

The Serious Illness & End-of-Life Funders Community

Celebrating Five Years of Learning Together



GRANTMAKERS
IN AGING



SERIOUS ILLNESS
AND END-OF-LIFE
FUNDERS
COMMUNITY

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Introduction

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As the [Serious Illness and End-of-Life Funders Community](#) reaches an important milestone — five years of collaboration in partnership with Grantmakers In Aging (GIA) — it's a fitting moment to celebrate the power of our network. This report details the synergy between funders in the Community and how these ties are fueling and supporting better care for people with serious illness and their caregivers across the country.

Here, you'll find stories of funders learning from each other, drawing inspiration to expand the scope of their work, finding ongoing funding for grantees whom their own portfolios could no longer support, creating opportunities to test and scale up promising practices outside their regions, and catalyzing this dynamic young field. As Dan Tuttle, Director of Health for the Stupski Foundation, puts it, "Because it's such a small funder field, there's a lot of value in being invited to sit at the same table with everybody, because you can learn about them and their priorities quickly."

A VIBRANT AND INFLUENTIAL COMMUNITY

The Community got its start in 2015 when The John A. Hartford Foundation (JAHF), one of the nation's largest philanthropies devoted to improving the care of older adults, gathered a group of funders interested in serious illness and end-of-life care. That convening grew to a monthly conference call, and within two years JAHF began funding GIA to host and cultivate the group.

Additional support for the project has come from the Gordon and Betty Moore Foundation, Stupski Foundation, the Fan Fox and Leslie R. Samuels Foundation, the Y.C. Ho/Helen and Michael Chiang Foundation, St. David's Foundation, The Rita and Alex Hillman Foundation, and the Arthur Vining Davis Foundations.

Today our Community includes more than 30 funders: a mix of small, local, and family foundations and regional and national grantmakers. Member surveys have found that a solid majority credit the Community with enhancing their work, informing their organization's strategic planning, sometimes resulting in new grants, and driving them to explore collaboration.

The success of the Serious Illness and End-of-Life Funders Community has inspired grantmakers to coalesce around other funding priorities. Now, with GIA's help, Funders Communities are working to mobilize social, intellectual, and financial capital for Family Caregiving, Rural Health and Aging, Housing Stability in Aging, Aging and Technology, and Master Plans on Aging.

A PATH TO GREATER IMPACT

Members of our Community have invested hundreds of millions of dollars in the past 25 years to advance the critical mission of improving care for people in their most challenging moments, as they contend with serious illness and, with their families and caregivers, prepare for the end of life.

We hope these case studies and personal reflections will inspire other cooperative funding efforts and encourage more grantmakers to join this important movement.

Emily Baransy Hinsey

*Director of Programs
Grantmakers In Aging*



MEMBER SURVEYS HAVE FOUND THAT A SOLID MAJORITY CREDIT THE COMMUNITY WITH ENHANCING THEIR WORK, INFORMING THEIR ORGANIZATION'S STRATEGIC PLANNING, SOMETIMES RESULTING IN NEW GRANTS, AND DRIVING THEM TO EXPLORE COLLABORATION.



Partnering to Maximize Impact and Catalyze the Field

*The Rita and Alex Hillman Foundation and
The Arthur Vining Davis Foundations*



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There was no way of knowing at the time, but the October 2019 in-person meeting of the Serious Illness and End-of-Life Funders Community would be the last before the COVID-19 pandemic brought an abrupt end to in-person meetings worldwide just a few months later.

As part of the agenda that day, Ahrin Mishan, Executive Director, and Rachael Watman, Vice President of Programs, of the [Rita and Alex Hillman Foundation](#), shared information about the Hillman Emergent Innovation program, which provides early-stage funding to jumpstart promising nursing-driven innovations to improve health and the healthcare of marginalized populations. The grant award was expanded in 2018 to include the Hillman Emergent Innovation: Serious Illness and End of Life program.

“We decided to create a stand-alone Emergent Innovation award in the area of serious illness and end-of-life care because of the need we saw emerging from the field and the pioneering response of nurses. There was also an interest expressed from members of the Funders Community,” Watman recalls.

Listening intently that day were Michael Murray, President and CEO, and Annie Bryan, Senior Program Officer, of the [Arthur Vining Davis Foundations](#). The Florida-based philanthropies — which provided the first grant to the Connecticut Hospice in 1976, helping to spawn the hospice movement in the United States — had renewed their commitment to serious illness and end-of-life care in 2017 with a three-year, invitation-only initiative seeking to improve palliative care nationwide.

That pilot program was winding down, and the Arthur Vining Davis Foundations needed to do an evaluation, which would take about a year, before making recommendations to their board regarding future work in the field.

“We were looking for something that was worth funding in this area, for just one year to start,” Murray says. “So I actually went to that meeting listening to what other foundations were up to and seeing what looked like good opportunities that, by their lights and ours, were undercapitalized.”

‘A REALLY GREAT AREA FOR COLLABORATION’

The Hillman Foundation was planning to invest \$250,000, enough to cover five awards of \$50,000 each, to help accelerate the development of bold, nursing-driven interventions targeting the unmet serious illness and end-of-life needs of marginalized populations, including Black, Indigenous, and People of Color (BIPOC), the economically disadvantaged, LGBTQ+ people, people experiencing homelessness, rural populations, immigrant and refugee populations, and other groups that encounter barriers to receiving quality care.

“I was really blown away by the numbers that they were sharing with us,” Murray says. “What we were seeing was a large number of applications, pretty selective when it came to invitations for full proposals, and even more selective when it came to the number of awards they were able to give — only five.”

Murray was so impressed, he approached Mishan and Watman during a break to get more information, and then continued discussions by phone after the meeting. “We talked about this and a few other



“SO WE CONTACTED THE HILLMAN FOUNDATION, SAID WE THINK THIS PROGRAM THAT YOU GUYS ARE RUNNING IS THE STUFF THAT WE’D LOVE TO PROVIDE SOME SUPPORT, AT LEAST INITIALLY, JUST ON A ONE YEAR BASIS. AND THEY WERE THRILLED.”

opportunities amongst ourselves as a staff, and we thought this looked like a really great area for collaboration,” Murray says.

“Our general posture when it comes to partnerships and collaboration is, if somebody else has got a really good idea, we should go ahead and get behind the idea. We don’t need to come up with something new just to show that we’re smart. We can be smart by finding good ideas and getting behind them,” Murray adds. “So we contacted the Hillman Foundation, said we think this program that you guys are running is the stuff that we’d love to provide some support, at least initially, just on a one year basis. And they were thrilled.”

THINKING ABOUT WHAT’S NEXT

The two foundations began formalizing their partnership in early 2020, and it was announced publicly in November 2020. The Arthur Vining Davis Foundations agreed to invest \$400,000 in the program and made the grant directly to the Hillman Foundation to create a single pool of \$650,000 — enough for up to thirteen \$50,000 grants, instead of the original five.

Although it required jumping through some additional hoops for the two foundations, creating the single pool of money simplified the application process considerably for potential grantees, who no longer had to fill out two different funding requests and two different proposals for two different foundations.

The Arthur Vining Davis Foundations have a seat on the committee vetting applications, which, as Bryan puts it, “also gave us an opportunity to see what was really happening in the field. As a funder who is thinking about what’s next, it’s an interesting way for us to see these people who are on the ground with these new ideas.”

Bryan adds that the partnership between the two foundations not only strengthens the program but — through the Funders Community — can also “potentially catalyze the field to think about how can we all collaborate together to advance these really strong programs.”

“This award has proven both important and timely because of lessons learned during the pandemic about the care of historically oppressed populations with serious illness,” Watman says. “The Arthur Vining Davis Foundations share our long-standing interest in marginalized populations and recognize the disparities in care.”

JOINING FORCES

While the partnership expands the number of grants available to support nursing innovation, it also benefits the foundations and the broader philanthropic community, Watman adds.

“This partnership allows the Arthur Vining Davis and the Hillman Foundation to maximize our overall impact and be more resourceful about the dollars allocated,” she says.

And other philanthropies — particularly those in the Funders Community — benefit by getting “introduced to new ideas that they might not have known about otherwise,” Watman says. “This award lets foundations see ideas percolating in the field. Furthermore, the award uses philanthropic dollars to legitimize nascent work to collect data and build the idea into an evidence-based model of care.”

“I know that we probably wouldn’t have partnered with the Arthur Vining Davis Foundations — we wouldn’t even have really known what they were interested in — had it not been for the Funders Community. For this, we are grateful.”

The Rita **Hillman**
and Alex **Foundation**

AVD The Arthur
Vining Davis
Foundations



Addressing Disparities in Serious Illness and End-of-Life Care

The John A. Hartford Foundation



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It began with a convening organized by [The John A. Hartford Foundation](#) (JAHF) that brought together funders interested in learning more about serious illness and end of life. The convening led to monthly phone calls, offering information and updates about the field. And eventually, the monthly calls led to JAHF's decision to provide funding to Grantmakers In Aging in 2015 to host the Serious Illness and End-of-Life Funders Community.

“It was always a shared endeavor. It is jointly run by all the funders. We take turns running meetings,” says Amy Berman, Senior Program Officer at The John A. Hartford Foundation. “The Funders Community offers a safe place for the participants to share and to learn. It really has been the genesis of many new grants and collaborations between funders doing larger pieces of work that any one funder might not be able to accomplish alone. The Serious Illness and End-of-Life Funders Community has been incredibly important.”

In addition to sharing, learning, and collaborating, Berman credits the Funders Community with playing a role in the Foundation’s decision to make Serious Illness and End of Life one of its three priority areas, along with Age-Friendly Health Systems and Family Caregiving.

“We’ve always made grants in this area because palliative care is an essential component of Age-Friendly Health Systems, and to be listed as a focus area, I think, was in part as a result of the Funders Community and the important partnerships that we were engaged in,” Berman says.

‘IF YOU’RE INTERESTED IN DISPARITIES, SERIOUS ILLNESS CARE IS GROUND ZERO’

As Berman sees it, funding to improve the quality of serious illness and end-of-life care is a fundamental matter of equity.

“When it comes to end-of-life care, we have huge disparities in this country,” Berman says. “There are people who have access to hospice, who know what palliative care is and can access it. Then there are those, especially in communities of color, who have no ability to get the care and services that they need — care that would improve their health outcomes and quality of their lives, help their families, and support them getting through serious or life-limiting illness. This is a tragic disparity that funders can address.”

“It’s important that we make these services more broadly available. These are critical healthcare issues that should be considered by anyone who’s concerned with chronic care, and anyone who’s interested in population health and the social determinants of health — they should include grantmaking to address serious illness and end of life care. Yet some say, ‘Well, that’s not my focus. I’m interested in disparities.’

“Well, if you’re interested in disparities, serious illness care is ground zero.”

A MESSAGING PROBLEM

One of the ways JAHF is working to make quality care for those with serious illness more broadly available is through a communications project called Building Public Engagement and Access to Palliative & End-of-Life Care.

It’s an example of a collaboration that developed through the Funders Community,



“ANYONE WHO’S CONCERNED WITH CHRONIC CARE, ANYONE WHO’S INTERESTED IN POPULATION HEALTH AND THE SOCIAL DETERMINANTS OF HEALTH — THEY SHOULD INCLUDE GRANTMAKING TO ADDRESS SERIOUS ILLNESS AND END OF LIFE CARE.”

as fellow member Cambia Health Foundation joined JAHF in funding the consortium project, which aims to increase the availability of — and public demand for — high-quality palliative care and advance care planning through the development of public messaging resources. Launched in 2019 and renewed in 2022, the project also seeks to foster collaboration and the scaling of innovative programs that improve serious illness and end-of-life care.

The project is led by Anthony Back, MD, co-director of the University of Washington Center for Excellence in Palliative Care and co-founder of VitalTalk, a national nonprofit that provides evidence-based clinician and faculty development courses to improve communication skills on an individual and institutional level.

“We are addressing a problem where the public doesn’t understand what palliative care is, so they don’t ask for it,” Berman says. “Some misconstrue palliative care, not understanding the benefits. It is an extra layer of support that goes along with the care you already receive for serious illness. It helps people manage the pain and symptoms associated with serious illness, and the palliative care team coordinates care, provides support for the family, and even offers spiritual care — all of the things that you would want if you were seriously ill.

“What’s interesting to me is that, if you use the wrong messages, you can essentially not just close a door to better care, but deadbolt it,” she adds. “Research has shown that some healthcare providers would talk about palliative care and conflate it with dying. In fact, when offered earlier, palliative care really helps people live well with serious illness.”

The project is working with national organizations related to serious illness care to review their communications and determine, “how we use an evidence-based message framework to shape information and better address the needs of different communities and people of color, thereby

increasing access. Our aim is to spread messages that resonate and help people get access to the good care that they might want, but don’t yet know that it exists.”

RESPONDING TO THE PANDEMIC

As the COVID-19 global pandemic surged in 2020, The John A. Hartford Foundation, along with many other foundations, initiated new grants to meet the critical needs that arose. One example was the need for palliative care training resources to help overwhelmed clinicians deal with the difficult conversations they suddenly needed to have with large numbers of patients and their families.

Foundations, including JAHF, stepped up to fund the creation of new COVID-specific resources and make them widely available.

“A lot of the grantees that we work with and support developed new tools specific to the pandemic and held webinars and office hours specifically to provide technical assistance to people all around the country to help them learn what they needed to fill that critical gap,” Berman says.

“Some of these resources typically would only have been available to paying members of the Center to Advance Palliative Care (CAPC). However, these pandemic-focused resources were all offered free. Without the support of foundations, that would not have been possible. Foundations are in a position to help address critical needs over the long term and critical needs that are immediate. This Community helps to inform funders about the opportunities and helps us forge the relationships so that we can address them together.”

MOVING CLOSER TO THE TIPPING POINT

Another way JAHF has advanced knowledge and competency around palliative care is through The John A. Hartford Foundation Tipping Point Challenge, run by CAPC. The challenge is the cornerstone of a five-year

campaign aimed at creating a tipping point in the improvement of care delivered to millions of Americans living with a serious illness.

There have been two rounds so far of the innovation and quality improvement challenge to spread palliative care skills among all clinicians.

The first round of competition in 2020 recognized achievements of sites such as those that had the most staff complete online palliative care courses offered by CAPC. “I do believe that this tipping point challenge had a real impact in moving the needle on competency, not just of the palliative care experts, but of the primary care clinicians, oncologists and other specialists caring for the seriously ill,” Berman says.

The second round, in 2021, “focused on awarding places that developed innovations that were poised to scale and spread palliative care and other serious illness approaches,” Berman says. The competition highlights and showcases innovative approaches that other funders can then take up and spread around the country, she adds.

‘OUR WORK IS MORE EFFECTIVE WHEN WE DO IT TOGETHER’

Berman says The John A. Hartford Foundation is grateful to GIA for their management and continued growth of the Funders Community. “It’s a vital role,” she says. “This is a critical area and we’re keenly appreciative of their support.”

Berman encourages grantmakers who don’t currently fund in serious illness and end-of-life care to consider joining the effort to address the gaps and disparities that exist.

“This is a great time to join because the field is ripe for support,” she says. “We have learned that our work is more effective when we do it together. That’s the purpose of this funders group — that we find ways that we can partner with others so together we can improve the care of people and families experiencing serious illness. This work should be top of mind in the pandemic, but the needs will be great long after COVID-19.”



The
John A. Hartford
Foundation



Finding Strength in Collaboration

California Health Care Foundation



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For the [California Health Care Foundation](#) (CHCF), the concept of collaboration takes on several different meanings as a member of Grantmakers In Aging's Serious Illness and End-of-Life Funders Community.

“It really has been a wonderful way to develop relationships with other people who are trying to make change in some of the same areas that we’re trying to make change and learning about how they’re approaching problems, learning about what’s important to them as funders, and learning about the kinds of organizations that they are working with as grantees and as partners,” says Kate Meyers, a Senior Program Officer at CHCF.

The group’s bi-monthly conference calls, and the in-person annual meetings that occurred before the COVID-19 pandemic provide valuable opportunities to learn from not only other members, but outside experts as well.

“We’ve had the opportunity in our web meetings to have external speakers come, for example, and sometimes those are grantees of someone on the call and sometimes they may not be, but they might have something that we should learn about,” Meyers says. “That’s been an opportunity to learn not just from the people who are part of the cooperative, but from the people that those groups are connected to.”

Those interactions have opened the door to informal networking and collaboration, she says. “For example, it’s so helpful to be able to just pick up the phone or send an email to people when I might hear about something that may not be a great fit for CHCF as a project, but sounds like it might be of interest to another organization based on something I heard on an earlier call.”

Then there are formal partnerships that emerge from engaging with other funders interested in serious illness and end-of-life care.

“At CHCF, we’re always interested in what approach can help have the greatest impact on the problem we’re trying to address or the situation we’re trying to improve,” Meyers says. “Sometimes, that’s through collaborating with other funder organizations so that each organization can

bring their separate resources to bear and those can be pooled toward a common goal.

“As a state-based foundation, sometimes there needs to be an attempt to find a kind of sweet spot or area of overlap with a foundation that might be national in focus or a foundation that might be local in focus, smaller than state level,” she adds. “We’ve had success with both those approaches.”

‘A STRATEGIC SHARPENING’

In addition to serious illness and end-of-life care, the Foundation makes grants in areas ranging from behavioral health to health equity to maternal health to telehealth.

When CHCF first started funding in serious illness and end-of-life care around 2007, the focus was primarily on expanding equitable in-patient palliative care services in California’s public hospitals and on implementing physician orders for life-sustaining treatment, known as POLST, in the state. But over the years, as the field has shifted from an emphasis on inpatient to outpatient care, CHCF focused increasingly on community-based palliative care in people’s homes, clinics, and other settings.

Two decisions — one internal, the other external — have led to a further evolution of the Foundation’s work in the field.

In 2017, CHCF made what Meyers calls “a strategic sharpening” of its grantmaking to focus on Californians with low incomes and on Medi-Cal, the state’s Medicaid program. “While that had always been a part of our work, it became the core of our work.”

The following year a new state law took effect requiring Medi-Cal to provide palliative care services to enrollees with certain serious illnesses, making California the first state in the nation with such a requirement.

The Foundation has worked to help Medi-Cal managed care plans and community-based palliative care providers implement required

services through technical assistance, peer learning, and bringing in experts to consult on specific challenges with individual plans or to provide broader education and opportunities on a statewide or regional basis.

However, the Foundation has also learned that having services and payment mechanisms in place for palliative care is not enough.

“There is still such misunderstanding and confusion about what palliative care is, and who it’s for and when it’s appropriate, that simply having provider organizations in the community and having a health plan that will pay for the services doesn’t mean that the people who are eligible for those services will receive them,” Meyers says. “Because there are still a lot of people who have no idea what palliative care is, including physicians, and patients and their families.”



“THERE ARE STILL A LOT OF PEOPLE WHO HAVE NO IDEA WHAT PALLIATIVE CARE IS, INCLUDING PHYSICIANS, AND PATIENTS AND THEIR FAMILIES.”

ADDRESSING MISUNDERSTANDING AND CONFUSION

The Foundation commissioned a statewide survey in 2019, titled *Help Wanted: Californians’ Views and Experiences of Serious Illness and End-of-Life Care*, to better understand the type of medical care and services Californians would prefer to receive if they had a serious illness or if they were approaching the end of life, and to explore the experiences of those actually dealing with these issues themselves or with loved ones.

Among the key findings was that, when palliative care was described to them, nine in 10 Californians without a serious illness said they would want this type of care if they had a serious illness. But only four in 10 of those with a serious illness said they receive this type of help.

The survey highlighted a Catch-22 for Californians with low incomes in particular, Meyers says: “Interest in the kinds of supports that are provided by palliative

care were highest among people with low incomes. However, awareness about the phrase ‘palliative care’ was lowest among that group.”

The survey also highlighted that people across income groups and across racial and ethnic groups are open to having conversations with health care professionals about the kind of care they want during serious illness or at end of life.

“I think that also makes the case for building skills, not just in the palliative care field, but the skills of all providers who work with people with serious illness, to do some of the basic elements of talking with people about their prognosis in clear and consistent ways, about their goals of care and what’s most important to them, and what worries and troubles them.”

In response, the Foundation is “trying to grow the field of people who have different levels of palliative care skills,” Meyers says, from primary care physicians to specialists in fields ranging from emergency

departments to radiation oncology, to cardiology nurses, among others.

Meyers encourages other funders who may not have considered grantmaking in serious illness and end-of-life to how it might fit into their work.

“Today’s healthcare system is very good at providing interventions aimed at curing disease or prolonging life,” Meyers says. “It is not very good at helping people with serious illnesses cope with what they’re going through. It is not very good at making sure people with serious illnesses feel as good as possible while undergoing treatments. It is not very good at making sure the interventions people are offered will actually get them the kind of outcomes that are most important to them. Those are the gaps that palliative care fills.”

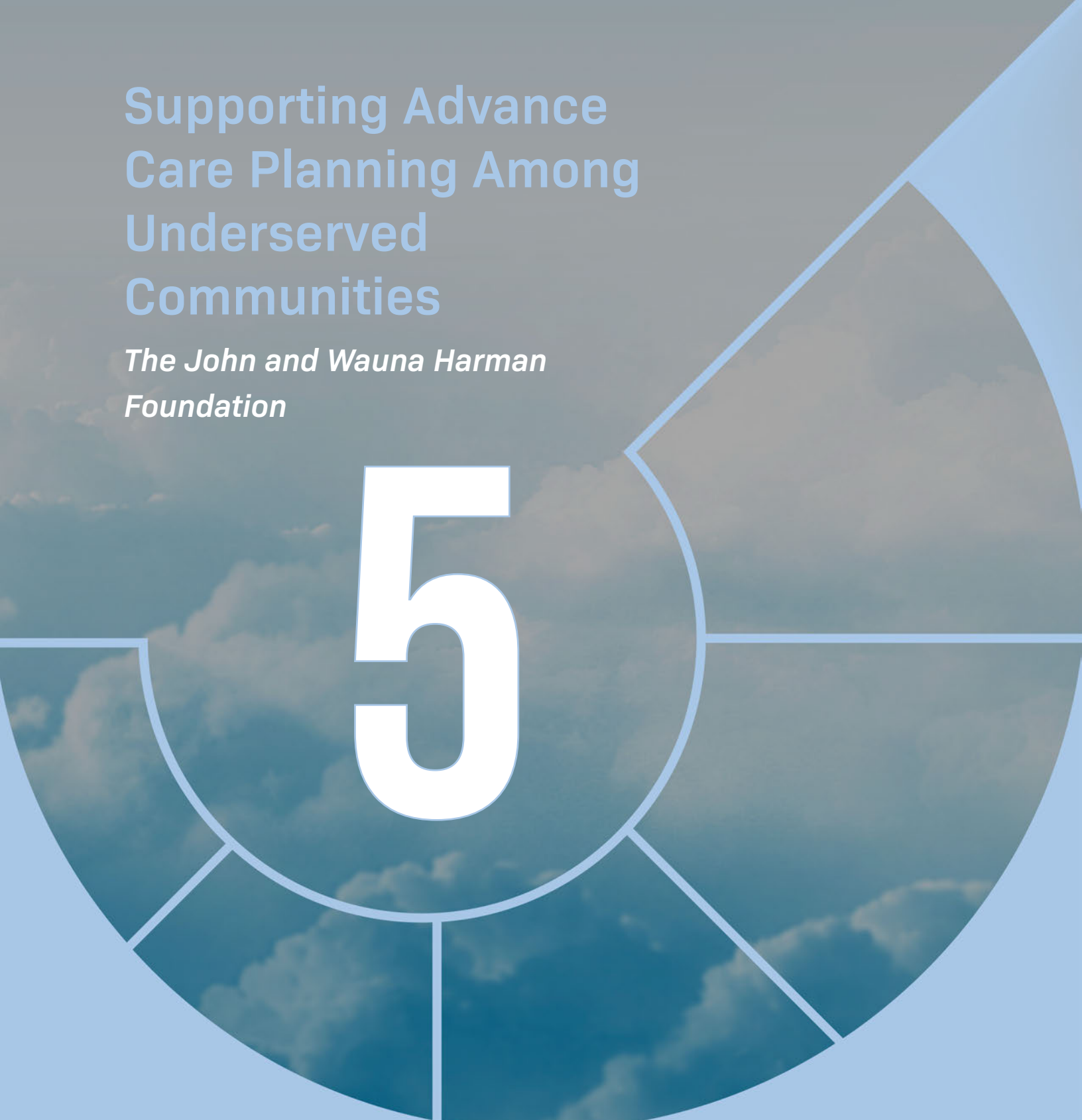


California Health Care Foundation



Supporting Advance Care Planning Among Underserved Communities

*The John and Wauna Harman
Foundation*



5

As a small, private family foundation, the John and Wauna Harman Foundation has benefited from its involvement with GIA's Serious Illness and End-of-Life Funders Community as it more strategically targets its grantmaking to underserved communities.

“In the very beginning, we wanted to see what was being done by the bigger funders so that we could situate our work within that context,” says Julie Boudreau, Executive Director of the foundation. “And often, there’s this little sliver of the puzzle that’s missing.”

The Alameda County Care Alliance Advanced Illness Care Program in California is a good example. The program predominantly serves African American adults with advanced illness and their caregivers, in alignment with their spiritual and religious values. It provides training for faith leaders to counsel congregants, as well as community care navigators and caregivers to support those dealing with advanced illness. The program, which is now in 14 African American churches in Alameda County and Contra Costa County, bridges the gap between health delivery systems, community organizations, and faith-based communities.

The Foundation awarded a \$25,000 grant specifically to support one part of the program’s work: training care navigators, who help identify and make referrals to local community resources, in advance care planning conversations. A subsequent \$15,000 grant supports development of the script for an end-of-life training video for use with faith leaders.

“They’ve been supported by many much larger entities, but we’re able to find that spot where our support makes sense at a scale that is both meaningful to them for a particular tool that needs development and also aligns with our mission,” Boudreau says.

WORKING WITH FAITH COMMUNITIES TO PROMOTE ADVANCE CARE PLANNING

The John and Wauna Harman Foundation has been exclusively focused for more than a decade on encouraging Americans of all backgrounds to have meaningful conversations about what matters most to them so they can have a say in their care when the end of life approaches. “Over time,” Boudreau says, “it became obvious that traditional advance care planning messages and approaches were not a fit for many groups and populations in the United States.”

They also found that too many organizations promoting advance care planning had not made a real effort to earn trust from underserved communities, especially African American communities.

To address the question of trustworthiness, the Foundation partnered in 2017 with Richard Payne, MD, an internationally renowned expert in neurology, oncology, pain management, palliative care, and bioethics, who was on the faculty at Duke Divinity School and the Center for Practical Bioethics, to lead a convening.

The gathering brought together clinicians, researchers, and faith leaders to explore the state of advance care planning among African Americans in the U.S. and how the historical foundation of trust between African Americans and churches could help address disparities in care.



“OVER TIME IT BECAME OBVIOUS THAT TRADITIONAL ADVANCE CARE PLANNING MESSAGES AND APPROACHES WERE NOT A FIT FOR MANY GROUPS AND POPULATIONS IN THE UNITED STATES.”

A \$330,000 Foundation grant to the Center for Practical Bioethics helped Dr. Payne establish a cohesive, national network of African American leaders, including ministers and others in faith communities, to host local events and do local education to encourage advance care planning.

Sadly, the death of Dr. Payne in 2019 and the COVID-19 pandemic have made implementation of the vision that came out of the convening more challenging. However, local event hosts have pivoted beautifully to virtual platforms, in the process expanding the ways in which congregations can be engaged in this important life activity.

STRAIGHT FROM THE HEART

Two other examples of projects the Foundation has funded further illustrate how the work has adapted and carried on.

Gloria Thomas Anderson, PhD, LMSW, literally wrote the book on advance care planning for African Americans: it is called *The African-American Spiritual and Ethical Guide to End-of-Life Care*. The Harman Foundation is partnering with Anderson's company, Heart Tones, and with Montgomery County Hospice in Maryland, which uses Anderson's guide for training purposes, to expand the guide's reach.

An original \$20,000 grant supported updating the guide, which was first published in 2006, and a companion training with information related to COVID-19. With the pandemic moving so much of the world online, a subsequent \$75,000 grant is now supporting adaptation of Anderson's book, which has been used for in-person training of faith leaders and others for years, for use in virtual settings. The grant also supports podcasts, webinars, and a new dedicated website, as well as a social media campaign to get the word out.

"People also will now have the opportunity to go online and actually do the process

themselves," Boudreau says. "We're excited about that because while there are several tools for people in general to go online and walk themselves through the advance care directive process, this will be the first time it's been presented specifically for an African American person within a faith context."

SAY HELLO

A pair of Foundation grants totaling \$320,000 funded a pilot project partnership between Lauren Van Scoy, MD, at Penn State and the Hospice Foundation of America that brought African American community members together to play a card game called "Hello." The game helps people "discuss in a comfortable and familiar social environment and setting their thoughts about end of life and end-of-life care," Boudreau says.

Reflecting the successful outcomes of this grant, Van Scoy's write-up of the pilot results was accepted for publication on the JAMA Open Network in 2020. As conveyed in that report: "Among a nationwide sample of African American individuals, the end-of-life conversation game appeared to be well received and was associated with high rates of (advance care planning) behavior. This low-cost and scalable tool may help reduce health disparities associated with end-of-life care."

Then followed thrilling news for a small foundation: In September of 2020, Dr. Van Scoy, with Hospice Foundation of America as co-investigator, was awarded a \$3.5 million clinical trial research project by the National Institute of Minority and Health Disparities, the first grant awarded by the National Institutes of Health (NIH) for game research related to advance care planning.

"Seeing the great things that can come from modest support and from excellent ideas taking root is so rewarding. It's just one more example of how foundations can act as water for a seed in fertile soil," Boudreau says about the NIH award.

LEARNING TOGETHER

At the end of the Funders Community annual meeting in November 2020, Boudreau helped conduct a survey which found that the highest-rated part of the experience was learning from other members.

“We do a lot of learning together in the Community, which I really value,” she says. “We each have different experts within our networks and we can bring those folks forward. We’ve developed relationships. I appreciate all of the meaningful support and content and networking that has happened in a year like 2020. I feel like it made all the difference.”



Spending Down Assets to Make Lasting Impact in Home Communities

Stupski Foundation



6

For the [Stupski Foundation](#), the decision to expand its grantmaking to include serious illness and end-of-life care couldn't have been more personal.

Larry Stupski, a leader in the financial industry who was president and chief operating officer of Charles Schwab for a decade, and his wife Joyce, an educator and entrepreneur, started the foundation in 1996 to transform education nationwide.

But Joyce's experiences caring for Larry over the last decade of his life as he battled prostate cancer led her to a new vision for the Foundation's work, including a new priority area focused on reducing unnecessary suffering at the end of life and ensuring that the wishes of people with serious illnesses are respected and followed. She also centered the Foundation's grantmaking efforts closer to home, on the communities of the San Francisco Bay Area and Hawai'i that she and her late husband loved.

"The really sad thing is, despite some of the best clinicians in the world working with Larry, he suffered more than he needed to through the last chapter of his life," says Dan Tuttle, Director of Health for the Stupski Foundation. "It's heartbreaking to look at it in retrospect, and Joyce's view was, look, we've been tremendously blessed with means, and if we're having this hard a time with our end-of-life care experience, I can only imagine what many others are also going through."

Since Joyce Stupski passed away in July 2021, the board and staff of the Foundation have remained committed to continuing her legacy. One of the reasons she launched the serious illness and end-of-life area was that there weren't many funders in the field nationally. That opening led the Stupski

Foundation to join GIA's Serious Illness and End-of-Life Funders Community.

"Because it's such a small funder field, there's a lot of value in being invited to sit at the same table with everybody because you can learn about them and their priorities quickly," Tuttle says. "There aren't a lot of other issues in philanthropy where that's the case."

LEARNING TO TALK MORE EFFECTIVELY ABOUT A SHARED PROBLEM

One of the main benefits Stupski Foundation has seen from the Community is gaining a clearer, shared understanding about how to talk more effectively about the benefits of palliative care, which is still often confused with hospice in the minds of many, Tuttle says.

"The much better way to talk about this is, it's an additional layer of support medically, emotionally, in terms of your psychosocial needs, some of your social needs overall," he says. "That evolution in being able to describe it in the first place came as a result of a multi-funder collaboration that also included the Center to Advance Palliative Care (CAPC) and [Vital Talk](#)."

"It turns out when you use the right language to describe the impact of being asked for your wishes, having those honored, being respected and making shared decisions, having additional pain management and somebody to check in on that — those are things that everybody wants. So, as one small example, the Funders Community itself was a chance to really amplify the effects of that single



"THE CONVERSATION IS EVOLVING FROM 'HOW DO WE TALK ABOUT THIS AS A FIELD?' TO 'HOW DO WE BETTER TAILOR IT, UNDERSTANDING THE DYNAMICS AND IMPACT OF RACE?'"

partnership and ensure that the small number of us who are in the field are trying a little harder to talk in the right way and in the same way about this shared problem.”

Tuttle is hopeful that the next phase will help funders refine how they talk about, market, and develop interventions for palliative care to better address issues of diversity, equity, and inclusion.

“Until you take the disparities in racial outcomes into account, you’re not going to get to the goal,” Tuttle says. “And if there’s anything that we’ve seen from COVID, it’s that there are disproportionate impacts and they largely correlate to race.”

“The conversation is evolving from ‘How do we talk about this as a field?’ to ‘How do we better tailor it, understanding the dynamics and impact of race?’ That is a tremendous source of value because it will help us reach our goals faster.”

SPENDING DOWN TO MAXIMIZE IMPACT

In addition to adding serious illness care to its portfolio as part of a localized focus on the San Francisco Bay Area and Hawai’i, Joyce Stupski also sought to maximize the impact of the Foundation’s remaining \$250 million in assets by establishing it as a “spend down” foundation in 2015. That means Stupski will invest all of its assets in community-led initiatives and collaborative systems change by 2029, “rather than trickle out the standard 5 percent every year that many foundations do to maintain their tax status,” Tuttle says.

“It had the added benefit of changing the way in which we talk with potential partners about the kinds of projects we’re doing because we know that we’re not going to be able to make the exact same operating support grant ad infinitum, from now until forever. So from the very get-go, we can explain a bit more of our hope to get to a new plateau with their programming or the type of impact or change that they’re

having and our willingness to partner with them creatively to try to figure out how to do that.”

The spend down approach has allowed the Foundation to have “slightly non-traditional conversations of partnering with people who are seeking grants to try to figure out what the ultimate case is for sustainability,” he adds. “We are trying to have the conversation early and also recognizing that the world changes quite a lot, and you can never anticipate what those changes are going to be. The type of trust you can build in trying to have those conversations up front really helps to reinforce the flexibility throughout a grant as the world does change.”

AND THEN, THE WORLD CHANGED

In the fall of 2019, the Stupski Foundation approved over \$14 million in grants to seven local health systems to support and enhance comprehensive serious illness care programs across San Francisco and Alameda Counties and support patients at the end of life. It represents the largest regional investment the Foundation has made as it seeks to transform how people experience the end of life in the communities the health systems serve.

The investments seek to:

- Expand specialty palliative care services by more than one-third, reaching thousands of additional patients a year;
- Double the number of patients receiving home-based palliative care, reaching hundreds more people a year in the comfort of their homes; and
- Train hundreds of primary care doctors and support staff on palliative care and how to have conversations about care preferences, document them, and ensure they are honored.

Less than six months into the new grants, however, the world changed in ways that

were unthinkable when the grants were announced. The COVID-19 global pandemic suddenly presented the greatest public health crisis in a century.

“In terms of how the palliative care and serious illness care program investments we made in 2019 changed as a result of COVID, to be honest with you, I was scared at the beginning that everything was going to be washed away just in dealing with the crisis,” Tuttle recalls. “And where we are right now, I’ve been tremendously impressed with the resilience of the teams that are continuing to provide those services because demand has just shot through the roof.”

“One of the barriers to people engaging in discussion about end of life is just pure willingness. Many people have to have some form of personal experience before it attains the emotional significance necessary to have really hard conversations with loved ones, whether it’s in a critical time or well upstream, many years before that. So we saw an increase in the demand for advanced care planning, both among the general population and among clinicians who were suddenly in their primary care appointments being asked, ‘How should I think about COVID risks?’ Or, ‘My loved one is on a ventilator right now, what do I do?’”

As a result, Tuttle says, “we saw a significant increase in the numbers who

wanted to go through the type of trainings that would better prepare them to be able to talk with patients in a really caring way.”

ENCOURAGEMENT FOR OTHER FUNDERS

Tuttle understands why some philanthropies may avoid funding in healthcare, thinking that it’s complicated and “trying to influence or change that might seem staggeringly hard and insurmountable.”

He encourages them not to underestimate the impact they could have.

“I’d ask them to just examine that thought and challenge it a little bit, because with the right conversations with the right partners and a little bit of geographic focus, a small amount of philanthropic investment can move a very large organization in directions it otherwise can’t go. It may want to go there, but internal processes and budgeting and accounting and strategies and trade-offs prevent it from happening.”

“One of the cool things about philanthropy is you can fix those budget problems. With a little bit of meaningful partnership at the get-go and planning into the medium term, you can create some semi-permanent, hopefully fully permanent changes in the way that healthcare is administered. And that’s nothing short of necessary in the America we live in today.”



STUPSKI
FOUNDATION



Cultivating the Next Generation of Palliative Care Leaders

Cambia Health Foundation



7

What do these projects have in common? Segments on PBS NewsHour's weekly series *Brief but Spectacular* focusing on palliative care during the COVID-19 pandemic, seen by millions.

A messaging project to help people better understand what palliative care actually is, and to counter common misconceptions that it is the same as hospice care.

A large-scale project to ensure that people who were unable to leave their homes during the pandemic could get COVID-19 vaccinations.

What these three projects, all funded in whole or in part by [Cambia Health Foundation](#), have in common is this: The Foundation likely would have never been aware of these funding opportunities if it were not a member of Grantmakers In Aging's Serious Illness and End-of-Life Funders Community, says Cambia's Jennifer Fuller.

“Clearly, there have been some real partnerships that have evolved through the Community,” says Fuller, a Senior Program Officer for the Cambia Health Foundation's Sojourns area of investments, which purposefully invests to advance access, awareness, and quality palliative care for those with serious illness across the nation. She oversees grants and initiatives regionally and nationally, including the Foundation's signature program, the Sojourns Scholars Leadership Program.

Elyse Salend, a former program officer for the Sojourns Program, recalls that the PBS NewsHour funding opportunity was mentioned briefly during a Funders Community meeting. She followed up with PBS and, after about nine months of discussions, the Foundation decided to fund

the five-part series titled “The Importance of Palliative Care.” The last episode aired in June 2021.

Each episode offered insight and perspectives from health care providers, caregivers, patients, and loved ones around the country on the importance of palliative care and the opportunities and challenges for increasing access to and providing palliative care in rural communities.

“It wouldn't have happened had we not been part of the Funders Community,” says Salend, who managed projects and initiatives regionally and nationally that improve quality care, including co-directing the Sojourns Scholar Leadership Program.

‘A SPARK OF CURIOSITY’

On both the messaging and the vaccination projects, Cambia Health Foundation partnered with fellow Funders Community member The John A. Hartford Foundation (JAHF).

The messaging project idea originated with JAHF about three years ago, and Cambia quickly signed on. There are now 10 organizations working on developing a shared understanding about how to talk more effectively and inclusively about the benefits of palliative care, Salend says.

The question of how to help people who are unable to leave their homes get vaccinated against COVID-19 grew out of discussions between parent company Cambia Health Solutions, a total health solutions company dedicated to transforming the way people



“IF I HAVE A QUESTION, I THINK, ‘OH, I’M GOING TO EMAIL THE COMMUNITY’ BECAUSE I’M USUALLY GOING TO GET SOME GOOD ANSWERS.”

experience health care, and Cambia Health Foundation, its corporate foundation. Fuller immediately brought the question to the Funders Community. “It always comes to mind first. If I have a question, I think, ‘Oh, I’m going to email the Community’ because I’m usually going to get some good answers.”

It turned out JAHF was going to fund a big project with Trust for America’s Health, “focusing exactly on this issue. And we joined in that effort to try to ensure that people who were unable to get out of their homes could get a vaccination. It was an extremely successful project with The John A. Hartford Foundation. So things like that just come about because you have a spark of curiosity and you have a group you can go to,” Fuller says.

INVESTING IN EMERGING LEADERS

In addition to the Sojourns Program, Cambia Health Foundation’s other main funding area is its Healthy People, Healthy Communities Program, which works to empower people and communities to achieve better health by investing in innovative ideas that promote a person-focused, economically sustainable, and accessible health care system for everyone. The program has invested more than \$20 million in organizations with a clear view of how they will change the health care experience. And its work is not done.

The goal of the Sojourns Program is to help people with serious illness and their caregivers live as well as possible for as long as possible. Since 2007, the Cambia Health Foundation has invested more than \$49 million to support the design and implementation of quality palliative care programs, build workforce capacity, develop future leaders, and increase consumer awareness.

Sojourns’ signature program is the Sojourns Scholars Leadership Program, which invests in the next generation of palliative care leaders — physicians, nurses, social workers, physician assistants, chaplains,

psychologists, pharmacists, and other emerging health system leaders. Sojourns Scholars receive \$180,000 in funding (\$90,000 a year over a two-year grant) to carry out an innovative and effective project in the field of palliative care and execute a leadership development plan designed to support the individual’s growth as a national leader in the field.

Since the program’s inception in 2014, the Foundation has awarded 84 grants to emerging leaders nationwide. Each grantee is a member of an interdisciplinary palliative care team or is otherwise working to advance the field.

That \$15 million investment has been leveraged by \$149 million in additional grants for the scholars’ work — or almost \$10 million for every \$1 million Cambia Health Foundation has invested.

But it’s not just about the money. The key to the program’s long-term impact is the network of palliative care leaders that is being created to guide the field into the future.

“Probably one of the greatest results of this program so far is that we have this network of 84 scholars across the country that are connecting with one another and now starting to do projects together or inform others on their projects,” Fuller says.

Salend agrees. “There will never be enough palliative care providers. But we’re creating a circle of people who will work together for maybe the next 30 years. That is the power. They’re on each other’s PCORI grants, they write papers together. We have special interest groups on anything from pediatric palliative care to policy. And these people are, I think, shaking things up and stepping up to the plate.”

ENGAGING OTHER ORGANIZATIONS IN THE WORK

There is still plenty of room at the table for other foundations that may be thinking about funding in serious illness and end of life.

“I think palliative care and aging in general is so underfunded,” Fuller says. “We’re all rooting for each other and want to see more and more engagement.”

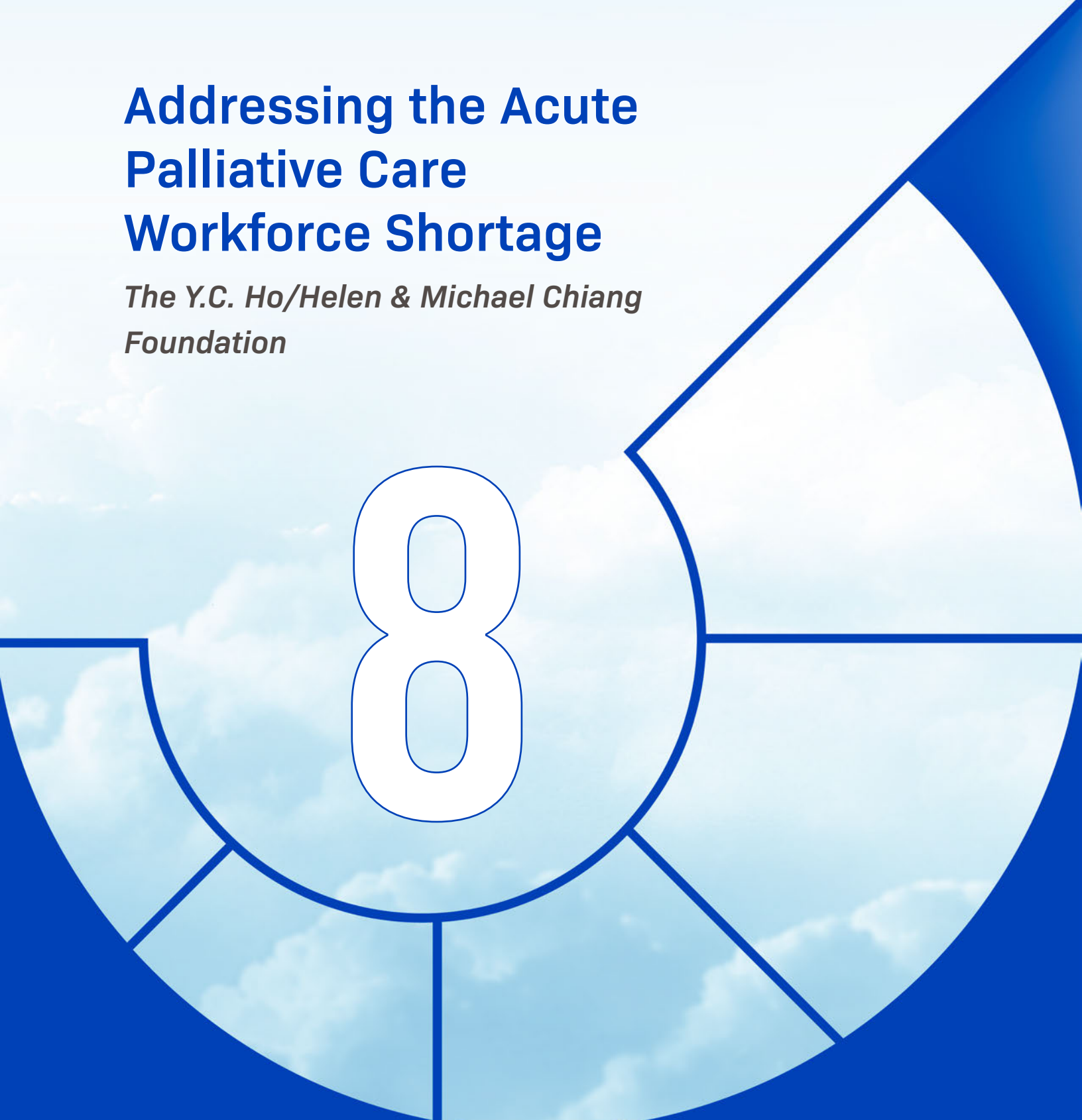
She understands that some organizations are reticent to fund in serious illness because they associate palliative care with hospice and death.

“You don’t have to be about end of life or death or serious illness care,” Fuller says. “If you believe in whole-person, person-centered, family-centered care, you belong in this space.”



Addressing the Acute Palliative Care Workforce Shortage

*The Y.C. Ho/Helen & Michael Chiang
Foundation*



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Since joining the [Y.C. Ho/Helen & Michael Chiang Foundation](#) as Executive Director in 2015, Carol Gallo has learned first-hand that there are compelling professional and personal reasons to fund in the area of serious illness and end-of-life care.

“From a philanthropic perspective, it’s exciting to be in a space where, even with limited grant dollars, you can make a big difference and have an impact,” says Gallo, who has been exposed to lots of different funding areas in her career working in philanthropy. “I know foundations that are much bigger, and I know there are many that are a lot smaller, and even the smaller ones can make a big difference.”

Then, there are the profound personal reasons for philanthropies to consider funding in the field. “Serious illness care is going to affect every single one of us in some way, whether we’re ill ourselves or one of our loved ones is,” she says.

In 2021, the Foundation awarded \$2.3 million in palliative care-related grants. Since it began grantmaking in 2007, the Ho/Chiang Foundation has awarded about \$42 million in grants in all areas. Of those, some 420 grants totaling \$28 million have been made to improve the quality of life for patients and families facing serious illness. Two-thirds of the Foundation’s grantmaking is focused on New York City, and it also funds some regional and national programs.

BUILDING THE WORKFORCE

The Ho/Chiang Foundation’s grantmaking in serious illness is mainly focused on addressing the acute palliative care workforce shortage, “which actually should scare all of us,” Gallo says.

The critical shortage of trained palliative care professionals is only projected to

get worse, as the number of specialists trained each year fails to keep pace with population growth and the numbers needed to adequately staff both hospital and community-based palliative care programs.

The Ho/Chiang Foundation’s grantmaking seeks to build and sustain interdisciplinary palliative care teams primarily through interdisciplinary education and training grants for doctors, nurses, social workers, chaplains, and other clinicians.

Fellowships — both for individuals and to support fellowship programs — are an important part of the Foundation’s education and training grantmaking. Since inception, the Ho/Chiang Foundation has invested about \$12.2 million in fellowships, including \$6.6 million in the past six years. Palliative care fellowships range from a nurse practitioner fellowship to a social work fellowship program in pediatrics.

On average, the Foundation’s fellowship grants support about nine fellows a year. “So overall, since inception, we figure we’ve helped about 120 fellows,” Gallo says.

Gallo admits “there’s always a little tug” in deciding whether to fund a training program that has the potential to reach many people, or individual fellowships, which train one person at a time in much greater depth.

“There’s merit in both,” she says. “That one person can then go off and start a palliative care program where none existed. And that has happened, especially with our pediatric palliative care fellows that we



“IF YOU CAN BRING SOME OF THE PALLIATIVE CARE PRINCIPLES INTO GENERAL MEDICINE, I THINK IT’LL MAKE SERIOUS ILLNESS CARE BETTER OVERALL.”

funded over the years. One went off to found the first pediatric palliative care program in a new state. When you look at the long-term effects of the fellowships, you see this branching out. From one person come many, because they go off and they train others themselves or set up new programs.”

Other strategies to address the palliative care workforce shortage include direct staff funding for palliative care chaplains (including one at Bellevue Hospital Center in New York City), supporting some palliative care research programs, and funding training for non-palliative care clinicians in palliative care principles.

“If you can bring some of the palliative care principles into general medicine, I think it’ll make serious illness care better overall,” Gallo says.

BRINGING CULTURALLY COMPETENT PALLIATIVE CARE TO PATIENTS AND FAMILIES

Next to addressing the critical workforce shortage, the Ho/Chiang Foundation’s second biggest area of focus is providing access to culturally competent palliative care to all who need it, where they need it.

That includes outpatient programs such as skilled nursing, home care, and telehealth, for patients and families who need care outside a hospital setting.

It also includes bringing palliative care to vulnerable populations. One example is a grant to New York Legal Assistance Group to support the LegalHealth Palliative Care Outreach Project, which provides free legal civil services to low-income palliative care patients.

ON THE FRONT LINES DURING THE PANDEMIC

The COVID-19 global pandemic turned a glaring spotlight on the need for a healthcare workforce trained in palliative care principles, such as how to have difficult

conversations regarding a poor prognosis with patients and families.

“It really was all hands on deck,” Gallo says. “In terms of the interdisciplinary palliative care teams that we were funding in large health systems, they were all brought into the front lines to talk to patients’ families — mostly over FaceTime or another app — because they were the only ones who were trained to have those conversations.”

Some palliative care teams set up hotlines so that other healthcare professionals on the front lines could call them when they needed assistance with a difficult conversation or related palliative care issue.

Gallo says: “It shouldn’t be something that only palliative care clinicians know how to do, right?”

There were days during the worst of the pandemic when she found her work difficult.

“But most of all, I find it inspiring that there are people out there who want to improve care for serious illness,” Gallo says. “Our grantees are the most wonderful, compassionate people you could possibly meet. They inspire me. I learn from them every day.”

THE VALUE OF COLLABORATION

Since she had not funded in serious illness and end-of-life prior to joining the Ho/Chiang Foundation, Gallo says meeting others in the field from around the country through the GIA Serious Illness and End-of-Life Funders Community has been very helpful.

“It’s a friendly group. People obviously care about what’s going on in the field,” she says. “It’s a great opportunity for collaboration and trying to build on things together to make serious illness care better in this country. I have been referred projects that fit into our mission very nicely from other funders in the group, and that’s been really helpful.”

During the pandemic, the Community held meetings to discuss ways to address the stark health inequities COVID-19 helped expose, and disparities remain a standing agenda item for their bimonthly virtual meetings.

“I think COVID 19 really laid bare the disparities and it just made everyone in the group realize that we need to help address this,” Gallo says.



Helping Booming Austin Cope with Mortality

St. David's Foundation



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It's a demographic narrative Texans often boast about: Austin, the state capital, is the heart of the fastest growing major metropolitan area in the nation. Its population has exploded by one-third in just the last decade, thanks to an accelerating rush of young and prosperous tech workers relocating from Silicon Valley.

Something else about the burgeoning of the population is less well understood — but may be just as important. People who flock to Austin for their careers largely stay on in retirement, which is why the metro area of 2.3 million also counts one of the nation’s fastest growing populations of older people. One in six in the region are older than 60 today, and that share is projected to be one in three in only two decades.

This is where the St. David’s Foundation comes in. With more than \$75 million granted annually to programs across the region’s five counties, it’s one of the largest philanthropies in the nation focused entirely on health equity. Its fall 2021 grantmaking cycle included \$13.2 million to support 37 organizations and initiatives that help Central Texans age in place.

“Within that, we have a particular and growing priority of end-of-life care, and within that, a particular focus on that issue in underserved communities,” explains Andrew Levack, the senior program officer in charge of the Foundation’s aging portfolio. Levack is a two-term GIA board member who becomes board chair in 2023.

SUPPORTING OPERATIONS, DEMONSTRATING VALUE

One thrust of that effort has been funding a pilot program started three years ago by Austin Palliative Care. Under the program, which received a \$450,000 grant in 2021, caregivers travel to low-income urban, suburban, and exurban neighborhoods to provide in-home palliative care — symptom management, psychological and spiritual care, and medical care coordination — to terminally ill people who are uninsured or under-insured for that benefit.

“What we’re trying to do is make the case to Medicaid and other insurers that there are real benefits from more comprehensively and generously covering that service,” Levack says. (The regional poverty rate remains above 10 percent.) Austin Palliative Care is a subsidiary of Hospice Austin, the

first organization of its kind in Central Texas when it opened 40 years ago and still one of the state’s biggest hospices. Regular funding from the Foundation, including \$665,000 for the next two years, helps cover for at-home and inpatient hospice services for those unable to pay. (The regional poverty rate remains above 10 percent and one-quarter of Texas adults are uninsured, the highest share of any state.)

LISTENING, LEARNING, ENCOURAGING EOL CONVERSATIONS

“The third piece of this work, which is still in its relatively early days, is a commitment to broaden the conversation about death and dying throughout the Central Texas community,” Levack says.

To that end, the Foundation has recently allocated \$341,000 to fund Hospice Austin’s Giving Instructions for Tomorrow, or GIFT, program, which educates health care providers in having end-of-life conversations with patients and families and encouraging the local population to complete advance directives.

The Foundation itself is taking the lead on a fresh front. While recruiting several local partners, it has commissioned a 2022 survey of Central Texans to gauge their knowledge, attitudes, and perceptions about end-of-life planning and to assess whether preferences for medical care and services in those final days vary by race and income. (The Austin metro area is 52 percent white, 33 percent Latinx, 7 percent Black and 6 percent Asian-American. An estimated 48,000 people older than 65 are living below 200 percent of the Federal Poverty Level line.)

The study will emulate one conducted in 2019 by another Community member, the California Health Care Foundation, which found an array of differences among demographic groups, including that Latinx people are by far the least likely to put their end-of-life wishes in writing;

Black Californians are by far the most likely to prioritize remaining alive as long as possible; and the state's poor put the highest priority on getting extra help on top of regular medical care, such as assistance with pain and handling stress.

GETTING STARTED IN END-OF-LIFE AND AGING WORK

The Foundation's generosity and local focus are the result of an unusual arrangement born 16 years ago. St. David's HealthCare formed a partnership with the for-profit hospital management company HCA, under which the proceeds from its seven hospitals in the region are shared with the St. David's Foundation and a smaller philanthropy focused on improving healthcare in Georgetown, one of the region's secondary cities.

"There's a pretty big firewall between us and St David's Health, so we don't have very much influence over their hospitals' palliative care, end-of-life training, or any other operations," Levack says, noting that any Foundation funding opportunity must be open equally to all three of the region's hospital chains.

In the past, the Foundation has also provided support for the operation of GIA's Serious Illness and End-of-Life Funders Community.

St. David's Foundation's portfolio on aging addresses more than end-of-life issues.

Adult day health centers, home-based care, addressing the labor shortage of skilled home care workers and subsidized direct services — in transportation, nutrition, case management, and home safety improvements — are other ways the Foundation supports Central Texans hoping to remain in their homes and live independently.

"This is a relatively new avenue of investment for us, within our aging portfolio," Levack says. "We've supported hospices, but not until a few years ago did we get involved in the more broad-based engagement with the community around end-of-life issues. So for me, it's been really helpful to be part of the Community, to help know and understand what other organizations and foundations have been doing around this work."

As one specific example, he credits others in the Community for steering him toward the California survey that's become the template for his Foundation's upcoming polling of Central Texans' view of the end of life.

"We all have a lot to do," Levack says. "So there is no need to reinvent the wheel, and the Community helps us not have to."



St. David's
FOUNDATION



“THERE IS NO NEED TO REINVENT THE WHEEL, AND THE COMMUNITY HELPS US NOT HAVE TO.”



A Veteran Funder Working to Tune In and Turn On the End-of-Life Community

The Jenifer Altman Foundation



10

Catherine Porter, a consultant who works mainly with foundations, has more than 25 years of experience in funder and nonprofit collaboration. Most of her work has been forming and sustaining coalitions in the areas of natural resources preservation on the West Coast, biological diversity and clean water in the developing world, and end-of-life issues in the United States. In her spare time, Porter is a hospice volunteer.

But it's her work with the [Jenifer Altman Foundation](#) that has led to her involvement in GIA's Serious Illness and End-of-Life Funders Community. Porter has been on the board of the Jenifer Altman Foundation since 1994, three years after the philanthropy was created with a bequest from its namesake, an environmentalist, photographer, and dancer who died of cancer at age 50.

The Foundation provides a sustaining annual grant to Commonweal, a nonprofit known for its integrative and nontraditional cancer therapy research and its California retreat center for oncology patients. Commonweal has been the fund's main but not exclusive beneficiary, because Jenifer Altman attended a retreat at its center overlooking the Pacific Ocean soon after her diagnosis and then remained for the rest of her life, working as a researcher and practicing healing through expressive arts.

BRINGING NEW IDEAS TO END-OF-LIFE CARE

"The conversations we members of the Community have, every other month or so, are about sharing ideas and insights across the field — what's working and what the new thinking is," Porter explains.

Porter has been eager to share what she's gleaned from one her newer involvements, as Director of Funder Engagement for the five-year-old Psychedelic Science Funders Collaborative — a collection of 85 individual and foundation donors.

"Psychedelic therapies are having a renaissance," Porter says, citing recent studies showing their potential to reduce

suicides among veterans with post-traumatic stress disorder (PTSD) and to relieve the wave of depression, anxiety, and grief confronting health care workers overwhelmed by the COVID-19 pandemic.

Further research, she says, shows us that, "these psychedelic therapies can become a very important tool in the palliative care toolbox."

The reason for her confidence, she says, is that many of the mental challenges confronting combat survivors and beleaguered ICU staffers also confront people who have received a terminal diagnosis: PTSD from the trauma of the news, anxiety, and grief about the coming unknowns, and depression that the inevitable is near.

"People confronting existential distress are going to benefit from a psychedelic experience," Porter says. "It's not a panacea and it will not be for everyone," she adds. But in past research trials, terminally ill patients given psychedelic treatments have been prone to conclude afterward: "My time now can be about living my life to the fullest, every day."

Porter and Shoshana Ungerleider, MD, founder of the End Well Foundation, planned a webinar for members of the Community articulating the benefits of psychedelic medicines in caring for the seriously and terminally ill, as well as the rapidly advancing science behind psychedelic drug development and the lingering stigma attached to psilocybin, ketamine, LSD, and MDMA (popularly known as Ecstasy or Molly).



"THESE PSYCHEDELIC THERAPIES CAN BECOME A VERY IMPORTANT TOOL IN THE PALLIATIVE CARE TOOLBOX."

That stigma does seem to be ebbing. A growing number of states and cities have moved to decriminalize some drugs. In 2023, Oregon will begin a mental health treatment program that uses psilocybin, the psychedelic substance in “magic mushrooms.” Investors, meanwhile, are flocking into the emerging market for psychedelic pharmacology. (Porter’s Psychedelic Science Funders Collaborative is working to raise \$90 million in venture capital to fund research in Europe, having completed in 2020 a \$30 million fundraising campaign that is helping pay for the final round of clinical trials before the Food and Drug Administration might approve MDMA as a part of PTSD therapy.)

“I know we can do better for those who imagine a peaceful, pain-managed death surrounded by loving care,” Porter says.

“There’s a big shift coming when it comes to psychedelics in mental health care,” she adds. “I’m happy that my Jenifer Altman role gives me a point of entry to work with members of the GIA Community as we discover what this can mean for patients confronting their emotional challenges at the end of their lives and looking to ease that kind of suffering.”

The logo for The Jenifer Altman Foundation is displayed on a black rectangular background. The text "THE" is in a small, white, sans-serif font above the name "Jenifer Altman", which is written in a large, white, serif font. Below the name, the word "FOUNDATION" is written in a smaller, white, sans-serif font.

THE
Jenifer Altman
FOUNDATION



A Physician Who Sees Talking About Death as a Cultural Salve

End Well



11

An experienced internal medicine physician, Shoshana Ungerleider, MD has emerged as one of the most visible and multifaceted forces in the end-of-life community.

In addition to her clinical practice, Ungerleider has established a pair of nonprofits while gaining renown as a forward-facing and media-savvy evangelist for changing misperceptions and antiquated views about the end of life, not only in the medical community but across the culture.

“Especially in this time of uncertainty, which has only been magnified by the persistence of COVID, we need to do much more to open the doors of communication about all the issues surrounding palliative care,” she says. “We need to work to get the entire population to shift its narrative about goals and values surrounding ending life well.”

That is the mission of one of Ungerleider’s nonprofits, End Well, a member of GIA’s Serious Illness and End-of-Life Funders Community: Create a societal shift that normalizes candid conversations that permit

patients to collaborate with their families and enjoy the best possible quality of life — emotionally and physically — in their final days.

“Conversations with wonderful colleagues in the Community have helped us think about innovative strategies and fledgling projects,” Ungerleider says. “The members of the group are all about improving care for the seriously ill, but we approach things from different perspectives. Some Community members support hospice or physicians’ work, others are about research, others are direct funders.

The End Well niche is about shifting the conversation so that a critical mass of consumers start to demand something different from the healthcare system about how palliative care gets delivered.



“WE NEED TO WORK TO GET THE ENTIRE POPULATION TO SHIFT ITS NARRATIVE ABOUT GOALS AND VALUES SURROUNDING ENDING LIFE WELL.”

TWO STRATEGIES FOR DRIVING CHANGE

Ungerleider traces her interest in end-of-life care to her time as an internal medicine resident. As with most programs, palliative care was taught as a brief rotation, at the end of the third and final residency year. Finding herself under-trained in ways to alleviate the emotional and physical suffering of her terminally ill patients, she resolved to try to fix that for future generations of physicians.

Her first philanthropic venture, the Ungerleider Palliative Care Education Fund, was created in 2014 with her father, noted sports psychologist Steven Ungerleider,

to fund a new program at Sutter Health’s California Pacific Medical Center in San Francisco, where she did her residency and now practices. The innovative and comprehensive program educates all residents at the hospital, each year, in palliative practices, skills for end-of-life communications with patients and family members, and ways to process their own emotions around death and dying.

End Well was born three years later, with a much more ambitious mission. The main “point of leverage” to change perceptions about end-of-life care, Ungerleider says she concluded, was not in engaging doctors but in getting buy-in from the public.

And the best way to do that, Ungerleider decided, was to mount a one-day symposium in San Francisco with an unusually diverse roster of 400 attendees. They were not only the nurses, doctors, religious figures, social workers, and public policy experts who are the usual voices in the end-of-life conversation, but also software designers, tech industry leaders, venture capitalists, educators, and artists, along with caregivers and patients.

“We invited a diverse but interdisciplinary collection of stakeholders, new voices to talk about who the end user is, and make sure that end user is at the center of the conversation,” she says. “Death and dying is not just a medical issue, it’s a human issue so it behooves all of us to get invested.”

After two more annual TED-like symposiums, the coronavirus pandemic meant End Well had to operate virtually for two years. End Well’s website has preserved much of the content — including 90 videos, generally 10 minutes or so, on an enormous range of topics and featuring not only mental and physical health care experts but celebrities including Who frontman Roger Daltry, actors Blair Underwood and Taraji P. Henson, and TV personalities Andy Cohen, Meghan McCain, and Maria Shriver.

“TAKE 10” TO REFLECT

Another project is the Take 10 Campaign, an effort to encourage all visitors to End Well’s site not only to share those videos on social media, but then to share a message of similar length with their own social networks and all of End Well’s online followers.

“The vision for how you’d like your life to be through sickness and through health begins with a simple but profound question: What do I value most for the time I’ve been given?” Ungerleider writes on the site. “By creating a campaign that asks everyone to #Take 10 to reflect on their goals and values, we can shift our relationship to living with illness, loss, and grief.”

End Well’s plans include fresh programming designed to incubate similar conversations in schools and faith communities.

It’s a logical extension for someone who has described her professional mission this way: “To have conversations about mortality be so commonplace that I don’t need to do this work anymore.”

Furthering that effort is Ungerleider’s work in the mainstream media. She hosts the TED Health Podcast, and she is a frequently booked guest to discuss medical issues and public health news on CNN, MSNBC, and CBS News.

She has also been behind a pair of documentaries available on Netflix. Before launching End Well, her family foundation funded the 24-minute “Extremis,” in which director Dan Krauss follows Jessica Zitter, MD, a palliative care specialist in the intensive care unit at Highland Hospital in Oakland, California. It won Best Documentary Short at the 2016 Tribeca Film Festival and was a 2017 Academy Award nominee in the same category.

The next year she was executive producer of the 40-minute “End Game,” by directors Rob Epstein and Jeffrey Friedman, in which an array of terminally ill patients in the Bay Area decide among different options for spending their final days. It was nominated for the best short documentary Oscar, in 2019.

“Films are a really powerful way to connect with people who maybe wouldn’t have encountered this subject, which is important to do because this is obviously an issue that touches us all, throughout life.”



Charting a New Course While Staying Close to Its Core

*Roots & Roads Community Hospice
Foundation*



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Arizona's [Roots & Roads Community Hospice Foundation](#) may not seem, on the surface, to have much in common with some other members of GIA's Serious Illness and End-of-Life Funders Community.

Roots & Roads is a public foundation providing financial assistance to hospice patients and their loved ones, focused on Southern Arizonans in financial distress and living in and near Tucson, to assist them in transitioning in comfort and with dignity. Additionally, the foundation provides end-of-life education to all community members in an effort “to transform the end-of-life experience into the final act of living well.”

Nonetheless, the foundation’s executive director, Julie M. Evans, has found the Community to be a substantial aid to her work, as a professional sounding board and network for sharing ideas and concerns.

“I have some great peers in the group that I connect with off-line,” she says. “It’s a really wonderful group of folks.”



“I HAVE SOME GREAT PEERS IN THE GROUP THAT I CONNECT WITH OFF-LINE. IT’S A REALLY WONDERFUL GROUP OF FOLKS.”

GROWING TO MEET COMMUNITY NEEDS

Evans says she’s likely to be reaching out to those colleagues for feedback and suggestions as Roots & Roads works to significantly expand its educational offerings.

It recently added a third full-time employee, veteran Tucson hospice worker and chaplain David Fife, as director of community engagement. He and Evans are seeking regional foundation funding so they can create a regularly updated online database detailing the features of and differences among the region’s score of hospices — some of which offer services in Spanish, for example, or are attuned to non-Christian faith traditions — as well as a website with frequently asked questions and links to resources for people confronting the often mystifying-to-them worlds of hospice and palliative care.

“It’s a natural fit for us and a huge need for the community,” Evans says. “We see an opportunity to be the trusted partner for community members looking for unbiased information and also to be the trusted

brokers for all these hospices that are more and more engaged in heavy competition.”

“Humbly, I think this could be a model,” she says promising to share the end product with the Community.

TAKING ON A NEW NAME

This will be the second significant shift Evans has shepherded since joining the organization in 2018. The first was its new name, unveiled in the spring of 2021. The organization took on an entirely new identity, a rebranding that reflects its desire to position itself differently in the eyes of southeastern Arizona without altering its core mission of two decades.

The organization was named the Casa de la Luz Foundation at its founding in 2000 by Agnes Ronstadt Poore and Lynette Jaramillo, who hoped to provide help with basic end-of-life needs to struggling families associated with the Casa de la Luz Hospice, the inpatient and outpatient operation they also ran. It grew to be the largest hospice provider in southern Arizona by the time one of the owners died and the other decided to sell to LHC Group Inc., a national chain.

The new name gives the foundation an identity distinct from the hospice business, and, coupled with the new locally-designed logo, evokes what many patients want to talk about as their life nears an end: a sense of where they came from (their roots), their life's journey (a labyrinth), and where they believe they are headed next (roads).

“We’re small, We’re nimble. We’re not your normal big family foundation or big corporate foundation,” Evans says. “So we were able to make these changes on a dime when circumstances changed quickly.”

RESPONDING TO PANDEMIC NEEDS

The renaming was being deliberated while the foundation, along with all end-of-life support organizations nationwide, confronted the COVID-19 pandemic – which in Roots & Roads’ case prompted a 38 percent increase in requests for financial help.

On the recommendation of social workers at area hospices and hospitals, it provided 98 people with more than \$79,000 in direct financial assistance in 2020, its largest amount ever. About half the aid was to cover rental and other housing expenses. Most of the rest helped pay for final arrangements, but the foundation also covered costs for such essentials as bed alarms and electric wheelchair batteries. (The foundation is particularly proud of its success at reviewing and approving payments within 24 hours of submission.)

Roots & Roads also distributed more than 6,000 free copies (in English and Spanish) of “Five Wishes,” the nation’s most popular end-of-life planning and health care decision making guide. Community bereavement groups benefited from foundation-supplied workbooks to support their grieving process. And, in response to the pandemic, it suspended its annual community conference on end-of-life issues and instead launched a series of virtual workshops on a range of topics, from grief during the holidays to the benefits of water cremation.

Finally, the foundation partnered with the national “We Honor Veterans” program to facilitate recognition of 108 hospice patients at ceremonies where they were presented with a blanket adorned with a symbol of their branch of the military. (These blankets are often passed on as heirlooms to other family members on active duty.)

Evans says the need for basic education about hospice is clear. Battling the lingering perception that a hospice’s mission is to hasten death is only the first step — especially in a region as demographically diverse as southeastern Arizona, where 40 percent of the population is Latinx, but only 12 percent of hospice patients are Latinx.

“There’s a lot of exploration to be done into the cultural beliefs of all groups in the region, including Black and Indigenous communities. ‘We take care of our own. And we’re not going to have strangers in our house.’ Then there’s the general distrust of the healthcare system.

“We have a lot of work to do.”





SERIOUS ILLNESS
AND END-OF-LIFE
FUNDERS
COMMUNITY

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