

**PRESENTE E FUTURO NELLA GESTIONE  
CONDIVISA DELLA INSUFFICIENZA  
INTESTINALE CRONICA BENIGNA:**

*l'unione fa la forza*



Sabato  
**DICE  
MBRE 6** Genova  
Hotel Continental



# ***IICB, si amplia lo scenario delle malattie pediatriche e dell'adulto***

***Teresa Capriati  
UOS Gastroenterologia e  
Riabilitazione Nutrizionale  
Ospedale Pediatrico Bambino  
Gesù, Roma***

*Ministero della Salute*



ISTITUTO GIANNINA GASLINI  
ISTITUTO PEDIATRICO  
DI RICOVERO E CURA  
A CARATTERE SCIENTIFICO



REGIONE LIGURIA



COMUNE DI GENOVA



Sistema Sanitario Regione Liguria



**SINPE**

Società Italiana di Nutrizione Artificiale e Metabolismo



**SIGENP**

Società Italiana di Gastroenterologia e Nutrizione Pediatrica

*Per quanto concerne i moderatori, relatori, formatori, tutor, docenti è richiesta dall'Accordo Stato-Regioni vigente apposita dichiarazione esplicita dell'interessato, di trasparenza delle fonti di finanziamento e dei rapporti con soggetti portatori di interessi commerciali relativi agli ultimi due anni dalla data dell'evento.  
La documentazione deve essere disponibile presso il Provider e conservata per almeno 5 anni.*

## **Dichiarazione sul Conflitto di Interessi**

Il sottoscritto \_\_\_\_\_ *Teresa Capriati* \_\_\_\_\_ in qualità di:

moderatore       docente       relatore       tutor

dell'evento

« Genova Hotel Continental – 06 dicembre 2025 »

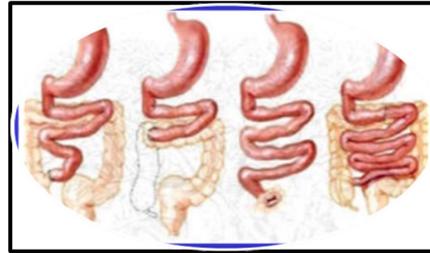
### **Presente e futuro nella gestione condivisa della insufficienza Intestinale Cronica benigna: l'unione fa la forza**

ai sensi dell'Accordo Stato-Regione in materia di formazione continua nel settore "Salute" (Formazione ECM)  
vigente,

#### ***Dichiara***

X che negli ultimi due anni NON ha avuto rapporti anche di finanziamento con soggetti portatori di interessi commerciali in campo sanitario

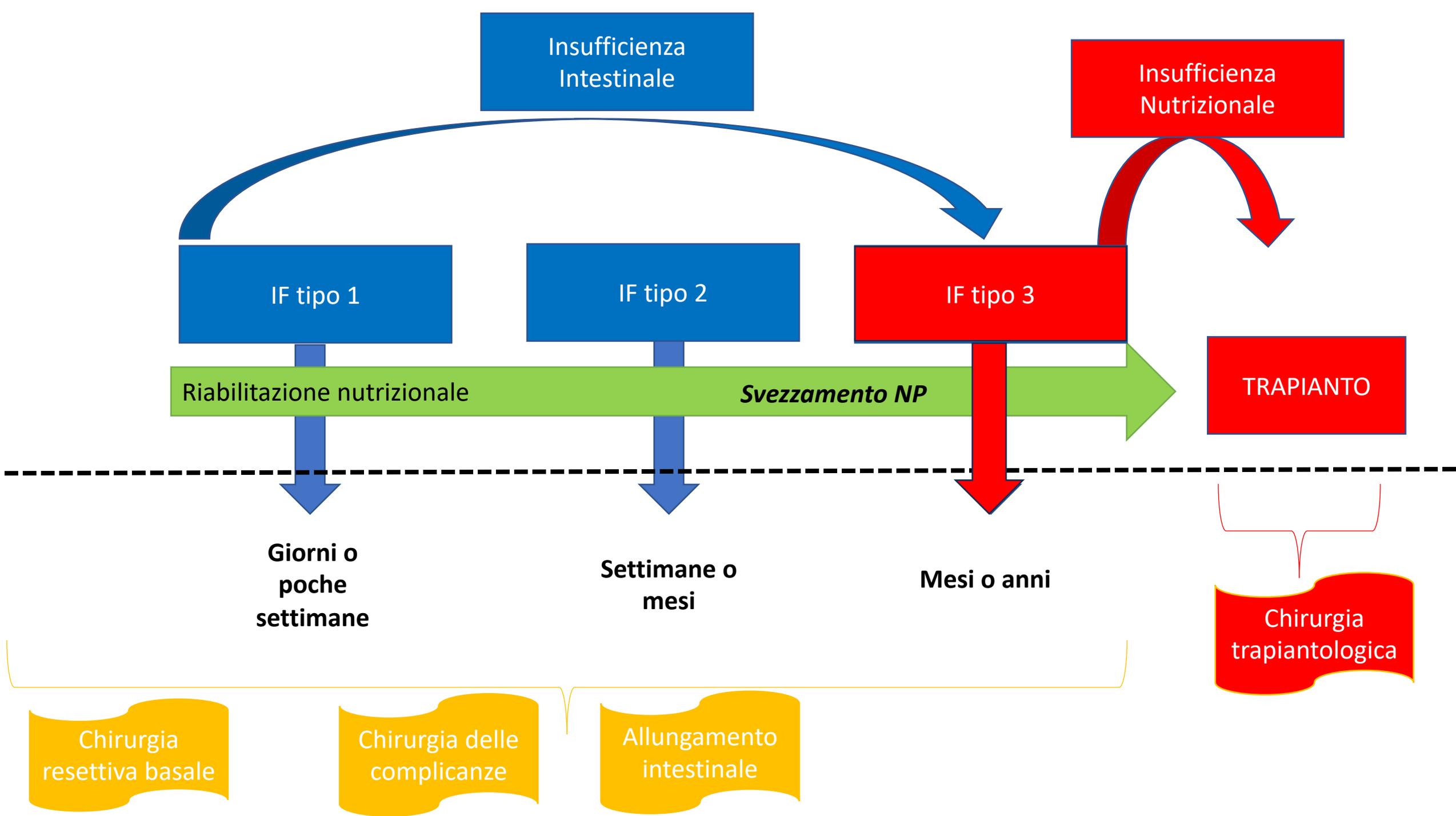
che negli ultimi due anni ha avuto rapporti anche di finanziamento con soggetti portatori di interessi commerciali in campo sanitario (indicare quali):



**Riduzione della funzione intestinale < minimo necessario a mantenere uno *stato nutrizionale stabile* e assicurare una *crescita normale nel bambino***

**IF definita dalla quota di intake per NP:  
*75% per almeno 1 mese*  
*50% per almeno 3 mesi***

***J Ped Gastroenterol Nutr, Vol. 43, 2006*  
*ESPEN Clinical Nutrition 34 (2015):171-180***



# 1. Incremento progressivo dei programmi di NPD

	2005 (SINPE)	2018 (SIGENP)	2025 (SIGENP)
<b>Programmi in NPD</b>	57	145	206
<b>Prevalenza IF in Italia</b>	6,3/milione di ab < 19 a	14,12/milione di ab < 19 a	21/milione di ab < 19 a
<b>Incidenza IF in Italia</b>	/	1,41/ milione di ab < 19 a	2/ milione di ab < 19 a
<b>Centri partecipanti</b>	16	19	8

Prevalence of home artificial nutrition in Italy in 2005: A survey by the Italian Society for Parenteral and Enteral Nutrition (SINPE) ☆

L. Pironi\*, M. Candusso, A. Biondo, A. Bosco, P. Castaldi, F. Contaldo, E. Finocchiaro, A. Giannoni, S. Mazzuoli, P. Orlandoni, A. Palozzo, C. Panella, S. Pastò, E. Ruggeri, G. Sandri, E. Stella, G. Toigo, the Italian Society for Parenteral and Enteral Nutrition (SINPE) Executive Committee

**Clinical Nutrition (2007) 26: 123–132**

Article

**Pediatric Chronic Intestinal Failure in Italy: Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP)**

Antonella Diamanti <sup>1,\*</sup>, Teresa Capriati <sup>1</sup>, Paolo Gandullia <sup>2</sup>, Grazia Di Leo <sup>3</sup>, Antonella Lezo <sup>4</sup>, Laura Lacitignola <sup>5</sup>, Maria Immacolata Spagnuolo <sup>6</sup>, Simona Gatti <sup>7</sup>, Lorenzo D'Antiga <sup>8</sup>, Giovanna Verlato <sup>9</sup>, Paola Roggero <sup>10</sup>, Sergio Amarri <sup>11</sup>, Maria Elisabetta Baldassarre <sup>12</sup>, Francesco Cirillo <sup>13</sup>, Domenica Elia <sup>1</sup>, Renata Boldrini <sup>14</sup>, Angelo Campanozzi <sup>15</sup>, Carlo Catassi <sup>7</sup>, Marina Aloï <sup>16</sup>, Claudio Romano <sup>17</sup>, Manila Candusso <sup>18</sup>, Nicola Cecchi <sup>19</sup>, Tommaso Bellini <sup>2</sup>, Elaine Tyndall <sup>1</sup>, Fabio Fusaro <sup>20</sup>, Tamara Caldaro <sup>21</sup>, Daniele Alberti <sup>22</sup>, Piergiorgio Gamba <sup>23</sup>, Mario Lima <sup>24</sup>, Pietro Bagolan <sup>20</sup>, Jean De Ville de Goyet <sup>13</sup>, Luigi Dall'Oglio <sup>21</sup>, Marco Spada <sup>19,25</sup> and Francesca Grandi <sup>23</sup>

**Nutrients (2017) 9: 1217**

Original article

Italian SIGENP (Italian Society of gastroenterology, hepatology and pediatric nutrition) registry of pediatric home artificial nutrition: First report

Antonella Lezo <sup>a,\*</sup>, Antonella Diamanti <sup>b</sup>, Leila Cravero <sup>c</sup>, Teresa Capriati <sup>b</sup>, Laura Lacitignola <sup>d</sup>, Paolo Gandullia <sup>e</sup>, Lorenzo Norsa <sup>f</sup>, Elvira Verduci <sup>g</sup>, Silvia Salvatore <sup>h</sup>, Giovanna Verlato <sup>i</sup>, Barbara Parma <sup>j</sup>, Giuseppe Pasolini <sup>k</sup>, Claudio Romano <sup>l</sup>, Maria Immacolata Spagnuolo <sup>m</sup>

**Clinical Nutrition ESPEN (2025) 70: 107–118**

## 2. Miglioramento gestionale complessivo ...riduzione mortalità e ...

REGULAR ARTICLE

### Ten-year experience of home parenteral nutrition in a single centre

Anthony E Wiskin<sup>1</sup>, Caroline Cole<sup>2</sup>, Daniel R Owens<sup>3</sup>, Mary Morgan<sup>4</sup>, David M Burge<sup>5</sup>, R Mark Beattie (mark.beattie@suht.swest.nhs.uk)<sup>4</sup>

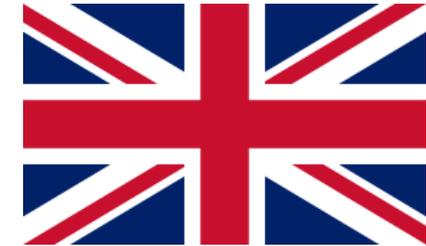
1.NIHR Biomedical Research Unit (Nutrition, Diet & Lifestyle) Southampton General Hospital, Southampton, UK

2.Pharmacy Department, Southampton General Hospital, Southampton, UK

3.School of Medicine, Southampton General Hospital, University of Southampton, Southampton, UK

4.Paediatric Medical Unit, Southampton General Hospital, Southampton, UK

5.Paediatric Surgical Unit, Southampton General Hospital, Southampton, UK



**Acta Paediatrica (2012) 101: 524-527**

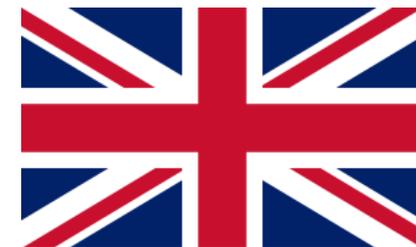
**Table 2** Summary of previous studies

Study	Number of patients	Length of follow-up, years	Mortality, %
<b>1987</b> Vargas et al. (11)	102 HPN	10	30
<b>1992</b> Bissett et al. (9)	10 HPN	5	10
<b>2007</b> Diamanti et al. (10)	60 HPN	16	19
<b>2007</b> Colomb et al. (3)	302 HPN	20	16
<b>2011</b> Gandullia et al. (4)	36 HPN	15	14
<b>2012</b> Wiskin (this study)	19 HPN	10	16

HPN, home parenteral nutrition.

# Prevalence of home parenteral nutrition in children

Anthony E. Wiskin <sup>a,\*</sup>, Rachel Russell <sup>b</sup>, Andrew R. Barclay <sup>c</sup>, Julian Thomas <sup>d</sup>, Akshay Batra <sup>b</sup>, On behalf of BANS committee of BAPEN



<sup>a</sup> Department of Paediatric Gastroenterology, Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol, BS2 8BJ, UK

<sup>b</sup> Department of Paediatric Gastroenterology, Southampton Children's Hospital, Tremona Road, Southampton, SO16 6YD, UK

<sup>c</sup> Department of Paediatric Gastroenterology, Royal Hospital for Sick Children, Govan Road, Glasgow, G51 4TF, UK

<sup>d</sup> Department of Paediatric Gastroenterology, Great North Children's Hospital, Royal Victoria Road, Newcastle Upon Tyne, NE1 4LP, UK

***Clinical Nutrition ESPEN (2021) 42: 138-141***

**Table 3**

Outcomes for 525 children from paediatric EBANS dataset between 2015 and 2019.

	Total Number of cases	Achieved Enteral Autonomy (%)	Transitioned to Adult Care (%)	Intestinal Transplant (%)	Died (%)
Short Bowel Syndrome	257	68 (26.5)	6 (2.3)	3 (1.2)	4 (1.6)
Neuromuscular Disorder	93	11 (11.8)	5 (5.4)	0	5 (5.4)
Congenital enterocyte disorders	47	3 (6.4)	1 (2.1)	0	5 (10.6)
Other Diagnosis	128	27 (21.1)	7 (5.5)	2 (1.6)	9 (7.0)
<b>Totals</b>	<b>525</b>	<b>109 (20.8)</b>	<b>19 (3.6)</b>	<b>5 (1.0)</b>	<b>23 (4.4)</b>

***Pazienti 525***

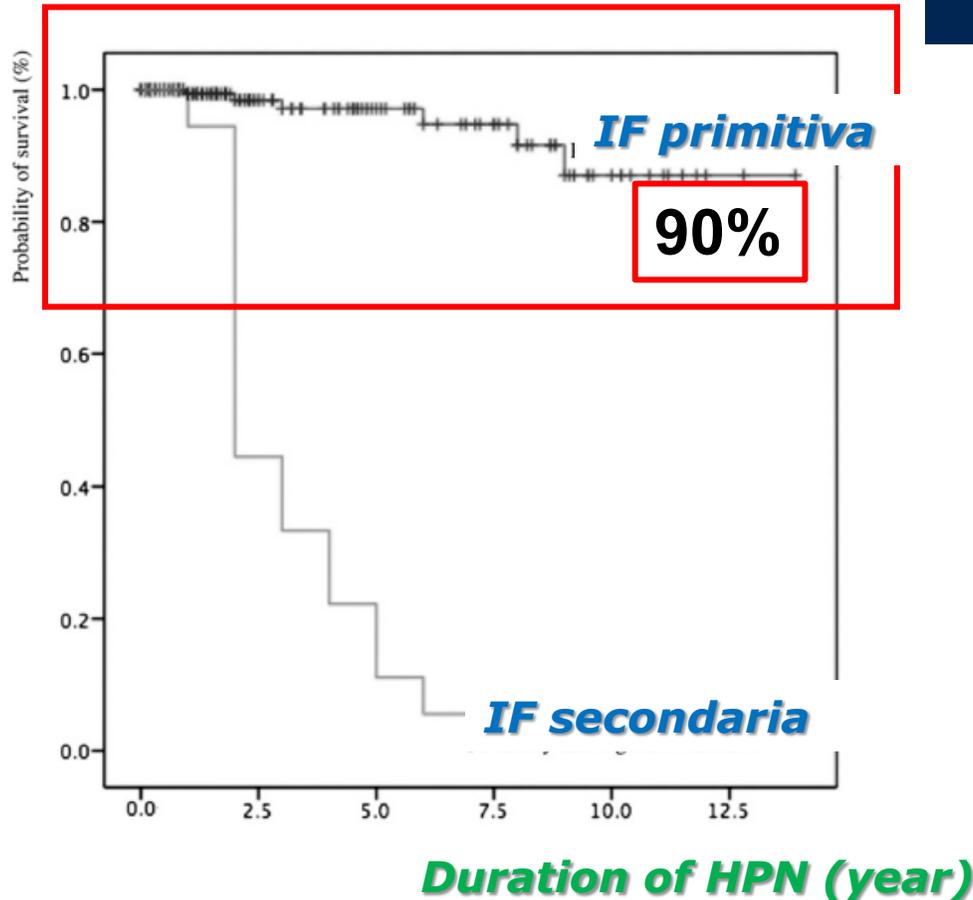
***55,8 months (mediana di durata NP)<sub>7</sub>***

Outcome of home parenteral nutrition in 251 children over a 14-y period: report of a single center<sup>1</sup>

Elie Abi Nader,<sup>2,6\*</sup> Cécile Lambe,<sup>2</sup> Cécile Talbotec,<sup>2</sup> Bénédicte Pigneur,<sup>2</sup> Florence Lacaille,<sup>2</sup> Hélène Garnier-Lengliné,<sup>2</sup> Laetitia-Marie Petit,<sup>2</sup> Catherine Poisson,<sup>2</sup> Amélia Rocha,<sup>2</sup> Odile Corriol,<sup>3,5</sup> Yves Aigrain,<sup>4,5</sup> Christophe Chardot,<sup>4,5</sup> Frank M Ruemmele,<sup>2,5</sup> Virginie Colomb-Jung,<sup>2</sup> and Olivier Goulet<sup>2,5</sup>

**Probability  
of survival  
(%)**

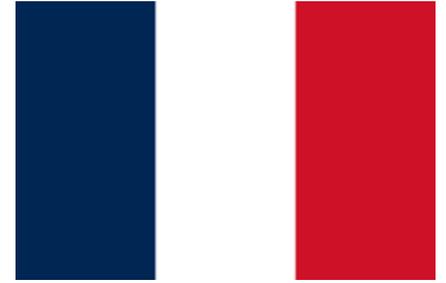
**...aumento della sopravvivenza...e**



# Pediatric Home Parenteral Nutrition in France: A six years national survey

*Clinical Nutrition (2021) 40: 5278-5287*

Olivier Goulet <sup>a</sup>, Anne Breton <sup>b</sup>, Marie-Edith Coste <sup>c</sup>, Béatrice Dubern <sup>d</sup>,  
Emmanuelle Ecochard-Dugelay <sup>e</sup>, Dominique Guimber <sup>f</sup>, Irène Loras-Duclaux <sup>g</sup>,  
Elie Abi Nader <sup>a</sup>, Evelyne Marinier <sup>e</sup>, Noel Peretti <sup>g</sup>, Cecile Lambe <sup>a,\*</sup>



- ✓ Di tutti i pazienti arruolati (n = 578), 21/578 *deceduti (3,6%)*
- ✓ il tasso di mortalità è rimasto *stabile durante i 6 anni di studio*.
- ✓ Il decesso è stato per lo più correlato a *cancro o immunodeficienza* (in 17 casi su 21)
- ✓ La differenza nel tasso di mortalità tra malattia digestiva non primaria e malattia digestiva primaria è stata altamente significativa (p < 0,0001).

## ***Entro 1-6 anni dal trapianto:***

- ✓ Il 60% (3 su 5) stava bene durante la sospensione della NP
- ✓ 1 LSHD (20%) → rigetto incontrollato.
- ✓ 1 LSHD (20%) → deceduto per rigetto umorale acuto incontrollabile del trapianto e complicazioni infettive.

# Trends in Pediatric Intestinal Failure: A Multicenter, Multinational Study

Daniela Gattini, MD<sup>1,2,\*</sup>, Amin J. Roberts, MD<sup>1,3,\*</sup>, Paul W. Wales, MD, MSc<sup>1,4</sup>, Sue V. Beath, MD<sup>5</sup>, Helen M. Evans, MD<sup>3</sup>, Jonathan Hind, MD<sup>6</sup>, David Mercer, MD, PhD<sup>7</sup>, Theodor Wong, MD<sup>5</sup>, Jason Yap, MD<sup>8</sup>, Christina Belza, MN<sup>1</sup>, Koen Huysentruyt, MD, PhD<sup>1,2</sup>, and Yaron Avitzur, MD<sup>1,2</sup>

**(J Pediatr 2021;237:16-23)**



N° pts	443
SBS	84,9%
PIPO	7,2%
CE	7,9%
Svezzamento da NP	53% (a 6 a)
<b>Trapianto</b>	<b>16,7% (a 6 a)</b>
Mortalità	10,5% (a 6 a)

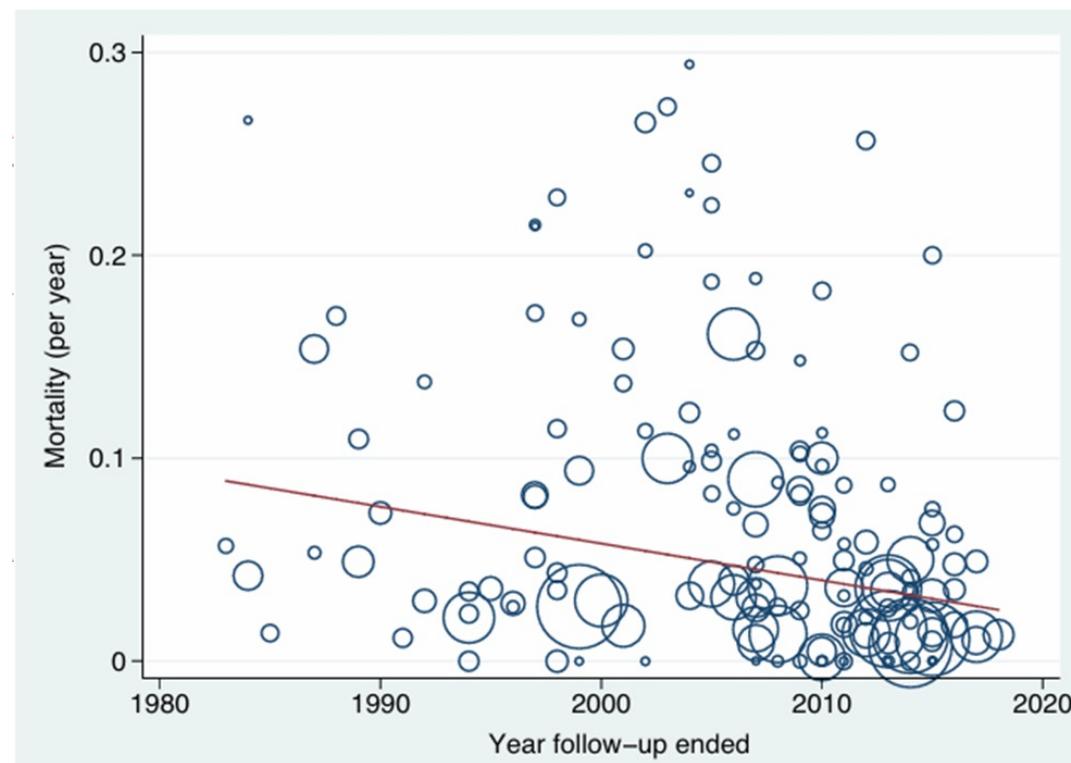
## Clinical outcomes in pediatric intestinal failure: a meta-analysis and meta-regression

Aureliane Chantal Stania Pierret,<sup>1,2</sup> James Thomas Wilkinson,<sup>2</sup> Matthias Zilbauer,<sup>3</sup> and Jake Peter Mann<sup>3,4,5</sup>

<sup>1</sup>Department of Pharmacology, University of Cambridge, Cambridge, UK; <sup>2</sup>Clinical School of Medicine, University of Cambridge, Cambridge, UK; <sup>3</sup>Department of Paediatrics, University of Cambridge, Cambridge, UK; <sup>4</sup>Metabolic Research Laboratories—Institute of Metabolic Science, University of Cambridge, Cambridge, UK; and <sup>5</sup>MRC Epidemiology Unit, Institute of Metabolic Science, University of Cambridge, Cambridge, UK

**Am J Clin Nutr 2019;110:430–436**

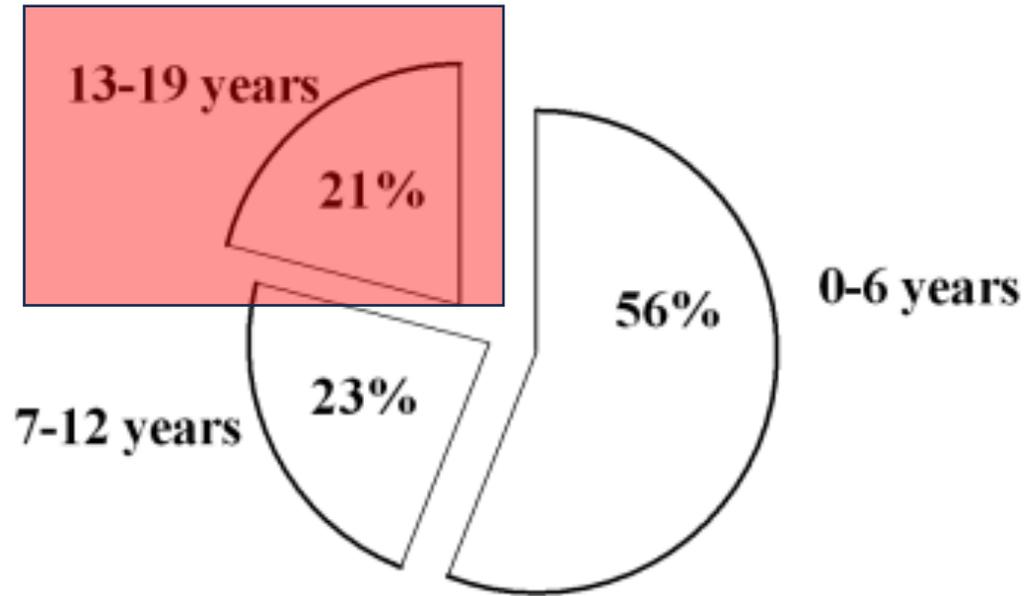
2203 articoli (201 inclusi)  
→ **175 coorti** (86% R; 80% bias basso)  
→ **9318 pazienti**  
→ 34,549 a pz di FU



## ...e della età dei pazienti...

### Pediatric Chronic Intestinal Failure in Italy: Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP)

Antonella Diamanti <sup>1,\*</sup>, Teresa Capriati <sup>1</sup>, Paolo Gandullia <sup>2</sup>, Grazia Di Leo <sup>3</sup>, Antonella Lezo <sup>4</sup>,  
Laura Lacitignola <sup>5</sup>, Maria Immacolata Spagnuolo <sup>6</sup>, Simona Gatti <sup>7</sup>, Lorenzo D'Antiga <sup>8</sup>,  
Giovanna Verlati <sup>9</sup>, Paola Roggero <sup>10</sup>, Sergio Amarri <sup>11</sup>, Maria Elisabetta Baldassarre <sup>12</sup>,  
Francesco Cirillo <sup>13</sup>, Domenica Elia <sup>1</sup>, Renata Boldrini <sup>14</sup>, Angelo Campanozzi <sup>15</sup>, Carlo Catassi <sup>7</sup>,  
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Mario Lima <sup>24</sup>, Pietro Bagolan <sup>20</sup>, Jean De Ville de Goyet <sup>13</sup>, Luigi Dall'Oglio <sup>21</sup>, Marco Spada <sup>19,25</sup>  
and Francesca Grandi <sup>23</sup>



**Nutrients (2017) 9: 1217**

**2025**



Year of home parenteral nutrition report

Italian SIGENP (Italian Society of gastroenterology, hepatology and pediatric nutrition) registry of pediatric home artificial nutrition: First report

Antonella Lezo <sup>a,\*</sup>, Antonella Diamanti <sup>b</sup>, Leila Cravero <sup>c</sup>, Teresa Capriati <sup>b</sup>,  
Laura Lacitignola <sup>d</sup>, Paolo Gandullia <sup>e</sup>, Lorenzo Norsa <sup>f</sup>, Elvira Verduci <sup>g</sup>, Silvia Salvatore <sup>h</sup>,  
Giovanna Verlati <sup>i</sup>, Barbara Parma <sup>j</sup>, Giuseppe Pasolini <sup>k</sup>, Claudio Romano <sup>l</sup>,  
Maria Immacolata Spagnuolo <sup>m</sup>

**Table 5**  
Characteristics of HPN by primary or secondary IF.

	Nr (%)	Primary IF	Secondary IF
HPN current age:	206 (100 %)	139 (67.5 %)	67 (32.5 %)
0-2 years	56 (27.2 %)	34 (24.5 %)	22 (32.8 %)
2-6 years	53 (25.7 %)	43 (30.9 %)	10 (14.9 %)
6-10 years	34 (16.5 %)	21 (15.1 %)	13 (19.4 %)
>10 years	63 (30.6 %)	41 (29.5 %)	22 (32.8 %)
HPN Duration		3.9 (8.1) <sup>a</sup>	0.7 (2.05) <sup>a</sup>
Median (IQR)			
Starting Age	<b>31%</b>	0.6 (2.9) <sup>a</sup>	2.5 (10.1) <sup>a</sup>
Median (IQR)			
HPN Type:			
Integrative	174 (84 %)	117 (84.2 %)	56 (83.6 %)
Exclusive	32 (16 %)	22 (15.8 %)	11 (16.4 %)
Indication to HPN:			
Short Bowel	117 (56.8 %)	94 (67.6 %)	23 (34.4 %)
Malabsorption	40 (19.4 %)	30 (21.6 %)	10 (14.9 %)
Dysphagia/impossible EN	4 (1.9 %)	1 (0.7 %)	3 (4.5 %)
Bowel Rest	3 (1.5 %)	0	3 (4.5 %)
Supportive HPN	31 (15 %)	7 (5 %)	24 (35.8 %)
Other	11 (5.3 %)	7 (5 %)	4 (6 %)

HPN: Home Parenteral Nutrition; Nr: number; IF: Intestinal Failure. EN: Enteral Nutrition.

<sup>a</sup> p < 0.01 primary vs secondary IF.

**AM J Clin Nutr (2016) 103: 1527-30**

**Elevata probabilità di transizione  
dall'età pediatrica all'età adulta**



***Cosa  
passiamo  
all'adulto?***

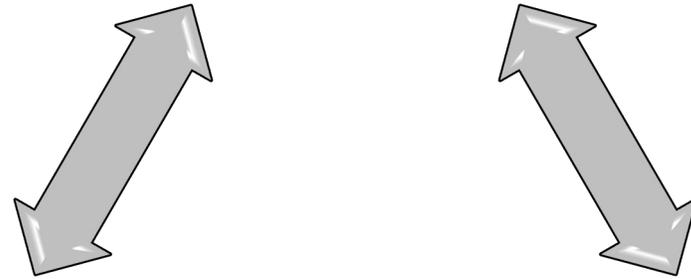


***Criticità***



***Strumenti***

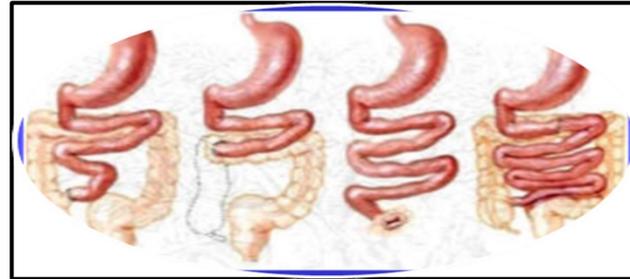
***Cosa  
passiamo  
all'adulto?***



***Criticità***



***Strumenti***



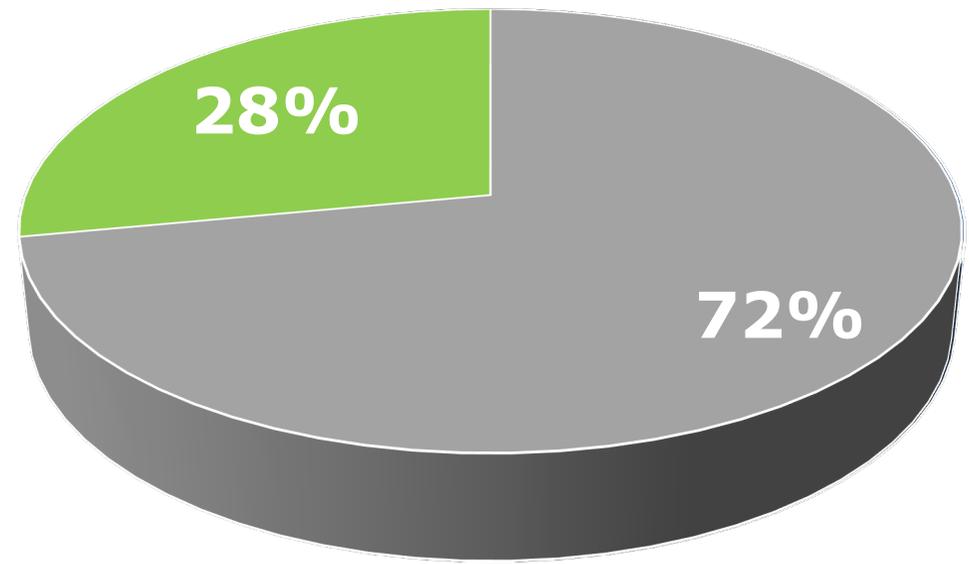
***Primitive***

***Secondarie***

Italian SIGENP (Italian Society of gastroenterology, hepatology and pediatric nutrition) registry of pediatric home artificial nutrition:  
First report ***Clinical Nutrition ESPEN 70 (2025) 107–118***

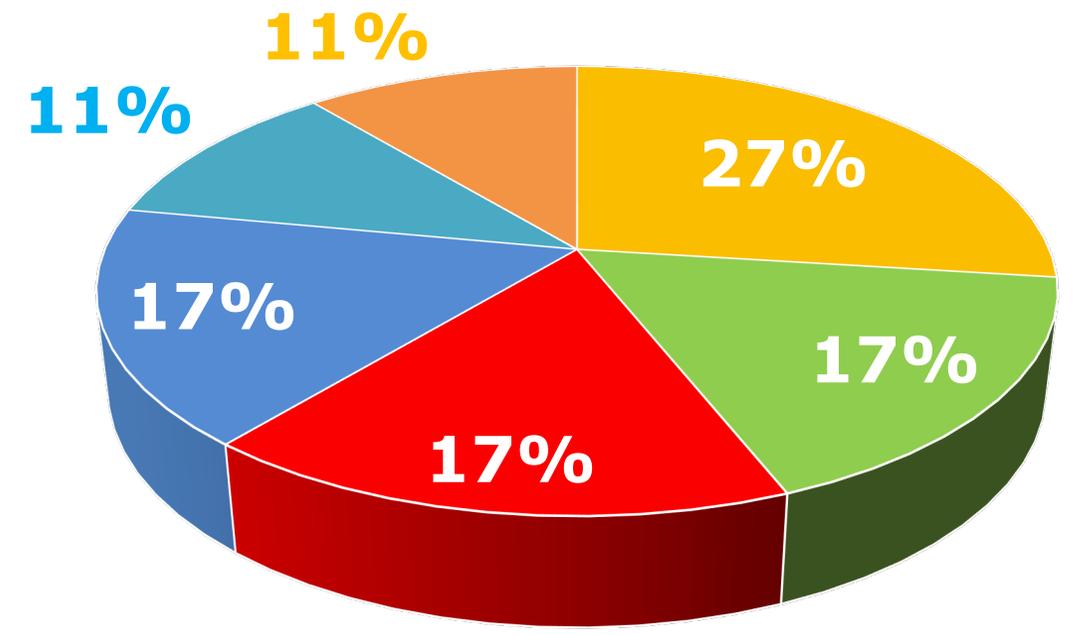
Antonella Lezo<sup>a,\*</sup>, Antonella Diamanti<sup>b</sup>, Leila Cravero<sup>c</sup>, Teresa Capriati<sup>b</sup>,  
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Maria Immacolata Spagnuolo<sup>m</sup>

### HPN



■ Primary IF ■ Non primary IF

### Non primary IF 2017



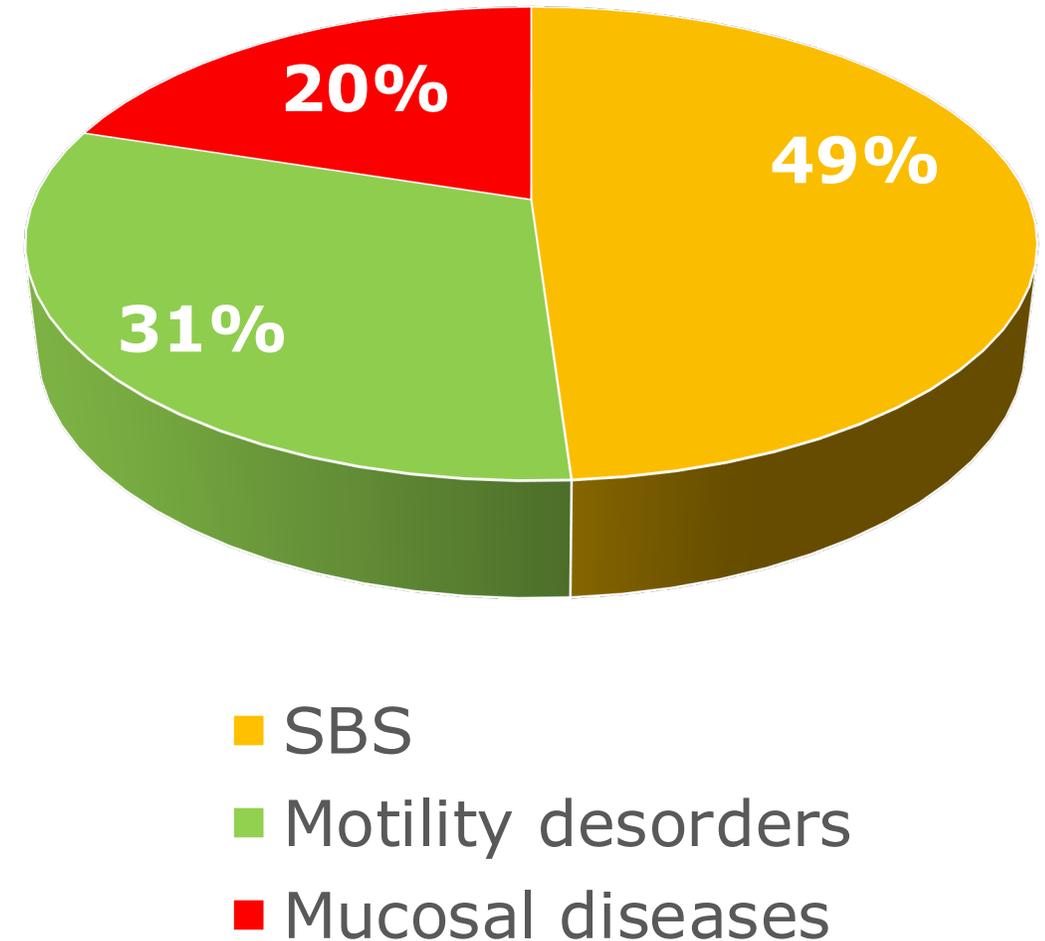
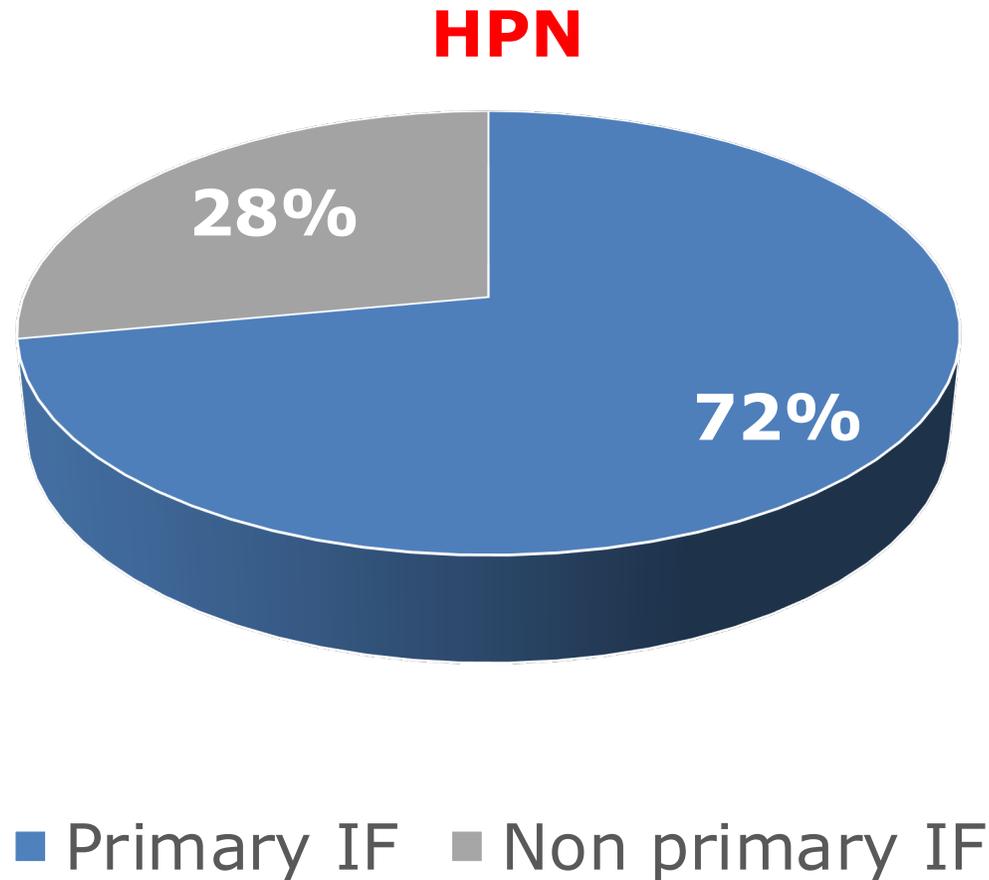
■ several cerebral palsy ■ Metabolic diseases  
■ Immunodeficiencies ■ Pancreatic diseases  
■ GVHD ■ Other

Italian SIGENP (Italian Society of gastroenterology, hepatology and pediatric nutrition) registry of pediatric home artificial nutrition:

First report ***Clinical Nutrition ESPEN 70 (2025) 107–118***

Antonella Lezo<sup>a,\*</sup>, Antonella Diamanti<sup>b</sup>, Leila Cravero<sup>c</sup>, Teresa Capriati<sup>b</sup>,  
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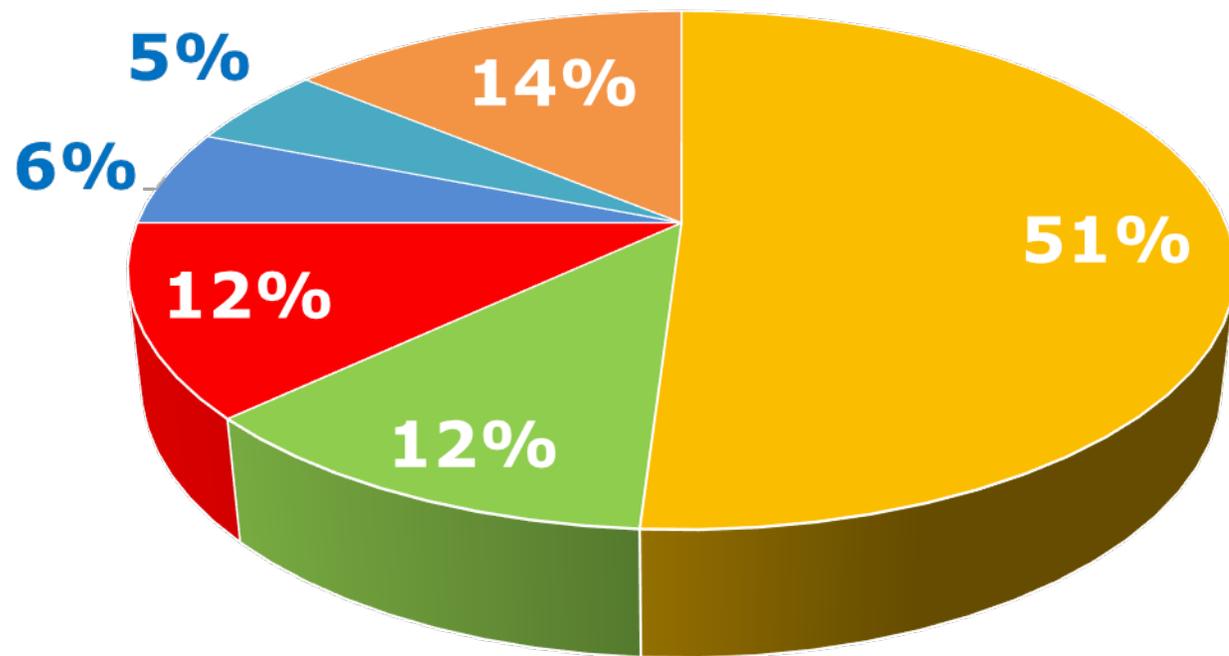
## Primary IF



# Pediatric Chronic Intestinal Failure in Italy: Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP)

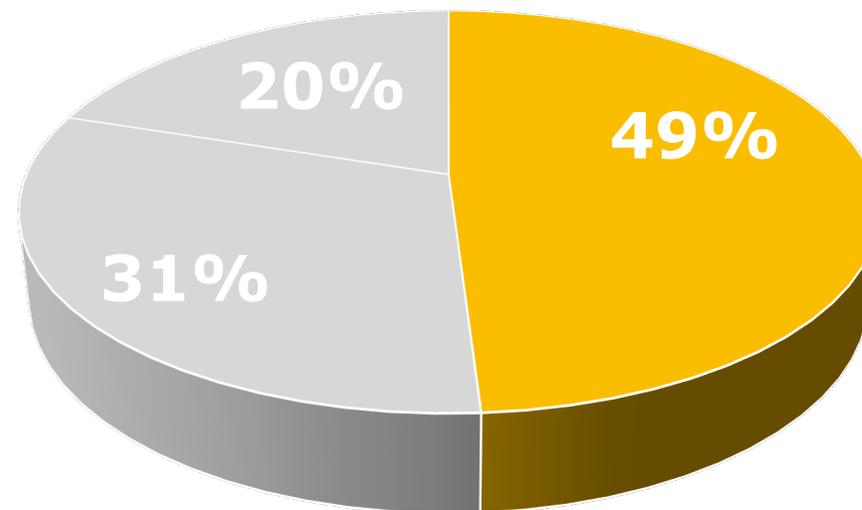
Antonella Diamanti <sup>1,\*</sup>, Teresa Capriati <sup>1</sup>, Paolo Gandullia <sup>2</sup>, Grazia Di Leo <sup>3</sup>, Antonella Lezo <sup>4</sup>,  
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and Francesca Grandi <sup>23</sup>

## SBS



- Volvolo
- NEC
- Malformazioni doppie
- Atresie multiple
- Mesenteric Ischemia
- altre

## Primary IF

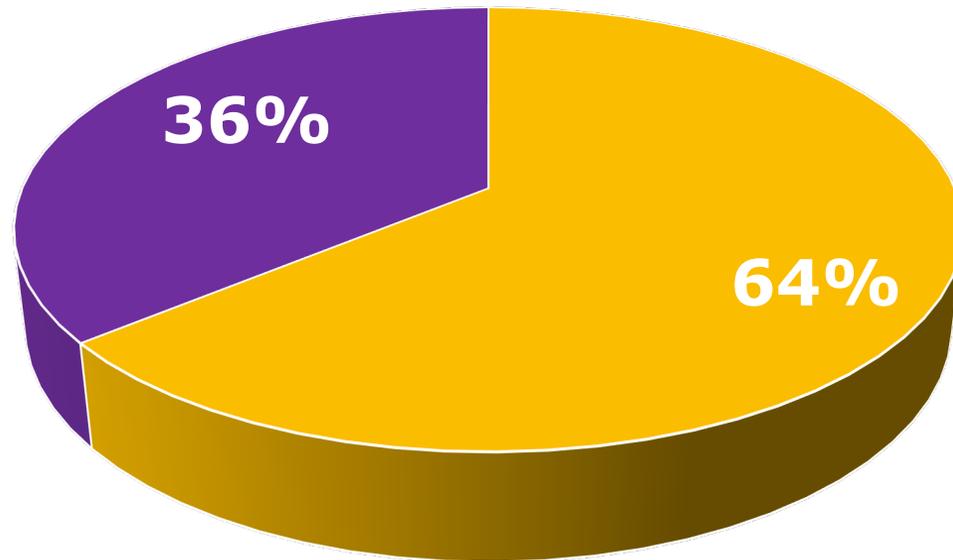


- SBS
- Motility disorders
- Mucosal diseases

# Pediatric Chronic Intestinal Failure in Italy: Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP)

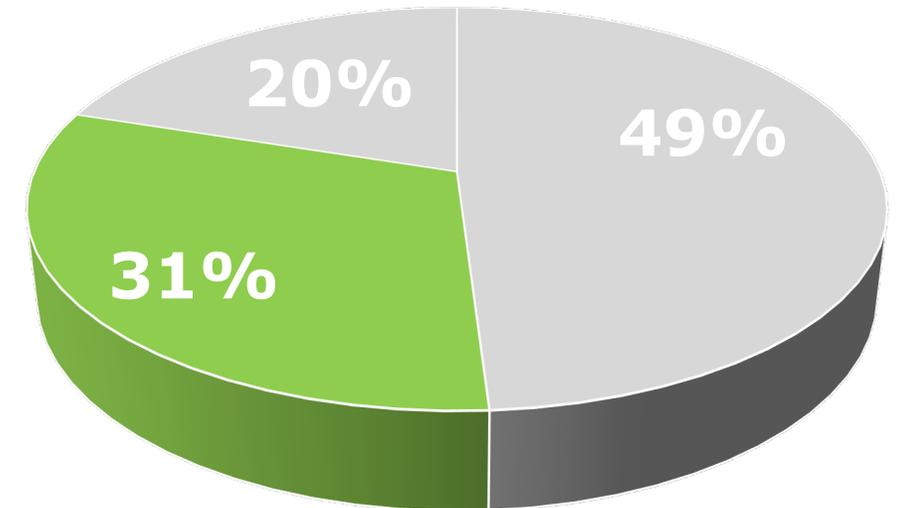
Antonella Diamanti <sup>1,\*</sup>, Teresa Capriati <sup>1</sup>, Paolo Gandullia <sup>2</sup>, Grazia Di Leo <sup>3</sup>, Antonella Lezo <sup>4</sup>,  
Laura Lacitignola <sup>5</sup>, Maria Immacolata Spagnuolo <sup>6</sup>, Simona Gatti <sup>7</sup>, Lorenzo D'Antiga <sup>8</sup>,  
Giovanna Verlatto <sup>9</sup>, Paola Roggero <sup>10</sup>, Sergio Amarri <sup>11</sup>, Maria Elisabetta Baldassarre <sup>12</sup>,  
Francesco Cirillo <sup>13</sup>, Domenica Elia <sup>1</sup>, Renata Boldrini <sup>14</sup>, Angelo Campanozzi <sup>15</sup>, Carlo Catassi <sup>7</sup>,  
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and Francesca Grandi <sup>23</sup>

## Motility disorders



- Chronic Intestinal Pseudo-obstruction
- Hirschsprung long segment

## Primary IF

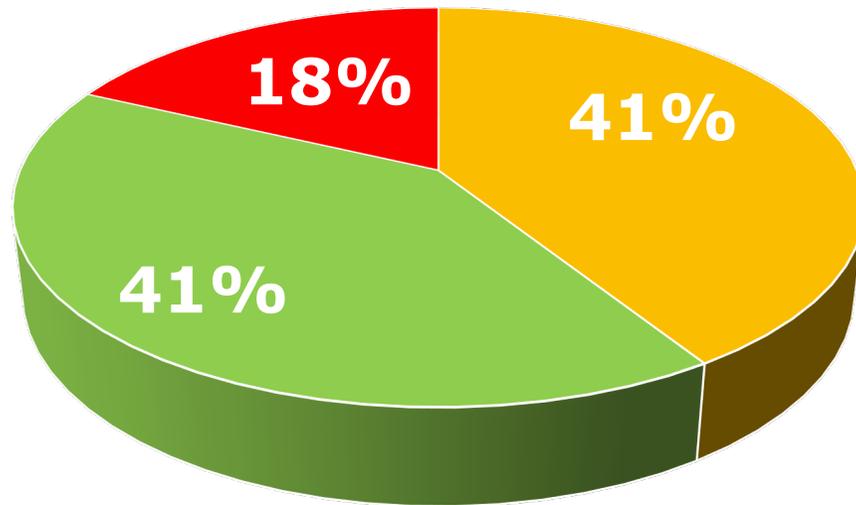


- SBS
- Motility disorders
- Mucosal diseases

# Pediatric Chronic Intestinal Failure in Italy: Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP)

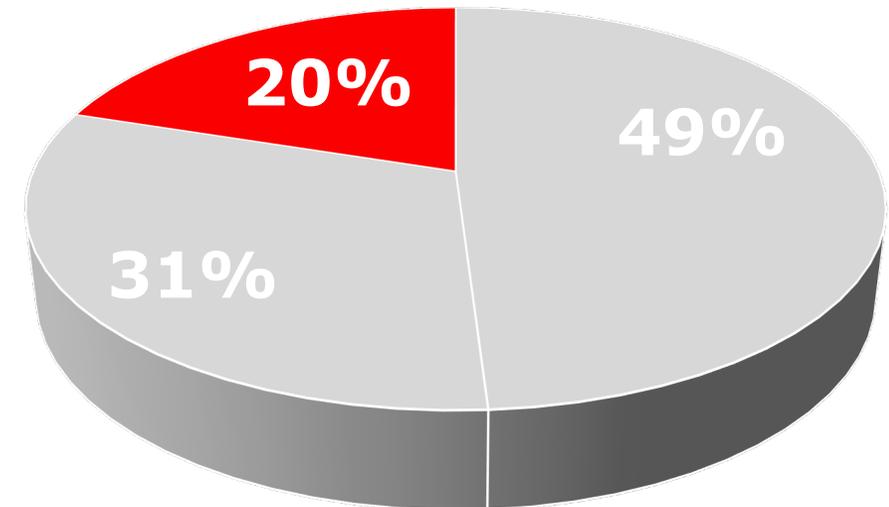
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and Francesca Grandi <sup>23</sup>

## Mucosal disease



- Microvillous Inclusion Disease
- Tufting Enteropathy
- Autoimmune enteropathy

## Primary IF

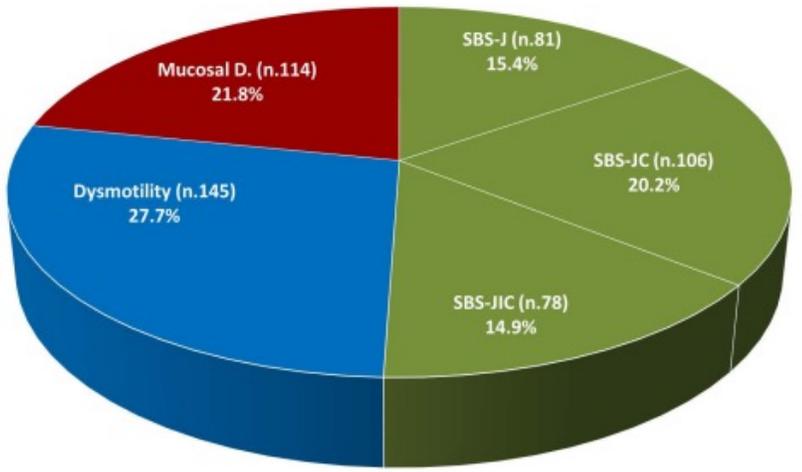


- SBS
- Motility disorders
- Mucosal diseases

	Adults (n. 2919)	Children (n. 524)
<b>Short bowel syndrome (No. (%))</b>	<b>1880 (64.4%)</b>	<b>265 (50.6%)</b>
• Mesenteric ischemia	28.2%	5.5%
• Crohn's disease	28.1%	
• Surgical complications	17.9%	
• Radiation enteritis	6.7%	
• Volvulus	3.8%	24.0%
• Adhesions	2.4%	
• Intestinal malformation		27.7%
• Necrotizing enterocolitis		16.6%
• Others	10.9%	26.2%
<b>Motility disorder</b>	<b>510 (17.5%)</b>	<b>145 (27.7%)</b>
• CIPO primary <sup>a</sup>	51.7%	60.4%
• Collagenous disease	13.3%	
• Surgical complications	11.7%	
• CIPO secondary <sup>b</sup>	9.1%	18.7%
• Neurologic disease	3.6%	5.2%
• Others	10.6%	15.7%
<b>Extensive mucosal disease</b>	<b>199 (6.8%)</b>	<b>114 (21.8%)</b>
• Crohn's disease	32.5%	1.8%
• Radiation enteritis	18.4%	
• Autoimmune enteropathy	8.3%	6.3%
• Chemotherapy enteritis	5.3%	
• CVID	5.3%	1.8%
• Celiac disease	4.9%	
• Other congenital mucosal D.	3.4%	24.3%
• Lymphangectasia	2.9%	3.6%
• Microvillus inclusion disease	2.9%	19.8%
• Tufting enteropathy		18.0%
• Others	16.1%	24.4%
<b>Intestinal fistulas</b>	<b>203 (7.0%)</b>	
• Surgical complication	45.8%	
• Crohn's disease	33.2%	
• Radiation enteritis	5.8%	
• Adhesions	2.1%	
• Others	13.1%	
<b>Mechanical Obstruction</b>	<b>127 (4.3%)</b>	
• Radiation enteritis	38.3%	
• Adhesions	29.0%	
• Crohn's disease	13.1%	
• Surgical complications	7.5%	
• Others	12.1%	

<sup>a</sup> Primary CIPO, chronic intestinal pseudo-obstruction, idiopathic.  
<sup>b</sup> Secondary CIPO, due to a known underlying disorder (including Hirschsprung's disease); CVID, common variable immunodeficiency.

Clinical classification of adult patients with chronic intestinal failure



al failure  
 ectional  
**018;37:728-738**

Vanten <sup>e</sup>,  
 i Theilla <sup>m</sup>,  
 Wu <sup>r</sup>,  
 uy <sup>v</sup>,  
 ielmi <sup>z</sup>,  
 legard <sup>ad</sup>,  
 ah <sup>h</sup>,  
 M. Virgili <sup>am</sup>,  
 i <sup>aq</sup>,  
 rlandoni <sup>av</sup>,  
 ñiga <sup>bb</sup>,

Łucja Schneider <sup>1</sup>, Jani Arinos <sup>2</sup>, Jose R. Suarez-Llanos <sup>3</sup>, Jon Sauer <sup>4</sup>, Simon Lal <sup>bm</sup>

## Chronic Intestinal Failure in Children: An International Multicenter Cross-Sectional Survey **Nutrients 2022, 14, 1889**

Antonella Lezo <sup>1</sup>, Antonella Diamanti <sup>2</sup>, Evelyne M. Marinier <sup>3</sup>, Merit Tabbers <sup>4</sup>, Anat Guz-Mark <sup>5,6</sup> , Paolo Gandullia <sup>7</sup> , Maria I. Spagnuolo <sup>8</sup> , Sue Protheroe <sup>9</sup>, Noel Peretti <sup>10</sup> , Laura Merras-Salmio <sup>11</sup>, Jessie M. Hulst <sup>12</sup>, Sanja Kolaček <sup>13</sup>, Looi C. Ee <sup>14</sup>, Joanna Lawrence <sup>15</sup>, Jonathan Hind <sup>16</sup> , Lorenzo D'Antiga <sup>17</sup>, Giovanna Verlatto <sup>18</sup>, Ieva Pukite <sup>19</sup> , Grazia Di Leo <sup>20</sup>, Tim Vanuytsel <sup>21</sup> , Maryana K. Doitchinova-Simeonova <sup>22</sup> , Lars Ellegard <sup>23</sup> , Luisa Masconale <sup>24</sup>, María Maíz-Jiménez <sup>25</sup>, Sheldon C. Cooper <sup>26</sup> , Giorgia Brillanti <sup>27</sup>, Elena Nardi <sup>28</sup> , Anna S. Sasdelli <sup>29</sup> , Simon Lal <sup>30</sup> and Loris Pironi <sup>27,29,\*</sup>

ESPEN Guideline **Clin Nutr. 2023;42(10):1940-2021**

## ESPEN guideline on chronic intestinal failure in adults – Update 2023

Loris Pironi <sup>a, b, \*</sup>, Cristina Cuerda <sup>c</sup>, Palle Bekker Jeppesen <sup>d</sup>, Francisca Joly <sup>e</sup>, Cora Jonkers <sup>f</sup>, Željko Krznarić <sup>g</sup>, Simon Lal <sup>h</sup>, Georg Lamprecht <sup>i</sup>, Marek Lichota <sup>j</sup>, Manpreet S. Mundi <sup>k</sup>, Stéphane Michel Schneider <sup>l</sup>, Kinga Szczepanek <sup>m</sup>, André Van Gossum <sup>n</sup>, Geert Wanten <sup>o</sup>, Carolyn Wheatley <sup>p</sup>, Arved Weimann <sup>q</sup>

## Long-term Outcome of Children Receiving Home Parenteral Nutrition: A 20-year Single-center Experience in 302 Patients

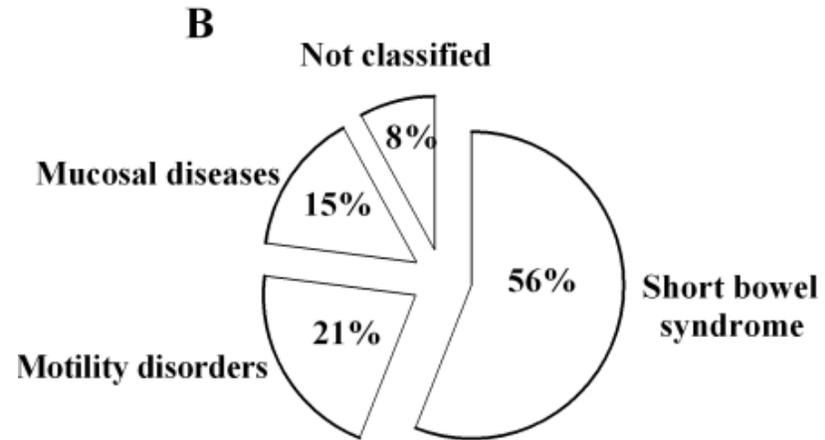
\*Virginie Colomb, \*Myriam Dabbas-Tyan, †Pierre Taupin, \*Cécile Talbotec, ‡Y. Révillon,  
‡D. Jan, \*Sophie De Potter, \*Anne-Marie Gorski-Colin, \*Michèle Lamor, \*Karen Herreman,  
§Odile Corriol, †Paul Landais, \*Claude Ricour, and \*Olivier Goulet

### *Outcome of patients according to the primary diagnosis*

	SBS	CIPOS	IDI
No. of patients	141	31	25
Death, %	7	13	24
Weaning off HPN, %	61	32	12
Weaning among survivors, %	65	38	15
Continuing HPN, %	26	52	48
Intestinal ( $\pm$ liver) transplantation, %	6	3	16

**Intestino corto**  
**30-40%**

**1°**



**3°**

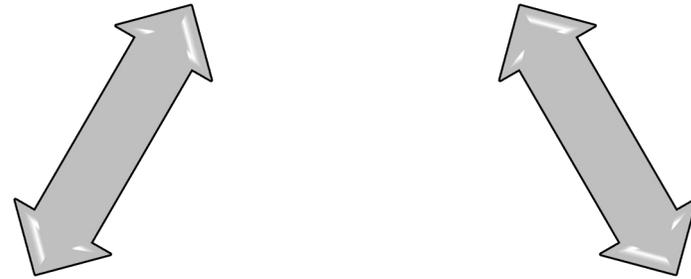
**Disordini mucosali**  
**~90%**



**Disordini della motilità**  
**~50%**

**2°**

*Cosa  
passiamo  
all'adulto?*



*Criticità*



*Strumenti*

# Perché la Transizione è Importante?

Senza un'adeguata assistenza durante la transizione, i pazienti sono esposti ad un rischio maggiore di:



**Interruzione  
o assenza di  
cura**



**Scarsa  
aderenza alla  
terapia**

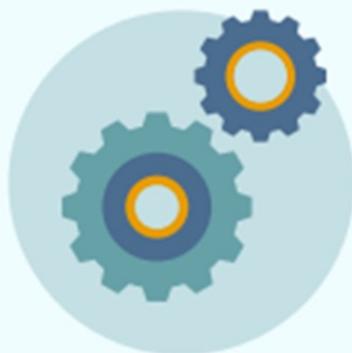


**Ansia e  
stress**



**Ridotta  
autonomia  
personale**

## Requisiti per la Transizione



**Coordinamento**

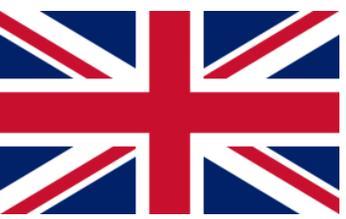


**Educazione**



**Supporto emotivo**

Un team dedicato composto da pediatri, medici dell'adulto ed altri specialisti è fondamentale per soddisfare le esigenze individuali del paziente quando passa dall'assistenza pediatrica a quella dell'adulto.



# Current practices and experience of transition of young people on long term home parenteral nutrition (PN) to adult services – A perspective from specialist centres

*Clinical Nutrition ESPEN 14 (2016) 9e13*

E. Kyrana <sup>a</sup>, S.V. Beath <sup>b</sup>, S. Gabe <sup>c</sup>, M. Small <sup>c</sup>, S. Hill <sup>a,\*</sup>, on behalf of the members BAPEN, and of the

<sup>a</sup> Paediatric Gastroenterology Department, Great Ormond Street Hospital, UK

<sup>b</sup> The Liver Unit (Including Small Bowel Transplantation), Birmingham Children's 14 Hospital, West Midlands B4 6NH, UK

<sup>c</sup> The Intestinal Failure Unit, St Mark's Hospital, Northwick Park, Watford Road, Harrow, Middlesex HA1 3UJ, UK

Questionario su transizione: 30 different centres: 12 A; 18 P

*612 pazienti – tempo per la transizione da 6 mesi a 2 anni*

**Table 3**  
Reported complications.

	Hardly ever	Sometimes	More than expected	Frequently
Hospital admissions	12.5%	50%	25%	12.5%
Catheter related blood stream infections	53%	47%	0%	0%
Psychological problems	13%	50%	25%	12.5%
Deterioration in academic performance	47%	40%	14%	0%
Confusion about care outcomes	29%	35%	12%	24%

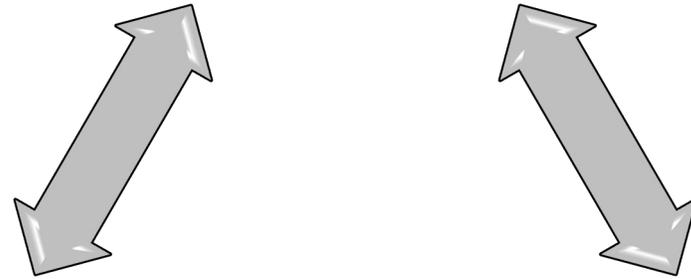
# Il Trasferimento **NON** è Transizione

Un **TRASFERIMENTO** è un evento singolo, mentre...

...la **TRANSIZIONE** è un percorso strutturato.



*Cosa  
passiamo  
all'adulto?*



*Criticità*



*Strumenti*



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## Digestive and Liver Disease

journal homepage: [www.elsevier.com/locate/dld](http://www.elsevier.com/locate/dld)



### Guidelines

Moving on: How to switch young people with chronic intestinal failure from pediatric to adult care. a position statement by italian society of gastroenterology and hepatology and nutrition (SIGENP) and italian society of artificial nutrition and metabolism (SINPE)



Antonella Diamanti<sup>a,\*</sup>, Teresa Capriati<sup>a</sup>, Antonella Lezo<sup>b</sup>, Maria Immacolata Spagnuolo<sup>c</sup>, Paolo Gandullia<sup>d</sup>, Lorenzo Norsa<sup>e</sup>, Laura Lacitignola<sup>f</sup>, Lidia Santarpia<sup>g</sup>, Francesco Walter Guglielmi<sup>h</sup>, Antonella De Francesco<sup>i</sup>, Loris Pironi<sup>l</sup>

# Regole di ingaggio: *criteri di scelta centro di riferimento e aspetti gestionali*

Digestive and Liver Disease 52 (2020) 1131–1136



➤ **Offerta clinica similare (team multidisciplinare)**

➤ **Affinità dei percorsi di cura (PO, DH, DEA)**

## Guidelines

Moving on: How to switch young people with chronic intestinal failure from pediatric to adult care. a position statement by italian society of gastroenterology and hepatology and nutrition (SIGENP) and italian society of artificial nutrition and metabolism (SINPE)



Antonella Diamanti<sup>a,\*</sup>, Teresa Capriati<sup>a</sup>, Antonella Lezo<sup>b</sup>, Maria Immacolata Spagnuolo<sup>c</sup>, Paolo Gandullia<sup>d</sup>, Lorenzo Norsca<sup>e</sup>, Laura Lacitignola<sup>f</sup>, Lidia Santarpia<sup>g</sup>, Francesco Walter Guglielmi<sup>h</sup>, Antonella De Francesco<sup>i</sup>, Loris Pironi<sup>l</sup>

➤ **Gestione invariata dei programmi nutrizionali (HPN)**

➤ **Modalità di gestione del CVC (sepsi, trombosi, IFALD)**



### Opuscolo UEG

Una guida sintetica che illustra le sfide della transizione con soluzioni pratiche raccomandate dagli esperti.



### Questionari "Pronti, Partenza, Via!"

Un set strutturato di **questionari adatti all'età**, studiati su misura per supportare ogni fase del processo di transizione.



### Passaporti Della Transizione

Un documento portatile che riassume la **storia clinica, i trattamenti attuali e gli obiettivi di salute** di un giovane paziente.

➤ **Area geografica**

## Transition from pediatric to adult care in patients with chronic intestinal failure on home parenteral nutrition: How to do it right?

Aysenur Demirok <sup>a,\*</sup>, Marc A. Benninga <sup>a</sup>, Antonella Diamanti <sup>b</sup>, Myriam El Khatib <sup>c</sup>, Anat Guz-Mark <sup>d</sup>, Johannes Hilberath <sup>e</sup>, Cécile Lambe <sup>f</sup>, Lorenzo Norsa <sup>g,1</sup>, Loris Pironi <sup>h,i</sup>, Alida A. Sanchez <sup>j</sup>, Mireille Serlie <sup>k</sup>, Merit M. Tabbers <sup>a,1</sup>

**2024**



## Optimizing transition from pediatric to adult care in short bowel syndrome and intestinal failure

Sivan Kinberg MD<sup>1,2</sup>  | Tanvi Verma MA<sup>1,2</sup> | Deeksha Kaura BDS<sup>2</sup> | David F. Mercer MD<sup>3</sup> 

**2023**



Original article

## In their shoes: Health care professionals walking a day in the life of patients with short bowel syndrome & intestinal failure

Katherine Twist, Sarah Kelly\*, Simon Lal

*Salford Royal Hospital, Northern Care Alliance NHS Foundation Trust UK*

**2023**



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...la **TRANSIZIONE** è un percorso strutturato.



## Optimizing transition from pediatric to adult care in short bowel syndrome and intestinal failure

Sivan Kinberg MD<sup>1,2</sup> | Tanvi Verma MA<sup>1,2</sup> | Deeksha Kaura BDS<sup>2</sup> | David F. Mercer MD<sup>3</sup>

Pediatric-focused intestinal rehabilitation

The healthcare transition process

Adult-focused intestinal rehabilitation

**Early transition**  
(10-12 years)

- **Parent:** Manager of healthcare tasks
- **Preadolescent:** Begins to participate

**Middle transition**  
(13-15 years)

- **Parent:** Supervisor of healthcare tasks
- **Adolescent:** Manager of healthcare tasks

**Late transition**  
(≥16 years)

- **Parent:** Consultant for healthcare tasks
- **Adolescent:** Manager of healthcare tasks with minimal or no supervision

# Modalità di lavoro individualizzata

Età di avvio:  
2 anni prima

Età fine:  
18-21 anni

6-12 mesi  
(max 2 a)

PEDIATRA

PROCESSO DI TRANSIZIONE (condivisione programmi/criticità)

MEDICO  
DELL'ADULTO

Maturità  
emotiva/psicologica

A

P

A

P

Stabilità della  
patologia

Aspettative delle  
famiglie

Stadio di sviluppo  
puberale

Gravità della patologia e  
complicanze

Pregressa  
condivisione della  
necessità di  
transizione con la  
famiglia

***Cosa passiamo  
all'adulto***

***Intestino corto 30%  
Disordini della motilità 50%  
Disordini mucosali 90%***

***GRAZIE***

***Dall'accudimento  
all'auto-gestione***

***Incontro tra  
esperti***

***Rispetto di  
regole chiare e  
condivise***

***Il collega dell'adulto  
deve farsi un po'  
"pediatra"***