



## Call the Coach: Opportunities and Challenges for Parent Coaching in Pediatric Type 1 Diabetes

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**Editor's Note:** This article was adapted from the address Dr. Streisand delivered as the recipient of the American Diabetes Association's Richard R. Rubin Award for 2020. This award recognizes a behavioral researcher who has made outstanding, innovative contributions to the study and understanding of the behavioral aspects of diabetes in diverse populations. Dr. Streisand delivered the address in June 2020 at the Association's virtual 80th Scientific Sessions.

Although these are unusual times, I am grateful that the American Diabetes Association (ADA) was able to make its 80th Scientific Sessions an online conference, allowing us to gather virtually to share our science. While I was disappointed not to be in Chicago, IL, for an in-person event, I was still glad for the opportunity to share my thoughts on supporting children's diabetes outcomes through parent coaching models.

Before doing so, I want to thank the ADA, Dr. Michael Harris, my peers who nominated me to receive the Richard R. Rubin Award, and members of the Behavioral Medicine and Psychology Interest Group. I am deeply honored to be recognized for my behavioral research in diabetes and to be joining past recipients who have made seminal contributions to our field.

Although I did not have the fortune of knowing Dr. Rubin personally, his impact on diabetes care has been longstanding and far reaching. Dr. Rubin grew up with a sister with type 1 diabetes. Later, after his own son was diagnosed with diabetes, he focused his career on helping others—children, families, and adults—to thrive while living with diabetes. As ADA President, Health Care & Education, and chair of the Behavioral Medicine and Psychology Interest Group, he helped make it possible for all of us to have a welcoming professional home at ADA. A certified diabetes educator, Dr. Rubin received numerous professional and service awards. I am so proud to be listed among the recipients of this honor in his name.

Speaking of professional homes, I have had the pleasure of building my career at Children's National Hospital in

Washington, D.C., for more than 20 years. My clinical research career has been a partnership with the Child and Adolescent Diabetes Team there. Teams are crucial, in clinical work and in research.

Teams are important to my topic as well. Mentors are often called coaches, and here, I will be focusing on how coaches are being used as extenders of care and natural helpers in supporting chronic illness management. Specifically, I will describe the role of coaches in the research I conduct with parents of children with type 1 diabetes. My work has truly been a team effort among children, families, their diabetes care providers, and my research colleagues who have joined me in this exciting area of learning and scientific discovery.

### My Path to Here

I would like to take a moment before describing my work to share with you how I became involved in behavioral medicine to begin with and working within diabetes in particular. During college at the University of Michigan in Ann Arbor, I planned to spend the summer in Washington, D.C., and looked for an internship as many college students do. I reached out to several psychologists, and by a stroke of luck, I began volunteering with Dr. Jill Weissberg-Benchell and the diabetes team at Children's National.

Through Dr. Weissberg-Benchell, I was introduced to the field of health psychology, its contribution to the interdisciplinary practice of behavioral medicine, and the ways in which it is integrated into children's health care. For those of you who know Dr. Weissberg-Benchell, it should come as no surprise how generous she was with her time. I

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was able to observe families of children who were newly diagnosed with diabetes and listen in as she spoke with these children and their parents in such a calming and confident way, reassuring them that they were going to be OK.

I recall feeling in awe during this experience, and that was what drew me to a doctoral program with a focus on child health psychology. At the University of Florida in Gainesville, I trained under the mentorship of Dr. Jim Rodrigue. I completed my practicums in the inpatient Diabetes Project unit with Dr. Gary Geffken and the outpatient diabetes clinic with a giant in the field of children's diabetes research: Dr. Suzanne Bennett Johnson. I owe debts of gratitude to Drs. Rodrigue, Geffken, and Johnson for introducing me to professional psychology practice and clinical research and helping me hone my skills as a behavioral scientist.

Since moving on from Gainesville, I have had the great fortune of training with some of the best, brightest, and most talented women faculty leaders. Their guidance and support always seemed to come just at the right time, and through the years, I have grown ever more grateful for the generosity they showed me and the wisdom they shared. They helped me launch a career in pediatric diabetes research, and I thank them all for their mentorship.

I like thinking of mentorship as a tree and hope that parts of my experience of being mentored by others has enabled me in turn to help others grow and blossom their own careers. Thus, I would like to recognize a few of my former mentees, who have transitioned into wonderful colleagues and have extended the research in new and different ways and with whom I have remained a close collaborator: Drs. Marisa Hilliard, Eleanor Mackey, Maureen Monaghan, Lauren Clary, and Carrie Tully.

One of the most enjoyable aspects of my career has been providing mentorship to others. At Children's National, I get to work with students, interns, fellows, and early-career faculty. If we were to look up the meaning of "mentor," we would find that a mentor is "an experienced and trusted advisor," and a "coach" is "one who instructs or trains." The word "mentor" brings many other concepts to mind, including not only "coach," but also "partnership," "relationship," "role model," "peer," "personal," and "sharing"—all of which I think are intertwined and crucial not only to supporting others' academic pursuits, but also to supporting people facing a chronic illness such as diabetes.

During my training as a clinical psychologist, I worked with children and adults experiencing different medical conditions. As a common thread throughout each of these

various health concerns, I was drawn to learning how family functioning and overall stress contributed to illness management. We are fortunate in the area of behavioral diabetes to have had strong and thoughtful leaders who have put forth models for conceptualizing the multitude of factors that play a role in health outcomes. For example, I know many of us in the field have used a version of Dr. Johnson's model on biobehavioral variables of health (1) in our understanding of what contributes to child health outcomes.

### Pediatric Parenting Stress

The ultimate goal of our research is to optimize not only children's health, but also quality of life (QoL) of both children and their parents. Toward that end, I have focused my career on developing interventions to support parents and, in so doing, to support their children. Much like A1C has been considered the gold standard outcome for glycemic management, our team has sought to examine child and parent outcomes that can help us better understand the variables that contribute to adherence behavior and improved health. Developing and validating such measures takes significant time.

As a graduate student, I designed and conducted my first behavioral intervention for my dissertation—not in the area of diabetes, but rather in oncology, and with a very small sample. It was an intervention for parents of children undergoing bone marrow transplantation. As a practicum student, I had been struck by this extremely stressful experience and thought that the principles of behavioral psychology could help support parents during this very challenging time. I remember struggling to find a measure of stress that would be applicable for these parents and, hopefully, that could help to measure the impact of the intervention. I ultimately used a general measure of daily stress.

Later, during my fellowship, I wanted to contribute to future research and so developed a measure of parenting stress specific to caring for a child with an illness. The Pediatric Inventory for Parents was designed to measure stress in parents of children with any type of medical condition (2). It has since been used widely and has been translated into many languages. We are now using it to examine impact of our own interventions in diabetes.

When I first started at Children's National Hospital, I had the pleasure of spending a few days each week providing clinical service to children with diabetes and their families. As was evident in my earlier clinical work with other pediatric populations, these families, who were now confronting their child's diagnosis of diabetes, were overwhelmed in learning how to keep their child safe and also

trying to figure out how to keep their child happy. Not surprisingly, most of these families experienced stress. And that was just at the beginning of diabetes; we know that, with time, many of the behavioral challenges continue for families facing diabetes. This realization has led me to strive to conduct clinically relevant research and develop interventions that can support parents and thereby better help their children.

### Stress in Parents of Children With Type 1 Diabetes

Our early descriptive work confirmed our clinical impressions, and we found that, similar to parents of children with other medical illness, parents of children with diabetes experience significant parenting stress (3–6). We have seen this for parents at the time of diagnosis, as well as years later. We know that parenting stress has also been related to other significant mental health and child health outcomes, including parents' mood and anxiety and parents' confidence in managing their child's diabetes.

From our descriptive studies, we moved on to behavioral interventions, trying to find the most translatable ways to increase QoL and decrease stress in parents. Because stress clearly played a role in diabetes management, we also addressed stress and challenges in clinical work with families, such as through parent support and parent/teen therapy groups. It took many clinical groups and a few clinical trials for us to realize that one potential answer to helping families better manage living with diabetes was right in front of us and in our waiting room the whole time: the parents themselves. The crosstalk we witnessed between parents—the ways in which they supported each another in a natural way—helped us to realize that we could capitalize on parents' own expertise and put parents in the driver's seat of future interventions.

### Pediatric Preventive Psychosocial Health

Among Dr. Anne Kazak's many contributions to the field of pediatric psychology has been to push us to think about how our clinic-based treatments can be delivered more broadly. How do we implement behavior change in real-world settings and without the tight controls of a randomized trial? For children and families with type 1 diabetes, that challenge means delivering the most effective treatments and providing the right amount of support when it will do the greatest good. According to Dr. Kazak's Pediatric Psychosocial Preventative Health Model (PPPHM) (Figure 1), all newly diagnosed children should receive diabetes education and nutrition counseling and learn the fundamentals of self-care (7).

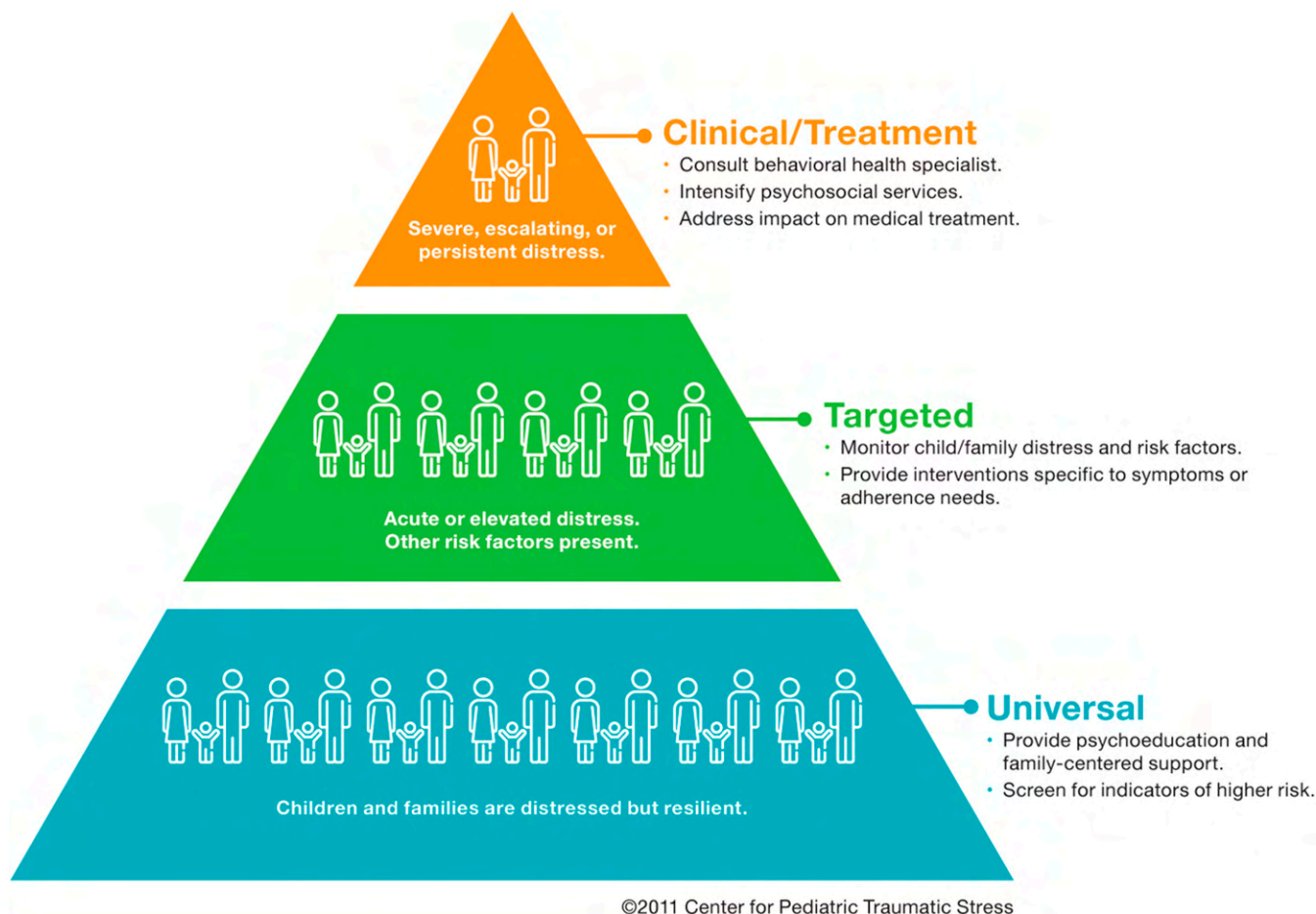
In our setting and others, we encourage parents to join diabetes-related community support groups. These are powerful, normalizing experiences for families. For some, this is sufficient to achieve diabetes management and good QoL. Others have more advanced needs and require greater care. In such cases, our behavioral consultations may become more frequent, and perhaps these families come to see us for ongoing behavioral treatment, too.

Clearly, though, mental health resources are limited in both number and capacity. This is why, in my own work, I strive toward the translation and back-translation of more intensive clinical interventions to those that are more broad-based and can be implemented. We asked ourselves, "How can we evaluate this in a more robust way?" We started to think about concepts such as the minimal interventions necessary to achieve change and stepped care models that are often used in community mental health settings and integrated primary care. By combining our approaches across trials, we explored the potential layering of natural helpers, minimal structured supports, and more intensive interventions for those in need. Rather than starting at the top of the PPPHM, we began at the bottom with parent-to-parent support.

### What Makes a Good Parent Coach?

Peer mentors or coaches have been used in interventions described in the adult literature across illness groups, and more recently with pediatric conditions such as asthma, obesity, and diabetes. It turns out that just about anyone can "train" to become a life coach or even a health coach. We have seen structured programs for people already in health care, but also weekend workshops and self-study courses for people with no medical background at all, and others who simply appoint themselves with the title. Although it may be difficult for the field of psychology to embrace this new reality and share domains of practice that we once protected, the reality is that coaching and coaches may appeal to some individuals even more than traditional psychotherapy. Thus, we have shifted our efforts to putting together the very best training and coaching programs possible to ensure that families receive the best care possible under the supervision of a knowledgeable health care provider.

We find that great coaches come in many forms and that the most important qualification is having the lived, shared experience of parenting a child with diabetes. From that starting point, we help our coaches develop boundaries, become good listeners, learn to express empathy, remain available, demonstrate support, and model good problem-solving skills. Some of this should sound familiar; indeed, it



**FIGURE 1** The Pediatric Psychosocial Preventive Health Model. Reprinted with permission from Kazak AE, Schneider S, Didonato S, Pai ALH. Family psychosocial risk screening guided by the Pediatric Psychosocial Preventative Health Model using the Psychosocial Assessment Tool (PAT). *Acta Oncol* 2015;54:574–580.

sounds a bit like being a good therapist. For that matter, it also sounds a bit like being a good parent.

Although we do not yet have a national or empirically supported training model for parent coaching in diabetes, leaders in our field are breaking new ground and guiding the way on identifying some best practices.

### Peers for Progress

I would like to briefly mention the work of Dr. Ed Fisher and colleagues, who pioneered much of this work in adults with type 2 diabetes and launched a successful global program (8). Peers for Progress offers assistance with daily disease management, social and emotional support, and links to clinical care and community resources, and it extends this relationship over time. With its numerous lay community partners, community health workers, and others, this program has built a network of tools and training resources. As a field, I think we have much we can learn from this example and should consider the merits of

developmental adaptations of those efforts and their application to children with type 1 diabetes and their families.

### Focus on Children

So why is developmental- and disease-specific adaptation so important? Perhaps the best illustration of why we cannot treat children as little adults is the experience of very young children with type 1 diabetes. Managing diabetes in young children is distinct from this process in any other age-group. I study parenting in many forms and ways to tap into the strengths that parents have in caring for their children's needs—social, medical, and otherwise. To do this well, we have to understand stress and to be honest when we say that not all stressors are created equally. Neither are all parents. How do we find each parent's strengths—and all parents have them somewhere—and bring those attributes to the forefront?

To borrow from a common conceptualization in health disparities work, we know that “equal” solutions are not necessarily the best solutions. For example, people want to



pick apples, so everyone is given the same size box to stand on, whether child or adult. That's a one-size-fits-all solution, or rather a one-size-fits-none solution; it does not take into account fundamental differences in individuals' development, background, upbringing, capacity, and so forth. An alternative and more truly equitable strategy would provide everyone the support they need, but there are likely to be individual differences that mean some will need something more than, or something different from, others. In the end, with the appropriate support, all can reach their goals.

We know that not all families can offer their children the exact same start in life. When you add in type 1 diabetes, parenting a child well while also managing a chronic illness may exceed some parents' natural abilities. These children and their parents may need more or bigger boxes to stand on. But how do we identify them at the outset, and is that even possible? Do they have to fail before they are given adequate support, or can we create structures that support them all along the way and avert crises?

### Challenges of Type 1 Diabetes in Young Children

We know the importance of a healthy start in life. My research has embraced the needs of parents raising very young children with diabetes and the unique stresses they face (9). Instead of waiting until these children may become teenagers with adherence struggles and then intervening, we follow the model of early intervention and help to form the foundation for good health behaviors that can hopefully persist over time.

Our research team has studied the impact and challenges of diabetes in young children (no more than 6 years of age) for many years now, and we understand that there are some specific challenges regarding diabetes management in this age-group. Young children are usually picky eaters, making decisions about how much insulin to give before a child eats difficult. Young children are also active in unpredictable ways. They do not usually have set times for physical activity such as soccer practices for older children; instead, they have bursts of play-based activity such as running around on the playground or in the backyard that often cannot be anticipated. Young children usually are not able to reliably report how they are feeling. Many young children with type 1 diabetes are not even using words or sentences to communicate, so even if they were able to identify that something felt strange, it might be hard for them to let a parent know.

With young children specifically, the burden of diabetes management falls exclusively on parents or other caregivers. Parents say it is an around-the-clock job with no

breaks, not even during their or their child's sleep when they are still worried about, and often monitoring for, symptoms of low blood glucose. It is truly the parents who carry the bulk of responsibility for keeping these kids healthy and safe, and the challenges are physiological and developmental as well as psychological.

### TOTs Multi-Component Parent Support Intervention

Coupled with our findings that parents of children with diabetes are stressed, as well as our observations that parents are each other's best resources in day-to-day diabetes management, our team first piloted a parent coach program with a small sample about 10 years ago (10). We had promising results and demonstrated feasibility and acceptability, which led to our use of parent coaches during an intervention development grant that we recently finished. This Type One Training project (affectionately known as "TOTs") involved parents of children ages 2–5 years with diabetes for at least 1 year, with a focus on healthy eating and physical activity to target glycemic control (11). We used parent coaches as one part of a larger, multicomponent intervention. Although we found feasibility and satisfaction with coaches and overall improvements in outcomes in our intervention group, we were not able to tease out the effects of the parent coaches in particular, given that this was a multicomponent intervention.

### First STEPS Parent Support Intervention

That brings me to the project we are just wrapping up, called First STEPS. This project takes into account the unique needs of young children and the challenges of a new diabetes diagnosis with an aim to support parents during that first year after diagnosis. This is a National Institutes of Health-funded behavioral intervention trial involving two sites: Children's National Hospital and Baylor College of Medicine/Texas Children's Hospital, in partnership with my colleague Dr. Marisa Hilliard. In this project, we wanted to include parent coaches, but this time, because we felt that this was a very important component and likely even more crucial for parents of newly diagnosed children, we separated out our intervention components.

Similar to Kazak's PPPHM, this study used a stepped-care intervention design to provide the least intensive treatment necessary to achieve optimal outcomes. We did this by closely monitoring progress and enhancing, or "stepping up," treatment when indicated, based on both child A1C and parent depressive symptoms, which we checked at diabetes clinic visits (12). For parent depressive symptoms, we used the Center for Epidemiologic Studies Depression (CES-D) scale with the clinical cutoff of  $\geq 16$ , indicating

clinically significant levels of depressive symptoms. For our other target of child glycemic control, we used A1C >8.0% as the cutoff.

For step 1, all participants in the intervention group were assigned a parent coach. At each child's next clinic visit, if either of our two study targets was not met, then parents moved up to the next step. The next step involved five phone sessions with a trained, Master's degree-prepared counselor who used cognitive behavioral strategies to support parents. After the next clinic visit, our study targets were again assessed, and if either or both were not met, parents moved up to step 3. This step consisted of a professional and blinded continuous glucose monitoring (CGM) trial for children not already using personal CGM, coupled with a consultation with the diabetes educator to review data and then a separate consultation with the diabetes team psychologist.

Parent coaches and participants were matched for the duration of the 9-month intervention. Parent coaches remained with participants even if they moved up to step 2 or step 3. Parent coaches were encouraged to meet in person with their participants one time, if possible, and then conduct the remainder of contacts by phone, text, or email. There were weekly contacts for the first 3 months, followed by monthly check-ins for months 4–9.

### *Parent Depressive Symptoms: 1 Month After Type 1 Diabetes Diagnosis*

Our preliminary data from baseline provide further indication that a significant percentage of parents are experiencing symptoms of depression at ~4 weeks after their child's diabetes diagnosis. We should not have to wait to find parents struggling before we are able to offer support. However, if we screen parents and children, we need to be ready to offer services or support them in line with their need. Almost half of our participants were found to be above the CES-D clinical cutoff of  $\geq 16$  (13). Almost half (47%) of these parents were experiencing clinically significant levels of depressive symptoms. By ~4 months after diagnosis, this percentage had decreased to 21% of parents.

### *Step Movement*

Our intervention is now complete, and we are wrapping up data collection, so the data reported here are preliminary. We started looking at progression from step 1 to step 2, and from step 2 to step 3. Across our three steps, we found that about one-third of the sample ended the study at each of the steps, and movement from one step to the next occurred mostly (61% of the time) because the child did not meet the

A1C target; however, 22% moved because of the CES-D score alone, and 17% were elevated on both outcomes.

### **Parent Coach From First STEPS: First Look**

Recruiting, training, and overseeing the parent coaches for this intervention study became a second trial in itself to explore ways to recruit, train, and retain our parent coaches. Based on earlier pilot work, our team put together a review on the use of parent coaches in children with diabetes, offering suggestions for those interested in starting their own parent coach programs (14). My best advice is to choose your coaches wisely and to use a thorough referral and screening process. In taking such measures, you can increase the likelihood that your parent coaches will stay involved in the program and maintain a significant degree of contact with intervention participants.

Here is a first look at our descriptive parent coach data. We trained 36 parent coaches across both sites, and each was matched with an average of three participants over the trial (ranging from one to eight). These coaches stayed with our trial for an average of 19 months and had, on average, 25 contacts with participants across the 9 months of the study.

We also looked at participant satisfaction with parent coaches and found that 87% agreed or strongly agreed with a statement that their parent coach was supportive. Participants also answered some open-ended questions about their experiences, including about working with their parent coach. It was nice to hear that some of the participants found parent coaches to be quite valuable. As one participant said, "I liked having someone with experience that could understand all the challenges we face and encourage us to keep going forward. Priceless."

### **Conclusion**

I hope I have demonstrated here why we think families of young children with diabetes may benefit from additional supports, as well as why and how parents of children with diabetes may be the best equipped to provide these supports.

I know the coronavirus 2019 (COVID-19) pandemic has affected much ongoing clinical research, including behavioral trials, and our trial was in the final stages of data collection when shut-downs were enacted. This made us go back and consider whether we could have carried out our trial intervention in a socially distanced manner, especially given that our team's diabetes clinic visits are now being conducted via telehealth. Indeed, we determined that all of the components of our intervention, which were designed to be as convenient as possible for families, could be carried

out virtually. Thus, moving forward, we will be able to continue supporting families through virtual means.

I am also hopeful that our findings will hold and that we will eventually be able to move our program into the clinic setting and perhaps to partner with colleagues beyond our institutions to expand its reach.

We do not yet have the benefit of hindsight to know how COVID-19 has changed our lives. In the meantime, what can we do? First, we can use technology available to us to make behavioral treatments more widely accessible. We can take the science of behavior change and make it as easily accessible as ordering a movie on Netflix or a dinner from Uber Eats. Second, I believe we need to partner between clinic and community and across sites in ways that meet parents' needs with regard to diabetes management. If this pandemic has taught us anything, it has been how vigilant we have to be to make sure that all people have equal access to health care. Finally, looking toward the future means training for the future, and every young person who is thinking of entering the field also needs a coach and a mentor. We must ask what we can do to ensure that we bring the best and brightest young professionals into the field and support their career development, just as Dr. Rubin did for so many and as I have benefitted from and am now trying to pay forward.

### ACKNOWLEDGMENTS

The work I have described here has been a team effort, and we all know that such work takes time, funding, and truly a village of support. I have been fortunate to work with excellent colleagues at Children's National Hospital and other institutions. I also appreciate the families who have willingly participated in our research through the years. Finally, I would be remiss if I did not mention my own team at home, including my three kids and my husband, Ken. I very much appreciate my family's support of my work and my career.

### DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

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