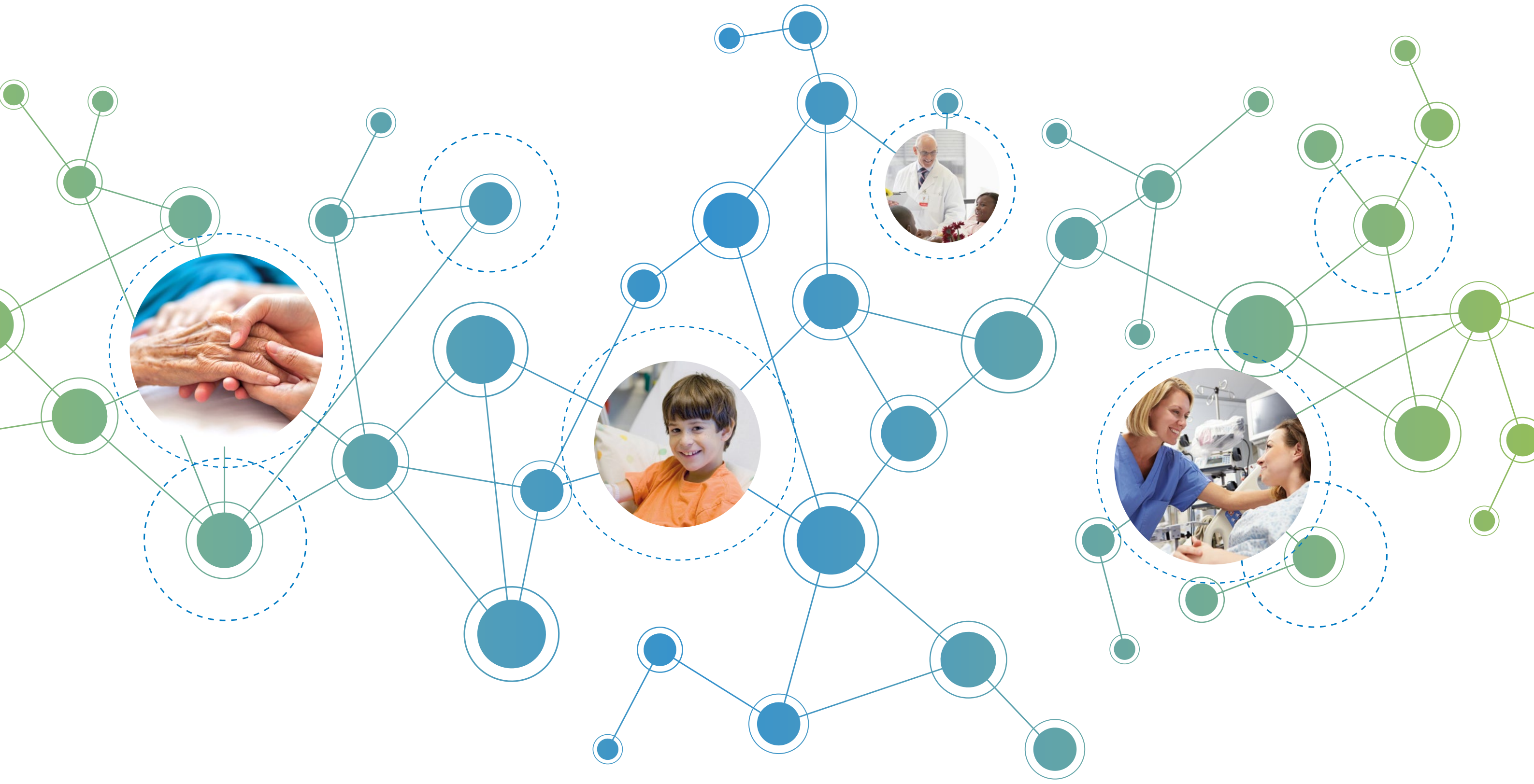
atlas

From failure to hope:
An agenda for change in Intestinal Failure



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About ATLAS

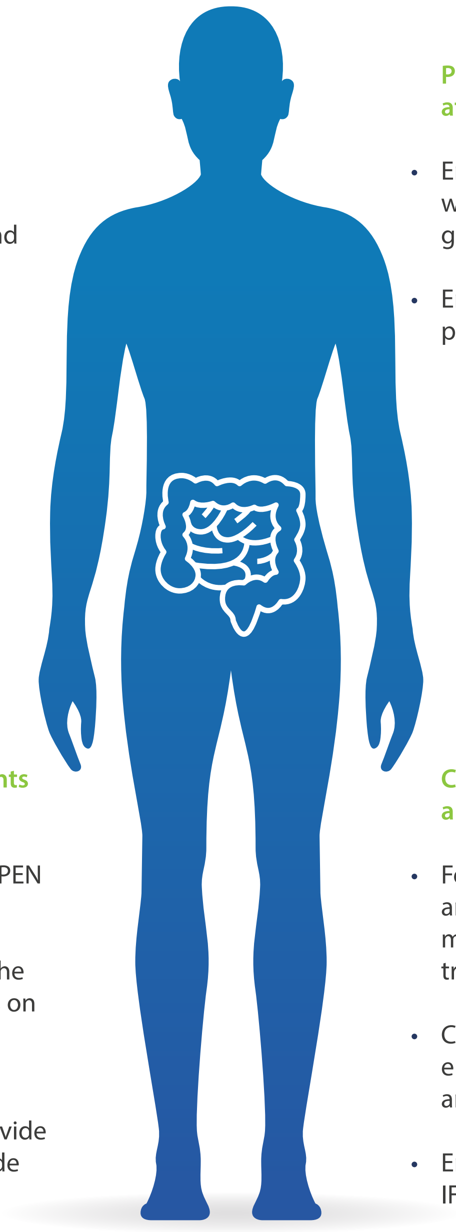
ATLAS is a group of expert clinicians, patient advocates, patient organisation leaders and Takeda that is focused on achieving the best possible treatment and care for all patients with intestinal failure (IF). Our vision is for all IF patients in Europe to receive an equal standard of care by 2030, as documented through the improvement in reported patient outcomes. The ATLAS programme is funded and initiated by Takeda.

Contents

Executive summary

The impact and burden of intestinal failure (IF) are poorly understood by healthcare professionals, payers and policymakers. As a result, services for the condition are underfunded and patients do not consistently receive the standard of care set out in clinical guidelines for chronic IF published by the European Society for Clinical Nutrition and Metabolism's (ESPEN).[1]

Policymakers have an opportunity to transform the care of patients with IF by:



Speeding up diagnosis

- Advocate for the implementation of an ICD code for IF and SBS
- Enable primary care physicians and non-specialist clinicians to access referral networks of specialist physicians who can confirm a suspected diagnosis of IF
- Invest in clinical education and training around diagnosis, appropriate care and treatment of IF patients

Delivering holistic care for patients

- Develop and implement national guidelines for IF care based on ESPEN clinical guidelines
- Identify, and address, barriers to the adoption of consensus guidelines on IF care and treatment
- Equip and resource European Reference Networks (ERNs) to provide leadership to improve Europe-wide health outcomes in IF

Providing access to the right treatments at the right time

- Ensure funding arrangements are aligned with recommendations the ESPEN clinical guidelines
- Enable conditional reimbursement to provide rapid access to new treatments

Collaborating to share best practice and data

- Forge partnerships with regional, national and international authorities to collect, monitor and share data on IF prevalence, treatment and outcomes
- Collect and disseminate agreed epidemiology and quality standards within and between countries
- Encourage and fund the establishment of IF specific patient groups at national level

What is intestinal failure?

Intestinal failure (IF) is the rarest form of organ failure.[1] There is a wide range of causes for IF, all of which prevent the body from absorbing the nutrients, fluids and electrolytes needed for survival due to significant loss of function of their gut.[2]

Despite being a highly debilitating condition, which affects people of all ages, IF is largely unrecognised.

The leading cause of IF is short bowel syndrome (SBS)[1], which results from loss of intestinal absorptive capacity due to underlying anatomic (extensive surgical resection) or functional (congenital, loss of functional tissue) causes.[2,3]

People living with IF need parenteral support (PN/IV) as it provides the necessary nutritional and fluid requirements to maintain adequate health and/or growth.[1]

Home parenteral nutrition (HPN), a form of parenteral support, is a life-sustaining therapy that prevents death from malnutrition or dehydration, but it does not cure the underlying condition.[4]

The burden of intestinal failure

IF places a significant burden on healthcare systems and has a profound impact on patients and their families.

- Treating IF poses a significant financial cost for healthcare providers who increasingly lack resources.[5,6] This is particularly owing to the high costs of hospitalization and HPN[7]
- There are major consequences linked with IF through SBS. These include gastrointestinal complications, liver failure, catheter-related complications and infections, metabolic complications, gallstones, renal failure, weight loss, fatigue, premature ageing, irritability, depression, increased susceptibility to other diseases and a high burden of morbidity and mortality[8,9,10]
- People with IF often have to endure long periods of hospitalisation and undergo many medical procedures.[11] Research has shown that quality of life in people with chronic IF is similar to chronically ill people requiring dialysis, liver transplantation or chemotherapy[12,13]

Our vision for patients with intestinal failure

Our vision is for a future where every patient with IF has equitable access to high-quality, patient-centred, and personalised care. To achieve our vision, we believe policymakers should focus on four strategic priorities.

1. Speeding up diagnosis

Early diagnosis of IF is critical if the condition is to be appropriately treated and patients' quality of life is to be ensured. However, awareness of IF and treatment options among primary care physicians and non-specialist clinicians is low, delaying diagnosis and further exacerbating the inaccessibility of necessary care. Before their condition is properly diagnosed and they are given the appropriate treatment, people's standard of living can be severely impacted.[14]

There is now an opportunity to improve stakeholder understanding of IF.[15] IF specialists can help by providing training to other healthcare professionals on the diagnosis and management of the condition, while policymakers can encourage and fund professional organisations and regulators to provide education and training opportunities.

There is currently no International Classification of Disease (ICD) code for IF and SBS.[16] Without an ICD code it is difficult for healthcare systems to generate the epidemiological and outcomes data that are vital to the maintenance of best-practice medical guidance. This in turn makes it challenging for healthcare systems to identify the resources needed to provide the appropriate level of care, and to make a case for investment in diagnosis, specialist services and treatment options.

CALLS TO ACTION

- Advocate for the implementation of an ICD code for IF and SBS
- Enable primary care physicians and non-specialist clinicians to access referral networks of specialist physicians who can confirm a suspected diagnosis of IF
- Invest in clinical education and training around diagnosis, appropriate care and treatment of IF patients

2. Delivering holistic care for patients

The ESPEN clinical guidelines on chronic IF in adults are the most prominent guidelines on the safe and effective management of the condition.[1]

In addition to ensuring that patients are cared for by an expert multidisciplinary team with a comprehensive care plan, clinical guidelines provide a blueprint for healthcare systems to design and deliver services that meet the specific needs of chronic IF patients (for example training on self-managing HPN).[1]

However, the ESPEN clinical guidelines are not consistently implemented across Europe. For example, a study of 17 IF centres in 6 European countries identified variations in:[17]

- Length of patient hospital stays
- Time spent with patients by HCPs
- Referral criteria
- Availability of centre-specific guidelines

Furthermore, our research has found that only four of 25 European countries have national IF guidelines.[18,19,20,21] Inequality of access to treatment is notable not just when comparing the provision of care between different European nations, but also often within individual countries themselves.[22]

CALLS TO ACTION

- Develop and implement national guidelines for IF care based on ESPEN clinical guidelines
- Identify, and address, barriers to the adoption of consensus guidelines on IF care and treatment
- Equip and resource European Reference Networks (ERNs) to provide leadership to improve Europe-wide health outcomes in IF

3. Providing access to the right treatments at the right time

In addition to ensuring that patients have access to the full range of treatment options in line with European and national guidelines, it is important that policymakers and regulators are made aware of innovations in treatment options and their benefits. This will allow them to understand and make the case for the approval of new therapies where necessary, ensuring that both patients and clinicians have access to the most appropriate treatments.

CALLS TO ACTION

- Ensure funding arrangements are aligned with recommendations the ESPEN clinical guidelines
- Enable conditional reimbursement to provide rapid access to new treatments

4. Collaborating to share best practice and data

There is currently a lack of epidemiological data collected on IF. Only three of 24 European countries have registries specifically for IF,[23,24,25] three specifically for SBS-IF,[23,26,27] and eight specifically for HPN.[23,27,28,29,30,31,32,33]

Enhancing and standardising the collection of epidemiological data on prevalence and outcomes for people with IF between countries, such as data on survival rates on HPN and CVC-related infection, would help policymakers to identify gaps in healthcare services that need addressing.

Countries need to work closely together to agree an approach to collecting and sharing data on prevalence, treatment and outcomes that can be used to drive improvements in care. Policymakers can also drive collaboration by encouraging and funding IF specific patient organisations at national level, which can in turn engage with regional organisations.

CALLS TO ACTION

- Forge partnerships with regional, national and international authorities to collect, monitor and share data on IF prevalence, treatment and outcomes
- Collect and disseminate agreed epidemiology and quality standards within and between countries
- Encourage and fund the establishment of IF specific patient groups at national level

Cristina, Romania

Cristina's life changed dramatically when she was diagnosed with intestinal failure (IF).

Cristina developed complications following surgery for a uterine leiomyoma, which led to her developing SBS-IF. The specialist care she needed was not available in Romania, meaning she was transferred over 1,000 miles away to France for further treatment in 2017. In order to receive the nutrients her body needs to survive, like many other patients in her position, Cristina spends 13 hours connected intravenously to parenteral nutrition (PN).

Just to survive, Cristina must live miles away from her family and friends.

The Romanian health service does not provide access to home parenteral nutrition (HPN) nor the specialist training to doctors and nurses to administer it, meaning Cristina was forced to make the life-changing decision of permanently moving from her home in order to survive.

Cristina found the move stressful and difficult to cope with.

> *"My move to France was life-saving but at the same time it came with trauma. The physical ones are obvious from the medical documents, but I can say that I felt and still feel psychological disorders generated by the lack of family and friends, as well as related to the difficulty of adapting to a country and foreign culture, especially in my condition (low mobility, chronic fatigue, foreign language, administrative difficulties, etc.)."*

Cristina has lived in France since 2017, approximately 80km from Beaujon Hospital where she is still cared for. She has been able to visit her family and friends in Romania just three times since her arrival in France, travelling with all the necessary medical equipment and self-medicating at her own risk. Cristina says:

> *"For me, it is obvious that I am not returning to Romania for good."*

Living with HPN

HPN has kept Cristina alive, although living with the constraints of HPN has been extremely difficult. Under the guidance of her physician, Cristina attempted to wean herself off the daily infusions to a less intense regimen, but found this to be a step too far:

> *"I couldn't rest at night, I couldn't get out of the house much, I couldn't take care of the small things in the household."*

Cristina's hopes for the future

Cristina hopes that, through the efforts of ATLAS, conditions for intestinal failure patients will improve and that parenteral nutrition programs are made more widely available.

> *"I hope that this project will have the desired effect at the European level so that all Member States can make adapted parenteral nutrition programmes available to their citizens. It would help many people, myself included, if I would like to visit my home, or simply go somewhere on vacation".*

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