

**The Clinical Bulletin
of the
Developmental Disabilities Program**

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Upcoming Conferences in Developmental Disabilities

The Ontario Association on Developmental Disabilities will hold their annual conference in Kingston Ontario, from April 10 – 13th, 2018.

The theme of the Conference is “*Working Together: Innovative Ideas for Complex Care*”. Registration will open in January 2018. For more information, and for more details on registration, email oadd@oadd.org.

Student Awards

The Annual Dr. Greta T. Swart Essay Competition

An annual essay award is available to both undergraduate medical students and postgraduate medical residents 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 we had 5 applicants. Each essay will be published in an upcoming issue of our clinical bulletin. The essay by Dr. Bethany Oeming, a resident in the department of Anesthesia & Perioperative Medicine at the Schulich School of Medicine & Dentistry at Western University was featured in our Summer 2017 issue. The essay by Joshua Friedland, MD Candidate, 2019 – Schulich School of Medicine & Dentistry, Western University, was featured in our Fall 2017 issue.

In this issue, we are featuring the entry by Haider Abed, a Medical Student at the Schulich School of Medicine & Dentistry at Western University. Haider’s essay was entitled; Sammy.

Sammy

Haider Abed, Meds 2020, Schulich School of Medicine & Dentistry, Western University

It's not often that you find yourself in an uncontrollable fit of laughter when at the hospital. This is a serious place with serious consequences, but sometimes you get a patient that just steals the air from the room. For me, this was a young kid in the cancer ward that the physicians and nurses would always complain about, and yet you would not go an hour without seeing one of them poking their heads in his room to see if he was awake to tell another one of his ridiculous stories.

Sammy was unfortunately diagnosed with childhood leukemia at a young age and had to undergo an aggressive course of chemotherapy and radiation, making him a long-term resident of the local hospitals. He was never very good at being the prototypical patient; Sammy was far too cheery and agreeable. Clerks and residents felt particularly comfortable with him because he pretended not to notice their imperfections, often ending each interaction with a big smile and a quirky, "I'm A-Okay!" That was his phrase. No fruit cups left? A-Okay! TV isn't working? A-Okay! Another round of chemicals pumped into your body, leaving you at the brink of death? A-Okay! It was this attitude that put me on edge. I wasn't sure if his optimism succeeded normalization of a medical setting since his prenatal diagnosis of Down's Syndrome, or if it was an unremarkable by-product of his developmental delay. I am ashamed to admit that I had originally assumed the latter, and that assumption made its mark. I made excuses not to see Sammy when the doctor came in to check up on him because to go in there would be to

recognize that a sweet child with Down's Syndrome was battling liquid cancer, and I was not yet ready to make that leap.

The problem was that I became addicted. I asked about Sammy and checked his chart as often as I could, trying to find out if he was responding well. I tried to deconstruct him into a series of numbers and images that told a story within a story, a cheap trick to detach myself from the situation. His fluctuating blast percentage, a surrogate marker for his prognosis, had unrelenting control over my actions. On good percentages, you'd see me skipping along the halls of the hospital humming Billy Joel while bad percentages meant briefer histories and physicals for other patients. On a particularly bad day, the worst it had ever been, I found myself doing something I promised I never would...I went into his room.

Sammy was asleep; had been for a while. Yet standing near his bed had me shaking uncontrollably. While the physicians, residents, and clerks could occupy their headspace with trying to make him better, I was burdened with the task of watching. They teach a lot of things in medical school, but real compassion is not one of them. Real compassion feels like the heaviest burden in the world: you feel their pain crawling up your nerves, amplified tenfold by the lens of your own emotions and experiences, stabbing you in all the worst places. I stole out his room and headed to the nearest washroom to be alone, hoping nobody had caught a glimpse of my glistening cheeks.

I made a habit of seeing him when he was asleep, feeling his essence through proximity. I had yet to speak a single word to him, but tried to stay in touch through his physicians and family. Sammy's favourite show was Teen Titans. His favourite colour was blue, and he didn't understand why trees grew so big. I also learned that he was also scared. Very scared. He knew that he was sick, and he knew that there's a chance he might not make it, but he knew he had

to be brave for his family, for they were even more afraid. If this was a proper story, this would be the point in time where I finally talked to Sammy, but this isn't that kind of experience. I remained behind the scenes throughout the course of his treatment and allowed for Sammy to fight his fight. His months in the hospital did not equipped him to point me out in a lineup, for we shared an undeniably one-sided venture.

When I heard that he was finally leaving the hospital for good, I went to his floor and watched. The family had brought balloons and stuffed toys, tribute to the great warrior that had fought the beast. Sammy and his family thanked the physicians and nurses for everything they had done, sealing each interaction with a lingering embrace. I thought that I was safe in my little corner that peaked outside of the room, but I had made the mistake of conspicuity. My gaze met Sammy's, a surge of lightening that spanned a century. He walked over towards me, leaving his room and the roaring crowd behind him. He lifted his right hand and extended his index finger, beckoning me to come closer. Losing all control of the muscles in my legs, I motioned towards him silently. He stood on his tiptoes and placed his hands around his lips, a standard procedure for the delivery of highly sensitive and highly confidential material. I followed protocol and placed my ears on the other end with a million thoughts running through my head. He shifted his eyes to one of the oncologist with an obvious case of male patterned baldness, then whispered, "do you think his hair will grow back too?"

3RD Annual Developmental Disabilities Academic Research Day

The Developmental Disabilities Program, in partnership with Dr. Julio Martinez-Trujillo, Province of Ontario Endowed Academic Chair in Autism, will host the Third Annual Developmental Disabilities Academic Research Day on May 3, 2018 at the Great Hall at Western University. The call for submissions for presentation is open. Those interested in submitting an abstract can do so at any time. Abstracts should be double spaced and be a maximum of 250 words. They should be typed in a minimum of 12-point font, preferably in Microsoft Word and submitted electronically to Sarah O'Flanagan at sarah.oflanagan@lhsc.on.ca

Abstracts should clearly summarize Study Objectives, Methods, Results, and Conclusions. We will consider submissions for studies currently in progress, but we will give preference to completed projects.

The deadline for submissions is **April 1, 2018**.

More information can be found on our website; www.ddd.uwo.ca

Developmental Disabilities Clinical and Research Rounds

The next talk in our Clinical and Research Rounds will be held on March 21 at 4pm, at the Child and Parent Resource Institute.

Dr. Susanne Schmid, Associate Professor, Department of Anatomy and Cell Biology at Western University will give a talk entitled; Sensory Processing and Filtering Disruption in Autism Spectrum Disorder.

This talk will also be available for viewing as a webinar. The webinar can be viewed live at <https://zoom.us/j/719431299>

The full speaker schedule is also available on our website; http://www.schulich.uwo.ca/ddp/education/continuing_professional_development.html

*These talks are recorded, and available for viewing after the fact on our website at the link here; http://www.schulich.uwo.ca/ddp/education/continuing_professional_development.html

16th Annual Spring CPD

The Developmental Disabilities Program will host the 16th Annual Developmental Disabilities Spring CPD on Wednesday April 18 from 12pm – 4pm.

This event is held at the Windermere Manor at Western University.

this year we will welcome the following speakers;

Dr. Joyce So

Dr. Joyce So is an Assistant Professor in the Department of Laboratory Medicine and Pathobiology, as well as an Assistant Professor in the Department of Psychiatry at the University of Toronto. Her research interests are Identification and characterization of rare genetic variants in psychiatric populations. Dr. So will speak about rare genetic conditions, and when health care providers should send their patients with developmental disabilities for genetic testing.

Dr. Nicole Neil

Dr. Nicole Neil is an Assistant Professor in the Faculty of Education and holds a cross appointment to the Developmental Disabilities Program in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University. Dr. Neil is a Board-Certified Behavior Analyst and she is the Coordinator of the MPED in Applied Behavior Analysis. Her research interests are Applied behavior analytic interventions for individuals with Down syndrome and Fragile X Syndrome, Assessment and treatment of comorbid mental health diagnoses for individuals with developmental disabilities, optimizing intervention intensity in behavior-analytic instruction for individuals with developmental disabilities, and social skills and support programs for children with developmental disabilities.

Dr. Neil will speak about behavior interventions that primary and other health care providers can suggest and/or provide for their patients with developmental disabilities.

Dr. Rob Nicolson

Dr. Rob Nicolson is the Chair of the Developmental Disabilities Program, and an Associate Professor in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University. He is a Child Psychiatrist at the Child and Parent Resource Institute, specializing in Autism Spectrum Disorder and other developmental disabilities. He is also a Scientist at the Lawson Health Research Institute.

Dr. Nicolson will speak about pharmaceutical options for behavior intervention in individuals with developmental disabilities.

Note; Registration is now open for this event. Please email Sarah O'Flanagan at sarah.oflanagan@lhsc.on.ca to register.

This event will be live streamed as well. Simply click on this link to join the webinar;

<https://zoom.us/j/991315903>

We accept 50 registrants for this event, and registration fills up quickly.

Lunch is provided for each participant, and there is no cost to register.

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Submissions welcome. Articles published or abstracted in this Bulletin do not necessarily reflect the opinions of Western University or the Developmental Disabilities Program.