Using the Social Media to Evaluate and Share Insights on Life on Home Parenteral Nutrition
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ThriveRx, Cincinnati, OH
Background

Ellie, SBS
Health care teams are responsible for providing information to their new consumers about:

• HPN Complications
• Issues that can arise
• Risks associated with HPN
• Their predictions for life style change
Background

Without personal experience medical teams cannot fully:

• Understand the impacts
• Understand the challenges

Of life with Home Parenteral Nutrition (HPN)

Cannot fully prepare new consumers
How Can We Bridge this Gap?

Go to the source

Current & Past HPN Consumers
First HPN Awareness Week

August 7-13, 2011

‘Help us spread the word that people can survive, and live a full life, on HPN, and help create understanding for some of the challenges HPN consumers face.’

-Oley Foundation Facebook Event Posting
ThriveRx

218 likes · 25 talking about this

ThriveRx is a national infusion pharmacy providing nutritional support for individuals on TPN and/or enteral feeds at home. Our home parenteral and enteral nutrition program is driven by health professionals with extensive experience.
Question/Poll on Facebook

Creates an evolving multiple choice survey

- Choices are created by the participants
- Able to add new choices
- Vote for choices listed
- Vote for more than one choice
- Return and add a new vote for a new choice added by another respondent
- Only vote once for each choice
- Evolves into an open ended survey
- Participants can ask their friends
- Interactions are visible in “News Feeds”
What should every new HPN consumer know about HPN and life with tubes?
Distribution

Posted question on ThriveRx’s Facebook page

Shared with support groups’ Facebook pages

Shared on personal Facebook pages
Viral Spread

- Personal pages
  - Friends
  - Friends

Fans of ThriveRx
  - Friends
  - Friends
  - Friends

Fans of support groups
  - Friends
  - Friends
  - Friends
HPN Awareness Week Question: What should every new HPN consumer know about HPN and life with tubes?

- HPN is scary in the beginning but it gets easier as time goes on
- Take control of it...it doesn't have to control you!
- You can still live your life while on TPN.
- Enjoy life! Do what you love to do, in spite of having tubes
- Oley programs help. Being informed and connected to those who have been sustained
- Keep asking questions, get organized, and you can do just about anything
- It supports life! Where would you be without it?
- HPN saves lives...it saves my son day after day!
- HPN saves lives...it saves my life day after day!
- HPN not only saves life but makes for a better quality of life outside the hosp...

+ Add an option...
Results

- 42 individual respondents
- Created 10 responses
- Total of 142 votes
Theme of Results

- Quality of Life: 60.56%
- Education: 21%
- Therapy Importance: 18%
### Results

**What should every new HPN consumer know about HPN and life with tubes?**

<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>% of total votes</th>
<th>Votes</th>
<th>Total # of votes</th>
<th>% of all votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPN is scary in the beginning but it gets easier as time goes on</td>
<td>33%</td>
<td>28</td>
<td>86</td>
<td>61%</td>
</tr>
<tr>
<td>You can still live you life while on TPN. Do what you love, in spite of tubes.</td>
<td>31%</td>
<td>27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take control of it...it doesn't have to control you!</td>
<td>26%</td>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is possible to find love and have good friendships</td>
<td>3%</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPN makes for a better quality of life outside the hospital</td>
<td>3%</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>While you're learning, have family and friends learn too. You'll love the help</td>
<td>3%</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What should every new HPN consumer know about HPN and life with tubes?

<table>
<thead>
<tr>
<th>Education</th>
<th>% of total votes</th>
<th>Votes</th>
<th>Total # of votes</th>
<th>% of all votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep asking questions, get organized, and you can do just about anything</td>
<td>50%</td>
<td>15</td>
<td>30</td>
<td>21%</td>
</tr>
<tr>
<td>Oley programs help with being informed and connected others with tubes</td>
<td>47%</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research SBBO, Gut Translocation, Vygon Tubing, Ethyl Alcohol, end cap covers</td>
<td>3%</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What should every new HPN consumer know about HPN and life with tubes?

<table>
<thead>
<tr>
<th>Therapy Importance</th>
<th>% of total votes</th>
<th>Votes</th>
<th>Total # of votes</th>
<th>% of all votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPN saves lives....it saves mine or my child's life day after day!</td>
<td>54%</td>
<td>14</td>
<td>26</td>
<td>18%</td>
</tr>
<tr>
<td>It supports life! Where would you be without it?</td>
<td>46%</td>
<td>12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HPN saves lives....it saves mine or my child's life day after day!
What Should Every New HPN Consumer Know

- Therapy Importance: 46%
- Quality of Life: 33%
- Education: 50%
- 54%
- 47%
- 3%
What do we do with all this information?
Educational Tool for New HPN Consumers:

Frequently Asked Questions: A handout for new HPN consumers.

- Guide for discussion for our consumer advocacy program
Clinician Guide for New HPN Consumers:

Assist clinicians in understanding what new consumers need in order to be successful on HPN
Conclusion

Our hope is that these tools will help improve:

• The quality of life
• The quality of care
• Affect patient outcome.
Help us spread the word that people can survive, and live a full life, on HPN, and help create understanding for some of the challenges HPN consumers face.’

-Oley Foundation Facebook Event Posting
Thank you

To all the consumers that responded to our question

You helped:
• Spread HPN awareness
• Build tools that will help others.
Second Annual HPN Awareness Week
August 5-11th, 2012