



# **Parkinson's Foundation Palliative Care Champion Newsletter**

**October 2022**





## **Palliative Care Project Updates**

### **1. Egnyte (File Sharing Resource for COEs)**

- The group coaching meeting notes will be uploaded into individual Egnyte folders after coaching meetings. All PC Champions have access to Egnyte, where you can find your center meeting notes and additional resources. Please contact Jinnia Nusrat if you need assistance accessing your Egnyte account. You can log-in to your Egnyte account [here](#).

### **2. Upcoming Advance Care Planning Models and Roadmap Town Hall – December 2022**

- In an effort to hold more in-depth discussions related to palliative care topics, we are planning to host our first virtual 1-hour town hall in December. We will have physicians, a social worker, and a person with PD discuss the importance of ACP and related topics, such as discussing roadmaps, billing, and unique clinical models. This will be the first town hall in our palliative care town hall series. Please look out for the invite coming soon.

### **3. Reminder: International Palliative Care Society (INPCS) Conference**

- The annual meeting for INPCS is November 10-12, 2022. The theme for this year's conference is "Building Community and Breaking Barriers." The 2-1/2 day virtual event will feature speakers such as Susan Schneider Williams (advocate and widow of late comedian/actor Robin Williams). Visit [here](#).

## **Palliative Care Resources & Tips**

### **• Practical Pointers for Implementing Palliative Care for Parkinson's**

- Dr. Benzi Kluger recently gave a talk highlighting some practical ways to implement the 5 pillars of palliative care at University of Rochester Medical Center. This talk provides a more in-depth look at how centers can practically address palliative care components and includes helpful tips and tricks. Access the recording [here](#).

### **• Advancing the Neuropalliative Care Approach – A Call to Action**

- A recent article published in JAMA Neurology highlights the need for a “widespread adoption of the neuropalliative care approach, given the enormity of unmet neuropalliative care needs across populations”. This article provides an overview of this challenge and the rationale to reimagine our approach and propose a coordinated call to action to address one of the greatest quality-of-care challenge and opportunities of our time. Access the article [here](#).

### **• Conversation Starter Kit**

- The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. This condensed 2-page kit will help you get started with what we know can be challenging discussions and serve as a quick guide to a conversation. See the 2-page conversation starter kit [here](#).



## Getting to Where You Want to Be by Appreciating Where You Are

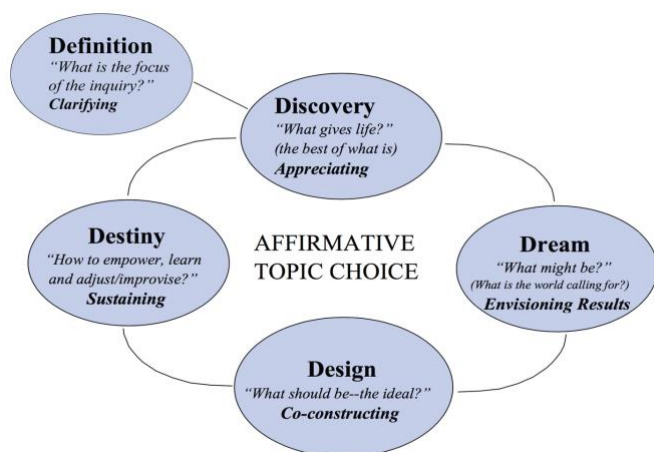
By Hillary Lum, MD, PhD, University of Colorado, Project Team Member

The Parkinson's Foundation is deeply appreciative of your efforts and progress in implementing palliative care strategies and improving supports available for your patients and their families. Because of your engagement as a COE, the Foundation is advancing on several ambitious strategic goals and is learning new and better ways to support COEs in their own missions and visions.

To advance care for PD on a large scale or pursue any other big dream, it's important to see what is possible. A great way to see what's possible is Appreciative Inquiry (AI). AI is a change management approach that focuses on identifying what is working well, thinking about why it is working well, and then doing more of it. The basic tenet of AI is that a team will grow in whichever direction the team focuses their attention. If all the attention is focused on problems, then identifying problems and dealing with them is what the organization will do best. *If all the attention is focused on strengths*, then identifying strengths and building on those strengths is what the organization will do best.

In health care, we tend to focus on problem-based thinking. We can find ourselves looking narrowly at the challenges and not seeing possibilities of what we could do together, based on our successes and strengths. As part of our journey on this project, we think AI would be an ideal way of celebrating each of our team's successes, widening the lens of what's possible, and generating exciting, vibrant, and meaningful options.

Here are questions you can ask as a team:



- What are our success stories? What's working?
- Where are we seeing culture change?
- What are the next possibilities here?
- What's the future we want to build and sustain?
- What shall we do to achieve it?

We hope these questions are helpful to you as you appreciate and celebrate the progress you're making and the journey we're on together. We'd also encourage you to use AI within your COE and ask how can you see integrating an AI approach in your COE team meetings?

For more information about Appreciative Inquiry, read [here](#).

References: Organizing Engagement. Models: appreciative inquiry. Accessed October 28<sup>th</sup>, 2022. <https://organizingengagement.org/models/appreciative-inquiry/>