Multi-Sensory Impairment Symposium

Multidisciplinary care for children and young adults with multi-sensory impairment

Friday 25 May 2018
Monash Health Translation Precinct (MHTP) Clayton
8:45am-4:00pm
Seminar Rooms 1 and 2

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Daniel Choo ENT Specialist, California, USA</td>
<td>Vestibular issues in CHARGE: anatomy, physiology, testing, behavioural outcomes; General ENT, audiological development and current discoveries.</td>
</tr>
<tr>
<td>Dr. Nancy Salem-Hartshorne Delta College, Michigan, USA</td>
<td>CHARGE 102: Effects of CHARGE Features on Development, Behaviour and Outcomes; Assessment for Children/Youth who are DeafBlind/Multisensory Impaired</td>
</tr>
<tr>
<td>Dr. Kim Blake Dalhousie University, Canada.</td>
<td>Gastrointestinal Dysfunction in CHARGE Syndrome and a Clinical Checklist: With Relevance to Your Complex Patients</td>
</tr>
<tr>
<td>David Brown Deafblind Education, California, US</td>
<td>Developmental and behavioural implications of vestibular dysfunction in children with multi-sensory impairment</td>
</tr>
<tr>
<td>Prof. Tim Hartshorne Central Michigan University, USA</td>
<td>Understanding behaviour in multisensory impairment: The Behaviour Triangle</td>
</tr>
<tr>
<td>Dr. Kasee Stratton Mississippi State University, USA</td>
<td>Pain and Non-vocal Pain Assessment in CHARGE syndrome; Poster session: Bulldog CHARGE Syndrome Research Lab, USA.</td>
</tr>
<tr>
<td>Dr. George Williams Menai, NSW</td>
<td>Update on CHARGE Syndrome and Current Genetic Research</td>
</tr>
<tr>
<td>Dr. Daniel Gadke Mississippi State University, USA</td>
<td>CHARGE Syndrome and Characteristics of Autism Spectrum Disorder: Examining Similarities and Differences</td>
</tr>
</tbody>
</table>

REGISTER HERE (or go to https://www.trybooking.com/339641)
Cost: $50 (inc morning tea, lunch)
Seminar Rooms 1&2, Monash Health Translation Precinct, 45 Kanooka Grove, Clayton
Further information: Madeleine Rich—m.rich@chargesyndrome.org.au Mob: 0409 423 373
Speaker Biographies and Abstracts

Dr. Daniel Choo, ENT Specialist, Cincinnati Deafblind Educational Specialist, CA, USA.
Daniel Choo, director of Division of Pediatric Otolaryngology-Head and Neck Surgery at Cincinnati Children’s Hospital Medical Center and professor of Otolaryngology at the University of Cincinnati Neuroscience Institute, University of Cincinnati College of Medicine. Dr. Choo is recognized as the leading expert for the diagnosis and management of children with hearing loss and for his study of the genetics of hearing loss and the molecular mechanisms guiding development of the inner ear. Dr. Choo is the co-director of CCHMC multi-disciplinary CHARGE program, an integrated care model for children with CHARGE syndrome which seeks to optimize medical and developmental outcomes.


In the setting of CHARGE syndrome, the atypical anatomy and physiology of affected individuals creates significant challenges for clinicians trying to optimize hearing, balance and overall communication functions. Further adding to the clinical complexity are the vision impairments, developmental delays and other conditions in CHARGE that can impact functional components such as phonation, sign language capabilities and auditory processing. This seminar will delineate the middle and inner ear structural anomalies that are commonly seen in CHARGE and the implications for hearing interventions (such as bone anchored hearing aids and cochlear implants). In addition, the almost universal inner ear vestibular anomalies can have direct ties to behaviors, postures and functional impairments seen in individuals affected by CHARGE. The discussion will correlate the vestibular anomalies (as demonstrated by CT and MRI studies) with the behaviors and functional outcomes seen in this population.

Dr. Nancy Salem-Hartshorne, Assoc Prof of Psychology, Delta College, MI, USA.
Nancy Salem-Hartshorne, Associate Professor of Psychology at Delta College is also a Nationally Certified School Psychologist. She has authored numerous articles and book chapters about developmental outcomes for individuals with CHARGE syndrome. Her son Jacob, 28, has CHARGE syndrome and lives in his own home and is integrated into his home community through individualized supported work and community engagement. Nancy is an advocate for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals. the CHARGE Syndrome Foundation.

Abstract: Assessment for Children/Youth who are DeafBlind/Multisensory Impaired
Children born with dual-/multisensory impairments have unique ways of learning about the world. Traditional educational assessment strategies are neither well-suited nor always appropriate for this population. This presentation will outline comprehensive, person- and family-centered assessment philosophy, strategies and procedures that lead to a clear understanding of the child’s sensory, educational, and language development and needs. These strategies will offer a clear path to positive outcomes for future education and life in the community.

Abstract: CHARGE 102: Effects of CHARGE Features on Development, Behaviour and Outcomes
Based on Dr. Hartshorne’s 20 years of research and observations.

Dr. Kim Blake, Paediatrician, Dalhousie University, Nova Scotia, Canada.
Professor of Pediatrics at Dalhousie University, Nova Scotia, Canada. She has been researching in multiple clinical aspects of CHARGE Syndrome for over 30 years including anesthesia risk, post-operative complications, cranial nerve anomalies and emerging issues in the older population. Dr. Blake has 100+ published articles and presented to parents and professionals both nationally and internationally. Her recent focus is on the Gastrointestinal (GI) System with an interest in gut motility; using Zebra Fish as a disease model.

Abstract: Gastrointestinal Dysfunction in CHARGE Syndrome and a Clinical Checklist: With Relevance to Your Complex Patients
CHARGE syndrome is an autosomal dominate genetic disorder resulting from the mutation of the CHD7 gene on chromosome 8 (8q12). CHD7 is a member of the chromodomain helicase DNA-binding (CHD) protein family and regulates genes involved in neural crest cell migration, as well as interactions with...
other cells during embryogenesis by chromatin remodeling. The acronym CHARGE stands for the Association of C - Coloboma of the eyes; H - Heart defects; A - Atresia of the choanae; R - Retardation of growth and development; G - Genital Hypogonadism; and E - Ear anomalies / deafness. Gastrointestinal (GI) symptoms and feeding difficulties are highly prevalent in CHARGE syndrome but are often neglected areas of diagnosis, treatment and research. GI involvement is often overlooked in many individuals who have a multitude of severe physical and behavioral manifestations. Patients with CHARGE syndrome experience a wide spectrum of medical, physical, and psychological issues. Thus, a multi-disciplinary healthcare team is usually involved in their care. Guided approaches to health supervision have been developed for some complex syndromes. We would like to present a CHARGE syndrome checklist that is appropriate for use by both professionals and families and could also easily be adapted for your chronic patient population.


David Brown, Deafblind Educational Specialist, California, USA.
David Brown is a deafblind educational specialist who has been working with children with CHARGE syndrome since 1983. In the United Kingdom he was the Head of Family & Children Services for Sense. He moved to California in 2000 to work with the state deafblind project, based in San Francisco. He has given presentations about CHARGE syndrome in 14 different countries, and in 24 states in the US. His articles about CHARGE syndrome have been translated into at least 12 different languages. In 2005 David was given the Star in CHARGE award by the CHARGE Syndrome Foundation, and in 2013 he received the Lifetime Achievement Award from Deafblind International.

Abstract: Developmental and behavioural implications of vestibular dysfunction in children with multisensory impairment
Although vestibular dysfunction, for many reasons, is very common in the entire population of children with multi-sensory impairment, there is little understanding of the vestibular sense, where it is located, how it works, and the functions that it serves. It is commonly referred to as the “balance” sense, even though it is only one component in the development of effective balance, but it does have far-reaching and crucially important impact on all areas of development. Observational assessment data from the field of CHARGE syndrome, including many photographs, will be presented to demonstrate probable outcomes of vestibular dysfunction as seen in characteristic postures, movement patterns, and self-stimulation behaviours in this population. The presentation will conclude with a very brief overview of possible strategies to help ameliorate the outcomes of congenital vestibular dysfunction and so promote more effective functioning, improved attention, and better educational progress.

Prof. Tim Hartshorne, Professor of Psychology, Central Michigan University, USA.
Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan’s Training and Resource Project, which provides support to children who are deafblind in Michigan. He has been researching and presenting about CHARGE syndrome since 1993, motivated by the birth of his son with CHARGE in 1989. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. He is first editor of the book CHARGE Syndrome.

Abstract: Understanding behavior in multisensory impairment: The Behavior Triangle
One sensory impairment limits a child’s understanding of the world, but two or more multiply their problems drastically. It is challenging to self-regulate one’s behavior in an oftentimes chaotic environment. Sometimes the behavior can become extreme and hard to cope with. In my research lab we have come to view the behavior of children with CHARGE syndrome as having three important sources: pain, sensory issues, and anxiety. These are likely to be very similar in other conditions with multisensory impairment. This presentation addresses the behavior triangle and how each component manifests with multisensory impairment.
Dr. Kasee Stratton, Assistant Professor of School Psychology, Mississippi State University, USA.

Kasee Stratton is an assistant professor of school psychology at Mississippi State University, and a licensed psychologist. Dr. Stratton directs the Bulldog CHARGE Syndrome Research Lab and has been researching and presenting on CHARGE since 2005. Dr. Stratton specializes in intervening on challenging behavior and improving adaptive and life skills.

Abstract: **Pain and Non-vocal Pain Assessment in CHARGE Syndrome**

Individuals with CHARGE experience acute and chronic pain experiences that are likely to impact their behavior and adaptive skills. Given that a majority of individuals with CHARGE have limited to no formal communication system, identifying pain in this population can be challenging and is exacerbated when typical pain indicators, such as facial expression, are not as well identified based on physical anomalies. This presentation will address the pain experience in CHARGE and will review a non-vocal pain assessment (CNVPA) designed to identify pain in this population.

**Poster Session:** The Bulldog CHARGE Syndrome Research Lab at Mississippi State University conducts research and has a mission to improve the lives of individuals with CHARGE syndrome in the school, home, and hospital through research and awareness. Most current research findings will be discussed.

Dr. George Williams, Menai, NSW.

Dr. Williams trained as a neonatal paediatrician at The McMaster University, Hamilton, Ontario, Canada. He is former director of the newborn intensive care unit at The Royal Alexandra Hospital for Children, Camperdown, NSW. He has worked in private practice for perinatal/paediatric consultation and currently provides Level 2 newborn care for sick babies at the St George Private Hospital, NSW. George has been involved with the CHARGE Syndrome Association of Australasia since the late 1980’s and has a keen interest in research related to CHARGE syndrome and deaf-blindness.

Abstract: **Update on CHARGE Syndrome and Current Genetic Research**

Outline recent medical publications related to the epidemiology, diagnosis, differential diagnosis, management and outcomes of CHARGE syndrome. Since the discovery of the CHD 7 gene, which is microdeletion affecting chromosome 8 in 2004, there has been a significant development in the understanding of CHARGE genetics. Medical management has improved with greater understanding and awareness of the condition. Early developmental therapy has shown to be effective in improving the language/communication and learning in this special group of children. The three major sensory systems, vision, hearing and balance can be augmented with improvement and developmental outcomes.

Dr. Daniel Gadke, Assistant Professor of School Psychology, Mississippi State University, USA.

Daniel Gadke earned his Ph.D. in School Psychology from Illinois State University and completed his pre-doctoral and post-doctoral work at Johns Hopkins University School of Medicine and the Kennedy Krieger Institute. Currently, Dr. Gadke is assistant professor of School Psychology at Mississippi State University where he started and runs the Autism and Developmental Disabilities Clinic. Specializing in behavior difficulties and skill acquisition, Dr. Gadke is a Licensed Psychologist, Board Certified Behavior Analyst, and a Nationally Certified School Psychologist.

Abstract: **CHARGE Syndrome & Characteristics of Autism Spectrum Disorder: Examining Similarities and Differences**

The incidence in the comorbidity of CHARGE and Autism Spectrum Disorder (ASD) appears to be on the rise. We caution professionals and families to consider the outcomes of an additional diagnosis of autism and discuss factors (diagnostic criteria and policy influences) that have likely lead to the increase in the diagnosis of ASD among individuals with CHARGE. Diagnostically, there are behavioral presentations across both disorders that may present as similar, which instigates the dual diagnosis. The discussion will also include clearly distinguishable differences between the two, with particular focus on social presentation. Misconceptions related to CHARGE and ASD will be highlighted in efforts to best help professionals and parents determine whether it is best to pursue the dual diagnosis.
Directions to the Monash Health Translation Precinct (MHTP)
45 Kanooka Grove, Clayton

The MHTP Translation Research Facility is located at the rear of Monash Medical Centre (246 Clayton Road, Clayton).

To get to the MHTP Translation Research Facility:
- Enter via main entrance of Monash Medical Centre
- Walk to Orange Lifts (follow the orange arrows on the map). Take Lift to Level 3
- At Level 3, turn left as soon as you exit the lifts and enter the link bridge/walkway to MHTP.

To get to the Seminar Rooms 1 & 2:
- At the end of the link bridge, take lift or stairs down to Level 1. Exit lift and walk to hallway directly opposite cafe. Seminar rooms are located down the hallway.

By Car
Street parking around the hospital is very limited and mostly restricted to one or two hours duration. Parking inspectors patrol the area regularly. There is a public multilevel car park (enter via Clayton Road entrance). Fees for parking apply.

By Train
Clayton railway station (on the Pakenham/Cranbourne line) is a 10 minute walk from Monash Medical Centre.

By Bus
631, 703 and 733 stop outside the main entrance to Monash Medical Centre.