

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 Gommonwealth of Australia

Foreword to the DonateLife Book of Life

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

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 indehted 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.

GOVERNMENT HOUSE CAMBERRA ACT 2600 AUSTRALIA FELEPHONE +61(9) 5082 1525 FAONIMALE #61(2) 5285 559 Discover the facts,
Decide about becoming
an organ and tissue
donor and Discuss your decision
with the people close to you.



Donate Life Book of Life

My transplant after 10 years wait!

dialysed successfully for nearly 10 years in Sydney but I was determined to live as much of a normal life as I could. To stay as healthy as possible, I found that if I dialysed five times a week at three hours a time, I was in tip-top health.

That allowed my wife and I to enjoy three overseas trips, organising dialysis by the world wide website www. globaldialysis.com which lists most clinics and centres around the world.

In 2004 we spent a week in Paris and a week in Calpe, Spain. In 2005 we spent five weeks driving around France. For

holidays, I drop back to three times a week at five hours a time on dialysis.

The final trip in 2007 was five weeks in Istanbul, Vienna, Venice, Taormina in Sicily and Rome.

My transplant has been marvellous and I now enjoy all the freedom I wanted—but dialysing, if planned, can let you do most things too!

So, do not give up but continue to enjoy life to its fullest!

Maxwell



My wife and I in Rome when dialysing.

DonateLife Book of Life

Any day is a good day to talk about organ and tissue donation.



JonateLife Book of Life

For the love of 'Adi' A life lived to the fullest

Our beautiful son, brother and uncle was pronounced brain dead from a Colloid cyst which had grown in the centre of his brain since he was born.

We had always talked about organ donation since Adrian's uncle Simon had passed away—he was an organ donor. We followed Adrian's courageous, unselfish wishes, he had a healthy body which was used to save many lives.

We were all thankful to have had the time with Adrian in the hospital before the organ retrieval for us to love and hold him.

His sisters Natalie, Jill and Nat's partner Gary, had fun reminiscing and being able to take hand prints.

It was sad for Adi's youngest sister Alyse and her fiancé Pate as they were in Norfolk Island and unable to get there in time to be with him at the hospital.

His niece Lara, nephews Zac and Jake talk about uncle Adi every day, they make us laugh with their stories.

Adi had just started an apprenticeship as a builders' carpenter. He loved his new job!

He travelled to Germany where he learnt to snowboard in Switzerland, rode a scooter in France and searched for ancestors in Scotland.

Adrian had many friends; three were like brothers to him, Kettle, Sheedy and Morrie, whether fishing, shooting or playing the

Playstation Adrian always made time for his mates.

Being best man in Morrie's wedding was one of the highlights in Adi's life.

We had his funeral service at home where he loved to be, we gave him a great send off. His faithful hound Zharn is ours to look after now for Adi.

Forever in our hearts and memories. Forever loved.

Mum, Dad, sisters and family xx



Any day is a good day to talk about organ and tissue donation.



ateLife Book of Life

My mum gave sight to two people

My beautiful and vibrant 61 year old mother died suddenly last year after being diagnosed six months earlier with a brain tumour. She had the most beautiful eyes, an eye for beauty, a sparkle in her eye for fun, an eye for a husband for me (she found me one), an eye for a good recipe and an eye for a bargain!

It is only nine months since she died and I miss her so much—as do her

grandchildren and her husband of 40 years that she left behind. It is so comforting to know that even though we don't have her, out there somewhere are two lucky people who benefited from the donation of her eyes.

What a beautiful world they must see through those eyes! In a way, her fabulous legacy lives on.

Christee



Do you know the donation wishes of your loved ones?



Danny and Edna A mothers gift to her son

Danny was two years old when he was diagnosed with kidney disease. Doctors gave him 11 months to live. Parents Ashley and Edna refused to accept this and looked for options to give Danny a future.

So started three decades of struggle. Dialysis started at the age of seven. At nine and a half Danny received his first kidney transplant and could be 'one of the kids'.

Danny's transplanted kidney failed when he was 16—a difficult time for a normal teenager. Danny's prime teenage years included struggles with depression and difficulties in connecting with people.

At 23 Danny received a second kidney transplant and he pursued a career in IT. Eight years on, aged 31, Danny started dialysis again. Danny made the most of the challenge. He was fitter than ever with Latin dancing and dialysis six times a week.

As the second kidney started failing Danny's mum Edna started to detoxify hoping to give her son a healthy kidney. Getting another mother's perspective helped Danny to gratefully accept his mother's wishes and Danny received his mother's kidney.

It didn't all go smoothly. Danny's lungs collapsed and he was in ICU for four days, but he bounced back and life blossomed.

Today Danny has four kidneys, the functioning one is named Shalah—its namesake a holy 16th century rabbi. Following the transplant Danny embarked on a start up and graduated from two top master's programs.

Edna aged 57 pursed peace in the Middle East and the global environment through her bicycle rides. In 2010 she completed a seven week, 4,000 km bike ride. Edna says, 'If you look after yourself, life is even better after donating, you appreciate life more.'

I met Danny the year after the transplant and we are now married. Danny says, 'experience tells me a normal life is how you define it. Life on dialysis wasn't terrible but it was limited. I aspire to succeed because I want to make something of my life, and also because a lot of effort by a lot of people has been put in to keep me alive. My success is a way of repaying that effort.'

Elif



Do the people close to you know your donation wishes?



A better man

y story starts in the early 70's when I contracted hepatitis which was not treated until 2009. By this time my liver was cirrhotic and needed replacing.

I was transferred from my hometown of Darwin to Adelaide and had a transplant soon after. This has allowed me to see my grandson born and grow closer to my daughters. I thank the donor every day for giving me this opportunity, for without their gift none of this would have been possible.

Dean



The majority of Australians support organ and tissue donation.



Ray Ray's story

My husband Ray received a kidney transplant. Ray had a rough life up to then with several medical problems including Alports Syndrome. After the transplant he spent many months in hospital.

Under the amazing care of doctors and staff, Ray survived another 14 years before he passed away aged 48 years, from unrelated complications.

We had the opportunity to travel and enjoyed doing things you cannot do on dialysis. When Ray received his kidney he was also given the opportunity to watch his two children grow up.

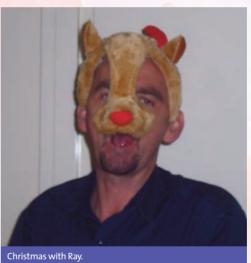
Without this gift our children Jamie and Emma would not have had their dad for the extra 14 years.

The gift of donation is amazing and it's so important to talk about your wishes when you are well.

We thank the donor and their family. We will be forever thankful to the Renal Transplant Team.

Also, there were so many other amazing people in Ray's life who gave him quality of life as well as support and guidance through his many challenges.

Karen



In Australia family consent is always sought before donation can proceed.



New found friends

We have known for 20 odd years that Tony, my husband, has Polycystic Kidney Disease. Three years ago, our lives were turned upside down.

Acute kidney failure knocked Tony into hospital and so began our journey. He endured several surgeries to prepare for dialysis, which started nine months later. Our life no longer belonged to us—our social life, our work commitments and holidays were governed by dialysis.

I did not hesitate in offering my kidney so Tony, we as a couple and our family, could have a better quality of life. I hated seeing him unwell, even after dialysis.

We were privileged to have the most amazing team assist us with our work up. My never ending questions were always answered and not once did I feel frightened, but I felt empowered that I could help my man.

This team soon became like new friends. They cared for us as individuals and wanted us both to be informed and make independent decisions about the transplant.

Surgery and recovery went smoothly, and I was home four days after surgery and Tony after six days. Three and a half months later, we marvel at all our spare time. We love that we can just take off for the weekend and are tied to no machine.

We are both back to work, but are monitored by our treating hospital and a friend on the end of the phone if we need to call.

Pamela



Australia is a world leader for successful transplant outcomes, yet has one of the world's lowest donation rates.



Naomi

My name is Judy and I'm the mother of two very beautiful daughters, Gayle who is still with me and Naomi, who passed away last year.

I am also the grandmother of two adorable grandchildren, Tyson and Dannika. We all had a very close relationship when the most unimaginable thing possible happened and our lives were changed forever.

My youngest daughter Naomi passed away. I couldn't and still can't believe it's happened. As far as we were concerned Naomi was a healthy 24-year-old and we had no idea what was to come.

Naomi was taken to hospital at lunchtime and passed away early that night. Being in the hospital with her as she slipped away from us was, I'm sure, any parent's nightmare. I felt like someone had just ripped my heart into pieces. I was so numb, like it wasn't happening to me.

It was a really bad nightmare and I wished I could just have a good night's sleep and it would all be okay in the morning. I realised when the doctors had come back to talk to us again that it was all real, no matter how much I wished it wasn't.

I knew once she had passed that I had to speak to the doctors about donating whatever we could as Naomi had made it very strongly known right from when she first got her learner's driver's licence, that she wanted to be an organ donor.

We all often talked about it, so to make that final decision for me wasn't that hard. We were, however, surprised to know that due to her circumstances, we were only able to donate her corneas which helped two people. I knew, even though I couldn't keep her here, that others would benefit and she would still live on in them. I know she would have been so excited to know she was able to help these people live easier lives.

It's been the hardest thing I've ever had to go through and every day is still a struggle but I know that Naomi is and always will be around us.

We love and miss her so much.

Judy



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



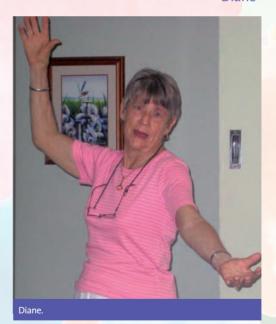
A dream come true

stood on the bank of the East Alligator River, Arnhem Land Northern Territory Australia. It was a dream come true. My husband and I were on the trip of a life time. A trip that a few years before would have been impossible for me to take.

I had suffered kidney disease since I was a young woman and now in my midfifties and having a new kidney I was at last able to fulfil my dream.

I had lived on just one fifth of one kidney for most of my adult life and the day the doctor told me that my little bit of kidney had died was devastating. I spent three years on a dialysis machine before being called up for my transplant. What a difference it made to my life. I have been able to enjoy the birth of five of our eight grandchildren since then and to watch them grow is wonderful. I will forever be thankful to the family who knew their loved ones wishes regarding donating organs as their gift has given me a new lease on life—a freedom that I would otherwise never have had. Thank you to the unknown donor.

Diane



Less than 60% of families give consent for donation to proceed – often because they do not know the wishes of the deceased.



Thank you for giving me my life back

When I was 23 years old I went to get a new pair of glasses. I was planning on a trip to see family and wanted to check my glasses were OK because it was a long drive. I fully expected to go in, have my test, pick out a pretty new pair of glasses and a week later go back and collect them.

Instead I was given the news that I had severe keratoconus (a degenerative condition of the cornea) and I was pronounced legally blind.

By the time my husband picked me up and I got into the car, I was sobbing. I couldn't believe that I had just received such life changing news with no warning what so ever. I started thinking about how much this would affect my life and my career (I was about to become a nursing student).

After extensive tests I was advised the extent of my condition was one of the worst they had seen. Nothing would fix it except a corneal transplant for both eyes.

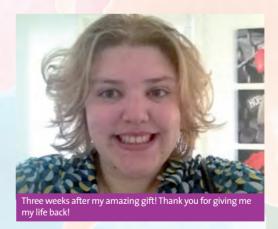
I remember feeling so upset, because while I was becoming excited about receiving new vision, a family would be mourning the loss of their loved one.

I have just received the most treasured gift—my first cornea transplant—and things are better than ever! My doctor is very impressed with my results and said that 'things could not have gone better'!

Against all odds and some very negative attitudes from people thinking I wouldn't make it, I'm more than half way through my nursing program. I have vowed to spend my life using the amazing gift that I have been given.

I have no idea who my donor is, and I will never be able to find the words to express how grateful I am. I owe them my life. Thank you, from the bottom of my heart, you have given me my life back.

Tara



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



To give and to take. To donate and to receive

My wife and I have witnessed both sides of the donation and transplantation equation. We became a donor family when our youngest son David died at the age of 20 and became an organ donor, and then later I was to become a recipient following my own lung transplant.

Many years ago we were advised our son David was in the local hospital, after suffering a severe cerebral haemorrhage due to Marfan's Syndrome. David was six feet seven inches tall (201 cms).

We were most appreciative of the way we were approached about donating David's organs. The respect, dignity, empathy and professionalism from all staff was beyond reproach and was unforgettable. The whole process was explained to us in a most satisfactory manner and we were with the doctors at David's bedside when we were advised that his condition was irreversible and terminal. The two doctors were very thorough in explaining to us how and why our son was pronounced 'brain dead'.

I cannot emphasize enough how the donation of David's organs has cushioned the shock of our loss. Every day since David's passing we have appreciated the fact that eight other people are either alive today or enjoying a better quality of life, thanks to David's generous gift. My own transplant story began after being diagnosed with pulmonary fibrosis. It was not until four years later that I was added to the waiting list for transplantation and a further three years after that I received the long awaited call offering me the gift of life.

My sincerest thanks to the donor and family for this wonderful gift. After having spent three years on oxygen and with a mobility scooter, I now enjoy a free and active life pottering about on the hobby farm acreage my wife and I have bought. I see every day as an absolute bonus and windfall.

John



If you want to donate life, discuss it today, OK?



Mitchell Taller, smarter, funnier

Our son Mitchell was a beautiful person inside and out. He was tall dark and handsome, sensitive, generous and kind, with a great sense of humour and a special gift for making the lives of those around him just a little bit brighter. Sadly our lovely son also suffered with bouts of deep depression and it was one such episode that ultimately ended his life.

The circumstances could not have been more heart wrenching when we (his family) were called upon to make a decision about organ and tissue donation. Thankfully we had discussed organ donation as a family. As reluctant as Mitchell was to share his emotional pain, he was surprisingly candid in his support for the organ donation and transplantation process. In this way, he had made our tough decision long before we were called upon to sign the papers necessary to honour his wishes —for that we are forever grateful.

I don't think anyone can be prepared for the conflicting emotions surrounding organ and tissue donation. At first I found it confronting and upsetting to think that parts of our lovely son were still living and supporting the lives of others. Over time, especially when we received a heartfelt 'Thank you' from a young recipient, it has become a little easier. Instead of our 'family' becoming smaller with Mitchell's passing, it has actually grown to include a number of people we shall never know. Like us they will never forget our son and what his kind, generous nature has meant for them in a very personal way.

Every day we miss the wonderful young man Mitchell grew into, but somehow his loss is made just a little easier to live with knowing that the enduring legacy of his life is not that he chose to end it, but that he has made the lives of several chronically ill people that much brighter by his gift.

Vanessa



Mitchell at his senior formal. Too thoroughly loveable to ever be forgotten.

Any day is a good day to talk about organ and tissue donation.



Appreciate life

arlene first got sick with kidney dysfunction after she had her twin girls Rachel and Lisa. By the time they turned 12, Marlene's failing kidneys meant immediate dialysis – four hours a day. The family's time together suddenly shrank.

A few months later Marlene was away in hospital when Martin had a stroke. It was weeks before things got back to normal. Martin at home looking after the girls and Marlene on dialysis four hours a day.

At 11.30 one night Marlene's doctor called, "We have a kidney here for you. Please be at the hospital by 8 o'clock tomorrow morning." The girls cried with their Mum. Rachel said to everyone, "It's really happening, I can't believe it."

The family had planned for this moment – the girls went to a friend's and Martin took Marlene to hospital. A few days later it was the girls' birthday. Finally Marlene was on the phone, "Happy birthday, the operation went well and I should be home in a few months."The

girls were over the moon and it wouldn't be that long until they could see their Mum again.

When Marlene came home they all started a new life. Marlene was healthy again, the girls were in upper primary school and Martin was on the road to recovery – healthier because he wasn't so worried about his wife.

The girls tell this story to all their friends and say, "We're so glad and proud that we still have a Mum. We don't know what we would do without her!"

The girls mean every single word, they adore their life, taking every day as it comes and they appreciate their parents for what they have been through.

Moral of the story: stand strong with your family through anything and never give up, happiness is waiting just around the corner.

Rachel



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



Donor wishes

In 2003 I lost my dearly beloved sister while she waited for a lung transplant. While she was ill my family had several conversations on organ donation. All three of our children have told their father and I that they wish to be donors—in the event of their death.

At the time of my sister's death my daughter was a married women and she told her husband her wishes. Since she turned eighteen, my daughter has indicated on her license her wish to become an organ and tissue donor.

Very recently I had a conversation with my daughter's husband and he told me that he would under no circumstances allow for her organs and tissues to be given away. I strongly believe that the donor's wishes should be respected at the time of their death. I cannot help but think that possibly if the rules on this matter where different in 2003 my dear sister may still have been with us today.

This has made my daughter very upset with her husband.

We believe that if the next of kin were not able to step into the way of the wishes of the donor there would be far more beloved sisters, brothers, sons, daughters, mums and dads saved and that the decision would be taken out of the hands of the grieving families.

Cheryl



Australia is a world leader for successful transplant outcomes



Julie's story

divorced working mum of one, Julie Awas constantly on the go. Julie was the older of two girls and like most sisters they had disagreements—but these spats were short lived and they would settle their differences.

Even though Julie was the elder, she was the littlest of the two girls and would be called 'the little princess'.

On receiving her High School Certificate she worked at various positions but was always looking to improve her career skills and jobs. She worked long hours with the Defence Department as well as managing a boys' soccer team.

She was known as a 'Pied Piper' picking up different team members of the local soccer team so that they could attend training and games.

She also was part of the local cricket team and ensured that her son was part of a team. She was a helper and constantly worried about family and friends, having the right gift for someone, cooking the right meal for guests and helping others if she thought they needed it.

In November, Julie complained of a head ache that she'd had all day, thinking that lying on her neck crookedly during the night was causing the pain.

After collapsing she was taken to hospital via ambulance where she began to have fits. Over the next ten days she was taken to the operating

theatre on three separate occasions. During this time she was not able to communicate very well and was terribly confused—thinking she still lived in Sydney. The skills of all the medical staff were not enough to save her.

Julie became a donor at the age of 40. She gave seven people another chance in life. Her heart, lungs, kidneys, spleen and liver were transplanted successfully. Big things from a girl who was not five foot tall and who had hearing loss.

Her organs have helped the recipients and their families and we can't imagine the joy that they have received. It would be great to know that some of her personality has rubbed off on them.

Peggy and David



Julie and her son Jarrod

If you want to donate life, discuss it today, OK?



Paired kidney exchange

Several years ago we found out that my wife Jenni had kidney disease and that this disease would eventually lead to renal failure. Not long after, we were told that she was in the last stage of renal failure and that she would have to prepare herself to start dialysis.

We heard about something that would change our lives forever—the option of a living donor transplantation. From that point forward I knew that if I could, I would donate a kidney to my wife.

Unfortunately, after a series of tests, we discovered that I was not compatible and that I would not be able to donate my kidney. We were told that we might be able to participate in a kidney donor exchange program. I would donate my kidney to someone, so that Jen could get a kidney from someone who was a match for her body.

The testing began once more, and soon after we received the call we had been waiting for. We were to be part of the first paired kidney exchange in our state and our transplant operations were scheduled for the following month.

The operation was one of the most significant days of our lives—for us and for our children. All three attended the hospital to be with us and to watch over us as we got through the day and those that followed.

We are both doing fantastically since the operation. It took Jen a while to adjust to her medication, but she has been lucky. We have both been so lucky.

Rodney



Most religions support organ and tissue donation for transplantation



Ken – As good as you can get

The one word that described my late partner Ken is 'helpful'. Always pitching in – setting up marquees, fixing broken items around our home or at friends', or just lending a hand to ensure things worked. If he found problems he solved them in a quirky way.

So it's fitting that even in death he's helping others. Five to be exact – who are able to live a better and more comfortable life, as Ken donated two corneas, two kidneys and a pair of lungs.

Ken was a practical but really fun-loving person who enjoyed life to the fullest. He was a 'bridesmaid' at the wedding of some running friends, complete with red dress, hosiery and a hair fascinator.

We had talked in general with mates about the fact 'you can't take it with you', and both of us had agreed to have Organ Donor on our driver's licences years ago, although you never really think it might be needed.

At 55 Ken was in Intensive Care on a ventilator, after suffering a massive heart attack and the prognosis was bleak. His loving family and I had to make some decisions.

Luckily the person who was relaying all the information to us was an absolutely wonderful ICU consultant – kind without condescension, factual rather than clinical, and happy to answer the questions of a grieving family. He reassured me I had done as much as possible and that without my CPR and the OOO call, Ken's family, who mostly live hours away, could not have said goodbye.

That word – GOODBYE. So very final.

We felt a terrible loss and grief, but the glimmer of hope and perhaps comfort was that others would benefit from his generosity.

It is empowering that a nearby stranger could potentially have Ken working in their body.

We shared 13 amazing years. If the recipients can have that, or more, they're not only privileged but doing exactly what he would expect – being as good as you can get.

Jo



The majority of Australians support organ and tissue donation.



Thank you

have always tried to face challenges head-on, something which I have had to do since I was born.

At birth I was diagnosed with 1/8th of a working kidney and was told that I would never see my second birthday. Instead I spent the first five years of my life in and out of hospital having numerous operations.

I never had a childhood like all the other kids and I never played sport. Instead I learnt to play the guitar. It was a special gift from my grandfather when I turned 10 and a way to escape the stress of my health.

Dad was my first kidney donor when I was 12 years old. The change in my health was hard to believe. Before the operation I was wearing size six children's clothes and was unable to walk without the aid of crutches. Seven weeks after my transplant surgery I ran from the plane to greet my family—which brought tears to every eye. I was finally able to live and love life.

Ten years and three months later (I was told my kidney would only last 10 years), I had to face the same tough challenges again. Initially I required dialysis three times a week, but this was not sustainable due to the risk of cardiac arrest every time. For three years I had dialysis at home.

I received a call to say another kidney was available for transplant, which was amazing!

To this day, it still raises emotions when I think and talk about what has happened. Knowing that a family was going through

so much pain and grief when they considered to donate a kidney which gave me back my life.

The challenges which I faced have taken a toll on my family, however I wouldn't have made it through these challenges without their continual love and support. Having Mum by my side gave me the strength to confront and overcome every hurdle that I was faced with.

Every year I have a very special anniversary and I promise to remember the generous gifts I received from my Dad and from that special stranger.

Adam



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



Life Book of Life

Dung's story

I am 36 years old and come from a Vietnamese background. One and a half years ago I was diagnosed with liver cancer. I felt like I was sentenced to death and was waiting to be hung. It was the hardest moment in my life.

I was diagnosed with liver cancer by a doctor who told me I needed a liver transplant to get rid of the cancer. I then had further tests and was told the tumour in my liver was too close to the main arteries and the cancer may have spread to my lungs and bones. If this was the case, then a transplant would not be possible.

After two weeks of worrying and waiting, I was very happy when I heard the news that my lungs and bones were normal. Two months later, I was placed on the transplant waiting list.

I hoped to receive a transplant as early as possible—before the cancer spread to other organs. If that happened then my name would have been withdrawn from transplant waiting list.

One year later, I received a call from the transplant coordinator that completely changed my life. Thanks to the generosity of the donor and their family, I am now cancer free and have a new liver. It has been two months since my surgery and my recovery is going really well. In another few months I will be able to go back to work and live a normal life.

Words cannot describe how grateful I am to the donor, their family and all the staff from the transplant team for giving me a special gift.

I will never forget you.

Dung



Any day is a good day to talk about organ and tissue donation.



