

The HAP Foundation


HAPPENINGS

Sharing stories on what's happening at HAP

April 2023



This month, join us in celebrating one year of The HAP Foundation.

We hope you enjoy this month's HAPpenings at HAP.

A Message from our President

Greetings,

As we celebrate the first anniversary of The HAP Foundation, I'd like to thank you for supporting our work to increase access to hospice, palliative care, and grief support for adults and children through community education, research, workforce development, and advocacy. Through our commitment to community, we have made significant strides in building relationships and bridging gaps in care for many individuals.

A sample of highlights over the past 12 months include:

- Near completion of a collaborative, qualitative research project with NORC at the University of Chicago that seeks to more deeply understand the knowledge, attitudes, and beliefs around hospice and palliative care in Black communities in Chicago.
- Received a federal research grant through Patient Centered Outcomes Research Institute (PCORI) for \$1.7 million over five years, in collaboration with partners at Ann & Robert H. Lurie Children's Hospital of Chicago and University of Chicago to study the impact of Missing Pieces, child loss network.
- Launched a Community Health Worker team to educate Chicago communities on serious illness, hospice, and palliative care resources to enable informed health care decisions.
- Became a licensed provider of Professional Continuing Education for social workers in the state of Illinois with a pending application for nursing.
- Hosted the Greater Illinois Pediatric Palliative Care Coalition's seventh annual Butterfly Run, Walk, and Flutter in support of families who suffered the loss of a child and the HAP Heritage dinner honoring Mary Runge, former president of Horizon Hospice.
- Educated clinical providers on Illinois' home-based pediatric palliative care law mandating Medicaid and state-regulated insurance companies provide coverage. This effort will continue throughout this year.
- Implemented a fundraising campaign on Giving Tuesday featuring the Missing Pieces program with Amy McNicholas' family story. As a result, NBC 5 Chicago TV news featured Missing Pieces and the HAP Foundation on Giving Tuesday as a notable charity.

Again, thank you for your support as our work has only begun. Working together, we can ensure that all patients facing serious illness and their families have access to quality care and bereavement resources when they need it most.

Sincerely,
Joseph Matty
President

Successful Pediatric Palliative Care Learning Session in Peoria and Rockford

The HAP Foundation hosted two regional learning sessions on pediatric palliative care that were full of meaningful conversations with parents, care providers, and community advocates. In Peoria, in partnership with the amazing team at Children's Hospital of Illinois, we highlighted the new Illinois law that provides funding for home-based pediatric palliative care and shared top tips for caring for seriously ill children. The stars of the evening were Eloise and Hans, whose parents bravely shared their experiences and pearls of wisdom on how best to help families. In Rockford, we hosted many local health care leaders who share in our commitment to helping seriously ill children. We look forward to hosting more regional educational sessions to come.



Joining with A Community of Love to Help Bereaved Families and Health Care Workers

In a move that underscores our commitment to the welfare of families coping with pediatric death, the HAP Foundation has partnered with A Community of Love organization and their August Boxes program. This innovative initiative provides families with bereavement support information and legacy-making materials to help them cope with the loss of a child.

The August Boxes program is the creation of Nick and Zoe Hoepfner, who tragically lost their 3-year-old son August in an accident. Drawing on the support of their "community of love,"

the Hoepfner's are dedicated to helping others impacted by pediatric death. The August Boxes program is designed to capture the physicality of a child with fingerprint-making kits, clay molds, and scissors to snip locks of hair allowing families to create mementos that will help them remember their child and cope with their grief.

At the heart of the August Boxes program is a desire to support bereaved families and health care workers, providing them with the tools they need with the emotional impact of pediatric death. The HAP Foundation is proud to partner with A Community of Love and looks forward to calling on corporate partners to host volunteer events, where they can help put the boxes together. Please contact Molly Conley at mconley@thehapfoundation for volunteer details.

Annual Tax Season Signals a Review of Your Will

For many, the April 15th tax deadline is a reminder to review recent changes in their circumstances. Some significant life events should serve as notice that it may be time to create or examine your will with the potential to add a charitable organization as a beneficiary. Review the list below and use the annual tax time as inspiration to prioritize your affairs.

- A change in your marital status – If recently married, you and your spouse will likely want to write or review your wills together, adding each other as a beneficiary and addressing your new joint assets, your separate assets, children from previous marriages, etc. If divorced, you will likely need a major review of changed assets and heirs. If recently widowed, you may face decisions about assets from your spouse's estate.
- New family members – Joyous additions to your family, such as new children, grandchildren, or stepchildren, likely mean you may want to consider adding them as beneficiaries in your estate plan. Conversely, the loss of a loved one can mean a beneficiary change.
- Plans to move – Probate and trust laws are determined by the state in which you live, so downsizing or moving to a new or seasonal home in a different state means a review of your estate is in order.
- Changes in assets – Over time you have likely acquired new assets or have assets that have increased in value and may now have the means to increase how much you leave to loved ones or to charitable beneficiaries in your estate plan. There may also be new tax considerations that need to be addressed with your larger estate.
- A change in your health – As people age and have a better idea of their final estate value, many add charitable beneficiaries that they have been considering for a long time.

If you would like to include The HAP Foundation in your will, ask your estate planning attorney to add this suggested wording to your will or trust: I give to The HAP Foundation, Oakbrook Terrace, IL 60181, (the sum of \$_____ or _____ percent of the rest, residue and remainder of my estate) for its general purposes.

If you would like to add The HAP Foundation as a beneficiary of your retirement account, life insurance policy, or other investment, please include our Federal Tax ID #36-3820916. If you or professional advisor have any questions or would like more information, please contact Christine Post-Duncan cpost-duncan@thehapfoundation.org, 312-741-1280.

Join the Conversation

The HAP Foundation's Community Health Learning Collective (CHLC)

The CHLC is a monthly convening of CHWs, Promotores de Salud, CHRs, CHW Ally's, community members and clinicians. It is an opportunity to discuss emerging issues in the field, share organizational announcements and experience fellowship with like-minded individuals! Each CHLC contains education programming to encourage us, inform our work and open dialogue about critical issues that impact our organizations. Not able to attend? Check our community education page for recordings of previous sessions [HAP Foundation](#).

To register for the CHLC, please contact Maureen Burns, Senior Community Education Associate and Research Liaison, at mburns@thehapfoundation.org.

- In April, our presenters will be Alma Olavarría Gallegos and Michelle Garcia from Access Living. The mission of Access Living is to ignite disability power and pride, provide critical services, and break down systemic barriers to create a stronger, more inclusive society. Michelle Garcia is the Manager of Organizing and Community Development. She will provide an overview of Disability Organizing and the resources and services provided by Access Living. Alma Olavarría Gallegos is the Latinx and Immigrant Community Development Organizer. She will discuss Cambiando Vidas, an organizing group for Latinx immigrants with disabilities. She will also discuss common barriers to care experienced by this population. This presentation will be on **April 26, 2023, Noon-1:30 p.m. CST virtually via Zoom.**

Upcoming Community Presentations

- [April 24: Community Resiliency Model workshop: Part One with Courage to Love in Action](#)
- [April 26: Community Health Learning Collective April Session](#)
- [April 27: Advance Care Planning workshop at Northtown Library](#)
- [May 2: Community Resiliency Mode workshop: Part Two with Courage to Love in Action](#)
- [May 8: Navigating Caregiver Stress workshop at the Arlington Heights Senior Center and Northwest Community Health](#)
- [May 15: Community Resiliency Model workshop at Edgebrook Library](#)

Pediatric Palliative Care Webinar

The 5Ws of Guidance for Pediatric End-of-Life Care

April 20 at 12:00 PST | 1:00 MST | 2:00 CST | 3:00 EST

In this month's webinar, our presenters will review the American Academy of Pediatrics report

outlining best practices for Pediatric End-of-Life Care, focusing especially on the days and hours leading up to and following a child's death. Topics will include family supports, serious decision-making, pain and symptom management, and interdisciplinary teamwork. Register [here](#).

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18W140 Butterfield RD. Suite 1120, Oakbrook Terrace, IL 60181