



icholastrust
for Paediatric Palliative Care





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Dedication

This book was produced in memory of Nicholas Butters — the inspiration behind the Nicholas Trust for Paediatric Palliative Care.

The Trust, through community and corporate support, has funded two stunning patient and family rooms, a parent retreat, a state of the art schoolroom, and teachers' offices.

The rooms will afford privacy, support and solace for all children with a life-limiting illness and their families.



Acknowledgements

Coen and Alexander Butters: your strength, resilience and love empowered us to initiate the Trust.

Thomas and the late Pat Scott, Nic's beloved grandparents: for your support, encouragement and guidance. You were pivotal during Nic's treatment.

Peter Cummings: for your unwavering friendship and guidance. You were instrumental in the establishment the Trust.

The Advisory Board of the Nicholas Trust: your wisdom and passion enabled the vision to become a reality.

The staff at the John Hunter Children's Hospital: for your support and love.

Jenny and Craig Butters
2011

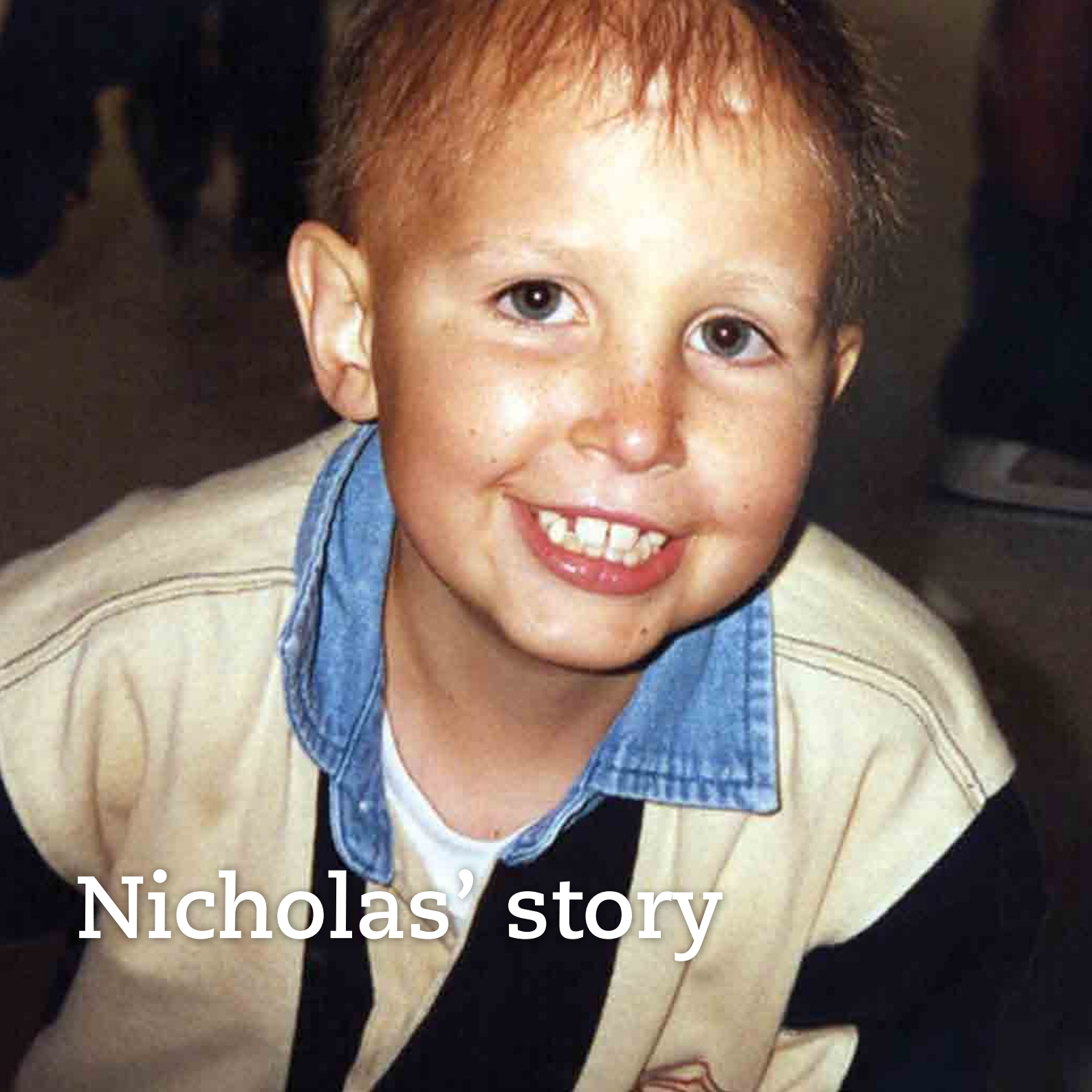


About the room you are in

If you are in this room it's because you, or someone you love – a son or a daughter, a brother or a sister, a grandchild, a nephew or a niece, someone in your care – has been diagnosed with an illness requiring long-term hospitalisation. This is an incredibly difficult time, and our thoughts are with you.

Hopefully, your hospital stay will be made a little easier through the existence of these rooms. Their creation was made possible through the work of many, many people over many years but they would not exist at all were it not for the courage of one boy and his family. That boy was Nicholas Butters and this small book has been created to keep his memory alive.

The stories that follow offer a little glimpse into Nicholas' journey and the events that challenged the Butters family, as well as the staff of the John Hunter Children's Hospital, to begin the work of creating these rooms.



Nicholas' story

NICHOLAS

*They say children with life-limiting illnesses are special.
Their strength supports those who would like to fall down.
Their love touches our hearts. We need only to meet Nicholas to feel his warmth,
he doesn't ask us to carry his pain.
His gentleness, kindness and trust carry us away from our own self-pity.
Nicholas has taught us many things:
to take time to appreciate the beauty around us, to enjoy the moment,
the spontaneous kiss, and I love you Mummy and Daddy.*

*Nicholas enriches our lives in so many ways;
to be able to share his life is the greatest gift of all.*

Written by JENNY BUTTERS – 1996

Children are incredible human beings with the amazing capacity to love unconditionally, to endure pain without complaint, to have complete trust in those around them and find beauty in all aspects of life. They possess the ability to alleviate the sadness that can, so often, lead to anger. Children can elevate us above the grief, and see only the beauty of each new day. Their purity is our strength.

Many children leave footprints wherever they travel. They stay forever in our heart.

Nic captured the hearts of all he met. His strength, courage and laughter echo still through the corridors of the John Hunter Hospital. He possessed wisdom beyond his years. He did not wallow in his own self-pity. He met each new challenge with resolute bravery.

Through his nine years of treatment, the JHH became his hide-out. As the chemotherapy depleted his physical strength, he relied on the staff to provide a recharge. Through the



Nicholas' story



drips, the fluids, the antibiotics, the blood transfusions; the days, the weeks the months spent in hospital, not a moment was wasted. Nic made it his mission to know everyone and to ask a thousand baffling, intelligent questions.

Nic never expected special treatment. He attended school more often than we ever imagined possible. He loved the social interaction. His many friends welcomed him, and the kindness of the staff at both his schools — Jewells Primary School then Newcastle Grammar — ensured his safety. He believed in himself, and although his physical appearance brought many questioning glances, his inner strength, resilience and self-esteem ensured no self-pity. A little boy with no hair, dual hearing aids, carrying an oxygen cylinder, does not go unnoticed.

Nicholas was a reflection of all the love, interest in learning, zest for living, the strength, goodness, compassion and sheer humanity that was shown to him by all those who were part of his life.

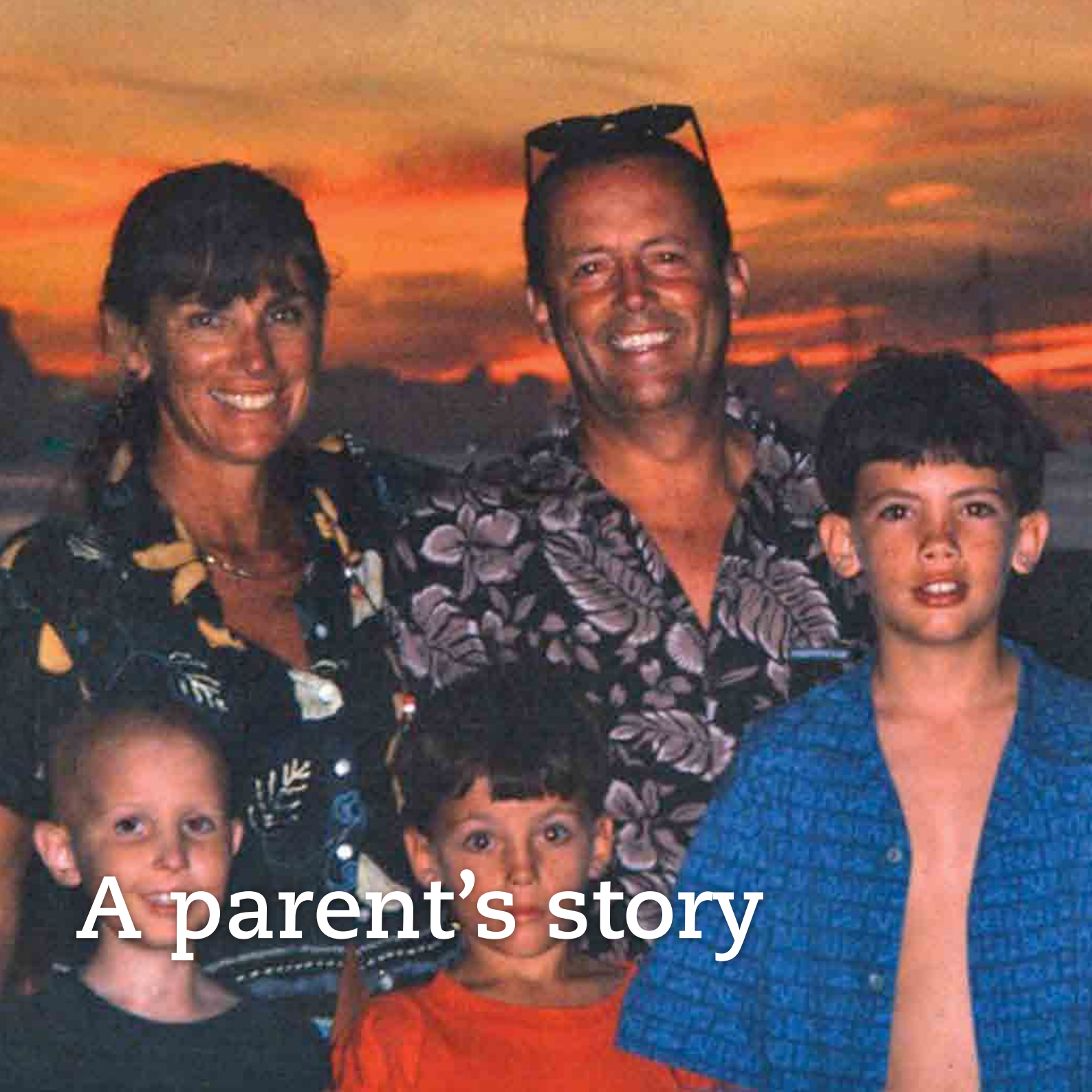
It is true that many people carried Nic, but it is also true that he carried us all. He carried us in his strength and in his determination. He carried us by never complaining about his sickness. He carried us in his wisdom and in his humour. He carried us with his winning smile of thanks. He carried us in his friendship and his love. He carries us still with the special gifts that he gave us and he still gives us.

His courage and his dignity are truly inspirational. His life was an inspiring triumph over adversity.

The establishment of the Nicholas Trust is testament to Nicholas' life.

Nicholas touched our lives bringing beauty and love. His life was far too short, but he lives in our heart forever.





A parent's story

1996

Nicholas bounds through the gates on his first day at kindergarten. His new shoes shine, his smile is radiant: he's ready to conquer the world. Three months later his enthusiasm is extinguished: he drags himself to school, hoping the vomiting won't disrupt his day. What happened to his infectious laugh, his desire to wreak havoc in the playground?

As his bouts of nausea increased, as we watched the colour drain from his face, as we became frustrated by diagnoses of "a virus", we decided to take him to the John Hunter Hospital. A short visit, a diagnosis of some obscure infection, a course of antibiotics and soothing words would see an instant recovery.

But even as we approached the hospital his condition deteriorated — he began complaining of a headache and sensitivity to light. It was obvious to the clerk that Nicholas was extremely unwell. A bed was found immediately.

As the doctors reviewed him, and hushed conferences were held, I felt (in my naivety) a confidence that illness could not touch my family. As they took him for a CAT scan the possibility of meningitis was discussed. Of course I was worried but at the back of my mind I thought, "That's okay: it's a terrible disease but, treated promptly, children recover quickly".

We sat in a darkened room. A group of "important looking" doctors entered the opposite bay and I felt sorrow for the sick child they must be attending. It simply did not occur to me that they were there to see us.

As they called our names my heart stopped. The world revolved in slow motion. Bewilderment, confusion and disbelief permeated my soul. Heartache and pain filled my being.

We were being shown an image on the screen but the words were incomprehensible. Our son had a brain tumour.



A parent's story



Cancer! Not cancer! Not our beautiful five-year-old son! You believe you can keep your family safe. How could the diagnosis of cancer seep through our protective shield?

The following days passed in a blur. Nicholas underwent eight hours of surgery. When he emerged in ICU, his head swathed in bandages, his innocence lay bare.

But his battle had just begun.

Nicholas made a remarkable recovery from the operation. Ice-cream played a large role. Still numb, we grappled with the enormity of the treatment. Six weeks of radiotherapy followed by twelve months of chemotherapy. The life we took for granted was shattered.

Nicholas is the middle of three boys, each separated by two years. It was difficult to tell his siblings that their brother had cancer. Coen, seven at the time, took control: "Nic will be fine, Mummy". Alexander, at three, was less sure about how to respond. From the outset we attempted to keep family life as normal as possible. Craig spent the nights with Nic in hospital, while I attended to the boys at home. We made an invincible team. With the help of family and friends, as well as the caring staff at the John Hunter Hospital, we made it through the regime.

Stronger as a family, resilient, conscious of life's frailties.

Our lives slipped back mirroring normality, though our outlook on life had changed. Our motto became "seize the day". Our cheeky little boy was moving forward. His zest for life, his inquisitiveness returned with vigour.

Known as "the boy with a thousand questions", he was frustrated by his inability to learn to read, remember simple tasks or make a decision. Within the nurturing environment of Jewells Primary School, Nic recognised his academic limitations and saw them not as a deterrent to learning but as a tool to discover methods to expand his knowledge. His belief in himself elevated him above academic inadequacies.

We never ceased to be amazed by Nic's positive self-esteem, his self-confidence, the lessons in life he taught us, the hearts he touched and the pleasure he gave to all who

knew him. He never asked us to share his pain — only to hold his hand and feel his beauty.

With experience, and knowledge, we understood that a relapse might occur, that the tumour might return. Yet you never prepare yourself for the moment when you hear the doctor say, “I’m sorry: we’ve found another lesion”. Hours spent searching the internet for any information pertaining to Medulloblastomas and their treatment, any studies, trials or management, anything that could give us hope that a “cure” was attainable, that more time could be bought.

Hope propelled us forward. We agonised over all treatments. No decision was easy. Our goal was never to trade Nic’s quality of life but to allow him to enjoy and experience life to the fullest.

1998

The heartbreak of hearing the cancer had returned.

“Don’t worry mummy, you’ll be fine.” It was Nic who gave me the encouragement!

Treatment was conducted in the Sydney Children’s Hospital under Dr Cohn. It was intensive, aggressive and frightening. High doses of chemotherapy were followed by stem cell infusion: it was a trial of escalating doses to gauge the amount of drugs tolerable and effective. I watched as the cytotoxins infiltrated his body, ebbing his strength, his tiny body wracked in pain.

As he battled the drugs we were once more awed by his courage, his determination, his unfailing trust in himself, in us and in his doctors. We were humbled by his strength and courage.

Nic again won the battle, stealing the hearts of all he met, the ward staff and the staff in ICU, where he spent considerable time. He defied the odds and, after stereotactic radiotherapy with Dr Smee, returned to living life to the fullest, dreaming about the future and planning for tomorrow.



A parent's story



The intensive treatment, the drug regimen and the radiotherapy rendered Nic oxygen-dependent, which meant that he was attached to oxygen 24 hours a day. He required a concentrator at home and at school and oxygen bottles for mobility. Nic wouldn't allow this need for oxygen to restrict his life. He swam, explored, and rode every ride at Movie World, willing the oxymetre to give him his independence. Doctors, unsure as to the progressiveness of his interstitial lung disease, informed us that "at best" the disease would stabilise.

Nic was not about to allow this prognosis to defeat him. He doggedly stared down his ill health and surprised everyone by regaining his strength. The oxygen bottles were discarded.

Again, we watched as he ran with his brothers, chasing them in the yard, swimming, hanging upside down at gymnastics and playing with his many friends.

His courage was inspirational. He never questioned the disease, was always aware of his condition and asked many questions regarding his treatment. He never said "No!", he never said "I've had enough! Why me?". He never cried. He carried us through.

2000

The dreaded words. We gather strength to once again make decisions to direct our course. We are guided by Nic and his doctors. We have come too far to give up. Hope never fades.

More chemotherapy. This time a drug, Topotecan, intrathecally delivered through an Omeyer reservoir directly into the brain and spinal fluid. This entails twice-weekly trips to Westmead for over six months. Although we don't complete the protocol by undertaking further intensive chemotherapy (a decision not to trade-in Nic's quality of life), Dr Smee agrees to deliver stereotactic radiotherapy. A month on, the tumour is shrinking.

Nic's determination enabled him to beat the odds. But, after six months of such invasive treatment, the effects of large doses of chemotherapy and radiotherapy were evident: sparse hair growth (six years with little to no hair), wearing dual hearing aids (these we

saw little of due to Nic's desire not to appear different!), an inactive thyroid, poor renal function and short stature. We set about helping Nic to reach his physical potential with growth hormone replacement and, gradually, the rounded face, the lethargy, the dry skin and the little rolls of fat began to disappear.

Unfortunately, with the changes came another tumour. Yet again those words: "I'm sorry, we've found another lesion". More stereotactic radiotherapy. Nic had become a regular patient of Dr Smee's. More heartache.

Nic still smiled, seeing the future as bright, never believing that he would not be cured. Nic used mental imagery to destroy the cancerous cells, an army of "Pac-Men" ridding his body of foreign cells.

2004

Eight months on and Nic is brimming with life. He starts high school with enthusiasm and the desire to excel, to charm, to steal more hearts.

For the final time we hear the words that penetrate to our core. "Sorry: the disease has spread, there are multiple lesions within the ventricles and spine." Shattered, we ride Nic's courage to enjoy each day, to ensure he completes his journey with happiness, fulfilment and achievement. Our family is strong, we trust our strength and draw courage from each other.

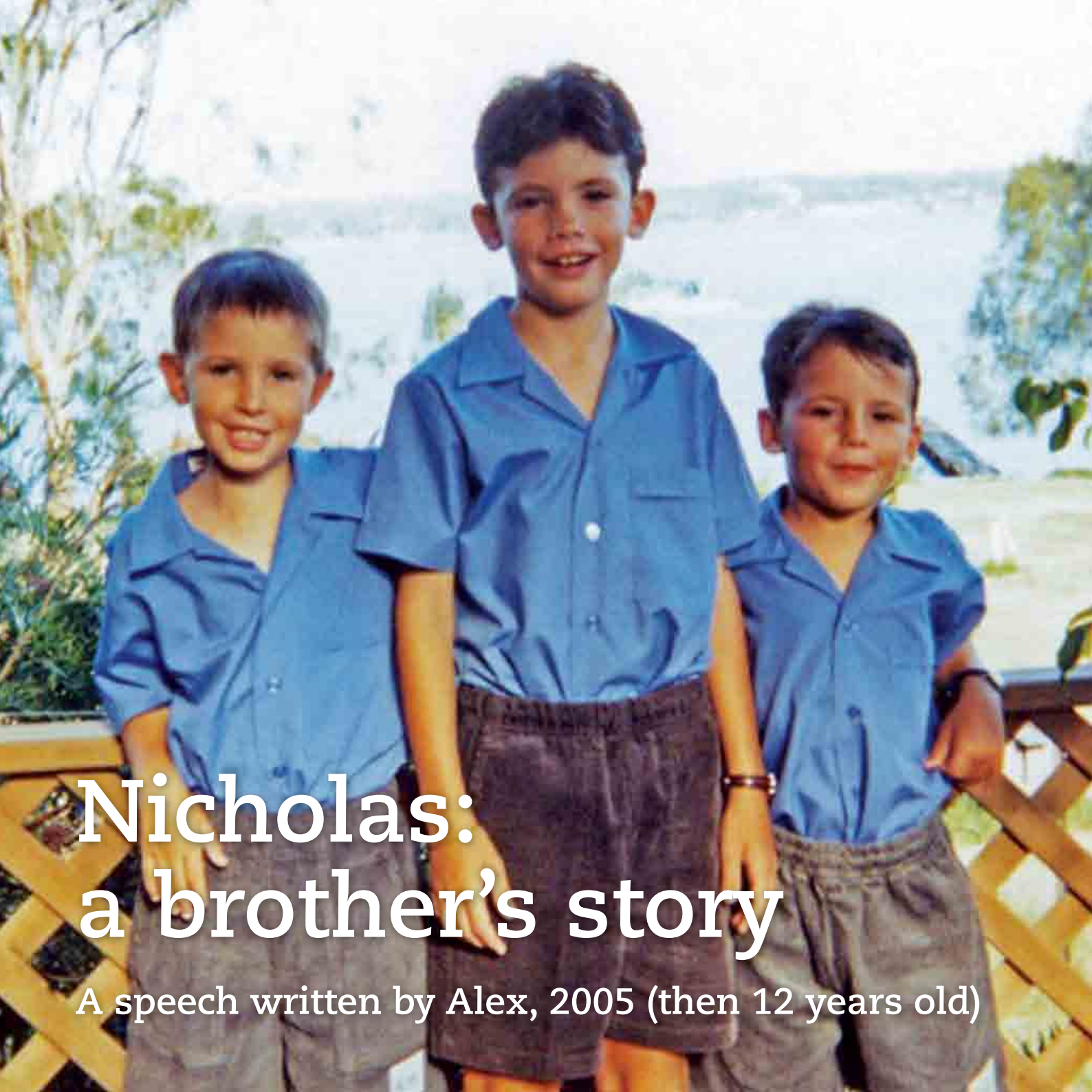
Nic's final words, "Mummy, I cannot fight them any more", completed his courageous battle.

Nicholas passed on the morning of 8 December 2004.

We miss him every day.

The Nicholas Trust is inspired by his courage. It is his legacy, and our belief that the journey of life ends in dignity and peace.





Nicholas: a brother's story

A speech written by Alex, 2005 (then 12 years old)

Experts say that by the time we are three years old our minds are already formed.

My third year of life was marked in my memory forever. It was the year my brother, and best friend, Nicholas was diagnosed with a medulloblastoma.

When I was small Nic generally ignored me; he never hurt me, just ignored me. Being the younger brother I always looked up to him and tried to attract his attention. I succeeded in doing that when I crawled my way over to the edge of our veranda.

Nic's worried shout: "Mum! Alex is about to fall off the edge!" It certainly bought a response! As soon as mum came to the rescue Nic returned to his own world.

As I learnt to walk and talk, Nic and I became best friends. We spent hours inventing imaginative games, disappearing into a world that only Nic and I could enter. We returned to reality when it was time for a round of bread and Vegemite. One game became a competition to see who could jump off the garden wall. This abruptly ended when my brother decided to help me, resulting in a two-centimetre cut across the bottom of my chin.

Not all games ended this way as we played many board games and card games. Now that I think about it, Nic always won. He had the ability to change the rules mid game: he was great at improvisation!

I was never completely aware of the seriousness of Nic's condition. I recall our family trips to Sydney with Nic to try a new form of cancer treatment. Mum and Dad would explain the treatment and we made decisions together, as a family. I remember the machines and the drugs: Topotecan, Vincristine, the porta-cath, the reservoir, the injections Nic gave himself daily. I remember thinking that treatments meant Nic would be sick for a while but always believed that he would get better so that we could resume our entry into our imaginary worlds.

My brother endured many treatments. They all looked promising, and some certainly did remove the tumours for a time. However, there is no cure for the relapses which



Nicholas: A brother's story



devastatingly occur in many cancer sufferers. My brother relapsed five times and each of those times was overwhelming. We always fought the battle together, with Nic leading the charge. Each new round of treatment gave us hope.

Seemingly unrelated and insignificant things remind me of Nic, and although it is sad, I am always happy when I remember my brother because we only ever shared good times together. The hardest reality is that the good times can't continue.

Through Nic's nine-year battle we received the best of care. Yet Nic's final days illustrated the real and pressing need for a specialised service and facilities. For Nic, and us as a family, all the beautiful memories we created were overshadowed by the circumstances and surroundings of those final days.

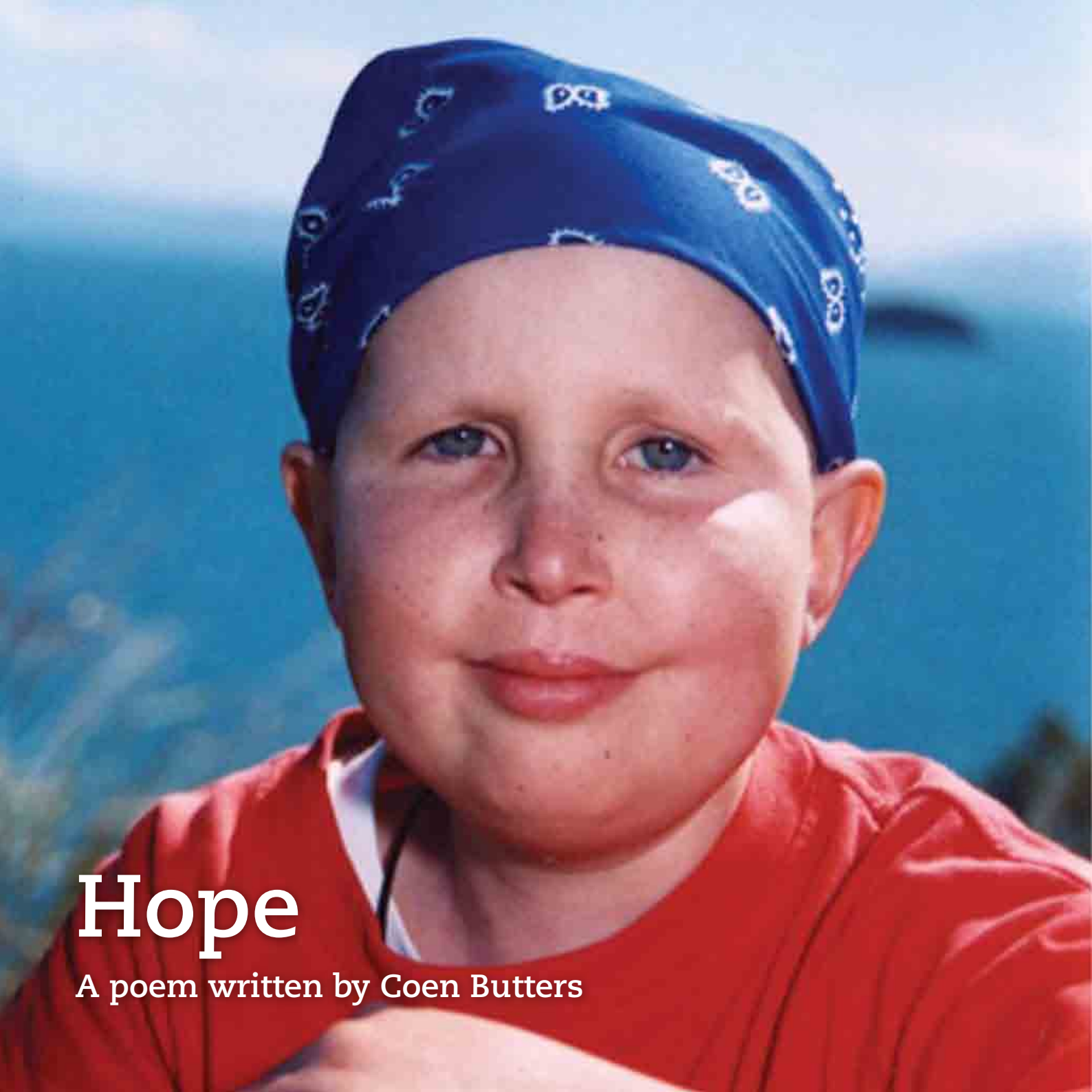
Each year 30 to 40 children in the Newcastle and Hunter region die from a terminal illness. Like Nic, each of these children is a brother, a son, a grandson, a nephew, a best friend. These children deserve the best that we can provide for them. We provide palliative care for adults but, until now, no such care for children with terminal illnesses.

When Nic died I lost my brother and my best friend. I know that he fought to the end but he lost his battle. My family and I face losing Nic every day. I feel for the other children and families fighting now to beat this disease and other life threatening illnesses.

I'll carry Nic's memory with me always, and his life continues to inspire me.

The Nicholas Trust recognises Nic's life and preserves his memory.

The Trust is Nic's legacy.



Hope

A poem written by Coen Butters

The young boy's life-filled eyes darted from mother, to father, to doctor
And settled on the toy car upon the desk.
Hope is the toy car, the aspiration to grow old,
To trust, to be healthy and happy.

The mother's eyes darted from son, to husband, to doctor
And settled on the oncology protocol on the desk.
Hope is the dream of a cure, hope is inspiration for the fight,
Hope is the love for one's child.

The father's anxious eyes darted from son, to wife, to doctor
And settled upon the tennis ball.
Hope is the plan for life, the future that lay with a child,
The goal of happiness and family.

The doctor's calm eyes darted from mother, to father, to the young boy
And settled on the computer.
Hope is the vision of respite, the injection of life, the relief from pain,
Saviour from injustice, the dream of a future.

In memory of Nicholas.

A bright, modern room with a white ceiling featuring recessed lighting and circular vents. The walls are painted in a light orange color. On the left, there is a white bookshelf filled with books. In the center, there are two red sofas facing each other. To the right, there is a large window with a view of green trees. The floor is painted in a blue and green pattern.

**Paediatric Palliative
Care Service at
the John Hunter
Children's Hospital**

Paediatric Palliative Care Service at the John Hunter Children's Hospital

The Paediatric Palliative Care Service at the John Hunter Children's Hospital provides support to children and young people from the Hunter, New England or North Coast regions with life-threatening or life-limiting illness, as well as support for their families and carers. The Service, established with Australian Government funding, also aims to provide education, advice and support to health care professionals providing care to these young patients.

The development and commissioning of these rooms took place in tandem with the establishment of the Service. In April 2010 the first member of the Service, Dr Sharon Ryan, was appointed Paediatric Palliative Medicine Specialist. Dr Ryan completed her medical degree and paediatric training in Newcastle. It was during this time that she met Nicholas Butters, and the rest of the Butters family, and this was when the shared vision for a paediatric palliative care service and facilities emerged.

Dr Ryan has subsequently been joined by a Clinical Nurse Consultant, a Senior Social Worker, an Occupational Therapist, a Paediatric Registrar and an Administrative Assistant. In the future the Service will also have involvement from other allied health practitioners and volunteers.

The Nicholas Trust rooms are intended primarily for use by paediatric palliative care patients and their families (although the rooms are used by other paediatric patients as needs require). The existence of the rooms enables the Service the ability to offer its patients a comfortable alternative to home in the supported environment of the Children's Hospital. All members of the Service, and staff of the Children's Hospital generally, are very proud of these exceptional facilities and wish to express their ongoing gratitude to the Nicholas Trust for making the vision a reality.

Paediatric Palliative Care Service at the John Hunter Children's Hospital



We hope that the Nicholas Trust rooms help to make your family's time in hospital as comfortable and stress-free as possible.

Paediatric Palliative Care Service at the John Hunter Children's Hospital



The Nicholas Trust

It is so often, through adversity, that we are challenged to make a difference.

We could not save Nicholas, but we could ensure support for families who find themselves in a similar situation.

Nicholas' story is not unique. It is estimated that within our region, 350–400 children suffer a life-limiting illness. Forty or 50 of these children will die this year. The Nicholas Trust was established to advocate for services to support these children and their families and provide facilities affording privacy and comfort through extended hospitalisation.

Palliative care is not just about symptom management and end-of-life care. For some, palliative care can last several years, while for others it may be a shorter time. However long the time, palliative care aims to enhance all aspects of the life of the sick child as well as their family, friends and community.

The construction of these facilities would not have been possible without the support of Hunter New England Area Health Service in partnership with the greater Hunter community.

Our sincere thanks are expressed to many individual, community and corporate groups.

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