ARE THE NEEDS OF INDIVIDUAL PATIENTS MET?

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PACIFHAN
CURRENT PACIFHAN MEMBERS

- PACIFHAN – international alliance of patient organisations for chronic intestinal failure (IF) and home artificial nutrition (HAN)

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>NATIONAL PATIENT ORGANISATION</th>
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<tr>
<td>Australia and New Zealand</td>
<td>PNDU</td>
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<tr>
<td>Czech republic</td>
<td>Život bez střeva</td>
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<tr>
<td>Denmark</td>
<td>HPN Patient</td>
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<tr>
<td>France</td>
<td>La Vie Par Un Fil</td>
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<tr>
<td>Italy</td>
<td>Un filo per la vita</td>
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<td>Poland</td>
<td>Appetite for life</td>
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<td>Sweden</td>
<td>Svenska HPN-Foreningen Barn &amp; Ungdom</td>
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<tr>
<td>United Kingdom</td>
<td>PINNT</td>
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<tr>
<td>USA</td>
<td>Oley</td>
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PACIFHAN GOALS

- To be a trusted international reference on Home Artificial Nutrition (HAN) from the patient's perspective
- To encourage exchange of peer reviewed published medical-scientific information related to HAN
- To assist HAN patients who wish to travel/stay abroad to seek guidance through the member association in the destination country affiliated to the international organization
- To organise an Annual General Meeting that will be attended by a representative of each member association
- Increase awareness of HAN
- Improve the quality of life of HAN patients
AREAS OF GREATEST UNMET NEED

- Joined-up thinking with other diseases
- United message about IF
- Social benefits
- Basic health/medical education for patients
- Home PN training
- Variation / inequity to access to equipment
- Multidisciplinary team
- National and international registry
- Cooperation between centres
- Information on medical/surgical and homecare services available
- National protocol (evidence-based)
- Joined-up thinking with other diseases
- Equity of care (access)
- Home PN training
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AREAS OF GREATEST UNMET NEED

- We prioritized the list of patients' unmet needs by assessing the greatest differentiation by their:
  - **level of importance**
    - i.e. how important patients perceived a service/support to be
  - **level of satisfaction**
    - i.e. how satisfied patients were with the current level of service/support provided

- Based on this assessment, the areas of greatest unmet need – from a patient perspective – were identified as:

  - **Equity of access to equipment and services**
    - Inequality in terms of areas, regions and countries
    - Type of equipment: Hospital-style or patient-friendly
  - **Cooperation between centres and coordinated care**
    - Improve collaboration between national centres and countries
    - Allow access to HPN centres all over the world
    - Enable patients to travel freely
  - **United message about IF**
    - What exactly are we talking about?
    - Confusing statements and terminology
  - **Countries protocols (evidence-based)**
    - Current practice can be inconsistent
    - Patients would welcome national protocols
    - Potential for international protocols ???
PACIFHAN ROLE

To complement the health care and services patients receive

- The way clinicians see HAN is different to how patients may perceive it.
- Thoughts from other people
  - „Some patients are achieving great things, travelling abroad, continuing with their sports while others are simply trying to exist.“
  - „Patients often really don’t know another single soul who is on HAN.“
  - „Empowering people with information and support has the potential to reduce complications and improve the quality of life.“

To increase awareness of HAN and improve the quality of life

- We want to involve more countries, more organisations and hear other patients
- We want to offer a broader opinion, we want to engage with ONCA, ESPEN, HAN manufacturers, etc.
- No two patients are the same – there’s a great variety from the medical as well as the social perspective
- We have shared experiences from our members that we want to share with you
“The more we share, the more we have” - Leonard Nimoy

“Let food be thy medicine and medicine be thy food.” - Hippocrates

“The whole is greater than the sum of its parts.” - Aristotle

“It's not the distance you travel, it's the journey.” - H. C. Andersen

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