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Over \$800k in funds
distributed to families



Over 188 families
supported



More than 30
wonderful volunteers

NEWSLETTER JANUARY - JUNE 2020

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Meet Our Family Support Coordinator - Gemma Sutherland

Dealing with rare childhood cancer amidst a global pandemic – 2 very different stories

A message from the Founding Directors:

Dr Andrew and Tracy Chow.

The last 6 months have been an extremely challenging time for the Foundation. At the same time, we are fortunate to be on a sound footing from a financial perspective. In the last 6 months we have had 15 new families enroll for support and currently have 53 active families. Since formation we have distributed financial support of \$800K and provided assistance to over 188 families affected by rare childhood cancer.

Fundraising is extremely difficult in the current environment. We have postponed several fundraisers due to the Covid-19 pandemic including the planned Rose Ball in Brisbane originally scheduled for Friday March 20th.

At the same time, many families have an even greater need for support given the impact on employment as a result of Covid-19. We are critically aware of this need and committed to maintaining our vital support for our families.



We thank Dr Lucy Forrest for providing this vital support over the past two years and welcome Gemma Sutherland, as Lucy's replacement. Gemma brings a great deal of experience in patient support as well as clinical experience. To contact Gemma, the Family Support Coordinator contact details remain the same.



We look forward to the easing of isolation restrictions and resuming face-to-face support for all of our families as soon as possible.

CEO reflections and hope:

Chris Broadley

If we look back where we were 6 months ago, few people if any could have predicted where we are now. Nobody could have imagined the impact of the bushfires and even more devastatingly the global impact of Covid-19. As a result of the Covid-19 crisis we are facing the biggest challenge from a health and economic perspective that we have faced in a century.



At Leila Rose Foundation we are mindful of the very real burden this crisis has added to the already daunting challenge facing the families dealing with a rare childhood cancer diagnosis. We are very much with them and here to help wherever possible. While we are also continuing to isolate and work from home, we are still very available through the benefits of modern technology to help and support in any way we can.

To that end, I was delighted to welcome Gemma Sutherland to the team during early March. Gemma has joined as our new Family Support Coordinator, replacing Dr Lucy Forrest who has moved to a clinical research role with the Olivia Newton-John Cancer Centre. We greatly appreciate Lucy's support for our supported families over the past two years and wish her well for the future. Gemma brings extensive general and oncology nursing experience in addition to practical experience as the Nurse-in-charge at the Very Special Kids Hospice. Gemma currently works two days with Cancer Council of Victoria as Clinical Nurse Specialist- Cancer Information and Support Services, and Tuesday and Wednesday with the Leila Rose Foundation.

During December, I was fortunate to be able to host Jacob Hamon and his mum Dominique at the President's Cup Golf Tournament which took place at Royal Melbourne Golf Club. Jacob from the Central Coast in NSW is in remission having been diagnosed with Wilm's Tumour and following the removal of a kidney. As an active and energetic five-year old, Jacob was forced to replace rugby and karate with golf in order to avoid contact sport post-treatment. It was wonderful to see Jacob with Marc Leishman, Leila Rose Foundation's newest Ambassador who provided Jacob with some impromptu coaching and introduced Jacob to the whole international President's Cup team.

Jacob is pictured below modelling one of two Leila Rose Foundation caps signed by the whole of the international team which we plan to auction off before the end of the year. Jacob's experience at the President's Cup now feels like it was a lifetime ago. I look forward to life getting back to relative normality again and in as much, to relieve the extra burden of isolation on all of our supported families impacted by a rare childhood cancer diagnosis.



Gemma Sutherland joins Leila Rose Foundation:

Meet Gemma Sutherland our new Family Support Coordinator.

Gemma is the new Family Support Coordinator at Leila Rose Foundation. Gemma commenced this role in March 2020 and since then has hit the ground running.

Gemma has been a Registered Nurse and Public Health Practitioner in Melbourne for the past nine years in a vast array of Cancer Clinical areas. These include Adult Oncology, Haematology, Radiotherapy and Palliative Care. Gemma has also worked in the cancer support services sector at Very Special Kid's, Children's Hospice and Cancer Council Victoria. Gemma's comprehensive cancer background allows her to have a thorough understanding of the holistic needs of not only the Child suffering from a rare Cancer but their whole family.



When asked about her view of her role as Family Support Coordinator with the Leila Rose Foundation, Gemma stated "I can't even begin to imagine the heartache and turmoil a family must go through when finding out their child has cancer, let alone a rare cancer that has little known about it."

"Having worked in the Oncology field for the many years, I have identified that the care needs of a family with an unwell child isn't just a one size fits all approach. Rather, it is multifaceted and requires a very individualised and tailor-made approach. The physical, psychological, social, and emotional needs of each family differ greatly, and these needs may change with varying importance during the cancer journey, from diagnosis through to survivorship or bereavement".

The role of the Family support coordinator at Leila Rose Foundation is to work in conjunction with specialists and Multidisciplinary teams to offer families with children with rare (less than 5% prevalence) cancer, practical and emotional support along the continuum of care. The role focuses on helping to assist families in navigating the challenges that may occur along the way.

"I started the role of Family Support Coordinator at Leila Rose Foundation in early March 2020 and within two days of my commencement I had two new families referred to me for acceptance into the foundation for assistance, represented the foundation at a not-for-profit Children's Cancer Charity meeting and attended a meeting with Professor Grant McArthur the Executive Director of the Victorian Comprehensive Cancer Centre. To say that I hit the ground running would be an understatement however I am so grateful I did, as it allowed me to have a greater understanding of my role as Family Support coordinator at LRF and the importance it holds to families with children with a rare cancer. It also gave me a great insight into current paediatric rare cancer information and best practice.

"Since my commencement, the Leila Rose Foundation has accepted eleven families for ongoing support, each with their own set of unique challenges. These have ranged from families requiring financial assistance, whether it be bills being paid, petrol vouchers given as often the families have to give up their work commitments to care for their unwell child. Emotional support, in the form of an empathetic ear to listen to their anxieties and offer advice and even practical support by way of providing information to families on best practice for children who are undergoing cancer treatment during Covid -19."

"I am astounded by the sheer resilience that the families demonstrate in adversity and I feel so honoured to be able to help them wherever I can in their time of need."

If you, or someone you know would like support please call Gemma on 0478 033 866 or email support@leilarosefoundation.org

Our personal rare childhood cancer journey:

Ange Croft on the impact of a rare cancer diagnosis on their fun loving 11 year-old, Molly.

Not in a million years would I have ever envisaged writing about my baby being diagnosed with bone cancer. Stories like this you only read about, right? They are someone else's story, not ours.

Our story went more like this – my husband and I were blessed with two beautiful daughters. Living in central west NSW, sport, friendships and fun was their life.

Molly our youngest was your ordinary happy go lucky 11-year-old girl. Moll followed in her big sister's footsteps and played rep netball, hockey and basketball for our hometown Dubbo. She was year six school leader and lucky enough to have played in the winning school NSW basketball side, followed a few weeks later with State age netball championships in Sydney.



Blessed she was, blessed we were, and not in a million years did we see what was coming for her.

Molly had had a little niggle in her calve when she played in the basketball side tournament – but nothing bad, she played it out. And when she played netball her leg was sore, her shin was hurting, we assumed shin splints but not enough that she did not finish off the weekend.

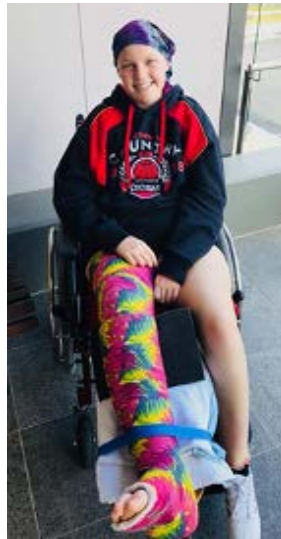
On our return to Dubbo we took her to the local doctor, she had an MRI and by the end of the week and on Molly's 12th birthday we arrived back in Sydney to see a doctor for a review. Here is when our story stopped, and we started role playing someone else's. That is the only way I can describe it.

Within the week Molly was diagnosed with high grade osteosarcoma, with a probable spread to her lungs and pelvis. Treatment started straight away. We were told that in about 10 weeks our Molly would lose most of her lower right leg, her knee and part of her thigh bone. Before this surgery could happen though, she would have to face some 6 rounds of the worst chemotherapy any adult or child can have.

If losing her beautiful hair and being told she could never again play any high-grade level sport wasn't enough for a just 12-year-old to hear, we were also told that there was only about a 40% chance that the treatment would be effective.

Our heads were spinning – how could this be happening to our girl – to our family. Molly had a rare cancer; we had never really heard of it before. With osteosarcoma making up less than 3% of all cancers it does not sit right to be then told that it kills more adolescents and young adults than any other type of cancer. And this is where our journey began with the Leila Rose Foundation, they were in our corner and ready to fight with us when we needed them.

After Molly's first round of chemo her leg broke right through the tumour. From then until surgery Molly was non-weight bearing and in a full leg cast as the bone was unable to heal itself. In November 2018 the tumour was removed.



From here Molly faced another 20 plus weeks of treatment. Her body was much weaker and still recovering from surgery. She faced a lot of trials as do all children battling cancer. We nearly lost her with bleeds and on some of Molly's darkest days we met the infectious diseases team, ear nose and throat specialists and became well known to the orthopaedic team too.

During her treatment she became accustomed to all the horrendous things that become a way of life for a cancer patient. PET, CT, x-rays, heart, kidney and hearing tests, blood and platelet transfusions, she knows them all too well.

May 2019 came around and as Molly finished her protocol, I guess you could say we were still living with our heads in the clouds. Molly had played the game and we were heading home after 292 nights in Sydney, returning every three months for follow up scans. Back to our "other life" as we referred to it.

With Molly's weakened immune system and her body still battling the effects of her treatment it was not long however before she developed an infection in her new internal prosthetic. We spent the next few months coming and going from Sydney and after multiple surgeries to work out what was happening our Molly was told the prosthetic needed to come out. In August 2019, the prosthetic was removed, and a nail inserted until the infection subsided.

After 12 weeks of non-weight bearing, in early December 2019 a new silver prosthetic was inserted and home we travelled once more. During all of this and since, the Leila Rose Foundation has been holding our hand. They have been there to listen, to help when we need them and in December, we were lucky enough that Lucy from their office was in Sydney and could meet Molly after her surgery.

A journey like this changes the way you look at life. Words like research and trials mean so much more than they ever did and no matter how hard you try, for anxiety not to set in before each review, it still does. A feeling you cannot describe unless you have experienced it as a parent of an oncology child.

Our Molly is hopefully going to return to school for the first time unaided after Covid-19 settles down and despite her still being on 13 antibiotic tablets a day and scans forever a part of her life, we feel hope for a way forward. What we thought was our Molly's life story may seem to have changed course, but we only count our blessings every single day that our beautiful strong, courageous girl is still here with us. We have so much love and respect for the doctors, nurses, researchers and those that have supported us. And we cannot thank the Leila Rose Foundation enough for all they have done. Not only done, but continue to do, not just for us but for so many other families battling a similar story. For that we will forever be grateful. Thank you from the bottom of our hearts.

Ange Croft



The Story of Jordan Liong

Where are you? Where are you hiding? These are questions often asked when playing hide and seek. As you might already know, hide and seek starts off with one person closing their eyes and the other going to hide. It's not when two people are standing next to each other. Jordan, my cheeky two-year-old, had been asking "Mummy, where are you" when I was just standing quietly a metre away from him, in his direct line of view. Ah, cheeky boy. Or so I thought.

Jordan loves to run, especially when his friends come over to play. He loves to chase them up and down the hallway, into his room and all around the house. He's often too busy chasing his friends to pay attention to his surroundings and often bumps into or trips over things. To wind down after a busy day, we read his favourite book and talk about a few characters that he would identify but recently all the characters had "gone outside to play". Ah, clumsy, cheeky boy. Or so I thought.



Sometimes, when we're in a dim room, I would see a white glow from his pupil when he's gazing lovingly at me or asking me to pick him up. It made me feel like I could see into his soul. Ah, a very special clumsy, cheeky boy. Or so I thought.

Maybe I got frustrated that he got bored with the activities I had planned. Maybe I got tired of playing hide and seek. Maybe I got annoyed that I have to tell Jordan to be careful what felt like 5 million times a day. I decided that enough was enough and so I took him to see my GP, who thought Jordan could be colourblind or needed to wear prescription glasses and so referred us to see an Ophthalmologist. My GP called an Ophthalmologist friend on his mobile phone and I overheard most of their conversation. "I know you normally see adults, but would you make an exception to see a two-year-old? He's very playful". "Is this cancer?". "No, no no". "Ok, ask them to make an appointment next week". This was a Thursday.

On Friday, Jordan complained of a headache during dinner. This special, clumsy, cheeky boy of mine also has an incredibly high tolerance level for pain. So, I immediately took him to the Royal Children's Hospital Emergency Department as I knew he has problems with his vision and was truly worried that his head would explode. We were told to come back on Saturday to see a Paediatric Ophthalmologist, who after many hours told us to come back again on the following Monday for an Examination Under Anaesthesia (EUA), ultrasound and MRI. Late on Monday afternoon, two consultants came to see us and asked us to sit down. They're just being thorough, right?

It was the 17th of February 2020. The day I was meant to return to work from maternity leave. The worst day of our lives. Jordan was diagnosed with Bilateral Retinoblastoma. My special, clumsy, cheeky little boy has cancer. His case is one of the worst cases that the two (very senior) Consultants had seen. His almost-one-year old brother is also at risk. That white glow that I had noticed for months is one of the biggest telltale signs and I ignored it, not knowing any better. Our world was turned upside down. Then, the world's world was turned upside down with Covid-19.

To date, he has had one double lumen port inserted in his chest, two bone scans, three MRIs, four cycles of intensive chemotherapy, five platelet transfusions, up to six different types of medication and fluids going down his nasogastric tube at the one time, seven red blood cells transfusions and a whole lot more. I believe that we're in the best of care and I'm so thankful for it.

This experience has been both overwhelming and amazing in so many different ways. I'm so overwhelmed by the myriad of emotions and thoughts running through my head. I'm so overwhelmed with guilt that I should have acted sooner. I'm so overwhelmed by the support from family and friends. I'm so overwhelmed by helplessness when Jordan cries every single time his port is accessed, a blood sample needs to be taken, nasal swabs need to be performed. Every time we approach the hospital, he begs me to turn around and go home. Despite all this, I'm so amazed by the power of prayer. I'm so amazed that Jordan has been such a resilient little fighter. I'm amazed at Jordan's spirit and love for God. The number of times Jordan has comforted me by singing his favourite worship songs with the exact lyrics I needed to hear truly amazes me. The number of times Jordan has reminded me to pray when I'm at a loss also amazes me. I mean, I'm meant to be the adult here!



I'm sharing my story in the hope that it will comfort and encourage you and let you know that you are not alone. Hearing what other parents have felt certainly has made me feel more normal. I also would like to highlight the importance of being educated and trusting your instinct when you feel something isn't quite right. If I had waited just a few more weeks, Jordan would most likely be completely blind. One day we'll get through this and boy, we'll have a story to tell!

I want to take this opportunity to thank Tracy and Andrew for establishing The Leila Rose Foundation. I'm so thankful to the Leila Rose Foundation for sending Gemma into our lives. Her advice, support and just remembering the little details I once mentioned makes me feel like I matter. Knowing that I can always come to her has been a much-needed breath of fresh air! Thank you so much. I hope I can return the support one day.

Blessings,

Ruth, Vince, Jordan and Judah.

2020 events in your area

In this Covid-19 world it is difficult to plan fundraising events. Our fundraising is the primary means through which we raise money to support our families. Unfortunately the Brisbane Rose Ball was cancelled during March and we have had to cancel the gala event planned for Melbourne during August 2020 – it is currently planned that a Melbourne event will take place during mid-2021. We still plan to hold our 2020 Annual Christmas Ball during late November – keep a look out on our Facebook page for booking details.

We acknowledge all of our partners and businesses who have donated to the Leila Rose Foundation. In this time of financial crisis where many businesses are hurting please support them where you can. Our key partners are listed on our home page at www.leilarosefoundation.org

About Leila Rose:

Leila Rose was 10 months old when she was diagnosed with a rare and aggressive cancer in 2009. She was diagnosed and treated at a leading children's hospital in Australia. Her cancer was so rare that the hospital had only seen two other cases. The cancer specialists were able to provide an initial treatment regime but when that failed, they could offer no other options.



There was a thirst for knowledge, a burning drive to make sure that no stone was left unturned and that every possible treatment option was considered. We also desperately wanted to achieve a balanced life for Leila – particularly in her last months.

Unfortunately, our experience was that these needs were unmet by the health system. The lack of funding and limited research into rare cancers meant that excellent practitioners did not have the capacity or resources to meet our needs.

After the passing of Leila, we wondered how many other families had experienced this turmoil and how many are still going through it. We established the Leila Rose Foundation in 2011, in memory of our daughter.

Dr Andrew Chow & Tracy Chow – Founders of Leila Rose Foundation

The Leila Rose Foundation:

www.leilarosefoundation.org

**The Leila Rose Foundation is registered as a charity with the Australian Charities and
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D O N A T E

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