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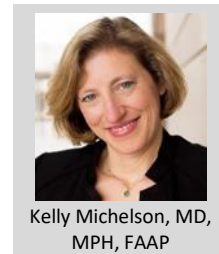
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From the Editor

Kelly Michelson, MD, MPH, FAAP

I am thrilled to introduce some exciting changes to the American Academy of Pediatrics Section on Bioethics newsletter. With this edition, we have the first article authored for the newsletter by our new Section Chair, Mark Mercurio, MD, FAAP. Dr Mercurio begins his tenure as leader of the Section with important comments on the need to create plans for anticipated ethical challenges in the healthcare setting.



Kelly Michelson, MD,
MPH, FAAP

I also have the great pleasure of introducing Dalia Feltman, MD, MA, FAAP in her new role on the team as the Associate Editor of the newsletter. Dr Feltman has been a regular contributor through her column “Just an Expression?” Now she expands her role to help develop new content and direction for the newsletter.

Finally, we have a new column dedicated to residents and fellows. For this edition, the Section’s first Liaison from the Section on Pediatric Trainees, Billy Sveen, MD, MA, uses the hypothetical notion of having clinicians wear body cameras in the hospital as a platform for thinking about bias in the healthcare setting.

From the other side of the career trajectory, Richard Lazaroff, MD, a retired pediatrician, reflects on the changes he experienced during his career and unexpected ethical challenges he has confronted upon retiring. We also have a pair of related articles by experts in special education Ann Turnbull, EdD and Rud Turnbull, LIM and Kathleen Kyzar, PhD. The first reflects on our limited understanding of and ability to assess quality of life for disabled children by reviewing the “Principles of Treatment of Disabled Infants” developed in response to Section 504 of the Rehabilitation Act of 1973, a law providing protections for people with disabilities. The second describes a family quality of life measurement tool for families of children and youth with disabilities and how the framework upon which this tool is based can inform clinicians’ efforts to develop trusting relationships with the families of their disabled pediatric patients. In “Just an Expression?” Jill Beck, MD, FAAP, a pediatric oncologist, considers some formidable communication challenges associated with the care of a young girl with a terminal brain tumor whose mother suffers from severe anxiety.

If you have an idea for the newsletter, I encourage you to contact me (kmichelson@luriechildrens.org) or Dalia Feltman (daliafeltman@gmail.com).

From the Chairperson: A Mission and a Plan (Cont.)

Mark R. Mercurio, MD, MA, FAAP

Greetings, friends. It is an honor to write my first column for our newsletter as the new Chairperson of the Executive Committee of the Section on Bioethics. Before anything else, I would like, on behalf of all members of this section, and the AAP, to thank our previous Chairperson, Brenda Jean Mears.



Mark R. Mercurio, MD,
MA, FAAP

Brenda has been a dedicated and indispensable part of the Executive Committee for a long time, culminating in her time as Chairperson - providing skilled leadership and giving generously of her time and expertise, in both bioethics and information technology. Brenda has made so much information available to us all, and that is just one way she has helped the Section move forward over the years. Thank you, Brenda!

The Section on Bioethics is 469 members strong, including AAP fellows, trainees, and many others. Our ranks include some who are rightly recognized as international experts in pediatric ethics, others with an interest but less expertise, some very early in their training, some closer to the end of their careers than the beginning, and, undoubtedly, some future leaders in our field. We are tied together by a dedication to children, and an interest in pediatric bioethics. And, I suggest, as members of this Section, we should be tied together by a shared mission. According to the AAP website, "The Section on Bioethics provides pediatricians and pediatric subspecialists with an understanding of the basic principles of bioethics and promoting compassion, sensitivity, commitment, and high moral standards in the delivery of health care."¹

To put it more simply, our mission is education in pediatric bioethics. Toward that end, the section (among other things) organizes a half-day session devoted to ethics at the AAP's annual National Conference and Exhibition, provides an outstanding [Resident Ethics Curriculum](#) available online, maintains a website with links to a variety of educational resources in pediatric ethics, hosts an annual ethics essay competition for pediatric trainees, and provides valuable periodic educational resources such as a stimulating case of the month on-line discussion and, not least, this excellent newsletter. I would like to

suggest that there may be something else we can provide to our colleagues, that is often sorely needed: a plan.

Several weeks ago, I was asked to join a discussion about a patient who presented to our Children's Hospital from another country, in need of very expensive life-saving treatment. What are our obligations to such children? How do those obligations compare with what we owe the sick children in our own community, state, or nation? What is the role of the pediatrician in such a decision? The nurse? The Ethics Committee? The hospital administration? Our discussion was aided by a thoughtful article recently published in the AAP journal *Pediatrics*, as part of the recurring feature called "Ethics Rounds."² This is a difficult issue, faced all over the country. One thing was clear: our hospital needs a fair, transparent, feasible plan before the next such patient presents. Yours could probably use one, too. Clearly written sound ethical discourse, such as that found in the *Pediatrics* article, can surely help toward that end.

More recently, I gave a Grand Rounds presentation at another institution, about the care of newborns with Trisomy 13 and Trisomy 18. Full disclosure, I am a neonatologist as well as a student of pediatric ethics. What treatments, medical or surgical, should be made available to these children and their parents? This is, as readers of this newsletter are likely aware, a controversial topic within neonatology, and throughout pediatrics. In many places the approach is much changed in recent years, now with a spectrum of options offered by individual clinicians, and by different institutions. For Grand Rounds, after working through some relevant data (hey, it was Grand Rounds, I had to have some data), a framework for decision-making, and a discussion of relevant rights and obligations, I had to choose my final point. I realized the final, and perhaps most essential point, needed to be about the plan - specifically, why it was best to have one, and how to go about developing one. This had been worked out in a recent paper published with one of my (now graduated) fellows and some colleagues in pediatric ethics.³ The point of the Grand Rounds was not necessarily what specifically should be done or offered for these patients, though I did in the end put my own cards on the table

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From the Chairperson: A Mission and a Plan (Cont.)

Mark R. Mercurio, MD, MA, FAAP

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with what we have decided to do at my institution, and how we got there. The fundamental point was that our colleagues may benefit from guidance on how to analyze the problem, and come up with a plan *before* an ethical crisis and the need for a difficult decision are upon us.

This, I would suggest, is a crucial component of the educational mission of the Section on Bioethics: helping our colleagues in clinical pediatrics, through education, to develop practical plans for the ethical crises they will inevitably face. Development of such plans should include a clear articulation of the question, a thorough review of the relevant data, a thoughtful ethical analysis ideally including contributions from various individuals with disparate viewpoints, feasibility considerations, and input from many stakeholders. Very often the operational plans that are developed by a given institution or individual will be informed by the carefully thought-out policies and guidelines published by our colleagues on the AAP Committee on Bioethics. Of course, no plan will obviate the need for consideration of the specifics of an individual case, but we are far better off when we have done most of the intellectual and moral work before we are faced with a patient in crisis. Training and experience in clinical medicine have surely taught us that lesson.

I would be very pleased any time to hear your thoughts on this, or suggestions about other things the Section

might do to promote education in pediatric ethics. I can be reached via email at mark.mercurio@yale.edu. If you are not yet a member of the AAP Section on Bioethics - join us! If you are already a member, spread the word. It is easy and inexpensive. Find membership information at <https://www.aap.org/en-us/about-the-aap/Sections/Section-on-Bioethics/Pages/SOB.aspx> or contact our outstanding AAP staff person, Anjie Emanuel, at AEmmanuel@aap.org.

I look forward to working with you.

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William G. Bartholome Award for Ethical Excellence

2019 Award Recipient — Aviva Katz, MD, FAAP

The Section on Bioethics Executive Committee is pleased to announce that Dr Katz will be awarded the Section's highest honor, the William G. Bartholome Award. The award will be presented posthumously during the Section's annual meeting at the AAP National Conference & Exhibition in New Orleans, LA on October 28, 2019.

Dr Katz, who passed away in 2018, was a vital and beloved part of the AAP Bioethics community, including serving as Chair of the Committee on Bioethics. She was a pediatric surgeon and bioethicist at the University of Pittsburgh. She is greatly missed, and we look forward to honoring her in the Fall.

More information about the award and about Dr Katz will be included in the Fall 2019 Section on Bioethics newsletter.



Aviva Katz, MD, FAAP

Resident/Fellow Corner: If I Wore a Body Cam

William Sveen, MD, MA

On July 6, 2016, Philando Castile, a 32-year-old Black man, was shot and killed by police officer Jeronimo Yanez a few miles from my house. The details of the case have been well documented elsewhere,^{1,2,3} but in summary, Castile was stopped because the officer thought he looked like a suspect from a local robbery, based on his “wide-set nose,” and proceeded to shoot at him seven times a mere 13 seconds after Castile disclosed he had a firearm in the car. Adding more tension to the national conversation of police shooting Black men, the bloody aftermath was recorded and posted live on Facebook by Castile’s girlfriend. In the criminal case that followed, Yanez was acquitted of second degree manslaughter and dangerous discharge of a firearm after claiming that he feared for his life.

As a pediatric resident caring for a diverse population of patients in the neighborhood of the shooting, I had many conversations with co-residents, faculty, friends, and family about the incident. One solution often proposed to increase transparency and accountability is to have police wear body cameras. That got me thinking, “What would you see in the footage if I wore a body camera?”

Research suggests that the camera would reveal more children from minority populations suffering from a ruptured appendicitis following a missed diagnosis,⁴ experiencing longer wait times for pain medication during emergency care,⁵ and dying from asthma⁶ than children from majority populations. However, I don’t think you’d notice most of those events. These outcomes often do not result from outwardly racist or biased interpersonal acts, but instead from a cumulative barrage of institutional injustice, socioeconomic inequalities, microaggressions, historical trauma, and underrepresentation in a society that is structured to benefit the majority over minorities.

What would you see through my body camera? You may see me spending extra time with the parents of a White patient who graduated from the same private college as I did. You may see me not calling the single mother of a Black patient who cannot come to the hospital regularly because she works multiple jobs and takes public transportation. You may notice which families I report to child protective services and which I do not. You might observe that I engage and encourage some families to participate in their own care, while I shy away from others. Perhaps you’ll see which patients have symptoms that I acknowledge and which I dismiss. You may bear witness to patients with pain that I do not adequately

address. You may see which families trust me and feel comfortable telling me sensitive information that affects their health and which families only give short answers to my directed questions. You may see me not speak up when a White family member of a patient makes a racially insensitive remark about one of my co-workers. You may see me skip a meeting on increasing diversity in hospital staff because I perceived my schedule as too busy to attend. You could see that many doctors and nurses have white skin like me, while many of the housekeepers and transporters do not.

These small actions exacerbate problems in a healthcare system that already disadvantages minorities. While every shooting of a Black man by a police officer should be mourned and thoroughly investigated, police shootings are an extreme symptom of a much deeper problem with the American criminal justice system which disproportionately imprisons millions of people of color. In similar ways, our systems of education, housing, banking, voting, employment, surveillance, and healthcare all have rules and norms that benefit American populations in the majority while disadvantaging minority populations. Unfortunately, even the actions of well-intentioned, not overtly racist members of society often result in discriminatory outcomes because of how the institutions and systems are designed.

Imagining the patient encounters that my body camera might record have made me more aware of my privilege as a white, middle class, educated, cis-gendered, heterosexual male doctor. I am seeing more how a system run mostly by people who look like me has the result of protecting people who look like me. Minority children are more likely to lack access to emergency medical care and more likely to have their healthcare underfunded.⁷ They have a larger burden of underinsured and high deductible plans.⁸ They experience food deserts and pollution at higher rates.^{9,10} The chronic stress of racial discrimination they experience increases the rate and morbidity of chronic diseases such as obesity and asthma as well as mental health issues.¹¹ Further, it is hard to imagine how these problems will change when Black physicians are less likely to receive grants and promotions, research into diseases that disproportionately affect minorities are underfunded, and minorities are underrepresented in research in general.¹²

What can we, especially those of us in the majority, do to

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Resident/Fellow Corner: If I Wore a Body Cam (Cont.)

William Sveen, MD, MA

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ally with minority patients and co-workers in this struggle? While I'm not suggesting we wear body cameras, the self-awareness that would accompany wearing cameras is essential. First, we must recognize implicit biases that come with our profession, our gender, our socioeconomic class, and our racial and ethnic backgrounds. Online tests can help increase awareness about one's biases, and courses, conferences, and lectures on improving diversity and inclusion can provide the tools needed to implement change in our daily lives. We all need to actively engage in our hospitals and communities to advocate for just policies and environments that deliver more equitable healthcare. We need to encourage cultural competency in the workplace, realizing that interacting with diverse populations is a teachable skill that can be improved. We need to talk with our coworkers and patients from underrepresented populations, and more importantly, listen to the stories they tell about their experience as a minority in healthcare. Also, don't be afraid to discuss the health implications of racism with your patients and coworkers. Lastly, take an active role in the community and politics as the scourge of racism extends well beyond the walls of our hospitals and clinics.

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Retiring “Gracefully”—Reflections on a Career in Pediatrics and the Unexpected Challenges of Retirement

Richard Lazaroff, MD

I recently retired after practicing primary care pediatrics for 35 years. I had a robust practice that saw incredible transformations. I thought it might be of interest to the readership of this newsletter to reflect on some of those changes in practice, on some of the simultaneous new ethical challenges, and to discuss an unexpected personal challenge I encountered upon retiring.

What were the most dramatic changes in practice? I started with handwritten medical records and schedules but finished with computerized ones. Though making eye contact during these latter visits was often compromised, I do believe safety and follow-up care was improved. I started with frequent visits requiring treatment with oral antibiotics to such visits becoming very infrequent due to the pneumococcal vaccine and research which paved the way for treating some conditions by watchful waiting and the judicious use of antibiotics. I saw fee-for-service reimbursements transition to managed care and then evolve to value-based care where the financial rewards were aligned with the patient’s best interests. I began when many utilized a paternalistic approach to care but finished with attention and focus on shared medical decision-making as a best practice standard. And while my initial training had little emphasis on managing the psychological needs of children, these problems came to dominate my days in the office as either our world was in fact creating more stress on children and adolescents or such needs were better recognized.

Many physicians of my era “burned out” or continued to work but complained in the doctor’s lounges about these and other changes. I was in a leadership position of a large independent medical group practice that embraced most of these changes—especially the move to the computerization of medicine and new methods of reimbursement. Practicing pediatrics was very satisfying when decisions were shared, antibiotics were used less often, high rates of immunization were achieved, and educating and re-educating myself to treat psychological and psychiatric conditions was the order of the day.

Surprisingly, the latter psychological issues became the most rewarding for me. Some of these issues hit you in the face as families and their children struggled with divorce, substance abuse, clinical depression and anxiety, issues surrounding sexuality, etc. But most of

the time, these issues only came out by being “available and open” at visits scheduled for other reasons. I could recount many of these, but perhaps a single one will make my point. A mother brought her thriving two-month-old in for a check-up. At the end of the visit, I asked her if she had any other questions. She wanted to discuss the behavior of her three-year-old son who was starting to prefer playing with toys traditionally stereotyped as more likely to be enjoyed by a female gender child. Each evening when hearing the garage door go up, her son scurried anxiously to hide these toys before his father came in the door. She wanted to know if this was a problem.

Just as the practice of pediatric medicine evolved over my career, so did the ethical issues. The explosion of technology and social media led to real conflicts between parents and their adolescents. Parents often expressed legitimate concerns about safety when their adolescent was using these technologies, but other times it was more a matter of control. Parental demands to perform “drug testing” without the adolescent’s knowledge were common. These were denied unless the adolescent consented, and when performed, there needed to be an agreement in advance as to what we would do with such information. Sexual activity occurred at earlier and earlier ages and even the President of the United States blurred the line as to what constituted sex. Many parents were surprised to learn that discussions about birth control options, including most importantly abstinence, and treatment of sexually transmitted infections could take place legally without



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Retiring “Gracefully”—Reflections on a Career in Pediatrics and the Unexpected Challenges of Retirement (Cont.)

Richard Lazaroff, MD

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the parent present. And the term LGBTQ youth did not pop up until 2005. Undoubtedly, LGBTQ children and adolescents have always been present in a pediatric practice, but the ethical issues surrounding hormonal therapies and acceptance in their own home and communities were new ground. Even the language required to care for these patients seemed to change rapidlyand yet, using the “right words” often made all the difference in how these patients perceived the care they were provided (affirmative care).

Though it should be obvious to the readers of this newsletter, a pediatrician in practice deals daily in their office with issues of confidentiality and trust, of being aware of how personal bias may affect medical advice and opinion, and of respecting autonomy and the need to provide care reflective of shared decision-making principles. Perhaps I was an outlier, but I also attended and actively participated in NICU and pediatric ICU care conferences when the most difficult discussions occurred with families about limiting or withholding care. These are just a few of the ethical issues that come quickly to mind.

Upon retiring, the visits involving such challenges and difficult conversations were those I thought I would miss most. This has been true. These visits allowed me to “stretch” myself and use all my personal strengths. In an effort to share my experiences and knowledge, I spent the first year after retiring writing a parenting book where I re-count many of these visits and write in a conversational format about advice I provided in addressing common problems seen from infancy through adolescence. These visits and opportunities often brought me close to families---never socially close ---but close in the sense that many parents, and especially their adolescents, reached out to me for advice when they needed a trusted adult.

During my last month or two of practice, I had many “last” visits with families. These were incredibly rewarding. It was always hard to say good-bye and often I accompanied these feelings with a statement that I will not be leaving the area and that they should know they can reach out to me through the office if ever they felt like talking to me was very important in



their lives or the life of their child. Perhaps naively, I did not realize how many patients already had my cell phone number, as I rarely took the extra time to dial *67 before calling a patient back when on-call. In addition, I told my partners that they could reach out to me directly, or give patients that opportunity for a while, if a difficult new diagnosis had been made and they wished to speak to me.

I had not contemplated that even in retirement I would face ethical choices. Should I have encouraged anyone to contact me for advice after retirement, including my patients or partners? How should I respond when someone actually calls my cell phone out of the blue (this has happened many times over the last two years) or when a former partner says that a family would like to speak to me about a newly diagnosed problem? And was my offer to be available more about me and my being ready to accept LOSS?

As medical providers, we are accustomed to the fact that much of what presents to our office as a physical complaint ultimately falls into the realm of a psychosocial issue. As a pediatrician, I was often called upon to make a diagnosis of depression or anxiety in a child with headaches, abdominal pain, and school avoidance. Perhaps more-subtle was the parent who worried about “everything” being ok with their child despite their healthy appearance and normal examination. When a detailed history was taken, it often revealed an event in the past, sometimes even a minor health scare to their own or another child in the

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Retiring “Gracefully”—Reflections on a Career in Pediatrics and the Unexpected Challenges of Retirement (Cont.)

Richard Lazaroff, MD

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community, and the proper diagnosis of vulnerable child syndrome¹ could be made as these parents carried their worry to a pathologic level.

But it did come as a surprise to me that now it was my turn to deal more strongly with the psychological. How important had it been to feel needed? For thirty-five years I had been “needed” by separate families 50-60 times per day. My practice was time consuming and emotionally consuming. I practiced with an “all in” manner and had been allowed by my patients to play a central role in their families’ lives. This was a big hole to fill.

Loss is common to all of us. It can be embraced or fought. None of us will escape death, but along the way there are many different and difficult experiences of loss: job changes, divorce, death of a loved one or friend, illnesses that result in the loss of independence of daily function or pain are just some obvious ones. Certainly, retirement is one of these experiences. I have come to realize that my offer to be available was cloaked in the guise of not abandoning my patients, but probably had more to do with my own need to cushion my own loss. I was never worried that my self-esteem would suddenly disappear. I knew what I had accomplished and I was proud of my work. Though retirement was never something I aspired to, it just seemed like time for the

next chapter in life. But anything short of accepting loss fully can deprive an individual from moving forward and experiencing personal growth. My retirement has been an opportunity to spend more time with my mother who is now in failing health and my grandchildren in and out of town, to improve my physical and emotional health, to write a book on parenting, to learn new skills like duplicate bridge, and to volunteer in a school in my local community.

I run into former patients all the time. It is really wonderful when that happens.

However now, when someone calls looking for advice, I still offer it, but more as any wise old friend or PawPaw might. I make certain never to practice medicine, never to interfere with the doctor-patient relationship that they should be building, and additionally, ever so slightly, I encourage former patients to move on from our relationship. After all, I need to move on as well, accept loss, and maximize my own personal growth.

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Disabled Newborns and Quality of Life

Rud Turnbull, LIM

Physicians' and families' decisions about treatment of infants with birth anomalies and disabilities are fraught with medical, legal, emotional, financial, and ethical issues. They involve assessments of an infant's and often the family's current and projected quality of life. Those assessments themselves are fraught with risk of error, a realization I have come to know on a personal level as the father of a child with special needs and in my professional life as an attorney and member of groups that negotiated the Principles of Treatment of Disabled Infants (hereafter 'Principles'). These Principles are incorporated into the notice that may be posted in hospitals, pursuant to regulations implementing Section 504 of the Rehabilitation Act of 1973 (anti-discrimination based solely on disability).¹ Since their inception, Principles have had an interesting history of support and opposition from professional organizations, including the American Academy of Pediatrics (AAP).^{2,3} Here, I focus on the Principles and their approach to quality of life.^{2,3}

The Principles took into account quality of life issues as they had arisen because of a report on withholding of treatment at Johns Hopkins Hospital,⁴ an article analyzing the reasons for withholding at Yale hospital,⁵ and an article proposing a formula on which physicians may rely to assess an infant's quality of life.⁶ That formula equated quality of life (QOL) with two factors, namely, natural endowment (NE) plus the sum of contributions by home (H) and society (S): $QOL = NE + (H + S)$.

The Principles begin by declaring that "(d)iscrimination of any type against any individual, regardless of the nature or severity of the disability, is morally and legally indefensible." The general legal claim against discrimination disregards the "nature or severity" of the disability. It is life-long and universal: "Throughout their lives, all disabled individuals have the same rights as other citizens." It is bolder than Sec. 504 provides, for that law benefits only "otherwise qualified" persons with disabilities. The Principles assert a right to health care; the right "must be recognized at birth," for if discrimination may occur at birth, it may occur at any other time of life, including in any end-of-life decision making.

The ethical claim acknowledges "the value and worth" of persons with disabilities, including infants. It insists



that "society" should be informed about their value and worth, and that "professional organizations, advocacy groups, the government and individual care givers should educate and inform the general public on the care, need, value and worth of disabled infants."

These two grounds justify education and dissemination of "updated information" to professionals and parents, standards and procedures for decision making, and government and community support.

In seeking to change the behavior and results of those involved in making health care decisions, the Principles rely on a familiar legal technique. The technique is to declare a presumption and then either to deny that the presumption may be rebutted (the non-rebuttable presumption) or to allow the presumption to be rebutted for cause (the rebuttable presumption). The Principle's adopts the rebuttable presumption: "When medical care is clearly beneficial, it should always be provided." The words "clearly beneficial" allow the governing presumption to be set aside.

Rebuttal, however, is limited: "Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards."

The only justification – the only grounds for rebutting the presumption – are also medical and medical alone. "It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only

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Disabled Newborns and Quality of Life (Cont.)

Rud Turnbull, LIM

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prolong the act of dying.” The principles do not define the medical or surgical procedures. Also, the Principles allow rebuttal only with respect to “withholding.” They are silent with respect to the withdrawal of treatment, including withdrawal of hydration and nutrition.

Equally notable, they do not permit quality of life considerations. They do make it clear, however, that “supportive care” should be forthcoming, including “sustenance as medically indicated and relief of pain and suffering.” Also note that the presumption and its rebuttal rest solely on medical grounds.

Finally, if it is “uncertain whether medical treatment will be beneficial,” the infant’s disability “must not be the basis of a decision to withhold treatment.” The treatment should be “appropriate” to the infant’s needs. Any “doubt” about whether to treat is also guided by the basic presumption: “When doubt exists... a presumption always should be in favor of treatment.”

As a lawyer, I have been taught never to make any assumptions. For the sake of this article, however, I wish to make several and then to respond to them. Let us assume that those who make the hard, fraught decisions about withholding treatment or withdrawing treatment that has already started take into account quality of life considerations, not medical-alone criteria. Let us also assume that a quality of life consideration focuses only on the infant, not on the parents or other likely care-givers. Let us also assume that the costs of short-term and long-term care are not factors – neither governments’ nor parents/families’ financial costs. Let us also put aside considerations about the emotional and physical responsibilities parents or a family will encounter, even as we discount the psychological, emotional and spiritual contributions the child will make to the parents and family and to others. In a word, let us put aside for the moment the “burden” and “positive contribution” factors.

Instead, let us recognize that the formula – $QOL = NE + (H + S)$ – is our concern. Questions arise:

Is one able to assess accurately the child’s natural endowment at birth or shortly thereafter? Perhaps so.

Certainly, developmental norms and stages exist, and the progress toward them that non-disabled infants, and some infants with disabilities, make, short-term or long-term, is measurable and measured, and is a factor that decision-makers take may and almost certainly do take into account. Arguably, these assessments are purely medical and permissible under the Principles. Arguably, too, they are unreliable, as the lives of so many people with disabilities now attest. As I explain in footnote 1, I personally found those assessments to be inapposite.

Is one able to assess accurately the contributions that an infant’s home (parents and family) may make, short-term or longer? That is more debatable and riskier to make, for foreseeing how a parent or family will respond to the duty of care is, according to the current research, not at all certain.

Is one able to assess accurately the contributions that “society” may make, short-term or long-term? Not likely. The science of intervention has consistently improved; new technologies and new disciplines and practitioners have arisen and more are inevitable. Law has evolved; new laws and amendments of existing laws occur regularly and, on the whole, for the benefit of infants, children, and adults with disabilities.

Have the ethics and values on the one hand and social and cultural norms on the other become more accommodating to difference and diversity of the human condition? Absolutely.



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Disabled Newborns and Quality of Life (Cont.)

Rud Turnbull, LIM

(Continued from page 10)

In light of these four factors, is quality of life the static condition – “as it exists at the time a decision must be made whether to treat” – that it seems to be, a reliable basis for a decision now that has immense consequences in the future? I doubt it.

So, what is to be done? With deep respect for the AAP’s work and in recognition that I served on a task force the AAP convened in the mid-1980s to develop training materials and that consisted of AAP members and external advocates, I recommend:

- continued research on quality of life, carried out jointly by physicians and social scientists,
- the immediate qualification of the infant for federal-state Medicaid benefits and states’ adoption of Medicaid expansion policies,
- vigorous enforcement by the now-resistant federal government of rights and entitlements for people with disabilities,
- the reassertion that “worth” and “value” are the elements of the principle of dignity that should inform legislators and judges as they decide about the rights and entitlements of people with disabilities, and
- the revision and then prompt adoption of a revised family support laws such as the Social Security SSI (supplemental security income) program and the family support program that the Rehabilitation Act authorizes

The AAP has been a force for much good for infants, children, and families affected by disability. It should hasten to ally with other advocates in their quest for rights and entitlements, for services and practices, and for research that informs services and practices, for those with disabilities. In a word, it can and should contribute to the dynamic plasticity and promise of quality of life.

Footnotes

1. I was a member of the group of representatives of professional and parent associations who

negotiated the Principles. I was an officer of The American Association on Mental Deficiency (now, The American Association on Intellectual and Developmental Disabilities, a professional association) and of The Arc of the United States (a parent and family association). I also was the father of a son, Jay, with intellectual disabilities, autism, and rapid-cycling emotional disorder, who died in 2009. His physicians at Johns Hopkins Hospital advised me and my then-wife to institutionalize him; they foresaw no acceptable quality of life for him or us. She and I did so when he was three years old, in response to my wife’s medical needs. I subsequently divorced her, remarried my present wife, brought Jay home to live with us, and we created what we call the “enviable life” for him – a life of previously unfathomable quality. I was trained as a lawyer and, at the time the Principles were negotiated and signed, was a professor of special education and courtesy professor of law at The University of Kansas. I have an original signed copy of The Principles and the drafts of the final statement in my archives.

2. The signatories were the American Academy of Pediatrics, the American Coalition of Citizens with Disabilities, the American Association of University Affiliated Programs, the American Association on Intellectual and Developmental Disabilities, The Arc of the United States, the National Association of Children’s Hospitals and Related Institutions, the National Down Syndrome Congress, the Spina-Bifida Association of America, and The Association for Persons with Severe Handicaps.
3. Sec. 504 prohibits discrimination based solely on disability against any “otherwise qualified” person with a disability, 29 U.S.C. Sec. 794. The Child Abuse Prevention and Treatment Act (CAPTA) authorizes federal aid to states to operate child abuse prevention and treatment programs, 42 U.S.C. 5101 et seq. The regulations implementing CAPTA, titled Procedures Relating to Health Care for Handicapped Infants, 45 C.F.R. 84.55 (promulgated January 12, 1984), encouraged recipients of federal financial assistance to

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Disabled Newborns and Quality of Life (Cont.)

Rud Turnbull, LIM

(Continued from page 11)

establish an Infant Care Review Committee and required each recipient to post an “informational notice” that recites the Principles of Treatment of Disabled Infants (the “Principles”). Section (b) of the Procedures required recipients to post a notice and recited the Principles; section (c) imposed duties on state child protective services agencies to enforce section (b); section (d) required expedited access to the recipient’s records when necessary to “protect the life or health of a handicapped individual”; and section (e) obviated the “expedited access” provision when, in the judgment of the responsible official of the Department of Health and Human Services, “immediate action to effect compliance is necessary to protect the life or health of a handicapped individual” and permits the Department to give the recipient “oral or written notice of its failure to comply, of the action to be taken to effect compliance, and its continuing opportunity to comply voluntarily.” Sec. 504 justified sections (b) through (e) of the regulations. The Supreme Court held sections (b) through (e) unenforceable, *Bowen v. American Hospital Association et al.*, 476 U.S. 610 (1986) (4). The sections remain in the text of the federal regulation; compliance is voluntary. Other parties joining the American Hospital Association were the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the American Medical Colleges, the American Academy of Family Physicians, and certain individual physicians. Although it was not a part to the case in the Supreme Court, the American Academy of Pediatrics had challenged the enforceability of the regulations in April 1983, and had succeeded in persuading a federal district court (trial court) to invalidate them on the basis that they were, among other things, “arbitrary and capricious.” The district court concluded that “haste and inexperience ha(d) resulted in agency action based on inadequate consideration” of several relevant concerns, *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (S.D.N.Y., 1983). In July, the Department issued new

“Proposed Rules,” requiring posting of notice, authorizing expedited access to records, and requiring federally assisted child protective services agencies to use their “full authority pursuant to State law to prevent instances of medical neglect of handicapped infants.” In *Bowen*, the Supreme Court noted that the Preamble and appendix to the Proposed Rules “did not acknowledge that hospitals and physicians lack authority to perform treatment to which parents have not given their consent.”

4. Report of the Joseph P. Kennedy Foundation International Symposium on Human Rights, Retardation, and Research. Washington, DC. The John F. Kennedy Center for the Performing Arts, October 16, 1971.
5. Duff RS, Campbell AGM. Moral and Ethical Dilemmas in the Special-Care Nursery, *New England Journal of Medicine*, 1973;289: 890-894.
6. Shaw A. A Formula without Numbers, *Hastings Institute of Society, Ethics and the Life Sciences*, *Hastings Center Report*. 1977;7: 11.



Enhancing Quality of Life for Families of Children with Disabilities through Trusting Partnerships

Kathleen B. Kyzar, PhD, Ann Turnbull, EdD, & Rud Turnbull, LIM

Pediatricians rarely care for their patients in a vacuum, recognizing quality of life for their patients is likely to correlate to the quality of life of the family. At the Beach Center on Disability at The University of Kansas, researchers have developed a family quality of life scale “FQOL Scale” (available for download at <https://beachcenter.lsi.ku.edu/beach-families/>); their methodologies have validated and confirmed the scale’s reliability as an instrument for measuring family quality of life (FQOL) satisfaction for families of children and youth with disabilities.¹ After reviewing the development and use of this instrument, we will explore how pediatricians as partners with families can improve FQOL.

Measuring FQOL

Old and new perspectives of FQOL can be contrasted according to three aspects:^{2,3}

- View of families’ capacity to care: moves from families being viewed from a deficit perspective to more holistic view which includes strength and needs.
- Family quality of life outcomes: moves from a consequence of families’ (eg, income, race/ethnicity) and/or children’s characteristics (eg, type and extent of disability, extent of behavior problems) to a consequence of services and supports available to all family members.
- Research focus: moves from measuring family stress, depression, and/or caregiver burden to FQOL as the anticipated outcome of individualized, equitable, and culturally respectful supports and services to all family members.

FQOL is “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.”⁴ Note the word “well-being.” It signifies that the FQOL Scale reflects a shift from a model of pathology to a newer perspective in which families provide the foundation for supports and services.

The FQOL Scale includes five domains of family life: Emotional Well-Being, Parenting, Family Interaction, Physical/Material Well-Being, and Disability-Related Services. The FQOL Scale has been most commonly used

as a research tool, but it also serves for program evaluation and documentation of the effectiveness of disability-related services and supports. The domains and examples of their indicators (to which respondents note levels of satisfaction) of the FQOL Scale follow:

FQOL Scale Domains		Sample indicators: <i>My family members...</i>
Emotional Well-Being	Feelings or affective considerations within the family	<i>...have outside help available to take care of the special needs of all family members</i>
Parenting	Those activities that adult family members do to help children grow and develop	<i>...know how to teach their child to get along with others</i>
Family Interaction	Relationships among family members	<i>...enjoy spending time together</i>
Physical/Material Well-Being	Resources available to the family to meet its members’ needs	<i>...get medical and dental help when needed</i>
Disability-Related Support	Support from family members, friends, and professionals to benefit the family member with a disability	<i>...can achieve goals at school or work</i>

Key predictors of FQOL

Research based on the FQOL Scale has identified key predictors of FQOL in three areas: (a) individual supports for the child/youth in the family with a disability, (b) family-level supports, and (c) partnership-related supports. The following summary of the research includes only the studies conducted in the US, although the scale has been used in 11 countries and translated into Mandarin Chinese, French, Spanish, Serbian, Turkish, Dutch and Greek. Furthermore, the summary excludes predictors related to internal family characteristics such as family income, marital status, severity of disability, or presence of behavior challenges.

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Enhancing Quality of Life for Families of Children with Disabilities through Trusting Partnerships (Cont.)

Kathleen B. Kyzar, PhD, Ann Turnbull, EdD, & Rud Turnbull, LIM

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Individual supports for the child/youth in the family with a disability:

- As needs for child supports increases, FQOL decreases.⁵
- As parent knowledge/skill in meeting their children's needs increases, FQOL increases.⁶
- As their child with autism receives intensive individual support services and/or therapeutic services, families report significantly higher FQOL satisfaction levels than families whose child does not receive these services.⁷

Family-level supports:

- As satisfaction with early childhood services increases, FQOL increases,^{6,8} and, as satisfaction with information and child care services increases (includes after-school care), FQOL increases.⁹
- As satisfaction with informal supports such as friends, neighbors, and family members increases, FQOL increases.⁹
- Families who receive Medicaid waiver services have significantly higher FQOL satisfaction levels than families who do not receive Medicaid waiver services.^{7,10,11}

Partnership-related supports:

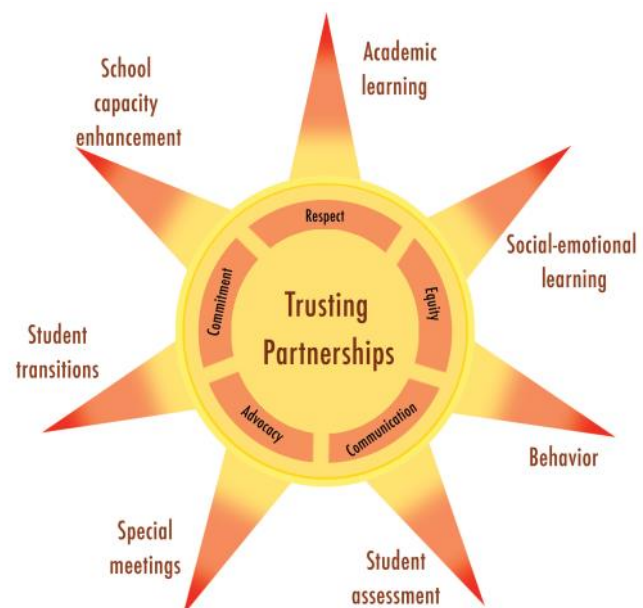
- As satisfaction with family-professional partnerships increases, FQOL increases.^{8,9,11}
- Families' satisfaction with services and FQOL depends on (a) families' perceived knowledge and skill in addressing their young children's needs,⁶ and (b) the level of satisfaction they have with their partnerships with professionals.^{8,9}
- Enhancing Connection Partnership, or the skills and abilities of a professional to form meaningful relationships with both the child and family, and Enhancing Capacity Partnership, or the skills and abilities of the professional to support the development of knowledge, skills, and outcomes for both the student and family interact to predict FQOL. Thus, when families are highly satisfied with Enhancing Capacity Partnership, higher levels of satisfaction with Enhancing Connection Partnership is associated with higher levels of FQOL. When

families have low levels of Enhancing Capacity Partnership satisfaction, high levels of Enhancing Connection Partnership satisfaction marginally predicts FQOL. Thus, Enhancing Connection Partnership is needed for higher FQOL, and it may serve to buffer the negative effects of poor Enhancing Capacity Partnership in predicting FQOL.¹²

Enhancing family-professional partnerships

For the remainder of our essay, we focus on partnership-related supports because those are ones that are most in your purview as a medical professional and most in our purview in family research and professional development of special and general education teachers. Based on the research cited above, we know that trusting partnerships contribute to strengthening families' satisfaction with their FQOL. Furthermore, we conjecture that trusting partnerships also contribute to enhanced positive outcomes for children and youth with disabilities and to enhanced professional quality of life.

Figure 1: The Sunshine Model of Trusting Family-Professional Partnerships in Education



We use the sun to illustrate our model of trusting partnerships focusing on educators, as illustrated in Figure 1. Although this model has not been adapted for

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Enhancing Quality of Life for Families of Children with Disabilities through Trusting Partnerships (Cont.)

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the pediatric field, we are optimistic that it has the potential to increase positive tripartite outcomes. Just as the sun illuminates Earth and generates energy for humankind's quality of life, so too does a trusting partnership affect FQOL and potentially the quality of life of children and youth, as well as professionals. More than that, our team's research reveals that trusting partnerships consist of multiple dimensions--respect, equity, communication, advocacy and commitment.¹² Alternatively stated, these dimensions (table below) create the trust; when one or more are absent from the partnership between families and professionals, the core – trusting partnerships – will be less powerful; it will shine less brightly.

Dimensions	Ways to foster dimensions for trusting partnerships
Equity	<ul style="list-style-type: none"> • Be aware of explicit and implicit biases; seek to eradicate biases • Be aware of barriers to equality of opportunity, fairness, and dignity for marginalized citizens • Provide accommodations and procedural modifications to remove barriers • "Level the playing field"
Respect	<ul style="list-style-type: none"> • Build on strengths • Empathize by seeking to "walk a mile in your families' and children's shoes" • Partner with cultural guides to increase the likelihood of culturally responsive practice • Ensure cultural justice and dignity
Communication	<ul style="list-style-type: none"> • Listen • Be friendly • Share good news • Be honest, even with bad news • Be clear
Commitment	<ul style="list-style-type: none"> • Be available for communication • Be flexible • Stay current with research and implement research-based practices • Go "above and beyond"
Advocacy	<ul style="list-style-type: none"> • Identify problems, gather facts, and develop viewpoints on key issues • Pinpoint and document concerns • Identify needed stakeholders and explore finding middle ground • Identify and explore feasible options • Select and vigorously pursue optimal solution

Just as the sun has a combustion process to produce heat, the dimensions of partnership have their own combustion process that produces trust. We speculate that these dimensions do not change from one profession to another. Thus, the *how* of partnerships that lead teachers to have trusting partnerships with families are likely the same dimensions/indicators that are important for you as physicians.

Emanating from the core of the Sunshine Model are sunrays that represent the opportunities that educators have to partner with families. Just as the dimensions are the *how* of partnerships, opportunities are the *what*. Partnership opportunities (sunrays) vary significantly across professions. For example, opportunities for teachers include: learning (academic and social-emotional); behavior; student assessment; special meetings; student transitions; school capacity enhancement.

Depending upon your pediatric specialty, the opportunities might include one or more of the following: diagnosis, development of health plans, access to resources, monitoring of plan, care coordination, and transition to next level of care.

Just as the light and heat of the sun's core radiates out into the sunrays, so do all five partnership dimensions infuse each partnership opportunity (sunray) in order create trusting partnerships. As professionals, you in your discipline, like we in ours, have the opportunity to affect others' quality of life and, indeed, our own as professionals. That opportunity exists because family quality of life is dynamic. It consists of much more than the negative darkness that obscures the sun. It consists of more than a formula (quality of life equals natural endowment plus the sum of contributions by home and society: $QOL = NE + H$ and S) long ago offered and now disputed by research. To enhance FQOL, consider what you can do as a partner of families and their children, as well as what research your field might undertake about your methods of practice, their relationships to trust, and their relationships to quality of life for families, their children, and yourselves.

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Enhancing Quality of Life for Families of Children with Disabilities through Trusting Partnerships (Cont.)

Kathleen B. Kyzar, PhD, Ann Turnbull, EdD, & Rud Turnbull, LIM

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Just an Expression?

Dalia Feltman, MD, MA, FAAP

Good communication requires meeting people in the “places” they are. If we ignore the fears, distractions, or misgivings that our patients or their families are experiencing, it is unlikely our message will be heard, or that effective collaboration will occur. Section member Jill Beck, MD, FAAP a pediatric hematologist/oncologist at the University of Nebraska Medical center, responded to the call for the current column topic—“missed opportunities for communication.” In her piece, Dr Beck illustrates how despite the adjustments the team made to meet a distraught mother in her often-shifting “place,” their efforts for an acceptable outcome failed. When parents are less articulate or less available to explain their rationale for decisions, we often question whether the outcome aligned with their values (but not ours), or whether an unacceptable default position resulted from unsuccessful communication. In those situations, perhaps we can take comfort in knowing everyone involved tried their best in spite of formidable challenges, like they did here.



Inevitable

Jill Beck, MD, FAAP

I walked into the room on a bright spring morning to find the shades drawn and a cheery seven-year-old sitting on the hospital bed. The nurse quickly pulled me aside, distraught because the child had been alone all night. Her mother had left to get a few things yesterday evening and never returned. The world of that family had been turned upside down the night before. They had come to the Emergency Room because their daughter had a headache and ended up in the hospital with a diagnosis of an inoperable, incurable brain tumor. Despite everyone’s concerns, the child was bright and warm as I walked in the room, smiling and chatty.

The questions began swirling, both from others and in my own mind:

How could she leave her child in the hospital overnight alone after she was just diagnosed with a brain tumor?

Did anyone tell the mother the diagnosis?

Does she understand?

Should Child Protective Services be notified?

What could be so important that she needed to leave?

Are there other kids?

Is she coming back?

Minutes later the mother arrived in the room without fanfare or regret. One question answered, yes she was coming back. And yes she was told the diagnosis. And yes she seemed to understand. And eventually we came to learn that the child’s mother had severe anxiety and it had become impossible to return to the hospital that night. Every last bit of her energy was used up in the Emergency Room.

We tried to start with a clean slate. As with most pediatric cancer diagnoses, we started a journey together that day. A journey which included radiation, chemotherapy, a ventriculoperitoneal shunt, and a phase I trial. We endured biomedical challenges – increased intracranial pressure, shunt malfunctions, seizures, and sepsis. And we had psychosocial struggles, all often grounded in the mother’s severe anxiety – refusal of palliative care consultation, difficulty making decisions, inability to participate in tough conversations.

With each biomedical set back, the patient never quite returned to her baseline and with each subsequent episode, the baseline slowly worsened until the patient lying in the hospital bed was unrecognizable compared to the spunky child I’d met a year earlier. She was puffy from steroids and unresponsive due to tumor progression. Each biomedical event was accompanied

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Just an Expression? (Cont.)

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by a discussion with her mother about prognosis and plans. Some days her mother dissociated completely and I knew we had pushed too far. Other days we would make it through the whole conversation and she would share all she understood, but that she was also hanging on to hope. Her daughter was her world and she couldn't live without her. She wanted everything done, including a tracheostomy and CPR.

The questions again began swirling, both from others and in my own mind:

Does she understand?

What does the patient want?

Who are we treating?

What does it really mean when her mother says she couldn't live without her?

How can I help to make the inevitable tolerable?

What should be done to honor the child lying in that bed?

Did you get the DNR yet?

I took a deep breath and dove into another conversation with the mother, this time about honesty and love. I had scoured my resources about effective communication – read articles, asked colleagues and consultants, attended workshops and talks. I still came up short. I wish I could say that after hours upon hours of sharing and listening that we ended up in the same place, doing best for the child. We didn't. We ended up with a child with a progressive terminal brain tumor being rushed down to the PICU for a tracheostomy. The inevitable never became tolerable.



Many thanks to Dr Beck for sharing her narrative. Please send me your ideas on what you'd like to explore in Just an Expression? in the Fall and in future newsletters. What topics interest you regarding effective communication? You can send your ideas for future topics to daliafeltman@gmail.com. Also, I thank Dr Michelson for introducing me as the newsletter's Associate Editor. I look forward to exploring any new ideas you might have for newsletter essays and columns.

Pediatric Academic Societies (PAS) Meeting

April 24 - May 1, 2019 in Baltimore, MD

The PAS Meeting brings together thousands of pediatricians and other health care providers united by a common mission: improve the health and wellbeing of children worldwide. This international gathering includes researchers, academicians, clinical care providers and community practitioners. Presentations cover issues of interest to generalists as well as topics critical to a wide array of specialty and sub-specialty areas. Sessions of interest include but are not limited to:

Friday, April 26

- PES Ethics and DSD SIG

Saturday, April 27

- When Parental Deportation Orders Clash with the Health of American Children: How Children's Hospitals Can Partner with Legislators and Families to Advocate for Chronically Ill Children in Immigrant Families
- A Taste of Balint: An Introductory Experience With the Balint Group Method to Learn How It Can Enhance Empathy and Reduce Burnout
- Clinical Decision-Making With Families and Children With Medical Complexity When Evidence Is Lacking
- Is Racism an Adverse Childhood Experience (ACE)? Addressing Racism as an ACE in Clinical Practice

Sunday, April 28

- APA Special Interest Group: Ethics SIG
- Clinical Bioethics Platform and Poster Sessions
- Vulnerable and Underserved Populations/Health Equity & Social Justice platform and poster sessions

Monday, April 29

- Bioethics Interest Club: The Moral Dimensions of Gun Policy: Voices from the Field

[Click here](#) to view the complete program. For additional information about this meeting, or to register, [click here](#).

2019 Ethics Essay Contest

Submission Deadline: June 15, 2019

The Section on Bioethics and the [Ethics Special Interest Group \(SIG\)](#) of the Academic Pediatric Association (APA) are pleased to announce the second joint Ethics Essay Contest. 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 1000 to 1700 words. Essays longer than 1800 words will be disqualified without review. Essays must be original and unpublished works by a single author. References to appropriate literature are encouraged.

One or both winners may be asked to read their essay at the [Pediatric Academic Societies \(PAS\) Meeting](#) on April 29 - May 6, 2020 in Philadelphia, PA. If able to present, winners will be provided with a \$300 travel scholarship to attend.

Winning essays will be published in the newsletters of both the APA Ethics SIG and the AAP Section on Bioethics. Winners will retain copyright of their works and will be free (even encouraged) to submit their manuscripts to peer-reviewed journals for publication. The essay organizers will provide feedback and mentorship to winners to facilitate submission to a journal. All submitters will be notified of the outcome of the contest by August 31, 2019.

Two awards will be offered:

- 1st Place - \$300
- 2nd Place - \$200

Submission Deadline: June 15, 2019

Submit essays to:

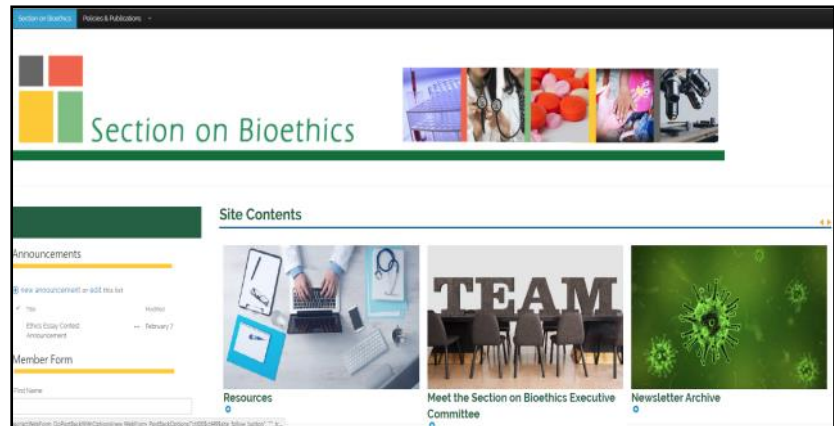
<https://www.surveymonkey.com/r/EthicsEssayContent>

Questions: Contact Anjie Emanuel at aemanuel@aap.org.

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- Newsletter Archive
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- Form for Members Interested in Getting More Involved in the Section
- Pediatric Essay Contest Winners
- William G. Batholome Award for Ethical Excellence
- Bioethics Case Based Teaching Guides for Resident Training



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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 Michelson, Newsletter Editor at k-michelson@northwestern.edu, or Dalia Feltman, Associate Newsletter Editor at daliafeltman@gmail.com.