

Newsletter: Jan 31, 2020

Happy New Year to the PONDA community! The start of a new year is a chance to refresh our goals and renew enthusiasm for our advocacy efforts. Lots has happened in the last few months, and so it is time for another PONDA newsletter to keep you up to date.

Join us to create an OMA Medical Interest Group on Neurodevelopmental Disorders

PONDA members are working to form a Medical Interest Group (MIG) of the Ontario Medical Association on Neurodevelopmental Disorders (NDD)

GOAL #1: Facilitate networking within and across physician specialties caring for patients with NDD across the lifespan.

Care of patients with NDD is highly complex involving both physician and non-physician health professionals as well as a great variety of physician specialties including family medicine, pediatrics, developmental pediatrics, dual diagnosis psychiatry, medical genetics and rehabilitation medicine.

An MIG in NDD could serve as a network to connect Ontario physicians from across different specialties who care for this population and provide useful sharing of clinical tools and guidelines that support comprehensive patient and family centered care, case coordination and capacity building.

GOAL #2. Act as a resource for broader OMA initiatives that are relevant for patients with NDD.

Both to ensure representation of this population within the OMA and to support the external health system advocacy and policy work of the association. Areas of relevance are numerous including health care transitions, care of vulnerable populations, management of complex patients, system navigation, health care access, high cost use/ALC/repeat hospitalization and ED visits, cross sectoral integration of care.

If you are interested in hearing more about the initiative and potentially joining as one of 50 signatories needed for the application, please email Dr Liz Grier at liz.grier@gmail.com

Updates

Ontario Autism Program

The autism advisory panel report was released immediately after being received by MCCSS and is available for all to [read](#). Mohammad Zubairi worked tirelessly on this panel to ensure evidence based practice is reflected in the recommendations. He presented a summary of the recommendations at our dinner meeting on November 22 in Toronto. Lots of work is still left to do, some of which will be completed by the implementation panel, members of which can be found [here](#). We are happy to see several familiar names of colleagues on the panel.

Meeting with MOH Mental Health re: Youth and Adults with IDD

On October 8th, a meeting was held with the Associate Minister of Mental Health and Addictions, Michael Tibollo and his director of policy Matthew MacGregor, to share PONDA's concerns and recommendations for the mental health care of individuals with intellectual and developmental disabilities. A panel of experts included Liz Grier, Alvin Loh, Vikram Dua, Mark Lachmann, Anupam Thakur, Yona Lunsky, and Jonathan Weiss.

The Key Points were:

- Addressing Gaps in health care for adults with DD – Yona Lunsky
- Increased utilization of health care services and premature mortality
- Areas of policy concern:
 - Higher prevalence of mental health conditions in children/youth and adults with NDD. Increasing complexity of supports and health care needs
 - Limited experts exist in Ontario
- Excellent research informed work being done in ON
- Creation of a centre of excellence on mental health and addictions

- PONDA offered potential policy solutions, including acting as a resource to government

Working Groups

Learning Disabilities

The Ontario Human Rights Commission launched the Right to Read inquiry into reading instruction in Ontario's public schools last October. Public hearings and community meetings are taking place around the province. There is a [survey](#) you can complete online. A report will be released later this year. We anticipate there will be a number of recommendations on how our education system needs to improve reading instruction to allow all children to benefit. PONDA is already working with other advocacy partners to make the most of the recommendations when the report is ready. For more information see the OHRC [website](#).

Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities (IHCCAN)

ECHO is a virtual training and capacity building model that supports healthcare providers in delivering high quality, evidence-based care in their local communities. Through multipoint videoconferencing, ECHO links expert inter-disciplinary teams with front line care providers in order to share best practices, jointly discuss practical recommendations for complex client care, and build sustainable communities of practice.

in Jan 2020, The Azrieli Adult Neurodevelopmental Center and Surrey Place, with the Project ECHO Ontario Mental Health, at the Centre for Addiction and Mental Health have launched an ECHO focused on Adults with Intellectual and Developmental Disabilities, and mental health. Every Friday morning for 12 weeks, there is didactic teaching and then in depth discussion of a case. For details, please see <https://camh.echoontario.ca/programs-aid/>

New Media

[PONDA podcasts](#) are multiplying! Dr. Jacqueline Ogilvie did an amazing job on a tight timeline to produce 2 podcasts ahead of our November 22 dinner meeting. The [first podcast](#) features an

interview with Bruce Bonyhady on the National Disability Insurance Scheme (Australia), and [the second](#) featured what this could look like in Canada with an interview of Bill Cowie from Every Canadian Counts Coalition.

[News from our Partners](#)

Every Canadian Counts Coalition

Bill Cowie and his team at ECCC is working to promote a National Disability Insurance program in Canada, similar to the NDIS in Australia. PONDA has discussed this idea, and has endorsed the need for further research on this proposal. There may be a role for PONDA members to contribute patient and family stories about the deficiencies in our system for children, youth and adults with disabilities in Ontario. For more info, check out <http://everycanadiancounts.com/our-vision/>

Membership in PONDA

Membership is open to all physicians and psychologists with an interest in improving the well-being of individuals with neurodevelopmental needs across the lifespan. We advocate for children, youth and adults with a wide variety of neurodevelopmental disabilities. Membership is informal with no fee. We simply add you to our mailing list if you are interested. Feel free to share our newsletter and advocacy tools. *The more members, the stronger our voice.*

Please email pondanetwork@icloud.com if you are interested in joining.

[What's New](#)

Leadership changes at PONDA

- **Chair:** Dr. Alvin Loh, Dev Paeds at Surrey Place, Toronto
- **Vice-Chair:** Dr. Mohammad Zubairi, Dev Paeds at McMaster, Hamilton
- The positions have 2-year terms.

Our hard working steering committee includes:

- **Communications:** Olaf Kraus de Camargo
- **Treasurer:** Jennifer MacLean
- **Secretary:** Open
- **Past Chair:** Nicky Jones-Stokreef
- **Members at large:** Liz Grier, Paige Church, Ben Klein, Ronit Mesterman and Pam Frid.

Last year we said goodbye to Dr. Beth Macklin. Thank you, Beth, for all your work over the years !

Get Involved

Do you want to learn more about advocacy or get involved in our work?

Here are some ideas:

- Join one of our working groups:
 - Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities
 - new communications strategies (podcasts)
 - literacy based learning disabilities
- Attend an OMA workshop to improve your advocacy skills advocacy@oma.org
- Meet with your local MPP, and voice your opinion on a subject important to you
- Write an Op Ed and submit to your favourite print media
- Send a message to Queen's Park through twitter #onpoli
- Use the Advocacy Toolkit on our website to learn how to approach your local school board and encourage evidence-based intervention for LDs
- Listen to our podcasts
- Write to the Ontario Human Rights Commission expressing your concerns about reading instruction in Ontario for the #RightToRead inquiry

Don't forget to follow us on twitter: @pondanetwork and like us on Facebook!

Sincerely,
Nicky Jones-Stokreef
Past-Chair of PONDA

Steering committee members: Alvin Loh, Mohammad Zubairi, Ronit Mesterman, Liz Grier, Olaf Kraus de Camargo, Pam Frid, Jennifer McLean, Ben Klein, Paige Church

MISSION: *PONDA is a volunteer network of physicians and psychologists advocating to optimize the well-being of individuals with neurodevelopmental needs in Ontario by promoting evidence informed policy in the systems of care.*