by Robin Robinson

The Evolving Role of Patient Advocates

Patient advocacy groups have long had relationships with pharma, and now, individual patients are also sharing their voices and their power.

While pharma has long had relationships with advocacy organizations, there is a growing wave of individual patients who are willing to speak up, be engaged, and provide insights to help the industry identify opportunities to improve both the patient experience and care. From the bench to the bedside, individual patients have the power to make a difference.

"Advocacy as a whole is evolving, and micro-advocacy is becoming a powerful complement to traditional models," says David Goldsmith, chief strategy officer, WEGO Health. "There are a growing number of extraordinary patient advocates who are highly visible on social media and recognized leaders within their communities."

Individual advocates today have become avid bloggers who manage Facebook groups, tell stories via Instagram, host Twitter chats, and have their own YouTube channels. These patients are well-known and well-respected apart from any affiliation with a specific advocacy group, Mr. Goldsmith says. Brands stand to gain when they can work directly with these advocates and build trusted, collaborative relationships.

At WEGO Health, advocates in its network are collaborating with pharma to map the patient journey, unearth qualitative insights, and develop highly relevant content that will resonate with patients and caregivers. The role of patient advocates is growing more expansive and diverse than ever.

"We see patient advocates using their influence and expertise in new ways, going beyond traditional ambassador roles to serve on advisory boards, speaking at industry events and co-authoring research papers," Mr. Goldsmith says. "A really exciting role we're seeing take off is in social media channels, where patients are sharing unbranded content designed to raise awareness and help other patients better manage their health. This role is likely to grow, as more companies discover that information shared by trusted patient influencers is an incredibly powerful way to reach deeper into patient communities."

Mr. Goldsmith credits two major factors with driving this trend. The first is the increased visibility of individual patients from their interaction on social media, presenting at industry events, and their role as recognized opinion leaders.

"These opinion leaders are easier to find, vet, and engage than ever," Mr. Goldsmith says. "This has diminished the intermediary role advocacy groups have been known to play. A second driver is the increased scrutiny of advocacy groups as potentially conflicted when it comes to advocating for their benefactors over the interests of patients. Right or wrong, these perceived conflicts of interest have forced some brands to rethink whether it's still prudent to enlist their help."

Patient Power

Individual patient advocates are valuable to larger patient organizations by providing necessary groundwork at the local level. Even a unified network of advocates such as NORD (National Organization of Rare Disorders) needs individuals on the ground to take action on issues impacting the lives of patients and caregivers. Tim Boyd, director of state policy, at NORD, credits patient advocates with being instrumental in helping NORD push legislation, create events, and further awareness.

"In Minnesota, NORD has worked closely with local patient advocates to push forward the creation of a Rare Disease Advisory Council in that state," Mr. Boyd says. "Led by our volunteer MN Rare Action Network State

If you consider the patient and the care partner community throughout development, patients will welcome the opportunity to serve as a voice for the brand.

CINDY PADGETT
PharmaCord

Advocates provide feedback regarding content strategy, approach, and language to ensure we ask the questions patients wish people would ask.

AMRITA BHOWMICK
Health Union

Given that NORD can only be in so many places at once, policies would not be implemented if not for the support of dedicated patient advocates throughout the country.

TIM BOYD
NORD

Ambassador Erica Barnes, patient advocates identified key legislative sponsors and supporters for the bill and coordinated local events to raise awareness about the bill's benefit to the rare community. Given that NORD can only be in so many places at once, policies such as this would not be implemented if not for the support of dedicated patient advocates throughout the country."

In another example of patients leveraging their power, WEGO Health recently worked with a major pharma company on an awareness campaign in the rare disease space in which patient advocates were the lynchpin of the campaign's success. A small number of patient advocates, who are known influencers in the community, created home-grown videos to tell their story. Their videos and social posts were shared on Facebook and Twitter to reach their followers and the broader patient community. "The combination of trust, authenticity, and social reach translated into measurable results for the brand, driving three times more qualified leads to its disease awareness site and a registration completion rate 17.5% higher than other sources," Mr. Goldsmith says.

Shazia Ahmad, director, patient and physician services, at UBC also has examples of how patients have impacted pharma. While at the NIH, she worked on an early shingles prevention study and held focus groups with elderly patients and their caregivers.

The information gathered from these focus groups contributed to the design of a clinical protocol for the vaccine that was easy for the patient to follow. By listening to advocates and caregivers, researchers were also able to determine the biggest challenge to many patients, which included not having transportation to get the vaccine.

"Having that information to provide to the sponsor helps develop a protocol that fits the patients," she says. In one case at UBC, a sponsor was extremely receptive to patient feedback and noted that it hadn't even considered some of the points the research uncovered. "The sponsor had looked at endpoints for walking or going shopping, but through patients' feedback, the sponsor discovered that what mattered most to the patients was just being able to go down the stairs," Ms. Ahmad says.

Another example comes from Health Union, which hosts condition-specific online communities and publishes original, daily content that cultivates social conversation for patients. During the launch of Migraine.com, Health Union's first community, patient advocates informed the team that while the term "migraine headache" is frequently used in medical literature, it is not a term that resonates well with patients. In fact, many find it to be offensive as it can feed into the stigma that migraine is "just a headache." Based on this feedback, Health Union adjusted its content strategy approach to maintain accuracy while avoiding use of this term.

"Patient advocates are an integral part of our community development process, from the launch phase through daily operations," says Amrita Bhowmick, chief community officer, Health Union. "Advocates provide feedback regarding content strategy, approach and language, in addition to reviewing our large-scale patient-focused surveys — to ensure we ask the questions patients wish people would ask.

"Additionally, advocates provided feedback regarding the lesser known symptoms of migraine that are commonly discussed among patients but are rarely researched by the scientific community," she says. "We included many of these symptoms, such as scalp pain and clumsiness, in our annual Migraine In America survey, which provided valuable quantitative data back to the migraine community."

Ms. Ahmad believes the patient advocate role will not only continue to be critical to drug development, but also in early education and awareness.

"I see education to others as a huge role that patient advocates will continue to play," she says. When her young daughter was diagnosed with the rare childhood illness Kawasaki disease, she learned from personal experience how important education about a disease is, especially when a person is trying to find a diagnosis or first diagnosed. "I had to educate myself on all of these things, and fortunately because of the early diagnosis my daughter was able to get the necessary treatment in time,

There's greater opportunity for patient advocates to play a bigger role in the management and treatment of conditions.

KATE GALLAGHER
Healthline

Patients' Voices

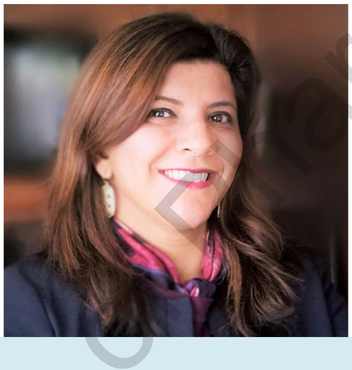
JUSTIN BIRCKBICHLER
Men's Health Activist, Testicular Cancer Survivor, and Founder
A Ballsy Sense of Tumor
Testicular cancer/men's health
@absotTC

My role as a patient advocate has mirrored my own personal journey from testicular cancer patient to survivor, advocate, and activist. In my first year of sharing my story, much of it was focused on my own life, whether it was the ups and downs of chemotherapy treatment, the continued healing afterwards, and navigating the new challenges of survivorship.

After hitting the one year post-chemo mark, my goals really changed. Rather than focusing on my own journey, I shifted my focus into using my story as a platform to bring more awareness and action about testicular cancer in general. Though I still share my experiences, it's more targeted on meeting the needs of the cancer community and raising awareness of men's health as a whole. It's less about me and more about we.

By providing a patient advocate with information about clinical research, we are able to educate patients and their loved ones about the process and options within clinical trials.

CHRIS TRIZNA
CSSi



I see education of others as a huge role that patient advocates will continue to play.

SHAZIA AHMAD
UBC

which is critical in preventing any long-term effects of the illness," she says. "Now I stay involved with the patient advocacy group because I want to be a resource to others."

In the world of patient recruitment, where working directly with patient advocates has high impact on the success of recruitment and enrollment, education by advocates plays a crucial role as well.

In fact, according to Chris Trizna, president, CSSi, there are two key factors to successful patient recruitment where the patient advocate plays a key role: education and study awareness.

Newly daignosed patients, family members, and caregivers are driven to find medical solutions and the patient advocate has information about the condition, health options, and resources to point the patient to. For example, Alzheimer's patient advocates hold meetings, support groups and seminars to help people navigate their way through the complex web of information. "By providing a patient advocate with information about clinical research, we are able to educate the patients and their loved ones about the process and options within clinical trials," Mr. Trizna says.

Patient advocates are also the voice of clinical trials, bringing awareness to the study in their area. Often the PI can be involved in events held by the patient advocate to better educate the patient/caregivers and lower the concerns about participating in clinical trials.

"We have involved patient advocates in all of our campaigns," Mr. Trizna says. "For example, we have used Alzheimer's or Crohn's groups to include the PI in speaking to caregivers, physicians, and other medical professionals that interact with the patient."

Based on a 2018 Healthline study, 76% of people living with conditions indicate that health influencers — who often refer to themselves as health advocates — have a very high level of impact on their day-to-day living with their condition.

"This data point is critical, since we know that daily life challenges adherence and overall treatment efficacy," says Kate Gallagher, senior director of marketing, Healthline. "As we look toward the future, there's greater opportunity for patient advocates to play a bigger role in the management and treatment of conditions. Whether it's through providing information, creating stronger connections, or expanding the definition of what treatment looks like to encompass the whole person, patient advocates will continue to be the real voice of quality of life."

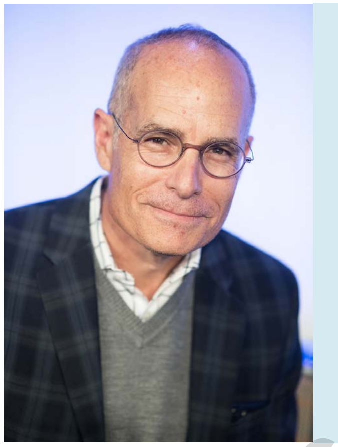
In the marketing arena, patient advocates are just as valuable, bringing pertinent infor-

What we learned from working with patients was priceless: Never stop moving, never stop trying, never stop fighting for patients.

ANDREA KRETZMANN
Fingerpaint

mation about how patients feel about their disease, how they want to be viewed, and what type of language people with the disease use.

Employees from Fingerpaint spent time getting to know patients with Parkinson's disease (PD) in order to really understand their perspectives and needs regarding the disease and available therapies. During this time spent, they learned about "parkies," the name for family, friends, and caregivers of people with PD. The marketers met a patient who stood out to them, "Mr. B," who was diagnosed fairly young and lives his life as normally as possible while advocating for others through his work with the Michael J. Fox Foundation. He ultimately became the face of the brand for a campaign they developed.



The patient adocate role is likely to grow, as more companies discover that information shared by trusted patient influencers is an incredibly powerful way to reach deeper into patient communities.

DAVID GOLDSMITH
WEGO Health

"Mr. B created his own obstacle challenge that raises money for the organization and builds awareness in his community," says Andrea Kretzmann, strategy at Fingerpaint. "We spent time in his home observing the challenges he faces. We met his wife and discussed how their lives have changed. He advocated for portraying his peers accurately and passionately. What we learned from Mr. B was priceless: Never stop moving, never stop trying, never stop fighting for those with PD."

Patient's Voice in Brand Story

The patient perspective can enhance a brand story by creating a very real, onpoint campaign. An authentic story and voice is revealed when patients have a voice in content development. Brands should continue to bring forward patient voices to build trust, strengthen connections, and make an impact with their audience. Health is personal, so when another person understands your health journey, those connection points build trust in a way that a faceless story can't.

According to a 2018 Healthline study, people with conditions who follow health influencers are 85% more likely to visit websites that health influencers partner with. By being real and vulnerable, patients and influencers alike build strong connections within the community through sharing intimate moments of their lives, which increases conversion, engagement, and drives health actions.

"As voices become louder, we focus on getting to the core of patients' stories," Ms. Gallagher says. "It is vital to enable patients to share their stories, whether written, through video, or with images."

By speaking directly to a cross-section of people living with a specific condition, it becomes easier to identify real health and real human aspects in their lives, such as how they talk about themselves, words they use and don't use, and what topics are most important. This allows content to speak authentically to the audience and drive engagement.

Patients' Voices

LAUREN DUNLOP
Executive Director, AAIDA
@MyAaida01

My role as a patient advocate has evolved tremendously over the last couple of years. Previously, I was just a rare disease (RD) patient and advocate for others. Then, two years ago, I decided to take it a step further and open up a 501(c)3, Advocacy & Awareness for Immune Disorders Association (AAIDA), with my own physician and friend, Dr. Maeve O'Connor, in Charlotte N.C. We both spent many years volunteering for other nonprofit groups and advocating for patients that it was only natural for us to pursue the dream of having our own and helping an array of patients. I have also evolved, more recently, into being a voice for RD patients on Capitol Hill as well as a voice at the state level. This is a role I had previously wanted to be involved with and I finally decided to take the leap and learn how to become that voice on the Hill a year ago.

I tell patients "Don't let your disease control who you are, who you want to become or what you want to do in life." I get hooked up to an IV for six hours every three weeks and this will happen for the rest of my life to receive my medication (IVIG) and often times I'm exhausted for multiple days. But I never let it keep me down. Nor do I let my disease or an illness keep me from accomplishing what I want to do. If I want to go climb up a mountain, drive across the country, start my own nonprofit, have dinner with friends — I do it and have done so for many years now. I don't let my rare disease — primary immunodeficiency — control me. There are many other RD patients out there, just like me. Even though you may not know it or can see them, you should always know they're there; just like stars in the day light. We should never feel isolated or alone and, as Winston Churchill once said, "Never, ever give up." You have to keep fighting, whether it be a disease, insurance companies, or even prior authorizations. You have to fight on, always. And when the time comes that you get to meet a patient with the same diagnoses as you, you will be thrilled beyond capacity, reenergized and willing to fight even harder than before.

Patients' Voices

KRISTINA FIGUEROA
Business Development Manager, George Clinical
JDRF and ADA
Type I diabetes
@tunaturns

My role as a patient advocate has become increasingly more involved in clinical development discussions with pharma over the years. Prior to that, my primary work was helping to spearhead and globalize many of the patient perspective discussions in the clinical trials space, by bringing patients into discussions about informed consents and protocols. Being active in my own patient communities, I shared my clinical trial experience with my peers regularly. Upon me recognizing, and sharing this study design with others in my patient community, that I wouldn't enroll myself in any of the trials I had been managing, I wanted to advocate for patients to have a say. From there, I became increasingly more involved in advocacy organizations for various patient groups, developing partnerships with these groups, and helping stir the appetite for patient engagement in protocol and clinical trial design conversations. I also joined the local board of directors for one of these advocacy groups, and continue to have the opportunity to develop relationships, fundraise, and engage in strategy with them.

As I started sharing my experiences and attending patient and industry conferences, my personal brand rapidly began to shift into a patient opinion leader and I finally had the chance to engage with pharma to provide my own feedback.

LORI-ANN HOLBROOK
Owner, CityGirlFlare.com
National Psoriasis Foundation
Psoriatic Arthritis
@CityGirlFlare

Over the past few years, my role as a patient leader has evolved from novice blogger to a credible source of information and compassion for my conditions. In the future I'd like to be more visible. I'd like to be the face of psoriatic arthritis.

Listen Up, Pharma. These Patients Have Something To Say.

Patient advocates talk about their evolving roles, patient experiences, and interactions with pharma.

JUSTIN BIRCKBICHLER
Patient Leader
A Ballsy Sense of Tumor

Starting in the second half of 2018 and continuing in 2019, I have been working with a pharmaceutical company to help produce a interactive series about what it's like to live with or beyond cancer. To date, I have worked with them on two different events, with another scheduled for later this spring. I have appeared in video clips and advised the company, doctors, and other patient advocate groups about the unmet and oft-unmentioned needs of cancer patients and survivors.

Throughout the past year of working with them, the experience has been wonderful. Though I am compensated for my time, I am never asked to push their products or company. In fact, I have never specifically even mentioned the company by name.

They have kept the focus on my story and what insight I have to share. I truly feel like they are focused on improving care and quality of life for cancer patients and survivors, rather than making money off of others' struggles.

LAUREN DUNLAP
Executive Director
Advocacy & Awareness for Immune Disorders Association

My knowledge has grown substantially in multiple categories as both a RD patient and advocate by interacting with pharma in the last six years. One personal example I enjoy telling other RD patients about is when I was invited to tour the Grifols manufacturing facility several years ago in Clayton, NC. It was a small, all-inclusive, private tour with the Immune Deficiency Foundation (IDF). This was a unique opportunity and personal to me because I actually got to witness how my life-saving medication (IVIG) was made from start to finish after it leaves the plasma donor centers, where I also volunteer. During the tour I also got to speak to an audience of employees who were invited to hear some of our patient stories and to better understand how they are making an impact in peoples lives by what they're doing in their career.

I'm also very lucky to have such a great network of Industry supporters that I work with and have met through the years, not only as a RD patient and advocate but also as the executive director for a smaller 501(c)3 organization. These individuals have given me knowledge that I then pass onto other patients and medical providers. I have been told multiple times that I have also taught the pharma employees many things as well.

I'd like the life-sciences industry to know that I want to make a greater impact and become the voice for other patients by becoming a liaison with industry/pharma and patients. A goal I have is to connect patients, providers, and Industry into a functioning, well-oiled machine that can all benefit each other.

We, in the rare disease community, are not just patients; not just numbers for Industry; we're people. We're human beings that sometimes need support from the manufacturers who are in charge of producing our life-saving medication. By helping connect patients with industry, a whole multitude of avenues can be opened to both, including valuable resources that industry has available for patients. RD patients can also help industry better understand the complexity of the disease when they interact and work with patients by giving feedback on different categories that affect (or potentially affect) patients. This includes drug cost, tolerability, routes of administration, site of care, drug availability, and many other categories. This would benefit the rare disease community as a whole.

"Nothing speaks louder to others than someone who can share a like experience," says Cindy Padgett, VP of commercial operations, PharmaCord. "It is often the most powerful way to articulate value." She adds that including the patient's voice is a two-part process. First, pharmaceutical companies should consider the patient's journey and his or her po-

Listen Up, Pharma. These Patients Have Something To Say.

KRISTINA FIGUEROA
Business Development Manager, George Clinical
JDRF and ADA
Type I Diabetes
@tunaturns

In my individual interactions, I've networked on various levels with many different companies. I've been a direct patient contributor to discussions on trial design and informed consents for trials in my disease space. I've been invited to work directly with medical affairs teams to share my life experience and help them understand the intricacies of dealing with standard of care and the accepted culture of managing my disease. I've been working with pharma companies not in my disease space, to share general methods of how to get patient input effectively for various parts of pharmaceutical research. I've also worked across a variety of different therapy areas to help brainstorm an effective standard and customizable communication framework to further engage patients in discussions.

From an advocacy group standpoint, my primary role with pharma companies, quite honestly, has only been to develop partnerships and sponsorships. The partnerships, in this case, encompass funding and advertising, though we have explored various options to incorporate clinical trial opportunities. The political drivers, in these instances, have been what has hindered these collaborations in the past.

Perhaps you could call me strong willed, or stubborn, but I've not historically had any problems. I've sensed discomfort and conversation shifts on occasion at networking events when my disease comes up, but I've learned to identify myself as a patient advocate and researcher, knowing well what the various laws require. It seems interesting to me that I may know more about this than some of the folks on the ground selling these drugs; perhaps this is something to address in corporate culture too?

Education is needed from the top down. We all know that over the past decade engagement for commercial sales has been different, along with sales strategies. Have our biopharmaceutical companies been trained on laws? All will say yes.

But let's ask the question of whether or not we've had interactive training sessions on this, perhaps even with patients in the room? Probably not. We have to maintain an audit trail, and so we probably automate most of our physician and patient trainings on engagement, right? This is an assumption based on my own past training.

Perhaps we can develop annual trainings, in person; and get the patients in the room with the teams. Not only could this make the experience more memorable, but it will actually allow people to apply the lessons learned before stepping out into the public.

I really believe that the pharma industry is starting to hear us — my fellow patients and I. It's taken long enough. To the public — those who have opinions based on their bad interactions with healthcare, insurance companies, and constant exposure to media, which frames pharma as "the bad guy" — I continue to have to defend everything that we are doing to save lives. I shouldn't have to do this, though it's my honor and privilege to keep fighting.

For the sake of all of the good we are trying to accomplish as a team — a collective team, not competitors or enemies or separate teams going for the same goal — can we please break down the barriers to collaboration. I get it; it's a business. But let's talk to each other since we're all working toward the same goal.

In my humble opinion, the only way that we can really make the public statement that we are doing everything we can to "develop innovative new treatments" that "cure" diseases or make them more manageable is if we publicly break down this wall of separation. Bring the stakeholders to the table. The innovators and thinkers. The lawyers and doctors. The researchers and the patients. And let's start sharing what works and

tential needs. Second, pharma companies and their partners need to select the appropriate vehicles for sharing the voice of the patient.

"To ensure the patient's story is captured, brand teams must take the time to listen to the patient's journey by interviewing the patient and care partner community," she says. "When considering the patient's voice, we

Patients' Voices

BARBY INGLE
President
International Pain Foundation

Over the past few years my role as a patient advocate has evolved in what I do. In the past, I attended many patients' doctor appointments to be their cheerleader in the corner, help back up their subjective symptoms, take notes and ask questions they may not of thought of. I also have done a lot with corporate as an NPO leader. Now interactions with the medical industry is more about my personal experiences to better their workflow, processes, and patient inclusion. I would love to have more opportunities to use my personal experiences to better the healthcare system, making it easier to navigate going forward for myself and other chronic patients and advocates.

I think that our voices are being heard by brands even more than the collective advocacy group voice because the brand can see that we are actually affected. Advocacy groups have taught patients to have a voice and individual patients are better at communicating direct input. I also believe in microinfluencing. Hearing from a patient you know can go a long way versus a collective group as the voice can be manipulated and not directly convey the individual patient's voice. Some challenges need a macro approach and some need the micro approach.

Most recently, MyIV.com did a great job sharing my story and including my personal journey in their branding of this project. It was so well-received they included me in a follow-up project as well. They then reached out to my friends and followers personally, who also expressed that they too have been through a similar story. The stories are making a difference and resonating with other patients.

Patients' Voices

BARBARA JACOBY
CEO and Founder, Let Life Happen
Cancer
@letlifehappen.com

I started by writing a weekly blog more than 11 years ago but as I received feedback from those in my community, I added a daily feature on my Website a number of years ago titled "In the News" that I curate from news feeds and direct emails regarding the latest in research, etc. in the cancer community.

In addition, because of what I had learned about the problems that patients were having with finding and joining clinical trials, I have added a second daily feature as of last November titled "Clinical Trials" specifically related to this arena. Because my advocacy is strictly dedicated to information and inspiration for the patient that was inspired by my own experiences and those of others who are experiencing problems with their treatment options, etc., I am now advocating for myself in the same ways that I have encouraged other patients to do.

KRISTAL KENT
Founder, The Fibromyalgia Pain Chronicles,
Co-Founder, Veteran Voices For Fibromyalgia; Patient Advocate Fibromyalgia and Military Veteran's Healthcare Needs

My role as an advocate has developed beyond simply promoting awareness and education. My role as a patient leader and advocate has moved toward networking with other organizations, to develop strategic plans in order to address systematic needs for the fibromyalgia community. My role as a patient advocate continues to grow, in which I am a part of different advocacy coalitions to support the fibromyalgia community and advocate changes within healthcare at a larger level than I could do individually. My hope is that my role as an advocate and patient leader will continue to grow and allow me to advocate changes in healthcare on a legislative level.

Listen Up, Pharma. These Patients Have Something To Say.

what doesn't work, and let's remember that if it's too high-level, no one can actually understand what happened on the ground.

LORI-ANN HOLBROOK
Owner, CityGirlFlare.com
National Psoriasis Foundation
Psoriatic Arthritis
@CityGirlFlare

As a patient advocate, I have had a wonderful experience interacting with pharma about my disease. For me, the only challenge is that there aren't enough projects for us. I would like companies to bring patients in on more of their process.

As a patient advocate, I want the life-sciences industry to know I am here to partner with them because I want to benefit my fellow patients in as many ways as I can. In the past, I have written for an unbranded website for psoriatic arthritis patients hosted by a drug company.

BARBY INGLE
President, International Pain Foundation

I have found the pharma companies that I have worked with have been very reserved when it comes to directly working with patients and patient organizations. I hope that they will open up more and include the patient voice in all of their aspects, from medication development to aftermarket comments.

The biggest challenge I have faced working with pharmaceutical companies has been getting access to the background data. I want to know the mechanical aspects of a treatment. I want to learn what type of patients were in the studies, were they like me? Who was most affected in the studies in a positive and negative way? I want to know if the company included patients who failed the trials in the final results that are published.

I think these challenges can be resolved with more transparency and communication from pharmaceutical companies and their research teams. These staff members are typically shielded from the public and influencers for patent and non-disclosure business reasons.

I want companies to know that we all deserve to be at the table to make decisions about how patients are treated, options that are brought forward, and that patient influencers have to bring great value in the process.

BARBARA JACOBY
CEO and Founder, Let Life Happen
@letlifehappen.com

I am a patient advocate as a result of what I experienced as a two-time breast cancer survivor. My messages are two-fold. First, we need to start treating the patient and not just the disease. Second, we need to empower patients to become involved in the doctor-patient relationship in order to improve outcomes and adherence to treatments that are mutually agreed upon.

I have not taken part in a clinical trial but I am hoping that sharing pertinent info daily on my site with the "clinical trials" feature there helps others.

KRISTAL KENT
Founder, The Fibromyalgia Pain Chronicles; Co-Founder, Veteran Voices For Fibromyalgia; Patient Advocate Fibromyalgia and Military Veteran's Healthcare Needs

There are many times I have been dismissed by pharmaceutical companies because I was advocating for fibromyalgia. One particular pharmaceutical company I reached out to, in order to network with, responded back that they felt "fibromyalgia is a misleading diagnosis and is what physicians use as a diagnosis when they do not know what is medically wrong with an individual." My response to this pharmaceutical company was "there could be some truth to your statement. To address this, we could work together to develop better diagnostic tools, in order to properly diagnose fibromyalgia in the fu- ▶

Listen Up, Pharma. These Patients Have Something To Say.

▶ ture.” I received no further communication from this pharmaceutical company, which illustrates one major drawback. Often times, patient leaders and advocates do not receive responses from pharmaceutical companies when we reach out to them. Not only is this frustrating but it can also be invalidating when a pharmaceutical company does not want to work on developing rapport with patients and gain their input.

EFFIE KOLIOPOULOS
Writer, Blogger, Vlogger and Patient Advocate
Wego Health, Arthritis Foundation and many other organizations
@risingabovera

I have more challenges with the insurance companies that deal with pharma. One particular challenge was when I ran out of medicine because it wasn’t delivered on time to my pharmacy. My doctor at the time didn’t help and the company wouldn’t send me a sample. I don’t get that. If companies want to help people get better, then help. Doing the opposite defeats the purpose of the messages they are always trying to convey to society.

MEGAN STARSHAK
Co-Founder, Creative, Patient, The Great Bowel Movement
Inflammatory Bowel Disease (Crohn’s and Colitis)
@thegreatbm

The challenges have been on more of a case-by-case basis. I think generally they are related to corporate structure and/or FDA regulations. Some experiences have been great. I feel like I’m really at the table and that I’m contributing to something valuable for patients. Other times, the interactions have been unclear, or hands off. Those two things can be improved with transparent communication and authentic purpose.

I would like the industry to know that the decisions companies make can literally affect my entire life, health, and well-being. Pharma is in a different place than say, a car manufacturer. Buying this car or that car won’t really affect me in a profound way. The working components that drive a pharma company are different. Developing good treatments, dispersing accurate and valuable information, providing support, financial assistance — all of it — and doing it right changes my life for the better. Not caring can destroy it.

MELISSA ADAMS VANHOUTEN
AGMD Patient Education and Advocacy Specialist
Association of Gastrointestinal Motility Disorders (AGMD)
Gastroparesis, Digestive Motility Disorders
@MelissaRVH

I have had limited interactions with pharma, but the few I have had have been positive. There seems to be a genuine desire on their part to understand our needs, as patients, to ease our burden, and to address our needs; however, many events and meetings have been in-person only and these are hugely burdensome for my community members.

recommend evaluating patients uniquely, as patients have different experiences.”

This process will help identify the most prevalent unmet needs. With this understanding, solutions to address these patient needs can be designed. It is important to remember to go back to patients to validate the solutions. This validation piece is often forgotten. In operationalizing any patient-support solution, it is critical to ensure customization to adapt to where the patient is in his or her journey; refine the solution over time to meet the changing needs of the community by continuing to incorporate patient feedback; and monitor and include feedback from all media sources. “If companies consider the patient and the care partner community throughout the development of their brand, patients will welcome the opportunity to serve as a voice for the brand,” Ms. Padgett says.

Patients’ Voices

EFFIE KOLIOPOULOS
Writer, Blogger, Vlogger, and Patient Advocate
Wego Health, Arthritis Foundation, and many other organizations
@risingabovera

I am not just a patient, I am also a human being, daughter, sibling, friend, cousin, loved one to many.

I got involved in patient advocacy 10 years ago. The past two years has been an extremely eye-opening experience. I’ve learned a lot more than I did a decade ago and that’s because I’ve fully immersed myself by starting a blog, joining various organizations, and from other personal efforts and projects. Eventually, I would like to delve deep into the political scene and get involved in deeper-rooted issues such as insurance coverage, pre-existing conditions and being a voice for those whose are struggling form constraints put on them from governmental reform.

WHITNEY PETIT
Epilepsy Patient Advocate
@CfEpilepsy

I continue to evolve as an advocate. I’ve gone from blogging about my life with epilepsy to sharing my experiences with industry leaders, to driving innovations on a bigger platform.

In the future, I would like to be the bridge that connects more patients to pharma to get their ideas on the table.

MEGAN STARSHAK
Co-Founder, Creative, Patient
The Great Bowel Movement
Inflammatory Bowel Disease (Crohn’s and Colitis)
@thegreatbm

I am not just a patient, I am also an empowered human who allows myself to learn a great deal from my disease.

I find purpose in taking what I’ve learned and translating it to the rest of my life, and transferring it to other patients who are seeking wisdom and strength in the face of their own disease.

I didn’t start in advocacy with the goal to be an advocate; it kind of grew organically. The last few years, as I’ve also worked to balance this with my full-time career, I’ve found that it’s helpful to narrow my focus to where I can have the most impact.

In the future, I’d like to have a capable team supporting our organization better than we have in the past.