

SPECIAL ARTICLE


Developing careers and strategies to promote advocacy and child health the APS-SPR virtual chat series

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Pediatric Research (2023) 93:63–71; <https://doi.org/10.1038/s41390-021-01826-7>

Steve Abman (SA): We are pleased to welcome you to our joint American Pediatric Society (APS) and Society for Pediatric Research (SPR) Virtual Chat Series on the challenges of academic medicine. Past sessions have included conversations on many aspects of academic medicine, including issues of career development, navigating career transitions, the “pipeline,” valuing and achieving diversity in academic medicine, and many other topics. Today’s session is entitled “Developing careers and strategies to promote advocacy and child health.” As pediatricians, we clearly recognize the vital importance of advocacy to optimize the health and well-being of our children and their families. Success within many roles, achievements and activities of academic medicine, as related to clinical care, research, training, community engagement, and public policy are all strongly dependent on successful advocacy. This is especially true in this time of so many overlapping challenges, including COVID, health disparities, racism and social injustice, and many issues regarding health-care delivery.

As advocacy has become so prominent in pediatrics, strategies regarding how to best train pediatricians to develop advocacy skills, expertise in this area as a career path, and leadership opportunities, reflecting our values of diversity and inclusion, are under extensive planning and implementation. Today, we will hear from three outstanding experts and leaders in advocacy during today’s session, whose extraordinary careers illustrate a full range of advocacy issues throughout pediatrics. It is my pleasure to briefly introduce our panelists.

The first is my good friend and colleague, Dr. Jon Davis, who has had an extraordinary career wearing many hats as scholar, scientist, clinician, academic leader, and advocate. Dr. Davis is the Vice-Chair of Pediatrics and Chief of Newborn Medicine at Tufts University. At Tufts, he serves in many additional leadership roles, which include Associate Director of the Tufts CTSI and Director of the Tufts Trial Innovation Network Center. He is also the Chair of the Neonatal Advisory Committee in the Office of the Commissioner of the FDA. He is Director of the International Neonatal Consortium (INC), which works in partnership with the FDA, NIH, European Medicines Agency (EMA), Critical Path Institute and others to coordinate activities of these diverse groups to improve the development of novel therapies for neonatal diseases. Jon has had major impact in many areas and has been especially successful linking academics with government agencies such as the NIH and FDA. Dr. Davis also serves on numerous

advisory boards and has been actively engaged in many legislative efforts over the years. Most recently, he has been especially active in tackling issues related to opioid addiction and the neonatal abstinence syndrome. Finally, he plays a key role in the APS Council and as a member of the Pediatric Policy Council.

Our second panelist is Dr. Moira Szilagyi who was recently named as President-elect of the American Academy of Pediatrics. Dr. Szilagyi is Professor of Pediatrics at UCLA, where she is also the Division Chief of the Developmental Behavioral Pediatrics Program, and is the Peter Shapiro Term Chair for Enhancing Children’s Development, and Behavioral Health in Pediatrics. Dr. Szilagyi has had an extensive, impactful and a very successful career as a clinician, administrative leader, and advocate for child health throughout many activities, especially as related to developing programs and health services for children in foster care, child abuse programs, and she has played major roles in establishing health guidelines for children and adolescents in foster care. She has served on many different national task forces, especially within the AAP. Dr. Szilagyi has been involved in many councils and organizations that address the needs of children and their families involved with child welfare, so clearly advocacy has been central to her outstanding work. She continues to work closely with the AAP Legislative Office in DC, specifically focusing on issues affecting vulnerable children and their families.

Our third panelist is another outstanding talent, Dr. Gary Freed. Dr. Freed is the Percy and Mary Murphy Professor of Pediatrics at the University of Michigan School of Medicine, and is also Professor of Health Management and Policy in the School of Public Health at the University of Michigan. He serves as the Director of Faculty Programs in the Office of Health Equity and Inclusion, and as the Associate Chair for Diversity, Equity, and Inclusion in the Department of Pediatrics at Michigan. Dr. Freed has had an enormous impact during his 30 years of leadership, primarily related to children’s health service-related research and advocacy. He has been the principal investigator of numerous grants on child health policy and health economics, immunizations, health-care quality measurements, physician behavior, and challenges to enhancing the medical workforce. He has an amazing curriculum vitae, which includes over 300 peer review articles, along with his many national leadership roles. He is past president of the SPR, past Chair of the Department of Health and Human Services National Vaccine Advisory Committee, and a Fellow of the AAP. His outstanding work has been recognized by

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many awards, including the Distinguished Alumni Award from Baylor College of Medicine and the Lifetime Achievement Award in Pediatric Health Services Research from Academy Health in 2019.

Finally, I am honored to introduce our co-host, Dr. Stephanie Davis, who is the Chair of Pediatrics at the University of North Carolina and President of the SPR. Dr. Davis will lead the panel and manage the discussion for today's session.

Stephanie Davis (SD) I would also like to welcome Dr. Davis, Dr. Szilagyi, and Dr. Freed. We will begin with Dr. Jon Davis.

Jonathan Davis (JD) Thanks very much, Stephanie, and thank you Steve for that really nice introduction. It's a pleasure to be here. I'm going to discuss several issues and the major take-home message that I hope you hear, is "don't let anyone ever tell you that one person can't make a difference." Each of us can really have a substantial impact which you'll hear throughout my comments. I'm going to focus on how clinical care is linked to research and advocacy and all three are inter-related and fit well together.

I knew I had promise in the area of advocacy as an intern at Boston Children's Hospital during my rotation on the old Division 27, the "baby ward." We just finished rounding with our Chief, Dr. Mary Ellen Avery, and we were sitting in the on-call room which also served as our office on the floor. Someone was sitting on one of the broken chairs and fell off. We were all commenting on the terrible condition of the office. So, I said, "we've got to do something about this." I picked up the phone and I called the Head of Environmental Services. I said, "this is Dr. Davis and I just finished rounding with Dr. Avery and she was shocked at the terrible condition of this on-call room." Dr. Avery was so upset and I told her that I would take care of this issue on her behalf. I said "you need to come up here and fix this office." Well 20 min later, someone arrived from Environmental Services and agreed that it actually was in terrible condition. Later that week, they painted the office, put in a new bed, put up new curtains, and fixed all the desks. We had a much better on-call room.

My real passion for advocacy started with my first job at the University of Rochester, where Moira and I were young faculty together. I was part of a Specialized Center of Research and was recruited by Don Shapiro, a brilliant guy who I tremendously respected. I had been approached by a company from the Weitzman Research Triangle in Israel because they had a product called "Recombinant Human Superoxide Dismutase." They thought it might be interesting to study this drug in preterm infants as a way of preventing acute and chronic lung injury caused by oxygen and mechanical ventilation. So, I set up a piglet intensive care unit at the University of Rochester and studied this drug in piglets. At the same time, we were studying this drug in cell culture models. We were also conducting gene transduction experiments. I reached out to someone who I had read about. His name was Dr. Steve Abman. He was in Colorado and along with his colleague, John Kinsella, we really formed a strong friendship and collaboration. Steve provided me great advice regarding these studies. After we made it through the piglet studies, showing that the drug really did seem to make a significant difference in lung histology and prevention of injury, we did a phase one study in preterm infants and then a phase two study. We enrolled 302 infants with half having received the antioxidant.

When we went to the FDA to present our data, we asked Steve to accompany us and present our results. He really did a magnificent job telling them that this drug was going to have a major impact in preterm infants. The problem was that there were no pediatricians in the room with us; no one had an understanding of what it was like to take care of a 24- or 25-week preterm infant. At 1-year corrected age, there was about a 50% reduction in hospital admissions, 50% reduction in emergency room visits, 50% reduction in retinopathy of prematurity, severe brain injury, and the use of asthma medications in infants who

had received the antioxidant. Some reviewers told us that it was too good to be true. They just didn't believe that the drug could work that well on this high-risk population. Ultimately, some of the infants had infections and we tried to convince them that certain bacteria were known contaminants and that most of the supposedly infected infants were treated for only a few days with antibiotics. The repeat cultures were all negative and the infants thrived and did well. None of these changes were statistically significant. Despite Steve's best efforts (I was told to keep quiet and sit in the corner and not say anything), the FDA division at the time requested a variety of immune and anti-bacterial studies. The FDA asked the company to spend the next 1 to 2 years conducting these types of studies. Ultimately, the company decided that it was not in their best interest to continue the program and shelved the drug. I was devastated because I thought this was going to be a major advance in care and yet we had to walk away from it.

The story continued at Tufts when I joined the CTSA program led by Harry Selker. I was appointed as the Pediatric Representative to the Child Health Oversight Committee and started working closely with Steven Hirschfeld, who was at NICHD and had led the National Children's Study. He had been at the FDA and we discussed our passion for drug development for children and that so many of the drugs that were being used for children were not FDA approved for this population. This really had a major impact on my career. I was appointed as the Chair of the Child Health Oversight Committee. In that role, I was able to contact people at the FDA. In particular, I met with Diane Murphy, who was the head of the Office of Pediatric Therapeutics and a real champion for children. I received a request for an interview from the General Accounting Office (GAO) because Congress needed a report highlighting the performance of the Best Pharmaceutical for Children's Act. They had heard that it was not helping neonates and that over 90% of the drugs were not FDA approved. There was minimal research at the time in this area.

I was smart enough to reach out to my colleagues. I contacted two people, Rich Polin and David Stevenson. We had a 2-h interview with multiple members of the General Accounting Office, informing them that this law had not really helped neonates. Well, fast-forward to the FDA Safety and Innovation Act that was passed by Congress; this Act mandated that the FDA hire more neonatologists and pediatric epidemiologists and that any drug developed for adults had to also have a pediatric plan for development, similar to Europe's policy. This was really revolutionary and significantly changed the agency. The FDA started hiring neonatologists, including Gerri Baer, who is just spectacular, and a number of other pediatricians. My good friend and colleague, Suzie McCune, was appointed the Director of the Office of Pediatric Therapeutics. They asked me to establish the first Neonatal Advisory Committee and to join the Pediatric Review Committee. Suzie is a real champion for children and one of my heroes. You can have a hero at any stage of your career. She is passionate about developing drugs for children, assuring that these drugs were safe for children, including children in clinical trials, and developing an International Neonatal Consortium. The regulators from Health Canada, the EMA, the Pharmaceutical and Medical Device Agency of Japan (PMDA), FDA, and others were driving the need to develop drugs for children. I thought this was a great idea.

I became the Director of this group and 3–4 years later, we have over 350 members from approximately 40 countries and every major pharmaceutical company. This was a major step forward. However, the Regulators couldn't lobby Congress. They couldn't really speak out due to being public employees and members of the government. They really taught me so much about what needed to be done and that has really stuck with me. I could speak loudly about these issues. Around that time, a fellow asked me, "Dr. Davis, you know, we have two infants in the NICU whose

mothers were both on methadone and one baby has severe neonatal abstinence syndrome (NAS) and withdrawal. The other baby is fine and the mothers were on the same dose. Why is that?" Of course, when you are asked questions and you don't know the answer, you realize that this is important. We've been using these drugs to treat opioid withdrawal in infants for many years and yet none of the drugs are FDA approved. There actually had never been a multi-site clinical trial of any drug in neonatal abstinence syndrome, so I wrote a grant to study this and the grant was funded. We were also interested in the genetics of NAS. Why are these two infants so different? We reached out to people like Bob Ward in Utah and Jack Aranda in Brooklyn as well as others who had extensive experience with opioids and pain. We received ideas about different genes that we may want to study. My fellow's project involved studying about 100 infants and examining differences in single-nucleotide polymorphisms in the opioid receptor gene. That paper was accepted in *JAMA* and reported significant differences between infants who had more severe signs of withdrawal compared to those that did not. Her project won the PAS Outstanding Fellows Project award. I became much more interested in the opioid epidemic.

Well, it was also very timely with the opioid epidemic growing dramatically. We were all wrestling with this epidemic as a major public health issue. At the same time, there was a new Congresswoman who had just been elected for her first term. Her name was Katherine Clark. Katherine was very interested in opioids and reached out to the NIH. The NIH informed her that I was interested in this area and just received grant funding. I met with Katherine and she was very interested in helping to protect these infants and their families, while reducing some of the stigma associated with NAS. We became good friends and colleagues and she drafted legislation entitled the "Protecting Our Infant Act." Katherine, the AAP, the March of Dimes, and ACOG all worked together and asked me if I would help get the legislation passed by speaking to the House of Representatives. I did speak to the House of Representatives and it was standing room only. I was delighted to see this much interest and the bill passed by unanimous vote in the House.

Then I was contacted by folks in the Senate who said "you did a pretty good job in the House, how about trying this in the Senate since we need to have someone sponsor the bill" I mentioned that I was concerned about the people of Kentucky, because they passed a law in Tennessee outlawing opioid use during pregnancy. Any woman who used opioids outside of a prescription would get arrested and placed in jail. Many women started driving across the border to Kentucky and delivered their infants there, so they wouldn't go to jail. I said that "I feel bad for the people of Kentucky, because Kentucky Medicaid is paying for all these people from Tennessee who cross the border and deliver their infants who then need prolonged treatment for NAS."

Two days later, Mitch McConnell announced that he was going to sponsor the legislation in the Senate where it ended up passing by unanimous vote as well. So once the bill passed, Katherine invited me to the State of the Union address where President Obama was speaking. I sat a few rows behind Michelle Obama. We had dinner in the Congressional Dining Room. I met Nancy Pelosi in her office and she was fascinated by the opioid work we were conducting. Katherine and President Obama actually sent me the signed legislation in a frame that now hangs on my wall.

I have participated in 46 federal advisory committees at last count because I thought it was important when I was funded to give back. These committees involved NIH, FDA, and Substance Abuse & Mental Health Services Administration. I am now working with Dr. Shahla Jilani and Rear Admiral Brett Giroir, the former Undersecretary of Health, who are coordinating the opioid response among all the different agencies of the federal government. So, that has been a terrific learning experience.

This work has led to me participating in advocacy efforts at the APS and SPR. I represent the APS on the Pediatric Policy Council, which has had a really tremendous impact. I've worked on the APS Advocacy Committee and on APS Council which has really made a difference. So, there are many opportunities for folks that want to do this type of work. I'm happy to talk to any of them. We'd love folks to be more active in advocacy efforts. I often say, "if not us, who, and if not now, when." The kids need our help. There's so much we can do and I think there are opportunities to start small and reach out to specific people within government. I was fortunate enough to spend time with Diane Murphy and even more now with Suzie McCune. These folks have really been real champions and can help you make a significant impact. So, I think I'll stop there and turn over to you, Stephanie.

(SD) You are right: one person can make a difference. For those who are new to advocacy, what are important skills to learn?

(JD) I often get asked "how do you participate in advocacy efforts?" I encourage the younger people at SPR and members of the APS to participate in advocacy efforts. I'll be curious to hear what Moira and Gary think about this as well. You can't be bashful and you have to feel comfortable reaching out to experts. I was smart enough, even through my research efforts, to reach out to people like Steve, to develop collaborations and friendships. This really makes a huge difference. This provides you with opportunities to see who is working in the field. Where else can you go? Who in the government is interested in these particular areas? When you're in Washington, reach out to your Representative or to your Senator and go to their office. Meet with their health aides, tell them about your interests, and what you'd like to see done. They really do listen and you create opportunities to make a difference on your own. Shetal Shah from SPR is now the Chair of our PPC. We work closely with the folks from the government affairs group of AAP, which is spectacular. The briefings we receive makes me feel like I'm sitting in the Oval Office. They inform us about what's happening in the health field. They are really valuable assets for all of us.

(SD) Moira will now tell us about her personal journey and share her wisdom regarding advocacy and child health.

Moira Szilagyi (MS) Thanks, Stephanie. I don't know if my advice will be as great as Jon's. Jon was much younger than me when we were both young faculty, but we were at the University of Rochester at the same time. My passion for advocacy also began during residency, but I don't think I even realized that that's what I was doing at the time. It actually occurred to me 10 years later, when somebody asked me to give a presentation on advocacy, when I said, "well, I don't participate in advocacy efforts" and they said "yes, you do." My self-insight was perhaps not as great as it should have been.

In Rochester I was job sharing my residency with another woman at a time when women really didn't have babies in medical school, yet both Jennifer and I did. My colleagues might remember residency was about 110 h a week back then, which was not really conducive to raising children. So, we job shared our residency, 2 months on and 2 months off, which I think is almost impossible to do anymore.

During my months off, I had this amazing opportunity to explore a variety of different pediatric experiences in and around Rochester, as well as spend more time with my children. So, I worked in a variety of settings, including a clinic for immigrant farm workers and an FQHC. I knew that I wanted to work with vulnerable children. I'm an immigrant, my parents had eighth grade educations, and I was the first in my family to graduate high school, let alone college or medical school. I had lived on the other side of a divide in our country, where we were uninsured. My father was a construction worker, and our biggest fear was that he would be injured. When we finally did receive health insurance, my parents struggled to pay for health insurance, which was \$90 a month, while our rent was \$35 a month, just to cover my dad.

I also witnessed some of the discrimination against immigrants at that time in the United States. So, I knew I wanted to work with vulnerable populations. I just hadn't really identified which one. Then one of the local doctors in Rochester who was working every Thursday morning for 2 h in a foster care clinic at the Health Department asked me to cover for her while she went out on maternity leave. I agreed. I walked into a clinic that conducted what I called the "army physical". Children all received a 9 AM appointment and a number. One doctor lined up the kids and literally looked in all their ears, then their throats and then listened to their chests. It was shocking because that was not the type of care that we were being trained to administer as part of the Rochester residency program. We were trained to administer in person-centered care at Rochester, which was the home of biopsychosocial medicine. So, I decided to speak with the leadership to alert them about what was happening in their clinic, completely expecting that they would change it immediately. However, as Mark Del Monte, our CEO at the AAP always says "hope is not a strategy." I quickly realized that the then health department director was focused elsewhere. So, I without an appointment, I wandered into the office of the Deputy Commissioner of Social Services, who immediately expressed an interest in making changes and implemented a taskforce to look into the health-care needs of these kids. I found myself assigned to this task force as a second-year resident with city and county leaders, including the head of a FQHC and the Deputy Commissioner of Social Services. I was a little bit intimidated, especially when one day, the team turned to me and said, "well, why don't you give us some ideas of how best to serve these children?" They tasked me with finding models of care and conducting cost and benefit analyses for these models of care. I quickly realized that I had a lot to learn about implementing system changes.

At that point, my knowledge of child welfare was limited and nothing in residency had prepared me to think about systems. Yet, I would say, at this point in my career, I started to realize that system problems require systemic solutions, and the task force taught me a lot about how to approach these types of issues. So, I took this very seriously, produced four models of care, conducted cost analyses, without really having the depth of knowledge to do it well. However, the task force agreed with my top recommendation and agreed that this option was the best and most economical way to provide care for children in foster care. This model centralized the care on-site at the Health Department by expanding and altering the current clinic. They then offered me a job when I completed residency to implement this change.

I graduated just in time to assume the medical directorship of what I identified as a "private practice model." The term medical home wasn't really being used in pediatrics then, but this model really was a centralized, pediatric medical home in the public health setting for children in foster care. Two years later, I suggested to the Chair of the Pediatrics Department, Dr. MacAnarney, that the Department should start a regional child abuse center, mostly because I discovered that everyone was sending children to me and the foster care clinic. I was not set up to conduct child abuse work as it should have been done. Dr. MacAnarney agreed and invited me to lead the effort. So, for a while, I had what felt like two full-time jobs. It was my entry to academic medicine.

As I started on the path of building the foster care clinic, I also realized that there was very little literature in pediatrics, perhaps two papers. All the literature focused on social services and mental health. So, I had to really learn a lot about these children and their needs. I learned that the issues of caring for a complex, highly mobile population of children were national in scope. There was no care coordination. There were high levels of mental health problems. Children would enter foster care with multiple medical diagnoses, developmental delays, and behavior problems.

I began working with mental health leaders in town. These children had tremendous grief and loss issues after being removed

from their families as well as histories of child maltreatment. I kept thinking that there had to be an underlying explanation for all the symptoms that I was seeing. In 2001, I started working with trauma experts in Rochester. These psychological trauma experts were Dante Cicchetti and Sherie Toth at Mt. Hope Family Center. I really started to understand that complex trauma was the unifying diagnosis for all the symptoms I was seeing. We were trying to treat a panoply of issues (depression, anxiety, learning issues, developmental delays), but in pediatrics, we did not have a good approach to help children heal from trauma.

Shortly after I started the clinic, a new health director, Andy Doniger, was named. When I approached him for more funding to integrate mental health care, he asked questions me two important questions. The first question was, "Who are your customers?" Of course, I said the kids. Then he asked, "But, who else?" It was a great question because in advocacy you have to know your customers. Your customers are going to become your partners. I quickly realized that the list of customers also included foster and kinship parents, mental health leaders, child welfare leaders, child welfare, child advocates, the court, and legislators. Foster care is a very bipartisan issue, at the local, state, and national levels.

At the AAP, our motto is "advocacy is a team sport." The team sport is not just across your institution, but also across all the people whom you are serving. My advocacy work has always been population-centered, children in foster care. I knew I couldn't fix everything, although I wanted to try. My goal was to optimize their health during the time that they were in foster care by providing them the best possible health care, the type of health care that any parent would want for their child in this country.

I also had to develop some talking points. I'm actually basically an incredibly shy person. I prefer to be in the background. Advocacy thrust me outside my comfort zone, but I did develop talking points. I could give an elevator speech in about two floors. "Children in foster care are a vulnerable special needs population with really poor outcomes, but we know how to meet their needs and improve those outcomes." I could usually get somebody to listen to me.

It also helped to have anecdotes about real children. One of the huge advantages of advocacy in pediatrics is that we use science and ethics, to inform advocacy. It does help to have those individual stories. Similar to Jon, due to my work in foster care issues with the AAP, I ended up testifying before Congress. I was new to foster care at that time and we had a surge in HIV-positive infants who were dying. I lost six patients in 11 months to AIDS. Congress was going to introduce legislation to prevent "experimenting" on HIV-positive children in foster care with new drugs. That experimental medication was AZT. It was the only option to treat any HIV-positive child. My job was to tell the stories of my patients in foster care who had died and those who were surviving now that they had the same access as any other HIV-positive child to this experimental medication. In this case, advocacy was designed to stop legislation and it worked.

In working with others whose viewpoint may differ from mine, I always express appreciation towards their commitment to children. I was raised to be persistent, patient, polite, and to listen, even if I disagree. It is really the way forward to finding common ground. I've worked on several pieces of federal legislation behind the scenes with the AAP. Since 1997, we've had probably five massive pieces of child welfare legislation. The AAP has been a powerful advocate for children in foster care, often working with multiple other child advocacy agencies and professional health-care organizations across the country. We bring the science to support the advocacy agenda.

I do want to highlight the Academic Pediatric Association (APS). They recently implemented an APA Health Policy Scholars Program, a 3-year faculty development program focused on advancing academic careers in health policy and advocacy. They

have 23 scholars from the US and Canada in their new class. This is a golden opportunity for general academic pediatricians to build skills and credentials in this area of work.

The AAP also has a national advocacy conference every year, and Stacey Abrams is our keynote. This conference provides skills training and focuses on one high profile children's issue. Participants can then meet with their Congressional representatives about this issue during the conference. This year, the conference is virtual. However, based on a day we just spent "on the Hill" virtually advocating for immunizations, these virtual meetings can be quite effective. There is an advocacy section on the AAP website where you can also find the Blueprint for Children, the AAP's proposal for the child health transition plan for the Biden Administration (much of which they've accepted), information about specific advocacy topics, a sign-up to become an advocate with the AAP, and detailed guidance on how to become an advocate.

I always say that "P is for advocacy". It is not that I don't know how to spell. There are a lot of important P words that are good to remember: identifying the **problem**, finding **partners**, having a **passion**, establishing your talking **points**, having anecdotes about **people**, being **positive**, **persistent**, **patient**, and **polite**. Thank you.

(SD) I love the "P's" that you just highlighted. For those who are active in advocacy, how does one achieve academic promotion at their medical center?

(MS) Advocacy has largely been viewed as a sideline in academic medicine. I think sometimes we may underestimate how promotion committees view advocacy, and I have observed at least two pathways. I think one pathway is to become an academic expert and leader in advocacy. This means building your own portfolio of skills and also becoming a leader. Many of our residents and medical students are engaged in advocacy. They need leaders and educators to teach and mentor them about advocacy, join them on advocacy missions, perhaps in partnership with the AAP, or with other community partners. I think that's one way to build academic credentials.

The other pathway is to make advocacy a natural extension of the rest of your work. I have been laser-focused on children in foster care for over 30 years now. The committee in Rochester, that promoted me to Professor, appreciated my deep scholarship in this population, scholarship that was comprised of clinical work, research, education, policy, and advocacy work. One of my younger faculty at UCLA was recently promoted from Assistant to Associate Professor for similar reasons. She has that same laser focus on a population of interest: youth involved with juvenile justice. She was deeply involved in translating some of the evidence from her research and that of others into legislation in the state of California.

Academics is about scholarship. I think these two approaches can be used together or separately to be potential pathways for faculty development and promotion, with the added advantage of translating important work into policy.

(SD) We are now going to turn to our third panelist, Dr. Freed, who will share his personal stories as well as wisdom regarding advocacy and child health.

Gary Freed (GF) I'm actually going to speak about a cautionary tale, the interface of advocacy and research, and the responsibilities surrounding this interface, especially if your research is in the realm of public policy, or the realm of health economics. These areas of research are political and highly charged. You honestly don't know who's going to be in power. Some of the time, it's going to be Democrats and some of the time, it's going to be Republicans. It doesn't matter who you like, that's just the way the world is going to be. If you stake out a particular position, and your research only supports a particular position or side, let's say reliably, then you're only going to be listened to half of the time. This is because the Democrats have their own think tanks from whom they receive pre-determined answers and the Republicans

have their own think tanks from whom they reliably receive their results. The question that arises, is, "what's the role of the researcher in this game, and how can the researcher be trusted, theoretically, no matter who is in power?" For those doing public policy research, the goal, I believe, is for people to not know your politics by your data. It doesn't mean you can't have an opinion. However, you need to be trusted, whether there are Democrats or Republicans in power.

Sometimes, I think we are so passionate about certain issues that quite honestly, for those of us who are engaged in this work, it can have an impact on the way in which we conduct what we might call "science." Sometimes it means that people end up doing studies to "show that", as opposed to "if." This happens all the time in our meetings. People say: "We need a study to show that kids need this," or "we need a study to show that." We're playing our biases out in front of others and I would contend that there are limited resources for health care, period. Those resources for kids are even more limited.

Because of this, we need to make sure that every dollar spent is a dollar well-spent. Even if it's our pet program, we must have the courage to be able to say whether it works or not. We're only going to be able to do this if we conduct studies to see "if," not "show that." I'm sure you've all been in rooms where people look at data that doesn't fit with their pre-conceived notions. When that happens, we change our analysis plan, or we change the variables in the regression. Well, maybe we shouldn't have put in that variable. Let's see what it looks like if we take that variable out. We're doing that analysis because we want a pre-determined result, and it doesn't fit with our ideological position. I would contend that there's a danger in what we want and what makes us feel good, versus perhaps what might be the best thing for children. We need to have the courage to explore that.

I will share an anecdote, where I learned this the hard way. I was a relatively new investigator, successful in the first five years of my career, when I received a call from what I would refer to as the pre-eminent child advocacy organization in America, not the AAP. (I just want to make sure that's clear!) This foundation is focused on advocacy for children. I was doing a lot of work in childhood immunizations at the time, and the foundation representatives told me about a new immunization program that had been launched in New York City for about 1 year. The representatives were asking me for an external evaluation because they were planning to ask Citibank for a second-year of funding. The foundation thought this initiative was the greatest thing in the world. They asked "Would you come and do this evaluation?"

I thought, "wow, I have really arrived, you know, I am hot stuff. I'm this young kid, and they are asking me to come and complete this evaluation for them." I'm not specifically saying the name of the foundation, because I was warned by Steve that one has to be cautious on these national webinars. I traveled to New York; a car picked me up at the airport. Now, I'm from this small town in Texas, so nothing like this had ever happened to me before. They took me to the apartment of the Chair of their Board, which was located in Manhattan. This was the type of apartment where the elevator opened and the whole floor was their own. I was stunned; I had never seen this type of wealth. The CEO of this advocacy organization as well as the person who was their board chair were at the apartment. I thought to myself, "you know, I am just the most amazing thing in the world, and I was very proud of myself." Then, they started telling me just that. I said, "I'm here for you because I believe in this organization and I believe in vaccines for kids." They said, "Alright, let us tell you about this program. We're really excited about it." The program is called, "Give Them 5, Help Them Thrive." At this point in time, if kids attended five visits to receive vaccines in their first year of life, then they would be up to date until 18 months of life. They said, "This program is the greatest thing in the world. We've got Sports Stars giving kids a high five, and we've got pictures of these New York Sports Stars in

all the subways and on billboards. We've stopped people on the street and asked them, have you heard of 'Give Them 5, Help Them Thrive?' 90% of the people we stopped have heard of this program." I said, "Well, wow, that's really cool." I was thinking in the back of my mind, maybe I would get to meet some of these Sports Stars.

I asked, "How many under-immunized kids are there in New York City that the program is trying to address?" They said, "Around 150,000". I thought, OK, that's a lot of kids. I asked, "What else have you all done?" I'm thinking while I ask the question, how does one evaluate something like this? They said, "We have tripled the calls to the vaccine hotline." I said, "Wow that's really amazing." They said, "We've gone from 50 calls a month to 150 a month, and you can receive information in 24 languages." Now, remember, there are 150,000 under-immunized kids, and this foundation is thrilled that they tripled the calls to the hotline.

Then I started to get a little nervous and asked, "What else has been done?" They said, "We attend health fairs and pass out lots of information. We pass out thousands and thousands of sheets informing people where they can receive their vaccines." I thought, wow that's really great. I asked, "Where do you tell them to go?" "Oh," they said, "These clinics are all over town." I asked "Do we know if there's been an increase in people going to these clinics?" They said, "No, we haven't checked." I asked "How many under-immunized kids do you think there's going to be next year?" They said that there would probably be around 150,000 children. I realized that this was the same number as when they started the initiative, just for those of you who might have forgotten. I said, "Well, I am a little concerned that if I do this evaluation, the initiative may not demonstrate a significant impact." They asked, "What do you mean? Everybody has heard of this program, and we've tripled the calls to the hotline,"...and on and on and on. I said, "Well, I think you might need to be prepared for a report that that doesn't show you've made a real dent in the problem." They said, "Well, we can't have that kind of report. We need a report to receive another \$500,000 from Citibank to be able to complete the second half of this program." Then I said, "I don't know," and they said, "Well, I don't think you're thinking about the type of evaluation that we're thinking we need." They sent me home.

The organization then hired a firm in New York City to provide them with the exact kind of evaluation that they wanted. They then received another \$500,000 from Citibank. However, there were still 150,000 under-immunized kids in New York City after a million dollars was spent on vaccination efforts for children. Now, I'm not saying it's always like what I just described, but actually, after this experience, I never trusted any data produced by that organization. In addition, I think that we need to take a hard look at our own work and our own efforts, to assure that we're conducting studies to see "if," not studies to "show that." It was someone from Rochester, I think it was Bob Hagerty, but it may have been Michael Weitzman, but I'm not sure, who stated "as pediatricians, we have soft hearts, but we don't have to have soft brains." So, we need to make sure that even though we care a lot, that's no excuse for not being true to data, even when we don't like what it shows us.

(SD) That's a great story Gary. There have been numerous advocacy efforts focused on workforce. You have been heavily involved and done a lot of work in this area. How did data or the lack thereof play into these advocacy efforts?

(GF) So that's a very touchy issue because everyone is an expert in Workforce because we all work and we're all pediatricians, so were all experts in the pediatric workforce, and our own anecdotes are obviously what is generalizable to the rest of the country. Or at least that's what you would think if you talk to most people, who are the shrillest voices, I would say, with regard to Workforce. I first got involved in the Workforce because the American Board of Pediatrics was concerned that there was no

research in pediatric workforce, that it was only advocacy efforts. And in fact, at that time, it was just around 20 years ago, one month, you could read in the newspapers that there's going to be 100,000, too many doctors, and in the next month you could read that there's going to be 100,000 too few doctors and it puzzled me. How this could be, how could really smart people come up with these wildly diverse things? So, I went away on the country, I asked Jim Stockman, when I was going to start doing this work for the board. I said I want to go and meet whoever these experts are in Workforce research, nothing relevant to kids, but it was for the general physician workforce. I want to understand what are the methods these people are using for that? And why would you get such a diversion answers to the exact same questions?

And I went around the country, there were five of these people and they all hated each other. I mean I've seen friendly competition in academics but these people would just as soon spit, as say each other's names. It was unbelievable, like nothing I'd ever seen. And it turns out that the reason they came up with such divergent views was because they selected data sources that would give them these different answers, because they supported their own political advocacy positions. Those who believed that health care was a market force, selected data sources, which would show there were more physicians, or there was not a need for more physicians, so that the market would remain the same. Those who were more concerned about access, were more concerned about showing a physician shortage, so that there would be a drive to increase the workforce, and bring down the cost of physician labor, and increase access.

So, I quickly learned that in Workforce, you can pick a data source. And I say, I have slides that say I can ask the exact same question in the pediatric workforce and give you wildly different answers, and you'd be none the wiser for it because they all seem like they are authoritative data sources.

I would contend currently, right now, and this isn't new, but certainly, right now and perhaps more recently, we as pediatricians, we want the data that support our pre-conceived notions. If we're a subspecialist in a particular subspecialty, we want data that show that we're either (a) underpaid, (b) there's not enough of us, (c) nobody does research, you can name it, you've heard it all. And I think sometimes people don't want, I'll be very candid, don't want data to get in the way of their advocacy position. And I review a lot of papers for journals where people deliberately don't cite papers that probably have greater methodological rigor than their own, simply because they go against whatever their advocacy position is.

And I'd say workforce research is kind of hard to do well. There're methods that are really necessary to do accurate work. And I think there's more what people call quick and dirty research to show that whatever you want to show is the thing, as opposed to rigorous studies to see. I think that we need to be really cautious, and I would just encourage everyone to be skeptical about any workforce research that they read.

(SD) Thank you, Gary. That was great.

I want to read a couple of comments from participants. Shetal Shah states that promotion deliverables are important in advocacy and include not just publications. More journals are publishing advocacy work, including legislation that's been drafted and opened. Highlighting teaching and mentoring focused on advocacy is also important. He comments that his promotion packet had letters of reference from members of Congress, with whom he had worked closely. This is really great advice regarding how to be promoted in the area of advocacy.

Dr. Gabriela Maradiaga states that she and her colleague just successfully proposed and lobbied for an advocacy track for promotion at Duke School of Medicine. Dr. Maradiaga thanks all the authors of the advocacy portfolio that provided valuable information to support the proposal. This is helpful regarding promotion if your area of focus is advocacy.

(MS) That's outstanding advice. I received advice years ago from another academic pediatrician, who advised putting together a portfolio of work when you are going up for promotion. Keep a portfolio on your computer of all the activities and initiatives that you are doing, even if they seem to be outside of academic medicine. Advocacy efforts may be viewed as outside the mainstream in many institutions. I think that's wonderful advice from Shetal. I was also advised to attach an introduction and a personal statement at the front of my CV, so that I'm framing my career for the reader, instead of relying on them to see the scope and depth of my work and how it all integrates. A personal statement allows you to address many topics, some of which may not have a clear spot in the CV: leadership, advocacy, faculty development.

(GF) I just want to say, it's a risk, I don't want people to think I'm an advocacy nihilist. I'm really not, and I think my only plea is that when we stakeout advocacy positions more strongly only when we can be certain of what we know because we want to first do no harm in this arena, and certainly that kind of stuff has happened. And I'm also not suggesting we have to wait for definitive data for any advocacy position, we don't. But I think we just have to be honest, both emotionally and intellectually when things are our opinion and not try and overstate what we know. I think there's courage, but I think there's also strength in admitting what we know, and what we don't know, but we can still have an opinion. We just need to make sure that we're honest.

(SD) What should we be teaching our residents about advocacy?

(JD) I think you should be promoting advocacy among the residents, and when I talk about it, they are generally fascinated to know that there are such people in their midst. I think that this career path does need to continue to be really stressed. All of us are role models for our residents and medical students and should encourage them to speak up. There are opportunities, for instance, with AAP and Mark Del Monte, where residents and fellows have an opportunity to speak out. I had a young fellow by the name of Haley Friedman who trained with me, was very active in the AAP, and ended up moderating national meetings, even as a fellow. She accomplished a great deal. I was quite proud of her and I really tried to encourage these activities.

So, I do think there is another way that we advocate for our children. You are doing this every time you provide anticipatory guidance. You are sitting with a family, advocating for that child and educating the parents. I've found that in many cases, especially in child health, it's like apple pie and ice cream. You enjoy it because everybody's got their own kids, nieces, nephews, et cetera. You recognize that it's important, but on the other hand, the kids can't vote. It is important for us to really push this agenda, but I agree with the participant that taking every opportunity to advocate is really important. Moira, do you want to comment on that as well?

(MS) I completely agree. I think that as pediatricians, advocacy is integral to our work, whether it's with families within our own practices or building services that children need. Medical-legal partnerships are a good example and there is some interesting work being done helping families with financial advice. It can be part of continuous quality improvement to be the advocate in your office.

Advocacy can also be local in your community, in your state or can be federal. Children and families have been challenged with a complex group of crises in the past year. Many of the services that support children have been threatened (school, childcare, early childhood education). Now is the time to really encourage our trainees to get involved in advocacy. The Blueprint for Children, which is on the AAP website, is a good place to start in terms of identifying the big issues.

The AAP Section on Pediatric Trainees (SOPT) is probably the single most active advocacy group in the AAP. They are amazing. Their leaders attend our annual leadership forum, where their

group often presents the most resolutions. These resolutions form the basis of the workplan for the AAP for the next several years. 500 plus leaders in the Academy vote on all the resolutions presented and there is usually well over 100 resolutions. The top 10 are taken very seriously by the AAP. So, it's another place to find like-minded people.

It does take a lot of time to be an advocate, but this work is very energizing, because it is teamwork. I do appreciate Gary's caveats about making sure that you have strong science to inform your advocacy when available. Sometimes there are just ethical principles that drive advocacy. Ending separation of children and parents at the border is an example with clear, ethical principles. While there is science about the traumatic impact of separation on children and parents, the fundamental immorality is powerful enough. Many other advocacy issues really do require clear science to make the case.

(JD) We've really had some successes, Stephanie. Certainly, through the PPC, the AAP and others, we have had success. I'll use one great example; for the first time, in 20 years, we received money from the CDC for gun violence prevention research. Everybody said, "Well, I guess there's really no reason that we can't do this, and we can fund this." That's a huge step forward and in an area that we all agree needs so much more than just a little bit of money for research. The whole approach to this issue really needs to change, but at least it's a start.

(SD) One of our participants states, "Great talk. Gary is like Dr. Phil. Do you want to be right or effective?" Then, another one of our participants states, "I couldn't agree with Dr. Freed more. My past chair, Harvey Cohen, taught me 'don't let your advocacy get ahead of your evidence.' I've always needed that." Gary, it sounds like a lot of people agree with you.

(GF) Every now and then that happens. Harvey Cohen was a wise man. That's a great saying, "don't let your advocacy get ahead of your evidence." I still want to make sure to state that Moira's point is well-taken. There are some issues that are moral imperatives, and these issues don't need to necessarily wait for the research. That doesn't excuse us from integrity, because we have limited resources for kids. If we're not going to try and make sure that every dollar is a dollar well spent, I don't think we're doing a service. I like the Dr. Phil comparison, maybe there's a future for me somewhere.

(MS) See you on the airwaves, or the TV ways.

(SD) Social media can really be a double-edge sword. Can you comment on how best to maximize advocacy with social media tools?

(MS) I may be the absolute worst person to talk about social media. I did become a "Tweetiatrian," that's another AAP activity. They had to twist my arm to do this. I'm just not a social media person, but, it is an opportunity to reach a broader group of people.

For example, there was a rapid and steep drop off in visits to pediatricians that occurred at the beginning of this pandemic. Children are now 10 million plus doses behind in their immunizations. The AAP started a "#call your pediatrician" campaign regarding the importance of routine preventive health care for children, including immunizations, even during the pandemic. Preventive health care also includes monitoring development and growth, as well as preventive and anticipatory guidance for parents about child health. The campaign stressed that it was now safe to see your pediatrician.

I think judicious use of social media is very important. It is important to be careful who choose as your partner. I stick to AAP social media and messaging because I trust how the message has been vetted and developed. I tend to stay away from other types of social media since I do not have the time to personally vet everything. Social media is a double-edged sword.

(JD) I think we've seen the really dark side of social media, certainly over the last four years. Regarding vaccines, I think the

anti-vaccine movement has really been brilliant in the way they've leveraged social media to present false information. The World Health Organization states that the anti-vaccine movement is one of the most important to address, as we focus on moral imperatives. All the progress we've made in the last couple of decades could disappear as people open up Facebook and read something and say, "Well, this must be true." We have to do a much better job with social media. Like Moira, I'm yelling at my kids every time they post something that I think isn't appropriate. I think that as pediatricians, we need to sort out how to present information that people can trust and follow.

I think that partnering with the AAP and tackling how to approach social media is important. I mean, finally, social media has started removing anti-vaccine pages. It took literally insurrection at the capitol to get people to move in this direction, recognizing how some of this negative data can negatively impact child health.

MS: I agree that the other voices out there are loud and savvy at marketing. They easily overwhelm the less well-funded voices of reason and science.

(SD) Shetal Shah commented that one may use "social media to advance your policy agenda, but never put out a fact without a reference. It's the transparency that separates us from the trolls." Great point, Shetal.

David Keller commented that "Some medical schools actually have public service as a mission. At UMass, for example, that's one of the pillars. Make sure you choose your institution carefully and match your mission with your organization for promotion." David Keller also shared an Advocacy Portfolio link that may be used for promotion purposes: https://journals.lww.com/academicmedicine/Fulltext/2018/06000/The_Advocacy_Portfolio__A_Standardized_Tool_for.29.aspx.

(JD) Stephanie, Matt Davis is one of the chairs of our APS Advocacy Committee. David Keller and Matt Davis have done a great job, so I think these are important points.

(SD) Lois Lee, Director of the Health Policy Scholars Program states, "Moira, thank you for discussing the APA's new Health Policy Scholars Program, which will advance careers in academic medicine, with a focus on advocacy and health policy. We will be using the advocacy portfolio and focusing on scholarly projects."

(MS) Yes, this is a brand-new program. They have 23 scholars from all over the United States and Canada at this point. And the goal is to help these young scholars develop their advocacy skills and approaches so that they can educate others, become leaders in their own institutions and actively lead advocacy efforts. During their third year, they're going to attend the AAP Legislative Conference and work more at the national level. The APA has multiple faculty development programs: educational scholars, research scholars, and now advocacy scholars. Some academic centers are better than others at faculty development. These APA programs are great for any general academic pediatrician, but especially for those where faculty development may not be a major focus of their institution. They are so well-mentored.

(SD) Success often requires elements of compromise. How do you navigate the balance of working with un-likeminded folks to be successful?

(GF) It's a great question. I think that's the constant struggle. Ultimately, almost all decisions in health-care policy or in health-care systems are political. That's just the nature of the beast, and we can't necessarily control the rhetoric. What we can hope for is to be able to both provide information, and as Moira points out, our moral compass at times, to help to frame the rhetorical debate. So, the debate isn't just based on the rhetoric, but it has some kind of shared basis. If everyone can agree, and they trust a certain source for information, then debate on that information. What you think it means, not whether it's true or not. And I think, perhaps, that's even more relevant today in the era of people not finding common news or information sources that they can agree

on, have any type of legitimacy. So, to be the legitimate voice in that debate, that brings together people from opposite sides. That's where you have to be.

To make long-term impact, if you're really in this game for the long haul for a variety of different issues, I'd say that "don't let perfect be the enemy of the good." Many battles are lost, because we dig our heels in for everything that we could ever want, but we miss opportunities to advance children's health incrementally, as opposed to thinking we're going to do things always dramatically. We need to make sure to recognize that ideological purity on any side is unlikely to carry the day at least in the long haul. If it does, you're going to leave a lot of dead bodies along the way, not literally dead bodies, but politically, dead bodies.

(JD) I think trying to find that middle ground is really important, and I agree with Gary completely. At one point, Massachusetts was one of the last states that required written informed consent for HIV testing. We found that only about 60% of the pregnant women in Massachusetts were being tested, and we tried to get a law passed to change this problem. In addition, we had tremendous differences between the gay and lesbian coalitions that really wanted to keep that data private and the Mass medical society, which sponsors the *New England Journal of Medicine*, didn't think we needed any consent because this was a disease that could be managed. After 4 years, the Governor and the March of Dimes asked me to try to see if I could help broker some kind of deal. I met with them over a six-month period, and it was amazing, they just would draw these lines in the sand. Ultimately, I would say to them, "OK, well, when we go back to the Governor, how many babies a year do we think should die from HIV before people are comfortable with moving a little bit more to the center?"

I would bring them pictures of babies and children with HIV who were admitted to the hospital and were so sick that they required treatment with mechanical ventilation, and they would say that you can't do this. Ultimately, we changed one word in the bill. We got them to agree to change written consent to verbal consent. That was it. And so, then the obstetricians could say, we're testing you for HIV and syphilis and trichomonas and gonorrhea and all these other sorts of things, and in one year, we went from 60 to 96% of the women being tested. So sometimes it's just the perseverance, and it took me awhile, but it was something that I was very satisfied with, but it was really, really hard work.

(MS) Thank you for using a P word there, Jon. It is also important to find that common ground across the aisle. I think I've been very fortunate with foster care work in that there are people on both sides of the aisle that feel very strongly that this particular population is very vulnerable and does deserve better care, and that we can improve their outcomes because they've been willing to listen to the evidence and that foster parents are of all political stripes. It's been very helpful for us in moving a cause forward. I always like to find a common mission: for kids in foster care, we all want the best outcomes for children. I acknowledge that sometimes that there's an upfront financial cost but that it is easy to make the case for investing in children. Going in with some data that shows return on investment and investing now versus not waiting five years to invest or until adulthood to rectify. I can see Gary has a comment.

(GF) I think it's also a good idea not to paint yourself into a rhetorical corner. And I'll give you an example. I deal a lot in prevention; people always want to try and show that prevention saves money. Sometimes, prevention doesn't save money. Sometimes, prevention costs more, because people live longer. If they live longer, they're going to cost more in the long run, and it doesn't mean that having a better quality of life isn't worth paying for sometimes. But if we paint ourselves into this corner, that we're only going to be able to justify prevention because it saves money, we're going to screw ourselves in the short and the long

term. Because the thing that we can do to save the most money and our healthcare system right now is to pass out unlimited liquor and cigarettes, and let people smoke and drink themselves into early grades. And that will save so much money in Social Security and Medicare in the long run. It'll be phenomenal, but it's not the right thing to do.

So, make sure your arguments in the advocacy world are sound, and don't try and vet or do gymnastics to show that things have a different economic output or a different economic value than they really do because you think that's what's needed to move things forward. Honesty and integrity. You don't always win, but, I think, in the long run, you have a greater chance.

(JD) I think I'll finish this question off by saying that it's really important to maintain your focus. And sometimes, you're meeting with people from one party, and it's easy. They feel the same way you do. And it's easy to just say, OK, I'll work with them. The harder part is to move across the aisle, as Moira said, and work with people who may not necessarily feel the same way you do. And you still need to make those cogent arguments. You may not convince them completely, but certain times, you might. As I met with Mitch McConnell's Chief of Staff, there're certainly policies that I didn't necessarily agree with him on, but I wanted to get this done for babies and for families. The only way I was going to do that is by meeting with her and being positive and working together, and that made a huge difference, so Gary's, right. Don't paint yourself into a corner and don't so strongly align with one or the other. You need both parties to sponsor a bill.

If you want that bill to pass, you've got to convince some people that what you're suggesting works. And what was very helpful to me is reaching out to people who are APS or SPR members, because I would find out that someone in Missouri had an important vote, and they wanted to sponsor, so I called Sesh Cole on the phone. They said to me, oh, Congressman Lujan from New Mexico. So I called Kristi Watterberg up in New Mexico people that I knew, and I said, you've got to help me here and get to these folks. And it worked. It really did work. So, reach out, try to stay as neutral, stick to the science, and to the policy, and as we're saying, what's right, and hopefully, you'll be successful.

(SD) Thanks for a wonderful discussion from our panelists and audience participants as well.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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