

The Immune Deficiency Foundation uses social media to connect patients, families

Few organizations supporting those with rare diseases offer the social networking tools that the Immune Deficiency Foundation (IDF) offers. Their website is an open book for those looking for more information about primary immunodeficiency diseases. The expected run-down of information can be found: definition, product and treatment details, and information on advocacy efforts. But, the IDF website offers something more: support.

Several areas of peer and legislative support can be found. Those coping with primary immunodeficiency disease (PIDD) and others who are affected by the disorder can connect through IDF's Peer Support Program. Also offered is IDF Friends, a social

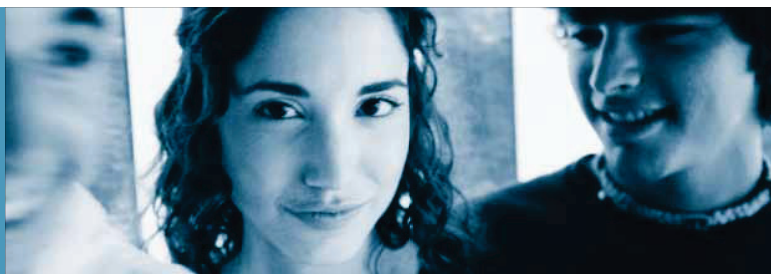
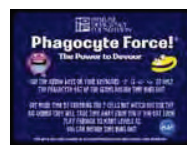
community for patients and families living with PIDD. IDF Friends offers PIDD-affected individuals the chance to connect with others who experience the same struggles. Members can create messages in the discussion forum, join a group, play games, watch videos of their peers talking about how they deal with PIDD, and much more.

President and Founder of IDF, Marcia Boyle, said, "People's media habits have changed and the digital revolution made social networking an essential tool for any non-profit organization. The use of social networking has allowed IDF to instantaneously engage and connect with patients, generate awareness, and provide a platform to better promote the IDF mission."

Christine Belser, Vice President of Programs for IDF, agrees that the rise in social media popularity has changed the way non-profits operate. Belser said IDF Friends and other social networking sites offered by the organization have taken off since they were launched just over a year ago. "There has been an overwhelming and very positive response to the IDF social media initiatives," said Belser. "IDF Friends has grown to over 1,600 registered users and our newly developed blogs are starting to get noticed. The IDF

Arcade, which is housed on both of our social networking sites, has increased in popularity as well."

Also produced by IDF is Our Immune System, a storybook that educates children about PIDD through playful character illustrations. The characters explain how the immune system works and what our bodies do to stay healthy and fight infection. The first edition of this book was published in 1990. Since then, new treatment options have been approved, technology has changed, and the PIDD audience has become more diverse. To help IDF revise and expand the storybook, ASD Healthcare awarded them an unrestricted educational grant to produce the second edition of the book. In addition, ASD Healthcare awarded IDF a grant to develop interactive video games based on the book. Although 'Whack-a-Germ,' 'Phagocyte Force' and 'Jigsaw Puzzler' were developed for children, many adults also enjoy these games, which can be accessed at www.primaryimmune.org.



"When my son was growing up with X-linked agammaglobulinemia, he had no peers with the same disorder," said Marcia Boyle, President and Founder

of the Immune Deficiency Foundation.

"Now, with our social network, educational meetings and materials, patients have a nationwide community of support and information. We thank ASD Healthcare for helping IDF provide this community to our patients and families!"

ASD Healthcare is proud to support IDF and the PIDD community. Those affected by rare diseases often have a difficult time coping with the stresses of the disease and its affect on their daily lives. By turning to social media to connect individuals from different communities, these people and their families can build a network of support.

Social networking sites offer an exciting opportunity for individuals and communities to connect. For those with rare diseases, the opportunity to meet others they can relate to is even more critical. ASD Healthcare hopes to see the social networking trend continue to be utilized in the rare disease community and beyond. For more information about IDF and their social communities, please visit www.primaryimmune.org or go to www.asdhealthcare.com.



Go to the Advocacy page on asdhealthcare.com to read more about organizations ASD Healthcare supports.

ABOUT THE IMMUNE DEFICIENCY FOUNDATION

Since 1980, IDF has provided accurate and timely information for the nearly quarter-million Americans who have been diagnosed with a primary immunodeficiency disease. Governed by a Board of Trustees and supported by a Medical Advisory Committee comprised of some of the world's leading clinical immunologists, as well as hundreds of grassroots volunteers and a compassionate, professional staff, IDF has provided individuals and their families with vital knowledge and made tremendous strides in:

Helping the patient and medical community gain a broader understanding of primary immunodeficiency diseases through education and outreach efforts

Promoting, participating and funding research that has helped characterize primary immunodeficiency diseases and given patients and physicians substantially improved treatment options

Addressing patient needs through public policy programs by focusing on issues such as insurance reimbursement, patient confidentiality, ensuring the safety and availability of immune globulin therapy, and maintaining and enhancing patient access to treatment options

Today, thousands of individuals and families affected by primary immunodeficiency diseases depend on IDF for advocacy, education and empowerment.

