

Social Media and Its Effects on the IG Community

Social networking platforms continue to transform the way people in the IG community connect.

By Mark T. Haggard

AN INFORMATION REVOLUTION continues to sweep across the world thanks to social media outlets like Facebook and Twitter. Not only have businesses and organizations reaped the benefits of these networks, so too have individuals — especially those like immune-deficient patients who rely on these networks to connect with others who face the same health issues. And, while each follower of a social media outlet participates for their own reasons, there's no disputing that individual lives have improved through the sharing of information on the social network.

A Need to Reach Out

Two issues that face many in the immune globulin (IG) community are isolation and the misunderstanding by others around them. Outside of the community, people do not understand the issues that confront us. The classic story is of the person telling someone with primary immunodeficiency (PIDD), "You look great," while inside the proverbial time bomb is waiting, ready to be detonated by the next pathogen that enters the body. Another issue faced is isolation because of the rarity of our disease. Few people have PIDD. You may find huge gatherings of those with other diseases, but those with immune deficiencies are few and far between.



Only members of our small IG community of PIDD patients and their families know what we are going through. Often, our closest friends and most family members have no idea of the challenges we face. When people ask us how we feel, we are troubled by the double-edged sword of a truthful answer. When we speak honestly, we may be derided as "crazy" or as "complainers." It is simpler to bite our tongues and lie, telling them that we are doing "fine."

So with so few of us who can relate to each other, we need a way to get and stay connected, to share our knowledge and to build friendships on common experiences and common concerns.

Social Media's Many Forms

Along came the social media sites like Facebook and Twitter. But, while these two social media sites have become household names, there exist many other social media forms, including Internet forums, weblogs,

social blogs, microblogging, wikis, podcasts, photographs or pictures, video, rating and social bookmarking. And, there has been rapid growth in the number of U.S. patent applications that cover new technologies related to social media. Today, there are more than 250 published applications.

According to a report by Nielsen (www.nielsen.com/us/en/insights/press-room/2009/time_on_facebook.html): "In the U.S. alone, total minutes spent on social networking sites has increased 83 percent year-over-year. In fact, total minutes spent on Facebook increased nearly 700 percent year-over-year, growing from 1.7 billion minutes in April 2008 to 13.9 billion in April 2009, making it the No. 1 social networking site for the month." Nielsen lists the top 10 social networking sites as Facebook, Myspace.com, Blogger, Tagged.com, Twitter.com, MyYearbook, LiveJournal, LinkedIn, SlashKey and Gaia Online.

IG Living is no stranger to the world of social media. On the *IG Living* website, social networking sites are listed for 15 disorders treated with IG (www.igliving.com/IGTreatedDisorders.aspx). As of this writing, the *IG Living* Facebook page has 965 fans, and by the time this goes to press, it will likely have surpassed the 1,000 mark. Each week, dozens of conversations are initiated about issues relating to chronic illness.

Benefits of an Online Community

One of the great things about a social media site is that we can quickly meet other people being treated with IG. Because they know exactly what we are going through, we no longer feel alone. It is the perfect place to

vent and be happy at the same time; it is a place where we do not have to worry about being judged. Some go so far as to say that, because it is a place to share our deepest feelings and concerns, it is a place to be truly "loved."

Beyond making emotional connections online, social media has proven practical for the IG community. It is a place where we can speak to the

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pioneers who have gone ahead of us who can now pass along invaluable information for our present situation — information about doctors, treatment, billing and any number of things. In turn, we may be someone else's pioneers. "It's incredible looking at stories; it's incredible to look at data," one user said. "Once you start, people tell others and the stories spread."

In a similar vein, getting opinions from many sources is likely to produce better options than those produced by the one person to whom you may be talking on the telephone.

But, with the good can also come the bad. The very thing that makes social networking such a useful tool is what can bring about the most grief. A statement posted on a Facebook site is in a public place for anyone to see; even communications that are considered "private" can be made public by an individual with above-

average computer skills and malice in their hearts. Once a statement is out, it stays out and cannot be retrieved. So, people should think twice before pressing "send." Nor are there checks and balances on a public forum; the person professing to be an expert might be passing along information that is out-and-out false. Discretion should be used when taking information from a social networking

site. In fact, it is best to run an idea by someone who is a trusted authority in the field, not some hack behind an avatar.

A Multipronged Platform

Social media offers numerous benefits for the IG community. It has proven to be a place for individuals to share ideas, to be understood and maybe even to feel loved. It also has grown into a platform to educate the public about the ordeals of those dependent on IG and for advocating on their behalf. Indeed, social networking just may be the path to accessing this life-giving therapy. ■

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