

## GPC Members Meeting 2018: Building Trust for Philanthropic Impact

Asia Society, 725 Park Avenue, New York, NY

Wednesday, May 9, 2018

9:00 am – 4:30 pm



### GPC Member Insight Talk

Jeannie Blaustein, Founding Board Chair, Re:Imagine

SPENCE: Thank you very much. So, earlier this year, I introduced a fellow GPC member to our next insight talk speaker, appending her bio to the email. He wrote back, I can't believe that one woman has done so much. This was wrong. Are you sure there was not a twin involved?

So, it is true that Dr. Jeannie Blaustein has done an extraordinary amount. And I won't go into it all here, but I just want to mention a couple of small things. She's Board President of her family foundation which works to advance racial, environmental and immigrant and refugee justice.

She's a film producer. She has an astonishingly deep commitment to issues related to end-of-life care and practices in this country. She served as a hospice volunteer at hospitals and people's homes.

She's the founding board chair of Reimagine, a nonprofit organization dedicated to creating evocative, city-wide, community-driven events about end-of-life designed to transform our thinking, our living and our dying.

It gives me a great pleasure to welcome her and to share her story. Thanks, Jeannie.

(APPLAUSE)

BLAUSTEIN: Hi, everybody. It's an honor to be here.

You know, this is essentially a coming-of-age story I suspect, both for me personally for -- as an organization and also from the point of view of culture and social change.

Philanthropically, I grew up as a child in a philanthropic family. My name was all over the town where I grew up because it was the era where names went on buildings and that was a challenge for me as a kid.

So, then I went into the anonymous phase where I would give anonymously. My father died in 1990 and so I became -- I had access to the wealth and the resources of our family, but I didn't know quite how to handle it. And I would say the last 10 to 15 years have really been an experience of coming into a relationship with these resources and the power and energy of that in the world.

I am happy to talk to you about a small organization and what I'm doing currently. We are in our first year. So, this is tiny compared to many of the things that we've been talking about today where extraordinary changes taking place.

Let me tell you a quick story. When my mother was 17 in the '40s, her mother died of cancer. Nobody told my mother that her mother was dying. My mother was alone on the porch as a 17-year-old while her mother was buried. This was the era when people didn't talk about death.

Well, I grew up with my grandmother's picture on the bedside table. I didn't know her story for many, many years. And really when I got to be pregnant with my first child, I realized I don't know how to do death because it was never a part of our family either.

And actually, I had a conversation with my mother and said, we're going to have to do this differently you and I. And I want to do this differently with my own children. And essentially my mother, who's an artist, went home and for the next 10 years or so started repainting -- painting her mother. And you can't make this up, but actually reimagining her mother into life, back into who she might have been had she aged because she was only 41 when she died, what she might have looked like with her grandchildren on her knees, et cetera, et cetera.

So, fast forward, my professional commitment has become very deep, as Marieke said, deep commitment to end-of-life work.

We have two species specific experiences as human beings. We care for our young longer than anyone else, and we care for our elders and our dying. And that is one of the sacred challenges and sacred opportunities of being a human being.

I was with someone yesterday who said, I don't want to be a burden to my family. And the woman next to her said, when you say that, you are depriving me of the opportunity to be present with you.

So, we live in a culture nevertheless, where serious illness and dying have been given over to medicine. It's become a problem to be solved. And the idea that there is a cure for almost everything is a culture that we, in this country and in the developed world, primarily live in.

By avoiding the topic of death, however, we have given over our agency in this critical sacred area of our lives. We have lost eons of wisdom around this and we have robbed ourselves of one of the essential experiences of being human and we are dying badly.

Why does the end-of-life space deserve our attention? You can tell I'm not a proficient slide person because all of the print is too small. So, I'll just tell you what's up there.

Ninety percent of the people in this country surveyed say that they think talking to loved ones about their end-of-life wishes is important, but less than a third have actually done so. Eighty-two percent of people surveyed say that they think it's important to put those wishes in writing. Less than 23 percent have done so.

Denial of this in our culture, denial of this conversation and that accepting death as a part of our lives leads to an inability to care for people and honor their wishes. Medical interventions lead to unnecessary suffering for the dying.

The poorest end-of-life outcomes, no surprise, happen in the most vulnerable communities for cultural reasons, economic reasons, issues of trust, profound distrust of vulnerable communities with the established medical community and, of course, exorbitant cost of healthcare in the end-of-life, the last two weeks.

Reimagine End of Life is a small organization. It's a holistic community engagement effort, dedicated to reclaiming death and dying as part of the human experience. By working directly with communities, Reimagine is reclaiming end-of-life from the cure of only focused medicine and putting it back into the personal sphere.

Our purpose is to launch a public conversation that transforms our purpose and approach to life. We have a goal, a vision where everyone is able to reflect on who they are, why we are here, prepare for a time when we won't be and live fully right up until the end.

And I'm not going to read the whole mission but essentially this is a citywide celebration across cities, one city at a time, with a week-long series of events focusing on wonder, preparation and remembrance.

So, as an example, we have a model of 50 plus events, focusing on four areas. And this is very much related to what Peggy just said; arts, spirituality, healthcare and design. Why? Because if you decide to have a panel in your organization, or your church, or your synagogue, or your healthcare institution about the differences between palliative and hospice care, not too many people are going to come.

But if you have an interactive theater performance where in fact people are moved and see their own experiences enacted and witnessed on the stage with each other and have their experiences shared, then people will come into the room and then they can start talking about palliative care and their end-of-life wishes.

This is not your typical professional conference. This takes place all over the city. I'm going to go to this. I'll be back.

So, picture the five boroughs of New York with events happening in bookstores, in living rooms, in synagogues, in cultural institutions, in theaters, all over reaching people where they live, work and pray. And I'm going to go back. Sorry.

So, how does Reimagine address these issues? We have a couple of key strategies. One of them is to develop strategic partnerships with public, private and healthcare institutions throughout the city, including faith communities.

We have citywide dedicated outreach to vulnerable communities, including a conversation Sabbath. I spoke with somebody in the mayor's office yesterday who works with 2,000 faith leaders across the country. The idea is to have preachers, and rabbis and all faith leaders speaking on one weekend, a conversation Sabbath about these issues from the pulpit.

Community engagement with and for the community; we have free advanced care planning workshops across the city, so that people are able to go to a safe space and get support, to think about these issues and what matters and what their values are.

And direct consumer engagement; we have strategic partnerships with the mayor's office in San Francisco. We're working on that here in New York as well.

As I said, we have four key pillars; arts and entertainment, healthcare and social services, spirituality and religion, and innovation and design. The idea here is to speak directly to the soul, because this is what we are all facing every single one of us, and everyone we know.

So, we are hoping to employ art, theater, music, conversation, poetry and every opportunity for people to engage with each other.

I want to tell you quickly, I think the folks at IDEO would be very pleased to know that they're appearing twice in our meeting today. This was born out of an initiative at IDEO two years ago; how might we reimagine the end of life? They sent out a digital challenge and they got back all kinds of submissions, everything from let's change the sounds of the ICU machine so that those aren't the last sounds that we hear, to let's put comics up on buses and subways and get people to start talking about mortality and the end of life.

Long story short, I landed myself at this conference, went up to the person in -- who seemed to be in charge, because I was astounded that of all the 2,000 people who were attending these various events, half seemed to be under 40 and the other half were not in healthcare.

So, this was clearly reaching a group of unusual suspects. And that seemed important to me. Basically, I went up to them and said, this is awesome, have you thought of taking this on the road?

So, this is my coming of age, of beginning to move out of the check writing and, yes, a little bit of initiative here and there, but really beginning to make an impact. So, we are now -- we just completed our first sort of relaunch in San Francisco. We're going to Cleveland and New York in the fall.

And I want to just show you just a little taste, on what happened in San Francisco, 7 days, 175 events, 10,000 people. And it was quite a remarkable experience of people coming together. This is a picture of the mayor declaring the week -- San Francisco's official Reimagine End of Life week.

This was a lot of press you don't need to see. This is just a short video that gives you a tiny taste.

(VIDEO BEGINS)

UNKNOWN: Can death be funny? I hope so because this is a comedy show.

UNKNOWN: Some people say hearing is the last sense to go when we die. So, what is the last sound I get to hear at the end of my life? Is it like this?

UNKNOWN: We talk a lot in medicine about humanizing the patient, but I think it's also really important to humanize the physician.

UNKNOWN: I think what we have to reimagine is how to live fully as mortal beings. Death will teach us a lot about life if we let it. In the face of death, the best and most healthy orientation is indeed to be joyful.

(VIDEO ENDS)

BLAUSTEIN: So, it's not coming next to San Francisco. It's coming next to New York. Sorry. There's a little bit -- there we go.

So, Reimagine is coming to New York at the end of October. As I said, it will be all over the city. This is just a short list of our partners to date, many faith communities, cultural institutions, folks from the mayor's office.

And I wanted to say just a couple quick anecdotes about wonder, preparation and remembrance and the impact. While we were in San Francisco, there was -- one of the things that we had a special interest in was committing, as I said, to outreach to vulnerable communities in San Francisco.

The Chinese-American community is one of those that has very low rates of advanced care planning. And one of the events we had was in a senior center for Chinese-Americans, 120 Chinese-Americans in translation weeping with through an interactive theater performance.

Another was in an advanced care planning session with another group of Chinese-Americans. This is the kind of outreach and culture change that we're hoping for.

In a closing ceremony, a woman stood up and said, I was diagnosed with terminal cancer four months ago. I'm so grateful for the week that I've had to be in a place with people who are willing to recognize that life has meaning and that legacy matters.

In terms of remembrance, I was with a group of people who would come together in grief around miscarriage and early child lost, another topic in this whole area that gets very little attention, because we're generally focused on the end of life. And there was a large circle of people. A woman could not even introduce herself. And at the end, she did introduce herself. She told her story and was embraced by everyone in the room, giving cards to support community.

There was a tremendous amount of connection and love and trust built across communities. I didn't know the theme for today was trust and bridging, but this is actually a collaborative enterprise reaching out to people that focuses specifically on those.

So, I want to thank you for your attention. I left a couple examples of things that we gave away to each person at the conference that really focuses on wonder, preparation and remembrance, opportunities for next steps, taking their own values and beliefs into their own hands, thinking about what matters to them and most importantly, having a conversation with your loved one.

Ten percent of us will die suddenly. But 90 percent of us will see our deaths on the horizon. So, if you have not had a conversation with your loved ones about what matters to you, and what you would want for yourself at the end of your life if there were choices to be made, I encourage every single one of you to do so with your parents, with your children and help us change this culture so that we can reclaim this is a part of our lives. Thank you so much.

(APPLAUSE)