

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

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6th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day.

The Developmental Disabilities Program hosted the 6th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day on Thursday June 3, 2021. This event was held online with over 100 attendees. Dr. Alysson Muotri, Professor of Paediatrics and Cellular and Molecular Medicine from the University of California, San Diego, gave the keynote address entitled, "Insights into Autism Spectrum Disorder Using Functional Brain Organoids".

The winner of the Maria Z. Gitta Award for best presentation by a student or trainee was Kara Hannah, a graduate student with Dr. Ryan Stevenson in the Department of Psychology at Western University. Kara's talk was titled: "Linking Social Communication and Meta-Linguistic Ability in Autism Spectrum Disorder."

Thank you to all who presented and all who participated.

Annual Dr. Benjamin Goldberg Research Grant

The Developmental Disabilities Program offers an annual research grant competition in the Spring. This grant is meant to facilitate research specific to Intellectual Disabilities.

It is open to any student registered at Western University, or a University or College in Southwestern Ontario.

This year, as always, we had many strong applications for this grant. This year's successful applicant was Kailee Liesemer, a graduate student in the Faculty of Education at Western University. Ms. Liesemer's project is titled: "The Effects of a Video-Based Modeling Intervention Package on the Inquiry Skill Development for Students With Intellectual and Developmental Disabilities".

Developmental Disabilities Clinical and Research Rounds

The final talk in the Developmental Disabilities Clinical and Research rounds was given by Dr. Jeff St. Pierre, a Clinical Psychologist at CPRI and faculty member in the Department of Psychology at Western University on Wednesday June 9, 2021.

Our rounds will begin again in October of 2021 to begin the 2021/2022 academic year. These rounds will once again be held on the second Wednesday of each month. We hope to be able to provide these talks in person again this coming year, but will continue to offer them as live webinars as well.

The schedule of speakers and topics will be available soon on our website:

www.ddp.uwo.ca

If you have a suggestion for a speaker and/or topic for the 2021/2022 academic year, please email Sarah O'Flanagan at sarah.oflanagan@lhsc.on.ca

Post-Graduate Education

The Faculty and staff in the Developmental Disabilities Program have been working tirelessly for several years to create and implement a Clinical Fellowship in Developmental Disabilities in the Department of Psychiatry at the Schulich School of Medicine & Dentistry. This project, which is, to our knowledge, is the first Clinical Fellowship specific to Developmental Disabilities in a Psychiatry program that is externally funded domestically in Canada. We are extremely proud of this project and are grateful to Shannon Bain, the Director of the Child and Parent Resource Institute in London and the Government of Ontario Ministry of Children, Community, and Social Services for their support.

We are thrilled to welcome Dr. Ashley Galloway to the Developmental Disabilities Program as our first ever Clinical Fellow. Dr. Galloway completed medical school at the University College Cork, Ireland and recently finished her psychiatry residency at Western University. Dr. Galloway's interest in Developmental Disabilities began prior to medical school, when she was a respite worker in a group home and a counsellor at a camp for people with Developmental Disabilities in Alberta.

Dr. Galloway notes that she "... love[s] this field for its challenges, it's amazing patient population, and the excellent people who come together to support them!"

Dr. Galloway began her clinical fellowship training in July of 2021.

Welcome, Dr. Galloway.

Student Awards

The 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 Anthony Zicarelli, MD Candidate, 2022.

You can read his essay below.

Sarah's Lesson

I had been waiting for this day since I was accepted into medical school. The past two years had been preparing me for this moment—Clerkship was starting.

Despite my vigour, I was nervous when I arrived at the hospital on my first day. This really was my first opportunity in the hospital with any responsibility, in pediatrics none the less. Taking care of adults was one thing but taking care of their children is another. After a day of orientation and instruction from the residents, I was on call my first night. As a medical student, my primary responsibility on call was to take the histories of patients who were to be admitted from the emergency department.

I was paged that evening to see a patient who the resident briefly described as a teenage girl, let's call her "Sarah", presenting with finger discoloration and pain. After struggling to find the emergency department, I took a deep breath, stepped into the examination room, and introduced myself. Sarah was laying on a gurney to my right, happily watching videos on her tablet. It wasn't until she looked up that I noticed many of the hallmark facial features I remembered from a lecture I attended just a few months

prior. Something the resident, knowingly or not, failed to mention earlier was that Sarah had Down Syndrome. She was my first patient who had a developmental disability, so I had no experience working with this patient population. I was immediately nervous and did not want to ignorantly do or say anything insensitive or inappropriate. Voices of professors from my first two years of clinical teaching popped into my head: ask questions directly to the patient, match the patient's tone and volume, be patient in waiting for answers. Although I follow these principles with my other patients, I felt it was especially important to make sure Sarah felt like she was included and an equal member in her healthcare.

In answering my questions, Sarah explained how her fingers on both hands started turning purple two days prior, and how her left wrist became swollen and painful that morning. A cursory physical exam corroborated her story and emphasized her limited range of motion. She knew her previous medical history, and clearly outlined her medications list. I was impressed with how knowledgeable Sarah was. When learning about Down Syndrome, our lecturer emphasized that people with Down Syndrome face many struggles in life with intellectual disability being one of them. Although Sarah had mentioned a few struggles she faces, Sarah seemed to contradict my lecturer's intellectual disability statements as she rhymed off medical terminology.

I reviewed the case with the resident and was adamant about having Sarah assigned to me once she was moved to the floor. I wanted to figure out what was happening to this girl, I wanted to help her, and I wanted to learn from her. Little did I know that during my time with Sarah and her family, I would learn even more about family, love, and life than I would about medicine.

A long night of answering pages was over, and I expected to be exhausted on my post-call day. However, I woke up rejuvenated and excited after meeting my patient. Sarah had an abnormal presentation that stumped even the smartest of doctors. The thrill of the unknown inspired me to dive into the literature on my post-call day and read around various cases of Down Syndrome, abnormal hand swelling, and vascular diseases. She was the first patient that made me excited to explore more than what was being taught in the classroom.

The next day I returned to my team with a plethora of differential diagnoses to explore and investigations to propose. As we initiated our plans, I went to see Sarah and tell her what I had learned the day prior. To my surprise, Sarah was now accompanied by her father instead of her mother. Due to the Covid-19 pandemic, only one visitor was allowed per pediatric patient. Sarah's father told me that he and his wife were taking turns spending days with their daughter, not so they could work or spend a night in their own bed, but because they each wanted to spend as much time as possible caring for her. This was something that I had not seen with any other pediatric patient. Despite only knowing Sarah's family briefly, their love for and commitment to one another was palpable. Sarah's parents adored her, and she clearly adored them, regardless of her developmental disability and the challenges it brought. Sarah's extensive medical history and repeated hospital stays did not frustrate her family. They never placed blame on Sarah or her Down Syndrome. In fact, it was almost as though Sarah's Down Syndrome brought her family closer and with that they created a stronger, more united family.

Throughout my assessment, Sarah's father held her hand and comforted her as she winced. I felt horrible as I conducted my physical examination, as I was the one inducing her pain. I offered to stop, but both Sarah and her father wanted me to continue; they understood the importance of a thorough and accurate physical examination, regardless of how uncomfortable it may be. I was impressed by both Sarah and her father's bravery. From her father's perspective, it must have been difficult to see his daughter in pain. As for Sarah, she was strong enough to endure the pain. I explained that although we were not quite sure what was causing Sarah's finger pain and discoloration, Sarah had inspired me to read the literature and investigate possible differential diagnoses. I relayed the different conditions I had learned about, and Sarah seemed so intrigued to hear what could be ailing her. Sarah's father's response was uplifting and instilled confidence in the team: "We'll stay as long as it takes to make sure our daughter is happy and healthy".

Sarah's parents' commitment to her was juxtaposed by other patients I saw during my time in pediatrics. Some less fortunate children rarely received the same level of love and compassion from their parents. Most often, their parents were complaining about how much time they had to spend in the hospital, how they could not leave the grounds to get food, or that we did not have their child's definitive diagnosis readily available. Other families were more concerned about the possibility of contracting Covid-19 while in hospital, and one child even spent their time in hospital completely alone.

Over the next few days, our test results returned frustratingly unremarkable. Sarah's fingers and hands remained purpled and cold despite the treatments we were providing. Thankfully, it did not seem as if her condition was worsening. I reassured her family that we were doing everything we could to figure out what was happening. Ultrasounds, MRIs, and CT scans were ordered. Specialists were consulted who sent for rheumatological and hematological panels. Biopsies were taken for tissue identification. Throughout the entire process, the family remained understanding and supportive of the team, and were completely committed to the well-being of their daughter.

Each day, I would be welcomed to Sarah's room with a smile. She answered my questions, and even asked her own. She never hesitated to allow me to perform a physical exam, even though it caused her significant pain. She remained cheerful and pleasant throughout her stay in hospital, despite the multitude of investigations and uncertainty of her condition.

It was very clear that Sarah enjoyed being around people and thrived in social situations. Despite being confined to their room due to Covid-19 protocols, her family made the best of a difficult circumstance. They organized a video conference between Sarah and her class, whom she missed dearly. A family friend who worked in the hospital was also a familiar face who visited frequently. Sarah's *joie de vivre* was infectious and made her an easy patient to work with and learn from. But it made me wonder why more people, who had fewer medical and developmental difficulties, did not exhibit the same joy? Was it Sarah and her personality? Was it the incredible support system established by her parents? Or was it that the rest of society simply took their health and their lives for granted?

Sadly, I would never find answers to these questions, nor would I find out what was causing Sarah's pain. Results were still pending when I stepped into Sarah's room on my last day. I thanked her and her family for allowing me to be a part of her care and apologized for not yet establishing a definitive diagnosis and treatment plan. Although I tried not to show it, I felt frustrated, I felt as if I had let the family down. But in typical fashion, Sarah's parents recognized the team's efforts in caring for their daughter and reaffirmed their commitment to her health.

As my time on the pediatric unit was coming to an end, I reflected on how ignorant my lecturer was the year prior. He painted a picture of an individual with Down Syndrome as someone who would be a burden and totally dependent on others. However, Sarah's family demonstrated that with the right love and support, any child, with T21 or not, could blossom into a loving, caring, joyful person with more capabilities than disabilities.

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