



CURALINK

ISSUE 20
October 2023
thecurafoundation.org

Welcome to CuraLink—a newsletter for innovators building a healthier future for all.

Dear Cura Community,

Welcome back to CuraLink, a newsletter and interview series featuring the most pressing issues in human health, unmet medical needs and the emerging innovations and technologies directed to address them.

Last month, we had a comprehensive and hopeful conversation with Dr. Thomas Insel, who discussed escalating deaths of despair and our path to collective healing. This conversation offers a guiding light for entrepreneurs, clinicians and families as tech innovations take on mental health. Find it at bit.ly/CuraLink-19.

In issue 20 of CuraLink, we speak with Dr. BJ Miller, a physician leading a revolution in hospice and palliative care. Our powerful discussion covers daring territory around the way we die and the failures of a “fix everything” medical system. The conversation should be helpful for anyone navigating a health challenge, caring for a loved one in their final days or treating patients.



Robin L. Smith, MD
*Founder, President and Chairman,
Cura Foundation*

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A conversation with Dr. BJ Miller

While much of health care revolves around fixing problems or treating disease, the specialty known as hospice and palliative care has another goal: support people's quality of life and provide comfort, dignity and assistance to the dying or those with serious illnesses.

According to Dr. BJ Miller, one of the leading specialists in the field, this approach is surprisingly rare. That's because medicine is hyperfixated on acute, life-preserving care, which can improve short-term outcomes but can also breed unnecessary suffering. It's a "fix on a fix on a fix," Dr. Miller says, without asking patients what they really want or need.

We need to have more resources to support and guide families in the face of healthcare challenges including end-of-life care. Dr. Miller feels that we wait too long to surround people with loving attention when they need it the most. We're long overdue for a comprehensive overhaul of the healthcare system and a total rethink around death and disease.



BJ Miller, MD, Co-Founder, Mettle Health

You had an experience early in life where you came close to death that shaped your career. Will you share the story?

When I was 19 and in college, I was horsing around on top of a commuter train one day. I had a metal watch on my left wrist, and when I stood up on top of the train, the electricity from the cables overhead arced to the watch. That was it. I got large electrical burns and nearly died. I ultimately lost my left arm below the elbow and both legs below the knees, but I survived.

How did this experience change the way you think about death?

At 19, I was aware that we all die. We all know that fact, intellectually, but knowing that in your bones and feeling life hanging by a thread—that was new to me. Experiencing that feeling was powerful—it opened me up, helped me sense the connections between me and everything else and how much I needed people to help me survive. It gave me a more nuanced appreciation for life and others.

This experience helped me see the world beyond intellectual and cerebral orientations. I wanted to learn from the experience and let it shape me—not just overcome it or put it behind me as some people would suggest that we do with a negative experience or disability. No, the experience was too fertile and rich, I decided to use it as grist, as a sort of nucleus to grow from.

Why choose medicine and specialize in hospice and palliative care?

Medicine saved my life. It is amazing what humans can do in the name of medicine. I felt some indebtedness to the field. But I was also aware of the weaknesses of our medical model. I found it fascinating.

To be honest, a career in medicine also seemed like a very high bar at that stage in my recovery, but it motivated me. When you're living with illness or disability, you see how the world reacts to you and treats you. The pity stuff can diminish your sense of self. If you take the bait of being special, you also take the bait that removes you from the flow of normal life and pulls you to the side.

At that point, the world didn't expect much of me except for maybe that I could get to the bathroom and back. I had a pass. It was appealing to me not to take it and choose something more extraordinary.

During your recovery, did you notice gaps or opportunities for improving this field of medicine?

From the beginning, it was so clear that besides medical technique and technology, it was in the relationships where healing happened. Not just with my doctors, but the nurses and, perhaps most poignantly, the burn techs, who have the ridiculously difficult job of debriding burns—causing so much pain to help someone survive. But relationships are afterthoughts in medicine, and it was very obvious to me that this was a problem. Medicine is not set up to honor relationships.

Another issue was our fixation on curing and fixing folks. Fixing things is beautiful, when it's possible. The problem is that

it's not always possible. For everybody, eventually, it's impossible. If you solely focus on fixing someone, you will abandon them when they're no longer fixable. I have watched that as someone who lives with disability—something that wasn't fixable in a way.

I watched how my dynamic with others changed as I moved through the healthcare system. Sometimes, I got second-class treatment, and people would avoid eye contact. I became an object and almost a projection of shame and failing. That is a terrible banner to operate under.

It became clear that beauty as a therapeutic mode is dramatically underappreciated in the medical world. I don't mean prettiness, but beauty like truth incarnate, the environment of care, how we treat each other and tend to our physical settings. That aesthetic domain was very attractive to me. I wanted to help make that a part of normal care.

You've counseled thousands of people at the end of life. What do the dying teach us about living?

First, there's a great book by Frank Ostaseski called [*The Five Invitations*](#). One of my favorite ideas that Frank mentions is: welcome everything and push away nothing.

Many of us move through life with a version of loving life that is very critical. We say: "I'll love life if this happens," or "I'll love myself if I do these things." We place lines between good and bad stuff, things we want or hate. But then you watch someone in a cascade of loss with everything falling away. Everything must go, even the parts of themselves they wish had been different. When it's about to go, people realize they kind of love that stuff, too.

So one big lesson is to aim for a more expansive idea of love, one that does not pick and choose or hold love hostage. A corollary of that would be to craft our views of ourselves in the world that includes every piece of us. It's like intrapersonal DEI (i.e., diversity, equity and inclusion)—welcoming every nook and cranny of your experience. That is a big, beautiful lesson that I see happen when people die. It's not a choice. It's because you have to say goodbye to everything. You realize that even pain has its place. Even the parts of you that you hated have a place.

We should also cultivate a more expansive notion of life that includes death. The rest of us, who are often unwashed by this stuff, buy into this idea that life and death are opposed. That's a heavily reduced notion of reality. Nature shows us this constantly, but we just ignore it. We are all living and dying at the same time.

**"Life includes death. They are inseparable.
Try to separate them, and you will hurt yourself and others."**

We are all connected. You could label that as something spiritual, but science can prove it too.

Understanding this, you think in terms of ecosystems and community. How does my own death affect my doctors or my family or others? You see relationships as alive compared to this ridiculous notion of the self as this autonomous thing in a vacuum.

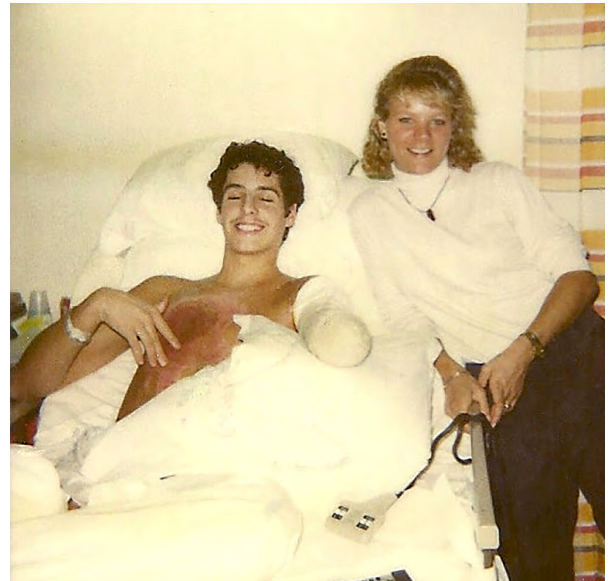
Do you have any advice for navigating health challenges or facing death?

If you read the definition of palliative care, you might ask, "Why is that a specialty? Aren't all doctors concerned with quality of life?" No, they're not. The healthcare system is wired for acute and curative care. Everything else is treated like a sort of stepchild.

You cannot rely on your doctor anymore to know you very well. Your doctors may change every week. You have to make sure to be known to them. You have to advocate for yourself. That's a tough pill to swallow when you're sick. But you shouldn't move passively through the healthcare system.

All the defaults in the healthcare system are heading towards the intensive care unit where you will be propped up by machines. If you don't upend those defaults, that is what is waiting for you. So this means doing your advanced care planning and directives—talking with your family and doctor about what's important to you.

If you're waiting for doctors to say: "There are no more treatments, go on to hospice," it won't happen. There's almost always something more that can be done. You cannot rely on the medical system to have your best interests at heart: not because it is a malevolent system, but because it's no longer smart or nimble. It's overwrought. You need to appreciate that as you plan your care.



Dr. Miller during his recovery from his near-death experience in January 1991 that influenced his choice to become a doctor and a hospice and palliative care specialist

It's helpful to tease out necessary suffering from unnecessary suffering. It's one thing to accept the pain that comes with being alive. Some suffering is normal and part of the deal. That's different from the pain that we make up with short-sighted systems that don't serve people well or include the reality that people experience. We can take a more nuanced view of pain asking: "What do I need to accept, and what can I push back on?"

If necessary suffering befalls us, thanks to nature, that begs acceptance. However, the suffering that we're creating and heaping on each other and ourselves begs activism to create something better. When you become aware of health care's unnecessary ills and where it accidentally hurts people, those become unforgivable, because it's a man-made invention. We can create something smarter and wiser. And the fact that we don't feel sadistic, uncaring, unloving and thoughtless.

What should people understand about hospice or palliative medicine?

Hospice and palliative care are poorly understood. Hospice is a form of palliative care that is reserved for the final months of life and tends to people's quality of life. The focus can feel like it is on death even though the mandate of the two fields is the same: The idea is to live well until you die. We're not "death happy." It's just that death happens, therefore we deal with it.

Hospice emerged in the 1970s. Medicare named hospice a benefit in the 1980s outlining that people need to have six months or less to live and must give up curative-intended care to get it. But we don't know when we have six months left. There are also many reasons to keep treating your illness while welcoming the eventual end. These false barriers end up causing problems. In the 1990s, palliative care stepped into that vacuum and removed the six-month timeline.

"The field asked: 'Why wait until people are dying to surround them with loving attention?'"

Since 2006, the specialty has been called hospice and palliative medicine. You need to be dying pretty soon to get hospice but not palliative care. You can receive palliative care even while you're fighting your illness or have years to live. That's an important distinction.

I'd encourage everyone to get clear on what palliative care is and to ask for it. The earlier, the better. Almost uniformly, people wait way too long to add this kind of care into the mix.

Why is this area of medicine not often at the forefront of discussions about public health crises?

One theory goes back to the mid-19th century when medicine got into bed with the scientific method and innovation. Through our big brains, we labeled illness and death as problems and went to war with them. We were going to beat them. We went to war with death, which is like going to war with life, which is going to war with yourself.

That's been the dominant thinking for the last 170 years. But that means that when humans, in our arrogance, realize that death still comes no matter what and we can't fix everything, death becomes a failure. We didn't try hard enough, or we quit. We throw horrible language around this eventuality that happens to all of us and make it feel like it's optional. If you're dying, that's on you because you didn't eat enough broccoli or have the right attitude.

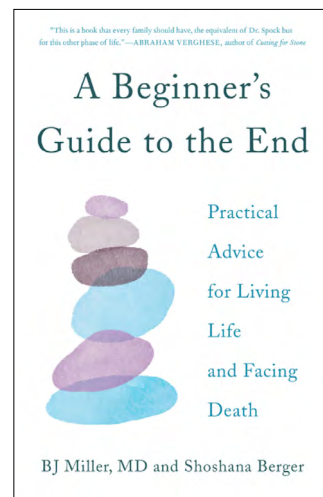
Buying into this notion that humans can fix any problem is very seductive. But it's led to the shaming and bastardizing of normal events like illness, disability and death.

In modern life, we also curate our experience so much. We've gotten further away from nature and its cycles. We don't live on farms or with multiple generations. Aging and death are isolated now. We're surprised to learn that we die. This was not the case pre-mid-19th century.

Death has become a shameful act that we're inexperienced with because we rammed it into a closet. A lot of us are trying to shed light on it now, so we don't have to be ashamed just because we die.

What trends are you seeing in hospice and palliative medicine? What are the major barriers people face when trying to access quality care?

It's becoming obvious to patients and clinicians that the system is broken. Navigating health care is a pretty miserable experience, whether you're a patient, family member, doctor or nurse. There's some hope that by reaching logical conclusions to this curative mindset, we will see a terminus of that thinking. This could force us to reimagine health care, rather than put another piece of duct tape on a system that has ceased to have a coherent design; it's just a fix on a fix on a fix. I'm hopeful that we're going to examine the entirety of the system, especially since the aging baby boomers are demanding different care.



Dr. Miller published [A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death](#) in 2019, which is an all-encompassing action plan for the end of life



HOSPICE VS PALLIATIVE CARE



Pain, symptom and stress management of serious illness with life expectancy of 6-months meant to alleviate suffering of patients and their caregivers.	Focus	Pain, symptom and stress management of serious illness while working with primary treatment meant to alleviate suffering of patients and their caregivers.
Serious illness/terminal prognosis measured in months.	Illness Status	Serious illness, regardless of life expectancy or prognosis.
No	Continuation of Curative Treatments	Yes
Pain and symptom management, 24-hour on-call service, in-person visits, medical equipment, related medications, inpatient care, continuous care in the home, respite care, volunteer services, spiritual care, bereavement and counseling services.	Types of Services	Pain and symptom management, in-person and telephonic visits, help navigating treatment options, advance care planning and referrals to community resources.
Home, Hospice Facility, Skilled Nursing Facility, Long-term Care Facility, Assisted Living Facility, Hospital (inpatient levels of care only), Group Home.	Locations of Services Provided	Home, Hospice Facility, Skilled Nursing Facility, Long-term Care Facility, Long-term Acute Care Facility, Assisted Living Facility, Hospital, Group Home, Clinics.
Physicians, nurses, social workers, chaplains, hospice aides and others in collaboration with the attending physician.	Service Providers	Physicians, nurses, social workers, chaplains and others in collaboration with the attending physician.
State Licensed and/or Medicare-certified Hospice Providers, Non-Medicare Certified Hospice Providers, Veteran Affairs Hospice.	Healthcare Organizations	Licensed Home Health Agencies, Licensed Hospice Agencies, Nursing Facilities, Healthcare Clinics, Hospitals.
As long as the patient meets Medicare, Medicaid or their private insurer's criteria for hospice care.	Length of Services	Not time limited. Depends on patient care needs and the coverage they have through Medicare, Medicaid or private insurance.
Medicare Hospice Benefit pays all costs related to a terminal diagnosis. In most states Medicaid pays all costs related to a terminal diagnosis. Some medications, services and/or equipment are not included. Most private insurers pay all related costs. Some medications, services and/or equipment may not be included in the individual's policy and may be subject to co-pay.	Payment	Covered through Medicare Part B, Medicaid and included as a covered service by most private insurers. Each payer is different. Some treatments and medications may not be covered and may be subject to co-pay.

An overview of the differences between hospice and palliative care outlined by The National Hospice and Palliative Care Organization representing U.S. hospice and palliative care providers in more detail at bit.ly/HospiceOrPalliativeCare

I'm also hopeful that society won't wait for medicine anymore. We see this in local efforts like death cafes where people care for each other and don't wait for the medical system to do it.

We're seeing a democratization of health, tech and non-doctorly players getting involved, as well as huge amounts of money pouring into integrative and alternative modes of care. Language and popular culture are starting to reflect the realities of humans aging and dying.

Within hospice and palliative care, we're seeing more acceptance, which is great. But medical system machinery has chewed us up, too. Now, palliative care visits are often only 15 minutes long. We thought we were going to change health care. But in fact, health care is often changing the field. So it's on hospice and palliative care as a community to fight that reduction.

We will see more social services, more of a focus on social determinants of health and more conversations around quality of life, not just quantity of life. I expect that the public will drive these conversations more than the medical community.

What will it take, in a practical sense, to make the changes you hope for a reality?

First, how we train clinicians is out of date. The last federal review of medical education and training was in 1910 with the Abraham Flexner Report, so that's the first piece.

The second piece of this puzzle is our health policy, which is also slowly changing. There are over 50 million unpaid caregivers in this country. The policies around family and medical leave need to be revisited, as well as how we pay for care and caregiving. We need to honor that work.

Third, it's on us, as human beings, to be self-aware and not outsource all our problems to others, not even our doctors. If you look at yourself, you see a piece of nature. Nature does many things. Nature falls apart. Nature dies. It's on us, as a society, to realize our interdependence. We need to start caring for each other differently.

The fourth piece of the puzzle is infrastructure: communications networks, technology and adaptive equipment that's beautiful and user-friendly. New hospitals, hospice houses and adult daycare facilities. Virtual care has its limits. We need to find ways to be together in-person again. That's where a lot of healing happens. I would love to see that every town or

municipality has a hospice house at the center that says: "We care about this issue. We built a beautiful house—someplace you'd want to be."

What inspired you to start [Mettle Health](#)? And how is the model helping reshape people's experiences when they're dealing with health challenges?

My partner, Sonya Dolan, and I started Mettle Health in 2020. The pandemic helped us all realize that we are mortal. Using telehealth, we wanted to give people a safe place to fall apart and someone to talk to in the throes of illness, disability and dying.

We started Mettle Health to make palliative care more accessible. To do so, we took on a counseling and coaching model and pulled it out of the medical model. I'm a physician, but if you're my patient at Mettle Health, I'm not becoming your doctor or prescribing medicines. I'm using my experiences as a doctor to coach you through navigating health care, to help you use the medical system wisely, instead of it using you.

We could talk about changing health care on a grand scale, but that's not going to happen in the timeframe of someone's illness. As subpar and problematic as the system may be, it's what we have to work with.

So Mettle Health is a savvy way to help people navigate systems and cope with the realities of illness. We tend to all the existential and spiritual dimensions that don't fit into a typical doctor visit. We don't have an electronic medical record, so I'm not typing into a computer when I'm talking to my patient. I'm not limited to 15 minutes with them.

I don't have to hide behind my white coat and stethoscope. I can share with my patients or offer opinions. We can talk as two human beings. It's been beautiful to see. This approach allows us to de-pathologize very normal human events.

What lessons from hospice and palliative care apply to other medical specialties?

The rest of medicine can take a more expansive view of healing. It's the idea of caring beyond the cure: seeing each other through even to endpoints that we wish weren't the case. That's not something to be ashamed of; that's something to love. That means not seeing ourselves as failures for being unable to do impossible things and cure people at any stage of illness.

Sometimes, as a crusader for hospice and palliative care, I find myself pitted against aggressive, intensive or invasive care. But in fact, I'm really not. There's a time and a place for that, too. For those in palliative care, let's fix what's fixable. I'm not against fixing things. But my request is to not be seduced into thinking that it is all there is.

We can all take an approach that includes curing and caring. Don't think that you have to choose. We can get to a much more nuanced, savvy and nimble mode of care.

What is your ultimate vision for the field? When can we expect to see that vision come to life?

Hospice and palliative care is a correction of a system that lost its way and became out of touch with what actually matters in human life. Health care was hurting too many people. So this little subspecialty came along with the notion that people's experiences matter. Our feelings matter. Our families matter.

So if you see hospice and palliative care as corrective, maybe someday our work will help health care change positively to become a vital, constructive tool in the world, not one that's accidentally causing harm or leaving people out. If medicine can heal itself and learn, then hospice and palliative care would go away. I would love to see the moment where these modes of care are integrated as they should be.

Right now, that idea is mostly fantasy. I don't think I'll see that in my lifetime. But who knows? We've been knocking on this door for decades. Sometimes change is incremental. But sometimes something breaks through the resistance, and the whole thing shifts rapidly. Maybe there has been enough unnecessary heartache that the door will finally just fly open one day.

I have hope. I go to work every day convinced that the changes we're talking about are possible. I just don't know when we'll see them.

This interview has been edited for length and clarity.



Dr. Miller speaking at Howard Center, a facility focused on providing support and services to address mental health, substance use and developmental needs



The Battle Against the Fungal Apocalypse Is Just Beginning

[Wired](#), August 2023

C. auris has invaded health care in dozens of countries, and other fungal infections have also surged. During the COVID-19 pandemic, India experienced tens of thousands of cases of mucormycosis. *Emergomyces*, a newly identified genus, is causing infections worldwide, most severely in Africa. Fungi are on the move, with endemic types like Valley fever, histoplasmosis and blastomycosis causing infections in a vast range. Research shows that these fungi are adapting to their new homes, and changes in temperature and precipitation patterns may be a part of this. Climate change has also been linked to the spread. Understanding fungi's changing behavior is an opportunity to identify more people in danger and improve outcomes.



The Food Industry Pays 'Influencer' Dietitians To Shape Your Eating Habits

[The Washington Post](#), September 2023

The World Health Organization (WHO) has raised concerns about the risks of artificial sweeteners, leading to a coordinated campaign by American Beverage, a trade and lobbying group representing Coca-Cola, PepsiCo and other companies. The campaign involved at least 35 posts from a dozen health professionals, who were paid to post videos to help blunt the WHO's announcement that aspartame is ineffective for weight loss and potentially carcinogenic. The analysis of thousands of posts found that companies and industry groups paid dietitians for content that encouraged viewers on Instagram and TikTok to eat candy and ice cream and downplayed the health risks of highly processed foods.



Rules To Keep AI in Check: Nations Carve Different Paths for Tech Regulation

[Nature](#), August 2023

After two years of debate, the European Union is set to pass its first broad AI laws this year. China already has AI regulations in place, but people still dispute what needs reining in, how risky AI is and what needs to be restricted. OpenAI and other firms have called for more oversight but have resisted some of the EU's proposed controls and advocated for international guidance bodies and voluntary commitments. Matthew Hutson reports that companies that violate rules could be fined 7% of their annual global profits, with about two years to comply after the act comes into force. The U.S. lacks broad federal AI-related laws and significant data-protection rules, while some U.S. states and cities already have their own AI-related rules.



Global and Regional Estimates of Genital Human Papillomavirus Prevalence Among Men: A Systematic Review and Meta-Analysis

[The Lancet Global Health](#), September 2023

A study published in *The Lancet Global Health* reveals that about 1 in 3 men (31%) over the age of 15 are infected with at least one genital human papillomavirus (HPV) type, with 1 in 5 (21%) infected with high-risk HPV types, reaching a maximum between 25 and 29 years. HPV infections are asymptomatic but can lead to long-term complications and mortality. In men, HPV infection manifests as anogenital warts, increasing transmission rates and causing significant morbidity. Considering the success of HPV vaccination roll-out for girls and young women in some countries, some countries are beginning to vaccinate boys. Future epidemiological studies are needed to monitor HPV prevalence trends in men.



MDMA Therapy Inches Closer to Approval

[The New York Times](#), September 2023

A study published in *Nature Medicine* suggests that MDMA-assisted therapy is effective in reducing symptoms of post-traumatic stress disorder (PTSD). Participants who received MDMA experienced significantly greater reductions in their PTSD symptoms compared to those who received a placebo. The study found that MDMA-assisted therapy was generally well-tolerated, with side effects including muscle tightness, nausea, decreased appetite and sweating. However, some participants experienced serious suicidal ideation and cardiovascular issues. MAPS Public Benefit Corporation is now working on a follow-up study examining the long-term durability of the effects of MDMA-assisted therapy and plans to submit a New Drug Application to the U.S. Food and Drug Administration seeking approval for the therapy.



Everything We Know About Neuralink's Brain Implant Trial

[Wired](#), September 2023

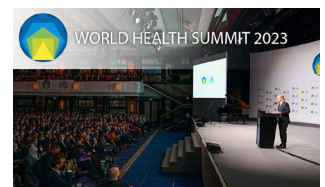
Neuralink, Elon Musk's brain implant company, is one step closer to putting brain implants in people. Patients with paralysis are being recruited to test the experimental brain implant for Precise Robotically Implanted Brain-Computer Interface (BCI). The BCI system collects brain signals, analyzes them and translates them into commands to control an external device. The clinical trial will test the safety of the implant and surgical robot and assess the BCI's functionality to "grant people the ability to control a computer cursor or keyboard using their thoughts alone." Neuralink has not revealed the exact region of the brain its device will be embedded in, which hospital has given the institutional review board approval nor how many participants it will ultimately enroll in the study.

Updates & Events

- Congratulations to Manny Ohonme, President and CEO of [Samaritan's Feet International](#), on the distribution of the 10,000,000th pair of shoes this October! Samaritan's Feet International provides shoes to individuals in need in 109 countries to help prevent infections, protect from diseases, provide economic and educational opportunities (by making it possible to attend school and/or work at greater distances) and propel individuals to pursue their dreams.
- The FDA's Center for Biologics Evaluation and Research Office of Therapeutic Products is hosting the RegenMedEd webinar "Warrior Families: Advancing Regenerative Medicine Through Science" on Thursday, October 5 at 11:00 am ET. The event features a panel of parents and caregivers sharing their experiences advocating for loved ones living with rare diseases. Learn more and register at bit.ly/WarriorFamilies
- The World Health Summit 2023 takes place from October 15 to 17 bringing together stakeholders from politics, science, the private sector and civil society from around the world in Berlin, Germany, and online. Held under the theme "A Defining Year for Global Health Action," WHS 2023 plans to set the agenda for a healthier future by inspiring innovative solutions for better health and well-being for all. Sustainability and climate change are key topics of this year's summit. Learn more and register at worldhealthsummit.org
- The STAT Summit occurring in Boston and virtually on October 18 and 19 focuses on the healthcare system. STAT takes a look at the entire healthcare system, incorporating the perspectives of innovators, those on the medical front lines and patients. Executives, scientists, economists and health outcomes researchers will cover topics such as biotech, finance, coronavirus, insurance and regulations. Speakers include Dr. Noubar Afeyan, Michael J. Fox, Dr. Priscilla Chan and Mark Zuckerberg. Learn more and register at statnews.com/2023/summit/stat-summit-2023
- The Prix Galien USA Awards presented by the Galien Foundation take place in New York on October 26. The 2023 Best Prize Categories acknowledging leading-edge scientific advances in life sciences include Pharmaceutical Product, Biotechnology Product, Product for Rare/Orphan Diseases, Medical Technology, Digital Health Solution, Incubator/Accelerator/Equity and Startup.



Manny and Tracie Ohonme in Cape Town, South Africa



Congratulations to Cura community members Dr. Albert Bourla, CEO of Pfizer, for several nominations in Best Pharmaceutical Product and Best Biotechnology Product categories and Steven Error, CEO of Solo-Dex, Inc. nominated in the Best Medical Technology category. Learn more at galienfoundation.org/prix-galien-usa

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