are the family and friends so vital to transplantation
MESSAGE FROM THE PRESIDENT

Behind every recipient

WTGF President Chris Thomas on the importance of carers, family and friends

As the headline suggests, behind every recipient is usually a family or friend who helps them get there.

I was reminded of the importance of family on two occasions recently. As you will see elsewhere in this Transplant World, the WTGF experienced a unique opportunity launching its new Organ Donation Ambassador Program at Olympic House in October.

We were thrilled International Olympic Committee President, Thomas Bach, spent more than an hour with us speaking of the importance of organ donation and welcoming us to ‘our house’ – because the WTGF and our recipient athletes are part of the Olympic family. What wonderful recognition.

Please see the transcript of his speech for further detail.

It was brilliant that two of our newly-installed Ambassadors – Australian Olympian Brooke Hanson and Swiss Olympian Dano Halsall could join us. Both excelled in the pool in their time and have gone on to have close and emotional connections with donation and transplantation.

But enough of the name-dropping. The star of the show was nine-year-old kidney recipient Eloise Baker and her mum Kristen. Eloise shone in her role presenting the new Gift of Life Baton to Australian Ambassador to Switzerland, Phillip Green. Kristen spoke emotionally of the new life Eloise enjoys with family, dad Nick and brother, Lorenz. And to think without living donation in this case, without the technology, the expertise and the medication, the life of this family would have been very different.

Equally, in Australia in November, we showcased the life of the Dixon family as they told their story of living donation from dad Rob to son, John, back in 2017. John’s kidney didn’t work when he was born and he started dialysis at just four months of age. Fast forward six years and he is now a bubbly, energetic seven-year-old getting ready for the 2023 World Transplant Games.

Transplantation benefits not just the individual but the family as a whole.”
MESSAGE FROM THE PRESIDENT

The opportunity for these two families now have – and that they will both meet in Perth next year is breathtaking. And we have the gift of life to thank for that.

After a couple of years of COVID it was brilliant to meet with some of my fellow trustees at Olympic House to celebrate this unique opportunity.

We were able to launch our new Gift of Life Baton, a gift from the Australian Government and Transplant Australia to the World Transplant Games Federation. The baton will be gifted to the transplant world at the Games in Perth.

We hope it will be seen as inclusive, embracing all donors from all countries and have a life with the WTGF for many years to come.

Our Board and Executive are proud of the work of the WTGF this year. We are proud, despite significant headwinds, the next instalment of the Summer World Transplant Games will proceed in Perth as originally scheduled.

Everything is on schedule – as you can see from just a few of the pictures from our inspirational recipients who celebrated the six-month countdown to the Games at the top of Optus Stadium. It hasn’t been easy but with commitment and dedication to our community it will happen. We hope to see you there.

Matty Hempstalk

Once in a while a special person comes along in your life and you end up working alongside each other and becoming great friends. And then, all of a sudden, they are gone.

I can’t let this message pass without mentioning our good friend Matty Hempstalk who passed away this month.

Matty started working at Transplant Australia in 2015 and quickly became the soul of our charity. He kept it real and us connected with the people we serve. We delivered two Australian Games together and he was instrumental in the planning for Perth. Sadly, he exemplified the belief that a transplant is not a cure but a step in an ongoing journey. And Matty’s journey was tough.

He will be missed by many people from around the world. I am just one of many who were proud to be his friend. Miss you mate.

Chris Thomas
WTGF President

“...It hasn’t been easy but with commitment and dedication to our community it will happen...”

Official proceedings with West Australian Deputy Premier, Roger Cook and City of Perth the Lord Mayor, Basil Zempilas and philanthropist Tonya McCusker, along with heart recipient Colleen Ashby and liver recipient, Jake Prince

On top of the world, Optus Stadium Perth – six-month countdown to the 2023 World Transplant Games

Matty Hempstalk
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Transplant World

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Registered Charity No.1179470
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Mr Thomas Bach, President of the International Olympic Committee

The WTGF was honoured to be joined by the President of the International Olympic Committee, Mr Thomas Bach, at Olympic House to launch our Organ Donation Ambassador Campaign. Realising not all of our transplant family would make it to Switzerland, we have reprinted his thoughts here – thoughts which emphasise the importance of the transplant sports movement to the Olympic family.

The President and friend of the World Transplant Games Federation, Chris Thomas, Your Excellency Philip Green, Eloise, and Mrs. Baker and the Olympic friends.

When I came here, I thought I would have an easy job, to welcome you to Olympic House and say some words about the importance of transplantation and the transplant games. Now I think I have the most difficult act to perform. To speak after Eloise. So that’s a real challenge. But therefore congratulations, Eloise, for your great performance here, and your inspiring words. Thank you to Mrs Baker, your mother, for giving such a great example of human love and solidarity.

And this is how we can see where the Olympic values and the values of the World Transplant Games Federation are really coming together. How they become concrete. How they are becoming a reality. The words and the mission we share is to make the world a better place, through sport.

And this is what we are sharing. And here you can see that the world was made a better place through Mrs. Baker’s donation of a kidney to her daughter, allowing her now to play sports, to share the joy of sport with all the kids and the friends in the school.

And because we are sharing these values, I can welcome you to your home, to Olympic House. This is not the house of the International Olympic Committee. This is the house of the Olympic community, and you are belonging to this Olympic community. So, welcome home to your house here in Lausanne, and I’m happy to see that so many Aussies have made the trip via to Lausanne. Obviously, it takes the Olympic spirit of Lausanne to get the Aussies together here.

At these forthcoming World Transplant Games. You will have your games Down Under in 2023. We will have our games in Down Under in 2032. And at your games there, every athlete will send a very powerful message, which is indeed on a human scale, going even beyond the message, an Olympic athlete is sending of excellence. We are all in the Olympic community and with the Olympic aims, we are sending the message of excellence, we are sending the message of solidarity, of peace, of understanding, and in your case, these athletes are sending the very special message of resilience.

They show that you can overcome illness, and health challenges, and they show that, having overcome and addressed it, you can enjoy what sport has to offer. This joy in life, this hope,

And this is how we can see where the Olympic values and the values of the World Transplant Games Federation are really coming together. How they become concrete. How they are becoming a reality. The words and the mission we share is to make the world a better place, through sport.”
this confidence in yourselves and in your environment; and that even after having overcome this challenge of the transplantation, that you can lead a healthy and an active life, and in this respect giving an example, not only to other people who are having health challenges, but giving an example to all of us what power a human being can have, when it is mobilizing all its inner forces and when it is supported there by a community.

So therefore, your Organ Donor Ambassador Campaign is really not just about “please donate your organ”. It is about “become a part of this movement, become an ambassador of these values”, and make it possible that these values can be promoted and displayed by the people who are receiving the donation.

And for exactly these reasons allow me this personal note. I joined an initiative in Germany many, many years ago, which was called, and is called Athletes for Organ Donation, where we tried to use the power of sport to spread this message. Of promoting the Olympic values in reality, and to show this solidarity with everybody and to show that there also these, and to show, to live the humanitarian mission, the Olympic movement always has. And this is why we are very happy, and it, you know, it did not take any kind of conviction. That we at the IOC, and I personally, that we are able to support there your Organ Donation Ambassador Campaign. And in this way to promote our shared values of the Olympic movement and of the World Transplant Games Federation.

This is another demonstration on how we can live our new Olympic motto, and, in fact, part of it is also a reason why we amended, recently our Olympic motto. Because the Olympic motto was always for more than a century “faster, higher, stronger”. We came to realize that in fact, you can only go faster. You can only aim higher. You can only become stronger if you are together. And this is true for our personal lives. This is true for every athlete. This is true for the world community, because all the challenges we are facing in this world at this moment, we can only overcome together. Nobody alone can overcome the challenges of climate change just to name one. Nobody alone can overcome, and we are still not there yet, to overcome COVID. Nobody alone can overcome the many wars and conflicts that we are facing in the world. It always needs getting together. It means that we have to stand together in solidarity.

So, thank you, Chris, for all your leadership in this respect, and thank you for wearing the nicest tie on the planet. I promise you, you will get another more decent one then you can display it everywhere you are going. That you and your Federation, you are a member of our great Olympic community, and you are very much welcome and appreciated in this community. Thank you to all the ambassadors of this campaign for leading by example, for living this Olympic motto of faster, higher, stronger, together. Welcome to your home! Welcome to Olympic House and have a very nice and successful and also enjoyable conference here at the Olympic House in Lausanne.

Thomas Bach
IOC President
The transplant and Olympic worlds came together in late October to celebrate the gift of life at Olympic House in Switzerland.

Transplant representatives from as far away as Nepal, Colombia, Australia, Canada and Uruguay travelled to the headquarters of Olympic sport for this unique once-in-a-generation opportunity.

The occasion was the launch of the Organ Donation Ambassador Campaign that will run in the lead up to the World Transplant Games in Perth in April. Two of the ambassadors - Australian Olympian Brooke Hanson and Swiss Olympian Dano Halsall - spoke of their personal connection with both donation and transplantation.

Brooke Hanson said: "As Olympians we know what it is like to strive to beat the odds, of achieving our dream on the sporting field. For these transplant athletes, they have started well behind but have still managed to achieve their dream."

IOC President Thomas Bach spoke passionately about organ donation. "I have been a long-time supporter of organ donation, and I am pleased to lend the support of the International Olympic Committee to raise awareness of the need for more organ donors," Mr Bach said. You can read more of his inspirational comments in the Guest Editorial.

Here's a selection of photos from the day.

Continued on next page
Canada’s Brenda Brown and Alison Hickman

Even TX made an appearance

Belgium’s Professor Diethard Monbaliu

Canada’s Brenda Brown and Alison Hickman

Dr Paul Harden and Daley Cross, UK

Olympian Brooke Hanson signing the Olympian Wall

Hari Marayan Sharma from Nepal, Gerardo Reyna and Alberto Carmona from Spain

Olympic House

Liz Schick with Lena and Dano Halsall

Olympian Dano Halsall with President Bach

Olympic House
We are excited to announce that the World Transplant Games Federation’s (WTGF) TX Teddy Bear Distribution Project has officially launched for online applications.

Members of our worldwide community are invited to request one of our legacy TX Teddies, available to all transplant youth under 18 years old, anywhere in the world.

Applications are via the WTGF website through an easy-to-use online platform. To be eligible, applicants would need to have either recently been transplanted (under 1 year) or be currently on the waiting list. Once the application is approved, our Transplant Next team will send one of our furry friends to you or to someone that you know. TX is delivered with hope to brighten any child’s day.

Our live worldwide map showcases the journey of where TX has been delivered and includes stories and photographs of transplant youth who have already received their new friend.

Follow the WTGF on social media for more updates and visit the website for more info @ https://wtgf.org/about-tx/

To celebrate the imminent arrival of TX, the WTGF team visited the recent British Transplant Games where some local youth transplant recipients as well as those on dialysis were able to claim a TX teddy for themselves.

Transplant Next Team
NEW FOR PERTH 2023

The World Transplant Games in Perth will be the 24th time this celebration of the gift of life has been staged. What started in 1978 with five countries has now grown to an organisation with over 60 member countries. The expanding role and recognition of the World Transplant Games Federation is demonstrated by the growing number of countries who will be participating in the World Transplant Games for the first time in Perth, Australia in 2023. This growing list of countries includes Guatemala and Uganda.

Guatemala

The Guatemalan Kidney Association / AGR is a non-profit organization that has been working to improve the prevention and diagnosis of chronic kidney disease for 20 years. Their main goal is to improve access to primary care clinics and dialysis services for everyone in the country suffering from chronic kidney disease and to reduce the incidence through education and early treatment. They are involved in many aspects of kidney disease from running medical days in departments and in cities; hosting education sessions; supporting patients on dialysis and in the transplant program; and donating medications to those undergoing transplantation or substitution treatment.

Although the incidence of chronic kidney disease is very high, at approximately 10% per million people, there is limited dialysis services with only four hospitals in the country providing dialysis services to over 7,500 patients. Many more patients unable to access services die due to lack of treatment.

Organ donation in Guatemala remains complicated. For over ten years, they have been hoping to get a bill passed for a national system for the registration of organ and tissue donors, but with no success. It means that transplants are only possible from living donors or from families who generously donate the organs of a deceased family member. However, with the assistance of some incredibly generous doctors, there has been a transplant program set up in one of the national hospitals.

Physically active

As well as working on the medical side of kidney disease and transplantation, AGR also encourage kidney and transplant patients to be physically active. For the last three years AGR have hosted transplant races, with the fourth scheduled for January 2023, and plans to stage the first National Transplant Games in mid-2023 including athletics, swimming, cycling, tennis and six-a-side football. 2023 will be another busy year for AGR with the first Guatemalan team to compete in the World Transplant Games in Perth - will have five members competing in athletics, cycling and tennis.

“We see participation in the World Transplant Games as an opportunity to show that people with transplants can do much more than people think, and they can achieve their dreams” said Rony German sum Velasquez, AGR President.

“We are excited to be coming to Perth and looking forward to meeting other teams and athletes from all over the world.”

“We would like to thank the Federation and all the countries involved in the Games for the work they do to support transplant recipients and for developing these Games. It is an opportunity for transplant recipients to show that dreams can be realized and that they can represent their country as athletes with pride.”

Guatemalan Kidney Association/ AGR

Kidney donor acknowledgement event

Renal medical day
THE UGANDAN TRANSPLANT TEAM READY FOR PERTH 2023!

Uganda is a country with rich biodiversity including impressive greenery, incredible wildlife including the elusive mountain gorillas, and some of the best national parks for safaris in the world. The magnificent beauty of Uganda is contrasted with the bleak yet constantly evolving and improving healthcare infrastructure in the country. There are many groups and organizations dedicated to advocating for access to better healthcare for Ugandans including the first Ugandan Transplant Team.

The Ugandan Transplant Team is made up of about thirty transplant recipients and donors who are passionate about social advocacy. They meet weekly to work out together and discuss what’s happening in healthcare in Uganda. The Ugandan Transplant Team plans to take a team of about 10 athletes to Perth, Australia for its first foray into the World Transplant Games competitions. The team was founded by Constance Darsha Collins, an American kidney transplant recipient who has represented Team USA at two previous World Transplant Games, and John Mary Kirima, a kidney donor to his wife, Rebecca. All physical activity is led by coach, Moses Okot, a personal trainer and kidney donor to his younger brother, Emmanuel Rackara. The idea to start an organization was to raise awareness of the beauty of organ transplantation, promote healthy lifestyles and physical well-being as preventative and protective measures, connect Uganda’s growing transplant community through physical activity, and advocate for greater attention to organ failure in healthcare policy.

Obstacles

Thousands of people in Uganda die each year from organ failure. There are seemingly insurmountable obstacles that prohibit organ replacement in the country. For one, organ transplants are not yet possible in Uganda therefore there is no infrastructure to support deceased donation which severely limits options for organ failure patients. Dialysis is severely limited for patients with kidney disease, only existing in a handful of places for a country with a population of over 41 million people. Financial inaccessibility is arguably the most pervasive hurdle to organ transplantation and adequate medical care. Because transplants are not performed in Uganda, patients must travel to other countries, predominantly India and Turkey, for their surgeries. Global healthcare coverage is rarely obtained in Uganda so patients have to cover the costs of these surgeries on their own, usually with fundraising.

Organ and tissue donation carries a deep stigma for many in Uganda due to religious, spiritual, and cultural beliefs that range in scope. Fear permeates the psyches of many, sometimes for completely valid reasons and other times because of the spread of misinformation. Sarah Nandula, a 44-year-old kidney donor spoke at the Uganda Kidney

Continued on next page
Foundation annual advocacy conference and shared her experience once she volunteered to donate to her sister. “People thought I was mad. They thought I would die or live a shorter life; many people did whatever they could to discourage me from making the choice to donate my kidney. But how could I not save my sister’s life?” Her story mirrors the story of some of the donors on our team including Sylvia Nabukenya who donated to her then 9-year-old daughter, Amani.

The team intends to bring global attention to the struggles facing Uganda with regard to organ failure and the necessary medical care, as well as eradicate the misinformation that abounds in Uganda around organ transplantation. The team’s participation is equal parts advocacy and celebration of life.

Athletes on the Ugandan Transplant Team range from ages 14-50+ and they are incredibly excited about representing the ‘Pearl of Africa’ in the Games in 2023. They are training to compete in a number of sports including basketball, athletics, swimming, bowling, table tennis, and more. On weekends, they train vigorously at facilities generously made available to us by the International School of Uganda. The team is small yet mighty and intends to grow over the next few years to take even more athletes to the 2025 Games planned for Germany!

Keep an eye out for this budding powerhouse from East Africa!

Constance Collins
Uganda
Confused about nutrition for CKD?

Hi there! I'm Emily, a registered dietitian and certified diabetes educator. Through my practice Kidney Nutrition, I help those living with chronic kidney disease overcome the confusing world of nutrition so they can improve their kidney function.

I'm excited to be creating a Nutrition for Kidney Health Series for the Refit for Life! Toolkit. In this 4-part video series, I will help you navigate the complex world of food & nutrition and show you how food can be both delicious and nutritious while achieving your health goals. Aimed at those with CKD, post-transplant or currently on dialysis, this series will breakdown what you need to do to improve your health while showing you how you can eat the foods you love!

Recipe from "The Complete Renal Diet Cookbook"

MEDITERRANEAN EGGPLANT CASSEROLE

The versatile eggplant comes in many colours and is a great source of fiber and antioxidants. This eggplant casserole has all the flavors of summer in one dish, but you can enjoy it all year long because it freezes well and is great for leftovers or weeknight dinners.

3 tablespoons of olive oil, divided
1 large white onion, diced
2 garlic cloves, minced
1 medium green bell pepper, diced
1 cup canned diced tomatoes, no added salt
3 tablespoons dried parsley
1 tablespoon dried thyme
2 large eggplants, sliced into 1/2 inch pieces (8 cups)
1 tablespoon all-purpose flour
1/4 cup shredded part-skim mozzarella cheese

1. Preheat the oven to 375°F. Coat a casserole dish with 1 1/2 tablespoons of olive oil.
2. In a large skillet, heat the remaining 1 1/2 tablespoons of olive oil and sauté the onion until tender, about 10 minutes. Add the garlic and bell pepper and cook for about 3 minutes. Add the tomatoes, parsley, and thyme and simmer for a few minutes. Transfer the mixture to a bowl and set aside.
3. In the same skillet, add the eggplant, stirring frequently until browned, about 5 minutes. Add the flour and stir. Add the tomato mixture and bring to a simmer.
4. Spoon half of the vegetable mixture into the prepared casserole dish. Top with 1/8 cup of mozzarella cheese. Add the remaining vegetables and top with the remaining 1/8 cup of mozzarella cheese. Bake for about 30 minutes, or until the cheese is bubbly.

Per serving: Calories: 202; Protein: 5g; Total fat: 12g; Saturated fat: 2.5g; Total carbohydrates: 20g; Fiber: 6.5g; Cholesterol: 5mg; Phosphorus: 106mg; Potassium: 680mg; Sodium: 71mg; Sugar: 9.5g

Join the Refit for Life program now!
This summer was a big one for sport in the UK and it was no different for the transplant community. The European Transplant and Dialysis Games (ETDG) was the second large-scale event celebrating the life-saving benefits of organ donation to take place in England in the space of just two months and saw hundreds of transplant recipients and dialysis patients travel to compete from across Europe.

Transplant Sport, the charity raising awareness of the importance of staying healthy and active post-transplant, was behind ETDG’s arrival in the UK for the first time ever in its history and hosted the week-long event in the picturesque city of Oxford and its surrounding areas.

From 21st - 28th August, over 500 competitors from over 27 European countries took part in sporting events including everything from football, volleyball and discus to archery, cycling and swimming.

The Games began with an athlete parade and emotional opening ceremony at Oxford’s iconic Sheldonian Theatre before the teams and supporters boarded a party boat flotilla, travelling down Oxford’s famed waterways to Radley College, a nearby boarding school for boys which provided accommodation and leisure and sporting facilities for the week.

Sporting highlights of the week included a cycling time trial and race, mini-marathon and pétanque in the stunning settings of Blenheim Palace, the birthplace of Sir Winston Churchill. A fierce football tournament also took

Continued on next page

The 2022 European Transplant and Dialysis Games

A week of events in Oxford, UK and surrounding areas

Photography by Richard Hall
place at Radley College which saw Team Great Britain and Northern Ireland (Team GB&NI) retain the gold medal position that they secured at the 2019 World Transplant Games in Newcastle.

Team GB&NI was the largest team to take part, comprising 186 competitors from across the UK including 12 dialysis patients and three live donors. Together the team topped the medal table, securing an impressive 99 gold medals, 78 silver medals and 77 bronze medals, scoring a total of 530 points. Hungary came in 2nd place with 37 gold medals and finishing with 221 points and in 3rd place came Poland with 16 golds and 83 points.

With the Games also aiming to build relationships between the transplant community and give transplant and dialysis patients the chance to share experiences with like-minded people from across Europe, the social event schedule was just as important as the sport. Across the week, Radley College also played host to a sing-along screening of Mamma Mia, a James Bond themed night, a youth club, live music and a glittering gala ball to bring everything to a close.

Dr Paul Harden Chairman European Transplant and Dialysis Games 2022 and Trustee of the World Transplant Games Federation: ‘It was a fabulous week and so rewarding to see so many competitors from so many countries proving the incredible value of the gift of life and honouring their donors. I would like to thank all the volunteers and staff of Radley College, Blenheim Palace and MLS for all their generosity and hard work making these games such a success’.

Hosting such a large number of transplant recipients and dialysis patients safely was made possible by the team from the Oxford Transplant Centre at Churchill Hospital and paramedic support from South Central Ambulance Service charity. Approximately 300 patients from across the south and midlands receive life-saving transplant procedures at the centre each year. It is the largest pancreas transplant centre in Europe and one of only two centres in the UK transplanting small bowels.

Dr Paul Harden
Chairman European Transplant and Dialysis Games 2022
A Symbol to Inspire – the Gift of Life Baton

Sleek, universal, inspiring, inclusive. These are just some of the concepts that spring to mind when admiring the new Gift of Life Baton launched recently at Olympic House.

The Baton is a gift from Transplant Australia and the Australian Government to the world transplant community to act as a beacon between each World Transplant Games.

The Baton, designed and produced in Australia by leading industrial design company, Form Designs Australia, is features a specially carved piece of jarrah wood native to the southwest of Western Australia.

WTGF President Chris Thomas said the Baton was the culmination of a six-year dream. “We are all familiar with Olympic torches as they wing their way across the world in the lead up to the Olympics. The Commonwealth Games also celebrates its contribution to the world of sport through a Baton,” Mr Thomas said.

“And I would like to acknowledge many countries have their own symbols recognizing organ donation and the gift of life.

“At Transplant Australia we wanted to recognize all donors through a baton, one which would be embraced by any country where it was displayed and a baton which was robust enough to serve the world for at least 20 years. It also needed to proudly display the World Transplant Games logo rather than a local symbol. It needed to have universal acceptance.”

Transplant Australia developed a brief working with Media Junction’s Jason Pearce. Jason was ideally suited to help bring the concept to life having had a heart transplant for 5 years.

From there Form Designs Australia was chosen to bring the project to life. Principal Edward Khoury explained, “Form Designs were honoured to be...”
involved in the development of this important, iconic symbol. It was with great pleasure that we could be part of this initiative supporting the Gift of Life. Form Designs have been involved in industrial design for four decades and have developed many global products but nothing as remarkable as this.”

Australian Federal Minister for Sport, The Hon Anika Wells, said transplant recipients were some of the most inspiring athletes she had met.

“The Australian Government is proud to have worked with Transplant Australia to gift this Baton to the world transplant community.”

The Gift of Life Baton was also unveiled in Australia at Parliament House in late November.

It will be presented at various hospitals across Perth, and at the Western Australian State Parliament before commencing a 4,340km journey on motorcycle from the last city to host the World Transplant Games in Australia – the Gold Coast – to Perth’s Optus Stadium for the Opening Ceremony on April 16 2023.

The Gift of Life Baton Tour will be led by altruistic kidney donor, Gordon Rutty. Gordon, who this year walked 400kms around the Gold Coast to raise funds to help children attend the World Transplant Games, has dedicated his life to helping promote the gift of life.

WTGF President, Chris Thomas, presented the baton at an International Organ Donation and Transplantation Conference in Abu Dhabi to the Abu Dhabi Department of Health Chairman, His Excellency Abdullah bin Mohammed Al Hamed
Almost 14 years ago, I was told I needed a kidney transplant. It was a very shocking moment, but it also motivated me to learn everything I could about organ transplantation. As a trained medical scientist with decades of professional experience in the health care industry, I had no issues with access to medical information and advice. But what I was lacking was connections with other patients.

I desperately wanted to connect with other people, similar to myself, who had gone through what I was about to confront. I was not looking for recommendations in treatment options, or surgical procedures, but more simple questions that are very critical to the quality of life I was searching for. What is the best diet to avoid nausea, how do you tell your employer, and is it possible to start a family? When I asked my physicians for personal connections, they really could not help me. Understandably, they had other priorities and a lack of time. On top of this, there are laws and regulations preventing providers from sharing personal data between patients.

That day, I decided to work toward creating a safe space for people to connect, share experiences and support each other, regardless of where they live.

**Platform launch**

In 2021, exactly 12 years from my first transplant (I had a pancreas transplant nine months following my kidney) we launched TransplantLyfe - a platform built for patients and care partners, designed and developed by Lyfebulb in partnership with many patients and care partners. TransplantLyfe connects patients both one-on-one and in a discussion forum, in a moderated and safe manner, so that no one will feel unsafe, harassed or alone.

We also included sections of curated resources as well as a health tracker, to empower people through recording their data, which helps facilitate data recall during appointments with providers. Our resources have expanded since the initial launch and now include educational seminars (webinars) in partnership with leading physicians and thought leaders, as well as written article. Soon TransplantLyfe will include a clinical trial hub with patient-centric educational materials as well as links to relevant clinical trials for patients to join at the center level.

Our users are grateful for a safe space to share their stories and ask their peers for support and advice. More and more people are joining TransplantLyfe, and our outreach is both widespread as well as targeted, to transplant centers and organizations focused on patients. There is no cost to patients to participate. As well, we listen to feedback from our community and we constantly innovate to provide the best possible user experiences.

Ultimately, in addition to facilitating connections and education, TransplantLyfe aims to further innovation, with big opportunities for research to be conducted on our platform to improve the future of care and even products for those in the organ transplantation ecosystem.

Karin Hehenberger, MD, PhD
TransplantLyfe
www.transplantlyfe.com
The WTGF’s social media team launched the new “Celebrating the Power of Sport” campaign earlier this year, driven by our global Tx Family and the upcoming #2023WTG in Perth.

Through this campaign, we highlight the various sports played at a summer World Transplant Games with the goal to keep our followers informed and inspired while we celebrate the Gift of Life, through sports!

Much excitement is building on the #roadtoperth, with National Games and training preparation well under way. Through a social campaign like this, we have the opportunity to share these stories, and meet and engage with transplant and living donor athletes around the world.

The initiative includes our Living Proof Project which shares the challenges and victories of our athletes around the world. These stories showcase what can be achieved through the generosity of organ donation and the determination of our athletes. By honouring our donors through self-care and a healthy lifestyle, our athletes are our ambassadors for the value of organ donation and demonstrate what successful transplantation looks like.

Throughout the build-up to the much anticipated 24th World Transplant Games, our team will share Top Tips from previous WTG athletes who share their experience and strategies for successful competition. Our cool infographics offer the benefits, fun facts and Perth Games’ highlights, while our athletes quotes and photos allow our global family to connect with fellow athletes who share the love of sport.

Over 26 member country associations have already contributed and we invite you all to join us, share your story and celebrate the power of sport with our Tx family around the world.

Link to participate: https://form.jotform.com/World_Transplant/power-of-sport

"Throughout the build-up to the much anticipated 24th World Transplant Games, our team will share Top Tips from previous WTG athletes who share their experience and strategies for successful competition."

Continued on next page
CAMPAIGN

Living Proof Project
TRANSPLANT ATHLETE STORYBOARD
Name: Sui Lung Lai
Country: Hong Kong
Age: 67
Transplant: Kidney recipient

When I was young, my left leg had received some surgical treatment and I lost a piece of quadriceps. I did not have enough muscle strength, couldn't participate in strenuous exercise, and was not a regular athlete.

In 1991 I was diagnosed with renal failure and received kidney transplantation in 2007. My doctor advised that exercise is the best medicine. I began to participate in light exercise, and gradually developed habits and interests: I love playing lawn bowls, petanque, table tennis and walking. I always evaluate my physical condition and set targets. I acknowledge my limits and try to make breakthroughs.

I first joined the WTC in 2009, Gold Coast, Australia, and was never absent since then. I enjoyed the opportunity of meeting transplant recipients from all places around the world. We made good friends and shared beliefs and experiences. Recently, I entered the WTC six times and luckily got some medals.

Sport activities strengthen our physical and mental health. Competition helps us build up confidence and concentration. We will take good care of ourselves, live well and continue to celebrate the gift of life and promote organ donation.

TABLE TENNIS
TOP TIPS for table tennis at a World Transplant Games
GABRIELLA SZABO – Kidney Recipient

Start preparing for the competition in time, the best thing is to visit continually to keep yourself in shape, as the risk of injury is lower, & less extra training is needed to achieve the best form.

The development of hitting techniques is very important, there is always something to polish off. Do your best to hit the dot well as many times as possible, not likely in training but slow in matches. Play matches many times, learn its pace, test yourself in critical situations. It's best if you play in the league all the time - you can constantly test your progress & better assess your shortcomings. Winning is a great motivation, but defeat is the best teacher.

- Sleep well & rest the night before the competition. Eat a healthy, light but nutritious breakfast that day. Drink plenty of fluids during the competition.
- Warm up well before the competition & keep your humid body warm during the games so you don’t catch a cold.
- During the match, you have to fight the opponent mentally. There is no shame in studying & analyzing your opponent's game.
- A bonus tip: Table tennis is not only a sport of skill, a rocket & cover suitable for your playing style will greatly increase your performance! Experiment to find the right combination for better performance.

Follow us on social media:

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One man’s driving adventure for the Gift of Life

Living kidney donor, Anil Srivatsa from India, is on the road to Perth unlike any other. His road will take him 57,000km through 17 countries as he drives to Perth, sharing the message of organ donation along the way.

Anil has been a campaigner for organ donation since 2014, when he donated one of his kidneys to his elder brother Dr Arjun Srivatsa.

What made you decide to take on this enormous trip? What are you hoping to achieve?

People find ways to get their point across and we are familiar with running marathons, or ice bucket challenge or walks and more. I chose driving for the following reasons:

1. More people are climbing Mt. Everest than what I am doing - driving around the world promoting this cause.

2. I get to drive through smaller communities and villages and speak to them about organ donation. They need more help than the city folk. Knowledge is powerful and driving allows me to reach these communities.

3. Driving around the world takes a lot of effort, mentally, financially, and physically. I have chosen this adventure to also demonstrate to the world that life can be any adventure you want it to be, post a living donation.

Where did you start and what countries have you been to so far?

I started the journey in February when I drove to Kashmir in India and back after speaking to about 5000 people, as well as media. Then I flew over to the USA and started driving at the International Rotary Convention in Houston in May. From there, I went up the Alaska, across to Toronto, back to New Jersey, then Kansas, Texas, Mexico and I am now in Belize.

What route will you be taking to Perth and will that be the end of your journey?

I am heading to Argentina where the car will be put on a boat to Sydney and I hope to drive across Australia to Perth for the World Transplant Games then on to Melbourne for the International Rotary Convention.

There is no end to the journey until we all get closer to a point where no one dies waiting for an organ transplant. I still have Africa to fire up to embrace organ donation.

With driving, I get to share my story firsthand. This beats social media where the attention span is so limited. Speaking to an attentive, engaged audience is a far more effective way to bring change, as you are creating ambassadors who will champion the cause long after you have left town.

Driving like this also helps me get the attention of the media. They like out of the box stories and this story is just that. You started your journey to the World Transplant Games back in April this year.

You have been doing presentations to Rotary clubs wherever you go. Why Rotary and what is the message you are sharing?

I am a Rotarian. We are ordinary people who are doing extraordinary things to make living on this planet better for everyone. Rotary, with a single-minded effort globally, has managed to almost eradicate polio from this planet. Who better partner than Rotary to get behind organ donation? This journey is about Uniting Rotary for Organ Donation. I speak to clubs along the route about how they can work to this objective in their own communities with advocacy, awareness and philanthropy for organ donation. The message is clear. The goal is to ensure their community is 100% committed to organ donation, their systems and processes are in place to enable not just signing up but also for retrieval and transplantation. Rotary can become the equalizer for many communities, as organ donation is still the privilege of the rich in most parts of the world.

Continued on next page
The people who I have met and are now champions and allies of organ donation. They make me want to continue this mission.

What do you enjoy about participating in the World Transplant Games?
I love the energy of thousands of athletes who have had similar shared journeys as me and showing the world that life can be active and as athletic as you want it to be after a living donation. I like that these Games will see more donors participating in vigorous athletic sports. It is the best way to build confidence in potential donors who are undecided about committing to save someone they love. Becoming the example for them is the driving factor of my participation. Of course, the self-achievement as a result is the cherry on the pie!

Any final words?
I would like to acknowledge all my supporters. My family who are standing behind me like a rock. Right next to them are my work colleagues who are holding the fort in my absence. My investors, for their continued support and confidence. They there are my never flinching sponsors who are seeing the impact of the effort and financially enabling me to continue. My Rotary family, who support me with gas money so I can keep getting to more meetings and spread the message. To friends and strangers who contribute via crowd funding to keep me on the road to serve humanity and save more lives.

Anil and his wife Deepali are currently in southern Central America. If you would like to follow and support Anil on his road to Perth you can follow him on Facebook and Instagram at Gift of Life Adventure.
“PG’s Prize”

Karin Green, Swedish Golf Champion!

Karin Green, Knistad Golf Club, was one of the favourites for “PG’s Prize”, the Swedish Championship for transplantees and dialyzing golfers, and she didn’t disappoint. With a net score of 73 shots, she took her fifth win and will have the pleasure of arranging the 2023 competition.

For personal reasons, last year’s Champion couldn’t participate this year but with the aid of Peter Sahlin, from Örebro, the competition was implemented in the best possible way on a quite hilly and challenging course at Söderköping’s Golf Club.

It was a very hot summer’s day and many of the golfers chose to use a golf buggy to better cope with the heat that reached over 30 degrees centigrade. It was important to drink a lot of fluids to keep the body balanced and not to lose concentration.

Second in the transplantee class was Henrik Röste, Fjällbacka GC and third place went to Tomas Bengtsson from Varberg’s GC. In the class for relatives, Jenny Röste won with Jessica Röste in second place. Third was Lars-Åke Thelander.

Next year Karin Green will arrange the 2023 “PG’s Prize” on her home turf at Knistad Golf Club close to the Swedish west coast. International friends are most welcome, however the dala horse, PG’s Prize, can only be won by a Swedish transplantee or dialysing golfer.

Welcome to Knistad Golf Club in 2023.

CJ Ahl
Sweden
Afsana was diagnosed with Primary Sclerosing Cholangitis (PSC) at the age of 16. The disease significantly impacted Afsana’s life and six years after she was diagnosed, she was told that she would need a new liver to save her life. She turned to her family first, but no one was compatible, and so, desperate to save her life, she turned to social media to find a donor. Through Afsana’s diligent posts and journaling of her situation and needs, Afsana received a living liver donation from a complete stranger.

Afsana joined the Great Actions Leave A Mark collaborative public awareness campaign to share her journey. Great Actions Leave a Mark is campaign designed to increase public awareness of the power of living kidney and liver donation. It showcases the scars (mark) and stories of living organ donors and living donor liver and kidney transplant recipients across Canada.

Afsana’s scar, her mark, is now a part of who she is. It is a part she loves. It is a reminder of everything she has been through and how strong she is.

This campaign was launched during Living Donation Week 2022 in partnership with BC Transplant, Manitoba Gift of Life, Canadian Blood Services, and the YE Agency, and although the week is over, the passion, dedication and action generated continues.

Living Donation Week is a public awareness event launched by the Centre for Living Organ Donation in 2020 with support from the Canadian Transplant Association and the transplant community across Canada that brings together transplant recipients, living donors, Team transplant, caregivers and the transplant community as a whole.

Each year, the week after the labour day long weekend, we raise awareness to improve access to living kidney and living liver donation, we celebrate living donors, transplant recipients and Team Transplant, and we hope to inspire those currently waiting for a transplant and those who care for them to explore
living organ donation.

We want you to join us! Do you have a story to tell about your journey as a living liver or kidney transplant recipient? Did you save a life by donating a part of your liver or kidney? Do you have a landmark close to you that could light up green for Living Donation Week? We are looking for national and international landmarks to #SharetheLight by joining others like the CN Tower, Niagara Falls, Sails of Light, the Ottawa Senators sign and many more to light up green to shine a light on living organ donation.

Living Donation Week 2022 brought many exciting events and campaign launches. We had our kick off Celebration Event which included stories and interviews from living donors, transplant recipients and Team Transplant; entertainment from Cree Rapper and Dialysis Warrior HelinBack, highlights from living donor medal selfies, Gratitude wall posts, and messages of hope from UHN Leadership, Community Leadership and partners. We sent medals to living donors who shared medal selfies. We hosted a Finding a Living Donor Hands Virtual Workshop that provided practical tips to help patients and advocates share their story, create email and social media campaigns and raise awareness about their journey.

Our goal is to have the world celebrate Living Donation Week 2023 but we need your help! We want to showcase living donors, transplant recipients, caregivers, family, friends and the community across Canada, and around the world to celebrate the gift of life and give hope to those waiting. We encourage you to get involved by encouraging your community to light up green and be part of the celebrations next year from September 10-16, 2023.

For more information about Living Donation Week, and living donor kidney and liver transplantation, please visit www.livingorgandonation.ca or email us at livingorgandonation@uhn.ca. To view stories about living organ donation, please visit www.greatactions.ca and visit us on social media @GiveLifeUHN.

We look forward to celebrating Living Donation Week with people from around the globe next year!

Candice Coghlan
The Centre for Living Organ Donation

Brenda Brown
Canadian Transplant Association
Earlier this year saw the return of the Westfield Health British Transplant Games for the first time since 2019 as the event travelled to Leeds for one big reunion of the transplant community from across the UK.

The long-awaited Games were finally able to take place physically after three years of lockdowns and shielding due to the Covid-19 pandemic and over 2,000 transplant recipients, live donors, donor families and supporters gathered for four days of sport, celebrations, and surprises.

Across the weekend, the flagship event of charity Transplant Sport saw 24 events take place, over 2,100 medals given out and 1,340 runners join the annual Donor Run, which is the only event open to everyone and designed to thank donors and donor families for giving the ultimate gift of life and bring together the Games with the communities of Host City Leeds in physical activity.

The Games began with a spectacular opening ceremony and an athlete parade which wound through the streets of Leeds City Centre, culminating at the Civic Centre where performers and special guests graced the stage to officially start the event. The Transplant Sport flag and Tom’s Baton, a commemorative sculpture donated to the charity by the Donor Family Network, were passed and the donor flame was lit. Shortly after crowds gave deafening cheers for donor families to say thank you for the ultimate sacrifice that their loved ones made.

**Weekend highlight**
A highlight of the weekend and an exciting first for the Games saw crowds at the John Charles Centre for Sport surprised by the Yorkshire Air Ambulance, when the first ever British Transplant Games branded, region-specific organ donor card arrived by helicopter.

Transplant Sport, together with Games events

“Crowds gave deafening cheers for donor families to say thank you for the ultimate sacrifice that their loved ones made.”

Continued on next page
organisers, have worked in partnership with NHS Blood and Transplant to develop the Yorkshire Donor Card, designed to leave a legacy and a commitment to organ donation in the region as the Games move on. 10,000 limited edition, Yorkshire Organ Donor cards have been created and will be given out by organisers and other local partners and organ donation ambassadors.

After the exciting arrival of the first Yorkshire Organ Donor card, the Games came to a sparkling end with a closing ceremony at Leeds’s Royal Armouries. More exciting announcements followed as headline sponsor, Westfield Health renewed its commitment to the Games, revealing that they would continue to support financially until 2028.

The 45th British Transplant Games was staged with the support of over 20 sponsors who generated over £400,000, including long-term partners Kidney Care UK and Anthony Nolan and crucial local supporters such as Leeds City Council, Leeds Hospitals Charity and the University of Leeds.

A new record
Transplant Sport is the largest UK charity raising awareness of the life-saving benefits of organ donation and the importance of staying active post-transplant. Each year the British Transplant Games acts as a vehicle to promote the charity’s messages, say thank you to donors and encourage families to have those crucial conversations about their wishes. The many partners and the marketing campaign behind the 2022 Games created a mammoth reach figure of 3.3 BILLION people a new record for the Charity and its Games partners.

Next year’s Games will be taking place back in the West Midlands and Coventry will finally take on the role of host city after the 2020 and 2021 Games were cancelled due to the Covid-19 pandemic.

Liquid Public Relations
On behalf of the Westfield Health British Transplant Games

“After the exciting arrival of the first Yorkshire Organ Donor card, the Games came to a sparkling end with a closing ceremony at Leeds’s Royal Armouries.”
The 1st edition of the National Games for Transplanted Persons in Colombia was successfully held in Santa Marta, Magdalena. Twenty five Colombian transplant athletes, family, friends and the medical community gathered to celebrate life, give thanks for their second chances and demonstrate once again that transplantation is a condition that does NOT limit and that it is achieved thanks to the altruistic decisions of Colombians who give a gift so that others can start over.

The events were cycling, athletics, swimming and triathlon - healthy competition was experienced; the bonds of friendship between transplant recipients were strengthened to continue to promote the improvement of the quality of life through physical activity and sports; and the message of donation as an act of love that saves lives was given.

The Ministry of Sport was present at the event, providing technical support to the athletes and encouraging them to stay active.

This first edition of these games opened the door to competitive sport in transplant recipients, contributing to sustainable development goals and underlining the idea, “Let no one be left behind”. Transplantation is a treatment that allows a person who has suffered a chronic disease – damaging the function of one or more of their organs – to count on a second chance allowing them to recover their life and make those dreams come true that they once thought lost.

Dream of being chosen
All of the athletes shone, each one of them felt the adrenaline of the competition, felt included and full of the desire to continue taking care of that gift that today allows them to dream of being chosen to form the Colombian selection of transplanted athletes that will represent Colombia in the next World Games in Perth, Australia 2023.

We thank those who have joined this initiative, their support has been essential in this project that seeks to give transplantation the prominence it deserves, it is a movement with many who play a fundamental role in the treatment of many diseases, all and each of them are essential for life to begin again with a decision to donate.

The first part of this relay race began with that decision, that baton was delivered so that life transcends, in the hands of transplant recipients today are those final meters that take them closer to the finish line, where they will hang the medal to say THANK YOU for giving me the privilege of telling your story through mine.

Colombia is heading to Perth 2023 to show the world that miles of gratitude are also added from Latin America.

Edith Alejandra Martin
Colombia
News from Greece

The 2nd Marathon Torch Relay named in memory of Iason Lalaounis

The 2nd Marathon Torch Relay from the Panathenaic Stadium to the Marathon Road Museum on 2nd October 2022, was successful beyond all expectations. The event was organized by the Sports Federation for Dialysis and Transplant Athletes under the auspices of the Region of Attica and the Municipality of Marathon, and dedicated to Organ-Tissue Donation and Transplantation.

The Marathon Torch Relay was named “IASON 23” in memory of Iason Lalaounis, who died in a car accident in front of the Hellenic Parliament and whose family donated his organs, saving the lives of seven fellow people.

Many participated: our Sports Federation athletes, the Lalaounis family and Jason’s friends, as well as a multitude of other athletes, long distance runners, “Tihio Race” athletes, runners of the National Police Sports Union, PASYNO-ESY athletes, the cyclist Nikolaos Moschis and Denise Dimaki – Greek champion and Olympian triathlete. Our Sports Federation thanks all the participating athletes.

The Torch of our Sports Federation, named “Torch of Life”, was handed over by the Deputy Governor of the Central Sector of Athens, Mr Dimopoulos Georgios, to our Sports Federation athlete, Mr Polidorou Christoforos. Our Sports Federation athletes carried the Torch of Life up to the Cross of Agia Paraskevi and from there long-distance runners carried the Torch to the Marathon Road Museum and handed it over to the Deputy Mayors of the Marathon, led by Mr Kyparissis Vangelis, who placed it in a special display case reserved for us at the Museum.

We sincerely thank the Region of Attica and the Deputy Regional Governor of the Central Sector of Athens, Mr Dimopoulos Georgios, the representative of the Transplantation Department of Laiko Hospital and Evangelismos Hospital, Mr Venardakis Spyridonas and Mr Vougas Vasilios as well as all our sponsors who contributed to the success of this event: TihioRace, Sesamis Natural Bars, Sklavenitis AE, First Aid Ambulance, Pythia KoinSep, IASO Thessalias, and Civil Developments Company. Finally, our special thanks go to the Municipality of Pallini and the Mayor, Mr Zoutsos Athanasios, for his support.

The Sports Federation of Dialysis and Transplant Athletes will organize this Marathon Torch Relay on a yearly basis for Organ-Tissue Donation and Transplantation awareness.

The Board of Sports Federation for Dialysis and Transplant Athletes
Greece

In memory of Iason Lalaounis

Iason’s parents at the Marathon Torch Relay
German Championships for Transplant Recipients and Dialysis Patients 2022

The German Championships went ahead thanks to Rotary Club Simmern/Hunsrück

Hooray, we did it. Against all odds, we were able to hold our German Championships for transplant recipients and dialysis patients at an unusual time, thanks to the help of the Rotary Club Simmern/Hunsrück.

Thanks to the long preparatory work and great commitment of the members of the Rotary Club, which was already well prepared for the championships in 2020, the Championships were postponed when the virus threw a spanner in the works. After a closer look at the infection situation, the board of TransDia Sport Deutschland e. V. and the Rotary Club Simmern/Hunsrück decided to hold a championship in 2022 in Simmern.

Simmern is an up-and coming district town near the Soonwald nature park in the middle of the German low mountain range Hunsrück, framed by the Rivers Rhine and Moselle. The traditional date, the weekend of Ascension Day, 26th May 2022, was not possible due to delays in construction work and delivery problems with the new hotel building. The good news is that we were able to book the last weekend in September 2022.

Determined to meet

As I said at the beginning, an unusual date, still an unstable risk situation due to the virus, but we were determined to offer our members the opportunity to meet, exchange ideas and participate in sports again. Many online conferences took place with the organizers - there were reservations and concerns to be discussed in order to find a safe way to achieve it.

Ultimately, our hygiene concept for the 2022 sports weekend encouraged us to hold the German Championships for transplant recipients and dialysis patients from 22nd to 25th September. The minimarathon began the event on 22nd September with bright sunshine, followed by the award ceremony and the general meeting of the association.

The badminton, tennis, table tennis, swimming, cycling, petanque, ten pin bowling and golf competitions took place on day two. The third and final day brought together all participants in the athletic stadium for ball throw, shot put, long and high jump and all of the running competitions.

The traditional conclusion, all participants, supporter and family members gathered in a large circle, commemorated all lifesavers, their

Continued on next page
organ donors, are one with their friends on waiting lists for a lifesaving organ transplant - a moving image that helps us all through sometimes difficult times.

Our appointment with the weather gods should not go unmentioned, three days of sunshine and pleasant temperatures, just in time for at the end of the championship it started to rain.

All of the organizers were happy and relieved that the hygiene concept worked out. Every participant had to undergo a daily Sars-Cov-2 quick test. If the test was negative, everyone received access to the events in the form of a coloured ribbon.

As a result, a participant in the championships with a Sars-Cov-2 positive test was detected on the 2nd day. He immediately started his journey home, but fortunately only had mild symptoms of the disease.

Afterwards we did not find out about any other Sars-Cov-2 infection of a participant, everyone behaved absolutely cooperatively.

The Board of Transdia Sport Deutschland e. V. sincerely thanks the Rotary Club Simmern/Hunsrück for their help and support in organizing this special German championship for transplant recipients and dialysis patients.

Gudrun Manuwald-Seemueller
First Chair TransDia Sport Deutschland e. V.
Germany
Hello Paradise!

PERTH 2023

The Wait is Almost Over...

REGISTRATION NOW OPEN
15 April - 21 April, 2023
www.worldtransplantgames.org

REGISTRATION CLOSES FEBRUARY 17

15 April - 21 April, 2023
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