

A MANIFESTO FOR CHANGE: CHILDHOOD LIVER DISEASE

The European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and the Children's Liver Disease Foundation are calling upon policy makers to drive greater awareness, research and understanding of childhood liver disease and pledge to take 4 key steps to improve the lives of paediatric patients and their families.

THE CHALLENGE FACING EUROPE



Childhood liver disease (CLD) refers to any condition that disrupts the function of the liver in a child. CLD has no immediate cure, can be life-threatening and can lead to a lifetime of medical treatment and care. The development of treatments for many rare liver diseases are still ongoing and not yet comprehensive. The prevalence of CLD is on the rise across Europe, with up to 1 in 10 children now thought to be impacted by the condition.¹

LATE DIAGNOSIS



CLD is often under-recognised and diagnosed late, as early symptoms are hard to detect.² If left to develop, CLD can lead to complications, including cirrhosis and the need for liver transplantation, that reduce quality of life and can even be life-threatening.³ To avoid these complications, minimise the impact of CLD, and ensure the best possible outcomes for patients, it is vital that a child with a liver disease is diagnosed as early as possible.

POOR PUBLIC AWARENESS



Poor public awareness and understanding is a key reason why CLD poses such a challenge. Many do not realise that liver disease impacts young people, even though it is becoming increasingly prevalent, and symptom awareness is very low.⁴ Additionally, misunderstandings of CLD have resulted in patients and families being unfairly stigmatised. There is a common misconception that CLD is related to alcohol in the parents despite many CLDs being genetic. To combat this and improve understanding, public awareness and education on CLD must improve.

RESOLVING THE CHALLENGE: OUR CALLS TO POLICY MAKERS

ESPGHAN and the Children's Liver Disease Foundation present 4 calls to action for policy makers to help ensure childhood liver diseases (CLD) are better identified, understood and managed, ensuring that infants, children and adolescents can live the best possible life:

1

Public awareness and education campaigns should

be implemented to improve the understanding of CLD. This will help support parents in identifying CLD, allowing for earlier diagnoses and helping to combat the misconceptions and stigma surrounding the conditions

2

Utilising available funds and grants for rare disease

initiatives, greater research should be commissioned to help drive the development of treatments for rare liver conditions

3

Children with a liver disease must receive care in a

specialist paediatric setting. This will ensure patients are diagnosed and treated in the most effective way, and provided with care tailored to their specific needs

4

Long-term and gradual transitional

arrangements from paediatric to adult care are vital to delivering an effective care pathway. This process must be improved to ensure patients receive the most effective and least disruptive care

Big Yellow Friday was established in the UK by the Children's Liver Disease Foundation as a national awareness and fundraising day for childhood liver disease, and to support its mission to promote research, and provide information and support for those affected by childhood liver disease.

From 2020, ESPGHAN will be promoting Big Yellow Friday across the whole of Europe.

About ESPGHAN

The European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) is a multi-professional organisation whose aim is to promote the health of children with special attention to the gastrointestinal tract, liver and nutritional status, through knowledge creation, the dissemination of science based information, the promotion of best practice in the delivery of care and the provision of high quality education for paediatric gastroenterology, hepatology and nutrition professionals in Europe and beyond. For more information visit: www.espghan.org

About the Children's Liver Disease Foundation

Formed in 1980, the Children's Liver Disease Foundation is the only UK charity dedicated to fighting all childhood liver diseases. They provide a comprehensive information hub on childhood liver disease for healthcare professionals and families, a tailored support service for children, young people and young adults with liver disease and their families, research into all aspects of childhood liver diseases and a collective voice for everyone affected by childhood liver disease. For more information visit: www.childliverdisease.org