

# Insights

ADVOCACY X EXCHANGE *From The Exchange*



Uniting Advocates to  
Accelerate Change

Read more



We appreciate all of the organizations that participated in making The Advocacy Exchange such a dynamic resource for the healthcare journey.



# Insights

ADVOCACY X EXCHANGE *From The Exchange*

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“These quotes and features were extracted from conversations that occurred on The Advocacy Exchange platform in 2020. Some words have been edited for flow. It is my belief that words heal and that surrounding yourself with quotes and inspiration can fortify your own sense of courage and belonging.”

**Jennifer Sertl, Creator**  
**Insights From The Exchange**  
**Strategic Alignment Advisor, GRYT Health**



**B**y April 2020, about half of the world's population was under some form of lockdown due to COVID-19, impacting more than 3.9 billion people in more than 90 countries. In terms of the impact to global healthcare, COVID-19:

1. Interrupted patient access to care
2. Created problems for new medicines development
3. Interrupted global advocacy initiatives, and
4. Illuminated racial and ethnic health and healthcare disparities

In response, Bristol Myers Squibb and GRYT Health partnered to launch the COVID Advocacy Exchange. The purpose was to create an INNOVATIVE and BOLD online resource to elevate awareness, engagement, and impact of advocacy efforts to support patients affected by COVID.

What's contained on these pages are the insights from the global advocacy community coming together. What we thought initially was a resource that would focus on health, has evolved into a broader initiative, leading with humanity.

Since our launch in May 2020, more than 35,000 people from 91 countries have visited the platform. Advocates from 328 advocacy organizations across disease areas and regions of the world have co-created the largest multi-cultural, cross-disease advocacy initiative of its kind. Hundreds of resources are available to support and educate attendees 24/7 and thousands of minutes of conversation have occurred on the platform discussing how we work together to create meaningful change in our healthcare systems.

Through co-creation and collaboration structural, and global change is possible, but we need your voice and your experience. Join us at [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com).

*David Craig, Cancer Survivor, Co-Founder and CEO, GRYT Health*

**GRYT**  
HEALTH

and

*Cathy Trzaskawka, Executive Director, BMS Patient Advocacy,  
Bristol Myers Squibb*

 Bristol Myers Squibb



## We Thought It Was About Health; It Is About Humanity.

“It is my greatest hope that by being a part of this together, we all will feel part of something bigger, feel more connected and more capable to make a difference in the work that we do.”

**David Craig, Cancer Survivor, Co-Founder and CEO, GRYT Health**

“We can all advocate for kindness.”

**Jeffrey Champagne, Healthcare Industry Collaborator**

“All of us are needing that human connection. Patients do really need to be connected.”

**Leticia Ferri, MD, MSc, MBA, PhD, Global Lead, OLA (Organization for Latino Achievement), Bristol Myers Squibb**

“One of the most important things that all of us can combat and help overcome is a sense of hopelessness and helplessness.”

**Richard Wender, MD, Professor, Family and Community Medicine, Thomas Jefferson University**

“How beautiful is it that we cannot so easily replace human connection with a computer? Thank God, human connection is special.”

**Catherine Benedict, PhD, Psychologist, Stanford University School of Medicine**

“I think this whole situation just raised the human that we have inside of us. If you don't seek with your heart and with your mind, what are we here for?”

**Gaetano Crupi, President and General Manager, Bristol Myers Squibb, Brazil**



# Your Voice Is

*Sometimes when we hear other people share their story, we get access to the words we need to tell our own.*



“It has gotten to the point where you cannot really participate in the healthcare system without having an advocate and also without knowing a great deal yourself.”

**Dan Platt, MD, Chief Medical Officer, GRYT Health**



“What is really important is for people to make their voices heard and to speak up.”

**Diane Gross, National Director of Advocacy and Programs, Lupus Research Alliance**



“In the United States we have such a high regard for physicians that we are afraid to give pushback or pursue some things that make us uncomfortable. It is so important that we are not afraid to speak up for ourselves or for others. If you feel like something is not right, you have to go for it, keep pushing. You only get one life.”

**Erin Mulqueen Galyean  
Author, Badass Advocate**



“There is always somebody who’s got it worse. There’s always somebody who is at a better place. I think we learn from both types of experiences.”

**Teri S. Brister, PhD, LPC, National Director Research & Quality Assurance, NAMI**



“Rather than talking about death, we need to talk about life and hope – and patients are key to that.”

**Andrea Vassalotti, Partnerships & Programmes Director, World Heart Federation**



“There were things inside me that were trapped before I knew how to find my voice. One of the most amazing miracles in life is finding our voice so that we can connect with others and make positive change.”

**Jessica Valence, Colon Cancer Survivor, Vice President, Education and Empowerment, GRYT Health**

Register today to lend your voice to upcoming sessions at [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com).



# The Missing Piece



“We have to continue to advocate and that’s where patients have to continue to make their voices heard and show that their lives count on us continuing to make progress. And we can’t slow down. We can’t halt. We have to dig in harder and deeper and faster.”

**Amy C. Moore, PhD, Vice President of Global Engagement and Patient Partnerships, Lungevity**



“For people who are immunocompromised, sometimes their own support systems – family, friends, colleagues – just don’t understand some of the necessary precautions. We want to tell people’s stories because we really feel that people with lupus and other chronic illnesses have a lot to teach the rest of us, and we want to help get their support networks to really understand what they go through on a regular basis.”

**Diane Gross, National Director of Advocacy and Programs, Lupus Research Alliance**



“I will scream to the rooftop to anyone who is struggling with mental health and having different feelings, whether happy or sad, to share them and work through them with a mental health professional.”

**Jasmin Watson-EI, MS Patient Ambassador**



“Probably the biggest mistake I made was before I actually got my diagnosis. I expected the doctors to run the right tests and to figure out what was wrong with me. So when they told me I had a UTI or a bladder infection and gave me meds and sent me out the door, I didn’t fight harder for more testing. They thought I had a UTI, when I actually had a tumor. I was pissed I didn’t fight for more testing sooner. I was pissed they didn’t listen to my symptoms and run the proper tests for what I was experiencing.”

**Liz Hiles, Cancer Survivor, Advocate, Engagement Specialist, GRYT Health**

Past session recordings and on-demand resources are available in our virtual exhibit space, open 24/7.

# We Are All Learners

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*Well-being is dynamic and one solution fits one. In order to make progress, it is important that we are open to listen and to learn.*

“I recommend a self-compassion approach, which is not about comparison. Life is hard for everybody. I am allowed to suffer and it is not a race. There is no award for the most or the least suffering person. We are all human. We are all having some kind of experience. We all have difficulties in different ways.”

**Kelly Davis, Director of Peer Advocacy, Supports and Services,  
Mental Health America (MHA)**

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“I think it’s a steep learning curve for not only patients, but also providers. Some centers have gone from almost no telemedicine visits to now over 80% of their visits are telemedicine. All of us are learning and jumping on board.”

**Matt Bouchonville, MD, Associate Professor, Division of Endocrinology,  
Associate Director, ECHO Institute, University of  
New Mexico School of Medicine**

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“Getting the patient’s story as partners in research projects and other projects is critical.”

**Robert C. Block, MD, MPH, FACP, FNLA, Associate Professor, Department  
of Public Health Sciences and the Cardiology Division, Department of  
Medicine, University of Rochester**

# In Her Own Words

Shanelle Gabriel, HBO Def Poet, Singer, Activist/Advocate for Lupus Awareness



“Art is seen as something recreational. I definitely realize that there is a way of moving into this idea of art as therapy over the past 10 years.

For me it is writing things down to myself in a poem or sometimes just how I am feeling. It doesn't always come out poetic. Sometimes it is just a brain dump, everything I am thinking of or feeling.

When I do go to the doctor, I actually have my journal. I might have had a stressful day and have a record where I didn't feel good, what I ate, what I was going through.

This part of finding my voice is also just like exploring my voice, using it in different ways. I do it to advocate for us.

It took me about two years before I ever thought about talking to mom about having lupus.

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“We don't always see our stories, our honesty, our transparency, our vulnerability as part of the support and the help that we can provide others as well as ourselves.”

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There is a space that we have to have for ourselves.

Something really important is the grace that we need to give ourselves.

Living with a chronic illness and sharing the experience is important because there is nobody else going through what I am going through.

It was just so insane to me that something that I said could inspire others to want to talk about what they are going through. We don't always see our voices as the advocate.

We don't always see our stories, our honesty, our transparency, our vulnerability as part of the support and the help that we can provide others as well as ourselves.

Poetry definitely gave me space to be able process what I was feeling.

Sometimes there are days I don't want to talk about myself. Healing is an up and down trajectory especially with lupus, which is a series of flares and remissions. It is important to say I don't feel good and I don't feel like sharing too.”



**Shanelle appeared on *The Advocacy Exchange for the Building Stronger Relationships Across Healthcare Through Empathy* session on December 17, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.**

**S**hanelle is a poet, singer, and lupus warrior from Brooklyn, NY who has performed internationally including Africa and Europe. Widely known for featuring on HBO's Def Poetry Jam, she has shared the stage with artists such as Jill Scott, Nas, Dave Chapelle and more. She was listed as one of Blavity.com's "Artist Activists You Should Know" and one of "8 Millennial Feminist Poets That Deserve Recognition" by BET.com. Shanelle is also a health activist who has spoken alongside the President of the National Institute of Health, on Capitol Hill, and has featured on the Lifetime Network, in Women's Health Magazine, and more about her continued battle with lupus.

Presently, she is working on her third album, pursuing her Master's in Education at Columbia University Teachers College while serving as the Interim Executive Director at Urban Word NYC, a youth organization that uses poetry & hip-hop to promote literacy and youth voice.



# Honor the Emotions of Your Healing Journey

“It is important that we do a lot more to talk about the maintenance of our mental health.”

Jasmin Watson-El, MS Patient Ambassador

“As I am working on my survivorship, I am stuck with all my thoughts and how I feel about that on top of my aches, my pains that I deal with having multiple sclerosis. I am really sick of being sick. You know? I’m tired of my legs hurting. I am tired of my back killing me. I am tired of all of this on top of being sad.

I am hoping particularly that reducing the mental health stigma hits home in the workplace. There are so many workplaces who are not sensitive to people with a chronic illness or struggle with mental health. Sometimes you might need to take five minutes to then go in a closet, let out a cry and then go back to work. I do not want anyone to use my health condition against me or to think differently of me and my abilities. I want to just be known for being Jasmine, the girl who gets it done. There is a stigma in the way that people in the workplace perceive these issues. It causes us to put a great deal of shame and guilt on ourselves.” ●

*Jasmin appeared on The Advocacy Exchange on the Mental Health, Well-Being, and Psychosocial Support for Patients session on June 25, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.*



*Jasmin is a program and project manager who hails from Baltimore, Maryland. She is trained in Change Management with certifications as a Scaled Agilist and Customer Experience*

*Professional. Jasmin earned her Bachelor’s Degree in Communications with a focus in Public Relations and dual minor in International and General Business from Xavier University in Cincinnati, Ohio. She went on to earn her MBA in Business Management from Indiana Wesleyan University. Jasmin has served on the Board of Directors for a local non-profit that serves the homeless community and as an adjunct faculty member for a university program that bridges underserved Baltimore students from high school to college. She is also a member of Delta Sigma Theta Sorority, Inc., an international public service-based sorority. Since Jasmin’s diagnosis with Multiple Sclerosis (MS) in 2013, she has pulled herself up to take control of – and thrive with – her disease, traveling and speaking to various groups in the MS community as a patient ambassador.*

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*“I will scream to the rooftop to anyone who is struggling with mental health and having different feelings, whether happy or sad, to share them and work through them with a mental health professional.”*

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## “There is no health without mental health.”

Kelly Davis, Director of Peer Advocacy, Supports, and Services, Mental Health America (MHA)

Teri S. Brister, PhD, LPC, National Director Research & Quality Assurance, National Alliance on Mental Illness (NAMI)

“When you have a chronic health condition that you are dealing with, regardless of what it is, whether it is diabetes, multiple sclerosis, or cancer, your life is regimented to a degree. Things that have to be done for you to take care of your physical health. Mental health requires the same level of diligence.

There is always somebody who’s got it worse. There’s always somebody who is at a better place. I think we learn from both types of experiences.” ●

**Teri appeared on *The Advocacy Exchange on the Mental Health, Well-Being, and Psychosocial Support for Patients* session on June 25, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.**



Teri serves as the national director of research & quality assurance at NAMI. She is responsible for ensuring that all content created and disseminated by NAMI attains the highest possible standards of accuracy, relevance, value and academic rigor. She is the author of *NAMI Basics* and co-author of the *NAMI Homefront* program. Prior to joining NAMI in 2005, Teri worked for 20 years in the community mental health system in Mississippi, working in both clinical and administrative roles, including assistant executive director in two different centers. Teri received her PhD in Public Policy and Administration from Jackson State University, and her Bachelor of Science and Master of Science Degrees in Counseling Psychology from the University of Southern Mississippi. She is a Licensed Professional Counselor in Mississippi.

Kelly Davis, Director of Peer Advocacy, Supports, and Services, Mental Health America (MHA)

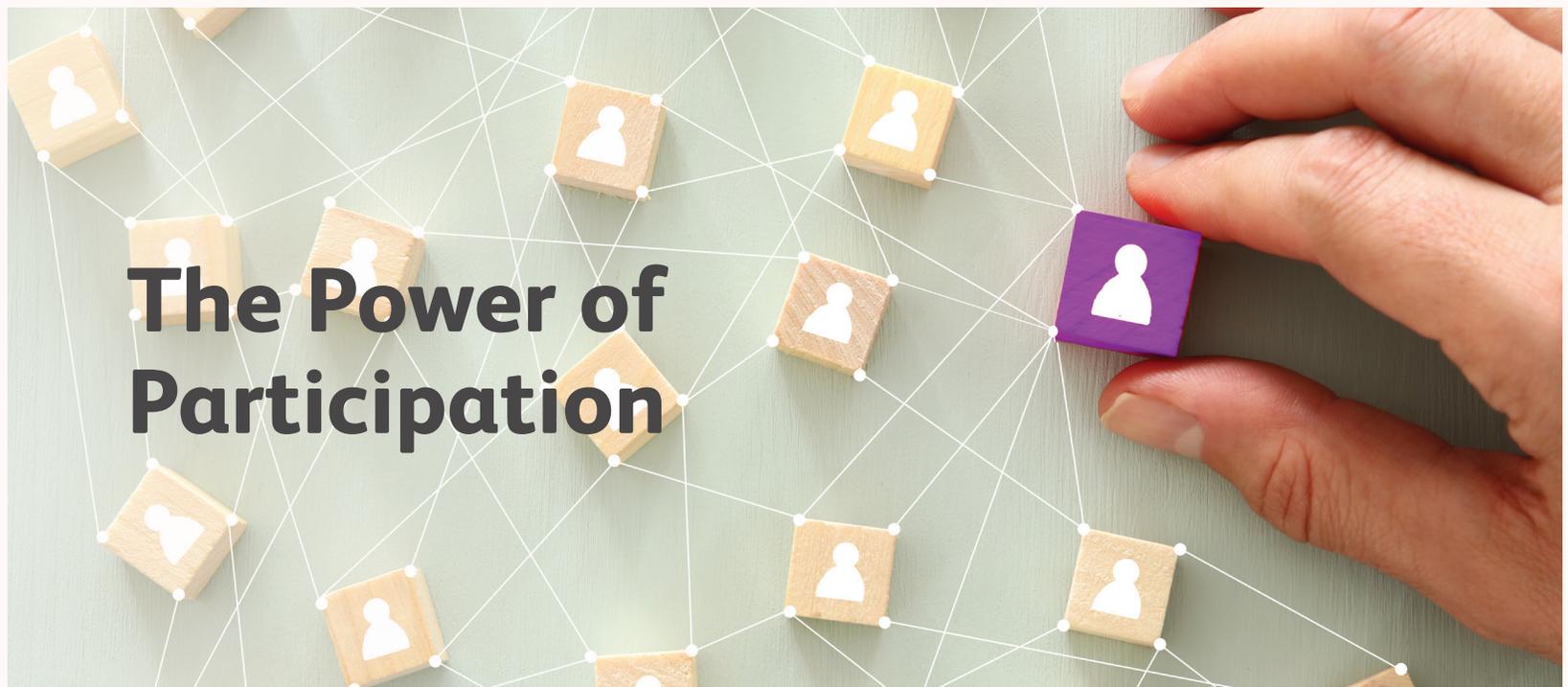
“I live with bipolar disorder and post-traumatic stress disorder. I know from my lived experience that mental health is not prioritized. I know that it is even worse for folks who are only looked at as somebody who is experiencing a physical health concern with no regard for how their mental health is impacted. Historically, we have separated those worlds even though there is so much overlap. I believe that letting folks with lived experience lead and have voices in design on how we build things for people is how we create a better world.

When we hear stories of people’s wellbeing, we can be inspired. Life is hard for everybody. I am allowed to suffer and it is not a race. There is no award for the most or the least suffering person. We are all human. We are all having some kind of experience. We all have difficulties in different ways. There is no health without mental health.” ●

**Kelly appeared on *The Advocacy Exchange on the Mental Health, Well-Being, and Psychosocial Support for Patients* session on June 25, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.**



Kelly is the director of peer advocacy, supports, and services at Mental Health America (MHA), where she promotes the expansion of peer support and youth and young adult leadership. In 2019, Kelly was awarded the Disruptive Innovator Award by the International Association of Peer Supporters, given to a young person making positive change in mental health through positive disruption. She is a certified yoga teacher and holds a certificate in applied positive psychology from The Flourishing Center. She is currently pursuing her Master’s Degree in Nonprofit Leadership at the University of Pennsylvania.



# The Power of Participation

We are learning more and more how a single voice can make positive change and how new solutions create a domino effect. The Advocacy Exchange includes a cross-section of voices from survivors, advocates and physicians, to hospital administration and leaders in the pharmaceutical industry, in order to have the stakeholders working together co-create the next generation of healthcare.

**More than 35,000 people from 91 countries have visited The Advocacy Exchange since May 2020.**



“In history, we have seen so many times that when we all unite our voices and we share our strong voices, we change things and good things happen.”

**Ester Banque, SVP & Head of  
Intercontinental Commercial, Bristol  
Myers Squibb**



“What are the workflows that the patients have to do? And what are the workflows the providers have to do? As long as you are mapping whatever you are implementing against those workflows, you’re likely to be more successful.”

**Sandeep Pulim MD, Chief Medical Officer,  
Bluestream Health**



“We knew that there were disparities and research has recognized these disparities; however, COVID-19 has made these disparities so much more obvious. They are an open wound that we now have to take care of.”

**Eleanor M. Perfetto Edwards, PhD, MS,  
Executive Vice President,  
Strategic Initiatives, National Health  
Council (NHC)**



“We need to be working with healthcare systems to help them better understand patients’ expectations.”

**Richard Wender, MD, Professor, Family  
and Community Medicine, Thomas  
Jefferson University**



“I believe that letting folks with lived experience lead and have voices in design on how we build things for people is how we create a better world.”

**Kelly Davis, Director of Peer Advocacy,  
Supports, and Services,  
Mental Health America (MHA)**



“There’s a flaw in the system. And we were talking about trust or not trusting the system. We can talk about the lack of communication, not having the physical touch, but I don’t think that’s the heart of the problem. The problem is the profit centered approach. Healthcare is a privilege, to those who have it and it’s not available to many of those who do not have it. The time is now to rethink the bigger framework.”

**Morhaf Al Achkar, MD, Lung Cancer Survivor,  
Family Physician, UW Medicine**



“I think that as we challenge the systems that we are all facing, we have to first and foremost own the fact that our healthcare system has been rooted in white cisgender male patriarchal hierarchy for decades, centuries, for 401 years. Unless we change how the power is shared in healthcare, in the pharmaceutical industry, in schools of public health, nothing is going to get better.”

**Perry N. Halkitis, PhD, MS, MPH, Dean, Professor of  
Urban-Global Public Health, and Director of Center for  
Health, Identity, Behavior and Prevention Studies (CHIBPS)  
at the Rutgers School of Public Health**



“The bottom line is just having a mechanism like a patient assistance foundation does not actually guarantee access. You have to think about all those structural barriers that stand in a patient’s way to actually even get to the front door of that foundation. Make sure you challenge your partners on those structural barriers. Who are the partners that are saying they can actually help you do that? What do they look like internally? You have to lean into the discomfort and have some of these difficult discussions. It is going to make a huge difference.”

**John L. Damonti, President, Bristol Myers  
Squibb Foundation**



“Even though I am in healthcare, I did not know how to advocate for myself. I felt that I needed to have a Master’s Degree to understand how to navigate the system. The system needs to be better. There is such an opportunity to improve.”

**Jeffery Champagne, Healthcare Industry Collaborator**



# Participation Changes The Future

Katie Rizvi, Co-Founder and Executive Director, Youth Cancer Europe

*Listening, asking a question, sharing your story, offering a resource are all ways to engage. What we know is that being part of a community reduces isolation and increases connection. When people are connected they learn new things and make new choices.*



“There is a way to reorganize care delivery with social distancing in mind with safe patient access and hospital reorganization. This is the moment for us to speak up locally in our respective communities and policy networks. The global emergency is forcing us to be smarter, forcing us to work more efficiently and forcing us to tie loose ends so that we can make systematic provisions. Geography should not determine on your survival rate.

There is strength in numbers and as we all band together with all of our advocacy organizations we can work together to try to achieve having the right kinds of policies in place. I don't think we are heard enough just yet. Patient advocacy is still wearing baby shoes.

It's very important for everyone to appreciate that no matter how small you are, no matter how insignificant you might feel, your voice really does matter.

Some people are intimidated by people in policy. Literally the people who sit there are not always the most knowledgeable. They are just you and I – students, people. Your voices could be sometimes a hundred times smarter than some of the other people's voices. So put yourself out there, let your story be heard constantly. Let's not lose momentum because we've learned so much. We want to reshape healthcare. Let's reshape it according to what we believe it should be like.” ●

***Katie appeared on The Advocacy Exchange on the Reshaping Healthcare: Thinking Differently after COVID session on July 16, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.***

*Katie is one of the founders of Youth Cancer Europe, a network of youth cancer organisations from across Europe, with a mission to help shape European policy and fix the disparities that exist across the continent for young people fighting cancer. Her special interest is youth empowerment and enabling survivorship communities, as well as endeavouring to make sure that Eastern Europe is firmly on the map as a part of*



*the dialogue and an active contributor to European health policy.*

*In 2016, she became a member of the Children's Medicines Working Party of The European Forum for Good Clinical Practice.*

*Since May 2015, Katie has sat on the Board of Directors of PanCare, a multidisciplinary pan-European network for the long-term care of childhood cancer survivors.*

*In 2002, she co-founded the Little People Children's Cancer Charity in Romania & the Republic of Moldova that today provides daily psychosocial support services in 10 hospitals, with nearly 100% patient reach in both countries, annually caring for up to 2000 inpatients and 300 or more young people in after-care, residential programmes.*

**“We cannot talk about survival if we are not talking about the person who is surviving.”** David Craig, Cancer Survivor, Co-Founder and CEO, GRYT Health

*GRYT Health’s team of survivors and caregivers work to improve quality of life and outcomes for anyone affected by cancer through the relentless focus on the patient experience.*



“I’m a lung cancer survivor and for many years I was very quiet about it because I had a sense of survivor’s guilt because I had such a great outcome. So many others that I knew did not have good outcomes. A friend of mine said, ‘You should get more on Twitter. You should write a blog.’ Once I started letting my voice be heard, I started connecting with other people and it is a magical experience.”

**Dave Bjork, Cancer Survivor, Vice President, Empowerment, GRYT Health**



“I am coming up on four years of survivorship. It took me about two years to unpack my diagnosis. I dealt with the physical first and worked on getting through treatment. I rushed myself to get back to normal. Then, probably about after two years, I started dealing with the emotional side of it. I began really asking myself ‘why did I have to go through this?’ ‘What good can come out of this?’ I actually hired a life coach to try and help me figure out what I wanted to do with this experience and what I wanted to do with my life. Here I am today, getting to use my voice every single day and help others do the same.”

**Nichole W. Owens, Breast Cancer Survivor, Chief Marketing Officer, GRYT Health**



“I look pretty darn healthy. Looks can be deceiving – the invisible illnesses. I think for many of us who are cancer warriors and chronic illness warriors, we consistently carry an additional stress and anxiety on a daily basis, which is even more heightened because we are in the midst of a pandemic with no vaccine. Going through cancer made me realize I can no longer just exist in the world. I need to live with purpose and do what I can to effect positive change.”

**Megan-Claire Chase, Cancer Survivor, Blogger, Patient Advocate, Partnership Director, GRYT Health**



“Be an advocate for yourself. Do not expect your doctors to call you. Make sure that you are staying on top of your own health and that you are following up for yourself.”

**Jessica Valence, Colon Cancer Survivor, Vice President, Education and Empowerment, GRYT Health**

The logo for GRYT Health, featuring the word "GRYT" in a large, bold, purple font with a registered trademark symbol, and the word "HEALTH" in a smaller, purple font below it. The logo is set against a background of overlapping purple speech bubbles of various sizes and orientations.

**GRYT**  
HEALTH

# Three Lessons In Empathy From the Lens of A Provider

Laura Adams, Special Advisor at the National Academy of Medicine (NAM)

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## Lesson One

### Self Forgiveness & Allowing Life Experience To Make A Difference

“I have this interesting background being a provider, being a mom and then being a breast cancer survivor. So I’ve had a chance to look at life from both sides. I speak from multiple perspectives. When I was about 22 years old, I was a young staff nurse working in rural Colorado in a tiny little hospital with 35 beds in the middle of nowhere. We were all they had. And I loved my job. I was super excited about taking care of all these patients.

One night changed my life and perspective. I worked the night shift with a 19 year old licensed practical nurse. We took care of 35 patients that night. There were two doctors on staff that were not on the premises. We did not have back up. We worked hard and took good care of our patients. We also lived in fear. Every clinician has that fear of the phone call or message that says you made a mistake. I did get that call, I made a catastrophic mistake. I made a catastrophic medicine overdose on a young child pre-op.

After a long night, I was headed off to the nurses’ station and I heard the Intercom come on from down in the surgery suite. I could hear the tone of our surgeon’s voice and it was ominous. I knew that something really bad was happening downstairs. The surgeon said ‘Laura, I don’t know what you gave this child pre-op but she is having a seizure and is in a coma. It’s got to be the pre-op medication. Please go find out.’ It was just the most horrific moment of my life.

I raced over to the medication area and I looked down

and much to my dismay, I could see immediately that I’d given her a 10 times overdose of a dangerous drug. I knew that the side effects of that overdose were seizures, coma, and death, and she was experiencing two out of three and headed to the third. I was terrified. I was summoning every prayer I had prayed in my life to please help this little girl and spare her life. She was going to die at my hands and I couldn’t believe it.

The team was absolutely stunningly effective in that operating room that morning and they saved her life. I was incapacitated at the hospital. I took some time off and spent it in a dark room thinking, just get out. The voices in my head kept saying, ‘You’re not competent to do this job. You’ve nearly killed a child from care that was intended to help. So you just have to stop.’

And after a few days went by, I was able to breathe again and started wondering what had happened.

I went back and did a little investigation and found



out that before that order had landed on my desk as the night shift nurse that night, it had been hand transcribed. The doctor wrote the order correctly. It had been hand transcribed six times before it got to me, two times by someone with no pharmacological background. So they would not know that the movement of a decimal point, especially in a pediatric dose, was going to be death by decimal point. I was horrified and thought, is this the design?

And then I realized that much of healthcare had grown up lacking design. I decided to spend the rest of my life and career dedicating myself to working on the design of healthcare systems so that never ever happens to another family member and other patient.”



## 2

### Lesson Two Understanding Vulnerability In A New Way

“When I was married, I married a man with a four year old set of twins and a six year old. We all grew up as a family together. We thought we’d have one of our own along the way until the twins got to be 19 years old and the oldest got to be 20.

It was only then that I learned I was able to conceive and so we started all over again. I was thrilled out of my mind to have the experience of being a mother to a newborn son.

I took him in for his first set of vaccinations and I saw them approaching his leg with that gigantic needle. I knew intimately about the fallibilities of the healthcare system. You can almost imagine that I was terrified by what I felt might be karma. And I just prayed at that moment. ‘Please make that the right dose, the right drug, the right everything, because you have my whole life in your hands with this baby.’

And I just felt a sense of vulnerability I had never felt before in my life. I understood it differently from a patient perspective. Family perspective is different.”

### Lesson Three

#### Just Because We Have An Experience, Does Not Make Us An Expert

## 3

“This last experience I am sharing with you is when my understanding of empathy really took root.

As a breast cancer survivor and consultant, I was chosen to help make a breast center in Michigan more patient centered. Now someone suggested we include some patients and families, and I said, ‘You have me. We don’t need any patients and families. I have taken care of them for years.’

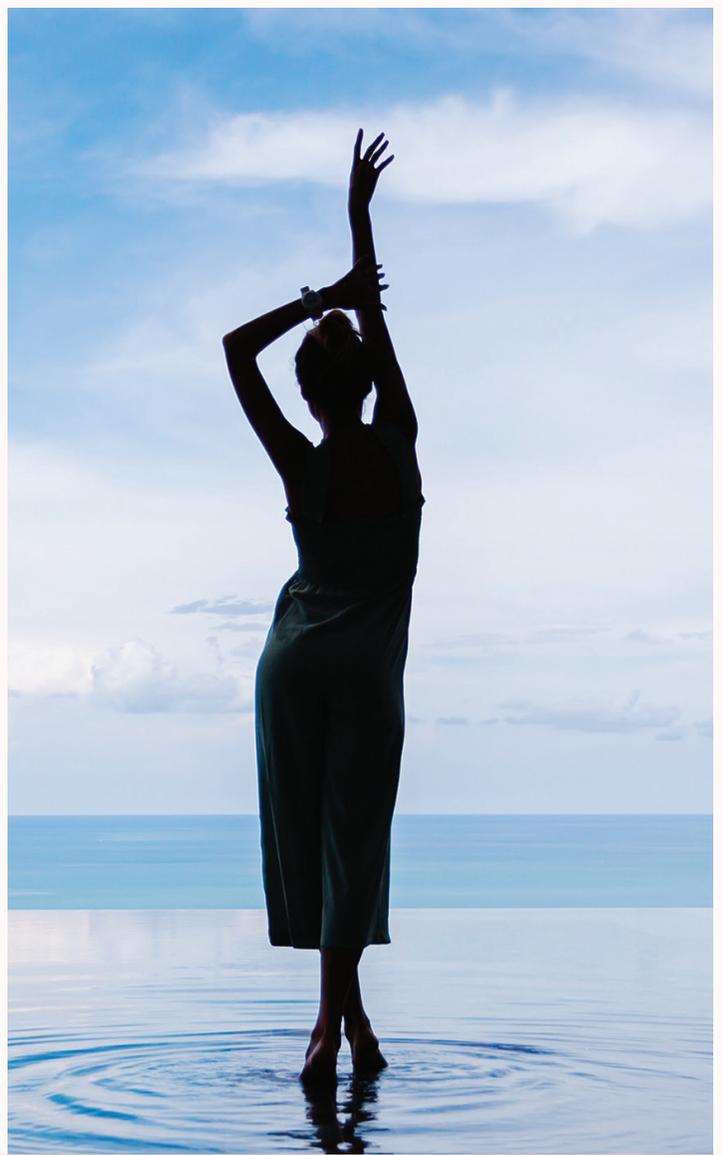
I decided we needed lovely light - I wanted it to be calm and soothing. I wanted there to be a water cooler with lemons as you know how welcome you feel at a hotel when there is water with lemons. Nothing says we care like water with lemons. The set up was beautiful and I couldn’t wait for the first group of women to tour our facility *The Breast Center*.

The first woman in the tour group takes me by surprise by saying, ‘What were you thinking? If this was a men’s health center, do you think they would call it *Testical Center*?! Every time I have to walk into this center under a sign in this small town that yells *The Breast Center* everyone knows there is something wrong with my breast. Why didn’t you just name it after whoever gave you the most money?’

I was taken aback as though I had been tased. All that was going through my mind was a name I couldn't shake for days – *The Penis Pavillion*. She had a point. A point I had missed.

Here is what I learned: Without listening deeply to the stories of your patients, you will never know a person's experience. Even after I had breast cancer and my own set of stories, it didn't mean I could stop listening to others' experiences. **Without the stories of the people I serve, I will never be able to practice at the top of my humanity.”** ●

*Laura appeared on The Advocacy Exchange for the Building Stronger Relationships Across Healthcare Through Empathy session on December 17, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.*



**L**aura serves as special advisor at the National Academy of Medicine (NAM), where she provides leadership for the Digital Health and Evidence Mobilization portfolios of the Leadership Consortium, with the COVID-19 response as a critical area of focus. She has expertise in digital health, health care innovation, and human-centered care. As Catalyst at X4 Health, Laura leads the national strategic partnerships for the 3rd Conversation (3C) project ([www.3rdconversation.org](http://www.3rdconversation.org)), also critical in the wake of COVID-19, helping to reweave humanity into the fabric of healthcare and healing. She serves on the Board of Translational Medicine Accelerator (TMA), a Boston-based precision medicine company focusing on patients with recalcitrant and rare diseases.



“I did not give up, I became informed, I fought for my survival, I risked everything to live.”

KT Jones, Cancer Survivor & Patient Advocate



“I am a cancer survivor originally diagnosed in 2002, terminally diagnosed in 2011. I am still here thanks to a lot of speaking up and pairing with the right people at the right time. I have had to take a lot of ‘nos’ and turn them into ‘yeses.’ I’ve had to argue my case in front of Congress. For somebody who’s normally introverted and shy, I had become a very squeaky wheel. I am now actually able to see some of the fruits of me speaking up and it is hard to shut me up.

I live in Delaware where we have one big hospital. As far as their protocols, they did everything they could for me. It wasn’t enough and thankfully, I had a doctor who knew I had a lot of fight in me and wanted to help me continue to fight. This doctor pointed me to [clinicaltrials.gov](http://clinicaltrials.gov). I put my diagnosis up there and created an algorithm that would allow standard letters to automatically be sent to everybody on the platform. I flooded mailboxes trying to get treatment or participate in clinical trials. I was sent to Johns Hopkins in Baltimore. I was sent to the University of Pennsylvania. It was like trying to get into an exclusive club. I had no idea how to do it. Despite diligent efforts, I heard absolutely nothing back.

My last resort was to put my disease on YouTube, of all places. It worked! A doctor for MD Anderson Cancer Center put out a video for testing people who have multiple recurrences of Hodgkin’s lymphoma. I reached out and literally got a response within 20 minutes. The doctor running the clinical trial called me. I was in Delaware, he was in Houston. I told my wife, ‘This is my last chance of survival.’ It meant that I was going to stop paying somebody’s bills in

an effort to live.

I flew out to Houston, Texas and did some treatments. In the process, I went completely bankrupt. Every time I flew out to Houston it was on my dime. I had to stay in Houston two weeks out of every month. I emptied my entire savings – everything – to survive.

I was able to get some treatments at Memorial Sloan Kettering in New York, which was much easier for me, as I found they were doing some tests on leukemia that were targeting a protein I had seen on my charts. I am the type of patient that reads everything, even if it is gibberish. I am going to know about myself. I have been in my body longer than doctors have been practicing medicine. This testing for leukemia ended up being my saving grace and as of today I haven’t had a treatment in over six years.

I had to change my priorities. Not just financially, but spiritually and physically. I had to focus on different things. I didn’t have a chance to grieve my mother’s death. I ended up in a battle with myself and at one point I had a spiritual moment where I actually questioned my own survival. I woke up one day and asked, ‘God, why am I still here?’

Of course there is so much more to the story. Here is what is essential to understand about my journey to

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“I have had to take a lot of ‘nos’ and turn them into ‘yeses.’”

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health that applies to your journey: I did not give up, I became informed, I fought for my survival, I risked everything to live.” ●

***KT appeared on The Advocacy Exchange on the Reshaping Healthcare: Thinking Differently after COVID session on July 16, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.***

*KT had been told many times that he had come to the end – the end of available treatments, the end of cutting edge options, the end of his life. But 16 years after being diagnosed with Hodgkin’s lymphoma, he’s still here, and he’s thriving.*

*How? Remarkable tenacity – and a clinical trial.*

*Before the clinical trial, KT had tried every treatment he could find, including chemotherapy, radiation, and bone marrow transplants. Each time the treatment worked well for a few months, but then the lymphoma would return.*

*Undeterred, the father of one and former R&D specialist used his training – researching his disease and every possible treatment, convinced that something out there could save his life.*



**“I am still here thanks to a lot of speaking up and pairing with the right people at the right time.”**

**KT Jones, Cancer Survivor & Patient Advocate**



# Optimal Health For Everyone

Perry N. Halkitis, PhD, MS, MPH, Dean, Professor of Urban-Global Public Health, and Director of Center for Health, Identity, Behavior and Prevention Studies (CHIBPS) at the Rutgers School of Public Health

“I challenge us to stop thinking about people living in one box because gay people are Black people, and Black people are immigrants, and immigrants are people from New York. Everybody has intersectional identities.

Sexual orientation and gender identity are not the same. And they also bring to the table, their race, their culture, their ethnicity, their nation of birth, all of these issues that define who they are. And so focusing on the role of that intersectionality in healthcare delivery is really key.

It is really important to think about the structural inequities that exist not only in the population at large, but in the population of LGBTQ people, and sexual and gender minority people more broadly.

It is our job to work with communities as equal partners. They know as much about their communities and know as much about their health as we do.

I challenge my students every day to be activists. I challenge you to be an activist. It is not enough to be an academic. It is not enough to be a scientist. It's not enough to be an educator at this particular moment. It is time to be an activist because as we have seen over the course of the last four years, politics shape public health. If we don't challenge the politics that continue to marginalize and oppress, we're not going to see an improvement in anybody's health in this country.” ●

*Perry appeared on The Advocacy Exchange on the Taking Action to Correct Health Inequities session on November 12, 2020. Visit [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com) to watch the full session.*



*Perry is a public health psychologist, researcher, educator, and advocate who is dean and professor of Biostatistics and Urban-Global Public Health at the Rutgers School of Public Health. He is the founder and director of the Center for Health, Identity, Behavior & Prevention Studies (CHIBPS). For three decades, Perry's program of research has examined the intersection between HIV, HPV and other STIs, drug abuse, and mental health burden, with regard to the biological, behavioral, psychosocial, and structural factors that predispose these and other health disparities in the LGBTQ+ population. His work focuses on the translation of this knowledge through implementation science research that examines the effectiveness of tailored and adaptive interventions in order to prevent and eliminate these disparities. His research program has been awarded over \$30 million in grant funding. Most recently, he has been involved with New Jersey's contact tracing efforts, helping to develop the curriculum and launch the New Jersey Community Contact Tracing Corps.*

# Our Commitment to Action

The Advocacy Exchange has brought the global advocacy community together to not only hear from each other, but to prioritize and begin to tackle global health issues.

Through hundreds of hours of conversations with patient advocacy leaders, we learned there were four core areas that mattered most where we should focus our time to create change. You are invited to join us and lend your voice to the discussions or continue your participation in our expert-led Working Group sessions.

*Together, we are co-creating the future of healthcare, the future of wellbeing.*



## The Future of Advocacy

The role of patient advocacy organizations is changing. There are increased demands, new challenges, and emerging opportunities for creating meaningful change within the healthcare system.

This Working Group will define where advocacy has been, where it is today, and create tangible steps toward defining the future of advocacy.

**Group Leaders: Gary Nolan, Jessica Valence, Chad Saward**



**Gary Nolan**  
Independent Advisor

Utilizing over 15 years of medical communications experience, Gary has developed a unique skill in forming, facilitating and nurturing community collaborations, in order to support mutually beneficial outcomes.

Over the years Gary has supported numerous communities in identifying common educational needs, navigating sensitivities and co-creating alliances. All initiatives are nationally neutral, yet globally inclusive, and strive to lift levels of knowledge. Gary applies his passion and scientific rigor to all partnerships and the collaborations he supports.



## Health Equity: Access to Care

Advancements in medicine and technology are creating better outcomes than ever before, which makes the disparities in accessing care even more devastating.

This Working Group will take an unflinching look at current access to care to define and then contribute to the change needed.

**Group Leaders: Brad Love, PhD, Eileen Shannon, Alison Handler, Nilam Perpich**



**Brad Love**  
PhD, Co-Founder and Chief Culture Officer, GRYT Health

Brad Love works to help people thrive. At the University of Texas at Austin, he serves as university distinguished teaching professor and an associate professor in the Center for Health Communication, where his work largely focuses on improving quality of life for young adults affected by cancer. In particular, his research focuses on boosting access to mental health, social, and informational support. Brad's projects have been supported by MD Anderson Cancer Center, the Livestrong Foundation, and the American Cancer Society, among others.



## Patient Voice/Patient-Focused Drug Development

Patient involvement is increasingly being recognized as important to successful research and development of medicines and care. Patient-focused drug development (PFDD) is an emerging set of practices for engagement with patients and generating data on patients' and caregivers' experiences.

This Working Group will consider current guidance and practices to identify needed tools and resources to further promote and embed the patient voice from molecule to market.

*Group Leaders: Neil Bertelsen, Dave Bjork, Miryah Morris*



### Neil Bertelsen

HTAi Patient and Citizen Involvement Group

Neil has over 25 years' experience in bringing the patient voice to life for healthcare decision makers. Neil has been a patient advocate, and is the past chair of HTAi's patient & citizen involvement group where he continues to work with HTA bodies around the world on improvements to patient engagement in HTA. Neil is also a board member of Patient Focused Medicines Development, an international multi-stakeholder effort to bring patients into the heart of medicine research and development. Neil regularly works with patient groups, healthcare decision-makers and the industry to collectively develop approaches that benefit patients.



## Health Equity: Racial & Ethnic Health and Healthcare Disparities

Many social and economic factors drive health outcomes. However, there are associated structural, institutional and systemic disparities that need to be corrected for everyone to have equitable healthcare and improved health.

This Working Group utilizes courageous conversations to better understand the current healthcare environment as it relates to racial and ethnic disparities in an effort to take tangible steps towards correcting inequities.

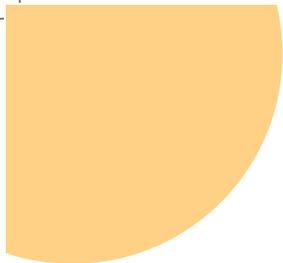
*Group Leaders: Sheila Thorne, David Craig, Kemi Osundina, Tammi Fanson*



### Sheila Thorne

President and CEO, Multicultural Healthcare Marketing Group, LLC

A native New Yorker, Sheila has spent more than two decades designing marketing, media and health education campaigns for the top 50 pharmaceutical companies across a broad range of therapeutic categories from molecule to market. A former high school teacher of foreign languages, she has worked on behalf of the healthcare industry throughout North America, Western Europe and Latin America with a focus on communities of color. She teaches and has lectured on health equity and cultural competency at Quinnipiac University School of Medicine, Rutgers, New York University and Queens College. Sheila is known for her unique ability to galvanize communities of color around health and social justice issues. Sheila has received numerous awards for her innovative health marketing strategies to reach people of color.



Register today to lend your voice to upcoming sessions at [TheAdvocacyExchange.com](https://TheAdvocacyExchange.com).  
Past session recordings and on-demand resources are available in our virtual exhibit space, open 24/7.

ADVOCACY  EXCHANGE

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