

DonateLife

# BOOK OF LIFE

A collection of life-saving and life-changing stories from people touched by **organ and tissue donation**.





Her Excellency Ms Quentin Bryce AC  
Governor-General of the Commonwealth of Australia

### *Foreword to the DonateLife Book of Life*

by Her Excellency Ms Quentin Bryce, AC  
Governor-General of the Commonwealth of Australia

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As the inaugural DonateLife Ambassador, I have been privileged to observe the impressive leadership of the DonateLife team and agency network in managing organ and tissue donations throughout the country, and in educating Australians about the issues that are central to our decisions to give life.

Inspired by the work of these outstanding professionals, the *DonateLife Book of Life* is a heartfelt appeal to all Australians urging us to find out the facts about organ and tissue donation, to make well informed decisions, and to discuss those decisions with the people close to us.

Here is a collection of stories from brave and thoughtful Australians whose lives have been touched and transformed by a donor's life-affirming decision. These honest and grateful accounts pay tribute to the generosity of lives tragically and abruptly ended: the ultimate act of giving life to another as one's own life passes.

The *DonateLife Book of Life* starts its journey around Australia in DonateLife Week, Sunday 20 to Sunday 27 February 2011, a campaign led by the Australian Government's Organ and Tissue Authority to raise donation awareness among Australians and to increase our donation rates.

It is my hope in 2011 that, as these stories are shared across the nation, many more of us will be moved to think, talk and act on a decision that can help bring life and healing to thousands of Australian lives.

This is a decision for all of us and each of us. We share life and we share a capacity to give life. Our personal experiences of living and giving are most powerfully told through our stories. This book is our carriage and our conduit for ensuring that our decisions bring the greatest good to the greatest number in the Australian community.

We are forever indebted to those Australians who have chosen to give life. They have made their mark in the most profound ways and the *DonateLife Book of Life* bears their courageous stamp.

May these pages travel far and deep across our generous land.

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**Do the people close to you  
know your donation wishes?**





## Taylor's gift

**T**aylor was just 15 months old when she became a donor. Her gifts have saved the lives of two baby boys who now not only have the gift of life, but also the gift of time and a chance to grow up with their loving families.

Taylor was a very independent, outgoing and lively child. Every day was an adventure and another excuse to laugh, smile and play. She had total confidence that she was the centre of her family and greatly adored by everyone around her, but was also a great sharer. When she died it seemed a very important and logical choice for us as her parents to decide to offer her organs for donation. We know with total certainty that she would have wanted to share anything she could with others and would be very proud of what she has been able to contribute after she left us.

We will probably never know Taylor's recipients nor get the chance to meet them or tell them about Taylor, but this doesn't diminish the importance of the gifts she gave or the rightness of the decision to authorise her donation.

Being a donor is more than the gift the donor gives – it's also about the community you join when you are a donor family, the joy you get from knowing someone else is healthy because of her, and the knowledge of how very proud she would be of the special gift she gave to these complete strangers, with not a thought of receiving anything in return. It's a great comfort to know that a little piece of our angel lives on in the precious children of other families.

Lea and Peter



Taylor.

**Register your donation  
decision on the Australian  
Organ Donor Register  
and make sure your  
loved ones know your decision.**





# Claude's story

Claude's life journey began on 30th January, 1968. He lived and went to school in Aitkenvale, experiencing the trials of early childhood and developed the qualities which endeared him to many people, empathy for others and generosity of spirit.

In sport he was always a team player, playing junior rugby league and soccer. He held the junior javelin record at high school for a number of years. As an adult he played touch football, and loved canoeing and bushwalking.

'I had a great adrenalin rush today' was his comment when he landed with only his auxiliary parachute. The family moved, and Claude learned to appreciate the simple meaningful things in life: family, the land and the bush.

He worked at C.B. Marine and Patrick Stevedoring. He was an active unionist, job delegate and crane driver.

When diagnosed with an inoperable brain tumour, his working career came to an end. With former partner Judy, a son Harlee was born. After their separation, Harlee became the main focus of his life. He adored doing things for and with his son; Thai Kwon Do, music, drama, sports and became a Scout leader. He loved watching Harlee grow and was a proud, loving and caring father. His partner Frances described him as kind and empathetic and showed nothing but

respect for her and her children, the centre of her life, as Harlee was the centre of his.

Claude's ultimate gift was to donate his organs, giving hope, happiness and better health to the recipients. He was a happy person who didn't have the best of everything but made the best of everything he had. Claude was always a deep thinker, a compassionate person, a loving father, son, brother, partner and friend. Our lives are richer for having shared his short life. Rest in Peace.

Elena & Bill (parents)



Claude.

**Ask and know your  
loved one's donation wishes**





# James helped save five Australians

James was waiting for an organ transplant as a result of the complications of a lifelong disease of juvenile diabetes (Type 1 diabetes).

A massive stroke left James brain dead but in his death he was able to donate organs and tissue so that the lives of 5 other Australians waiting for a transplant were saved and improved.

James was married to Sarah with three girls.

'His hypos were gradually getting worse and more frequent – he would pass out', Sarah recalls.

He was then diagnosed with kidney failure, started dialysis and was placed on the waiting list for a kidney-pancreas transplant.

After going to bed James complained that his head was sore and so Sarah gave him paracetamol.

Sarah rang the ambulance – she noticed his left side wasn't moving, he was drifting in and out of consciousness and his speech was slurred. An ICU ambulance was called and he was taken to Blacktown Hospital.

He was transferred to Westmead and his family were told that he would never walk again. James was taken off to surgery to try and stop further bleeding.

Tests confirmed that James was brain dead at 31 years of age. When the question of donation was raised Sarah felt anxious as she knew the quicker they did it, the better it was for the recipients.

Sarah was grateful for the support of the Organ Donor Coordinator and Westmead medical staff.

James indeed left a life saving legacy - heart, lungs, liver and the corneas of his eyes – yes, his corneas were in fine condition even though his disease was causing his blindness.

Through the organ donation Sarah said she thought of the recipients – 'they were getting the call we were about to get, how their lives were going to change for the better'.

'Coping as a single mum with three young girls I am so proud of their father for being an organ donor.'



James with his family.

Do the people close to you  
know your donation wishes?





## Linda is helping to lead the way

Linda Thomas is a former ICU nurse and has been working in the organ and tissue donation sector for the past five years. Previously Linda was a Project Officer for the National Organ Donation Collaborative and worked as a Donor Coordinator with DonateLife. For the last twelve months she's been a Clinical Nurse Consultant (CNC) sharing her role between hospitals.

This is a very exciting time for WA as due to Linda's CNC role, organ and tissue donation has had a major presence at the above sites with one being the children's hospital and the other being in the private sector.

As Linda describes it, the best part of being a CNC is introducing and developing the CNC role and in a way being a 'pioneer' at each site. The unpleasant aspect of the

job is seeing families disappointed and disheartened when they would really like to donate their loved one's organs and/or tissues and they are unable due to medical reasons or logistics.

At each site Linda works with the Hospital Based Medical Director to provide leadership and consultancy to nursing, medical and allied health care professionals in the area of organ and tissue donation.

Linda finds great satisfaction in seeing donor families find some kind of comfort in their grief knowing that from a tragic situation another person has benefited.

When asked what people's reaction is when you tell them what you do for a living: 'That must be hard!'



Linda (centre) with colleagues.

**The most important thing  
that helps a family's decision  
is their knowing the donation  
wishes of their loved ones.**





# Back on track

The first thing I remember when I woke up from a liver transplant operation was that I didn't have a headache.

In the lead-up to my transplant my health got worse and worse. I always had a headache, felt tired and had no energy. I couldn't work, couldn't play with my kids and couldn't exercise.

I was diagnosed with a liver disease at 22, so I've known for years that one day I would ultimately need a transplant. Last year my condition deteriorated suddenly and I was put on the transplant waiting list.

The transplant team thought I wouldn't last 10 days without a new liver. It was an emotional time for my wife and quite stressful for my little girl who was old enough to understand her dad wasn't well. She would ask 'Have you got your liver yet?'

I wasn't worried about dying. I was worried about not being there for my family—financially and emotionally.

Surprisingly my blood tests improved, but I would still need a transplant to live.

I was to be discharged from hospital to wait for that phone call that would save my life, but then the transplant coordinator came to see me and said, 'we have got you one.'

It was all systems go. I thought I was about to go home and then early the next morning I was waking up with a new liver.

Straight away I felt better. After a month or so, I started to go back to my normal routine, the routine I'd had before becoming really sick.

I am now back at work and have the energy to play with my kids—five year old Sarcha and two year old Finn.

I am jogging again and a regular 50km bike ride is the norm these days.

It took me three months to sit down to write to the donor family. I did it when everyone was out and it took me six hours to write. It's hard to write. What do you say to thank someone for saving your life.

Johnny



Sarcha, Johnny and Finn.

**Start the organ  
and tissue donation  
discussion today**



# A very special Christmas

In December I donated a kidney to my older brother Stephen at the Royal Melbourne Hospital. The decision to donate was a quick one, but the process to do so took over a year. I travelled to hospital twice before the operation and met the surgeons, anaesthetists, coordinators and physicians.

From my home town in Nowra, 1000 kilometres away from my brother, it all had seemed rather disconnected and surreal at times but those trips to Melbourne, where I would meet him at hospital for our tests, made me realise that this all made sense. His condition was deteriorating and when I saw this, I was completely comfortable with my choice to donate.

One great thing about live donation is that you know when it will happen. This gave me the best chance of being as physically and mentally prepared as possible. I made sure that I researched

the subject and spoke to other donors to learn as much as I could before the surgery. This helped me, my partner and children to have a clear understanding of what was in store for us.

The transplant was successful and both of us were home for Christmas—which was spent quietly recovering. Stephen is now doing really well and I notice no difference in my health now that I only have one kidney. I feel so glad that I could make such a difference to someone's quality of life.

Support from family and friends was there before, during and after the event and for that I am so grateful. When I think about my experience, I remember I wasn't alone. Stephen and the rest of our family members had also gone through the whole experience too. We did it together.

Robin



A lighter moment after surgery with a kidney dish!



**Organ and tissue donation  
for transplantation is based  
on the concept of altruism.**





## Gift from my mother

If you ever have a doubt about organ donation then please read my story.

I was sick for a year before eventually being diagnosed with chronic renal failure.

My first thoughts were—no way, I am only 25 and stay fit by playing sports, they must have it wrong—but they were right.

We went through all the tests and I spent almost a year getting healthy enough to receive a kidney transplant from my mother—God bless her.

It has now been over 15 years and I am lucky enough to have a beautiful family of my own and I live life to the fullest. The gift you give WILL change or save a life and in turn can fulfil other people's lives also. Please register to donate today.

Mike



Me with my daughter Georgia on her birthday.



Me today, living life to the maximum... lol.

**Do the people close to you  
know your donation wishes?**





# The gift

It was in March that I went to see my GP regarding headaches that would not go away over a two week period. Preliminary observations showed a very high reading of blood pressure which had been left unchecked for a lengthy period of time. Blood and urine tests were also taken. Less then a few hours later my GP called to tell me to pack my clothes and head for hospital as I was in renal failure.

Initially I was in shock, then told myself it would be alright as I was only 29 and kidney failure is usually more present in the older generation. After several days of testing and a kidney biopsy, the bad news was delivered. It was revealed that I had a disease known as IGA nephropathy and was at end stage kidney failure with a combined kidney function of only 7 per cent.

The news was initially hard to swallow as my long term partner and I had just had our first child and life was just taking a new and exciting path. The challenging road began as I was put on the transplant waiting list and was told it could be a lengthy wait.

My family had discussed the possibility of donating a kidney. My parents and four other siblings were more then willing to donate a kidney. As all my family members underwent a series of tests, my health was weakening. I had lost a significant amount of weight and was struggling to get out of bed in the mornings.

As the toxins continued to build in my body (through lack of filtration) I was told I would need to start dialysis. I underwent surgery to have the tubes inserted into my stomach so I could start peritoneal dialysis. During this period tests revealed that my eldest brother, Matthew, was considered a perfect match for donation.

In September I was transplanted with my brother's kidney. It is now a little over a year on and my partner and I are expecting our second child. I now have the energy to enjoy life with my family.

Matthew has done a very selfless deed in that of giving. I hope that the way I continue to live my life brings joy to my brother, as without his gift I could not have planned for a future.

Stephen



Kylie, Stephen and son Joseph.

One organ and tissue donor  
can save or enhance the lives  
of 10 or more people





# Corneal transplants: the gift of sight

**M**y journey began when it was found that my eyesight was deteriorating and I was having severe discomfort from contact lenses. The eye specialist and optometrist advised that my problem was caused from Keratoconus. Keratoconus is a degenerative disorder of the eye in which structural change within the cornea causes it to thin to a more conical shape than its normal gradual curve.

I was not able to obtain satisfactory vision from spectacles because of Keratoconus.

After years of treatment and extensive trials and experiments with contact lenses, I was informed that there was nothing more that could be done with contact lenses. This was a major trauma. If I could not wear contact lenses, I would be declared legally blind. I had a wife and two children to support and my focused vision, without aids, was limited to perhaps 30 centimetres. The outlook was indeed bleak.

The eye specialist recommended I consider corneal transplants for both eyes.

I received a corneal transplant for my right eye and struggled for vision, working and supporting my family, with one increasingly painful left contact lens, until the sutures were removed.

This first transplant was an emotional experience for me. I had to come to grips with the fact that a person would have to die in order for me to receive a desperately needed cornea.

I had the second transplant. I was then able to wear spectacles with satisfactory vision, no pain or discomfort for the first time in many years.

The vision in my right eye had deteriorated with the recurrence of the Keratoconus condition. This resulted in a replacement corneal transplant. This was successful.

This has been a long and involved journey. I hate to think what life would have been like had I not been able to receive the wonderful donation of three corneas.

John

Australia is  
a world leader  
for successful  
transplant outcomes



## The value of 'thank you'

**M**y wonderful husband who appeared to be the picture of health suffered a massive stroke. Having completed 10 ultra-marathons, playing touch rugby, coaching my son's rugby team and having a recent check-up with the doctor. We were in disbelief when the doctor in ICU told us that John had suffered brain death.

The next words from this doctor were 'have you thought about organ donation?'. I knew my husband's wishes and in keeping with his generous nature, my children and I agreed to donate his heart, lungs, kidneys and corneas. The trauma of watching him being wheeled to the operating theatre—knowing that any hope of recovery was about to end, haunts me still.

Many people thought we should find comfort in this generous donation. I'm afraid I couldn't at the time. A few months later, we received two thank-you letters/cards from the families of recipients. These were much appreciated. My husband donated seven organs and we received two thank you notes! I send 'thank you' cards for flowers and food, but many recipients haven't said thank you for a gift that potentially gave them life. It makes me wonder.

My advice to recipients who wonder about saying thanks is—DO IT! It can't possibly make the family feel worse knowing that someone values the gift and the chance they have been given.

Colleen



**Less than 1 in 5 Australians  
have discussed in detail their  
donation wishes with  
their loved ones.**





## New vision for a young artist

I was driving along to a clinic appointment last week and I was amazed by the shape of the ripples in the river and the crispness of lines in the big old trees. Once I arrived at the clinic, I found I could read one more line on the eye chart since last month's visit! These 'small' joys make me realise the gift of sight is the most valuable thing I have ever received.



As an artist attention to detail is important—a work I completed after my surgery.

A couple of years ago when I was 18, I received my first corneal transplant. It was a tumultuous and exciting time for me. I had just moved out of my parents' house to a new city in order to study a fine art degree at university. I had been chosen to exhibit in the Year 12 Perspectives at the Art Gallery of WA. Since I was eight years old I had been coping with only one eye capable of vision with aids. That was until I got the call on a Friday and I was in surgery on the Monday.

Recovery was a challenge and journey, and it was often very hard to cope with. But everyday I experience amazing feats of vision that as an artist and a person, are invaluable. I cherish my new cornea and the donor who so generously allowed me this gift.

Bree-Anna

Do the people close to you  
know your donation wishes?



# 10 years on and still going strong

I've had bronchiectasis all my life as a result of whooping cough when I was two years old. My lung function got so bad I knew a dose of flu could be fatal so I dreaded every winter.

A few years ago my lung function was so poor my doctors told me I should seriously consider going on the lung transplant waiting list, where the average waiting time was 12 to 18 months.

After waiting 15 months I received a phone call telling me suitable lungs had been donated. After nine hours in the operating theatre with two surgeons working together, the operation was a success and I was taken to the Intensive Care Unit to recover.

The first time I tried to walk was very hard and I needed the support of the handrails on the wall, but gradually I got stronger. The following three months involved three sessions a week at the physio gym, numerous doctors appointments and giving blood regularly. The medication consists of over 30 pills a day and at first it was very daunting but now it is a habit like cleaning your teeth.

As we had been away for 18 months it was very emotional arriving home and being

met by our family. I couldn't wait to go to the beach for a swim and to be able to enjoy the clean fresh air and ocean water.

I feel stronger as time goes by and since my double lung transplant the transformation to my life is amazing. I feel very privileged having a second chance at life and am very appreciative to all concerned. It wasn't easy but positive thinking and a very supportive husband helped me get through it.

Shirley



Shirley.



**40% of Australians  
do not know the donation  
wishes of their loved ones.**



# Christopher's story

Christopher's donation story started when he collapsed at school one day from a cerebral haemorrhage just five weeks short of his 15th birthday. That evening we were told that Christopher was not going to survive. Michael, our two other boys (Daniel and Harrison) and I sat huddled together absorbing the news. Our beautiful, happy, and seemingly healthy boy would not be coming home. He would never be coming home. It was unimaginable!

There were many thoughts that went through our minds at the time but the one constant thought was that Christopher's big, beautiful, loving heart had to keep beating. Knowing that part of Christopher was going to keep living was a great comfort to us whilst we were dealing with losing him. Christopher donated his heart, lungs, liver and kidneys.

Although he hadn't specifically stated that he wanted to donate his organs, in a family conversation about organ donation a short while before his death, Christopher had indicated that he was a supporter of organ donation. Michael, Daniel, Harrison and I just knew that he would have wanted to help others in this way and so it was an easy decision. The transplant team lead us through the long process, showing great care and compassion and treating Christopher with dignity and respect.

It has been said that donating Christopher's organs was a very generous thing for us to do. We didn't feel generous,

instead we felt that we were just doing what felt right—right for us to help get through our loss and right for Christopher.

It is now nine months since we lost Christopher and we miss him terribly. We miss many things about him but mostly we miss the love and laughter he brought to our lives. We know that his gift has given five very lucky recipients and their families a new beginning. We hope that they all lead happy and healthy lives filled with some of the love and laughter he brought into our lives. We are so very proud of Christopher. He will live forever in our hearts.

Judy, Michael, Daniel and Harrison



Christopher.

**Register your donation  
decision on the Australian  
Organ Donor Register  
and make sure your  
loved ones know your decision.**





## From the other side

I was working as a regional donor coordinator for four years when my dad was diagnosed with end stage kidney failure secondary to undiagnosed cardiomyopathy.

My dad was a farmer and was used to working 15 hours a day. To see him on dialysis and the restrictions to his life, gave me new found respect for people on dialysis.

Two heart surgeries and two years later, my dad received a call that there was a kidney available. After the initial excitement, my parents and I became very emotional, knowing while we were celebrating there was a family going through one of the worst days of their life. Dad's surgery was uncomplicated, but five days later his condition deteriorated. He was admitted into the intensive care unit with high temperatures and decreasing renal function. My dad's diagnosis of Adeno Virus did not give us any comfort as his prognosis was bleak but miraculously he survived and so did his new kidney.

Dad has named his kidney Sidney, after his 80 year old neighbour who works like a Trojan. We celebrate two birthdays a year—one for dad and one for Sidney.

Dad has resumed being an active member of the community and is a fantastic 'papa' to his grandchildren. Our family is eternally grateful to the donor and donor family.

On a personal note, this experience has given me a richer insight to families with loved ones who have organ failure; the mixed emotions of receiving a transplant and the difficulty of putting pen to paper to thank the donor family.

This first-hand knowledge has helped me when speaking to a donor family—having gone through the process I have the utmost faith in the people and the process of organ and tissue donation and the benefits that it can bring.

Sue



Sue and her dad.

**The majority of  
Australians support organ  
and tissue donation.**



# DonateLife Week

I hope my story will help start a discussion about organ donation. Here is a life that was saved because of DonateLife Week.

My father had been slightly ill with liver disease for a few years. Bloating, drainage, tubes, inability to walk etc soon became standard events and words in our house. Before that, he was the owner of his own business, a grandfather of two and a father of two daughters. He was pretty active overall.

I received a call from my mother telling me to 'come home, there's something wrong; I think he's had a stroke'. No, it wasn't a stroke; it was to be the first of many encephalopathy attacks that my father was to suffer. They were horrific for all of us—him, Mum, my sister and me. It was gut wrenching to see my father like this.

These attacks turned him into a shell of the man he formally was. He didn't know his name or where he lived, he couldn't even drink through a straw at some points. Forever—2am calls. There were many trips in the ambulance and many waits in emergency.

Then his kidneys started shutting down. The liver is vital for getting rid of toxins and without the liver the kidneys had to pick up the slack. They were getting tired.

Our wonderful hospital team helped his kidneys to kick-start many times. But for each time the kidneys failed there was another 'touch and go' time in ICU,

another weakness that he was struggling to fight and another hope that this would all go away was gone.

Eventually we were told 'they don't get any sicker'. They gave him seven days. Our odds weren't great, as Dad's blood type wasn't common.

It was just after DonateLife Week that I got a call from Mum. At first, she hung up. I honestly thought he'd died. But, she called back and struggled with 'we've got a liver'. The surgery was a great success and really, he's had a dream run. He's now up and moving again, pottering at work and he's out in his boat. The most important thing is—he's spending time with his two grandsons and the rest of his family.

I can't find words that even come close to thanking the people who said 'yes, I would like to donate my loved one's organs'. To make such a selfless decision at such a harrowing time is something I couldn't possibly begin to understand. But they have and because of that my father is alive today. And not only alive—but thriving!

I honestly believe that, if it weren't for DonateLife and the drive they had, that my father wouldn't have received the organ he was so desperate for. All I can do is thank them from the bottom of my heart.

Shelley



**Organ and tissue donation  
for transplantation is based  
on the concept of altruism.**



# My donor kidney and me

I was diagnosed with renal failure after a number of years of non-specific illness, which was not diagnosed as relating to my kidneys. At this time, I was married with two adult children and was aged 49.

I suffered a partial loss of my eyesight. The eye specialist to whom I was referred told me that the problem could be related to my kidneys. I subsequently consulted a renal specialist and after a kidney biopsy was told that I was in renal failure.

I commenced haemodialysis at a Sydney renal unit. After two years, I started home training after being encouraged by the wonderful renal nurses and later undertook renal dialysis at home.

We then relocated to Forster on the North Coast with the home dialysis machine. I received a late night call about a kidney being available for transplant in Sydney. However, after being prepared for surgery, the kidney was found to have been damaged and the operation was cancelled.

The day after my 60th birthday, I received a call to say that another kidney was available. We were told that the kidney was not a match, apart from the blood type, but we decided to take the risk after nearly 10 years of dialysis. The operation proceeded well, due in no small part to the wonderful doctors and nurses at the transplant unit and the great follow-up staff.

As you may notice, I have used the term 'we' as my husband was my carer for the period I was on dialysis and also attended all medical appointments and discussions. I found this to be most important as I did not always take in what was being said and was sometimes emotional.

Since my transplant, my health has improved beyond belief. I have always tried to follow medical advice and stay healthy even during dialysis, so that any transplant would have more chance of success. I have kept this attitude as I realise that a transplant is not a cure but another form of treatment.

The hardest thing about dialysis was that my family, including grandchildren, were a long distance away and we could not travel to see them without having to arrange dialysis in hospitals. This was particularly difficult on short notice when a family emergency arose and left me feeling helpless.

I would just like to let donor families know that their brave decision to donate the organs of their lost loved one means so much to so many recipients and their whole families.

I have lived with my donor kidney for nearly 10 years. I would not have been able to see so much of Australia had I not had a transplant. I bless the donor family every night.

Judy

**Start the organ  
and tissue donation  
discussion today**





## Danielle's Story

On the 5th June, a baby girl was born to Barrie and Helen, baby sister to Darryn, eight, and Denise, six.

Danielle always wanted to grow up fast and do the things her big brother and sister were allowed to do. She was very fussy about what she wore and how she had her hair.

When she was old enough to go out, she was always amused that her older sister was required to show her ID and not her.

Danielle was always willing to help anyone out if they needed assistance, so her decision to donate her organs was not a surprise to her family.

Her illness was sudden and would have taken her life immediately if it were not for a dedicated team of intensive care staff who tried to halt the effects of meningitis. It was a virulent strain of the virus and had already shut her system down. Obviously it came as a huge shock to her family and friends—she was only 21.

We take some comfort in losing Danielle from the fact that she was able to continue to help people by saving and improving their lives. We are fortunate that we have been kept informed of her recipients' progress.

Helen and Barrie



Danielle.

Australia is  
a world leader  
for successful  
transplant outcomes



# Aaron's story

**A**aron was diagnosed with Cystic Fibrosis at the age of one. He spent most of his early life battling the disease with trips to hospital. At 19 he had to defer his university studies due to ill health and was placed on the transplant waiting list. At the age of 20 he was given a second chance by receiving a double lung transplant.

After this he qualified as a Registered Nurse, joined the board of Cystic Fibrosis Tasmania and become its president two years later. He married; bought a home; was prominent in the media; was a leader for the Ready for Life diabetes camps; worked with Transplant Australia to promote organ donation; competed in multiple Transplant Games; and, was Tasmanian Team Manager for the games held in Perth and won over 15 medals. Aaron took part in the City to Casino fun run; was named Tasmanian Young Achiever of the Year 2008, and he also received the Young Achiever Community Service Award and the Pride of Australia Courage Medal in the same year.

All this (plus too many other achievements to list) were all made possible by the gift he received. Unfortunately Aaron passed away on Anzac Day, aged 29, but he made the most of the extra 10 years he was given and left behind a great legacy.

Judi



Aaron at the Perth Transplant Games.



**Ask and know your  
loved one's donation wishes**



## Kylie's story

**W**hen I was 14, I was dying. I said no to transplant a million times and even walked out of clinic appointments whenever it was mentioned. I thought that being born with cystic fibrosis meant that dying was my destiny and that was OK with me.

At age 15, I did the work up and I was put on the official waiting list for a double lung transplant. I waited almost four years for a donor. Because I am very small in stature and I have a specific blood type, the wait was grueling. When I was 17, I had a stroke and I believe that this deprivation of my abilities was what gave me the strength I needed to keep on going until I got my second chance.

A year later, I received the phone call (the frantic footsteps up the stairs confirmed it). No matter what happened from that moment on, I had a chance at living. I felt peaceful, though sad that somebody must have lost their child that night... and that's never an easy thought to process.

After it was all over, I could not believe the inhale could be so long and not in gasps! It was the most amazing feeling.

Since my transplant I have done things that I have always wanted to do including becoming a qualified youth worker/counsellor to young people. I volunteer support to young people living with chronic conditions, I help run support groups, I have been part of a rotary club, I have spoken at international and national events and

I also sit on an advisory council for the children's hospital.

I have learnt to appreciate the people who love you. I have watched 17 of my very close friends pass away from illness and complications. But they all taught me something that I take with me through this journey and for that I am always grateful.

I think of my donor family literally every single day. I think of their loved one and I'm always imagining they are enjoying things alongside me. I think the word hero gets thrown around so flippantly these days....but donor families are true heroes in every sense of the word. They literally save the lives of people they have never and will most likely never meet. In their darkest hours, when they are at their most vulnerable and in so much pain...they choose to save lives and bring a light to the end of the tunnel for so many people who are suffering. That is something i will never ever forget for as long as I live.

I think that you need to be able to see the beauty that every single day brings to you. And if one day you are having a really hard time seeing it, then make the beauty yourself. Go out and try something new, do something new, see someone you love and be grateful you have them there to make you smile. Life is there to enjoy and I'm so unbelievably lucky to be here to experience it in all its glory!

Kylie

**Ask and know your  
loved one's donation wishes**









**Australian Government**  
Organ and Tissue Authority

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#### Enquiries

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#### Alternative format

The *DonateliLife Book of Life* is available electronically on the Authority's website at [www.donatelifelife.gov.au](http://www.donatelifelife.gov.au)

