

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

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Program Announcements

Dr. Rob Nicolson, Chair of the Developmental Disabilities Program, received the Continuing Medical Educator Award at the 2018 Schulich School of Medicine & Dentistry **Awards of Excellence** Celebration. This award recognizes one outstanding faculty member for their contributions to Continuing Medical Education. Dr. Nicolson was honoured for his innovative ongoing work in creating and implementing both the Developmental Disabilities Clinical and Research Rounds, and the Developmental Disabilities: Assessment and Treatment Education Series.

Dr. Jay Rao was honoured at the Ontario Association on Developmental Disabilities Conference with the Hull-Roeher Award of Merit for 2018 in recognition of his work in the field of developmental disabilities. It was the unanimous decision of the Board of Directors of the Ontario Association on Developmental Disabilities (OADD). This award is presented in honour of John Hull and G. Allan Roeher, each of whom made a significant contribution in the field of developmental disabilities within the Province of Ontario and is to be presented to an individual who has made an outstanding contribution or special achievement in the following areas.

- Education: for promotion of education or training in the field of developmental disabilities
- Humanitarianism: for promotion of human welfare and/or social reform
- Research: for advancement of knowledge in the field of developmental disabilities
- Service: for enhancing services to individuals with developmental disabilities

Congratulations to Drs. Nicolson and Rao.

We would also like to offer our congratulations on behalf of the Developmental Disabilities Program to Dr. Sahza Hatibovic-Kofman on her retirement. Dr. Hatibovic-Kofman has been a member of the Advisory Board of the program for many years, and we thank her for her contributions and wish her well in retirement.

Department of Psychiatry, Grand Rounds

On September 13, 2018, the Developmental Disabilities will host the Department of Psychiatry Grand Rounds. This year we are thrilled to welcome Dr. Paige Church as our invited speaker.

Dr. Church is an Associate Staff Neonatologist at The Hospital for Sick Children in Toronto, an Assistant Professor in the Department of Paediatrics, and the Director of the Neonatal Follow Up Program at the University of Toronto. Dr. Church is also the Medical Director of the Neonatal Follow Up Clinic at Sunnybrook Health Sciences Centre and the physician lead for the Spina Bifida/Spinal Cord injury program at Holland Bloorview Kids Rehabilitation Hospital. She holds dual certification through the American Board of Pediatrics in neonatal-perinatal Medicine as well as developmental behavioral pediatrics.

Recently Dr. Church was part of a medical team that achieved a first in Canadian medicine – a successful, in-utero surgery to repair a fetus with spina bifida. Dr. Church is uniquely suited for her role counselling families who have received a diagnosis of spina bifida for their unborn children, as she herself has spina bifida.

Dr. Church was interviewed by Dr. Brian Goldman on “White Coat, Black Art” on CBC radio, back in the fall of 2017, and that interview was what ultimately prompted the program to ask her to be our invited speaker in September.

You can read more about Dr. Church, and listen to that interview here; <http://www.cbc.ca/radio/whitecoat/she-kept-quiet-for-years-now-this-doctor-is-talking-about-her-own-disability-1.4405228>

This talk will be held at Victoria Hospital, zone E Amphitheater, on Thursday September 13, starting at 8:30am. The morning will begin with a psychiatry resident giving a complex case presentation, then an address by our invited speaker. This event will also be broadcast to the other London Hospital sites and will be accessible through OTN.

If you cannot attend in person, please contact ddp@uwo.ca for OTN information.

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 2018, we had 2 applicants. The winning essay was by Anish Srinivasan Naidu, and is entitled; "I guess there is light at the end of the tunnel..." and is featured below.

"I guess there is light at the end of the tunnel..."

By: Anish Srinivasan Naidu (Meds Class of 2019, Schulich School of Medicine & Dentistry)

It was my seventh week of clerkship, partway through my second week in the Developmental Paediatrics selective in my Paediatrics rotation, when my most memorable patient encounter to date took place. It was a new consultation for the assessment of a 5-year-old boy with query Autism Spectrum Disorder and intellectual disability, who was accompanied by his single young mother.

I find it fascinating how the early intervention by a Developmental Pediatrician can make significant improvements the future life of a child with developmental disorders. This selective was my opportunity to learn more about this subspecialty, and also gain a better understanding of the challenges faced by the family of a child with a developmental disability and the resources available to help them. Over the course of the selective, I worked with several pediatricians and paediatric psychiatrists at the Child and Parent Resource Institute, London. The clinical encounters were hour-

long assessments and follow-ups with the child and their guardians. The assessment encounters were the most interesting for me since it allowed me to learn about the observations that developmental pediatricians make to arrive at various diagnoses. During these encounters, my role usually was to interview the guardians regarding the child along with my supervisor, and then play and/or interact with the child to elicit certain behaviours that we wanted to observe.

The assessment of this adorable 5-year-old boy started as usual with me obtaining a supervised history from his mother. As I was chatting with his mother, I started getting a sense that she was somewhat depressed and anxious. This is not uncommon as one can imagine that having a child with developmental disabilities is very stressful. However, I had a feeling that there was something else going on besides the boy, but nothing concerning came up during the interview. My supervisor confronted the mother about her depressed mood and anxiety, and she admitted to being worried about her son's future. We continued on to the observation phase and I started interacting with the boy. The interaction quite clearly elicited many features of mild autism, but our strategy was to only provide the final diagnoses at a follow-up appointment after gathering some additional information from his teachers at his school.

At the conclusion of the appointment, we explained the follow-up plan to the mother, and I accompanied her back downstairs to the waiting room. She seemed quite happy with the outcome of the appointment. She expressed that she was feeling reassured that CPRI will be able to organize good care for her boy. As I thanked her and called out for the next patient, she received a call on her cell-phone. While I was introducing myself to the parents of the next patient, I overheard the tone of the mother's voice getting sadder... almost sobbing. I was growing suspicious that the call might be related to the feeling I had earlier about something else going on in her life.

I directed the next family upstairs to the assessment room and asked them to tell my supervisor that I will be up shortly. I then built up the courage to confront the mother about the call, while apologizing for eavesdropping unintentionally. I requested the mother and the boy to

come with me to a private room nearby. As soon as I closed the door and turned around, she broke down and started crying. She confessed that she has not been coping well at all, and that was trying quite hard to keep herself together during the appointment. She was worried about being identified as unable to care for her boy with special needs, and that Children's Aid Services would get involved. With the boy's father out of the picture, she had no reliable supports. Her younger sister had depression and had completed suicide a month ago, leaving her parents with their own grief to cope with and unable to provide much support to her. The phone-call was from her mother that reminded her of the sister's death. We did not specifically ask about the status of the extended family, so this did not come up during the initial interview.

I consoled her by reassuring her that our responsibility is to provide the best care for not only her son, but her as well. I told her that the potential involvement of Children's Aid Services would not necessarily mean that she will be separated from her son, but rather that we will all work together to ensure that they are well supported. She held her son's arm tightly, and cry decreased to a sob. I convinced her to return to the office upstairs with me. I apologetically interrupted the ongoing follow-up session with the next family and requested my supervisor to talk to the mother in another room. We spent a half-hour exploring the social situation in great detail, and we planned a follow-up in a week to talk further. We were looking to involve social work, adult psychiatry, the family physician, the school and several community services to develop a comprehensive plan.

It was a very emotional experience to hear about the challenges being faced by the single mother. I am aware of the hardships that a single parent of a child with a developmental disability may face, but actually hearing about it directly from a parent in the situation was heartbreaking. When the mother initially broke down crying, I was a bit stunned and unsure of what I got myself into. I felt that I was in an uncharted territory as I never had such an experience before. I fell back onto the basics of being empathetic and a patient listener, which allowed me to understand her story and orient myself to what was going on. It was quite difficult to stay professional and not start

tearing up myself. Initially, I felt quite helpless as I was not able to think of how I could help her, but when talking to her with my supervisor, we were able to come up with a plan that seemed to satisfy her, which made me feel satisfied as well.

By the end, the mother thanked the both of us with tears of relief, and I felt really happy that we were able to make such a huge positive difference in her life with just half-hour of honest conversation and reassurance. As she was leaving, she said to us, “I guess there is light at the end of the tunnel...” Both my supervisor and I smiled and nodded, and she smiled back as well. At this moment, it hit me that we would not have discovered any of this had I not gone down to the waiting area with the mother and confronted her about the phone-call. I also realized that I should not have hesitated to reassure and explore further when I got the feeling of missing something earlier during the interview.

Reflecting on this, I have learnt several valuable lessons from the single encounter. My intention behind choosing Development Pediatrics as a selective was indeed to get a better understanding of the experiences of such parents. This experience helped me to continue building on my ability to handle difficult patient encounters. Gaining a better understanding of where I can help and where I cannot, and being comfortable with that, will be one of my first steps. To me, this was a great example where knowing what resources are available to help a patient and their family, which my supervisor did, enabled us to have a positive conclusion to a difficult encounter.

As medical professionals, we have the privilege of being able to change people’s lives for the better, but the first step in the process is to not hesitate in diving deep and exploring all relevant issues that a patient and their family are facing. It is quite easy to get too focused on the presenting issue at hand and not get a full picture, and having limited time with each patient is one of the major barriers. In my future practice, I will try my best to give additional time for first encounters to be able to explore the social history of my patients in sufficient detail. I gained a better understanding of the value of good rapport and reassurance to make patients comfortable and willing to disclose

any concerns they may have, without the fear of negative outcomes. Being upfront with patients regarding having their best interests in our hearts may help with having them open up to us sooner. Picking up on any subtle cues during interviews, and not brushing them off, will be crucial in ensuring that I do not miss details like this again. This is definitely a skill that I need to continue developing.

I am sure that I am not alone when I say that as a fresh clerk, I used to feel that I am not really contributing much towards patient care. I felt more like a burden to the team because I was there to learn, and others had to take the time to teach me and answer my questions. After this encounter, I realized that even as a novice clerk, I can be a very valuable part of the team if I stay diligent, observant and responsible. Completing even the basic history and physical exam as thoroughly as possible can go a long way in improving patient care. Quite frequently, clerks have the privilege of being able to spend a lot more time with patients than a resident or staff physician can. Using this time to develop a good rapport with patients and to explore their social history in sufficient detail will help improve their care. This experience has definitely reinforced my commitment to medicine, and given me a lifelong memory that I will cherish.

Developmental Disabilities Clinical and Research Rounds

The Developmental Disabilities Program has completed another academic year of our monthly Clinical and Research Rounds. The second year was even more successful than the first. These rounds will begin again in October 2018, on the second Wednesday of each month at CPRI at 4pm.

The speaker schedule is almost complete.

As always, the presentations from previous sessions are available on the DDP website;

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

16th Annual Spring CPD

The Developmental Disabilities Program hosted the 16th annual Developmental Disabilities Spring CPD on Wednesday April 18, 2018, at the Windermere Manor.

This year we welcomed 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 spoke about rare genetic conditions, and when health care providers should send their patients with developmental disabilities for genetic testing.

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 spoke about pharmaceutical options for behavior intervention in individuals with developmental disabilities.

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

Updated Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities

The Developmental Disabilities Primary Care Program at Surrey Place Centre in Toronto has recently published updated Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities. The Program at Surrey Place will bridge gaps between research and practice in primary care of adults with IDD by developing, publishing and promoting clinical practice guidelines, tools and other resources for primary care providers. It is co-funded by the Ontario Ministry of Health and Long Term Care and the Ministry of Community and Social Services. The launch of their program coincides with the publication of the *Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines* in the *Canadian Family Physician's* April 2018 issue. In addition, the first of two special issues of the journal on primary care of adults with IDD is now available online at [cfp.ca](http://www.cfp.ca).

These guidelines and articles offer up-to-date information on the most significant health needs of adults with IDD and recommendations for assessment and intervention. They are informed by Canadian population-based data, empirical research, clinician expertise, and knowledge of patients' and caregivers' experiences in health care.

The guidelines can be accessed here; <http://www.cfp.ca/content/64/4/254>

Should you have any questions or require additional information, please contact a member of the program at ddpcp@surreyplace.on.ca.

Knowledge Translation

Members of the Developmental Disabilities Program have been active over the last academic year in Knowledge Translation activities pertaining to our educational initiatives and research productivity.

In the Fall of 2017, Sarah O’Flanagan presented a program model at the Health & Wellbeing for people with Developmental Disabilities Conference in Toronto, Ontario.

In April, 2018, Sarah presented data from a research study entitled; “Training in Developmental Disabilities in Canadian Psychiatry Residency Programs” at the Ontario Association on Developmental Disabilities Research Special Interest Group Day, then again at the Joint Mental Health Research Day in London Ontario in June, 2018.

Sarah also presented an educational model specific to our Developmental Disabilities Clinical and Research Rounds at the American Association on Intellectual and Developmental Disabilities Conference in St. Louis, MO.

In September, 2018, Sarah O’Flanagan and Dr. Rob Nicolson will present preliminary data on a research study entitled; “Training in Developmental Disabilities in Canadian Psychiatry Residency Programs: Resident’s Perspectives”.

In November, 2018, Sarah and Dr. Nicolson will present data from the study entitled; “Training in Developmental Disabilities in Canadian Psychiatry Residency Programs” as well as present a workshop specific to our Clinical and Research Rounds at the North American Association on Developmental Disabilities Conference in Seattle, WA.

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