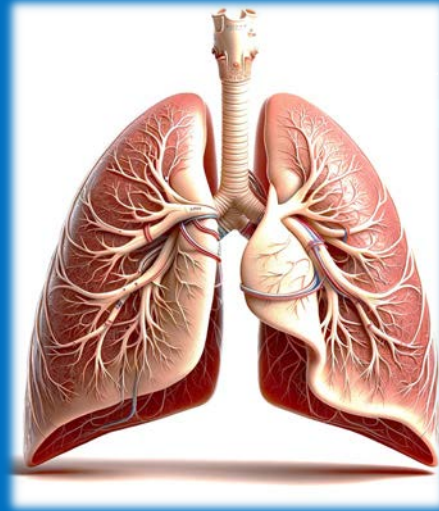
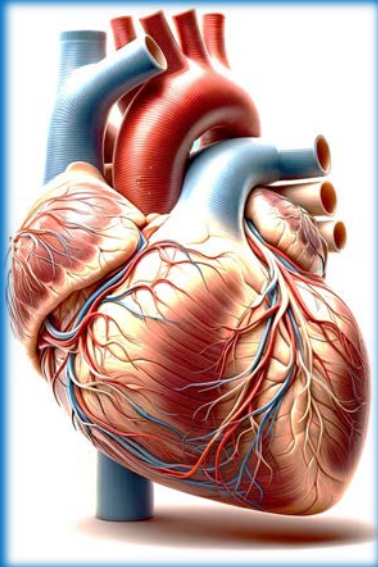


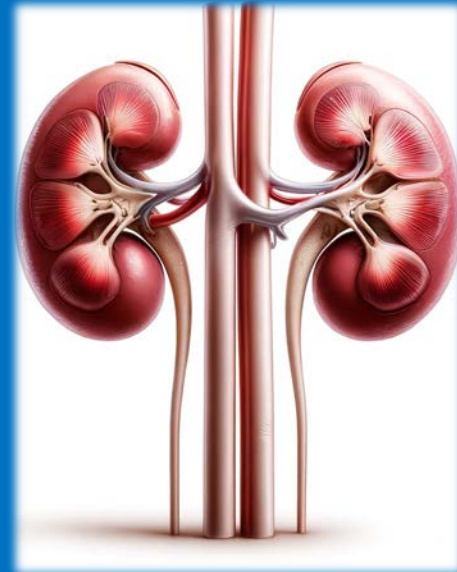
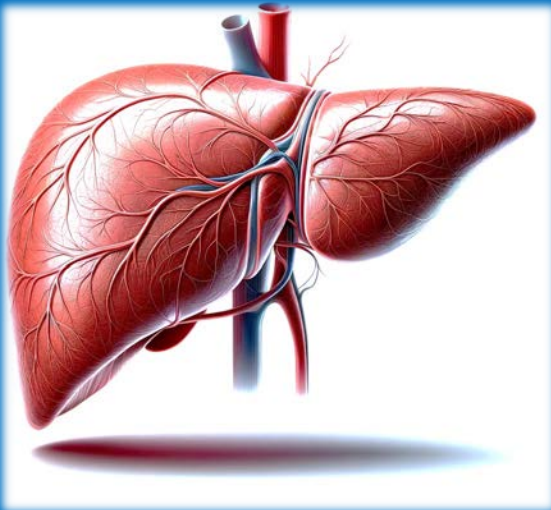
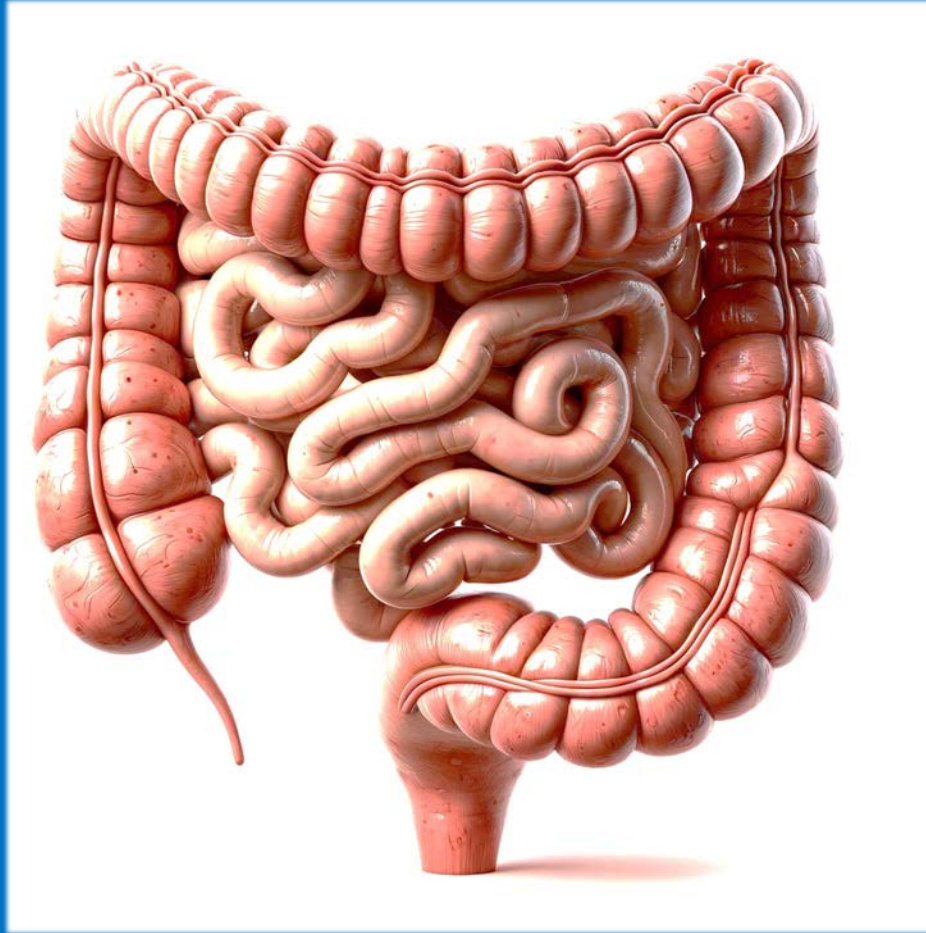
# Investing in Health: Transforming lives through Intestinal Failure Awareness

A campaign by the Optimal Nutritional Care For All (ONCA) and  
the IF Awareness Steering Committee

Simon Lal  
Marek Lichota  
Stéphane Schneider  
Joost Wesselink



nal care  
for all



# Intestinal failure

The reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth

Intestinal insufficiency: the reduction of gut absorptive function that doesn't require intravenous supplementation to maintain health and/or growth

# Types of intestinal failure

		Description	Duration	Examples	Goals of management
Type I	Acute IF I	Acute condition. Other organ dysfunctions often present. AIF often self-limiting when other organ dysfunctions corrected.	Days	Paralytic ileus postoperatively or as a part of MODS	Survival of acute phase. Stabilization of homeostasis. Resolution of IF.
Type II	Acute IF II	Prolonged acute condition. Continuing metabolic instability.	Weeks to months	Recurrent abdominal sepsis with or without fistulation. Acute phase of short bowel syndrome?	Achievement of steady-state without sepsis and other organ dysfunctions. Resolution of IF or moving to chronic IF.
Type III	Chronic IF	<b>Chronic organ failure without concomitant acute organ dysfunctions. Steady-state condition.</b>	Months to years	<b>Short bowel syndrome Intestinal dysmotility</b>	<b>Maintenance of homeostasis. Optimization of nutritional and wound status. Restoration of the gut integrity where possible.</b>

## How to participate?



1

Go to [wooclap.com](https://wooclap.com)

2

Enter the event code in the top banner

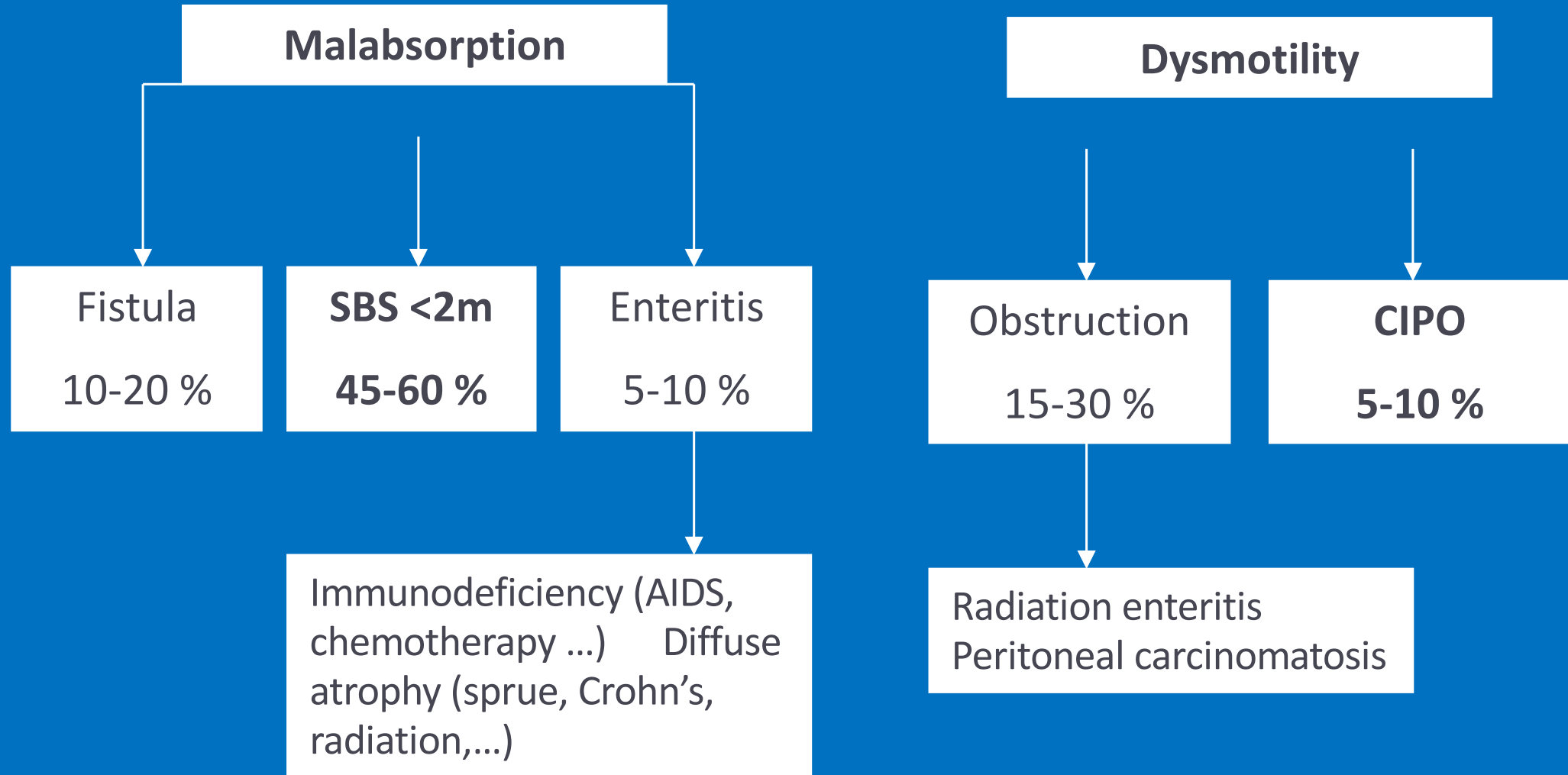
Event code

**FFNPYU**





# Causes of intestinal failure

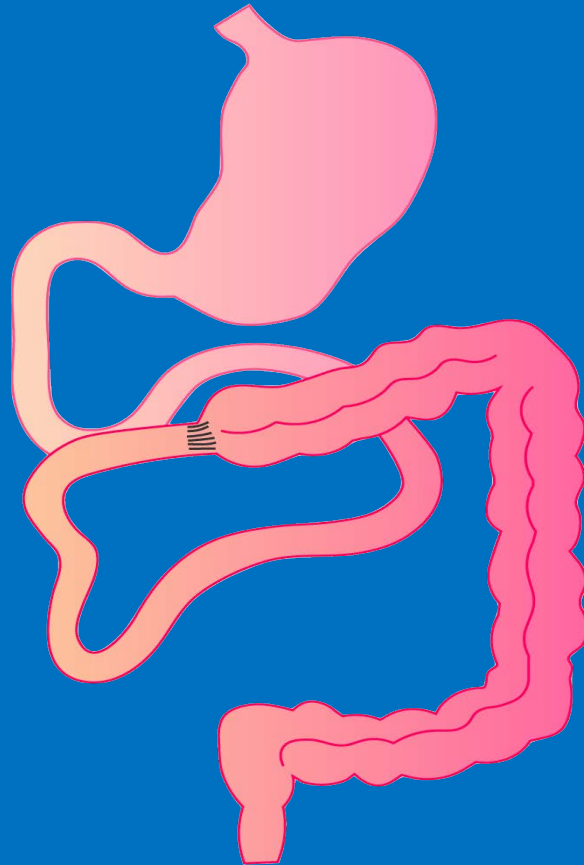




# Main types of short bowel syndrome

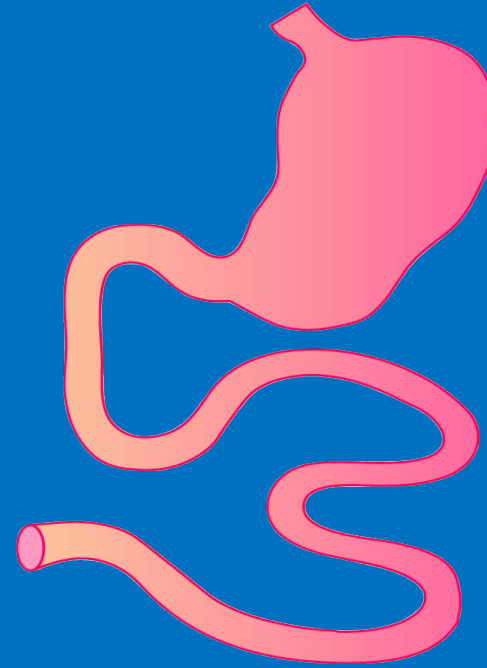
## Jejunocolic anastomosis

- Ileum and some of jejunum resected leaving jejunocolic anastomosis

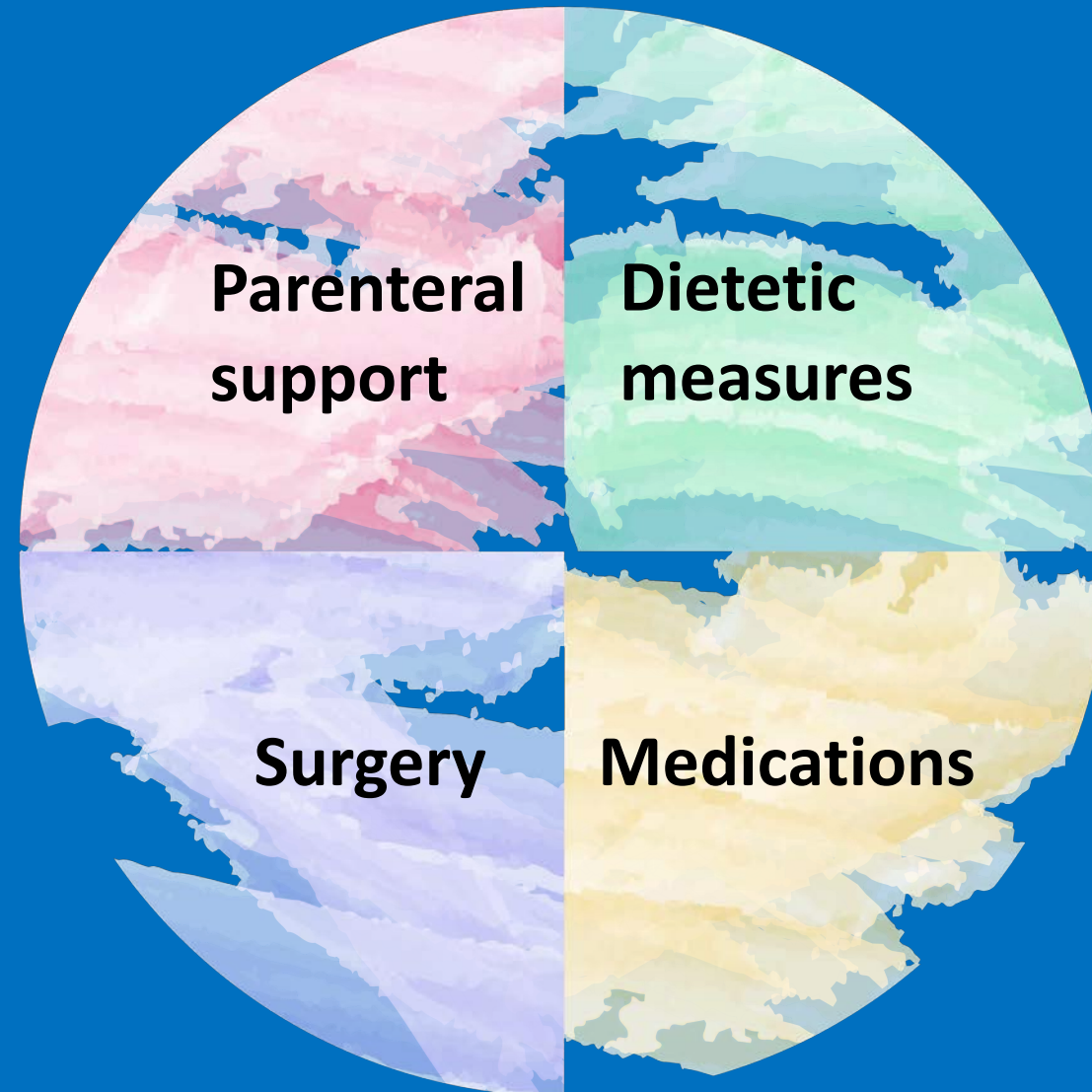


## Jejunostomy

- Colon, ileum and some of jejunum resected, leaving a jejunostomy

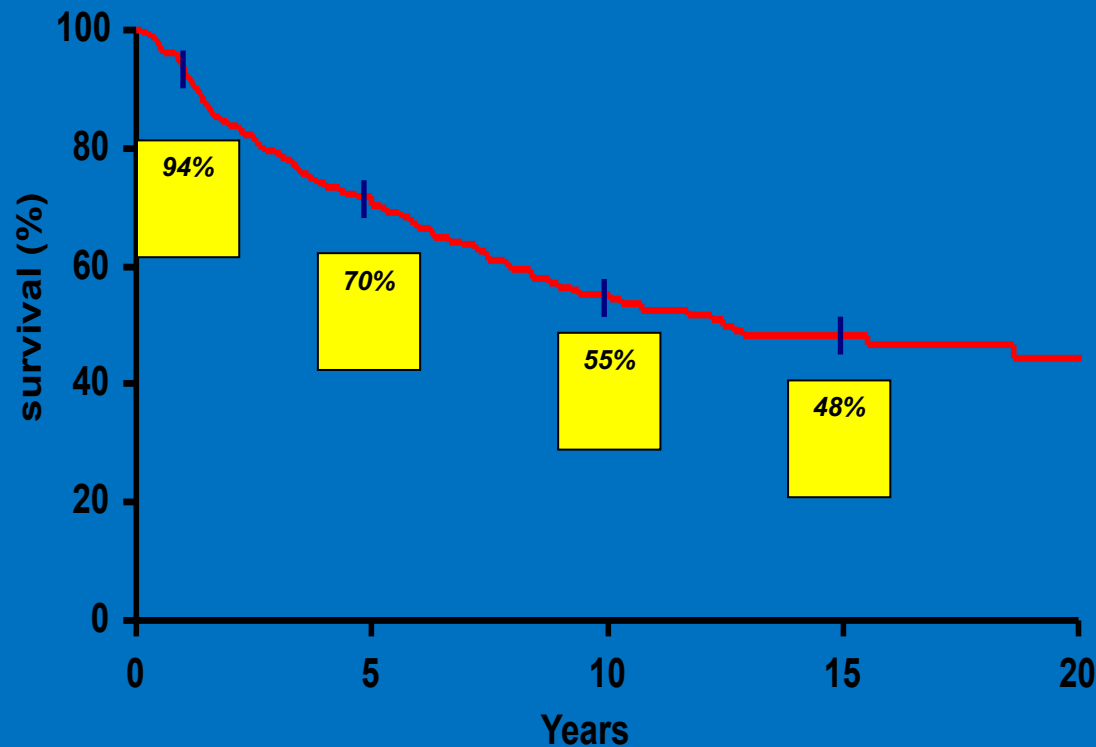


# Principles of IF therapy





# Outcome of HPN patients



- ▶ 308 SBS-IF patients
- ▶ Mean follow-up of 4.5 (0.1 – 30) years
- ▶ Mortality: 33% (n=113)
- ▶ Dependency: 60% at 2 years, 43% at 5 years

- ▶ Comorbidities
- ▶ Loss of venous access
- ▶ Compliance
- ▶ Quality of life
- ▶ Professional activities

# Patient case study



## Cristina, Romania

“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.”

- Cristina was diagnosed with IF following complications from uterine leiomyoma surgery, relies on parenteral nutrition for survival.
- Lack of specialist care in Romania forced her to travel over 1,000 miles to France in 2017, where she continues to receive care.
- Unable to access home parenteral nutrition in Romania, Cristina made the life-altering decision to permanently move to France, living apart from family and friends.
- Despite the challenges of HPN, Cristina attempted to reduce the intensity of daily infusions under medical guidance but faced difficulties in managing daily activities.
- Cristina expresses hope for improved conditions for intestinal failure patients through initiatives like these, advocating for broader availability of parenteral nutrition programs.

# History of ATLAS: steering group



Professor  
**Stéphane Schneider**  
France  
Chair of ATLAS Steering Committee  
Archet Hospital



Professor  
**Francisca Joly**  
France  
Hospital Beaujon AP-HP



Professor  
**Palle Jeppesen**  
Denmark  
Rigshospitalet



Professor  
**Stanislaw Klek**  
Poland  
Stanley Dudrick's Memorial  
Hospital



Professor  
**Greger Lindberg**  
Sweden  
Karolinska University  
Hospital



Professor  
**Loris Pironi**  
Italy  
St. Orsola-Malpighia Hospital



Professor  
**Miguel Leon-Sanz**  
Spain  
University Hospital Doce  
de Octubre



Professor  
**Simon Lal**  
UK  
Salford Royal NHS  
Foundation Trust



**Luisa Avedano**  
Belgium  
CEO, EFCCA



**Marek Lichota**  
Poland  
CEO, Appetite for Life  
IF patient



**Carolyn Wheatley**  
UK  
Chair, PINNT  
IF patient



# Six unmet needs

**1.**

Chronic IF is treatable, but access to treatment is unequal between and within countries.

**2.**

There is a need to disseminate agreed epidemiological and quality standards within and between countries.

**3.**

There is an opportunity to improve the education of stakeholders.

**4.**

The current home and social care are inadequate to ensure the quality of life for people with chronic IF and their families.

**5.**

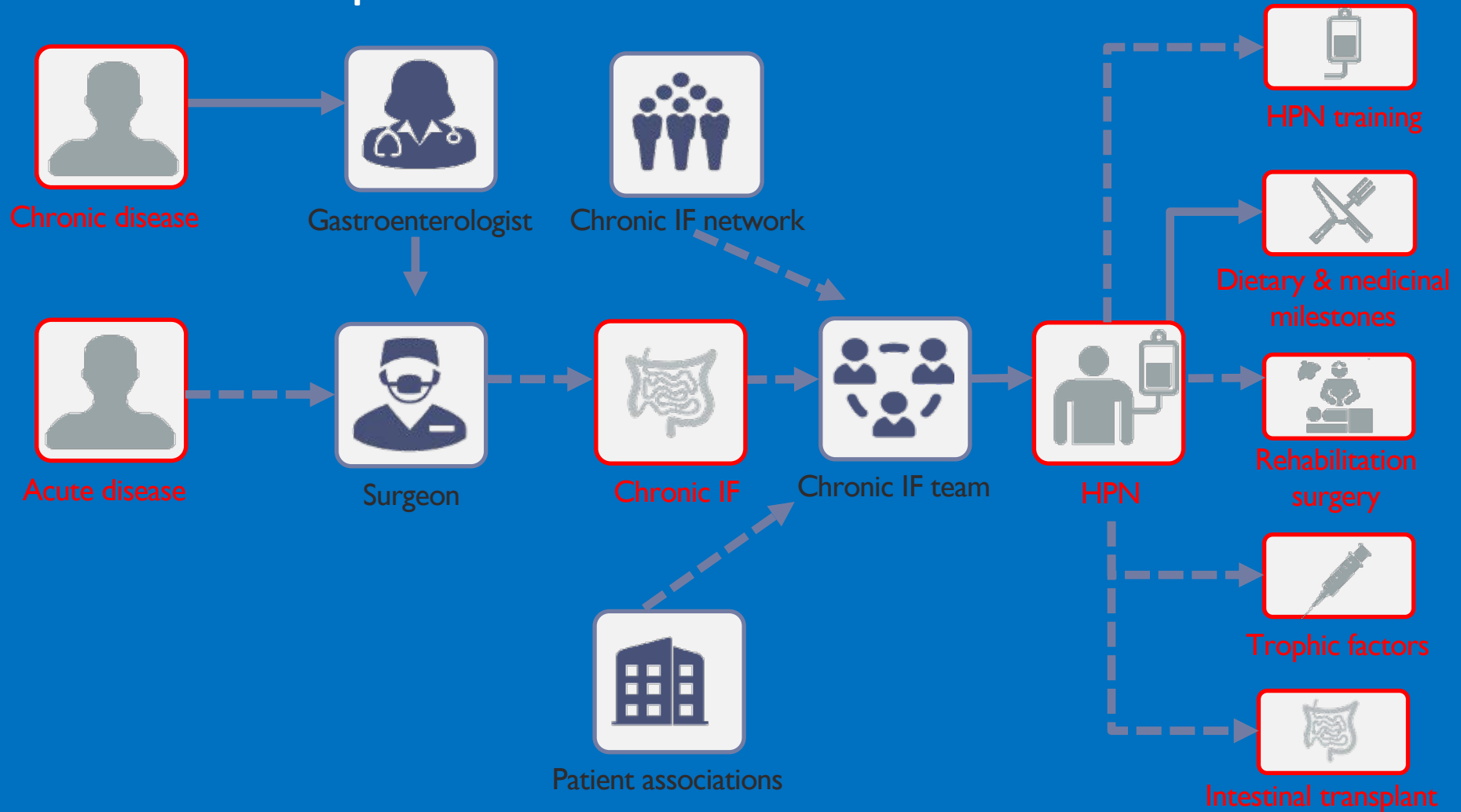
Research is inadequate to drive service improvement.

**6.**

There is a lack of accredited reference centres.



# Clinical landscape of CIF



# History of ATLAS: accomplishments



# The IF Awareness Steering Group

The IF Awareness Steering Committee was initiated by ONCA with some of the founding members of the ATLAS steering committee, and included expert clinicians and patient groups from across Europe



**Our vision is for all IF patients in Europe to receive an equal standard of care by 2030**

# The 2024 – 2030 IF Awareness Campaign

This campaign aims to raise awareness about (chronic) intestinal failure (IF), a condition characterized by insufficient nutrient absorption due to reduced gut function. It will leverage existing events like Optimal Nutritional Care for All (ONCA) and EU4Nutrition to expand its reach through various platforms and partnerships.

The focus is on advocating for access to specialized, patient-centred care and therapies, including home parenteral nutrition, to improve patient outcomes and quality of life. Disparities in access to care and reimbursement systems across Europe underscore the need for greater awareness among healthcare professionals (HCPs) and policymakers.

The campaign will engage stakeholders such as professional societies, patient organizations, and decision-makers to address diagnosis, equity in care, and the patient perspective. Patient stories will be central to highlighting the impact of IF on daily life and advocating for better support and resources.

# Key gaps

 Chronic IF is treatable, but there is inequity of access to treatment between and within countries

 Home & social care are inadequate to meet the quality of life needs of those living with chronic IF and their families

 There is a lack of accredited reference centres

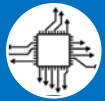
 There is inadequate research to drive service improvement



# Key messaging



Equity of access to IF treatment between and within countries



We need home & social care meeting the quality of life needs of those living with chronic IF and their families, so that...



Establish more accredited reference centres for collaboration



We need adequate research to better understand intestinal failure needs and drive service improvement



There is a need to disseminate agreed epidemiology and quality standards within and between countries



There is an opportunity to improve stakeholder education

# Quality-of-Care Standards in Adult Type 3 IF caused by benign disease: European Society of Clinical Nutrition and Metabolism (ESPEN) Position Paper.

Lal S et al. *In Draft (Delphi round completed February 2024)*

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## Structure

- Referral criteria.
- Multi-disciplinary team staffing, experience & education.
- Clinical services, facilities & networks.

## Process

- Waiting list management
- In-patient care, optimisation & Home PN commencement.
- Outpatient & emergency care, with local hospital networking.

## Outcomes

- Service delivery (e.g. waiting times, length of stay, readmission rates)
- IF & Home PN-related complications: morbidity and mortality.
- Quality of life: patients & families.



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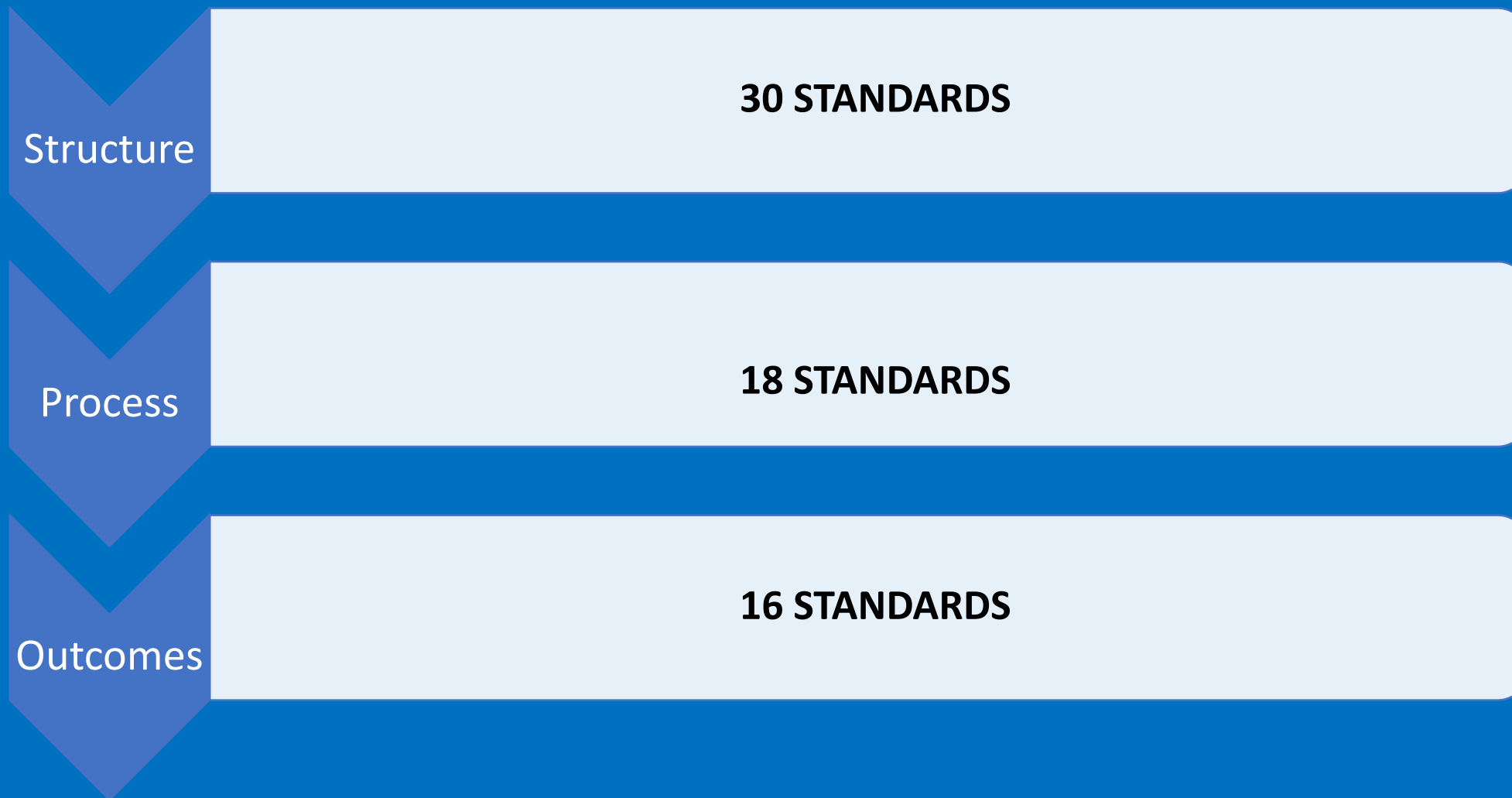


- Standards drafted by ESPEN CIF-HAN committee.
- Modified Delphi process: CIF centres contributing to the ESPEN database.
- Grade: 'essential', 'recommended' or 'not required'.
- *Aimed at defining optimal care, not current practice.*

# Quality-of-Care Standards in Adult Type 3 IF caused by benign disease: European Society of Clinical Nutrition and Metabolism (ESPEN) Position Paper.

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Structure

- Referral criteria

Standard	Essential	Recommended	Not required
There is a service that provides advice and, when referral criteria are met, clinical care of patients with type 3 IF.	94%	6%	0
Services should have a referral proforma available to local hospitals and linked to the patient's records to ensure consistency of clinical details and aid transfer of care.	58%	42%	0%

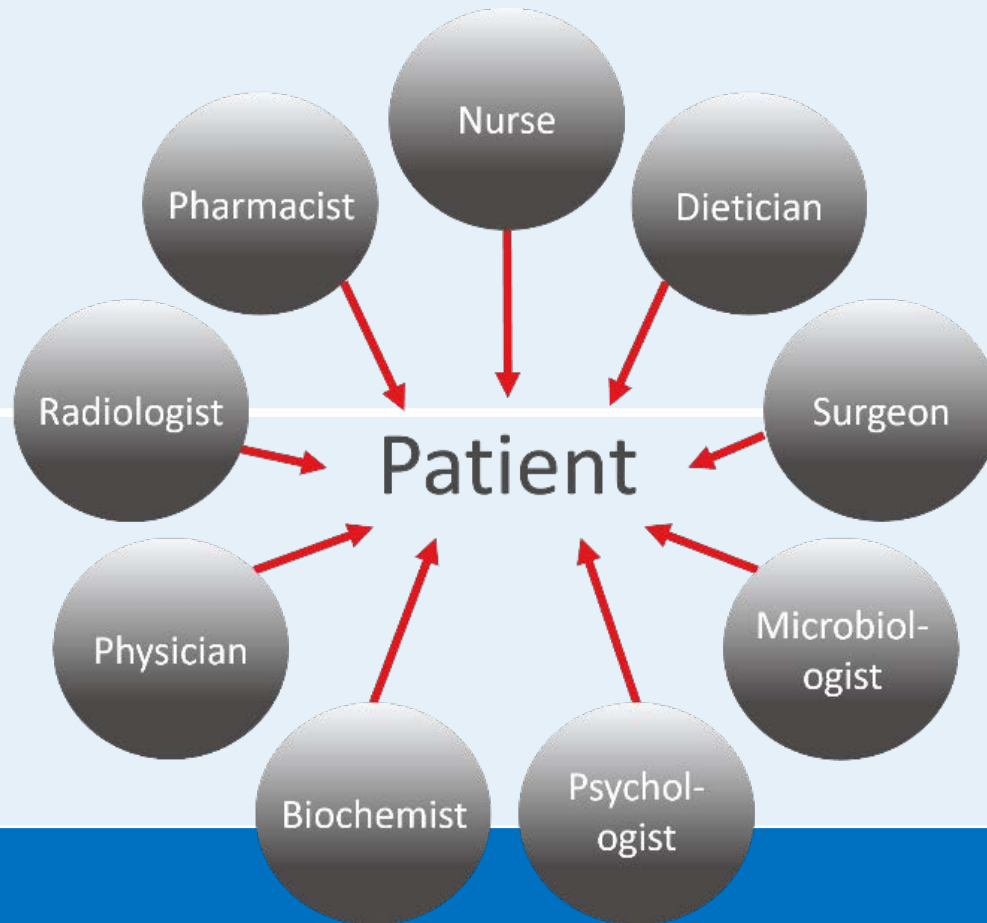
## Structure

- **Multi-disciplinary team staffing, experience & education**

Standard	Essential	Recommended	Not required
Chronic IF services should have at least 20 ongoing HPN-dependent adults in order to maintain the multi-disciplinary team's (MDT) skill base. This should include a minimum of 10 new patients per year.	40%	42%	18%

## Structure

- Multi-disciplinary team staffing, experience & education



- Minimum number of each discipline.
- Specific expertise (e.g. CVC handling according to local/national protocol)
- Cross-cover arrangements.
- Inter-disciplinary referral pathways.
- Education and continued professional development.

## Structure

## • Clinical services, facilities &amp; networks



- Dedicated IF ward area.
- Intensive care unit.
- Vascular access & Interventional radiology.
- PN pharmacy production.
- Clinical policies & protocols.
- Patient forum and feedback.
- Governance structure.

## Process

- **Waiting list management**

<b>Standard</b>	<b>Essential</b>	<b>Recommended</b>	<b>Not required</b>
The service monitors its elective waiting list and ensures that all accepted referrals are transferred to its site within 2 weeks or managed remotely within 24-48h of receipt of referral containing all required clinical information from the referrer.	52%	14%	3%
The service provides clinical advice as needed to the referring unit prior to transfer.	68%	32%	0%

## Process

- In-patient care, optimisation & Home PN commencement.

Standard	Essential	Recommended	Not required
The service provides daily ward rounds and urgent attention at all hours for in-patients, including those readmitted with HPN/CIF-related complications. This can be provided in collaboration with another service, such as gastroenterology.	73%	23%	3%
The service can establish patients on a HPN regime and can train patients or family members/carers to be independent with their procedures, where appropriate.	87%	13%	0%



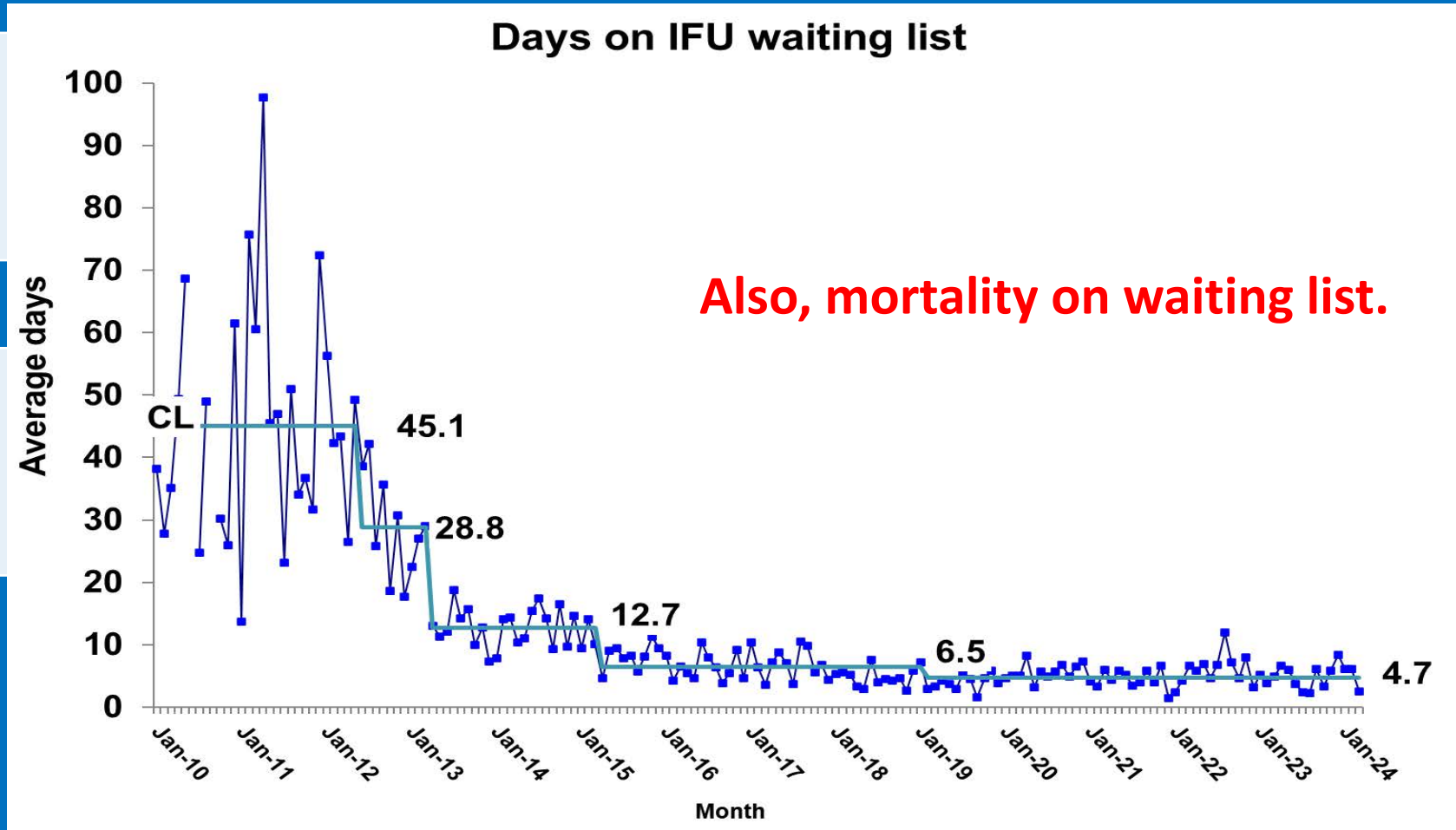
## Process

- **Outpatient & emergency care, with local hospital networking**

Standard	Essential	Recommended	Not required
All appropriate disciplines are available for all HPN out-patient clinic reviews, including a physician and dietitian and, where required, a nurse and/or pharmacist.	77%	19%	3%
The service has close networks of care with local hospitals where HPN-dependent patients are likely to present with HPN/CIF-related complications. This may include dissemination of appropriate management protocols and development education networks for local nutrition support teams and provision of advice for immediate treatment or arrangement for timely patient transfer to the chronic IF service where required.	43%	57%	0%

- Service delivery (e.g. waiting times, length of stay, readmission rates)

# Outcomes



## Outcomes

- IF & Home PN-related complications: morbidity and mortality

Standard	Essential	Recommended	Not required
The service monitors its in-patient catheter-related blood stream infection rates.	83%	17%	0%
The service monitors its out-patient catheter-related blood stream infection rates.	86%	14%	0%
The service aims to achieve an out-patient catheter-related blood stream infection rate that is less than 1 episode per 1000 catheter days	77%	20%	3%
The service monitors HPN catheter salvage rates.	62%	38%	0%

## Outcomes

- **Quality of life: patients & families**

<b>Standard</b>	<b>Essential</b>	<b>Recommended</b>	<b>Not required</b>
The service monitors HPN weaning rates and associated timeframes, detailed according to underlying pathophysiological mechanism and, where appropriate, intestinal anatomy.	53%	40%	7%
The service monitors the quality of life of patients using a validated tool.	27%	63%	10%

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# What needs to be done?

With the vision of the steering committee being for all IF patients in Europe to receive an equal standard of care by 2030, what can be done?

This vision can become a reality by working with stakeholders across Europe to:

- Increase the awareness of IF
- Improve the diagnosis rate of IF
- Facilitate the sharing of clinical excellence across borders
- Alert the scientific community to inequalities in the provision of care
- Quality standards for IF, including access to specialist expertise

Sharing **patient's story** is a **powerful way to inspire, change and raise awareness** about particular medical condition. **Impact** is **multifaceted** and **long-lasting** (1)

Wide coverage of ONCA member has got potential to gather patient stories and put them in central to highlight the impact of IF and nutrition therapy on daily life and **advocating for better support and resources.**



## HOW TO ACHIEVE THIS?



Raising awareness of Intestinal Failure (IF) and the current IF and nutritional care landscape.



There is a lack of accredited IF reference centres. Centers of excellence have the ability to dramatically enhance the depth and breadth of healthcare services available in communities.

The shift from **volume** to **value** in healthcare delivery is promising **step forward** in truly **addressing patients' needs**, **improving patients' experience** while **cutting** unnecessary costs.



## HOW TO ACHIEVE THIS?



Supporting with the continued development of centers of excellence across Europe

Engagement with Patients Advocacy Groups (PAGs) and policy makers can directly influence access to treatment at national and EU level.



## HOW TO ACHIEVE THIS?



Advocating for IF & optimal nutrition care to be included on the political agenda

# Strategy



# Campaign activities



**Manifesto on IF awareness and implementation**



**IF Day February 1<sup>st</sup> 2025 ('1F Day')**

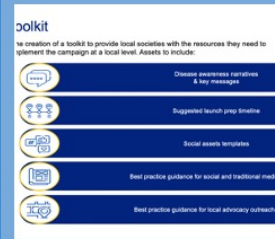


**Malnutrition Awareness Week -> IF (webinar/toolkit)**

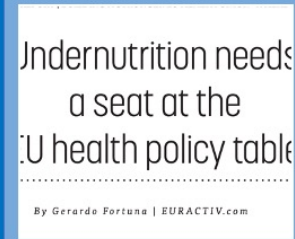


**Survey**  

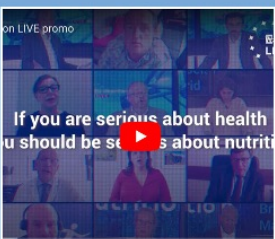


**Toolkit policymakers and HCPs**



**Opinion Editorial**




**Webinars**



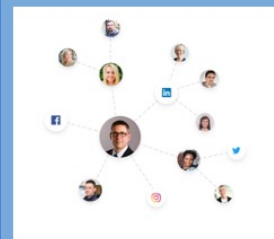
**Policy Seminars**



**Local patient forum**



**Good practice sharing**



**Online/socials communication**



# 1F - 1st of February - IF AWARENESS DAY

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## ❑ GET INVOLVED ( DEDICATED CONTENT SHAREABLE BY ALL ONCA MEMBER COUNTRIES)

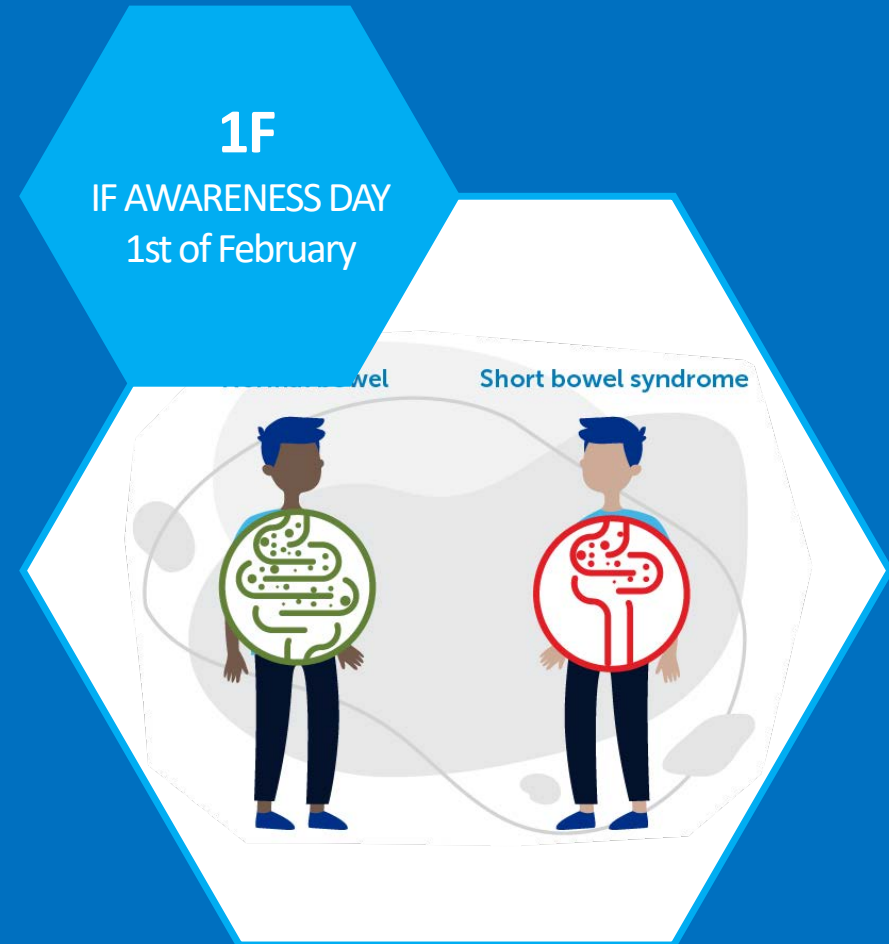
- IF DAY OFFICIAL VIDEO,
- SOCIAL MEDIA (HASHTAG, GRAPHICS, PROFILE FRAMES, BANNERS)
- KEY STATISTICS AND INFOGRAPHICS
- TELL YOUR STORY (WRITTEN OR VIDEO TESTIMONY)
- BECOME IF DAY FRIEND (IF FRIENDS DATABASE)
- CONTACT PRESS
- GET POLITICAL (LOCALLY, EU, MEP's)

## ❑ IF EVENT ORGANISATION

- ON-LINE IF WEBINAR/SYMPOSIUM
- IF WALKATHON, SPORTING EVENT (CENTRAL/LOCAL)
- ILLUMINATE A BUILDING
- HOST AN IF ART/PHOTOGRAPHY EXHIBIT

## ❑ DOWNLOADABLE TOOLKITS, COMMUNICATION MATERIALS

- ILLUMINATIONS TOOLKIT (BUILDING, HOME)
- EQUITY TOOLKIT
- SCHOOL TOOLKIT
- DIFFERENT LANGUAGES









## IF & NUTRITION WEBINARS/PODCASTS

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### □ WEBINARS FOR HCP & MEDICAL STUDENTS

- DIAGNOSIS OF IF
- STANDARDS OF CARE
- IF IN GENERAL PRACTITIONER OFFICE
- ORAL DIET IN IF

### □ WEBINARS FOR PATIENTS

- UNDERSTANDING IF
- DIAGNOSIS AND THERAPY OPTIONS
- TRANSITION FROM CHILD TO ADULT CARE
- NAVIGATING LIFE WITH IF
- WHERE AND HOW I FIND SUPPORT







# Messaging

It's crucial that everyone, regardless of where they live, has **equal access** to treatment for intestinal failure (IF). We must ensure that **home and social care services** meet the needs of those with chronic IF and their families, leaving no one behind.

To achieve this, we need to establish more **accredited reference centres** where experts can collaborate to improve IF care. **Investing in research** will help us better understand the needs of those with IF and drive improvements in services. Sharing agreed-upon **epidemiological data and quality standards** within and across countries is essential.

There's a significant opportunity to **enhance the education** of healthcare professionals, patients, and policymakers about IF. By increasing **awareness and understanding**, we can work together to ensure that everyone affected by IF receives the support and care they deserve.