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NAPSW FORUM

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To Talk About Burnout, We Need Better Words

Cathy Humikowski, MD*

In 1974 American psychologist Herbert Freudenberger published a paper in the *Journal of Social Issues* describing a new syndrome he had observed among workers in New York City's free public clinics.[1] The syndrome was marked by exhaustion, disengagement and apathy. The symptoms emerged from relentless work in the service of others. The syndrome, as Freudenberger first named it, was called "burn-out."

Much has been written about burnout since, and while I drop the hyphen for the remainder of this article, the hyphen itself bears great significance (more on that point later). Burnout is everywhere these days, featured in articles across the popular media with increasing frequency throughout the COVID-19 pandemic. Almost anyone can succumb to it — not just public health workers — and a whole cottage industry has erupted around its positive-sounding antonym: "wellness." With proper measures of resilience, balance and self-care (the wellness gurus say) burnout disappears.

When I first heard the word burnout applied to me (alongside other words in the same lexicon: balance, resilience, self-care) I was offended. It was 2017 and I had just announced my resignation at work. I was a pediatric intensive care physician at a major academic hospital and the director of my unit. I had wanted to become a doctor since I was very young, as a survivor of childhood cancer. My sister's experience with my illness had driven her career choice too; she became a social worker specialized in end-of-life care and chronic disease. We both entered service professions, like most of our colleagues, because personal experiences compelled us. I did not know then (but came to understand later) that this level of investment is prerequisite for Freudenberger's version of burnout. Only "the dedicated and committed" succumb to the syndrome as he originally defined it, but it would take years for me to know this. At the time, the word burnout struck me as an insult.

I was working full-time, tending to my ailing parents alongside a new marriage, new home and new career as a clinician and researcher. Despite my "advanced maternal age" and history of toxic chemotherapy, I became pregnant and had a healthy baby girl. After delivery, I suffered a cardiac arrest from massive hemorrhage due to amniotic fluid embolism. My physical recovery was quick—a day on the ventilator, a couple of emergency surgeries, a few follow-up appointments—so I moved forward without pause. I nursed my baby. I stored breast milk in the freezer for my eventual return to work. After a short maternity leave, I resumed my professional duties as though nothing had ever happened, with stacked make-up shifts back-to-back. All the women in my practice had done the same. Like me, they were the primary earners for their families (alongside women in nearly half of American households) and couldn't afford to take more time off.[2,3]

I was promoted to medical director soon after my return. At a time when I was still learning how to navigate clinical work as both a parent and a survivor of critical illness, my responsibilities redoubled. It was an exciting and challenging role, but it kept me away from my daughter most days. I left the house each morning before she woke up and returned most nights after she went to bed. I had nearly given my life for her but I almost never saw her.

A caustic fatigue settled over me. I bickered with my husband. I no longer enjoyed my work. I felt incompetent at almost everything. I lost my sense of empathy. I didn't know what to do, but I knew something had to change.

Emboldened by surviving a near-death experience (and lacking any other ideas about what to do), I quit my job. I had never quit anything before and I didn't know who I would be if not a doctor. The leap was unmooring but necessary. When news of my departure reached my colleagues, one of my partners voiced his support.

"Burnout is real," he said. "I'm glad you're taking a break." It was the first time I had heard, or even considered, the word burnout applied to me. I took immediate offence.

"I'm not burned out," I snapped

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NAPSW FORUM

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from the president

It's Autumn in Iowa. A gorgeous season — blue skies, crisp air and yummy apples. The maple trees are breathtaking. People seem motivated following a lazy summer. I've noticed that NAPSW has its seasons also. Everyone is exhausted after the conference. We turn the page to a new year in the organization every July with a new Board of Directors and Officers. I think that we really settle into our groove in September when school has started and vacations have ended. I don't know about your job, but mine is especially busy in the summer as we cover each other's well deserved vacations. We are now refreshed and ready to dig in with a fresh start!

Midterm elections are less than 3 weeks from today. I don't know when you'll be reading this, but my message is the same: "Let your voice be heard." Social justice is a core principle of social work. We speak loudly for others whose voices are hard to hear. We help them to articulate their needs to others. We speak for them to others when they are unable to. It's a sacred trust and one of the most important responsibilities that we have.

In their Standard of Practice for Social Workers in Health Care, NASW states: "Social workers practicing in health care settings shall advocate for the needs and interests of clients and client support systems and promote system-level change to improve outcomes, access to care, and delivery of services, particularly for marginalized, medically complex, or disadvantaged populations".

At our annual NAPSW Board meeting, the Board gave direction to our Advocacy Committee to focus on the issues of birth equity and maternal mental health. Erin Danahy is the new chair to this committee, and she's jumped right in. She's always welcoming your ideas for how we can best shine our light on these issues. Reproductive rights quickly took the spotlight as NAPSW firmly took the stand that reproductive rights are human rights.

One way that NAPSW makes our voice louder is by joining with other organizations. The National Social Work Voter Mobilization Campaign (votingissocialwork.org) is one such organization that we have an informal partnership with. They reached out last month and we were happy to share their efforts with our members. I am currently in the process of reviewing the existing partnerships that we have with other organizations and developing some new ones for the Board to consider. Together, we are stronger. Stay tuned …

I mentioned NASW's Standards of Practice, but I encourage everyone to review our own standards the next time you are looking for guidance on a challenging situation. Linda DeBaer and her Standards Committee work hard to make sure that our standards are following current best practices. I'm thrilled to share that this committee developed a new "Standard for Perinatal Social Workers Working with Patients Experiencing Differences in Sex Development." It's been approved by the Board and you'll be hearing more about it soon. It should make it to the website any time.

Speaking of our website, the biggest work currently happening at NAPSW is actually happening behind the scenes. Heather Ousley and Jennifer Russell, our co-chairs of the Web Committee, are working diligently to move us to a new membership software system. "MemberLeap" will allow us to do the work of our organization more efficiently and at a greatly reduced price. This is no small feat and we ask for patience while we make this transition.

Very soon you will be seeing a Call for Papers for our Virtual Conference April 27–28, 2023. Conference Chairs, Heather Ousley and Adriana Salcido, are making plans for a wonderful conference. But why wait for a conference? You now have between-conference opportunities. Karen Anderson is coordinating the NAPSW Journal Club. Please watch the listserv for announcements. Megan Hazel and Karen Kelsch, Co-Chairs of our Education Committee, have ideas for learning between conferences that they will develop once we transition to MemberLeap. Grace Amend and Rachel Daliva have begun their planning for our 2024 conference in Seattle. I'm already looking forward to it!

The Nomination Committee will soon be reaching out for members to step up for leadership positions. Please consider throwing your name in the hat. There's a place for everyone in the organization. If you're looking for where you fit in, please reach out to me and I'll find you a spot!

Whew, this organization is clearly feeling the energy that autumn brings. Let's continue to advocate and support our clients as well as our partners so we can build on this momentum. If you read this before November 8th, GO VOTE!!!

Jenny Duffy, LISW
NAPSW President 2021–23

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Burnout

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back, like a child defending myself on the playground. I glared at him as though he had spit at me and he apologized, for what I am certain he did not know. Burnout, as I understood it then, was for weaklings who lacked sufficient resilience. I was nothing if not resilient. Did he not see what I had just endured? *What a jerk,* I thought.

Except, he was not a jerk. He was a caring colleague who meant to support me. I knew this. Why, then, was I so offended? It wasn't because he didn't understand me, as I first surmised. It was because I didn't understand myself, or the word he had applied to me.

When I endeavored to understand it, I didn't just read Freudenberger's original paper about burnout. I read everything I could get my hands on in the academic and popular literature about the topic, drawing comparisons between what I read and my own experiences. From this exercise, I drew three enduring conclusions.

First, I was indeed burned out. In the most commonly cited definition, burnout is a syndrome of emotional exhaustion, depersonalization and reduced personal accomplishment that can occur among individuals who work in the service of others.[4] In 2019, the World Health Organization acknowledged burnout as an official medical diagnosis, listing it in the eleventh international classification of diseases (ICD-11) under "problems associated with employment or unemployment."[5] I realized the description fit, as it fits for at least half the physician workforce.[6,7]

The rate of burnout is similar among social workers. In a 2005 analysis (long before COVID-19 further strained the service workforce), 39% of social workers reported current symptoms of burnout and a full three quarters reported some experience with burnout over the course of their careers.[8]

I was embarrassed to have overlooked this blatantly obvious diagnosis in myself, especially one so common in my profession. How could I have missed it? And how did it happen to me? I had thought I was so resilient.

Resilience, in the most basic sense, is flexible strength. It allows a subject under pressure to recoil to the original posture, like a spring. I considered this feature in relation to Freudenberger's observations in New York City's free clinics in the 1970s. It was hard to imagine a more resilient phenotype than the workers there, people who devoted their professional service to indigent clients for little pay and limited tangible results. No syndrome would have emerged from Freudenberger's observations if these workers simply quit when the work overwhelmed them. But they remained dedicated and only experienced burnout after protracted effort. In other words, burnout does not stem from weakness or lack of resilience. On the contrary, burnout might actually require a certain degree of resilience to take root in the first place. To be clear, resilience is a valuable personal attribute that indeed enhances professional wellbeing, but it can also contribute to tolerance of external pressure beyond what is reasonable to bear.

> **The word burnout had not resonated with me when my colleague said it because it shifted the locus of control entirely to me, when in truth I had little control over the events sucking energy from my stores.**

My second conclusion, after considering this, was that *burnout was not my fault.* The word burnout invokes a sense of depleted energy, an appropriate connotation considering every formal definition of burnout includes the word *exhaustion.*[1,4,9] But the popular notion around burnout (and wellness) is that individuals can replenish this energy — restore it and reserve it — with sufficient resilience, self-care and balance. I considered the various stressors in my life, work-related and otherwise, that preceded my resignation. My mother had died unexpectedly and my father's Alzheimer's disease advanced. I survived a cardiac arrest. Our baby barely slept and so neither did we. The patient load at my hospital continued to rise, in volume and acuity. The unit was short-staffed — lacking nurses, pharmacists, case workers and respiratory therapists. No doubt I retained insufficient energy to manage all of this simultaneously, but it wasn't because I lacked energy. Flipping the script, I realized excess energy was being drawn from my stores, not that I failed to restore it. The energy crisis was not under my control.

My third conclusion was that the language around burnout was insufficient for the modern version of the problem. I was beyond burned out. I had been "fracked." Fracking is a term for mining oil or natural gas from deep reservoirs inside solid stone. Pressure is applied to the rock until it cracks, exposing the oil or gas for extraction. This seemed like a much more appropriate term for my state of affairs. The word burnout had not resonated with me when my colleague said it because it shifted the locus of control entirely to me, when in truth I had little control over the events sucking energy from my stores.

Freudenberger hyphenated the word burnout in his original 1974 paper, like this: burn-out. Looking at the words side by side, the same letters arranged in the same order, burn-out looks different. It isolates the word "burn" on its own, invoking a sense of injury from an external event. To burn is not passive; it implies an injurious force. This is how I think of burnout now, a milder version of human fracking.

Another feature of Freudenberger's definition, and codified in the ICD-11, is that burnout stems from working in the service of others. Public servants — physicians, social workers, teachers and the like — are uniquely prone to burnout as originally described. But in recent years, especially during the COVID-19 pandemic, everyone has become a public servant in some sense. Mask mandates, stay-at-home orders (including home schooling), and vaccination efforts all involve personal work for the benefit of others. If there is a unique and rare energy required for such service, everyone might succumb to burnout nowadays, not just service professionals. As such, there should be another word to describe this common sense of energy depletion that so many people experienced during the pandemic. If fracking surpasses burnout on the spectrum of wellbeing, what precedes it?

Languishing is the word social psychologists use to describe a state of stagnation and emptiness distinct from burnout or depression.[10] In a 2021 *New York Times* article, psychologist Adam Grant called it "the neglected middle child of mental health" and (unlike burnout) languishing is modifiable with personal effort. I had languished long before I had burned out, but I didn't recognize it partly because I didn't know what to call it. It's hard to solve a problem that you can't name.

Languishing, as I now picture it, sits on the pre-burnout side of the wellbeing spectrum (being fracked sits on the opposite side, beyond burnout). On the languishing end of the spectrum, personal effort may still impact one's progression in either direction. This model retains a role for the familiar tools of wellbeing: resilience, balance and self-care. Like any intervention, they must be applied at the right time to have an effect. They must also not be granted powers they do not possess.

Among the general population, service workers tend toward resiliency, a trait that allows flexibility in the face of adversity. However critical resilience may be, its capacity is not boundless within an individual. Resilience must apply across groups and organizations, not just individuals, to maximize benefit. Furthermore, individual resilience should not be conflated with toughness. A more resilient workforce honors vulnerability and accepts realistic limits.

Vulnerability invites self-compassion, a better goal than self-care. Self-care sounds like a trip to the spa or an hour of yoga. To be clear, I don't disparage such revitalizing indulgences. But a person languishing may not be able to muster the effort for such activities, making that person feel worse. Self-compassion, on the contrary, requires no additional time or energy. It is the simple mental practice of forgiveness and grace turned inward, and it correlates with improved wellbeing.[11]

Alongside grace I consider the notion of balance, my least favorite word in the wellbeing lexicon. Balance connotes a state of precarious impossibility, fleeting and unsustainable. If steadiness is the goal, strive for *grounded* instead. A grounded person prepares for adversity, braces for it, flexes against it when needed. A balanced person might simply topple over as the scales tip out of control.

> **Public servants – physicians, social workers, teachers and the like – are uniquely prone to burnout.**

This is what happened to me in 2017. I felt out of control, unprotected by my resilience and uncomfortable in my own vulnerability. I have a better sense of these words now, which ones serve me and which ones don't. Broadening my lexicon and examining the full spectrum of burnout, I can better identify my own place along it.

I am back at work with a part-time clinical load that allows space for other passions. I became a licensed foster parent, adopted a baby, rescued a needy mutt, planted a garden, revitalized a century-old house, and got to know my husband and older daughter again. Through writing, speaking and informal coaching, I work to expand other service workers' vocabularies around burnout so they could realize more efficiently what took me years to understand.

Be grounded, practice self-compassion, and exit a workplace that fracks you. Burnout is not your fault, but that doesn't mean you have no control.

**This essay is based on Cathy Humikowski's keynote address at the 2022 NAPSW National Conference, "If that was burnout, what is this? A new lexicon for professional fulfillment." Her writing has been published in JAMA, Mutha Magazine and the Chicago Tribune and she is currently pitching her first book. She is Assistant Professor of Pediatrics at Northwestern University's Feinberg School of Medicine and practices critical care at Ann & Robert H Lurie Children's Hospital of Chicago. Connect with Dr. Humikowski on Twitter @AGoodSave.*

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Parental Refusals in the Nursery

Lainie Friedman Ross, MD, PhD*

Note to readers: the author is a pediatrician with a PhD in philosophy. This article is an ethical discussion of parental refusals in the nursery from a pediatric ethics perspective. It is not meant to provide any legal advice. Policies and practices discussed in the article may vary by state. Please consult your own institution's legal department regarding state and institutional policies, how and when to take medical protective custody, when to involve legal counsel, and when to go to court.

Introduction

Conventional bioethics begins with the axiom that the competent adult has the right to accept or refuse any and all medical treatment, including life-saving treatment. When the patient is a child, however, the patient is presumed to lack decision-making capacity and his or her parents are presumed to be his or her health care decision makers. The presumptions can be overridden: some children (e.g., older adolescents) can make some health care decisions in some circumstances, and parental discretion is not absolute. In this article I will focus on the infant or young child who cannot speak for him or herself.

Although pediatric ethics asserts that parents make decisions on behalf of their infants, this does not mean that parental decisions are always necessary nor that they are always respected. Parental permission is not needed in the case of a medical emergency (e.g., trauma). And in some cases, the state may mandate some therapies (e.g., immunizations) even over parental objections. Finally, when parental decisions or actions put their child in imminent serious direct risk of harm, health care professionals, as mandatory reporters, must seek third party intervention to override their decisions. These challenges often arise in the scenario where parents seek to refuse standard of care medical treatment for their infant/young child.

The Brock and Buchanan framework for medical decisions was designed for decision-making when the patient (either adult or child) could not make decisions for themselves (either permanently or temporarily). The model is comprised of four ethical principles:

1. underlying values
2. surrogate decision-making
3. guidance and
4. intervention.

Let us consider each principle in turn and how it helps us examine parental refusals. The two main ethical principles that undergird surrogate decision-making for adult patients are autonomy and well-being (beneficence). However, when the patient is a child, Buchanan and Brock switch the order of the principles, giving primacy to well-being over autonomy and add a third principle: parental interests. The change in order (priority) is appropriate because it is important to respect the well-informed preferences of an adult (autonomy) even over what is medically beneficial, but since young children do not have pre-formed preferences, emphasis should be on their medical well-being. Buchanan and Brock give four reasons to include parental interests as an important underlying ethical value:

1. Parents care deeply about their child's welfare, know them and their needs best, and are better able to ensure that the decisions serve their child's welfare.
2. Parents bear the consequences of their choices.
3. The right of parents, within limits, to raise their children according to their own values and to seek to transmit these values to their children.
4. The family is a valuable institution and its preservation requires some degree of freedom and privacy (within limits) to make decisions about the welfare of its incompetent members.

Elsewhere I have offered a fifth reason: To allow parents to make intrafamilial trade-offs, provided that it does not sacrifice the "basic needs" of any child-member.

The addition of parental interests as an underlying value in a pediatric decision-making framework means that parents have legitimate needs and interests of their own which they can take into consideration when making decisions for their children (provided that they do not violate their child's basic needs). Those legitimate interests include some degree of family privacy to make decisions on behalf of minors and the freedom to try to inculcate their children with their cultural and religious values.

The second principle focuses on who is the appropriate decision-maker. While adults can select their surrogate decision-maker, parents are the presumed decision-makers for their children, although parental authority is defeasible as we explore below. The third principle addresses what principle should guide the surrogate decision maker. In the case of children, parents are held to a "best interest" standard. Now I put best interest in quotes because Buchanan and Brock acknowledge that parents are not really held to a strict best interest standard. If they were, then any time a parent made a good decision, but a physician thought another decision was better, the physician would have to go to court to impose their decision. But instead, as Buchanan and Brock note, "best interest is a regulative ideal" and the fourth principle (the intervention principle) is invoked not because there is a better decision, but only when the parents' decision reaches some level of serious direct harm (e.g. abuse or neglect).

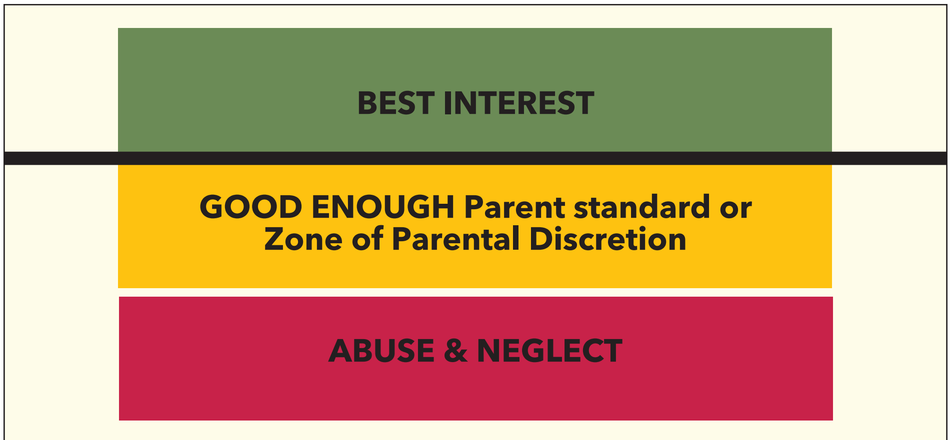

Figure 1: When should third parties intervene?

There is then this gap between what may be best for a child and when a decision places the child at such great harm of abuse or neglect that the state should intervene. This gap has been known as "the zone of parental discretion" or "the good enough parent standard" (see Fig 1).

In the US at least, physicians would not intervene until the parents' decision fell below the abuse and neglect threshold.

To understand how the Buchanan and Brock framework helps to address parental refusals, let us examine a few cases.

Case 1: Infant at risk for retinoblastoma

Mr. and Mrs. D are the proud parents of David, a well appearing 6-week-old boy. During their first well-baby visit, you learn that Mr. D had retinoblastoma as a child and had his left eye removed. He had no family history so it was clearly a de novo mutation. You recommend genetic counseling to determine if David is at risk because retinoblastoma is an autosomal dominant condition, meaning that David has a 50% chance of getting the gene from his father, and if he does inherit the gene, he will most likely develop retinoblastoma. Mrs. D states that they were offered such testing in utero and that they refused and still refuse genetic testing. Despite several conversations, they continue to refuse genetic testing.

Mrs. D may have refused in utero testing because prenatal testing would expose the fetus to risks ranging from infection to miscarriage. But once the infant is born, the physical risk of testing the child is a simple blood test. If David did not inherit the gene, then he is not at risk and no further follow-up is needed. If he has inherited the gene, he will need to undergo serial eye exams because if cancer appears, it is best to treat early.

Before the discovery of the retinoblastoma gene, all children born to parents with a history of retinoblastoma would undergo eye exams every 3 months for a few years and then every 6 months until they reached the age of 5 years when it would be determined that they most likely had not inherited the genetic variant. While eye exams are relatively noninvasive, one must realize that to perform a proper examination in a young child often requires anesthesia with its attendant risks. So clearly it is best to know whether these examinations are necessary.

Mr. and Mrs. D may be refusing the genetic test because they fear potential genetic discrimination. They may also not understand the inheritance pattern because David's grandparents did not have the gene. So what should the clinician do? As is often the case in ethics, the answer is to continue talking to try to find common ground. On further conversation, parents continue to refuse genetic testing but state that they are willing to have David evaluated every 3 months for a retinal eye examination by a pediatric ophthalmologist. This compromise exposes some children to the unnecessary risk of eye exams under anesthesia but it does ensure that a child who is at risk of developing retinoblastoma will be identified early. The unnecessary exposure to anesthesia has risks and is not ideal, but how much risk it entails is quite controversial.

While David's parents' decision is not best, should it be respected? I think it should be; the compromise is "good enough." And over the next year, I would make sure David got eye evaluations and I would continue conversations with his parents because if I can get them to test David, maybe we can avoid further exposure to anesthesia. Often as clinicians and parents get to know each other, they can forge a relationship of trust and that may sway the parents to do what is best. Yet, if I cannot, I know that we are taking appropriate precautions to identify cancer early and I would not badger them.

However, if David's parents do not come in for the serial eye examinations, I would be very concerned because if the child is at risk and there is a delay in diagnosis, then the cancer can spread beyond the retina and can cause preventable morbidity or mortality. Refusal to have David followed closely by ophthalmology would be neglectful and I would get child protective services involved in order to mandate routine eye exams.

Thus, this case shows that clinicians like myself are often willing to tolerate parental decisions that are good enough even though there is a better treatment plan. That is we do not seek state intervention unless the decision falls below some threshold of harm.

How much leeway are we willing to give parents? Consider another case.

Case 2: Parental Refusal of Vitamin K

Susan is the first child of Ms. A and her wife, Ms. B. Ms. A is a healthy primiparous woman with no past medical history. She had a natural

Table 1: Vitamin K Deficiency Bleeding (VKDB)

Type	Risk	When	Comments
Early	1/60 - 1/250	0-24 hrs.	SEVERE Maternal meds
Classical	1/60-1/250	1-7 days	Bruising and oozing at risk for trauma?
Late	1/14K-1/25K	2-12 weeks up to 6 months	30-60% ICH No warning

This table is copied from the Centers for Disease Control website: https://www.cdc.gov/ncbddd/vitamink/facts.html

birth delivery with a midwife and the infant is full-term with Apgar scores of 8 and 9 at one and five minutes. She plans to exclusively breastfeed. When the clinician comes to give Susan an intramuscular shot of vitamin K, Ms. A refuses. She agrees to newborn metabolic screening, cardiac screening and hearing screening. On exam, the infant is well appearing without bruises. The question is what do you do next?

Good ethics always begins with good facts. All infants are born vitamin K deficient and it takes months until they have sufficient stores. Vitamin K deficiency leads to bleeding because vitamin K is necessary for the blood to clot. To prevent bleeding it is best to give vitamin K within the first 6 hours after birth. There are three types of vitamin K deficient bleeding (VKDB). See Table 1.

The first step to take when a parent refuses a recommended treatment is to ask why and to address any misinformation. One must make sure that Ms. A understands the risks of the three types of VKDB and the fact that human milk does not contain enough vitamin K to be protective against VKDB. In fact, infants who are breastfed are at greater risk for VKDB because breast milk has very little fat soluble vitamin content (Vitamins A, D, E and K). The American Academy of Pediatrics and the World Health Organization both endorse intramuscular (IM) vitamin K. While some countries use an oral dosing schema, it is less effective against late-onset VKDB and is not approved in the US. Second, we need to make sure she does not have inaccurate information. Two reports in 1992 claimed to have found an increased risk of cancer in infants given injected with vitamin K. Klebanoff and colleagues are American researchers who examined the relation between vitamin K and cancer "in a nested case-control study that used data from the Collaborative Perinatal Project". Their study, published in the New England Journal of Medicine in 1993, found no increased risk. Fear and colleagues in the UK also re-examined the relationship between neonatal vitamin K administration and cancer, and in 2003 published their findings that again found "no convincing evidence that neonatal vitamin K administration, irrespective of the route by which it is given, influences the risk of children developing leukaemia or any other cancer." Nevertheless, parents continue to express this fear despite numerous studies disconfirming the relationship. Finally, some parents may want to avoid the temporary pain and possible bruising at the injection site. This is a short-sighted perspective that exposes their child to a low likelihood of internal bleeding, a serious risk which can result in significant morbidity, if not mortality.

Parental refusals of vitamin K appear to have increased in recent years. Different states and different hospitals have different policies on how to handle this. What is clear is that if Susan were premature or was at risk of perinatally acquired infection or had any signs of liver disease and needed to be admitted to the neonatal intensive care unit at my institution, vitamin K would be given without consent. At my institution, clinicians can take medical custody and give the injection even without calling a judge first. But in the well-baby nursery, the question of whether this reaches a level of neglect that justifies taking medical custody to administer the shot is less clear. This does not mean that refusal of vitamin K of full term healthy infants does not have consequences as even full term healthy infants can develop VKDB. In some well-baby units, the parents will be asked to sign a document attesting that they understand the refusal puts their child at risk.

Like the retinoblastoma case, this case also raises the question of whether you would accept this patient into your practice. Many clinicians are reluctant to accept these patients because it is clear that the parents do not respect the physicians' expertise. However, a key issue is to remember that the parents are making a bad decision but refusing to accept the child into your practice harms the child. This child is at risk and it is better to have them in a medical home than to let the child fall through the cracks. If the child is in your practice and is a passenger in a car that is in an accident, you can tell the emergency department to take protective custody and administer vitamin K immediately and hopefully minimize bleeding risks. Second, one must remember that this child does not expose other patients in your practice to risks (in contrast to parents who refuse vaccines for infectious diseases). Third, by accepting the child and following them across the first year of life, there is the chance to continue the conversation and possibly change the parents' minds or at least help the parents make better decisions regarding future treatment options.

Case 3: Parental Refusal of Metabolic Newborn Screening

What if Ms. A and Ms. B also refused the metabolic newborn screening blood spot? Depending on which conditions are included in a state newborn screening program, the risk that a child from a non-high-risk family has any of the condition is rare, ranging from 1/3000 to 1/>100,000. Since most of these conditions are autosomal recessive (one exception being some forms of hypothyroidism which are not genetic), if a sibling has a condition that is included in a state newborn screening test, then biological siblings would have a 25% risk which changes the analysis. In the case described, there is no family history of metabolic disorders.

The two main ethical principles that undergird surrogate decision-making for adult patients are autonomy and well-being (beneficence). However, when the patient is a child, Buchanan and Brock switch the order of the principles, giving primacy to well-being over autonomy and add a third principle: parental interests.

Again, good ethics begins with good facts. Newborn screening in the US began in the early 1960s when Robert Guthrie developed the Bacterial Inhibition Assay (BIA) test to identify children with phenylketonuria (PKU) as well as the filter paper (Guthrie card) on which to collect the blood sample. PKU is an autosomal condition that causes severe developmental delay unless treated with an appropriate diet. Guthrie was a strong advocate for population screening and by 1973, newborn screening for PKU had been adopted in 43 states despite the objections of some clinicians who did not support state-based governmental involvement in medical care. The criteria that would justify universal screening for a condition like PKU were not enumerated until 1968 when Wilson and Junger enumerated 10 conditions for population screening for the World Health Organization. See Table 2. The condition must be serious and need to be identified early in order to begin prompt treatment that prevents morbidity or mortality.

Today, metabolic newborn screening is just one component of the newborn screening program in the US. Other components include hearing screening and screening for critical congenital heart defects using pulse-ox. Different states screen for different disorders although there is much greater uniformity today because in 2005 the Secretary of the Department of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children (established in 2003) promulgated a framework to determine if a condition should be included in the recommended uniform screening panel. The framework has been evolving but has many of the features first enumerated by Wilson and Jungner.

Table 2: Wilson and Jungner 10 Criteria for Population Screening

1. The condition sought should be an important health problem.
2. There should be an accepted treatment for patients with recognized disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognizable latent or early symptomatic state.
5. There should be a suitable test or examination.
6. The test or examination should be acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
8. There should be an agreed policy on whom to treat as patients.
9. The cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
10. Case-finding should be a continuing process and not a "once and for all" project.

Wilson JMG, Jungner F. 1968. Principles and practice of screening for disease. Public Health Papers. no. 34. Geneva: World Health Organization

Although it is not mandatory that all states test all children for all recommended conditions, most states do. Some states lag behind when a new condition requires a new testing platform (e.g., the inclusion of severe combined immunodeficiency required the ability to include genetic testing as a first line test). And some states screen for metabolic conditions that have not yet been recommended and other states screen for metabolic conditions that have been reviewed and rejected from inclusion in the uniform screening panel. Parent advocacy groups have been a strong force behind expansion of newborn screening.

Clearly it is best for all children to undergo newborn screening. But there are a few caveats that the clinician must understand when engaging with hesitant parents. First, screening is not diagnostic. If a child has a posi-

> **[T]his gap between what may be best for a child and when a decision places the child at such great harm of abuse or neglect that the state should intervene … [is] known as the *zone of parental discretion* or the *good enough parent standard*. … How much leeway are we willing to give parents?**

tive screen, the child has to undergo further testing to determine if the child actually has the condition (true positive) or whether the screening identified a child who is a false positive, meaning that the child does not have the disease. Given that treatment for these conditions must begin promptly, parents are called in the first days of life and told to return for follow up immediately. Sometimes they are told to stop breastfeeding (e.g., PKU) which may cause parental stress. Second, while the benefits of screening clearly outweigh the risks for those conditions for which early treatment is necessary to prevent serious morbidity or mortality, as newborn screening has expanded, recommended screening now includes some conditions with variable penetrance leaving some families with children who are, to use the phrase of Timmermans and Buchbinder, "patients in waiting". An example of this is the diagnosis of spinal muscular atrophy as many of the children will be asymptomatic in the newborn period and may not require treatment for months or possibly years. Third, some states go beyond what is recommended. In fact, despite rejection of several lysosomal storage disorders for screening recommendations, it is still mandated in New York, Illinois and a number of other states. Although the risk/benefit ratio is debatable, these conditions are bundled with other metabolic conditions and parents cannot pick and choose — newborn metabolic screening is an all-or-none choice.

So what should the clinician do if a parent refuses metabolic newborn screening? Step one is to understand why and to correct any misinformation. Step two is to explain to parents that without screening many of these conditions would go undetected until irreversible harm has already been done. Step three is to explain that if a parent refuses the metabolic blood test, the child may undergo individual testing for these conditions at greater expense. For example, if an infant is gaining weight poorly in the first month and did not get screening, the clinician will order a sweat test and a blood test for thyroid measurements even if the most likely explanation is difficulty in establishing breastfeeding.

From an ethics framework, parents make non-ideal decisions all the time — that is they do not always act in their child's medical best interest, but third party intervention is limited to those cases in which the decision reaches a threshold of abuse or neglect. Does the refusal of the metabolic newborn screening blood spot justify third-party intervention? Probably not. This is not to say that I agree with the decision or that I am not distressed by their decision. And especially during the first month of life, I will try to convince the parents to permit screening. What should be obvious, however, is that despite our disagreement, I will continue to work with the family and will accept them into my practice. Like the scenario of vitamin K refusal, this child is "at risk" and it is better to have them in a medical home than to let this child fall through the cracks. If the child has any symptoms of any condition usually identified by the newborn screening blood test, I can order the test individually (even though it would have been better to have diagnosed it pre-symptomatically).

Third party interventions

There are times when clinicians must seek third-party intervention. That is, clinicians must seek third-party intervention when the parents' decision puts the child at serious risk of direct harm, for example, 1) refusal of blood transfusions for an infant born with immune hydrops; or 2) refusal of a diagnostic work-up and antibiotics for suspected meningitis for an irritable infant with a fever and bulging fontanelle. In pediatrics, proxy decision makers are constrained by the fact that the state, as parens patria, has the right to protect citizens from well-meaning but misguided decisions.

Concluding remarks

Refusals in pediatrics can occur at all stages, from screening to diagnostic tests, from preventive therapies and vaccines to life-saving treatment in emergencies (e.g. blood transfusion). Not all refusals are the same — there is wide variability in the degree and likelihood of harm. Refusals in the well-baby nursery are more likely to be tolerated than refusals in the neonatal intensive care unit. For example, clinicians will be more likely to take medical custody to give vitamin K in a child with potential liver disease or sepsis because the risk of serious life-threatening intracranial hemorrhage is greater.

As clinicians we want to do what is clinically best for our patients. While we can strive to engage and educate parents to do what is in "the child's (medical) best interest" we often must accept parents' "good enough" decisions. Respecting their refusal does not mean shrugging one's shoulders and muttering "it's their choice."

By establishing a relationship with parents who refuse medical recommendations, we have the opportunity to continue the conversation and engagement and, hopefully, change their minds or at least help the parents make better decisions for future interventions.

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Advisory Committee on Heritable Disorders in Newborns and Children. On the web at: https://www.hrsa.gov/advisory-committees/heritable-disorders

Baby's first test. On the web at: https://www.babysfirsttest.org/

**Lainie Friedman Ross, MD, PhD, is the Carolyn and Matthew Bucksbaum Professor of Clinical Ethics, Professor in the Departments of Pediatrics, Medicine, Surgery and The College, Associate Director of the MacLean Center for Clinical Medical Ethics, and Co-Director of the Institute for Translational Medicine at the University of Chicago.*

NAPSW JOURNAL CLUB

Journal Club Virtual Meeting Schedule

The NAPSW Education Committee is canceling Journal Club for November and December. We will resume in January 2023. We hope you will add NAPSW Journal Club to your New Year's resolution and plan to participate in this collaborative and educational experience.

Each month, starting again in January, the Journal Club article send an article via the NAPSW membership email list. Please review the article prior to the meeting and then the group will discuss it together.

Meetings are held on the fourth Thursday of each month at 1:00 pm Pacific Time (or the equivalent in your time zone). Our next meeting will be **Thursday, January 26, 2023**.

The Journal Club is interested in YOUR suggestions for exciting, relevant articles for future discussions. We hope you will consider volunteering to lead the discussion on an article you have suggested.

Recent articles reviewed by the NAPSW Journal Club:

Lantos, John D. Ethics of care for the micropreemies. Just because we can, should we? *Seminars in Fetal and Neonatal Medicine* 27 (2022), 101343.

Craig, Shelley and Muskat, Barbara. Bouncers, Brokers, and Glue: The Self-described Roles of Social Workers in Urban Hospitals. *Health and Social Work* 38 (1), Feb 2013.

NAPSW Committee Reports for 2021-2022

Advocacy Committee

Co-Chairs: Erin Denahy (2022-2023) and Heather Ousley (2022)

Activities 2021-2022

NAPSW was represented as a content expert for the TECaN Carousel Campaign, an organization for Trainees and Early Career Neonatologists, providing education and awareness about family mental health and wellness in the NICU.

Goals for 2022-2023

- The primary goal for this committee is to identify what issues and populations NAPSW should focus their advocacy efforts on. Ideas for consideration are screening during the perinatal period for maternal mood concerns or birth equity. Reach out to organizations actively advocating with the hope to partner in these efforts.
- Provide speaker suggestions on chosen focus topics to the 2023 conference committee.

Awards Committee

Chair: Ali Tiedke (Immediate Past President)

Activities 2021-2022

- Facilitated nominations and determination of this year's recipient for the NAPSW Award for Excellence.
- Certificate of recognition for outgoing Executive Officers and Board of Directors.

Goals for 2022-2023

Oversee awards and plan for 2023.

Bylaws Committee

Chair: Debby Segi-Kovach

Activities 2021-2022

- Copy of current Bylaws were sent to new board members and updated on the NAPSW website.
- Reviewed recommendations received throughout the year regarding wording changes in the mission statement, changing the names of the Nominating, Program and Social Networking Committees and wording in each section, and adding 3 new standing committees: advocacy, bylaws and social media.
- Ballot of suggested Bylaws changes emailed to membership, with results to be communicated to membership.

Goals for 2022-2023

- Ballots will be counted. If the amendments pass, then changes will be made to the Bylaws. A copy of the new changes will be available to membership through the NAPSW website. Copy to be sent to officers, board members, committee chairs, and anyone that requests a hard copy.

Communication Committee

Co-Chairs: Shelly Bunker and Dasi Schlup

Activities 2021-2022

- Publication of 3 issues of NAPSW FORUM.

Goals for 2022-2023

- Explore possibility and member interest in moving the FORUM to a solely online platform (NAPSW website) with ongoing yearly publication timelines.
- Update/modernize the look of the newsletter and add some modern touches: humor, memes, etc.
- Summarize one subject discussed through the email list in the previous quarter.

Education Committee

Co-Chairs: Kim Stobbe and Megan Hazel

Activities 2021-2022

- Develop resource database.
- Increase NAPSW footprint for online connections, resources and journaling discussions for our members for online education.
- Assist conference committee with CEUs, and conference scholarships.
- Develop Journal Club to meet quarterly.
- Facilitate Innovative Research and Program Award.

Goals for 2022-2023

- Continue with development and implementation of the above goals.

Historian

Chair: Shelly Bunker

Activities 2021-2022

- Maintain an archive of all NAPSW documents, with easy access to all NAPSW leadership.
- Facilitation of History articles for NAPSW FORUM.

Goals for 2022-2023

- Maintain the NAPSW archive.
- Contribute NAPSW history articles to be included in the NAPSW FORUM.
- Create a History section on the NAPSW website with goal of adding new information quarterly.

International Committee

Chair: Beth Maudsley

Activities 2021-2022

- The committee has communicated with Perinatal Social Workers in Canada by email to distribute the NAPSW conference brochure.
- Responded to communication from social workers outside of the US who had questions about the organization or membership.

Goals for 2022-2023

- Continue supporting international recruitment and Provincial/Country Representatives.
- Continue to liaise with all members of Region X.
- Respond by email to any inquiries through the NAPSW website coming from outside the US.
- Be the voice to all the NAPSW Board for the needs and issues of international membership.

Long-Range Planning Committee

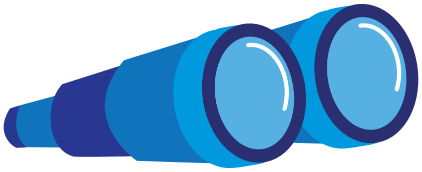
Chair: Ali Tiedke (Immediate Past President)

Activities 2021-2022

It is recommended that the board consider focusing on strengthening advocacy in NAPSW. Membership recruitment and continuing education throughout the year have been ongoing recommendations for the organization and continue to be. It is also recommended that the board consider the option of the annual conference being virtual every other year.

Goals for 2022-2023

Continue to monitor progress on all initiatives.



Membership Committee

Chair: Karina Ousley

Activities 2021-2022

- Ongoing management of membership database system, new membership applicants, renewing members, and membership payments.
- Facilitated March 2022 membership campaign, with 84 new members joining NAPSW from this drive.
- Attended and participated in NAPSW quarterly teleconference meetings.
- Attended the annual NAPSW Board Meeting.

Current Membership Data: 267 Regular Members, 50 Student Members, 13 Associate Members, 12 Retired Members and 4 Lifetime Members.

Goals for 2022-2023

- Continue management of the membership database. Evaluate possible other membership database options.
- Manage 2023 membership campaign with goal to surpass this year's totals by at least 10%.
- Update and improve the New Member Packet as needed.

Nominations Committee

Chair: Margery Pentland

Activities 2021-2022

- Facilitated 2021 election; publication of results by email and in the NAPSW FORUM.
- Solicited nominations for 2022 elections, sending information via email, the website and FORUM.
- Reviewed all nominations received, contacted nominated candidates, finalized ballot and sent to membership with 3 options to vote.

Goals for 2022-2023

- Count ballots for 2022 and publicize results by the Annual Conference.
- Begin earlier to identify and solicit potential candidates for 2023 (President, Secretary, and 5 BOD).
- Publicize through emails, website, and FORUM the need for nominations.

President's Report

Jenny Duffy, NAPSW President

Activities 2021-2022

- Facilitated Partnerships/Endorsements
  - —Endorsement of Caring Essentials Trauma Informed Professional Program
  - —National Perinatal Association (NPA)
  - —Pregnancy Loss and Infant Death Alliance (PLIDA)
  - —Postpartum Support International (PSI)
  - —Society of Social Work Leadership in Health Care (SSWLHC)
  - —Maternal Mental Health Leadership Alliance (MMHLA)
- Identified committee chairs for Advocacy and Social Media.
- Suggested updates to the Bylaws for membership consideration.
- Conference planning: Chicago 2022, Virtual in 2023, and Seattle 2024.
- Submitted Letters from the President for NAPSW FORUM.
- Facilitated meetings with newly elected board members, Quarterly BOD teleconferences, Executive Board Meetings, Conference Program Committee meetings.

Goals for 2022-2023

- Continue to explore, develop, and finalize partnerships.
- Increase scholarships awarded by NAPSW.
- Support the work of committees with special focus on Advocacy Committee per direction of Long-Range Planning Committee.

Social Networking Committee

Chair: Tiffany Hanff

Activities 2021-2022

- Manage and oversee NAPSW sites for Facebook, Twitter, LinkedIn, and Instagram
- Postings included articles and links to a variety of subjects including: general social work topics, perinatal social work topics, social justice advocacy, NAPSW information, current events related to perinatal social work both in the US and internationally, self-care, and support for NAPSW strategic partners.
- Increased numbers following each account across the board.
- Discontinued Pinterest account

Goals for 2022-2023

- Identify a new committee chair for 2022-2023.
- Work towards engaging our perinatal community more to have them involved in discussions on the Facebook, Twitter, Linked In, and Instagram pages.
- Continue to post on all NAPSW social media sites, with goal to increase topic range and diversity of topics.
- Explore creative ideas in expanding NAPSW outreach on social media platforms.
- Identify members interested and willing to participate in postings for social media platforms.

Standards Committee

Chair: Linda DeBaer

Activities 2021-2022

- Development of new standard: Standards for Perinatal Social Workers Working with Patients Experiencing Differences in Sex Development.
- Submit completed new standard to the NAPSW Board for approval.
- Ongoing review of all NAPSW standards.

Goals for 2022-2023

- Edit new standard as needed
- Print new standard once Board has approved.

Vice-President Report

Tiffany Hanff

Activities 2021-2022

- Filled open positions for regional and state representatives. We were able to fill more slots; however, we also needed to open new positions.
- Requested support for 2022 Conference publicity from regional and state representatives in their respective areas.
- Provided support to the NAPSW President as requested.
- Attended BOD meetings and teleconferences, conference planning meetings and long-range planning meetings.

Goals for 2022-2023

- Continue to increase and interact with regional and state representatives. There has been discussion in the past to revamp this program as well.

Web Committee

Co-Chairs: Jen Russell and Heather Ousley

Activities 2021-2022

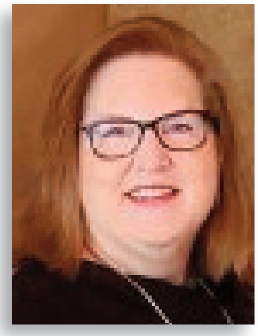
- Maintain the NAPSW website
- Website Presence: our website continues to receive good traffic with our home page receiving almost 516K hits.
- Elections: support online voting process for NAPSW elections
- NAPSW Updates for Members: NAPSW front page blog is updated semi-regularly with announcements. Periodic information is sent to membership including announcements, conference information, call for papers, conference registration, awards nominations, conference scholarships, FORUM issues, March membership drive, election results and Award recipients.
- Website Resources page: Audrey Halden is now managing the resources page
- Moderate Email List
- Step-by-step training guide developed and uploaded for NAPSW Leadership use.

Goals for 2022-2023

- Assess additional web-hosting options
- Have NAPSW Standards converted to include on website.
- Explore options for non-members to order and pay for Standards and FORUM newsletters, per Board approval.
- Review adding advertising space on NAPSW website. Identify appropriate guidelines that align with NAPSW values and mission to provide potential advertisers. Identify a point person for soliciting and accepting advertising requests.

New Board Members

New NAPSW Board Member Daphne L. Fielder, MSW, LMSW



Daphne received her BA in Human Services and Psychology from Carson-Newman University and her MSW from Barry University. She has been a NICU Social Worker for 36 years and a Social Worker for 38 years. She has worked in Southern Illinois, South Florida, East Tennessee, and Las Vegas. For over 9 years she has worked as a NICU/Perinatal Social Worker at Sunrise Children's Hospital in Las Vegas Nevada.

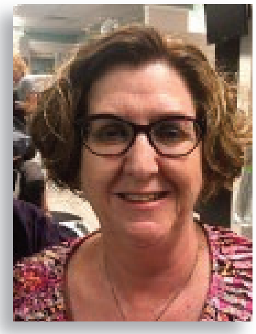
When I was a young teen, my mother was diagnosed with breast cancer. Unfortunately, this was before self-exams, early detection and better treatments. Her cancer metastasized and a year later she passed away. From this experience, I felt drawn to working in healthcare and medical social work.

I started my career in Southern Illinois just as DRG's were being implemented. After a move to South Florida, an opportunity arose to be the Perinatal Social Worker. I saw this as an opportunity to learn and grow professionally but quickly discovered that this was not just my job but my calling. Over the years, it has been incredible to watch healthcare and treatments improve and progress. To see babies who at 28 weeks were incompatible with life now not only survive but thrive, has been one of the greatest joys in my journey.

I consider it a privilege to work with our families and the NICU team. Each day presents new challenges and experiences along with opportunities to support and assist families as they navigate the NICU experience with their child or children.

I am honored and humbled to be a new NAPSW Board Member and my hope is to share my experience as a Perinatal/NICU Social Worker, to encourage and support other Perinatal Social Workers in their practice, to help train and grow new Perinatal Social Workers and to see the NAPSW Community continue to flourish. I believe that by sharing with our colleagues and learning from our colleagues, strategies and best practice, we not only benefit our members but also our clients.

New NAPSW Board Member Mary Denato, LCSW



I received my MSW from the University of Illinois Jane Addams School of Social Work over 30 years ago and went to work as a medical social worker I loved working in maternal child health and pediatrics, but I didn't find my true passion until I moved to California and got my first full time job in an NICU. I have been a perinatal/NICU social worker for over 20 years and involved with NAPSW since attending my first conference in 2011 in San Diego. This is my third time serving on the Board. I have also held various NAPSW positions, including Regional Representative for Region VII and Nominating Committee. I co-chaired the 2011 San Francisco conference. In 2015 I received the Award for Excellence.

I decided to run for the Board again as I am so passionate and grateful for all I have gained as a member of NAPSW for many years and felt I would have more time to devote to the organization as I am nearing retirement. This wonderful group of professionals is so unique as a support network for the difficult, specialized work we do with babies and families and I feel privileged to be able to give back to the organization. I am excited to serve with the amazing group of energetic members of the Board and Committees and great leaders, such as our president Jenny Duffy.

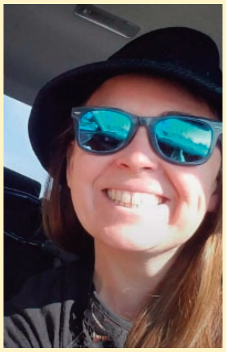
As we have expanded and continue to reach out to new members and provide ongoing education and mentoring, I hope to continue working to enhance the scope of the organization with continued outreach and involvement.

NAPSW wants to send a BIG THANK YOU to our outgoing Board members for 2020–2022:

Tiffany Hanff, Vice President	**Barbara Menard, Treasurer**
Meredith Huber, Board of Directors	**Beth Maudsley, Board of Directors**
Karina Ousley, Board of Directors	**Erika Munoz, Board of Directors**

Thank you as well to Kim Stobbe for serving as a Board of Director for the past two years. Kim was recently elected to be the new NAPSW Vice President.

Tiffany Hanff shares her thoughts about serving for many years, in SO many positions, with NAPSW. She is an invaluable asset to the organization.



I was given the responsibility of the social networking committee (SNC) at the Vancouver conference. I really did not have any idea of what I was getting myself into. I was new to the board, and Lisa (who was president at the time) asked if I would do it, and I was like … "sure." I found that I actually really enjoyed it. I had a goal of posting something every day, from either a random fact, to a motivational quote to asking questions. The biggest challenge was getting a response though.

When it comes to the parts that stood out, I think one part that I am proud of is how big we grew our following. I don't have the exact numbers, but we continuously gained followers on a somewhat slow but steady basis. I truly enjoyed the campaigns we created: Advocating for wearing our masks during COVID and getting the COVID vaccine. Advocating for why voting was important. Also, the campaigns on why we continue to go to the NAPSW conferences.

I enjoyed being able to advocate for our social work values and bringing awareness to issues that impact our populations; such as domestic violence, gun safety, right to make our own medical decisions, climate change, mental health and discrimination. The busiest time was definitely in 2017 after the 2016 presidential race. JaNeen was working with NASW at that time and she was providing information hourly (it felt like) for Hannah (who ran the website) and me to post and advocate for.

I truly enjoyed managing our social network over the last seven years. Unfortunately, I felt that it was time for someone with fresh ideas and motivation to take it over and stepped down after the 2022 conference in Chicago. I am looking forward to seeing what the next SNC chair does with it.

Tiffany Hanff, LCSW

A Long Career Helping Families

Clinical social worker **Debby Segi-Kovach** will retire on Oct. 14 after 36 years dedicated to helping families of our smallest patients.

Debby arrived in St. Petersburg from Ohio, where she had completed her Master's in Clinical Social Work at Case Western University with a focus on maternal and child health. She had been at an adult hospital in Cleveland, often working with pregnant women and women who were battling cancer. She interviewed for the role of NICU social worker and was both intrigued and cautious about the challenge. Early on at All Children's she was often surprised by how small the tiny babies in the 40-bed NICU were.

Over the years, the NICU continued to grow. The premature infants admitted to the unit were even smaller and the issues and crises facing families became more complex. Debby has especially enjoyed working with young moms, teen moms and their families, helping them through a critical period as they learn about their baby's needs and prepare to leave the NICU.

She launched Sharing Stories and Support, a scrapbooking program where NICU parents could document their journey and share stories and advice with other families. "It provided many special memories that I will carry with me," she reflects.

In addition to her NICU role, Debby was also the hospital's first transplant social worker. Among a treasure trove of memorable moments, a highlight is the hospital's first heart transplant in 1995. "The state had given All Children's approval to perform transplants in infants with hypoplastic left heart syndrome — one of the most challenging groups," she recalls. "The team was well-prepared, and I was helping the parents cope with the anxiety and the unknowns while waiting for the transplant to take place. Everything went beautifully, and it was great to see the patient head home with the family and grow up in excellent health."

Debby continues to work with families of heart transplant patients, and it was a point of pride when the recent CMS Transplant Verification Survey made note of the excellent documentation by the social work team. She has great admiration for all members of the neonatal and cardiac transplant team and their outstanding work.

In addition to the thousands of families she has helped at over the years, part of Debby's legacy has been helping to train new generations of clinical social workers. She supervises social work interns and advises students pursuing their graduate degree. Debby has been recognized locally and nationally for her work, including receiving the 2005 Excellence in Perinatal Social Work award from the National Organization of Perinatal Social Work. The NICU has remained her true passion.

What will she miss most? Debby gets a little teary when she thinks of the families, coworkers and teams who give meaning to her work every day. She and her husband, Glen, are looking forward to the holidays at home and thinking about some travel plans for next year. She also envisions finding a way to give back to children and families through volunteering or even part-time work.

We are grateful for the abundant ways in which Debby has helped our patients and families and inspired her colleagues. We wish her much happiness ahead.

Board of Directors Nominations Are Open

It is time to think about whom to nominate for the upcoming 2023 elections. WE NEED YOU to think about who is Board of Directors' "material"— or to volunteer yourself to run!

During the April 2023 virtual conference, we will elect individuals for the following positions: President, Secretary and five Board of Director members. We really want to provide a full ballot with many options for our membership at the time of elections. Nominations are now open and ready to be received immediately and no later than February 3, 2023 — but don't put it off! Send your nominations NOW.

Please consider nominating yourself or other NAPSW members you know for these positions. Candidates for Board of Director positions need to be members in good standing for one year prior to running for the Board of Directors. Candidates for Officer positions need to have served at least one term on the Board of Directors.

This is your opportunity to develop and share leadership skills and contribute to keeping NAPSW a strong, vibrant and relevant organization. Email your nominations to the committee members listed below. Send nominations ASAP but no later than February 3, 2023.

Thanks!

Margery Pentland, Nominations Chair, pentlandm@comcast.net
Dasi Schlup, schlupd@health.missouri.edu
Sandy Dykstra, sandydykstra@sbcglobal.net

NEW MEMBER SPOTLIGHT

Kendra Fuemmeler, LMSW

I received a BSW at University of Central Missouri in 2006 and then earned an MSW in 2010 at the University of Missouri-Kansas City. I am currently a licensed social worker (LMSW) in the state of Missouri. I work in the maternal-child health setting (Post Partum, Labor & Delivery, Newborn, and NICU) at Boone Hospital in Columbia, MO.

My first eleven years of professional life was spent working in child welfare as a frontline worker: Supervisor, Trainer, and Quality Improvement Specialist. Always planned on continuing work — until I delivered twin boys at 25 weeks of life and realized they would need to be home with me for at least the first year, if not longer. At 1 year of age, one of the twins was diagnosed with hepatoblastoma (liver cancer) and I continued to stay home. The twins are both 5 years old now. They started kindergarten this year and are overall, very healthy!

My husband I now have another baby boy (almost 3 years old). About a year ago, after staying home during the pandemic with three young boys, I decided it was time to get back to work! In working as the Maternal Child Health social worker at Boone, I work 30 hours each week, which allows that one day off a week for the children's appointments and, of course, all of life's other "duties." When I started this position, the Hospital was going through a lot of changes. I threw myself into helping wherever I was needed. Just now, in the last 3–4 months, I am starting to focus solely on MCH and develop myself more professionally, specifically in MCH. I am very excited for this!

I specifically enjoy being able to provide true empathy to parents of babies in the NICU and being able to provide perspective to other team members regarding parents' perspectives and worries. My experience in child welfare has been very helpful in regards to understanding the other side of those "calls we make" and being able to work ahead a bit with families when it makes sense and not always have to rely on the child welfare system — as we know, unfortunately, it will always be overwhelmed and understaffed. I enjoy getting to work with younger parents and learn their worries and provide support and validation.

In my personal life, my husband and I experienced the ups and downs of miscarriages and infertility. I was also adopted as a baby. These experiences have enabled me to be especially compassionate about all the experiences people have with regard to starting a family and to bring a very true non-judgmental attitude towards situations.

In the near future I hope to obtain my Perinatal Mood and Anxiety Disorder Certification. I also want to explore what other areas are doing with more and more mothers using marijuana and what this looks like regarding reports to the state, etc.

I am so glad I joined the NAPSW. As a member I will be more connected to others doing what I do, as it can feel like a lonely role at times (I am the only one at my Hospital in this role). I already feel more excited about my role now that I am able to focus mostly on MCH and have a little bit more time for professional development.

When I am not working or taking care of life's "duties" — which is not very often, but, when I do have time —I enjoy playing in a softball league with my husband, going to parks and for walks around town on our trails (most of the time with children), running on the trails (SOLO), and trying out new places to eat. We also love vacations and are getting ready for a Trip to Disney World for my sons' "Make a Wish, wish." My dad is a Veteran and lives in the Veterans Home about 1 hour away from me, so I spend time with him as often as possible. My goal in the near future is to volunteer to drive their van — to allow my dad and others more scenic drives, something my dad thoroughly enjoys.

Innovative Programs / Research Grant

The National Association of Perinatal Social Workers invites applications for the Innovation Programs/Research Grant. This grant provides seed money for perinatal social workers to fund special programs or research efforts that would otherwise be unfunded through their agency or place of employment. This purpose of this program is to:

- Assist social workers in funding new programs designed to identify or meet the needs of their client population.
- Encourage the translation of evidence-based findings to practice through the development of novel or unique interventions.
- Encourage the evaluation of best practices through research projects designed to inform practice.

Interested applicants should submit a 3 to 5 page proposal that includes the following elements:

- Discuss how the proposed project contributes to the objectives of NAPSW.
- Description of the need and population being served.
- Description of the program implementation or research plan to include:
  - –Aims
  - –How those aims will be carried out (specific plan)
  - –Outcomes–include evaluation of outcomes or benchmarks
  - –Time line
  - –Budget
  - –Agency letter of support

This program is open to social workers of any level currently practicing in a perinatal field, as well as full-time students currently enrolled in an accredited social work graduate or undergraduate degree program with a research agenda that directly relates to perinatal social work. Applicants will receive a one-time funding award in the amount of $1000.00 and are expected to submit a poster presentation of their outcomes or research findings at the NAPSW Annual conference the year following the award. A two-page summary of findings should accompany the poster presentation. Award recipients must be a member of NAPSW or agree to join and maintain membership in NAPSW for the year in which funding is provided.

Please submit proposals via email to Dasi Schlup at schlupd@health.missouri.edu no later than Friday, February 17, 2023.

Call for Papers

2023 Virtual Conference

www.napsw.org

NAPSW is seeking workshop presentations for the 2023 virtual annual conference. Specific areas of interest are:

- perinatal and social work ethics
- enhancing social work clinical skills
- surrogacy
- adoption
- difficult conversations with perinatal families
- antenatal support
- fetal diagnosis and support
- diversity and inclusion
- NAS
- end-of-life and bereavement
- staff support
- professional boundaries
- cultural competency
- perinatal social work research
- NICU

If you have would like to submit an abstract for consideration, or know of a speaker or topic that you'd like to be included in 2023, please email the conference co-chairs:

Heather Ousley OusleyH@email.chop.edu and
Adriana Salcido adrianamsalcido@yahoo.com