by J. Doug Gill

It should come as no surprise that the president and founder of the Immune Deficiency Foundation thinks that the entire primary immunodeficiency disease community should attend the upcoming IDF National Conference — one that will mark the 30th Anniversary of the organization.

What might surprise you is the reasoning behind that desire.

“The National Conference has been life-changing for so many,” Marcia Boyle tells me, leaving the highlighting of its noted medical and education programs and entertaining activities to marketing. “When you attend (the conference) you can look around and see hundreds of our patients and families that feel less isolated — less alone — as a result of our conference.”

If you know Marcia, you know that her no-nonsense answer reinforces her serious approach to standing beside (and fighting on behalf of) the primary immunodeficiency community.

If you have yet to make her acquaintance, then perhaps a quick introduction is in order.

Marcia Boyle and her husband, John, didn’t set out to form a foundation; it arose from a distressing scenario in which no parent wishes to find his or herself: as the result of having a very sick child.

Prior to the trying times that lie ahead, Marcia graduated from college, and later obtained a Master’s Degree in Library Science, and, after spending numerous years in New York and New England (she was born in Massachusetts) found herself living in Columbia, Maryland.

That connection to the library sciences would prove monumental to Marcia personally, and instrumental in the founding of IDF.

“Our son was very ill,” Marcia explains. “The first year-and-a-half was pretty rough.” Once her son, also named John, was diagnosed with a primary immunodeficiency disease and received the necessary immunoglobulin replacement therapy, he was well on his way to recovery and an increased quality of life.

Marcia admits she was fortunate; her son’s diagnosis came quickly — something of great importance for which the IDF president has tirelessly advocated for the past 30 years. Determined to research and absorb as much information as she could about her son’s primary immunodeficiency, Marcia took advantage of her library connection and digested the limited publications pertaining to the disease.

Still, with her focus fixed — naturally — on the wellbeing of her son and her family, Marcia’s journey through the then-practically unknown realm of primary immunodeficiency revealed a glaring absence of not only information and
materials for patients and families, but also a lack of organizations working on behalf of those diagnosed with the disease.

"There was absolutely nothing out there – not a single organization at the time that was advocating or lobbying on behalf of immunodeficient patients." Marcia says. "And there was nothing out there to help the families; no one out there to even talk to them."

Enter Dr. Jerry Winkelstein, a pediatrician and specialist in primary immunodeficiency at Johns Hopkins in Baltimore, influential not only in the Boyle's lives, but also in the birth of the Immune Deficiency Foundation.

"Dr. Winkelstein's advice and assistance was immeasurable," Marcia recalls. "We knew very little about certain aspects, but what we did know was that we wanted a strong national patient organization – not just a local one – that would seek successful partnering with the medical community and take a leading role in advocating on behalf of the primary immunodeficiency community."

Once Dr. Winkelstein reached out to the medical community and began recruiting members of the fledgling foundation’s Medical Advisory Committee, the journey had begun. The Immune Deficiency Foundation made its debut in December 1980. "Seemed kind of silly to celebrate our anniversary last year," Marcia laughs. "We were not even around for a month in 1980."

Clarification, then, on why the organization will spend 2011 – instead of 2010 – touting its three decades of existence!

Marcia Boyle’s pride is palpable when she considers the thirty-years of accomplishments attained by the Foundation.

"We have created a voice for a community that didn’t have one," Marcia says proudly. "And we created opportunities to help members of our community build a better life."

Obviously gratifying, too, is IDF’s celebrated status as a preeminent source of information and educational materials; the irony of which can’t be lost given that a lack of then-available materials was the impetus for the founding of the organization.

"Not only were we the first U.S.-based foundation dedicated to primary immunodeficiency (and the second in the world), but our ‘Patient and Family Handbook’ was the first publication of its kind to be developed specifically for those whose lives have been affected by PIDD."

While thirty years is – in calendar terms – a very long time, the period is but a blip on the generational stage; especially when the era is spent confronting a chronic, sometimes devastating disease.

Still, she has no qualms about what has come before and the hard work that lies ahead.

"I accepted early on that things weren’t going to happen overnight," Marcia says, "and all in all, I think we have done very well. I find it amazing how we were able to grow – through physicians' and nurses’ word-of-mouth early on, and later through the Internet. We have a strong network of support through our dedicated volunteers, medical community and our generous supporters who really make things happen!"

The IDF National Conference is an integral part of the foundation’s past and future growth. First held in 2001 – in cities such as Baltimore, Orlando and St. Louis – the paramount gathering is headed West in 2011, and landing at one of the most popular vacation destinations in the Southwest: the JW Marriott Desert Ridge Resort & Spa in Phoenix, AZ.

Recreational opportunities will abound – both on and off the sprawling, Desert Ridge grounds – but the real activities will take place in the meeting rooms and exhibit hall. That is where world-renowned immunologists, skilled professionals, industry sponsors, dedicated volunteers and an exceptional patient population will come together from June 23 – 25 to learn, network, and share their experiences with people who understand what primary immunodeficiency is all about.

“Our National Conference is such an important event held for those patients and families touched by primary immunodeficiency disease. The entire event was developed with the needs of our community in mind.” Marcia says as our conversation draws to a close, “I would tell people that they owe it to themselves to join us in Phoenix and help strengthen the voice that IDF provides. Come celebrate IDF and our community!”