



Newsletter

September 2020

From the Chair

Jennifer Linebarger, MD, MPH, FAAP
Kansas City, Missouri

Section on Hospice and Palliative Medicine



What are your hopes and worries? Tell me more. Help me understand.

I often have to muffle a little chuckle when I use these palliative care phrases out of the context of a patient encounter. And yet in the past months I've found myself leaning on this language in new ways, hearing it applied broadly by others, and appreciating the profound impact of pausing to listen for the answer. As I listen, I hear grief and weariness as well as resilience and strength. And I wonder, how do we best share our field's strategies for connecting with humankind?

Palliative Care and COVID-19

Members of the AAP Section on Hospice and Palliative Care worked at the local, state / chapter, and national levels calling attention to the importance of naming emotions such as grief, recognizing the anxiety brought by uncertainty, and calling attention to moral distress brought about by the COVID-19 pandemic. I invite you to look at AAP News for two great articles by our peers. In May, Drs Marsac and Ragsdale published "Tips for recognizing, managing secondary traumatic stress in yourself" ([link](#)). In June, Drs Morvant and Humphrey wrote "Pediatric palliative care specialists can support colleagues during pandemic" ([link](#)).

AAP COVID-19 Material:

The AAP is working broadly to educate pediatricians and families on the knowledge and efforts needed to care for children at this time – routine health care, vaccines, and education are still important – and advocating around the key issue of providing financial support for pediatricians impacted by COVID-19. If you want to learn more, go to www.aap.org and then click into the "COVID-19 Guidance for Pediatricians" (all but the discussion board is open access!).

Palliative Care and Racism

As I work on being antiracist, I've realized that many of the tools I need are those in my palliative care skill-set, simply given new use. I recognize people of color carry a grief and experience I do not, that all people are humans first (more than a label), and that it is important for me to meet others where they are and stand with them in support and solidarity. I also realize there is a need to create safer spaces for all, address policies that are inequitable, and continue to listen and learn from those whose experiences have been different from mine.

AAP and Impacts of Racism

The AAP published policy in August 2019 entitled "[The Impact of Racism on Child and Adolescent Health](#)". The organization continues to work toward a health equity and find ways pediatricians can make a positive impact and reduce disparities. The AAP is actively reflecting on their policies and practices and looking for more ways to improve diversity and inclusion both in the field of pediatrics and within the organization.

What do I hope for? A new societal awareness of the importance of public health and equitable policies. A continued willingness and imperative for each of us to do the hard work to promote healing.

Help me understand what your journey has been like? I want to listen to your stories of grief and distress, of resilience and overcoming barriers.

Tell me more...

IN THIS ISSUE

From the Chair	Page 1
Who I Hope to Be: Thoughts of Resilience, Progress, and Purpose	Page 2
Coping with the Loss of Team Identity Amidst COVID	Page 3
Book Review: The Gift of Gerbert's Feathers	Page 4
Patient Column: A Letter of Promise and of Gratitude	Page 5
Parent Column: Child Illness and Death in the Time of COVID	Page 7
AAP Advocacy Updates	Page 9
AAP Resources on Racism	Page 10
COVID-19 Resources	Page 11
AAP Updates	Page 11

SOHPM EXECUTIVE COMMITTEE

Jennifer Linebarger, MD, MPH, FAAP
Chairperson

jslinebarger@cmh.edu

Renee Boss, MD, FAAP

rboss1@jhmi.edu

Lisa Michelle Humphrey, MD, FAAP

lisa.humphrey31@gmail.com

Jeffrey Klick, MD, FAAP

jeffrey.klick@choa.org

Elissa Miller, MD, FAAP

elissa.miller@nemours.org

Conrad Williams, MD, FAAP

wilcon@musc.edu

Carolyn McCarty
AAP Staff

cmccarty@aap.org

Molly Feeney
AAP Staff

mfeeney@aap.org

Views expressed in this newsletter are not necessarily endorsed by the American Academy of Pediatrics

SOPHM NEWSLETTER • 345 PARK BLVD • ITASCA, IL 60143

Copyright © 2020, American Academy of Pediatrics Section on Hospice and Palliative Medicine. Permission to reprint for noncommercial, educational purposes granted with acknowledgment. The perspectives within the articles reflect the opinion of the authors, and do not necessarily reflect the perspective of the Section or the AAP.

Who I Hope to Be: Thoughts of Resilience, Progress, and Purpose

By: Abby R. Rosenberg, MD, MS, MA^{1,2,3}

¹ Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, Seattle, WA

² Cambia Palliative Care Center of Excellence at the University of Washington, Seattle, WA

³ Department of Pediatrics, University of Washington School of Medicine, Seattle, WA

Today, I joined thousands of other healthcare workers and knelt for 8 minutes and 46 seconds in silence and solidarity for #whitecoatsforblacklives. When my knees screamed for me to remove them from the gravel, I thought about George Floyd and how my pain paled in comparison to what he endured for the same period of time before his death. I thought about how I had the privilege to move. I thought about the terrible prices we pay for change in our society. I thought about how the words on the sign I carried were the same words my father recited while being arrested at a peaceful civil rights sit-in over 50 years ago. I thought about how extraordinarily sad and ashamed I felt to know that the changes my father fought for have not happened. I thought about what that says about resilience.

A decade of studying resilience has taught me that all people and communities have the capacity for it.¹ Defined as “the process of harnessing the resources needed to sustain well-being in the face of adversity,”² people and societies appear (eventually) to figure out what they need to navigate tough times. Sometimes by trial and error, sometimes intuition, sometimes deliberate intention, and sometimes sheer luck. The resources they harness often fall into the same three categories: (1) “Individual” resilience resources (personal attributes like grit, hardiness, and optimism, as well as personal skills like managing stress, emotional awareness, mindfulness, self-compassion, and goal-setting); (2) “community” resilience resources (social supports, peer-networks, family, and friends); and, (3) “existential” resilience resources (faith, spirituality, gratitude-finding, and the ability to seek and find meaning and purpose).

Which resources work for an individual is highly contextual and variable. I have learned that sometimes the best way to promote resilience in our patients, families, and even ourselves, is to help bolster predominant resources and foster ones that are under-utilized. I do this by asking 3 questions: (Individual resources): What have you done before when times were hard? (Community Resources): Who helps you? And, (existential resources): When you think about the day when you will be able to look back on all of this, who do you hope to be?

I have also learned that defining resilience as a “process” is important because refining it takes time. It appears to evolve over three, not necessarily linear, phases. Phase 1 is what I call the “getting through” phase. The experience of bewilderment and uncertainty that comes with a new or worsening adversity. The exercise of simply getting through a day, week, or month, because we know no other way to move forward. This phase is often when we feel afraid, vulnerable, angry, disempowered, or lost. It is important to recognize that these negative feelings do not imply a lack of resilience but normal emotional reactions to what is hard. Phase 2 is the “harnessing resources” phase. This is when we start to deliberately consider, leverage, and build our individual, community, and existential resources. This phase is

not passive, although some folks may not know they are doing the work. When done deliberately, it can ease the sense of challenge and accelerate forward momentum. I call the last phase “looking back.” Here, we finally have the capacity to reflect and learn from our experience. We finally have the ability to shape our (perhaps evolving) identities. We finally have the space to find gratitude and embrace purpose.

My resilience thoughts today were about how we find ourselves simultaneously navigating all three of these phases. We are a society plagued by COVID-19 who is also experiencing a necessary resurgence of civil rights movements. We are, sometimes desperately, figuring out how to get through. We are struggling, wondering, and moving towards an uncertain future. At the same time, we are harnessing resilience resources. We are leveraging individual skills to set goals and move forward with intention. We are bringing communities together both virtually and, with social distancing and masks, en masse. We are creating a sense of meaning and purpose to stand up for what we believe is right and wrong. And finally, we are learning. We are looking back on decades of lessons learned and not-learned. We are hoping to do better.

During those 8 minutes and 46 seconds, I wondered whether I was exaggerating or celebrating our collective resilience. In over 50 years of civil rights movements, we have moved both forwards *and* backwards. I cannot say the forward has been enough. I cannot say if we have successfully “sustained our wellbeing.” Today, I felt like the answer was no. Today, I thought perhaps we had settled for stagnation rather than forward momentum. Today, I worried my and others’ complacency and acceptance of the status quo was hindering societal resilience.

I also appreciated that we are at another turning point in our collective wisdom and capacity for resilience. I have faith in the thousands of pediatricians and pediatric healthcare workers who took to the streets to demonstrate our intolerance to racism, bigotry, and bias. I am optimistic about a future where we will do better. I look forward to a future where my children do not have to march again, holding a sign with words written in another century. It is with this final glimmer of hope that I ask you, our collective pediatric hospice and palliative medicine community, to consider: “When we think about the day when we look back on all this, who do we hope to be?” Carry your answer with you. Use it to get through and move forward with wellness, meaning, and purpose.

1. Rosenberg AR: Cultivating Deliberate Resilience During the Coronavirus Disease 2019 Pandemic. *JAMA Pediatr*, 2020

2. Southwick SM, Bonanno GA, Masten AS, et al: Resilience definitions, theory, and challenges: interdisciplinary perspectives. *Eur J Psychotraumatol* 5, 2014

**Does “Team Depression” Have an ICD10 Code?
Coping with the Loss of Team Identity Amidst COVID**

By: Lisa Humphrey

My palliative care teammates and I have a phenomenal team spirit. We share laughs, anguish, feisty outbursts about a referring team, irreverent moments of mirth, and when a patient dies, quiet, reflective periods. We also have moments of disagreement and frustration at our jobs, and even at each other. We view all of it as signs of a healthy team, and we feel proud about it. We work diligently on the vitality of the team and we all see our daily team meeting as critical to our work. Yes, we grumble at its inefficiency as we have an extraordinary predilection for tangents. We have attempted to modify this meeting when the wish for efficiency heightens. Yet we have never successfully maintained a more efficient plan and recently admitted to ourselves that we need this time for the health of our team. We have surrendered to the inefficiency.

Then COVID occurred. We came together as we always do when large decisions need to be made for the team. We agreed to split the team up so that only half of the team is in the building at any time lest we all become exposed and quarantined simultaneously. We strategized our revised communication pathways, re-oriented the workspace to isolate each member when in-house, organized remote access meetings, and said our goodbyes.

That was multiple months ago. We are all back in the office but still physically separated. We pass each other in our tight quarters with the constant apologies of being too close and a haste to our tone and footwork as if being social will increase our risk of transmission. It is as if “physical distancing” really has led to “social distancing” in that we feel more socially isolated still even though we are back in the same space. Our daily meeting has been demoted to brief video encounters with laser focus. Gone are the tangents and too often, the belly laughs. Reflective periods have lengthened while our angst has remained or worsened.

We did not consider the impact of the separation on our team dynamics, and thus the collective mental health of our team, on the day we decided to “split up.” We were not afforded such a luxury; rather, we were forced to dismantle the best tool in our collective coping toolbox at the very time we needed it to navigate our fears and stressors - and we mourn its loss. Things have changed, we don't know for how long, and some of the best parts of our day are gone. If team depression and grief are valid constructs, I would diagnosis our team with them, and currently cannot find a team anti-depressant to improve its mood.

In the end, I have come to realize that akin to patient/family encounters, I cannot will “better” into being merely because I wish it. Nor should I attempt to wash over the team's feelings and struggles. Rather, I need to honor it, give it the space we would give any scared family facing uncertainty, and attend to each member but also the concept of team as an independent entity. I think we are up for the challenge as another opportunity to grow as a team. Experiences like this make me grateful to have the colleagues I have, both institutionally and nationally, to navigate all of this together.



Book Review
By: Abimbola Olayinka

The Gift of Gerbert's Feathers
By Meaghann Weaver MD, MPH, FAAP and Lori Wiener PHD, DCSW
Illustrated by Mikki Butterley

"...we're always together."

The Gift of Gerbert's Feathers is an illustrated book that tackles the issues of sickness and death of a little one. The book follows Gerbert, a young goose, from the time he hatches, through his experience of progressive illness and finally death. When the reader first encounters Gerbert, he is supported and loved by his fellow geese including his parents, his siblings and his friends. Every winter, Gerbert travels with his community on the annual migration. As the years pass, Gerbert becomes ill and begins to notice that what once was so natural to him becomes increasingly challenging. His decline does not go unnoticed by his family and friends, who each show their love to him in practical ways. Gerbert ultimately realizes that he will be unable to continue journeying with the flock and decides to gift his loved ones with tokens to help them remember him. What a precious storyline!

This book is a bittersweet journey through the individual and community experience of loss. One of the strengths of this book is the interweaving of fanciful storytelling and practicality. Children and adults who go through this book cannot help but have a better understanding of what a healthy grief journey can look like. In a gentle, unobtrusive way, readers are encouraged to consider issues such as the symptoms commonly experienced by children who are sick or dying; the isolation that occurs when a child becomes sick and can no longer participate in typical family or group activities; and the steps that allow families and communities to maintain a sense of kinship with their dying loved one even as they give permission for that person to die. A particularly lovely moment comes when Gerbert and his parents join in with their community to perform some of their traditions with Gerbert present one last time.

Additionally, Gerbert's family does what they can to seek and provide treatment for a time. Gerbert's family's choice to pursue treatment comes from a place of love and a desire to care. That same love and caring is used as Gerbert and his family decide to allow Gerbert's body to make its Final Migration later in the story, when Gerbert's body is clearly showing signs of strain and decline. The book treats both paths with equal tenderness, showing that it is not the decision itself that is loving, but the goal behind the decisions is what makes a choice into the best, most loving path for that child and family. This is a key message for patients and families, who often arrive at decision points to continue or stop treatments with much trepidation and guilt. Yes, I can just imagine...

Employing a melancholy palette, with pops of color scattered throughout, the illustrations serve to both accompany and enhance the story being told through the prose of the book. The picture panels allow the reader to access Gerbert's everyday life and to better understand how he is affected by his changing health. They invite the reader to consider how health or loss of health has affected them in their own life. And regardless of the activity they are engaged in, the geese are often shown in close proximity to each other, a visual representation of one of the most important messages of the book: love is what binds us together in this life and beyond.

As the introduction indicates, this book was written with intention of helping children process anticipatory grief, grief and loss. The authors created supplemental resources including a note to help adults guide children through the reading experience. This guide, along with the text and illustrations will serve many families well as they work towards an understanding of their individual, family and community grief experiences.

Appendices at www.apa.org/pubs/magination/441B266.

Patient Column
A Letter of Promise and of Gratitude
By: Aly Becker

Receiving a college degree has always been a primary goal of mine. After graduating from high school as a valedictorian, I was eager for college and prepared to work as hard as necessary to do well. Obviously, life had other plans. In the years since graduating from high school, I have spent over 300 days on inpatient units – though at some point stopped counting. This significantly altered my academic course and my ability to continue my education... at least on any timeline I would have preferred. I was forced to take multiple years off from school completely while I spent literally more time in the hospital than out of it. During this period, I underwent over 60 surgeries/procedures – I stopped counting these as well, and for many of those, I did not have a diagnosis that was able to explain what was happening to me medically. The lack of a clear diagnosis added significant extra stress during healthcare encounters, as I had to explain everything to each provider without a unifying diagnosis to show how my symptoms and medical issues were related. It took nearly 6 years for the diagnoses I currently have, Eosinophilic Granulomatosis with Polyangiitis (EGPA) and Mast Cell Activation Syndrome (MCAS) to be found.

Despite these circumstances, I was eventually able to resume school part time and work towards the goals I most cherished. I began with just one class a semester, and then two. Eventually, I moved to three classes a semester and then back to two...the whole 2 steps forward, 1 step back thing couldn't be more accurate. Then, last year, despite ongoing health issues, I made the decision to resume college coursework full time again. I pushed myself harder than ever, in a healthy and responsible manner, determined to achieve my life dream of a college degree. In May of 2020, I finally graduated from the University of Iowa with a bachelors degree in Psychology with a secondary area of interest in Rehabilitation Counseling.

This degree means everything to me. I was able to achieve my goal even though every single semester involved at least one hospital admission and at least one surgery. Some semesters were completed despite spending over 6 of the 15-week semester in the hospital. I wrote papers and completed exams from my hospital bed. On one occasion, I received special permission from my inpatient doctor to unhook from my pole and sneak to an exam on campus between medications. I went directly from class to endoscopy procedures and ran IV infusions with a pump in my backpack during class. I watched lectures from my ICU bed and took courses over the summer to make up for courses I had to drop when I was simply too sick to make it work, no matter how determined I may have been.

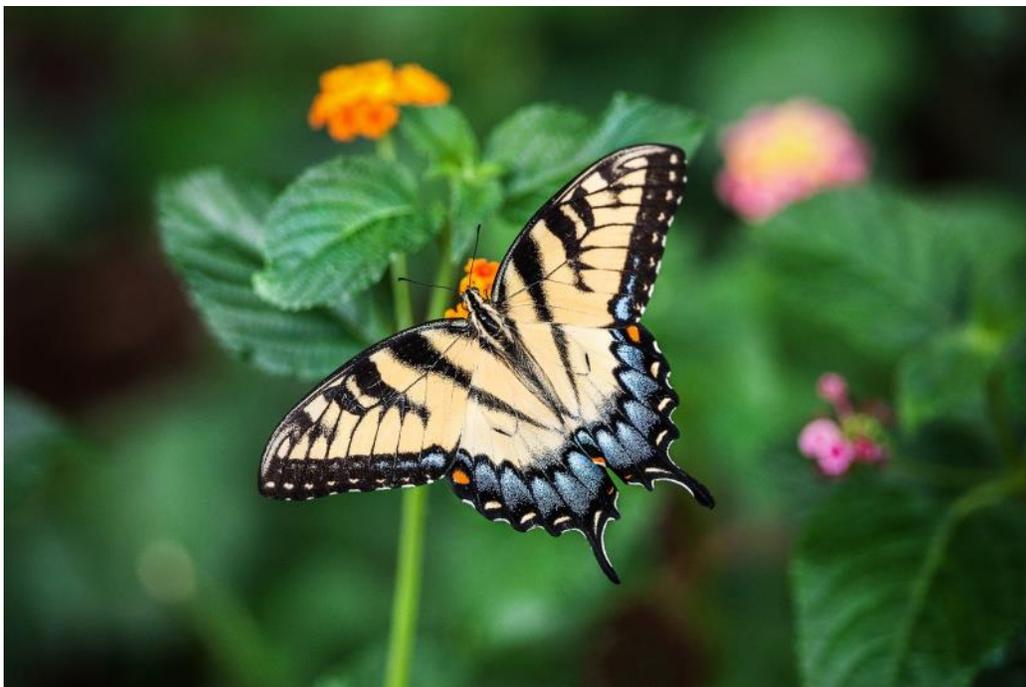
Achieving my degree was a symbolic accomplishment as well. It serves as proof that my chronic illness doesn't define me completely, nor take my dreams from me if I am willing to work harder to make it happen than typically required and lean on others for needed support. With the COVID-19 crisis, I unfortunately did NOT get to actually walk across the stage in cap and gown to receive my degree. I am incredibly sad that this experience wasn't possible, especially considering all of the blood, sweat, and tears that went into realizing this dream. On the other hand, it is also somehow fitting... par for the course of my life, honestly. An unprecedented situation occurring at the same time that I finally graduate, years after my peers. While I wish this wasn't the case and that I could get the iconic cap and gown picture, I am still immeasurably blessed. I have nothing to be upset about and a million and one things to be grateful for which have no bearing on how I actually receive my diploma. My diploma is more than enough. How lucky am I to have had the opportunity to achieve this dream despite my situation? Again, I feel immeasurably blessed.

Continued on Page 6

I also have much more to look forward to as I embark on my next chapter. I was accepted to Northwestern's graduate program in Clinical Mental Health Counseling with an emphasis in child and adolescent therapy and started in June. It is the first step toward receiving a master's degree in counseling and becoming a licensed therapist. This is a career that will allow me to capitalize on the life experiences, wisdom and compassion I have gained as a result of my chronic illness – a career that will allow me to work clinically in the medical field, utilizing a highly humanistic and holistic approach to health and wellness.

My experiences have taught me firsthand the importance of the mind-body relationship. I have learned how a person's psychological state of mind, temperament, and exposure to psychosocial stressors invariably impacts overall health and the importance of incorporating counseling as a modality into the treatment process. A career in counseling provides me the opportunity to draw upon and productively use my life experiences and personal strengths to affect positive change in the lives of others. It is my hope that I will be a counselor who, although not infallible, will be able to demonstrate in action how barriers can facilitate meaningful change and personal growth.

There are no words sufficient to convey my gratitude and excitement. To each and every person who has continually supported and encouraged me these last 15 years of living with a severe and life-threatening chronic illness - I thank you so much. Without this support, I would not be thriving in this manner despite the ongoing trials. This graduate program will be extremely challenging, and I will have to continue facing these challenges head on while battling my illness. Fatigue, pain, clinic appointments, hospital admissions, surgeries, central lines, IV medications, and daily IV infusions will remain a part of my future, just as they make up a part of my past. Still, I am fully determined to succeed and I continually gain confidence in myself as a result of the support I receive from everyone in my life. I am over the moon ecstatic and forever grateful for this opportunity. I can't wait to continue my Northwestern chapter and my professional training – but don't worry Hawkeye fans, I still BLEED black and gold, and Iowa athletics will always come first.



Parent Column
Child Illness and Death in the Time of COVID
By: Holly Simione

We knew losing Elizabeth was going to be awful but we counted on it also being peaceful with the support we had through Hospice. We counted on tenderness and caring, made possible in a safe, controlled environment with the comforts of home and the people who loved her. COVID got in the way. We made sure that tenderness and caring wouldn't be stopped.

Elizabeth was never her diagnosis: we never wanted that, and she never acted that way. She was strong and resilient, a fighter and a joker. She was a tremendous big sister to Ava and adored every minute of her attention. She would place her arm or drop a heavy foot near her and tell her how much she loved her in her own language. She would respond to her father John's presence before he said a single word. She brought her loud belly laugh everywhere she went—school, her prom, her family. She loved to be included and acknowledged. She needed complex medical care her entire life and I was always her primary caregiver. She had been on hospice the last two years, but we weren't living like she would die.

When she required emergency surgery in January, COVID was a curiosity in the international news. The immediate impact was that we couldn't get all of her necessary medical supplies, but we were absorbed in complications from her surgery and her declining health. A severe complication was liver failure, and when it required re-admission in March the hospital was unrecognizable. In the emergency room she was tested for COVID and together we remained in an isolation room for several days. Additional blood work, diagnostic testing or the use of a nebulizer were not permitted until the COVID test came back.

On the first night, she stopped breathing after receiving anti-epileptic medicine. In a zero-pressure room

they can't hear you scream or bang on the thick glass wall. I hit the emergency button, but the door system delayed the entry of the code team. It seemed like forever for them to get in the room to help me while they put on all the protective gear. Elizabeth coded again and they raced her to the ICU. Despite required blood transfusions, multiple infections and treatments for her catastrophic decline, lab work became infrequent because of COVID. She was doing poorly and yet we were hearing 'we have to be really careful. We have to conserve things.' We lost the ability to measure treatments and were flying blind.

Conserving during COVID meant the rules for PPE changed daily. Parents weren't given masks, although their movements were not restricted. During our 14 day stay, the ICU staff took usual precautions with the addition of a fresh N95 mask issued each day in the lobby. As days passed, rules shifted from staff always donning gowns, gloves and masks to only wearing gloves for IV care 'to conserve supplies.' Boxes of gloves were removed from patient rooms. As COVID cases increased, all non-clinical staff wore PPE at all times. Visitors were limited to 1 parent at each bedside yet we remained free to wander without masks and hand sanitizer stations located throughout the hospital were empty.

We wanted to take Elizabeth home but we ran into problems with that. Local companies refused to send anything early, and [the state health plan] wouldn't pay for overnight delivery. To bring Elizabeth home, I needed sterile gloves for her new central line and PPE for her homecare nurses, but hospice no longer had supplies. We knew that being in the hospital for 2 weeks only made it more likely that we would get COVID or bring it home with us. Her survival was always in question but COVID would be a certain end.

Continued on Page 8

After our admission in the hospital, away from Ava, unable to switch with my husband, I returned home for another 14 days of isolation with Elizabeth on one side of the bedroom door and John and Ava on the other. I lost several nurses immediately because they couldn't risk taking care of someone who had been in the hospital, and I didn't want the risk from a nurse who was also treating someone else. We faced a critical shortage in homecare nurses and I often cared for her alone, sometimes for 72 hours straight. There were never enough supplies, even with friends helping me. I had to clean every surface, every knob and light switch, after every shift of those nurses we had. We had no supplies to care for Elizabeth's central line. No one from any of the agencies, none of our doctors, could help.

As Elizabeth became increasingly ill, it seemed like all of healthcare was making it up as they went along. We didn't want her to go back to the hospital as we knew we would never leave. We had problems with outpatient testing. We had problems finding food. We had problems getting medicines. We faced long delays in receiving comfort medication while the pharmacist disputed billing liability with hospice. The pharmacist told me 'rules were rules, there are protocols.' I told her she was showing no remorse or compassion for the pain of a dying child. I spent the morning Elizabeth died on the phone pleading for help. Elizabeth never got the medicine.

But COVID kept us all home. When the hospice nurse told us weeks or days, and that we should stop, suctioning, feeding her and giving her meds, it crushed us. I was asking our pediatrician how we were going to talk to Ava when the nurse called us to come to Elizabeth because her breathing was shallow. I turned off the monitor because it no longer mattered, and we just stayed there with her. Ava got very upset because she didn't know why we weren't calling 911 to come help. We told her there was nobody who could help, there was nothing to do. But Ava knew that there was something to do and sang Elizabeth her favorite song, "You

are my sunshine." And we held her together. We were together.

The funeral home mercifully gave us time alone before they came into the home. John lifted her up for the last time from her bed into their quilt and they zipped it up. He never used the ceiling lift. He always picked up his girl. There is comfort in that.

I had always imagined that Elizabeth's funeral would be a celebration of how wonderful she was and what she meant to so many. The funeral was at the graveside on a cold day in May. My parents were not allowed to leave their Assisted Living to attend. The funeral home wouldn't allow mention of the cemetery in the obituary for fear that people would show up.

But people did show up. More than 125 people, all wearing masks, including members of Elizabeth's T-ball team, her doctors, and teachers. Ava's friends were there to support her. We settled for the best flowers we could find in a pandemic 2 days after Mother's Day. Those who attended couldn't hear what we said, they couldn't hear the priest, the eulogy. They stood in the cold, far away with the wind blowing fierce and the birds singing in the trees above Elizabeth's grave. They were the closeness that the universe afforded us. It means so much to me.

In the months since Elizabeth has died, there have been no meals with friends, no celebrating Elizabeth; no long cries hugging family and friends. It's been 3 months since Elizabeth passed. Food gets dropped at our back door but we are largely alone. Maybe the world is always indifferent to loss. Maybe a bereaved mother always finds sources for gratitude. Maybe I can tell myself that, despite it all, Elizabeth knew that she was loved for her entire life.

Still, COVID got in the way. Elizabeth left the house without shoes. I will always worry that her feet were cold.

Holly began a campaign to raise awareness for the needs for PPE for in-home healthcare workers. She was interviewed by multiple news outlets. A graduate student who had been organizing with other students to get face masks to healthcare workers and vulnerable populations reached out to help. (The PPEople First Procurement Team delivered 4,000 masks to the state's Developmental Disabilities Council, which is now still mailing masks out to families for homecare, across the state.) She continues to advocate for homecare nursing rates and safety, as well as actively support local government to apply ADA thoughtfully and consistently removing barriers for those 'who roll.'

AAP Advocacy Updates

The American Academy of Pediatrics (AAP) continues to advocate on behalf of children, youth, and pediatrics. The resources below may be of interest to AAP Section on Hospice and Palliative Medicine members. Note that many resources are only available to current members. If you are interested in learning more about AAP advocacy, [consider joining the Section here](#)

Final Medicaid Coordinating Care RFI for Children with Medical Complexity

The AAP submitted comments in response to the Centers for Medicare and Medicaid Request for Information related to Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions. The following themes were identified and formed the basis for AAP's comment letter:

- [Issues Related to Access to Care and Network Adequacy](#)
- [Lack of Adequate Payment](#)
- [Administrative Burden](#)
- [Improvements to Pediatric Telehealth Care](#)
- [Children with Chronic Kidney Disease \(CKD\) and End Stage Renal Disease \(ESRD\)](#)

The information collected as part of the RFI will inform guidance to state Medicaid directors on coordinating care from out-of-state providers for children with medically complex conditions. This guidance, set to be released later this year, is mandated as part of the Advancing Care for Exceptional Kids (ACE Kids) Act. Beginning October 1, 2022, states have the option to cover health home services, at enhanced federal match, for Medicaid-eligible children with medically complex conditions who choose to enroll in a health home. A [detailed summary](#) of the ACE Kids Act, which was endorsed by the Academy, is available.

Letter to Payers Urging Telehealth Extension Benefits Coverage

As part of AAP payer advocacy, The AAP sent [letters](#) to the national and largest regional health plan carriers advocating for continued expansion of the current telehealth benefits coverage and payment. During the COVID-19 public health emergency (PHE), payers have expanded their telehealth benefits, however, the time period varies among payers and some are set to expire over the next few months. Telehealth provides an important opportunity to support access to care with general pediatricians, pediatric subspecialists and pediatric surgeons.

To ensure children and families can continue to receive needed care, the AAP strongly urges payers to extend all expanded telehealth policies for 90 days beyond the expiration date of the nationwide PHE. The letter is inclusive of children with special health care needs, disabilities, and medical complexity. This letter has also been distributed to chapter pediatric councils and leaders, and the AAP encourages members to collaborate with chapter efforts to support the use of telehealth by general pediatricians, pediatric subspecialists and pediatric surgeons. At the federal level, our most recent advocacy was a joint letter to Congress with AAFP and ACP urging that the flexibility to offer telehealth services be balanced with safety and quality, in addition to promoting and supporting the medical home.

AAP Advocacy Updates

Vaccine information

The Academy created two new resources for members focused on its vaccine advocacy: [a one-page document](#) on its vaccine advocacy strategy and a [policy white paper](#), *Policies to Preserve the Vaccine Delivery System for Children*.

Provider Relief for Pediatricians

The Department of Health and Human Services (HHS) announced that pediatricians, pediatric medical subspecialists and pediatric surgeons will be able to access financial relief from the [Provider Relief Fund](#). In response to AAP's advocacy, HHS announced that they are making approximately \$15 billion available to Medicaid and Children's Health Insurance Program (CHIP) providers who have been left out of previous waves of financial relief. See the message from AAP President Sally Goza, MD, FAAP, [here](#). HHS has posted [instructions](#) for [applying for this funding](#) along with answers to some [anticipated questions](#). The deadline to apply for financial relief has been extended to September 13th. Additionally, pediatricians who received a small Medicare-based payment but did not apply for additional funding can now be able to apply for a second, "true-up" payment.

Election 2020: Vote Like Children's Futures Depend On It

Election Day 2020 is Tuesday, November 3. The American Academy of Pediatrics is leading a robust Get Out the Vote campaign focused on the connection between health equity and voting. Everyone deserves the opportunity to live up to their full health potential. Voting is one of the main ways we can influence the public policies that address health inequities in our communities. This election, we encourage pediatricians and those who care about children to vote like children's futures depend on it.

Visit [AAP.org/VoteKids](https://www.aap.org/VoteKids) for a suite of AAP resources, including information on key child health issues and their ties to health equity, voter registration resources, sample social media messages and graphics and other tools to help pediatricians share the importance of voting.

AAP Resources on Racism

In 2019, the AAP published a policy statement titled, "[The Impact of Racism on Child and Adolescent Health](#)." This policy serves as the foundation for AAP advocacy efforts related to racism. Additional AAP activities and resources related to racism are included below.

- [Dismantle racism at every level: AAP president](#)
- [The Impact of Racism on Child and Adolescent Health](#)
- [Talking to Children about Racism: The Time is Now](#)
- [A Framework to Approach Racial Health Inequities during the COVID 19 Pandemic](#)

COVID-19 Resources

- The general AAP [COVID-19 Web page](#) is updated on a daily basis with new materials, resources, and [advocacy messages](#).
- All advocacy resources related to [COVID-19 are linked here](#) (AAP ID and password required).
- AAP's latest COVID-19 Advocacy Report is available [here](#).
- Members are encouraged to share their stories via this [form](#) for the AAP Story Bank project.
- Many members who share their stories then are asked to contribute to the AAP Voices blog. Here's a [recent blog post as an example](#). Please consider this opportunity to help ensure that the perspective of palliative care pediatricians is adequately represented in AAP blog posts.
- AAP has collected updated [state-level data](#) on confirmed child COVID-19 cases in the United States.

Additional AAP Updates

National Conference & Exhibition

[Register now](#) for the 2020 National Conference & Exhibition, October 2-5. The flexible and innovative [virtual program](#) is packed with over 150 on-demand sessions and more than 35 live sessions. The conference provides a range of opportunities for learning on your schedule. There are many educational sessions relevant for SOHPM members as well as a robust set of abstracts on topics related to hospice and palliative medicine.



Moira A. Szilagyi, MD, PhD, FAAP, Elected AAP President-Elect

Moira A. Szilagyi, MD, PhD, FAAP, of Marina Del Rey, Calif., has been voted AAP president-elect

- She ran against Mobeen H. Rathore, MD, FAAP, of Jacksonville, Fla.
- Dr. Szilagyi will take over as president on January 1, 2022, following Lee Savio Beers, MD, FAAP, of Washington, D.C., who will serve as president in 2021.

SOHPM Newsletter Subcommittee

Newsletter Co-Editors:

Rebecca Benson, MD, PhD, FAAP, *Iowa City, IA*
rebecca-benson@uiowa.edu

Rick Goldstein, MD, FAAP, *Cambridge, MA*
Richard.goldstein@childrens.harvard.edu

Lawrence Fenton, MD, FAAP — *Sioux Falls, SD*
Stephen Hays, MD, FAAP — *Iowa City, IA*
Blyth Lord, parent — *Newton, MA*
Helene Morgan, MSW — *Los Angeles, CA*
Tressia Shaw, MD, FAAP — *Phoenix, AZ*
Steven Smith, MD, FAAP — *Columbus, OH*
Megan J. Thorvilson, MD, FAAP — *Rochester, MN*
Abimbola Olayinka, MD, FAAP — *Iowa City, IA*

SOPHM NEWSLETTER • 345 PARK BLVD • ITASCA, IL 60143

Copyright © 2020, American Academy of Pediatrics Section on Hospice and Palliative Medicine. Permission to reprint for noncommercial, educational purposes granted with acknowledgment. The perspectives within the articles reflect the opinion of the authors, and do not necessarily reflect the perspective of the Section or the AAP.