

# CARING FOR SOMEONE WITH WHIM SYNDROME

## TIPS AND RESOURCES

### Take care of yourself, so you can take care of others

Being a parent or caregiver of someone with WHIM syndrome can be challenging at times. It is important to maintain your own health and manage both your physical and mental wellbeing.



### Educate yourself about WHIM syndrome

The best way to advocate for your loved one 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.
- [The Immune Deficiency Foundation](http://TheImmuneDeficiencyFoundation.org)  
Explains WHIM syndrome and offers helpful information to guide daily life. [www.primaryimmune.org](http://www.primaryimmune.org)
- [The Jeffrey Modell Foundation](http://TheJeffreyModellFoundation.org)  
Offers connections to immunologists and other resources. [www.info4pi.org](http://www.info4pi.org)
- [International Patient Organisation for Primary Immunodeficiencies](http://InternationalPatientOrganisationforPrimaryImmunodeficiencies.org)  
Offers WHIM syndrome brochures, webcasts and other information. [www.ipopi.org](http://www.ipopi.org)



# Find a support network

One of the hardest parts of caring for someone 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.

- **Caregiver Action Network**

Provides education, support, practical tips and resources to family caregivers.

[www.caregiveraction.org](http://www.caregiveraction.org)

- **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**

An 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)

- **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)

- **Rare Mamas**

Podcast, blog and community to help mothers of children with rare diseases navigate rare disease parenting. [www.raremamas.com](http://www.raremamas.com)

- **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](#).

