

CHILDREN'S HOSPICE AND PALLIATIVE CARE COALITION OF CALIFORNIA

Sept. 2022

Keeping in Touch-

We want to hear from you!

Welcome to our first newsletter! Over the last 18 months, the Children's Hospice and Palliative Care Coalition of California has been reignited, and it could not have happened without all of you. As we start to work towards our next steps, we wanted to share some highlights and ask for your input to help us steer our coalition into the future in the best way to meet the greatest needs.

First, we hope you all have checked out the California Pediatric Hospice and Palliative Resource Map on our website – <http://www.chpcc.org/resources>. We have made improvements based on feedback we've received and overall have heard that the resource has been useful. Please reach out with your feedback; we would love to hear about your experience using the map. Don't forget to let us know if there are any edits or additions needed by emailing us at info@chpcc.org

Second, as we reported in our last update, our steering committee, and transitional task force decided we would best be served by continuing under the umbrella (fiscal sponsorship) of an established 501(c)3 organization as we are still growing our organization. This fiscal sponsorship allows us to be a separate organization under the non-profit status of the sponsoring group. We want to thank our prior fiscal sponsor, Jacob's Heart, for their unwavering support for the past few years, and we look forward to the potential of working together in the future. We also want to thank the Pediatric Palliative Care Coalition of Pennsylvania (PPCC-PA) for becoming our new fiscal sponsor as we work on our next steps to becoming an independent organization. While we will operate as a California-based organization, in many ways, this relationship with PPCC-PA reinforces our shared values and the work we are already doing together (see more information on our webinar series at the end of this newsletter 😊).

Third, we want to continue the excitement we've seen in the last several months in re-energizing the CHPCC of California. As part of a strategic planning process, we will be scheduling a series of small group discussion sessions in late September/early October. Please look to your emails for the invitation! We want to hear from as many of you as possible!



Resources & Items of Interest:

1. The National Hospice and Palliative Care Organization (NHPCO) has many pediatric palliative care resources available for members and non-members alike, including the longest continuous publication focused on pediatric palliative and hospice care in the US. The current and archived copies and other resources are available at <https://www.nhpco.org/pediatrics>
2. The Optum Hospice Annual Conference is on October 7. This FREE one-day conference will provide valuable education to all hospice clinicians. More information and registration available at <https://optumhospicerx.vfairs.com>
3. The NHPCO 2023 Virtual Interdisciplinary Conference Call for Proposals is now open! Submit your proposal by October 7, 2022. Please review here for more details: <https://www.nhpco.org/idc-call-for-proposals/>
4. AAHPM/HPNA Annual Assembly Second Call for Abstracts will be Sept 29 – October 13th

We Have a NEW E-Mail Address!



You can now reach us at

info@chpcc.org

PPCC Sibling Grief & Bereavement Toolkit

The Pediatric Palliative Care Coalition of Pennsylvania

Has made a new resource available – a Sibling Grief and Bereavement Toolkit. This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities.

To the right is a link to the toolkit and one of the activities – “Make a Feelings Chart”.

[Click HERE](#) to view the PPCC Sibling Grief and Bereavement Toolkit.

TOOLKIT ACTIVITY

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month’s highlighted activity from the toolkit that may help children and teens in the upcoming school year.

Make a Feelings Chart



[Click HERE](#) to download the activity.

PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.

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Pediatric Palliative Care

WEBINAR SERIES



Pediatric Palliative Care Series

A collaborative effort between the Children’s Hospice & Palliative Care Coalition of California, the Pediatric Palliative Care Coalition of Pennsylvania, & the Greater Illinois Pediatric Palliative Care Coalition this webinar series is focused on providing up-to-date information in the field in a way to enable participants to use or replicate the lessons learned. Continuing education units are available & recorded webinars are available for purchase.

Visit <https://www.ppcwebinars.org> for more information.

Upcoming Webinars 2022:

September 22, Interprofessional Spiritual Care in PPC, Christina Puchalski, MD, MS, OCDS, FACP, FAAHPM

October 18, A Collaborative Approach to Addressing Trauma & Building Resilience in Palliative Care Providers, Colleen Cicchetti, Ph.D.

November 17, Palliative Care: A cloak of Comfort in Sickle Cell Disease, Anne Marsh, MD

Continued...

Resources & Items of Interest:

5. Dr. Lisa Lindley has developed a program of research focused on concurrent hospice care for children in the United States. One of her most recent publications was focused on care in California. She and her team have developed a wonderful website full of resources on concurrent care and pediatric end-of-life care, **Pediatric End-of-Life Care Research** and it can be found [HERE](#).

6. **Trends in Pediatric Palliative Care Research** – Every month, [PedPalAScNET](#) collects new pediatric palliative care research. For past lists visit their blog, browse their library, or join the Zotero group. View the New Citation list in their library.

7. Did you know that several major organizations that focus on hospice and palliative care joined to form **the National Coalition for Hospice and Palliative Care**? The coalition also has a Pediatric Palliative Care Taskforce. You can also subscribe to their newsletter [HERE](#).

8. **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 Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Issue Topics: 2022

- Issue #69: PPC in the Community, submissions due 9/30/2022; Publication November 2022

• Issue Topics: 2023

- Issue #70: Perinatal/Neonatal, submissions due 12/2022; Publication February 2023
- Issue #71: Standards, submissions due 02/2023; Publication May 2023

Please note that archived issues are available as a community-service by NHPCO and can be found at www.nhpc.org/pediatrics

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 <https://chpcc.org> or e-mail us at info@chpcc.org

THANK YOU

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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

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