

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

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Developmental Disabilities Clinical and Research Rounds

The Developmental Disabilities Program continues to host their monthly Clinical and Research rounds **on the second Wednesday of every month**, at the Child and Parent Resource Institute. The last session of the 2016/2017 academic year will take place on Wednesday June 14, from 4pm until 5pm, in the Zarfes Hall at CPRI.

We welcome Dr. Russell Schachar from the Hospital for Sick Children in Toronto to give a special presentation.

Dr. Schachar is a Senior Scientist and Psychiatrist at the Hospital for Sick Children, a Senior Scientist at the Research Institute at Sick Kids, a Professor in the Department of Psychiatry at the University of Toronto, and is the TD Bank Financial Group Chair in Child and Adolescent Psychiatry.

The Schachar Lab is directed by Dr. Russell Schachar, MD, FRCPC, Dr. Schachar is a psychiatrist at the Hospital for Sick Children (SickKids), Senior Scientist at the SickKids Research Institute, Professor of Psychiatry at the University of Toronto, and holds the Toronto Dominion Bank Financial Group Chair in Child and Adolescent Psychiatry.

Research in the Schachar lab focuses on attention deficit hyperactivity disorder (ADHD) and related psychiatric disorders. ADHD is a common, persistent, and impairing psychiatric disorder that is characterized by developmentally abnormal inattention, hyperactivity, and impulsiveness. It begins in early childhood and affects three to nine per cent of school-age children, 50 per cent of individuals referred to children's mental health facilities, and four

per cent of adults. Over two million children in North America take stimulant medication to treat ADHD on a daily basis. Childhood ADHD increases the risks for mental, physical and scholastic difficulties in adolescence and adulthood. For these reasons, ADHD poses a substantial burden on health care, educational, and judicial services and raises critical clinical, service delivery and ethical issues. Most importantly, ADHD is a source of considerable distress and impairment for affected individuals and their families.

Our research in both clinical and normally-developing individuals examines how genetic and environmental influences interacting from the moment of conception and over time influence thinking, feeling and actions causing problems in attention, learning and behaviour. We are particularly interested in how people differ in their abilities to pay attention, control their impulses, or control their activity levels and how these competencies influence the onset, maintenance and treatment of ADHD and other disorders. Our goal is to improve early detection, outcome and treatment prediction and therapy.

There is no fee to attend this talk, and no need to register.

For more information about this talk, please contact Sarah O'Flanagan at sarah.oflanagan@lhsc.on.ca

Research in the Developmental Disabilities Program

The C. Kingsley Allison Research Award

The Developmental Disabilities Program offers 2 Research Grants every year. One of which is the C. Kingsley Allison Research Grant. This grant is intended to provide seed money in grants of up to \$9,000 to members of the Western University Community, in order to conduct research of relevance to the field of intellectual and developmental disabilities, thereby helping to improve the lives of individuals with this condition.

Our last competition for this grant was held in the fall of 2016. We had 6 successful applicants in this competition.

Study results from our successful applicants will be published in this bulletin upon completion of data analysis.

Developmental Disabilities Research Day.

The Developmental Disabilities Program hosted their second annual Developmental Disabilities Research Day, in partnership with Dr. Julio Martinez-Trujillo and Mabel Mendoza.

The event was held at the Great Hall at Western University, and featured oral presentations from trainees and faculty members from different schools and faculties across the University.

Our keynote address this year was provided by Dr. Daniel Ansari, Professor in the Department of Psychology. Dr. Ansari's research interests include Developmental Cognitive Neuroscience, Mind, Brain and Education, Development of Numerical and Mathematical Skills and Developmental Dyscalculia.

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 first essay featured is by Dr. Bethany Oeming, a resident in the department of Anesthesia & Perioperative Medicine at the Schulich School of Medicine & Dentistry at Western University. Dr. Oeming's essay (beginning on the next page) was the winner in the Postgraduate Medical Resident category of this competition for 2017.

The Underlying Rhythm

Dr. Bethany Oeming

PGY3 Anesthesia & Perioperative Medicine

“Most people do not listen with the intent to understand; they listen with the intent to reply.”

-Stephen R. Covey

It was during the end of my palliative care rotation as a second year anesthesiology resident that I was paged one afternoon to the pre-admission clinic at University Hospital to help discuss a young man’s “Do Not Resuscitate” status prior to his upcoming procedure. He was scheduled to have a pacemaker battery placement procedure the following week. Fortunately, my attending physician (Dr. Valerie Schulz) was well known for her ability to navigate clinical encounters like this one with ease, and colleagues often reached out to her for help. As her resident for the week, I was tasked with starting the consultation.

I arrived at the clinic and received some information from the anesthesiologist (Dr. Christopher Harle) who was running the clinic that day. What I knew so far was that Mr. A was a 24-year-old male with cerebral palsy and developmental delay from complications due to a congenital cardiac condition that required multiple surgeries at a very young age. Unfortunately, somewhere along the way he had been deprived of oxygen to his brain. This made him reliant on others for personal care and unable to walk. As a result of his numerous cardiac surgeries, Mr. A’s heart depended on a pacemaker to maintain a normal heart beat. Without it, his underlying cardiac rhythm was not sustainable with life.

I glanced at the stack of old charts that comprised his medical records. They documented a lifetime of clinic and emergency room visits. His electronic medical record was similarly full of clinic notes, blood work and investigations. It was immediately clear to me that Mr. A and his parents were not strangers to the hospital environment. In fact, there had been many recent visits in the last few months to see his cardiologist. The battery that supplied power to his pacemaker was running low.

Usually, a pacemaker battery change is a relatively simple procedure, requiring just a bit of local anesthetic and perhaps some light sedation. Mr. A was an exception to this rule given his comorbidities and behavioural challenges. In the past, he was known to get quite combative when confronted by health care professionals, and he also engaged in self-injurious behaviours such as biting and hitting himself. It was impossible to start an intravenous line when he was awake. Most medical professionals wouldn't be able to get near him if he was frightened, let alone attach any monitors or administer medications. His parents were gravely concerned about him harming himself and others. Indeed, he was known to strike out at his personal support workers at home when he was in distress.

Mr. A was also wheelchair bound with a number of painful contractures. Contractures are a permanent shortening of a muscle or joint, most often seen in people with conditions like spastic cerebral palsy. This made positioning him a challenge. For this procedure to go smoothly, it was clear that Mr. A required a general anesthetic. I had to find out more about Mr. A before coming up with my anesthetic plan, so I sat down with Mr. A and his parents to get started.

Part 1: Pre-Admission Clinic

Mr. A lived in a group home a short drive from his parent's house. He depended on a feeding tube to get

most of his nutrition, and he was still very thin. He was bound to his wheelchair at all times except at night. He had chronic pain, and was on a number of strong pain medications. I asked more about this. I wanted to know his pain medication regime including doses and times of administration. Did he have any problem areas that were particularly painful for him? How often was he needing his breakthrough pain medications? I had to develop a good understanding of his baseline level of functioning and how he spent his days. What made him nervous? What calmed him down?

Most of the story came from his parents, as Mr. A functioned at roughly the level of a 10-year-old boy.

He was able to proudly tell me he needed a “Ticker Change” and pointed to the site of his previous pacemaker incision. He wore headphones and listened to music all day long. He even had a Tragically Hip T-shirt on. His dad tells me they had gone to a concert earlier that year, and Mr. A had loved it. I introduced myself, and held out my hand. He took it with caution. I told him my favourite Tragically Hip song was “Wheat Kings”.

After I was satisfied with my knowledge of his medical history and past anesthetic experiences, I brought up the “Do Not Resuscitate” status. Given everything he had been through, and his current quality of life and medical co-morbidities, Mr. A had maintained a “DNR” status for some time. His parents mentioned that they wouldn’t want Mr. A to get CPR if his heart stopped. We agreed that this would not be in Mr. A’s best interests. However, Mr. A was getting a pacemaker changed - a device that he depended on to maintain a normal cardiac rhythm. If something went wrong, his heart could potentially stop. What were we to do if this happened during the procedure?

It is not common to encounter a “Do Not Resuscitate” or DNR status in a young patient, and as you might imagine in these scenarios it can be challenging in the perioperative setting to know what constitutes appropriate patient care that doesn’t violate his or her wishes. Many interventions that are

considered standard of care and/or necessary in the operating room may be considered “resuscitation” on the hospital floor. For this reason, a common practice is for DNR orders to be revoked temporarily on entering the operating room. This is felt to be reasonable given that many intraoperative cardiac arrests are a direct result of anesthetic or surgical complications and can be easily corrected with good clinical outcomes. Clarifying these issues, and exploring goals of care can be complex and takes time.

After a lengthy discussion, I stepped out of the room and presented my notes on the case to Dr. Schulz and Dr. Harle, and we came up with a plan.

Part 2: New Battery

The following week, I went in early to meet with Mr. A and his parents on the morning of his scheduled procedure. Mr. A seemed to recognize me from our previous appointment. Outside the operating room, we had Mr. A drink a small amount of apple juice (his favourite) with a sedating medication. Then we had Mr. A’s parents lift him out of his wheelchair and on to a stretcher, with lots of pillows underneath his joints in an effort to lessen the discomfort caused by his contractures. We put some music on in the background of the procedure room. His parents were escorted to the waiting room. He was sedated enough not to notice his parents leaving his side. I moved quickly to start the intravenous line and my staff gave him extra oxygen and applied the ECG leads to monitor his heart, the pulse oximetry to measure his oxygen levels, and a blood pressure cuff to monitor his blood pressure. Finally, we placed a device in the back of his throat to protect his airway and put him on the breathing machine. We gave the remaining medications needed to make sure Mr. A was completely asleep. The surgeon came into the room and started the procedure. It went smoothly and was done within 30 minutes. His pacemaker now had another 8 years of battery life.

I gave him medications to prevent nausea and to treat pain from the incision. We proceeded to wake him up slowly, and as we brought him to the recovery room I went out to the waiting room and brought his parents in immediately so that he would wake up to familiar faces. I reassured them everything went well.

One of the aspects of my job I enjoy the most is being able to tailor the surgical experience to an individual and his or her needs. I have the privilege of helping people through their surgeries – whether it's appendicitis, a broken bone, a new cancer diagnosis, or a new mom who needs a caesarian section waiting to meet her baby. All require a unique anesthetic plan tailored to the patient's past medical history, current illness, and type of surgery. In the operating room, it is my responsibility to get a patient safely through their surgery.

It can be particularly challenging to navigate the anesthetic care of those with developmental disabilities.

Often times, there is high patient and parent anxiety. In medical school, we are taught to use the mnemonic "FIFE" – meaning "Feelings, Ideas, Function, Expectations" to guide us in challenging conversations with patients and their families. It's about getting to know what matters most to patients. For Mr. A and his family, it was important for us to reduce the stress of the procedure, get him safely off to sleep and have him wake up comfortably in the company of his parents, with minimal pain and nausea.

This was all possible with just a bit of advance planning.

At the end of the day, my patients come from a variety of backgrounds – from newborns and teenagers to the frail elderly. Among these will be patients with a wide range of physical and mental disabilities. Mr. A is just one of many I will encounter over my career. Every patient, regardless of their abilities, deserves a caring and empathetic approach when it comes to treating symptoms, alleviating suffering, and minimizing the risk of complications. This approach is especially critical when it comes to patients like Mr. A, as is appropriate planning and communication with the patient and their substitute decision

makers. I strive to bring this compassion to all of my future patients so that, like Mr. A, they too can benefit from the best possible care.

Upcoming Conferences on Developmental Disabilities.

AAIDD (American Association on Intellectual and Developmental Disabilities)

The American Association on Intellectual and Developmental Disabilities will host their annual conference from June 26 – 29, 2017 in Hartford Connecticut.

The theme of the conference this year is “Promoting Health and Wellness” in the Developmentally Disabled population.

Information and registration information can be found on their website;

www.aidd.org

Health and Wellbeing in Developmental Disabilities

The University of Toronto and the Community Networks of Specialized Care are hosting the Health and Wellbeing in Developmental Disabilities Conference in Toronto from November 29 – November 30, 2017, in Toronto Ontario.

This conference aims to engage health care professionals to improve the health and wellbeing across the lifespan for persons with a developmental disability.

Submissions for poster presentations are open until June 9, 2017. More information can be found on their website; <https://www.healthandwellbeingindd.ca/>

Regional Support Associates Annual Conference

Regional Support Associates will hold their annual conference from September 21-September 22, 2017 in London Ontario.

The theme of this year’s event is; Walking the Line; Minimizing Risk and Maximizing Resiliency, and will feature a keynote address by Mandy Wintink from the Centre for Applied Neuroscience.

More information can be found by contacting Karen Araujo at karaujo@wgh.on.ca or 519-421-4248

Editor: Sarah O'Flanagan, Coordinator. Developmental Disabilities Program,
Department of Psychiatry, Schulich School of Medicine & Dentistry, Western University.
Parkwood Institute, Mental Health Care Building.
550 Wellington Road, London ON. N6C 0A7.

www.ddp.uwo.ca

sarah.oflanagan@lhsc.on.ca

ddp@uwo.ca

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