I’ve long practiced a pause at transition points, sometimes for reflection, sometimes for a pep talk. My coming transition off the executive committee for the Section on Hospice and Palliative Medicine (SOHPM) after 10 years of service called for both. I reflected on my call to work on behalf of the AAP and prepped my mind to find future ways to both continue to serve the AAP and the specialty of pediatric palliative care.

I joined the AAP in 2003 as they opened membership to medical students. I maintained membership during residency (like most residency programs, mine paid the membership dues for trainees) and got more involved in the advocacy efforts and leadership opportunities available (culminating in election to Chairperson of the Section on Pediatric Trainees). By then, I was hooked, and jumped at the opportunity to be elected to the executive committee for the SOHPM. Now here I am, saying goodbye to that role.

I’ve learned a lot about the AAP over this time and want to share five key take-aways. They encompass the points I highlight most often when talking about my commitment to serving the AAP.

1. The AAP was founded to advance child health and support those providing pediatric care. The Academy has kept this mission at its core since 1930, and it directly impacts the approach to advocacy, policy, and education.

The issues that affect children’s health have evolved over time. It is humbling and inspiring to hear about efforts to support pediatric care in settings where transgender care is limited, where immigrants are detained, or where gun violence impacts daily life (https://www.aap.org/en/advocacy/). Hearing the ways AAP gives voice to these issues inspires my commitment to the work of this organization.

SOHPM partnered with the AAP Advocacy team for our H-Program at the National Conference and Exhibition on October 9. The session encouraged those working in pediatric palliative care to use their voice – telling their own stories or amplifying the stories of families to bring about positive changes at all levels of policy and legislation. Be on the lookout for ways you can become more involved with the SOHPM Advocacy Subcommittee and for the SOHPM-sponsored scholarships to the annual Advocacy Conference.

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2) The AAP is invested in maintaining standards of child health.

In my work for the AAP, I have sometimes experienced frustration, feeling that there are many “hoops” to jump through before “getting to yes.” At the same time, I’ve gained appreciation for why some of these hoops exist in a big organization with many stakeholders. As an example, the SOHPM executive committee routinely gets to review new and updated policy, clinical reports, and chapters that will serve as the foundation for child health. While such review lengthens the process, it also provides us an opportunity to improve how palliative care is framed across the AAP.

SOHPM’s policy authorship list includes:
- Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations, 2013
- Guidance on Forgoing Life-Sustaining Medical Treatment, 2017
- Pain Assessment and Treatment in Children with Significant Impairment of the Central Nervous System, 2017
- Guidance for Pediatric End-of-Life Care, 2022
- Supporting the Family After the Death of a Child (forthcoming revision)

3. The AAP wants to “do right” by kids and the clinicians providing healthcare.

There can be tension between the components important for child health and the impact on the clinician providing such care. It can feel overwhelming to keep up with all of the new information that needs to be integrated into pediatric practice, in addition to navigating the systems in which we provide care. The AAP has long-offered a robust set of resources for the general pediatrician – from Bright Futures health promotion and prevention to Practice Management tools. During my time with SOHPM, the AAP has increased interest in providing resources for clinicians caring for children with medical complexity, including publishing a clinical report on the care of this population and supporting a national grant-funded effort focused on systems of care for this population. The AAP is also invested in increasing access to subspecialty care (including Palliative Medicine), and clinician well-being.

To learn more about these efforts:
- Pediatric Subspecialty Shortage: https://www.aap.org/en/advocacy/pediatric-subspecialty-shortages-fact-sheets/

4. The AAP is not the ABP.

The American Board of Pediatrics (ABP) is the organization representing the medical specialty of pediatrics and the associated subspecialties. The ABP “strives to improve training, establishes the requirements for certification, and sets standards for its examinations.” The AAP offers education and opportunities to help pediatricians meet the certification standards. Examples of that include the PREP materials for learning and practicing for the certification as well as Maintenance of Certification options for continuing medical education and quality improvement projects. You can learn more at www.pedialink.org

SOHPM has utilized the education infrastructure:
- PREP Palliative Medicine offers 40 questions (10 questions quarterly) for CME/MOC 2 credit (https://shop.aap.org/2023-prep-palliative-medicine/)
- EQIPP Talking about Serious Illness as an online guide for serious illness discussions and process improvement efforts for 25 MOC 4 credits (https://shop.aap.org/eqipp-talking-about-serious-illness/)

5. The AAP is ever-evolving and looking to grow and support membership.

During my time in AAP leadership roles, I’ve seen the AAP begin to welcome non-physician members, expand efforts beyond “healthy children”, and really practice what they preach when it comes to things like climate change and Equity, Diversity, and Inclusion. I feel confident that the AAP will remain relevant within pediatrics and committed to ongoing improvement.
The time of year between the holidays is a time for reflection. We may be preparing for transitions at work and at home – reaching the end of the academic semester, planning for vacations, prioritizing time with family and friends. Weather may be transitioning - here in the Midwest, it can be 70 degrees one day and 20 the next. We can anticipate the change in the weather, even look forward to it, but we still feel the impact when the temperature drops 50 degrees overnight.

In this newsletter, we acknowledge the transition of leadership of the Section on Hospice and Palliative Medicine, with Jenni Linebarger completing her term, and Jeff Klick beginning his at the beginning of November. We would like to thank Jenni for all she has shared with us over the last few years, and for all her work for the AAP SOHPM. We welcome Jeff to his leadership role and look forward to his contributions.

This is also a season for reflecting on hope, new beginnings, and gratitude to help get us through the darker, colder months. Shari Gatlin shares her thoughts on hope during her pediatric fellowship in hospice and palliative medicine – including how much hope can be found even in the darkest of times. We highlight several stories from family members by sharing popular blog posts from Courageous Parents Network. We hear from Katherine Brock, Naomi Goloff, and Amy Trowbridge, who share about the journey to launch the Network of Pediatric Palliative Care Educators – a new project that took time to come to fruition and will continue to help clinicians grow and thrive. Finally, Hadley Bloomhardt and Heather Fackelman share about their experiences at the AAP Advocacy Conference. Thanks to scholarships from the AAP SOHPM, they were able to learn to amplify the voice and experience of our patients and families as they advocate with legislators for the good of children.

We hope this newsletter will be good reading and companionship for whatever transitions and reflection this fall is bringing your way.
Fellow Reflection Column
Shari Gitlin

Entering the quiet, dark room, with curtains drawn, I introduced myself as a member of the palliative care team. I hadn’t been a point of continuity for this family, but with the privilege of the connection built by my team, I was accepted as a familiar face. I joined the mother standing at the bedside of her daughter, a young girl with a rare genetic condition resulting in neurodevelopment impairment, chronic complications, and frequent hospitalizations. Her mother shared how much uncertainty there had been at the time of diagnosis – no one could be sure how her daughter’s disease would evolve, the degree to which she would be affected, or what kind of life she would have. She expressed how much they had hoped for a miracle for the best possible outcome, but saw that miracle fading away with each complication and hospitalization. Their daughter’s disease – and her suffering – were progressing. She shared relief that in the prior twenty-four hours, her daughter’s symptoms were better controlled, and she was able to, finally, rest comfortably. Perhaps this, I reflected with her, was the miracle. Though far from the one they had been praying for, she found comfort in recognizing there were still miracles they could find in this unexpected place.

The concept of hope is often a point of concern for medical teams. As palliative care providers, we hear from medical teams that a family is in denial or “doesn’t get it” because of these expressions of hope, wishes for a miracle, plans for an upcoming birthday, or dreams for their child’s future. But after my fellowship year, I now recognize how hope captures how deeply they do “get it.” You only hope for a miracle when you recognize a tragic possibility. When you find yourself in the most dire, terrifying reality, you keenly know you need an otherworldly intervention to pull you out. This is the time when people seek divine intervention or bargain with the universe.

As a medical student, I chose pediatrics because of the overwhelming hope that lived in this space. I thought about the chance to prevent long-term chronic conditions of adulthood, to heal and cure with an entire future ahead, and to foster the resilience of children to overcome what, in the moment, seems to be devastating illness and injury. In my application for residency I wrote, “Pediatrics carries an abundance of hope which can be elusive in other fields.” So it might seem odd to some, and at times to myself, that I have landed in the field of pediatric palliative medicine.

Today, looking back at that personal statement, I see with a fresh lens that even as a medical student, I was looking for palliative medicine without knowing it. I wrote of seeing my patients as not just the child in the bed, but the whole family at and beyond the bedside, of recognizing the physical and emotional impact of a child’s illness on a family, of the commitment to make experiences less grueling for patients and families, and of the fulfillment of empowering patients and parents to make decisions aligned with their values and goals. Perhaps it was beshert. While many Yiddish speaking grandmothers use the word beshert to mean “soulmate,” it translates as destiny, or “meant to be.” I don’t know that I believe in destiny, but when I reflect on my journey into and through medical training it is hard not to believe that finding this field was meant to be.

As I write this reflection, I admit that I am still surprised by how much hope there is in pediatric palliative care. I recently read in a novel by Quan Barry, “The Buddha says when the only hope is a boat and there is no boat, I will be the boat.” Suffering and loss are inevitable parts of life, but we have the ability to create a space of hope in the midst of this reality; hope for each other, for our patients, for their families. We can find the day-to-day miracles. I relished hearing about a mom’s plans for her son’s upcoming fourth birthday, where he would dress as Gru and everyone else as Minions. I marveled at the blue and white streamers, the fish and sea creatures hanging in the window, and the matching blue tablecloth on a table full of cupcakes and treats in a patient’s room in the cardiac intensive care unit for an ocean themed first birthday. I shared excitement with a nine-year-old in the ICU about her new puppy named Milkshake, and with her mother who planned a surprise for this bundle of fur to come meet her daughter in the hospital.

This is the hope I hold when frequently asked by friends how I do this work. I try to be someone’s boat, a raft, a paddle, or even just a life jacket. May we continue to find hope in the hardest to find places, sharing the weight of what they must carry and simply being present.
This month’s Parent/Caregiver column is a little different. Here are the five most popular blog posts written by family members from Courageous Parents Network. Their titles are self-explanatory.

Sam: A mother’s eulogy to her son
https://courageousparentsnetwork.org/blog/my-sam-a-mothers-eulogy-to-her-son

Dear Kaia: A little sister’s letter to a fellow little sister
https://courageousparentsnetwork.org/blog/dear-kaia-a-little-sisters-letter-to-a-fellow-little-sister

Making informed decisions about our daughter’s end of life.
https://courageousparentsnetwork.org/blog/making-informed-decisions-about-our-daughters-end-of-life

We couldn’t save our girl but we could save our marriage.
https://courageousparentsnetwork.org/blog/we-couldnt-save-our-girl-but-we-could-save-our-marriage

Mothers are warriors but some battles cannot be won.
https://courageousparentsnetwork.org/blog/mothers-are-warriors-but-some-battles-cant-be-won
The Network of Pediatric Palliative Care Educators (NPPCE) launched in January 2022 with the goal of advancing access to quality interprofessional pediatric palliative care education through a community for collaboration and dissemination of educational best practices, research and resources. The vision of NPPCE is to transform palliative care education through organization of an interprofessional community of educators, with the ultimate goal of improving care for children with serious illness and their families.

Having worked on educational research and scholarship as a pediatric oncology fellow at Stanford, Katharine Brock, MD, MS, recognized the need for assessment tools in pediatric palliative care education and simulation-based cases for teaching pediatric fellows about palliative care communication. She realized that faculty and clinicians likely had many educational projects on their computers that never made it to databases such as MedEdPORTAL. With the help of palliative care and simulation experts, she developed her own simulation-based communication curriculum that was piloted with pediatric hematology/oncology, cardiology, critical care medicine, and neonatology fellows. Since arriving to Emory University/Children’s Healthcare of Atlanta as a faculty member, she continued to work on simulation-based curricula for residents and fellows, and later expanded to nursing curricula.

At the same time, Naomi Goloff, MD, saw the opportunity to create dedicated end-of-life (EOL) education for residents, fellows, nurses, social workers and other clinicians working with children with serious illness which directly impacted their care as well as clinician wellbeing. Working together with simulation experts, as well as an interprofessional and interdisciplinary team at the University of Minnesota/University of Minnesota Children’s Hospital, she developed and piloted a simulation-based EOL care curriculum for pediatric subspecialty fellows, which later expanded to nurses and social workers.

In 2017, Katharine and Naomi were at the Pediatric Palliative Oncology Symposium at St. Jude. Katharine heard Naomi speak on her own educational projects over dinner. On the bus ride back to the hotel, Katharine shared an idea she was thinking about for sharing curricula and cases so that busy clinician-educators across the country didn’t have to keep reinventing the wheel. Surely, we were all trying to teach the same palliative care concepts and communication pearls. The two conversed about a far-fetched plan for a national group of pediatric palliative care educators to also help create a community.

Then, like so many stories, they both got busy and the idea just went back and forth in their inboxes...until 2019 when Naomi and Katharine asked Amy Trowbridge, MD, to join them. At the University of Washington/Seattle Children’s, Amy had been working on many similar projects to them, including developing curricula in serious illness communication for medical students, pediatric residents, and pediatric subspecialty fellows. Additionally, as director of the Palliative Care Training Center at the University of Washington, she was developing a pediatric-specific Graduate Certificate Program for interprofessional clinicians looking to deepen their practice in both primary and subspecialty pediatric palliative care. She was the perfect addition to add momentum to the group.
Continued from Page 6

The three NPPCE co-founders then formed an interdisciplinary advisory committee comprised of US and Canadian-based physicians, advance practice providers, nurses, and social workers, including: Gitanjali (Tanya) Arora, MD, Jody Chrastek, RN, DNP, Sarah Friebert, MD, Jennifer Hwang, MD, Jenni Linebarger, MD, MPH, Arika Patneaude, LICSW, Stacy Remke, LICSW, Kyle Sue, MD, MHM, Camara Van Breemen, MN, NP, and Joanne Wolfe, MD, MPH. The co-founders and the advisory board honed the idea, mission, vision, schedule, and goals for the group.

And finally, NPPCE launched in January 2022, and so far has nearly 400 registered members! The plan is to hold every other month educational sessions and promote collaboration around educational projects. NPPCE is open internationally to all types of interprofessional team members who teach pediatric palliative care. NPPCE hosts different types of sessions: Works in Progress or Educational Innovations, Best Practices in palliative care education, Spotlight on an educational method, and Interactive Educational Exchange. So far, the group has held sessions on Interprofessional Education, Family Engagement in Education, Improv in PPC education, and Applying an Anti-Racist Lens to PPC Teaching. There are sessions in November 2022 with a new group of topics in 2023. To obtain more information about NPPCE, please see the NPPCE website (www.nppce.org) and register at: https://www.nppce.org/home/subscribe.
Reflections from the 2022 AAP Advocacy Conference  
By: Heather Fackelman, DO

Advocacy: any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others. Having spent my year in pediatric hospice and palliative medicine fellowship focusing both on my research and grand rounds presentation on advocacy, I felt very familiar with the concept prior to attending the AAP Advocacy Conference. The conference was an incredible educational experience and provided me a rare glimpse into the world of policy and legislation, topics almost entirely unfamiliar to me, given that I’ve spent the last decade dedicated to medical education.

It’s not lost on those organizing the conference that these topics are likely foreign to most of us in attendance. As such, the majority of the conference is spent reminding us of the basics: the branches of our government and their functions, how policy is written, and how that is translated into legislation and change. That process is easier said than done, as we learned through the 3-day experience. I was both enlightened and overwhelmed to learn the complexity of the process. This is highlighted when one considers that we were only focusing on a single subject for which to advocate: child and adolescent mental health.

Our last day of the conference was spent putting what we learned to the test; we met virtually in small groups with our local representatives to advocate for bills that would improve mental health access and provide additional resources to children. These bills would not only provide these supports in the healthcare setting but also meet kids where they are at in schools. I admit, I was intimidated prior to the first meeting. I was humbled to consider what a representative might learn from me—a pediatric hospice and palliative medicine fellow, someone still in training. I was pleasantly surprised to find that in addition to appreciating my context they were also open to hearing our perspective. I was encouraged by this posture of genuine interest in learning our medical perspective. I quickly learned that, though many political issues are divisive in today’s climate, one issue with common ground is investing in the health and wellbeing of our nation’s children. I was pleased to hear that the bills for which we were advocating already had a tremendous amount of support from many of our representatives. What I feared would be a debate instead gave us the chance to provide key information to further strengthen that support.

I spent much of my fellowship reading, teaching, and executing initiatives focused on topics under the umbrella of advocacy. However, through this conference I am grateful to have had the opportunity to discover a huge avenue in which physicians can effect change. It was incredibly gratifying to be able to take the knowledge I have, even as a trainee, and to share it with people in a position to facilitate change on a legislative level. Pediatricians are, by definition, natural advocates, as we all work to ensure our patients’ voices are heard. This was something of which I was reminded during the conference, and it was empowering to discover this pathway to further amplify the voices of children.
As pediatric palliative care providers, we intimately recognize the value of an interdisciplinary team; we work to amplify the skills and expertise of each team member with the goal of supporting those receiving our care. While attending the 2022 American Academy of Pediatrics Advocacy Conference, I should not have been surprised to find that an interdisciplinary team was also a highly effective approach to legislative advocacy.

Thanks to the AAP SOHPM scholarship, I was able to participate in the AAP Advocacy Conference this year. This provided additional training from experts in advocacy, as well as learn directly from pediatricians with governmental roles who practice advocacy every day. The most impactful part of the conference was using the advocacy skills from these sessions to personally advocate my own district’s congressional endorsement for two bills supporting the mental health crisis in children. We joined together on zoom as a group of pediatric providers in our region to share this important message on Capitol Hill. This group, a selection of pediatric providers attending the conference that year, covered a full range of specialties. It included individuals from outpatient pediatrics to interventional cardiologists, and included members from all stages of training and practice. Despite the variability in experience and clinical focus, every single provider had multiple examples of the mental health challenges their patients are facing, highlighting the importance of these bills.

Our stories, coming from so many different areas of pediatric practice, clearly impacted our elected officials, who were interested and engaged in supporting these bills. Over the subsequent months, the AAP advocacy team provided updates to conference attendees about cosponsors for the bill (including my Representative!). Outlining steps towards the bills being passed, and ultimately the inclusion of the Supporting Children’s Mental Health Care Access Act in a major bipartisan bill passed in July. This bill reauthorizes and expands a Pediatric Mental Health Care Access program into schools and emergency rooms, and provides primary care pediatricians with telehealth consultation by child mental health provider teams. Seeing this bill move from our participation during the conference to being signed into law was an incredible way to experience the advocacy of our group and the broader AAP advocacy team.

The conference brought together an interdisciplinary group of passionate pediatric providers with diverse backgrounds and a common mission to amplify the voice and experience of our patients. This mission is one that many pediatric palliative care providers among us take on, and one we are all called to do as advocates for our patients and their families. The AAP legislative advocacy conference helps provide a foundation and approach to this form of advocacy in local or national government, and I highly recommend it to all who are interested!
Grief and Loss Curriculum
Physician resilience in the face of grief and loss helps sustain and strengthen therapeutic relationships between patients, families and health care providers while helping health care providers maintain the values of their profession. The Resilience in the Face of Grief and Loss curriculum provides opportunities to reflect and gain critical skills in order to enhance one’s resilience as a pediatric health care provider. This curriculum was developed with leadership from the Section on Hospice and Palliative Medicine alongside other groups.

EQIPP Course: Talking About Serious Illness
Developed by the Section on Hospice in collaboration with the Center to Advance Palliative Care and Courageous Parents Network, this course will help clinicians engage in discussions that facilitate open, honest, and compassionate care for seriously ill children and their families in your practice setting. The main goals of this course are to:
1. Prepare for discussions with patients and families that address goals of care for children with serious illness. This key clinical activity guides you through important considerations that precede successful discussions and involves both preparing yourself and preparing the family.
2. Provide a structured plan for talking to a parent or other family members about a child’s serious illness. Worksheets provided in this key clinical activity will guide you through essential topics in the discussion and will contain ways to address goals of care, techniques to enhance the dialogue, and suggestions about how to conclude with focused understanding and concrete next steps.
3. Document and share content and major points from a serious illness discussion. This activity provides you with several preformatted documents to streamline these final tasks.
4. Create plans for improvement to address gaps identified in serious illness discussions. (You will collect baseline and follow-up data as you work to improve care and processes through Plan, Do, Study, and Act [PDSA] cycles.)

PREP Palliative Care
Developed with leadership from the Section on Hospice and Palliative Medicine, this PREP self-assessment includes 40 questions to support clinicians in gaining knowledge about caring for children with serious illness. Topics include pain medications to avoid, cultural considerations when providing end-of-life care, among others. This PREP self-assessment provides Maintenance of Certification Part 2 and Continuing Medical Education credit.

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