

# VCU Palliative Care ECHO\*

May 23, 2019

Helping Children of Adult Patients

# Continuing Medical Education

May 23, 2019 | 12:00 PM | teleECHO Conference

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Physicians should claim only the credit commensurate with the extent of their participation in the activity.

## **Continuing Nursing Education: 1.5 CE Contact Hours**

VCUHealth is approved as a provider of continuing nursing education by the Virginia Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

# Disclosures

May 23, 2019 | 12:00 PM | teleECHO Conference

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The following Planning Committee and Presenting Faculty Members report relevant financial relationships to disclose:

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

**Amanda Gideon, CPNP**  
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**Patricia Roberts, LCSW**  
**Heather Rossi, CCLS**

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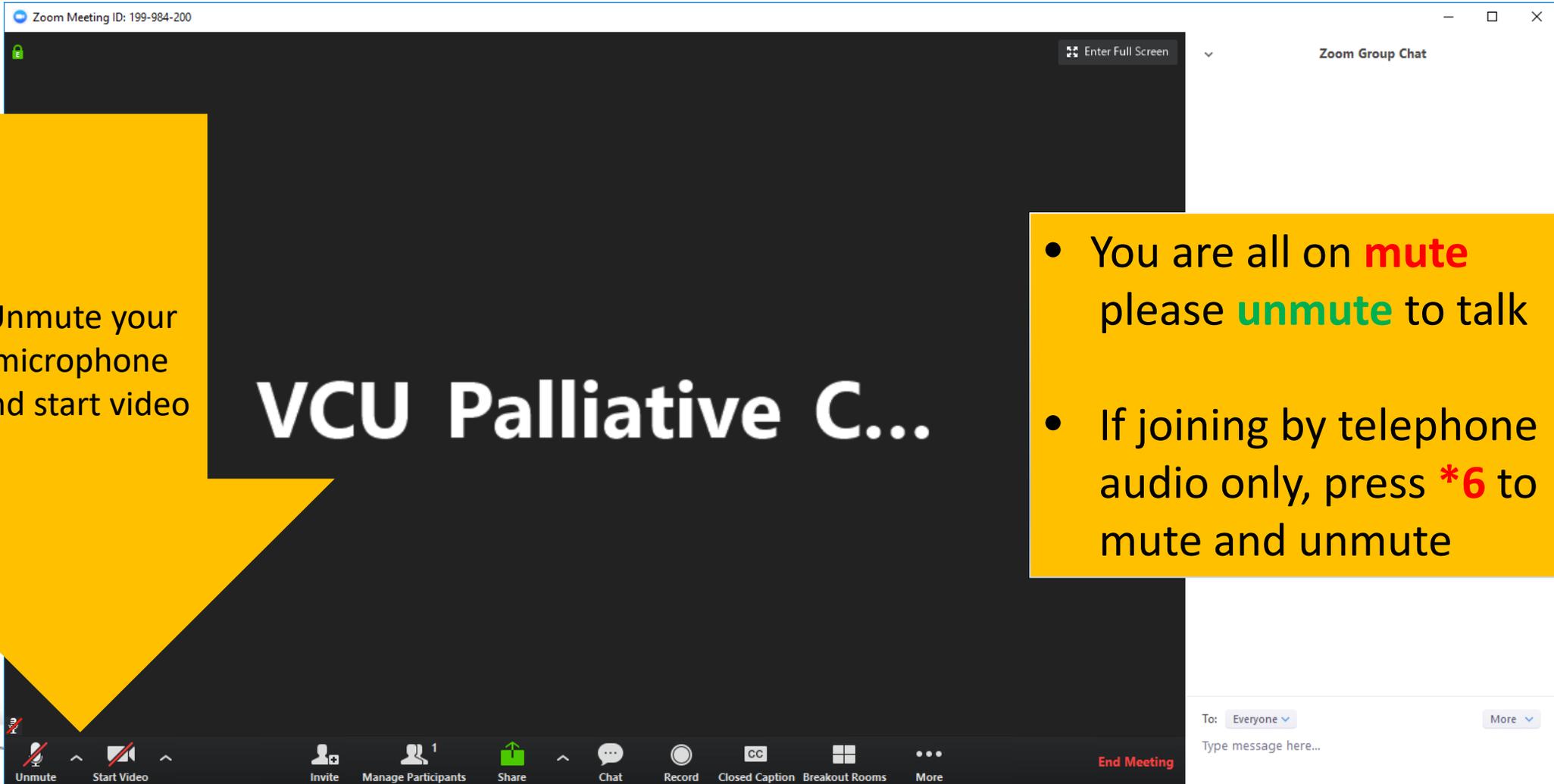
***No commercial or in-kind support was provided for this activity***

# Helpful Reminders

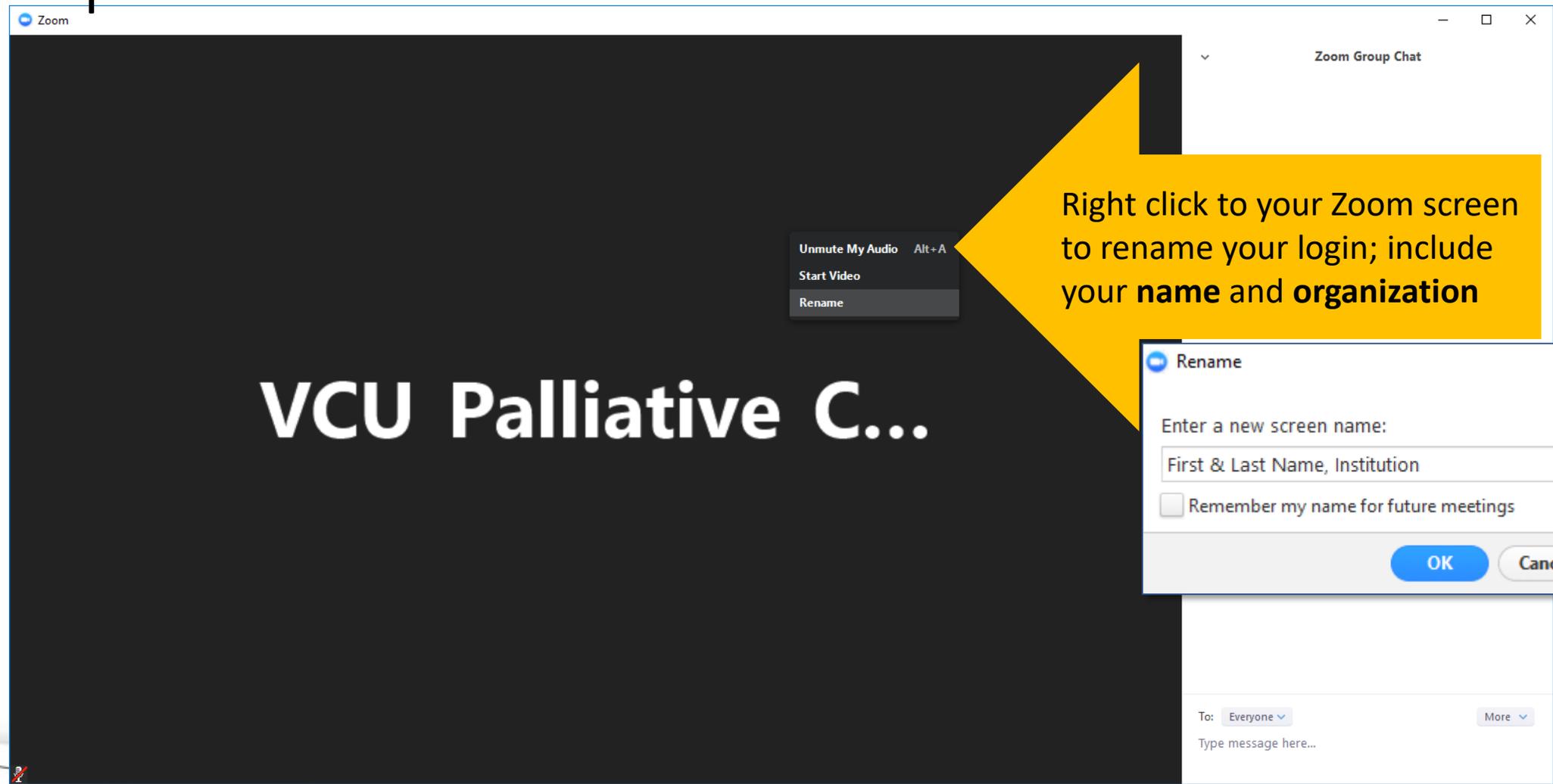
Unmute your  
microphone  
and start video

## 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

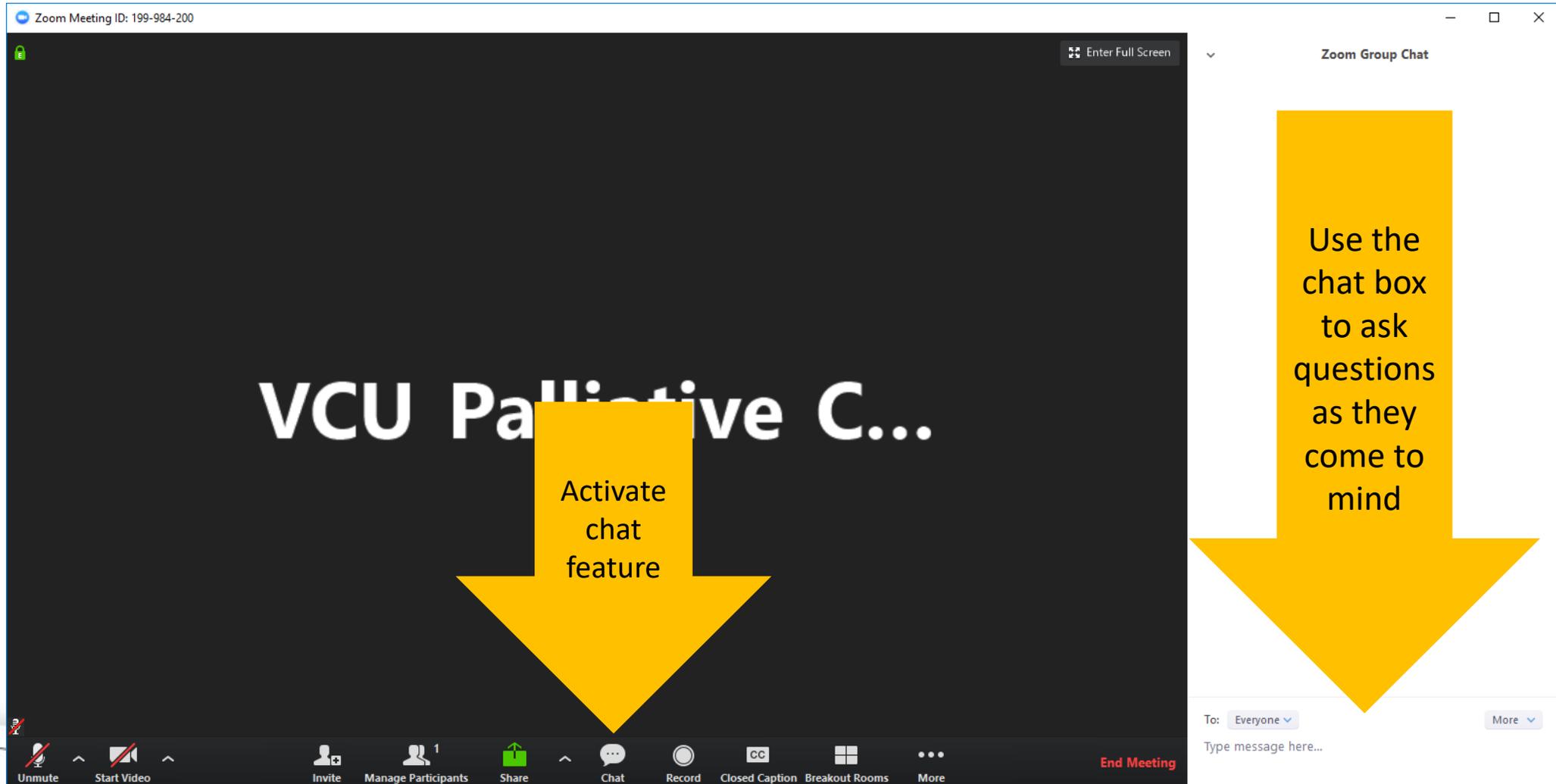
Remember my name for future meetings

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. To the right, a "Zoom Group Chat" window is open, showing a text input field with the placeholder "Type message here...". A large yellow arrow points from the text "Use the chat box to ask questions as they come to mind" to the chat input area. The bottom toolbar includes icons for Unmute, Start Video, Invite, Manage Participants, Share, Chat, Record, Closed Caption, Breakout Rooms, and More, along with an "End Meeting" button.

Zoom Meeting ID: 199-984-200

Enter Full Screen

Zoom Group Chat

VCU Palliative C...

Activate chat feature

Use the chat box to ask questions as they come to mind

To: Everyone

Type message here...

Unmute Start Video Invite Manage Participants Share Chat Record Closed Caption Breakout Rooms More End Meeting

# What to Expect

- I. Didactic Presentation  
20 minutes + Q&A
- II. Case Discussions
  - 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](http://www.vcuhealth.org/pcecho)
- Email: [pcecho@vcuhealth.org](mailto:pcecho@vcuhealth.org)



# Hub Introductions

<b>VCU Team</b>	
<b>Clinical Director</b>	Danielle Noreika, MD, FACP, FAAHPM Medical Director/Fellowship Director VCU Palliative Care
<b>Clinical Experts</b>	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 Coley – RN Candace Blades, JD, RN – Advance Care Planning Coordinator Brian Cassel, PhD – Palliative Care Outcomes Researcher
<b>Support Staff</b> Program Manager Telemedicine 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**

**HCAP**  
**Helping Children of Adult Patients**  
**2019**  
**ECHO presentation**

# Outline of orientation

- What is HCAP?
- HCAP history & importance
- Ages & stages of development
- Questions children ask
- Talking with children
- Consults – How to's
- Questions families ask
- Case studies
- Resources

# What is HCAP?

- A free hospital-wide consult service available to support the children in the families of adult patients who are experiencing a life-altering illness, serious injury, or death. Services are available for both immediate and extended family minors.
- Interdisciplinary team of pediatric staff with training in one or more of the following: child development, counseling, social work, and child life
- All incoming HCAP members attend an HCAP orientation, training, and shadowing opportunities
- 24/7 coverage

# HCAP history

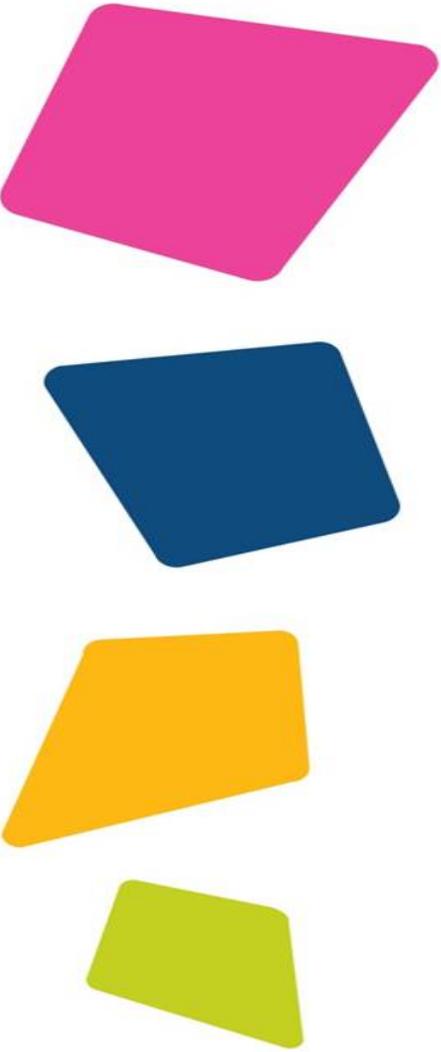
- For many years, these calls came directly to the Child Life Department here at VCU and were handled solely by child life specialists as other obligations allowed
- In the early 2000's, the interdisciplinary HCAP team was formed by the director of Women's and Children's services and was under the direction of the Pediatric Palliative Care Director (a Nurse Practitioner)
- Initial team included Child Life, pastoral care, and nursing (peds, trauma, and palliative care)
- Challenges of initial model

# HCAP today

- Nationwide, we are among few, if not the only *interdisciplinary* team providing this type of care
- Areas other than ICUs and Palliative Care include: Antepartum, Labor & Delivery, Psychology, Emergency Department, Oncology
- How we decide who to orient to team/process  
(All CCLS' coming to CHoR have to be oriented to HCAP, being mindful of workload)
- Ways we're advertising/expanding our reach

# Why HCAP matters

- Exclusion and dishonesty lead to fantasies more terrible than reality
- Opportunity to clarify incorrect perceptions
- Children cope best when able to assimilate both facts and feelings and are helped to master the trauma through extensive emotional support (M. Barnes, 1961)
- Proactive (prior to death) grief support facilitates grieving & the completion of essential developmental tasks (Christ, 2008)
- Avoidance of unresolved grief, which can lead to serious psychological complications (Davis, 1989)
- Children “need stability, need to be included, need to be curious, and they need to express their feelings.” (Andrew Puckett)
- Avoidance of discussion of death contributes to the child’s mistrust of adults and compounds feelings of isolation (E. Kubler-Ross)



# Grief: Resolved vs. Unresolved

## Complications of Unresolved Grief

- Social withdrawal
- Oppositional or conduct disorder
- Decline in school performance
- Persistent sleep problems
- Psychosomatic symptoms
- Promiscuity or delinquent behavior (Nobris 2005, Davis 1989, Younger 1993, Kubler Ross)

## Positive Outcomes for Resolved Grief

- Greater self-confidence in coping skills
- Resiliency, increased maturity
- Heightened empathy for parents
- Overall psychological growth
- Avoidance of social isolation from siblings & peers

(Balk, 1981, 1983, 1990; Hogan, 1987, 1988, 1990; Pollock 1978, 1986; Nobris et al. 2005)

# Children's understanding of illness and death

- Infants and Toddlers
- Preschool
- School-age
- Adolescents

# Infants and Toddlers (birth – 2yrs)

- Recognize that something significant, sad occurred
- Pick up on surrounding tension and emotions
- Are stressed with the change in their routine
- No understanding of death except as a loss
- Ways to comfort: touch, rocking, keeping familiar people around, engage in play, maintain routine
- Infants (toys, blankets, pacifiers)
- Toddlers (puppets, dolls as visual aids; encourage parents to be present for talks; use concrete language)

## Preschool (3-5 yrs)

- Likely to believe that death is temporary and/or reversible
- May be combative (verbal or physical), ask a lot of questions about death
- Magical thinking (may think they caused the event/death)
- Less likely to think they can die also, but this could be a fear
- May equate death with sleep
- May feel cranky, scared, confused about changes, withdrawn, sad
- May cry, act as if nothing happened,
- Play may show acting out death
- Provide concrete information: “A dead person no longer breathes or eats.”
- Reassure child that they did not cause the illness or death to happen
- Allow child to handle equipment, provide opportunities to ask questions, use visual aids

## School-age (6-12yrs)

- May begin to understand finality of death
- Wonder about biological process of death
- Understand causality by external reasons (accident) and internal causes (illness)
- Magical thinking (may still feel responsible and powerful)
- May feel sad, angry, cranky, withdrawn
- May behave aggressively, have nightmares, have a hard time concentrating, grades may drop, could act withdrawn.
- Play may include violence, crashes, death.
- May feel vulnerable, confused, angry, isolated, sad, lonely
- May giggle or joke about death
- May worry about the other parent or caregiver dying

## Adolescents (13yrs+)

- Understand finality, universality, irreversibility, nonfunctionality, causality, and noncorporeality
- Don't think it will happen to them, have a sense of immortality
- May act out with risk-taking behavior because "it won't happen to me" or "everyone dies anyway"
- Often expected to act like / wants to act like an adult and doesn't get the developmentally appropriate support they still need
- Provide privacy, do not pry - but they need to know they aren't alone

## Questions children often ask

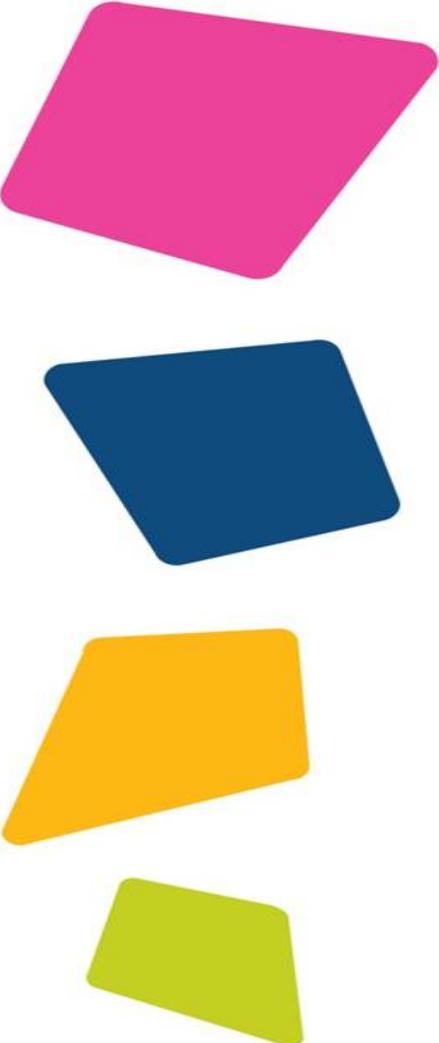
1. Did I cause this (illness/death) to happen?
2. Will it (illness/death) happen to me?
3. Who will take care of me?
4. Will it (illness/death) happen to the person taking care of me?
5. Who will take me to soccer tomorrow?  
Are we still going to the beach?  
(asked during actual HCAP consults)

## Questions families often ask

- “How do I tell them? What do I tell them?”
- “Should they come see her like this? Should they wait until after she dies?”
- “What about the funeral? Should they go?”
- “Who should I tell about what has happened?”
- “How much should we tell the school?”
- “When should they go back to school?”
- “Should we tell the kids together or separately?”

# HCAP Referral Process

- **Any staff member** on any unit who recognizes the need for help communicating with children of an adult patient can consult HCAP via a virtual pager
- Upon receiving a consult, our goal is to respond by phone within 20 minutes to gain more information and further assess the situation/needs
  - fill out the HCAP intake form
  - assess the urgency of the matter
- Address the consult as appropriate (in-person visit with the family, phone call to family, or phone assistance to staff)
- Document HCAP consult and actions taken in patient's EMR
- All HCAP team members are full-time employees at VCU in another role and take on HCAP coverage and duties in addition.
  - What if a referral cannot be completed?

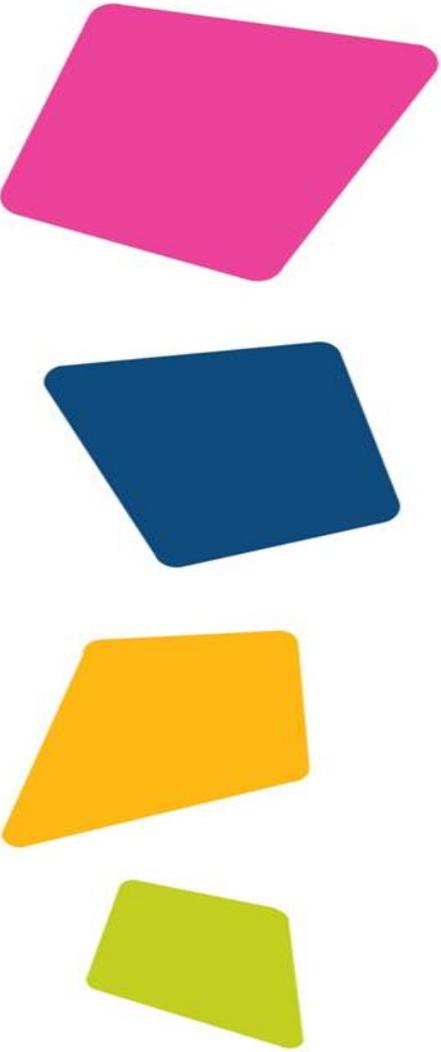


# Things to include in your preparation for a bedside visit

- 4 senses (what they will see, hear, smell, can touch)
- What the child can and cannot do while bedside
- Remind family and child that the child's comfort level should guide the interaction, including the length of their visit
- Talk with the RN, ensure no procedures are needed at that time and that MDs will also stay out of the room
- Talk with RN about any tubes that can be covered or hidden, is the pt comfortable and calm or are pain/sedation meds almost due?
- Is one of the patient's hands free of monitors or IVs and thus easier for the child to hold or touch, have this hand on top of the blanket

# Things to consider during a bedside visit

- Keep an eye on both the children and family to be able to help as needed, but also on the door to potentially redirect care providers
- Some children will look for all the things you discussed with them, and have many questions while others become overwhelmed and quiet and just stare
- An overwhelmed child can be encouraged to come look out the window with you and when they are more at ease may choose to return to the bedside
- Be the person to leave the room with an upset or anxious child if they feel unable to stay (if a family member cannot take on this role)
- Sometimes at the bedside, you can stand back and allow family time (or even leave the room once it's going well), but other times your interaction throughout the visit is necessary



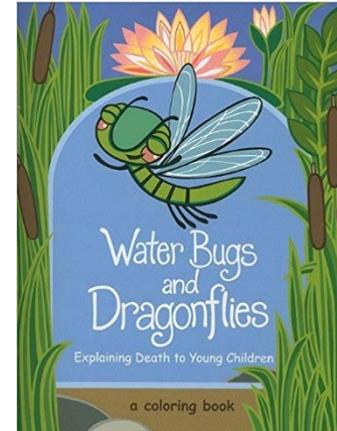
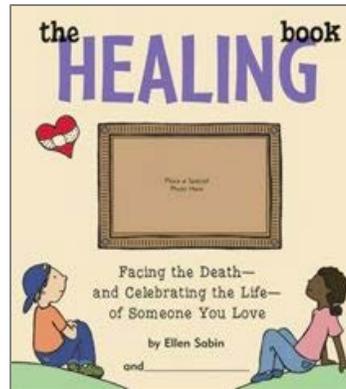
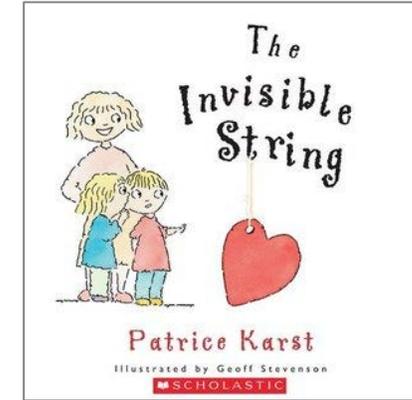
# When talking with children under stress (at the hospital)

- Offer diversional activities to help develop rapport and build trust
- Avoid sudden advances, prolonged eye contact or other gestures that may seem threatening
- If child is shy, talk with parent first, children will listen!
- Consider giving older children opportunity to talk without parents
- Get on their eye level
- Speak clearly, be honest, use simple words and short sentences
- Offer appropriate choices only if they exist
- Allow children to express their fears and concerns

## Resources, tips & memory making

- Crayons/markers, coloring pages/plain paper, Playdoh, Hot Wheels cars, puzzles – to distract and occupy children while you talk to them
- iPad – if you need to photograph the patient to prep the children or for distraction
- Stuffed animals – both for comfort and to discuss courage (Duffy)
- Developmentally appropriate tip sheets
- Appropriate books
- **Get these items from Child Life Office**

# Resources



## Case studies



- Heather



- Josh



- Patty



- Siri

# Case Study #1: Heather

- **Type of Visit:** End-of-life
- **Referral Source:** Palliative care team
- **Medical Snapshot:** terminal lung cancer
- **Child's Age:** 16yo
- **Background:** Pt is father of a “daddy’s girl” who had withdrawn from all family activities, staying in her room at home. Now present at the hospital, mother seeking support for her and for their relationship.
- **Intervention:** conversation with teen and mother held in private space; encouraged them to communicate and not shut each other out of their own private grief, suggested texting or shared journal to pass between themselves. Both felt this was doable and expressed relief at having connected with each other before the patient died. Provided a journal and fingerprint charm.

# Case Study #2: Josh

- **Type of Visit:** New Diagnosis / Potential end-of-life
- **Referral Source:** Nurse
- **Medical Snapshot:** recurrence of breast cancer
- **Background:** Mother of three sons (twin 6yo, 3yo), husband requesting help with how to talk to the boys
- **Intervention:** Encourage balance between honesty & overwhelming with information; explored how the boys experienced previous bout with cancer; discussed step-wise approach to sharing information; talked about parental resilience.

# Case Study #3: Patty

- **Type of Visit:** New Diagnosis/ICU visit
- **Referral Source:** Nurse
- **Medical Snapshot:** Pedestrian vs. Car
- **Background:** Father of two girls (5yo, 11yo) who was struck by a vehicle at a high speed, polytrauma including TBI. Wife wondering if she should have the children visit him in the hospital.
- **Intervention:** Three total meetings; helped mother process the pros and cons of having the children visit and encouraged her to provide choice and involved them in the decision; discussed some strategies for supporting the children before and during the visit; participated in bedside visit including prepping children; provided comfort and distraction items for visit

# Case Study #4: Siri

- **Type of Visit:** ICU visit/End-of-life
- **Referral Source:** Nurse
- **Medical Snapshot:** motor vehicle accident
- **Background:** grandfather of 2 children (ages 10y and 13y), patient's daughter (mother of children) seeking help with how to help explain what happened and assist in bedside visit
- **Intervention:** Encouraged honesty and preparation with siblings; discussed step-wise approach to sharing information; facilitated several bedside visits; facilitated memory making with grandchildren and family members; provided resources on grief expression in school aged children and teenagers

# Questions?



# Accessing CME credit



# Submit your evaluation to claim your CME

After our live ECHO session, visit [www.vcuhealth.org/pcecho](http://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!

<b>Name</b> <small>* must provide value</small>	<input type="text"/>
<b>Credentials (MD, DO, NP, RN, ...)</b> <small>* must provide value</small>	<input type="text"/>
<b>Email Address</b> <small>* must provide value</small>	<input type="text"/>
<b>I attest that I have successfully attended the Virginia Palliative Care ECHO Clinic.</b> <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No
<b>Do you intend to make changes based on this presentation?</b> <small>* must provide value</small>	<input type="radio"/> Yes <input type="radio"/> No <span>reset</span>
<b>What was the quality of the brief lecture?</b> <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 <span>reset</span>
<b>What feature of the TeleECHO clinic did you enjoy most?</b> <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 <span>reset</span>
<b>What other palliative related topics would you like addressed?</b>	





# View previously recorded ECHOs for CME

To view previously recorded sessions and claim credit, visit

[www.vcuhealth.org/pcecho](http://www.vcuhealth.org/pcecho)

Click "Curriculum"

The screenshot shows the VCU Health Palliative Care ECHO website. The main content area features a heading "VCU Health Palliative Care ECHO" followed by a description of the program. Below this, there are three links: "Register now for an upcoming clinic.", "Submit a case study (registered participants only).", and "Contact us for more information or help with any questions about our program." On the right side, there is a "Telehealth" sidebar menu with several options. A large red arrow points to the "Curriculum" option in this menu.





# View previously recorded ECHOs for CME

Select the session you would like to view

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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.](#)

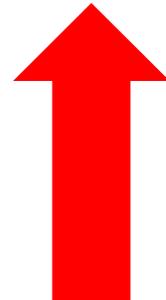
Topic	Date	Speaker & Resources
Introduction to Palliative and Supportive Care	02/14/19	Danielle Noreika, MD <a href="#">Video of Clinic</a>

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

[Overview](#)

[Faculty](#)

[Tests](#)

### 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

