



Identifying research targets by Merging Patient And Clinician Treatment information

## October Focus Group Discussion Summary

October 24<sup>th</sup>, 2023

### Project Team:

Melissa Kochanowsky, Programs Manager, PFIC Network

Dr Gitta Lubke, Research Associate, PFIC Network

Emily Ventura, Executive Director, PFIC Network

Dr James Squires, UPMC Children's Hospital of Pittsburgh

Alexandra Perez, Community Council Chair, PFIC Network



## October Focus Group Overview

We held our second IMPACT Focus Group meeting on October 24, 2023!

- Attendees: 12 patients & parents + 5 clinicians & researchers
- The goal of the meeting was to organize and produce information about PFIC treatments to include in the IMPACT web app.
- We are hoping to design the web app as a mix of a PFIC treatment education tool and a data collection tool.
  - Why data collection? □ We want to understand the outcomes (benefits and burdens) that matter most to patients in their treatment journeys so we can design research studies together that are directly meaningful to our community.
- During the meeting, we broke out into two groups (patients and clinicians) to work on different types of information for the app at the same time.

## Web App Background

- Information in the app will be organized into 3 categories: Surgeries, Medications, and Nutrition/Vitamins.
- Our goal is to include educational information and clinical reasons for each item within each category:



## IMPACT Web App Treatment Lists



### Nutrition/Vitamins

Multivitamin  
Vitamin A  
Vitamin D  
Vitamin E  
Vitamin K  
MCT-based Formulas

### Surgeries

Cholecysto appendicostomy  
Ileal Exclusion  
PEBD  
PIBD  
Transplant

### Medications

Antihistamine  
Carbamazepine  
Cholestyramine  
Maralixibat  
Mycophenolate  
Odansetron  
Odevixibat  
Rifampicin  
Tacrolimus  
Sirolimus  
Ursodiol  
Naltrexone  
Sodium Phenylbutyrate  
Sertraline  
Loperamide



## Patient Breakout Group - Discussion Summary

The patient/parent breakout group focused on reviewing and expanding the list of treatments to be included in the IMPACT web app, then discussed their experienced benefits and burdens for each treatment.

For the list of treatments to be included in the web app, group members suggested:

- Adding MCT based formulas and organizing them based on their different formulations (i.e., g-tube, solids)
- Adding Loperamide (Imodium)
- Including information about breastfeeding and indications for formula supplementation
- Organizing the treatments into pre- and post- transplant categories
- Providing information about the implications of specific medications, such as sirolimus and tacrolimus, on kidney function and cholesterol levels, to help users better understand the potential side effects and benefits of these medications.
- Highlighting the importance of a holistic approach to treatment that considers the complexities of managing multiple health conditions simultaneously.

While none of the patient focus group members had experienced a Cholecysto-appendicostomy or Ileal Exclusion, they were able to discuss benefits and burdens for PEBD, PIBD, and Liver Transplant.

Group members suggested creating a table of benefits and burdens for each treatment in a collaborative Google Document so that more community members have the chance to share their experiences and help us gather as much information as possible for each treatment.



## Clinician Breakout Group - Discussion Summary

The clinician/researcher breakout group discussed how to approach providing clinical information about different treatments listed for the web app:

- Various attendees expressed concerns about implying endorsement of any specific treatments, given the individual nature of patient care for PFIC.
- The group explored ways to provide basic information on vitamins and fat-soluble vitamins, considering their importance, formulations, and potential complications associated with their deficiency.
- It was decided to organize the medications into categories: antipruritic, bile acid modulator, choloretic, and immunosuppressant.
- Group members expressed concern about including immunosuppressants and post-transplant care in the web app. They caution that attempting to document post-transplant experiences involving immunosuppression might be challenging without a comprehensive understanding of each individual patients' medical progress.
- Group members highlighted the importance of distinguishing between a medication's intended use and its off label uses, especially in the case of antihistamines used for sleep instead of their typical anti-itch purposes.
- Group members also stressed the need to consider the presentation format for the information on surgeries, advocating for visual aids and clear, simple language to facilitate better comprehension for users.
- The meeting concluded with a discussion on how to describe various surgeries performed on PFIC patients, with an emphasis on maintaining a neutral stance on the choice of surgeries and presenting the information in a manner that doesn't suggest the superiority of one over the other.

The clinician breakout agreed to continue refining the information to ensure it aligns with the app's purpose of providing valuable insights and support to PFIC patients and their families.



## October Focus Group Wrap-Up

- The breakout groups came back together to share what they discussed and organize next steps...
- Both groups decided to fill in the treatment information for the web app as homework.
- Patients and parents will work to fill in information about benefits and burdens for all the treatments listed. Clinicians and researchers will work to fill in clinical information for the treatments listed.
- Our goal is to send a first full draft of the treatment information to our web developer for IMPACT by November 16! Paolo Catalla (Semi:Formal Studio) is the developer for project IMPACT. <https://www.semiformal.studio/>

## Don't miss it! Next IMPACT activities...

- Module 2 will go live in December!
  - Look out for emails from Melissa with an invitation!
- Our next focus group will also take place in December as well!
  - Joint meeting with clinicians and researchers on weekday evening
- Please continue to participate!!!
  - Special awards if you complete every module and attend each bi-monthly focus group ;)

Please contact us anytime with feedback, questions, or concerns: [melissa@pfic.org](mailto:melissa@pfic.org)