

The Raelene Boyle Outreach Program

Impact Report

2020



Executive Summary

Children's Hospital Foundation and its beneficiaries 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 more than 880 children, reducing their time spent in hospital and helping regional kids get home as soon as possible, even whilst undergoing treatment for cancer. During a year marked by incredible change and overwhelming challenges from bushfires and flooding to a global pandemic this program has been more crucial than ever in continuing to achieve significant quality of life outcomes for children with a cancer diagnosis.

The information in this report outlines the impact of your generosity, as it continues to make a difference and improve the lives of sick kids in Queensland. Thank you!

The Raelene Boyle Outreach Program

Across Australia, over 750 children under 14 are diagnosed with cancer every year. The Australian Institute for Health and Wellbeing estimated this would increase to over 870 children under 14 years receiving a new cancer diagnosis in 2020 (AIHW, Cancer Data in Australia, 2020). Every week, three children die from this disease, which does not discriminate. When a child is diagnosed, it impacts the entire family. 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 of time without being able to see other family members or friends. Many families have shared stories of the difficulty and pressure to maintain consistent employment or operate family-owned businesses because of the need to be at the hospital to support their child.

Kids miss out on school or kindy, birthday parties, family holidays, friends' sleepovers and visits from cousins and grandparents. They miss out on making friends. They miss out on sleeping in their own bed, surrounded by their own toys, their books and seeing their family pets.

The Raelene Boyle Outreach Program helps ease this enormous burden and is specifically designed to keep kids at home where they should be, even while facing cancer treatment. Operating from Queensland Children's Hospital in Brisbane, the Raelene Boyle Oncology and Palliative Care Outreach Nurse helps identify and transition eligible families to the *Hospital in the Home* program. This program allows kids to continue their treatment from their local hospital and health service while maintaining quality of care.

Because of the **Sporting Chance Cancer Foundation**, kids can receive the best possible cancer treatment and go home knowing the Palliative Care Outreach Nurse is just a phone call away.

Sporting Chance Outreach Nurse

Rebekah Orford continues to create significant impact in the role of Sporting Chance Outreach Nurse, using her considerable experience working with kids with a cancer diagnosis, and their families.

Nurse Bek has worked as a nurse in the oncology outpatients service for Queensland Children's Hospital and has a passion for helping regional families.

"I cherish building relationships with the children and their families and having the opportunity to provide care and support to patients outside of the hospital is an incredible privilege."



What does an Oncology and Palliative Care Outreach Nurse do?

Cancer treatments can be incredibly complex, and often come with many short and long-term side effects.

Kids need a lot of routine tests and checks, receive a mix of medications, and have to cope with and manage a range of symptoms. They also have fixed vein access devices and nasal gastric tubes which need dressing and cleaning regularly. In a hospital setting this would involve many different staff members. In some cases, these procedures could be safely managed at home by parents or caregivers.

In the role as the Sporting Chance Outreach Nurse, Nurse Bek is responsible for delivering the following services and support:

- Meeting with families to help transition them into the *Hospital in the Home* program and assisting both the family and the community to keep kids living comfortably 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.
- Works directly with regional hospitals to ensure they have the supplies and expertise to support the patient in the community.
- Visits schools and kindies to provide kids with simple ways they can care for and look out for their friends.
- Conduct home visits to children in palliative care, so they can stay at home as much as possible.

What Sporting Chance's Investment Has Done for Sick Kids in Queensland

246

246 kids received a new cancer diagnosis in 2020 and were supported by the *Raelene Boyle Outreach Program*.

50

Nurse Bek conducted **50 education sessions** for parents on medications, managing central lines, and managing nasal gastric tubes. There was a significant reduction in the number of sessions delivered, during implementation of COVID-19 restrictions, as many families continued to have treatment in their regional centres.

80

Nurse Bek undertook **80 'virtual' sessions to regional Queensland schools** and kindergartens in 2020. These sessions were delivered via email, phone and video conference to provide kids with strategies and ideas to support their friend and answer any questions they might have.

200

More than **200 support calls** were received from parents, caregivers, and health professionals across Queensland. In addition to questions about chemo treatments, blood counts and possible infections, with a majority of calls related to COVID-19 and travel restrictions and requirements to and from Brisbane.

50

Over 50 orders for consumables were placed – things like dressings, syringes, medications for regional families so they didn't have to worry about ordering themselves or travelling to hospital to pick them up.

Even though intrastate travel was greatly impacted because of COVID restrictions, Nurse Bek was able to make one regional visit to an oncology palliative patient in Charters Towers. During this visit she met with the patient and family, staff at Charters Towers Hospital, the patient's GP clinic, school and Blue Care (community nursing group), to facilitate and ensure care arrangements were made to support the needs of the patient and their family.

Sadly, we farewelled 25 precious kids with a cancer diagnosis in 2020 - all of whom were supported by the *Raelene Boyle Outreach Program*.

Where do the kids live?



Figure 1 - Map of hometowns for children supported by the Raelene Boyle Outreach Program in 2020

The kids supported by Sporting Chance come from all over Queensland and Northern New South Wales, and regional and remote areas including the Pacific Islands, Papua New Guinea and Northern Territory. Of the 246 children supported by the *Raelene Boyle Outreach Program* during 2020, 158 were from regional and remote areas and 88 patients were from the Greater Brisbane region.

Nurse Bek continues to work closely with ten Regional Case Managers spread across the state (*Figure 1*) to support their local patients. These Case Managers are typically nurses, who help administer tricky medications or organise local appointments for the patients in their area. Collectively the Regional Case Managers, four Clinical Nurse Consultants based in Brisbane, and Nurse Bec support more than **600 Queensland kids with cancer** – both active patients who are undergoing treatment, and those in remission who are at risk of relapsing.

Twelve (12) Indigenous kids were supported by the *Raelene Boyle Outreach Program*, some of whom were also in the palliative care program. The kids came from far and wide, including Northern Territory and Northern New South Wales (*Figure 2*).



Figure 2 - Map of hometowns for the Indigenous kids supported by the Raelene Boyle Outreach Program

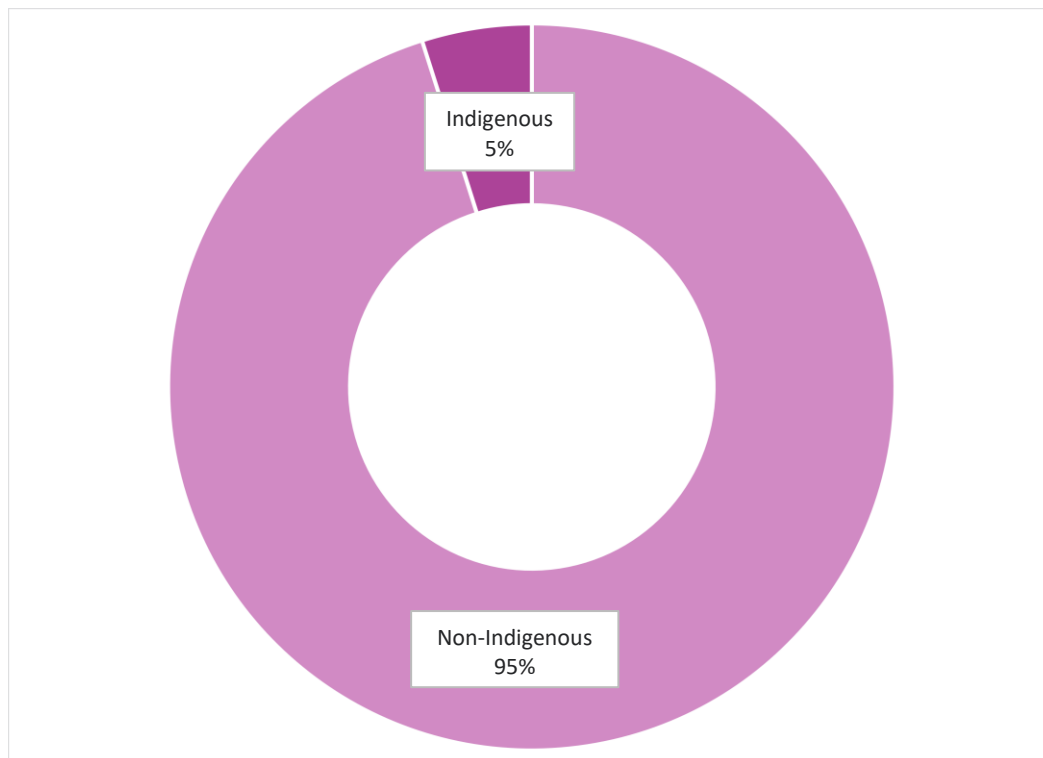


Figure 3 - Proportion of children supported by the program who identify as Aboriginal or Torres Strait Islander

Violet's Story



In November 2015, after months of feeling unwell and unexplained aches and pains, as well as weight loss, Violet, 6 years old, was diagnosed with stage 4 Neuroblastoma. Doctors found a fist-sized tumour on Violet's adrenal gland above her left kidney and additional spots throughout the bones in her little body. Within a week of her diagnosis Violet was unable to walk, due to the pain resulting from the cancer in her legs. Doctors commenced treatment immediately, but the intense chemotherapy made Violet incredibly ill. She needed to be hospitalised a week at a time and often readmitted, due to side effects in between her 3-week chemotherapy cycles.

Violet endured more than any person can imagine; six cycles of chemotherapy, a 9-hour surgery to remove the main tumour and her left kidney, a bone marrow transplant, radiation to her abdomen, legs and spine and six months of immunotherapy which required many nights in a hospital bed and strong pain medication. Immunotherapy treatment required Violet to be directly attached to an IV stand which meant she was unable to leave her room. During these hours and hours of isolation, the one thing that kept Violet hopeful and excited was the arrival of the musical therapist – the highlight of Violet's day! Violet loved making the nurses sing, dance and rap to her tunes, with her infectious laughter filling the ward. In between music therapy visits, the bedside play volunteers helped Violet pass the hours by playing games and doing craft activities whilst providing her parents with a much-needed break.

"When Violet was first diagnosed, we had a feeling of relief as we had tried for so long to find a cause for all her symptoms. When we eventually found out the extent of her disease, we were completely shocked to know how advanced her condition was."

After 15 months of treatment, Violet was finally given the all clear in February 2017. Then, 10 months later during her routine 6-weekly tests, a new tumour was found in the back of Violet's jaw. Violet started chemotherapy again, although this time as an outpatient. This meant hours and hours of sitting around a waiting room before each treatment. Thanks to the enthusiasm and energy of CHF volunteers, Violet could play games, craft and make playdough creations rather than focusing on the treatment to come. After a further 19 cycles of chemotherapy and 20 fractions of radiation, the chemotherapy was no longer effective in keeping the cancer at bay. Violet is now undergoing radionuclide therapy in the hope that it will eradicate the cancer once and for all.

“Hospital visits have been challenging for Violet during COVID. Inpatient stays were much harder as there were no volunteers or visitors. Things were much more enjoyable when she could meet all the volunteers, tell jokes and beat them at board and card games.”

It’s been over 5 years since Violet and her family were first introduced to the Oncology team at Children’s Hospital Queensland.

During that time Violet’s illness has had a huge impact on her and her family’s everyday life. For over 4 years, life revolved around Violet’s treatment schedule, which included hospital stays for weeks at a time, to midnight dashes to emergency, to regular weekly check-ups. This uncertainty had a significant effect on Violet’s whole family, especially her two siblings, Oliver and Piper.

Over the years Violet has benefited from flexibility in her treatment to improve her quality of care and everyday life. Hydration at Home is one approach that has made a huge difference to Violet and her family in providing a sense of stability and balance to everyone’s daily life. Hydration at Home has allowed Violet to be more connected to family and friends and continue her normal routines, whilst reducing pressure on her parents and siblings.

“After a chemo week [with Violet at home] Colleen and I have not required as much time to catch up on sleep or chores. Violet’s siblings have had less meltdowns and the whole family wellbeing has improved. The only downside is we see less of the staff we love in 11B [oncology].”

The importance of Violet’s family being able to support her and each other from their home, close to friends and family, is immeasurable. Thanks to Sporting Chance Cancer Foundation’s support of the Raelene Boyle Outreach Program, Violet and her family can continue to tackle this disease from the comfort of their home and with support from their community.



Program Outcomes

In 2017, *The Raelene Boyle Outreach Program* established several key objectives and we are pleased to report these objectives continue to be achieved on a yearly basis.

Objective	Completed?
Seek to facilitate 40 + children per year returning to home to continue their oncology treatments through the support of regional case managers.	Achieved. More than 80 patients were supported in the calendar year January – January. This includes new patients and existing patients who became ready for transition.
Continue to conduct regular school and home visits.	Achieved. Even though this service was impacted considerably by COVID-19, Nurse Bek provided ‘virtual’ sessions and information to more than 80 schools, kindergartens, and day-care centres for Hospital in the Home. These sessions were delivered via phone and video conference.
Develop and implement a program for intravenous fluids and certain drugs to be administered by CADD-Solis® Portable Medication Pumps within the child’s home.	Achieved. Eight (8) families trained and facilitated with the CADD program during 2020. These 8 children have been able to spend a night at home post chemotherapy which has been a saving of approximately 50 nights for the hospital and increased wellbeing for the families. Usually these children would need to stay 24 hours for intravenous fluids however this can now be facilitated in their own home. Education of the program can take 2-3 weeks before families are competent to take part in this program.
Develop and implement a teaching package for central line care for parents to reduce the incidence of central line infections in children and reduce the number of avoidable hospitalisations.	Achieved. Central Venous Line management can be complex, so families are individually identified by the Clinical Nurse Consultants as being competent to complete this training and administer the necessary management.

THANK YOU for being there during COVID-19

It goes without saying that 2020 was a year unlike any other and we are so grateful for the support of **Sporting Chance Cancer Foundation** to help kids with cancer face their disease and treatment, in addition to the uncertainty and challenges they faced during the COVID-19 pandemic.

Sadly, for many of our children with cancer, and their families, this year was exceptionally difficult and significantly impacted families that lived across the border in New South Wales or living in regional Queensland. Queensland Children's Hospital (QCH) Oncology team needed to revise how and where some treatments were going to be delivered safely and in a timely manner to ensure consistency and quality of care. Border restrictions between NSW and QLD resulted in families feeling isolated at times, confused about changing information regarding restrictions and required Nurse Bek and the team to increase phone consultations, support letters and constant communication with local regional centres to provide ongoing care to patients and their families.

The QCH Oncology team have worked tirelessly to upskill regional health teams and provide support to deliver chemotherapy safely, keeping families at home for sustained periods of time within their communities. In order to maintain the safety of patients and health providers during the COVID-19 outbreak, *The Raelene Boyle Outreach Program*, like many other outreach services, employed the use of telehealth with 3 - 4 sessions delivered every week to palliative care patients, throughout the year. Telehealth also played an important part in assisting regional and remote health professionals to provide vital care to patients during this time. The flexibility of telehealth meant regional patients could receive care within their home or at their regional health centre with the clinical team in attendance.

Kirsty's Story



In late January 2020, Kirsty began complaining of multiple bone and muscle aches which were originally thought to be the result of her busy softball training schedule and competing at the U16 national softball championships. When Kirsty returned home from her first day of starting Year 11, she went straight to bed and slept for several hours; that's when her mum first noticed something wasn't right. The bone pain, muscle aches and weight loss continued and increased in severity until Kirsty couldn't make it through classes at school, play her weekend softball games or get any sleep at night.

Kirsty's parents took her to their local doctor in Gladstone to investigate possible causes for her pain and fatigue. During this time Kirsty became seriously unwell and her doctor organised an emergency referral to a rheumatologist who was a private consultant from Queensland Rheumatology Services.

Kirsty underwent an MRI and extensive blood tests in April 2020 and was then referred to the Queensland Children's Hospital Oncology Department where she had further scans (MRI, CT and PET scans), numerous ultrasounds and a double biopsy. On 15th April 2020 Kirsty was diagnosed with metastasised Ewing's Sarcoma, a rare cancer that occurs in the bones and soft tissue. There were numerous tumours throughout Kirsty's body; the primary cancer was located in her right femur, there was a tumour between the muscles of the right thigh, and metastatic cancer in her pelvis, vertebrae, scapula, sternum, ribs, in both humeri, left leg and also in her liver. Within 3 weeks of diagnosis Kirsty was undergoing aggressive induction chemotherapy cycles.

"We were deeply saddened that our healthy teenager would have to fight hard to beat an aggressive cancer."

Kirsty's family were in complete shock and distressed that cancer could have been the cause of Kirsty's pain. By the time she was referred to the Queensland Children's Hospital Kirsty had lost a significant amount of weight and was so ill she needed constant care. Kirsty struggled to comprehend how this could happen to her; she was healthy, exercised and strived to be a good person. Kirsty has now come to understand that cancer does not discriminate, and she is just one of many unlucky kids. Kirsty and her family prepared for the battle ahead and sought comfort in the realisation that she was in the right place to receive the best treatment and care.

The impact and disruption to normal life was immediate for Kirsty and her family. Kirsty could not leave Brisbane because of her condition, with treatment involving short and long-term admittances to hospital. This disruption and separation from the comforts of home became significantly more challenging during the COVID-19 pandemic.

As a result of COVID restrictions within the hospital, it became almost impossible for Kirsty's Dad and brother to visit, let alone any other family members or friends. This placed an immense personal and financial strain on the family with her Dad eventually forced to leave his job in Gladstone and move to Brisbane so he could be closer to Kirsty and her mum. The disease and intense treatment took an immense toll on Kirsty's physical wellbeing and eventually she was unable to continue with her Year 11 studies.

"Leaving Gladstone so quickly affected Kirsty emotionally because she lost her social, sporting and schooling connections."

The Children's Hospital Foundation (CHF) family liaison officers were introduced to Kirsty and her family by the Clinical Oncology nurse. The CHF team quickly looked at ways to boost Kirsty's morale in the early weeks of treatment. Knowing Kirsty was a dedicated softball fan, the CHF team were able to organise a signed jersey from the current Australian women's softball team, *The Aussie Spirit*. Kirsty was also introduced to Juiced TV where she participated in a virtual visit with Chris Hemsworth (subsequently making him blush) – something she has treasured as one of her favourite moments of the year.



Thanks to the Sporting Chance Cancer Foundation, Kirsty has been able to access the Hydration at Home program during her chemotherapy treatment. Even as a regional patient who has relocated to Brisbane, Nurse Bek has been able to support Kirsty in her Brisbane accommodation to receive home hydration which has decreased the number of day/night stays in hospital. This is another example of the importance of this program to improve our patients, and their families, health and wellbeing by ensuring more time spent in their home or temporary accommodation with the support of oncology and the Hospital in the Home program.

At the end of 2020 Kirsty received some promising news. After completing her 6-week chemotherapy cycle, scans showed that treatment had eradicated the metastasised cancer throughout her body and some of the primary bone cancer in her right leg. With this news Kirsty and her family were able to take a much-needed break, travelling home to Gladstone and enjoying a short holiday in Hervey Bay. Kirsty is now preparing for the final stages of her treatment; chemotherapy followed by radiation therapy and then surgery in early 2021.

Thank you, Sporting Chance Cancer Foundation!

2020 has been an incredibly significant year for delivering *The Raelene Boyle Outreach Program*, helping hundreds of children get well, and get home sooner to their families thanks to the support of **Sporting Chance Cancer Foundation**.

We are deeply grateful to **Sporting Chance Cancer Foundation**, its team, patrons, supporters and friends.

Your help means sick kids in Queensland can rest easier in their own beds and face their many challenges with their family and friends by their side. Thank you!



Media Coverage

Palliative paediatric nurse talks about her 'resilient and amazing' patients

<https://honey.nine.com.au/latest/children-with-cancer-palliative-paediatic-nurse/b7e91e2e-5aac-4ef8-b757-99de85610eac>

Appendix A

Funder Recognition

Sporting Chance Cancer Foundation's support is acknowledged on Oncology Service magnets.

These handy fridge magnets are given with many other resources to families when they begin their Hospital in the Home journey.

Paediatric Palliative Care Service

Non-Oncology Service :: **1800 249 648**

Oncology Service :: **1800 501 670**

If there are any difficulties contacting staff please call
Queensland Children's Hospital on (07) 3068 1111
and ask to speak with the Palliative Care Service.

Non urgent requests can be sent to ppcs@health.qld.gov.au

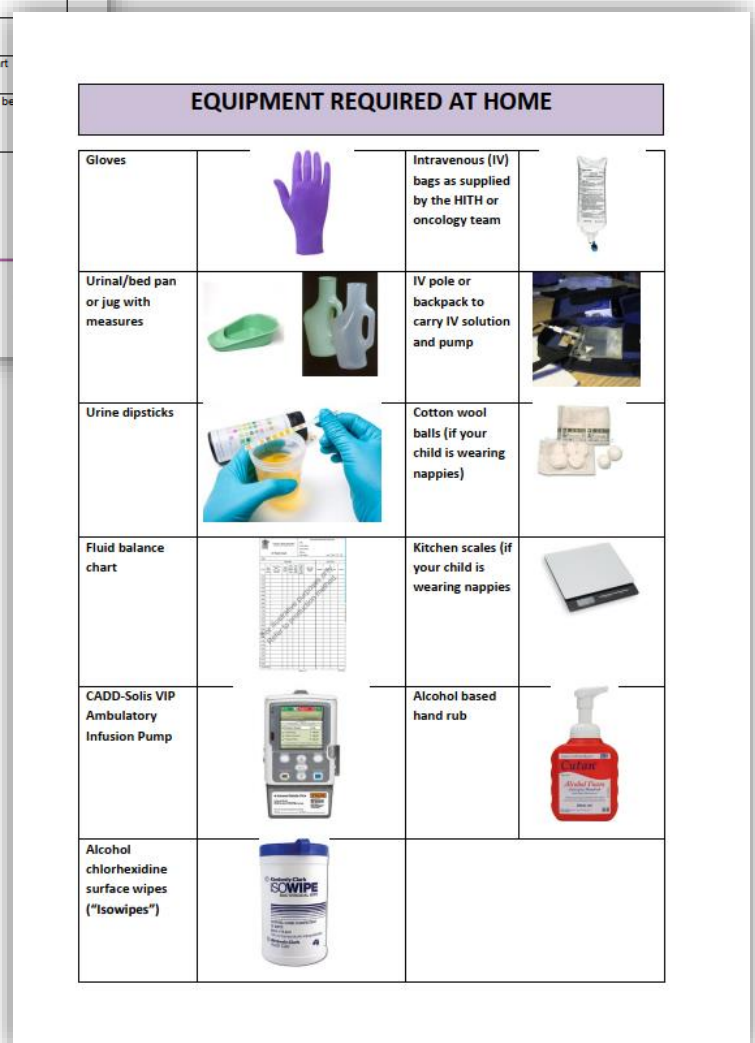
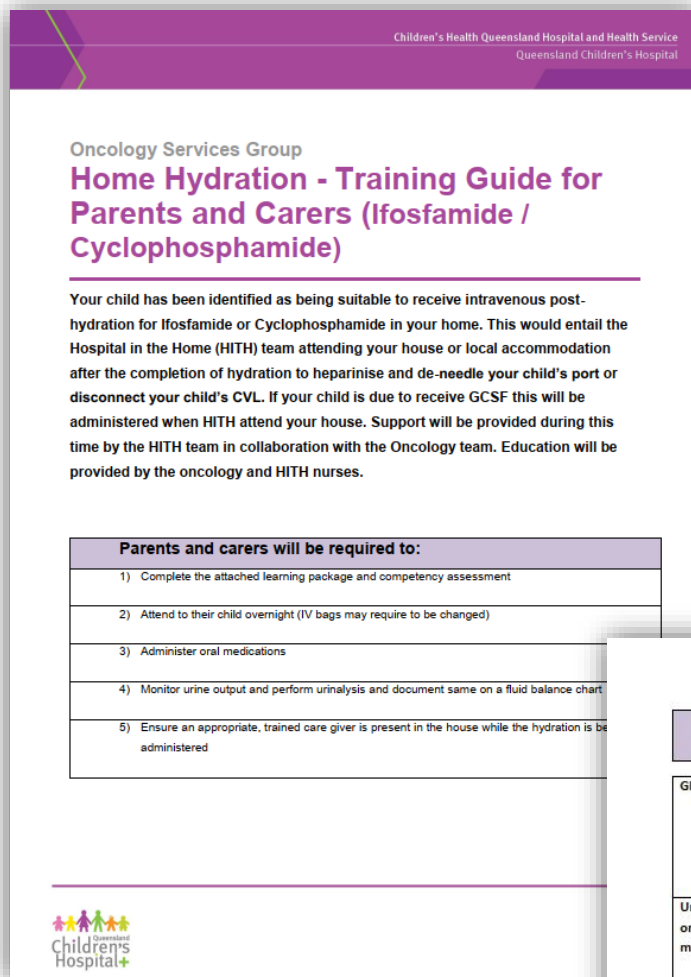


Appendix B

Family Resources Supported by the Raelene Boyle Outreach Program

Excerpts from the Parent Education Pack for Home Hydration Program as part of the Hospital in the Home Service.

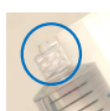
The training parents and caregivers must go through can be intensive and requires plenty of support from the hospital teams to ensure parents and caregivers feel comfortable putting this training into action.



ASEPTIC NON-TOUCH TECHNIQUE (ANTT)

Aseptic non-touch technique (ANTT) is the process by which we ensure the cleanliness of your child's CVL or PORT. It is used to prevent infection and contamination of an "at-risk" site such as your child's CVL or port.

ANTT uses the terms "key part" and "key site". "Key part" refers to equipment and consumables such as bungs and syringes while "key site" refers to your child's port or CVL access site (i.e. where the line or needle enters through the skin). It is vital that only sterile medical equipment comes in contact with a key part or key site once it has been cleaned. If either of these are contaminated by germs there is an increased risk of infection.



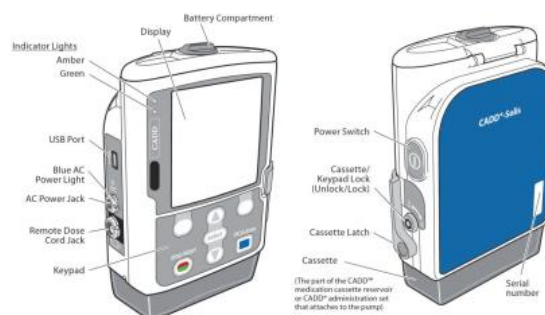
Key parts are circled

CHANGING AN INTRAVENOUS (IV) BAG

Aseptic Non-Touch Technique must be used when spiking an IV bag

1. Remove jewellery and perform hand hygiene
2. Prepare a work surface. A flat surface that is easily cleaned and away from high levels of household traffic is best. The work surface should be wiped with Isopwipes and allowed to air dry. Once this surface has been cleaned, only equipment required to change the bag should be placed on it. Pets should not be allowed in the room while this procedure is occurring
3. Place required equipment on work surface
4. Check that IV bag is still in date and that it is labelled with your child's details. Check that the fluid in the bag is clear. If the fluid is cloudy or discoloured, or you see precipitate (solid particles) in the bag, do not use. Call HITH (0438 015 145) for further instructions.
5. Remove outer bag if present
6. Perform hand hygiene
7. Put on gloves
8. Identify blue port for spiking
9. Press "Stop/Start" on the CADD pump keyboard. When "stop pump?" appears, select "Yes"
10. Leaving the IV bag on the work surface, twist the cap off the blue port. The open end of the bag should not touch anything else once the cap is removed. It is safe to leave the bag on the surface while you perform step 11
11. Hold the blue port of the empty bag with your non-dominant hand.
12. Gently twist the spike out of the empty bag. Once the spike has been removed it must not touch anything else. The empty bag should be disposed of
13. Leaving the new bag on the work surface, hold the blue port of the new bag with your non-dominant hand.

PUMP TROUBLESHOOTING AND USE



Indicator lights

- **Green** – flashes when the pump is running and delivering fluid as programmed
- **Amber** – flashes when the pump is stopped, an alarm condition exists, or the reservoir volume is low. It stays on continuously when the pump is inoperable

Power switch – turns the pump on or off. Press and hold the switch

Key pad – "stop/start" starts and stops the pump delivering fluids

Battery compartment – Rechargeable battery and four (4) AA batteries can be replaced to fit into this compartment if rechargeable battery ceases to work

Installing batteries

1. Stop the pump (using the "stop/start" button on the keypad)
2. Using your fingers or a coin, turn the knob on the battery door anti-clockwise to open the battery door
3. Remove the old batteries
4. Hold the pump on an angle and insert the four (4) AA batteries in the pump (from the bottom up). Match the + and the – markings on the new batteries with the markings on the pump
5. Close the battery door lid and using your fingers or a coin, turn the knob on the battery door clockwise to lock it
6. Restart the pump (using the "stop/start" button on the keypad)