



Teens

How to explain your PI in casual and emergency situations

Since primary immunodeficiency (PI) is a rare disorder, most people have probably not heard of it before. 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 is not working. 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 immunodeficiencies are genetic conditions and not contagious.

You can also connect with other teens through IDF Common Ground and find out how they explain their PI to others: <http://idfcommonground.org>.

Emergency Situations

Explaining your PI under emergency situations may be more difficult. It also depends on the type of 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 the IDF eHealthRecord. In extreme emergencies, in situations where you are unable to communicate, it might be helpful to wear a medical alert band (which is available through many organizations including <http://www.medicalert.org/>) that would provide emergency personnel with important medical information before they begin treatment.

The following IDF publications can be shared 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 eHealthRecord: www.idfehealthrecord.org

They can be downloaded or ordered at www.primaryimmune.org/idf-publications.