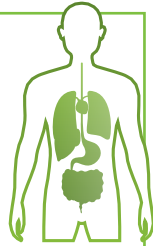


# AIMING FOR BETTER OUTCOMES FOR YOU IN YOUR INTESTINAL FAILURE CARE



## UNDERSTANDING INTESTINAL FAILURE



**Intestinal failure (IF) is the rarest form of organ failure and prevents the body from absorbing the vital fluids and nutrients it needs for survival.**<sup>1</sup> One of the leading causes of IF is short bowel syndrome (SBS).<sup>1</sup> The gold-standard treatment for IF patients is long-term parenteral nutrition and/or intravenous hydration (PN/IV), as it provides the necessary nutritional and fluid requirements to maintain adequate health and/or growth. Although PS provides vital, life-sustaining fluid and nutrient support for patients with chronic IF, this therapeutic approach is associated with potentially serious or life-threatening complications (e.g., risk for catheter-related infection and liver failure).<sup>2</sup>

**IF WE ADDRESS THESE UNMET NEEDS AND UNITE AS A COMMUNITY, WE CAN TURN OUR VISION OF IMPROVED STANDARDS OF CARE INTO REALITY.**

## UNMET NEEDS<sup>3</sup>

## WHAT CAN WE DO?



There is an opportunity to **improve everyone's understanding** of IF.



We encourage patients to **establish IF-specific patient organisations** at a national level.



There is a **need to collect and share health data and align treatment quality standards** within, and between, countries.



We urge patient organisations to call for **more widespread patient registries**.



Current **home and social care provisions are not meeting the quality of life needs** of those with IF and their families.



We ask you to **advocate for the use of relevant quality of life measurement tools** for IF patient assessments.



There is **inadequate research** to drive the much-needed healthcare service improvement.



We want **all voices to be heard**, especially those of patients participating in IF clinical research.



There is a **lack of established reference centres**.



We encourage patients to **engage with patient organisations** to increase their representation and voice in European Reference Networks such as ERN-ERNICA\*.



## 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 IF. The project was formed in 2016 as a response to a lack of awareness, and poor coordination of European standards for 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. In 2018, a policy paper was launched at an event in the European Parliament, and marked a key milestone for the IF community by introducing the issues faced by patients directly to policy makers. The ATLAS programme is funded and initiated by Takeda.

1. PIRONI, L. et al. (2016). ESPEN guidelines on chronic intestinal failure in adults. Clinical Nutrition. 35, 247-307. 2. HOFSTETTER, S. et al. (2013). Key issues in addressing the clinical and humanistic burden of short bowel syndrome in the US. Current Medical Research and Opinion. 29(5). 495-504. 3. SCHNEIDER, S. et al. (2017). ATLAS - Transforming the vision - Giving chronic intestinal failure patients the care they need - a call to action. Shire International. 2-4.

\* ERN-ERNICA is the European Reference Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies. ERN-ERNICA has a working group on intestinal failure.

