

# Advocacy Cheerleader

**BARBY INGLE**

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I have been battling chronic pain since 1997. First with endometriosis, which resulted in a full hysterectomy and left oophorectomy. Then in 2002, I developed Reflex Sympathetic Dystrophy (RSD), which is also known as Central Pain Syndrome. This is a progressive neuro-autoimmune condition that affects multiple systems in the body and needs to be treated early so that disability does not take over. I also have secondary conditions including migraplesy, TMJ disease, osteoarthritis, gastroparesis, and tricuspid insufficiency. Last year, I also developed valley fever phenomena and am currently dealing with the complications of this new challenge. I go through stages of physical abilities now in and out of remission, but have had times when my physical abilities were poor and was bed bound for years. As needed, I use a wheelchair or scooter to get around.

It took three years to get a proper diagnosis and another four years to get the proper treatment. As I search for solutions, I have become my own best advocate and work share the information so that others do not have the same life challenges that I have. Even after seeing more than 100 healthcare professionals, having major surgeries I didn't need, complications such as internal bleeding, medication interactions, kidney stones, tumors, severe constipation, and so much more — I did not give up or give in. I was tested to my limits and realized, as with most people, they are past the boundaries I placed on myself. I had to become the chief of staff of my own medical team. If I can do it, anyone can.

I am excited about making life better for all who live with a rare or chronic disease. I continually find ways to do this that are meaningful, inspirational, and creative. I have my yearly projects such as participating in NERVEr, Rare Disease Day activities, and Chronic Pain Awareness Month activities. One of my highlights was teaming up with a pharmaceutical company and working on a Super Bowl commercial, but I also enjoy smaller advocacy projects such as serving on advisory boards, giving input on upcoming

## WHAT PHARMA CAN LEARN FROM ME:

Pharmaceutical companies can learn about and share the importance of individualized access to treatment options and ways to overcome challenges from the patient experience perspective from me.



clinical trials, and learning about what is coming down the pipeline for me and others living with the conditions that will improve our daily living. I also work to include other activities such as participating in documentaries, awareness events, and other media pieces.

The reason I became an advocate was the challenges I faced when it came to navigating the health system. It can be difficult, but success should be obtainable. My energy pennies are spent working to make it better for the disadvantaged, low income, and underserved populations through advocacy. I want to be there for others as I wish someone had been there for me when I became chronically ill. I was not always disabled. When my life changed, I was not prepared, and it took losing everything and learning to rebuild through trial and error.

My background was as a cheerleader, dancer, and gymnast. I started at age 4 and continued through college. Straight out of college, I started my own cheer/dance training company. A year later, I was hired by Washington State University as the head spirit program coach. I was living my dreams.

Now, I advocate for all who are challenged with a condition involving chronic pain as well as their family, caregivers, healthcare professionals, industry, and public. Until you feel the freezing fire of chronic pain that is unrelenting and oftentimes thought-consuming, it is difficult to understand all of the challenges it brings. We need to share our stories to help raise awareness as well as tools from industry that help bring proper and timely care for each of us. This care must be individualized to our unique needs with common steps that can be replicated to streamline care. Whether physical or mental, chronic illness can and will consume you if you allow it to and only the patient can begin the process of healing and asking for help. It is up to industry, providers, and the public

to be there and make available tools and support.

I have learned that honing and defining my story is an important aspect of being an advocate. I used to spew it all out and see what stuck, but I have learned that when I concentrate on a few key points specific to my audience I will be a more effective communicator. For instance, when I spoke at a recent rare disease event, I focused on how living with rare conditions has influenced me and how more rare disease research and funding are needed.

There are thousands of health challenges that need working on, from access to medication to finding a compassionate doctor. Defining the issue that is important to you is key. You must be able to explain your point of view and back it up with data and science that is relevant and recent. Being yourself, being vulnerable, and sharing your story are powerful ways to engage the public and create change. I am but one of millions who work to make a difference in others' lives.

It is always nice to be recognized for sharing my story, helping create tools and resources for others in similar situations to my own. When I reflect on the honors placed on me, I remember one of my favorite quotes directly related to a cause that chose me, "The ultimate measure of a person is not where they stand in moments of comfort and convenience, but rather where they stand during times of challenge and crisis." If I did not live through the pain and other chronic symptoms, I would not be the person I am today.

Unfortunately, so many other patients experience a similar story. I had to learn the hard way and now I pass on my knowledge to give hope and answers to all patients, caregivers, industry, and healthcare professionals. I hope speaking out about my journey stops it from happening to anyone else. **PV**

# Living and working with rare: A unique lens.



**D**eveloping a marketing strategy in the rare disease space is an opportunity to look at a complex experience that includes multiple stakeholders and many decisions along the diagnostic and treatment journey. These decisions, which may already be challenging to make, can be made more complicated by managing physical or cognitive symptoms or by shifting social and financial circumstances. Many times, care partners navigating a rare disease develop an array of communication strategies and practical skills over time.



Steve Bell



Laura Wilson

*“For those who live with or care for people with a rare disease, the reality is that every decision they make has to take their condition into consideration.”*  
— Steve Bell

Steve Bell, a *Fingerprint* strategist with more than 15 years of healthcare communications experience, is no stranger to rare disease. He lives with cystic fibrosis. His experience navigating this condition gives him a personal viewpoint when assessing the impact rare diseases can have on patients and those around them. Bell's colleague, Laura Wilson, a patient strategist at *Fingerprint*, sat down with Bell to talk about how his experience as a patient gives him unique insight into healthcare marketing.

**LAURA:** What have you learned about the relationship between families and healthcare providers in navigating a rare disease?

**STEVE:** The dynamics of caring for people with a rare disease takes a village. The relationship often transcends the boundaries of medicine and, in many cases, healthcare providers—especially nurses or social workers—become “part of the family.” Patients rely on their healthcare team to not only give medical advice, but also to help guide them through the uncertainties of life. It's important to remember that marketing in rare disease isn't just about the drug, but it's also about providing resources (of all kinds) to help patients and their care partners navigate life.

Most times, care partners and patients are very knowledgeable about the condition. It's important to remember that shared decision-making is foundational to success when living with a rare condition or caring for someone who does.

**LAURA:** In some disease states, patient care is managed primarily by one physician. What is your experience/takeaway about how managing a rare disease can be a different model?

**STEVE:** The unfortunate circumstance of rare diseases is that they rarely just impact one part of the body. With that in mind, it's important to understand who the primary and support treaters are. Furthermore, many patients and care partners are just as informed about their disease, treatments, and potential future interventions. This makes discussion and shared decision-making vital. The interactions between parties are the most critical aspect of the journey to keep in mind when creating

marketing and/or educational materials for healthcare providers or patients.

**LAURA:** Beyond the patient/family-provider relationship, what are some of the other observations that inform your work?

**STEVE:** For those who live with or care for people with a rare disease, the reality is that every decision they make has to take their condition into consideration. It's a weight that people always feel. Furthermore, there are uncertainties and frustrations at every turn of the journey. Whether it's access to medicine or figuring out how to start kindergarten or trying to explain your disease to peers, the dynamics of life with a rare disease are complicated.

**LAURA:** What are some key takeaways we can recommend to teams who are communicating about rare disease treatments?

**STEVE:** We all know that new treatments can make a profound difference in the lives of people living with a rare disease. At the same time, it is important to clearly communicate the potential benefits—and limitations—of what medications can achieve. While each treatment can advance our understanding of what is possible, it is critical to balance marketing messages with an awareness that medication may only be one part of a complex regimen and daily routine. Find ways to provide that much-needed hope while also demonstrating an understanding of the full experience of living with a rare disease.

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*Fingerprint, with five offices across the country, is built on a foundation of empathy, and at its core is committed to creating and executing meaningful brand experiences that are never painted by number for healthcare providers, care partners, and patients. In 2020, Fingerprint acquired 1798, a market access and commercialization firm located in La Jolla, Calif., adding to its portfolio of services in support of biopharma customers. The agency also launched Photo 51, a gene therapy consultancy. To learn more about Fingerprint, visit, [www.fingerprint.com](http://www.fingerprint.com).*

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