

LIVING WITH WHIM SYNDROME

BUILDING A CARE TEAM



One of the best ways to manage your WHIM syndrome is to build a care team of health care providers. You may not need all these specialists but it's good to know who they are and how they can help you if you need their specialized care. The health care providers involved in your care may include:

- Pediatrician/primary care physician for day-to-day healthcare needs
- Immunologist for immune system management
- Hematologist to monitor white blood cells that fight infection
- Dermatologist for chronic skin infections and warts
- Ear, nose, and throat (ENT) physician for infections in those areas of the body
- Dentist for gum and teeth infections
- Pulmonologist for lung infections
- Mental health professional for support in living with a chronic illness

With so many health care providers caring for you, it can be very helpful to have one doctor serve as your care team leader. They can care for you as a whole person and watch out for medication interactions and other complications. Typically your primary care provider or immunologist can be your care team leader, even if your healthcare providers work at different locations.

HELPFUL TIPS FOR FINDING AN IMMUNOLOGIST

- Look for an immunologist who specializes in primary immunodeficiencies
- Ask your primary care physician/pediatrician for a referral
- Ask your insurance provider for a list of in-network providers
- Check the database of specialists these patient advocacy organizations maintain:
 - Immune Deficiency Foundation (IDF) www.primaryimmune.org
 - Jeffrey Modell Foundation (JMF) www.info4pi.org/information-booth

RESOURCES FOR MANAGING YOUR CARE

You are also a central part of the treatment care team. Your role is to be informed and play an active role in your care. One way to do this is to track your care by creating a care notebook or using an app. If your care and treatment history are organized, you will be prepared for conversations with doctors, insurance companies and others.

- **Global Genes: Build a Care Notebook**
Toolkit that shares tips and resources to help patients and caregivers manage information related to their care www.globalgenes.org/learn