



CHARGE Syndrome Association of Australasia Ltd

Making the **CHARGE** syndrome journey simpler and easier

COMPLEX CARE SEMINAR

Complex care needs across
the lifespan for patients
with multi-sensory
impairments



Dr Kim Blake

Professor of Pediatrics,
Dalhousie University,
Nova Scotia, Canada



Angela Arra RN, MSN

Clinical Nurse Specialist
IWK Health Centre
Halifax, Nova Scotia,
Canada

1 APRIL

11am-12:30pm

Seminar Room 1, TRF
45 Kanooka Grove, Clayton

Topics Covered:

- **Overview of a complex syndrome:** CHARGE syndrome 101 brief overview
- **Complex care across the lifespan:** Review of the CHARGE syndrome checklist and how it guides inter-professional care of individuals with CHARGE syndrome. Adaptable for complex conditions.
- **Gastrointestinal issues** with a focus on the microbiome.
- **Anaesthesia issues:** Relevant to conditions with a crowded airway.
- **Bone health and delayed puberty:** Relevance also for adolescents with low sex hormones
- **Migraines** and their association with cranial nerve V/VII use of botox.
- **Unseen medical issues** in CHARGE syndrome.

Suitable for health professionals:

Senior medical students
Neonatologists
General Paediatricians
Anesthesiologists
Physical Therapists

Gastroenterologists
Cardiologists
Psychologists/Psychiatrists
Endocrinologists
Social Workers

Orthopaedics
Nurses/Nurse Practitioners
Dietitians
Occupational Therapists

Register here: <https://www.trybooking.com/BIGST>

For live streaming, register [here](#)

CHARGE Syndrome Association of Australasia Ltd ABN 69 073 186 437

Australia PO Box 343, Seaford, Vic, 3198 | Tel: 0480 121 345 | admin@chargesyndrome.org.au
www.chargesyndrome.org.au

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Wednesday 1 April 2020

Dr. Kim Blake is a professor of Pediatrics at Dalhousie University in Nova Scotia, Canada. She has been researching in CHARGE syndrome over the last 35 years and has published extensively. She has answered research questions concerning post-operative airway events, sleep apnea, bone health, cranial nerve abnormalities and gastrointestinal issues. In the last 10 years Dr. Blake has partnered with Dr. Jason Berman and they have developed a zebra-fish-model of CHARGE syndrome to answer further research questions. With this model they have been able to understand in more detail the Vagus Nerve in CHARGE syndrome which has influenced our clinical knowledge of poor gut motility. Adverse events following anesthesia has also been researched in our Zebra-fish-model and support the clinical findings that individuals with CHARGE syndrome respond adversely to anesthesia. Given the increased risk following anesthesia, individuals with CHARGE syndrome should have combined procedures where possible in one anesthesia. Dr. Blake is very proud of the CHARGE syndrome checklist which has been developed both for families, individuals, and professionals to use as a clinical guide and a teaching tool for managing CHARGE syndrome.

Angela Arra, RN MSN is a Clinical Nurse Specialist (CNS) with children with medical complexities at the IWK Health Centre in Halifax, Nova Scotia. Angela is a graduate of the University of Western Sydney (Australia) and Canyon College (USA) where she completed her Masters of Science in Nursing in 2006. Over the past twenty-four years, Angela has held a variety of nursing positions in both Canada and the United States. Most of her clinical experience has been in the specialty of medical-surgical nursing in both adult and pediatric settings. She has worked as a staff nurse, clinical instructor and nurse educator prior to her current role as a CNS. Angela has worked with children with CHARGE syndrome in Atlantic Canada for the past 15 years. Together with Dr. Kim Blake, they run a monthly clinic specifically for children and youth with CHARGE in order to provide continuity in care and support youth and their families to be able to self-manage their healthcare.

Publications and References

The following papers and resources are available for download from Dr. Blake's website:

www.drkimblake.com

- Morgan, A., Hudson, A., Arra-Robar, A., and Blake, K. Late dumping syndrome in a seventeen-year old with CHARGE syndrome. *J Paediatr Child Health*. 2017 Dec;53(12):1244-1245.
- Trider, CL., Arra-Robar, A., van Ravenswaaij-Arts, C. and Blake, K. Developing a CHARGE syndrome checklist: Health supervision across the lifespan (from head to toe). *Am J Med Genet A*. Mar 173 (3): 684-691.
- Hudson A., Macdonald M., Friedman J.N., Blake K. CHARGE syndrome gastrointestinal involvement: from mouth to anus. *Clin Genet* 2017; 92: 10–17.
- Trider, CL, Blake KD. SENSE CHARGE Book, "Anesthesia issues in CHARGE syndrome – what are the risks?" Nov. 2014 www.drkimblake.com
- Understanding Sleep Apnea in children with CHARGE syndrome – www.drkimblake.com
- Gastrointestinal (GI) and feeding difficulties in CHARGE syndrome; the guts of it. 14th International CHARGE Syndrome conference. www.drkimblake.com
- Feeding Assessment Scale for CHARGE syndrome www.drkimblake.com
- Gastrointestinal and feeding difficulties in CHARGE syndrome; A review from head to toe. *AJMG*. 2017;175C;496-506

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Patrons: His Excellency General the Honourable David Hurley AC DSC (Retd) and Her Excellency Mrs Linda Hurley

Australia PO Box 343, Seaford, Vic, 3198 | New Zealand PO Box 38792, Auckland, 1143
Tel: 0480 121 345 | admin@chargesyndrome.org.au