



International Conference

optimal  
nutritional care  
for all

# MALNUTRITION: FROM AWARENESS TOWARDS CONTROL

A NUTRITIONAL CARE POLICY SUMMIT

Turin 6 & 7 June 2024





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# Uniting Patient leveraging the Patient Associations

ONCA CONFERENCE 2024

Turin June 6 – 7

Sergio Settanni – Marek Lichota

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**Sergio Settanni**

**Father of a 15 years old Daughter  
Affected by CIF and with total PN  
for 17 h/day 7 day/week**

**Member of the Association  
Un Filo per la Vita Onlus**



**ITALY**

**Marek Lichota**

**Crohn's Patient, SBS-IF,  
HPN dependend since 2008.**

**Dietitian, HAN patient advocate,  
Founder & Chairman of the  
Association 'APPETITE FOR LIFE'**



**POLAND**





## About Un filo per la vita Onlus

The Association Un Filo per la Vita Onlus represents and protects at national level every people with CIF (Chronic Intestinal Failure) a rare disease that doesn't give the right intestinal functionality. The patients affected have to resort to the artificial nutrition or at the transplantation of bowel to survive

The Association was founded in 2005 by parents of children on Home Artificial Nutrition

*Un Filo la Vita*

MISSION  
to protect patients

to improve the quality of life of patients

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# APPETITE FOR LIFE ASSOCIATION...



**EMPOWER, EDUCATE,  
SUPPORT AND UNITE**

IF & HAN PATIENTS  
AND THOSE WHO  
SUFFER FROM IBD.

**APPETITE FOR LIFE WAS FOUNDED IN 2012**

WE STRIVE FOR IMPROVEMENT  
OF STANDARDS OF IF CARE FOR THOSE  
WHO CANNOT EAT OR DRINK NORMALLY  
DUE TO MEDICAL REASONS





# Parental Nutrition as a life saver treatment in the Intestinal Failure patients

To achieve the objective of an Optimal Nutritional Care for All it is fundamental that:

- All disease requiring Parental Nutrition to support the patient life needs to be diagnosed and recognized in due course and dealt with a proper protocol to ensure:
  - The achievement of a minimum Standard of Care for the treatment of the specific disease of each patient
  - A common approach to the support of the patient independently from the place where the patient is leaving or requiring support.

Ideally this should be available:

- In each Health System of any given Region, Nation part of the European Community





## Intestinal Failure as a rare Disease. Status as of today in Europe

The intestinal Failure has been inserted in the European list of rare disease under the Orphanet code 294422.

Despite this acknowledgment at European level, several of the Member States (including Italy) have not recognized the IF in their list of Rare diseases with same exception for some pathology which have been included or for some region or provinces.

With the above situation, patients can be properly treated and supported only based on where they live, or if they can support long travels for being followed by a centre that recognize their pathology and has a proper protocol.

So we are still far from having a standardized treatment for all.





## The role of the IF Patient Associations

Because of the scattered recognition of the disease, IF parent association were initially born with the intention to:

- Support new patients affected by IF but leaving in a Country/Region/Province with poor support.
- Share best practices with the other patients to improve quality of life.
- Network with each other just for the need of being connected.
- Interface with the Health system to create proper representativeness and interest where missing.

But then the role of the Patient association evolved to support the recognition of the IF as a a rare disease in the National Health system but also trying to support it in the wider European area.





## The importance to interface with different Stakeholders

For the IF patient associations is important to interface not only with Patients and their families, but to achieve the objective to have IF recognized as a chronic disease it is important to start a dialogue with:

- The Medical and Scientific society
- The Local and national Health System
- The Local Politic including the technical team supporting the Ministry.
- Network with other associations to increase the representativeness and the impact when dealing with the Authorities

**Multi Stakeholder network which requires time and dedication.**





## Leveraging the Associations to develop and share Best practices

It is of paramount importance that Best Practice sharing done at local level is extended at European level to speed up the implementation of proper protocols everywhere.

How to Identify a best practice:

- Positive Impact on the Patient, their family and care giver
- Positive Impact on the work of the Doctors
- Reduction of the overall cost of treatment thanks to a proper diagnose and timely application of the proper protocol.

Let's start to include in the return of investment calculations, the positive effect of a well and timely managed situation, the improvement of the quality of life for patients and their family, the reduction of the total cost for the society to support the patient.





# Italian Best Practices

## Creation of a Manifest to support the proper information and alignment of authorities and medical community, while working to improve the support of the CIF patients

- Recognition of CIF as a rare disease for all regions
- Standardization of treatment for all patients
- Definition of Centers of Excellence with an Hub & Spoke multidisciplinary approach
- Timeliness in the diagnosis and eventual hospitalization of affected patients
- Improved specific Training for Healthcare professionals
- Greater support to Caregivers
- Improve the process to recognize the disability
- Promote research and development



**2. Omogeneità e appropriatezza degli standard di cura delle persone con IICB, inclusa la nutrizione parenterale domiciliare**

Si registrano enormi differenze nella presa in carico e nel trattamento del paziente a causa della mancanza di un percorso terapeutico codificato a livello nazionale. L'erogazione della nutrizione parenterale domiciliare (NPD) dovrebbe, infatti, corrispondere agli stessi standard clinico-organizzativi sul territorio, per garantire a tutti i pazienti pari opportunità di accesso ad una terapia sicura ed efficace. Una erogazione inappropriata espone il paziente ad un maggior rischio di complicanze, con ripercussioni in termini di costi sociali e sanitari. È quindi necessario un percorso standardizzato della NPD, anche attraverso linee guida o atti di indirizzo nazionali.

**6. Maggiore supporto al caregiver**

Il supporto al caregiver (familiare o altra persona dedicata) è essenzialmente condizionato dal grado di autonomia che il paziente riesce a conquistare e l'elemento più impattante sulla qualità di vita è la nutrizione parenterale domiciliare. Pertanto, la qualità dell'erogazione di tale terapia, soprattutto in termini di assistenza, è un elemento fondamentale nel fornire un supporto adeguato al caregiver. È inoltre auspicabile, vista la complessità e la cronicità dell'IICB, offrire percorsi di educazione al paziente e al caregiver.

**7. Timeliness in the diagnosis and eventual hospitalization of affected patients**

La criticità riscontrata nei Centri di riferimento è il ritardo del paziente, il mancato riconoscimento del rischio di complicanze, e la probabilità di riabilitazione, disabilità, peggioramento della qualità di vita e, quindi, maggiori costi a carico del sistema sanitario. È necessario assicurare una precoce presa in carico del paziente e, quindi, un tempestivo riconoscimento del rischio di complicanze, individuando i Centri di riferimento, individuando i Centri di riferimento, individuando i Centri di riferimento.

**8. Promote research and development**

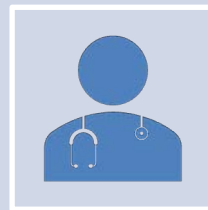
La ricerca, dalla patogenesi alla diagnosi, è fondamentale per il miglioramento della conoscenza sull'IICB e sulle numerose e diverse condizioni morbose che ne sono causa al fine di garantire maggiori possibilità di cura e migliorare la qualità di vita dei pazienti. Il pieno raggiungimento di questo obiettivo implica la necessità del riconoscimento della IICB come malattia rara, anche al fine di poter usufruire dei fondi e degli incentivi previsti per le malattie rare e il sostegno alla ricerca.



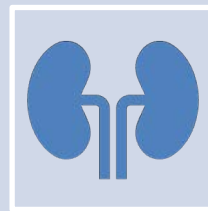


## Italian Best Practices

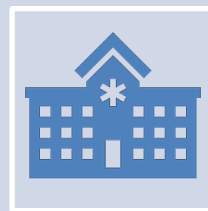
Together with other 9 National association supporting patient affected by disease to the Gastrointestinal system requiring Enteral or Parental Nutrition a document has been discussed agreed and presented to INPS (Social Security System in Italy) to:



Support the commission that evaluate the Patient to provide the status of Rare disease with experts Doctors that are working in the Centers of Excellence even remotely to avoid un needed additional costs for further visit following an improper evaluation of the condition.



Remove the need to revise the condition of the patient in case of presence of inadequacy of organ since the pathology cannot have any significant improvement in time, saving time and money to the patient but also o the health system.



Create a workstream with the Scientific Community, the Commission and the Patient Association to uniform the evaluation of the cases and support a standardization of treatment for the patients.





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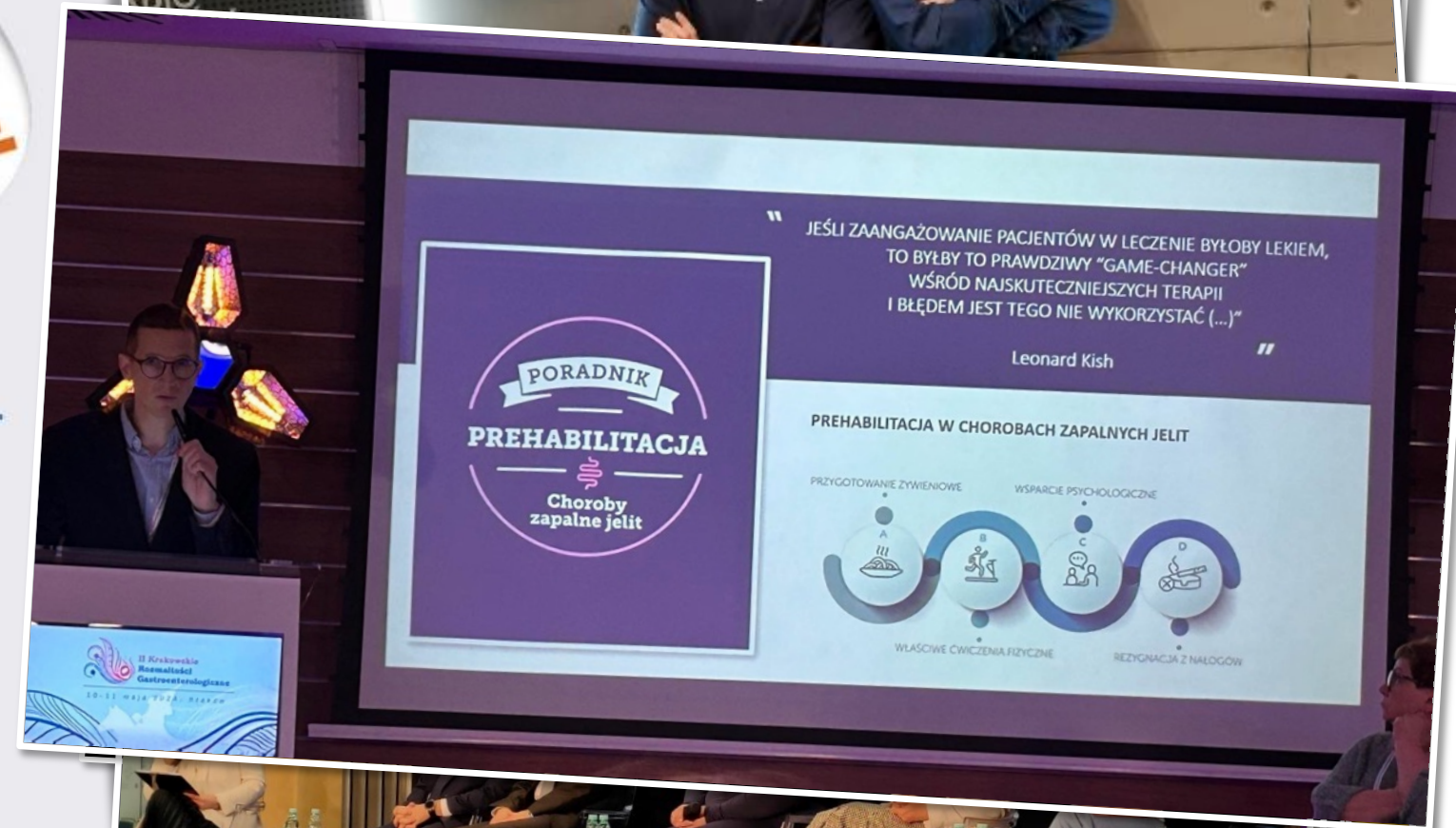
## EDUCATION & RAISING AWARENESS



- ✓ ORGANIZATION OF EDUCATIONAL CONFERENCES AND WORKSHOPS FOR PATIENTS AND THEIR FAMILIES
- ✓ SHARING PATIENTS PERSPECTIVE AT CONGRESSES FOR HCP & PAGs
- ✓ LAUNCHING IF, HAN & IBD CAMPAIGNS AND MEDIA ACTIVITY



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# PATIENT ADVOCACY & POLICY ENGAGEMENT

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- ✓ PROACTIVE COMMUNICATION & MEETINGS WITH **MoH, NHF, HTA AGENCY** (other HEALTH related INSTITUTIONS)
- ✓ PATIENT ADVOCACY AT **POLISH & EU PARLIAMENT**





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# PATIENT EMPOWERMENT & SUPPORT

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WE GOT BACK THE 'APPETITE FOR LIFE' OF MANY PATIENTS, WHICH STRIVE TO TAKE A PART IN THEIR LIFE ON THE FULL BASIS.





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# SUPPORT FOR THE UKRAINIAN PATIENTS

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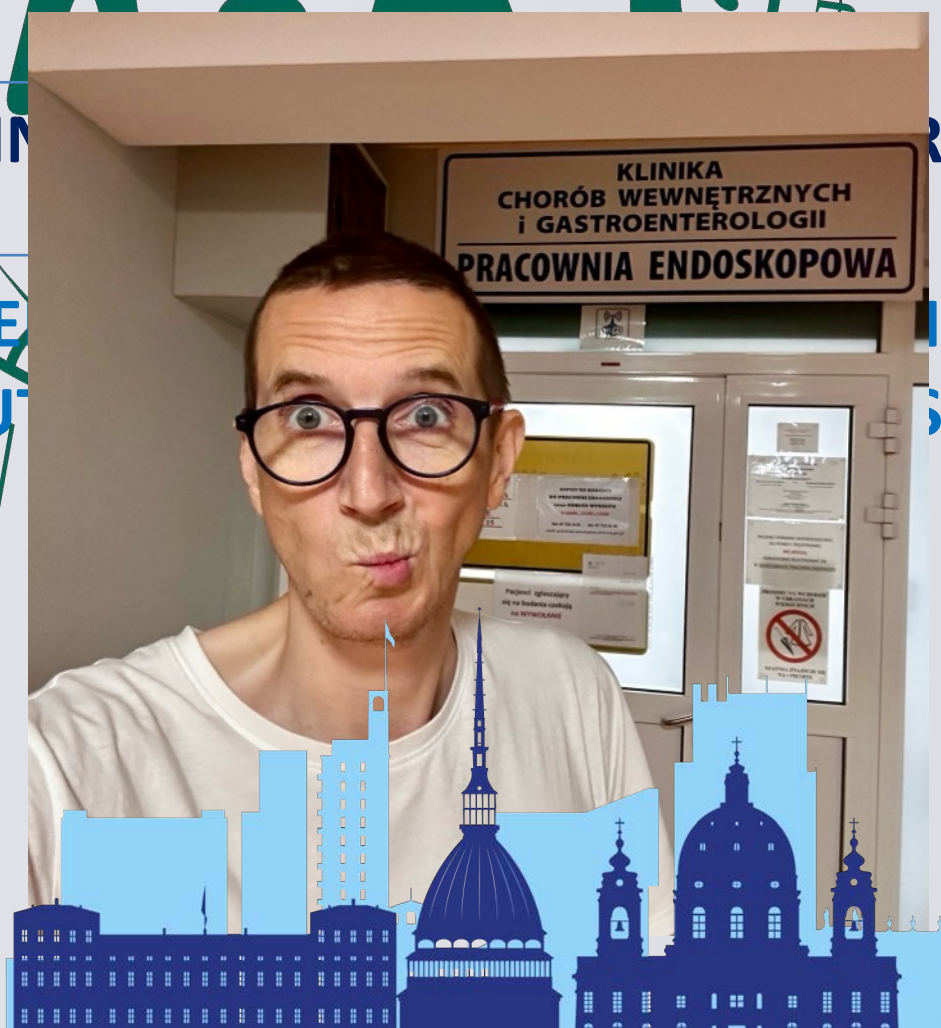




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# UNITING IF PATIENTS' VOICES ARE WE READY TO ACCEPT THE CHALLENGE?

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## Leveraging the network

IF Patient associations are generally locally based and mostly support by patients, or patient's parents.

The complexity of Stakeholders to be involved in the process to recognize the rare disease is such that it is of paramount importance that we could leverage the Scientific Community, the Political connection that other Association either European or local might have to support each other to achieve the common goal

**OPTIMAL NUTRITION CARE for ALL**

**THANK YOU**

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