

## LCC Session: Advocacy on the Ground

### CanMEDS Competency: Advocacy

Dr. S. Marjerrison

**GOAL:** *This LCC session will expose the residents to narratives from pediatricians in the community who are exceptional childhood advocates. The resources provided will also encourage them to consider other advocacy approaches. Through these stories, the residents are encouraged to consider if their definition of advocacy changes, or if they see new opportunities to incorporate advocacy into their future independent practices.*

#### **PRE-SESSION MATERIALS**

##### **Mandatory:**

1. *Read the attached stories*
2. *Review the CPS advocacy website for the ‘Are We Doing Enough’ priority list:*  
<https://www.cps.ca/en/status-report>

##### **Optional:**

3. *Watch this video:*  
Climate change advocacy:  
[https://www.youtube.com/watch?v=GGiGN5UO\\_C0&list=PLKYV5259WcZ0JZpNevYku7nGqmNvN\\_7jk](https://www.youtube.com/watch?v=GGiGN5UO_C0&list=PLKYV5259WcZ0JZpNevYku7nGqmNvN_7jk)
4. *Listen to this podcast*  
Combating vaccine hesitancy: <https://www.cbc.ca/radio/whitecoat/dr-noni-macdonald-anti-vaxx-redux-1.4373981>

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#### **NARRATIVES FROM COMMUNITY PEDIATRICIANS**

##### **DR. KAROLYN HARDY-BROWN**

###### **1. About myself...**

I am a community general paediatrician in Peterborough with a variety of clinics and interests and have been in practice since 2009. I have a small consult-based office practice (1 day a week) and also provide on call/hospitalist paediatric coverage at Peterborough Regional Health Centre. I also participate in/coordinate a variety of speciality clinics:

- I am the physician lead for the Paediatric Diabetes Education Centre (PDEC) and carry ~140 type 1 & 2 diabetic patients. This is a multidisciplinary clinic that includes social work, nursing and nutrition.

- I am the physician lead for the (SickKids affiliated satellite) Complex Care Clinic and provide some clinic coverage as well as policy development and community engagement

- I co-run a high-risk antenatal/neonatal abstinence syndrome (NAS) clinic consultation clinic that also provides post-discharge follow up for at-risk newborns and mothers. We also have totally changed the in-hospital approach to management of NAS, which has been cool.
- I participate in our local Transgender clinic with another paediatrician and 4 mental health clinicians. Between this one and the PDEC, I joined CPEG (Canadian paediatric endocrinology group)
- I recently assumed the mantle of Chief of Paediatrics

## ***2. What does advocacy mean to me?***

It means taking that "This isn't right" feeling, and exploring how you can address it...it also means meeting as many people in your professional community, inside and outside the hospital. It means exploring your community and finding out what infrastructure there is, how you can participate in it, how you can participate in changing it. It's intense curiosity about what does exist, how other people experience clinical care (this means the patient, the parents, the counsellor, the teacher, the nurse....) and what other people see as a need. Advocacy is part toddler-level-curiosity and part-MacGyver. It's taking what does exist and building it into something better.

## ***3. How are some ways I advocate for patients/children in my community?***

I say yes to every opportunity that presents itself and ask everyone what they think. Every time I see a leader administrator or policy developer I think of what I have to talk to them about and have an 'elevator speech' ready if there is something I am pursuing. I spend a huge amount of time understanding what initiatives have come forward in the past and why they did or did not come to fruition. I have cold-turkey presented to a hospital VP finance, high level members of public health and members of provincial bodies.

## ***4. Why do I incorporate advocacy? What do I get out of it?***

Honestly, I don't really think there is a choice, ie advocating or not advocating. Part of our role as paediatricians involves speaking for those who may not be able to speak for themselves and I could not practice medicine without finding out how I can best speak for children and their families. I think HOW we do that is infinitely deep...I quite enjoy policy development and stakeholder engagement but others may see education or awareness as valuable advocacy projects. I feel like advocacy is a huge domain with many, many possibilities. In terms of what I get out of it? Pride, perhaps, but also a closer connection to the community I live in. I love meeting people, and I love finding out their interests and if we can build something together. I'm grateful to be part of the fabric of where I live, in part because of the opportunities I have been given, but also because it is where my children were born and are being raised. I want to be able to give back somehow, and that feels really good.

## ***5. Issues plaguing children in Canada for which more advocacy is needed?***

- transition to adult care for children of medical complexity or chronic health conditions
- impacting ACEs, using ACEs to determine at-risk youth (mental health, adhd)
- better collaborative care with family physicians, better models for shared care and communication
- affordable and healthy nutrition
- access to/affordability of psychoeducational profiles

## ***DR. SEAN MURRAY***

### ***1. Tell us a little about yourself and your pediatric practice?***

My name is Sean Murray and I have been a general consultant pediatrician for the last 18 1/2 years. I was born and raised here in Sudbury and returned to practice after medical school at UofT and my pediatric training at Sick Kids. In residency, I had no idea as to the extent of the importance of advocacy and never really knew how to approach it. I never understood what my role could be, nor how I might go about it. My practice is quite broad. I do typical hospital and NICU call and my office is the breadth of general pediatrics—from simplistic pediatric issues to looking after children with very complex medical needs. I have also been blessed with the opportunity to work with children in a little bit of a subspecialized context, serving my community with a Botox clinic for CP patients and also working in the Pediatric Oncology Group of Ontario's outreach clinic here in Sudbury at our hospital.

### ***2-3. What does advocacy mean to you? How are some of the ways you advocate for patients in your practice, and children in your community?***

Advocacy to me means being able to make some kind of difference to my community. I believe it starts with a clinical need and then from there grows based upon good will. My earliest advocacy spans back to my first year of practice when I was seeing what turned out to be a complex autism case. Despite my training and previous exposure, I had no idea where to start with the young fellow. I called someone that agreed to help me out when I went up North; someone who helped to train me and who was very experienced in the area of Autism. Through that, I organized (with her) ADOS training for myself and my colleagues across Northeastern Ontario. Once that was completed, I thought that would be the saving grace and muddling through ASD diagnoses would be simple. I was very incorrect with that assumption. Additional education about our Autism system of care made me realize how huge the gaps were in all aspects, from diagnosis to treatment. The system was complicated for families and fragmented significantly. I then teamed up with a colleague of mine and together we began upon the largest amount of advocacy that I had to that point been involved with. After some conflict, resolution and compromise and too many meetings to count, we all managed to change the system for children with Autism and that system continues to grow and improve to this day.

From there, I took on the cause of children travelling far distances from Northern Ontario to receive their care. Out of it, the concept of NEOKids was born (the Northeastern Ontario Health Centre for Kids). This has been a lot of work for me over the last 10-15 years and has probably consumed the most of my time in advocacy. Part of the concept is a capital project, but a lot of work has been and continues to need to be done in regards to how children's programming is structured here in the North. I got involved in hospital admin to try and help accomplish this and I always encourage medical learners to try and systematically change from within. As a result, I feel that being involved in medical administration can be incredibly valuable and rewarding. This work is not yet finished, but I hope to see it conclude positively.

That said, advocacy always occurs day to day. Every patient encounter is an opportunity to make a difference and I feel as a general pediatrician that we have a great deal to contribute. Whether or not it is a school note or a school visit to help the educational programming for a child, whether its talking to my MP about the recent inequities regarding the

children's disability tax credit or just picking up the phone to speak with a health care provider on behalf of a patient, advocacy I feel comes in many forms. I have also watched and helped my colleagues here advocate and make changes for the better in relation to many aspects of pediatric health care, here in Sudbury and throughout Northern Ontario.

***4. Why do you incorporate advocacy in your practice? What do you get out of it?***

For me, advocacy is both rewarding and frustrating. Thankfully, most of the outcomes are favourable. From it, I get a huge amount of job satisfaction. Although I appreciate the impact, I must fully admit that there is some selfish gratification that comes from making positive changes. I have been very lucky in my career to have accomplished some positive things, but I have also been challenged with failures as well. Nevertheless, the importance of trying cannot be understated. As long as I am a pediatrician, I will advocate on behalf of my patients, across all levels of the spectrum of care.

***5. Beyond what you do, what are some of the major issues plaguing kids in Canada for which more advocacy is needed?***

Unfortunately, there is so much that needs to be done for children. In my region of the world, marginalized and vulnerable populations still need help. Advocacy to improve the health access and health outcomes for our indigenous child and youth population is very important. I feel that great strides have begun, but there is much more to make things equitable. There are still far too many children who live in poverty and suffer untold harms that are preventable. Finally, we are seeing a burgeoning and significant increase in babies born to drug addicted mothers. I don't think that we have even scraped the surface of the needs that these babies will have in the future and I worry a great deal about them. Hopefully, I can turn my thoughts and energy to working on some of these important issues moving forward.

***DR. CAROLYN HUTZAL***

***1. Tell us a little about yourself and your pediatric practice?***

I am a consulting pediatrician in a medium sized community in Ontario with three tertiary care centres within an hours drive. My practice is divided between office consulting, where I largely address developmental issues, and hospitalist work including a level 2 NICU and satellite oncology clinic, with on-call responsibilities. I also teach students and residents through the McMaster Medical School.

***2-4. What does advocacy mean to you? How are some of the ways you advocate for patients in your practice, and children in your community? Why do you incorporate advocacy in your practice? What do you get out of it?***

I am passionate about being an advocate for my patients for many reasons. Being a community pediatrician who lives and is raising my own children in the city, I feel that I am caring for the kids and families of my community. As a physician, I feel that I have a responsibility to help my patients, and I have been given the ability to do this through my position. Being an advocate for patients often involves the work that is done after your visit is through. It's calling schools and community resources and specialists to make sure your patients are taken care of. It's completing

paperwork to help them pay for their health care needs. It's ensuring your patients know how to navigate the healthcare system, and receive the best possible care. This is the work that isn't usually recognized financially as a fee-for-service physician, but it is the work your patients will be most grateful for and is the most practical and rewarding work I feel I can do for my patients to improve their lives.

Being a good advocate also involves understanding your patients' unique needs, life-challenges, and their values. One area I have enjoyed being a patient advocate is in my work with Syrian refugees who are settling in our community. They are referred to me with multiple medical issues, which have often been undiagnosed and mismanaged due to their displacement. They are unfamiliar with our healthcare system when they arrive, and they do not yet speak English, which disadvantages them in receiving the best care in many ways. Even though their lives have been very different from my own living in Canada, I try to understand how their life-experiences, cultural values and hopes for their child will impact how I can best advocate for them. This has been one of my most rewarding experiences in medicine so far, and has helped me realize I have more in common with my patients than we have differences.

***5. Beyond what you do, what are some of the major issues plaguing kids in Canada for which more advocacy is needed?***

An area I continue to find challenging to be a good advocate is in child mental health. It is hard to talk with families who are struggling to help their children and cannot access counselling, parenting supports and school programs that I know are needed. I often feel like I have little to offer them but to listen. Medication is often not the answer. We need to implement more comprehensive community programs to help children with mental illness.