

### PRIMARY IMMUNE DEFICIENCY DISEASES - RELATED BOOKS

#### **As I Live and Breathe** -Weisman, Jamie MD

Notes of a patient-doctor with an immune deficiency and her trials and tribulations of being both a patient and a doctor.

#### **Igi V Is Just Like Me, Igi V's Medical Records, and**

#### **A Guide to Therapeutic Play** – Baxter Healthcare

This therapeutic play kit contains books, an infusion tool kit, and a plus bear especially designed with common body markers to help identify and communicate pain points. It is designed to help toddlers and school age readers express their thoughts and feelings about receiving infusions and learn how to record infusion information.

#### **Charlie's IVIG Book** – Charlie's Parents

This book explains what it's like to have an IVIG infusion and provides stickers and colored construction paper for a child to make his own book!

#### **The ABCs of Kids Like Me** – Walker Bozarth, Emma Jane

A story of a child with CVID, which is helpful for children living with a chronic illness or undergoing treatment procedures. It contains a template and crayons for a child to add his own words and photos.

#### **Celina's Story** – Frelinghuysen, Celina Prentiss

A teen's story of living with Primary Immunodeficiency

### BROCHURES & FLYERS

#### **Off to College Brochure** - BioRx

An easy-to-use checklist to help the PIDD patient & family prepare for the start of college

#### **Back To School** - BioRx

A guide to "school life" for students with PIDD

#### **Pregnancy and PIDD** - BioRx

Suggestions and information on Pregnancy and PIDD

### IMMUNE DEFICIENCY FOUNDATION PUBLICATIONS

#### **Patient and Family Handbook** - *Immune Deficiency Foundation*

This handbook provides general information about Immune Deficiencies, as well as specific information on the most common types. There is also information on how to care for yourself, a chapter on health insurance, types of therapy and lab tests.

#### **Our Immune System** - *LeBien, Sara*

This is an excellent explanation of the immune system geared towards children, but works well with adults too.

#### **IDF Guide for Nurses** - *Immune Deficiency Foundation*

A booklet designed specifically for infusion nurses covering IVIG and SCIG

#### **IDF School Guide, Information about Students with Primary Immunodeficiency Diseases** - *Immune Deficiency Foundation*

This booklet includes key medical points about primary immunodeficiency diseases and associated special needs, legal rights of children with chronic disease, and resource referrals. It is a valuable resource tool for both parents and educators.

### WEBSITES

[www.niaid.gov](http://www.niaid.gov)

*National Institute of Allergy and Infectious Diseases*

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

*Immune Deficiency Foundation*

[www.jmfworld.com](http://www.jmfworld.com)

*Jeffrey Modell Foundation*

[www.nih.gov](http://www.nih.gov)

*National Institute of Health*

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

*Patient Services Incorporated*, a national non-profit committed to providing a variety of services to PIDD patients

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

Fast, confidential notification of Plasma-derived withdrawals and recalls

## **GAMES, ACTIVITIES, DVD'S AND VIDEOS**

### **The Awesome Adventures of Andibody**

- *Talecris Biotherapeutics*

This coloring book explains what antibodies are to children

### **Sally's First Infusion - *Talecris Biotherapeutics***

A coloring book for children getting their first infusion at an infusion center

### **Play Your Best Defense, Know Your Immune System\_- *Doris Theato and Jurgen Frey***

This comic book explains the immune system to children