Immune Deficiency Foundation Among the First Rare Disease Patient Organizations to Launch Major Social Networking Initiatives

Towson, MD, October 6, 2009 – People with primary immunodeficiency diseases (PIDD) and their families will now be able to connect with one another and share their experiences through a new multidimensional social networking initiative, the Immune Deficiency Foundation (IDF) announced today. Primary immunodeficiency diseases are a group of rare, chronic illnesses, caused by hereditary or genetic defects in the immune system. In the U.S., approximately 250,000 people are diagnosed with PIDD, with thousands more undetected. By reaching out to this community, IDF is one of the first rare disease patient groups to make full use of social media tools and technologies.

“We are creating a living, breathing online community, where patients and families can share their experiences, hopes and challenges of living with PIDD,” said IDF founder and president Marcia Boyle. “It is easy to feel lost among the millions who use popular social media sites like Facebook – especially if you are someone with a rare disease. Now, our patients and families have a trusted social networking community they can call their own and find others who share their particular primary immunodeficiency disorder or life circumstance.”

IDF’s social network includes:

- **IDF Friends** (http://my.primaryimmune.org) – The flagship social media site for patients and families living with PIDD helps members find and connect with others who share common disorders, and concerns.

- **IDF Common Ground** (http://www.idfcommonground.org) – Created just for teens and young adults with PIDD, this social media site is an important destination – one that enables this generation of patients to receive support and guidance on their own terms.

- **IDF Arcade** (http://www.primaryimmune.org/flashgames/idf_flashgames.asp) – Using the popular characters from IDF’s “Our Immune System” booklet, the arcade combines education and entertainment to teach young children about their disease through interactive games.

- **IDF TV** (http://www.youtube.com/idfreelstories) – Bringing PIDD to life through patient-generated YouTube testimonials, IDF TV includes a patient advocacy channel on breaking public policy issues and a “Reel Stories” channel featuring relevant videos on a range of topics of interest to individual patients and their families.

As IDF’s social media communities continue to evolve in sophistication and content, patients and families will increasingly be able to benefit from both the collective intelligence and one-to-one communications that such sites make possible. “We are redefining what it means to be a truly engaged and empowered patient community,” Marcia Boyle added.

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About The Immune Deficiency Foundation

The Immune Deficiency Foundation, founded in 1980, is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. People diagnosed with PIDD often find it difficult to receive specialized health care, proper diagnosis and treatment. They experience difficulties financing health care, finding educational materials and locating others to share their experiences. IDF helps individuals overcome these difficulties and live healthy and productive lives.

To learn more about IDF’s social media initiative, visit www.primaryimmune.org

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