

Press release – embargoed until 00.00hrs 28th February 2025

28th February 2025

International Rare Diseases Day – Equity¹

Rare Diseases Day aims to raise awareness about diseases not commonly known and the challenges faced by children, young people and their families. The day also advocates for equitable access to diagnosis, treatment, and care for people affected by rare diseases.

A disease is rare when it affects fewer than 1 in 2,000 people. There are around 7,000 known rare diseases.

300 million people are living with a rare disease across the world. In the UK it is estimated that around 3.5 million people have a rare disease, over 75% of whom are children².

Around 3.5 million people in the UK have a rare disease, and 75% of those are children.

1 in 17 people are affected by a rare condition at some point in their lifetime. For example: 1 in 5 cancers is rare, affecting fewer than 1 in 100,000 people. The 5-year survival rate is lower than more common cancers.

The most common rare diseases include:

- Ehlers –Danlos Syndrome (EDS)
- Sickle Cell.
- Cystic Fibrosis.
- Duchenne Muscular Dystrophy (DMD)
- Haemophilia.

Many rare diseases are genetic (72%), of which 70% start in childhood³. The 100,000 Genomes Project sequencing genomes from those affected by rare disease or cancer is leading to groundbreaking insights and potential treatments⁴.

More than 3 in 10 children with a rare condition die before their fifth birthday

Rare diseases are often chronic and life-threatening. They can be difficult to diagnose, and people with rare diseases can face challenges accessing services and treatments.

¹ www.rarediseasesday.org

² www.contact.org.uk/

³ www.geneticalliance.org.uk/

⁴ <https://www.genomicsengland.co.uk/initiatives/100000-genomes-project>

Many parents live with uncertainty until such a time as they receive a diagnosis/name for their child's condition. Support from organisations such as the SWAN charity⁵ and the important role of children's nurses during this time should not be underestimated.

The ABPN believes that

- Every child has a right to access high quality health care services in age-appropriate facilities that meets their specific needs ^{6,7}
- The voices of children and young people should be heard and inform the development and planning/ commissioning of services for them.
- Infants, children and young people should receive care from nurses that have the child specific knowledge, skills and competencies to meet their unique needs^{8,9}
- Child field specific pre-registration undergraduate education programmes, as well as specific post registration education is crucial to equip nurses to meet the needs of children and young people, including at home or closer to home in the community

“Life is changed for parents of children with a rare disease as they not only have the responsibilities associated with providing their child's care but the rarity of the condition creates additional challenges. Among other things, nurses working with children with a rare condition, need to be able to support parents and children navigate the many uncertainties associated with diagnosis, prognosis and interventions”

Professor Bernie Carter, President

Rare Diseases YouTube video <https://youtu.be/flvqxQPjisI>

Notes for editors

The term child refers to infants, children, young people and young adults up to 25 years of age

The ABPN recognises that primary and community services, as well as child public health and mental health services, including school nurses and health visitors also have a key role in supporting children, young people and families.

⁵ <https://rarediseases.org/organizations/swan-uk/>

⁶ See ABPN Position statement on Children and Young People's rights [abpn_position_statement_children_and_young_peoples_rights.pdf](#) and ABPN Background briefing on Children and Young People's Rights [abpn_background_briefing_children_and_young_people.pdf](#)

⁷ UN Declaration of Human Rights 1948 see <https://www.un.org/en/about-us/universal-declaration-of-human-rights/>

⁸ See ABPN position statement Workforce planning and nurse staffing [abpn_position_statement_workforce_planning_and_nurse_staffing-final_nov_2024.docx](#) and ABPN Background briefing on Workforce planning and nurse staffing [abpn_workforce_planning_and_nurse_staffing_background_briefing_paper-final_nov_2024.docx](#)

⁹ See ABPN Position Statement on Children's Nurse Education [abpn_position_statement_nurse_education_final_24_november_2024.pdf](#) and ABPN Background Paper on Children's Nurse Education [abpn_cn_education_background_paper_final_22nd_november_2024.pdf](#)

The ABPN is a network of children's nurses with a wide membership of experts in clinical practice, education, leadership and research. It is the oldest children's nursing association in the world, established in 1938.

www.abpn-uk.com

X (formerly Twitter): @ABPN_ChildNurse

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