# CHILDREN'S HOSPICE AND PALLIATIVE CARE COALITION OF CALIFORNIA

## Happy New Year

## Keeping in Touch-We want to hear from you!

**Welcome** to our end-of-year Newsletter! It is hard to believe we are ending 2023 and but we are looking forward to 2024. We were looking forward to seeing many of you at the Coalition for Compassionate Care of California's Annual Summit at the Hyatt Regency Sacramento, April 3 & 4. Registration is open, click <u>HERE</u> for more information! More information on a Children's Hospice and Palliative Care Coalition of California Meet Up will be coming closer to the date!

As many of you may know, CHPCC and the Pediatric Palliative Care Coalition of Pennsylvania (PPCC-PA) have partnered for the past several years to bring you the Pediatric Palliative Care Webinar Series. The 2024 series and individual webinars are now open for registration. Click <u>HERE</u> for more information.

As many of you know, we are working on updating our map of resources on our website at <u>https://chpcc.org/resources</u>. We want to thank those of you who have been waiting patiently for us to update the map. We have been delayed in updating, but now have the resources needed to do so! To ensure we have the most up-to-date information we will be sending out a new, short, survey in the New Year. The survey will take less than 10 minutes to complete, and we hope you will help us keep the map up to date! Please keep an eye out for the email and link to the survey in early January!

As we come to the end of 2023 and look to the future, we wish you and yours good health, time with family and friends, and time to just be. If you are considering end of year gifts, we hope you consider CHPCC. If you wish to donate, please click <u>HERE</u> and be sure to select Children's Hospice and Palliative Care of California as the recipient of your gift.

#### Wishing you many blessings in the New Year and THANK YOU ALL!

**CHPCC Steering Committee** 

Save the Date! <u>CCCC 16<sup>th</sup> Annual Summit</u> April 3 & 4, 2024. Hyatt Regency Sacramento CHILDREN'S HOSPICE ALLIATIVE CARE C O A L I T I O N

## Resources & Items of Interest:

- The 2024 Pediatric Palliative Care Webinar Series is now open for registration and click <u>HERE</u> for more information.
- The Pediatric e-Journal, a project supported by the National Hospice and Palliative Care Organization (NHPCO) since the mid-1990s, will be celebrating its 75<sup>th</sup> issue in 2024! They are seeking articles focused on the future of Pediatric Palliative and Hospice Care. For more information, please contact Christy at

#### Christy.Torkildson@gcu.edu

- AAHPM & HPNA Annual Assembly 2024 will be in Phoenix, Arizona in March. More information can be accessed HERE.
- The 2024 NHPCO Interdisciplinary Team Conference will be held in April Virtually. More information can be found <u>HERE</u>.
- 5. Courageous Parent's Network (CPN) has a wealth of resources for parents, caregivers, and providers. Please click <u>HERE</u> to access CPN. We do want to highlight their newest resource for families and clinicians – NeuroJourney. Please click <u>HERE</u> for more information

#### Continued..

# Resources & Items of Interest:

7. The Lucille Packard Foundation for Children's Health, provides a wonderful newsletter full of policy updates, resourcws, events and advocacy opportunities. To access the newsletter archive or to subscribe please click <u>HERE.</u>

8. The California HealthCare Foundation (CHCF), provides a weekly newsletter, offering resources and information on health policy issues. Click <u>HERE</u> to subscribe. To access the CHCH website click <u>HERE</u>.

9. The Pediatric e-Journal, a project of the NHPCO, is looking for contributors for its upcoming issues and suggestions for themes for future issues. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at <u>Christy.Torkildson@gcu.edu</u> or Melissa Hunt at <u>Melissa.Hunt@optum.com</u>. The current issue is focused on pain and symptom management and has a wealth of resources included. It is their largest issue to date! You can access the current issue, archives, and other pediatric resources <u>HERE</u>. Upcoming issues for 2024 include:

- Issue #74: Children with Medical Complexities and Rare Disorders, Published February 2023
- Issue #75: State of Pediatric Palliative Care, Published May 2024
- Issue #76: Social Media, REchnology, Communication in Pediatric Palliative and Hospice Care, Published August 2024
- Issue #77: Home Care, Published November 2024

The Pediatric e-Journal is Open Access Please note that archived issues are available as a communityservice by NHPCO and can be found at www.nhpco.org/pediatrics

#### HAVE NEWS TO SHARE LET US KNOW!

#### Have items of interest to share? E-mail us at info@chpcc.org

Please feel free to forward this newsletter!

Are you part of a pediatric palliative, hospice, or supportive care team/organization? Please check our resource map and let us know if your information is up-to-date or if changes are needed. Please contact us via our website <u>https://chpcc.org</u> or e-mail us at info@chpcc.org

#### THANK YOU

CHPCC Steering Committee Kim Bower, MD, FAHPM, HMD-C; Kim@chpcc.org Debra Lotstein, MD, MPH, FAAP, FAHPM; Debra@chpcc.org Christy Torkildson, Ph.D., RN, PHN, FPCN, HEC-C Christy@chpcc.org

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#### Transitional Task Force

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Colleen Cherry MSCL, CCLS, CT, GCCA-D Parent	Kathy Cleberg, RN,			
Joan Fisher, MD, Ph.D. CNL, NP, CHPN	Mary Ford, RN,			
Julie Lussier, RN, BSN				

This and future issues of our newsletter will be available on our website and emailed to our mailing list. To join our mailing list or change your preferences, please contact us via our website at <u>https://chpcc.org</u> or email us at info@chpcc.org

All information in this newsletter is for your information only. The news reported in the CHPCC Newsletter does not necessarily reflect the official opinion of CHPCC. Some links in CHPCC Newsletter are time-sensitive and may move or expire over time. Some sources also may require registration or fee-based subscriptions.

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### Pediatric Palliative Care WEBINAR SERIES

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#### ppcwebinars.org

12 p.m. PST | 1 p.m. MST 2 p.m. CST | 3 p.m. EST

\$35 individual registration

Discounts for organizations registering 5 or more people

CE hours available for Nurses and Social Workers

#### Additional info:

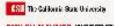
info@ppcwebinars.org

1.16 Embracing Uncertainty: The Role of Narrative in Decision-Making Tue for Children with Medical Complexity Kate Nelson, MD, PhD

- 2.20 Palliative-Aware Anticipatory Guidance: NeuroJourney.org Tue Julie Hauer, MD Jennifer Siedman, M.Ed
- 3.21 Navigating Facts and Values: Palliative Care in the Face of Significant Distress Ian D. Wolfe, PhD, MA, RN, HEC-C
- 4.18 Hope and "Holding Both" Thu Michelle Freeman, MD Deana Deeter, CRNP Nicole Hahnlen, RN
- 5.21 Chronic Home Ventilation: Helping Families Make Decisions Tue Renee D. Boss, MD, MHS
- 6.20 Pediatric to Adult Health Transition for Adolescents with Medical Thu Complexity: The Role of Family and Social Determinants of Health Kim Mooney-Doyle, PhD, RN, CPNP-AC Erika Ventura Castellano, BSN, RN Lisa Lindley, PhD, RN, FPCN, FAAN
- 8.22 Nurturing Children's Spirituality: Relationship, Connection and Thu Expression Amanda Borchik, MDiv, BCC
- P.17 Anxiety in Seriously III Children and Adolescents: Definitions, Tue Assessment and Management Gabrielle Langmann, MD, MS
- 10.15 Palliative Care Birth Plans: Preparing for Uncertainty Tue Kat Kowalski, MDiv, BCC
- 11.19 I Want to Go Home: The Role of a Palliative Care Transport Tue Jenni Linebarger, MD, MPH, FAAP, FAAHPM Sam Kaplan, MD







SHILEY HAYNES INSTITUTE For Palliative care