

VCU Palliative Care ECHO*

April 11, 2019

Pediatric Palliative Care

Continuing Medical Education

April 11, 2019 | 12:00 PM | teleECHO Conference

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Disclosures

April 11, 2019 | 12:00 PM | teleECHO Conference

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The following Planning Committee and Presenting Faculty Members report having no relevant financial relationships:

Danielle Noreika, MD

Kelly Lastrapes, MD

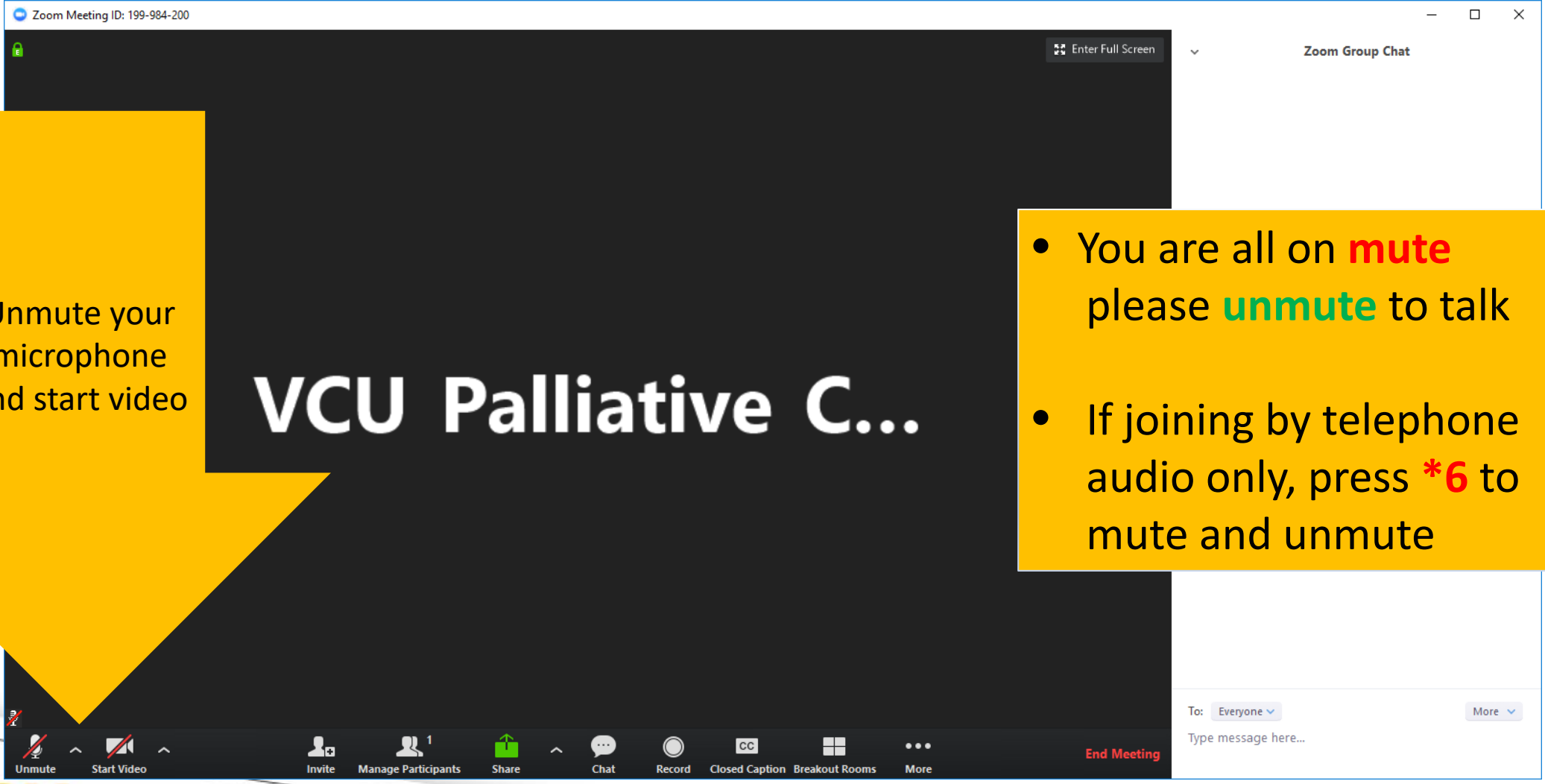
No commercial or in-kind support was provided for this activity

Helpful Reminders

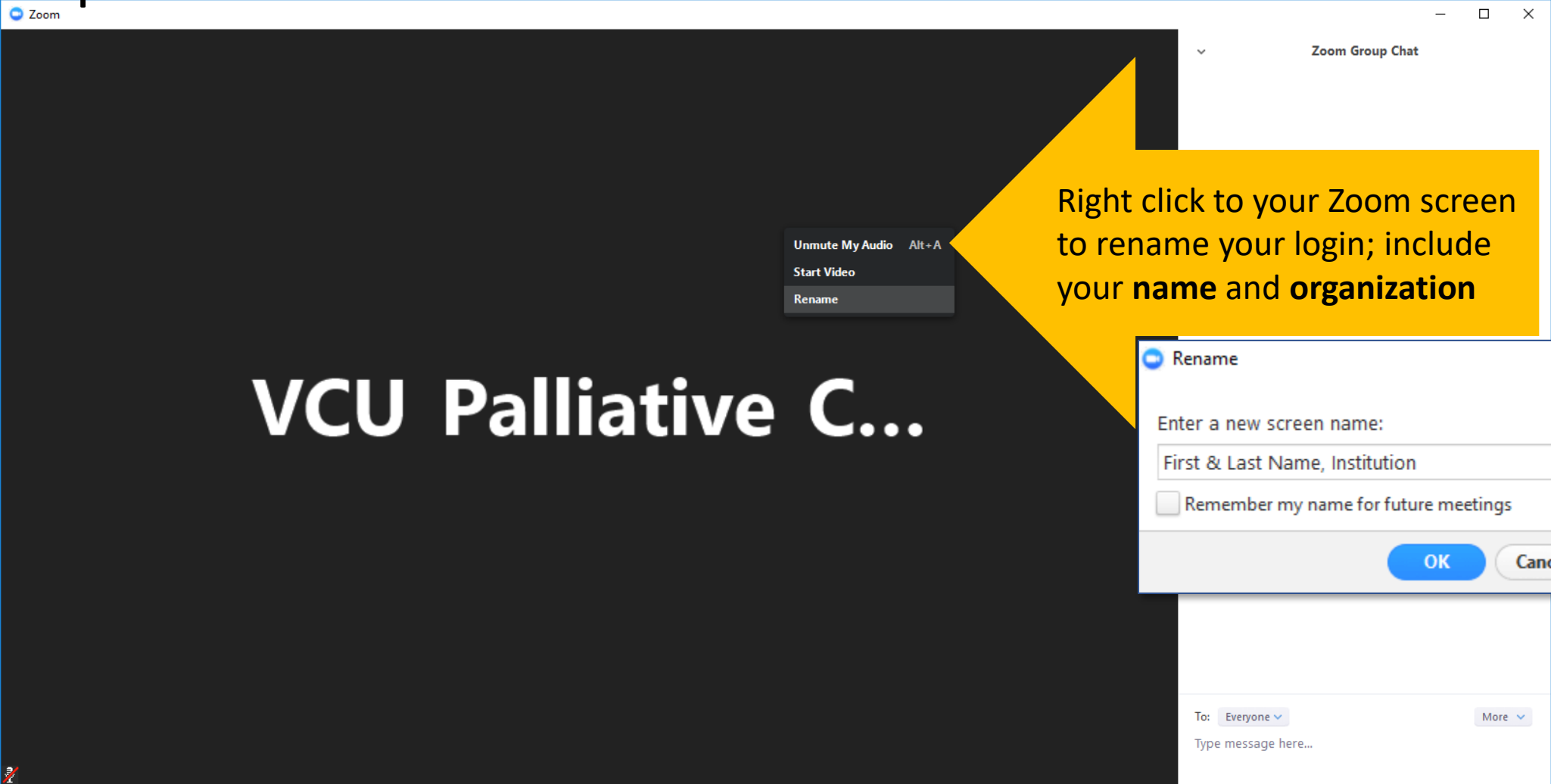
Unmute your
microphone
and start video

VCU Palliative C...

- You are all on **mute** please **unmute** to talk
- If joining by telephone audio only, press ***6** to mute and unmute



Helpful Reminders



Zoom Group Chat

- Unmute My Audio Alt+A
- Start Video
- Rename**

VCU Palliative C...

Right click to your Zoom screen to rename your login; include your **name** and **organization**

Rename

Enter a new screen name:

First & Last Name, Institution

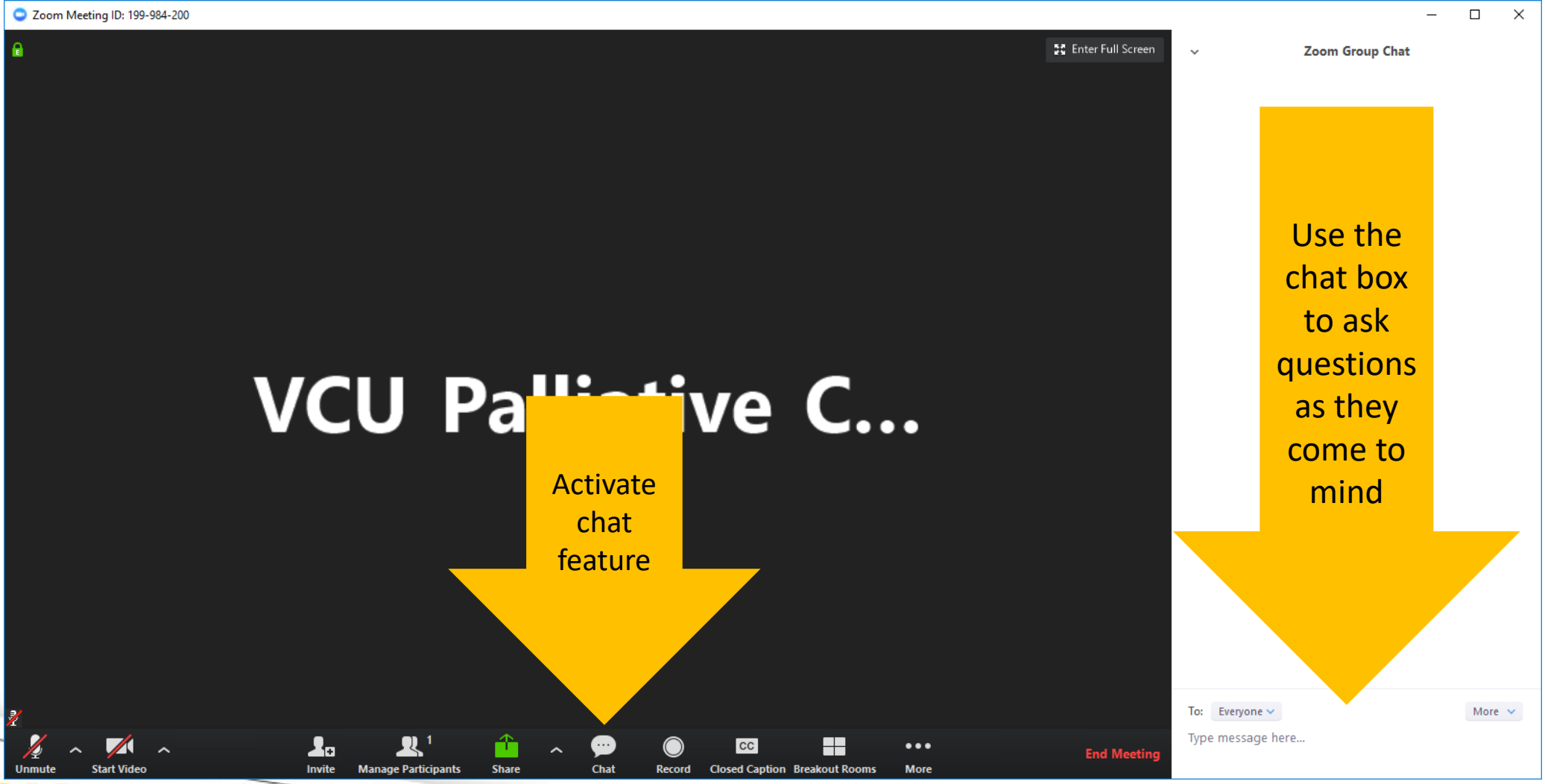
Remember my name for future meetings

OK Cancel

To: Everyone More

Type message here...

Helpful Reminders

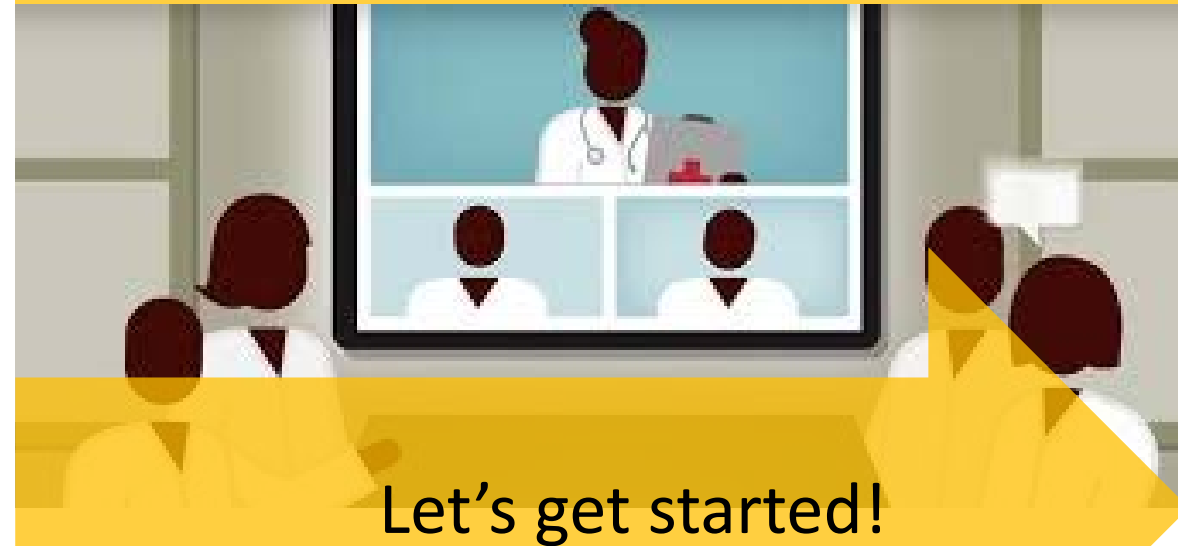


The screenshot shows a Zoom meeting window with a dark background. The title bar at the top reads "Zoom Meeting ID: 199-984-200". The main content area displays "VCU Palliative C...". A yellow arrow points from the text "Activate chat feature" to the "Chat" icon in the bottom toolbar. On the right side, a "Zoom Group Chat" panel is visible, containing a text input field "Type message here..." and a "More" dropdown menu. A large yellow arrow points from the text "Use the chat box to ask questions as they come to mind" to the chat input field.

What to Expect

- I. Didactic Presentation
20 minutes + Q&A
- II. Case Discussions (x2)
 - Case Presentation
5 min.
 - Clarifying questions from spokes,
then hub
2 min. each
 - Recommendations from spokes,
then hub
2 min. each
 - Summary (hub)
5 min.
- III. Closing and Questions

- Bi-weekly tele-ECHO sessions (1.5 hours)
- Didactic presentations developed by inter-professional experts in palliative care
- Website: www.vcuhealth.org/pcecho
- Email: pcecho@vcuhealth.org



Hub Introductions

VCU Team	
Clinical Director	Danielle Noreika, MD, FACP, FAAHPM Medical Director/Fellowship Director VCU Palliative Care
Clinical Experts	Egidio Del Fabbro, MD – VCU Palliative Care Chair Jason Callahan, MDiv – Palliative Care Specialty Certified Tamara Orr, PhD, LCP – Clinical Psychologist Diane Kane, LCSW – Palliative Care Specialty Certified Felicia Hope Barner – RN Candace Blades, JD, RN – Advance Care Planning Coordinator Brian Cassel, PhD – Palliative Care Outcomes Researcher
Support Staff Program Manager Practice Administrator IT Support	Teri Dulong-Rae / Bhakti Dave, MPH David Collins, MHA Frank Green

Spoke Participant Introductions

Name and Institution



CHILDREN'S
HOSPITAL OF RICHMOND AT **VCU**

Pediatric Palliative Care

Kelly Lastrapes, MD
**Assistant Professor, Division of
Pediatric Hematology, Oncology and
Stem Cell Transplant**



CHoR Definition of PPC

- “PPC is an extra layer of support focused on identifying, preventing and treating suffering in children with serious illnesses, their families and the teams that care for them. Palliative care is appropriate at any stage of a serious illness and can be provided together with disease-directed treatment. Palliative care supports ongoing treatment of the patient’s underlying illness and at the same time strives for optimal quality of life.”

Our Team at CHOR!

- The Supportive Care Team

- Medical providers

- Jean Teasley, MD (medical director)
- Kelly Lastrapes, MD
- Amanda Gideon, CPNP

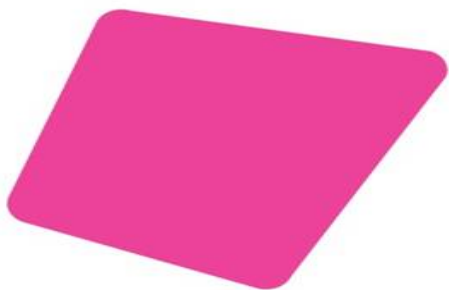
- Social workers

- Patty Roberts, LCSW
- Ellen Hanson, LCSW
- Robyn Dillon, LCSW

- Pastoral Care

- Josh Andrzejewski, BCC





FACTS AND FIGURES



The Numbers...

- In 2013
 - 2.6 million deaths
 - Children aged 0-19 accounted for 1.6% or 42, 328 deaths
 - 55% in infancy
 - » 66% in the neonatal period

Table 3. Causes of Death, Children Birth - 19 years

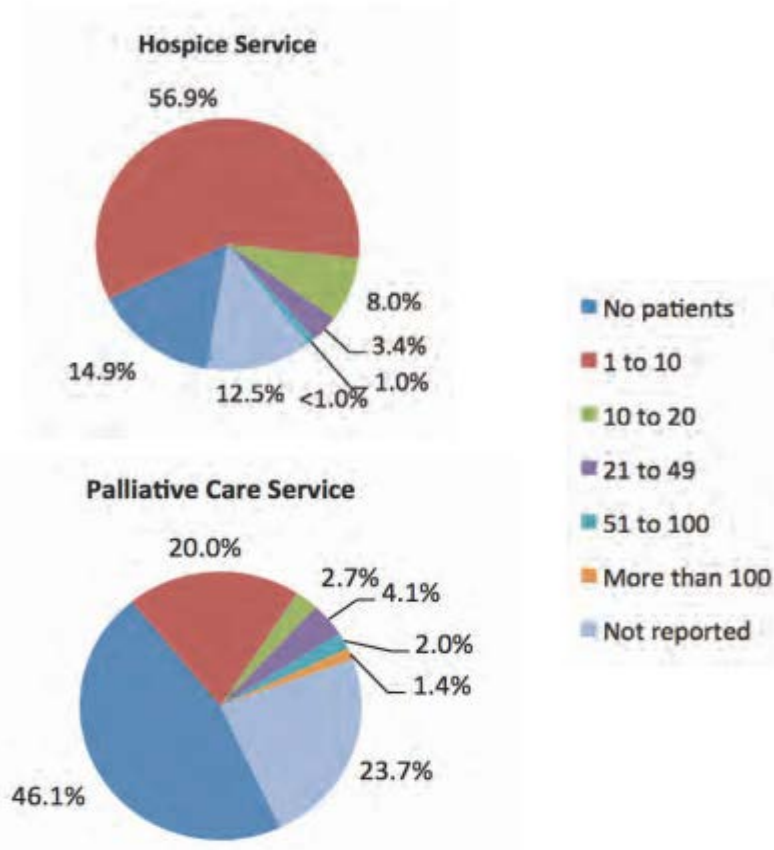
All Infants	Infants with CCC	All Children 1-19 Years	All Children 1-19 Years with CCC
1. Congenital malformations	1. Cardiovascular	1. Accidents	1. Malignancy
2. Short gestation / LBW	2. Congenital / genetic	2. Suicide	2. Neuromuscular*
3. Maternal complications	3. Respiratory	3. Assault	3. Cardiovascular
4. SIDS	4. Neuromuscular*	4. Malignancy	
5. Accidents/unintentional injury		5. Congenital malformations, deformations and chromosomal abnormalities	
6. Complications of placenta, cord, or membranes		6. Heart disease	
		7. Influenza and pneumonia	

* Includes static neurologic and neurodegenerative conditions

Access...

- NHPCO 2018
– 78% served
• 36.6% h
• 21.7% t
“special

Figure 2. Average number of pediatric patients served per year, by type of hospice



ric program had a

Concurrent Care

- Patient Protection and Affordable Care Act (ACA) 2010
 - Section 2302
 - Mandates that children in a state Medicaid or Children’s Health Insurance Program who are eligible for hospice care also be eligible to receive coverage for curative, disease-directed therapy



PEDIATRIC PALLIATIVE AND HOSPICE CARE COMMITMENTS



AMERICAN ACADEMY OF PEDIATRICS

Committee on Bioethics and Committee on Hospital Care

Palliative Care for Children

ABSTRACT. This statement presents an integrated model for providing palliative care for children living with a life-threatening or terminal condition. Advice on the development of a palliative care plan and on working with parents and children is also provided. Barriers to the provision of effective pediatric palliative care and potential solutions are identified. The American Academy of Pediatrics recommends the development and broad availability of pediatric palliative care services based on child-specific guidelines and standards. Such services will require widely distributed and effective palliative care education of pediatric health care professionals. The Academy offers guidance on responding to requests for hastening death, but does not support the practice of physician-assisted suicide or euthanasia for children.

Palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of children (and their families) living with life-threatening or terminal conditions.^{2,3} The goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient.⁴ The American Academy of Pediatrics (AAP) has previously addressed the limitation or withdrawal of life-sustaining medical treatment.⁵⁻⁷ Specific strategies for palliative management of pain, dyspnea, agitation, nausea, vomiting, seizures, depression, anxiety, grief, and other symptoms can be found in other sources.⁸⁻¹¹

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

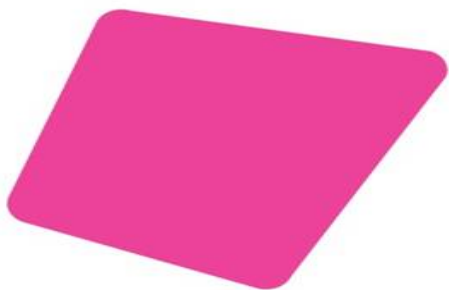
Organizational Principles to Guide and Define the Child
Health Care System and/or Improve the Health of all Children

POLICY STATEMENT

Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations

PPC-PHC Commitments

- Patient centered and family-engaged
- Respect and partnering
- Quality, access and equality
- Care across the age spectrum and life span
- Integration into the continuum of care
- Universal preparedness and consultation
- Research and continuous improvement



If I may...

SOME ANECDOTES



Differences between adult and PPC

- Diagnoses
 - CSHCN= children with special health care needs
 - CCC= chronic complex condition
 - LLC= life-limiting condition
 - LTC= life-threatening condition
- Prognostic uncertainty
 - Children are resilient, therefore unpredictable



Differences between adult and PPC

- Providing developmentally-appropriate PC
 - Lack of PROs (until PediQUEST study)
- Autonomy/Consent/Assent
 - That delicate balance between autonomy and parental protection

Where our paths intersect...

- COMMUNICATION
- Family members as barriers to care
- Medication abuse/addiction
- AYA population

Some motivation...

The end-of-life physician Evan had through Children's National never met him before or after he started to receive hospice care at home.



"The person who cared for my son at home when he needed it the most never met him and never spoke to him," Lindberg stressed. In addition, he added, "The wonderful oncology nurses at Children's National never had an opportunity to care for our son while he was at home. Instead we had nurses who came to see us from an adult hospital. Their experience and expertise was in caring for adults."

Because the nurses were not comfortable administering intravenous pain medicines to pediatric patients, Evan was not given effective pain relievers and experienced extreme discomfort, distress, and anxiety. In addition, Evan had respiratory challenges that were not appropriately anticipated or addressed. When his end-of-life physician was called and asked to address these issues, the doctor said to expect Evan would live another week or two, but he died the next morning "after a horrific night that my wife and I will forever have seared in our memory," Lindberg said. "Unfortunately, there are a lot of kids like Evan and that is just simply unacceptable in this country. Home was the right place for my son to pass, but what was wrong was the type of care he received. We put our trust and faith in the providers and in the system and that was a mistake on our part. There was a lack of communication. There was a lack of transparency about what was happening and why. Children with cancer fight too hard every single day to be left with a fate like that. If we can't get this right, then shame on us. The hospice system failed our son and as a result, we feel like we failed our son. Those thoughts stay with you. On your worst days, they haunt you."



Noah's Children[®]



CHILDREN'S
HOSPITAL OF RICHMOND AT **VCU**

References

- American Academy of Pediatrics. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Recommendations. *Pediatrics* 2013;132;966; originally published online October 28, 2013; DOI: 10.1542/peds.2013-273
- National Academies of Sciences, Engineering, and Medicine. 2015. Comprehensive cancer care for children and their families: Summary of a joint workshop by the Institute of Medicine and the American Cancer Society. Washington, DC: The National Academies Press.
- NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, September 2014.

Case Presentation 1

Emily Rivet, MD

Kasia Trebska-McGowan, MD

Virginia Commonwealth University

Case 1: Question

Main question:

How to best communicate unforeseen events to patients and families

What is the nature of your question?

- **Treatment options (goals of care)**
- **Communication**
- **Determining Prognosis**

Case 1: History

Patient history

66-year-old female

Current medications and therapies

- None

Patient social and spiritual history

- Very involved son and brother

Pertinent findings

- Delirium was a major symptom and significant factor in disease course.

Brief history of serious illness and other comorbid disorders:

Patient initially seen and underwent surgery for colovesical fistula. Surgical recovery complicated by anastomotic leak. Diagnosed with plasma cell leukemia post-operatively. Patient developed multi system organ failure and required dialysis, trach although weaned from ventilator.

Accessing CME credit



Submit your evaluation to claim your CME

After our live ECHO session, visit www.vcuhealth.org/pcecho

Click “Claim CME and Provide Evaluation”

The screenshot shows the VCU Health website for the Palliative Care ECHO program. The main navigation bar includes links for 'Explore VCU Health', 'Search', 'CAREERS at VCU Health', 'SUPPORT VCU Health', 'MY VCU HEALTH Patient Portal', and 'CONTACT VCU Health'. Below this is a secondary navigation bar with 'VCUHealth' logo and links for 'Our Providers', 'Our Services', 'Locations', 'Patients & Visitors', 'For Your Health', and 'Our Story'. A breadcrumb trail reads: Home > For Providers > Education > VCU Health Palliative Care ECHO > Home.

The main content area features the title 'VCU Health Palliative Care ECHO' with social media icons for print, Facebook, Twitter, and email. The text describes the program's partnership with community practices to provide care and education. It includes links for 'Register now for an upcoming clinic.', 'Submit a case study' (for registered participants), and 'Contact us' for more information.

On the right side, there is a 'Telehealth' sidebar menu with the following items: 'About Telehealth at VCU Health', 'For Patients', 'For Providers' (highlighted), 'Virginia Opioid Addiction ECHO', 'VCU Health Palliative Care ECHO' (expanded), 'Register Now!', 'Submit Your Case Study', 'About', 'Curriculum', 'Claim CME and Provide Evaluation' (highlighted with a red arrow), 'Virginia Sickle Cell Disease ECHO', and 'Telehealth Programs'.



Submit your evaluation to claim your CME

+

VCU Health Palliative Care ECHO Survey Resize font: + | -

Please complete the survey below.

Thank you!

Name <small>* must provide value</small>	<input type="text"/>
Credentials (MD, DO, NP, RN, ...) <small>* must provide value</small>	<input type="text"/>
Email Address <small>* must provide value</small>	<input type="text"/>
I attest that I have successfully attended the Virginia Palliative Care ECHO Clinic. <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No
Do you intend to make changes based on this presentation? <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No reset
What was the quality of the brief lecture? <small>* must provide value</small>	<input type="radio"/> Poor <input type="radio"/> Fair <input type="radio"/> Neutral <input type="radio"/> Good <input type="radio"/> Excellent reset
What feature of the TeleECHO clinic did you enjoy most? <small>* must provide value</small>	<input type="radio"/> Didactic Presentation <input type="radio"/> Case Presentation <input type="radio"/> Discussions & interactions between hubs and spokes (participants) <input type="radio"/> Other reset
What other palliative related topics would you like addressed?	





View previously recorded ECHOs for CME

To view previously recorded sessions and claim credit, visit

www.vcuhealth.org/pcecho

Click "Curriculum"

The screenshot shows the VCU Health Palliative Care ECHO website. The main heading is "VCU Health Palliative Care ECHO". Below it, there is a paragraph describing the program's partnership with community practices. Further down, there are links for "Register now for an upcoming clinic.", "Submit a case study", and "Contact us". On the right side, there is a "Telehealth" sidebar menu with several options, including "Curriculum", which is highlighted by a large red arrow pointing to it.





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VCUHealth. Our Providers Our Services Locations Patients & Visitors For Your Health Our Story

Home > For Providers > Education > VCU Health Palliative Care ECHO > Curriculum

Curriculum

[Register now for an upcoming clinic on palliative care.](#)

Topic	Date	Speaker & Resources
Introduction to Palliative and Supportive Care	02/14/19	Danielle Noreika, MD Video of Clinic

Learning Objectives:

1. Define palliative care and differentiate from hospice.
2. Describe reasons for referral to palliative care.
3. Describe basic structure of palliative care team.

Telehealth

- About Telehealth at VCU Health
- For Patients
- For Providers**
- Virginia Opioid Addiction ECHO
- VCU Health Palliative Care ECHO**
- Register Now!
- Submit Your Case Study
- About



View previously recorded ECHOs for CME

Click “Tests” to view video of the session and take a short quiz for continuing education credit



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Introduction to Palliative and Supportive Care

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Date & Location

Wednesday, March 6, 2019, 9:09 AM - Friday, March 13, 2020, 10:09 AM

Target Audience

Hospitalist, Internal Medicine, Multiple Specialties, Gerontology, Social Work

Overview

Online archived sessions include a video, a listing of reading materials and a post-test assessment

Objectives

1. Define palliative care and differentiate from hospice
2. Define palliative care and differentiate from hospice
3. Describe basic structure of palliative care team



THANK YOU!

We hope to see you at our next ECHO

