Happy Summer, everyone! To kick things off, I'm going to tell you a story about my hair. Those who know me well will be surprised, as this represents the most energy I've spent on my hair in years. However odd the topic—and I acknowledge it's an unusual one—there is a point (so hang in there!)

For my whole life, I've had stick-straight hair—hair that was nearly impossible to style. Formal events in high school required professional styling with shellack-level hairspray. As I grew older, I stopped trying to fight it and just embraced it. I washed it, brushed it, and cut it, but I didn't attempt anything else. While not my idea of "perfect," my hair and I co-existed harmoniously.

During the pandemic, this routine was thrown off. Just like everybody, my haircuts stopped. My once-short hair just grew and grew, eventually long enough for a ponytail. This change was welcome: it was one less thing to worry about, in between work and raising three kids (a newborn to boot!), and it was easier to navigate the endless PPE.

However, as my hair grew long, it became increasingly frizzy. "Momma," my eldest child said, "Your hair is big!"

After a long absence, I finally broke down and went to see my stylist, telling her about my frizzy hair woes. She chided me, "Your hair is frizzy because you haven't had a haircut in two years. There are just so many split ends." And she chopped them off.

But the frizz continued.

I went back. She told me my hair was frizzy because I was using the wrong ponytail holders. "You need to buy scrunchies," she told me. So, I did.

But my hair was still frizzy.

By the time I returned, my old stylist had left; the salon assigned me to a recent graduate. I briefly mentioned my frizzy hair as she was examining it. "Hmm," she paused thoughtfully, "You know you have curly hair, right?"

"I had a baby."

"Well, that's it then—the pregnancy changed your hair. You have curly hair now," she stated.
From the Editor (Cont’d)
Kelly A. Curran, MD, MA, FAAP

(Continued from page 1)

She cut my hair, put in some product, used a diffuser, and voila! Beautiful curly hair!

I sat there agape. How could this be? Still in disbelief, I texted my OB from the beautician’s chair: “Dumb question: Can pregnancy cause you to have curly hair?” Her reply was simple, “Yes.”

The mystery of the frizzy hair was solved, but I was still shocked. This fairly inconsequential change required a perspective shift—a transformation in how I saw myself. My experience reminded me of a family-favorite kids’ book, Red: A Crayon’s Story by Michael Hall. This story is about a crayon whose label says that he is red, but in reality, he is blue. Blue’s fellow crayons were full of expectations and judgments—his strawberries were never red enough. However, once someone recognized his true identity, these judgments evaporated, and his strengths were embraced.

Both of these stories highlight the importance of beginner’s mind in one’s approach. In the mind of an expert, there are few solutions to problems, but to a beginner, there are many possibilities. To me, the articles this month highlight this change and a new perspective.

I want to thank all the authors for their thoughtful pieces for this newsletter. I’m thankful for the past leadership of Dr Mark Mercurio as chair, and I’m excited to work again with Dr Steve Leuthner in his new role as chair. I’m grateful for Dr Dalia Feltman, the former editor of this newsletter, whose creativity and passion leave big shoes to fill. I want to also recognize our new executive committee member and associate editor, Dr Becky Benson, for her assistance with newsletter content and editing. I want to acknowledge Ms Sue Wizniak from the AAP for her excellent job on the layout. Lastly—but definitely not least—a special thanks to our readers. This newsletter couldn’t be what it is without you. As always, we welcome your thoughts and perspectives and encourage you to submit them for future editions of the newsletter.

From the Chairperson: Introduction, Gratitude & Challenge
Steven R. Leuthner, MD, MA, FAAP

With my inaugural column as the incoming Chair to the Section on Bioethics, I would like to first introduce myself. I completed my medical school training, residency, and neonatal fellowship all in Chicago, and during my fellowship, I received my MA in Bioethics. I then moved to Milwaukee, WI, and have been a practicing neonatologist for some time now at the Medical College of Wisconsin and Children’s Wisconsin. As some know, I have had a focus on perinatal and neonatal palliative care, and more recently took on the role as Medical Director of Children’s Wisconsin Palliative Care program. More importantly to who I am is my goal to be a dedicated husband and father of four. These relationships have taught me about commitment, love, forgiveness, joy, and sorrow at times.

Regarding my involvement with the AAP, it began a long time ago at the state level. I have had the privilege to serve for 6 years on both the Committee on Bioethics and the Section on Bioethics. And now it is with gratitude, humbleness, and enthusiasm that I take on the role as

(Continued on page 3)
the SOB Chair position. I must acknowledge the work that has gone on before me, giving kudos to our former Chair, Mark Mercurio, for his outstanding leadership. He leaves me with an outstanding group of people on the executive committee, with an eye toward the future. I hope to build on this momentum!

So it is with gratitude that I take on this role. Gratitude for my past experience on the Committee, gratitude for the people I have previously met in my work, gratitude for the current Executive Committee Members and the work they continue to do for the AAP and our section, and gratitude for all of you who are section members. And with this gratitude comes my challenge to you — to be involved!

When I think back to the beginning of my time working within the AAP, I acknowledge I came to it not exactly sure what it was I could even do. I have found that this is not an uncommon feeling for those who initially become involved. There is often a lack of understanding of sections and councils and committees, and what role each plays within the AAP. I can share from my experience that the Committee on Bioethics has had the basic function of serving to write policy statements, clinical reports, or technical reports as they relate to bioethical issues. The Section on Bioethics has taken on the basic functions and role of education on bioethical issues. This tends to be focused on National Conference & Exhibition (NCE) activities including a half-day program of education that is typically a joint program with another section or council on bioethical issues within their clinical activities, as well as other plenary or short program submissions. The Section has also developed a residency education curriculum that has undergone a few renditions and continues to grow. And we support this newsletter, a bioethics trainee paper award, and hand out the William G. Bartholome Award for Ethical Excellence.

So why do I share this? Well, my challenge to our Executive Committee and section membership at large is to step up and be involved. Historically, it feels like it is the Executive Committee that does the work. We essentially market via the website to members the benefits of belonging to our section, such as 1) Access to section-sponsored programs at Academy national meetings at no charge above the general meeting registration fee, 2) Access to the section listserv which encourages member discussion on the bioethical care for kids, 3) Unrestricted access to the section member collaboration site, 4) The biannual Section on Bioethics Newsletter and other section correspondence, and 5) Networking opportunities at the section meeting held in conjunction with the NCE.

There have been no doubt efforts to try and engage membership, perhaps most obvious through newsletter offerings and our historical “case of the month.” But our current executive committee wants to see how we can expand and pull more people in to be active participants in our section. The goal in this is to continue to network, learn more about the AAP system, and bring in new people and ideas to make the section work. In fact, a few of our current executive committee members began their journey by participating in newsletter writing and editing as section members. John Kennedy once said, “Ask not what your country can do for you... ask what you can do for your country.” I suppose I am asking all members to not just think about what the Section can do for you, but what you can do and bring to the section.

So what can you do? Number one, know we are willing to hear about your interests and what you would like to see from the section. If you have a topic for an NCE presentation or a newsletter article to share, we would like to invite you to share it.
William G. Bartholome Award for Ethical Excellence
2023 Award Recipient - Mark Mercurio, MD, MA, FAAP

Dr. Mercurio was selected as the 2023 William G. Bartholome Award for Ethical Excellence recipient. He will be presented with the award on Monday, October 23, 2023, at the (H4051) Joint Program: Section on Bioethics, Section on LGBT Health and Wellness, and Section on Minority Health, Equity, and Inclusion held in conjunction with the National Conference and Exhibition in Washington, DC.

Dr. Mercurio is Professor of Pediatrics and the Director of the Program for Biomedical Ethics at Yale School of Medicine. Until recently he also served as Chief of the Division of Neonatal-Perinatal Medicine. He is actively involved in the ethics education of Yale medical students, attending physicians, fellows, residents, nurses, and physician associate students. He has more than 35 years of experience as a clinical neonatologist, including the training of fellows and residents in the Newborn ICU, and over 35 years of experience in clinical ethics consultation in adult and pediatric medicine. Dr. Mercurio has been an invited lecturer nationally and internationally, focusing on analyses of ethical issues in adult and pediatric medicine, primarily pediatrics. He has for many years served as medical faculty for the Fellowships at Auschwitz for the Study of Professional Ethics (FASPE). Published work has appeared in Pediatrics, The Hastings Center Report, Seminars in Perinatology, the Journal of Medicine and Philosophy, The Journal of Perinatology, American Journal of Bioethics, and others. He is a former Chair of the American Academy of Pediatrics Section on Bioethics Executive Committee, has served on the American Academy of Pediatrics Committee on Bioethics, is co-editor of the six-volume textbook Bioethics, and is co-editor of the textbook Clinical Ethics in Pediatrics.

Dr. Mercurio received his undergraduate degree in Biochemical Sciences from Princeton University, and his MD from Columbia University. He completed Pediatrics Residency and Neonatology Fellowship at Yale University, and received a Master’s Degree in Philosophy from Brown University.

2023 National Conference & Exhibition (NCE)

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<td>S3601: Ethical Considerations in Whole Genome Sequencing for Newborns</td>
<td>Sunday, October 22, 2023</td>
<td>3:30PM - 4:30PM</td>
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<td>I4704: At a Loss for Words: Decolonizing the Language of Global Health and Health Equity</td>
<td>Monday, October 23, 2023</td>
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Interested in learning more out these, and other sessions, registering...anything else NCE-related? Please click here and you will be taken to the NCE site.
### Monday, October 23, 2023

**H4051: Joint Program: Section on Bioethics, Section on LGBT Health and Wellness, and Section on Minority Health, Equity, and Inclusion**

**Advocating for patients at risk for healthcare inequities: identity and ethics**

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<td>Introduction/Welcome*&lt;br&gt;<strong>Moderators:</strong> Dr Anthony Cooley, MD, FAAP; Dr Daria Feltman MD, MA, FAAP; Dr Valencia Walker MD, MPH, FAAP</td>
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<td>1:05PM</td>
<td>Bartholome Award*&lt;br&gt;Presented by Dr Steven Leuthner MD, MA, FAAP to Dr Mark Mercurio, MD, MA, FAAP</td>
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<td>Introduction*&lt;br&gt;<strong>Moderators</strong></td>
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<td>Advancing Health Equity: Race Concordance and Diversity in Medicine&lt;br&gt;Dr Errol Fields, MD, PhD, MPH, FAAP</td>
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<td>Visibility in Medicine, Advocating for LGBTQ+ patients and providers&lt;br&gt;Dr Henry Ng MD, MPH, FAAP</td>
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<td>Applying ethics principles and tools to advocate for vulnerable populations&lt;br&gt;Dr Vanessa Madrigal MD, MSCE, FAAP</td>
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<td>Case presentations and discussion&lt;br&gt;Faculty panel and moderators</td>
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*This portion of the program is not designated for CME credit.*
The Section on Bioethics (SOB) of the American Academy of Pediatrics (AAP) and the Ethics Special Interest Group (SIG) of the Academic Pediatric Association (APA) are pleased to announce the joint Ethics Essay Contest.

Contest Rules:

- The contest is open to all residents in pediatrics or medicine-pediatrics, and all pediatric subspecialty fellows (including fellows in pediatric surgery, pediatric psychiatry, and pediatric neurology) in North America. The contest is also open to medical students who have successfully matched into one of these programs by the submission deadline.
- Essays should focus on the ethical issues that residents and fellows face while caring for patients or conducting research. Possible topics include (but are not limited to) cases or issues related to clinical ethics, research ethics, organizational ethics, public health ethics, or global health ethics.
- Essays should be between 1,000 to 1,700 words. Essays longer than 1,800 words will be disqualified without review. References are not counted towards the word count.
- Essays must be original and unpublished works by a single author. Receiving feedback from mentors is acceptable, but the essay must be the author’s own work.
- Essays must be deidentified and HIPAA compliant.
- References to appropriate literature are encouraged. References should be prepared according to the most current AMA Manual of Style (http://www.amamanualofstyle.com).

One or both winners may be asked to read their essay at the Pediatric Academic Societies (PAS) Meeting on May 2-6, 2024 in Toronto, Canada. If able to present, winners will be provided with a travel scholarship to attend ($200 each for 1st place and 2nd place). Winning essays will be published in the newsletters of both the APA Ethics SIG and the AAP Section on Bioethics. Contest winners will need to complete copyright release forms prior to essay publication. Additional information regarding copyright will be provided to contest winners.

Submission Deadline: September 1, 2023
Submit essays to: https://www.surveymonkey.com/r/P3NQBV9
All submitters will be notified of the outcome of the contest by October 20, 2023.

Questions:
Contact Heather Stob, Program Manager, Child Safety, Health and Wellness at hstob@aap.org.
Mandatory Reporting of Child Abuse: What if There’s Nothing to Report?
Abigail Laudi, MD (Pediatric Resident, Seattle Children’s Hospital)

A toddler was brought to the emergency room in the middle of the night by her parents for a urinary tract infection and dehydration. During the encounter, she was hard to console, but her exam was otherwise normal apart from signs of dehydration. She received IV fluids, antibiotics and was admitted to the inpatient unit. Because of the hospital’s COVID precautions, only one parent was allowed during admission; her mother volunteered to stay.

The following morning, I took over her care as the daytime resident. In reviewing her chart, I discovered a recent emergency room visit at another hospital for an unrelated complaint. At that hospital, her mom reported concerns to staff for physical and sexual abuse by the patient’s father which was documented. The patient’s father was questioned by the medical team, who denied the accusations. He ultimately got so upset that he took the patient and her mother home without completing the medical assessment. The attempts to recover the family in the coming days following this ED visit were not obvious. From what I could see, was the last documented interaction between this child and the healthcare system in the chart.

After handoff and chart review, I followed the standard evaluation: I recruited a nurse chaperone during a complete head-to-toe physical exam; I monitored for concerning behaviors and interactions between Mom and the child; I ordered a standard laboratory and radiologic examination for evidence of child abuse. I asked Mom about the prior incident at the outside hospital to verify the story from her perspective, which is when she told me she is still concerned about sexual abuse from the patient’s father. He no longer lived with the family since that incident, she said, but after that ED visit, he got a lawyer to refute all accusations of abuse. According to this mother, the father’s lawyer had used the documented reports from the outside hospital to claim Mom as “unstable” in caring for their daughter and has since been working on trying to obtain full custody of the child. Mom says currently he is allowed unsupervised visits with her at his home every other day and she is concerned this current infection is related to a new sexual abuse incident.

I thanked her for telling me, validated her concerns, and gently mentioned my obligation as a mandatory reporter to notify my preceptor and law enforcement. I also consulted the hospital’s child abuse team for recommendations on how to protect my patient and her mother.

To me, I was doing right by this patient; there was a reported concern for abuse, an identified abuser, and a victim. And as the person trusted by Mom with this information, it was my responsibility to do something with it.

However, the child abuse team wasn’t as convinced. They questioned: Did you find any bruising or signs of trauma on the torso, ears, neck, or face inconsistent with a play injury? Did you find any patterned bruising such as burn or slap marks? Did you find any decreased range of motion of any of the extremities concerning for a broken bone?

I was relieved to report “no” to all these questions for the patient’s sake.

After these questions, he only had one additional recommendation: a social work consult if not done already.

I was immediately confused and frustrated. Maybe he didn’t hear my entire presentation? I questioned him, “Aren’t we going to call the police? Ban Dad from coming into the hospital? Get Mom some sort of restraining order?”

The child abuse fellow explained, “Because the child has no obvious markings or radiographic findings of abuse, we have no evidence that the mother’s account was true.

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Mandatory Reporting of Child Abuse: What if There’s Nothing to Report? (Cont’d)
Abigail Laudi, MD (Pediatric Resident, Seattle Children’s Hospital)

(Continued from page 7)

Sexual abuse of toddlers who cannot verbally express that they’ve been abused is also hard to prove. Even if she has a UTI, we cannot prove definitively that it is because of sexual abuse, because female toddlers get UTIs even when they’re not sexually abused.” At the end, he re-emphasized his recommendation for the social work consult to provide resources to the mother.

As he spoke about the limitations of reporting, the more helpless and panicked I became. I ran this recommendation by my senior resident and the inpatient social work team; everybody agreed there was nothing more we could other than “provide resources”.

When I brought up my discussion with the medical team to the patient’s mom, she didn’t even blink in surprise. Her response was calm, but assured, “This is always what happens. The system fails women like us.”

I thought to myself, What system? This hospital system? Wait, am I now ‘the system?’

Apparently, my face showed my feeling of utter helplessness because she smiled and asked me if I was ok. Everything was backwards. She shouldn’t be taking care of me; I should be taking care of her. We wouldn’t send a child home with an untreated asthma exacerbation; how could we send this patient home to an unsafe environment, who may be abused again?

For context, this patient was my first sexual abuse patient of residency. I was in the first month of my training, I was not yet sleep deprived, and felt enough energy with two new letters behind my last name to act and fight the system from within to advocate for the most vulnerable in our population. This is at least what I wrote in my personal statement to residency programs not even a year before this patient interaction took place. But did my good intentions even matter, were my claims from my personal statement enough to help this family?

Ultimately, the patient’s laboratory studies revealed an uncommon organism as the cause of her UTI, though it was still not enough evidence for potential sexual abuse. As we were wrapping up discharge of this patient from the hospital with a prescription for oral antibiotics to treat her UTI, Mom asked the nurse if she could speak with the doctor before she left. When I entered the room, Mom requested that I didn’t document anything related to her abuse concerns. When I asked why, she said the patient’s father had a very good lawyer and was trying to build a case against her to gain full custody.

Without my documentation, there was no detailed medical record of this patient’s encounter, there could be no additional police involvement, and there was no one following up with this patient upon discharge to ensure safety besides her mother. And this is when the reality of the situation truly sunk in. I am part of the system. A broken, confusing system. I sent them home against my better judgment an hour after this conversation because the hospital was overflowing and we needed the bed for someone “who was actually sick”.

On the Washington State Department of Social and Health Services website, signs of sexual abuse include bruising around the genitals, unexplained genital infections, anal/vaginal bleeding, or an individual’s report of being sexually assaulted. None of these applied to my patient or to many other pediatric cases of sexual abuse. Sexual abuse is harmful but insidious; it will not show up as a patterned bruise or a broken bone. It is discrete and invisible to the naked eye. It is silent and defenseless in our pediatric population who cannot express themselves with words or protect themselves with actions. In a case-control study of close to 400 prepubertal children, genital examinations did not differ between sexually abused children and controls. Physical findings specific to previous genital trauma were found in only 2.5% of abused children. This evidence is well stated in the American Academy of Pediatrics journal articles on pediatric sexual abuse, as is the evidence on the

(Continued on page 9)
psychological distress this causes children as they grow up. Every article ends with the following recommendation: mandatory reporting. Mandatory reporting laws exist in all 50 states when clinicians have a suspicion of child abuse. If you see something, say something. But in cases like these, it feels like that’s where it ends. What if saying something is not enough? In this case, it wasn’t.

Just to call this out to the reader, I know I had bias in this case: I was immediately biased against the patient’s father based on the outside hospital report prior to even meeting the family. I was biased because of this patient’s race and ethnicity. I was biased to believe the mother at face value in our initial meeting. But it has been more than a year since I took care of this patient and I still think about her and her mother, I still see her mother’s face and hear her voice in my head. I think of her every time I have another abuse case in the hospital, which is not uncommon. Regardless of what the reader believes or how much more evidence was required for the reader to believe or not, to report or not, to act or not, this mother represents so many parents whose stories have not been listened to or who have not been believed. Let this mother be a sign of urgency to you, as well as an affirmation that if you also went into pediatrics to be an advocate for your patients but don’t always feel like one, you’re not alone.

References


Bioethics Spotlight: Dr Naomi Laventhal
By Colleen Parrish, MD, FAAP (Assistant Professor, University of Oklahoma Health Sciences Center)

Dr Naomi Laventhal is a Neonatologist at the University of Michigan and a bioethicist. She is currently the chair of the Committee on Bioethics (COB) for the American Academy of Pediatrics. In this interview, she shares her role on and her journey to the COB.

Tell us a little about yourself and how you became involved in bioethics.

I’m a mid-career academic neonatologist at University of Michigan. I came here after I finished my training at University of Chicago – I did my Pediatrics residency and Neonatology fellowship there, and while I was a fellow, I did my clinical ethics training at the MacLean Center for Clinical Medical Ethics and got additional training at the Harris School for Public Policy. I’m not sure that I specifically knew what bioethics was until my residency interview day at University of Chicago, which happened to be ethics case morning report day - Bill Meadow, John Lantos, Lainie Ross, and others lead an intense discussion of a recent case – and it was immediately and intuitively clear to me that I wanted to be like them. In college, I had cultivated other interests along with my pre-med classes – I majored in anthropology, minored in Spanish, and took as many humanities classes as I could squeeze in. In hindsight, I took and loved a class that was a bioethics overview course... but I didn’t realize it at the time!

My work is now spread over a few areas – I spend a lot of time taking care of patients in the NICU, and doing other activities like teaching, writing clinical guidelines, and administrative leadership. I have a strong interest in prenatal consultation and perinatal care coordination. I am a clinical ethics consultant for patients throughout the health system (across the age spectrum – not just kids) and recently got certified via the HEC-C program (Healthcare Ethics Consultant-Certified Program). I love doing and teaching clinical ethics, but I’ve also always had a strong interest in research ethics and integrity. As such, I was recently appointed as the research ethics service co-chief as well.

Tell us a little about the Committee on Bioethics. How does it differ from the Section on Bioethics? How is the group comprised?

The committee and the section complement each other well – I’ve had the opportunity to work with both. The committee’s primary role is to write and review statements for the AAP (policy statements, clinical reports, and technical reports). Fundamentally, this means that we are responsible for providing the members of the AAP with guidance for the ethical dimensions of their professional work. We write some of our statements as a solo authoring group, but many of our statements are written collaboratively with other committees, councils, and sections. We also review statements written by other groups; the section does this as well. The committee is comprised of Board-appointed members – upcoming open seats are posted for applications, and these applications are reviewed by several entities that make recommendations to the board. Committee terms are 2 years, renewable three times (6 years max on the committee). We also work with liaisons from the American College of Obstetrics and Gynecology, the American Academy of Child and Adolescent Psychiatry, and the American Board of Pediatrics and have a legal consultant.

The AAP has policies that relate to critical ethics topics in pediatric health. Can you tell us a little more about how these policies come to be?

a. Given ever-evolving topics, how does the committee decide and prioritize policy topics?

All policies that are developed and published are considered policies of the AAP. There is a lot that goes into that: the expertise that we have on the committee, the priorities of the AAP, and the urgency of the issue. If other organizations have solid guidance on a topic and we don’t think we need to add very much, we may opt not to write on that topic. If we are co-authoring a statement with another group that has a lot of momentum,

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Bioethics Spotlight: Dr Naomi Laventhal (Cont’d)
By Colleen Parrish, MD, FAAP, (Assistant Professor, University of Oklahoma Health Sciences Center)

(Continued from page 10)

that statement might be moving quickly. We also are focusing on making sure that we are keeping our current policies up to date.

b. How long does the process take for a new policy to be developed?
A new statement idea or updated evidence to revise an existing statement is submitted as an “intent” which lays out a plan for the proposed policy statement, clinical report, or technical report (technical report are rarely stand-alone – usually they accompany a clinical report or policy statement). Once the authoring group(s) all agree on the intent, it is submitted for approval to the AAP Board of Directors. Once approval is granted a 2-year clock starts to get the finished policy back to the Board for approval. During those two years, the authoring group(s) write the statement, which goes through multiple levels of peer review, and then to the Board for final approval.

c. Who participates/provides feedback for these policies?
Generally, all members of any authoring group are expected to give feedback and sign off on all statements – that’s certainly true for the COB. The various committees, councils and sections review the statements for feedback to ensure the guidance matches other policies. The statements are also reviewed by senior leadership and the Board of Directors before being submitted to the AAP Executive Committee for final review/approval.

d. Can general AAP members submit topics/issues to the committee for review?
Yes, and people do – there’s a mechanism on the website that allows people to do this officially, or sometimes people contact leadership for this directly. We can also be asked by the Board to work on a policy following a Leadership Conference resolution.

e. Where do people easily access them for review?
All policies are published in Pediatrics. If you look on the website, there’s something called “Policy Collections” and you can find all our policies in one place. It’s important to note that our policies don’t stand in perpetuity; they are reviewed every few years for currency and can only be renewed without revision once. Policies that are not explicitly reaffirmed or revised are retired – they are still searchable, however.

The US is a large country, and pediatricians practice in all areas—in differing political and geographic climates, in rural and urban locations, in private practices and academic centers, in general and in subspecialty practices, in resource-rich and poor areas, to name a few. These factors influence how medicine is practiced. How does the committee consider these differences in practices when developing policies?

Making sure that AAP policies speak to pediatricians and other pediatric clinicians for the whole country is important. The Board considers diversity and representation along multiple axis in committee appointments. In general, all sections and councils have elected executive committees. State and district leadership is also elected and has a powerful voice in setting the AAP’s agenda at the Leadership Conference. AAP District Chairpersons comprise most of the AAP Board Seats; thus, the Board always represents the entire country. The Board also has three members at large seats that are elected by the entire AAP membership. We also have a Parent Partnership Network who participate and are involved in advising the AAP.

The US is a pluralistic society, and within pediatrics ethics, there can be a diversity of views on emerging ethical topics. How do you incorporate divergent views in the AAP membership and on the committee membership?

Not every complicated ethical issue has a clear consensus among bioethicists, and we always try to acknowledge and explore that in our statements.

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Bioethics Spotlight: Dr Naomi Laventhal (Cont’d)
By Colleen Parrish, MD, FAAP, (Assistant Professor, University of Oklahoma Health Sciences Center)

(Continued from page 11)

I can imagine there might be several topics that don’t get to be fully discussed every year, what happens to those that don’t get talked about?

I have a “back-burner” list — we do a lot of forecasting with the timeline of other statements and try to anticipate when we think it will be a good time to start working on something new.

What are topics you want to see addressed or highlighted in the coming years?

Right now, I’m focused on getting the statements that we’re developing over the finish line and making sure that our great collection of previous policies is up to date. I don’t think there’s an obvious gap in AAP ethics guidance that isn’t covered by other organizations. I’m trying to make sure that we feel good about the quality of the work we’re doing and leave ourselves some time and headspace to talk about the issues, so that we have the creativity and opportunity to let new ideas come up organically and can be open to the needs of the AAPs members as they arise.

We want to express our gratitude to Dr Naomi Laventhal for her willingness to share her thoughts and experiences and to Dr Colleen Parrish for writing this piece. We encourage our members to contact us (kcurran@uams.edu) to share their thoughts for future interviews.

Breaking Bad News: Disclosing Loss to a Sick Child
Gloria Chen, MD (Surgery Resident, University of Iowa Healthcare)

It is often debated if, how, and when to disclose medical information to children as they move through different phases of child development. In a typical adult patient-provider relationship, being honest about the medical condition is important to maintaining trust and respect, and allows for self-determination, as encapsulated in the principle of autonomy. The level of maturity in children varies greatly with age and with illness experience, as some conditions cause temporary or permanent cognitive impairment. For these reasons, we rely on parents/guardians to receive the medical information and make appropriate decisions in their child’s best interest. In this role as information-holders and decision-makers, parents have the right to decide how much medical information is revealed to their minor children.

Over the past several decades, there has been a push towards increasing medical transparency with children, allowing them to more fully participate in the decision-making related to their own health based on their age and maturity level. While parents are the expert on their child, and know them better than anyone else, the medical team brings the expertise in child development and often has experience helping families in similar situations. When a parent decides to not tell a child the truth in a situation where medical team members feel it would be developmentally and situationally appropriate, it gives us pause. We balance the risks and benefits of the decision, keeping in mind not only the interest of the patient medically but also psychologically.

Providers usually abide by parent’s decisions about what information to share with young children, but often encourage truth-telling, even with difficult news, as it allows the child to process the information in a supported environment, rather than feeling isolated. This is especially relevant in circumstances where the child is asking for specific information that the parents want to withhold. One unique type of situation occurs when the information being withheld is not directly related to the child’s own health condition, but is expected to impact the child emotionally and psychologically.

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For example, “Anna” is a 10-year-old girl who presented with polytrauma after a motor vehicle accident where she was an unrestrained passenger. Her father was also in the vehicle and was declared dead at the scene of the accident. Initially, Anna required immediate intubation and multiple surgeries. Despite the seriousness of her injuries, she recovered quickly, and within a few weeks, she had regained her cognitive abilities and was working towards physical independence.

As soon as she became oriented and able to converse, Anna began repeatedly asking about her father. She asked multiple staff members as well as her mother if her father had died. The mother expressed the desire to wait until she was stronger to disclose the information about her father’s death, responding to her questions by telling her that her father was also in the hospital getting better. When asked when she thought Anna would be strong enough to be told, she indicated different times in the future, including after Anna was able to walk by herself, and after she was discharged from the hospital. Staff members did not want to lie to Anna and struggled to know what to say in response to her direct questions, feeling any answer was a form of deception since they knew the truth. Many of the medical team members felt she was ready to receive the information about her father’s death, and that she might have a suspicion based on what she had witnessed at the scene of the accident.

She had been asking in a variety of different ways, which seemed to indicate to the team that she was cognitively able to understand the information. It appeared that she was emotionally as ready as one could anticipate a 10-year-old to be, and it was hoped that telling her would give her the opportunity to begin to grieve. On the other hand, her mother felt it would be best for her to begin grieving once she was much closer to her baseline and able to have family members with her consistently. Child life specialists, chaplains, and social workers with expertise in helping families experiencing trauma and loss were involved in providing support to both the patient and her mother during her hospitalization. The team was concerned that she would be angry with her mother and the team that the information had been withheld for so long and that would create a lack of trust with both parties.

When looking at the interests of a child, it is important to evaluate both the short-term and the long-term effects of decisions being made, how it impacts their current well-being as well as how it impacts their foundation for life as an adult. Telling the truth can be viewed as an act of respect that can strengthen the therapeutic relationship, which should encourage continued healing. While the focus is often on the medical needs, psychosocial and developmental interests should also be considered. How will the timing of the disclosure about her father’s death impact her emotional maturation, her relationship with her family, her ability to cope with this and future trauma and loss, and even her future interactions with healthcare providers?

Despite offers of support and several conversations encouraging her to share, the mother remained adamant about withholding the news, stating she wanted Anna to have more physical independence and be at home before she disclosed this news to her. She limited Anna’s interaction with friends, family, and social media to protect her from learning about her father’s death before she felt Anna was ready. She believed this was in her best interest and would allow her to recover most effectively. After a few days, Anna stopped asking the medical team about her father.

Family dynamics are often complicated and not something a healthcare professional can fully understand, even when the family is familiar to us. The roles and relationships within a family are often nuanced and parents may not be able to articulate the deep-rooted

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values and concerns behind decisions such as these. Additionally, communication within families is influenced by multiple factors that are not always obvious to observers and these family dynamics shape a child’s understanding of the world and their lived experiences. Especially in situations like the death of a parent, the grieving process of a family is unique. And while medical staff interacts with the child and the family for a short period of time, their relationship with each other is for a lifetime. The mother will live with the outcomes of the disclosure process in a way that the healthcare professionals will not.

The conflict then, is how to balance respecting the mother’s decision to withhold information and maintaining a therapeutic relationship with the child. Are the two mutually exclusive? As a staff member who is being asked about the status of her father by the patient, how can we respond appropriately? Sometimes we wish for straightforward answers to questions such as these. But reality is never as simple. As the team tried to understand the mother’s decision, it was revealed that she was not concerned about not knowing what to say, but rather her biggest reason for not telling her daughter was to give her the best conditions for healing. She wanted to disclose the information when she was home in a familiar space and back to baseline. The team decided to respect the mother’s decision while offering support and resources for her to talk about the death when she was ready to give Anna the information. Staff members were encouraged to continue to defer questions about her father to the mother rather than answering the question themselves.

Pediatric patients are unique because their maturity increases over time and should have increased levels of involvement in their medical decisions as they age. When faced with challenging information that is not directly related to the child’s own health, it is important to consider how disclosure of that information may impact their well-being, not only from a medical standpoint but also from a psychosocial and emotional development. Their experience may be formative in how they approach their relationships with their family and the healthcare system as adults. As healthcare professionals, we must find ways to work with families and patients to not only provide care that is in their best interests medically but to support them as a whole person in and out of the hospital room.

References:
In Nasty, Brutish, and Short: Adventures in Philosophy with My Kids, Scott Hershovitz shares humorous interactions with children. However, embedded in these tales, is a larger point: as described in his own words “The point of this book is that anyone can do philosophy and every kid does.”

In one such anecdote from the book, a philosopher father discusses dreaming with children:

“I wonder if I’m dreaming my entire life,” says 4-year-old Rex.

“A guy named Descartes wondered the same thing,” responds his philosopher father.

“Is there anything Descartes can know for sure, even if there is an evil genius trying to deceive him?”

The father poses this question and Hank, 8 years old, answers instantly: “He knows he’s thinking.”

This seemingly innocuous dialogue highlights the complex elements of the Dream Argument from Descartes’ First Meditation.

Some may wonder why pediatricians would be interested in the philosophical questions that kids ask. Philosophy may seem somewhat antithetical or irrelevant to our work as pediatricians; we are interested in health, wellness, vaccination, and practical advice to parents. However, I would posit that we also have meaningful conversations with children, often which have philosophic undercurrents. At times, this is challenging as time is too short. Occasionally, we have moments where there is time to do more. One such example occurred in my own practice:

It was the end of a long clinic day and there was just one patient still waiting to see me. Joey, age 8, had been a patient of mine with acute lymphoblastic leukemia for the past two years. On examination I found that there was pus draining from one ear, indicating he had otitis media. He was otherwise well, but he had severe neutropenia secondary to the chemotherapy he was receiving. Thus, he was at significant risk of the ear infection spreading both locally and into his blood, a potentially lethal complication. I advised his mother that he should be admitted to receive intravenous antibiotics. She agreed, but he adamantly refused. His mother stood by helplessly. At this point, I spoke to Joey directly.

Me: “It will only be for a few days.”

Joey: “That’s what you said the last time. And I was in the hospital for eight days!”

He was right; he remembered his last hospital stay precisely.

We continued the conversation, with me explaining the reasons for his being admitted this time and with Joey continuing to express his feelings about it. The tone of the conversation was calm and reasonable. One of the things that came out in our general conversation was that there had been the promise of a hamburger, fries, and milkshake for supper after the visit. That knowledge gave us the opportunity to agree on a compromise: he would go for his hamburger, fries, and milkshake first, after which he promised to come back for admission. I said to him, “I trust you.”

It was a win-win situation: he would get the treatment he needed, he had the opportunity to express his feelings about it, and he was able to agree without losing face.

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Observing this whole interaction was a philosopher, preparing to teach a course in bioethics, who was shadowing in the Friday clinics. “That was amazing,” she said to me.

“Yes,” I answered, “it’s good that he will get the care that he needs.”

“That’s not what I meant,” she said. “It was the way you talked to him. You showed him such respect, you took his line of reasoning seriously, and you didn’t pull rank or expect his mother to discipline him. It was a negotiation, a compromise. You didn’t put him down but respected the fact that he had feelings and opinions that needed to be taken into account.”

She helped me to realize that during this encounter Joey and I had established a new kind of relationship, one that involved mutual respect and admiration. After this realization, I changed the way I spoke to all of my young patients. Children are more thoughtful and analytic than I had thought, more capable of working with me to figure out the best management and quality of life. They possess wisdom and capacity to reflect on philosophical quandaries.

On the basis of this experience and the insights in Horowitz’s book, I suggest that we as pediatricians make an effort to engage in meaningful conversations with our patients, however short they may be. Direct your attention to the child, if only for a moment. Ask a simple question and encourage an answer. Involve him in discussions about the management of his illness. Encourage him to ask questions. These actions show respect for the child as a person. They establish a model for the doctor/patient relationship. Additionally, they role model interactions for parents to pay attention to their child’s thinking and physical well-being. By doing so, it could lead to a more trusting and joyful parent/child relationship and improve emotional and intellectual development.

In conclusion, Mr Hershovitz’s book presents a fresh understanding of children as philosophers. When coupled with our experience, this perspective could improve the doctor/child and parent/child relationships.
Member Publications
Various Members - Section on Bioethics

The Section on Bioethics Executive Committee solicited articles by members that pertained to bioethics and were published between November 22, 2022 and March 31, 2023. Here is a list of the authors, and the references to their articles that they submitted. (Submitting members’ names in bold)

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We want to hear from YOU!
Help us continue to highlight our Section on Bioethics members' successes by sharing references to articles you've authored.

Information on your bioethics-related articles, books, etc. published between April 1-August 31, 2023 can be submitted by completing this form by 9/8/23: https://forms.office.com/r/12SqghahYN
Nominations are being sought for an award to recognize an individual impacting public discussion of ethical issues in pediatric medicine. The award will be presented to a Fellow of the American Academy of Pediatrics (FAAP) or another individual who has made a significant contribution to the field. For a list of past winners visit: AAP Collaborate/SOB/Bartholome.

The award recipient will receive a plaque, honorarium, and reimbursement for expenses to attend the Section on Bioethics program at the AAP National Conference and Exhibition. The recipient will be asked to briefly address the members of the Section on Bioethics at the time of the award presentation.

To be considered for the 2024 award, nominations, and supporting material(s) must be received by September 15, 2023. Nominations should be filled out using the Survey Monkey Questionnaire and be prepared to include the following information for the nominee:

- Name
- City/Town
- State/Province
- Email Address
- Phone Number
- The reason/explanation for your nomination.
- Upload the *Nominee's bio sketch (up to 250 words maximum)
- OPTIONAL: Upload *Letter of Support (up to 2 will be accepted)

If you have any questions (*or have issues uploading the bio sketch or optional letters of support), please feel free to contact Anjie Emanuel at 630/626-6479 or aemanuel@aap.org. Thank you for your input.

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*Contribute to the Newsletter!

Thanks to everyone who has submitted papers for the Section on Bioethics newsletter. Your work makes it great. We are always interested in hearing from others.

Have an idea for a paper? Or a theme issue? Want to review a recent book or movie? Analyze a case? The newsletter is a great way to share your ideas with friends and colleagues. Please contact Kelly Curran, Newsletter Editor at kcurran@uams.edu.

*All articles submitted to the Section on Bioethics newsletter will be published at the discretion of the editor. Selection decisions for all submissions are based in part on the following minimal requirements: The article must be written in a respectful and professional tone, be factually accurate, and present a cogent ethical argument. An article submitted for the AAP bioethics newsletter that does not align with an AAP policy or guideline may be considered for publication. If the editor feels the article meets the minimal requirements, and feels it is worthy of publication, it will be presented to AAP leadership with the recommendation that it be published. Members of the Section on Bioethics EC and/or other relevant sections will be invited to write a companion piece for the same issue of the newsletter, explaining arguments in favor of the AAP position.
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