



Teens

How to explain your PI in casual and emergency situations

Since primary immunodeficiency disease (PI) is rare, most people have probably not heard of it before. In some situations, you may have to explain PI to them; which can be a complicated disorder to understand.

Casual Situations

Examples:

When I was <insert your age>, I was diagnosed with <your type of PI>, which means part of my immune system doesn't work. I am fortunate that through <your type of treatment>, I am able to lead a healthy and normal life.

Or

I have a primary immunodeficiency disease, <your type of PI>, which means I was born with <all or part> of my immune system missing. The treatment for <your type of PI> is <your type of treatment>, which helps me live a normal life. Primary immunodeficiency diseases are genetic conditions and not contagious.

Emergency Situations

Explaining your PI during emergencies may be more difficult, depending on the situation. In one instance, it may be just a matter of giving the medical response team a copy of your personal health record or In Case of Emergency (ICE) page from your IDF ePHR. In extreme emergencies and/or situations where you are unable to communicate, it might be helpful to wear a medical alert band (which is available through many organizations including www.medicalert.org) that would provide emergency personnel with important medical information before they begin treatment.

The following IDF publications can be shared with healthcare professionals in non-emergency situations.

- IDF Diagnostic & Clinical Care Guidelines
- IDF Guide for Nurses
- Chapter(s) from the IDF Patient & Family Handbook about your diagnosis & treatment
- ICE page from the IDF ePHR: www.idfephr.org

Download or order these IDF resources at www.primaryimmune.org/publications.