



## Background:

- More than **100 epigenetic disorders** are now known and collectively this group of conditions are estimated to affect up to in **1 in 500 to 1 in 100 individuals**.
- Several of these disorders share research challenges that are hampering progress in improving the lives of individuals with these conditions.
- **Our Vision** that the networking and research activities of the EpiGenRare node will provide a platform to overcome these challenges by:
  - **Enhancing opportunities for collaboration**
  - **Perform ground-breaking research that would lead to identification of new rare diseases**
  - **Deepen understanding of disease mechanisms**
  - **Develop epigenomic methods for diagnostic and prognostic biomarker discovery**
  - **Create pre-clinical experimental systems to speed up the evaluation of therapies**

## PPIE Aims:

- Our PPI approach will be underpinned by the principles that people living with epigenetic disorders and rare diseases, families, patient groups and advocates must be **involved in, benefit from, and inform** the activities of EpiGenRare.
- We will build upon our relationships with various relevant **patient-family support groups**.
- The named patient support group partners will be part of the **advisory board** and participate in driving the networking activities and the research and collaboration agenda.

## Networking & Co-ordination

