

Manifesto for Paediatric IBD (PIBD)

This World IBD Day, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) are calling on policy makers to recognise the invisible cost of Inflammatory Bowel Diseases (IBD) and pledge to take four key steps to reduce the burden of the diseases on society and improve the lives of patients and their families.

This World IBD Day, lets #maketheinvisiblevisible

The Hidden Cost of IBD

Inflammatory Bowel Diseases (IBD) are chronic diseases of the bowel and intestine and include Crohn's Disease and Ulcerative Colitis, affecting 10 million people around the world every day. Up to 20% of IBD cases develop in childhood, which is known as Paediatric IBD or PIBD.

IBD is reported to cost Europe up to €5.6 billion per year in direct healthcare costs. However, the costs of IBD, in children and in adults, are not just borne in the healthcare setting. IBD and PIBD costs society in lost working days, lost days at school or in education, lost family time and can cause psychological issues such as anxiety and depression.

Studies have shown that the economic burden of IBD on society is up to 68% of the total cost, meaning that the true cost is likely to be in the tens of billions of Euros.

But it doesn't have to be this way. With the right policies, we can deliver treatment and effective disease management which will result in reduced healthcare and non-healthcare costs but most importantly, allow patients and their families to lead happier, healthier lives.



On average, parents and carers of children with IBD have to take an additional week off work each year to care for their poorly child



52% of patients report that their IBD negatively affects their education



People with IBD lose up to 20 days of family and recreational time every year due to their illness



68% of the total cost burden of IBD is the societal cost (non-healthcare related)

A Multidisciplinary Approach

The average age of a child diagnosed with PIBD is 11-12 years - a critical time for the development of children physiologically, socially and educationally - making effective management even more critical. Paediatric patients often find the symptoms of IBD embarrassing and humiliating, which can lead to psychological problems, and some medical treatments for IBD can cause side effects such as weight gain and acne, compounding the issue.

As such, it is important that treatment of PIBD is undertaken by a multidisciplinary team, comprising not only gastroenterologists but experts in diet and nutrition, nurse specialists and professionals who can offer counselling.



Calls to Policy Makers

1

Recognising the true cost of PIBD, greater resources should be provided to enable more subspecialty paediatric GI training to better manage the diseases in childhood, as optimal PIBD treatment has been proven to reduce both the direct and indirect costs of the disease.

2

Long-term and gradual transitional arrangements between paediatric care and adult care should be a key part of the care pathway to ensure the most effective and least disruptive long-term disease management.

3

Improved education and workplace policies that better consider the needs of PIBD patients and parents and carers of children with PIBD should be implemented.

4

Children with IBD must be treated by a multidisciplinary team looking not only at the medical aspects but also areas related to the patient's life, such as lifestyle, diet, social and physiological needs.

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 EFCCA

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 36 national Crohn's and Ulcerative Colitis (collectively known as Inflammatory Bowel Disease or IBD) patient associations. We are an organisation of people united in our commitment to improve the life of the over 10 million people living with IBD worldwide (3.4 million in Europe alone) and to give them a louder voice and more visibility. For more information visit: www.efcca.org

This policy document has been produced by the ESPGHAN Public Affairs Committee, in collaboration with members of the ESPGHAN Allied Health Professional Committee, the ESPGHAN IBD Special Interest Group and the European Federation of Crohn's and Ulcerative Colitis Associations to mark World IBD Day 2019.