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of the
Developmental Disabilities Program**

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Annual Dr. Greta T. Swart Essay Competition

An annual essay award is available to an undergraduate medical student at the Schulich School of Medicine & Dentistry, Western University. The essay should describe an experience managing a patient at any stage in the lifespan with a developmental disability. This includes management of physical health, mental health or both, either in the hospital system or in the community, including family medicine.

This year, the winner of the annual competition was Helen Jin.
Helen's essay is below.

A Sister's Perspective

At the age of 5 my sister Grace contracted encephalitis, which left her with lifelong epilepsy and cognitive impairment. At age 10, she moved into a group home after social workers deemed her a safety hazard to my mother's pregnancy and my soon-to-be brother. I had limited interactions with her after that, being occupied with my own teenage pursuits and lack of interest in family life. I soon left for university overseas and all contact between us sisters was lost.

I only made the effort to reconnect with Grace after returning to Canada six years later. During my time abroad, I grew to regret our absent relationship and had committed myself to helping others with developmental disabilities; I volunteered in care homes, led advocacy organizations, and interned at developmental disorder clinics. Armed with all my experiences, I came home fully confident in my ability to understand, care for, and emotionally connect with my sister. When summer vacation began, we scheduled Grace a one-week home visit, and I couldn't have been more excited.

It was going to be a long, hard, and humbling week. As an outside observer, it can be so easy to forget the stresses and hardships families face caring for these special individuals and just how rapidly burnout can occur. This was the week I received my wake up call.

Day 1

Grace and I were so happy to see each other. I asked how she'd been, what she'd been doing, and whether she'd missed me. It was difficult to communicate with each other, as her thought processes were unclear, her answers were sporadic at best, and her speech was garbled. But this was nothing new to me and I was just happy to engage her in conversation.

My parents' typical approach to managing Grace during home visits was to sit her in front of the TV as much as possible. I scoffed at this plan, deeming it a lazy-person's way out. I wanted to get to know Grace on a personal level, engage her in mentally stimulating activities, and create an educational environment for her. To that end, I asked Grace about her favourite activities, and we started the day off gardening.

For the next hour or so, I gardened while Grace remained resolutely uninvolved, standing beside me, unresponsive to my requests for help. She stared blankly at me

when I talked to her, and I worried this might mean her disinterest. My mom assured me that this was how she normally acted, but I was unconvinced – surely there must be a way to persuade her to engage with me, but the most I managed was to have her hold the tools.

I tried other approaches: we played her favourite games, drew pictures, read stories, none of which elicited any reaction from her. After a full day of activities, I was mentally and physically drained: it was hard to maintain a cheerful and optimistic attitude with such an unresponsive audience. But again, this was nothing I hadn't encountered before, and I vowed to continue trying the next day. Patience is key when working with individuals with developmental disabilities; I knew that and I would not give up.

Grace woke me up in the middle of the night – insomnia is a symptom of her condition and she wanted to play. She didn't understand my desire to sleep and refused to go back to her room. I tried leaving her to play by herself, but a crash of pots from the kitchen brought the whole family running down. My mom tried to intervene, volunteering to stay up with Grace, but Grace didn't want anyone but me. Despite my previous contempt of using TV as a child-care device, I could think of little alternative in my tired state and sat us down for movies. Eventually Grace fell asleep on the couch and I went back to bed.

Day 2

Early next morning, I was again awoken by Grace. She still could not comprehend my reluctance to get up and refused my requests for personal time. As I had done numerous times before in a professional capacity, I attempted to be firm and

set appropriate boundaries. I iterated to her that play time was not until 2 hours later and that she needed to entertain herself for now. This made Grace mad and she started to act out: she threw away my pillow, blanket, and cellphone, yelling at me to get up. Eventually, Grace began to get physical. Despite our 6-year age difference, she was already much taller and heavier than me, and her blows were powerful. One kick landed so forcefully in the center of my chest that it took the air out of my lungs. Now, I was scared; I couldn't breathe, I couldn't call out for help, and my vision became spotty. All the while, Grace continued her rampage.

Eventually, the noise woke my parents and they intervened. My mom comforted me, reminding me that Grace didn't know what she was doing: "*now that she's so big, it's hard to stand against her. We normally just give her whatever she wants*". This was hard for me to accept; could such a strategy really be considered good parenting? But the pain in my chest persuaded me and I resigned myself to not antagonizing Grace anymore.

The rest of the day, Grace had what my parents called an "off-day". She was restless. She picked fights with my 6-year-old brother. She couldn't focus on any activity for more than a few minutes. She yelled, she threw things, she attempted to run away from home. It was all hands on deck for the family, as we did damage control and tried to settle Grace down. There was no time or space for mental stimulation, education, or emotional connection; I barely noticed or cared about the lack.

Day 3

At 1am, yelling from downstairs pulled me awake. Grace and my parents were having a standoff in the foyer: Grace was attempting to leave home to "go to China" but my dad was blocking the front doors. My dad tried to rationalize with her while my mom

made soothing noises in her direction. None of this was effective however, as Grace continued to physically attack my parents while angrily exclaiming her desire to go. She attempted to jump kick my dad's face and pushed my mom against the wall. In the subsequent flurry of activity, she made it out the door and took off running towards the road, without even any shoes on.

My dad ran after her while my mom bolted for the car keys – this was a dance they had performed many times previously.

My mom and I caught up to them three blocks over. My dad was attempting to grab a hold of Grace while Grace continued to struggle. They both fell to the ground, and in the ensuing fight, my dad sprained his finger and banged his head against the pavement.

As we had been instructed to do by social workers in such a situation, my mom called the police, who came to help us restrain Grace. She was handcuffed and taken to the hospital in a police car. The officer asked us how we could let this happen: did we not lock the front door? Did we not keep a good eye on her? What did we do to aggravate her?

I felt so much shame under the officer's scrutiny. How did it come to this? Was it me who started this "off-day" by refusing to play with her that morning?

Finally, my mom set off for the hospital to accompany Grace while my dad and I returned home for the night. I couldn't shake the mental image of my sister being treated so much like a criminal.

In the morning, Grace and my mom were back. My mom had called the group home and had asked for the home visit to be cut short. *"We can't handle her in her current mood"* she explained, *"we need to think about [my brother]'s safety. The staff will pick her up in the afternoon."*

After two and a half days with Grace, we were all tired: physically, emotionally, and mentally. I was scared, sad, and defeated. While we waited for the staff to arrive, I made no protest when my parents turned on the TV and we all sat down to watch movies for the next 5 hours.

After my sister left, I looked around at the damage wrought over the last few days: the house was in disarray, my family was battered and bruised, my emotions were in turmoil. I thought I could handle taking care of Grace for one week, but I barely lasted three days. And in those three days, none of my plans had come to fruition; the visit had been nothing like what I'd expected.

I couldn't understand how this experience was so different from what I was used to in my volunteering and work positions. I was never this demoralized working with other individuals with developmental disability, despite interacting with them every day for months at a time. Why did I fail so dramatically when it came to my own family?

It was a while before I could properly reflect on this question. The difference between caregiving as a professional and caregiving as a family member was all a matter of exposure. When taking care of my sister, there was no respite; I couldn't clock out at the end of the day, I couldn't "Return to my normal life" when my shift was over, I couldn't even get a full night's sleep. When the stress, exposure, and emotional rollercoaster of doubt, worry, and fear was constant and seemingly endless, burnout happened so much faster than I'd ever thought possible.

As physicians, there will always be a degree of removal between us and the patients we care for. No matter how long we've known them, how many hours we've

interacted, or how much we empathize, we will only ever be tourists – we make quick trips into these patients’ lives, but at the end of the day, we leave, go home, and take our reprieve.

But for the families, this is their reality, and will likely continue to be their reality for the rest of their lives. My family had the benefit of knowing that reprieve would eventually come when Grace was scheduled to return to the group home in one weeks’ time, but many families don’t even have that luxury. When the duty is endless and the work so thankless, it is no wonder why burnout occurs so rapidly and so frequently. It is no wonder why people cannot be “ideal parents” or implement all the well intentioned suggestions offered. It is no wonder why my parents rely so heavily on the TV.

But despite everything, my parents have never failed to invite Grace home at each opportunity. They sacrifice their own physical and mental wellbeing to be with my sister, because they love her and want to spend time with her. And, as I’ve come to experience myself, the love that Grace shows us back, that fierce and innocent love hiding behind her “off days”, does indeed make it all worthwhile. There is so much joy and fulfillment caregivers can obtain from knowing amazing individuals like Grace, but this is not possible when they’re burnt out.

We, as healthcare providers, do not, and likely never will, understand what the families of our patients have been through, why they’ve made the decisions they’ve made, or why they’ve neglected to follow our advice. The best we can do is ask, listen, and withhold judgement. There is so much we can do to help these families and combat caregiver burnout, but that cannot happen when we approach the situation with assumptions of superiority. Grace taught me that lesson, and is one I hold close to my heart as I begin my medical career.

7th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day

The 7th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day was held online on Thursday June 2, 2022.

We were thrilled to welcome **Professor David Wright** as our Keynote Speaker this year. David Wright is a Professor of History and Canada Research Chair in the History of Health Policy at McGill University.

His 2011 book, *DOWNS: the history of a disability* (Oxford University Press), won the biennial Dingle Prize for best book in the history of science and medicine.

He has also co-authored (with Sasha Mullally) *Foreign Practices: Immigrant Doctors and the History of Canadian Medicare* (McGill Queen's University Press, 2020).

He was recently elected Fellow of the Royal Society of Canada.

This event also featured talks by trainees and junior faculty members from Western and other universities in Ontario.

The winner of the annual Maria Z. Gitta award for the best talk by a student/trainee this year was Julia Montenegro. Her talk was entitled “Joint Attention in 4 and 6-month old Infants at High Familial Risk for Autism Spectrum Disorder: Association with brain development”.

Congratulations to Julia and all the speakers for a wonderful event.

Dr. Wright's keynote address is available for viewing below.



Department of Psychiatry Grand Rounds

The Developmental Disabilities Program hosts the Grand Rounds for the Department of Psychiatry at the Schulich School of Medicine & Dentistry every September.

Our speaker this year is Dr. Rob Nicolson.

Dr. Nicolson is the Chair of the Developmental Disabilities Program in the Department of Psychiatry at Schulich. He is also a Child and Adolescent Psychiatrist at both CPRI and the Children's Hospital in London Ontario. Dr. Nicolson's practice is dedicated to people with Developmental Disabilities.

The title of Dr. Nicolson's talk will be "Autism Spectrum Disorder – How Far Does the Spectrum Extend?"

This talk will be held online on Thursday September 8, 2022 at 8:30am. For information about this event, visit the Department of Psychiatry's "events" page here:

https://www.schulich.uwo.ca/psychiatry/about_us/events/2022/index.html or email Kate Hayes (Program Coordinator – Continuing Professional Development for the Department of Psychiatry at the Schulich School of Medicine & Dentistry) at CPDPsychiatry@lhsc.on.ca.

Continuing Professional Development Rounds are a self-approved group learning activity (Section 1) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada (2 credits).

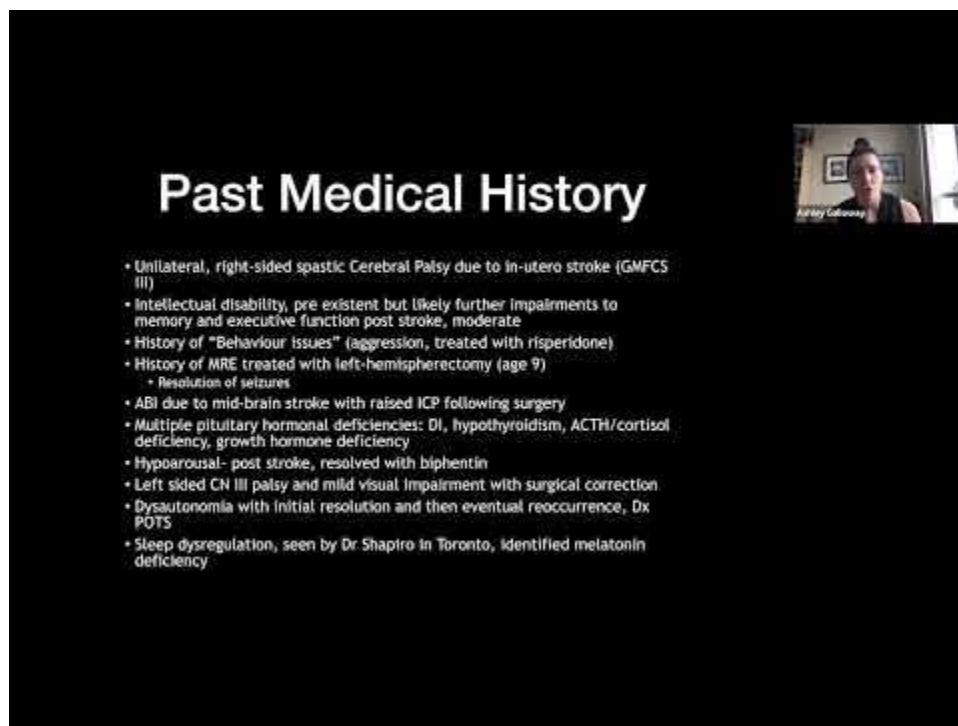
Developmental Disabilities Clinical and Research Rounds

The Developmental Disabilities Program hosts a series of rounds on the second Wednesday of every month during the academic year (October – June).

The last talk of the 2021/2022 academic year was given by Dr. Ashley Galloway on June 8, 2022. Dr. Galloway is the first Clinical Fellow in the Psychiatry of Developmental Disabilities in the Department of Psychiatry at the Schulich School of Medicine & Dentistry.

Dr. Galloway gave a case presentation entitled: **“Lessons Learned in a Year: Management of severe behavioural problems in a medically complex patient.”**

You can view Dr. Galloway’s talk below



Past Medical History

- Unilateral, right-sided spastic Cerebral Palsy due to in-utero stroke (GMFCS III)
- Intellectual disability, pre existent but likely further impairments to memory and executive function post stroke, moderate
- History of “Behaviour issues” (aggression, treated with risperidone)
- History of MRE treated with left-hemispherectomy (age 9)
 - + Resolution of seizures
- ABI due to mid-brain stroke with raised ICP following surgery
- Multiple pituitary hormonal deficiencies: DI, hypothyroidism, ACTH/cortisol deficiency, growth hormone deficiency
- Hypoarousal- post stroke, resolved with biphentin
- Left sided CN III palsy and mild visual impairment with surgical correction
- Dysautonomia with initial resolution and then eventual reoccurrence, Dx POTS
- Sleep dysregulation, seen by Dr Shapiro in Toronto, identified melatonin deficiency

You can also access recordings of other previous talks on our website here:

https://www.schulich.uwo.ca/ddp/education/continuing_professional_development.html

The 2022/2023 Developmental Disabilities Clinical and Research Rounds will begin again on October 12, 2022. You can see our schedule for the next year at the link above when it becomes available.

Developmental Disabilities Clinical and Research Rounds are a self-approved group learning activity (Section 1) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada (1 credit).

The Developmental Disabilities Program is approved by the Canadian Psychological Association to offer continuing education for psychologists. The Developmental Disabilities Program maintains responsibility for the program.

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