



Clinical Research at the Child and Adolescent Health Service



An overview of the clinical research happening at our health service



Foreword from the CAHS Chief Executive

hank you for taking the time to explore the clinical research pathways available at the Child and Adolescent Health Service (CAHS).

CAHS is committed to having a lead role in child health research in Western Australia because it links so vitally to our vision of 'healthy kids, healthy communities'. Being research active means that we draw on the latest and best knowledge from around the world and participate in research that directly translates into better outcomes.

Research is also critical to our aspiration of being a world class provider of healthcare and is one of the core aspects of our mission and strategic priorities. Research is not isolated to academic institutions – high calibre and translational health research is best delivered in an organisation that aligns academic excellence with best practice clinical care.

As you work through this document, you may be surprised at the depth and breadth of research that is taking place in our departments. We are proud of our research staff and the way they continuously strive to find new and innovative ways to prevent, diagnose, treat and cure health conditions that impact on children and adolescents.

As we mature as a health service, research is becoming embedded into everyday work. That is why we want to attract the brightest and best clinicians and researchers to be part of our team.

Our research support team is strong and always exploring ways to deliver services to researchers that will enhance and grow the capacity and quality of child health research at CAHS and with our research partners.

Our collaboration with our campus partner, Telethon Kids Institute, is another boost to child health research in Western Australia. Along with our other research partners, there is a clear vision that demonstrates a willingness to work together to ensure good health outcomes for children and families in our State and around the world.

Please get in touch with our research support team to find out more. If you are passionate about research and child health, then you are sure to find a pathway to do clinical research here at CAHS.

Aresh Anwar CAHS Chief Executive

Research support, development and governance

Dedicated research support available to enhance research

The Child and Adolescent Health Service (CAHS) is committed to supporting our researchers so that a research culture is embedded into everyday clinical practice.

There is a dedicated team offering specialised support services to assist in the development, governance and implementation of effective research across our health service. The team supports CAHS researchers as well as our partners who engage in research at our sites or with our patients.

We look forward to hearing from experienced researchers or those looking to start their research journey at CAHS. There are many ways we can improve and enhance the quality of your research.

Research Support: What does the team offer?

- Research facilitation and advice
- Research development and design
- Business support and advice
- Research feasibility advice
- Research education resources
- Ethics and governance application support
- Marketing and communications

Contact Us

Option 1: Website

You may find what you need on our website. Our pages are regularly updated and include templates, guidelines, educational resources and general information. Website: cahs.health.wa.gov.au/Research

Option 2: General Enquiries

Not quite sure where to start or what help is available? Get in touch and we can direct your enquiry to a suitable team member who can help.

Email: CAHS.ResearchSupport@health.wa.gov.au

Option 3: Drop In Sessions

Another way to get some guidance is via 'drop in support' from 9am to 10am and 2pm to 3pm every work day. Individual appointments can be made outside these times. Office 5E, Level 5 Perth Children's Hospital. Ask for the Research Facilitators.

Option 4: Direct contact with relevant team members

If you know what you need, contact the specific team member/s.

- Research suites (Telethon Clinical Research Centre – Outpatient Clinic D)
- ✓ Consumer involvement / engagement
- ✓ Biostatistics and data management
- Research funding and grant support
- Clinical Trials liaison and support
- ✓ Access to CAHS Research Nurse Register

Postgraduate Medical Education

The Postgraduate Medical Education team offers Resident Medical Officers at Perth Children's Hospital with teaching and learning opportunities during employment with us.

Contact

PCH.PGME@health.wa.gov.au

Teaching Opportunities

- Weekly RMO Teaching
- STARS Simulation Sessions with "Sim-Baby" and "Sim-Junior" to simulate real-life scenarios with unwell and deteriorating patients.
- Senior RMO Teaching
- Hospital Paediatric Life Support
- Advanced Paediatric Life Support
- Grand Rounds with presentations from health service departments and international speakers (when available).
- Protected Registrar Teaching/ Clinical Paediatric Conferences Sessions

Departmental Teaching

- Individual departments may have teaching programs specific to that discipline.
- Seminars on Research Methodology (run by the CAHS Research Education Program)
- Sydney Children's Health Program (formally the Diploma of Child Health)

CAHS Research Education Program

https://pch.health.wa.gov.au/Research/For-researchers/ ResearchEducationProgram

CAHS Research Education Program

The CAHS Research Education Program provides open-access resource that includes the Research Skills Seminar Series and a number of workshops throughout the year to facilitate research projects by busy students, and staff from any clinical background (e.g. medical, nursing, allied health, laboratory etc.)

Research Skills Seminar Series

The aim of the 20+ seminars is for each to provide a one hour overview of a large topic representing a part of the research process. Seminars are designed to be practical, and suitable for staff and students of any clinical discipline. The one hour format is specifically to assist busy clinical staff to access condensed information. Because of this, in addition to the recording, accompanying handouts contain not just the PowerPoint slides, but also extra information and resources such as useful websites, references, and further training opportunities where available.

Workshops

The program includes workshops that include topics such as ethics, governance, data management, REDCap use and more. They program also facilitates Pitch your Project Idea sessions to support emerging clinical research at CAHS.



Clinical Audit Handbook

The Clinical Audit Handbook is a resource that has been developed by the Research Education Program and is open access for anyone. It is an opportunity to support audit processes for those needing training or a refresher in methodology and is also useful for those planning to conduct other types of surveys. The handbook is a deliberately generic and open access guide that is suitable for students and staff from any clinical discipline.

https://pch.health.wa.gov.au/Research/For-researchers/ ResearchEducationProgram/Clinical-Audit-Handbook

CAHS Department Clinical **Research Overview**

he following pages contain a snapshot of current research projects underway within our departments at CAHS. Research projects are spread across clinical, mental health and community services for child and adolescent health. While not a complete list, this does provide the reader with an overview of the capacity and breadth of work our staff are engaged in. All departments listed have provided contact details for the lead researchers who can be contacted should you have any questions or be interested in participating in their research programs as part of further clinical training or research degrees.

The Research Support team at CAHS can be contacted for any further information you may need about running a research project based at CAHS.

Email: CAHS.ResearchSupport@health.wa.gov.au

Rheumatology, Metabolic Medicine and Complex Pain

Contact: Dr Kevin Murray Anaesthesia Senior Medicine Consultant Kevin.Murray@health.wa.gov.au

Research includes clinical trials and investigative research. The department supports and enhances the close working relationships between research, clinical practice and teaching in order to provide better health care.

Rheumatology Research Projects

• Genetics in Juvenile Arthritis - a new Australia wide autoimmunity biobank study (A3BC)

Metabolic Research Projects

Long term study of outcome in mucopolysaccharoidosis disease (Morquio Registry)

Complex Pain Service Research Projects

- Feasibility of delivering paediatric pain services via telehealth videoconferencing
- Feasibility of a physical test battery to evaluate outcomes involving quantitative sensory testing and accelerometry
- Development of evidence based and disease specific self-management resources for children and their parents. These will ultimately be delivered via an app. Initial stages of this project include:
- 1. Paediatric field testing of new World Health Organisation chronic pain codes
- 2. Identification of the biopsychosocial characteristics of families presenting for tertiary chronic pain care.

The knowledge gained from these two studies will allow tailoring of interventions to the needs of the child and their family.

PCH Allied Health Service Unit

Departmental Overview

The Allied Health Service Unit at Perth Children's Hospital delivers inpatient and outpatient services to children from birth to 16 years and is composed of

- Audioloav
- Child Protection Unit (Allied Health)
- Newborn Hearing Screening Program
- Nutrition and Dietetics
- Occupational Therapy (including Play Services and Music Therapy)
- Orthotics
- Pastoral Care
- Physiotherapy
- Social Work (including Aboriginal Liaison Officers and Language Services)
- Speech Pathology

Allied Health conducts research as an individual department and/or in partnership with other allied health services and/or with CAHS Medical and Surgical specialties and/or other services and organisations including universities.

Current Allied Health Research Projects

- Survey of all PCH Allied health staff via use of the Research Capacity and capacity tool. This survey was developed by Griffiths University and Queensland Health in 2012. The results at PCH demonstrated a idea
- Participation and engagement (e.g. Tube Feed Weaning: Connecting to Disconnect Development, implementation and evaluation of a Tube Feed Weaning clinical practice guideline)
- Trauma informed care (e.g. Evaluation of a Psychosocial Parent Group for Children Newly Diagnosed with Cancer)
- Systematic Review of intervention and management of Children and Adolescents with Functional Disorders.

Audiology

Contacts: Erin Maywood | Head of Department of Audiology Erin.Maywood@health.wa.gov.au Dr Chris Brennan-Jones | Senior Audiologist and NHMRC Research Fellow Christopher.Brennan-Jones@health.wa.gov.au

The Department of Audiology, in collaboration with the University of Western Australia and the Ear Health team at Telethon Kids Institute has an active program of competitively funded clinical research. We can offer a wide range of opportunities for allied health, nursing and medical staff to become involved in these activities (including opportunity to pursue PhD studies).

Together with the Department of Otolaryngology, we co-ordinate the PCH Hearing Research Group that brings together a number of researchers and clinical teams with a common aim; to find and deliver new and improved solutions to prevent, treat and rehabilitate ear and hearing related disorders experienced by children or adolescents.

strong motivation to undertake research (80%) as well as barriers that primarily related to limited time and resources. Allied health is developing pathways to improve support for research from the conception of an

The Department is well supported by a research coordinator, research assistants and research fellows working within the department.

We use a wide range of research methods, including epidemiological studies (including data linkage), clinical trials, qualitative research and clinical audit activities.

Current Research Projects

- Pilot trial of targeted screening for congenital cytomegalovirus at newborn hearing screening
- Telehealth implementation for paediatric audiology and otolaryngology services
- Cochrane reviews to determine most effective treatments for chronic ear infections
- Electrophysiological research examining effects of sedation on auditory brainstem responses
- Developmental outcomes for cochlear implant recipients

Orthotics

Contacts: Rhiannon Assetta | Manager and Lauren Bell | Orthotist

PCHOutpatients.Orthotics@health.wa.gov.au

The PCH Orthotics Service has three orthotists and two technical officers who work across two sites. The service assesses, prescribes and manufactures orthotics for children in Western Australia. The department regularly accepts student placements for students studying a Clinical Masters of Prosthetics and Orthotics at Latrobe University in Melbourne.

Key Research Areas

- Casting for Early Onset Scoliosis
- Collaboration across all orthotics services within Australia to develop an effective evidence based service
- Advancing technologies in orthotics, particularly 3D printing

Occupational Therapy

Contacts: Sally Wojnar-Horton | Head of Department

Sally.Wojnar-Horton@health.wa.gov.au Dr Suzi Taylor | Research Coordinator Susan.Taylor4@health.wa.gov.au

Occupational Therapists are committed to maximising a child's potential for building and recovering skills that enable participation in everyday activities and occupations e.g. self-care, productivity (school, peer interaction), play, relationships and leisure, which can be disrupted as a result of disease, trauma, and medical interventions requiring admission to an acute paediatric hospital. Fifty percent of staff have research gualifications including Masters, PhD or 1st class honours. The department also supports a university honours program linked with Curtin University.

Key Research Areas

- Evidence Based Practice for all clinical interventions
- Therapeutic use of play
- Assessment and modification of equipment (e.g. Application of PROMs and PREMs in paediatric Occupational Therapy – A systematic review)
- Cognition (Cognitive assessment of children with acquired brain injury scoping review)

Dietetics

Contacts: Beth Martino | Head of Department and Leah Bryant | Senior Dietitian PCH.Dietetics@health.wa.gov.au

Dietitians provide nutrition assessment and medical nutrition therapy for patients such as:

- management of inpatients and outpatients on tube feeds
- diet and/ or specialised nutritional feeds, education and monitoring
- consultancy to medical teams regarding the nutritional therapy of patients

The department provides student placements for students studying a Masters of Dietetics at Edith Cowan University and Curtin University in Perth.

Key Research Areas

- Research currently undertaken in the area of nutrition and diabetes is around the management of blood glucose levels after consuming a meal. Specifically the consistency within individual and between individuals and the impact and management of fat, protein and variable carbohydrate quantities. In addition the change in blood glucose fluctuations, diet quality and quality of life once started on a gluten free diet in children and young adults newly diagnosed with coeliac disease. Service delivery changes are being trialled and evaluated to reduce length of hospital stay for those newly diagnosed with diabetes
- Muscular Dystrophy Western Australia-funded Neuromuscular project includes nutrition screening of all children attending the Neuromuscular clinic at PCH, the development of nutrition care pathways and clinical guidelines, and the development of evidence-based patient information.

Physiotherapy

Contacts: Kim Laird | Head of Department Kim.Laird@health.wa.gov.au Dr Noula Gibson | Research Coordinator Noula.Gibson@healh.wa.gov.au

Physiotherapists at PCH work in partnership with other organisations with aim to minimise the effects of physical impairment, facilitate timely discharge, enhance quality of life and maximise functional mobility. They provide assessment, advice and a range of interventions in areas including neurology/neurodevelopmental, respiratory, musculoskeletal, oncology and other complex presentations.

The physiotherapist's role includes training and educating families, carers and other staff in understanding the nature of the patient's mobility and/or functional challenges and their role in managing these problems. Sixty percent of staff have or are currently undertaking formal post graduate education in their area of expertise including research related Masters, PhD and Honours degrees.

Physiotherapy staff provides formal teaching, training and education to undergraduate and postgraduate physiotherapists from Curtin University of Technology and University of Notre Dame.

Current National and International Research Collaborations

- European Respiratory Statement on Tracheomalacia and Bronchomalacia in Children
- Wet cough in Aboriginal Children in North Western Australia
- Aquatic Physiotherapy in Cerebral Palsy
- Management of Chronic Pain in Children
- Australian National Registry for Selective Dorsal Root Rhizotomy

medical nutritional therapy including nutrition screening, assessment, nutritional support via a therapeutic

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- Development of Evidence-based guidelines for prevention and management of respiratory disease in young people with cerebral palsv
- 10 year Review of the Hip Surveillance Guidelines for children with cerebral palsy

Speech Pathology

Contacts: Jodi Lipscombe | Head of Department Jodi.Lipscombe@health.wa.gov.au Carolin Jentzsch | Senior Speech Pathologist Carolin.Jentzsch@healh.wa.gov.au

The Speech Pathology Department provides inpatient and outpatient services to patients referred with communication and feeding disorders. Our speech pathologists work in partnership with caregivers and other health service providers to provide assessment and management for infants, children and adolescents with communication and/or swallowing difficulties.

Our department is a state-wide service for consultation, second opinion and diagnostic assessment of complex medically based swallowing and communication disorders. Speech Pathology staff provides formal teaching, training and education to undergraduate and postgraduate speech pathologists from Curtin University of Technology and Edith Cowan University.

The speech pathology department has a commitment to supporting best practice service delivery through quality improvement and research partnerships. Our current focus is on the continuing to collaborate and engage with our Curtin and ECU University partners in facilitating and supporting Honours Student research projects.

Current research collaborations

- The development of evidence-based guidelines for prevention and management of respiratory disease in young people with cerebral palsy
- The impact of parent coaching on early communication development with infants and toddlers
- The outcomes of cochlear implant habitation by speech pathology and audiology

Department of Anaesthesia and Pain Medicine

Contacts: Prof Britta von Ungern-Sternberg | Professor of Anaesthesia Britta.Regli-VonUngern@health.wa.gov.au Lliana Slevin and Aine Sommerfield | Research Coordinators Lliana.Slevin@health.wa.gov.au Aine.Sommerfield@health.wa.gov.au

Departmental Overview

The PCH Department of Anaesthesia and Pain Medicine provides the only tertiary paediatric Anaesthesia and Pain Medicine service in Western Australia.

The anaesthetic research team led by Prof Britta Regli-von Ungern-Sternberg focusses not only on anaesthesia and pain management but also on perioperative outcomes and the improvement of care for our young patients. The team works within a large interdisciplinary network with many local, national and international collaborations. Locally, it collaborates with multiple departments within PCH, The University of Western Australia, the Telethon Kids Institute, Curtin University and other local non-government agencies in Western Australia. Nationally, the team works in close collaboration with all tertiary paediatric anaesthesia departments and internationally with numerous centres overseas, mainly in the US and Europe.

Consumer Stream

The Anaesthetic Research team is a very active team with up to 20 research studies in progress at any one time. The research is founded around a holistic approach along the perioperative pathway as shown below. Some examples are listed below:

Holistic care: Improving patient outcomes along the perioperative pathway		
Preoperative	Day of Surgery / Hospital	Family Centred Care
Risk Identification		
Optimisation		
Translation		

Stream 1: Optimisation of the Perioperative Journey including Anaesthesia

- 1A: Tonsillectomy, OSA and Risk Stratification
- 1B: Trial of jelly snakes to prevent postoperative nausea and vomiting after ENT surgery 1C: A multi-centre randomized non-inferiority trial of chewing gum versus ondansetron to treat
- 1D: Oxygen Delivery during Anaesthesia

Stream 2: Lung Physiology during Anaesthesia

- 2A: Effect of different lung recruitment strategies in anaesthetized children on oscillatory mechanics.
- 2B: Forced oscillation measurement of lung recruitment during mechanical ventilation in children undergoing laparoscopic surgery

Stream 3: Pain Management

- 3A: A multi-centre, double-blinded, randomised controlled trial to investigate honey use to reduce pain in children post tonsillectomy
- 3B: A multi-centre, double-blinded randomised placebo-controlled study to investigate Gabapentin use to manage post tonsillectomy pain

Stream 4: Anaesthesia and the Brain

- 4A: TREX Neurodevelopmental outcome after sevoflurane versus dexmedetomidine/remifentanil anaesthesia in infancy: a randomised controlled trial
- 4B: EEG An international multicentre study of isoelectric EEG events in infants and young children during anaesthesia for surgery

Stream 5: Future Formulations of Medications Optimised for Children

• 5A: Antibiotics

Consumer Stream

In 2019, we established an Anaesthetic Research Consumer Reference Panel comprising 9 parents who have multiple personal experiences of perioperative care at Perth Children's Hospital. This group works with us to facilitate:

- Advice and support on research grant applications and plain language summaries
- Links between consumers, the community and researchers
- Advice and expertise on consumer and community issues
- Advocacy on behalf of consumers and the community where appropriate
- Input into the development of strategies to inform the wider community about research associated with the group

postoperative nausea and vomiting in female patients after breast or laparoscopic surgery

Department of Burn Injury

Contact: Prof Fiona Wood | Director of the Burns Service of WA | Director of the Burn Injury Research Unit UWA

Fiona.wood@health.wa.gov.au

Departmental Overview

The paediatric Burns Service of WA based at PCH is the home of the Stan Perron Centre of Excellence in Childhood Burn Injury supported by the PCHF. The research is based on the understanding that every intervention from the time of injury influences the scar worn for life. As such, activity spans the community, prehospital, links with the basic science of injury and healing, on to the focused interventions and holistic rehabilitation.



Key Research Questions

- What is the mechanism that leads acute burn injury to sustain health problems long after recovery from the burn?
- How can we ameliorate scarring and minimise the impacts of scarring on children as they grow?
- How can we identify the patients 'at-risk' and provide personalised interventions to optimise their health journey?
- What is the role of tissue regeneration in reduction of lifelong scarring?
- How can we reduce the pain and stress on\f burn injury?

Using a range of tools and collaborations the aim is to reduce the scar worn for life physically, functionally and psychologically outlined in the examples below:

Biobanking: Establishing a paediatric burn trauma biobank to obtain biological samples (hair, urine, faecal and blood samples) together with clinical data for up to 500 paediatric patients facilitating new studies using systems biology and other approaches to understand the systemic and long-term physiological impact of burn injury and how this changes life trajectory.

Chemistry of trauma and Healing: A multi-centre paediatric study to investigate markers of burn severity (to assist with acute clinical decision making) and to understand the impact of burn injury on immune cells. This project is supported by NHMRC funding and involves Queensland and NSW paediatric burn centres.

3D printing in situ for acute surgical intervention: In collaboration with Inventia (Sydney) developing a 3D printer that can be used in the operating theatre to deliver cells and scaffolds to promote healing extending the well-established work in cell based therapies.

Long-term impacts of burn injury on the immune system: We have investigated the circulating cytokine (cell-to-cell signals) in paediatric patients following their burn injury and shown increased levels of three pro-inflammatory cytokines was also analysed for antibody levels to the diphtheria, tetanus and pertussis vaccine, and burn patients were found to have lower rates of vaccine-mediated protection.

In collaboration with TKI a blue sky grant has been submitted to expand the capacity for further work in the area of vaccine responses.

Burn injury and cancer: We are collaborating with researchers in the Cancer Immunotherapy Unit at TKI to investigate the link between burn injury and cancer. We have tested and confirmed that burn injury results in increased incidence of cancer in mouse models and have sown that this increase is immune-mediated via the use of immunogenic tumour models. Our preliminary functional testing in infectious mouse models has identified two key immune cell types that may be dysfunctional after burn injury.

Laser intervention - understanding the impact and optimal timing/type of intervention: The use of laser therapy commenced in 2014 in the paediatric burns unit, in particular for hand injuries. A retrospective review in 2016/17 suggested the introduction of laser has coincided with a reduction in surgical intervention for the treated burns, which is a significant benefit for patients and the Department of Health. This review is currently being re-performed to assess the results with a further 2 years of data to assess whether this trend has been sustained and if we are managing to stretch out the times between reconstructions, which could improve the long term scar quality, appearance and Quality of Life (QoL) of our patients.

Cardiology

Contacts: Dr Deane Yim | Consultant Paediatric and Fetal Cardiologist Deane.Yim@health.wa.gov.au Cardiologist Andrew.Bullock@health.wa.gov.au

Departmental Overview

The PCH Department of Cardiology provides a unique opportunity of performing comprehensive Western Australia-wide clinical research in patients with Congenital or Acquired Heart Disease, both in a rural or metropolitan setting. The Cardiology team actively participates in clinical research, both within the unit and collaboratively with other Departments (Cardiothoracic surgery, Oncology, Intensive Care, Telethon Kids Institute). We welcome and support any trainees or staff interested in engaging in original topics or research already underway.

Current Research Projects

- Epidemiology of Congenital Heart Disease to establish fetal and postnatal trends in diagnosis and prevalence over time
- Cardiac structural and ventricular remodelling in Rheumatic Heart Disease to better understand changes that occur over time or after cardiac surgery
- Review and outcomes of cardiac surgeries, such as mitral valve repairs in Rheumatic Heart Disease or systemic to pulmonary shunts in Congenital Heart Disease (CHD)

Future Research Projects

- Cardiology teaching for the future: Virtual reality and 3D printing as adjunct educational modalities
- Cardio-Oncology studies to better define Oncology patients at risk of anthracycline toxicity
- Long term follow-up and outcomes of Kawasaki disease using Western Australian Linked Data Transforming Mental Health Outcomes in CHD

Dr Andrew Bullock | Consultant Paediatric and Adult Congenital

- An Australia-Wide Study of the Characteristics, Burden and Outcomes of Congenital Heart Disease across the Life-Course
- CHD LIFE+ family-centred care models supporting long-term neurodevelopment
- Long term follow-up of adults with severe forms of CHD using Fontan registry data
- The Congenital Heart Fitness Intervention Trial (CH-FIT) An Australia-wide trial

Child and Adolescent Mental Health Service

Contact: Dr Simon Davies | Director - Specialised Services | CAMHS

Simon.Davies@health.wa.gov.au

Departmental Overview

The type of research conducted in CAMHS ranges from basic science, translational (clinical and systems), evaluation, through to participation in multi-site investigations (locally/intrastate, interstate, and international). At present, CAMHS has 27 research projects registered on the WA Research Governance System (RGS). In addition to progressing its own research, CAMHS services and staff collaborate with TKI, CAH Community Health, PCH, local, interstate and international universities, as well as a range of other government and non-government organisations (e.g. Australian Mental Health Outcomes Classification Network, Butterfly Foundation).

Key Research Areas

- Physical and Mental Health outcomes in Gender Diverse Children
- Deliberate Self Harm and Personality Disorders
- Exercise and Physical Health
- Biological Psychiatry and Neuropsychology
- Evaluation of Treatment Programs
- Paediatric Eating Disorders
- Recovery in Children and Adolescents

Future Research Opportunities

- Mental Health and Chronic Conditions (e.g. diabetes)
- Mental Health and Digital Innovation (e.g. Application development) •
- Use of big data/registers (e.g. Helping Outline Paediatric Eating disorders, The Gender identity ٠ Longitudinal Experience (GENTLE Cohort),)
- Clinical outcomes
- Patient experience •
- Implementation

Five CAMHS teams and the CAMHS leadership/corporate team have dedicated research positions (research psychologists, research officers). CAMHS has membership on:

- CAHS Child Health Research Advisory Committee •
- Child Health Research Committee (reporting to Strategic Council) •
- CAHS Human Research Ethics Committee •

CAMHS also has a position Professor of Child & Adolescent Psychiatry who has the remit to establish and sustain a research program with particular focus into childhood trauma, in particular the intergenerational trauma of Aboriginal children, families and communities.

Child Development Service

Contact: Deborah Flynn | A/Service Co-Director, Community Health Deborah.flynn@health.wa.gov.au

Departmental Overview

The Child Development Service (CDS) is part of the Child and Adolescent Health Service. We provide free services for children in the Perth metropolitan area who are experiencing (or at risk of) developmental delays or difficulties.

We have a team of clinicians who work in different areas of child development, such as Speech Pathologists, Occupational Therapists, Physiotherapists, Social Workers, Clinical Psychologists, Paediatricians, Therapy Assistants, Audiologists and Nurses. Depending on the child's needs, they may see one or more clinicians. We provide parent information workshops, assessments, individual /group therapy, and team assessments as needed.

Consultation and communication regarding projects within CDS is provided through Discipline Managers, Team Leaders and the CDS Leadership Group. The Clinical Services Reference Group provide clinical guidance and recommendations and final decisions are made by the CDS Management Team and/or CAHS - Community Health Leadership Group.

Current Research Projects

- Autism Group AICES project with TKI (SP and CP involvement)
- Engaging vulnerable families with PhD student at Curtin Uni (data analysis of non-engagement)
- The use of online training/information modules for parents internal to CDS, funded through a PCH Foundation grant (SP)
- Learn, Engage and Play (LEaP) project a CDS Occupational Therapist PhD project
- Our Paediatricians are also involved in a number of ongoing research projects outside of CDS e.g. The ORIGINS Project, DABBED etc
- We are also keen to explore research into clinical/service outcomes, which is a key area of focus for us in the next year or two.

Child Protection Unit

Contact: Dr Allice Johnston | Paediatric Consultant Alice.Johnson@health.wa.gov.au

Departmental Overview

The PCH Child Protection Unit (CPU) is a specialised, hospital-based service providing medical, forensic, social work and therapeutic services for children and their families when there is a concern that a child has, or may have suffered from child abuse.

Our staff coordinate assessment, planning and (when appropriate) intervention strategies and ongoing therapy for children and families where there are child protection concerns.

Current and Future Projects:

- Consumer feedback (parents and children) on their experience of genito-anal examination in possible CSA cases
- Incidence and type of occult injury detected in children < 2 having skeletal surveys for possible inflicted injury

- Audit of last 5 years forensic specimens collected in cases of acute sexual assault (how often are they positive)
- Assessment of programs available in WA to manage persistent crying in babies
- Incidence and outcomes of children in WA with abusive head trauma over the last 5 years

Paediatric Critical Care

Contact: Dr Simon Erickson | Paediatric Critical Care Consultant Simon.Erickson@health.wa.gov.au

Departmental Overview

Paediatric Critical Care (PCC) at Perth Children's Hospital is a multipurpose intensive care/high dependency unit that offers a state-wide service for critically ill infants, children and young people. With the only tertiary level paediatric intensive care unit in Western Australia, PCC is a leading centre for teaching and research in paediatric intensive care medicine. In collaboration with local and international partners, PCC actively participates in world class research projects aimed at improving health care outcomes among the critically ill paediatric population.

Research Projects:

 Nitric Oxide During Cardiopulmonary Bypass: A multicentre, international trial to determine if Nitric Oxide administered during cardiopulmonary bypass reduces the inflammatory response. This study seeks to reduce complications associated with inflammation and shorten recovery time. If the use of Nitric Oxide is proven to be effective at improving outcomes, this research has the potential to change practice in heart surgery throughout the world

• **PROSpect:** The PRone and OScillation PEdiatric Clinical Trial is a multicentre, international study investigating the best way to care for children with acute and severe respiratory failure. 1000 Children worldwide will be assigned to receive one of four treatment strategies combining two forms of mechanical ventilation and two forms of positioning. The study aims to identify the strategy that is most effective at reducing the number of days children require mechanical ventilation and improving long term survival and quality of life outcomes

 KIDS THRIVE: The Trans-nasal Humidifed Rapid Insufflation Ventilatory Exchange in children requiring emergency intubation is a multicentre trial looking at developing a new method for the intubation of children in an emergency setting. KIDS THRIVE will compare current standard practice with the use of high flow nasal prong oxygen during intubation to reduce complications and increase successful first intubation attempts

• DAB: Dexamethasone and Adrenaline for infants with Bronchiolitis is a randomised controlled trial comparing the use of corticosteroids plus nebulised adrenaline with current standard practice. The study aims to determine whether this intervention can reduce the time spent requiring ventilatory support and improve other patient centred outcomes such as length of hospital stay

• BabySPICE: This pilot study evaluates the use of dexmedetomidine as the primary sedative agent for mechanically ventilated children to improve patient centred outcomes. The data from the BabySPICE pilot study will be used to determine the feasibility and safety of conducting larger scale studies in this area. As of June 2018, this project has been completed and publication is currently in preparation

 ANZPIC Registry Studies: PCC is an active member of the Australia and New Zealand Intensive Care Society Paediatric Study Group (ANZICS PSG). Through collaborative research, PCC have contributed to the high-quality collection and analysis of paediatric intensive care data within the central ANZICS Paediatric Intensive Care Registry. Focus areas have included indigenous health and specific childhood diseases such as bronchiolitis and sepsis

Emergency Medicine

Clinical Professor Meredith Borland | Director Emergency Department Meredith.Borland@health.wa.gov.au

Contacts: Sharon O'Brien | Research Coordinator Sharon.O'Brien@health.wa.gov.au

Departmental Overview

The Emergency Department currently manages over 65,000 patients per year with a wide variety of acute conditions in children from birth to 16 years. There are a number of research projects running within the ED, some solely within ED and some in collaboration with PCH inpatient teams (immunology, anaesthetics, general paediatrics, respiratory medicine, orthopaedics and oncology), TKI and multicentre studies through our involvement in the Paediatric Research in Emergency Department International Collaborative (PREDICT) network and the international Paediatric Emergency Research Network (PERN).

Current Research Projects

- PARIS 2 Paediatric Acute Respiratory Failure Intervention Study exploring use of high flow nasal flow vs standard oxygen delivery in children 1-4 years
- ToFI Toddlers fracture immobilisation management for children 1-5 years
- Bell's Palsy RCT to determine if prednisolone vs placebo improves recovery
- PEA Developing an antibiogram to guide antibiotics use in UTIs
- PERN management of community acquired pneumonia

Future Research Projects

- SONIC derivation and validation of imaging rules for children with neck injuries
- BiPED RCT on Bronchiolitis in Infants Placebo versus Epinephrine and Dexamethasone
- CHA Bronchiolitis Improvement project review of bronchiolitis management at PCH in line with the Australasian Bronchiolitis Guideline
- Multiple studies relating to ED mental health presentations, behavioural disturbance and safety planning as part of collaboration in the MRFF Million Minds grant "The kids are not OK"

Endocrinology and Diabetes

Contact: Niru Paramalingam | Endocrinology and Diabetes niru.paramalingam@health.wa.gov.au

Departmental Overview

The Endocrinology and Diabetes Department provides a multidisciplinary service to children and adolescents in Western Australia with endocrine disorders, complicated obesity, Type 1 and Type 2 diabetes, Neonatal diabetes and other types of diabetes.

The objectives of the Department of Diabetes & Endocrinology are to provide:

- A comprehensive specialist clinical service in paediatric endocrinology, complicated obesity and Type 1 and Type 2 diabetes, Neonatal diabetes and other types of diabetes
- Endocrinology investigative services for children and adolescents • Expertise and resources for initial and continuing education and support for parents and their children with diabetes, endocrinology disorders and/or severe/complicated obesity
- Education in all aspects of paediatric endocrinology, diabetes and paediatric obesity for medical students, doctors, nurses, other health professionals, teachers and community organisations

- Facilities and where possible staff and funding for research into basic scientific, clinical or epidemiological aspects of paediatric endocrinology, obesity and diabetes
- Promotion of community awareness of the specific needs of children with diabetes, endocrine disorders or obesity and participation in community projects related to these disorders

The Department has an active research programme offering opportunities for MD students, masters, honours and PhD theses. The Department has robust national and international collaborations and has been involved in the development of national and international clinical guidelines in several areas of Endocrinology and Diabetes.

The Department is a clinical centre for the Western Australian Bone Research Collaboration (Division of Paediatrics, Medical School, University of Western Australia; Institute of Health Research, University of Notre Dame/ Fremantle; Exercise Research Institute, Edith Cowan University/ Joondalup; Department of Endocrinology, Sir Charles Gardiner Hospital) and a partner in the Children's Diabetes Centre; an integrated clinical and research centre with a focus on research to improve the lives of children living with diabetes and their families.

Current Departmental Research Program

- Bone and Muscular Health in Chronic Diseases
- Evaluation of the Genetic aetiology and application of new therapeutics in Growth and Neuroendocrine ٠ Disorders
- Evaluation of Exercise interventions in improving endocrine, metabolic, bone and psychological health of **Cancer Survivors**
- Improving health and wellbeing in Prader Willi Syndrome
- Investigation of parental health and early environments on Growth and Development : Collaboration with the Origins Project and Raine Study
- Diabetes Technology Trials including trials of hybrid closed loop therapies and continuous glucose sensor performance studies
- In clinic and free living studies on the impact of exercise on blood glucose control
- Studies investigating exercise and blood glucose control including translation research studies make ٠ current clinical guidelines accessible to young people
- In clinic and free living studies on the relationship between food and insulin to maintain healthy blood glucose levels
- Aetiology and disease origin studies looking at risk factors and determinants of type 1 diabetes
- Studies aimed at improving understanding of the impact of type 1 diabetes on mental health that will lead to the development of interventions to improve the mental wellbeing of children and young people with type 1 and their families

Research Projects

Some of the key research projects are:

- Recommendations and guidelines for Vitamin D supplementation
- Impact of vitamin D on allergy development (Collaboration with the Department of Immunology at PCH)
- Characterisation of children and adolescents presenting with multiple fractures (Collaboration with the • Departments of Emergency and Orthopaedics at PCH)
- International multicentre trials on new therapeutic agents for the treatment of osteoporosis in children and adolescents
- Strategies to optimise bone health in youth for the prevention of osteoporosis later in life (Western Australian Bone Research Collaboration)
- Novel areas of medical imaging for the characterisation of bone health in youth (Western Australian Bone Research Collaboration)
- Targeted exercise modalities to optimise bone health in youth (Western Australian Bone Research Collaboration)
- Natural history of osteogenesis imperfecta in Western Australia
- Multidisciplinary model of care for children and adolescents with osteogenesis imperfecta
- International registry for patients on growth hormone (PATRO)

- Consequences of hormone therapy in individuals from the gender diversity clinic at PCH
- Database for patients with paediatric endocrine diagnoses in Western Australia
- Population based database to track patient outcomes from diagnosis to adulthood for people living with type 1 diabetes
- Randomised Controlled Trial of a hybrid closed loop system for adults and children
- Trial to improve glycaemic control for patients at risk
- Free living trial of new generation continuous glucose monitor
- Development and trial of an exercise intervention to improve mental health of young people with type 1 diabetes
- An overnight trial investigating the amount of protein required to prevent overnight hypoglycaemia following afternoon moderate intensity exercise in young adults with type 1 diabetes
- A free living study investigating whether similar patterns exist in the rise in glucose levels for a young person with diabetes and whether the pattern of glucose rise is different between people to inform recommendations to help reduce the rise in glucose levels after meals
- A longitudinal cohort study exploring widespread genetic and environmental factors through to be related to the risk of type 1 diabetes for babies born in a family with a history of type 1 diabetes
- Type1Screen: Diabetes autoantibody screening to identify individuals at risk for type 1 diabetes

Paediatric Gastroenterology, Hepatology and Nutrition

Contact: Dr Cathy Mews | Consultant Gastroenterologist Cathy.Mews@health.wa.gov.au

Departmental Overview

Department Of Paediatric Gastroenterology, Hepatology and Nutrition offers potential research opportunities. Our research philosophy is embedded in our day to day clinical care; in particular patient's perspective is central in setting our research priorities.

Our department participates and encourages research focussing on diverse gastrointestinal issues ranging from inflammatory bowel disease, non-invasive surrogate markers of chronic bowel inflammation, eosinophilic esophagitis, long term surgical outcomes of congenital gastrointestinal conditions, coeliac disease and outcomes following artificial following feeding devices. We also encourage participation of all members of multidisciplinary team including IBD specialist nurses, dietitians, gastroenterologists and colorectal surgeons.

Current Research Projects

- Reliability of symptoms and biomarkers in predicting endoscopic activity in children with Crohn's disease
- WA Biologic and Immunosuppressant Registry (WABIR) initiative to maintain long term registry and measure real life outcomes in children and adult with inflammatory bowel disease. (Collaboration with all major Adult and Paediatric hospital in Western Australia)
- Can we avoid endoscopy in children with abnormal coeliac serology an evaluation of this approach in Australian Paediatric Population
- Treating parents of children with cystic fibrosis with unresolved grief, how can we improve health outcomes? a collaboration with Respiratory Department
- Human intestinal organoids for assessing response to new CF drugs in children with Cystic fibrosis collaboration with Telethon institute

• Development and evaluation of an App for young people with type 1 diabetes to assist in exercising safely

• Predictors of refractory strictures in children with Oesophageal Atresia and Tracheo-oesophageal fistula

Department of General **Paediatrics**

Contact: Dr Andrew Martin | General Paediatric Medicine PCH.GeneralPaeds.Admin@health.wa.gov.au

Departmental Overview

The Department of General Paediatrics (DGP) is one of PCH's largest and busiest medical departments, delivering inpatient and outpatient care across many clinical areas including: general paediatrics, Aboriginal health (Koorliny Moort Aboriginal Ambulatory Care Team), refugee health, palliative care, developmental paediatrics and infant monitoring.

Current Research Areas

- Optimising febrile infant management
- Improving outcomes for vulnerable populations refugee health, Aboriginal health, juvenile justice The management of chronic diseases, including paediatric cancer surveillance and familial
- hypercholesterolemia "Choosing Wisely" recommendations

Genetic Services

Contact: Dr Nick Pachter | Clinical Geneticist and Director

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Departmental Overview

Genetic Services of Western Australia provides diagnostic and management advice to patients with or at risk of a broad range of genetic disorders. GSWA runs outpatient clinics in General and Obstetric Genetics and Familial Cancer at King Edward Memorial Hospital, Genetic Paediatric Genetics at Perth Children's Hospital and General Genetics at Joondalup and Rockingham Hospitals and Outreach Clinics at Albany, Kalgoorlie, Bunbury, Geraldton, Port Headland and Karratha.

Research Areas

- Familial cancer
- Cardiac Genetics
- Renal Genetics
- Undiagnosed Diseases Program (Paediatric and Transitional)

Haematology and Oncology

Contact: Dr Nick Gottardo | Consultant

Nick.Gottardo@health.wa.gov.au

Departmental Overview

This is the only specialized paediatric haematology, oncology and BMT department in Western Australia which diagnoses, treats and follows all children and adolescents with cancers and complex non-malignant haematological disorders. 80-90 new oncology patients are diagnosed annually with around approximately 20 inpatients at any given times. We have a large multidisciplinary team providing a comprehensive service with medical and psychosocial expertise.

We are members of a number of national and international collaborative clinical trials groups including ANZCHOG (Australian and New Zealand Childrens Haematology/Oncology Group) and Children's Oncology Group (COG) benefitting our patients from state of the art clinical trials. Our aim is to achieve a 100% cure rate and minimise complications. To achieve this, we have robust research programmes at Telethon Kids Institute and our staff have made significant contributions to the field of cancer research and treatment with many publications in peer-reviewed journals.

Some of the key research projects are:

· Pre-clinical research in association with Telethon Kids Institute

Brain Tumour Research Team

Dr Nick Gottardo is Co-Head of Brain Tumour Research Team. The team strives to improve the understanding of paediatric brain tumour biology and finding more effective treatments.

Medulloblastoma research - We established two new models of medulloblastoma using surgical samples obtained from Perth Children's Hospital. These models represent a subgroup of medulloblastoma with a poor prognosis, and allow us to test new therapies on this specific subtype. We found that treatment of mice bearing these tumor types with a drug that targets the cancer cells' ability to repair the damage caused by conventional chemotherapeutics resulted in decreased cancer cell growth and increased cancer cell death, indicating treatment efficacy. These new models established by our laboratory enable rigorous assessment of new treatments for this subgroup of medulloblastoma, allowing the identification of viable new agents for clinical trials.

The AIM-BRAIN Project - The project is Australian-first collaboration coordinated via ANZCHOG. This project will ensure that every child in Australia and New Zealand has the opportunity to rapidly access the best and most accurate diagnostic information about their brain tumour to inform their treatment pathways and optimise their chance of survival. It will also build capacity within Australasia to future-proof our ability to participate in research (including clinical trials) that stratify patients by molecular profiling.

Leukaemia and Cancer Genetics Research Team

Dr Rishi Kotecha is Co-Head of Leukaemia and Cancer Genetics Research Team. The overarching goals of the team are to understand the genetic features and mechanisms underlying different types of childhood leukaemia and to develop novel therapeutic strategies.

New preclinical models of childhood Leukaemia - Leukaemia accounts for a third of cancers diagnosed in children worldwide. Modern treatment protocols have risk-stratified patients according to genetic features of their leukaemia cells, which has significantly improved the outcome for children with leukaemia. The precise characterisation of the genetic mutations found in human leukaemia are associated with a better understanding of how leukaemia is initiated and progresses, and will ultimately open new avenues for therapeutic intervention. This project is focused on two specific aims: (i) reproduce human leukaemia in preclinical models using the genetic information gathered from primary samples. This will allow identification of key genetic factors in leukaemia development to reveal new vulnerabilities that can be therapeutically targeted; (ii) In parallel, we will continuously develop new models from human samples to assess the efficacy of thousands of new molecules targeting these key factors directly in patients` cells. These models will provide the relevant experimental tools to perform preclinical studies and facilitate rapid translation of novel efficacious therapies into the clinic.

Novel therapies for patients with high-risk infant Leukaemia - Modern therapies for children with leukaemia are curative in more than 90% patients. In contrast, event-free survival for infants less than one year of age at the time of diagnosis is less than 50%. From laboratory testing we have discovered effective novel cancer drugs, which are not currently used for treatment of babies with leukaemia. This project uses patient cells grown in the laboratory. These cells are comprehensively tested for their drug responses against hundreds

of promising novel therapeutic agents. Promising candidate drugs are further investigated to precisely determine how they work to kill the cancer cells. These agents are then tested for their potential use in patients using preclinical models we have developed onsite or through our collaborations.

Clinical Research

Phase III Clinical Trials - We participate in phase III clinical trials conducted by international collaborative groups like Children's Oncology Group and International Society of Paediatric Oncology.

Early Phase Clinical Trials - We participate in national and international Phase I & II Clinical Trials. We are in the process of establishing an Early Phase Clinical Trials Unit.

Immunology and Dermatology

Contact: Dr Michael O'Sullivan | Immunology Consultant Micheal.O'sullivan@health.wa.gov.au

Departmental Overview

The Department of Allergy, Immunology and Dermatology is engaged in a wide range of clinical and translational research projects to improve the prevention, diagnosis and management of immune and dermatological disorders. The Department has close collaborations with Telethon Kids Institute, the University of Western Australia, and other local and interstate clinical and academic centres, as well as with communitybased health professionals and consumers to broaden the reach and impact of our research activities.

Research Projects

Some of the key research projects are:

Peanut Allergy Treatment Projects (PPOIT, PEOPLE, EPITOPE): In collaboration with Telethon Kids Institute and the University of Western Australia, these projects seek to investigate the efficacy of available treatments for peanut allergy (PI Michael O'Sullivan). Current studies within this project include:

- The PPOIT study, a world-first multi-centre NHMRC funded trial (lead site Murdoch Children's Research) Institute) of a combined peanut and probiotic oral immunotherapy treatment, for which results are expect in early 2020
- The PEOPLE and EPITOPE studies, investigating a peanut patch that has been developed by DBV Technologies. We are still actively recruiting children aged 1-3 years with a peanut allergy to participate
- Upcoming research also includes the development of a consumer reference group to conduct a discreet choice experiment, which will inform priorities for future food allergy treatment trials

Antibiotic De-labelling Projects (CHAD Study, SPECIAL): Led by Michaela Lucas, these projects seek to evaluate the best approach to investigation and ultimately de-labelling of children with suspected antibiotic allergies. The majority of children labelled as antibiotic-allergic may not have a true allergy, and these unnecessary labels may lead to less-than-ideal treatment of infections and ultimately result in poorer patient outcomes. An ongoing randomised controlled trial will assess the impact of antibiotic de-labelling on patient outcomes and healthcare associated costs.

Infant feeding implementation projects: (PIPPA Project: Promoting Introduction to Prevent Peanut Allergy; SmartStart Allergy: Active real-time surveillance of food introduction): Led by Michael O'Sullivan these studies aim to promote and measure the uptake of the current infant feeding guidelines in the community for the prevention of food allergy. PIPPA will inform a novel community based clinical service for the early introduction of peanut in high risk infants. SmartStartAllergy, developed in collaboration with the creators of the SmartVax vaccine surveillance tool, is a smartphone application that delivers real-time surveillance data of food introduction and associated parent reported allergic reactions in the community. Both of these studies are still active.

Optimising diagnostic tools for food allergy (BAT Study: Basophil Activation Tests): Led by Grace Gong in collaboration with the PathWest Immunology Laboratory this study aims to investigate the efficacy of BAT testing for accurately diagnosing nut allergies, potentially avoiding the need for children to undertake oral food challenges. This study is actively recruiting participants.

Introducing electronic patient reported outcome measures (PROMs) into the dermatology clinic: Dr Stephanie Weston is leading a trial to pilot the implementation of PROMs, commonly used in clinical trials but rarely in routine practice, into the dermatology clinic with an aim to improve the efficiency and quality of care provided to children in one of PCH's busiest outpatient services.

Australian Genomics Health Alliance Genetic Immunology Flagship: This national, multi-institutional study, led at PCH by Andrew McLean-Tooke, seeks to demonstrate the benefits that flow from obtaining early genetic diagnoses for patients with primary immunodeficiencies, and to enhance our chances of resolving cases in which known disease-associated mutations are not identified.

Infectious Diseases

Contact: Dr Christopher Blyth | Infectious Diseases christopher.blyth@uwa.edu.au

Departmental Overview

The Department of Infectious Diseases seeks to create a healthier start to life for all children through the prompt management and prevention of infectious diseases. In collaboration with research partners, particularly the Wesfarmers Centre for Vaccines and Infectious Diseases at Telethon Kids Institute, the Department mission is to lead paediatric infectious disease clinical care, education and research in our city, state, country and region and ensure translation into practice and policy to improving the lives of children.

Research Projects

Some of the key research projects are:

- "Healthy Skin" Projects (e.g. SToP trial, Missing Piece project, Urban Healthy Skin Project). Led by children, explore the pathogenesis of complications including acute rheumatic fever and optimise treatment and prevention strategies for downstream complications of Group A Streptococcal and S. aureus infections
- Staphylococcus aureus Projects (e.g. ISAIAH; a prospective multicentred cohort study examining the paediatric clinical and microbiological epidemiology of S. aureus bacteraemia; CASSETTE: Clindamycin Adjunctive therapy for Severe Staphylococcus aureus Treatment Evaluation). Led by Anita Campbell and Asha Bowen, these projects seek to understand the contemporary burden of invasive S aureus infections and optimise, through multi-centred clinical trials, the management of severe S. aureus infection
- Cystic Fibrosis Projects (e.g. BEAT-CF: Bayesian Evidence Adaptive Trial to optimise management of Cystic Fibrosis; IMPACT-CF: Improving the methodology for patient-centred trials in cystic fibrosis). Led by Charlie McLeod and Tom Snelling, in collaboration with Telethon Kids Institute and the Department of Respiratory Medicine, these projects will optimising outcomes in children and adolescents with cystic fibrosis, designing patient and parent reported outcomes and using an adaptive trial methodology to optimising antimicrobial treatment)
- Bone & Joint infection Projects (e.g. WARSABI: A prospective cohort study of hospitalised children admitted to PMH/PCH with osteoarticular infections). Led by Charlie McLeod, in collaboration with Telethon Kids Institute and the Department of Orthopaedics, the project describes the contemporary epidemiology, microbiology and outcomes of children with bone and joint infections and seeks to design predictive tools that can be designed for use at the bed side

Asha Bowen, these projects seek to understand the burden and microbiology of skin disease in Aboriginal

- Fungal infection Projects (e.g. TERIFIC: The Epidemiology and Risk Factors for Invasive Fungal Infections in immunocompromised Children; Invasive fungal infection in children with haematological malignancy). Led by Daniel Yeoh, in collaboration with the Department of Haematology and Oncology, these multi-centred projects seeks to describe the epidemiology of invasive fungal infection and evaluate diagnostic, prevention and treatment pathways for children with or at risk of invasive fungal infection
- Pneumonia and Acute Respiratory Infection Projects (e.g. PATRIC: Pragmatic Adaptive Trial for Respiratory Infection in Childhood; PneumoBNA: Using Bayesian network models to facilitate a microbiological diagnosis in childhood pneumonia; PNG-Aetiology & PneuCAPTIVE: Prospective pneumonia cohort studies in the PNG highlands). Led by Chris Blyth and in collaboration with Telethon Kids Institute, Departments of General Paediatrics and PCH Emergency Department and Papua New Guinea Institute of Medical Research, these studies seek to optimise the diagnosis, management and prevention of children with acute respiratory infection both in Australia and internationally. Specifically, they seek to test varying management strategies using a registry and platform trial, use Bayesian networks to optimising pneumonia diagnostics and evaluate both pneumococcal and influenza vaccination programs in Australia and PNG
- Influenza Projects (e.g. PAEDS-FluCAN; P3FluKids). Led by Chris Blyth, in collaboration with Telethon Kids Institute and paediatric hospitals Australia wide, these studies provide real-time influenza surveillance data to public health authorities during the influenza season. In addition, data are used to assess compliance with antiviral and immunisation recommendation and assess the direct and indirect benefits of influenza vaccination. P3FluKids is a multimodal strategy which will be used to improve and assess influenza vaccination coverage in those at greatest risk of disease
- Rheumatic Heart Disease and Group A Streptococcal Projects: Led by Jonathan Carapetis, the Telethon Kids Institute RHD and Strep A team is conducting research to optimise the diagnosis, prevention and management of rheumatic heart disease, and lead the enduring challenge of developing an effective Strep A vaccine (through leadership of ASAVI - the Australian Strep A Vaccine Initiative), with the objective of eliminating RHD in Australia and controlling RHD and Strep A diseases globally
- Human Vaccines Project: Led by Tobi Kollman and collaborators at Telethon Kids Institute and numerous other institutions globally, the HPV project seeks to leverage cutting-edge technologies to decode the human immune system, thereby unlocking new preventions, diagnostics, and treatments for many of the globes most important infectious diseases
- Additional Infectious Diseases and Immunisation Research Projects: Numerous other research and guality assurance projects are being conducted by staff from the Department of Infectious Diseases and Stan Perron Immunisation Centre

For those interested in infectious diseases research, please visit the following site https://infectiousdiseases.telethonkids.org.au/

Kids Rehab WA

Contact: Dr Caroline Alexander | Research Manager research.kidsrehabwa@health.wa.gov.au

Departmental Overview

Kids Rehab WA is a state-wide, integrated tertiary clinical, research, education and training unit. Kids Rehab WA delivers inter-disciplinary services to children and adolescents in Western Australia with acquired or congenital neurological impairments, with links to satellite secondary units throughout the state. We offer research informed and infused services to children and youth with acquired or congenital neurological impairments, to improve functional outcomes, which are unique to this state. Our research areas include the development of screening and early detection tools, validation of new assessments and the development and assessment of new interventions. Kids Rehab WA is also happy to support trainees with college projects. Integral to our research is the involvement of consumers, who are represented by the Kids Rehab

WA Consumer Steering group. The group has regular meetings and are an important voice in the planning, implementation and dissemination of the research findings. Along with publication in top ranking academic journals, and presenting at national and international conferences, knowledge translation is achieved through training and education within the department, to the wider hospital and external service providers to ensure all children and youth are given the opportunity to improve functional outcomes, and unlock their potential, with the latest evidence based medicine and services.

Current Research Projects

Early Intervention research

A number of multi-site projects are currently underway and actively recruiting in the area of early intervention for young children and infants who have, or are at risk of developing, cerebral palsy.

Clinical program specific research

Nested within the different clinical programs are a range of research projects including assessment of long term outcomes of botulinum toxin use in children with cerebral palsy, and outcomes for children with acquired brain injury, among others.

Participate CP

The Participate CP project explores the effect of 12 weeks of individualised home therapy, focusing on goals identified by the child, on participation in physical activity goals. Recruitment for this project has started and the first participants are currently receiving therapy.

- Discovering the Sense of Touch The Sense project is interested in understanding the effect of 6 weeks of intensive sensation training on functional sensation for children and adolescents with cerebral palsy. This randomised controlled trial is actively recruiting.
- Early Moves

Looking to identify very early biomarkers for cognitive impairment, the study will see 3000 babies recruited through the large scale ORIGINS project (Joondalup Health Campus/Telethon Kids Institute), with assessments including the General Movements assessments and Bayley Scales of Toddler and Infant development.

Neonatology

Contact: Prof Karen Simmer | Co-Director NHMRC Centre of Research Excellence for Preterm Infants |Director Neonatal Intensive Care Units Karen.Simmer@health.wa.gov.au

Departmental Overview

The Neonatal Division is comprised of the Neonatal ICU at PCH (30 beds), the Neonatal ICU at KEMH (100 beds), the Newborn Emergency Transport Service WA (NETS WA) the Human Milk Bank and the Centre for Neonatal Research and Education. Neonatal research is managed under 4 major screams.

Key Research Areas and Projects

Nutrition, Development and Gut Health

- Probiotics for preterm infants and for surgical patients (Pro-Para trial, PRINS trial)
- Parenteral nutrition for preterm and term infants
- Breastfeeding, lactation and human milk processing
- infants with erythropoietin (PAEAN trial, NHMRC-funded, coordinated by Sydney University)
- developmental follow up of surgical infants to two years of age
- Screening for retinopathy of prematurity to prevent blindness (RETCAM)

 Improving disability-free survival or preterm infants by establishing a circadian rhythm (CIRCADIEM trial) Improving developmental outcomes after hypoxic ischaemic encephalopathy in late-preterm and term Long-term developmental follow-up of very preterm infants to school age and to young adulthood, and

Infection and Inflammation

- Improving disability-free survival of extremely preterm infants with anti-inflammatory agent as an adjunct to antibiotics for late-onset sepsis and necrotising enterocolitis (PROTECT trial, NHMRC-funded)
- Prediction, prevention and management of late-onset sepsis in very preterm infants
- Topical coconut oil to improve skin integrity and prevent LOS in preterm infants (COSI 1 and COSI 2 trials)

Respiratory medicine

- Vitamin A supplementation of extremely preterm infants to reduce the severity of bronchopulmonary dvsplasia (BPD) (EVARO trial)
- Cuffed v un-cuffed endotracheal tubes for ventilation of neonates
- Lung ultrasound in the management of preterm respiratory disease
- Preclinical studies of ventilation, antenatal steroids and stem cells to prevent BPD
- PLUSS (steroid and surfactant v surfactant to prevent BPD, NHMRC-funded, co-ordinated by Murdoch Children's Research Institute (MCRI)

Neonatal transition

- POLAR (dynamic PEEP v Standard PEEP for resuscitation of very preterm infants to prevent BPD, NHMRC-funded, co-ordinated by MCRI
- Physiological clamping of the umbilical cord (in collaboration with Monash University)

Nephrology and Hypertension

Contact: Dr Nick Larkins | Paediatric Nephrologist

nicholas.larkins@uwa.edu.au

Departmental Overview

The Department of Nephrology and Hypertension has a strong research history based on collaboration with other Australian and international sites. We are engaged in clinical research, with a focus on epidemiology, including strong links with the ANZDATA registry and Cochrane Kidney and Transplant. We recognise the role of randomised trials in improving patient care and access to novel therapies, and are working with collaborators to develop new trials through the Australasian Kidney Trials Network.

Current Research Projects

- Australia and New Zealand Dialysis and Transplant Registry (ANZDATA): the department are active contributors to ANZDATA and are engaged in multiple projects using this world-class resource to improve patient outcomes
- Improve immuNologiCal assessment to improve PaediaTric kidney transplantION outcomes (INCEPTION) study): a multi-centre study of immune response following kidney transplantation and how different levels of donor-recipient matching influences antibody formation
- Transition Outcomes: we are reviewing the outcomes of our recently established transition clinic involving PCH and SCGH staff. These data will inform ongoing quality improvement, which aims improve patient outcomes through the delivery of holistic care
- Thresholds for defining hypertension in Australian children: we are collaborating with University of Western Australia researchers to investigate how newly proposed international blood pressure thresholds relate to Australian children. Ultimately, we aim to inform the development of blood pressure guidelines designed specifically for Australian children

Department of Neurology and Neurosurgery

Contact: Prof Lakshmi Nagarajan | Paediatric Neurologist/ Epileptologist Lakshmi.Nagarajan@health.wa.gov.au

Departmental Overview

The Children's Neuroscience Service has a research program that spans a wide spectrum of neurological disorders. Areas of active research are Epilepsy (investigation and treatment), Non Invasive Brain stimulation, Neonatal Neurology, Neurophysiology, Neurogenetics, Neuromuscular and Neurometabolic Disorders.

Members of the department are recipients of several research grants. We are currently running several clinical trials and research studies. We have collaborative projects with other departments at Perth Children's Hospital, Telethon Kids Research Institute, other Universities in Australia and internationally. We have a highly productive research program with several peer reviewed publications each year. We present our research in national and international conferences and have been Invited and Plenary speakers at these meetings. Members of our staff are on scientific and advisory committees in the hospital and professional organizations and societies.

Current Research Projects

- Epileptic Encephalopathy with Status Epilepticus in Sleep (Led by Shah and Nagarajan)
- NS Pharma NS-065/NCNP-01-301 study: A Phase 3 Randomized, Double-blind, Placebo-controlled, Multi-center Study to Assess the Efficacy and Safety of Viltolarsen in Ambulant Boys with Duchenne Muscular Dystrophy (DMD) (Led by M.Kava)
- Using wearable technology to support health and wellbeing in young people with Duchenne muscular dystrophy (Led by Downs et al and M.Kava)
- Active Implementation of Australian Consensus Guidelines for the Effective Delivery of Clinical Services to Patients with Mitochondrial Disorders-collaborative project (Project Member M. Kava)
- Taurine as a therapy for Duchenne Muscular Dystrophy (DMD), and Becker Muscular Dystrophy (BMD) (Led by Arthur and Kava)
- The characterisation of Three Dimensional facial profiles of Children with Syndromes (Led by Baynam et al ;Project member M. Kava)
- Transcranial Magnetic Stimulation in children with Benign Focal Epilepsy of Childhood + BFEC spectrum (Led by Ghosh)
- Transcranial Direct current Stimulation tDCS for Children and Adolescents with Refractory Epilepsy (Led by Nagarajan and Ghosh)
- Understanding Brain maturation in premature babies: Use of standard V-EEG to study electrical activity of the brain and neonatal seizures and predict neurodevelopmental outcome (Led by Nagarajan)
- VEEG vs aEEG study in Neonates (Led by Nagarajan, Ghosh, Palumbo and Neonatology Dept.)
- Intra-operative Neurophysiology Monitoring INM (Led by Ghosh and Nagarajan)
- Neonatal Neurophysiology and Neurology (Led by Nagarajan)
- A multi-centre international open label extension study to investigate safety and efficacy of Lacosamide as adjuvant therapy in Paediatric subjects with partial onset seizures (Led by Nagarajan) New Onset Seizure Clinic (Led by Nagarajan)
- Comprehensive Outcomes Registry in Patients with refractory epilepsy treated with Vagal Nerve Stimulation Therapy (Led by Nagarajan)
- IVIG therapy in children with Refractory Epilepsy (Led by Nagarajan)
- Gastrostomy and Neurodevelopmental Disability (Led by Downs....and Nagarajan (TKI))

PCH Nursing Research

Contact: Prof Evalotte Mörelius | Nursing Research

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Departmental Overview

Our nursing research team lead projects focused on improving the experience and outcomes for children and their families in hospital and community health care. Our research spring from three main streams, examples of ongoing studies are shown below. We also offer opportunities for new researchers to be involved including opportunities to pursue higher degree research.

Stress Research

- Parents stress when the child is sick
- Parents sleep when the child is sick

Acute Care

- Unifying systems for recognising and responding to paediatric clinical deterioration
- Evaluation of the move to the new children's hospital
- Paediatric palliative care
- Implementing knowledge into practice

Community Health

- Integrated service hubs for families in the community
- School aged psychosocial assessment tools
- Community health workforce development

Team Projects

- Priority setting
- Needs of Children's Questionnaire
- Parents experiences of care
- · Building capacity for patients and families to participate in research

Otolaryngology Head and Neck Surgery (ENT)

Contact: Dr Shyan Vijayasekaran | Clinical Associate Professor | **Otolaryngology Head and Neck Surgery**

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Departmental Overview

The Otolaryngology department is heavily involved in research to improve our understanding of ear nose and throat disorders but also to help guide and direct future treatments. The department collaborates widely with other teams in the hospital such as audiology, speech pathology, anaesthesia, respiratory medicine, immunology and is also involved in bench top research in collaboration with researchers at the Telethon Kids Institute.

Key Research Areas and Projects

- Outcomes of airway surgical procedure (such as tongue base surgery for sleep apnoea and laryngotracheal reconstruction for glottic and subglottic stenosis)
- Immunology, microbiology and genetic causes of otitis media and adenotonsillar hypertrophy and novel therapeutic option for the same
- ATOMIC Ears: A Phase IIB randomised controlled trial to assess safety, tolerability and acceptability of a 5-day Dornase alfa treatment as an adjunct therapy to ventilation tube insertion for otitis media in children
- Development of novel medication delivery options for the middle ear

Tonsillectomy safety studies

- The Obstructive Sleep Apnoea study: making Tonsillectomies Safer (OSATS) Enhancing Management of Perioperative High risk patients through Assessment of oxygen Saturation
- and Sleep quality (EMPHASIS) SNAKES: a pilot trial of Jelly Snakes to prevent postoperative Nausea and Vomiting in Kids after ENT Surgerv
- Tranexamic acid in post- tonsillar haemorrhage

Ear and hearing studies

- An international multi-center study of isoelectric EEG events in infants and young children during anaesthesia for surgery.
- Cockburn Ear Portal: An ENT and Audiology referral portal for improving access to ear health services for Aboriginal children in metropolitan areas using telehealth
- PCH Ear Portal: An urban-based ENT and Audiology referral telehealth portal to provide equitable access to specialist ear health services for children.

Global Tracheostomy Collaborative.

Refugee Health Service

Contact: Dr Sarah Cherian |General Paediatrician and Clinical Lead Refugee **Health Service**

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Departmental Overview

The PCH Refugee Health Service (RHS) coordinates and manages the complex care needs of recently resettled refugee and asylum seeker children and adolescents up to 16 years of age. Our specialist multidisciplinary medical, nursing, social work, dietetic, dental, mental health and school liaison staff offer a holistic service to meet the needs of refugee children, adolescents and their families. The CAHS RHS integration project is also underway with an aim to improving the journey of refugee families across CAHS.

The PCH RHS is committed to culturally appropriate and trauma-informed clinical research and quality assurance projects. Current studies aim to improve patient care, identify gaps in current clinical knowledge and provide an evidence base to inform state and national refugee health policy and practice. Collaborative gualitative and guantitative research studies are undertaken RHS in collaboration with other PCH departments, Division of Paediatrics and Child Health (UWA) and/or other groups (e.g. Oral Health Centre of Western Australia, Telethon Kids Institute. Professional interpreters are utilised to ensure that families with limited English proficiency are able to participate in clinical research.

Research Projects

Ethical approval is obtained through the Child and Adolescent Health Service (CAHS) Human Research Ethics Committee and/or other relevant Human Ethics boards. Awareness of the issues surrounding

appropriate informed consent (especially in low literacy and/or traumatised populations) is an important consideration in this cohort.

Consumer participatory research as well as qualitative research has been undertaken by the RHS, with results contributing to the national refugee health evidence base and treatment frameworks. The PCH RHS is also part of the Australian Paediatric Refugee Health Network. Please contact the RHS Clinical Lead if you are interested in undertaking research, quality assurance or collaborating with the RHS.

Current Research Projects

- Audit of Middle Eastern families resettled through the PMH/PCH RHS (Led by Lindsay K)
- Identifying barriers to the management of Type 1 Diabetes in non-Caucasian families (Led by Abraham M)
- Use of SDF application to arrest dental caries in paediatric refugees a conservative approach (Led by Patel J)
- Exploring the impact of interpreters on health care needs of refugee children and families with limited English proficiency (LEP) in a Western Australian paediatric hospital setting (Led by Cherian S)
- Oral health delivery to refugee children in WA perspective of health stakeholders (Led by Slack-Smith L)
- Evaluation of the impact of migration and culturally linguistically diverse backgrounds on developmental and behavioural conditions (Led by Abduhllahi I)
- RHS database analyses (Led by Mutch R)
- Evaluation of national paediatric refugee health services (Led by Gunasakera H).

Future Research Projects

- Assessing readiness of transition of RHS patients into mainstream health pathways using standardised RHS transition assessment proformas
- Adverse Childhood Experiences in refugee families
- Longitudinal health outcomes of RHS families
- Audit of refugees with complex health and/or disability and access to mainstream services, adult transition and NDIS
- Role of improving interpreter use (QI/SI project)
- Development of community outreach clinics for adolescent refugees.

Respiratory and Sleep Medicine

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Departmental Overview

The Department of Respiratory and Sleep Medicine provides full diagnostic evaluation and management for inpatients and outpatients being investigated or requiring management of respiratory or sleep conditions. The service consists of Respiratory Medicine, the Sleep Service and the Respiratory Function Laboratory.

In collaboration with the Telethon Kids Institute, the Department is actively involved in research conducting studies under 6 major streams.

Key Research Areas and Projects

Cystic Fibrosis: Led by Prof Steve Stick and Dr André Schultz in collaboration with Telethon Kids Institute Clinical research is embedded within our multidisciplinary CF service, key projects include: AREST CF, a Longitudinal cohort study investigating the early determinants of lung disease in children and adolescents with cystic fibrosis, this large study also comprises of research platform to study disease mechanisms and develop novel treatments; BEAT CF, in collaboration with Prof. Tom Snelling, a Bayesian Evidence informed

multicentre Adaptive Platform Trial for studying exacerbations of Cystic Fibrosis; and COMBAT CF, the first ever randomised clinical trial aiming to slow the progression of lung disease in CF.

Further areas of research focus include improving outcomes of children with cystic fibrosis by identifying and treating parents with unresolved grief associated with their child's diagnosis and the characterization of the early cystic fibrosis airway surface micro-environment in order to develop strategies for the delay of disease onset.

Asthma / Wheeze / Respiratory Tract Infection: Led by Prof. Peter Le Souëf, Dr Ingrid Laing and Dr André Schultz in collaboration with Telethon Kids Institute, and Prof Mark Everard in collaboration with the University of Western Australia.

Key Asthma studies include the Perth Infant Asthma Follow-up study, a 30 year follow-up of a birth cohort started in 1988 scheduled for 2020; Mechanisms of Acute Viral Respiratory Infection in Children (MAVRIC study), an investigative platform providing specimens for several studies investigating mechanisms of respiratory infection, inflammation and immunity in young children with acute respiratory problems and POWER a multi-centre, multi-disciplinary study using a systems biology approach to investigate immunomodulation in children with acute wheeze. In addition the MAP study is developing metabolomics profiles to differentiate between healthy, preschool wheeze and asthma, aiming to develop new diagnostic processes.

Prof Mark Everard has a research programme in aerosol therapy working with A/Prof Sunalene Devadason head of Aerosol Research Group. Current focus is on strategies that promote both regimen and device compliance and exploring novel approaches to improving pulmonary drug delivery in moderate to severe pulmonary disease. He is investigating persistent bacterial bronchitis addressing mechanisms of bacterial persistence, the impact of poly microbial infections, development of biofilm disruptors, prevalence, developing phenomics diagnostic tests and optimising treatment with a view to ensuring a cure and preventing the development of the radiological sign of bronchiectasis which in most cases represents a marker of inadequate care.

Aboriginal Lung Health: Led by Dr André Schultz in collaboration with Telethon Kids Institute

Preventing permanent lung damage through improving the recognition and management of chronic wet cough in young Aboriginal children parents and health care professionals.

Aboriginal Children deserve Excellent Lung Health (ACE Lung Health) study: Ensuring the delivery of culturally appropriate lung health information for families to ensure timely follow-up of children admitted to hospital with chest infections.

Neuromuscular Disorders: Led by Dr Andrew Wilson in collaboration with Telethon Kids Institute, Curtin University and Muscular Dystrophy WA.

These studies are aiming to develop better methods for predicting respiratory illness in individuals with neuromuscular disease, and to reduce the burden of these investigations.

Long term Respiratory Outcomes of Preterm Birth: Led by Dr Andrew Wilson in collaboration with Telethon Kids Institute (Prof. Graham Hall and Dr Shannon Simpson).

Studies include the WA Lung Health in Prematurity cohort (WALHIP), a longitudinal cohort now following up young adults with a history of preterm birth and PICSI a clinical trial investigating the role of inhaled corticosteroids in the management of respiratory symptoms in school aged children with a history of preterm birth.

Respiratory illness in cerebral palsy: Led by Dr Andrew Wilson in collaboration with Dr Katy Langdon (Dept. of Paediatric Rehabilitation), and The Ability Centre.

These studies have described the risk factors for respiratory illness in cerebral palsy. We are currently developing a risk prediction model for respiratory hospitalisation, and in 2020 will launch a pilot randomised controlled trial aiming to prevent respiratory illness in individuals with cerebral palsy.





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This brochure is part of a project to increase involvement in child health research at CAHS. The processes and details relating to a future research database may change if or when implemented across CAHS.