

A Blueprint for Advocacy in Neonatology

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OBJECTIVES *After completing this article, readers should be able to:*

1. Describe why neonatologists need to incorporate advocacy into their professional work to improve the health of all children.
2. Define physician advocacy and how advocacy work can create change for overall health and well-being of children and families we serve.
3. Recognize that neonatologists, as experts in the care of infants and their families, are in a unique position to incorporate science, data, and stories to create meaningful change.
4. Discuss how participating in advocacy can help neonatologists and other neonatology clinicians to reconnect with their purpose and joy in medicine.
5. Describe potential advocacy opportunities that can be incorporated into any professional child health career.

ABSTRACT

Advocacy is at the heart of pediatrics and neonatal care. Historically and currently, numerous pediatricians have used their expertise to raise the voices of children and families to promote child health and welfare. Despite a lack of formal training in advocacy and health policy, many of the skills required for daily clinical care can, and ought to, be applied to affect systemic change within neonatology. Advocacy can no longer be considered an optional activity, but rather a core competency and professional responsibility. In this review, the authors describe the necessity and foundational principles for advocacy success as well as provide guidance, resources, and opportunities for neonatologists and clinicians providing newborn care.

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INTRODUCTION

Neonatologists and other clinicians providing newborn care are uniquely positioned to be among the earliest advocates for the health and well-being of children. At its most basic level, advocacy involves using our professional expertise, credibility, and experience to ensure that the patients and families we serve are heard. Physician advocacy has been defined as, "action by a physician to promote those social,

economic, educational, and political changes that ameliorate the suffering and threats to human health and well-being that he [sic] identifies through his or her professional work and expertise.”(1) As neonatologists, we advocate for patients every day in the clinical care we provide; however, there is an urgent need for us to move beyond problem-solving for individual patients and families and collectively create positive sustainable change at the systems level (Table 1). (2)

THE FOUNDATION OF NEONATOLOGY: AN ADVOCACY STORY

The American Academy of Pediatrics (AAP) was created to support the health of children during the Great Depression, a time when the country had many competing hardships. (3) The catalyst for its development, the Sheppard-Towner Act of 1921, was the first major federal legislation that focused on improving maternal-infant health, through federal funding along with the medicalization of pregnancy and childbirth. This nonpartisan legislation was

instrumental in decreasing infant mortality rates and increasing federal support for both in-home nurse visits as well as for the dissemination of education around the care of infants. Although the American Medical Association (AMA) expressed strong opposition, pediatricians within the AMA voted to support the Act. Subsequently, with a working group of 35 pediatricians, the AAP was officially incorporated in 1930.

In its infancy, AAP members led the effort to create The Children’s Charter from the White House Conference of 1930 under President Herbert Hoover that stated, “If we want civilization to move forward...it will march only on the feet of healthy children.” The Children’s Charter included 19 innovative ideals that were created to better the lives of all children and specifically states “regardless of race, or color, or situation, wherever he [sic] may live under the protection of the American flag.” (4)

Similarly, the AAP Section on Neonatal-Perinatal Medicine (SoNPM) was born in the early 1970s when Dr Joseph

Table 1. Why Advocacy?

The What	The Why
1. Make use of expertise	Neonatologists are trusted experts by parents and decision makers in fetal, perinatal, neonatal, and early childhood health. They can use their medical expertise to influence decision makers in policy discussions related to health and well-being of their patients.
2. Translate experience	Neonatologists can contribute patient stories to illustrate the need for change on issues affecting their patients and families. Neonatologists can speak about a broad spectrum of advocacy issues, ranging from maternal health before conception to prenatal, neonatal, and early childhood.
3. Offer an antidote to cynicism	Neonatologists experiencing burnout and feeling that they have lost their voice can translate their experiences and patient stories into meaningful change beyond the bedside. This can create a new sense of purpose for neonatologists.
4. Fuel a sense of energy and community	Neonatologists can use their skills in a different way through advocacy, which can be energizing and empowering. Through curating a circle of like-minded advocates, neonatologists can experience an increased sense of community and belonging, and decision makers will notice.
5. Show strength in numbers	Neonatologists can collaborate with partners in medicine, education, child advocacy, parent groups, and more. The compelling patient stories shared by neonatologists will engage and empower others with similar interests.
6. Create and inspire change	Neonatologists can “be the change” as they create and inspire systemic changes by highlighting current issues affecting maternal and child health in their communities and states. This will elevate the health and well-being of children in these areas.
7. Influence policy	Neonatologists can advocate for policy change by making decision makers aware of problems affecting maternal and child health with real-life examples; providing education; and proposing practical solutions.
8. Encourage the democratic process	Neonatologists can leverage their expertise and experience to encourage patient families, colleagues, friends and family, and community members to vote with the health of sick and premature infants in mind.
9. Build long-term success in advocacy	The enthusiasm from advocacy is contagious and inspiring. By practicing and sharing advocacy work, neonatologists can empower more neonatologists and multidisciplinary team members within the NICU to take action to make continual and sustainable change.
10. Renew your commitment	Neonatologists can channel their passion and clinical expertise into system-level changes through advocacy. This is a powerful way for neonatologists to renew their commitment to making a difference and improving neonatal-perinatal care and outcomes.

Adapted from AAP Advocacy Guide. (2)

Butterfield recognized the need for a national forum for neonatologists. Following the blueprint for advocacy, a problem was identified: in this case, the need to encourage specific expertise in newborn medicine. In response, the founding executive committee brought awareness to decision makers, and together, they collaborated on a solution that resulted in the creation of what is now the largest section of the AAP and the professional home for neonatologists. (5)

The long-standing history of activism within pediatrics and neonatology ought to help us forge our path forward. In these unprecedented times, the COVID-19 pandemic and persistent racial injustices have further highlighted the need for renewed effort to honor the work of the founding principles of the AAP. Although the specific diseases affecting infants and children almost a century ago were different, the threats to overall child health and welfare remain, including health care access, health care disparities, and the impacts of social determinants of health. (6)

THE FRAMEWORK FOR NEONATOLOGISTS AS ADVOCATES

Neonatologists are advocates at the core. Even without formal advocacy or health policy training, physicians are privileged to be seen as having credibility, medical expertise, trustworthiness, and communication skills. (7) These attributes can be coupled with our authentic clinical experience to effect systemic change by sharing stories, data, and experiences with decision makers at the institutional, community, state, and/or federal levels. This individualized, narrative-based approach can raise awareness, promote education, and/or create policy to optimize child health and welfare.

Neonatologists also are uniquely situated to use their collective voice to improve outcomes for both maternal and child health. The mission of the AAP SoNPM specifically includes advocacy and states: “To improve the health and outcomes of the newborn infant, as well as the pregnant woman and fetus, through the sponsorship of programs which encourage the professional growth of the neonatal-perinatal providers, continuously improve clinical care delivery, support continuing and postgraduate education, foster basic, clinical, and outcomes research, and seek to advocate for our patients and their families.” (5)

Evidence demonstrates that as much as 85% of our health is related to social determinants, factors that lie beyond our scope as clinicians. (8)(9) We must use our clinical experience and expertise to identify opportunities to speak up for child health and welfare at the community and policy levels, where decisions on these determinants are made. Advocating at these levels may seem over-

whelming, not in the least because many of us were never effectively trained to do this work and lack the requisite skills. Consequently, a real or perceived lack of competence and confidence can be intimidating, even paralyzing. This sense can impede both our authority and our ability to act. However, the skills can be learned and the agency adopted. There are many resources and partners available to assist in this work (Table 2). (2) Many neonatal clinicians find it a natural extension of their daily work and are empowered by their ability to effect systemic change.

The benefits of advocacy work extend beyond its impact on patients and society to include individual neonatologists. Advocacy could be the burnout prophylaxis the profession of medicine is seeking. Leo Eisenstein recently wrote in the *New England Journal of Medicine*, “In this link between social determinants of health and burnout, I see a problem, but also a way forward. If individual powerlessness is the crux of this source of burnout, then organizing toward a collective action should be part of the solution.” (10). Participating in advocacy work can remind us of our “why”: the reason we choose a career in pediatrics and neonatology. Neonatologists want to make a positive impact on the lives of their patients and families. Advocacy allows us to have a more profound effect on larger populations of neonates and families beyond the walls of the NICU. As the cadre of skilled child advocates grows within the profession of pediatrics and neonatology, our collective impact can be colossal. At this critical moment in history, neonatologists must act as activists, leaders, scientists, and clinicians to drive change for the optimal health of the maternal-infant dyad.

ART OF ADVOCACY

Advocacy starts when the problem finds you, often from a clinical experience or patient or family narrative (Table 3). The next step is using your passion, experience, and expertise to build relationships, bring awareness to the problem, collaborate on a solution, and create a larger impact at a health care system or policy level. While it is true that change takes time, meaningful change can occur when small actions build upon one another.

Just as neonatology has evolved to achieve significantly improved clinical outcomes through advances in clinical care and science, it is time for advocacy to further spur change in neonatal care. From the evidence-based principles of the Neonatal Resuscitation Program, research and development of surfactant, and standardized feeding protocols, to quality improvement processes and clinical guidelines that ensure quality care, each advancement has built upon the others.

Table 2. Advocacy Resources List

Resource	Description	Link
American Academy of Pediatrics (AAP)	Provides the latest resources and information to guide advocacy efforts at the state and federal level	https://www.aap.org/
		https://services.aap.org/en/advocacy/
		https://services.aap.org/en/advocacy/state-advocacy/
AAP key contacts	Join email list to receive regular advocacy updates and alerts	https://services.aap.org/en/advocacy/become-an-advocate/
AAP Advocacy Action Center	Highlights federal child health issues and provides template to contact members of congress on key issues	https://services.aap.org/en/members/advocacy-action-center/#/home/main
AAP Blueprint for Children	Outlines a comprehensive child health policy agenda	https://services.aap.org/en/advocacy/blueprint-for-children/
AAP districts and chapters	Chapters are divided into districts for governing and election purposes. See district map illustrating organization of chapters into districts and current leaders.	https://services.aap.org/en/community/district-map/
	Chapters advocate for kids at the local level while providing education, quality improvement initiatives, grant opportunities, mentorship, and career and leadership development	https://services.aap.org/en/community/join-your-chapter/
AAP advocacy training modules	Advocacy modules teach basic advocacy skills in a user-friendly legislative advocacy curriculum and can be used for independent learning or as a guide for an interactive session. Includes slide presentations, trainer guides, case examples, and advocacy pearls	https://services.aap.org/en/advocacy/advocacy-training-modules
AAP Advocacy Guide	A complete advocacy handbook for pediatricians at all career stages with tips, tools, and examples of advocacy for child	https://downloads.aap.org/AAP/PDF/aap_advocacy_guide.pdf
AAP Community Pediatrics Training Initiative	National program “that aims to improve child health by strengthening community health and advocacy training” including pediatric resident engagement in the community, collaboration among residency programs to influence child health and policies, faculty development, partnerships with community organizations	https://www.aap.org/CPTI
Legislative decision makers	Find and contact your legislators and decision makers at the local, state, and federal levels	https://fiscalnote.com/find-your-legislator
		https://www.usa.gov/elected-officials
		https://www.congress.gov/state-legislature-websites
Vote!	Check to ensure you are registered to vote	https://www.usa.gov/confirm-voter-registration
Vot-ER	Nonpartisan, nonprofit organization with the goal of engaging health care professionals to empower patients to register and vote to improve health outcomes as policies implemented by decision makers greatly affect health and the health care system	https://vot-er.org/
Center for Children and Families of the Georgetown University Health Policy Institute	Nonpartisan policy and research center focused on promoting access to affordable, high-quality health care and health care coverage for children and families	https://ccf.georgetown.edu/
Center on Budget and Policy Priorities	Nonpartisan research and policy institute that engages in federal and state policies to reduce inequities and impoverishment through economic aptitude	https://www.cbpp.org/

Continued

Table 2. (Continued)

Resource	Description	Link
Annie E. Casey Foundation (AECF®)	Foundation focused on empowering children, families, and communities through research, evidence-based strategies, and solutions, and creating opportunities for children at high risk for adverse health, education, and/or economic outcomes.	https://www.aecf.org/
National Alliance on Mental Illness	Grassroots organization dedicated to improving overall health by focusing on mental health through awareness, education, and support for individuals and families	https://www.nami.org/
Children's Defense Fund	Originating from the civil rights movement, this organization champions policies and programs to provide every child with a healthy start early in life through access to quality health care, education, and safety in their families and communities	https://www.nami.org/Advocacy/Advocate-for-Change https://www.childrensdefense.org
Everytown for Gun Safety	Organization focused on uniting ordinary citizens with decision makers, teachers, students, gun owners, and mothers to mobilize and implement evidence-based solutions to end gun violence and foster safer communities	https://www.childrensdefense.org/policy/resources/soac-2020-child-poverty/ https://everytown.org
Court Appointed Special Advocates Guardians Ad Litem (CASA/GAL)	Organization that collaborates with state and local partners to support children who have experienced trauma, abuse, or neglect through court-appointed volunteers advocating in the best interest of the child with the goal of a safe and permanent home	https://everytownresearch.org/report/the-impact-of-gun-violence-on-children-and-teens/ https://nationalcasagal.org/
Safe Kids Worldwide ®	Nonprofit organization focused on child injury prevention including traffic safety, drownings and water safety, burns and fire safety, falls, poisonings, and home safety	https://www.safekids.org/
Feeding America Action	Hunger-relief organization that promotes a healthy future through nutrition and food security to those in need with a network of charities, food banks, government, and private sector partners	https://www.feedingamerica.org/
National Institute of Mental Health (NIMH)	Federal mental health research agency that aims to transform mental health disorders with the goal of prevention, recovery, and cure through basic and clinical research	https://feedingamericaaction.org/act/ https://www.nimh.nih.gov/

The addition of advocacy to the toolbox of neonatal medicine will continue this progression, providing a different mechanism for change on a different scale. In an ideal world, advocacy would not only inform system-level changes but also guide research questions and empower medical trainees to connect with and learn from their community to improve overall health of patients and their families. Advocacy could be the innovation that allows neonatology to continue to grow as a specialty in unimaginable ways, moving the work

outside the traditional clinical role, and upstream, in terms of systems change.

There are many opportunities to begin your quest for change, which can be done in a matter of minutes (Table 4). Professional societies like the AAP, at the national or regional level, provide important resources to amplify the voice of clinicians and make advocacy more efficient and effective. Neonatal care depends on the diverse skills of the multidisciplinary team to achieve target outcomes; no one

Table 3. Foundational Advocacy Principles

1. Let the problem find you.
<ul style="list-style-type: none"> ● It all starts with passion, concern, or even anger about what is important to us personally and professionally. ● We see a thing or two, so we need to do a thing or two. ● Principle in practice: Raise your awareness by scanning your daily practice and social media to identify what is important to you, your patients, and your families.
2. Think outside and upstream.
<ul style="list-style-type: none"> ● Our advocacy impact increases as we move from individual to community to systems level to policy. ● While we often want to address issues in our clinical wheelhouse, a focus on the root causes and determinants of health and well-being can lead to impactful and durable change. ● Principle in practice: Perform a root cause analysis of the issues that you have identified and try to address at least 1 of those root causes in your campaign.
3. Start small, fail small.
<ul style="list-style-type: none"> ● Often the problems are daunting, and we can be paralyzed by the scope and seemingly infinite complexity. ● Dream big but starting simply as a series of small wins can bring momentum. ● Recognize and celebrate small victories along the way! ● Principle in practice: Be sure that you and your team take an incremental approach and celebrate with them along the way.
4. Be credible.
<ul style="list-style-type: none"> ● Our credibility comes from our expertise, experience, and reliance on the best available evidence. We cannot betray that credibility. ● National and state AAP resources are always a great place to start. Use the chapter for help. ● Provide district/state level data to decision makers. ● Principle in practice: Apply the same level of scientific rigor in data as you would for clinical work. Engage with policy experts in your local and national AAP chapter and other reliable resources such as those listed in Table 2.
5. Assume someone has already figured it out.
<ul style="list-style-type: none"> ● Steal shamelessly and share selflessly. ● Investigate what might already exist around your problem locally, regionally, or nationally. ● Principle in practice: Reach out to national or state AAP for resources on a problem you would like to advocate for a solution.
6. While data are essential, stories can change the game.
<ul style="list-style-type: none"> ● “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”— Maya Angelou ● Combine your message with personal stories to put a human face on an issue. ● Draw attention to solutions and emphasize how others can contribute to problem solving. ● Principle in practice: Connect your story with local data to illustrate importance.
7. Remember the 5 Cs for effective messaging:
<ul style="list-style-type: none"> ● Clear = Say it simply. ● Concise = Keep it short and sweet. ● Correct = Speak the truth and share the data. ● Colloquial = Use normal English. ● Clear = Remember to say it simply.
8. We cannot (and should not try to) do it alone: relationships and coalitions are key.
<ul style="list-style-type: none"> ● Community partners increase advocacy efforts exponentially in strength/power, momentum, and effectiveness. ● Think of other individuals, organizations, alliances, and coalitions that you can involve to accomplish your advocacy goals. ● Principle in practice: Start with people you already know. Communicate the significance of your issue, the value added by their participation, and align your goals with those of your partners. Find the win-win!
9. Make sure we are doing things WITH communities, not TO them.
<ul style="list-style-type: none"> ● Physicians often assume they know the problem and the solution best. This works for clinical medical issues but may not work for your community. No orders or prescriptions in advocacy! ● Assume the community is the expert on the community. It is essential we listen and develop authentic partnerships with them. ● Principle in practice: Engage and include members from the community affected by the problem in codeveloping an advocacy campaign.

Adapted from the CPTI Project Planning Tool (13) with permission from Ben Hoffman.

person can be an expert at all things. Advocacy also hinges on this same concept. You are only one person, but once you find your passion, you will find a community and create collaborations. It often does not matter what you do or where you start, but rather that you take action and do *something*.

CALL TO ACTION

Looking to our past for guidance, advocacy has been at the core of pediatrics since its inception as a specialty. Dr Isaac Abt, the first president of the AAP said, “It should be our aim

to discover neglected problems and, so far as in our power, to correct evil and introduce reform.” (11) More recently, leaders within pediatrics have recognized that physician advocacy should no longer be an optional endeavor, but rather a professional obligation. (12) With the privilege of caring for the youngest of children, our responsibility to create change is the greatest. Neonatologists and clinicians providing health care for newborns must incorporate advocacy into our core skill set, as being as important as neonatal resuscitation, in helping infants survive and thrive.

Table 4. Advocacy Opportunities: What you can do in 5, 30, 60 minutes or more

Advocacy opportunities in as little as 5 mins
<i>Patients and partners</i>
<ul style="list-style-type: none"> ● Be aware of issues and potential barriers affecting your patients and learn how these issues relate to policies at the local, state, and federal level ● Identify local community partners who are likely to care about issues affecting your patients ● Identify a patient story to illustrate why an issue you care about is important, ask yourself, “how does this affect children’s health?” ● Share an advocacy story or opportunity at a group practice meeting to raise awareness
<i>Legislative advocacy</i>
<ul style="list-style-type: none"> ● Identify your state and federal legislators, and review their official websites (state/federal legislature and campaign sites) ● Contact your local, state, or federal decision maker about an issue you care about at https://www.usa.gov/elected-officials ● Learn about how Congress stands on issues you care about by going to: http://www.vote-smart.org ● Look for opportunities to talk to others about the value of voting on issues related to the health of children
<i>AAP advocacy</i>
<ul style="list-style-type: none"> ● Sign-up for AAP Capitol Connection alerts to ascertain when you can weigh-in on federal bills affecting children’s health at https://services.aap.org/en/advocacy/become-an-advocate/ ● Contact and join your AAP chapter ● Sign up for state advocacy e-mail alerts to receive updates ● Sign up for the AAP SoNPM advocacy listserv at https://services.aap.org/en/community/aap-sections/sonpm/neonatologists/advocacy/advocacy-listserv/
<i>Local communication and media</i>
<ul style="list-style-type: none"> ● Find the website of your local newspaper and set it as your home page on your computer ● Watch the news, listen to the radio, or read the paper; identify and reflect on how stories may affect children’s health ● Look for opportunities at work to discuss issues that are important to you and share your thoughts with your patients’ families, colleagues, friends, and family members ● Write social media posts on an advocacy issue you care about
Advocacy opportunities in <30 mins
<i>Patients and partners</i>
<ul style="list-style-type: none"> ● Maintain an advocacy journal that summarizes the issues you see at work and how to talk about them with others ● Identify child advocacy groups in your community and state (see Table 2) and follow their advocacy agendas online ● Search online for advocacy organizations or community groups working on the issue(s) you care about. Sign up to obtain updates and alerts or contact them to learn how you can get involved. Add their website as a favorite on your computer ● Ask your patients’ families about barriers they experience to voting and help them find a solution, such as connecting them with a community resource that can provide transportation or childcare ● Order promotional material such as buttons, stickers, or brochures from advocacy organizations and distribute to your friends, families, colleagues, or create your own
<i>Legislative advocacy</i>
<ul style="list-style-type: none"> ● Meet your state legislators by attending a town hall, or over coffee ● Contact your candidates with an issue that is important to you. Provide them with credible links to find more information on child health ● VOTE! Either in person or by absentee ballot
<i>AAP advocacy</i>
<ul style="list-style-type: none"> ● Contact the AAP to get nonpartisan election buttons, stickers, or magnets related to child health. Wear and exhibit while at work and in your community ● Contact your AAP chapter to learn about active state and federal issues and the status of these bills in the legislative process. Join their advocacy committee, if they have one
<i>Local communication and media</i>
<ul style="list-style-type: none"> ● Write a response about an issue you care about on your newspaper’s comments page, blog, or website ● Develop a social networking page or participate in a social networking group that shares your interest in children’s health and well-being ● Log on to a nonpartisan children’s health website (see Table 2) to learn the candidates’ views on the children’s health issues that are significant to you. ● Meet with your institutional government affairs/relation and media affairs teams to establish a relationship
Advocacy opportunities in >1 h
<i>Patients and partners</i>
<ul style="list-style-type: none"> ● VOTE! Either in person or by absentee ballot ● Talk to a local community-based organization about an issue that is important to you ● Present Grand Rounds on an advocacy issue that impacts child health
<i>Legislative advocacy</i>
<ul style="list-style-type: none"> ● Go to a city council, county commissioner, or state legislative hearing, or congressional townhall meeting that is presenting an issue that you care about
<i>AAP advocacy</i>
<ul style="list-style-type: none"> ● Join your AAP chapter in going to your Capitol on Advocacy Day ● Attend the AAP Advocacy Conference
<i>Local communications and media</i>
<ul style="list-style-type: none"> ● Write an Op-ed or letter-to-the-editor on a topic you are passionate about

Continued

- Attend a media training from your institution, chapter, or national AAP
- Meet with the advocacy training director for your residency program to share your passion and expertise for community health and advocacy

The long game: advocacy opportunities over weeks, months, years

- Build relationships with decision makers and offices of elected officials
- Meet with your legislators to propose or advocate for laws, join the board of directors for a community-based organization
- Appointment to governmental councils and bodies
- Run for elected office
- Contact your AAP chapter and sections and ask about opportunities to serve

Adapted from the American Academy of Pediatrics (AAP) Advocacy Guide. (2)

American Board of Pediatrics Neonatal-Perinatal Content Specification

- Know the issues in the organization of perinatal care (e.g., regionalization, transport, practice guidelines, benchmarking data, quality improvement) for Advocacy.

Suggested Reading

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