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

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.

GOVERNMENT HOUSE CANBERRA ACT 2600 AUSTRALIA
FELEPHONE +61(2) 6283 3525 FAOSIMILE +61(2) 6283 359

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



DonateLife Book of Life

I owe my life to a stranger

t was mid-February when I woke up feeling very ill and assumed I had gastro. I was very wrong.

I was eventually diagnosed with Hepatitis A, most likely from food poisoning. Ninety-nine per cent of people get over Hepatitis A, but unfortunately I was in the one per cent. I had gone from being a healthy, active woman to someone who was facing death. I needed a liver transplant and without it, I would not survive.

Four months after waking up feeling unwell, I was put on life support in ICU. My liver had poisoned my whole body, my kidneys were collapsing, my brain was swelling, my lungs were suffering and everything was collapsing rapidly. At 10:00pm that evening my family gathered to say goodbye.

Later that night my family got the phone call. They had found a liver that matched—a liver that would save my life.

I had been given the ultimate gift. If I had not received the transplant, I would have died. It is as simple as that. Organ donation is a very simple choice but I think it is one that everyone should consider.

My road to recovery has been very slow, my family and friends have been an amazing support for me.

I have had many further stays in hospital fighting severe rejection, but I now have a new outlook on life. After being stuck in bed unable to do anything and so close to death, everything changes.

I am so very thankful for being given my second chance, and I owe my life to a stranger.

Racquel



Discover the facts,
Decide about becoming
an organ and tissue
denor and Discuss your decision
with the people close to you.



My lucky day to attend.

date forever etched in my mind was Friday the 13th June 1994, whilst it might be seen as unlucky for some; this date would change my life forever!

After suffering with heart blockages, I finally presented to hospital for treatment and found myself whisked off to Sydney, operated on for thirteen hours and told that I was now a candidate for a heart transplant.

As a fit, hard working young man and father of four, this came as a surprise to my family. After waiting for four years in 2000, I got the call that a heart was available and I had my first transplant.

At first things were fantastic I was out of bed the next day, (not quite ready to take on the world), feeling good and then about a week later I had my first rejection and other infections. After about six months recuperation in hospital I was able to return to work while still dealing with bouts of rejection.

Unfortunately, in 2006 I was back in hospital with heart failure. I was told I needed a second heart transplant. After learning to walk, talk and eat again I was released from hospital and within a month of my discharge I was able to celebrate our 25th wedding anniversary and see my children get married. I now have grandchildren and three weddings

I am currently the President of the Australian Heart/Lung Transplants Association and I am forever grateful to the two people who have given me the gift of life and I thank the transplant coordinators, doctors and nursing staff for saving my life.

People I will never forget!



On average, people on transplant lists wait between 6 months and 4 years.



JonateLife Book of Life

Finding hope in grief

One of our organ donor coordinators could get a call at 2am saying a family has consented to donating a loved one's organs. The impacting part of that call is you know there's a family out there facing sudden grief and coming to terms with the loss of a loved one who was healthy 24 hours ago.

It's extremely powerful to see donor families who, in their acute grief are able to make the decision to donate and in the end help people they never get to meet.

Although a vast number of people support organ donation, when it comes to making that decision in the Intensive Care Unit, approximately 50 percent of families say no.

What we do know from our experience of working with many families, is that they find it much easier to say 'yes' to organ donation when they have known the wishes of their loved one.

The most important message is, even if you don't register as an organ donor, tell your family what your wishes are.

We know that it is rare for a person's wishes not to be supported by their family, if the family know what those wishes are. However, if they don't know what their loved ones wishes were, they can go the other way and decide to say no.

We tell the donor families that whatever they want or don't want to donate, we will respect their decision. We are there for the donor's family and to see that the donor's wishes are followed. We ensure that the donor is treated with the respect they deserve.

We offer hand prints and locks of hair of their loved one as mementos.

We also offer counselling services and send the donor family a rose voucher for a Reflection Rose that's been specifically bred for donor families.



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



The best thing you'll ever do

For any of you who are contemplating donating a kidney to a loved one, I can only encourage you to do it.

Making the decision to donate a kidney to a friend in end-stage renal failure wasn't easy, but I have never regretted it.

The transplant was four years ago and my friend is doing really well (completely normal!). I have taken up jogging and will compete in my first half marathon this April.

I'm not saying there aren't risks—but it can be the best, most rewarding decision you ever make!

Christine



In 2011 337 organ donors gave 1001 Australians a new chance in life



JonateLife Book of Life

Great life after transplantation

had my kidney transpl<mark>ant when I was 40 my tran</mark>splant health and I still look years old and still live life to the full. forward to more travelling and mee

Great things have happened since my transplant:

I travelled overseas and all around
Australia – plenty of barbecues and a
small amount of drink to keep celebrating
my great life after transplantation; seeing
my grandkids grow up; going to the
Transplant Games to celebrate with other
transplant recipients to tell stories of life
given to them by their wonderful donors
– plus the on-going care by our Australian
doctors are just some of the highlights.

After my transplant, I moved back to the bush, to Echuca, and built a caravan park, boat marina. I joined Lions International and became President and also became a City Councillor. I started a busy caravan and boat retail business with my son Raymond. I took up lawn bowls and became a committee member. I have enjoyed three overseas cruises seeing the world and travelled to many Australian districts. Being able to do this has helped

my transplant health and I still look forward to more travelling and meeting people – I am now 81 years and so appreciate my kidney of 41 years.

> Jeffrey Member of Transplant Australia



Around 1600 people are on official transplant waiting lists at any one time



DonateLife Book of Lif

Courage rises above all heartache and despair to save a life

The hardest moments in life are the ones that are unpredictable and the ones you can't control. I was born healthy but at about four weeks old I became sick and was diagnosed with Biliary Atresia—a rare condition in newborns. As a five month old baby I was put on a transplant waiting list for a liver transplant which would end up deciding the fate of my life.

For the following two months I was in and out of the hospital. It was hard on my family because they lived up here in Toowoomba and my parents had to look after my brother and sister who were five and seven at the time. So day after day, my parents watched me deteriorate a bit more.

In all honesty I was dying before their eyes. My parents prayed for that phone call that would save my life, the one that would give me a new liver, a new life. It was Christmas Day. The doctors had given me to the end of that week, and after that I would most probably not have been here. Mum had just sat down

to eat her lunch when the phone call she had been waiting for arrived. They had a new liver for me. My parents carried me into the theatre where I would spend the next nine hours. The liver transplant was a success.

So that period of time brought heartache to one family and joy to mine. Through their heartache of the loss of their loved one, they were able to make the decision that saved my life. Something that would have been so hard for them to do, but something I am so grateful for and something I will treasure for my whole life—something that has made me, me.

If it wasn't for that decision to be an organ donor I would not be here, I would not be a daughter, a sister, a friend and so on. So I thank that family every day of my life and I will continue to do so for the rest of my life.

So donate, save a baby that once was like me and help bring joy to their family. But ultimately it's your choice.

Elizabeth

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



Waste not, want not

For me, the decision to donate Dad's organs was obvious, but it was not easy. I always knew what my Dad thought about an issue, even if I didn't want to know! Dad was a man of strong convictions and an incredible work ethic. He was funny, tough and incredibly clever.

I knew Dad would want to donate his organs. He was very pragmatic, why waste what could be used? However, trying to discuss this decision with your family is incredibly hard. We were in various stages of shock, grief, anger and bewilderment. I think Dad's strength of character was the deciding factor in helping us to make the decision to change another person's life for the better. Amongst the confusion I focused on the people that might have been waiting for years for an opportunity to live a healthy life.

Our family had spent three days in the intensive care unit of the hospital hoping

that Dad would survive. To then switch our mindset to contemplating his death and organ donation was a significant shock.

Like my father, I'm very pragmatic and practical. I knew it was the right thing to do. For other members of my family, processing this information was too much to comprehend. We talked and we fought, until finally the decision to donate was made.

The comfort we have, knowing that Dad was able to help so many other people is very important. Dad was an optimist. We believe in looking for the good amongst the bad. Organ donation was our hope that Dad's strength might provide a new beginning in life for an organ recipient.

Organ donation presents a very unique and sometimes overwhelming decision to families, but its potential to create powerful change makes it more than worthwhile.

Sarah



Around 1600 people are on official transplant waiting lists at any one time



Have a chat, see what people are thinking?

am 28 years old and I'm currently on the transplant waiting list hoping to receive a new pair of lungs. My life at the moment is just about staying well and waiting for the day my number comes up.

I attend twice weekly a pre-transplant gym. There I see and speak with fellow transplant candidates, some who are waiting for lungs, and some waiting for hearts. Straight after my session is the group of people who are post-transplant. Because I have been listed now for about four months, I have been able to see a few people go through the two stages of gym.

Honestly it's the biggest turn-around imaginable. I just can't believe the physical improvement and total change in mind set and attitude. It is one of the most amazing transformations I have ever seen. From such bleak futures to 'the sky is the limit'. I have seen this not only with

the recipients, but with the partners and family members also. The sheer relief is priceless.

There are also some very uncomfortable moments—like when someone new asks you what blood type you are? Instantly you hope the answer you give is not the same as theirs, as there is such a shortage of donors. You can't help but feel you're in competition. In some ways this is true.

My personal opinion regarding organ donation, is that it's as much a family decision as it is the person who is willing to put their hand up and register. I believe that everyone should sit down and hear each other's views and wishes on the subject.

Dearan



Most religions support organ and tissue donation for transplantation



Wife, mother and now a nan

At 37, I was diagnosed with primary sclerosing cholangitis (liver disease).

Some 13 years later, my liver was failing. I found I was spending more and more time in hospital. The doctors and nursing staff at the liver transplant clinic prepared me for a major operation—physically and mentally.

It might sound strange but I was actually relieved that I was now going on the transplant waiting list. I accepted the idea of the transplant as I was so unwell.

Seven months later the hospital rang and we swung into action. After being admitted, I was informed that the operation wouldn't take place till the morning.

I remember that morning of the transplant. My family was with me as we looked at the possibility of organ donation (tears did roll). My life now depended on the skills of the doctors in theatre.

Finally, despite the pain, I felt so happy and relieved. I had my life back because of a donor, a medical team, my family and friends. There was no turning back. I had to be worthy of it and smile and shine so others could see. I reached into myself and told myself to find that tiny spark and be very thankful I had received a second chance of life.

I thank the donor and their family and hope they can find some comfort in the knowledge that their gift provided me with the opportunity to share a happier and healthier future with my family.

Their generous and courageous decision became a precious gift of life for which I am eternally grateful. It has given life to a complete stranger and I see this as incredibly special.

The donor and family are rarely out of my thoughts and I hope they have some comfort knowing they have saved a life by this wonderful gift.

Ronwyn



Wife, mother and nan 2011.

Do the people close to you know your donation wishes?



Thank you

Deing told that I had liver disease and then needing a liver transplant came as a relief as finally someone had told us why I kept getting crook and being admitted to hospital all the time.

After an initial work up at the hospital I was placed on the transplant waiting list with no guarantees. We had two false starts where we were called but sent home because of different complications. After twelve months on the list we received the call that was to change my life completely. To go from close to death to being well in a matter of weeks was unbelievable.

The doctors and nurses that perform transplants are nothing short of miracle workers. I need to take medication every day for the rest of my life, as well as monthly blood tests and regular visits to the doctors but I am very lucky.

One of the hardest things I did was to write a letter of thanks to the donor family, it was one of the hardest yet easiest things to do—to say thank you. I was taken aback when I received a letter back thanking me for my letter.

If they hadn't discussed organ donation I wouldn't be here writing this, so thank you.

Gary



Discover the facts,
Decide about becoming
an organ and tissue
denor and Discuss your decision
with the people close to you.



DonateLife Book of Life

Someone was looking after me

emigrated from Croatia to Australia in 1959, first arriving in Melbourne and then moving to Adelaide before finally settling on the new capital being carved out of the limestone plains in Canberra. At that time Canberra had a large Croatian community and I felt at home in this new growing city. I married a local girl and started a plumbing business and a family.

After feeling tired and unwell for some time, I was finally diagnosed with Hepatitis B. Back then there was not that much in the way of treatment for the condition. I again started to feel unwell and was told by my GP that my liver was failing.

When you are having liver problems, you have no energy for any kind of work and you have to be extremely careful with your diet. No alcohol, no roasted food, no pre-packaged food and no condiments. I survived on boiled spinach, potato with a little oil and pasta with honey. Meals were small portions consumed frequently.

I later became very sick and returned to hospital with severe abdominal pain and lots of hot and cold flushes (which I wouldn't wish on anyone). I was informed that a liver transplant was my only chance of survival. I had a liver transplant at Royal Prince Alfred and the staff (my

Guardian Angels) were working overtime for me.

I am extremely grateful to my family, all the hospital staff and to my organ donor (and family) for their generosity. I offer daily thanks to all involved in my recovery and my gift of life.

I would like to offer my appreciation, thanks and gratitude to our dear Lord and all the Guardian Angels who helped during those difficult times.

Ivar



an and Steve.

Do you know the donation wishes of your loved ones?



Broden's story

have heard the most terrible news a mother can hear: my son was killed in a motorbike accident.

Broden was my second son. Growing up with an older brother and a younger brother, there was lots of fun and just as much mischief. Everything Broden did he seemed to do well without too much effort. In his teen years his friends would turn to him for support, as he had reason beyond his age.

When he found a plumbing apprenticeship his life goals were set to take off.

Then the boys lost their father due to illness. Broden found that hard to deal with. One day, while talking to a mate, Broden decided to give motor bike racing a go. He bought all the safety gear and headed off to race. This seemed to help with his grief and brought a smile to him and to the rest of us.

We always had Sunday night tea together so this was the perfect opportunity to

discuss our wishes, and that's how I had the privilege of discussing organ donation with my boys Corey, Broden, Curt and Tarlen. The conversation went like this: "Well boys, just letting you know I think we should all be organ donors." Their reply was "Yep no worries mum, that sounds good to us." The boys then decided it would be a good idea to select the parts of their anatomy they thought would be appropriate! We had made a serious conversation into one that wasn't scary or uncomfortable. In the end we all agreed it was just the right thing for us to do.

When the day came that this decision could be put into action, the door had closed. As a mother one of the hardest parts of my grief has been that Broden's wish to donate his organs could not be met. Now though, I'm very proud of my son's generous, selfless wish.

Words Broden lived by: You never know what you've got till it's gone so go hard or go home!

Paula



Australia is a world leader for successful transplant outcomes



JonateLife Book of Life

A gift to treasure

y kidney failure had been a relatively slow process until the beginning of 2010 when I became very unwell. In April of that year I started dialysis and in August began home dialysis.

Even though you are told not to let dialysis rule your life it becomes very difficult when you are hooked up to a machine three days a week for five hours. You don't feel like doing anything after dialysis so your social life changes. I am a primary school teacher and dialysis affected my work—which I enjoyed very much.

I had a kidney transplant. I received the kidney from my amazing partner Greg. Before the transplant took place my partner and I were well aware that we were high risk. I had some antibodies which I had got from a blood transfusion when I was 18. My partner's kidney had a couple of extra arteries which could make it difficult to attach to me during the transplant.

Following the transplant I had to have plasma and albumin exchange which hopefully would suppress the antibodies and help my body to accept the new kidney. This took place over a number of days each week for 11 weeks. I am finally not attached to any machine but still going to the hospital two days a week and have to be monitored very carefully.

During my time at the hospital Greg and I have met and become friends with many kidney transplant recipients. Like myself their lives have been changed for the better.

Everyone's story is different, but the one thing that is the same is the gratitude and thanks we all feel for the families who made the decision to donate their loved one's organs—or in my case and some others, a family member or loving partner—who were selfless in their decision to donate their kidney so as to make our lives healthier and happier.

Cheryl



Cheryl and Greg.

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



Donate Life Book of Life

A second life through the gift of sight

In 1953 I was losing my sight because of the genetic condition keratoconus. A surgeon told me a graft was a risky procedure but it could be beneficial.

I had tried contact lenses but they were hard and uncomfortable, so I wore them only when I had to—on special occasions such as going to the pictures with my boyfriend.

I didn't sit down and say 'poor old me'. Facing legal blindness at the age of 21, I thought I should go for it.

The donor was believed to be aged 80. Six months after that first successful operation on my left eye, I received a second cornea in my right eye and became the first person in Australia to have two successful corneal grafts. The first cornea was replaced and had lasted two people 130 years.

Following the operations I had to lie still for days, sipping blended food so I didn't move any facial muscles. My head was packed with sandbags and I remember the dressing being removed and being asked how many fingers I could see.

The surgery opened up all sorts of new avenues for me. As a trained comptometrist (a comptometer was a forerunner of the calculator) I returned to work and gained my driver's licence. I then graduated with a Bachelor of Education majoring in textile studies and later became a Lecturer at TAFE.

At the age of 55, I learned to play the trumpet and then the French Horn, following a musical thread that ran throughout my family. I established two community bands for adults with little or no prior knowledge of music. It gave me immense pleasure and a real sense of camaraderie.

I am now quilting and doing other craft work, drawing on knowledge gained through studying graphic design and have also traced my family history.

The blessing of sight has given me a very different life.

Shirley



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



Quality of life restored

As an active 75 year old widow I had to curtail many of my activities because of failing eye sight. I had to stop driving my car and doing dress making which I had done since I was a teenager. Reading was difficult and only possible with the aid of a strong magnifier. The cells of my cornea were disintegrating and as cells of the cornea do not replace themselves, as do other body cells, my only hope of improved vision was a corneal transplant.

When I visited the ophthalmologist I could not see the big letter on the top of the eye chart with my right eye. The left eye, while not as bad, was also deteriorating. I was put onto a waiting list and seven months later received a call as a cornea had become available. After a 50 minute operation my own cornea had

been removed and the donated cornea stitched into place. It was about three months before it had settled enough for my glasses to be prescribed. The left eye received a cornea 12 months later.

Five years later, with correct glasses, I am able to read the second bottom line on the eye chart, am able to drive my car, use my sewing machine and read comfortably.

Thank you to the two donors and their families who, even while coping with their own grief, consented to the donation and restored my quality of life. Through the Eye Bank I was able to write an anonymous thank you letter to them. Once again THANK YOU wherever you may be.

Linda



Ask and know your loved one's donation wishes



JonateLife Book of Life

A special gift

While you are reading this I may be admiring my newly painted bedroom walls, switching on the television set or planning my next overseas trip. I might read a book or magazine, choose a recipe or perform any number of activities which we 'sighted' people take for granted.

A few years ago I was warned that eventually the ability to see my young grandson, my family's faces and the beautiful world around us all would be lost. I was devastated.

But during the last two years the gift of sight was given to me by not one, but two, human beings whose corneas had been donated for use in eye surgery.

Nowadays I ask everyone that I meet to discuss and decide to donate organs or tissues.

Someone, somewhere, will receive a most special gift.

Elaine



Donors and recipients vary in age from infants to the elderly.



DonateLife Book of Life

Special gift

Nold and was born with a condition called biliary atresia, which is a blockage of the main bile duct from the liver. This led me to have a liver transplant at the age of nine. I was lucky that my liver lasted until I was nine, as most require a liver transplant straight away.

I remember in my early school years I was often not able to participate in sports and activities at lunchtime as I was sick, tired and had no energy. I was always in and out of hospital with infections to the liver which made me jaundiced.

Once I had the liver transplant the jaundice went and I slowly regained my energy levels. I have learnt to live life to the fullest and take every opportunity given to me.

I picked up sports such as netball, dance and swimming. I was starting to feel like I really fitted in with all the other children and my friends at school. I graduated, studied and received a Diploma in Fitness.

I trekked the Kokoda Trail with the Kokoda Brothers starting on Anzac Day. There were 25 Australians of all ages (whom I made friends with) and 20–25 porters. The 96 kilometre trek through heavy terrain over eight days was the hardest, yet best experience I have had to date.

This year I completed my first 14 kilometre Run for Kids walk (with a friend Kate who has also had a liver transplant), the Royal Childrens Hospital Good Friday Appeal and also a 12 kilometre run for the Geelong Hospital Childrens Ward.

This year I volunteered with Transplant Australia to help raise funds at events. I will continue to participate and volunteer for these important causes that have helped shape my life today.

Please register to become an organ and tissue donor like myself and please discuss your decision with your friends and family during DonateLife Week.

Jessica



Kokoda Trail–Anzac Day 2011.

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



Jonate Life Book of Life

Michael's story

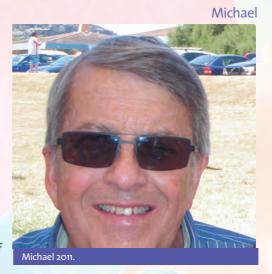
When I was first diagnosed with cardiomyopathy I received conventional treatment for my left ventricular failure until my condition worsened, requiring the implantation of an implantable cardiac defibrillator(ICD).

At the same time I was assessed for suitability for a heart transplant. I was one of the very lucky people put on the transplant waiting list. I was even luckier to receive a call to hospital after a lapse of only two and a half weeks!

I survived the transplant, but did suffer some infection. I survived this to emerge as a new man. I no longer suffer from heart congestion and regained the ability to walk normally.

My family was of enormous support throughout this time. I am now fit and healthy and consider myself to be one of the luckiest people alive—because I am alive!

Most people I know had to wait at least six months for a heart to become available. I am extremely grateful to the family of my donor for their sacrifice and will live to express it.



Most religions support organ and tissue donation for transplantation



DonateLife Book of Life

A life renewed

The words 'you need a heart transplant' are very difficult to hear. After three operations, the prospect of facing more heart surgery was pretty terrifying. I knew that this was the only way I would survive. After all the tests and appointments to prepare me for the transplant, I received the call that would give me life! It was the hospital saying they thought they had a new heart for me.

This was such a surreal moment.
I had been living on 24 hour a day intravenous infusions for six months to keep my heart from failing completely.
I had to fight just to live and everything I did was so difficult and so exhausting that I hardly managed.
I couldn't care for my family, play with my grandchildren or walk more than a few metres.

I was driven by two strong feelings that night. One was of extreme gratitude to the generous person who had decided to donate their organs and the other one was that my fight had to go on for a little longer so I could make the best of this gift I had been given.

Since that day, I have regained so much energy. I can now do many things I couldn't even have thought of doing before. I have climbed the harbour bridge, been away on a holiday with my husband, been to the gym and played cricket in the backyard with my grandson! My husband and family

have been wonderful in supporting and encouraging me to live life to the full. I will be able to watch five grandchildren grow up and I have a wedding to plan for my son. Things that I never thought I would do.

I am so grateful for this precious gift. I celebrate and give thanks to the donor and their family every day.

I want to tell everyone that it is so important to talk to your loved ones about your decision to donate. The fact that I can live my life to the full shows what an amazing gift organ donation is. I want to celebrate the doctors and nurses who do this fantastic work. Their magnificent skill gives the gift of life to those who need it.

I'm off for a bike ride now!





Ask and know your loved one's donation wishes



