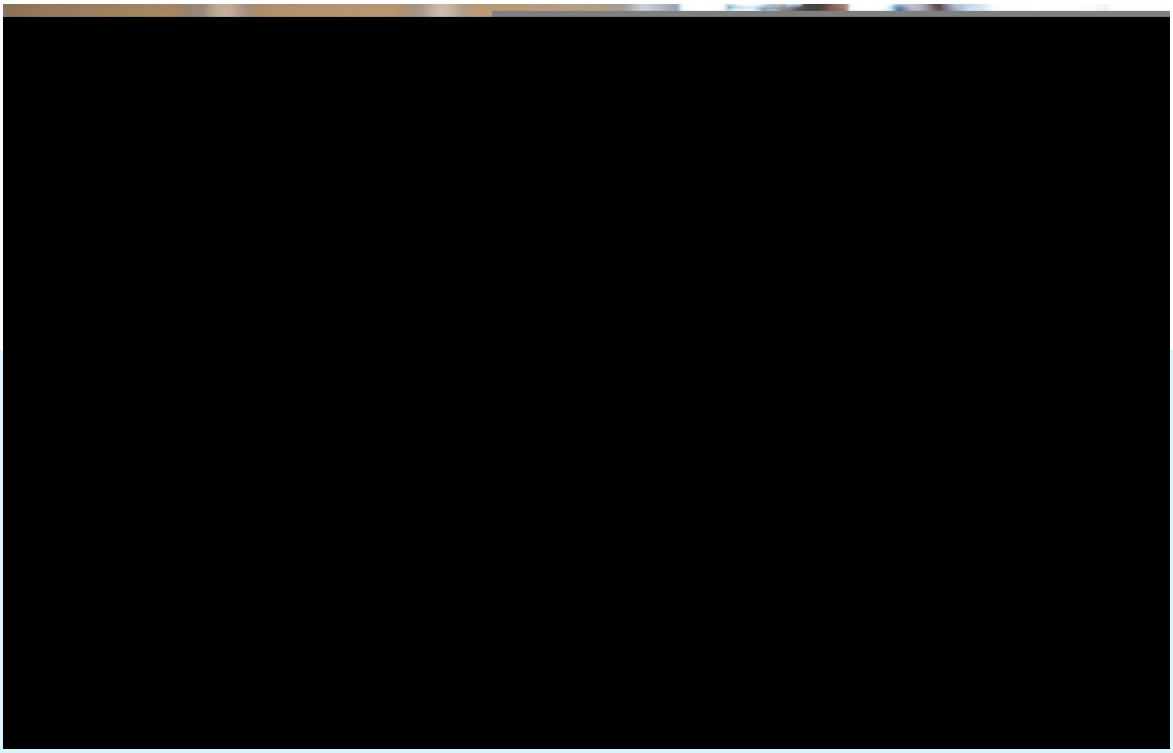
Parkinson's Foundation Palliative Care Champion Newsletter

August 2022



Palliative Care Project Updates

- All participating COEs should have receieved an update regarding the completion status of their center for the online palliative care eduation course ". Please reach out to Megan Dini at mdini@parkinson.org if you have any questions regarding your center status, extension requests, or any other concerns related to the course.

- We also want to thank you for your patience as we transition the course to our new learning plartform and acredit the course through the Parkinson's Foundation. Our goal is to re-launch the course in . We will follow-up with you once the course is closer to launching and provide additional information on accessing it in our new platform.

- During July 2020, due to the pandemic we received an enhancement to the original award from PCORI to gather data and modify the implementation of the project as needed. An article based on data collected as part of that enhancement was recently published in the *American Journal of Hospice and Palliative Medicine*, titled The article aims to understand Parkinson's Disease (PD) care partners' a) specific challenges that led to worsening strain and b) their suggestions for supports to help them during the ongoing pandemic. You can find the article here:

Palliative Care Resources & Tips

1. **Egnyte (File Sharing Resource for COEs)**
   - Looking for your coaching meeting notes or project resources? These can be found in Egnyte, the Parkinson's Foundation file sharing resource. Each center has a private folder containing all previous coaching notes, along with access to project resources for all of the pillars. You can access your Egnyte account here: **https://parkinson.egnyte.com**

2. **International Palliative Care Society (INPCS) Conference**
   - The 2nd annual meeting for **INPCS** is **November 10-12, 2022.** The theme for this year's conference is "Building Community and Breaking Barriers," and the 2-1/2 day virtual event will feature speakers, discussion panels, poster presentations, and more. For more information on the conference, please visit **https://www.inpcs.org/i4a/pages/index.cfm?pageid=3269**

3. **Spiritual Care**
   - In our coaching calls we have had great discussions around assessing and supporting the spiritual needs of patients and families. There is a recent publication in JAMA entitled, **"Spirituality in Serious Illness and Health,"** where the authors provide clear definitions of spirituality, religiosity, spiritual needs, and spiritual care to help us all understand these concepts better as we work with PD patients and families. Access it here: **https://jamanetwork.com/journals/jama/article-abstract/2794049**
   - Another article, written by spiritual care providers and PC and hospice clinicians, aims to offer a practical roadmap for screening for spiritual distress and partnering with colleagues to address spiritual needs. Access it here: **https://www.liebertpub.com/doi/10.1089/jpm.2021.0522**

Center Spotlight: Palliative Care COE Implementation

Danielle Shpiner, MD, Palliative Care Champion

While our team at the University of Miami (UM) was going through the education phase of the Parkinson's Foundation PCORI Palliative Care project, we would meet periodically to discuss what we had learned from the modules, and to brainstorm ideas to implement at our center. Through these discussions, we discovered two important points: 1) we did not know any of the palliative care specialists at our institution (and as a result, none of us were referring patients to their team regularly), and 2) while learning about advance care planning, we had several questions about legal requirements specific to completing advance care paperwork in the state of Florida. In working to find answers to some of our questions, I reached out to one of the palliative care specialists at UM, and arranged a one-on-one meeting with her to establish a relationship and discuss our participation in this project. During our meeting, she offered to hold an in-service training session with our team, which was primarily focused on our questions on advance care planning requirements in the state of Florida. We held a one-hour training session over Zoom in June 2022 for all of our Movement Disorders neurologists, fellows, and nurse practitioners. During the session, we learned about the aspects of advance care planning specific to our state, and some additional tips about holding advance care planning conversations with patients and care partners. It was also an amazing opportunity to build the relationship between our team and the palliative care department. At the end of the session, we had the chance to discuss criteria for future referrals to palliative care. As a result of the session, we now know which patients will benefit from a referral to the palliative care team at our institution, and have standardized advance care planning resources that we are using to help our patients establish health care proxies and advance directives. I would encourage all of the palliative care champions to reach out to the palliative care teams at their own institutions to build a relationship and see what resources they might be able to share!

Danielle Feigenbaum, MD, Palliative Care Champion

The University of Southern California Parkinson's Disease Center of Excellence recently conducted a retreat at The Huntington Library and Gardens in Pasadena, CA. The goal was to provide an uninterrupted time to come together as a multi-disciplinary team to reflect and focus on building the palliative care program, which included the development of an advanced care directive planning mission for individuals with Parkinson's disease and their families. The multi-disciplinary team included movement disorders specialists, psychiatry, speech therapy, physical and occupational therapy and social work. The USC PF COE team invited the USC palliative care program within the USC Norris Cancer Center to join them in the discussion and to provide their expertise and guidance and to discuss a possible collaboration. The format started with watching the first chapter of the Parkinson's Foundation Palliative Care Course. This laid out the overall goals of the palliative care program and advanced care directive planning and provided a good foundation to begin the round table discussion.

The roundtable discussion allowed the USC PF COE team to exchange different perspectives/ideas on palliative care while partnering with the USC Norris Cancer Center Palliative Care Program who helped answer common questions including (i) when to refer patients to palliative care providers, (ii) how to refer to hospice care, (iii) and what existing home health palliative care options there are for more in home nursing assistance and therapy services. The USC PF COE retreat was timely since it also provided a platform for sharing the needs of the neuro-palliative program with the planned expansion of the existing palliative care department at USC. Overall, the retreat enabled a partnership and better understanding and roadmap for moving forward with the PF palliative care program. The retreat was organized by Dr. Danielle Feigenbaum, USC Palliative Care Champion, Dr Giselle Petzinger, USC COE director, and Sarah Ingersoll, USC COE administrative coordinator.

Question and Answer:

Question from Jennifer Koebert, PA-C, University of South Florida Palliative Care Champion: I want to ask for your advice regarding Chaplain services based on your experience with your neuropalliative care program. We have a chaplain who is willing to volunteer their services one day a week. We want to know what you recommend for documentation? Does your chaplain document in your EMR or write something up for your review?

Response from Dr. Benzi Kluger, MD: As most chaplains can't bill (unless they carry another license), I think it makes sense for documentation to be as short and focused as needed to: a) allow chaplains to track progress/concerns; b) communicate main issues to other providers. We do have notes in our EMR, as I and other providers find it helpful to know what is going on with shared patients and gain insights into other issues. It also helps to have them in the EMR to message providers as they may get useful info (e.g. on depression, confusion around diagnosis).

Response from Dr. Sue Ouellette Ph.D., M.Div.: At a minimum, their note should include why the patient was seen, what issues were discussed, what interventions were employed, and what the plan of care is. The inpatient chaplains document every encounter using a template that includes when the patient was seen, what issue the patient was seen for (e.g. . bereavement, family support, trauma, spiritual support etc.) and what the primary intervention was (reflective listening, normalization of feelings, clarify a spiritual issue, etc.) and the patient's faith tradition and emotional state (sad, anticipatory grieving, grateful). As an outpatient chaplain, I base my note on a checklist that the team I work with has agreed upon. My standardized note includes issues discussed, intervention/outcome, and plan of care. My initial (intake note) is more elaborate and includes family structure, education, social/support system, suicidal ideation, drug, alcohol screen, religious or spiritual background, issues discussed, and plan of care. It is also best to utilize a professional chaplain, if possible. Professional chaplains have at least Master's degrees, residencies, and should be board certified. They should be available to provide support to patients, families, and staff regardless of religious preference or lack thereof.