

ANNE QUINN YOUNG

For Pushing MMRF's Mission Forward

With a laser vision on MMRF's mission to extend the lives of patients with multiple myeloma and accelerate a cure for every patient, Anne Quinn Young is passionate about providing patients with the tools to optimize their decision-making and outcomes, particularly in this era of precision medicine.

"Technology is rapidly evolving where direct-to-patient efforts will be vitally important to accelerating progress overall and optimizing individual outcomes," Anne says. "This is a large focus of my work right now."

As one of the first employees at MMRF (Multiple Myeloma Research Foundation), Anne serves as senior VP of marketing and communications, working tirelessly and creatively to educate, empower, and engage patients from the moment of diagnosis through remission and relapse.

"Our patients deserve nothing less than our all," she says. Her goal is to see a cure for multiple myeloma, saying if she can engage and empower patients, she believes the tools will be there to make this a reality.

Anne always ensures that the MMRF vigorously pursues patient-focused research efforts and never loses focus of what's most important to patients: treatments that help them live longer with fewer side effects, and the promise of a cure. Her unparalleled commitment to patients, her keen understanding of the unique needs and challenges throughout their

cancer journey, and her ability to continually innovate on behalf of patients have ensured that patients receive better care and that the availability of precision medicine treatments and cures are accelerated for all patients.

She has cultivated strong, long-lasting, and deeply personal relationships with patients and families affected by the disease. Understanding that precision medicine will not be realized without patients' full engagement in their treatment and care, including research participation, Anne has never stopped questioning: "What more can we do to empower patients to make educated decisions about their diagnosis and treatment?"

She makes it her mission to give patients the tools they need to drive their own care, whether that's finding the right doctor/center, enrolling in a trial outside their center, sharing their data, or directly viewing real-world, evidenced-based data, ideally with their doctor.

She inspires those around her through her passion and dedication to MMRF's mission, noting that the vision should always drive the strategy and then the allocation of resources. "The MMRF can be an intense place because of not only our mission and work but our urgency and results-focus, and I find that it is critical to keep everyone grounded in why we do what we do," she says.

Anne's reach is extensive. She now works with the Harvard Business School Kraft Precision Medicine Accelerator, a \$20 million initiative funded by the Robert and Myra

Kraft Family Foundation, which is co-chaired by MMRF Founder Kathy Giusti. The Accelerator aims to speed precision medicine by convening best-in-class leaders to share knowledge and apply a business model to science. Anne, who serves on the direct-to-patient work stream, stepped into a leadership role, which includes helping to spearhead a direct-to-patient social media campaign aimed at optimizing patient care and decision-making throughout the patient journey.

In the 16 years she has been with MMRF, Anne has been part of a team that helped to triple the survival rate of myeloma patients — from three years to more than 10 years.

"I see the changes first-hand," she says. "When I joined the MMRF Kathy's health was so uncertain and patients were dying very soon after diagnosis because of the lack of effective treatments. They now live so much longer with a better quality of life." Today, Kathy, a PharmaVOICE 100 Red Jacket, is doing well.

Anne's work has given her a different perspective that spills into her personal life. "You never know what surprises life may throw your way, so I am all about doing whatever it takes to maximize the experience," she says. **PV**

TRANSFORMATION IS: CHANGE FOR A PURPOSE

Anne Quinn Young

TITLE: Senior VP, Marketing and Communications

COMPANY: Multiple Myeloma Research Foundation

EDUCATION: BA, Dartmouth College; MPH, Mailman School of Public Health, Columbia University

FAMILY: Husband of 17 years, Brandon; daughters Keira, Lara, and Mia

HOBBIES: Rock climbing, soccer, basketball, lacrosse, traveling, volunteer coaching

ASSOCIATIONS: Cancer Leadership Council, Cancer Support Community Frankly Speaking About Cancer, Multiple Myeloma National Advisory Board, Harvard Business School Kraft Precision Medicine Accelerator DTP Working Group

SOCIAL MEDIA: [f](#) [in](#) [ig](#) [t](#)

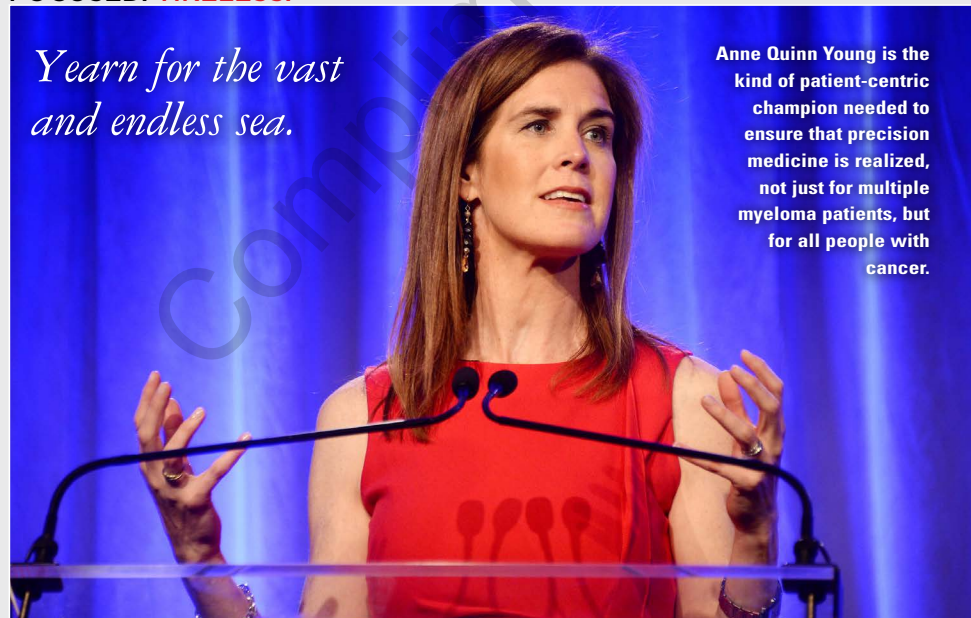
TWEET: @annequinnyoung

PERSONAL BRAND: Driven by compassion

FOCUSED. TIRELESS.

*Yearn for the vast
and endless sea.*

Anne Quinn Young is the kind of patient-centric champion needed to ensure that precision medicine is realized, not just for multiple myeloma patients, but for all people with cancer.



DR. ROZ SCHNEIDER

For Being a Healing Force for Patients

For 32 years, Roz Schneider, M.D., has been partnering with patients with an unwavering commitment to healing.

In her role as global patient affairs lead at Pfizer she is a force multiplier in leading one of the largest pharmaceutical companies in the industry to transform to a patients-first culture.

"In my role, I create partnerships within and outside the organization to drive patient-centricity," she says.

Roz spent her first two decades in the industry as an opinion leader in clinical practice, academia, and training physicians and students, and for the last 12 years in medical and clinical development roles at Pfizer.

Roz has used her experiences, expertise, and extensive network to drive Pfizer to a new model of patient-centered culture and action.

Four years ago, she defined and made the business case to create her function, global patient affairs (GPA) in the chief medical office of Pfizer.

She relied on her powerful network of colleagues, patient advocates, and medical professionals to understand what the patient community wanted and needed, and then framed how Pfizer should integrate these learnings into everything the company does.

She has infused a new model of "patients as experts," which led to updates in processes and templates, including the company's clinical development plan. That is no small feat in a company of Pfizer's breadth and depth, but she never let that hold her and her team back from accomplishing their important goal. Her impact is reflected in improvements in efficiency and quality of clinical trials, communications, and decision making in each of Pfizer's businesses.

Roz is motivated to achieve these and other goals by an unwavering commitment to healing, and she makes change happen by having the vision to imagine the possible and the ability to inspire and mobilize people to make it happen.

Her ability to make a difference is built upon the way she develops relationships through identifying shared purpose and intense collaborations. As a result, Roz is recognized as a trusted partner who catalyzes positive change in health.

TRANSFORMATION IS: RADICAL CHANGE

ENERGIZING. TRUSTWORTHY.



Dr. Roz Schneider has helped to drive the transformation at Pfizer to a patients-first culture.

Explore more, plan less.

Colleagues admire her willingness to step up whenever there is a need and unfailingly she provides value at every opportunity. An energizing and empathetic force, Roz's optimism and confidence make people around her believe they can do more and be more.

Success for Roz is more than metrics. She derives satisfaction by being able to improve health, as well as having joyfulness and harmony in her life.

She is a recognized leader and serves on global, U.S., and European coalitions and advisory councils to advance patient centricity across the health ecosystem.

Her intellect and guidance are also appreciated by the many organizations in which she serves as a volunteer leader. Roz has served on the global board of directors of the Healthcare Businesswomen's Association; contributed to the leadership team of the American College of Chest Physicians; co-chaired the Healthcare Roundtable of the American College of Physicians; sat on the advisory council of the Keck Graduate Institute; and contributed to the PA Foundation as a trustee.

Over her career, she has published 30 peer-reviewed articles or book chapters and contributed to many more, which in addition to her commitment to lifelong learning and teaching, contributed to her promotion to clinical professor of medicine at Albert Einstein College of Medicine.

Her professional goals, she says, are to expand her reach and create a lasting

Roslyn F. Schneider, M.D.

TITLE: Global Patient Affairs Lead

COMPANY: Pfizer

EDUCATION: BS, Sophie Davis School of Biomedical Education at City College of New York; MSc, Hibernia College; MD, Mount Sinai School of Medicine

FAMILY: Her daughter is her daily inspiration; her husband is her soul mate of 41 years and her beloved partner in all aspects of life; her sister is her BFF who is always there to help her; her parents, who were persecuted before immigrating to the U.S., had a singular goal: to ensure their children would have opportunities

HOBBIES: Zumba and tap dancing, playing the piano, and attending musical theater and opera

AWARDS/HONORS: Individual colleague recognition and four team awards; recognition for Chairing the Clinical Research Network of the American College of Chest Physicians; recognition for Chairing the Healthcare Roundtable of the American College of Physicians

ASSOCIATIONS: Healthcare Businesswomen's Association, Association of Women in Science, Drug Information Association, American College of Physicians, American College of Chest Physicians, American Thoracic Society, Medical Society of the State of New York, New York County Medical Society

SOCIAL MEDIA: [f](#) [in](#) [ig](#) [yt](#) [g+](#) [t](#)


TWEET: @Roslyndoc

PERSONAL BRAND: Jar of Joy

impact on improving health in new and interesting ways.

A mentor both formally and informally, Roz has guided hundreds of medical professionals throughout her career, and many of these individuals have gone on to have successful medical clinical practices, lead academic and hospital departments, author books, articles, perform groundbreaking research, and advance to roles of increasing scope and accountability within the industry.

"Mentorship is a personal pleasure and I feel it's an obligation to our professional community," she says.

She herself has had both formal and informal mentors. The most influential of whom was the late Dr. Jack Watters, who led external medical affairs at Pfizer. 

Jeri Burtchell

TITLE: Director, Patient Initiatives

COMPANY: HealthiVibe LLC

EDUCATION: University of Maryland; St. Augustine Technical Center

FAMILY: Her mom and dad, who taught her to be inquisitive and compassionate

HOBBIES: Writing, painting, and quilting

AWARDS/HONORS: Biogen's Hack MS Award, 2015; HealthiVibe's Circle of Excellence Award, 2016

ASSOCIATIONS: Multiple sclerosis support group leader

SOCIAL MEDIA: [f](#) [in](#) [t](#)

TWEET: @FingoHead

PERSONAL BRAND: Amplifying the patient voice since 2012

Jeri Burtchell's life — and the pharma industry — was changed forever when she participated in a clinical trial. Her journey began 19 years ago with a diagnosis of multiple sclerosis. For eight years, she struggled with out-of-control symptoms that often left her unable to walk. Her neurologist refused to explore other treatment options, so she felt there was no hope. She considered ending her life, but instead she found another doctor and joined a clinical trial on Sept. 20, 2007.

At that time, Jeri realized there was a gap in patient education: there were no blogs or websites discussing clinical trials from a patient's perspective. So she began a first-of-its-kind blog about her clinical trial journey titled *Gilenya and Me*. Her blog led to celebrity-like status within the MS community, even being featured in the *Wall Street Journal*.

Now as director of patient initiatives at HealthiVibe, Jeri ensures that everything the company does optimizes the patient experience. Her blog experience led perfectly into a role overseeing the company's patient advocacy work, social media relationships, and anything that touches the patient.

Her insights are inspired and well-respected by everyone in the organization and she is a sought-after presenter and patient advocate. Her work within the pharmaceutical industry as a spokesperson for more patient

JERI BURTCHELL

For Amplifying The Patient Voice

AUTHENTIC. PASSIONATE.



A patient herself, Jeri Burtchell has a passion and relentless drive to raise awareness for clinical trials and make them better designed for patients.

TRANSFORMATION IS: INNOVATION

friendly clinical trials is widely known. Colleagues say she is, quite simply, a force to be reckoned with.

Jeri is constantly thinking about how HealthiVibe can better connect patients to the pharmaceutical industry in more meaningful ways to spark innovative solutions when it comes to understanding and addressing the hurdles patients live with on a daily basis because of their diseases and to help create a better quality of life for us all.

She helped to shape clinical trials as the only layperson invited to speak at a town hall conducted by the National Institutes of Health (NIH) regarding changes to the Common Rule, which governs the ethical treatment

Take each opportunity that comes to you.

of clinical trial participants who take part in federally funded studies. This is just one example of how Jeri works tirelessly every day to change the face of clinical trials, advocating for their use, and making them more centered around patient needs.

A career highlight, she says, is being part of the HealthiVibe team that developed the HealthiPerspectives survey instrument to capture feedback from clinical trial participants in order to make real-time adjustments to current protocols and inform the design of future studies to ultimately be more patient friendly.

"Having participated in several clinical trials over the past decade, I've always felt strongly that my experience throughout the study should matter," she says. "Being part of a team that took this from an idea to a service offering that uses scientific methodology to provide actionable feedback from trial participants makes me very proud. We're making a difference and that's a great feeling."

Jeri is motivated to go to work every day, inspired by patients and caregivers who defy their conditions and overcome challenges.

"I am driven to play a role in helping improve the lives of all people living with chronic, acute, or terminal health conditions," she says. "Knowing these patients has made me a better person and I will never forget that every data point we collect in this industry reflects a real person's experience. I hope I inspire people by the way I live my life despite the limitations of my disease, and through my authenticity and drive to make the world a better place."

If Jeri were to give advice to her younger self, she would say in the darkest times, when all hope seems lost, don't give up. "You will discover untapped strength and your life will turn around because of it. Take each opportunity that comes to you and go through those open doors. Oh, and don't be so afraid to join that clinical trial — it ends up being the best decision you'll ever make." ^{PV}

JAYNE GERSHKOWITZ

For Being a Trailblazer in Patient Advocacy

Amicus Therapeutics — a global biotechnology company at the forefront of advances in rare and orphan diseases — is a company that puts patients at the heart of everything it does. To achieve this lofty and admirable goal, the company needed an advocate — someone with a seat at the table to represent patients, who would listen to and speak to those patients, and who understands the needs of patients and their families, while serving as the face of the company to rare disease patient communities, organizations, and rare disease policy associations.

They found the right person in Jayne Gershkowitz, chief patient advocate, who joined the company in 2006. Amicus Therapeutics is led by John Crowley, a fellow PharmaVOICE 100 honoree, whose story is well-known in the rare disease community.

Jayne's compassionate and empathetic vision, combined with her focus on innovation and compliance, have driven many of the company's most important programs. She launched Amicus Therapeutics' Patient Advisory Boards Program in 2007 — which was unheard of then but is now growing to be an industry standard — to ensure the patient perspective is incorporated throughout the development process and beyond. This innovative focus on education goes both ways, as Jayne leads ongoing efforts to educate patients and to empower them to be their own best advocates in the healthcare journey.

In another recent initiative, Jayne led the patient and professional advocacy team in the development of Our Good Stuff. Inspired by a patient family, this is a positivity program designed specifically for individuals and families affected by rare diseases. Either using paper notes saved in a jar, or Amicus' recently launched mobile app, patients can record their good stuff, the moments that make life good in the face of the challenges of rare diseases.

Jayne considers her work at Amicus in guiding the strategic development of patient advocacy to become a model for the industry as a career highlight. "I am proud to have built a team of nine dedicated patient advocates — a far cry from a one-person shop — as an indicator of this success," she says.

Beyond Amicus, Jayne is a giant in the field of patient advocacy, seen as the "god mother" of patient

advocacy. Together with Jean Campbell, Barbara Wuebbels, and Meg Leal, she launched Professional Patient Advocates in Life Sciences (PPALS), a nonprofit organization committed to supporting the function of patient advocacy within the biotech and pharmaceutical industries. With the PPALS team, Jayne is educating a new generation of patient advocates to better establish the necessity of this function within all life-sciences companies and to help set the corresponding ethics, standards, and best practices. The organization has forged partnerships with academic institutions and is introducing a national certification program for patient advocates in the industry.

"At this stage, my goal is to shepherd the next generation of patient advocates in our industry and contribute to the establishment of at least one master's degree program in patient advocacy, which is now undergoing feasibility by PPALS," she says.

Those who know Jayne say she is passionate and compassionate, and she serves as a mentor in helping rare disease stakeholders understand how to engage intimately and respectfully with each other.

EMPATHETIC. AMBITIOUS.



Jayne Gershkowitz has pioneered innovative programs that embody the gold standard for how biopharmaceutical companies should engage with patients.

Always try to understand patients.

"Throughout my career, I have strived to be a positive, supporting force for my teams, for all colleagues and the professional organizations to which I've belonged," she says. "Ensuring those I'm working with have the resources, knowledge, and tools they need to succeed has helped with organizational success, but most importantly has helped these individuals grow personally and in their professional careers. To me, being a mentor is key to supporting people to envision and achieve their dreams. Mentoring certainly helped me get to where I'm at today." **PV**

Jayne C. Gershkowitz

TITLE: Chief Patient Advocate

COMPANY: Amicus Therapeutics

EDUCATION: BA, Newspaper Journalism, Newhouse School of Public Communications and English Literature, College of Arts & Sciences, Syracuse University

FAMILY: Her parents, who instilled self-confidence and encouraged her to pursue what she wanted; two older brothers, who contributed to her resilience and well-roundedness; husband, whose enduring love and support goes hand-in-hand with her accomplishments; adult children, who reflect back true determination and dedication in their own work ethic

HOBBIES: Reading, theater and museums, making the most of travel, the beach

AWARDS/HONORS: RARE Champion in Advocacy nominee, Global Genes; Executive Mother of the Month, BlueSuitMom.com

ASSOCIATIONS: Board of Trustees, Healthcare Institute of New Jersey; co-founding chair, Patient Advocacy Committee of BioNJ; member, Government Relations Committee, BIO; member, Corporate Alliance of Global Genes; member, Policy Working Group of the National Organization for Rare Disorders Corporate Council; member, inaugural Board of Directors, Together Strong NPC Foundation; co-founder and vice chair, Professional Patient Advocates in Life Sciences

SOCIAL MEDIA: [f](#) [in](#) [ig](#) [yt](#) [g+](#) [t](#)

TWEET: @jgersh1115

PERSONAL BRAND: Tell it like it is

LIZ LEWIS

For Making the Patient a Central Stakeholder

Liz Lewis has taken her passion for patient advocacy to a new level — literally. To help drive awareness of multiple myeloma and raise funds for life-extending cancer research, she summited the iconic Mount Fuji with Moving Mountains for Multiple Myeloma, a collaboration between CURE, Takeda Oncology, and the Multiple Myeloma Research Foundation.

A 15-year veteran of Takeda Oncology, Liz oversees two extremely critical functions that intersect within the organization, which she executes with thoughtful precision. As the company's chief counsel, she has helped set Takeda Oncology's global legal strategies and priorities and has been instrumental in creating Takeda's legal function that supports both the commercialization side of the global oncology business unit, as well as the R&D unit. Liz also serves as the head of patient advocacy at Takeda. She believes the patient is an important strategic partner who plays a defined and critical role in company business. Patients share their insights into clinical trial design and provide direct and ongoing feedback on ways the company can improve patient experiences on commercialized products.

"I am extremely proud of the work I've done to transform Takeda's patient advocacy organization," she says. "Today, patient advocacy is a global, highly strategic business function that includes patients in every part of the product life cycle, from discovery to commercialization and access. I am forever grateful to Christophe Bianchi, president of the Takeda Oncology Business Unit, for the opportunities he has given me, as well as the business unit management and legal teams for their support."

With an always-present focus on the patient, Liz has played a vital role in the company's major product launches for drugs to treat rare and difficult-to-treat cancers, including multiple myeloma, Hodgkin's lymphoma, and ALK+ non-small cell lung cancer.

TRANSFORMATION IS:

COURAGE IN THE FACE OF CHANGE

*I'm passionate
about patients.*

Elizabeth Lewis

TITLE: Chief Counsel and Head of Patient Advocacy

COMPANY: Takeda Pharmaceuticals

EDUCATION: JD, Washington College of Law at American University, BA, Hamilton College

FAMILY: Her husband Nick, who supports her and allows her to do what she does; daughters Sophie and Ellie push her to think about the world in a different way and challenge the status quo; she owes everything she is to her parents, who encouraged her to set her sights high and find ways to realize success

HOBBIES: Hiking, biking, skiing with family

AWARDS/HONORS: 20 Women to Watch, Boston Business Journal, 2014; a graduate of the Women's Unlimited FEW program, which grooms female executives; Global Leadership Award

ASSOCIATIONS: Member of the Boards of Director for BIO and MassBIO

SOCIAL MEDIA:  

PERSONAL BRAND: Be who you are and say what you feel because those who mind don't matter and those who matter don't mind



As the daughter of a physician, Liz Lewis learned the value of patient advocacy and empathy for the patient experience.

PASSIONATE. DYNAMIC.

Within Takeda Oncology, Liz says she wants to continue to grow the legal and advocacy functions and ensure they deliver value to the company's internal and external stakeholders. Within the broader industry, she wants to address the challenging issues confronted by BIO, where she is a member of the board. Liz says one of the most challenging assignments was stepping up as a board member for BIO, where she is in the minority as one of the few non-CEOs and few women on the board.

"I am proud that I have found my own voice and enriched industry thinking about value and access, patient advocacy, and diversity and inclusion," she says. "My experience as a member of the MassBIO board of directors helped me find my feet."

In a rapidly changing environment, Liz believes in challenging the status quo and to help people think differently. "If you feel like you're in your comfort zone, it may be time to think about new approaches," she says. "Balancing complacency with innovation is a necessary challenge."

In addition to being passionate about patients, Liz is equally passionate about mentoring, believing that her true legacy lies in the leaders she is developing to meet tomorrow's business challenges. "I consider it a professional imperative to develop the next generation of leaders," she says. "I am particularly invested in helping colleagues understand the challenges they face in their personal and professional lives. I hope that my mentorship helps them be more effective and more fulfilled in their roles." **PV**

BOB LOLL

For Having a Passion for Patients

All industries would be lucky to have such a vocal and passionate champion as the clinical research industry does in Bob Loll, senior VP of business development and strategic planning at Praxis Communications. His energy and enthusiasm are contagious, and he is always looking for unique, custom solutions on every project or study he is involved in to improve the process for patients.

Colleagues say they have never met or worked with anyone so passionate about the industry. They call Bob a natural leader and hardworking professional who inspires those around him with his energetic attitude and unrelenting drive to succeed.

In addition to an extensive clinical background, for more than 15 years Bob has provided patient care to top collegiate, Olympic, and disabled athletes around the world, including at the Paralympic Games in Seoul, Barcelona, and Atlanta.

He has also worked for outpatient rehabil-

itation companies such as Baxter, Caremark, and NovaCare, after working for the University of Iowa's athletic department.

Bob has been a clinical trial participant himself and is currently a member of the advisory board for the Center for Information and Study on Clinical Research Participation (CISCRP). He believes that making clinical trial participation easier and more accessible for patients is critical, especially as protocols continue to become more and more complex.

"Clinical trial awareness, literacy, and participation continue to be a universal challenge that our industry needs to navigate," he says. "I constantly and consistently remind anyone who works in this industry that we are 100% dependent on total strangers who trust us and elect to participate in clinical research."

Bob is well-known on the conference circuit, where he continues to soak up as much knowledge as possible, as well as impart his own industry wisdom to others. He recently moderated a roundtable discussion titled Optimizing Enrollment for Challenging Research Studies, which tackled hot recruitment topics such as how sponsors leverage the patient voice to enhance enrollment and whether a CRO or a PRO should be ultimately responsible for achieving recruitment targets. He has also chaired multiple international patient recruitment and retention conferences, which tend to focus on developing strategies to ensure optimized enrollment based on patient-centric approaches.

Bob's selfless devotion to the people around him — both patients and colleagues — sets him apart as one of the best in the business. His dedication to the care of others is apparent in every interaction he has.

In an industry that too often uses patient-centricity as a buzzword, Bob stands out for his commitment to bringing the patient voice into everything he, and Praxis, does. For example, he engineered a Praxis-sponsored and patient-led session at SCOPE (Summit for Clinical Ops Executives) that allowed attendees to walk in a patient's shoes as they navigated the clinical trial landscape. It's this commitment to the patient journey that he wants and expects from his colleagues, his company, and his clients.

"At Praxis, we live and breathe

Robert Loll

TITLE: Senior VP, Business Development & Strategic Planning

COMPANY: Praxis Communications

EDUCATION: BA, Communication Studies, University of Iowa

FAMILY: Wife, Lisa, of 30-plus years, who keeps him grounded as the nurse manager for the local emergency room and mother of three adult sons, which makes her a saint

HOBBIES: Cycling, hiking, Ironman triathlons, kayaking, open water swims, trail runs, boating

ASSOCIATIONS: Drug Information Association

SOCIAL MEDIA: 

TRANSFORMATION IS: ESSENTIAL


patient-centric recruitment and retention strategies every day, looking to humanize clinical research," he says. Bob's actions embody Praxis' mission as a company but also the field of clinical research, and he does it simply by putting people first. He cares about his team, clients, partners, and most importantly, patients.

He supports the industry along a number of fronts, including supporting early morning CISCRP 5K events that promote research participation. Colleagues wonder if he ever sleeps, as he appears to be 100% dedicated and focused to his position at Praxis and how he can better serve the industry, and is on call 24/7.

What impresses colleagues most about Bob though is his passion for and dedication to the clinical trial industry. He truly loves what he does and believes in the importance of the work. He respects every individual who participates in clinical research, from the study sponsor to the investigators, site staff, patients, and caregivers; he values their commitment and the sacrifices they make to move medicine forward.

Colleagues say it is inspiring to be around someone who has such faith in the power of the work being done. Bob says this is his secret sauce.

"I believe serving others, clients, industry colleagues, or a complete stranger, such as a clinical research patient is the key to success."

He serves the industry with humility, hard work, and a smile — recognizing at the end of the day those who participate in the research studies are far more brave than those who conduct this important research. 

RESOURCEFUL. PERSISTENT.



There is humility in contributing to clinical trials.

Robert Loll brings a passion to the clinical trial industry that carries colleagues and peers forward to bettering patient experiences and outcomes.

GAIL MOORE

For Advancing the Voice of Patients

As a patient with a rare disease and a parent to children living with rare diseases, Gail Moore's role as director, global patient advocacy, at Horizon Pharma is not merely just a job; it's a passion and a mission.

Gail's daughter, Kinsey, became seriously ill shortly after birth; she spent the next several years in and out of hospitals. After four years, Kinsey was diagnosed with dysgammaglobulinemia, a primary immunodeficiency (PI).

After her daughter's diagnosis, Gail volunteered with the Immune Deficiency Foundation (IDF). While volunteering with IDF, she created the IDF Family Retreat Program, taking time to learn everything she could about her daughter's condition and treatment. Then in 2003, her place into the rare disease world took an even more personal turn when both she and her son, Garret, 22, were also diagnosed with the same rare disease.

"Although both myself and my children have been affected by a rare disease, I have not allowed the condition to dictate my life," she says. "Instead, I have gained knowledge about it and have become an empowered advocate."

At Horizon Pharma, Gail serves as a connector between patient communities and the company, aiming to raise disease awareness and act as both a sounding board and a megaphone for patients, both of which she does with motivation and an enthusiasm that are contagious, her colleagues say.

Throughout her career, she has created and fostered relationships with advocacy organizations that stretch far and wide. Her fierce dedication to giving patients a voice helped to forge a strong relationship with the Jeffrey Modell Foundation, an organization honoring Jeffrey Modell, who lost his life to a PI. This year, under her leadership, Horizon partnered with the foundation to support the dedication of the Jeffrey Modell Diagnostic Center for Primary Immunodeficiencies at the St. Louis Children's Hospital.

Gail also worked extensively with the Friedrich's Ataxia Research Alliance (FARA) to help develop Horizon's Phase III clinical study and post-commercial plans for a treatment for Friedrich's ataxia, a life-shortening,

AUTHENTIC. DEDICATED.



I give my all to all I do.

degenerative neuromuscular disorder. About one in 50,000 people in the United States have Friedrich's ataxia. And though the trial was unsuccessful, Gail still remains close and active within the FA community to this day.

Most recently, she began collaborating with the Graves' Disease and Thyroid Foundation in the development of a Phase III study of a potential therapy for thyroid eye disease.

Colleagues say patients connect with Gail because she intimately understands the brave, emotional, and distinct journey of those living with rare diseases. They also are inspired by Gail's attention to patient needs, whether they need her to weigh in on an important cause or if there are boxes to be carried, she is there until the job is done. "The relationships, concern, compassion, and effort I share in my work and personal life are real," she says. "I have always given from the heart without an agenda or desired gain. I just want to help others and make a difference. I am fortunate to have this opportunity every day in my work."

Through her commitment to building relationships with these organizations earlier in the clinical development program, Horizon has been able to better understand the nuanced needs from the community successfully develop and implement commercial plans.

She recognizes that in the rare disease field there are moments of aspiration and moments of despair. One of her biggest achievements was developing a collaboration with a rare disease patient organization that provided education to more than 100,000 frontline physicians on that specific rare disease. One of her most challenging assignments was working with a rare disease patient organization in a clinical

Gail Moore's personal connection to the rare disease community fuels her intent to make a difference.

Gail Moore

TITLE: Director, Global Patient Advocacy

COMPANY: Horizon Pharma

EDUCATION: BA, Psychology, St. Leo University

FAMILY: Her parents for teaching her to give her all and the importance of helping others; Kinsey and Garret Moore, her children for their love and support; her dogs for always welcoming her home with love

HOBBIES: Traveling, volunteering, watercolor painting, anything involving the water

AWARDS/HONORS: Five Year Service Award, Talecris/Grifols; Passion for Patients, Horizon; Teamwork, Horizon; Get Stuff Done, Horizon; Outstanding Program, IDF Family Retreats, Immune Deficiency Foundation; She Knows Where She is Going, Girl's Inc.; Volunteer Appreciation, Immune Deficiency Foundation; Global Genes Champions of Hope in the Category of Collaborations in Advocacy

ASSOCIATIONS: Professional Patient Advocates in Life Sciences; board member, GBS-CIDP Foundation International; Immune Deficiency Foundation

SOCIAL MEDIA: [f](#) [in](#) [ig](#) [t](#)

TWEET: @gailmoore77

PERSONAL BRAND: Until every patient is reached — I'll never stop

TRANSFORMATION IS: CRITICAL TO GROWTH

trial that ultimately failed. "This assignment was challenging for me because the patients, their caregivers, and the organization had become family to me," she says. "It was so hard to see their disappointment and know that it would be years before another treatment option would be available."

Gail says she draws inspiration from her children to be a voice for those with rare diseases. "I am inspired by the families I have met throughout the years who deal gracefully with a disease that they didn't plan," she says. "I am motivated by my industry colleagues who tirelessly work to ensure that the patient is represented throughout the organization." **PV**