### International Pediatric Sleep Association 2024

Application of the Pan-Canadian IPSA 2024 Interest Group

#### **Local Organizing Team**

Osman Ipsiroglu, Elizabeth Keys, Adetayo Adeleye, Calvin Kuo, Joanna MacLean

#### **Trainees & Associates**

TainLin Michon, graduate student (SLUMBER/Keys Research Lab, UBC Okanagan)

&

Nadia Beyzaei, Communications Designer; Scout McWilliams, Pediatric Resident; Kristina Calli, Research Coordinator (all H-Behaviours Lab, previously Sleep/Wake-Behaviour Lab, BC Children's Hospital Research Institute, UBC, Vancouver)

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## Application of the Pan-Canadian IPSA 2024 Interest Group

#### February 28, 2023

Dear Ms. President, Dear Professor Owens,

### Dear distinguished Board Members of the International Pediatric Sleep Association,

Allow us, the Pan-Canadian IPSA 2024 Interest Group, to apply to host the IPSA 2024. It will be a great honor and distinct pleasure to host the prestigious IPSA Conference in Vancouver, Canada. It would be an ideal location for the first IPSA conference in North America. Vancouver is a large multicultural urban centre on the Pacific Ocean with excellent conference facilities, opportunities for travel (e.g., direct flights from Paris, London, Frankfurt, Melbourne, Istanbul, etc.), and recreational activities. Vancouver hosted the World Sleep Conference in 2019.

Our Pan-Canadian IPSA 2024 Interest Group is a multiprofessional and diverse pediatric interest group, with colleagues and partners from across Canada, who are working in major academic centers and the community. The local organizing committee consists of members from western Canada (e.g., Calgary, Edmonton, Kelowna, and Vancouver).

We have considered critical issues for our field as part of developing this proposal. Sleep is an important public health issue, yet, the current emphasis on sleep as a Western-centric urban sub-specialty across Canada means we have not implemented a universal screening concept for sleep health and the knowledge regarding first-line interventions is often overlooked or even unknown. Despite the significant impact of sleep on general health and development, basic sleep investigations remain inaccessible and general knowledge of sleep disorders very poor among care providers. Partners in the community, such as public health nurses, occupational therapists or psychologists, who conduct neuropsychological assessments, family physicians, pediatricians, pediatric dentists and child and adolescent psychiatrists, very often lack basic sleep health training and knowledge. Thus, we unanimously agree to advocate for establishing sleep as a priority on the Canadian public health agenda. At this first stage, we have received the support of the Canadian Sleep Society, the Nurses and Nurse Practitioners of BC and two non-governmental organizations.

Together with our national and provincial partners, we have reviewed the ideas for knowledge dissemination/consensus meeting workshops for community members and practitioners to address their unmet training and educational needs. Already at the planning stage, we have generated excitement and interest in collaboration with multiple national and international societies/ associations (see attachment). In hosting the IPSA Conference in Vancouver, our committee's and supporting societies/ associations/institutions' shared goal is to start the discussion on implementing sleep as a public health priority in Canada, with the help of the IPSA Board and IPSA Scientific Committee. Therefore, after further review of the communication-related challenges of such a hot topic with a communication designer, we suggest 'ChildRight2Sleep' as the communication leitmotif of IPSA 2024. Such a leitmotif would allow, not only the Canadian, but all IPSA members to use the motto and associated information materials in their potential World Sleep 2024 activities and develop a shared understanding for reaching out to their communities.

We hope that the members of the IPSA Board will review our application and suggestions positively, despite not having a national society as the host organization but an enthusiastic committee of 45+ clinicians and researchers from various fields and the support of several societies/associations/institutions; however, for the implementation of sleep in the community this route might also be one of the first steps.

Yours sincerely,

#### Dr. Osman Ipsiroglu MD, PhD, FRCPC

BCCH Interdisciplinary Sleep Program, UBC Vancouver

#### Dr. Adetayo Adeleye MSc, MD, FRCPC

Department of Pediatrics, University of Calgary, Alberta

#### Dr. Elizabeth Keys PhD, RN, CCHN(C)

School of Nursing, UBC Okanagan

#### Dr. Calvin Kuo PhD

School of Biomedical Engineering, UBC Vancouver

#### Dr. Joanna MacLean, BSc(Hon), MD, PhD, FRCPC

Department of Pediatrics, University of Alberta, Edmonton

### Strategic Plan

Dr. Adetayo Adeleye, Calgary
Dr. Osman Ipsiroglu, Vancouver
Dr. Elizabeth Keys, Kelowna
Dr. Calvin Kuo, Vancouver
Dr. Joanna MacLean, Edmonton

The suggested projectable strategic master plan (January 2023–March 2024) for hosting IPSA 2024 successfully in Vancouver and reaching out to all pediatric sleep-interested Canadian professionals consists of the following:

- Establishing a local organizing Western-Canadian Pediatric Sleep Working Group (see bios on pages 6-7)
- 2. Developing the Pan-Canadian IPSA 2024 Interest Group (in evolvement, see pages 10-11)
- 3. Building partnerships with professional and community organizations (in evolvement, see pages #X-X)
- Identifying a possible venue for hosting IPSA and contingent dates (done, see page 12)
- Developing an internal communications concept using MIRO 'brainstorming board' to enable seamless direct communication and the creation of clusters and interest groups among a large number of committee members (ongoing)
- Developing the Canadian signature pre-conference workshops together with the identified members of the pan-Canadian IPSA Interest Group in collaboration with the IPSA Scientific Board (in evolvement, see pages 13)
- 7. Identifying investigators and securing external funding for the pre-conference workshops and meetings (planning phase; the subject of the IPSA 2024 Interest Group meeting at the Canadian Sleep Society's biennial meeting in April 2023). Working on the content, reaching out to national and international partner societies and associations in collaboration with the Canadian Sleep Society, IPSA and others.
- 8. Creating an external communications concept for promoting and developing the necessary materials, which justify the 'ChildRight2Sleep' communications leitmotif (in evolvement, see pages 14-15).
- Hosting multiple World Sleep Day events in Canada under the motto 'ChildRight2Sleep'. Developing information for knowledge dissemination, reviewing that with CSS, IPSA and others.
- Review applications for knowledge dissemination workshops in various Canadian societies and academies, e.g., CanadianPediatric Society, Academy of Child and Adolescent Psychiatrists, etc.
- 11. After March 2024, review monthly/bi-weekly with IPSA administration team project development.

## Why a Western-Canadian Initiative?

We combined forces because clinicians, researchers and parent advocates from BC and Alberta work in unison and serve similar populations in substantial geographic areas including the Yukon and Northwest Territories. Consequently, we have created a local multi professional organizing committee comprised of members with multiple backgrounds, e.g., physicians from various subspecialties, nursing, biomedical engineering, pharmacy/pharmacology, respiratory therapy, occupational therapy and youth and parent advisory boards.

### Biographies of the Western-Canadian Pediatric Sleep Working Group:

#### Adetayo Adeleye, MSc MD FRCPC.

I am a Clinical Associate Professor at the Cumming School of Medicine, Pediatric Respirologist, and sleep medicine specialist at the Alberta Children's Hospital. My research focus is on pediatric sleep medicine with emphasis on sleep related breathing disorders in young children, children with complex congenital respiratory anomalies, neuromuscular conditions and respiratory diagnoses that predispose children to breathing challenges during sleep. I am engaged in quality improvement work to enhance sleep care delivery to children by training and supporting community practitioners to provide sleep care in the community and liaising with adult sleep providers to ensure the successful transition of pediatric sleep patients onwards to adult care. I serve as the medical director of the pediatric sleep service at the Alberta Children's Hospital and program director for the pediatric sleep medicine program at the Cumming school of medicine.

#### Osman Ipsiroglu, MD (FRCPC), PhD.

In Canada, working as a Clinical Associate Professor at UBC, I embarked on a PhD to expand my knowledge and learn/ develop a concept for assessing sleep in complex patients with neurodevelopmental or mental health disorders; currently, I am working on the recognition of painful RLS in non-verbal children. I am leading the Sleep/Wake-Behaviour Clinic, which is part of the Interdisciplinary Sleep Program at BC Children's Hospital and the Transdisciplinary H-Behaviours Lab at BCCH Research Institute. My pediatric sleep medicine endeavor started exactly 25 years ago, when I became the director of the pediatric sleep lab at the Vienna University Hospital. In the clinical setting, I had the privilege to accredit the first pediatric sleep lab in Austria; from a public health perspective, I facilitated the SIDS prevention campaign 'Secure Sleep' for the Town of Vienna and ended SIDS-screening with PSGs. At the societal level, in close collaboration with the Boards of the Austrian Pediatric and Sleep Societies, I initiated the creation of a pediatric sleep interest group, thus a transdisciplinary collaboration among the two societies and hosted one national, two international conferences and multiple workshops.

#### Elizabeth Keys, PhD, RN, CCHN(C)

PhD, RN, CCHN(C) I am an Assistant Professor in the School of Nursing, Faculty of Health and Social Development at The University of British Columbia Okanagan campus. I am a registered nurse with national certification in community health nursing and a clinical background in community and public health nursing focused on promoting child and family wellbeing. The goal of my research is to promote and maintain the health and wellbeing of families with children by supporting their sleep health. In my research, I examine how innovative approaches and interdisciplinary models of care can be leveraged to support healthy sleep in children and their families. My lab is currently developing a digital program that will provide families of young children in the community with personalized recommendations for how to improve their sleep. I am also the lead investigator for the early childhood hub of the CIHR-funded Sleep Consortium: Better Nights and Better Days for Canadians: An Innovative National Strategy to Prevent and Improve Insomnia Across the Lifespan Using Digital Approaches for Sleep Promotion, Intervention, and Provider Training (2022-2027).

#### Calvin Kuo, PhD, PEng.

PhD, PEng. I am an assistant professor in the School of Biomedical Engineering at the University of British Columbia and member of the Centre for Aging SMART at the Vancouver Coastal Health Research Institute. I run the Human Motion Biomechanics Laboratory which specializes in designing and deploying wearable sensors to clinical populations and developing the analytical tools to process large real-world datasets to extract clinically meaningful metrics. My lab focuses on customizing sensors for specific applications in order to reduce sources of error brought on by unpredictable environments in real-world settings and by user misuse and noncompliance. My lab is actively working with clinicians to

implement wearable technologies in the assessment of sleep, developing both hardware tools such as Actigraph sensors to monitor restlessness and machine learning algorithms such as identifying movements in videos to translate clinical sleep assessments to the home setting. My lab is specifically concerned with ensuring high quality at-home sleep data with robust sensing and validity in populations of interest, from children with autism spectrum disorder to athletes who are recovering from concussions.

#### Joanna E MacLean, BSc(Hon), MD, PhD, FRCPC.

I am an Associate Professor and Clinician-Scientist in the Department of Pediatrics at the University of Alberta and a Pediatric Respiratory and Sleep Medicine physician and the Medical Director for the Sleep Laboratory at the Stollery Children's Hospital. My research program and clinical practice focus on understanding and treating respiratory and sleeprelated breathing disorders in childhood with a focus on highrisk groups. My on-going studies include a provincial population study of children using non-invasive ventilation, a scoping review with subsequent systematic reviews of non-invasive ventilation use in children, and a data linkage study exploring phenotypes of pediatric obstructive sleep apnea. I co-lead the sleep data sub-team of the provincial Medicine Strategic Clinical Network and currently chair a joint Canadian Thoracic Society/Canadian Sleep Society initiative to develop national guidelines for the diagnosis of pediatric OSA in Canada. I have served on the Scientific Planning Committee for the Canadian Sleep Society Meeting (2017), the Canadian Respiratory Conference (2020-2022), and the Pediatric Program Committee of the American Thoracic Society (2018-2022).

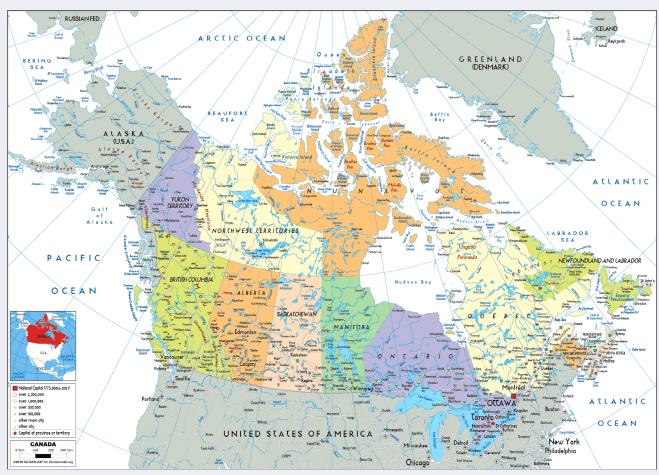
### Why Canada?

The Canadian sleep community has made vital contributions to pediatric and adult sleep; however, Canada has not yet hosted an IPSA Conference. The Canadian consensus, which brings all ethnicities together, is to empower and enable young generations to develop and help them to flourish. We have created a pan-Canadian organizing committee and informed and invited First Nations authorities and Canadian Advocacy Groups to join our academy/communityfocused discussion.

Canada is not a 'country' but a 'continent'; Canadians are practicing multi-ethnic, transcultural communication on the unseeded lands of Indigenous peoples, bringing many different parties together in a mindful way, and trying to learn from the mistakes of the past.

#### What novel aspects do we want to highlight?

Sleep medicine is at an intersection. Are we continuing as a Western-centric urban sub-specialty or stepping back to reflect and review how we could build alliances in the community and implement a screening process for sleep health earlier, at tier service I level? Should we vote for the latter, the consequence would be setting sleep as a national health priority, as our colleagues in New Zealand successfully did. The implementation of sleep as a national health priority is our aim.



Map of Canada By Worldometer, 2023

## Members of the Pan-Canadian IPSA 2024 Interest Group

#### Pediatricians, Pediatric Sub-specialists & Clinician Scientists

- Adetayo Adeleye, Pediatric Respiratory & Sleep Medicine, Calgary
- Ali Amid, Pediatric Hematology, Vancouver
- Reshma Amin, Pediatric Respirology and Sleep Medicine, Toronto
- Candice Bjornson, Pediatric Respirology and Sleep Medicine, Calgary
- Maria Castro, Pediatric Respirology and Sleep Medicine, Edmonton
- Evelyn Constantin, Pediatric Respirology and Sleep Medicine, Montreal
- Kathrine Edwards, Child and Adolescent Psychiatry/ Neuropsychiatry, Vancouver
- Refika Ersu, Pediatric Respirology and Sleep Medicine, Ottawa
- Ana Hanlon-Dearman, Developmental Pediatrics, Winnipeg
- Carole Anne Hapchyn, Infant and Early Childhood Psychiatry, Edmonton
- Osman Ipsiroglu, Pediatric Sleep Medicine (Mental Health/Neurodisability), Vancouver

- Shaikh Mohammed Iqbal, Pediatric Respirology and Sleep Medicine, Winnipeg
- Sherri Katz, Pediatric Respirology and Sleep Medicine, Ottawa
- Joanna MacLean, Pediatric Respiratory & Sleep Medicine, Edmonton
- Scout McWilliams, Pediatrics Resident, Toronto
- Suzanne Lewis, Pediatrician, Geneticist, Liaison Person with PAFN, Vancouver
- Indra Narang, Pediatric Respiratory & Sleep Medicine, Toronto
- Jacqueline Purtzki, Pediatric Physical Medicine & Rehabilitation, Vancouver
- **Sylvia Stockler**, Pediatric Biochemical Geneticist, Vancouver
- Megan Thomas, Developmental Pediatrics (and Neurodisability), Halifax
- Stephen Wainer, Developmental Paediatrics, Calgary
- Manisha Wittmans, Pediatric Respiratory & Sleep Medicine. Edmonton
- Marie Wright, Pediatric Respirology and Sleep Medicine, Vancouver

## Specialized Practitioners & Clinician Scientists

- Neil Chadha, Pediatric Otolaryngologist, Vancouver
- Dean Elbe, Child & Adolescent Mental Health Pharmacy Specialist, Vancouver
- Carlos Flores-Mir, Orthodontics, Edmonton
- Reut Gruber, Pediatric Sleep Medicine, Psychology, Applied Neuroscience, Montreal
- Susan Hass, Public Health Nursing, Calgary
- Elizabeth Keys, Pediatric Sleep Medicine, Nursing, Kelowna
- Wayne Lai, Neurologist & Sleep Medicine Lead of the Sleep Interest Group Application for Doctors of BC, Kelowna
- Edmund Liem, Dentistry, Burnaby
- Kevin MacNeil, Pediatric Sleep Medicine, RPSGT, Edmonton
- Michael Major, Dentistry, Orthodontics, Calgary
- Mansfield Mela, Psychiatrist, Correction Services, Saskatchewan
- Benjamin Pliska, Orthodontics, Vancouver
- Graham Reid, Pediatric Sleep Medicine, Psychology, Waterloo
- Robyn Stremler, Pediatric Sleep Medicine, Nursing, Toronto

#### Parent Advisory Groups

 Dorothy Reid, Liaison Person with CanFASD Research Network, Abbotsford

#### Scientists — Other

- Nadia Beyzaei, Communication Designer, Vancouver
- Michael X. Chen, Medical Biochemistry, Victoria
- Guy Dumont, Electrical and Computer Engineering, Vancouver
- Calvin Kuo, Biomedical Engineering, Vancouver
- Andre Mattman, Medical Biochemist, Vancouver
- Kate Storey, Community & Public Health, Edmonton
- Mark Stephen Tremblay, Community & Public Health, Physiology, Community Health, Ottawa

## Possible Venue for Hosting IPSA & Contingent Dates

We propose the conference be held over five days with the registration and welcome on Day 1 followed by the conference spanning the next 3.5 consecutive days. Flexible date options include May, June or October in order to take advantage of offpeak travel, accommodation and venue expenses.

We have several well regarded conference venue options with sufficient availability and capacity. Below is a collection of rough cost estimates that we have amassed to-date:

Venue	Location	Attendee Capacoty	Conference venue costs for 5 days <sup>a</sup> *	Food and Beverage costs for 4 days* (light lunch +2 coffee breaks for 500 ppl)	Gala cost* (500 people)	Conference Hotel Room Rate
Westin Bayshore	Downtown Vancouver	1,750	\$50,000 + taxes (\$10,000/day for ballroom)	\$140,000 + taxes (\$35,000/day)	\$50,000 + taxes	\$369 CAD + taxes *Add \$30 for triple occupancy or *\$60 for quad occupancy
Pinnacle Hotel Harbourfront	Downtown Vancouver	500	Quote in progress	Downtown Vancouver	Downtown Vancouver	Downtown Vancouver
University of British Columbia Conference Centre	University Endowment Lands, Vancouver	800	Quote in progress	Quote in progress	Quote in progress	Quote in progress
	Downtown Vacnouver (for workshops)	240	Quote in progress	Quote in progress	Quote in progress	N/A
Vancouver Convention Centre	Downtown Vancouver	3,600	Quote in progress	Quote in progress	Quote in progress	N/A
Simon Fraser University	Downtown Vancouver (for workshops)	450	Quote in progress	Quote in progress	Quote in progress	N/A
Pacific Autism Family Network	Richmond (for workshops)	400	Quote in progress	Quote in progress	Quote in progress	N/A

<sup>&</sup>lt;sup>a</sup> Includes audio-visual support

<sup>\*</sup> Canadian Dollars

# Suggestions for the Canadian Signature Pre-Conference Workshops

## Should we revisit knowledge dissemination concepts?

We have considered critical issues for our field as part of developing this proposal. Our goal is to set sleep as a national health priority. We have already built alliances with NGOs in the community. This will help us implement a sleep health screening concept that would address all children in the community, including those living in rural and remote areas. To take this initiative further, we need partners in the community, such as public health nurses or occupational therapists, general practitioners, and dentists, who will support dissemination of our mutual understanding. Therefore, the questions we are looking forward to discussing are: what are the needs of our colleagues in the community? What are the needs of our colleagues in rural areas? What can we learn from colleagues elsewhere that could inform a Canadian approach to this important issue? IPSA 2024 will offer a perfect venue to discuss this together and develop a consensus approach.

## What will be the Canadian signature workshops?

We will promote several workshops to the IPSA Scientific Committee. Additional funding (e.g., from CIHR, Michael Smith Foundation for Health Research) will help us develop the consensus and publish the results. So far, we identified four main themes, which have the potential to address highly qualified professionals with different backgrounds and position IPSA as the international leader of novel concepts or support the implementation of these:

- "Too Urban, Subspecialized and Western Centric: Do we need a Universal Screening for Capturing the Social Ecology of Sleep Health?",
- "Hematological/ Functional/ Brain Iron Deficiency: The root of hyper-motor-restless behaviors in ADHD, ASD, FASD and Restless Legs Syndrome/Restless Sleep Disorder?"
- "Management of Concussion -- Sleep Disturbances in mild Traumatic Brain Injury",
- "Transition of Patients with Complex Chronic Care Needs",

In addition, we would like to offer within a "Sleep Expo" two specific workshops for adolescents and our partners in the educational system (teachers, coaches) with focus on:

- "Sleep the Legal Doping" and
- "Concussion & Sleep."

## #ChildRight2Sleep

### Communications Concept for Promotion of IPSA 2024: ChildRight2Sleep

Involving multiple stakeholders in managing patients with complex care needs, e.g., children with ASD, FASD or mental health comorbidities who experience sleep disturbances, is complex. Members of the medical and educational systems who manage such children need to be connected with each other, speak a mutually shared language, and have access to the tools necessary for grounding their suggestions in the culturally diverse communities of the affected individuals and their caregivers. Each patient's narrative is unique, thus requiring an individualized approach.

The communications leitmotiv, **ChildRight2Sleep**, invites us to review its meaning critically and, in this context, the service delivery model for Sleep Medicine and approach to assessing and managing children and adolescents with sleep disturbances with/without neurodevelopmental disability and/or mental illness. Sleep is the most commonly neglected functional domain for the patient and their family/caregiver, significantly affecting their quality of life and emotional and physical well-being. The motto allows us to ground our approach to Sleep Health and Sleep Medicine in a broader context and overcome specific interprofessional boundaries and highlights the affected child's (and families) needs.

Research has demonstrated that the participatory, transdiagnostic, and transdisciplinary approach is the most efficient strategy to improve the quality of care. Understanding and acknowledging one's counterpart to be different and having different needs improves communication and negotiation of interventional goals, particularly in the context of sleep. The main theme **ChildRight2Sleep** invites the creation of a respectful communication environment without imposing one's will on the counterpart and improves therapeutic interactions, motivation, and thus participation, adherence and engagement.

## **Appendix A**Letters of Support

## **01 Dr. Célyne H. Bastien**President of the Canadian Sleep Society, Montreal

## **02 Dr. Richard Leigh**President of the Canadian Thoracic Society

# **03 Ms. Alix Arndt**Interim CEO of Nurses and Nurse Practitioners of BC, Vancouver

#### 04 Ms. Audrey McFarlane

Executive Director, for the Canada Fetal Alcohol Spectrum Disorder Research Network

#### 05 Dr. Suzanne Lewis

Chief Medical Officer & VP Research, Pacific Autism Family Network, Vice-Chair, Autism Canada, Vancouver

#### www.canadiansleepsociety.com

February 22<sup>nd</sup> 2023

Dr. Osman Ipsiroglu University of British Columbia

Re: IPSA meeting in 2024

Dear Dr. Ipsiroglu,

It is with great pleasure that the Canadian Sleep Society (CSS) supports your effort to position Canada (Vancouver) for the venue of the International Pediatric Sleep Association (IPSA) meeting.

### Secretary/Treasurer Members-at-Large:

Officers:

President

**FRCPC** 

Past President Robert Skomro, MD.

Célyne Bastien, Ph.D.

Charles Samuels, MD, CCFP. D.ABSM

Vice-President Clinical

Thanh Dang-Vu, MD, PhD Vice-President Research Najib Ayas, MD, MPH

Jonathan Charest, PhD Media & Advocacy Liza Perez, BSc, **RPSGT** Communications Nelly Huynh, DMD Dental Santixay Homsombath, BSc, RPSGT, RST, CCSH Technologist Nicholas van den Berg Student Sara Pintwala Student James MacFarlane, PhD, FAASM Membership Julie Carrier PhD Knowledge Translation

#### President's Office:

& Mobilisation

Dr. Célyne Bastien School of Psychology Laval University 2325 rue des bibliothèques Québec, Québec, G1V 0A6 Email: <u>President@css-</u>

Phone number: (418) 656-2131

General Inquiries: Email: info@cssscs.ca

#### WHAT IS CSS?

For over 35 years, the Canadian Sleep Society (CSS) has been an active bilingual national organization committed to improving sleep for all Canadians through: research support, promotion of high-quality clinical care, education of professionals and the public, and advocacy for sleep and sleep disorders medicine.

Importantly, the CSS operationalized strong promotion capacities and adapted tools to reach out to different sleep communities including scientists, clinicians, technologists, trainees, patients and the general public. CSS website (<a href="https://scs-css.ca/">https://scs-css.ca/</a>), Vigilance newsletter, CSS annual report, the Insomnia Rounds, and the sleep and sleep disorders' pamphlets for sleep clinics and professionals are few examples of these tools. In addition, the CSS scientific meeting attracts close to 1000 professionals, researchers and trainees from around the world every two years.

Synergically to promotion efforts, the CSS actively contributes to the maintenance of a critical mass of competencies on sleep among professionals. Hence, The CSS is providing continuous medical education and training for professionals. Educational days with medical, technologist, clinical psychology and dental tracks are held every year. The CSS is also highly involved in the creation and maintenance of certification for professionals – the AFC program in Sleep Disorder Medicine of the Royal College and the on-going planification of Pan-Canadian certification for dental specialists and sleep technologists.



#### www.canadiansleepsociety.com

Sleep trainees benefit from the joint ICRH-CSS fellowships for building careers for young researchers, several CSS travel and excellence awards. The CSS and the Canadian Sleep and Circadian Network (CSCN) Trainee Task Force is a joint effort co-created by both organizations with the goal of developing opportunities and tools for trainees in the field of sleep, sleep disorder medicine and circadian rhythms. Ongoing projects include organizing activities for the World Sleep Day to raise public awareness for healthy sleep practices, creating a map for the CSS website that will help prospective trainees identifying potential academic opportunities across Canada, knowledge translation and content development for the "Sleep on it" campaign (Website, Social media), as well as development of a research corner to provide trainees and other professionals with tips on specific research techniques.

The CSS is highly involved with patient community and the general public. As a testimonial, our last public and patient engagements sessions held last October, attracted more than 400 individuals. Together with its multi-stakeholders' network, the CSS is deploying the Sleep on It pan-Canadian public health campaign which aims at a) mobilizing expertise and resources to raise awareness on the critical economic, health & social consequences that sleep issues generate for our society and, b) leveraging sleep science through innovative partnerships with public and private stakeholders to bridge the gaps between knowledge and efficient solutions implementation using sleep management as an opportunity. The Sleep on It campaign also serves as an unavoidable dissemination platform (<a href="https://sleeponitcanada.ca/">https://sleeponitcanada.ca/</a>) which leads the CSS to deepen its role as a converging hub for a range of organizations interested in sleep including industry partners, policy makers, professional and scientific associations, patients, and community groups.

#### **CSS CONTRIBUTION TO IPSA MEETING IN VANCOUVER**

Although, it is understood that IPSA will be taking charge of all aspects of the planning, management and fees associated to this event, the CSS is happy to confirm its intention and capacity to contribute to the success of the event by way of disseminating and assisting the local team members for distribution of news and information of the meeting. In order to do so, the CSS will mobilize its dissemination capacities to ensure that all CSS members and extended lists of potential attendees be informed about the meeting.

Should the IPSA board be also open to discuss opportunity for the CSS to play a larger role as a partner to the event, that would allow to capitalize on the CSS Canadian scientific leadership, expertise and educational infrastructure, CSS already announce its readiness to engage into a formal discussion leading to any potential funded partnership.



#### www.canadiansleepsociety.com

The CSS is excited to be able to participate once more in the development of a healthy sleep for all Canadians through its expertise.

Sincerely,

Célyne Bastien PhD

**CSS President** 





February 28, 2023

Joanna MacLean
University of Alberta

Re: Vancouver 2024 IPSA conference proposal

Dear Joanna,

Thank you for contacting the Canadian Thoracic Society (CTS) to ask for our support to the proposal to host the International Pediatric Sleep Association (IPSA) conference in Vancouver in September 2024. We are delighted to offer our support for this application.

The CTS is the national specialty society for respirology in Canada, a membership association including adult and pediatric respiratory and allergy specialists, physicians, scientists, and other respiratory healthcare professionals like nurses, respiratory therapists, physiotherapists, and pulmonary function technologists. Together, we collaborate to enhance the prevention and treatment of respiratory diseases through leadership, education, research, and the development and implementation of clinical practice guidelines. As an Accredited CPD Provider, designated by the Royal College, CTS supports, designs, and delivers high quality continuing professional development opportunities for its members and key stakeholders in the respiratory community.

Sleep-related breathing disorders affect children of all ages and levels of medical complexity. Some of these children use non-invasive ventilation (CPAP, BPAP) and were impacted by the machine and mask recalls where the CTS took a leading role in supporting clinicians who care for these children. Obstructive sleep apnea, the most prevalent of the sleep-related breathing disorders, impacts 2-5% of children across the world. The CTS, in collaboration with the Canadian Sleep Society, is leading the development of Canadian guidelines for the diagnosis of obstructive sleep apnea (OSA) which will be released in early 2024. The timing on the proposed International Pediatric Sleep Association in Vancouver in September 2024 means that these guidelines can help to inform the discussion of moving pediatric sleep care from the realm of sub-specialist to community-based care so that sleep disorders like OSA are identified and managed earlier.



CTS commits to disseminating information about the IPSA conference to our members. We would also be interested in considering co-developing a symposium focused on sleep-related breathing disorders as part of the conference agenda, should this be an opportunity available to supporting partners.

We look forward to hearing the outcomes of the deliberation process and continuing to support this important initiative.

Yours sincerely,

Richard Leigh, MB, PhD, FRCPC, FCAHS



Nurses and Nurse Practitioners of British Columbia #500-3777 Kingsway Burnaby, BC V5H 2Z7 info@nnpbc.com

February 27, 2023

International Pediatric Sleep Association (IPSA) 3270 19th Street NW, Suite 109, Rochester, MN 55901

#### RE: Support for the Pan-Canadian IPSA 2024 Proposal to host 2024 International Pediatric Sleep Association Conference

Dear IPSA Board,

The Association of Nurses and Nurse Practitioners of British Columbia (NNPBC) is the professional association representing all four nursing designations in British Columbia including registered nurses, licensed practical nurses, nurse practitioners and registered psychiatric nurses. Our mission is to support and promote excellence in nursing practice, education, research, and leadership by empowering nurses to actively influence and advocate for positive changes to health and social policy.

We recognize that sleep is an important component of health, however, there are often unmet educational needs for nurses regarding how sleep health can support overall health and wellbeing. NNPBC recognizes the value of the Pan-Canadian IPSA 2024 Interest Group's proposal to host the 2024 International Pediatric Sleep Association conference in Vancouver, BC.

If the proposal to host IPSA in Vancouver is successful, we will be pleased to assist in distributing information about the conference, including relevant associated professional education opportunities for nurses, to our NNPBC members.

We wish the Pan-Canadian IPSA 2024 Interest Group the best of luck with their submission and look forward to learning of its outcomes,

Sincerely,

Alix Arndt

Interim Chief Executive Officer/Chief Operating Officer Nurses and Nurse Practitioners of British Columbia



February 27, 2023

Audrey McFarlane Executive Director Canada Fetal Alcohol Spectrum Disorder Research Network audrey.mcfarlane@canfasd.ca

This letter of support is written to support and secure the involvement of the highly motivated CanFASD Team in the IPSA 2024 application led by Dr. Osman Ipsiroglu and a pan-Canadian team of multi-professional co-investigators.

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a collaborative, interdisciplinary research network, with collaborators, researchers and partners across the nation. It is Canada's first comprehensive national Fetal Alcohol Spectrum Disorder (FASD) research network. CanFASD's unique partnership brings together many scientific viewpoints to address complexities of FASD, with a focus of ensuring that research knowledge is translated to community and policy action. Our mission is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by Fetal Alcohol Spectrum Disorder.

Working in partnership across the country – CanFASD is collaborating with national entities concerned with FASD, including the Public Health Agency of Canada (PHAC), Health Canada and Kids Brain Health Network. Both provincial and federal levels of government have invested in projects related to FASD with CanFASD.

As the Executive Director of CanFASD, I know that several leading members of our research network have successfully collaborated with Dr. Ipsiroglu in the past. We, as the CanFASD Team, are thrilled to collaborate on this proposal for hosting the prestigious IPSA Conference in Vancouver in 2024. We see this proposal as a great opportunity to promote primary, secondary and tertiary *sleep health* and *sleep medicine* related prevention measures in a structured way by world leaders within our network of end-users, professionals, lay-persons and affected individuals.

A large proportion, more than 80%, of children and youth with mental health and neurodevelopmental disorders such as Fetal Alcohol Spectrum Disorder (FASD) suffer from sleep problems. These sleep problems often remain unrecognized in the face of multiple comorbidities, which may mask underlying disorders. Furthermore, treatments are focused on daytime symptoms associated with the co-morbidities, which may cause additional risks to the wellbeing of the child. Standardized and structured clinical concepts for approaching sleep problems in vulnerable populations and guidelines/ policies for addressing their therapeutic options are *essential* and currently *missing* on local and international levels. Thus, this conference, with its for community needs tailored preconference workshops with focus on universal sleep screening at tier service 1/2/3 levels is a huge stride towards addressing this systematic gap and developing concrete bridging strategies.

The Canada FASD Intervention Team is excited for the opportunity to collaborate on this knowledge dissemination project and will be pleased not only to structure together some of the content addressing our network members

but also to promote the workshops among our network members. For optimizing communication, we have suggested that Dr. Ana Hanlon-Dearman (Winnipeg, University of Manitoba; Diagnostic Co-Lead) and Ms. Dorothy Reid (Abbotsford, Co-Chair of Family Advisory Board) join the pan-Canadian IPSA 2024 Interest Group as Liaison Persons of CanFASD.

In summary, CanFASD is in agreement to support the proposal of the IPSA 2024 Interest Group full heartedly and assure our collaboration.

Sincerely,

Audrey McFarlane Executive Director









February 27th, 2023

#### Re: The International Pediatric Sleep Association (IPSA) 2024 IPSA Conference Proposal for Vancouver

Dear Dr. Ipsiroglu,

We would like to lend our strong support for and commitment to your bid endeavour for Vancouver being the host site for *The International Pediatric Sleep Association (IPSA) 2024 IPSA Conference*. We acknowledge that Canadian sleep clinicians and researchers have made strong contributions to the field of pediatric sleep; yet Canada has not yet hosted this important conference. With this in mind, we fully support and will help to host IPSA 2024 in Vancouver as a Western Canada Initiative, which would include researchers from BC and Alberta working in unison.

Pediatric sleep medicine is at an intersection where it is important to decide whether the field of sleep medicine continue as a Western-centric urban sub-specialty-driven healthcare model, or, step back to reflect and review how we could help to build alliances in the community and implement a screening process for sleep health at the tier 1 service level? The Pacific Autism Family Network (PAFN) and its integral partners AIDE-Canada, ABLE Development Clinic and Autism Integrated Medical Services (AIMS) and associated community partners fully support the latter alliance.

If Vancouver should receive the bid and be able to host the International Pediatric Sleep Association's Biennial Conference in 2024, the PAFN, AIDE-CANADA, ABLE and AIMS would support this important initiative by:

- 1. Be involved with community partners in the harmonization discussion and meeting promotion amongst our physicians, clinicians, patient families, self-advocates, and other members of our organizations.
- 2. Provide guidance in an advisory capacity to the steering committee.
- 3. Support recruitment of meeting participants through our organizations
- 4. Provide use of the PAFN and AIDE-Canada platform to reach a pan Canadian audience.
- 5. Provide use of any space requirements at our Hub facility.
- 6. Provide connection to 7 Hub and Spoke PAFN/AIDE-Canada partners.
- 7. Offer an in-kind contribution of approximately \$25,000.
- 8. Host within our Hub facility, a "Sleep Expo" concept for up to two specific workshops for adolescents and our community partners in the educational system (teachers, coaches) on topics of interest to the steering committee. We hope that the partnership, collaboration and support of ABLE/AIMS Clinics, the PAFN and AIE-Canada in the creation of the specific workshops would assist the organizing committee and help to ground academic knowledge for practitioners in the community.

Our parent organization, The Pacific Autism Family Network (PAFN) is a charitable organization with a mandate to serve the lifespan needs of individuals and families affected by autism and all related neurodevelopmental disorders (NDDs), which commonly include dysregulated sleep patterns. With the vision to break down barriers to access across the province and country, PAFN has collaborated with many organizations to bring together essential lifespan needs for those affected by NDDs, all within one network. PAFN brings together state-of-the-art resources for research, information, learning, assessment, treatment,

and support in order to build capacity for addressing the lifespan needs of individuals with NDDs, and their families. Our goals are to help maximize potential and achieve meaningful and optimal inclusion in the community across the lifespan.

Fusing individualized "person-centered" values with the best of what technology and research can offer, the PAFN presents a vision for treating and supporting persons with ASD, as families, governments, healthcare, education, and the communities come together to link research, teaching and direct care.

Funded by the Public Health Agency of Canada, the <u>Autism & Intellectual Disabilities Knowledge Exchange</u>
<u>Network (AIDE)</u> is a pan-Canadian initiative with a goal of enhancing access to credible, reliable and evidence informed resources and information for individuals living with Autism Spectrum Disorder (ASD) and/or Intellectual Disabilities (ID), and their families. Fully launching summer 2020 the initiative has been active building a network of resources and organizations across Canada.

The ABLE Developmental Clinic Inc. and AIMS: Autism Integrated Medical Services are two of the largest organizations serving children with autism and NDDs in British Columbia. ABLE is a multidisciplinary clinic with 50 health professionals specializing in neurodevelopmental disorders and serving over 1500 individuals with ASD and related disorders per year. AIMS comprises the 4 medical practitioners at PAFN serving 500 children with ASD per year. Dr. Davies also serves as a professional advisor to Autism BC, Autism Support Network, and Pacific Autism Family Network which represent the majority of families dealing with ASD in the province.

The PAFN, ABLE Developmental Clinic Inc. and AIMS: Autism Integrated Medical Services strongly supports your tireless efforts and enthusiasm in bidding for this timely conference opportunity and related meeting initiatives to support this vulnerable community.

Sincerely,

Suzanne Lewis, MD, FRCPC, FCCMG,

Senior Clinician Investigator, BC Children's Hospital Research Institute, Clinical Professor, Dept. of Medical Genetics, The University of British Columbia Vice-Chair, Autism Canada, Co-Director, AIMS Clinic Chief Medical Officer and VP Research, PAFN)

Sergio Cocchia O.B.C., LLD (Hon) PAFN Cofounder and Board Chair

Glen Davies, PhD, R Psych

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Director, ABLE Developmental Clinic Inc.

Co-Director, AIMS: Autism Integrated Medical Services Pacific Autism Family Network