NASEM Workshop on Serious Illness Care Research: The Importance of Lived Experience

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Outline

- Share some of the personal stories underlying progress in improving the quality and accessibility of palliative care for a serious illness (Parkinson’s disease)
- Highlight the critical role of diverse stakeholders and real-world experience experts in driving impactful research
- Outline priorities for increasing meaningful involvement of persons with lived experience in serious illness research

Story # 1: Accidental Palliative Care Researcher

REFLECTIONS: NEUROLOGY AND THE HUMANITIES

The head leads to the heart

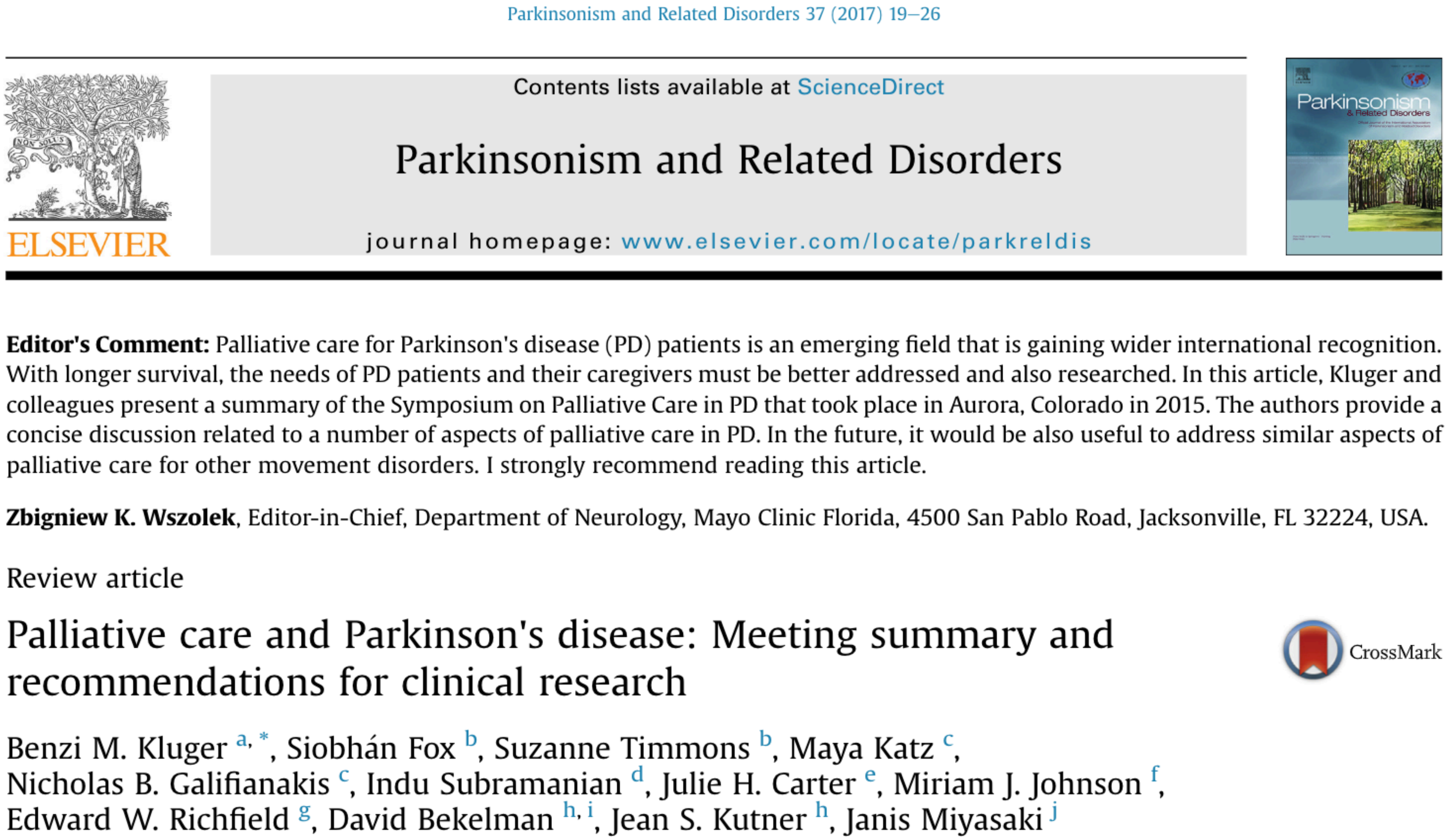
Benzi M. Kluger, MD, MS, FAAN

Neurology® 2018;91:713-714. doi:10.1212/WNL.00000000000

Story #1 Lessons:

- Clinical researchers need encouragement, community, and practice to follow their heart
- Relationships with people living with serious illness in and out of clinic are critical to inform research priorities and questions.
- Clinical innovation and quality improvement can drive research.

Results of our first international working group.



Parkinsonism and Related Disorders 37 (2017) 19–26

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Editor's Comment: Palliative care for Parkinson's disease (PD) patients is an emerging field that is gaining wider international recognition. With longer survival, the needs of PD patients and their caregivers must be better addressed and also researched. In this article, Kluger and colleagues present a summary of the Symposium on Palliative Care in PD that took place in Aurora, Colorado in 2015. The authors provide a concise discussion related to a number of aspects of palliative care in PD. In the future, it would be also useful to address similar aspects of palliative care for other movement disorders. I strongly recommend reading this article.

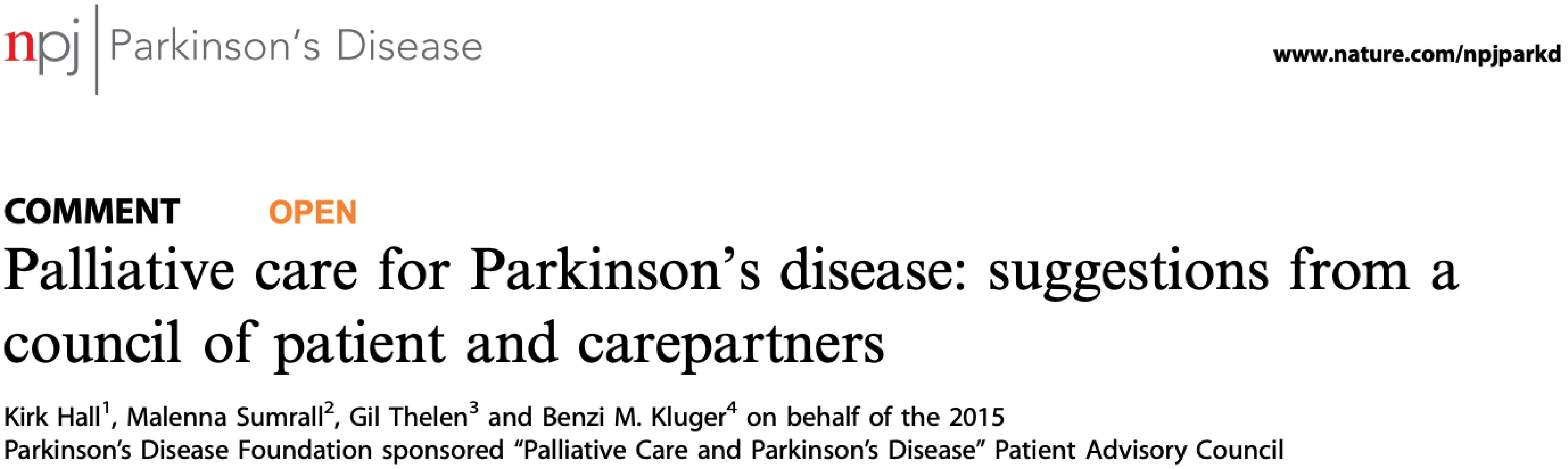
Zbigniew K. Wszolek, Editor-in-Chief, Department of Neurology, Mayo Clinic Florida, 4500 San Pablo Road, Jacksonville, FL 32224, USA.

Review article

Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research

Benzi M. Kluger [a, *], Siobhán Fox [b], Suzanne Timmons [b], Maya Katz [c],
Nicholas B. Galifianakis [c], Indu Subramanian [d], Julie H. Carter [e], Miriam J. Johnson [f],
Edward W. Richfield [g], David Bekelman [h, i], Jean S. Kutner [h], Janis Miyasaki [j]

Patient and family input was critical.
Parity of esteem made it possible.



npj | Parkinson's Disease

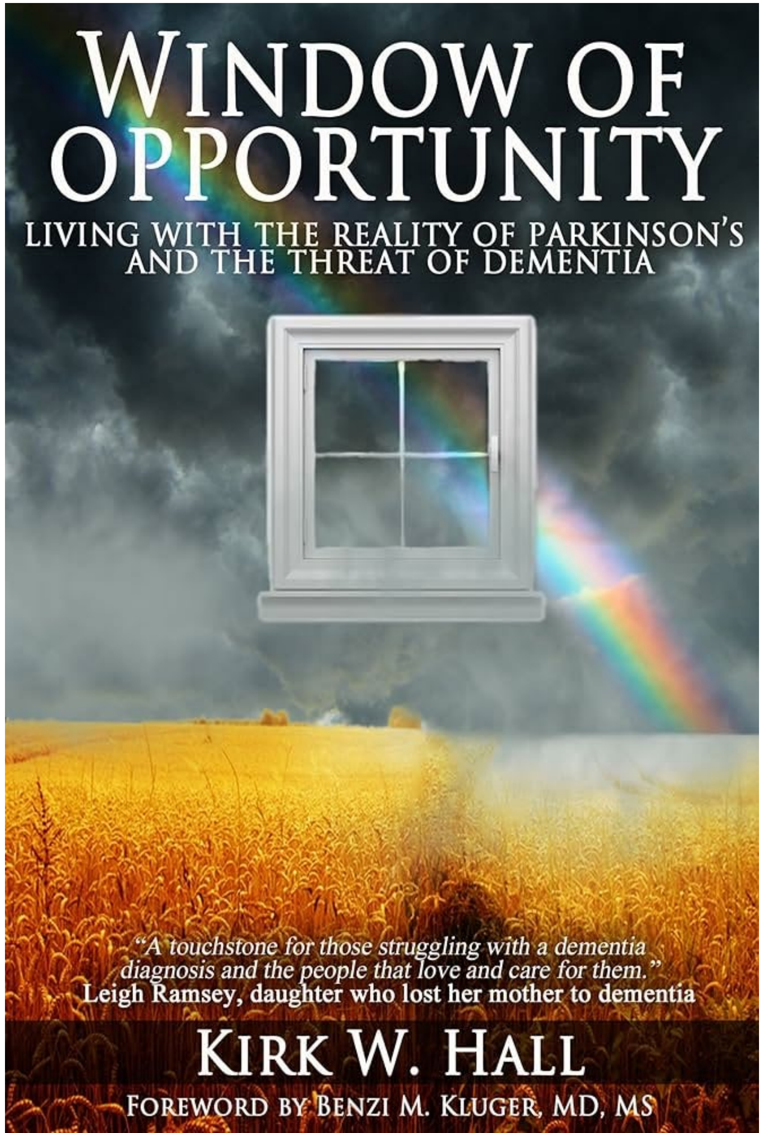
www.nature.com/npjparkd

COMMENT **OPEN**

Palliative care for Parkinson's disease: suggestions from a council of patient and carepartners

Kirk Hall[1], Malenna Sumrall[2], Gil Thelen[3] and Benzi M. Kluger[4] on behalf of the 2015
Parkinson's Disease Foundation sponsored "Palliative Care and Parkinson's Disease" Patient Advisory Council

Story #2: A passionate and visionary patient.



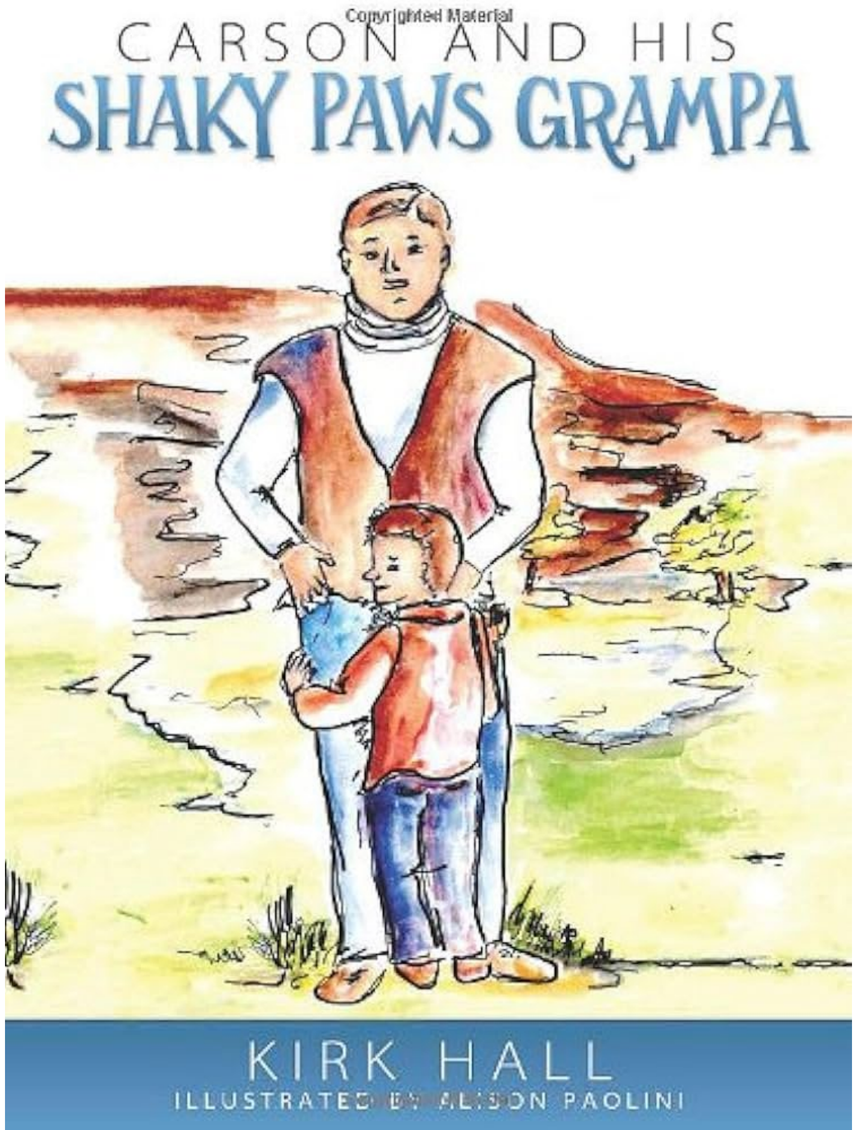
WINDOW OF OPPORTUNITY

LIVING WITH THE REALITY OF PARKINSON'S AND THE THREAT OF DEMENTIA

"A touchstone for those struggling with a dementia diagnosis and the people that love and care for them."
Leigh Ramsey, daughter who lost her mother to dementia

KIRK W. HALL

FOREWORD BY BENZI M. KLUGER, MD, MS



CARSON AND HIS SHAKY PAWS GRAMPA

KIRK HALL

ILLUSTRATED BY ALISON PAOLINI

Story # 2 Lessons

- No one knows a serious illness better than the person living it.
- People living with an illness know the real urgency and importance of improving care.
- Patients improve research when they are treated as experts.

Family Carers tend to be the least supported and most important members of the care team.

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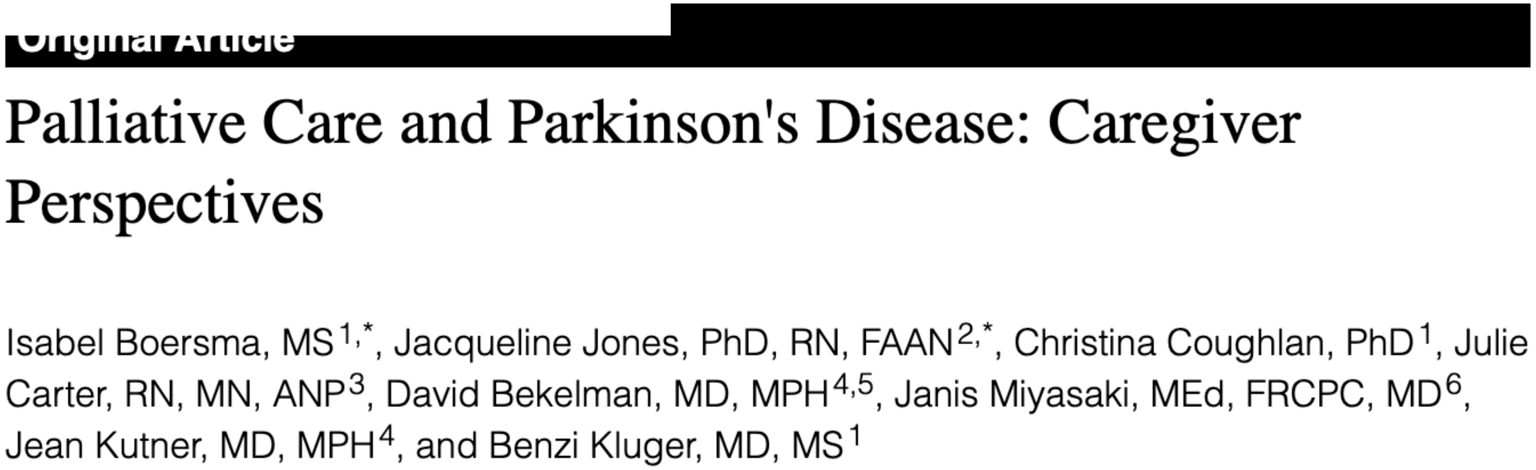
The presence of a caregiver is associated with patient outcomes in patients with Parkinson's disease and atypical parkinsonisms

Lindsay Penny Prizer[a,*], Benzi M. Kluger[b], Stefan Sillau[c], Maya Katz[d], Nicholas B. Galifianakis[d], Janis M. Miyasaki[e]

Mary Ann Liebert, Inc. publishers



Original Article

Palliative Care and Parkinson's Disease: Caregiver Perspectives

Isabel Boersma, MS[1,*], Jacqueline Jones, PhD, RN, FAAN[2,*], Christina Coughlan, PhD[1], Julie Carter, RN, MN, ANP[3], David Bekelman, MD, MPH[4,5], Janis Miyasaki, MEd, FRCPC, MD[6], Jean Kutner, MD, MPH[4], and Benzi Kluger, MD, MS[1]

Story # 3: The amazing generosity of a dedicated care partner.

Story # 3 Lessons

- Family carers need to be recognized and included as part of the care team in both clinical care and research.
- Carers have unique perspectives, expertise and unbelievable amounts of lived experience.
- Carers need attention and support as individuals and care partners, not simply as caregivers.

PCORI is a leading voice in elevating lived experience in research.

- Setting research agenda
- Evaluating projects
- Engagement at all steps
- Making research questions relevant for real-world settings and decisions

Palliative care can improve patient and family-centered outcomes in an academic setting.

Research

JAMA Neurology | Original Investigation

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders

A Randomized Clinical Trial

Benzi M. Kluger, MD; Janis Miyasaki, MD; Maya Katz, MD; Nicholas Galifianakis, MD; Kirk Hall, MBA; Steven Pantilat, MD; Ryan Khan, MDiv; Cari Friedman, LCSW; Wendy Cernik, BSN; Yuika Goto, MD; Judith Long, MS; Diane Fairclough, DrPH; Stefan Sillau, PhD; Jean S. Kutner, MD

IMPORTANCE Parkinson disease and related disorders (PDRD) have consequences for quality of life (QoL) and are the 14th leading cause of death in the United States. Despite growing interest in palliative care (PC) for persons with PDRD, few studies are available supporting its effectiveness.

OBJECTIVE To determine if outpatient PC is associated with improvements in patient-centered outcomes compared with standard care among patients with PDRD and their caregivers.

+ Editorial
+ Supplemental content

Dissemination and implementation:
Changing culture & challenging systems to improve care.

Parkinson's Foundation Launches Palliative Care Program Across U.S. Centers of Excellence

Funds awarded by the Patient-Centered Outcomes Research Institute

MIAMI & NEW YORK – August 11, 2020 – The Parkinson's Foundation is partnering with the University of Rochester Medical Center, a Parkinson's Foundation Center of

Story #4: The power of nonprofits

5 PILLARS OF
Palliative Care & Parkinson's

- Assess and manage non-movement symptoms
- Support emotional and spiritual needs
- Support care partners
- Advance care planning
- Refer to palliative care specialist and hospice, when ready

Learn more at Parkinson.org/PalliativeCare.

OUR VOICE

Nicole Yarab

BA, RN

Vice President

Clinical Affairs and Information & Resources, Parkinson's Foundation

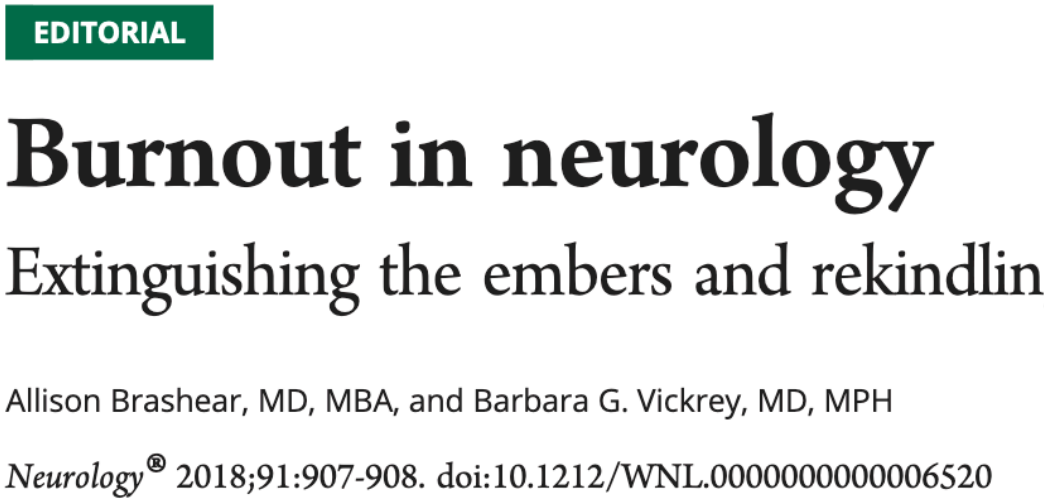
Today, it's my pleasure to welcome you

Story #4 Lessons

- Nonprofits provide key resources to their communities yet are often overlooked by researchers as partners.
- Nonprofits have outstanding reach and can accelerate implementation and dissemination efforts.
- Nonprofits possess unique perspectives and expertise on systems, policy, communication and community.

How do we bring palliative care to people who receive care outside of academic settings (e.g. most people)?

Story #5: Clinicians Care



EDITORIAL

Burnout in neurology

Extinguishing the embers and rekindling the joy in practice

Allison Brashear, MD, MBA, and Barbara G. Vickrey, MD, MPH

Neurology® 2018;91:907-908. doi:10.1212/WNL.0000000000006520

COMMUNITY OUTREACH
FOR PALLIATIVE ENGAGEMENT
PARKINSON DISEASE

Story #5 Lessons

- Healthcare providers are very interested in improving care for people with serious illness.
- There is a strong need to ”feel less alone in caring”.
- Researchers can create alignment by collaborating in identifying systems’ issues and solutions.

Other Stories

- Underserved communities
- Administrators
- Insurance and industry
- Paid nonmedical aides
- …

Recommendations I

- Research questions, priorities, and outcomes must come from thoughtful collaboration with people with lived experience including patients, family carers, and other key stakeholders.
- Principles of parity and respect should need to all aspects of collaborative research with lived experience experts.
- For research to be applicable to underserved communities additional efforts are needed to capture their lived experience

Recommendations II

- There is a need for early career support and community for researchers with a heart for serious illness/palliative care.
- There is a need for training programs to increase the skills and confidence of persons with lived experience to approach and work with researchers.
- There is a complementary need for training programs to improve the skills and openness of researchers to foster optimal collaborations.
- Channels are needed for persons with lived experience to raise research questions and find collaborators.
- Dissemination plans must consider real-world impact and involve influential community partners including nonprofits.