



Improving Life on Nutrition Support



## Using the Social Media to Evaluate and Share Insights on Life on Home Parenteral Nutrition

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# Background



**Ellie, SBS**

# Background

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.’

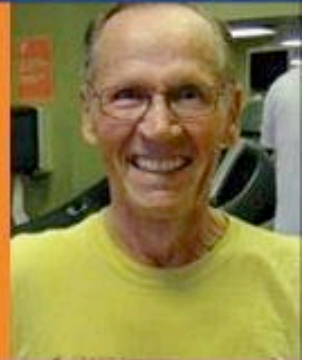
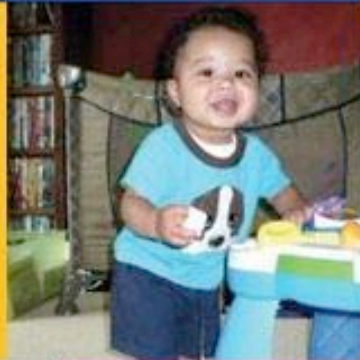
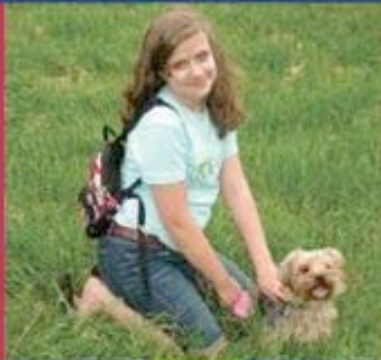
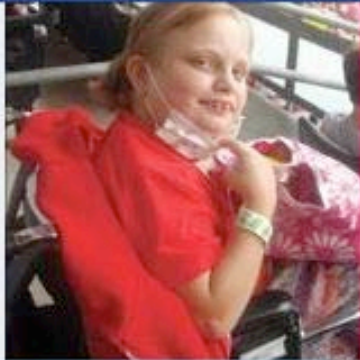
-Oley Foundation Facebook  
Event Posting



# Facebook

facebook

Search for people, places and things



**ThriveRx**

218 likes · 25 talking about this



Health/Medical/Pharmaceuticals

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



About

Photos

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Highlights

# 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”



# Question

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

# Distribution

**Posted question on ThriveRx's  
Facebook page**

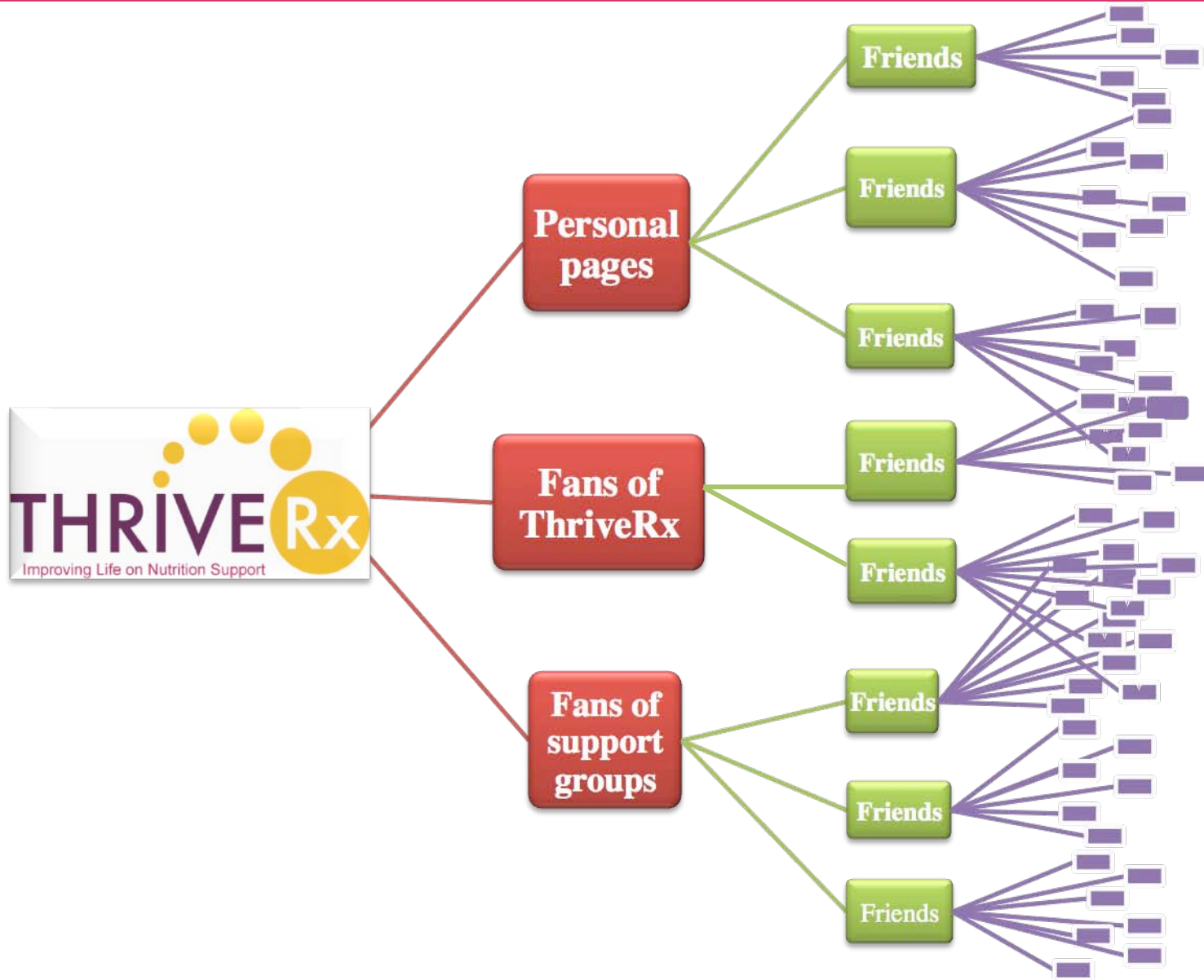


**Shared with support groups'  
Facebook pages**



**Shared on personal  
Facebook pages**

# Viral Spread



# Results

HPN Awareness Week Question: What should every new HPN consumer know about HPN and life with tubes? ×

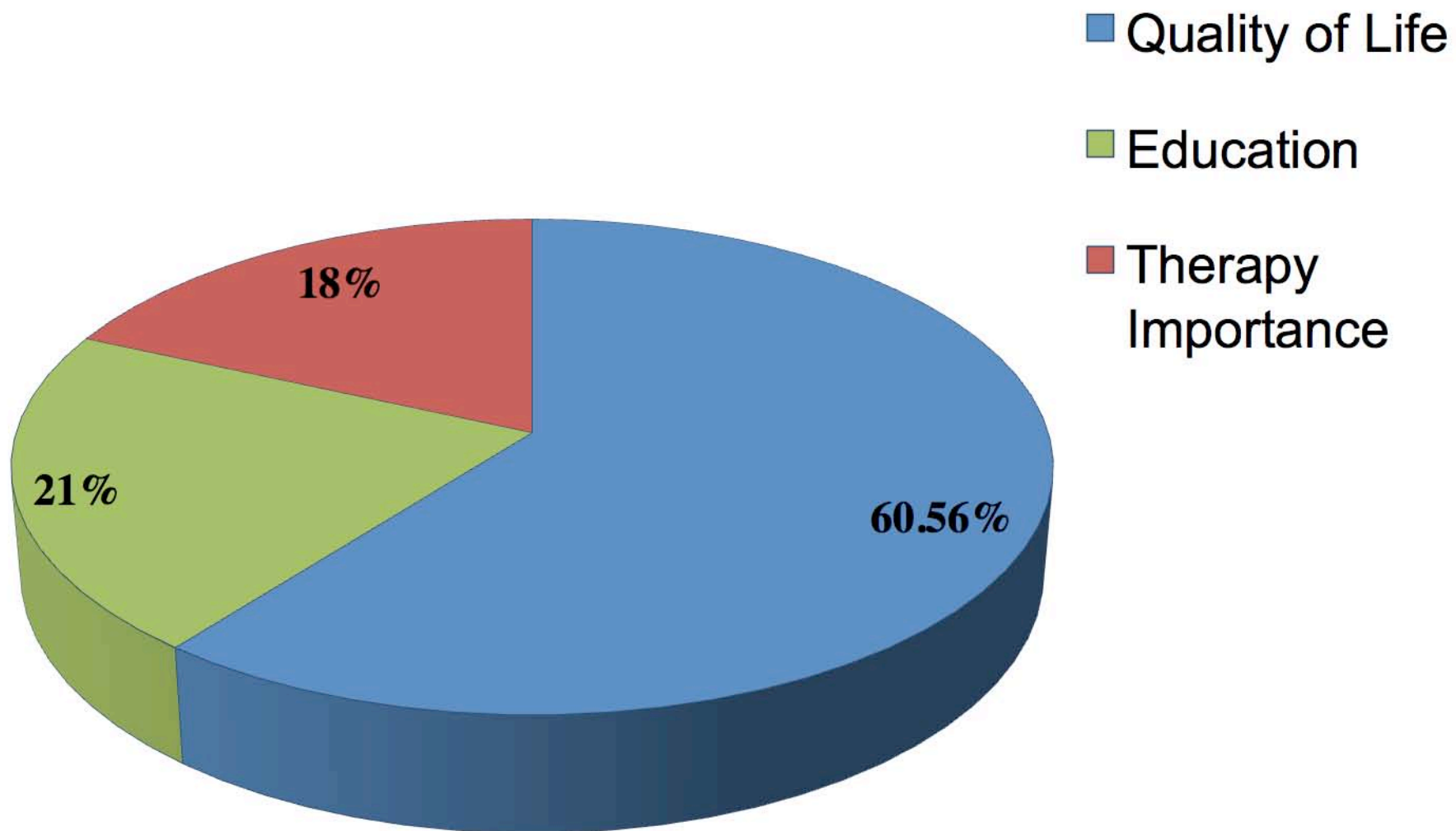
- HPN is scary in the beginning but it gets easier as time goes on ...
- Take control of it...it doesn't have to control you! ...
- You can still live your life while on TPN. ...
- Enjoy life! Do what you love to do, in spite of having tubes ...
- Oley programs help. Being informed and connected to those 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 hospital ...

+ Add an option...

# Results

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

# Theme of Results



# Results

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

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



# Results

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

| <b>Education</b>   | <b>% of total votes</b> | <b>Votes</b> | <b>Total # of votes</b> | <b>% of all votes</b> |
|--|-------------------------|--------------|-------------------------|-----------------------|
|  |                         |              | <b>30</b>               | <b>21%</b>            |
| <b>Keep asking questions, get organized, and you can do just about anything</b>      | <b>50%</b>              | <b>15</b>    |                         |                       |
| <b>Oley programs help with being informed and connected others with tubes</b>        | <b>47%</b>              | <b>14</b>    |                         |                       |
| <b>Research SBBO, Gut Translocation, Vygon Tubing, Ethyl Alcohol, end cap covers</b> | <b>3%</b>               | <b>1</b>     |                         |                       |



# Results

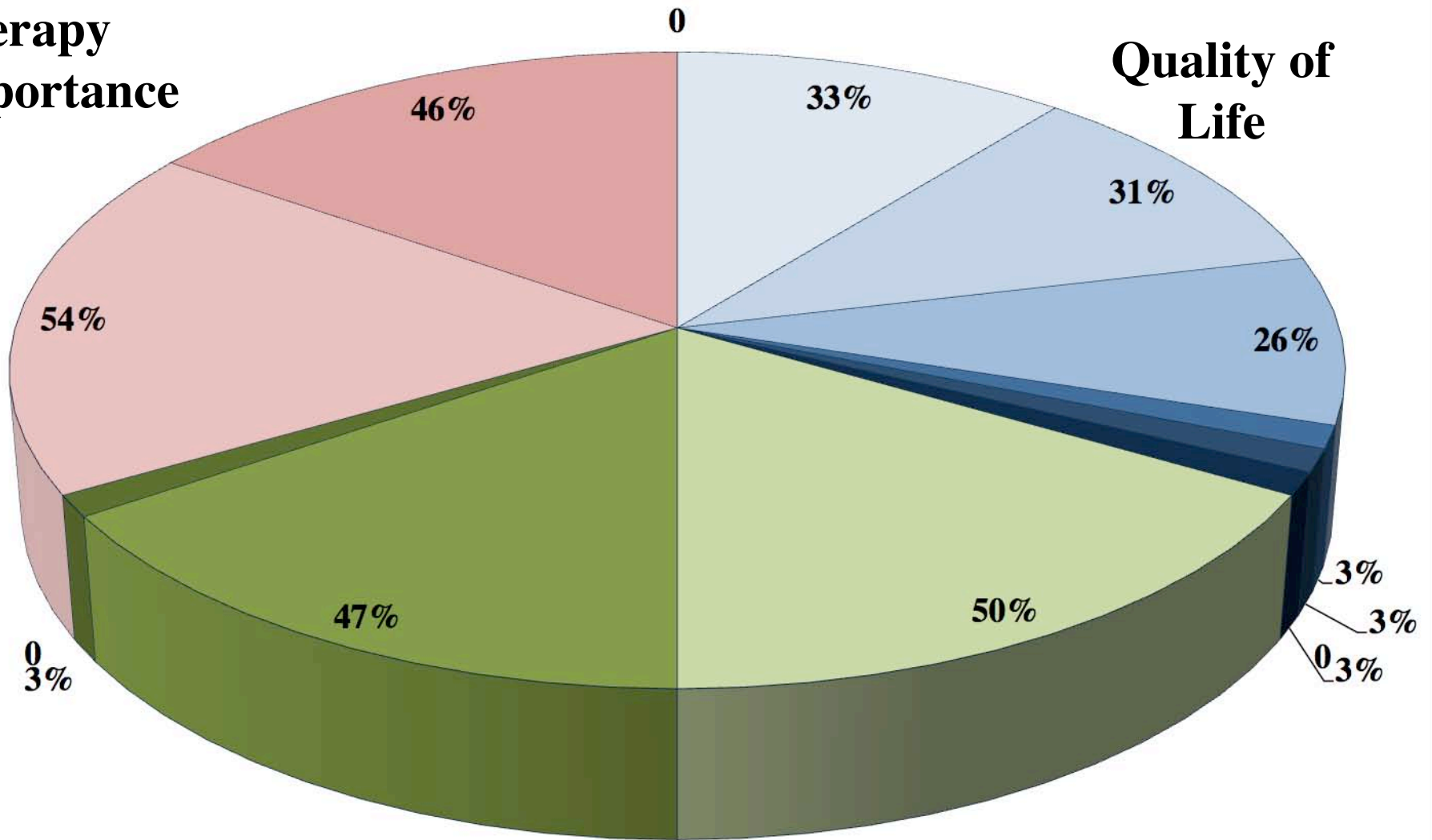
**What should every new HPN consumer know about HPN and life with tubes?**

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

# What Should Every New HPN Consumer Know

**Therapy  
Importance**

**Quality of  
Life**



**Education**

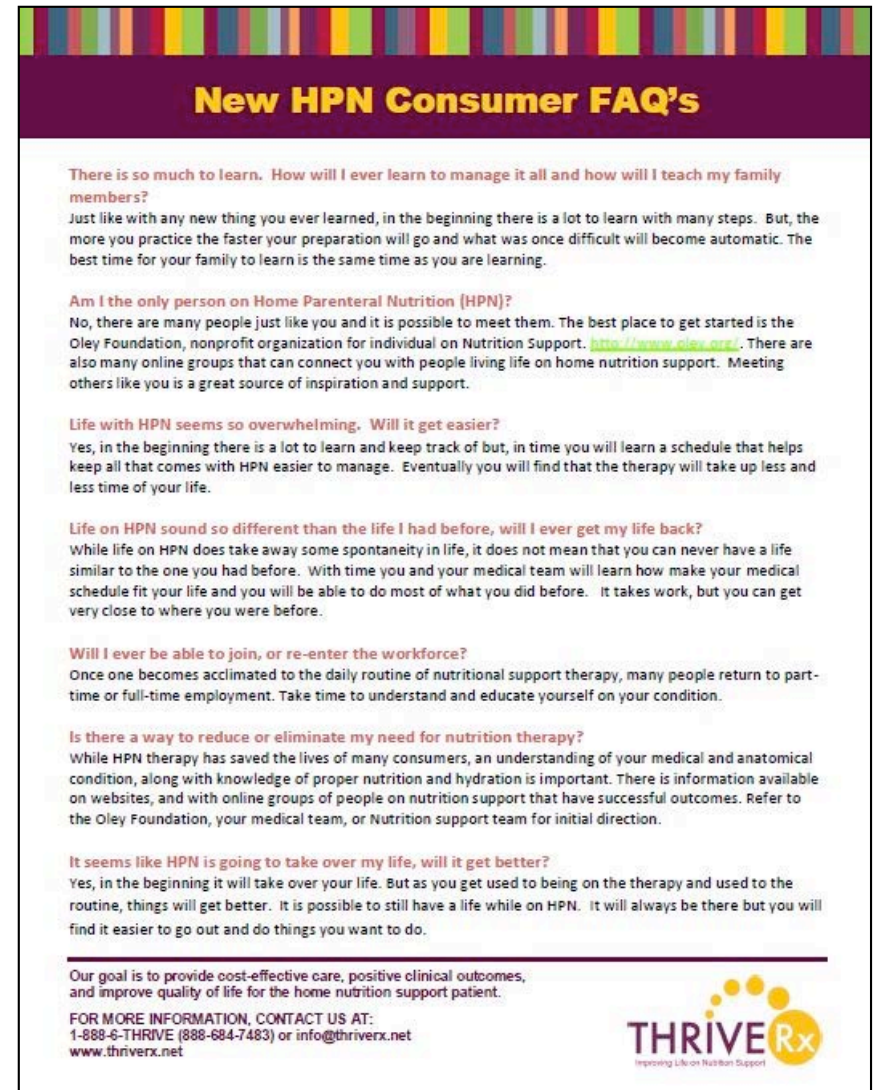
**What do we do with all this  
information?**

# Sharing the Knowledge

## Educational Tool for New HPN Consumers:

**Frequently Asked Questions:** A handout for new HPN consumers.

•Guide for discussion for our consumer advocacy program



**New HPN Consumer FAQ's**

**There is so much to learn. How will I ever learn to manage it all and how will I teach my family members?**  
Just like with any new thing you ever learned, in the beginning there is a lot to learn with many steps. But, the more you practice the faster your preparation will go and what was once difficult will become automatic. The best time for your family to learn is the same time as you are learning.

**Am I the only person on Home Parenteral Nutrition (HPN)?**  
No, there are many people just like you and it is possible to meet them. The best place to get started is the Oley Foundation, nonprofit organization for individual on Nutrition Support. <http://www.oley.org/>. There are also many online groups that can connect you with people living life on home nutrition support. Meeting others like you is a great source of inspiration and support.

**Life with HPN seems so overwhelming. Will it get easier?**  
Yes, in the beginning there is a lot to learn and keep track of but, in time you will learn a schedule that helps keep all that comes with HPN easier to manage. Eventually you will find that the therapy will take up less and less time of your life.

**Life on HPN sound so different than the life I had before, will I ever get my life back?**  
While life on HPN does take away some spontaneity in life, it does not mean that you can never have a life similar to the one you had before. With time you and your medical team will learn how make your medical schedule fit your life and you will be able to do most of what you did before. It takes work, but you can get very close to where you were before.

**Will I ever be able to join, or re-enter the workforce?**  
Once one becomes acclimated to the daily routine of nutritional support therapy, many people return to part-time or full-time employment. Take time to understand and educate yourself on your condition.


**Is there a way to reduce or eliminate my need for nutrition therapy?**  
While HPN therapy has saved the lives of many consumers, an understanding of your medical and anatomical condition, along with knowledge of proper nutrition and hydration is important. There is information available on websites, and with online groups of people on nutrition support that have successful outcomes. Refer to the Oley Foundation, your medical team, or Nutrition support team for initial direction.

**It seems like HPN is going to take over my life, will it get better?**  
Yes, in the beginning it will take over your life. But as you get used to being on the therapy and used to the routine, things will get better. It is possible to still have a life while on HPN. It will always be there but you will find it easier to go out and do things you want to do.

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Our goal is to provide cost-effective care, positive clinical outcomes, and improve quality of life for the home nutrition support patient.

FOR MORE INFORMATION, CONTACT US AT:  
1-888-6-THRIVE (888-684-7483) or [info@thriverrx.net](mailto:info@thriverrx.net)  
[www.thriverrx.net](http://www.thriverrx.net)



# Sharing the Knowledge

## Clinician Guide for New HPN Consumers:

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

### New Home Parenteral Nutrition Consumers

#### A Clinician's Guide

**History:** To better understand the challenges faced by new Home PN consumers we created a survey that was distributed to individuals with HPN experience and with chosen HPN support groups. We posed the question: **What should every new HPN consumer know about life on HPN?** Respondents could answer in an open-ended format that allowed for personalized answers, and/or vote for answers provided by other respondents. This created an evolving multiple choice survey. The flexibility provided by the social media networking platform allowed current and past HPN consumers to share personal insight that would have been limited through the use of set survey responses. The information gathered was used to develop the following talking points:

#### What current HPN consumers what your client to know:

- Life on HPN is hard and scary at the beginning, but most consumers find that it gets easier as time goes on.
- You can still live your life while on TPN. Do what you love, in spite of tubes.
- Keep asking questions, get organized, and you can do just about anything
- Take control of your HPN. While HPN can be overwhelming, it is best not to allow it to control of your life.
- HPN saves lives....it saves mine or my child's life day after day!

#### How can you help new HPN patients:

- **Let them know they are not alone:**

Provide information about pertinent support organizations; including local and online support groups. Groups like this will enable your new HPN patient to connect with current HPN consumers who will be able to share insight, knowledge and hope. These groups can also help your new HPN patient and their family adapt to life on HPN and the challenges that come with it. List of support groups can be found at [ThriveRx.net](http://ThriveRx.net) or [Oley.org](http://Oley.org).

- **Welcome them as Part of their Care team:**

Encourage them become part of their medical team. The more involved in their care they are the better it will be for both of you. Either when they first go home or in time, they will have many questions. They need to know it is ok to ask whatever they need.

Our goal is to provide cost-effective care, positive clinical outcomes, and improve quality of life for the home nutrition support patient.

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# Conclusion

**Our hope is that these tools will help improve:**

- The quality of life
- The quality of care
- Affect patient outcome.

# Goal

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 5-11<sup>th</sup>, 2012***

