



Patients Are Waiting...

Patient-focused initiatives are taking hold throughout the industry from R&D through commercialization, yet there is still room for improvement.

Progress is being made to include patient insights and perspectives throughout the life-sciences more holistically. Companies are engaging patients to weigh in on protocol development for clinical trials, to help refine corporate thinking and culture, understand the role of caregivers as part of the journey, and reimagine communications and education. Yet, with all the progress gaps still remain. This second annual Patient Voice special issue strives to highlight patient insights on a variety of topics ranging

Because Patients



Patient advocate Max Schill receives the Heart of BioNJ award.

Please go to <https://vimeo.com/318491401> to view the video of Max and BioNJ CEO and President Debbie Hart.

FAST FACT

PHARMACEUTICAL COMPANIES WILL CONTINUE HIRING SPECIALISTS IN PATIENT AFFAIRS AND PATIENT ADVOCACY, BUILDING ROLES INTERNALLY WITH MOST OF THE TOP 20 PHARMA COMPANIES HAVING A SENIOR-LEVEL OR C-SUITE PATIENT ROLE BY 2019.

Source: IQVIA Institute

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from their personal interactions working with pharma companies and the need for corporate cultures to become more patient inclusive, to their thoughts on how they can add value to research and development, to the role that

caregivers play, and to their personal journeys and where and how companies can ease some of the transition stages. Most importantly, real patients talk about how they define themselves outside of their disease state. More than 100

Patients' Voices

HOPE AGUILAR

Ovarian Cancer Research Alliance & National Ovarian Cancer Coalition

Ovarian cancer

@HOPethrucancer

I am not just a patient, I am also an advocate, an activist, a survivor, and a thriver.



JOHN-MANUEL ANDRIOTE

HIV and Mental Health Advocate

@jmandriote

I am not just a patient, I am also a longtime HIV advocate who doesn't like the word patient — just like the first people with HIV to go public about their illness, in 1983, insisting they not be called patients or victims, but "people with AIDS."

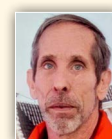


JUSTIN BIRCKBICHLER

Men's Health Activist, Testicular Cancer Survivor, and Founder A Ballsy Sense of Tumor Testicular Cancer/Men's Health

@absotTC

I am not just a patient, I am also a men's health activist.



BILL CLARK

Senior Director of Community Engagement COPD Foundation

I am not just a patient, I am also just like you, trying to live my life each day as best I can.



KRISTINA FIGUEROA

Business Development Manager, George Clinical JDRF and ADA Type I Diabetes

@tunaturns

I am not just a patient, I am also undefined — I hate being limited by type-cast titles.



BROOKE GANT

Clear Cell Ovarian Cancer @BGant21

I am not just a patient, I am also a survivor and warrior.

Patient Advocacy From the Top



Dr. Freda Lewis-Hall

PharmaVOICE had a chance to catch up with Pfizer's Executive VP and newly named Chief Patient Officer Freda Lewis-Hall, M.D., at the The Patient Congress in Philadelphia

to discuss her new role. Dr. Lewis-Hall's vision of patient-centricity is to serve patients around the world by seeking their voice and input, as well as understanding and responding to their needs. She believes biopharmaceutical companies can leverage their resources to put patients first by advocating on behalf of patients who are counting on the delivery of innovative medicines and vaccines. To fulfill this mission, Dr. Lewis-Hall is taking a multi-pronged approach, which centers on the following principles:

- ▶ Deepen insights into patient needs to ensure that the patient voice is thoroughly embedded in research and development
- ▶ Target gender, age, and race inequities in our health system to help patients' access medicines
- ▶ Extend the reach of health information and education initiatives to improve public health literacy
- ▶ Galvanize thousands of employees to become individual "chief patient officers" in their own right

PV: As Pfizer's first chief patient officer, what does this mean for you and the organization?

Lewis-Hall: First of all, I'm really excited about the opportunity. This is the result of an exciting evolution in our thinking and in our strategy. Since the inception of the company we have been patient-focused; Pfizer employees around the world think about patients, we often are patients, we're taking care of patients,

and we bring this perspective to work. The new role is a way to focus and to make sure that we have everything that we need for our colleagues to get up every day, come to work, listen carefully, and then do our work with patients. I want to be one of the 9,000 of us who are doing this every day.

PV: How are you deepening the patient-based culture within the organization?

Lewis-Hall: Our new CEO had the continued vision of putting patients at the front of everything that we do for a purpose-driven future. As we've evolved, we are now putting together a construct to have the tools, processes, and opportunities to make sure that patient insights are integrated along the entire life cycle of the product from the beginning to the time it reaches patients in the marketplace, and beyond as we learn more about the product and the patients it serves. I have the accountability as a part of the leadership team reporting into our CEO to embed this culture as a lifestyle within the company.

PV: How are you strategizing around AI, blockchain, and other new technologies?

Lewis-Hall: It's interesting that you bring this up, because along with the vision for a chief patient officer our CEO had a vision for a chief digital and technology officer. Lidia Fonesca joined the executive team last fall.

When we think about the need to integrate a digital perspective across the entire life cycle around patient-centricity, we now have two people who are part of the senior leadership team whose jobs it is to think about this every day. We are building a horizontal structure so that each of us is focused on optimizing patient insights and incorporating new technology into every step of what we do.



Patients' Voices



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

I am not just a patient, I am also a leader.



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

I am not just a patient, I am also a patient advocate who has learned about the importance of the doctor/patient relationships in the treatment of any disease.



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

I am not just a patient, I am also a pioneer bringing understanding and support to fibromyalgia.



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

@Risingabovera

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



WHITNEY PETIT
 Epilepsy Patient Advocate
 @CfEpilepsy

I am not just a patient, I am also a person with a mission.

Patients at the Center



World Congress' World-Class Faculty, including (l to r): Jayne Gershkowitz, Chief Patient Advocate, Amicus Therapeutics; Camilla Krogh Lauritzen, Chief Patient Officer, Rare Diseases, Leo Pharma; Christine Janus, CEO, International Alliance of Dermatology Patient Organizations; Todd Hobbs, M.D., Chief Medical Officer, NovoNordisk; Cathryn Gunther, VP, Global Population Health, Merck & Co, Inc.; and Tom Croce, VP, Global Advocacy, Amgen.



Patient Choice Award winners: Daemion Johnson, GSK, Patient Centricity Trendsetter; Denise Vosseller, Sage Therapeutics, Most Influential Patient Advocacy Collaboration; and Lynn Hagger, AstraZeneca, Excellence in Patient Engagement.

In March, The Patient Congress brought together more than 250 industry leaders representing life-sciences companies, pharmacies, health plans, provider organizations, patient groups, and patient leaders to examine the pieces integral to the patient journey, including patient access, adherence, and advocacy. Discussions centered around collaborative ways to improve access and health outcomes, develop an organization's patient-centric strategy from drug development through commercialization, how to break down internal silos, and ways to improve patients' lives across the entire continuum of care.

PATIENT CHOICE AWARDS

World Congress conference organizers believe the key to advancing patient outcomes is to learn from game changers in the industry who are pushing the envelope and developing solutions that improve the lives

of patients. World Congress, in partnership with Wego Health created the Patient Choice Awards to showcase pharma organizations, collaborations, and programs that demonstrate measurably better and more transparent health outcomes and promote a better patient experience. Awards were presented in three categories. AstraZeneca was recognized for its Patient Partnership Program in the Excellence in Patient Engagement category. The Most Influential Patient Advocacy Collaboration award was presented to Sage Therapeutics for its "Planning Beyond the Baby" campaign. And the Patient Centricity Trendsetter award was presented to Daemion Johnson, director, patient engagement and advocacy, GSK, or the "US in Lupus" campaign.

patients and industry experts are featured in this special issue. We want to thank them for their time and transparency in sharing their thoughts on the hot topics of today.

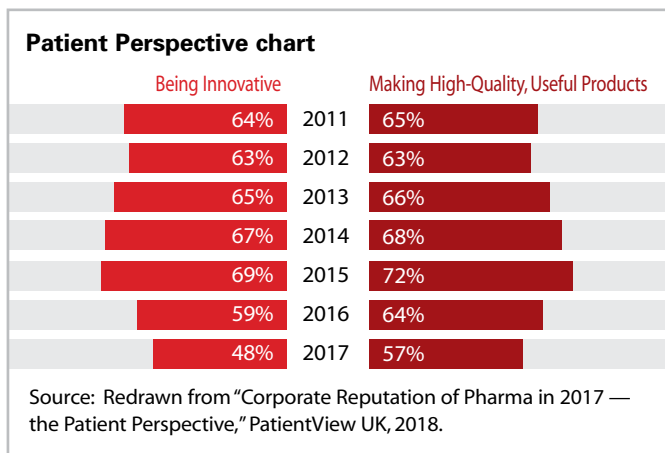
For the first time in its almost 20-year history, PharmaVOICE has taken a departure to feature a piece of original art work for this special issue on the cover. This heart-felt image was created by 10-year-old Max Schill, who received the second annual Heart of BioNJ award in honor of his dedication and selfless work on behalf of patients, at BioNJ's

26th Annual Dinner Meeting & Innovation Celebration in February 2019. Max played a key role in the passage of the 21st Century Cures Act, so much so that he was invited to the White House for the bill signing with a personal letter from President Obama excusing him from school that day. Max tirelessly walked the halls of Congress back in 2017, checking in with 83 congressional offices in just two days, delivering hand-drawn pictures, which have become his signature asking for their votes.

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Patient-Group Attitudes Survey


At the Conference Forum's 6th annual Patients as Partners event held in Philadelphia, more than 200 attendees and 75 speakers from pharma and biotech, patient advocacy, and FDA met to demonstrate how to involve patients throughout the entire medicines development life cycle to drive greater efficiencies in clinical research. Conference organizers shared research about how patients view the industry's ability to be innovative and deliver high-quality, useful products. The results of the global survey of more than 1,000 patient advocacy groups, found that in 2017 the majority no longer believed the industry is innovative and only just more than half believe the industry makes high-quality, useful products.



This is not Max's first honor. In 2017, BioNJ, whose tag line is "Because Patients Can't Wait," bestowed upon him the BioNJ Innovator Award. Max is now on the speaking circuit and advocating on behalf of innovation everywhere, in particular for RASopathies research. Max was diagnosed with RASopathies, a group of rare genetic conditions caused by mutations in genes of the Ras-MAPK pathway, at 18 months old. Max is now joining his mother Lisa Schill, VP of the RASopathies Network, to raise awareness and funds to help advance RASopathies research by participating in the Million Dollar Bike Ride. Joining BioNJ President and CEO Debbie Hart, who presented Max with a personal donation, PharmaVOICE is pleased to support Max in his efforts to raise \$20,000. For more information about the Million Dollar Bike Ride, please go to <http://www.milliondollarbikeride.org/>. To see Max's progress in reaching his goal, check out his webpage at: <http://givingpages.upenn.edu/milesformax>.

Max is not alone in his efforts to raise visibility around the need for a more patient inclusive culture across the board — from R&D to communications.

As you will read in the following pages, this second annual Patient VOICE issue is designed to bring patients' voices to the forefront, to understand their challenges, and to celebrate what drives them to be part of the solution.

As Max said in his acceptance speech: "Treatments and cures would not be possible unless we work together as a team. We can't just sit around waiting for treatments and cures; we need to fight for them because patients can't wait." 

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