



21ST BIENNIAL MEETING OF
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HUMAN INBORN ERRORS OF IMMUNITY: AN EXPANDING UNIVERSE

Unmet needs in rare diseases, differing perspectives – nurse perspective

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Expert practitioners and centers

- a significant gap in knowledge about PID among healthcare providers
- lack of specialized training contributes to delays in diagnosis, mismanagement of symptoms, and insufficient patient education
- Implementing comprehensive, ongoing training specific to PID would greatly enhance care delivery, allowing nurses to identify and manage PID cases more effectively.
- Language



Lack of multidisciplinary support

- PID is a chronic condition that often takes a psychological toll on patients and their families.
- Particularly in children and teens, there is a need to normalize their experience as much as possible to avoid feelings of isolation or being "different."
- Social workers
- Dieticians



Transition support and services

Continuous Education and support of our patients re their condition and time for them to ask questions. As patients concerns change at different stages of their lives with

- Transition from Paediatrics to adult,
- Moving out of home,
- Relationships, new partner or person in their life they may want to have at appointments to discuss the condition



Patient and Family Education on PID Management

- There is a notable lack of structured and continuous education for PID patients and their families regarding symptom management, treatment adherence, infection prevention, and emergency care.
- Nurses are well-positioned to bridge this gap, providing essential guidance to improve health outcomes.
- Ensuring that nurses are equipped to educate patients, and their caregivers would empower families to better manage the condition at home, thereby reducing the reliance on hospital visits and promoting a more independent lifestyle for the patient.



Managing fatigue

- Stress
- Isolation
- Quality of life

- Exercise
- Energy management
- Mindfulness
- Sleep
- Nutrition
- Brain training



Thank you

