

A SALUTE TO MARCIA BOYLE

IDF PRESIDENT & FOUNDER,
LEADER, AND VISIONARY

BY JULIE BIRKOFER, SENIOR VICE PRESIDENT,
NORTH AMERICA & GLOBAL HEALTH POLICY



The Immune Deficiency Foundation (IDF), the national non-profit patient organization for the primary immunodeficiency (PI) diseases, stands as it is today because of the visionary and inspirational leadership of Marcia Boyle. In 1980, a small group gathered, both families and physicians, and agreed there was an urgent need for a strong national patient organization dedicated to individuals affected by PI. Now, 37 years later, thousands of families, patients, and medical professionals have joined IDF's efforts to improve the diagnosis, treatment, and quality of life of persons with PI through advocacy, education, and research.

Q Share with our readers a little more information about what inspired you to create the Foundation?

My son was born in 1977, and in 1978, at the age of 6 months, was diagnosed with a primary immunodeficiency. At that time there was no patient organization, no educational materials, and no one advocating for this group or rare diseases. My husband and I wanted to do something positive to help our son and others like him. With a handful of others, including Dr. Jerry Winkelstein, our son's immunologist at Johns Hopkins, we decided to create a national organization dedicated to improving the diagnosis, treatment, and quality of life of people with PI through advocacy, education, and research. The idea started in Maryland, but over time, others joined us from around the country.

Q You were among nine individuals who received the "Champions of Change for Precision Medicine" recognition during President Obama's Administration. What did that moment mean to you?

It was very powerful to have primary immunodeficiency diseases and IDF recognized so prominently. I was nominated because of our commitment to innovation on behalf of patients. Specifically, building an electronic personal health record and developing PI CONNECT, our Patient Powered Research Network, to help patients better track their experiences and take control of their care. I was quite humbled to see the efforts of our rare disease organization chosen as an example of innovation and excellence.

Q Marcia's son was diagnosed with a primary immunodeficiency disease in 1978. At that time, no organization existed and no materials were available for patients and families. Today, because many others have shared a common vision, information and resources are available for the PI community. However, the problems of diagnosis, treatment, and access to care have not gone away. What do you consider the greatest challenge facing the PI community?

As a rare disease community, our patients and families face obstacles in obtaining a diagnosis, as well as challenges accessing expert care. Many physicians don't know enough about these disorders and are treating the symptoms, rather than looking for the underlying disorders. Even after receiving a diagnosis, some individuals with PI don't have access to true specialists who know how to best manage these individuals with complex health issues. Because approximately 70 percent of the people who contact us have antibody deficiencies and depend on lifelong and lifesaving immunoglobulin replacement therapy, early diagnosis, and proper care are essential to their health.

Because these are lifelong conditions with expensive therapies, people with PI can face overwhelming obstacles with health insurance. In addition, the patient protections under the Affordable Care Act are now in question, representing a tremendous threat to our community. Some of these protections include prohibiting insurers from denying insurance coverage to individuals with pre-existing medical conditions, charging more based on health status, and dropping people because of such conditions; prohibiting annual or lifetime caps on coverage, retaining annual out-of-pocket costs, prohibiting insurers from instituting discriminatory benefit designs; and retaining a requirement that health plans include prescription drug coverage as a covered benefit.

Left (top to bottom): IDF President & Founder, Marcia Boyle, arm wrestles PPTA President & CEO, Jan M. Bult, during the IDF 2017 National Conference in Anaheim, Calif.

Marcia with staff at the IDF office during World PI Week, Thinking Zebra!

Marcia and her husband at the IDF 2017 National Conference Zebra Gala in Anaheim, Calif., June 16, 2017.

Marcia with her son John G. Boyle, new IDF President & Chief Executive Officer, and her husband, John, member of the IDF Board of Trustees.

WE ALL WEAR SLIGHTLY DIFFERENT HATS, BUT WE ARE UNITED IN OUR EFFORTS TO ENSURE PATIENTS HAVE ACCESS TO THEIR LIFESAVING THERAPIES. PLASMA THERAPIES ARE UNIQUE, AND OUR GOAL IS TO ENSURE THESE ESSENTIAL THERAPIES CONTINUE TO BE ACCESSIBLE TO ALL WHOSE LIVES DEPEND ON THEM.

Q What do you consider the most important resource IDF has created for patients and why?

Most important, IDF has created a platform for PI and given the members of our community a voice. We are probably best known for our educational materials and programs. In fact, IDF created the first educational resources and programs for patients and families with primary immunodeficiencies and has launched many programs for healthcare professionals. IDF continues to listen to the needs of our community and develop resources to help solve these problems. All of the programs developed were created in reaction to issues faced by the PI community, including the need for educational resources, answers to health insurance and reimbursement questions, access to optimal care and therapies, and advances in the diagnosis and treatment of these diseases.

IDF has helped educate countless physicians on the recognition and diagnosis of these disorders and has supported numerous training fellowships and research grants. IDF's advocacy efforts have mobilized all stakeholders in the PI community to stay in the forefront of issues that impact patients and families. IDF developed a wonderful peer support network of volunteers and continues to initiate educational programs throughout the country.

Q In terms of advocacy, what do you consider IDF's most significant accomplishment?

For nearly 25 years, IDF has weighed in on advocacy issues surrounding access to care for Ig replacement therapy. We were successful in including in the Medicare Modernization Act (MMA) a provision for home infusion for intravenous immunoglobulin (IVIG) in PI, and then we advocated for a number of years to provide sufficient funding for this provision. In 2013, the president signed the Medicare IVIG Access Act into law to create a three-year demonstration project for IVIG for Medicare beneficiaries with PI. We also were successful in incorporating language into the 21st Century Cures Act, which used a reduction in the reimbursement of durable medical equipment infused drugs, including subcutaneous immunoglobulin (SCIG), to pay for training, education, and monitoring. Unfortunately, this

provision is not slated to go into effect until 2021, and we are now advocating to speed up this provision to 2018.

In addition, we're very proud of our efforts, and the efforts of the whole PI community, surrounding the implementation of newborn screening for Severe Combined Immunodeficiency (SCID) in all states. To date, 44 states are screening, four states will be screening by the end of 2017, and only two states don't currently have definite plans.

Q What has your experience been partnering with PPTA on patient access to care issues?

We've had a very productive partnership over the years with PPTA. Since so many of our advocacy issues revolve around access to Ig therapy, we have worked together on benefits in the MMA, the Medicare IVIG Access Act, and the current issues surrounding reimbursement for SCIG. We all wear slightly different hats, but we are united in our efforts to ensure patients have access to their lifesaving therapies. Plasma therapies are unique, and our goal is to ensure these essential therapies continue to be accessible to all whose lives depend on them.

Q By the time this issue prints, you will have officially "retired" from your current role as President & Founder. So much of your life and your family's life has been dedicated to the Foundation. What does retirement look like for Marcia Boyle?

I'll never retire from being Founder! That is something I'll always be proud of. I plan to remain very involved in the community, serving as a volunteer for the foundation. I know I leave IDF in a strong position, with an excellent staff. My husband, John, and I plan to travel more, which is something we have enjoyed doing for many years but now with the time to do it a little more leisurely! Right now, I'm too busy to worry about what I will do, but I know that I won't be bored. There are volunteer projects to take on, family to be involved with, courses to explore, and trips to take. And, if there's a need for a passionate advocate for PI, I'll be there! ●