

Marcia Boyle
Immune Deficiency Foundation
President & Founder

Marcia Boyle is the president and founder of the Immune Deficiency Foundation (IDF), 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.

She has been a passionate patient advocate for more than 31 years, after starting IDF in 1980 in reaction to the diagnosis of her son, John, with X-linked Agammaglobulinemia. She oversees all aspects of IDF's programs and services and has been instrumental in developing new resources to meet the needs of patients with primary immunodeficiencies in an ever-changing world.

Marcia spends a great deal of her time on issues designed to improve the lives of patients, including education and resources for patients and families to manage their lives and health, advocacy, expanded research, and education for physicians to improve the rate of diagnosis and optimal care.

Previous professional experience: As a founder of IDF in 1980, Marcia served as the chair and president until 1995, as chair until 2001, and has continued as a member of the Board of Trustees since that time. During her earlier tenure as president and CEO, Marcia developed many of the patient and medical programs for which IDF is known. She was also a co-founder of IPOPI, the International Patient Organization for Primary Immunodeficiencies in 1992 and presently serves on its board.

Prior to returning to IDF in 2005 as the president, Marcia held the positions of Director of Departmental Programs and Capital Projects and the Director of Principal Gifts for the Fund for Johns Hopkins Medicine, and had served as Director of Development for the Wilmer Eye Institute and Director of Development, Neurology and Brain Sciences at Johns Hopkins Medicine. Earlier, Marcia served as a research librarian at Reader's Digest and Columbia University.

Education: Marcia received a B.A. from Skidmore College and an M.S. in Library Service from Columbia University. She also did graduate work through a National Endowment for the Arts Fellowship in American Studies at George Washington University.

HONORS

National Endowment for the Arts Fellowship in American Studies, 1970; Founder's Award, Immune Deficiency Foundation, 2001; Distinguished Lay Person Award, American Academy of Asthma, Allergy and Immunology, 2003; Arnall Patz, M.D. Fellow, Lions Vision Research Foundation, Wilmer Eye Institute, 2000; Patient Services Inc. President's Award, 2013; Innovator of the Year, Daily Record, 2013; International Patient Organization for Primary Immunodeficiencies (IPOPI) Board 2006 – Present; National Health Council Board 2015 – Present; White House Champion of Change in Precision Medicine, 2015

SELECTED PEER-REVIEWED PUBLICATIONS

1. Chan, A., Scalchunes, C., **Boyle, M.**, & Puck, J. M. (2011). Early vs. delayed diagnosis of severe combined immunodeficiency: a family perspective survey. *Clinical Immunology*, 138(1), 3-8.
2. **Boyle, M. L.**, & Scalchunes, C. (2008). Impact of intravenous immunoglobulin (IVIG) treatment among patients with Primary Immunodeficiency diseases. *Pharmaceuticals Policy and Law*, 10(1), 133-146.
3. Hernandez-Trujillo, H. S., Chapel, H., Re III, L., Notarangelo, L. D., Gathmann, B., Grimbacher, B., C. Scalchunes & Orange, J. S. (2012). Comparison of American and European practices in the management of patients with primary immunodeficiencies. *Clinical & Experimental Immunology*, 169(1), 57-69.

4. Seeborg, F., **Boyle, M.**, Scalchunes, C., Xu, L., & Orange, J. (2013). Associations Between Patient Perceived Health Status, Disease Severity, and Specific Demographic or Individual Factors in Primary Immunodeficiency. *Journal of Allergy and Clinical Immunology*, 131(2), AB107
5. Yong, P., Boyle, J., Ballow, **M.**, **Boyle, M.**, Berger, M., Blessing, J., Bonilla, F., Chinen, J., Cunningham-Rundles, C., Fuleihan, R., Nelson, L., Wasserman, R., Williams, K. Orange, J. "Use of intravenous immunoglobulin and adjunctive therapies in the treatment of primary immunodeficiencies", A working group report of and study by the Primary Immunodeficiency Committee of the American Academy of Allergy, Asthma and Immunology. *Clinical Immunology*, 2009.10.003, 255-263.
6. Hovermale, E., Scalchunes, C., & **Boyle, M.** (2011). Comparative effectiveness research in the United States and primary immunodeficiency diseases. *Pharmaceuticals Policy and Law*, 13(3), 183-191.
7. Gundlapalli, A., Scalchunes, C. **Boyle, M.**, Hill, H.R. (2015) Fertility, Pregnancies and Outcomes Reported by Females with Common Variable Immune Deficiency and Hypogammaglobulinemia: Results from an Internet-Based Survey. *Journal of Clinical Immunology: Volume 35, Issue 2 (2015)*, Page 125-134.
8. Sullivan KE, Boyle M, Nauman E, Carton T. Health care utilization by patients with common variable immune deficiency defined by International Classification of Diseases, Ninth Revision code 279.06. *Ann Allergy Asthma Immunol*. 2015 Sep;115(3):248-50.

PUBLIC SPEAKING OR PRESENTATIONS

07/06	Testimony to U.S. Ways and Means Committee on Health	Washington	DC
08/06 – 05/07	Testimony to the HHS Advisory Committee on Blood, Safety and Availability	Washington	DC
09/28/06	ASPE Public Meeting on Patient and Physician concerns in Access to Intravenous Immunoglobulin	Arlington	VA
3/15/2010	International Plasma Protein Conference,	Berlin	
10/4/2010	IPOPI Biennial Meeting	Istanbul	
10/28/2010	Newborn Screening	Atlanta	GA
2/7/2012	PPTA Stakeholders Mtg	Washington	DC
3/26/2012	PIDTC Meeting	Cambridge	MA
5/11/2012	Testimony at FDA Hearing on Biosimilars	Silver Spring	MD
5/21/2012	PPTA Forum	Washington	DC
6/13/2012	Nurse Presentation at Walter Reed Medical Center	Bethesda	MD
6/15/2012	Perkin Elmer	Finland	
10/04/12	IPOPI Biennial	Florence	Italy
06/27/13	Advocacy Day	Washington	DC
11/08/13	International Primary Immunodeficiencies Congress	Portugal	
06/25/14	PPTA Regulatory Workshop	Washington	DC
09/24/14	IPFA/Plasma Supplies Symposium	Sacramento	Calif.
10/30/14	IPOPI Biennial	Prague	

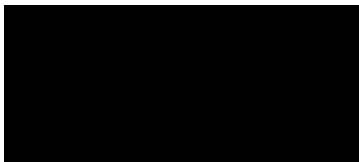
02/11-14/15	National Health Council Voluntary Health Leadership Conference	Ponte Vedra Beach	Florida
03/05/15	PPTA Stakeholder Mtg.	Washington	DC
03/10/15	International Primary Immunodeficiencies Congress	Rome	Italy
04/08/15	Walgreens National Meeting	Chicago	Illinois
04/09-12/15	CIS Annual Meeting	Houston	Texas
04/30/15	PIDTC Annual Scientific Workshop	Montreal	Canada
06/23-28/15	IDF National Conference	New Orleans	LA
07/08/15	The White House Champions of Change	Washington	DC
07/29/15	SCID In-Person Meeting	Bethesda	MD
10/08/15	Baxalta PEARLS Event	Boston	MA
11/04/15	International Primary Immunodeficiencies Congress 2015	Budapest	Hungary
11/17/15	Walter Reed National Military Hospital	Bethesda	MD
12/02/15	Cadillac Tax Press conference Capitol Hill	Washington	DC
12/11/15	Johns Hopkins Hospital 25 th Annual Fall Symposium	Baltimore	MD
02/02/16	PPTA Stakeholder Mtg.	Washington	DC

Committee on Energy and Commerce
U.S. House of Representatives

Witness Disclosure Requirement - "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(5)

1. Your Name: Marcia Boyle		
2. Your Title: President and Founder		
3. The Entity(ies) You are Representing: Immune Deficiency Foundation (IDF)		
4. Are you testifying on behalf of the Federal, or a State or local government entity?	Yes	No X
5. Please list any Federal grants or contracts, or contracts or payments originating with a foreign government, that you or the entity(ies) you represent have received on or after January 1, 2013. Only grants, contracts, or payments related to the subject matter of the hearing must be listed. N/A		
6. Please attach your curriculum vitae to your completed disclosure form.		

Signature: _____



Date: 5/12/16

INSTRUCTIONS FOR COMPLETING THE TRUTH-IN-TESTIMONY DISCLOSURE FORM

In General. The attached form is intended to assist witnesses appearing before the Committee on Energy and Commerce in complying with Rule XI, clause 2(g)(5) of the Rules of the House of Representatives, which provides:

(B) In the case of a witness appearing in a nongovernmental capacity, a written statement of proposed testimony shall include a curriculum vitae and a disclosure of any Federal grants or contracts, or contracts or payments originating with a foreign government, received during the current calendar year or either of the two previous calendar years by the witness or by an entity represented by the witness and related to the subject matter of the hearing. (C) The disclosure referred to in subdivision (B) shall include (i) the amount and source of each Federal grant (or subgrant thereof) or contract (or subcontract thereof) related to the subject matter of the hearing; and (ii) the amount and country of origin of any payment or contract related to the subject matter of the hearing originating with a foreign government. (D) Such statements, with appropriate redactions to protect the privacy or security of the witness, shall be made publicly available in electronic form not later than one day after the witness appears.

Please complete the form in accordance with these directions.

1. ***Name, Title, Entity(ies) (Items 1-3 on the form).*** Please provide the name and title of the witness and the entity(ies) on whose behalf the witness is testifying.
2. ***Governmental Entity (Item 4).*** Please check the box indicating whether or not the witness is testifying on behalf of a government entity, such as a Federal department or agency, or a State or local department, agency, or jurisdiction. Trade or professional associations of public officials are not considered to be governmental organizations.

Grants and Contracts (Item 5). Please list any Federal grants or contracts, or contracts or payments originating with a foreign government, that you or the entity(ies) you represent have received on or after January 1, 2013. For each Federal grant (or subgrant thereof) or contract (or subcontract thereof) related to the subject matter of the hearing, please include the amount and source of each. For each payment or contract originating with a foreign government related to the subject matter of the hearing, please include the amount and country of origin of each. Only grants, contracts, or payments related to the subject matter of the hearing must be listed.
3. ***Curriculum Vitae (Item 6).*** Please attach your CV to your completed disclosure form.
4. ***Submission.*** Please sign and date the form in the appropriate place. Please submit this form with your written testimony. Please note that under the Committee's rules, copies of a written statement of your proposed testimony must be submitted before the commencement of the hearing. To the greatest extent practicable, please also provide a copy in electronic format according to the Electronic Format Guidelines that accompany these instructions.