About Primary Immunodeficiency Diseases (PI)

In the United States, approximately 1 in every 1,200 individuals are diagnosed with a primary immunodeficiency disease (PI), and many more go undetected. Representing a group of more than 300 rare, chronic disorders, PI can be difficult to diagnose. While not contagious, these diseases are caused by hereditary or genetic defects, in which part of the body’s immune system is missing or functions improperly.

Many people with PI live their entire lives more susceptible to infections – enduring recurrent health problems and often developing serious illnesses. Fortunately, with proper medical care, many people with PI are able to live healthy and independent lives.

The IDF Teen Program empowers teens living with PI to contribute and help others.

- Awareness and Advocacy - Teens distribute IDF materials and speak to legislators and others about PI
- Teen Council - Council members share stories and offer support to other youths with PI while serving as leaders at IDF events.
- Fundraising - Teens participate in IDF Walk for Primary Immunodeficiency and organize fundraising campaigns to raise funds and PI awareness.

The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency disease (PI) through advocacy, education and research.

The IDF Teen Program is supported by charitable donations from CSL Behring, Grifols, Horizon Pharma and Shire.

Immune Deficiency Foundation
110 West Road, Suite 300
Towson, MD 21204
www.primaryimmune.org
IDF offers many resources for individuals diagnosed with PI. From publications to videos to programs, there is always something new to learn. The teen section of the IDF website is the go-to place to get all the information about living with these rare, chronic disorders, www.primaryimmune.org/teens. There, you can find everything you need, like tips to managing your health, advice on friends and dating, and how to juggle school and health at the same time.

IDF Reel Stories are videos where teens, families and other individuals who are living with PI have participated in and have had the opportunity to share their stories with IDF and the PI community. These stories inspire others and promote awareness. Find a video that helps and inspires you here: www.primaryimmune.org/idf-reel-stories.

In Tune with Your Immune System is a rockin’ video comparing the human immune system to a band. All the parts must function to make great music!

IDF Presents the Battle of the Bands is a comic book that goes with In Tune with Your Immune System and shows the band face off in a battle of the bands contest against an unfriendly infectious band that’s making the entire crowd sick.

IDF Teen Escape is a weekend getaway exclusively for teens, ages 12-18, who have been diagnosed with PI. This fun weekend lets teens meet other young people who understand what it’s like to live with PI while having fun and learning from healthcare and life skills experts.

The weekend offers:
- Fun activities that promote friendship, build leadership skills and develop coping abilities
- Presentations from medical and life skills experts
- An entertaining outing on Saturday evening developing confidence
- Separate sessions just for parents

In addition to an opportunity to network with other teens who have been diagnosed with PI, teens participate in fun activities and develop skills to help manage their disease. With an ever-evolving, age-appropriate program, medical and life skill experts present invaluable information for teens with PI.

Teen Escapes are held in cities across the country. Learn more at www.primaryimmune.org/idf-teen-escape/