Wales 1106065

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ABOUT MY ROLE as ePAG in ERNICA:

I see my role in ERNICA as a voice for patients and families across Europe and an opportunity to help effect better outcomes for patients, by working closely and collaborating with other patient representatives, medical professionals, healthcare providers and policymakers.

My current roles within the network are:

1. Member of the Advisory Board as Patient Representative for ERNICA
2. Member of the working package for Congenital Diaphragmatic Hernia
3. Member of the working package for Research
4. Member of the working package for Fetal Medicine
5. Member of the sub working package to assist in the development of ePAG guidelines and terms of reference
6. Member of the Standards of Care working package.

MY STORY:

I joined the CDH UK Team in 2009 following the death of my Grandson caused by the complications of Congenital Diaphragmatic Hernia (CDH).

I utilised my background experiences in nursing, project management and business to help grow and improve the charity and to reach out to more families and medical professionals.

My aims are to ensure that all patients and families have access to quality support both psychologically and practically and that the same standard of care is provided, irrespective of where a patient lives, or is treated. I also want to help improve outcomes through education and research..

Some of my achievements to date include:

Production of information materials for patients, carers and medical professionals.

Creation of various types of media including a website and other platforms plus awareness video.

Setting up and management of patient forums.

Creation and management of a Research Fund.

Successful collaborations with other UK and international charities and organisations.

Campaigning for better management and treatments for CDH in the UK and overseas

I am currently a Trustee and the Secretary for CDH UK.

I hope that my membership of ERNICA is beneficial for the progression and aims of the network and has a positive impact for patients and Healthcare Providers.

How to contact me:

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