

Clinical Trial Participants

Patient & Family Advisory Council for Quality (PFACQ)

Clinical Research Study Management and Compliance (CRSMC) Course

October 23, 2005



Memorial Sloan Kettering
Cancer Center

QSURE Panel: Clinical Trial Participants



Jodi Eisner



Joan Frankle



Ray Gustin



Annie Ellis

PFACQ

*a partnership of patients, family, caregivers and staff working to ensure **the patient and family voice** is integrated into the institution's strategy & processes with the goal of providing the highest quality patient- and family-centered care*



Memorial Sloan Kettering
Cancer Center

THE UNIVERSITY OF TEXAS
MDAnderson
Cancer Center



UCSF Health



Our Strategy

To integrate the **patient, family, and caregiver perspective** into every aspect of MSK's efforts of ending cancer for life.

Our Goal

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.

Ten years of partnership:
delivering patient and caregiver
perspectives to improve patient care

Annie Ellis, Co-chair
Judy Yudenfriend, Co-chair
Joan Taback Frankle, Vice Chair

DQS Leadership & Support

Dr. Garrett Nash
VP, Quality & Safety

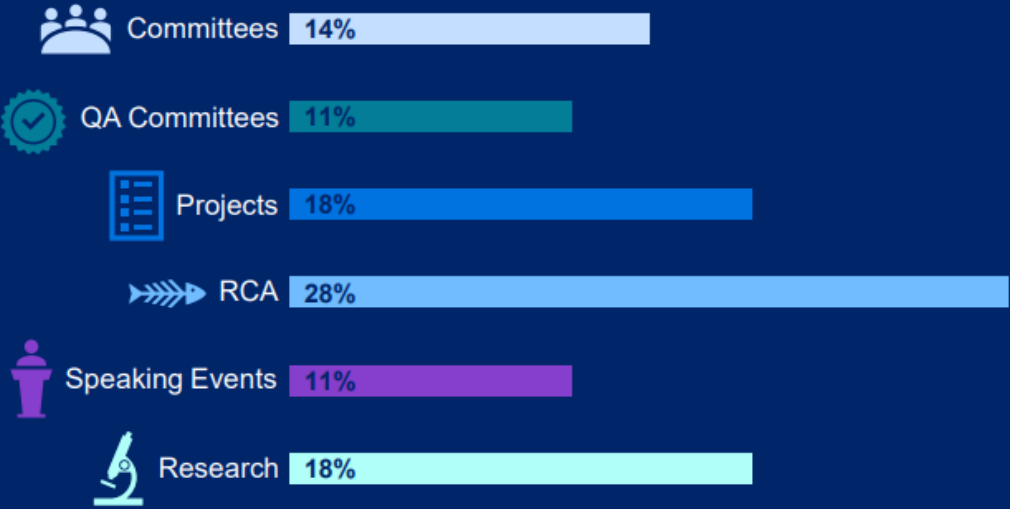
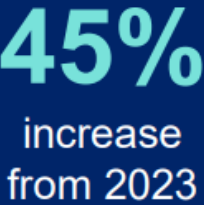
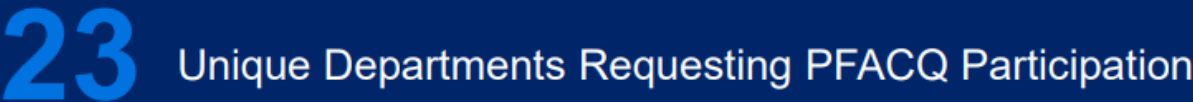
Elizabeth Dunlop
PFACQ Senior Manager

Christine Mezzina
PFACQ Coordinator

Physician Champions:

Dr. Gabriela “Gaby Bambrick-Santoyo
Dr. Fiyinfolu Folu” Balogun

PFACQ in Numbers



PFACQ-Initiated Priorities



Death Over Dinner



Sleep Study



Adult Survivorship



Annual Panels



Genetics



**EOL: Clinicians'
Roundtable**



**National PFAC
Conference**

PFACQ Research Committee



Share patient stories



Sounding boards



Review lay abstracts



Provide LOS



Serve as part of research team



Build relationships with researchers



Connect patients with training and support to serve in research activities



Forum for research dialogues

PFACQ

Research Committee

Core Members

Ellen Landsberger, MD (Ret)

- MetsBC, Endometrial
- Project LEAD
- CRUK Grand Challenges
- ASCO Breast Cancer Survivorship WG
- Translational Breast Cancer Research Consortium
- GRASP

Mike Philbin, PhD (Chemistry)

- Prostate
- BRCA2, Screening CLTR
- PCORI Advisory Board
- SNMMI: Society of Nuclear Medicine and Molecular Imaging
- FORCE
- MSK Prostate SPORE

Sabine Schwab, PhD

- Brain
- American Brain Tumor Association
- National Brain Tumor Society
- Stanford MedX ePatient

Kate Niehaus, MBA

- Breast, melanoma, urothelial
- Lynch Syndrome
- I/O CLTR
- Research Advocacy Network
- ASCO/Conquer Cancer

Gitte Joergenson, PhD (Psychology) (Non-MSK PFACQ)

- Lobular BC
- AACR SSP
- Lobular BC Alliance
- DoD BCRP
- ASCO/CC

Annie Ellis

- Ovarian (recurrent), breast, CLTR
- Past Chair of NCI Council of Research Advocates
- Past Co-Chair NCI Patient Advocate Steering Committee (Gynecologic Cancer Steering Committee)
- FDA, ASCO/Conquer Cancer, AACR, SGO/FWC, IGCS, OCRA, DoD CDMRP OCRP, RTFCCR

We welcome opportunities to connect:



Meetings w/PFACQ Co-chairs
as needed (initiatives, concerns)



Attend PFACQ meetings
as observer or presenter (10-20 minutes)



PFACQ Patients and Caregivers

- **Focus Groups and Speaking Panels** (*convened as needed*)
- **Engage individual PFACQ members**
 - ◆ **Informal Advisor** (*quick feedback/viewpoints*)
 - ◆ **Consultant** (*short-term commitment*)
 - ◆ **Collaborator/Project Team Member** (*ongoing involvement*)

To arrange: contact Elizabeth Dunlop / Christine Mezzina / Co-chairs



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