

# LIVING WITH WHIM SYNDROME

## TIPS AND RESOURCES

### Educate yourself about WHIM syndrome

The best way to advocate for yourself is to become educated about WHIM syndrome. The more you know, the more confident you will feel in asking questions and making care decisions.

- [WHIMSyndrome.com](http://WHIMSyndrome.com)  
Lists many resources and patient stories for people living with WHIM. This site is developed and hosted by X4 Pharmaceuticals.
- **International Patient Organisation for Primary Immunodeficiencies**  
Offers WHIM syndrome brochures, webcasts and other information.  
[www.ipopi.org](http://www.ipopi.org)
- **The Immune Deficiency Foundation**  
Explains WHIM syndrome and offers helpful information to guide daily life.  
[www.primaryimmune.org](http://www.primaryimmune.org)
- **The Jeffrey Modell Foundation**  
Offers connections to immunologists and other resources.  
[www.info4pi.org](http://www.info4pi.org)



### Find ways to care for your mind and body

Living with WHIM syndrome can be challenging at times. It can help to learn about healthy ways to cope. The resources listed here can provide tips and support.

- **Global Genes:** The “Caring for Yourself and Your Children” toolkit is a guide for parents who live with a rare disease and includes guidance and practical tips.  
[www.lnkd.in/eM5z3Dtt](http://www.lnkd.in/eM5z3Dtt)
- **National Institute of Mental Health:** Resources and information about mental health for children and adults living with chronic illness.  
[www.nimh.nih.gov/health/publications/chronic-illness-mental-health](http://www.nimh.nih.gov/health/publications/chronic-illness-mental-health)



# Find a support network

One of the hardest parts of living with a rare disease is feeling like you are alone. The good news is there are many ways to connect with and learn from others.

- **Facebook**

Search “**WHIM Syndrome Community**” to find a private Facebook group that offers support and connection with other families living with WHIM Syndrome.

- **Global Genes RARE Portal**

A new online community for patients, caregivers and advocates. [www.globalgenes.org/rare-portal](http://www.globalgenes.org/rare-portal)

- **Immune Deficiency Foundation**

Hosts patient and caregiver communities. [www.primaryimmune.org](http://www.primaryimmune.org)

- **The Jeffrey Modell Foundation**

Offers connections to immunologists and other resources. [www.info4pi.org](http://www.info4pi.org)

- **Primary immunodeficiency support groups**

Ask your doctor if there are any local support groups you could join either in person or online.

- **RareConnect**

Global online community platform for patients, families and advocates. [www.rareconnect.org](http://www.rareconnect.org)

- **X4 Pharmaceuticals Patient Education Program**

Connect with an X4 Patient Education Liaison (PEL), a clinical nurse who may help you and your family learn more about WHIM syndrome and navigate its unique challenges. The PEL can provide disease and genetic testing information and other education resources.

- PELs are provided at no cost by X4 Pharmaceuticals and do not work under the direction of your healthcare professional or offer medical or treatment-related advice. For treatment and medical questions, contact your healthcare provider.
- For more information, please complete the [patient education authorization and consent form](#).

