MSK's Patient & Family Advisory Council for Quality (PFACQ) presents:

# RAISE YOUR VOICE

**Patients & Caregivers Effecting Change** 







# **Overview**

Raise Your Voice is a complimentary Symposium for patients, caregivers, and staff from patient and family advisory councils focused on strategizing around how to most effectively partner with their respective hospitals in better advancing patient-centered care.

Hospitals are increasingly realizing that they must effectively partner with their patients and caregivers in order to deliver patient-centered care. Patient and Family Advisory Councils are the most effective vehicle for leveraging the experiences of patients and caregivers.

Memorial Sloan Kettering's (MSK) **Patient & Family Advisory Council for Quality (PFACQ)** is hosting this inaugural Symposium designed to bring together clinicians, hospital leaders, patients, and caregivers to strategize around how to most effectively partner with their respective organizations so that they may integrate their perspectives and better advance patient-centered care.

Highlights of this three-day program include:

On **Wednesday, September 13**, the Symposium will kick off with a conversation about the challenges of openly discussing the taboo of death and dying, followed by an opportunity to experience the international phenomenon of "**Death Over Dinner**" firsthand. We will form profound connections with one another and engage for an evening of uplifting dialogue about what matters most to us all.

On Thursday, September 14, and Friday, September 15, the Symposium will include a series of keynote addresses, panels, and workshops to empower attendees to enact change, understand the latest advancements across the healthcare landscape, and share respective lessons learned while actively engaging with one another. Agenda highlights include the history of cancer activism, the emergence of human-computer interactions, patient-centric and systematic problem-solving, continuous improvement, and the latest successes across cancer center advisory councils.

The final session of the symposium, the **Patient** Journey Visualization Workshop, will end at 3:00 PM. However, we will make to-go lunches available at 12:00 PM to facilitate the departure of attendees who need to leave earlier. During this workshop, we will brainstorm and discuss the value of a patient journey tool and how such an asset might be optimized to facilitate candid patient-clinician dialogue. Patients often don't know where they are in their cancer journey, which can lead to confusion and decision-making challenges along the way. PFACQ is currently collaborating with MSK's Strategy & Innovation team on the development of a patient journey tool that clinicians can use to ground patients throughout their journey. The tool can help show patients what may lie ahead and can be referenced by clinicians at specific milestones along the way to better support patients. Participants of the workshop will:

- (a) learn about process and insights;
- **(b)** share where they see challenges and opportunities in their own hospitals; and
- **(c)** collectively prototype interventions on the topic of end-of-life expectation setting and patient journeys.

MSK's Raise Your Voice Symposium is made possible due to the generous support of MSK's Digital Products & Informatics team.

#### **Learning Objectives**

By attending this program, learners will be able to:

- Identify effective strategies of engagement utilized by other PFACs
- Discuss how to successfully challenge the cultural taboos surrounding the open discussion of end-of-life preparedness
- Describe the factors that led to the creation of PFACs
- Recognize the opportunities and challenges of emerging information technologies to support patients and caregivers
- Explain systematic approaches to problem solving within the context of improving the patient and caregiver experience

#### **Who Should Attend**

This Symposium is designed for staff, patients, and caregivers of cancer centers around the country who are currently participating with their respective patient and family advisory councils. Additionally, other staff at cancer centers interested in collaborating with patient and caregiver advocates are also welcome to attend.

The program will be held **in-person only** (no virtual option will be available). While MSK requests that institutional guests are vaccinated against COVID-19, we are no longer requiring proof of vaccination.

#### **Online Syllabus**

Attendees will receive access to an online syllabus after the course, which includes select PDFs of the faculty presentations (slides) from the course.

Founded in 2015, the Patient and Family Advisory Council for Quality (PFACQ) at MSK is a partnership of current and former patients, family members, caregivers, and clinical and administrative staff.

In order for every patient, family member, and caregiver to experience state-of-the-art cancer care that is safe, responsive, compassionate, efficient, collaborative, transparent, and respectful, we seek to integrate the patient, family, and caregiver perspective into every aspect of MSK's efforts to prevent, diagnose, treat, and cure cancer.

This Symposium is complimentary for all to attend. Attendees will be provided continental breakfast, lunch, dinner, and refreshment breaks.

Register online at mskcc.org/RaiseYourVoice

## **Symposium Directors**



FRANK LICCIARDI Chair Emeritus, PFACQ Memorial Sloan Kettering Cancer Center New York, NY



JOHANNA SCHOEN, PHD Co-Chair, PFACQ Memorial Sloan Kettering Cancer Center Lambertville, NJ

## **Symposium Speakers**

#### **JAVIERA ARENAS, MFA**

Design Strategist Department of Strategy & Innovation Memorial Sloan Kettering Cancer Center New York, NY

#### MARGARET BRENNAN, MD

PFAC Patient Co-Chair Johns Hopkins Sidney Kimmel Comprehensive Cancer Institute Retired, Hopkins Cardiology Baltimore, MD

#### KIM BURGAS, MA

Design Strategist Department of Strategy & Innovation Memorial Sloan Kettering Cancer Center Brooklyn, NY

#### MONICA CFARKU, MSN, RN

Assistant Vice President and Chief, Oncology Nursing Services Duke Health System Durham, NC

#### JENNY DAHLSTEIN, BA

Co-Chair, Patient & Family Advisory Council (PFAC) Dana-Farber Cancer Institute Boston, MA

#### **DAVID DAUMAN**

Co-Chair, Patient & Family Advisory Council Moffitt Cancer Center Tampa, FL

#### **MEGHAN DEWITT SURITZ, MBA**

Senior Director, Competitive Intelligence & Strategic Insight Memorial Sloan Kettering Cancer Center New York, NY

#### ERIKA DUGGAN, MS, LEAN SIX SIGMA BLACK BELT

Lead Process Improvement Engineer Department of Operational Excellence Memorial Sloan Kettering Cancer Center New York, NY

#### **DEBORAH ESTRIN, PHD**

Professor, Computer Science Cornell Tech, Cornell University New York, NY

#### **RAY GUSTIN, MBA**

Co-Chair, PFACQ Memorial Sloan Kettering Cancer Center Greenwich, CT

#### JACKLYN LE, MBA, PMP, CPXP

Program Director, Department of Patient Experience The University of Texas MD Anderson Cancer Center Houston, TX

Complimentary registration:

#### **BARRON LERNER, MD, PHD**

Professor, Department of Medicine and Population Health New York University Grossman School of Medicine New York, NY

#### **DONALD LEVINE, JD**

Patient and Family Advisory Council University of Chicago Comprehensive Cancer Center Chicago, IL

### JESSICA MACINTYRE, DNP, MBA, APRN, AOCNP

Executive Director, Clinical Operations University of Miami/Sylvester Comprehensive Cancer Center Miami, FL

#### ALISON NALEZYNKSI, BS, LEAN SIX SIGMA BLACK BELT

Process Improvement Engineer Memorial Sloan Kettering Cancer Center New York, NY

#### KATE NIEHAUS, BA, MBA

Chair Emeritus, PFACQ Memorial Sloan Kettering Cancer Center New York, NY

#### CRISTINA PEREZ, MBA

Director of Patient Experience Moffitt Cancer Center Tampa, FL

#### FERNANDA POLUBRIAGINOF, MD, PHD

Senior Director, Clinical Informatics Memorial Sloan Kettering Cancer Center New York, NY

#### TATE RONDOT, BS

Manager Patient Support Services Siteman Cancer Center Saint Louis, MO

#### KEREN STRONACH, MPH

Cancer Services Patient Experience Manager UCSF Health San Francisco, CA

#### ANN THALER-SHORE, MPA, MPT, BS

Associate Director, Operational Excellence Memorial Sloan Kettering Cancer Center New York, NY

#### **ELIZA WEBER, MBA**

Chair Emeritus, PFACQ Memorial Sloan Kettering Cancer Center New York, NY

#### **MELISSA ZABLOCKI, MPH**

Associate Director, Strategic Initiatives Memorial Sloan Kettering Cancer Center New York, NY

# **Schedule**

Wednesday, September 13, 2023 Rockefeller Research Laboratories (Board Room 104)			
3:00 рм	Registration, Check-In, and Refreshments		
4:00 рм	Death Over Dinner: Inspiring Conversations About Life and Death Frank Licciardi Memorial Sloan Kettering Cancer Center An overview of how MSK's PFACQ successfully challenged the MSK community to openly discuss the taboo topic of death and dying.		
5:30 рм	Cocktail Reception		
6:00 рм	Death Over Dinner  Experience the international phenomenon firsthand as we form profound connections with one another and engage for an evening of uplifting dialogue about what matters most to us all.  Please contact cme@mskcc.org at least one week prior to the program if you have any special dietary requests or require any specific accommodations.		
7:30 рм	Reflections and Debrief  An opportunity for everyone to reflect on what they experienced and share their candid thoughts and insights.		
8:00 рм	Adjourn		

Thursday, September 14, 2023 Rockefeller Research Laboratories (Board Room 104)			
8:00 AM	Networking Breakfast		
9:00 AM	Welcome and Opening Remarks Johanna Schoen Memorial Sloan Kettering Cancer Center Lisa M. DeAngelis, MD Memorial Sloan Kettering Cancer Center		
9:30 AM	Now You Are Being a Very Silly and Stubborn Woman: The Often-Forgotten History of Breast Cancer Activism Barron Lerner New York University Grossman School of Medicine		
10:30 ам	Digital Technology in the Cancer Journey: Considering Human-Computer Interaction for Patients and Caregiver  MODERATOR Fernanda Polubriaginof Memorial Sloan Kettering Cancer Center  SPEAKER Deborah Estrin, PhD Cornell Tech, Cornell University		
12:00 рм	Lunch Break		

12:30 рм	PANEL DISCUSSION  Recruitment and Onboarding of Patient and Caregiver Advisors		
	MODERATOR	Kate Niehaus Memorial Sloan Kettering Cancer Center	
	PANELISTS	Jessica MacIntyre University of Miami/Sylvester Comprehensive Cancer Center	
		Tate Rondot Siteman Cancer Center	
		Jacklyn Le The University of Texas MD Anderson Cancer Center	
2:00 PM	PANEL DISCUSSION		
	Leveraging Your Seat at the Table		
	MODERATOR	Eliza Weber Memorial Sloan Kettering Cancer Center	
	PANELISTS	Keren Stronach UCSF Health	
		Margaret Brennan Johns Hopkins Sidney Kimmel Comprehensive Cancer Institute	
		David Dauman Moffitt Cancer Center	
		Cristina Perez Moffit Cancer Center	
3:30 рм	Break		
4:00 рм		ds Shaping Healthcare Delivery	
	_	witt Suritz ban Kettering Cancer Center	
5:30 рм	The Day's D	Debrief	
	MODERATOR	Johanna Schoen Memorial Sloan Kettering Cancer Center	
6:00 рм	<b>Dinner at Serena's Wine Bar</b> 1268 2 <sup>nd</sup> Ave, New York, NY		
8:00 рм	Adjourn		

## Friday, September 15, 2023

Rockefeller Research Laboratories (Board Room 104)

Johanna Schoen  Memorial Sloan Kettering Cancer Center  *Attendees who need to leave early will be given a to-go lunch.				
Frank Licciardi Memorial Sloan Kettering Cancer Center  9:00 AM  Systematic Problem Solving to Foster Patient-Centric Continuous Improvement Ann Thaler-Shore Memorial Sloan Kettering Cancer Center Erika Duggan Memorial Sloan Kettering Cancer Center Allson Nalezynksi Memorial Sloan Kettering Cancer Center  10:30 AM  PANEL DISCUSSION Overcoming Challenges and Effecting Change  MODERATOR Ray Gustin Memorial Sloan Kettering Cancer Center  PANELISTS Monica Cfarku Duke Health System Jenny Dahlstein Danar-Farber Cancer Institute Donald Levine University of Chicago Comprehensive Cancer Center  12:00 PM  Lunch: Symposium Debrief* Johanna Schoen Memorial Sloan Kettering Cancer Center *Attendees who need to leave early will be given a to-go lunch.  WORKSHOP  Visualizing the Patient Journey Javiera Arenas Memorial Sloan Kettering Cancer Center Kim Burgas Memorial Sloan Kettering Cancer Center Melissa Zablocki Memorial Sloan Kettering Cancer Center Melissa Zablocki Memorial Sloan Kettering Cancer Center	8:00 AM			
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3:00 PM Adjourn	12:30 рм	Visualizing the Patient Journey Javiera Arenas Memorial Sloan Kettering Cancer Center Kim Burgas Memorial Sloan Kettering Cancer Center Melissa Zablocki		
	3:00 рм	Adjourn		





# **Accreditation**

Memorial Sloan Kettering Cancer Center is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

The content of this activity is non-clinical.

#### **AMA Credit Designation Statement**

Memorial Sloan Kettering Cancer Center designates this live activity for a maximum of **16.00** *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

#### **ANCC CNE Statement**

Memorial Sloan Kettering Cancer Center is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

**16.00 contact hours** will be awarded to participants who attend the program in its entirety and complete a program evaluation. **Partial credit not awarded.** 

#### **Social Work Accreditation Statement\***

This presentation is approved for a maximum of 14.0 Continuing Education Contact Hours of Live Training. Memorial Sloan Kettering Cancer Center is recognized by the New York State Education Department's State Board for Social Work as an approved provider of continuing education for licensed social workers #SW-0228.

\*Not all states accept NYS CEUs. Please check with the licensing board in your state for guidance on their acceptance of the credit types offered for this course.

# Continuing Education for Licensed Psychologists in New York State\*

This event offers 16.00 NYS Psychology Contact Hours.

Memorial Sloan Kettering Cancer Center is recognized by the New York State Education Department State Board for Psychology as an approved provider of continuing education for licensed psychologists #PSY-0166

\*Not all states accept NYS Psychology Contact Hours. Please check with the licensing board in your state for guidance on their acceptance of the credit types offered for this course.

#### **PXE Credit Statement**

Memorial Sloan Kettering Cancer Center is excited to offer 14.00 Patient Experience Continuing Education credits (PXEs) through Patient Experience Institute (PXI). PXI is an independent, non-profit, committed to the improvement of patient experience through evidence-based research, continuing education and professional certification. PXEs can be applied towards Certified Patient Experience Professional (CPXP) applications and/or to maintain certification designation.







# **Biographies**



JAVIERA ARENAS, MFA
Design Strategist, Department of
Strategy & Innovation
Memorial Sloan Kettering Cancer Center
New York, NY
LinkedIn

Javiera Arenas, MFA is a Design Strategist within the Strategy and Innovation department and an embedded designer within the Training & Compliance department at Memorial Sloan Kettering Cancer Center. She received her MFA in Transdisciplinary Design from Parsons and became a part-time faculty offering a design research course to undergrads at The New School. As a healthcare and human-centered designer, she has worked with multidisciplinary teams to improve MSK's patient, clinical, and admin staff experience and services. Since 2020, a specific topic of interest has been how to shift her team's design practice to an equity and anti-racism-focused approach — having a particular interest in understanding the impact of unintended consequences and harms of services and strategies, as well as connecting these to non-clinical essential needs in healthcare (such as mental health, language barriers, among many more).

Javiera is passionate about design ethics, social impact, and the end of life affairs. Related to the last, she has actively participated in MSK's *Death Over Dinner* community, moderating many events over the previous five years.



MARGARET BRENNAN, MD PFAC Patient Co-Chair Johns Hopkins Sidney Kimmel Comprehensive Cancer Institute Retired, Hopkins Cardiology Baltimore, MD

**Margaret Brennan, MD** is a retired physician and an experienced patient who has learned that patient self-advocacy promotes healing. That patient voice also has the power to improve systems of care when bringing patient experience and insight into productive collaboration with institutions.

Following a strep infection at age five, Margaret was hospitalized for weeks with post- streptococcal glomerulonephritis. Dr. Nussbaum's daily visits sustained her hope of returning home. Seventeen years later she went to medical school.

Following a Vanderbilt Internal Medicine residency and a Johns Hopkins Cardiology fellowship, she gratefully practiced medicine for decades before breast cancer and the rare autoimmune disease it provoked interrupted the narrative.

Her oncologist is a remarkable person and a remarkable physician. Throughout a complicated survivorship, he has taught her to identify what matters most each day and to use her voice to clearly communicate what she needs.

Advocacy for all patients cared for in our institutions is the essential mission of our PFACs. Success requires clear, meaningful, collaborative communication and participation with our cancer center partners.



KIM BURGAS, MA
Design Strategist
Department of Strategy & Innovation
Memorial Sloan Kettering Cancer Center
Brooklyn, NY

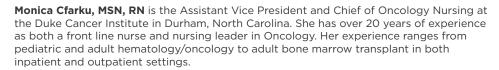
**Kim Burgas, MA** is a Design Strategist within the Strategy and Innovation Department at Memorial Sloan Kettering Cancer Center. Her background is in sociology, with a focus on sensory sociology, and user experience design. She holds a MA in visual sociology from Goldsmiths, University of London.

She has consulted as a UX designer for teams at New York University, the National Domestic Workers Alliance, Teaching Lab, and Indiana University. She previously led design efforts at PhotoShelter as the Director of User Experience Design and taught UX and human-centered design at General Assembly, CUNY TechWorks, and at the University of Reading, UK.

Kim is passionate about ethics in design, inclusive design, and the social impacts of the design of digital and ecological environments.



MONICA CFARKU, MSN, RN
Assistant Vice President and Chief,
Oncology Nursing Services
Duke Health System
Durham, NC
LinkedIn



Monica has spent the majority of her career working in major academic hospital settings and understands that partnering with patients and their loved ones is imperative to building and running successful cancer programs. As both a nurse and nursing leader Monica is dedicated to providing the highest quality of patient centered nursing care to those she serves through advancing nursing professional practice.

Monica is married with 2 kids and enjoys swimming, traveling, and spending time with her family.



JENNY DAHLSTEIN, BA
Design Strategist
Department of Strategy & Innovation
Memorial Sloan Kettering Cancer Center
Brooklyn, NY

**Jenny Dahlstein, BA** is a breast cancer survivor serving as volunteer Co-Chair of Dana-Farber Cancer Institute's Adult Patient & Family Advisory Council, which is the nation's first PFAC.

Professionally, Jenny works as an independent consultant specializing in non-profit operations and management in the education and public health fields.



**DAVID DAUMAN**Co-Chair, Patient and Family
Advisory Council
Moffitt Cancer Center
Tampa, FL

**David Dauman** is a cancer patient at the Moffitt Cancer Center since 2013 being treated for Multiple Myeloma. After successful treatment, he started to volunteer and joined the Moffitt Patient and Family Advisory Council in 2017. He became co-chair in 2023. He is also the caregiver for his mother who is also a Moffitt patient.

David is CEO of the training and communications consulting firm Solutions House of Tampa Florida.

David is married to Rona, has two children (Jacob 13 and Lauren 11) and pet parent to future therapy golden retriever Sadie. They live in Palm Harbor, Florida.



MEGHAN DEWITT SURITZ, MBA
Design Strategist
Department of Strategy & Innovation
Memorial Sloan Kettering Cancer Center
Brooklyn, NY

**Meghan DeWitt Suritz, MBA** is the Senior Director of Competitive Intelligence and Strategic Insight at Memorial Sloan Kettering Cancer Center (MSK). Meg has been working in Strategy at MSK for the last 10 years and has enjoyed collaborating with PFACQ on a variety of initiatives.

She has an MBA from the NYU Stern School of Business and an undergraduate degree in biomedical engineering from Rensselaer Polytechnic Institute.

In addition to her work at MSK, Meg is an Adjunct Professor of Management Communication at NYU Stern where she is able to fulfill her passion for coaching and developing communication skills in early career professionals.



ERIKA DUGGAN, MS, LEAN SIX SIGMA BLACK BELT Lead Process Improvement Engineer Department of Operational Excellence Memorial Sloan Kettering Cancer Center New York, NY

**Erika Duggan, MS, Lean Six Sigma Black Belt** is a Lead Process Improvement Engineer in the Operational Excellence Department of MSK. Erika leverages her continuous improvement knowledge in vital projects across the institution. She also creates training content and facilitates staff trainings to support the utilization of continuous improvement tools across all departments.

During her 8 years at MSK, Erika has worked on the process for the administration of the COVID-19 vaccine for both patients and staff as well as supporting the PFACQ in their last 3 yearly council meetings.



**DEBORAH ESTRIN, PHD**Professor, Computer Science
Cornell Tech, Cornell University
New York, NY
LinkedIn

**Deborah Estrin, PhD** is a Professor of Computer Science at Cornell Tech in New York City where she holds The Robert V. Tishman Founder's Chair, serves as the Associate Dean for Impact, and is an Affiliate Faculty at Weill Cornell Medicine. Estrin's current research activities include technologies for caregiving, immersive health, small data, participatory sensing, and Public Interest Technology.

Before joining Cornell University Estrin was the Founding Director of the NSF Center for Embedded Networked Sensing (CENS) at UCLA; pioneering the development of mobile and wireless systems to collect and analyze real time data about the physical world. From 1986-2000 Estrin was a member of the Computer Science Faculty at University of Southern California and an active member of the USC/Information Sciences Institute research community. Estrin co-founded the non-profit startup, Open mHealth, and has served on several scientific advisory boards for early stage mobile health startups and as an Amazon Scholar.

Estrin received her B.S. in Electrical Engineering and Computer Science at UC Berkeley (1980), her MS in Technology Policy at MIT (1982), and her PhD in Electrical Engineering and Computer Science at MIT (1985) advised by Jerome Seltzer.

Estrin's honors include: ACM Athena Lecture (2006), Anita Borg Institute's Women of Vision Award for Innovation (2007), the IEEE Internet Award (2017), and MacArthur Fellowship (2018). She is an elected member of the American Academy of Arts and Sciences (2007), the National Academy of Engineering (2009), and the National Academy of Medicine (2019). She was awarded honorary doctorates from EPFL (2008), Uppsala (2011), and Concordia (2023). She is a Fellow of the IEEE and ACM.



RAY GUSTIN, MBA Co-Chair, PFACQ Memorial Sloan Kettering Cancer Center Greenwich, CT

**Ray Gustin, MBA** is co-chair of MSK's Patient & Family Advisory Council for Quality and is a cancer survivor. In this role, Ray jointly oversees all aspects of MSK's PFACQ organization with the goal of collaborating with MSK clinical staff to continuously improve patient care. Major PFACQ initiatives undertaken during Ray's tenure include:

- 1) an institution-wide conference on patients living with long-term cancer; 2) active participation in MSK's multi-year implementation of the Epic health management system;
- 3) facilitating cross-departmental discussions to improve end-of-life care for cancer patients; and
- 4) developing a living library of recorded reflections by cancer patients and caregivers.

Ray is also a member, since 2020, of MSK's Institutional Review Board, where he has shared responsibility for evaluating clinical trials. Outside MSK, Ray has served other cancer-focused institutions as an independent clinical trial reviewer and has funded the development of promising new cancer therapies.



JACKLYN LE, MBA, PMP, CPXP Program Director, Department of Patient Experience The University of Texas MD Anderson Cancer Center Houston, TX

**Jacklyn Le, MBA, PMP, CPXP** is Program Director in Patient Experience at MD Anderson Cancer Center. Patient Experience supports institutional efforts to deliver patient-centered, value-driven care through a myriad of services and programs.

She leads the Patient and Family Advisor Program, Patient Satisfaction Survey Education and Process Improvement, and many initiatives within the division.

Jacklyn has a Bachelor of Science degree from Texas A&M University and Master of Business degree from Texas Woman's University. She also holds certifications in Project Management and Patient Experience.



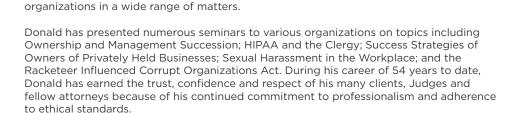
BARRON LERNER, MD, PHD
Professor, Department of Medicine
and Population Health
New York University
Grossman School of Medicine
New York, NY
Website | Twitter

**Barron Lerner, MD, PhD** is a Professor of Medicine and Population Health at the NYU Grossman School of Medicine. He received his MD from Columbia in 1986 and his PhD in history from the University of Washington in 1996. In addition to his research, Lerner practices internal medicine and teaches medical ethics and the history of medicine.

Dr. Lerner is the author of five books, including *The Breast Cancer Wars: Hope, Fear and the Pursuit of a Cure in Twentieth-Century America*, which won the William H. Welch award from the American Association for the History of Medicine. Dr. Lerner also publishes extensively in scholarly journals and contributes essays to the New York Times, Slate and the Washington Post, among others. He has also appeared on numerous NPR broadcasts, including "Fresh Air," "All Things Considered" and "Science Friday."



**DONALD LEVINE, JD**Patient and Family Advisory Council
University of Chicago Comprehensive
Cancer Center
Chicago, IL



**Donald Levine, JD**, partner in the Chicago, Illinois, law firm of Latimer LeVay Fyock LLC, has extensive experience and significant expertise providing services to clients in practice areas including corporate, banking and business transactions, commercial and residential real estate and financing transactions, employment law, construction disputes and general commercial litigation. He also provides guidance to certain charitable and religious

As part of his ongoing commitment to community service, Donald has participated for over six years as a member of the Cancer Center Patient and Family Advisory Council at the University of Chicago Medical Center. As a member of that PFAC, he is and has been able to share his insight on patient and caregiver issues as a cancer survivor himself and as the primary caregiver for over 20 years for his late wife Susan, and then several years later, as primary caregiver for 3 years for his partner Terry before her passing late last year.



FRANK LICCIARDI Chair Emeritus, PFACQ Memorial Sloan Kettering Cancer Center New York, NY

**Frank Licciardi** is Chair Emeritus of the Patient & Family Advisory Council for Quality (PFACQ) at Memorial Sloan Kettering Cancer Center (MSKCC).

Following his successful treatment for metastatic gastric cancer, Mr. Licciardi began offering emotional support to patients via the Patient-to-Patient counselling program. He subsequently helped with the development and launch of PFACQ—eventually serving as a Co-Chair. He has served on the Hospital Quality Assurance Committee, Data Governance Committee, Operational Excellence Integration Team, Teleoncology Steering Committee, the Radiology Quality Assurance Committee, and multiple working groups comprising the Epic implementation initiative.

Mr. Licciardi developed, launched, and continues to host MSK's version of Death Over Dinner which has brought over 1,200 people within the MSK community together to openly discuss grief and end-of-life preparedness. Mr. Licciardi has also partnered on an initiative which has led to an increase in referrals of patients to MSK's Survivorship clinics, as well as the development of a suite of educational assets, and the integration of a new technology platform to create more robust and scalable Survivorship Care Plans. In 2020, he became the first patient advocate from any healthcare facility to receive the United Hospital Fund's Excellence in Health Care Award.

Mr. Licciardi also serves on the Board of Directors for the DeGregorio Family Foundation — a non-profit that has funded over \$4 million in innovative research grants focused on curing gastric and esophageal cancers. These grants have attracted over \$40 million in institutional follow-on funding from entities including the NIH. In addition, he serves as the patient advocate on the NCCN Esophageal / Gastric Clinical Guidelines committee.

Mr. Licciardi has more than 20 years of experience in wealth management and private equity and has held various leadership positions at companies including JPMorgan, Merrill Lynch, and CapitalSpring.



JESSICA MACINTYRE, DNP, MBA, APRN, AOCNP Executive Director, Clinical Operations University of Miami/Sylvester Comprehensive Cancer Center Miami, FL Twitter | LinkedIn

**Jessica MacIntyre, DNP, MBA, APRN, AOCNP** is the Executive Director of Clinical Operations and an Advanced Registered Nurse Practitioner at the University of Miami/Sylvester Comprehensive Cancer Center. Dr. MacIntyre received her Doctor in Nursing Practice and MBA from Johns Hopkins University.

She has been practicing for over 20 years in the field of oncology and currently oversees the clinical operations of various department and programs at the cancer center including, cancer support services, cancer prevention programs, cancer survivorship, the phase I research clinic, and the advanced practice providers involved in these areas. Additionally, she has publications in the areas of gastrointestinal malignances, advanced practice, and is an avid speaker on topics revolving around patient navigation, survivorship, and supportive care.

She is also the co-founder and the Director of the Oncology Nurse Practitioner Fellowship Program at the University of Miami; the first and only one in Florida as well as the founder of the Sylvester Patient Family Advisory Council. Most recently, she was appointed on the Board of Directors for the Oncology Nursing Society.



ALISON NALEZYNKSI, BS, LEAN SIX SIGMA BLACK BELT Process Improvement Engineer Memorial Sloan Kettering Cancer Center New York, NY LinkedIn

**Alison Nalezynksi, BS, Lean Six Sigma Black Belt** is a Process Improvement Engineer at Memorial Sloan Kettering Cancer Center. She works on the Training, Education, & Development team within the Operational Excellence department.

Alison received her Bachelor of Science in Industrial Engineering from Quinnipiac University, has seven years of experience in the healthcare industry, and has earned a Six Sigma Black Belt.

She is passionate about training and empowering others to leverage continuous improvement techniques across MSK.



KATE NIEHAUS, BA, MBA Chair Emeritus, PFACQ Memorial Sloan Kettering Cancer Center New York, NY

**Kate Niehaus, BA, MBA** was the Founder and Inaugural Chair of the Memorial Sloan Kettering Cancer Center's Patient and Family Advisory Council for Quality (PFACQ) and continues to serve as a patient advisor in that group. She is also a member of the Inter-disciplinary Quality Assessment Committee at the hospital and provides peer support to other cancer patients through the Patient to Patient Program.

Ms. Niehaus has been a patient advocate or stakeholder on a number of studies at MSK and is Co-Chair of the Research Advocacy Subcommittee of MSK's PFACQ. She is a member of ASCO's Conquer Cancer Grants Selection Committee and was trained as an advocate through a pilot program run by ASCO.

She has served on a Technical Expert Panel for the project, "Quality Measure Development: Supporting Efficiency and Innovation in the Process of Developing CMS Quality Measures" and as a member of the Quality Committee for the Alliance of Dedicated Cancers Centers. She has spoken publicly about her experience as a patient and has published articles through NEJM Catalyst and the Journal of Oncology Practice about her experience as MSK's PFAC Chair and the use of a PFAC to hear the patient's voice.

She has a BA from Wesleyan University and an MBA from Harvard University.



CRISTINA PEREZ, MBA
Director of Patient Experience
Moffitt Cancer Center
Tampa, FL
LinkedIn

**Cristina Perez, MBA** is the Director of Patient Experience at Moffitt Cancer Center in Tampa, FL, she joined the Cancer Center in January 1997. As the Director of Patient Experience, Mrs. Perez is responsible for leading the patient experience efforts for Moffitt Cancer Center. Mrs. Perez is committed to enhancing the level of personalized, compassionate, care that patients receive at Moffitt. Mrs. Perez oversees different areas such as patient relations, patient satisfaction, international relations, concierge services, Patient and Family resource center, and Patient and Family Advisory Program and Council.

The patient experience team leads the patient satisfaction efforts for the Center, specializing in patient satisfaction surveying, reporting and analysis, training, and patient experience performance improvement initiatives. The team collaborates with the Center's leaders, team member, patients, and their loved ones to translate the voice of the patient into the delivery of compassionate service and coordinated care with the goal of reducing patient suffering.

The Patient and Family Advisory Program and council works to instill the fundamental ideas of patient- and family-centered care in the minds and hearts of Moffitt team members, faculty, and researchers by forming cooperative relationships with patients and families. The team collaborates closely with those who have battled cancer and have chosen to support Moffitt as peer visitors and patient and family advisers. This provides patients and caregivers a venue to share their experiences and to make a difference for the next Moffitt patient.



FERNANDA POLUBRIAGINOF, MD, PHD Senior Director, Clinical Informatics Memorial Sloan Kettering Cancer Center New York, NY

**Fernanda Polubriaginof, MD, PhD** is a Senior Director in the Informatics Division and Assistant Attending Informaticist at Memorial Sloan Kettering Cancer Center. Leading product strategy, she created a portfolio of consumer digital products that supports health consumers and patients including telemedicine, electronic patient-reported outcomes, remote patient monitoring, and MSK's patient portal. As a physician scientist, she is co-investigator in large federal grants investigating ways to utilize technology to enable innovative hybrid care models and foster consumer engagement.

Prior to her arrival at MSK, she worked at NewYork-Presbyterian Hospital where she led the evaluation of enterprise-wide telemedicine initiatives and the development of the analytics capabilities to support the first heart failure value-based care program. She received her medical degree (MD) at Universidade de Santo Amaro (São Paulo, Brazil) in 2012 and her PhD in Biomedical Informatics at Columbia University in 2018.



**TATE RONDOT, BS**Manager Patient Support Services
Siteman Cancer Center
Saint Louis, MO

**Tate Rondot, BS** is Manager of Patient Support Services at Siteman Cancer Center in St. Louis Missouri. Tate manages the Volunteer Services program, the Barnard Health and Cancer Information Center, grant-funded programs and leads the Young Women's Breast Cancer Program. She also manages Siteman's Patient and Family Advisory Council (PFAC).

With extensive knowledge and experience in the healthcare industry, Tate believes strongly that patient engagement is crucial with regards to positive patient outcomes. Working alongside Siteman's PFAC, Tate identifies problems and offers solutions throughout the care continuum, leading to an improved patient experience and increased satisfaction scores. Tate understands that each patient is someone's family member and keeps that in mind when developing programs and services.

When she isn't trying to help make the cancer journey easier for patients, Tate enjoys doing anything outdoors, watching her kids play sports and spending time with family.



JOHANNA SCHOEN, PHD Co-Chair, PFACQ Memorial Sloan Kettering Cancer Center Lambertville, NJ

**Johanna Schoen, PhD** is a caregiver volunteer and currently co-chair of the Patient and Family Advisory Council [PFACQ] at MSK. She joined PFACQ in 2017 and currently sits on the Ethics Committee and the LGBTQ Committee.

In her professional life, Johanna is a professor of History at Rutgers University-New Brunswick where she teaches and researches the history of medicine. She is the author of two books: Choice and Coercion: Birth Control, Sterilization, and Abortion in Public Health and Welfare in the Twentieth Century, (Chapel Hill: University of North Carolina Press, 2005) and Abortion After Roe (Chapel Hill: Univ. of North Carolina Press, 2015) which won the Welch Medal of the American Association for the History of Medicine. In addition, she has edited an anthology on Abortion Care as Moral Work: Ethical Considerations of Maternal and Fetal Bodies (New Brunswick, NJ: Rutgers University Press, 2022). She is now working on a book, Life and Death in the Nursery, on the history of Neonatal Intensive Care Units. At MSK, she works on improving end of life conversations between clinicians, patients, and caregivers.

Johanna lives with her wife Bev and their heavily shedding black lab, George, in Lambertville, NJ.



**KEREN STRONACH, MPH**Cancer Services Patient Experience
Manager
UCSF Health
San Francisco, CA



Her past experience includes directing the Ida and Joseph Cancer Resource Center at the UCSF Comprehensive Cancer Center; managing Pathways, a breast cancer trial at Kaiser Permanente; and founding and running the Israel AIDS task force in Haifa, Israel.

She has authored a number of publications, including *Survivors' Guide to a Bone Marrow Transplant: What to Expect and How to Get Through It*, and a follow-up book *Survivorship Guide for Bone Marrow/Stem Cell Transplant: Coping with Late Effects*.



ANN THALER-SHORE, MPA, MPT, BS Associate Director, Operational Excellence Memorial Sloan Kettering Cancer Center New York, NY

**Ann Thaler-Shore, MPA, MPT, BS** is currently Associate Director of the Training, Education and Development portfolio in the Operational Excellence department at MSK. She holds Masters degrees in Public Administration and Physical Therapy as well as a Bachelors of Science in Exercise Physiology.

Ann has has earned certifications as a Lean Six Sigma Black Belt, Improvement Advisor, and Change Management practitioner. She has extensive experience in health care in various roles, and is passionate about empowering others.



**ELIZA WEBER, MBA**Chair Emeritus, PFACQ
Memorial Sloan Kettering Cancer Center
New York, NY

**Eliza Weber, MBA** is Chair Emeritus of MSK's Patient Family Advisory Council for Quality and has been a member of the council since its inception in 2015. She has served on MSK's Hospital Quality Committee, Department of Medicine QA, Pediatric QA as well as the Quarterly Quality Leadership and Patient Care Committees. On PFACQ, she has led initiatives to increase referrals of patients to MSK Survivorship, increase patient representation on quality committees, and improve sleep for patients staying at the hospital. She is also deeply involved in the hospital's patient facing digital initiatives including the transition to Epic.

Eliza has been a dedicated activist for pediatric cancer causes since her son was diagnosed with cancer in 2004. She has lobbied members of Congress, served on the Manhattan board of the Pediatric Cancer Foundation and as annual campaign chair for Chai Lifeline, and led an MSK Cycle for Survival Team for 12 years. She actively raises money for pediatric cancer awareness, research, patient care, and legislative reform.



MELISSA ZABLOCKI, MPH Associate Director, Strategic Initiatives Memorial Sloan Kettering Cancer Center New York, NY

**Melissa Zablocki, MPH** is an Associate Director - Strategic Initiatives at Memorial Sloan Kettering Cancer Center (MSK) in the Department of Strategy and Innovation. She manages complex, multi-disciplinary programs with a concentration on innovation implementation; this entails ideation, refinement, build and implementation of strategic innovation programs within a large organization. These programs aim to transform how individuals connect with MSK through the design of human-centered strategies, experiences, services and spaces throughout the cancer continuum. Specifically, Melissa has worked on programs for those at high-risk, in active treatment, or at end-of-life.

Melissa continues to be focused on building and leading high-performing, crossfunctional teams, integrating innovative thinking and practice into structures of work, fostering cultures of psychological safety and bringing new ideas to life!

Melissa received her MPH from New York Medical College, with a concentration in health policy and management. She is passionate about volunteering for organizations striving to end food insecurity.

We'd like to extend our sincerest gratitude to all the speakers for their contribution to this Symposium.

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