



AARDA 2019 Summit

Caregiving & IBD Patients: Research Insights

AARDA has conducted summits for autoimmune patients across the country on public policy priorities and strategies for patient advocacy at the federal and state levels. On October 23rd, AARDA convened three expert panels in Washington, DC to provide information, advocacy models, and a “call to action” for patients on research, step therapy, and caregiving for people with intermittent chronic conditions.

You can watch the recording of “Caregiving & IBD Patients: Research Insights” by following this link: <https://youtu.be/fx6U1YJohMs>.

Below are the biographies of the panelists and additional information.

View the Caregiving Report Here: https://www.caregiving.org/wp-content/uploads/2019/09/September-2019_National-IBD-Caregiving-Report_digital.pdf

Grace C. Whiting

C. Grace Whiting, J.D., is the President and Chief Executive Officer at the National Alliance for Caregiving (NAC), where she continues her tenure from previous roles including Chief Operating Officer and the Director of Strategic Partnerships. Grace led the launch of the Caregiving in the U.S. 2015 report with AARP and directed the first national study of rare disease caregiving with Global Genes. She has contributed to several national reports on caregiving, including Cancer Caregiving in the U.S. with the National Cancer Institute and Cancer Support Community, and Dementia Caregiving in the U.S. with the Alzheimer’s Association. She has spoken on caregiving at national and international conferences, including the 7th International Carers Conference in Adelaide, Australia and at multiple national summits at the National Institutes of Health. Grace has also served as a resource to major media on the topic of caregiving and aging, including C-SPAN, The Wall Street Journal, Time Magazine, Oprah Magazine, Women’s Health Magazine, and Kiplinger’s Retirement Report. In addition to her leadership role at NAC, Grace represents the United States on the Governing Board of the International Alliance for Carer Organizations and offers ex officio support for NAC’s role as Secretariat.

In previous roles, Grace has served as the Advocacy and Communications Director at Leaders Engaged on Alzheimer’s Disease (LEAD Coalition) and as the Director of Strategic Initiatives & Communications and as the Special Assistant to the Executive Director at the Alliance for Home Health Quality and Innovation in Washington, DC.

She is currently a licensed attorney with the District of Columbia Bar and a member of the American Society on Aging, the American Society of Association Executives, and the Gerontological Society of America. Named an “Outstanding Law Student” by the National Association of Women Lawyers, Grace earned her law degree from the University of Memphis School of Law and her undergraduate degree with honors in Communication Studies from Louisiana State University. She lives in Silver Spring, Maryland with writer and darling husband Geoffrey Whiting and their rambunctious pug, Chief Justice.



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National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.

Lilly Stairs

Lilly is recognized as a leading voice in the rapidly growing patient engagement field. She has served as an advocate for over a decade, transitioning into patient advocacy after she was diagnosed with multiple autoimmune diseases. She is passionate about infusing the patient voice into the healthcare ecosystem and making a positive impact in the lives of patients.

Lilly currently serves as the Head of Growth & Partnerships at Savvy Cooperative, a patient-owned cooperative dedicated to giving patients direct ways to share their experiences with health innovators, and advocating that they be fairly compensated for their contributions. Prior to Saavy Cooperative, Ms Stairs was the Head of Patient Advocacy at Clara Health where she was responsible for conceiving and executing patient engagement strategy and ensuring the patient voice remained firmly at the center of the company.

She also serves as a Board Member for the American Autoimmune Related Diseases Association (AARDA) and is a Lead Patient Advisor for Clara Health, ZappRx, and Janssen.

Randall Rutta

Mr. Rutta is a senior health care executive dedicated to policy-to-practice solutions that interpret, influence, and improve federal and state health care policies to enhance public and private sector health care innovation, outcomes, and efficiency.

Mr. Rutta is President & CEO of the American Autoimmune Related Disease Association (AARDA), a national organization dedicated to addressing the problem of autoimmunity, the major cause of more than 100 serious chronic diseases. AARDA initiated and hosts the 39-member National Coalition of Autoimmune Patient Groups and is a longtime member of the National Health Council. Prior to stepping into his current role on October 1, 2019, he served as AARDA's Federal Policy Consultant since March 2018.

Mr. Rutta is a Principal in ConnectHealth, LLC a Washington, DC-based consulting services company he established in 2017 and incorporated in 2018 to provide senior health/behavior health executives strategic insight and support in achieving objectives across the healthcare eco-system. His portfolio emphasizes the experiences of patients, their families and communities, and the role of diverse stakeholders in improving individual and population health, especially for persons with autism and other chronic conditions, age-related impairments and disabilities. Client partners include: patient advocacy groups, coalitions, associations, service providers, and investment firms.



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In 2017, he transitioned from the position of President and CEO at Easterseals, a global nonprofit organization dedicated to the health, well-being, and success of people with disabilities, veterans, seniors, and families. For most of his career, he was located in Washington, DC, at Easterseals' Office of Public Affairs, overseeing federal and state legislative and regulatory activities, federal grant development, and international knowledge exchange. His career experience has been in acute care, health care quality assurance, and health policy development and implementation.

He chairs the Board of the Partnership to Fight Chronic Disease (PFCD), a national coalition of nearly 100 patient, provider, and community organizations, business and labor groups, and health policy experts committed to raising awareness of chronic disease in America and globally. He has been involved with PFCD as a partner organization leader and board member since 2007.

He is a Vice President and Secretary of American Eagle Lifecare Corporation and has been a member of its Board of Directors since 2008.

He holds a Bachelors of Arts degree in Sociology and a Masters of Arts degree in Politics, focusing on international health policy.