



# ILANA JACQUELINE

PATIENT ADVOCACY STRATEGIST | ILANAJACQUELINE.COM

## OBJECTIVE

Ilana Jacqueline is a patient advocacy strategist and media specialist in the rare disease, chronic illness, and general healthcare field. She is a best-selling author, healthcare influencer, and celebrated journalist who has worked closely with non-profits, pharmaceutical companies, digital health and biotechnology firms over the last decade.

## CONTACT



[IlanaWrites@gmail.com](mailto:IlanaWrites@gmail.com)



561-542-1105



[IlanaJacqueline.com](http://IlanaJacqueline.com)



5198 Majorca Club Drive  
Boca Raton, FL, 33486

## EXPERIENCE

### ASSOCIATE DIRECTOR • HEALTH UNION • JULY 2019 – PRESENT

Ilana joined the team as Editorial Director, working on products for the WEGO Health Answers platform. As project manager she created and directed editorial content, video content and managed creative and technical development teams. She assisted in advocacy education and course creation for the consumer-facing community and then moved on to work on the agency side of the company in their Pharmaceutical Grade Influencer Marketing department, recruiting and media-training patients for client campaigns, working with the sales teams to present insights on different health communities and creating and presenting research decks to clients. (Health Union acquired WEGO Health in 2021)

### ADVOCACY CONSULTANT/TEMPORARY DIRECTOR • NEBULA GENOMICS • JANUARY 2019 – MARCH 2019

Ilana established partnerships with major rare disease organizations, launched collaboration to promote clinical-grade whole genome sequencing tests. Managed public relations, social media, responded to user inquiries and created content for the main website and blog. Responsibilities also included copywriting, negotiations, and team-wide sensitivity training on the rare disease and chronic illness community.

**MANAGER OF PATIENT ADVOCACY • FDNA - FACE2GENE •  
SEPTEMBER 2017 – OCTOBER 2018**

Ilana served as the primary point of contact for national patient organizations and external stakeholders. Led the alliance development between advocacy groups, informal patient groups, universities, clinics, and research labs, physicians, and their user base to develop research studies to further disease understanding. This position included community engagement, acting as a patient liaison, conducting interviews with scientists and researchers as well as marketing, public relations, social media, content creation, project management, survey design and reporting. During her time at FDNA, she created, designed, and operated the Genomics Collaborative project which hosted over 30 consecutive research partnerships, producing discoveries in various disease populations.

**MANAGING EDITOR • GLOBAL GENES • FEBRUARY 2013 – APRIL  
2017**

Ilana operated The RARE Daily news, which produced multiple daily stories. She recruited, trained, and managed a team of contributing writers, editing posts, holding pitch sessions, creating an editorial calendar, and approving or improving outside submissions. She was also responsible for creating graphics, formatting posts, and uploading them to Wordpress (with light Wordpress design work.) She interviewed and helped to tell the stories of several thousand rare disease patients and their families, produced collateral marketing material for the organization, participated in networking events, represented the organization as a speaker during webinars and events, and worked as an educator to help their Rare Foundation Alliance and Rare Supporters. She helped to establish, build, and strengthen relationships with organizations and promote tools and programs to the patient community.

## **PRESIDENT • ABOUT TIME PUBLIC RELATIONS • AUGUST 2010 – MAY 2015**

Ilana managed a portfolio of clients seeking media attention. Clients spanned a variety of talent, including physicians, personal trainers, family therapists, reality stars, tattoo artists, lawyers, naturopaths, and fashion designers. She also represented several businesses including a biofeedback clinic, several clothing lines, tech startups, an indoor sports arena, and two non-profit organizations. Her daily responsibilities included writing press releases, contributed content, handling client's social media, event planning, media training, media kit design, pitching, strategic planning, directing photo shoots, crisis management, and seeking sponsorships and ambassadorships for clients. She also handled overflow copywriting and PR for three Miami based advertising firms.

---

## **SKILLS AND SPECIAL EXPERIENCE**

Ilana is the best-selling author of the self-help book, *Surviving and Thriving with an Invisible Chronic Illness* (New Harbinger, 2018). She is experienced in creating programs for corporations and non-profits surrounding patient education, engagement, and empowerment. She has sat on the board of three organizations including The Invisible Disabilities Association of America, the Rare and Undiagnosed Network, and the Health Advocacy Summit.

She is a member of the Association for Healthcare Social Media and has unique experience in patient influencer marketing. She is a rare disease patient and has written about her own experience and advice for publications like *The Huffington Post*, *AOL*, *Cosmopolitan*, *Marie Claire*, *xoJane*, *xoVain*, *Everyday Health*, *WEGO Health*, *Pharma Phorum*, *Rare Disease Report*, *The RARE Daily*, *The Palm Beach Post*, *The Sun-Sentinel*, *Mashable*, *Crowdmed*, *Patient Worthy*, *MultipleSclerosis.net*, *The Boca Raton Observer*, *Boca Magazine*, *Fort Lauderdale Daily*, *The Miami Herald*, *IG Living* and *Biosupply Magazine*.