

Newsletter - January 2018

Dear PONDA Members,
Happy New Year!

PONDA had a very busy year in 2017. We look forward to many new challenges and advocacy opportunities in 2018 to make Ontario better for children, youth and adults with developmental disorders. The steering committee is interested in your participation, so please let us know if you have ideas or want to help out. Below you will find an update on what we have been up to in the last 6 months, and the exciting opportunities in store for us this year.

Our general membership meeting was held on the Monday night of the OACRS Annual meeting, November 27th, in Toronto. We had an excellent turn out, with the room filled to capacity. Some lively debate was facilitated on topics such as FASD, Autism hub models, and the perception of the role of physicians at CTCs. In addition, Ronit Mesterman was presented with a leadership award by OACRS for her work founding and leading PONDA. Well done Ronit!



We have had some change in leadership reflecting our succession planning, and two new members have joined the steering committee. The current positions are as follows:

Chair: Nicky Jones-Stokreef

Vice Chair: Alvin Loh

Past Chair: Ronit Mesterman

Secretary: Ben Klein

Treasurer: Mohammad Zubairi

Communications: Olaf Kraus de Camargo

General members: Pam Frid, Jennifer McLean, Paige Church, Beth Macklin and Gillian Hogan

Activities since our last Newsletter:

FASD: A teleconference meeting was held in September of interested members. A letter was sent in December to Sophie Kiwala, MPP, asking for a meeting to discuss government FASD program plans, looking to include children with Adverse Childhood Experiences for assessment and coordination planning.

Physicians at CTCs: Our survey of all 21 CTCs was presented at the OACRS Annual meeting. We were delighted to have results to share from all the CTCs, reflecting a 100% response rate. We received lots of interest and positive feedback about the need for physicians to be working at all CTCs as part of the standard of care in multidisciplinary teams. This information was also presented to MCYS on December 6th with a follow up meeting with Minister Coteau planned for February. We would like to see dedicated funding for developmental physician involvement at all CTCs in Ontario.

Autism Hubs: At our bi-annual general meeting in November, we had formal presentations about hub-specific experiences as a result of the MCYS autism diagnostic hub funding that came into place earlier this year. These included presentations from the central region (Children's Treatment Network) and east region (Ottawa Children's Treatment Centre and Children's Hospital of Eastern Ontario). There was an excellent discussion that followed about the successes and challenges in implementing the diagnostic hubs across different regions. Themes included: capacity building, family satisfaction, and broader implications on the system. There is some optimism that the hub funding will continue.

Special Needs Strategy: The local tables discussing Integrated Delivery of Rehab Services were halted in September and a Provincial Advisory Group was struck to address barriers to the implementation of this program. Two members of PONDA were invited and are participating in the PAG which started meeting in December.

Learning Disabilities: The [Advocacy Toolkit for language based learning disabilities \(Dyslexia\)](#) is in its third edition. It is now ready to be used by parents as well as physicians, and any other interested party. Contacts with literacy experts have been made in British Columbia and Nova Scotia, with significant interest in engaging physicians and having a similar toolkit for their jurisdictions. Dr. Gabi Jacob's paper, *Literacy promotion by health care professionals: A comprehensive biomedical and psychosocial approach*, was just published in the November issue of Paediatrics and Child Health, with PONDA's Advocacy Toolkit cited as a resource for primary care physicians. An invitation to speak at the Ontario ResearchED Conference on April 14th has also been accepted. Nicky has joined the Minister's Advisory Committee for Special Education in Ontario (MACSE) as the medical representative.

Developmental outreach: Children and youth living in the far north have difficulty accessing developmental paediatric care. PONDA has been approached to help fill this need. Some paediatricians have been doing excellent work in this domain for years, and we hope to build on their experience and find ways to expand services to the north.

Improving access to behaviour analyst assessment and treatment for all children with neurodevelopmental diagnoses at CTCs: This was raised at the June PONDA meeting and a similar presentation at OACRS was made and was well received. Suggestions for local

collaboration with Autism agencies, and ideas for collaboration with the local LHIN were discussed.

Increasing physician capacity for adults with intellectual and developmental disabilities:

- There is increased interest in the third year of family medicine training specializing in developmental disorders at Queens University, <https://familymedicine.queensu.ca/education/enhanced/developmental> , with three successful applicants for the next academic year. The program director, Dr. Meg Gemmill, is interested in finding placements for residents in settings relevant to primary care. If interested, please contact her at meg.gemmill@dfm.queensu.ca .
- Dr. Liz Grier, presented a workshop on diagnosis and management of Autism Spectrum Disorder in adults for primary care physicians in December, hosted by the OMA. The archive can be accessed at <https://learn.oma.org/topics/patient-care/adults-with-autism-spectrum-disorder/>
- The Developmental Disabilities Primary Care Program will publish updated guidelines on the Primary care of adults with Intellectual and Developmental Disabilities in April 2018 in Canadian Family Physician along with a special issue expanding on some of the guidelines. More to come in our next newsletter.

Plans for the future: The steering committee would like to develop a strategic plan involving the general membership in June 2018. A facilitator will be hired to help us redefine ourselves and our goals. Please hold the date of June 22nd, 2018.

A provincial election in Ontario is coming this spring. This is an opportunity to ask questions to those running for office about how government can improve services and supports for people with developmental disorders. Prepare your questions now so you are ready for all candidates' meetings and canvassers knocking on your door.

Thank you to all our members for continuing to support the work of PONDA. We have a stronger voice by working together. If you know of a physician or psychologist interested in joining our membership, please share this newsletter. Inquiries can be directed to anyone on the steering committee.

A special thank you to Abby and Stan Siapno who manage the PONDA website www.PONDA.ca. Follow us on twitter: @pondanetwork and like us on Facebook!

Sincerely,

Nicky Jones-Stokreef,
Chair of PONDA

