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In this month's Web alert, we have an extensive review of the Primary Immune Deficiency Foundation website. This is a useful site for professionals, patients, and parents facing the problems of a primary immune deficiency disorder. We more briefly describe a second interesting site for the same diseases.

### **Immune Deficiency Foundation**

<http://www.primaryimmune.org>

The first patient information tab describes in general terms what a primary immune deficiency is. There is a 10-page patient education PDF file that can be downloaded or printed. This describes how the normal immune system works, in terms that a layperson can understand. The illustrations in the pamphlets are well done and complement the discussion. The information includes a description of what happens when the immune system is deficient. The text is so well written that a layperson with a high school education can understand it.

Besides this general patient information piece, there are patient information sheets about each specific primary immunodeficiency. These are available as 4- to 10-page PDF files that can be downloaded and printed. Each specific immunodeficiency is described in a clear manner, including clinical presentations, causes (if known), and treatments.

For example, the patient education pamphlet on severe combined immunodeficiency describes the basic disease and the recognized causes. There is a section on actions to be taken by the patient and parents. There is a description of the benefits of transplantation therapy with bone marrow or cord blood stem cells. The first bone marrow transplant for severe combined immunodeficiency disease was performed in 1968, and the recipient is still alive. After reading this information, one has to realize how the fate of these disorders has changed with our better understanding of immunology.

There are two additional patient guidelines, which I recommend for patient use and for your review. The first deals with how to live with primary immunodeficiency as a child or teenager. It gives guidelines to promote as normal a life as possible, including participation in all aspects of a fruitful childhood.

The second guideline is for adults with primary immunodeficiency. It gives advice about employment, health insurance, and effects of emotional strain on the immune system. In a sound and realistic fashion, it offers ways to handle some of the obstacles facing an adult with primary immune deficiency.

There is another feature that allows you as a clinician to get a free second opinion about a patient's immune disorder. This is the consulting immunologist program. There is a toll-free number that you can call. I would prefer to use the provided e-mail address. This allows you to attach relevant records or laboratory data. I am not certain if this method is Health Insurance Portability and Accountability Act (HIPAA) compliant, but the patient's identifiers can be removed before attachment.

For the patient there is a patient notification program feature. This allows the patient to receive updates about whenever plasma products are recalled or withdrawn from the marketplace. This is an easy service to sign on. If you are a patient receiving intravenous immunoglobulin, this is a source of comfort, considering the past problems with plasma-based products.

There is a tab called Clinical Trials on this site. It gives a general statement of the Primary Immune Deficiency Foundation's opinion on being involved in clinical research. It is, in general, a supportive but not coercive stance. The viewer is then directed to <http://www.clinicaltrials.gov> to seek specific clinical trials for their disease.

**The National Primary Immune Deficiency Information Site**

<http://www.info4pi.org>

This valuable site is sponsored by the Jeffrey Modell foundation. The foundation memorializes Jeffrey Modell, who died at age 15 from complications of a primary immunodeficiency disorder. It is divided into sections of professional medical information, general information, patient information, and foundation information.

The site contains information about disease states similar to those found on the Primary Immune Deficiency Foundation website. But this site also offers a list of immunology referral centers and immunologists recognized as the leaders in treating primary immune deficiency. The site is notable for an unusual Kids Corner. Here are a set of age-adjusted computer games for the children to play and enjoy. This is a unique feature of the site, as the games are purely for enjoyment.

There is also a description of the activities of the Jeffrey Modell foundation. These are both national and international, involving support for centers of excellence in the treatment and research of primary immune deficiency disorders. The list of such centers is impressive and shows a high level of commitment and financial activity by the foundation. It is worthwhile for the allergy and immunology specialist to take a few moments to review this site.