

The Raelene Boyle Outreach Program

Impact Report 2021



Executive Summary

The Children's Hospital Foundation and Queensland Children's Hospital are deeply grateful to Sporting Chance Cancer Foundation for the ongoing partnership and commitment to deliver the Raelene Boyle Outreach Program.

Since 2017, this critical service has supported almost 1,000 children with cancer by reducing time spent in hospital and helping regional kids return home, even whilst undergoing treatment. This program continues to deliver crucial in-home care and clinical support to kids with cancer, and their families, even as families navigate the new norm of ongoing challenges and disruption to everyday life because of the COVID pandemic.

This report has been prepared by Tracy Till (Clinical Nurse Consultant, Children's Health QLD Hospital and Health Service) and Stacy Turner (Philanthropy Manager, Children's Hospital Foundation) to outline the impact and outcomes of the Raelene Boyle Outreach Program, delivered at Queensland Children's Hospital and to children with cancer throughout Queensland in 2021.

The Raelene Boyle Outreach Program

Every year, over 750 children under 14, across Australia, are diagnosed with cancer. The Australian Institute for Health and Wellbeing has estimated this number will increase to 870 children receiving a new cancer diagnosis every year (AIHW, Cancer Data in Australia, 2020).

Every week, three children will die from this disease; a disease which does not discriminate. For families living in regional and remote areas, travelling to Brisbane for treatments, check-ups and consultations can create enormous emotional and financial strain. The uncertainty and impact of a new schedule revolving around medical appointments and treatment can mean extended periods without being able to see other family members or friends. Many families have shared stories of the difficulties and pressure to maintain consistent employment or operate family-owned businesses because of the need to be at the hospital to support their child.

The Raelene Boyle Outreach Program commenced in 2016 at the Queensland Children's Hospital, South Brisbane, to fund a Clinical Nurse Consultant who has played a critical role in easing the enormous burden for Queensland families supporting a child with cancer and working to keep kids at home while undergoing cancer treatment. The Raelene Boyle Oncology Outreach clinical nurse works to identify and transition eligible families to the Hospital in the Home program. This program allows children and young people to continue their treatment from their local hospital and health service while maintaining quality of care.

Thanks to the **Sporting Chance Cancer Foundation**, Queensland children are receiving the best possible cancer treatment even after they return home and with the support of the Outreach Clinical Nurse.

Program Changes in 2021

In November 2021 the Queensland Children's Hospital and the Children's Hospital Foundation farewelled our pioneer Clinical Nurse Consultant, Rebekah Orford (or Nurse Bek as many people knew her). Nurse Bek has left an incredible legacy as the Outreach Nurse, delivering consistent and responsive care, guidance and education to regional and remote families caring for a child with cancer at home, since 2017.

Nurse Bek has made an incredible impact on the lives of the many families that have received support through the Raelene Boyle Outreach Program and created a strong structure and network to ensure this critical work continues to support the needs of children with cancer and their families.

Upon Nurse Bek's departure, registered nurse Tracy Till was appointed temporarily to the Outreach Clinical Nurse role to continue delivering services through the Raelene Boyle Outreach Program whilst formal recruitment of a permanent Clinical Nurse Consultant has been undertaken. Tracy has extensive experience in paediatric oncology and has worked with children with cancer and their families for many years.

"My favourite aspect of this job, so far, is working with families to help them care for their child at home. It is so rewarding. You can see the positive impact being at home has on the children and their families." Tracy Till.

Through the Raelene Boyle Outreach Program, the Queensland Children's Hospital have supported regional children and their families transition to the home through connection to their closest regional hospital and local health care team. The outreach nurse provides direct care and support for regional and remote families through:

- Meeting with and guiding families to help transition them into the *Hospital in the Home* program and assisting both the family and the community to ensure children are comfortably receiving treatment at home for as long as possible.
- Providing education and awareness to families on:
 - Administering medication, line and dressing management.
 - Identifying which symptoms to look out for, and when to contact her or their local hospital.
- Working directly with regional hospitals to ensure they have the supplies and expertise to support the patient in the community.
- Visiting schools and childcare centres to provide kids with simple ways they can care for and look out for their friends.
- Conducting home visits to children in palliative care, providing the care required to maintain their comfort.

Program Overview for 2021

278

278 children received a new cancer diagnosis in 2021 and were supported by the Raelene Boyle Outreach Program.

36

36 education sessions were conducted for parents to administer medications and manage central lines and nasal gastric tubes. There was a significant reduction in the number of sessions delivered, due to ongoing impacts of COVID-19 restrictions.

67

67 'virtual' sessions were delivered to regional Queensland schools and childcare centres in 2021. These sessions were delivered via phone, and video conference to provide kids with strategies and ideas to support their friend and answer any questions.

100

Over **100 support calls** were received from parents, caregivers, and health professionals across Queensland, including questions about chemotherapy treatments, blood counts and possible infections, as well as ongoing questions about COVID-19, travel restrictions and requirements to QCH in Brisbane.

50

Over **50 requests for consumables** were fulfilled for items including dressings, syringes, medications for regional families to reduce the necessity for parents to travel to the nearest hospital to collect.

With greater ability to travel regionally due to the lifting of COVID restrictions intermittently throughout the year, Nurse Bek was able to visit several regional and rural communities including Charters Towers, Townsville, and Mackay. In Charters Towers, Nurse Bek worked with several stakeholders to support a young oncology patient in palliative care. This included staff at Charters Towers Hospital and Townsville University Hospital, the patient's GP clinic, school and BlueCare (community nursing group) to facilitate and ensure care arrangements were made to support the end-of-life care needs of the patient and their family.

In March 2021, Nurse Bek travelled to Mackay Base Hospital and delivered a full day educational program on Paediatric Oncology and Palliative Care to 21 nurses, medical students, and allied health staff.

Sadly, we farewelled **29 brave kids** with cancer in 2021 - all of whom were supported by the Raelene Boyle Outreach Program.

Program Impact



FIGURE 1: LOCATION OF ALL CHILDREN SUPPORTED BY THE RAELENE BOYLE OUTREACH PROGRAM IN 2021

Children supported by the Raelene Boyle Outreach Program come from all over Queensland and Northern New South Wales, as well as interstate locations including the Northern Territory, Victoria and Tasmania (Figure 1). Of the 278 children supported by the Raelene Boyle Outreach Program during 2020, 174 were from regional and rural areas and 104 patients lived within the Greater Brisbane region.

The Sporting Chance Oncology Outreach Nurse continues to work closely with the ten Regional Case Managers working throughout the state to support their local patients. These Case Managers are typically nurses, who help administer complex medication regimens or organise local appointments for patients in their area. Collectively, in 2021, the Regional Case Managers, four Clinical Nurse Consultants based in Brisbane, and the Raelene Boyle Outreach nurse supported more than 400 Queensland kids with cancer – this included active patients undergoing treatment, and those in remission and at risk of relapsing.

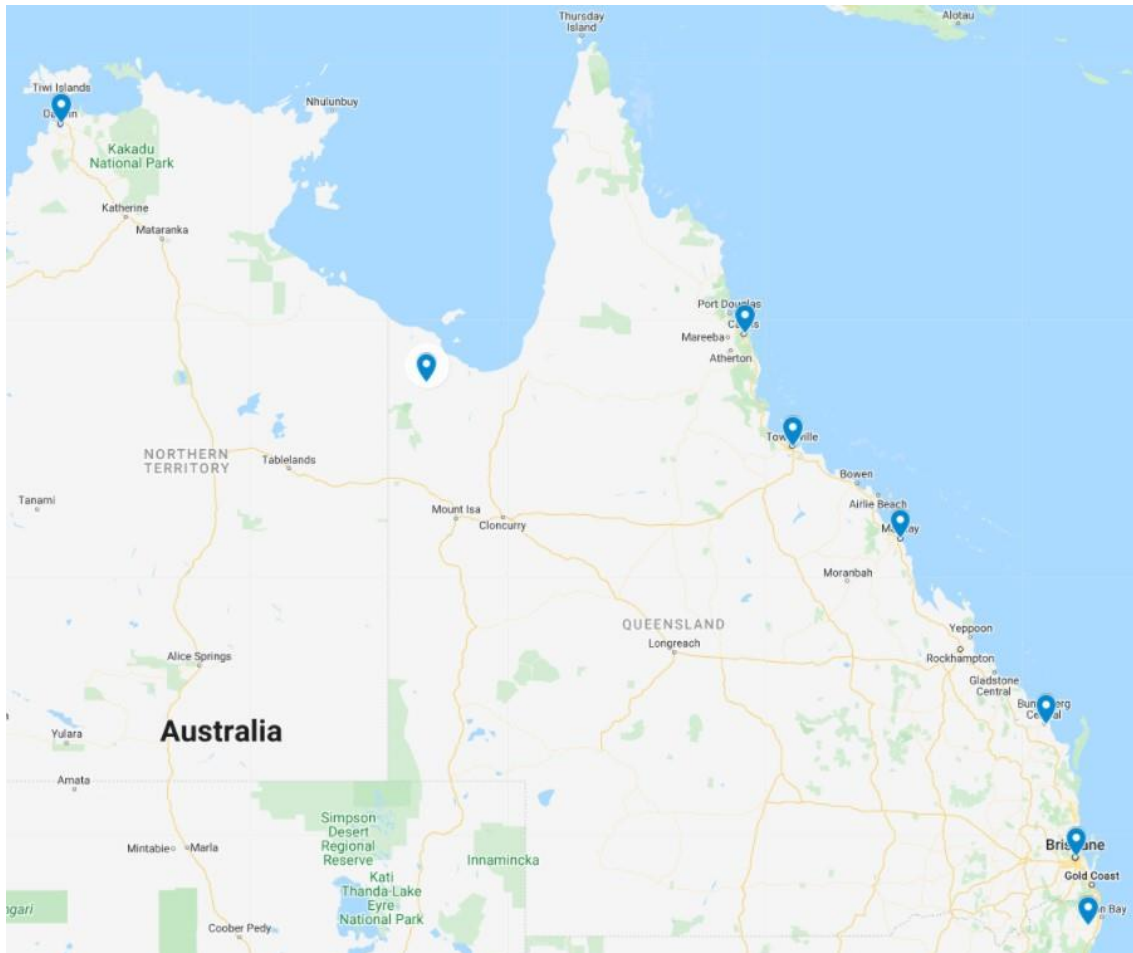


FIGURE 2: LOCATION OF FIRST NATIONS CHILDREN SUPPORTED BY THE RAELENE BOYLE OUTREACH PROGRAM IN 2021

Thirteen (13) First Nations children were supported by the Raelene Boyle Outreach Program, some of whom were also receiving palliative care. These children were from communities in

- Doomadgee
- Northern Territory
- Cairns
- Townsville
- Mackay
- Bundaberg
- Brisbane and Lismore.

Luca's Story

In January 2021, 10-year-old Luca was diagnosed with Grade 4 medulloblastoma. Luca had fallen from his mountain bike and suffered a concussion which resulted in his mum Sarah taking him to Lismore Base Hospital Emergency Department. It was during assessment of his concussion that Luca's brain tumour was discovered. Within moments of being diagnosed Luca and his family were airlifted by helicopter from Lismore Base Hospital to Queensland Children's Hospital, Brisbane for immediate surgery to relieve pressure on his brain.

"We were in such a daze with everything [happening so quickly]; within a week our son was a completely different kid, and we were facing the difficult choices we had to make to save his life." **Sarah, Luca's Mum**

Luca has undergone numerous surgeries and procedures since his diagnosis, in addition to six weeks of radiation and seven cycles of chemotherapy, totaling over 40 weeks of treatment. Luca's first surgical procedure involved placing an external ventricular drainage (EVD) point into his brain in preparation for brain surgery. The surgery to remove the tumour attached to his brain stem, took over 8 hours. He underwent further surgery to place a ventricular to peritoneal (VP) shunt in the side of his head to drain excess fluid from his brain and regulate the pressure in his head.

Luca's family were required to relocate to Brisbane during his treatment and simply having the opportunity to stay in their accommodation and administer hydration meant a great deal to Luca and his family.

"Being able to spend his time hooked up to hydration at home rather than in a hospital bed is a gift we are forever grateful for. As a child with cancer, these guys spend more time as an inpatient than most adults do in their whole life, so for a program like this to allow them more time out of hospital is a relief to us as parents, whilst we juggle siblings and life. This program should be made an integral part of children's treatment plans, not only for the family's relief, but it also provides more beds for those that need it." **Sarah, Luca's Mum**

After his brain surgery Luca was unable to talk, walk or feed himself and required a wheelchair to move independently. His recovery has been slow, but Luca is now able to get around his house without a wheelchair, although he does require it when going outside. Thanks to rehabilitation he can now grasp things using his left hand and other motor skill functions are gradually improving.

Everyday life for Luca and his family has been irrevocably changed. Once a completely self-sufficient pre-teen, Luca now requires help and assistance to complete what we deem as basic, everyday tasks. The journey will be long and challenging but for Luca and his family they are happy to be home and settling in to their new normal and a life they never ever thought they would be living.



Program Achievements

In 2017, at the commencement of The Raelene Boyle Outreach Program several key objectives were established to measure impact on the children and families. We are pleased to report these objectives continue to be achieved on an annual basis.

Objective	Completed?
Facilitate 40 + children per year returning to home to continue their oncology treatments through the support of regional case managers.	Achieved. More than 75 patients were supported between January 2021 – January 2022. This includes new patients and existing patients who presented as ready for transition to home.
Conduct regular school and home visits.	Achieved. The oncology outreach nurses provided 'virtual' sessions and information to 67 schools, kindergartens, and day-care centres for Hospital in the Home. These sessions were delivered via phone and video conference. The outreach nurse also assisted three students with their ATAR paperwork and collating medical reports.
Develop and implement a program for intravenous fluids (IV) and specific drugs to be administered by CADD-Solis® Portable Medication Pumps within the child's home.	Achieved. Eight (8) families were trained in the use of CADD pumps. With this knowledge these families have been able to provide their children with the care needed to stay home after chemo, avoiding hospital stays between 24 – 48 hours to receive IV fluids. This has alleviated the equivalent of 52 nights in hospital and significantly improved health and wellbeing of children and families.
Develop and implement a teaching package for central venous line (CVL) care for parents to reduce the incidence of central line infections in children and the number of avoidable hospitalisations.	Achieved. CVL management can be complex. The Clinical Nurse individually identifies families who are deemed competent to complete this training and administer the necessary management. In 2021, two (2) families received training to provide CVL care at home, resulting in less distress for the child and freedom to provide care when convenient for patient and family. Increasing the number of families trained in CVL management is a key focus of this program in 2022.

Peachy's Story

In September 2021, Peachy's mum, Brooke received the news that her beautiful, daughter, at almost two years old, had Ewing's Sarcoma after a large tumour was discovered on her spine. Sadly, Brooke and her family are devastatingly all too familiar with the fear and uncertainty that cancer brings, having lost Peachy's beloved father Joel, to a brain tumour just 18 months prior.

Brooke and Peachy live in the Byron Shire, NSW, and during the height of the COVID pandemic and restrictions were granted an exemption to cross the Queensland border for admission to Queensland Children's Hospital for immediate treatment.

Peachy celebrated her 2nd birthday in October 2021 at Queensland Children's Hospital whilst undergoing treatment for her cancer. Understandably she suffers a great deal of stress and anxiety in hospital which has made her and her mum's journey so difficult.

Over the course of six months Peachy has endured 16 cycles of chemotherapy, two surgeries and all that comes in between, and the family are only half-way through their journey.

Thanks to the Raelene Boyle Outreach Program, Peachy and Brooke have been able to return home between some of the chemotherapy cycles to receive care and support from both Nurse Bek and Nurse Tracy in delivering Hospital in the Home (HITH) services and care.

"I honestly wish we could do this (HITH) every single cycle. Both Nurse Bek and Nurse Tracy make myself and Peachy feel at ease when doing the procedures at home. They are friendly, professional, and warm. Each visit has been so needed as it reduces our hospital stays." **Brooke, Peachy's Mum**



THANK YOU FOR YOUR INVESTMENT

It goes without saying that 2021 was a year unlike any other, presenting challenges and disruption to the lives of children with cancer and their families. Restrictions and impacts of the COVID pandemic continued to create issues for the delivery of specific services and the provision of outreach care for children with cancer. Through the Raelene Boyle Outreach Program, Children's Hospital Foundation and Queensland Children's Hospital have continued to help hundreds of children, like Luca and Peachy, thanks to the Clinical Outreach Nurse role funded by **Sporting Chance Cancer Foundation**.

The Children's Hospital Foundation and Queensland Children's Hospital are grateful for the support of **Sporting Chance Cancer Foundation, its patrons, supporters, and friends** to help kids with cancer face their disease and treatment surrounded by family and friends and reduce their time in



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