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4th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day

The Developmental Disabilities Program hosted their 4th Annual Developmental Disabilities Research Day on Thursday May 30, 2019. This annual event showcases research from trainees and faculty members across Schools and Faculties at Western University.

In honour of Dr. Benjamin Goldberg, past Chair of the Developmental Disabilities Program, and his immeasurable contributions to care for people with Developmental Disabilities, the committee for the Developmental Disabilities Research day voted unanimously to append the name of the day to "The Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day".

Dr. Benjamin Goldberg

Dr. Ben Goldberg received his bachelor's degree in biology from the University of New Brunswick and his medical degree from Dalhousie University. He then completed his psychiatric residency at the Meninger Clinic in Kansas.

Dr. Goldberg dedicated his 53-year psychiatric career to people with developmental disabilities. He worked at CPRI for 35 years and was the founder of the Developmental Disabilities Program at Western.

Dr. Goldberg's contribution to the field of developmental dis abilities is highlighted by his numerous awards. He won the distinguished contributor award from the Ontario Association of Children's Mental Health Centres and the Hull Roeher Award of Merit from the OADD. He was also the United Nations Technical Advisor to Guatemala and later was a consultant to the United Nations Rehabilitation Directorate. More recently, Dr. Goldberg was appointed to the Order of Ontario in 2003, received the Queen Elizabeth II Diamond Jubilee Award in 2012 and the NADD Lifetime Achievement Award in 2013.

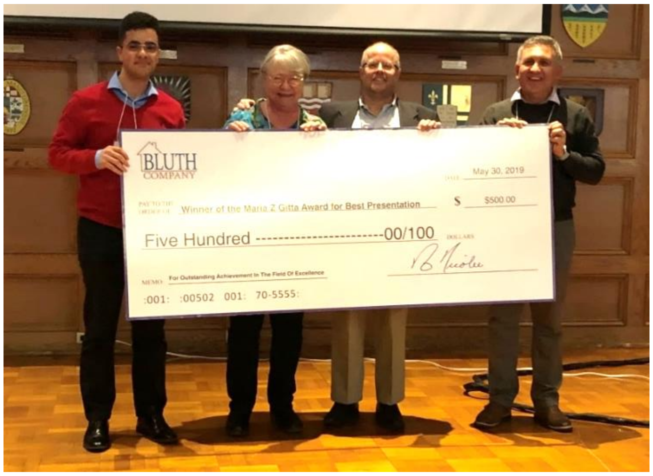
Maria Z Gitta

This year also marked the inauguration of the Maria Z. Gitta award for best presentation by a trainee at the Benjamin Goldberg Developmental Disabilities Research Day.

Maria Z Gitta was a Research Associate and Administrator for the Developmental Disabilities Program at Western University for 25 years. Ms. Gitta represented the developmental disabilities field on various task forces and groups throughout her career. In 2013, Ms. Gitta was the recipient of the OADD Hull-Roeher Award of Merit as well as the recipient of the NADD Ontario President's award.

Maria was on hand to present the award to Faraj Haddad, this year's winner of the Maria Z. Gitta award. Faraj's talk was entitled: "The Role of Interleukin-15/Natural Killer Cells in Maternal Immune Activation's Effects on Offspring Hearing and Behaviour"

Picture below from L to R:
Faraj Haddad (winner of the Maria Z Gitta award for best presentation), Maria Z Gitta, Dr. Rob Nicolson (chair, Developmental Disabilities Program and co-chair for Research Day), Dr. Julio Martinez-Trujillo (co-chair for Research Day).



The Developmental Disabilities Program would also like to extend a heartfelt thank you to the following people and departments for their help and wonderful work in preparation for research day, and during the event:

Mabel Mendoza
Our Keynote speaker, Dr. Daniel Messinger
The Staff of the Great Hall at Western University
Natalie Wakabayashi and the Communications Department at the Schulich School of Medicine & Dentistry.

Annual Dr. Benjamin Goldberg Research Grant Competition

Every spring, the Developmental Disabilities Program has a grant competition for students and trainees. This grant competition is meant to provide seed funding to a trainee doing research in the developmental sector.

This year, we had a robust cohort of submissions, with a record number of applications.

The winner for the 2019 competition was Kaela Scott, a trainee in Dr. Susanne Schmid and Dr. Brian Allman's lab at the Schulich School of Medicine & Dentistry.

Kaela's application was entitled: Cognitive Processing in the CNTNAP2 Rodent Model for Neurodevelopmental Disorders.

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.

In 2019, we had 4 applicants. All 4 submissions will be published in upcoming issues of the Clinical Bulletin. The first submission, presented below, was written by the winning applicant, Abbas Bukhari.

Brett

During my internal medicine clerkship rotation, I was part of the care team for Brett, a patient with cerebral palsy. My experience being a part of Brett's care was eye opening, emotional, and provided a brief window into his life and the difficult decisions that must be made, not by physicians, but by a person's loved ones.

I was a third-year medical student rotating through the Clinical Teaching Unit. The team is responsible for dozens of adult patients who have been admitted to hospital. As I sat in the team room, the resident on call began handing over the new overnight admissions and the day team would volunteer to take the patient on. The resident started to describe Brett, a 49-year-old non-verbal man with cerebral palsy, who was admitted with a pneumonia and slight pleural effusion. Now, I did not know much about cerebral palsy nor had I ever worked with a non-verbal adult patient, but I felt like I knew how to manage a pneumonia. I thought to myself:

Just give him antibiotics, IV fluids, maybe drain the effusion and watch his elevated white blood cell count decline into a normal range. Easy. Non-verbal? No problem.

I skimmed Brett's admission note, jotted down his most recent bloodwork and made my way up to the 6th floor of the hospital to meet him. I glanced at his vitals prior to entering the room that housed Brett and two other patients. He was febrile and breathing rapidly with some nasal prongs. Nothing I hadn't seen before, I continued to act under the impression that this would be routine for me.

I entered the room and pulled back the curtain to reveal Brett, a think man with a sparse head of hair curled up in a hospital bed; his nasal prongs twirled along his cheek and mouth rather than in his nose. He would not speak but his eyes were a deep blue and very expressive. Brett fixed his gaze onto me for a moment followed by what appeared to be some panic in his eyes; he started to hack a mucus filled cough and his face turned a bright red. He settled down soon after. Though non-verbal, Brett was expressive. He'd shake his head with certainty when he wanted to say 'no'. His mother, a woman in her early 70s, stood over the bed and began to adjust the misplaced nasal prongs. "He hates these things!" she joked as she placed the prongs back into his nose. Just as quickly, Brett began to grunt and twist his head in an attempt to displace the prongs again. I noticed Brett reaching for the prongs with his hands, but his arms had little range of motion and seemed partially locked to his chest at the elbow.

I introduced myself to the two and noticed I did not exactly know who to direct my questions and statements towards. "Uhhhh how are we feeling today?" I awkwardly asked Brett. Again, he fixed his gaze onto me, but nothing more. “About the same as yesterday” his mother answered. I continued to question Brett, but his mom would be the one to answer. Eventually, I found myself having the conversation about Brett and his health exclusively with his mother, with Brett more of a bystander than active participant. His mother informed me that he was the oldest of three siblings. She’d told me Brett had been living in a group home since he was about 9 years old and he was very popular there – loved by the staff and other residents. She informed me Brett had been admitted to hospitals a handful of times over the past few years with similar lung infections. Due to his condition, Brett was unable to clear the secretions from his airway effectively and often aspirated. I asked about some of the previous admissions and got a more nuanced understanding of not only Brett’s life, but that of his mother who was his substitute decision maker and seemed to be his sole caregiver outside of the home. It seemed much of her life and time had been dedicated to juggling caring for Brett into his adult years, the lives of her other children and grandchildren, and her own career and interests. Despite this, she was cordial and seemed confident and earnest about his care. We discussed the plan to manage his symptoms, give him antibiotics and keep an eye on the fluid around his lung to see if it needed draining. We had a good chat, we were on the same page, and I told Brett’s mother I would return daily to check on Brett.

I had started caring for Brett on Monday and it was now Friday. Brett’s condition was fluctuating. His lab values seemed to be improving slowly but surely, but this clinical appearance was highly variable. One day he’d appear to be in pain, taking over 25 breaths a minute, and the next, he’d be more stable and comfortable. I couldn’t exactly say if he was making huge strides in the right direction, but I thought he was improving. However, his mother started to change slightly in her demeanor. “I just don’t want him to suffer, he’s suffering” she’d repeat as I examined Brett while he coughed and turned red in the face. “Is there anything we can do to make him more comfortable?” I asked. “His labs seem to be trending in the right direction, I think he’s getting better” I added.

I don’t remember exactly what his mother said here, but it was something along the lines of: “I’m not sure, I think this maybe the end for him. I think we should take another look at his goals of care.” I was taken aback. We continued the conversation, but I didn’t really know what to say. “But the lab values… he’s getting better I think…” is all I could really muster. I was not expecting this from his mother an di had not had this sort of conversation with a patient yet. His mother was insistent. I balked at this idea but did not really know how to proceed and his mother seemed set. I did not know how to handle the situation, I called one of the senior residents to take the reins on this conversation and he arrived promptly. I quickly updated him on the situation, and he started to talk with the mother about goals of care. “I’m nearly 75 and I don’t want my son to outlive me. I don’t want these difficult decisions about him to be left to my other children, his siblings; this is my responsibility and he’s suffering” she said tearfully.

What made this especially difficult is that I felt so odd having this conversation in this space. Brett was there. He was looking at us. We were discussing *his life* and making a decision that could end it with him right there in the room as a bystander to a judgement that ultimately decided whether he lived or died. It was then that a very ugly thought entered my mind:

> *This is crazy. He's getting better. She just wants to get rid of him.*

Ultimately, Brett's mother decided to focus on comfort care, and we consulted the palliative care team. I felt defeated. I felt like we were doing wrong by Brett and his mother was acting selfishly trying to rid herself of a burden. Though disabled, I knew Brett understood things, I knew he had feelings and thoughts, and this move to palliation and end of life care felt unjust and borderline immoral to me. I was angry, confused, and filled with judgement and bitterness towards Brett's mother. This was a simple pneumonia. We had failed as healthcare providers and in my eyes, I felt that his mother had failed as a care provider.

These thoughts and judgements, as I mentioned earlier, were very ugly. In hindsight, I was caught in the moment, emotional, and lacked empathy. I was so focused on the medicine that I paid little attention to the holistic nature of the situation. Firstly, I acted like an expert on Brett, and I was far from that. I questioned the intentions of the person who had cared for Brett all his life, who knew him far better than I did and understood him more than I ever would. I acted as if I knew what was best for Brett when really this was not my domain. Secondly, I was criticizing a person who had undoubtedly put all of herself and her time into caring for her son. This was clear, she was always there, always at the bedside, always asking questions, always fixing his nasal prongs, cleaning his shirt, and chatting with him. This had taken a toll on her and I'm sure every other admission was just as hard. These things build up and it's not easy to juggle all that care and responsibility. We are only human after all. I failed to see this at the time. Finally, I acted as though it was easy for her to make this decision. She was not trying to get rid of him. This decision was incredibly hard for her. I'm sure she'd fought with it before. She was just trying to do what was best for her son and her family.

Over that weekend, they stopped taking Brett's vitals, ceased his treatment and moved him to a private room. On the Monday, I entered Brett's room to assess him. No vitals, no treatment, I was unsure of what to do. I sat down in front of Brett and asked if he wanted me to examine him. He furiously shook his head. "Do you want to be left alone?"

He shook his head affirmatively. "I wanna make sure I'm understanding you right, so if you want me to leave you alone hit my hand with yours". Brett lifted his hand, grabbed mine and pushed our locked hands towards my chest. He looked me in the eye for what felt like an eternity. My eyes started to swell with tears and Brett began to cough and turn red. I let go of his hand, thanked and apologized to Brett and left. He was under the care of the palliative team from then on and I did not see him again. I later found out that he passed away on New Year's Eve.

I do not know what exactly to take from the whole experience, but it enters my mind regularly and my feelings clash with one another. Overall, I think it's a testament to how hard these situations are for all those involved, especially the patient and their family. As care providers, we have a passing look into the lives of these individuals at vulnerable times. We often focus on medicine and science and try to guide these difficult decisions but ultimately, they are not our decisions and there is a great deal of nuance that goes into making these tough decisions and living with them. I have learned the importance of stepping back, observing the whole picture in context. My own mental struggle is undoubtedly dwarfed by what his mother must have had to grapple with.

Upcoming Conferences on Developmental Disabilities

The 9th International Research Conference on Adolescents and Adults with FASD: Review, Respond and Relate – Integrating Research, Policy and Practice Around the World

April 22-25, 2020

The Hyatt Regency, Vancouver, BC, Canada

Although there have been thousands of published articles in FASD in general, there has been limited research specifically on adolescents and adults with FASD or on individuals across the lifespan. As those individuals diagnosed with FASD continue to age, the "need to know" across a broad spectrum of areas is becoming critically important for identifying clinically relevant research questions and directions.

This interactive 2020 conference will provide an opportunity to be at the forefront of addressing these issues. We will welcome a diverse group of professionals, researchers, students, families and individuals with FASD.

The Call for Abstracts is now open, **deadline: September 13, 2019:** http://interprofessional.ubc.ca/initiatives/fasd2020/call-for-abstracts/

For more information, please visit the website at http://interprofessional.ubc.ca/initiatives/fasd2020/, and follow us on **Twitter: @IPCE_UBC**. Email marketing.ipce@ubc.ca to get on an enquiry list for updates.

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