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The presence of siblings in the Newborn Intensive Care Unit is encouraged and recommended by the Standards for Newborn Care and parent organisations. Sibling support programs in the NICU have a vital role in implementation of Individualized Family and Infant Developmental Care. Siblings are an important part of a family's experiences and Sophia's story illustrates how the experience of having a sibling in the NICU can influence one's life and impact career choices.

## How being a NICU sibling influenced my life

Sophia Gerassis

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I was two years old when my sister Dimi was born on Mother's Day, critically ill and premature at 30 weeks gestation with a 500-gram tumour in her chest. I would spend time with my family in the Newborn Intensive Care Unit (NICU) although I don't remember this. I grew up as a sibling to a baby that was in the NICU, and over the years I found it hard watching my sister in pain and the trauma she and my parents faced. It was very challenging in those early years of my sister's life. My parents spent many hours at the hospital, and I stayed with my aunty and grandparents, who gave me a lot of support. While I was growing up, the experience of sharing Dimi's history made me stronger in a way. I needed to be there for her, especially when I could see that she was worried and scared. After Dimi was discharged from the NICU she needed to go to the Children's Hospital for follow up blood tests and scans till she was six years old. I would usually go with mum and Dimi and remember how scared Dimi would be. I was extremely protective of my little sister, and we were inseparable. As we got older, the bond we had continued. I am proud of Dimi, and we have a good relationship, although she is two years younger, we are still very close.

As I grew older my parents became involved in fundraising for the NICU and hospital. I was very grateful to be involved as it taught me to be appreciative and that raising awareness of the work of the NICU is important. Other people get to see what my family went through and the important role NICUs play. My Mum fundraises a lot and she shares Dimi's story to give other families hope.

I have been actively involved with fundraising. Mum has encouraged us to give back to the hospital. As a family we have organised a successful Gala Dinner in 2016 and other fundraising events, and we also wrap and deliver gift packs for Mother's Day, Father's Day, Christmas, NIDCAP Day as well as take part as a family in the annual Race for Grace bike marathon. My parents attend the annual Grace Gala and my sister, and I have also attended two of them. I think my life has been entwined with the NICU, the doctors, nurses and therapists.

### Bringing our story to life

In 2023, I graduated from year 12 high school at All Saint's

Grammar in Sydney. For my subject of Visual Arts, I had to complete the theory of various influential artists and a practical of a series of major works based on a theme.

I created a series of oil paintings to portray the trauma faced by my family because of my sister's complicated birth. My family was informed in the NICU my sister had a 10% survival rate, leaving them in an extremely vulnerable and emotional state.

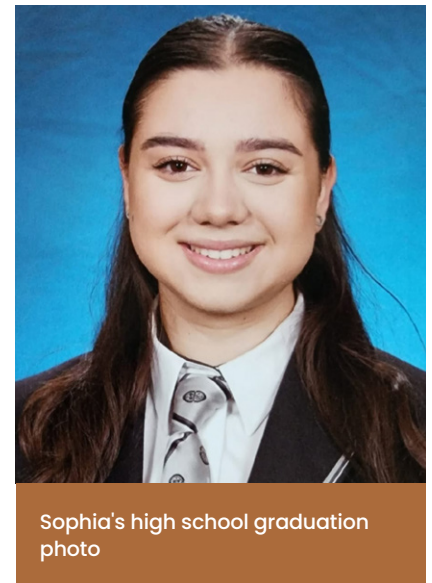
These emotionally charged artworks serve as a testament to my family's challenging and unforgettable experience, with the aim to raise awareness of the severity of this situation. Through this body of work, I sought to evoke a poignant blend of vulnerability and hope, capturing the transformative journey of my younger sister.

The first canvas shows my sister just after surgery – this was her worst point. It draws out vulnerability and is confronting to capture the audience. My intention is to show people the power of faith.

The second canvas shows people that from a bad situation things can get better – it portrays hope and faith. I wanted to raise awareness that without the NICU the situation would have been different.

The third canvas shows me and my sister. She is getting better on the road to recovery. It is very special as it shows me and her connecting on the road home.

While the genesis of my art is rooted in personal experience, various artists have influenced my creative practice. Among them, Alyssa Monks (<https://www.alyssamonks.com/>)



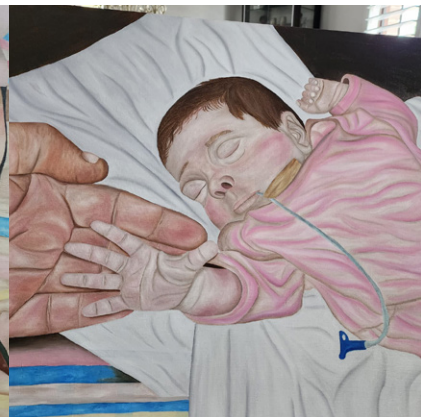
Sophia's high school graduation photo



Canvas 1



Canvas 2



Canvas 3

stands as a significant inspiration. Her profound artworks capture the essence of vulnerability and intimacy in the human experience, navigating the disquieting spaces of emotional distress. Drawing from the same medium, I have endeavoured to emulate Alyssa Monks' painting style, melding realism with a confrontational subject matter, thereby attempting to forge a powerful connection with the viewer.

The paintings not only offer a glimpse into my family's perseverance through our personal journey but also serve as a catalyst for broader discussions about the challenges faced by families in similar situations.

### The power of storytelling through art

I found when my art was on display people don't say much – maybe they are in a state of shock. However, when they read the story, they seem to understand.

The three pieces took me nine months to complete. While I was painting, it brought back feelings and emotions. It also brought back emotions for my mother which I found was very touching. It was hard to balance all my studies during my final year of school. I had to meet a deadline with my bodies of work which needed to be submitted for Higher School Certificate marking. I also needed to allow time to study for my upcoming exams. It was difficult but I am proud of myself for being able to complete and achieve great results.

### Creating connections through art

I would like people to see things from a sibling's perspective and to be aware of the effect the experience and the trauma can have on a sibling. For me it resulted in a strong connection between me and my family to the NICU (Grace), that's why we fundraise and are passionate about making a difference in the lives of others.

I want people to feel a connection to the artwork. They may not have had the same experience, but they can appreciate those who have.

My message to other siblings of NICU babies is to have hope and be there for them. In the end, with lots of love, patience and with all the amazing medical help, everything will be okay.

You must have strength. I also think it is important for siblings to be present in the NICU, so that the family is whole during that stressful time.

I am now about to embark on my career. I started at Macquarie University in February 2024 where I have enrolled in a double degree of Speech & Hearing Sciences and Psychology. This is a four-year course with an additional two years for a Masters in Speech Therapy, a total of six years. My sister was seeing a speech therapist when she was younger, and I became interested in Speech Therapy. Ultimately, I would love to work with children and help them overcome their speech issues. Helping others makes me happy. I was also looking at courses that would not be taken over by Artificial Intelligence in the next few years, as well as courses in demand. I am hoping eventually to have my own practice.

Painting is a hobby, and I will keep doing it as I enjoy it and it helps me relax. I have attended art classes since I was six years old and now teach art to other children. I have also sold a few of my creations. My favourite works are my series of major works – called Tiny Miracles – named after Mum's organisation. It was very personal – links into my sister who was tiny and also our miracle!



Sophia painting

## Words from my sister

“Seeing the paintings made me feel special and honoured that Sophia did her major works on me and my difficult start to life. It made me feel different and the way it affected my family. My sister Sophia is very special to me, more than just my sister, she is an inbuilt best friend. I want to keep doing things for the hospital and keep a connection as they saved my life and also save the lives of other babies every day.”

## Words from my mother

“It was emotional watching Sophia paint. I am very proud and impressed with her work, even more so because of the strength and maturity she showed during the whole process. It has shown me that Sophia felt strongly about the subject and her connection to Dimi. As a two-year-old, Sophia always sat quietly with Dimi in the NICU. It was important for her to be there, so we were all a family together.”



Sophia's family contributing at fundraising event for the NICU

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