



RAReST

Rare Disease
Awareness, Education,
Support, and Training



Key learnings from Rare Disease Project ECHO®

Series 1: Session 7 – Partnering with patient advocacy groups.

Opening presentation

Louise Healy, Education and Advocacy Manager at Rare Voices Australia, spoke on the roles of patient advocacy groups and how health professionals can work with them.

You can find a recording of the presentation [here](#).

For more on partnering with patient advocacy groups, check out Lesson 8 in our **Rare Disease 101 Australia module**. You can register for this short, free CPD on the [Medics for Rare Disease](#) website.

Opening presentation discussion

Discussion included that if there is no Australian advocacy group for a patient's condition, health professionals can:

- Connect them to an international group
- Contact RareConnect who can facilitate introductions and setup online communities
- Reach out to other clinicians who might have patients with the same condition

Additionally, sometimes patients and families often do not feel able engage in peer support as the supporters. Health professionals can help them build their coping skills and resilience first, including through organisations like MindSpot, CarerGateway, and state-based carer support groups.

Case presentation

A nurse presented the case of a woman with Phenylketonuria (PKU). Due to her condition, she must follow strict dietary requirements around protein intake. She has depression, complex PTSD, type 2 diabetes, osteoporosis, osteoarthritis, mild cognitive impairment and gastric bypass.

She was hospitalised for a major depressive episode. This made it very difficult to maintain her diet, which in turn further impacted her mental state.

Challenges that a patient advocacy group assisted with overcoming included:

- Her deteriorating mental health: By coordinating with and between her healthcare team (primary care, subacute, acute)
- Maintaining her diet initially: By supporting her carer in helping her prepare meals
- Maintaining her diet during a hospital stay, as the hospital was unable to purchase specialised medical low protein foods: By providing information to staff and a food hamper

Case discussion

The case discussion covered:

- Patient groups can provide highly practical support
- Mental and physical health are highly interconnected

- Many smaller hospitals are not equipped to support patients with metabolic disorders and complex dietary requirements
- The requirements to receive the Inborn Errors of Metabolism Food Grant (\$270/month) which include following a specialised diet and attending metabolic clinics
- That to support collaboration, it can be helpful to immediately contact a health professional after receiving consent from a client to advocate on their behalf

Key recommendations that the Project ECHO® participants and experts shared at the end of this discussion were:

- Patient advocacy groups play a crucial role in overcoming barriers and challenges in the health system
- Connecting people living with a rare disease and their families with peers is important for both emotional support and practical guidance

Useful resources for clinicians and patients include:

- [Carer Gateway](#)
- [Kiind](#) (WA)
- [Kindred](#)
- [LiveWire](#) (for children living with a rare disease)
- [MindSpot](#)
- [Rare Voices Australia](#)
- [RareConnect](#)
- [Rare Awareness Rare Education \(RARE\) Portal](#)
- [Siblings Australia](#)

Thank you to all who attended. Please do not forget to let us know how we did via [a short survey](#), so we can continue to improve.

Send us questions, discuss presenting a case, or let us know your 'go to' resources by emailing us at rarest@unsw.edu.au