optimal
nutritional care
for all

A call for equal access to care across europe

Manifesto of the Leading Intestinal Failure Equality (LIFE) initiative

This manifesto is a call for systematic change – better awareness, more robust protocols, and an equal standard of care for people living with IF through efficient collaboration.

Intestinal Failure (IF) is a life-threatening condition that impairs the body's ability to absorb vital nutrients, fluids and electrolytes, due to significant loss of gut function.[1] It often results in prolonged hospitalisations and many distressing medical procedures, that can have a destructive impact on daily life.[2] IF is a form of organ failure which affects an estimated 5–80 people per million.[3]

The need

Across Europe, there are major inconsistencies in the awareness of the disease and the standard of care patients living with IF receive.[4] Not all countries in Europe have established national guidelines for the management of IF, which leaves many without the option of life-saving treatment, integrated support and specialised care.[5]

LIFE
Leading Intestinal Failure Equality

The situation

While home parenteral nutrition (HPN) is a life-saving therapy for many IF patients, and considered the gold-standard of care, its availability varies significantly.[6] Countries with good access to specialised care may have around 20 patients per million receiving HPN, while other countries with more limited access have around 5 patients per million receiving HPN. Unfortunately, HPN remains unavailable in some countries.[4]

€14,000 - €77,000

estimated related costs of HPN, per patient, per year in Europe

Though life-saving, the cost of HPN for patients can be significant if not covered by their respective healthcare system. It is estimated that HPN related expenses account for the majority of total medical expenses for patients living with IF, averaging between €14,000 - €77,000 per year.[7,8] If the cost of HPN is not covered by healthcare systems, it can bear a large financial burden on patients and their families.

Challenges

Disparities in access to care: While some countries offer specialised treatment centres, others lack sufficient resources, forcing patients to travel long distances or suffer without adequate care.

Low awareness: IF remains under-recognised, even among healthcare professionals in economically developed countries. This results in delayed diagnosis, inadequate treatment and a lack of support for patients and their families.[9]

Insufficient research: A lack of research means knowledge of IF is generally limited. Investment in research and cross-border networks will help to improve understanding of the needs of those living with IF and drive improvements in services.

Shortage of reference centres: Treatment of IF can require the collaborative efforts of a multidisciplinary team (MDT). Accredited reference centres help to drive improved patient outcomes by offering high quality care, guided by best practices.

Through greater education and cross-country collaboration relating to IF, governments can significantly improve the standards of care for those affected. In turn, harmonised care and early diagnosis can prevent complications that affect quality of life, reduce hospitalisations and lower healthcare costs.[10]

Vision

LIFE's vision is that all patients with IF in Europe should receive a high, standardized level of care by 2030.

How we can make a difference

The Leading Intestinal Failure Equality (LIFE) initiative and its partners call upon policymakers to focus on these four strategic priorities:

1. Speeding up diagnosis

Early diagnosis is imperative so that IF can be appropriately treated, and quality of life maintained. **There is an urgent need to improve stakeholder understanding of IF through funding of professional organisations and regulators to provide educational and training opportunities.** Establishment of more accredited reference centres will mean experts can more easily collaborate to improve IF care.

- Advocate for the establishment of more reference centres for collaboration across Europe
- Enable access to referral networks of specialist physicians who can confirm a suspected diagnosis of IF
- Invest in clinical education and training around diagnosis, care and treatment of IF.

2. Delivering comprehensive care

The European Society for Clinical Nutrition and Metabolism (ESPEN) clinical guidelines on chronic IF in adults are the most prominent guidelines on the safe and effective management of the condition,[1] **however they are not consistently implemented across Europe.** Clinical guidelines provide a framework for healthcare systems to **design and deliver services that meet the needs of IF patients.**

- Develop and implement national guidelines for IF care based on ESPEN clinical guidelines
- Identify and address barriers to adoption of consensus guidelines on IF care and treatment
- Support home and social care to meet the quality of life needs of those living with IF and their families.

3. Providing access to appropriate treatments

As well as ensuring patients can access the full range of treatment options in line with European and national guidelines, **policymakers and regulators must also be made aware of innovations in treatment options to accelerate access.**

- Ensure funding arrangements are aligned with recommendations in the ESPEN clinical guidelines
- Enable conditional reimbursement to fast-track access to innovative treatments.

4. Working together to share best practice and data

Enhancing and standardizing the collection of epidemiological data on prevalence and outcomes for people with IF between countries would **help policymakers to identify gaps in healthcare services that need addressing.** By aligning with the ESPEN-recommended quality standards, **we can build a stronger foundation for improving outcomes for IF patients.**

- Develop partnerships with authorities to establish national, regional and international IF registries that track prevalence, treatments and long-term outcomes
- Harmonise quality care standards by integrating shared protocols for monitoring clinical and psychosocial outcomes
- Support the creation and empowerment of IF-specific patient groups to provide valuable insights, advocate for better care, and foster a patient-centred approach at national and European levels.

For more information, please visit: **www.intestinalfailure.org**

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