

# Small But Powerful: How two family foundations boosted a researcher's dream to address health disparities

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Lauren Jodi Van Scoy grew up in Doylestown, Pennsylvania. At 16, after reading Richard Preston's 1994 best-selling nonfiction thriller, *The Hot Zone*, she wanted to be an Ebola hunter. Day one as a freshman at Emory University in Atlanta, she called the Epidemic Intelligence Service at the Centers for Disease Control to ask their advice: What credential would be more helpful to be accepted as a special pathogens officer? MD or PhD?

Told that 59 of 60 members of the incoming officer class were MDs, she hung up the phone and said, "I guess I'm pre-med." Thus, began her journey from aspiring infectious disease scientist to pulmonary disease specialist to principal investigator on Project Talk, a \$3.5 million clinical trial research project funded in September 2020 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.

Project Talk will investigate whether an end-of-life conversation game motivates African American participants to engage in advance care planning and to assess whether the game is well received and endorsed.

The path to winning a Research Project Grant, the oldest grant mechanism used by the NIH to support health-related research and development, better known as an R01, is arduous. Van Scoy's path demonstrates the impact that persistence leveraged by family philanthropy can have on the advancement of health, healthcare and science.

## Inspired by Stories

Van Scoy stuck with her plan to specialize in infectious diseases or rheumatology until a medical ICU/critical care rotation in her fourth year of medical school at Drexel University College of Medicine.

"I wasn't the smartest person on rounds with an answer to every medical mystery," she said, "but I was able to sit at a bedside and chit chat. I realized that's where my skill set was. So, I became interested in end-of-life as a place where I could make a unique difference."

Van Scoy was a resident and chief resident in Internal Medicine at Drexel when patients' life stories inspired her to write a book.

“Everybody has a story,” she said. “I wanted to write about my patients’ stories almost as a way to cope with all the illness and horror.”

Originally self-published, *Last Wish Stories to Inspire a Peaceful Passing* tells true stories of six patients as they encounter and face critical illness. It was picked up and published in 2011 by Ellen Stieffler, who had agented Jill Bolte Taylor’s *My Stroke of Insight*. During that time, Van Scoy also created the Last Wish Compass, a guide to help patients and families discuss and make decisions about critical end-of-life issues.

### **An End-of Life Conversation Game**

After serving as chief resident and fellow in Pulmonary and Critical Care at Drexel, Van Scoy joined the Penn State University Hershey Medical Center faculty as an assistant professor in 2013.

Searching for a research focus, her curiosity was roused by a call from Nick Jehlan, co-founder of Common Practice, who had seen her book. Jehlan and his partner, Jethro Heiko, designed the *Hello* game to make end-of-life conversations more accessible to everyone.

The game includes 32 open-ended questions that ask groups of three to five people to think about and discuss issues related to advance care planning, end of life, decision making, funeral planning, values and preferences.

Van Scoy was skeptical at first.

“A game out of end of life?” she thought but was interested enough to mention it to colleagues. “They thought it was nuts too but encouraged me to go for it,” she said.

Van Scoy designed a small study and, seeing the game actually played, was struck by the quality of the conversations it prompted. Conversations on subjects that, as a clinician, she had not been able to get people to talk deeply about. She decided to pursue the game as her research program. The main barrier was funding.

### **Pulmonary Research**

Encouraged by her mentors at Penn, Doctors Benjamin H. Levi and Michael J. Greene, Van Scoy applied to the Parker B. Francis (PBF) Fellowship in Pulmonary Research. PBF Fellowship grants are awarded to institutions to provide stipends, fringe benefits and modest travel expenses in support of qualified post-doctoral fellows or newly appointed faculty members. Critically, the

#### **Sample Hello Game Questions**

*Write down any fears you might have about playing this game.*

*In order to provide you with the best medical care, what three non-medical facts should your doctor know about you?*

*Name the three-person committee who should be consulted on any decisions made about whether to continue life-saving care if you can’t communicate.*

grant covers institutional expenses in order to assure that at least 75 percent of the fellow's time is available for research.

The history of the PBF Fellowship began in 1913 when Parker B. Francis launched the Kansas City Oxygen Company, renamed the Puritan Compressed Gas Corporation in 1931. In 1968, Parker merged his company with V. Ray Bennett, who constructed the first Bennett Resuscitator unit for a hospital in Los Angeles. The Puritan Bennett Corporation became a leading manufacturer of respiratory and medical gases. The Parker B. Francis Foundation, established in 1951, made grants to universities and research foundations to fund research in anesthesiology and related sciences.

Parker's sons, John B. Francis and Parker B. Francis III, assumed leadership of Puritan-Bennett after Parker's death in 1957, at which time Parker B. Francis III established a separate foundation to fund his interests in education, arts and culture in the Kansas City area. John B. Francis established the Parker B. Francis Fellowship Program in 1975, and in 1989 the two foundations merged to become the Francis Family Foundation.

Since the first PBF Fellows were selected in 1976, the Francis Family Foundation has invested more than \$74 million in support of more than 880 Fellows, and the program has become second only to the NIH in the funding of pulmonary research.

### **The Gift of Time**

Van Scoy's application endured rigorous review.

"Foundation staff work in partnership with a review committee," said Liana Riesinger, senior program officer for the Francis Family Foundation. "In 2015, when Lauren's fellowship was awarded, the committee was chaired by former Program Director Dr. Tom Martin."

"The Parker grant, which was \$150,000 a year for three years, was pivotal in my career," said Van Scoy, "because it provided me with dedicated time away from patient care to develop my research, leading up to the R01 grant from the NIH."

Yet, it almost didn't happen. Indeed, Van Scoy recalls that a colleague discouraged her from applying for the PBF Fellowship because those grants were mainly awarded to MDs and PhDs doing bench research, not behavioral social science researchers. And, as Van Scoy was well aware, the fellowship had never funded issues surrounding end-of-life values and preferences.

The advice from Van Scoy's colleague would likely have been prescient if not for the late Dr. Richard Payne, who served on the committee that reviewed her application.

As Riesinger explains, the review committee comes together for three days of discussion culminating in award recommendations ranked from one to ten. Dr. Martin had a mixed message for Van Scoy following review of her proposal.

“The good news,” he said, “is that your application did really well. The bad news is that it ranked number eleven, and we’re only awarding ten. So, if someone drops out, you’ll be awarded the fellowship.”

“Someone did drop out,” said Van Scoy. “And I’ve been told that Dr. Payne was the one who advocated strongly for my portfolio and pushed it up in the ranking in the first place.”

“Richard had a long-standing interest in advance care planning for the underserved,” said John Carney, president and CEO of the Center for Practical Bioethics, where Dr. Payne held the John B. Francis Chair from 2013 until his death in 2019. “He was especially focused on the role that faith communities play in providing nurturing relationships and trusted messengers among patients and families who have suffered discrimination or been ill-served by the healthcare system.”

### **Community-Based Delivery Model**

The Parker B. Francis Fellowship enabled Van Scoy to begin collecting the data that served as the foundation for subsequent support.

“The fellowship furthered the creation of what I now call the ‘community-based delivery model,’ for advance care planning,” said Van Scoy. “We researched the game. We learned how to invite people to game events. How to measure the quality of communication happening during the games. Whether playing the game impacted behavior. Seeing how it was played in different environments, such as libraries, senior centers and nursing homes.”

Van Scoy’s PBF fellowship was close to the finish line around the same time that the John and Wauna Harman Foundation was exploring how, as a small family foundation with under a half million dollars a year available to award in grants, they could have the greatest impact.

“We found a great body of research on physician-patient dialog about end-of-life issues, but a dearth of what works at the community level,” said Julie Boudreau, executive director of the foundation.

Boudreau, who had served as education and outreach program manager for Hospice of Santa Cruz County, recalls her excitement upon clicking the “Research” tab on the *Hello* game website in May 2017 and learning about Van Scoy and her projects. She became even more excited after talking to Van Scoy on the phone.

The fundamental problem with advance care planning, as Van Scoy bluntly put it to Boudreau, is that humans don’t like to talk about death. And, when they do talk about it, the conversation typically involves hard-to-scale, one-to-one encounters with clinicians focused on clinical issues. The solution, she believed, was to address normal psychological inhibitions involved in talking about death through a process she calls priming.

Van Scoy wanted to know: What happens if you remove the barriers that typically inhibit end-of-life conversations and, instead, prime individuals for such conversations with a game played in familiar and comfortable settings?

### **Communities of Color**

Both Van Scoy and the Harman Foundation knew that less than 25% of African American individuals have completed advance directives and are thus vulnerable to poor end-of-life care. Their conversations quickly converged on a plan to evaluate whether the *Hello* game would be effective in African American communities.

The Harman Foundation had decided to focus its grantmaking on increasing participation in advance care planning by African Americans based on results from its earlier work with Hospice Foundation of America to fund and promote screenings of *Being Mortal*, a 2015 PBS Frontline film about end-of-life that explores the relationship doctors have with patients nearing the end of life.

“In spite of our best efforts to make the screening events attractive to communities of color,” said Boudreau, “it didn’t go that way. Between 80 and 90 percent of participants were white. We needed to address that.”

At the same time, Van Scoy needed to show that people of different cultures and backgrounds would engage with the game as effectively as more affluent white people. Would a serious game that promotes advance care planning conversations by combining an important topic with an enjoyable activity help overcome reluctance to discuss death and dying?

“Hospice Foundation of America did such a good job on *Being Mortal*, we thought they would be the perfect partner to work with Van Scoy on her project,” said Boudreau.

In November 2017, Harman granted \$170,000 to HFA and \$140,000 to Penn State Milton S. Hershey Medical Center with Van Scoy as principal investigator to conduct “Using an End-of-Life Conversation Game to Engage Underserved Communities in Advance Care Planning: A National Community Outreach and Research Program.” HFA identified game locations, supplied selected sites with the *Hello* game, and provided training to support community game events.

Van Scoy and her colleagues at Penn State and HFA published the results of their study in the May 8, 2020 issue of *JAMA Network*, noting that “Although our study was not designed to assess the effectiveness of the intervention with regard to behavior, our finding that 41% of participants completed a new advance directive is encouraging given the less than 25% baseline rate of advance directive completion among African American individuals.”

The article concludes:

This project successfully engaged a nationwide audience of underserved communities in ACP. The present findings suggest that a serious game may be a feasible and well-received intervention in African American communities. As a low-cost and pragmatic intervention for increasing ACP engagement in underserved African American communities, such a game may help reduce health disparities associated with end-of-life care. Randomized clinical trials are needed to assess its effect on ACP behavioral performance and actual end-of-life care.

In another article published about the study on September 18, 2020 in the *Journal of General Internal Medicine*, the authors highlight results that belie common belief that African Americans' low participation in advance care planning is due to skepticism and negative attitudes toward the process. "In contrast," they write, "this study revealed overwhelmingly positive attitudes about ACP, and the importance/value of advance directives in particular."

### **Family Philanthropy**

The benefits to individuals from giving as a family are well documented. What this story further illustrates are the benefits of family philanthropy to health, healthcare and society.

The Francis Family Foundation acted boldly when it awarded a PBF Fellowship for a project outside its traditional focus area. In doing so, the foundation enabled Van Scoy to devote necessary time to conduct research, the results of which came to the attention of the Harman Foundation.

The results of the Harman Foundation's investment in *Being Mortal* encouraged that foundation to continue expanding ways to promote advance care planning in communities of color. At the same time, Van Scoy was searching for ways to evaluate whether the *Hello* game could facilitate high-quality enjoyable conversations about end-of-life decision making among underserved communities and African Americans in particular.

Van Scoy submitted several versions of her Project Talk proposal to the NIH before the grant was awarded in 2020. Her ultimate success may have hinged, at least in part, on the Harman Foundation's relationship with Hospice Foundation of America, which provided Van Scoy with the network and infrastructure needed to pilot the community engagement process, demonstrate the strength of her research model and intervention (the game), and successfully apply for the grant.

The NIH project will involve 75 underserved community sites, urban, suburban and rural. Of the 75, one-third will be randomly assigned to host game events in small groups of approximately 20 people, mostly in churches. Another third will participate in events using Conversation Project end-of-life resources (i.e., not a game). The control group will play a game but not related to end of life. Six months after each event, participants will be surveyed to find out if they've completed advance directives. Van Scoy hypothesizes that completion rates will be highest at those sites playing the *Hello* game and lowest with no game.

The pre-Covid five-year timeline for this project called for 12 to 15 events a year to be held in years two, three and four, with final data analysis in year five. Van Scoy anticipates that game events may need to be delayed several months.

### **Flexible, Agile and Impactful**

Small family foundations rarely have the capacity to be the sole funder of a major research project. What they lack in resources, however, they often make up for in flexibility and willingness to innovate and take risks as demonstrated by the Francis Family Foundation in awarding a PBF Fellowship for a project that blurs the boundaries of pulmonary research by relying heavily on qualitative analysis.

Small foundations can also be agile, as demonstrated by the Harman Foundation in moving quickly and deliberately to leverage its relationship with the Hospice Foundation of America and to support Van Scoy's work as a means to innovate with a population poorly served by traditional medical research.

Prior to "Project Talk," the NIH had funded research on advance care planning but nothing that involved games and their effect on behavior related to advance care planning.

COVID-19 has amplified the need for advance care planning, especially among African Americans who have been disproportionately affected by the pandemic. Thanks largely to pioneering grantmaking by two small family foundations, we will soon know the extent to which an end-of-life conversation game is a useful tool for engaging underserved African American communities in advance care planning and in reducing health disparities related to end-of-life care.

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*For more information about the Project Talk Trial, and how your organization might participate, visit [projecttalktrial.org](http://projecttalktrial.org) and follow @\_ProjectTalk on Twitter!*

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