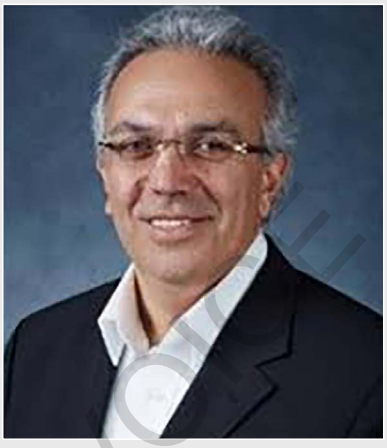
Centered. Mindful.

Transforming Medical Affairs Across the Industry



RAMIN FARHOOD

Saving babies, that's what we do." This is the mantra of Ramin Farhood, Pharm.D., VP and head of global medical affairs at AveXis, a gene therapy company and part of Novartis.

He inspires his team with a laser-focused perspective around transforming the treatment landscape for spinal muscular atrophy (SMA) and other rare, life-threatening neurological genetic diseases. He is particularly proud of his role in launching Zolgensma, the first and only gene therapy for pediatric patients with SMA. And he was instrumental in the development of a market access program that provided this life-saving treatment to babies and families in need at no charge. "Working in the pharma industry offers me a great opportunity to make a profound difference in the lives of patients directly," Ramin says. "This is especially true in life-threatening rare diseases."

"Working in the pharmaceutical industry offers me a great opportunity to make a profound difference in the lives of patients directly," Ramin says. "This is especially true in rare diseases, the area in which I am working in now where many are life-threatening."

Ramin has more than 20 years of experience in scientific and strategic operational leadership in global medical affairs, scientific affairs, and shared medical excellence. He has proven expertise in building scalable worldwide organizational and operational capabilities of medical affairs while driving efficiencies and implementing best practices.

As a founding member of the Medical Affairs Professional Society (MAPS), Ramin volunteers a considerable amount of his personal time working to advance the mission of the organization, which is to promote excellence across medical affairs functions, develop guidelines to support industry standards and best practices, foster advocacy for the medical affairs position, and build capabilities and provide a platform that supports the practice of medical affairs. MAPS puts on four international seminars per year with 800-plus attendees.

"With our nonprofit status, MAPS is able to reinvest all revenue back into the society, which ensures our ability to create valuable programs and resources that support the medical affairs community," Ramin says.

Colleagues laud his leadership style of building teams of experts and providing them with the vision, structure, tools, support, and process improvements needed to allow them to excel at their jobs. He inspires others by being centered, which enables him to remain calm, empathize, listen deeply, and remain present.

"I'm intent on finding ways to constructively disrupt established behaviors to help employees break out of culture-weakening routines," he says.

He describes himself as a life-long student of leadership with a style that is a combination of coach, visionary, and servant leader with an ability to adapt to the required situation.

"At times, a good leader needs to listen and influence in a subtle way," he says. "Other times, you may be required to be on stage, upfront and vocal. Or a leader may need to be persuasive and influence behind the scenes. The best leaders are constantly changing styles to serve others and to serve the intended goal."

Ramin is known for his ability to encourage, motivate, and lead others with passion, integrity, and a supportive culture.

"I align my leadership with the organization's mission, set a clear vision for the future, and actively listen to the needs of my team," he says. "I measure my success as a leader by how team members gain new capabilities, take on new initiatives, and demonstrate creativity in solving problems Additionally, I measure success by what we achieve as a department and a company Within an organization, there is a higher purpose to realize. Success is measured in how well we perform in achieving that higher purpose."

Ramin, who has had the benefit of strong mentorship throughout his career, strives to pay it forward and is a dedicated professional mentor who genuinely cares about his team and ensures they consistently have access to the tools they need to succeed to be the leaders of tomorrow. PV

Stay centered.

Ramin Farhood, Pharm.D.

TITLE: VP, Head of Global Medical Affairs
COMPANY: AveXis, a Novartis Company
INDUSTRY AWARDS: Alumnus of the Year Award for distinguished career, leadership, and contribution to the profession as a clinician, educator, and executive
COMPANY AWARDS: Run Hard Finishing Strong!, 2018
ASSOCIATIONS: American Academy of Allergy Asthma and Immunology (AAAAI); Clinical Society of Immunodeficiency (CSI); International Neuropathy Consortium (INC)/ Peripheral Nerve Society (PNS); American Society of Hospital Pharmacists (ASHP); Investigator Initiated Studies and Research Association (ISSRA); International Society for Medical Publication Professionals (ISMPP); Association of Medical Affairs Professionals (AMAP); University of Southern California (USC), Adjunct Professor of Pharmacy Practice, 2002-Present; Keck Graduate Institute (KGI), Adjunct Professor of Pharmacy Practice, 2013-Present; Board of Directors, Medical Affairs Professional Society (MAPS); Board of Trustees, Keck Graduate Institute

IMAGINE IF...

we could find ways to constructively disrupt established behaviors to help employees break out of culture-weakening routines.

DAEMION JOHNSON

INSPIRATIONAL. PATIENT-FOCUSED.

Patient Engagement at Its Best

Daemion T. Johnson

TITLE: Director, Patient Engagement, GSK Specialty Business Unit
COMPANY: GSK Pharmaceuticals
INDUSTRY AWARD: World Congress and WEGO Health's Patient Centricity Trendsetter Award, 2019
COMPANY AWARDS: GSK US Pharma Marketing Excellence Award for Trust, 2018 and 2010; GSK US Pharma People's Choice Marketing Excellence Award, 2018 and 2019
ASSOCIATIONS: Kappa Alpha Psi Fraternity Inc.; GSK Women's Leadership Initiative BRG, Male Aly Site Lead; GSK MOSAIC (African-American) BRG

In the new health economy, pharma leaders are challenged to provide relevant patient experiences that deliver value to patients. GSK's Director, Patient Engagement Daemion Johnson is on a mission to provide a more personal patient experience, specifically to provide education and empowerment for multicultural lupus patients.

Daemion has held many positions at GSK, from sales/field management to brand marketing, but colleagues say his patient advocate role is his true calling. His passion for the patient, his creative thinking, and his personal commitment to provide culturally appropriate care for the lupus patient community is not just what the doctor ordered but what patients need.

To cut to the chase, Daemion has initiated a number of great ideas to assist patients, but his best and brightest initiative, according to him and his colleagues, is the Night of Beauty for women living with lupus.

Because many lupus patients experience a lack of self-esteem and confidence due to the symptoms and challenges of the disease, Daemion and GSK are collaborating with one of the most globally recognized beauty brands — NARS — to host an informative social-engagement series in Sephora retail stores. The events are designed to address the special needs of lupus sufferers and their "village" of family, friends, doctors, clinicians, and healthcare providers.

Lupus sufferers, who often feel isolated, are empowered through free makeovers, professional headshots, and educational resources and materials to encourage self-management of their disease. Attendees hear firsthand from inspirational Lupus Warriors, healthcare professionals who work with lupus patients, and NARS makeup experts.

With DJ-spun music, bright lights, and lots of action, Night of Beauty feels like a fashion show or a music industry red carpet event, not patient education around lupus awareness.

Keep your values in line and your vision will follow.

During one event, a lively and honest panel discussion featuring a health psychologist, rheumatologist, and a lupus patient kept the vibe flowing. Local celebrities, state representatives, and patient advocacy groups (LFA and LRA) and patients added authenticity and relevance to the event. People living with lupus received post-makeover photo shoots by a professional photographer, adding to the glam feel of the evening. Patients loved their photos and readily shared them on social media, influencing friends, family members, and followers. The press coverage and social media pull through provided a lot of buzz, and, ultimately, drove new registrations for the GSK "Us in Lupus" unbranded patient support program.

To date, Daemion and his team have hosted more than 400 lupus patients and their villages in four markets — Atlanta, Washington, DC, Philadelphia, and Chicago. There are plans to visit three more cities in 2019.

And Night of Beauty is just the start of the "Night of" series. Daemion has the first Night of Nutrition already booked in just a few months. Following a similar framework of community engagement and expert advice, Night of Nutrition will help people living with lupus better understand how the food they eat supports better living.

IMAGINE IF...

there was a cure for lupus.

Daemion continues to push creative and corporate boundaries to discover new and innovative ways to educate patients.

Colleagues say Daemion's success is attributable to his compassion, passion, and ability to correctly identify patient needs. He listens to patients and how they describe their symptoms, their interactions with their doctors, and their treatment decisions, as well as how the disease impacts their physical image and self-confidence. Daemion takes a grassroots approach instead of an academic one. He connects with patients in their communities, talking with family and friends, and meeting with members of the lupus patient advocacy community. He believes this face-to-face, person-to-person effort is the best way to understand the unique needs of people of color who are living with lupus with respect to their health management.

To move his ideas forward, he had to challenge the status quo at GSK and break down organizational barriers, including expediting the review process. He aligned key decision makers across the organization and got them to buy into a common goal: to provide lupus patients something they truly deserve and that no one else has been able to give them.

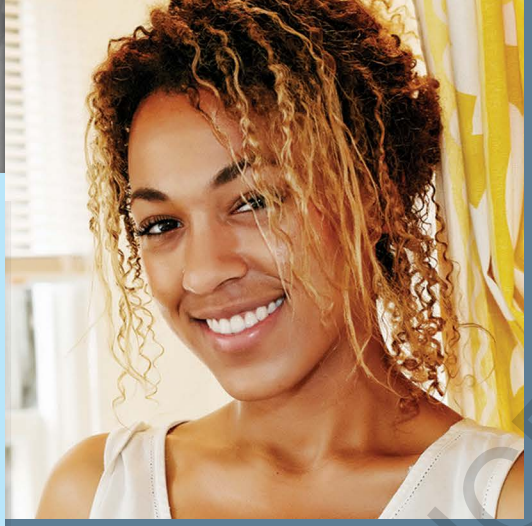
Daemion is a patient himself; he was diagnosed with Type II diabetes six years ago. "I have used my personal diabetes journey to fuel my passion and advocacy for other people with chronic illness — lupus, EGPA, and severe asthma — in my current role," he says.

Managing his diabetes was extremely challenging, but after some significant lifestyle changes and modifying his diet, he began training for his first 5k. Six years, 30 lbs., and four full marathons later, Daemion is pursuing his personal goal of completing the six major marathons by the age of 50. He has two — NYC and Chicago — under his belt, and will do Berlin in September, and then London, Tokyo, and Boston in the next three years. PV

Are you living with **lupus?**

Join us.

Us in **Lupus** is designed to give you more than just the facts about lupus. It's a resource created by GSK that offers people living with lupus the skills, tools, and confidence they need to help them face their lupus.



Find **confidence** to share honestly and clearly about your lupus.

Get **support** from us to help you be there for your loved ones.

Become a true **partner** with your doctor.

Join **Us** in **Lupus** today.

Visit DiscoverUsInLupus.com or follow us on Facebook @UsinLupus

Us in **Lupus**

Power against lupus

Resolute. Affecting.

LISA DILWORTH

Clinical Innovation with Patients at the Center

As VP of rare and orphan disease drug development at Synteract, Lisa Dilworth brings deep, personal insights into the challenges facing patients. Lisa has watched her mother's battle with myasthenia gravis, or MG, for years. MG is a chronic, autoimmune disorder affecting muscles. This has inspired Lisa to find ways to help patients such as her mother. As an undergraduate, she was drawn to clinical research to bring hope to patients in need and she has not looked back since.

Lisa is passionate about finding solutions to the disease states that impact so many with no cure in sight. She is equally as passionate about engaging with her colleagues, the industry, patient communities, and advocacy groups at large to achieve this goal.

She is tireless in her support and advocacy for rare disease awareness and studies both within her role at Synteract and beyond. She has been a volunteer for more than two decades for multiple patient advocacy groups such as the Myasthenia Gravis Foundation of America (MGFA), Parent Project Muscular Dystrophy, and Cure SMA. Patient advocacy groups such as have these have played a large part in the process of gaining FDA approvals for new treatments. Representing the organization at a patient-focused drug development session for the drug has been the highlight of her career thus far.

"Hearing the brave voices of the children from our trials and the greater disease community inspired me and touched my heart," she says. "It justified all the effort that goes into drug development."

Because Lisa has a keen understanding of what patients need from a study perspective and a comfort level, she encourages team members to challenge protocols and not to accept the status quo. And her team is happy to rise to the occasion, time and time again. She motivates her team to question how a study will impact the patient, to look at how they can better prepare patients for a visit, and to encourage sites to use technologies such as wearable devices instead of in-person site visits.

"While innovations such as virtual trials, wearables, and ePROs have made clinical trials less burdensome once patients are enrolled, we still aren't able to reach patients in rural areas with the option of a clinical trial," she says. "Patients without Internet access or other resources are not aware of trials. There is still a bias of clinical trial participants being those connected with an advocacy group or being seen by key opinion leaders at large institutions."

As a volunteer for Parent Project Muscular Dystrophy, Lisa is working with the organization and regulators from the FDA on designing an innovative umbrella trial to address enrollment challenges, as often only a tiny subset of patients are eligible for studies of this disease. The trial is designed to help share data across panels and sponsors and to involve patient input from around the globe so as to ensure a more holistic approach, for example what are the main concerns for a mother in France with the disease, versus a mother in Africa. Lisa also gives back to the group "We Carry Kevan," which provides accessibility to clinical trials for nonambulatory children.

She works to ensure patients are the center of everything she does, and she brings patients into internal meetings regularly so nobody forgets what their main focus needs to be.

Lisa leads by example and looks for ways to pay forward her own success in the industry. She is honored and excited to be part of each project and she hopes that feeling is contagious.

"I'm a transformational leader," she says. "I believe that you should surround yourself with brilliant and passionate people and give them the trust, autonomy, and support they need to achieve greatness and they will." She sees challenges and even failures as an opportunity to grow, evolve, and push the process.

Mentoring is important to Lisa and she offers advice to young adults and children within the community, especially youngsters interested in a career in the sciences. "It's important to me that we foster collaboration and build up the next generation of innovators and professionals," she says. "We are still years away from so many novel treatment options making it from the benchside to the bedside so these young children are critical as they'll be the ones to get these drugs to market."

One of the toughest aspects of her job is telling clients that the trial they have designed will not succeed and needs to be completely rebuilt. "It's a tough message to deliver but poorly designed clinical trials cost time and money and patients are waiting," she says. "We have lost entire generations of children to rare diseases." PV

Find your breakthrough.

Lisa Marie Dilworth

TITLE: VP, Rare and Orphan Disease Drug Development
COMPANY: Synteract Inc.
AWARDS: CEO Award, PRA Health Sciences
ASSOCIATIONS: Myasthenia Gravis Foundation of America; Parent Project Muscular Dystrophy

IMAGINE IF...

a physician's duty of care included educating patients on clinical trials as a care option.

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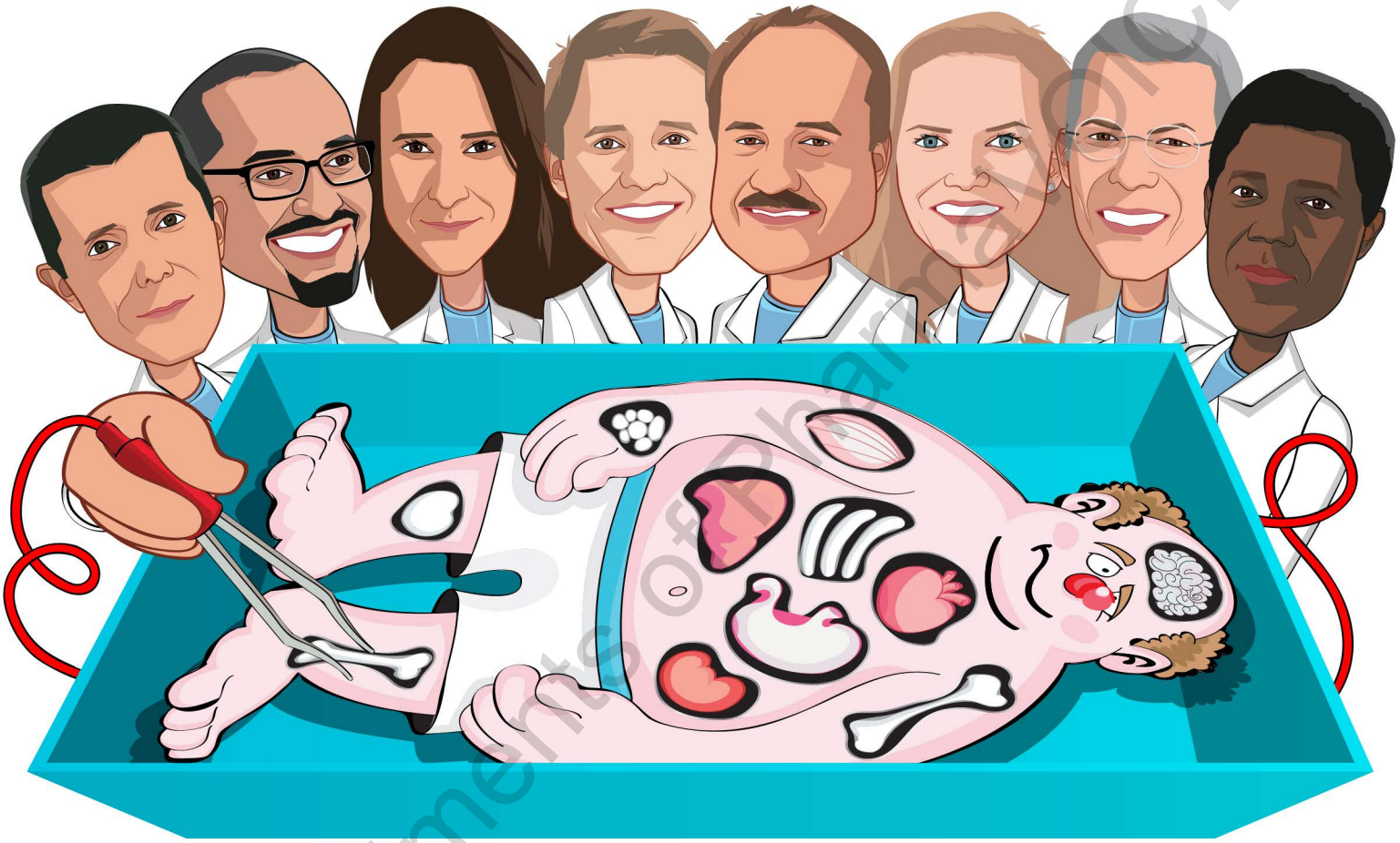

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MICHELE RHEE
Breaking Barriers for Patients

PASSIONATE. EFFECTIVE.

Michele Rhee is head of patient affairs for the biotech start-up Enzyvant, and as a patient herself, she has deep insight into what patients with cancer and rare diseases face.

In her early 20s, Michele was diagnosed with cancer. She considers herself "the luckiest of the unlucky or the unluckiest of the lucky" because although her cancer quickly went into remission, the follow-up care led to the diagnosis of a treatable rare disease, even though fewer than 95% of rare diseases have FDA-approved therapies.

"I wanted to help others like me and to make sure that they had a better experience than I had," she says. "But just surviving was a challenge, and I'm grateful that I was able to live to finish college, get through graduate school, and help people every day."

Her experience of living with cancer and a rare disease has led Michele to dedicate her personal and professional life to advocating for other patients — through ensuring patient representation in drug development and developing compassionate and accurate resources for those embarking on a difficult treatment odyssey.

Colleagues say Michele's passionate and energetic spirit is matched by her ingenuity and innovative approach to problem solving. She plays an integral role in Enzyvant's decision-making processes as the organization continues to build its mission, strategy, and operations. Her approach to patient advocacy is holistic and integrative. Before making a decision she evaluates the company's objectives and then strategically incorporates the patient perspective. She engages with patient communities as well as medical and scientific leaders and executives to understand and align each community's needs and goals. Through this approach, she has made a sustainable impact on Enzyvant's rare disease patient communities.

One of Enzyvant's programs aims to treat children with an ultra-rare disease called congenital athymia that affects only 20 infants in the United States per year. These infants all lack an immune system, also known as primary immune deficiency. Parents caring for these infants manage not only the issues related to the disease, but also the co-morbidities associated with this condition. Although the patient community wanted to connect with and provide support for each other in the past, they didn't have the capacity nor resources to do so.

"When I learned about this gap, I led an initiative in partnership with Global Genes, a global rare disease patient advocacy group, that allowed for the congenital athymia patient community to convene in person for one weekend, for the first time ever, to share their needs and discuss the patient support tools, including disease education that they would like to see," Michele says.

Ultimately, this initiative provided an opportunity for these parents to not only support one another, but to identify their priorities and be empowered to act on the issues of greatest importance to them.

The possibility of helping even one family is what motivates Michele every day, and she motivates her team members by ensuring that they hear the real-life accounts of families and patients impacted by the diseases they study.

"I share the stories of the families we could one day help with the work we do," she says. "Every single person at our company plays a role in helping to develop and test rare disease therapies — hopefully through to approval and to the patients who may benefit from them. How could someone not feel inspired hearing from the amazing people we're helping?"

Her passion for patients is carried into every part of her life. For example, she won't speak at patient-relevant meetings that haven't accommodated for patients in the meeting plan. "There are basic steps that conference planners can take to ensure that the very people who our industry is built to serve can attend the meetings that are about them," she says. "Patient-centric is a buzzword, and including patients in decision-making has become a check-the-box exercise at many companies, but genuine inclusion and accommodation for patients still isn't consistent throughout the industry, even if many believe that it is because of how frequently it is spoken about."

Michele also cares deeply about those she works with and wants to know how they are in their life outside of work, if they find enjoyment in their job, and what bottlenecks they encounter so she can help them move to that next career step. Caring about the whole person is part of how she mentors. It was only through the generous mentors in her life that she learned what patient advocacy was and how to navigate the complexities of the function.

"Whether nonprofit or for-profit, patient advocacy is a complicated, analytical field that people don't always fully understand, and I believe that we should all share what we've learned with each other because it ultimately benefits our patients when we do," she says. PV

Everything with exuberance.

Michele Rhee

TITLE: Head of Patient Affairs
COMPANY: Enzyvant
INDUSTRY AWARDS: MassBio's inaugural Caring Collaborations award, 2015; Rare Disease Difference Maker, 2018; Global Genes's RARE Champion of Hope Collaboration Award Nominee, 2019
ASSOCIATIONS: Costs of Care, founding board member; Samfund, Sambassador
TWITTER: @michelerhee