

The Raelene Boyle Outreach Program



Executive Summary

Children's Hospital Foundation and its recipients are deeply grateful to Sporting Chance Cancer Foundation for their many years of partnership to deliver the *Raelene Boyle Outreach Program*.

This critical service has supported more than 600 children since 2017, reducing their time spent in hospital and helping regional kids get home as soon as possible, even when undergoing treatment for cancer. The below report covers the key achievements and impact through 2019.

The information in this report reflects the impact of your generosity, as it truly has improved the lives of sick kids in Queensland. Thank you!

The Raelene Boyle Outreach Program

Across Australia, 750 children under 14 are diagnosed with cancer each year. Every week, three children will die from this horrid disease. When a child is diagnosed, it impacts the entire family. Travelling to Brisbane for treatments, check-ups and more put an enormous emotional and financial strain on a family. Too often we hear stories of parents and patients who barely get to see the rest of their family because they're away all the time. We hear stories of a parent losing their job or selling their businesses, because they need to be at the hospital.

Kids miss out on school, kindy, birthday parties, family holidays, visits from grandparents. They miss out on making friends. They miss out on sleeping in their own bed, with their own sheets and teddies.

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 Sporting Chance Cancer 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.

Without Sporting Chance's generous support, hundreds of Queensland kids and families would remain separated, isolated, exhausted.

Because of the **Sporting Chance Cancer Foundation**, kids can now get the best possible cancer treatments and go home knowing the Raelene Boyle Outreach Nurse is just a phone call away.

Meet Nurse Bek

The Raelene Boyle Outreach Nurse is Rebekah Orford, who has extensive experience working with kids with a cancer diagnosis. Nurse Bek was previously a nurse in the oncology outpatients service for Queensland Children's Hospital and has a passion for helping regional families.

"Helping kids and families get home as soon as possible is the best part of my job. Knowing they can call me at any time, get help, and avoid an unnecessary trip is a wonderful thing to be able to do"

Nurse Bek has worked with thousands of families in her career and loves to travel to regional areas and meet the communities supporting her patients. Nurse Bek is pictured here with her Dying to Yarn Symposium team [far left].



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, need to receive a mix of medications, and manage their 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.

Nurse Bek meets with families, helps transition them into the Hospital in the Home program, and then assists both the family and the community to keep kids living comfortably at home for as long as possible. Nurse Bek helps educate families on:

- Administering medication, line and dressing management;
- Which symptoms to look out for, and when to contact her or their local hospital.

Nurse Bek also:

- Works with regional hospitals so they have the supplies and the expertise to support their patient in the community;
- Visits schools and kindies and teaches them how to care for and look out for their friend; and
- Conducts home visits for 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



225 kids received a new cancer diagnosis in 2019 and were supported by the *Raelene Boyle Outreach Program.*



Nurse Bek conducted **80 educations sessions** (more than 1 a week!) for parents on medications, managing central lines, and managing nasal gastric tubes.



Nurse Bek visited 90 regional Queensland schools and kindergartens in 2019, helping them to support their friend and answer any questions they might have.



More than 170 support calls were answered from parents, caregivers, and health professionals across Queensland addressing questions about chemo treatments, blood counts, possible infections, and more.



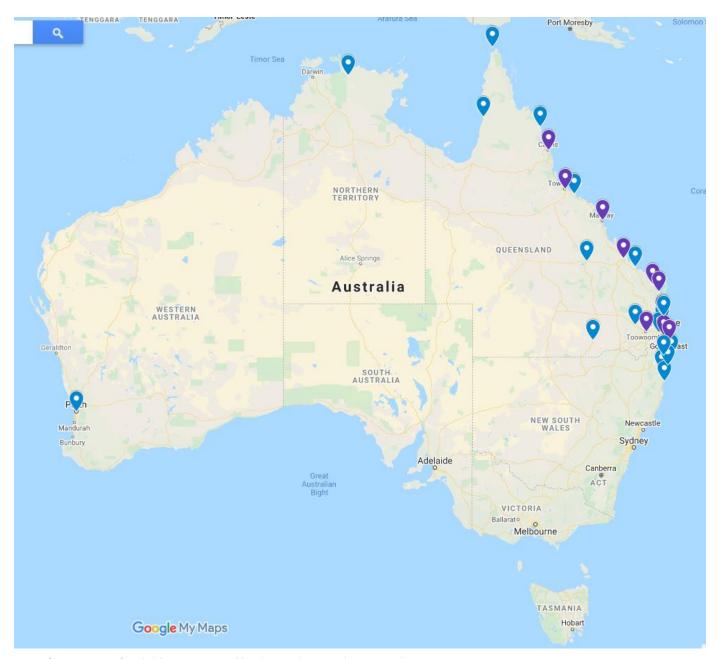
Over 60 orders for consumables were placed – things like dressings, syringes, medications) for regional families so they didn't have to worry about ordering themselves or travelling to hospital to pick them up.

Nurse Bek also made on average two (2) visits a week to children in the palliative stage of their care across Queensland. Thanks to Sporting Chance, these precious children were able to be at home and with their loved ones instead of hospital during this important time.

Sporting Chance and the Berowra Riders of the "BNT" Challenge also enabled a further ten (10) children to go home for their palliative care this year, thanks to the purchase of ten specialised NIKI Pumps which administer pain management medications.

Sadly, we farewelled 19 beautiful kids in 2019 - all supported by the Raelene Boyle Outreach Program.

Where do the kids live?



Map of hometowns for children supported by the Raelene Boyle Outreach Program in 2019

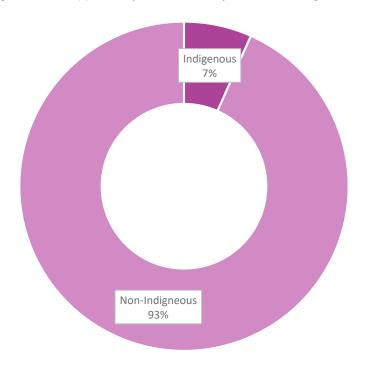
The kids supported by Sporting Chance come from all over Queensland and Northern New South Wales, and sometimes from the Pacific Islands or Northern Territory. This year we also supported a little patient from Perth in Western Australia, who qualified for a clinical trial here in Queensland.

Nurse Bek works with ten Regional Case Managers spread across the state (highlighted in purple, above) 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.

Fifteen (15) 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, Thursday Island, and Northern New South Wales (below).



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



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

Emerson's Story



During 2018 Emerson, now 8, complained to his mum on and off about pain in his shoulder. It would come and go unpredictably. His mum Jacinta originally thought he'd bumped it during a hockey game somehow. During a camping trip another kid tackled into him during some play hurting his shoulder further. The pain continued intermittently for the next couple of months, and so both mum and the GP assumed it was related to the bumps and scrapes. An x-ray revealed nothing suspicious. When a lump appeared on his neck, everyone thought it was a muscle knot from overcompensating to protect his shoulder.

Everything seemed to make sense.

A few weeks later, Emerson had trouble lifting his right arm. Since GP visits and x-rays had turned up nothing, they went to a physio to try and get the right arm moving again. But it didn't help. He slept in mum's room at night so she could wake up every couple of hours, reheat a heat pack for his "muscle knot" and try and help him sleep. Pain medication wasn't working.

Finally, they went back to the GP to demand answers.

After his GP visit, Emerson was taken straight to Queensland Children's Hospital for a battery of tests and procedures – MRIs, bone scans, PET scan, blood tests, ultrasounds, biopsies, bone marrow aspirate. Emerson was diagnosed in July 2019 with metastatic Ewing's Sarcoma in his spine, a rare bone cancer common in children of his age. It typically takes 5-6 visits to the GP before it is diagnosed, because it often presents like growing pains or sporting injuries common of children that age.

"Being told your child has cancer is like a train hitting you full force"

The primary tumour is on his spine, which has attached to soft tissue in the neck causing the lump. The lump in turn was pushing on the nerve controlling the shoulder and arm. He also has lesions on the skull, right knee, left femur, and chest. He is currently undergoing 10 months of intensive chemotherapy and radiation to reduce or kill the existing tumours. Surgery may still be considered.

"I have gone over everything that happened in the last 12 months a thousand times. If only I'd asked for more tests, if only I'd gone back to the GP... At the time everything had a reasonable explanation."

Emerson was highlighted to Nurse Bek by the oncology team, who felt he and mum would be suitable for the Home Hydration Program. Nurse Bek met with Emerson and Jacinta over the next month to talk about what would be involved, and practice different procedures. Emerson was responding well to treatment, with no unexpected complications. Mum diligently practiced changing hydration bags, washing her hands safely, resetting the portable medication pumps, testing Emerson's urine. She learnt to administer oral medications, identify potential complications, and memorised who to call and where to come in an emergency. Emerson had his portable pump put on a few days early, so they could practice their new routines together.



Now they were ready to go home a whole day earlier!

Being at home was a "massive relief" said mum. At first she said

"We thought home hydration may not be worth it. If there had been air in the pump he wold have been awake all night. But this wasn't the case. I hope we can do it again. Emerson was absolutely fine with the equipment, and so were our dogs. I was a bit worried they'd jump on him, but they picked up on the fact something was different and behaved. We only had to get up three times in the night. In hospital, we'd be awake every hour. We slept in our own beds... and it meant only getting up three times during the night. Emerson is a different child at home [compared] to the hospital. His mood is very different, so for his mental health, it's much better to be at home. Even 24 hours earlier makes a difference."

Emerson is facing his cancer battle enormously well and is taking everything in his stride. He loves BeyBlades and going to school with his mates. His horrific experience has been made easier thanks to Sporting Chance's support of the *Raelene Boyle Outreach Program* allowing him to resume as many normal activities as possible.

Program Outcomes

In 2017 The Raelene Boyle Outreach Program established a number of key goals, and we are pleased to report all four objectives have now been achieved.

| 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. As detailed, more than 80 schools, kindergartens and day-care centres were visited for Hospital in the Home; approximately 50 visits were conducted for Palliative Care support. |
| 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. Five (5) families trained and facilitated with the CADD program since April 2019. The 5 children have been able to spend a night at home post chemotherapy which has been a saving of approximately 30 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. |

In addition to achieving the original aims of the program, Nurse Bek has also been asked to establish a new home management program for patients with low-risk febrile neutropenia (slight fevers and infections signs occurring in children with low white blood cell counts).

It is a common complication of chemotherapy and would normally mean a trip to hospital.

For those who are low risk, *The Raelene Boyle Outreach Program* is now able to keep kids at home instead, by recommending safe antibiotics and educating regional staff on febrile neutropenia so hospitalisation can be avoided – reducing unnecessary stress and strain on the family and healthcare system.

Budget Summary

| Year | Awarded | Spent | Balance brought forward |
|-----------------------|-----------|--------------|-------------------------|
| Labour Nurse Bek 2018 | \$118,000 | \$63,990.42 | \$54,009.58 |
| Labour Nurse Bek 2019 | \$118,000 | \$119,040.01 | - \$1,040.01 |
| Total | \$236,000 | \$183,030.43 | \$52,969.57 |

The remaining balance is due the position being vacant in early 2018. Nurse Bek began in her role officially in February 2018. These funds will be spent to continue delivering the program. The small overspend in 2019 is the yearly increase in base salary from Queensland Health, covered by the generous increase in support from Sporting Chance Cancer Foundation.

Other Achievements

The Raelene Boyle Outreach Program is a highly specialised area of health practice, and as such continues to be a leader in Oncology and Palliative Care.

Nurse Bek attended three professional conferences during 2019, and made presentations at two including:

- Education in Palliative and End-of-life Care (EPEC) Paediatrics Trainer. Professional attendance in Sydney, March 2019; and
- "Never to far: the importance of return to country and value of working together with rural and remote Indigenous communities" Poster Presentation at the National Rural Health Conference in Hobart, March 2019;
- 3. "Paediatric Palliative Care and returning to country" Presentation at the Dying to Yarn Symposium in Brisbane, November 2019.

Information on the Poster Presentation and the Presentation is included in Appendix A.

Maddison's Story



When Maddison was four years old, she was an energetic and "very happy little munchkin" says mum Vanessa. They were on a family ski trip in New Zealand when Maddison first started feeling lethargic and run down, very unlike her. Not long after, she had trouble bearing weight on her legs and went to the Bundaberg Hospital with a suspected broken leg.

It wasn't long after admission she was rushed to Queensland Children's Hospital, and scans revealed a lump in her pelvis about the size of a grapefruit.

It turned out to be Rhabdomyosarcoma – a cancer made up of cells which normally develop into skeletal muscles. Since her diagnosis in 2017 Maddison has had fourteen (14) rounds of chemotherapy, 28 high doses of radiation, and surgery to cut blood supply to the tumour in the hopes of shrinking it. It worked, but not enough.

Since then, she's had a further three doses of high intensity radiation directly to her pelvis. This has helped shrink the tumour to about the size of a grain of rice.

The side effects of this aggressive regime have meant multiple trips to Brisbane for mum and Maddison. She is still undergoing several more months of maintenance chemotherapy and has been receiving hyperbaric oxygen therapy to try and resolve the ongoing bleeding and pain coming from her bladder as a result of the radiation treatments she needed.

Maddison and her mum spend long periods away from home receiving treatments at Queensland Children's Hospital. *The Raelene Boyle Outreach Program* has meant that during 'quiet' times between intensive therapies, Maddison has been able to return home to Bundaberg. Her big brother Andrew and dad miss the girls terribly, so all the time they can have together is precious.

Being able to go home often enough through the year means Maddison can also complete her schooling. She started Year 1 in 2019 (despite missing most of pre-prep and prep), and thanks to the support she received to come home, she'll continue to Year 2 in early 2020.

An extra big THANK YOU

In 2019 Sporting Chance Cancer Foundation went above and beyond for kids with cancer.

BNT Challenge for regional kids in palliative care

Thanks to the awesome lads of Berowra who jumped on their bikes in 2019 for the Bicentennial National Trail "BNT" Challenge, enough money was raised to purchase ten (10) NIKI Pumps for kids in Queensland in palliative care. Many kids in palliative care require intravenous medication to keep them comfortable. Normally with this type of medication they would have to be in hospital, receiving regular bolus injections. But it means being away from home.

NIKI pumps are small portable pumps which can be pre-programmed to deliver injections on a timer.



Having these pumps means kids can return home for the last stage of their care. We have only one chance to get it right for kids in palliative care. In 2019, 28 kids in palliative care were able to get home more comfortably thanks to the BNT Riders and Sporting Chance.



Helping the Regional Case Managers get on the road

With your support, we were able to purchase ten (10) backpacks filled with books and supplies for each of the Regional Case Managers supporting the Raelene Boyle Outreach Role.

These special nurses work with Nurse Bek to take care of kids with cancer in regional areas and make regular house calls to families undergoing treatment and in palliative care.

Before the RCMs carried all their disposables, medications and family resources around in plastic Woolies bags. Now they can simply 'grab-and-go' and have everything they need to help kids at their finger-tips, which is especially helpful if they get an emergency callout.

Thank you Sporting Chance Cancer Foundation!

Thank you Sporting Chance Cancer Foundation!

2019 has been another wonderful year of *The Raelene Boyle Outreach Program*, helping hundreds of families get well, and get home sooner thanks to the support of **Sporting Chance Cancer Foundation**.

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

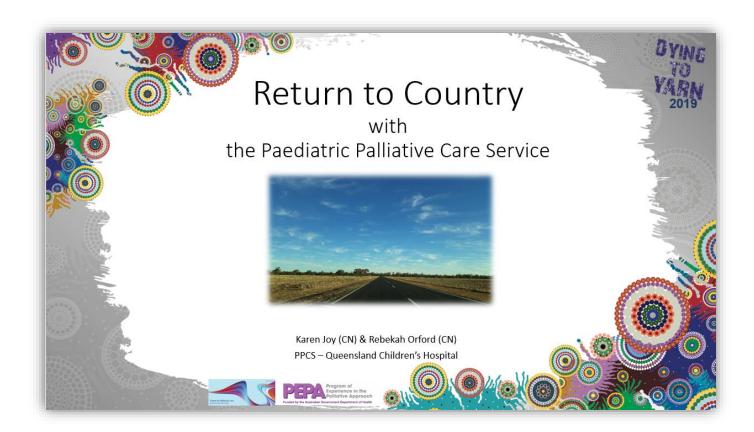
Your help means sick kids in Queensland can rest a little easier in their own beds and face their many challenges with their family and friends by their side. Thank you!

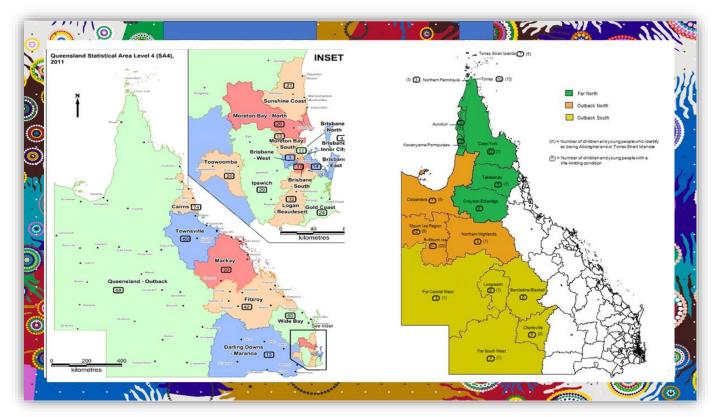


Conference Presentations



Poster presentation from the National Rural Health Conference.





Samples of the presentation at the Dying to Yarn Symposium, which included a case study of a beautiful baby boy who was supported to return home for the end of his life, and spend time with his family in South East Queensland.

Appendix B

Funder Recognition

Sporting Chance Cancer Foundation's support was acknowledged on the new 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







Sporting Chance's support was also acknowledged on the 9Telethon in November 2019, thanking Sporting Chance for their investment into sick kids in Queensland. A link to the full video is below.



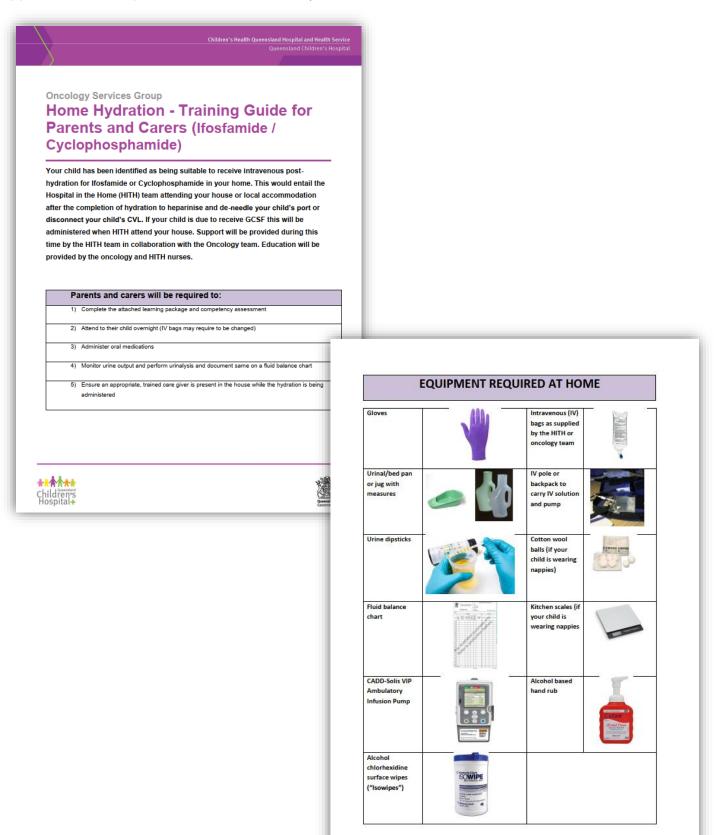


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Appendix C

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 make a reality.



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 nort

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.







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 aloves
- 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 blue port should not touch anything else once the cap is removed. It is safe to leave the bag surface while you perform step 11
- 11. Hold the blue port of the empty bag with your non-dominant hand.
- Gently twist the spike out of the empty bag. Once the spike has been removed it 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

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)
- Using your fingers or a coin, turn the knob on the battery door anti-clockwise to open the battery door
- Remove the old batteries
- 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
- 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)