



JULY 2022

Patient Family Advisory Council

ANNUAL REPORT

June 2021-July 2022

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PFAC OVERVIEW

MISSION

To promote and support patient-and family-centered care at The Sidney Kimmel Cancer Center at Thomas Jefferson University Hospital by personalizing, humanizing, and demystifying the healthcare experience.

PURPOSE

The Sidney Kimmel Cancer Center created a Patient and Family Advisory Council (PFAC) because we recognize that patients and families are a valuable and critical resource. The purpose of our PFAC is to create a venue where staff and patient and family advisors can work in partnership to identify and address challenges in our cancer center.

OBJECTIVES

- To provide ongoing feedback that aids in establishing organizational priorities and in addressing patient service issues.
- To assist in promoting highly effective practices in response to patient/family needs and priorities.
- To improve the patient experience as measured by patient satisfaction survey scores, personal letters, data-gathering tools and metrics.
- To educate PFAC membership so they can become ambassadors to and for Thomas Jefferson University Hospital and the community.
- To strengthen communication and collaboration among patients, families, caregivers and staff.
- To promote patient and family advocacy and involvement.



EXECUTIVE SUMMARY

The establishment of the Sidney Kimmel Cancer Center at Jefferson Hospitals' Patient and Family Advisory Council (PFAC) was initiated by the Cancer Support and Welcome Center in September 2019. We adopted an approach to guarantee that members listen better and hear more, that we consider and converse more easily as a team, and that we transmit our thoughts and recommendations to those who can take action. All of this is being done with a respect – if not a reverence—for the core values of Jefferson. The demographic of the council is nineteen patient and family volunteer Advisors supported by members of Jefferson's leadership team, staff, and members of our medical community.

The Patient Family Advisory Council meets 6 times a year for 2 hours at a time. We work with a well-defined agenda structured to:

- 1) encourage guest speakers to bring relevant topics to be reviewed by the advisors,
- 2) allow for open discussion and feedback among advisors
- 3) suggest an action plan based upon feedback.

We welcome expert guest speakers throughout the campus. To be more patient-centric, most guest speakers are seeking ways to improve their specific area of expertise, policies, or procedures. These bi-monthly meetings also allow us to follow-up on topics we have already worked on and discuss new areas of interest that need further exploration.

In 2020, the COVID-19 pandemic dominated the headlines and daily life around the globe. The new, but solid foundation of the patient and family advisory committee and their engagement enabled SKCC's PFAC to quickly transition to virtual collaboration. Health care, along with the PFAC, was forced to adapt to changes and challenges brought by the coronavirus. For patient and staff safety, visitor restrictions were implemented, the use of telehealth grew exponentially, and stringent infection control measures were put into place. Despite these interruptions, staff continued to seek feedback, and members of the PFAC were quick to respond. As group gatherings were restricted, the PFAC successfully moved to a virtual platform with minor interruptions to our scheduled meetings. Member participation remained high despite the move to online meetings. Online meetings also allowed new members to join the PFAC that are geographically distant to our facility, thus highlighting the voice of patients traveling for care.

This report is a collaboration between advisors and Co-Chair Members. Distribution of the document is at the sole discretion of the Jefferson Hospital.

PFAC MEMBERS

DIRECTORS

Lisa Capparella, MSS, LCSW, OSW-C

Patient, Family Community Programs Manager

Miriam Pomerantz Kadosh, MSW, LSW

Oncology Social Worker

STAFF ADVISORS

Andrew E. Chapman, DO, FACP

Director, Sidney Kimmel Cancer Center, EVP
Oncology Services, Professor of Medical
Oncology, Clinical Professor, Jefferson
College of Nursing, Co-Director, Jefferson
Senior Adult Oncology Center

Christopher Gantz, MBA, DBA

Senior Director Research Office

Gregory Garber, MSW, LCSW

Administrative Director, Division of
Supportive Oncology

Matthew Huesser, MBA, DBA

Vice President Cancer Research
Administration

Katherine Rehm, MSW, LCSW

Clinical Oncology Social Worker

Jodi Sandos, MSW, LCSW

Clinical Oncology Social Worker

Sung Whang, CRNP

Thoracic/Esophageal Surgery

Lindsay Wilde, MD

Acute Leukemia Program

PATIENT & FAMILY ADVISORS

David Caldarella

Denise Carroll

Patti Colucci

Beverly Duncan

Mark Hughson

Sue Hughson

Felicia Johnson

Pete Liston

Peter Lonngren

Brigid Maguire

Margo Murray

Stuart Porter

Cheri Venturi

IN HONOR OF

RETIRED MEMBERS

John Harbold

Esophageal and Prostate Cancer Survivor

Ernest Distefano

AL amyloidosis Survivor

Sharon Distefano

Caregiver

Saleem Allen

Acute Myeloid Leukemia Survivor

Dr. Robert Palma

Prostate Cancer Survivor

IN MEMORY OF

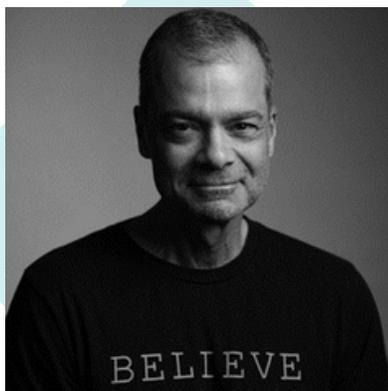
Sarah Rosentein

Colon Cancer

Carmela DiMaria

Colon Cancer

MEMBER BIOGRAPHIES



DAVID CALDARELLA was diagnosed at age 41 with Stage IV head and neck cancer. He successfully completed treatment at Thomas Jefferson University Hospital and joined the PFAC to support current patients and the hospital system. He is the CEO and co-founder of David's Dream & Believe Cancer Foundation (DDBCF), a 501(c)(3) grassroots nonprofit that provides hope through financial assistance, wellness resources, and patient support to families affected by a cancer diagnosis. As of April 2022, DDBCF has provided 2,285 patients with two million dollars in direct financial aid! David is a proud Villanova University alum who served on multiple patient advocacy committees at the National Institute of Health (NIH) between 2014-2018. In addition to his life's work, David's family means the world to him especially, his nephew Tim and nieces Isabella and Sabrina.

DENISE CARROLL is a 13 year breast cancer survivor. She was then diagnosed with metastatic endometrial cancer in 2018. She has been married to her husband for 32 years, has two daughters and a grandson. She loves spending time with her family and is forever grateful for the love and support from family and friends. Denise joined the PFAC in 2020 to share in the mission of supporting and promoting patient and family-centered care at the SKCC, and to be a voice in the constant progress of cancer care.



PATTI COLUCCI joined the PFAC after losing her husband, Sam, to Glioblastoma Multiforme in February 2020. She recognizes the important work of the Patient and Family Advisory Council for the Sidney Kimmel Cancer Center. Patti hopes to represent the voice of those facing terminal cancer diagnosis as well as their family and caregivers. She is grateful to be involved with this important work. In addition to being involved with the PFAC, Patti is a mother of two children (both now in college), works as a school social worker and runs a nonprofit, Cancer Legacy in Action Projects (CLAP).

MEMBER BIOGRAPHIES



BEVERLY DUNCAN was diagnosed and treated for Endometrial Cancer in May 2018 at Sidney Kimmel Cancer Center and was treated with chemotherapy and radiation. She is well connected to her church and assists with a food pantry. Ms. Duncan has been connected with a peer buddy and is a buddy for those newly diagnosed with endometrial cancer. In her spare time, she enjoys being with her family and babysitting her grandchildren. She is compassionate about health care disparities and screening for cancer.

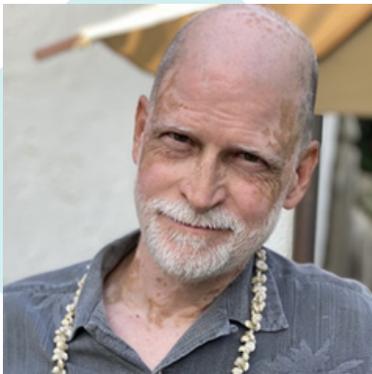
MARK HUGHSON grew up in Somerville, New Jersey and works in the insurance industry. Mark just celebrated his 25th anniversary with his company Erie Insurance! Mark was diagnosed with APL leukemia in 2019 and is grateful for the quick response of Dr. Husseinzardeh and Dr. Wilde who knew something was not right. Dr. Wilde quickly got the lab to run a full profile and was able to catch the APL diagnosis and admit Mark into the oncology unit to be treated immediately. Mark and his wife Sue, also a member of the PFAC, are college sweethearts. They are filled with gratitude for the support they have received and are committed to giving back to this community.



SUE HUGHSON has lived in the South Jersey area all of her life. She is a retired special education teacher. Sue has a lifetime of caregiving for various family members and represents the caregiver voice on the PFAC. When her husband Mark was diagnosed with APL leukemia in 2019, Sue was his caregiver. Sue has a lot of experience as an advocate for senior citizens as well as for children and families with special needs. Sue has a passion for health equity and health care for all.

MEMBER BIOGRAPHIES

FELICIA JOHNSON joined the PFAC in 2019, and she is a Patient Advocate in the Cancer Community. Her experience as a breast cancer patient has inspired her to use her voice to advocate for patients' needs. Felicia has attended the National Breast Cancer Coalition's Project LEAD, Breast Cancer Scientific-Training Program, the Patient advocate program at the San Antonio Breast Cancer Symposium, and is a Thomas Jefferson Hospital's Cancer Buddy. Her heart's desire is to bring information to the toolbox to help those affected by cancer.



PETE LISTON has been a patient at the Sidney Kimmel Cancer Center since 2015 and has been a member of the Patient and Family Advocacy Council (PFAC) for two years. Diagnosed with acute myeloid leukemia (AML) in 2015, Pete's cancer journey has included a stem cell transplant, surgery, radiation and ongoing chemotherapy. Before his diagnosis, he was the primary caregiver during his wife's illness with Stage IV colon cancer. His participation on the PFAC has allowed him to consult for the Patient Centered Outcome Research Institute and Jazz Pharmaceutical's Find the Right Fit program. Additionally he is a mentor of Imerman Angels, a program that matches patients with similar diagnoses to offer one-on-one comfort and understanding.

MEMBER BIOGRAPHIES

PETER LONNGREN came to Thomas Jefferson University Hospital in 2007 and was diagnosed with head and neck cancer. He also has been treated for numerous skin cancers including melanoma and in 2016 prostate cancer. Peter retired in 2012 and became a Cancer Buddy in the in the Buddy Program as a phone buddy and later as a Buddy-on-the-Spot volunteer. He served a term on the Thomas Jefferson University Hospital Patient and Family Advisory Council and now on the Patient and Family Advisory Council for the Sidney Kimmel Cancer Center. His goal is to help cancer patients get through a difficult time and give back to his Thomas Jefferson University Hospital family for helping him.



BRIGID MAGUIRE was diagnosed with stage IV colon cancer in August of 2012. She received her treatment at Sidney Kimmel Cancer Center. She is also the primary caregiver for her husband who is being treated for relapsing leukemia. She has been a member of the Patient and Family Advocacy Council for two years. Brigid hopes her unique perspective as both a cancer patient and a primary caregiver will help to inform others on what families as well as patients need during and after treatment.

MEMBER BIOGRAPHIES

MARGO MURRAY was diagnosed with ovarian cancer in 2019. Having two daughters and a strong family history of breast cancer, she joined a clinical trial to try and help move the treatment of ovarian cancer forward. Margo joined PFAC in 2020 and is glad to represent the patient voice on a council whose goal is to improve the communication between patient and doctor.



STUART C. PORTER, PH.D. was diagnosed with Prostate Cancer in 2016. Stuart successfully underwent radiation treatment at Jefferson. On retiring in 2017, Stuart joined the Jefferson Buddy program to provide encouragement to cancer patients and their caregivers by showing that cancer treatment can truly lead to a successful outcome. Stuart joined the Jefferson Cancer PFAC team in 2021 to provide a patient's perspective that hopefully may help to guide the future direction for cancer treatment at Jefferson.

CHERI VENTURI was diagnosed with Thyroid Cancer in 1995 and Breast Cancer in 2020. She has been dealing with doctors and hospitals for many years. Recently, she became an ambassador for UNITE FOR HER helping other women navigate their program. She has been a special education teacher, college mentor, and student advocate for over 30 years. She wanted to join the Patient & Family Advisory Council to help other patients have a positive experience and not to feel so alone in their cancer journey.

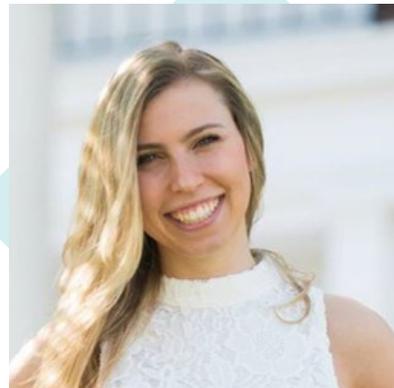


STAFF BIOGRAPHIES



LISA CAPPARELLA is an clinical licensed and board certified oncology social worker with over 17 years of experience dedicated to the medical field. She is the manager of The Cancer Support and Welcome Center at the NCI-designated Thomas Jefferson University Hospital. Lisa co-creates programs to support patients, staff and the community. In addition she manages a medical legal partnership, a massage and reiki clinic, and utilizes patient voices for important input and collaboration through the Patient and Family Advisory Council. Lisa is the co-facilitator of Schwartz Center Rounds at Jefferson. She is an active member of AOSW and helps to plan local and regional oncology conferences. She is a graduate of Bryn Mawr School of Social Work and Research and completed the Leadership Fellowship at NYU Zelda Foster Program. Lisa mentors new graduates and helps them to identify their professional identity.

MIRIAM POMERANTZ KADOSH is a licensed social worker at SKCC. Miriam works at the Cancer Support and Welcome Center where she develops and evaluates patient and family programming including support groups, wellness programs, and educational programs. She is a graduate of the University of Pennsylvania's School of Social Policy and Practice with a Master's in Social Work. Miriam is a co-facilitator of the Patient and Family advisory council, co-manages the Buddy peer match program, and an active member of the Schwartz Rounds planning committee creating a safe space for healthcare providers to talk about the human side of healthcare.



STAFF BIOGRAPHIES

ANDREW E. CHAPMAN D.O., FACP is a Professor of Medical Oncology in the Department of Medical Oncology of the Sidney Kimmel Cancer Center and a Clinical Professor in Jefferson's College of Nursing. Dr. Chapman is the Enterprise Director and Chief of Cancer Services for the Sidney Kimmel Cancer Center, the Enterprise EVP for Oncology Services and SVP for Medical Oncology at Jefferson Health, and Vice Chair for Clinical Operations for the Department of Medical Oncology. In these roles he oversees all aspects of cancer care delivery throughout the health system with a clear emphasis on patient centered comprehensive care. Additionally, Dr. Chapman is the co-founder/co-director of the Jefferson Senior Adult Oncology Center specializing in the multidisciplinary evaluation and management of older adults with cancer. Dr. Chapman is board certified in Hematology and Medical Oncology, and is a Fellow of the American College of Physicians.



DR. CHRISTOPHER GANTZ is the Senior Director of the Research Liaison Office at the Sidney Kimmel Cancer Center at Thomas Jefferson University. Since 2002 Dr. Gantz has worked on multiple projects with recruitment goals ranging from 500 to 10,000 participants. He has developed centralized research engagement programs and is leading the initiative to develop services that will reduce the burden of study recruitment across the research institute.

STAFF BIOGRAPHIES

GREG GARBER is a Licensed Clinical Social Worker and Director of Patient Support Services for the Neu Center for Supportive Medicine and Cancer Survivorship at the Sidney Kimmel Cancer Center (SKCC). In that role he manages all patient facing programs and services including Patient Education and Support Programming, Clinical Nutrition Support, Social Work Services, and numerous initiatives to better understand and address cancer disparities as they relate to health literacy, digital literacy, access, transportation, cancer screening and prevention. Greg has lectured and taught on local regional and national levels on issues related to psychosocial aspects of cancer care and have presented at numerous national conferences. Additionally Greg co-directs SKCC's Patient and Family Advisory Council.



MATTHEW HUESSER serves as the Vice President for Cancer Research Administration at the Sidney Kimmel Cancer Center at Jefferson Health/Thomas Jefferson University. Dr. Huesser has more than 17 years of business and healthcare experience, with approximately 12 years concentrated within an NCI designated cancer center. Dr. Huesser oversees cancer research administration operations for the enterprise and has played a key role in revitalizing and sustaining the SKCC working with Cancer Center leadership by providing oversight for the cancer center support grant and the NCI-designation.

KATHERINE REHM is a licensed clinical social worker at Sidney Kimmel Cancer Center. She primarily works with Neuro-Oncology and Genitourinary patients providing a safe place for supportive counseling and case management. Kate co-directs the Buddy Program and creates meaningful training programs for the peer support program. She enjoys supporting patients in helping others in the buddy program.



STAFF BIOGRAPHIES

JODI SANDOS

is a licensed oncology social worker at Sidney Kimmel Cancer Center. She has been at Jefferson for the past eight years and has worked as an oncology social worker for the past twenty-three years. She is the supervising BMT/Hematological social worker and works as an integral member of the multidisciplinary team to work with patients and families through the trajectory of their illness. As a social worker, her passion is to help patients, families, and caregivers address the psychological, social, financial, and emotional concerns that come up as they face a cancer diagnosis.



SUNG WHANG

has been a nurse practitioner in the Division of Thoracic and Esophageal Surgery for the last eight years and worked five years as a floor nurse. She has the pleasure of helping patients and families navigate the earlier stages of both lung and esophageal cancers pre-and postoperatively through work up and treatment.

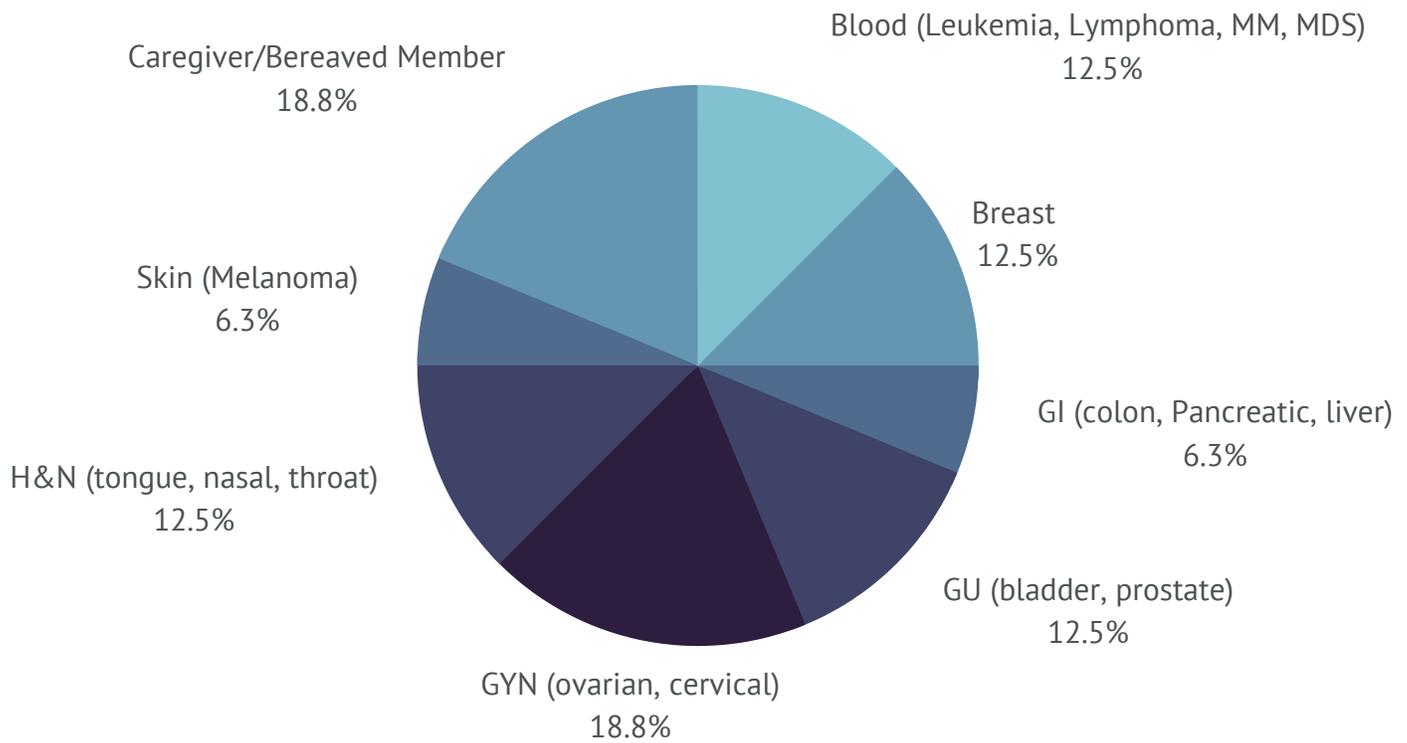
DR. LINDSAY WILDE

is an Assistant Professor of Medical Oncology at the Sidney Kimmel Cancer Center at Thomas Jefferson University Hospital. She specializes in the care of patients with blood cancers, predominantly those with acute leukemia. Dr. Wilde joined the PFAC as another way of partnering with cancer patients and caregivers with a goal of amplifying their voices to create positive changes in cancer care delivery at Jefferson



PFAC ADVISORS

DISTRIBUTION OF DISEASE SITES



FOCUS AREAS AND TOPICS

ONCOLOGY PFAC ANNUAL REPORT

Presenter: Lisa Capparella, MSS, LCSW, OSW-C

- Importance of adding more representation to the council where there is 0% representation, for example, lung cancer, brain cancer ocular melanoma, and pancreatic cancer
- Other areas for improvement include adding diversity to the panel and gaining more feedback about what council members would like to discuss in future meetings

INTEGRATIVE ONCOLOGY IN THE CANCER JOURNEY

Presenters: Dr. Nathan Handley, Greg Garber, MSW, LCSW, Lisa Capparella, MSS, LCSW, OSW-C

- Defining integrative health reaffirms the importance of the relationship between the practitioner and the patient. It focuses on the whole person. It is informed by evidence and makes use of all appropriate therapeutic approaches, health care professionals and professions to achieve optimal health and healing.
- Integrative medicine can be very effective with care where there are a lot of symptoms, stress, and burdens.
- PFAC members discussed integrative approaches they have tried and what has worked. They discussed when the appropriate time for referrals to Integrative Oncology (IO).
- HOPE note discussed- Healing Oriented Practice Environment

FOCUS AREAS AND TOPICS

MOBILE SCREEN UNIT; COMMUNITY OUTREACH AND ENGAGEMENT

Presenter: Dr. Amy Leader

- Mobile Screening Unit equipped with all the same breast cancer screening technology that is available in the hospital. Plans to extend testing to other types of cancer
- Same care received on van as hospital
- Process of Community Outreach and Engagement
 - Identifying priority neighborhoods using multiple sources to determine where cancer is most prevalent
 - Identify community partners
 - Identify who needs screening and where
- Dr. Leader and team plan to bring together researchers, patients, community members, and advocates to create a space where everyone can learn from each other.

INTRODUCTION TO TENDO

Presenter: Nanci Gonzalez

- Healthcare software app (Tendo) that plans to:
 - Attract and Book patients for appointments
 - Welcome and Check-in
 - Exam Consult
 - Check-out and Treatment
 - Follow-up and Referrals
 - Wellness and Education
- Seeking Volunteer to sit on new research as a patient reviewer for

WELCOME CENTER RE-OPENING PLAN

- Currently open for appointment only.
- Virtual Programming Success

FOCUS AREAS AND TOPICS

23RD ANNUAL CANCER SURVIVOR AND THRIVER DAY

Presenter: Lisa Capparella, MSS, LCSW, OSW-C

- Motivational panel - The Gift of Giving Back
- How should we engage care teams in a meaningful way?
- How to involve volunteers/Buddies
- Celebratory feel, first in person event in 2 years -strategic planning

CLINICAL TRIALS AT JEFFERSON- SKCC

Presenter: Dr. William Kelly

- How to engage community members and educate on clinical trial availability
- Discussion of insurance/financial concerns
- Note on history of racism, discrimination, and trauma of trial/research history in communities of color, discussion of why diversity is important

MUSIC THERAPY AS TREATMENT IN CANCER PATIENTS

Presenters: John Glaubitz MA, MT-BC, Allison McCrea MMT, MT-BC, Michelle Balcer

- How to bring individualized treatment to patients and families through music therapy
- Ideas to stream music therapy through TVs instead of TV options currently playing in waiting rooms
- Long term goal: Having a MT that follows patient all the way through their care or access at various points of treatment – how can MT therapist & interventions itself play a role at various stages
- Short term: Partner to offer music based classes in CSWC

Our Year

2021-2022



Meetings



Staff Advisors



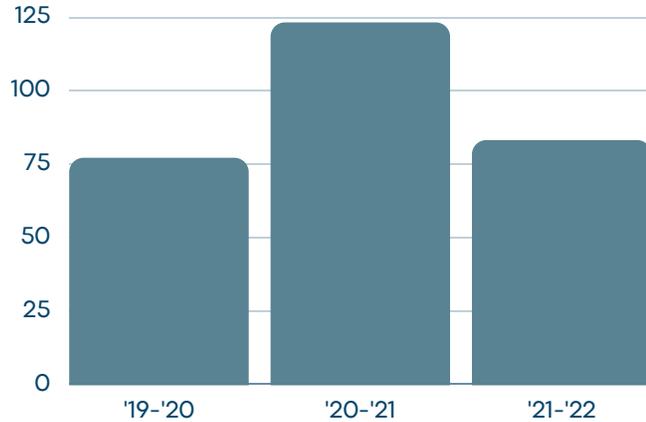
Patient, Family and
Community
Members



Guest Speakers

Program Participation

Attendance



Average Participation (per meeting)

JUL- JUN 2020	JUL - JUN 2021	JUL - JUN 2022
19.25	20.5	20.75

Though participation rates throughout the years have fluctuated, the number of meetings has also differed. Between Jul of 2019 and Jun of 2020 there were 4 meetings, 6 between 2020 and 2021, and 4 between 2021 and 2022. The average rate of participation has trended positively.

MAIN CHALLENGES

Staff Engagement and Proper use of PFAC

During the pandemic staffing was stretched thin and we experienced issues finding staff to present valuable patient-centered topics, resulting in two canceled meetings.

Membership Recruitment

Our PFAC aims to have diversity represented in all aspects, and we recognize the need to expand membership to those frequently underrepresented.

Effective use of PFAC

The PFAC functions best when presenters have a goal in mind with presenting to the PFAC as well as providing their slides in advance.

AREAS OF IMPROVEMENT

SUGGESTED FROM PFAC MEMBERS

PFAC members have asked for more senior leadership and physicians to be present to hear their voices

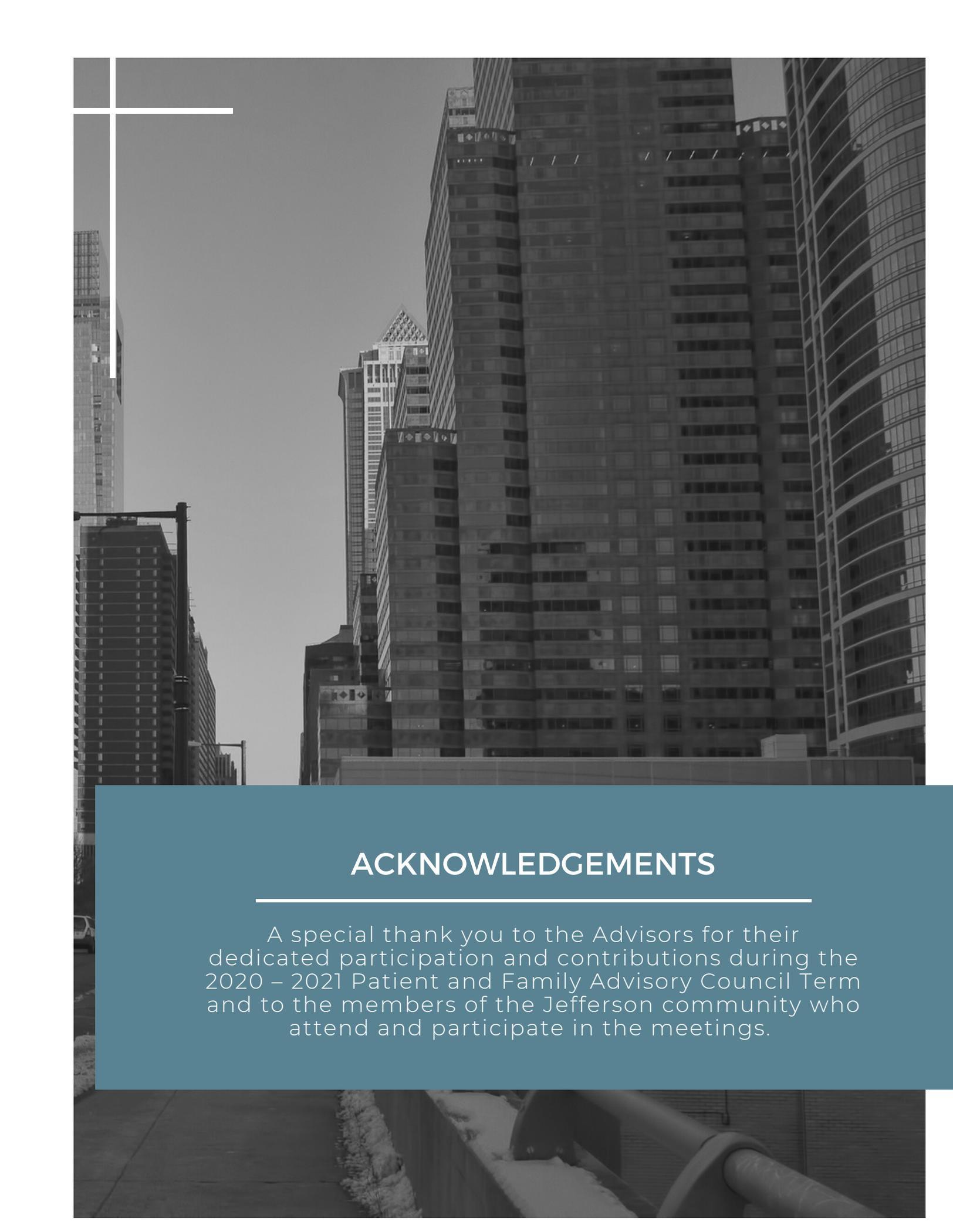
PFAC members expressed an interest in having hybrid options for meetings

PFAC members have ask for high level overview and minutes to be concise

Future Directions

2022-2023

- The PFAC will meet in a hybrid model if at least 5 members will be present in person
- Recruit potential new members to represent those cancer diagnoses not represented, with the goal of adding three new members by November 2022.
- Sign annual Confidentiality Statements beginning in September
- Engage staff to present new protocols, center, research, and policies to the PFAC



ACKNOWLEDGEMENTS

A special thank you to the Advisors for their dedicated participation and contributions during the 2020 – 2021 Patient and Family Advisory Council Term and to the members of the Jefferson community who attend and participate in the meetings.