

CONNECTIONS. MENTORSHIPS. EVIDENCE.



2005-2020
AND BEYOND



“ I wanted to create a ‘home’ for researchers who were much like my younger self. ”

—R. Sean Morrison, MD, NPCRC Director

EVERY ORGANIZATION HAS AN ORIGIN STORY...

...and I'd like to tell you ours. When I began my research career in palliative care 25 years ago, the landscape of our field was bleak. Having recently finished my geriatrics fellowship I had witnessed the suffering associated with many illnesses impacting older adults, but I was especially disturbed by the suffering associated with dementia — both from the disease itself and from its sometimes questionable treatments (tube feeding, restraints). I was determined to improve the quality of life for these patients and their families. I set out with a plan to develop a five-year NIH career development (K08) award, focused on identifying sources of suffering in advanced dementia.

But as I began developing my research ideas with mentors and advisors — sharing specific aims with NIH program officers — it quickly became clear that a palliative care proposal was unlikely to do well at a study section. With concerns about significance, measurement, patient dropout, and a lack of reviewers with palliative care expertise, my grant seemed doomed to fail.

Working with my mentor I shifted gears. I crafted a new proposal, this time targeting issues that better aligned with funding priorities (hip fracture outcomes and delirium risk factors). While these topics tangentially touched on what I truly wanted to study, the work that made my heart beat faster had to be done on the side, or funded through philanthropic dollars. I accepted I'd chosen to travel on a "safe" research pathway — which is where I remained for almost a decade, writing "fundable" proposals that were specifically focused on traditional areas of geriatrics research, such as functional and cognitive outcomes and means of enhancing them. At this point practical necessity was fully leading the charge. My passionate interests remained in the shadows, and I sorely lacked the support and fellowship of a like-minded professional community that might have convinced me to do otherwise.

So when our team was approached by the Kornfeld Foundation in 2005 to seek insight into promoting palliative care research, I thought back over my own research career. What contributions might I have made if I'd had the required pilot data to convince an NIH study section that my methods were feasible and my measures were reliable and valid? What if the study sections to which I'd sent my work had even one or two members with palliative care expertise? And what if I'd enjoyed the support, guidance, and feedback of a community of palliative care researchers who saw the importance of my work and shared my vision?

As I strategized over the course of several weeks, I realized the true work I wanted to do with the Kornfeld Foundation was to create a "home" for researchers who were much like my younger self. I envisioned a place that would eliminate their distractions; connect them to their true ambitions; and allow them to conduct the research they are most passionate about.

Today, 15 years after that thought experiment, I remain overjoyed by the impact that the National Palliative Care Research Center has made in the palliative care community. I recognize that none of this would have been possible if it hadn't been for the courage of the Kornfeld Foundation to take a leap of faith in us, which in turn paved the way for so many other generous funders and organizations to support my vision. Finally, I would like to extend a special thanks to our entire palliative care research community. Your ambition, scientific talent, and educated risk-taking are infectious and inspiring. Undeniably, palliative care research and its evidence base are in a better place today because of all of you.



R. Sean Morrison, MD, NPCRC Director

WE'VE GROWN INTO A HIGHLY RESPECTED NATIONAL ORGANIZATION.

Since our founding in 2005, the National Palliative Care Research Center (NPCRC) has become a home for groundbreaking researchers who share a commitment to easing the suffering and improving the quality of life for patients and families facing serious illness.

We are known for leading the scientific and palliative care communities with:



GOALS

CREATING
a new cadre of
scientific leaders

PROVIDING
technical assistance
for palliative care
investigators to better
compete for and access
federal research
funding

ESTABLISHING
and nourishing a
national community
of palliative care
scientists



RESEARCH AREAS

RELIEF of pain and
other suffering

COMMUNICATION
among patients,
families, and clinicians

EVALUATION AND
DEVELOPMENT
of new palliative care
clinical models



MISSION

Strengthening the evidence base
needed to advance palliative care health
policy and clinical practice

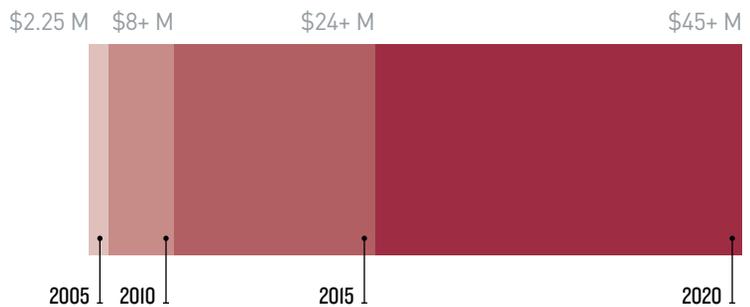
WE'VE PUT VISIONARY PHILANTHROPY TO WORK.

NPCRC is the result of visionary philanthropy. In 2005 the Emily Davie and Joseph S. Kornfeld Foundation established NPCRC at New York City's Icahn School of Medicine at Mount Sinai. Funded with an initial challenge grant of \$2.25 million, we subsequently received investments by more than 20 organizations and individual donors, which more than doubled our initial annual operating budget.

RAISED MORE WEALTH

Since our inception, NPCRC's financial growth has been steady and robust.

\$45 M+
RAISED FOR PALLIATIVE CARE RESEARCH SINCE 2005



PRESENT AND PAST DONORS

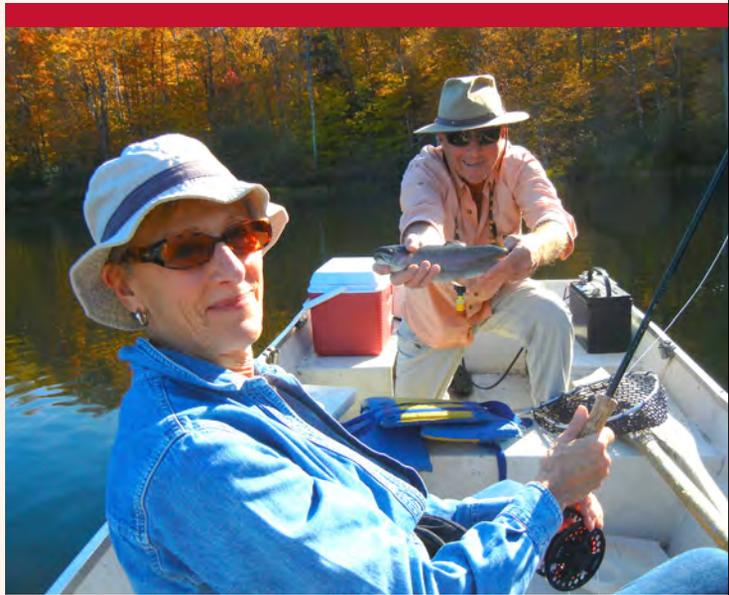
ALZHEIMER'S FOUNDATION OF AMERICA • AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE • AMERICAN CANCER SOCIETY • THE ARTHUR VINING DAVIS FOUNDATIONS • THE ATLANTIC PHILANTHROPIES • THE BROOKDALE FOUNDATION • CAMERON AND HAYDEN LORD FOUNDATION • EMILY DAVIE AND JOSEPH S. KORNFELD FOUNDATION • GORDON AND BETTY MOORE FOUNDATION • GOTTESMAN FOUNDATION • HEARST FOUNDATIONS • HOSPICE & PALLIATIVE NURSES ASSOCIATION • LIVESTRONG FOUNDATION • MILL PARK FOUNDATION • NATIONAL INSTITUTE ON AGING • THE OLIVE BRANCH FOUNDATION • OPEN SOCIETY FOUNDATIONS • PARTNERSHIP FOR PALLIATIVE CARE • PAT & JAY BAKER FOUNDATION • THE Y.C. HO/HELEN AND MICHAEL CHIANG FOUNDATION

A SPECIAL THANK YOU

To all those who have believed in our mission: Your trust and financial support have ensured a strong return on your investment, and we are deeply grateful. To the Kornfeld Foundation, our founding partner, we extend special thanks for your loyal friendship.

We would particularly like to recognize the great achievements of Ms. Bobye List, the Kornfeld Foundation's executive director since 2000. Ms. List is widely celebrated in the funding community as a thought leader, an inspirational collaborator with other funders, an innovative grantmaker, and a fierce advocate for palliative care. As a palliative care research funder pioneer, she co-funded the first training grants for early palliative care fellowships. Realizing research was the field's critical need, in 2004 Ms. List approached Dr. Diane Meier and Dr. Sean Morrison with the idea of creating a philanthropically-funded research center that could help lead and develop the much needed evidence base of palliative care. As Dr. Morrison recalls, "Boby List understood the fastest and most effective way to grow a field was to invest in research leaders — both those at the beginning and those at the midstages of their careers — and provide them with the support, tools, and technical assistance they needed to be successful." Her insight seeded the ground from which NPCRC has grown.

Over the past decades — and in her quiet, unassuming way — Ms. List has asked all the right questions of all the right people. An eager participant in the Foley retreats, she reveled in meeting and befriending junior researchers and following up with past grantees. Together they hiked, fished, shared meals, and discussed the details of each scientist's research. Each



Ms. Bobye List and a fly fishing guide in Canada during the tenth annual Foley Retreat. Both the snapshot and the fish were caught by Dr. James Tulsky.

investigator who crossed paths with Ms. List left the encounter feeling supported, invigorated, and encouraged. As Dr. Kathleen Foley herself noted, "Both Bobye and the Kornfeld Foundation should be honored as exemplars of how philanthropy can help build a field."

Along with bestowing upon NPCRC the generous financial support of the Kornfeld Foundation, Bobye List has freely given us new ideas and wise counsel as to how philanthropy can make a difference. She taught us to leverage investments to further fund NPCRC and helped us achieve our two most important sustainable outcomes: creating and supporting palliative care researchers throughout the country, and increasing funding for palliative care research. Today Ms. List's impact on palliative care extends well beyond NPCRC; hers is a far-reaching legacy.

We will deeply miss our friend Bobye. We wish her an active and well-earned retirement.

WE'VE PUT PALLIATIVE CARE ON THE MAP.

NPCRC established partnerships and built community with leading federal organizations and private sector philanthropists. Our early partnerships strengthened NPCRC's reach and impact by providing a united voice focused on palliative care research. Together we continue to support national palliative care policy, increase public awareness of palliative care's importance, and embed and formalize palliative care within the nation's research infrastructure.

Notable Outcomes:

- > Development of National Institutes of Health (NIH) and Patient-Centered Outcomes Research Institute (PCORI) program announcements and funding opportunities in palliative care research
- > Federal legislation advancing palliative care research funding
- > Inclusion of palliative care in the National Quality Forum's quality initiatives
- > Stimulated the creation of the first U.S. palliative care research meeting: American Academy of Hospice and Palliative Medicine (AAHPM) *State of the Science* meeting

COLLABORATED WITH PARTNERS



BROOKINGS



WE'VE CREATED A NEW GENERATION OF SCIENTIFIC LEADERS.

There has historically been — and there currently remains — a national shortage of qualified investigators conducting research in palliative care. According to the Institute of Medicine, the lack of trained investigators is a major impediment to the growth of our field.

When NPCRC was created in 2005, most of the existing 51 fellowship training programs in the U.S. had only one or two fellows, and the programs followed an apprenticeship model of education, offering zero to limited research training. Starting in 2009 — following Accreditation Council for Graduate Medical Education guidelines — palliative care fellowship programs began to be designed as one-year clinical training programs...but to this day they continue to lack support for research training. Those interested in pursuing research careers must seek increased training support; for this they turn to philanthropic dollars, institutional intramural funding, or related training grants in other fields, such as oncology, geriatrics, or heart disease. In the absence of large well-funded palliative care research centers/departments, junior faculty are typically supported under the auspices of a senior investigator's grant funding. Given the small number of established senior investigators and the limited research dollars available even to them, the ability of the field to sustain and grow itself has been limited.

The annual Kathleen M. Foley Research Retreat brings together the brightest palliative care researchers in the country. It creates community, nurtures ideas, and grows the field.

NPCRC's grants have strongly contributed to addressing both the workforce and evidence gaps in palliative care research. We are best known for two signature programs that have supported investigator development: the Pilot/Exploratory Support Grants and the Kornfeld Scholars Program (formerly known as the NPCRC Career Development Awards).



Between 2005 and 2020 the NPCRC has:

FUNDED RESEARCH

121

INVESTIGATORS

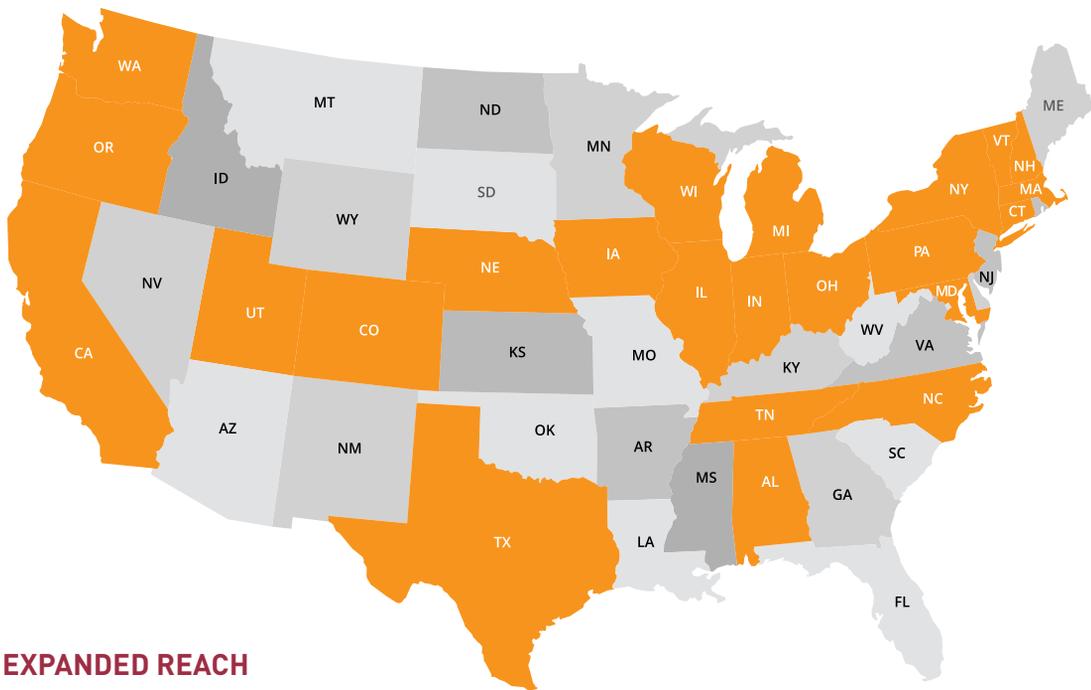
AWARDED GRANTS

101

GRANTS

> > \$18.5 M

TOTAL AWARDS



EXPANDED REACH

FUNDED

47

DIFFERENT INSTITUTIONS IN

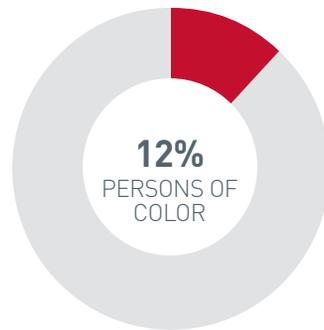
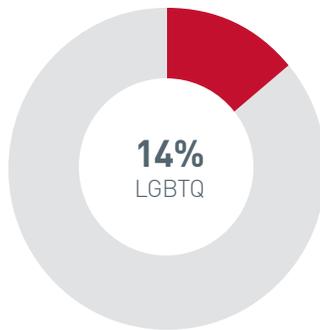
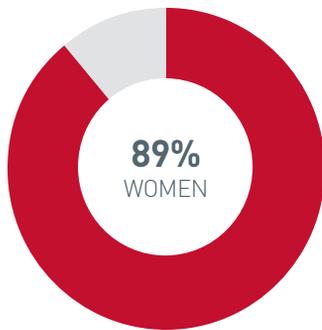
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STATES

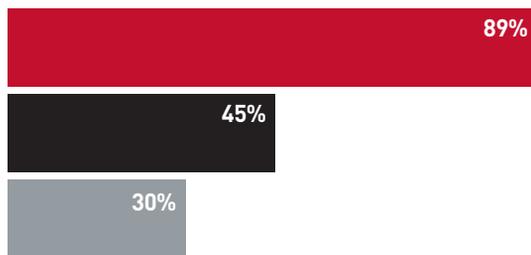
Number of NPCRC Grantees by State:

5 ALABAMA	1 IOWA	14 NEW YORK	1 TEXAS
23 CALIFORNIA	4 MARYLAND	11 NORTH CAROLINA	1 UTAH
5 COLORADO	17 MASSACHUSETTS	2 OHIO	3 VERMONT
2 CONNECTICUT	1 MICHIGAN	1 OREGON	10 WASHINGTON
3 ILLINOIS	1 NEBRASKA	1 PENNSYLVANIA	1 WISCONSIN
3 INDIANA	2 NEW HAMPSHIRE	1 TENNESSEE	

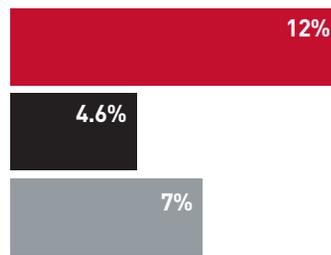
SUPPORTED UNDERREPRESENTED RESEARCHERS



WOMEN



PERSONS OF COLOR



- NPCRC Grantees
- NIH Career Development Awardees
- NIH R01 Principal Investigators

- NPCRC Grantees
- NIH Career Development Awardees
- Full-Time U.S. Medical School Faculty

NURTURED RESEARCH IN VULNERABLE POPULATIONS

NPCRC's palliative care-related grants have focused on a wide variety of subjects, including:



17%
UNDER-REPRESENTED MINORITIES



15%
CHILDREN



13%
PERSONS WITH ADVANCED DEMENTIA



9%
RURAL HEALTH



2%
OLDER PRISONERS



SHINING A LIGHT ON RACIAL DISPARITY

KIMBERLY S. JOHNSON, MD

Professor of Medicine, Duke University

Senior Fellow in the Center for the Study of Aging and Human Development

Member of the Duke Cancer Institute

2007 NPCRC Career Development Awardee:

Organizational Variability and Racial Disparities in Hospice Use

Dr. Kimberly S. Johnson was already a geriatrician and faculty member at Duke when her gaze turned to research. She began applying for grant after grant, meeting with failure every time. Her fifth attempt and first external award was from NPCRC: her first funding opportunity that specifically addressed palliative care. As a member of NPCRC's first grantee cohort, Dr. Johnson's proposal sought to determine which programs and policies among hospice providers were associated with greater service to African Americans. This work followed her research examining the influence of cultural beliefs and preferences on end-of-life decision-making. Today Dr. Johnson remains focused on equity issues around hospice and palliative care through the lens of the African-American experience. She currently runs a large multi-site study examining the effectiveness of two interventions in reducing disparities between seriously ill older African Americans and Whites in advance care planning and end-of-life care. An active mentor and established investigator, Dr. Johnson has spoken often at the annual NPCRC Foley Retreat, each time shining a light on the subject of racial disparities in palliative care.

“I was over the moon the day Sean Morrison called to announce I'd won a CDA! NPCRC re-energized me. It confirmed this work is important and other people think so, too. My earliest role models were primary care doctors, many working in my small, all-African-American Mississippi hometown. They inspired me to improve equitable access to care for underserved populations. One mentor advised me to identify exactly what gets me up in the morning and stick to it, since successful investigators are known for doing the thing they most love to think and talk about. I absolutely believe my research is better because as a clinician I'm inspired by my patients.

“While I'm always the minority in just about every professional medical setting and while I'm always talking about opportunities to improve care for minorities, particularly African Americans, I've felt very supported by NPCRC. This fantastic community of investigators — many of whom have become my collaborators — are extremely open to dealing with the impact of disparities, and they join me in addressing these issues. My hope is to pay it forward and serve as a role model for other investigators from underrepresented racial and ethnic groups and those who passionately wish to improve equitable access to palliative care.”

The Pilot/Exploratory Awards Program

NPCRC's Pilot/Exploratory grants are known for having funded experienced investigators conducting research projects whose purpose was to test interventions, develop research methodologies, and explore novel areas of palliative care research. A condition of funding was a clearly defined plan as to how the investigator would use the results of the project to develop larger, federally funded (NIH, VA) research projects. Pilot/Exploratory grant support helped experienced palliative care investigators strengthen their federal grant submissions and better compete with investigators from more established fields of biomedical research.

Former Pilot/Exploratory grantees are now highly experienced investigators who lead sustainable research programs at major institutions. Each has effectively leveraged NPCRC's investment into subsequent NIH and other federal grants (e.g., Veterans Administration or Patient-Centered Outcomes Research Center). In addition to having become extremely competitive NIH applicants, they are generating original data that can support new grant proposals and new junior faculty mentees. This is precisely the infrastructure building that we envisioned — and evidence that the Pilot/Exploratory program effectively achieved our goals. As a result, we funded our last cycle of pilot/exploratory grants in 2018 and chose to increase our focus and resources on the Kornfeld Scholars Program.

Pilot/Exploratory Support Project grantees work in prestigious institutions all around the country, such as:

- Beth Israel Medical Center*
- Boston Children's Hospital*
- Brigham and Women's Hospital*
- Dana Farber Cancer Institute*
- Duke University*
- Icahn School of Medicine*
- Indiana University*
- Massachusetts General Hospital*
- New York University*
- Stanford University*
- University of Alabama at Birmingham*
- University of Maryland*
- University of North Carolina*
- University of Pennsylvania*
- University of Pittsburgh*
- University of Utah*
- University of Washington*
- Yale School of Medicine*

TRANSFORMED AMERICAN MEDICAL INFRASTRUCTURE

In 2005 we estimated that only four academic medical centers had the infrastructure and number of investigators needed to support large-scale research projects in palliative care.

But by 2017 NPCRC had:

AWARDED PILOT/
EXPLORATORY GRANTS TO

33

EXPERIENCED
INVESTIGATORS FROM

22

DIFFERENT INSTITUTIONS

LEVERAGED A

\$5.8 M

INVESTMENT INTO



136

SUBSEQUENT GRANTS

SUBSEQUENT GRANT FUNDING

\$104.5 M

RETURN ON INVESTMENT

18:1

“*Being a successful palliative care innovator and being able to positively affect patients and families in a high-impact way is something all of us can do. NPCRC’s Pilot and Exploratory award helped expand and grow our field; it offered the kind of support that made our tent bigger. Being able to go to NPCRC and say, ‘I know you understand the value of my work and with your help I’m going to put my idea forward so it will help patients faster,’ has been invaluable to me personally — and vital to the palliative care community as a whole.*”

— Abby Rosenberg, MD, MS, MA; 2016 Pilot and Exploratory Awardee

> Pilot Grant Awardees
2007-2018





Kornfeld Scholars
2007-2020



The Kornfeld Scholars Program

NPCRC’s Kornfeld Scholars Program provides two-year grants to palliative care researchers at the start of their investigative careers.

Historically, externally funded research by senior investigators has cross-subsidized mentoring and pilot studies for their mentees; this has helped establish a mentee’s research publication track record and provided access to pilot data that supported NIH project and career development award proposals. Beginning in the early 2000s—due to more stringent NIH funding requirements, downwardly negotiated budgets, the expectation of contributed time on the part of funders, reduced indirect costs, and the reluctance of institutions to support contributed time — such cross-subsidization has become increasingly difficult. Since lack of an investigator pipeline has been one of the major barriers to the growth of palliative care, the early support of the Kornfeld Scholars Program has proven itself crucial to the healthy future of our field.

BRIDGED A GAP

Since 2007 the Kornfeld Scholars Program has:

STIMULATED FUNDING

52

FEDERAL GRANTS

69

FOUNDATION GRANTS

SUSTAINED GIVING

70% OF GRANTEES

RECEIVED EXTRAMURAL FUNDING WITHIN TWO YEARS OF EARNING THEIR NPCRC AWARD

OVER 90% OF GRANTEES

RECEIVED EITHER FEDERAL OR FOUNDATION FUNDING SUBSEQUENT TO THEIR NPCRC AWARD

EMPOWERED VISION

\$7.8 M

NPCRC INVESTED IN THE KORNFELD SCHOLARS PROGRAM

GENERATED RETURN ON INVESTMENT

10:1

ENHANCING CAREGIVER DECISION-MAKING

NICHOLAS DIONNE-ODOM, PhD, RN, ACHPN

Assistant Professor, University of Alabama at Birmingham (UAB)
School of Nursing, Department of Acute, Chronic, and Continuing Care

Co-Director, Caregiver and Bereavement Support Services,
UAB Center for Palliative and Supportive Care

Associate Chair, Palliative Care Research Cooperative
Group Caregiver Core

2015 Career Development Awardee: *Developing an Upstream Palliative Care Telehealth Intervention for Family Caregivers of Persons with Advanced Cancer Living in the Rural South*

2019 Pilot and Exploratory Awardee: *An Optimization Trial to Prepare Advanced Cancer Family Caregivers for Decision Partnering Using the Multiphase Optimization Strategy (MOST)*



For Dr. Nick Dionne-Odom, a priority focus in palliative care, oncology, and geriatrics is to prepare the 3.3 million U.S. family caregivers of persons with cancer to effectively partner in healthcare decision-making. But because few interventions exist that target this exact issue, Dr. Dionne-Odom is developing and testing early palliative care coaching interventions to enhance support skills for family caregivers of persons with advanced cancer. While most interventions think about decision-making as focusing on a singular choice point, Dr. Dionne-Odom's formative research shows that decision-making might be better conceived as a health behavior process that consists of a variety of skills, conversations, behaviors, and tasks, which both precede the actual moment when a decision is made and continue on after that choice is made. Using an innovative factorial trial design — structured to test the individual and collective efficacy of intervention components — Dr. Dionne-Odom hopes to develop the early preparation that caregivers need to enhance their entire constellation of decision-making skills before any actual decision is faced.

“ I was an ICU nurse for about 10 years. I was struck by how hard it was for families to make decisions for patients nearing end of life. I always thought we could do better, which led me to become a palliative care nurse scientist. Through the lens of holistic, whole-person, relationship-centered care, I can examine and enhance my patients' and their families' responses to illness, going beyond just treating the underlying disease.

“ Palliative care is truly a one-of-a-kind specialty in both practice and research. Its essence includes a parity among clinicians and researchers — not just physicians and nurses, but also social workers, chaplains, and the rest of the interdisciplinary care team whose collective mission is exploring new and better ways to maximize quality of life. NPCRC has been absolutely vital to the growth, health, and life of our specialty. ”



SHIFTING PARADIGMS: THE PRISM OF COLLABORATION

ABBY ROSENBERG, MD, MS, MA

*Director, Palliative Care and Resilience Lab,
Seattle Children's Research Institute*

*Director, Pediatrics, Cambia Palliative Care Center of
Excellence at the University of Washington*

*Associate Professor, Division of Hematology-Oncology;
Associate Professor, Department of Pediatrics,
University of Washington School of Medicine*

2016 Pilot and Exploratory Awardee: *Promoting Resilience
in Stress Management (PRISM): A Novel Supportive
Intervention for Parents of Children with Cancer*

Dr. Abby Rosenberg is a celebrated medical innovator, dedicated to improving quality of life for people with serious illness and their families. Her work focuses on building interventions to improve resilience; simply said, she figures out how to help people feel more resilient when illness makes that a difficult state of mind to achieve. After developing PRISM—a resilience intervention for teenagers with serious illness, developed with patients for patients—Dr. Rosenberg expanded the reach of her program, adapting and transforming it to meet the needs of the parents of seriously ill teenagers. Today PRISM has expanded in highly original and unexpected ways. Within the palliative care community, people are refining its use for adult patients with congenital heart disease and for people of color who have experienced discrimination in the healthcare setting. In response to the pandemic, the intervention is being used to build resilience for frontline healthcare workers and for school-age kids suffering from the stress of social isolation. Dr. Rosenberg and her team are testing PRISM in the cystic fibrosis and chronic pain communities, and in her world of pediatric oncology, Dr. Rosenberg has continued to expand the application of PRISM with two big, multisite NIH trials. One is evaluating PRISM's impact and cost-effectiveness among youth receiving hematopoietic cell transplantation; the other is evaluating PRISM's impact on quality of life and advance care planning among youth with advanced cancer.

“*Palliative care research is hard to fund, partly because our work goes against the traditional basic science paradigm; it's about seeing the patient's whole experience and recognizing that this person, who happens to be ill, is a human being with all the emotional, familial, medical, and spiritual needs that being human entails. So palliative care researchers spend lots of time convincing potential funders of the value of our work.*”

“*The beauty of NPCRC is that it recognizes this value from the start. It provides a forum, a meeting place, and badly needed funding, all of which form the backbone of innovation. By bringing together our small, spread out community, experts can join forces to break boundaries and advance our shared cause. Through collaboration we're improving our science by extraordinary leaps and bounds. We're shifting conventional perceptions, inspiring breakthrough ideas, and finding new and powerful ways of helping patients.*”

WE'VE BUILT COMMUNITY AND GROWN A NATIONAL NETWORK.



The Foley Retreat – named for palliative care leader Dr. Kathleen M. Foley – celebrates its namesake’s inspiring contributions to the field.

Since it began in 2007, NPCRC’s Kathleen M. Foley Research Retreat and Symposium has been universally celebrated as a key contribution to the palliative care research community. The Foley Retreat, as it is known, continues to serve three essential purposes:

- Nurtures early-stage investigators through research and career development training seminars that foster relationships with senior investigators and create a peer support network.
- Brings early-stage and experienced palliative care investigators together in a forum where cutting-edge research can be presented and critically evaluated.
- Provides a home for diverse palliative care investigators to meet, exchange ideas, create collaborations, and build a national community.

According to its more than 1,200 participants over the past 13 years, attending the Foley retreat is like “coming home to family.” For early-stage investigators, the retreat is the wellspring of lifelong professional connections and the nexus of an ever-growing network of like-minded colleagues across institutions and disciplines. For experienced investigators it is the ideal space in which to present next-generation research, establish working groups, outline palliative care research priorities, promote collaboration, and deepen community.

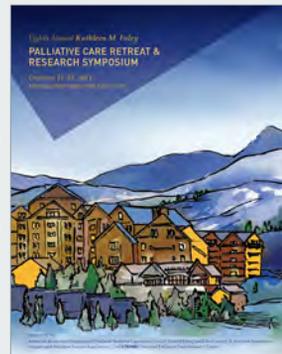
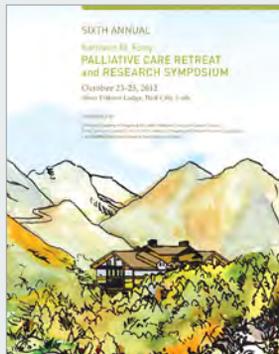
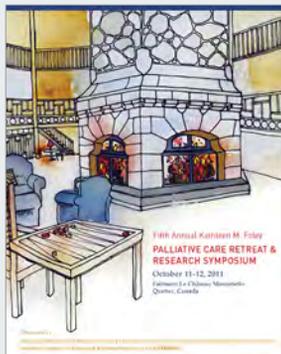
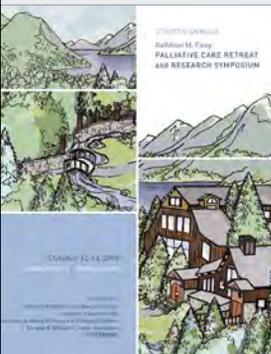
2010

2011

2012

2013

2014



UNITED INTERESTS

Since 2005 the Foley Retreat has:

GATHERED PEOPLE

13

MEETINGS WERE HELD WITH MORE THAN

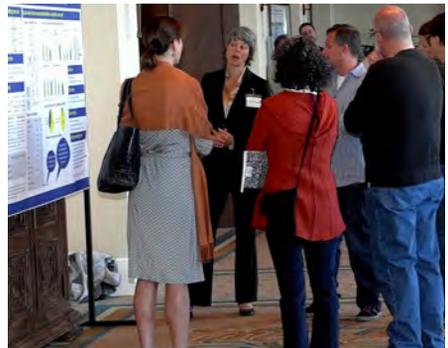
1,267

ATTENDEES

INSPIRED CONTINUITY

100%

OF PARTICIPANTS WISHED TO RETURN



At the annual Kathleen M. Foley Research Retreat, researchers come together from over ten disciplines and specialties for learning, networking, and recreation.

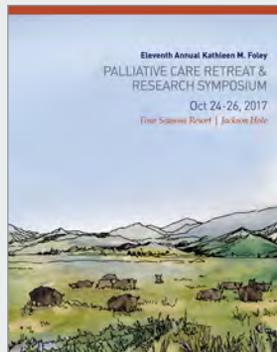
2015

2016

2017

2018

2019



SWIMMING UPSTREAM WITH SPECIALTY PALLIATIVE CARE

REBECCA A. ASLAKSON, MD, PhD

Associate Professor of Anesthesiology and Medicine – Palliative Care Section, Division Chief of Adult Critical Care Anesthesia, Stanford University

2011 Career Development Awardee: *Crafting a Palliative Care Intervention for Surgical Intensive Care Unit Patients*

2017 Transition to Independence Awardee: *What Palliative Care Can Be ‘Baked In’ to a Preoperative Assessment? Operationalizing Primary Palliative Care in Surgical Settings*



Dr. Rebecca Aslakson — boarded in critical care, anesthesiology, and hospice and palliative medicine — has a similarly ambitious research and clinical goal: to improve delivery of effective and equitable palliative care to perioperative and intensive care unit patients, with particular focus on the traditionally-underserved subset of surgical patients. The foundational research Dr. Aslakson did for her first NPCRC grant led to developing a video-based advance care planning tool for patients and families preparing for major cancer surgery. Today, in collaboration with Massachusetts General Hospital’s Dr. Jennifer Temel, Dr. Aslakson is conducting the first-ever, multisite randomized controlled trial integrating specialist palliative care into perioperative care as they compare surgeon-alone versus surgeon-palliative care team co-management for patients pursuing major surgeries for cancer. The aim is to bring specialty palliative care even further upstream to improve the quality of life for just-diagnosed patients with cancer who are still pursuing major curative-intent surgeries.

“When I started, I was a critical care anesthesiologist interested in long-stay ICU patients. I was also interested in communication, families, and research. I had no community — and as far as I knew, palliative care didn’t even exist. Today I do perioperative palliative care, but everything continues to be rooted in the clinical challenges of the ICU, particularly the surgical ICU. Although there are still very few anesthesiologists in palliative care, slowly things are changing. Specialty palliative care is finding its way, particularly with the support of NPCRC.”

“Attending my first Foley Retreat was like finally finding home. I was with my tribe: people who, like me, cared about doing transformational research. I remember seeing everyone I’d only read or heard about, and feeling like I was at a rock concert! I came to learn I could collaborate with these terrific people and experience a sense of community. It’s hard for me to imagine my career if it weren’t for NPCRC.”

WE'VE ENCOURAGED THE MEETING OF MINDS.

In addition to hosting the **Foley Retreat**, NPCRC convenes small working groups, both on our own and in collaboration with other institutions, such as the NIH. These intimate, focused 'mini-conferences' bring together researchers and their mentors to identify and outline their research priorities. Wide-ranging in both focus and specialty, conference topics have included everything from palliative care for geriatrics and advanced dementia to the relationship between palliative care and spirituality, communication, heart disease, surgery, medical subspecialties, and more.

TARGETED ADVANCED DEMENTIA

When the National Alzheimer's Project Act (NAPA) was signed into law in 2011, the subject of palliative care research was nowhere in sight. To develop a research agenda NPCRC funded a conference, led by Dr. Susan Mitchell, of the nation's foremost experts in palliative care and advanced dementia. Based on their findings and ensuing NPCRC advocacy efforts, NAPA was amended to include provisions focused on enhancing palliative care research and promoting such clinical care for persons with advanced dementia.

GENERATED IDEAS

24

MANUSCRIPTS PUBLISHED
AS A RESULT OF
NPCRC SPONSORED
MINI-CONFERENCES

WE'VE FOSTERED MENTORING.

Mentor/mentee relationships are about guidance, support, learning, and inspiration; they are mutually enriching. Mentors expand their intellectual and academic range by interacting with their mentees' wide-ranging research interests. Mentees lean on their mentors' experience and expertise to help focus research and sharpen funding application skills. These collaborative relationships are fundamental to creating ongoing cadres of influential palliative care researchers.

CONNECTED MENTORS AND MENTEES

FUNDED

58

EARLY-STAGE INVESTIGATOR/
MENTOR PAIRS FROM



34

DIFFERENT INSTITUTIONS
REPRESENTING



10

DISCIPLINES

BRIDGING THE FUNDING GAP THROUGH MENTORING

ALEXANDER K. SMITH, MD, MPH, MS

Associate Professor of Medicine,
University of California, San Francisco

2009 Career Development Awardee:

The Scientific Basis for Palliative Care in the ED

2015 Pilot and Exploratory Awardee:

Communication of Prognosis in Older Adults



Dr. Alex Smith is a loyal, active, and deeply engaged member of the palliative care community, who has participated in every aspect of the NPCRC journey. After successfully completing his CDA research, Dr. Smith received a Pilot Exploratory grant to study prognosis communication with disabled elders. This resulted in the creation of ePrognosis: a website that directs clinicians toward the best prognostic calculator for each seriously ill patient's specific circumstances. The site, which has been expanded to address patient communication and cancer screening, gets about 10,000 views each month. Currently Dr. Smith is collaborating with NPCRC director Dr. R. Sean Morrison to explore the impact of disruptive events — hip fracture, hospitalization for pneumonia, and death of a spouse — on the lives of older adults with dementia. A frequent Foley Retreat speaker and a sought-after mentor to Kornfeld Scholar awardees, Dr. Smith is dedicated to helping junior researchers make the challenging competitive leap to NIH career development awards from their postdoctoral or fellowship trainings.

“There aren't a lot of established palliative care investigators, so it's a vital part of our professional responsibility to support the next generation of junior folks in medicine, nursing, and social work who are interested in palliative care research. Being a researcher is intimidating and uncertain: living from grant to grant, wondering if you're going to make it. I don't want anyone to meet with a dead end when they finish their training. I want to nurture them, give them a boost.

“I spend most of my time working as primary mentor for eight or nine mentees at once because it helps us grow the field and build a stronger foundation of science for the clinical practice of palliative care. Mentoring has become the most enjoyable aspect of my work. It allows me to maintain interest in a wide variety of compelling subjects: everything from anesthesia and cognition to loneliness and social isolation in the last years of life...from building a better hospice for people with dementia to creating health policy around home-based palliative care models, to improving communication in the ICU. I learn so much from my mentees and I love seeing their success.”

WE'VE IMPROVED RESEARCH AND DEVELOPMENT SKILLS.

Because NPCRC's palliative care evidence base is built on the most rigorous study designs and analytics, investigators turn to us for a wide range of research technical assistance. Administered across varied formats, our technical support includes study design, instrument development, and quantitative and qualitative analytic techniques. Junior investigators participate in in-person workshops, web-based seminars, work-in-progress webinars, and peer review training; they receive grant reviews by experienced NIH reviewers prior to formal grant submission.

OFFERED HANDS-ON HELP

NPCRC's Research Technical Assistance Program, led by Melissa Aldridge, PhD, has:

EDUCATED PARTICIPANTS

12

WORKSHOPS

14

TRAINING
WEBINARS

43

WORKS-IN-PROGRESS
WEBINARS

11

GRANT WRITING
WORKSHOPS

BUILT CONNECTIONS

25

SCIENTISTS FROM

17

INSTITUTIONS

GUIDED INVESTIGATIONS

25

GRANT REVIEWS FOR

18

RESEARCHERS



WE'RE STILL HARD AT WORK.

Looking back over NPCRC's last 15 years makes us proud to see how much we have accomplished. But looking ahead is even more exciting, as we find ourselves in the early stages of an ambitious strategic transition plan, with a goal of sunsetting our organization in 2025.

Our ultimate goal is to ensure that the work we began continues long into the future, and that other programs and institutions continue to build on our vision and values. How are we doing this? By firmly securing the programs we have already set in place into the infrastructure of organized medicine. By helping to create new programs that amplify NPCRC's work. And by working in tandem with partners at seven-and-counting academic medical centers, where we have co-created a network of institutionally-based postdoctoral career development programs.

Supported by both federal and non-federal funding, each of these programs has the capacity to train and support four to five early-stage palliative care investigators on an annual basis. This new network connects training programs, trainees, and leaders with their counterparts throughout the country to catalyze research collaborations, training, and technical assistance.

In addition, in collaboration with the American Academy of Hospice and Palliative Medicine (AAHPM) and the NINR-funded Palliative Care Research Collaborative, we have created the first national research meeting in palliative care: AAHPM's *State of the Science* conference. While the meeting was held virtually in September 2020 due to the COVID-19 pandemic, the inaugural in-person meeting is scheduled for February 2022 in Nashville, Tennessee. This conference will bring together hundreds of palliative care investigators from across the U.S. and the globe to network, collaborate, present cutting-edge research, and create mentoring opportunities for early-stage investigators.

These examples are indicative of how hard we at NPCRC are still working to secure the future of palliative care research. We look forward to the next stage of our journey with confidence, energy, and optimism.

WITH GRATITUDE TO OUR SCIENTIFIC ADVISORY COMMITTEE



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