INITIATIVE FOR PEDIATRIC PALLIATIVE CARE VIRGINIA RETREAT October 26-28, 2008

University of Virginia, Jordan Hall Conference Center, Charlottesville, Virginia

Supported by: The Byrd Family

Infants, children, and adolescents with life threatening illnesses deserve the very best care possible. Interdisciplinary teams of healthcare providers, family members and those whose professions bring them into contact with such children and their families are invited to join us in this interactive, "train-the-trainer" educational retreat.

Presented by: The University of Virginia Children's Hospital & The Initiative for Pediatric Palliative Care, Education Development Center, Newton, Massachusetts

Sponsored by: The Office of Continuing Medical Education University of Virginia School of Medicine









WHAT IS IPPC?

Spearheaded by the Education Development Center, The Initiative for Pediatric Palliative Care (IPPC) is a national consortium aimed at enhancing culturally respectful, family-centered care of gravely ill children. The IPPC curriculum reflects five years of research and development and includes more than 25 hours of peer-reviewed curriculum and an award winning video series. Using a retreat format to intensify the learning experience for participants, IPPC addresses key domains of pediatric palliative care through:

- An interactive, interdisciplinary team approach
- Plenary sessions interspersed with small group "train the trainer sessions"
- Collaborative learning in a practitioner/family member partnership

WHO SHOULD ATTEND?

IPPC's educational program is designed for small interdisciplinary teams of 3-5 persons from:

- Children's hospitals
- Pediatric services of general hospitals
- Hospice/home care services
- Other organizations serving gravely ill children.

Teams will be prepared to return to their own institutions equipped with knowledge, skills and quality improvement tools to implement educational programming and organizational change in pediatric palliative care.

WHAT MAKES THIS RETREAT SPECIAL ?

- Experiencing the unique IPPC learning approach for the first time in this area
- Opportunities for family members and clinicians to learn together as a team
- Care provider teams build enthusiasm and develop plans to take back to their home institutions

Here is what some previous attendees had to say about the IPPC approach:

"Since attending an IPPC retreat in October 2005, our institution implemented its own 7-week training program in pediatric palliative care using the IPPC curriculum. The first series was completed in November 2006 and we are offering additional ones in 2007. Two bereaved parents are part of the faculty for the training. Our institution was also one of the co-sponsors for a later IPPC retreat in April 2006 at St. Jude Children's Research Hospital." -Greg Adams, Arkansas Children's Hospital

"Our group, representative of a number of institutions in North Carolina, met with IPPC staff for several months to plan a retreat which was held in October 2006 at Duke's Divinity School. Afterwards, we decided that the planning group should remain intact and become an active and knowledgeable voice for pediatric palliative care at the state level. We are now offi cially the Pediatric Palliative Care Coalition of North Carolina!" -Wanda Baker, Carolinas Healthcare/ Levine Children's Hospital

HOW CAN WE BEST HELP CHILDREN AND FAMILIES?

The IPPC approach addresses compelling challenges in pediatric palliative care, including how best to honor the knowledge and insight of parents in a medical world when their children are seriously ill, and how best to address the anguish of patients, family members, and practitioners alike.

MORE ABOUT IPPC

Visit IPPC on the web at <u>www.ippcweb.org</u>. Hear about IPPC on National Public Radio! Go to: www.herenow.orgshows/2004/08/20040823.asp — Scroll down to "Pallia-tive Care for Children" and click "Listen."

Read about IPPC in the Baltimore Sun's four-part series "If I Die" by Pulitzer Prize-winning reporter Diana Sugg at <u>www.baltimoresun.com/angels</u>.

Teams attending this training who wish to purchase the IPPC video series for their institution will receive a 50% discount.

EDUCATIONAL GOALS AND OBJECTIVES

At the conclusion of the conference, participants will be able to:

- Plan and conduct ongoing, multidisciplinary education sessions, formal and informal, in pediatric palliative care utilizing the IPPC curriculum materials in their home institutions.
- Discuss the value and purpose of collaborative learning in interdisciplinary teams and practitioner-family member partnerships.
- Communicate more effectively with children and families in difficult situations, listening to fears and respecting family values in determination of goals.
- Recognize the unique cultural, psychosocial, and spiritual needs of children and families including siblings in palliative care situations.
- Continue networking with local and regional colleagues to address challenges, needs, and opportunities for program development in pediatric palliative care.
- Discuss the impact on professionals working in pediatric palliative care and plan institutional supports with positive coping strategies for staff that can be fostered in their home institutions.

ACCREDITATION

The University of Virginia School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The University of Virginia School of Medicine designates this educational activity for a maximum of 14.75 *AMA PRA Category 1Credit(s)*TM. Physicians should only claim credit commensurate with the extent of their participation in the activity.

The University of Virginia School of Medicine awards 0.1 CEU per contact hour to each non-physician participant who successfully completes this educational activity. The CEU (Continuing Education Unit) is a nationally recognized unit of measure for continuing education and training activities that meet specific educational planning requirements. The University of Virginia School of Medicine maintains a permanent record of participants who have been awarded CEUs.

CONTACT INFORMATION

For additional information concerning this conference, please call Pam MacIntyre, M.Ed, M.S. at the University of Virginia Office of Continuing Medical Education:

Phone (434) 982-4136

Fax: (434) 982-1415

Email: <u>pam2n@virginia.edu</u>.

Our conference registrar, Bebe Moore, can be reached at 434-924-5310, Fax 434-243-6393.

IPPC RETREAT: UVA CHILDREN'S HOSPITAL AGENDA

SUNDAY, OCTOBER 26

12:00 – 1:30 pm	Faculty Meeting
2:00 – 3:00 pm	Registration
*	Family Meeting
3:00 – 4:00 pm	Plenary: Welcome and Setting the Context
*	Cornerstones of Clinical Practice and Education
	Speaker: David Browning, MSW
4:00 – 5:30 pm	Small Group Session #1: Opening Activity
5:30 – 6:45 pm	Plenary: Relational Approach to Communication
1	(Adaptation of Activities 5.1 & 5.2 in IPPC Curriculum)
	Speaker: David Browning, MSW
7:00 pm	Dinner as a group
1	Monday, October 27
8:00 – 9:00 am	Registration and Continental Breakfast
9:00 – 10:15 am	Small Group Session #2: Honoring Parental Values When Benefits
9.00 - 10.13 all	
	are Marginal or Uncertain (Activity 3.3 in IPPC Curriculum)
10.15 10.20	Speakers: IPPC Faculty (attached)
10:15 – 10:30 am 10:30 – 12:00	Break Small Group Session #3: Addressing Parents' Fears About Opioid
10.30 - 12.00	Analgesia (Activity 2.6 in IPPC Curriculum)
	Speakers: IPPC Faculty
12:00 – 1:00 pm	Lunch
12.00 1.00 pm	
2:00 – 3:15 pm	Family Meeting Topical Breakout and Regional Sessions
2.00 5.15 pm	Speakers: IPPC and Regional Faculty
3:15 – 3:30 pm	Break
3:30 – 5:00 pm	Small Group Session #4: Difficult Conversations in Pediatric Palliative
5.00 5.00 pm	Care - Supporting an Adolescent Facing Death
	(Activity 5.3 in IPPC Curriculum)
	Speakers: IPPC Faculty
5:00 – 6:15 pm	Team Planning Session
F	Dinner on your own
6:15 – 7:00 pm	Faculty Meeting
I I I I I I I I I I I I I I I I I I I	
7:30 – 8:30 am	TUESDAY, OCTOBER 28 Provinteration and Continental Breakfast
7.50 - 8.50 and	Registration and Continental Breakfast
8:30 – 9:45 am	Family Meeting
8.30 - 9.43 all	Plenary : Family Panel Speakers: Deborah Dokken, Parents/family members
9:45 – 10:00 am	Break
10:00 - 11:30 pm	Small Group Session #5: The Experience of Professional Caregivers in
10.00 11.30 pm	Pediatric Palliative Care (Activity 4.1 in IPPC Curriculum)
	Speakers: IPPC Faculty
11:30 – 12:15 pm	Small Group Session #6: Closing Activity
12:15 – 1:00 pm	Closing Plenary: Summary and Future Directions
12.13 1.00 pm	Speakers: David Browning, MSW, IPPC Faculty
1:00 – 1:30 pm	Faculty Meeting
1.00 1.00 Pill	1 acuity 1/1000111g

IPPC RETREAT: UVA CHILDREN'S HOSPITAL

RETREAT CO-DIRECTORS

DAVID M. BROWNING, MSW, BCD, FT Director, Initiative for Pediatric Palliative Care; Senior Research and Development Associate, Center for Applied Ethics, Education Development Center, Inc., Newton MA

DEBORAH L. DOKKEN, MPA Associate Director, Initiative for Pediatric Palliative Care, Center for Applied Ethics, Education Development Center, Inc., Newton, MA

UNIVERSITY OF VIRGINIA COURSE DIRECTOR & IPPC FACULTY

NOREEN CRAIN, MD Assistant Professor, Pediatrics and Anesthesia, Division of Pediatric Critical Care, UVA Children's Hospital, Charlottesville, VA

IPPC FACULTY

GARY D. CENEVIVA, MD Pediatric Critical Care Medicine, Penn State Children's Hospital, Hershey, PA

DEBORAH L. DOKKEN, MPA Associate Director, Initiative for Pediatric Palliative Care, Center for Applied Ethics, Education Development Center, Inc., Newton, MA

MARY JO GILMER, PHD, MBA, APRN Professor and Director, Clinical Management Program, Vanderbilt University School of Nursing; Co-Director, Pediatric Advanced Comfort Team, Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN

> DEBORAH A. LAFOND, MS, APRN-BC Nurse Practitioner, Dept. of Hematology/Oncology, Children's National Medical Center, Washington, DC

STACY F. ORLOFF, ED.D., LCSW Vice President, Palliative Care and Community Programs, The Hospice of the Florida Suncoast, Clearwater, FL

MICHELE TRYON, BS, CCLS Certified Child Life Specialist, PICU/IMCU, Children's Hospital of the King's Daughters, Norfolk, VA

ABOUT CHARLOTTESVILLE

Charlottesville was home to Thomas Jefferson who founded the University of Virginia. It is a small but dynamic and sophisticated city of 40,000. It is known for an abundance of live arts (music, dance, theatre), excellent restaurants and surrounded by vineyards. The downtown mall is a pedestrian mall with a variety of shops and restaurants. Visit Charlottesville online at <u>www.pursuecharlottesville.com</u>.

HOTEL ACCOMMODATIONS IN CHARLOTTESVILLE

Blocks of rooms have been reserved for you at the following hotels:

Courtyard by Marriott University Medical Center 1201 West Main St. Charlottesville, VA 22903 - (434) 977-1700 Event Name: Pediatric IPPC Conference \$99 plus tax. Room block expires September 25, 2008 *Walking distance to Jordan Hall*

Hampton Inn & Suites

900 West Main St. Charlottesville, VA 22903 - (434) 923-8600 Group Name: C-IPC \$103 plus tax. Room block expires September 25, 2008 *Walking distance to Jordan Hall*

Best Western Cavalier Inn

105 N. Emmet St. Charlottesville, VA 22903 - (434) 296-8111 Group Name: Continuing Medical Education-Palliative Care \$87 plus tax. Room block expires September 25, 2008 *About one mile from Jordan Hall*

PARKING

Parking is limited at the Medical Center at the University of Virginia. On Sunday, you may park in patient parking across from the emergency room of the hospital for free. However, on weekdays the garage charges \$4.00 an hour and we are not able to reimburse you. For those booking sleeping rooms we suggest you leave your car at the hotel and walk to Jordan Hall which is next to the hospital. For those traveling from out of town by car, please park at the 14th St. garage behind the Red Roof Inn on Wertland St. That garage charges \$2.00 an hour.

INCLUDED IN YOUR REGISTRATION FEE:

Course fee includes all conference materials, continuing education credits, dinner Sunday, breakfast and lunch on Monday, breakfast on Tuesday.

CONFIRMATION & CANCELLATION POLICY

Upon receipt of registration and payment, you will receive an email confirmation. If payment is not received 14 days prior to this activity, space will not be reserved. We recommend that you secure payment with your own credit card, then seek reimbursement from your employer (where appropriate).

Registration fees will be refunded (less a \$50 administrative fee) for written cancellations (emails and faxed requests are acceptable) received a minimum of 14 days prior to the activity date. No refunds will be granted for registration fees of less than \$50 or for cancellations made within 13 days of the activity.

The University of Virginia School of Medicine reserves the right to cancel CME activities if necessary. In this case, the entire registration fee will be refunded. All other expenses incurred in conjunction with this CME activity are the sole responsibility of the participant

DISCLOSURES

Disclosure of Faculty Financial Affiliations

The University of Virginia School of Medicine, as an ACCME accredited provider, endorses and strives to comply with the Accreditation Council for Continuing Medical Education (ACCME) Standards of Commercial Support, Commonwealth of Virginia statutes, University of Virginia policies and procedures, and associated federal and private regulations and guidelines on the need for disclosure and monitoring of proprietary and financial interests that may affect the scientific integrity and balance of content delivered in continuing medical education activities under our auspices.

The University of Virginia School of Medicine requires that all CME activities accredited through this institution be developed independently and be scientifically rigorous, balanced and objective in the presentation/discussion of its content, theories and practices.

All faculty presenters participating in an accredited CME activity are expected to disclose relevant financial relationships with commercial entities occurring within the past 12 months (such as grants or research support, employee, consultant, stock holder, member of speakers bureau, etc.). The University of Virginia School of Medicine will employ appropriate mechanisms to resolve potential conflicts of interest to maintain the standards of fair and balanced education to the reader. Questions about specific strategies can be directed to the Office of Continuing Medical Education, University of Virginia School of Medicine, Charlottesville, Virginia.

The faculty and staff of the University of Virginia Office of Continuing Medical Education have no financial affiliations to disclose.

Disclosure of discussion of non-FDA approved uses for pharmaceutical products and/or medical devices

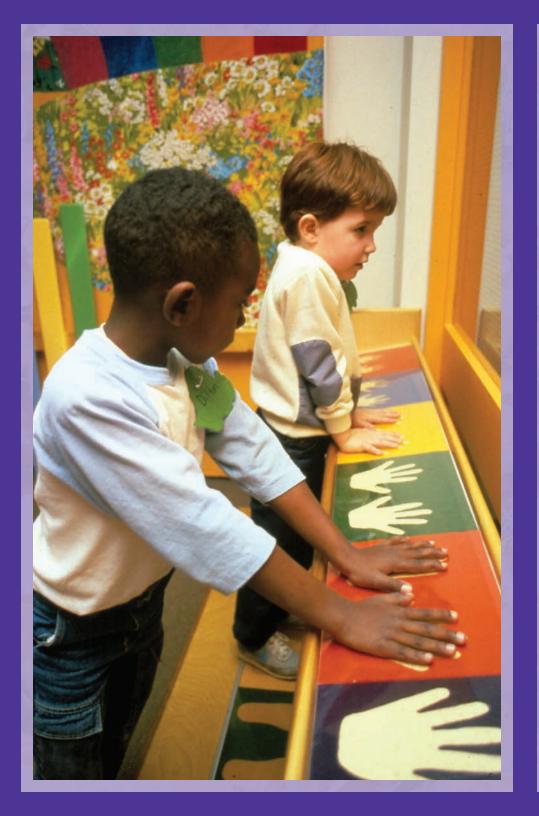
The University of Virginia School of Medicine, as an ACCME provider, requires that all faculty presenters identify and disclose any "off-label" uses for pharmaceutical and medical device products. The University of Virginia School of Medicine recommends that each physician fully review all the available data on new products or procedures prior to clinical use.

Disclosure for Attendance Records and Certificate Distribution

The University of Virginia Office of Continuing Medical Education requires that all participants at live CME activities sign attendance sheets daily to confirm participation in the CME activity for that day. Certificates of attendance, designating the maximum number of hours of participation, are distributed to each participant at the CME activity. Participants are responsible for accurately tracking their actual participation at live events.

SPECIAL NEEDS

The Americans with Disabilities Act of 1990 requires that all individuals, regardless of their disabilities, have equal access. The Office of Continuing Medical Education at the University of Virginia School of Medicine is pleased to assist participants with special needs. Written requests must be received 30 days prior to the conference date. These should be mailed to UVA Office of Continuing Medical Education, Box 800711, Charlottesville, VA 22908 or to <u>uvacme@virginia.edu</u>. Some of the conference venues used by the University of Virginia Office of Continuing Medical Education are registered historic properties and may not be fully ADA accessible. Please feel free to contact the facility if you have specific questions.



REGISTRATION FORM

INITIATIVE FOR PEDIATRIC PALLIATIVE CARE VIRGINIA RETREAT October 26-28, 2008, Jordan Hall Conference Center

Please PRINT legibly to ensure accuracy.

Please visit our website, <u>www.cmevillage.com</u>, to see if online registration is available for this conference. Pre-registration for this conference will close two business days (three days for online registrations) prior to the conference date. Please call to confirm that onsite registration will be available.

Mr. Mrs. Ms. Dr. First Name:	M.I.:	_ Last Name:		
Credentials: (MD, PhD, RN, etc.):	Specialty:			
Affiliation/Business./Organization:				
If part of a Team, pease indicate name of Team:				
Primary Address: This is: 🗆 home 🛛 work				
Street:				
City:	State/Province:	Zip:		
Country:	Phone:	Fax:		
Email:	Please print clearly for success	ful email delivery of your confirmation letter.		
Are you an employee of the University of Virginia? 🗆 Yes 🗀 No				
Are you a resident physician? 🗆 Yes 🗀 No 🛛 Are you a fellow? 🗀 Yes 🗀 No				
Do you require special assistance because of a disability, or have any dietary restrictions? If so, please describe:				

Birth date (required for tracking CME credits/CEU): ____/____ REGISTRATION FEES Physicians:\$300 Other Healthcare Professionals:\$200 Residents/Fellows:\$200 Hospice Healthcare Professionals:\$150 Family Members:Complimentary but must register

Payment is required with registration. An exception is made for institutional checks; however, these must be received at least 14 days prior to the scheduled CME activity. *If payment is not received by the deadline, you will <u>NOT</u> be registered for the conference. You will receive written confirmation (by email) upon receipt of your payment.*

PAYMENT OPTIONS

Check or money order made payable to "UVA-CME." Please indicate the name of the conference on your check.

Charge payment to:

□ Visa □ MasterCard □ American Express □ Discover

Your credit card number:______ Expiration date_____

Signature:_____

SEND REGISTRATIONS TO: Bebe Moore, Registrar, Initiative for Pediatric Palliative Care Retreat Office of Continuing Medical Education, P.O. Box 800711 University of Virginia School of Medicine, McKim Hall Charlottesville, VA 22908 Tel: (434) 924-5310, Fax: (434) 243-6393, MIRS Tel: 1-800-552-3723