

# CHILDREN'S HOSPICE AND PALLIATIVE CARE COALITION OF CALIFORNIA

June 2024

## Keeping in Touch

Dear CHPCC Members!

We had a great pediatric turn out at the CCCC annual summit. It was so nice to be together as a community and we missed all of you who couldn't attend this year. While we are a separate entity from CCCC, the Annual Summit provides a great forum for our pediatric community to be together, build relationships, and share ideas with each other and our adult-focused colleagues. Many assembly topics were just as relevant to pediatrics as they are to adult HPM care, including the keynote speech by the open plenary.

The assembly kicked off with an amazing talk on health equity given by Dr. Kim Curseen. Dr. Curseen spoke with passion about how we can all work together to better serve historically marginalized communities. The summit included a full pediatric track with pediatric focused sessions available during each breakout session. The first day of the pediatric track focused on the current state of pediatric palliative care across the state during two of the breakout sessions. We heard updates on exciting programs developments at UCSF and Stanford. We reviewed the policy victories that have supported the growth of pediatric palliative care in California over the last 20 years and the challenges and victories as we have implemented these policies. We shared our challenges including staffing challenges and the opportunity increasing collaboration between tertiary care centers and agencies providing community-based care.

On the second day of the summit, we learned about the use of Dignity Therapy in Pediatrics and considered approaches to parental requests for nondisclosure. We hope to see even more of you at next year's Summit (to be held in the Southern California area) and to continue to have a strong pediatric presence among the presentations and workshops.

**Wishing you a safe summer and THANK YOU ALL!**  
**CHPCC Steering Committee**

**This newsletter has several resources & educational opportunities. Additionally, the Northern California Collaborative for PPC is meeting again! Save the date 12/5/2024!**

**If you have not yet completed the NHPCCO Needs Assessment, please do so before the end of July 2024!**



## Resources & Items of Interest:

- 1. The 2024 Pediatric Palliative Care Webinar Series** is taking July off but there are more webinars scheduled for
  - August 22, Nurturing children's spirituality: Relationship, connection, & expression
  - September 17, Anxiety in seriously ill children & adolescents: Definitions, assessment, & management
  - October 15, Palliative care birth plans: Preparing for uncertainty
  - November 19, I want to go home: The role of a palliative care transport
  - For more information and to register click [HERE](#).
- 2. The Pediatric e-Journal**, a project supported by the NHPCCO distributed their 75<sup>th</sup> Issue in May of this year and it can be accessed at [www.nhpcco.org/pediatrics](http://www.nhpcco.org/pediatrics) We are still welcoming contributions for 1.) Social Media, Technology, Communication due July 15 and 2.) Home Care due Sept. 30<sup>th</sup>. Each issue is focused on a main theme offering many different perspectives on the theme, including the families. To contribute or for more information, please contact [Christy.Torkildson@gcu.edu](mailto:Christy.Torkildson@gcu.edu)

Continued...

## Resources & Items of Interest:

3. We continue conversations with the state regarding the palliative care benefits. We will keep you updated when we have information to share. Please share your stories to help us frame your needs in our discussions. E-Mail us at [Info@chpcc.org](mailto:Info@chpcc.org)

4. Stanford Medicine Division of Quality of Life and Pediatric Palliative Care is offering several educational opportunities this Fall. More information and links can be found on our website at <https://chpcc.org/education-events> including:

- October 8, Palliative Care Faire
- October 9 & 10, ELNEC-Perinatal & Pediatric
- December 5, Northern California Collaborative for Pediatric Palliative Care Meeting

5. The Stad Center for Pediatric Pain, Palliative Care and Integrative Medicine is offering several educational opportunities. More information is on our website at <https://chpcc.org/education-events>

- July 11, From Evidence to Action? Preventing Pain & Anxiety Before, During & After Vaccination
- August 1, Pediatric End-of-Life Care: At home, hospice house, or hospital?
- September 5, Practicing Grief Informed Care
- October 3, The Comfort Promise 2.0: Preventing or Easing Pain and Anxiety Caused by Needle Procedures. For Every Child Every Time
- November 7, Management of Neurological Symptoms in Children with Serious Illness
- December 7-13, 15<sup>th</sup> Pediatric Pain Master Class

**HAVE NEWS TO SHARE LET US KNOW!**  
E-Mail us at [Info@chpcc.org](mailto:Info@chpcc.org)

## HELP NEEDED

Help needed to keep our website updated including our Environmental Map. For more information, please email Christy at [Christy@chpcc.org](mailto:Christy@chpcc.org)

**Have items of interest to share?**  
E-mail us at [info@chpcc.org](mailto: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 <https://chpcc.org> or e-mail us at [info@chpcc.org](mailto:info@chpcc.org)

## THANK YOU

### CHPCC Steering Committee

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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 <https://chpcc.org> or email us at [info@chpcc.org](mailto: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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## The National Hospice and Palliative Care Organization Needs Our Help!

Please consider completing the 2024 Needs Assessment. This data will be shared with all state coalitions and help update the Pediatric Palliative Care Facts & Figures. If your organization has cared for at least one pediatric patient in the last four years, complete the 2024 Pediatric Palliative and Hospice Care Needs Assessment!

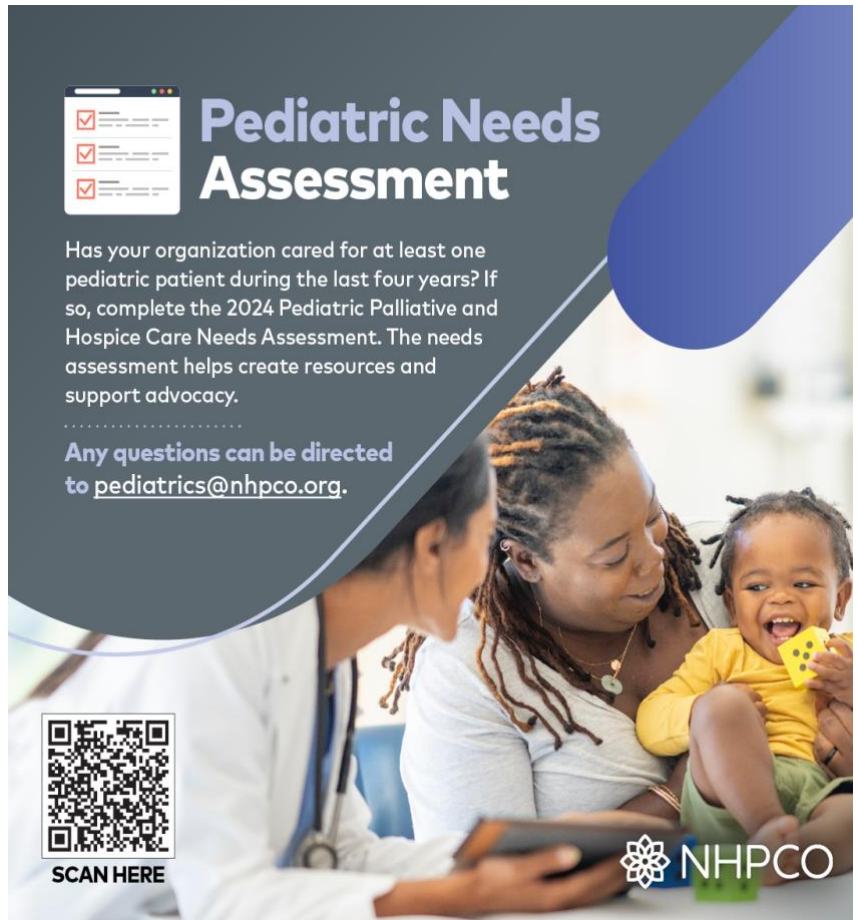
The Needs Assessment is a product of NHPCO's Pediatric Advisory Council. Council members are gathering data to gain a better understanding of the organizations and providers caring for pediatric patients with serious illnesses throughout the country. This understanding will inform future resource creation and support advocacy efforts. If possible, please complete by July 30<sup>th</sup>.

Be sure to share this post with your network to help us reach as many provider organizations as possible! Everyone is welcome to respond!

The survey will take approximately on average 15 - 30 minutes to complete; it may take up to one hour for larger, multi – site organizations.

There is a PDF available to gather your answers before completing the Qualtrics survey on the Needs Assessment website. View Frequently Asked Questions [here](#).

Please email [pediatrics@nhpco.org](mailto:pediatrics@nhpco.org) if you have any questions!



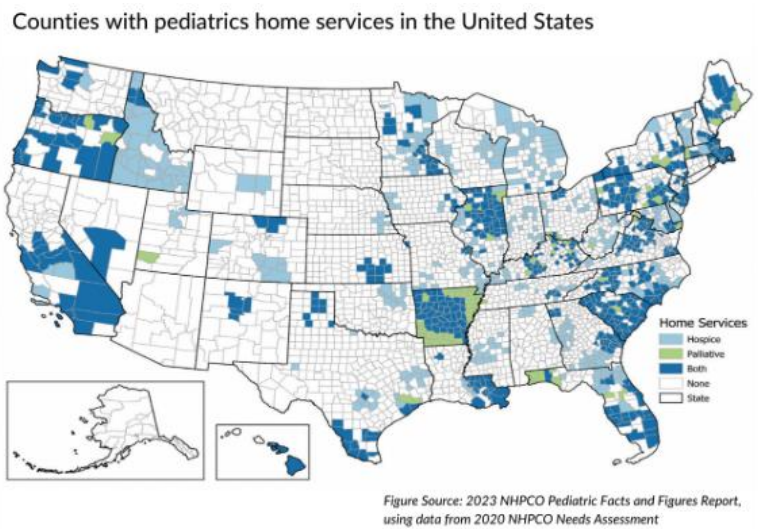
### Pediatric Needs Assessment

Has your organization cared for at least one pediatric patient during the last four years? If so, complete the 2024 Pediatric Palliative and Hospice Care Needs Assessment. The needs assessment helps create resources and support advocacy.

Any questions can be directed to [pediatrics@nhpco.org](mailto:pediatrics@nhpco.org).

SCAN HERE

NHPCO



Make sure your program is included on this map. Your survey input will help to accurately reflect the pediatric palliative and hospice care landscape across the country.

Take the survey here or scan the QR code above:

[https://nhpco1.az1.qualtrics.com/jfe/form/SV\\_6zXcLhICIGnc54W](https://nhpco1.az1.qualtrics.com/jfe/form/SV_6zXcLhICIGnc54W)



# 2024

## Pediatric Palliative Care WEBINAR SERIES



### REGISTRATION + INFO:

[ppcwebinars.org](http://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](mailto:info@ppcwebinars.org)

**1.16** **Embracing Uncertainty: The Role of Narrative in Decision-Making for Children with Medical Complexity**  
Tue  
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**  
Thu  
Ian D. Wolfe, PhD, MA, RN, HEC-C

**4.18** **Hope and "Holding Both"**  
Thu  
Michelle Freeman, MD | Deana Deeter, CRNP  
Nicole Hahnen, 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 Complexity: The Role of Family and Social Determinants of Health**  
Thu  
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 Expression**  
Thu  
Amanda Borchik, MDiv, BCC

**9.17** **Anxiety in Seriously Ill Children and Adolescents: Definitions, Assessment and Management**  
Tue  
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

