

**Testimony of John G. Boyle, President & CEO
Immune Deficiency Foundation**

**Before the Senate Health, Education, Labor and Pensions (HELP) Committee
Vaccines Save Lives: What Is Driving Preventable Disease Outbreaks?**

**March 5, 2019
Washington, DC**

Chairman Alexander, Ranking Member Murray, and Members of the Committee:

Thank you for inviting me to testify on the importance of herd immunity for vaccine preventable diseases.

My name is John G. Boyle, and I am the President and CEO of the Immune Deficiency Foundation. IDF is a not-for-profit patient organization representing people with primary immunodeficiency diseases, or PI.

Primary immunodeficiency diseases are a group of more than 350 rare, chronic disorders in which part of the body's immune system is missing or does not function properly. There are an estimated 250,000 people diagnosed with a form of PI in the U.S. alone. That's approximately 1 in 1,200 of your constituents.

These disorders are caused by genetic defects and are not contagious. Many are first recognized shortly after birth or in early childhood, but many more are not diagnosed until much later in life.

There is some variety between the different forms of PI, but one thing unites all of us: we are immunocompromised, meaning that we are potentially vulnerable to even the most common viruses and bacteria. We all struggle, to varying degrees, with recurring infections and persistent illnesses even when treatments are available that lessen the impact of our diagnoses.

I have a form of PI known as X-Linked Agammaglobulinemia, or XLA. I was diagnosed with it when I was six months old after a respiratory infection nearly killed me. In short, I don't produce antibodies. I'm able to be with you today because I receive weekly infusions of antibodies from other people through a blood plasma product called immunoglobulin, or Ig.

These infusions give me back some of what I'm missing, but I'm still very susceptible to infections.

Because I was diagnosed early and receive Ig therapy, my day-to-day health is better than many others with PI. However, a simple cold can wreak havoc with the lives of many members of our community. Without a fully-functioning immune system, we're incredibly vulnerable to communicable illnesses.

For some members of our community, infections are unquestionably a life and death matter. I suspect that all of you recall David Vetter, affectionately known as the "boy in the bubble," who was born with Severe Combined Immunodeficiency or SCID, one of the most severe forms of PI. Infants born with SCID are missing vital portions of their immune system, and their survival is based on receiving a bone-marrow transplant or gene therapy in their first few months of life.

Children diagnosed with SCID, XLA, or any other form of PI face multiple challenges with simple, everyday pathogens. Children with PI regularly fall ill and miss school because of Rhinovirus and other diseases that are not that serious to most people. **Exposing these children to something as severe as measles could be life threatening.** Parents who live in communities where vaccine use is being questioned have shared that they are afraid to send their child to school—even when their child is not sick and should be able to participate.

They're afraid because they understand the science, the math, and the history. They know the stakes: **if people stop vaccinating and the safety net of "community immunity" fails, their children will be among the first casualties.**

As a father, I gravitate to talking about children first. But this issue affects adults too. While there is now newborn screening for SCID in all 50 states, most members of our community go years or even decades dealing with serious and recurrent infections without knowing they have a compromised immune system. Because of this, we know there are many people living with PI who are undiagnosed. I am particularly concerned for the health of this

segment of our community, the undiagnosed. **If community immunity fails, they do not know that they need to take precautions.** Those of us who know we have PI do what we can to avoid exposure to infections. But the undiagnosed lack this basic knowledge and are even more at-risk.

The reason that all of us, young and old, diagnosed or undiagnosed are so dependent on community immunity is that vaccines do not work for most of us with PI. The basic concept of a vaccine is to expose the body's immune system to an inert version of a pathogen so it can "remember" that pathogen and make antibodies when necessary. This does not work with us because our systems either don't remember the pathogens or we physically can't create the antibodies.

A further complication is that being immunocompromised as we are there are some vaccines that could actually be dangerous to us, particularly "live" vaccines. As a result, those in the field of immunology have studied this issue thoroughly to produce evidence-based guidelines to best safeguard those with PI.

In 2014, the IDF Medical Advisory Committee published an article in The Journal of Allergy and Clinical Immunology called "Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts," to help clarify which vaccines can be given to patients with PI. While the primary purpose of the article was to provide clarity about which vaccines were either indicated or contraindicated for people with various PI diagnoses, it also addressed the growing neglect of societal adherence to routine vaccinations, a topic particularly relevant to this morning's discussion. I would like to submit the full copy of this article for the committee report.

The authors clearly recommend, "Education about the critical need for maintenance of herd immunity (community immunity) in the population at large." In essence, community immunity offers valuable protection to patients with PI who are unable to mount protective antibody responses. It is particularly important for *family members* of patients with T and B cell

immunodeficiencies, such as Common Variable Immune Deficiency (or CVID), SCID, and XLA to receive all of the available standard immunizations in order to protect their family member with these types of PI. I will note that any person with PI should consult a healthcare provider, particularly an immunologist, to discuss whether there should be any adjustments to the specifics of their vaccination care plan depending on their diagnosis. Of course, consulting a healthcare provider is what *everyone* should do when it comes to discussing vaccine-related questions. They can answer your questions, and—I hope—allay concerns and put things into perspective.

In closing, let me say this: my life, along with the lives of hundreds of thousands of others who are immunocompromised depend upon herd immunity. We depend on vaccines. I understand the concern that some new parents have particularly given the misinformation on social media, but that fear can't override facts. History has shown us that vaccines work. Science has shown us that vaccines are necessary. And mathematics has shown that the odds of children having a healthy life are magnitudes greater if they've had their vaccines.

The current decline in vaccine usage is literally bringing back plagues of the past. While those of us who are immunocompromised will suffer first and suffer more—the loss of community immunity is a threat to us all. We need to band together to dispel myths, combat misinformation campaigns, and help ensure that measles and other vaccine-preventable diseases are once again put in their place—in history books, not in our communities.

I thank you for inviting me to testify, and I look forward to any questions you may have.

Founded in 1980, the Immune Deficiency Foundation, or IDF, is dedicated to improving the diagnosis, treatment and quality of life of people with primary immunodeficiency diseases through advocacy, education and research.