

TransplantWorld

2016 | Issue 1

Journal of the



World Transplant Games Federation
Powered by the gift of life



Out of Your Comfort Zone

Two athletes tackling very different challenges



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Artwork: Inkap Design, UK

www.inkapdesign.co.uk

Printer: Printech Europe Ltd,

Chelmsford, UK

www.printecheurope.com

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GUEST EDITORIAL

Stepping Out of Your Comfort Zone Post-Transplant

It is difficult to expect someone receiving an organ transplant to know what they should do for physical activity or exercise. When I started the Transplant Rehabilitation program at the University of California-San Francisco in 1998, there were no guidelines, no research - nothing about exercise in this population...we were all outside our comfort zones in embarking on this! There were, however, examples of very fit transplant recipients, even competitive athletes who clearly demonstrated that exercise was safe, and it was very important to them in their quality of life. Despite these examples, there remained an underlying (although undocumented) fear amongst many transplant surgeons and some physicians that vigorous exercise may somehow harm their new organ. This often resulted in avoidance of the topic, and/or general comments like "well, don't overdo it". There were many who felt 'well, you've got a good functioning transplant, let's not do anything to harm that'. When no specifics were given, most people remained sedentary.

We told our transplant recipients. Each person presents for transplant with a different medical history, different experiences with exercise, different goals, support systems for recovery and needs for rehabilitation. It is important to establish common goals and guidelines for optimizing physical functioning after transplant. Here's some thoughts and observations from over 20 years' work in this unique area.

1) The goal should be to optimize physical ability following transplant to a) optimize quality of life, which might be participation in competitive athletics for some, and for others just the ability to be fully involved with their family activities and work responsibilities; and b) to reduce risk for cardiovascular disease (i.e. minimize body weight, help manage blood glucose, blood pressure and stress), which is the leading cause of complications and death following most organ transplants.



"It is never too late following transplant to get started!"

2) Following a successful transplant, all recipients should start moving (ideally starting a program of walking within the first several days following surgery). The key is to start slowly and progress gradually. So, whatever exercise is preferred, start with 10 minutes at a very low effort, gradually progress in duration (i.e. add 2-3 minutes every day or every week) to 45 minutes (or more), then gradually increase the effort (i.e. start walking slowly, then walk faster such that you feel your heart beating faster, you begin to sweat and you breathe harder - but not so hard you are unable to carry on a conversation). It is never too late following transplant to get started!

Enlist support from others, especially family and friends. My experience is that family members are often over-protective of the transplant recipient. In fact, one of my very first encounters was a mother (who donated a kidney to her 14 year old son) whose son told me that he was not allowed to go roller-skating with his friends because she was afraid he would hurt his kidney. I have counseled parents who are concerned about their transplanted children playing soccer or other competitive sports. This is understandable, because before the transplant, medical issues and fatigue were often major concerns associated with exertion. The transplant usually corrects these concerns, and a MAJOR concern following transplant is remaining sedentary and inactive, resulting in remaining an invalid. Remember, Chris Klug was bronze medal winner in the 2002 Winter Olympics - 18 months after a liver transplant! He continues to compete on the world snowboard circuit and has been World Cup Champion four times! www.chrisklug.com Both of these accomplishments were pushing the envelope on physical performance following transplantation.

The key is to start slowly and achieve a basic foundation of fitness (strength and endurance) and then move to vigorous activities/sports if that is the goal. Clearly there may be some circumstances in which vigorous exercise is not recommended, however everyone should be able to gain muscle strength and gradually gain endurance. To help reduce fear and anxiety, a) watch a video from the World Transplant Games or a local or regional Games in your country, realizing that those participants came from the same place prior to transplant; and b) to create a plan to incorporate a walk, a trip to the gym, regular exercises at home into a regular routine (on most, if not all days of the week). I used to remind kidney transplant recipients of the 3-4 hours, 3 days per week they spent on dialysis... your exercise program only is asking 30-45 minutes per session on at least 3 days each week!

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Message from the President

How would you rate the advice you received from your transplant team as you were discharged from hospital?

How well did they set you on your new journey as a transplant recipient?

No doubt most recipients received good advice regarding their immunosuppression, nutrition and healthy eating. But did that advice extend into ensuring you remained physically active? Did they take time out to talk about the simple equation of energy in and energy out? Does your regular clinic check-ups extend to this advice? How often do they take your weight or calculate your Body Mass Index?

You don't have to be a transplant recipient to struggle with this equation. In fact age and sedentary behaviour are perhaps more relevant contributing factors to creating an imbalance in this equation although undoubtedly high levels of different steroids and immunosuppression play their part.

The World Transplant Games Federation is on a mission to ensure that **'more transplant recipients are more active more often'**. While the World Transplant Games, both in summer and winter form, are wonderful events, we do recognise that they are only staged each once every two years. To achieve this mission we need to look beyond just our participants in the Games and consider how we can best influence a regime of activity and lifestyle post-transplant?

That work begins in August this year when the Federation presents for the first time to the delegates of The Transplant Society World Congress. This is a wonderful opportunity for the Federation to state its case in front of thousands of transplant physicians, nurses and coordinators.

As President I was pleased to help create this opportunity alongside our Medical Committee Chair, Dr Ka-Foon Chau who is also on the Local Organising Committee.

Our session will consist of 90 minutes and include a speech from myself and our newly elected Honorary Secretary, Liz Schick. Liz is well known throughout the transplant recipient sports world and is extremely active and a great role model, especially for kids who attend the annual Tackers ski camp.

Our keynote speaker will be Dr Paul Harden, Team Doctor of the British Transplant Team while four other doctors will give updates on transplant sports in their home countries. A panel

session and presentation by a children's choir will round off a wonderful opportunity.

The theme of my presentation is still in development and I look forward to enunciating it in detail in August and in a future issue of TransplantWorld later this year. We are hopeful we will be able to introduce a program to inspire all recipients to get active and involved in sport, their local, national, regional and world transplant games.

Delivering on our promise

I am writing this message somewhere over an American cornfield (well perhaps a little bit of liberty shown in that description) on my way to meet with the Houston Sports Authority which is bidding for the 2019 World Transplant Games along with Newcastle/Gateshead from the United Kingdom.

I can't believe in just a few short months Council was able to oversee the review and delivery of a totally new way of receiving bids, assessing them and, in July, voting on them.

Ensuring your health and safety in the World Transplant Games is our Council's number one priority. We can't eliminate all risks but we can certainly minimise them and ensure we have processes in place to address those risks when they happen.

Overhauling our legal documentation was high on our agenda as we need to ensure we learn from both our successes and failures in the past. The most recent Games in Mar del Plata in particular presented us with some significant challenges not least being the wrap-up of the Games by the Local Organising Committee. I remember how utterly exhausted the Gold Coast Organising Committee was after the 2009 World Transplant Games. It seems that with the lowering of the flag it is easy to collapse and forget about all the legacy matters that need tidying up including results and world records.

That's just one of the minor but nevertheless important changes in our documentation.

I need to give credit where it is due. The bulk of the work to review these documents was undertaken by an Australian sports consultancy on a pro-bono basis for the Federation. I can't thank Eugenie Buckley and Juliet Tetley from Suiko Consulting. Suiko uses industry expertise and commercial acumen to provide strategic advice to clients including major international sporting events such as Rugby League World Cup 2017, ICC World Cricket Cup 2015, and the Asian Football Federation Asian Cup 2015.

For the Federation they took on our brief and, with the support of our staff, Kim Renyard, Gary Green and Karen Cole, delivered a draft that absolutely nailed our requirements 95 per cent first up. From there it was some minor tweaking and we had a new and comprehensive way to approach bids in the future.

What does this mean for you?

Our Council's expectation is that with this legal basis behind us we will be able to deliver a far more professional Games

"The World Transplant Games Federation is on a mission to ensure that 'more transplant recipients are more active more often'."

into the future. Everyone likes each Games to be different but equally consistent. It is a real challenge. From Council's perspective we need to have confidence that the best bid has won and that all aspects of the Games, from sports to venues, accommodation, special events, marketing, promotion and finance, will be delivered within what we would accept as an acceptable range. We now have that confidence.

So on behalf of recipient athletes worldwide, thank you to Eugenie and Juliet.



We look forward to reviewing bids from Houston and Newcastle/Gateshead. Both are extremely worthy contenders.

Chris Thomas
President

"Ensuring your health and safety in the World Transplant Games is our Council's number one priority. We can't eliminate all risks but we can certainly minimise them and ensure we have processes in place to address those risks when they happen."

Overall these are the changes:

1. Development of a Bid Manual including:

- minimum standards and requirements for venues, accommodation, sport, medical, transport, safety and security, and environment
- commercial and financial arrangements
- ceremonies and official functions
- host city information

2. Development of a new Hosting Agreement

3. Development of objective Assessment Criteria, based on Bid Manual requirements and incorporating a weighted scoring system

4. Development of Voting Procedures within Council for Host selection

GUEST EDITORIAL

> Continued from page 3

Each individual will respond differently to exercise, meaning some will make rapid progress, others may take longer and reach limits that may be difficult to overcome. The goal is to optimize functioning within the constraints imposed by previous or current medical concerns, which are often unrelated to the transplant.

A program of exercise does not require you to spend money on gym membership, equipment, or personal trainer, it does require you to step out of your comfort zone, put one foot in

front of the other, get started slowly and progress gradually. The saying "use it or lose it" applies to your muscles (including heart muscle function), bones, and your overall health! Challenge yourself to make exercise a part of your post-transplant life, even if you've never been regularly active: get going and stick with it for at least 3 months, feel the results, and after that it will become a routine part of your life, and you will miss it when you don't do it!

Patricia Painter, PhD
Associate Research Faculty
Dept of Physical Therapy
University of Utah, USA

"The saying "use it or lose it" applies to your muscles (including heart muscle function), bones, and your overall health!"

STEPPING OUT OF YOUR COMFORT ZONE • STEPPING OUT OF YOUR COMFORT ZONE

Kate Clark

Kate Clark (nee Farne) is a long-time participant in the World Transplant Games, holding several World Records in athletics and winning the Athlete of the Games Award at the World Transplant Games on the Gold Coast in 2009. Kate received a liver transplant in 1998 at the age of 17.

In this article Kate addresses the challenges of getting out of her comfort zone in her new sporting interest, obstacle racing.

Standing on the start line, surrounded by chiseled athletes preparing to run, your heart is pounding and mind racing. The nerves, apprehension and adrenaline kick in as the starter announces: "Athletes – you are the elite of the elite, you deserve to be at the start line today. This course is designed to challenge you and test your limits, there may be a day that you will not finish but today is not that day. Are you ready!?" In that moment despite all the fear there is nowhere in the world you'd rather be, the hairs on the back of your neck tingle and before you know it you are racing.

Obstacle Course Racing or OCR is defined by Wikipedia as *a sport in which a competitor, traveling on foot, must overcome various physical challenges that are in the form of obstacles. Mud and trail runs are combined and the races are designed to result in mental and physical collapse.* I guess that puts it simply but for me it is much more than that.

Unlike many other sports no two OCR courses are the same, but all of them will be a test of stamina, agility and mental

toughness. That is the beauty of OCR. Like life (and transplantation) obstacles are put in our way to see if what we want is really worth fighting for, and you must fight until the end. I am yet to run a perfect race (if there is such a thing) but it's not the thought of this that keeps me motivated to train hard and return for each event. Out on the course you see and hear inspirational stories all the time, from the wheelchair bound paraplegic who along with his team have competed several grueling events, to those that have battled cancer and triumphed and the many who are on their own personal weight loss and fitness journeys.

You see, these OCR events are not just for the elite. They are for anyone and everyone – whether it's a test of self, or celebration for obstacles overcome, the feeling that you get when you are handed the finishers' medal, t-shirt and coconut water (or beer) is a rewarding experience - not to mention being able to parade your cuts and bruises as badges of honour when you return to work on Monday.



I have 10 pieces of advice for anyone keen to take up the challenge:

1. Don't take the things too seriously – enjoy the ride, but keep your mouth closed in the mud pits.
2. Be prepared to accept failure, pay the penalty and move on. It's never pays to dwell on the past.
3. The water will be cold – if it's warm question the guy/girl in front!
4. At some point throughout the race you will question your sanity. This is normal but don't give up.
5. It's a community sport. Camaraderie is key and selfishness is frowned upon.
6. Don't wear new clothes or shoes. They may not make it home in one piece.
7. Do not expect a hot shower at the finish, the best you may get is a cold hose down by the fire department.
8. Take wet wipes, toilet roll and alcohol wash – don't question this just take my word that you WILL need them.
9. You will find mud in places you didn't think possible and also feel muscles you didn't know existed.
10. Finally, it's addictive – be prepared to talk about it for weeks and be planning your next event within days.

For anyone keen to give obstacle course racing a go, good luck and have fun. If you would like any more advice, please don't hesitate to look me up and be sure to come and say "hi" out on the course.



STEPPING OUT OF YOUR COMFORT ZONE • STEPPING OUT OF YOUR COMFORT ZONE

Michel Stückelberger

For someone born with cystic fibrosis and a life expectancy of 20 years at best, cycling might not have been the most obvious choice. But when Michel read of Claude Mathaler cycling the world, the seed was planted.

I had always loved cycling even though I could not breathe like my friends. At my lowest my lung capacity was as low as 30%. Even the simplest task could leave me completely breathless.

I surprised my doctors by being relatively healthy for a CF patient. There were of course the usual problems, the physiotherapy, constant courses of antibiotics, infections and the terrifying struggle to breathe.

My way of fighting this affliction was to get on my bike. Cycling gently eroded my fear and made me stronger, improved my lung capacity and became my drug, a healthy addiction, with only beneficial side effects. It was my escape.

My childhood friend Vincent and I decided we wanted to raise awareness and funds for CF. Our first trip out of our comfort zone was a ride from Verbier, Switzerland, to Athens in 2002. What freedom to be on the road with no doctors around! We were hooked, and after working like demons to save money to finance our trip, we set off in May 2008 on a 10,000km adventure lasting

ten months through Canada, the USA and Mexico.

It was then that my health deteriorated. My lung capacity was at its very lowest. My only hope was a transplant. I found myself on the super urgent list. I was put into an artificial coma, my breathing was through a respirator via a tracheotomy and this is how I remained for 2½ months. And then came the miracle: the transplant. It took 10 days for me to come round but complication followed complication. It was at that time I just felt like letting go.

And then we turned a corner. My donor and I were breathing together, we were a team, we had places to go, we were on a mission, and my most important mission was to be worthy of this gift.

And so it was that 15 months later, we left Geneva to cycle to Gothenburg to attend the World Transplant Games. 2,300km and 50 days with my donor, my saddle bags, my medication and a tent! This time Vincent was not by my side. I had to do this alone. I slept on camp sites and met wonderful people, like Konrad,



81, wiry and alert, who had had 4 bypass operations and who told me 'If it wasn't for my bike I would be dead!'

The closer I got to Gothenburg the greater my trepidation. I knew no one on the Swiss team, I had never been on a racing bike or clipped into pedals and the idea of competing made me feel ill!

I arrived on my birthday, June 15th, and was met by Asa from the LOC. She greeted me like a hero but all I could think of was my journey, a road even longer than that I had just cycled, from my hospital bed and the moment I was ready to give up to where I was now.

My team persuaded me to hire a racing bike, so I did. I had a new drug – the Games, the people, being one of a team. This was my first competition ever. It inspired me to take part in the European Games in Apeldoorn in the Netherlands where I actually won a gold medal! The Swiss Team members then urged me to join them in Mar Del Plata for the World Games last summer. I was reunited with old friends and made new ones.

At present I feel no further need to be out of my comfort zone. I have the Salève on my doorstep near Geneva, a magnificent climb of 980m over 16km, that I can enjoy before 'going on duty' to look after our 17 month old twins, Alexia and Mathias, born thanks to my donor and through the love of the woman that gave me the courage to carry on in my darkest hour, my shining light.



PROFILE • PROFILE • PROFILE • PROFILE • PROFILE • PROFILE • PROFILE • PROFILE

Kim Renyard

World Transplant Games Federation Executive Manager



The World Transplant Games Federation is pleased to introduce their new Executive Manager, Kim Renyard from South Africa, who joined the Federation in December 2015.

Kim entered the sports and eventing industry 16 years ago, and soon became a well-recognised and experienced Event Director and Project Manager. As a Project Manager for the 2010 FIFA World Cup South Africa™, and more recently Event Director for the BBC Top Gear Festival in South Africa, she brings with her many years of experience, operational management and a sincere passion to work on major events and sporting experiences. Although Kim has had the privilege of working on many major events both in South Africa and around the world, it was her role as General Manager for the highly successful World Transplant Games in Durban 2013, which resonates as her most memorable and enjoyable event.

"The World Transplant Games in Durban, has always remained my most favoured event of all time. As an event which celebrates life and sport it truly opened up my eyes to the gift of life, and the astounding achievements which these athletes now celebrate. It was an honor to manage this prestigious event, and I have spent many a day wishing it would return to South Africa. To have a fulfilling life and career, it's imperative to merge what you are good at with what you are passionate about, and joining the World Transplant Games Federation, has given me that opportunity."

Kim, who has a degree in Marketing, a detail-orientated mindset and an eye for strategic business development believes her entrepreneurial spirit from a young age lead to her love for event management.

"From a young age, I've always loved the process of creating, planning and executing events. Initially this started with small projects like family

events, gatherings or celebrations, moving to school tours and national and international sporting events, and eventually it lead to major events like the 2010 FIFA World Cup, the Top Gear Festival and of course the World Transplant Games. Seeing an event come alive, cultures interacting, witnessing participants enjoying themselves, and watching people leave an event having had a wonderful experience, has always been a great reward for me and a major driving force."

Apart from her professional achievements, Kim considers her family another great success in life. Kim is married with two young daughters, aged 10 and 11 years. She enjoys participating in most sporting disciplines and grabs every opportunity to sneak in a round of golf with her husband.

"My family have always supported me and my career in event management which requires long hours and

dedication. My daughters loved the World Transplant Games in Durban, and found any and every opportunity to get involved. Many will remember them as the two young girls (then 7 and 8 years) helping to sell memorabilia and assist at the information desks."

Kim has spent the past few months settling into her role as Executive Manager and is excited for the growth which the Games and the Federation is set to achieve.

"We have a strong business plan in hand, and I am confident that the Games and our many other exciting initiatives, will place the Federation in a very unique spot, as a pioneer in many areas related to transplantation, organ donation and sports. I'm excited for the future, and for working alongside this group of passionate individuals as we ultimately aim to share the message of organ donation and continue to encourage the benefits of exercise post-transplant."



Kim with her husband and their daughters



“Help for Children with Organ Transplants”

Kinderhilfe Organtransplantation (KiO) was founded on 25th April 2004 by Sportler für Organspende (VSO), Athletes for Organ Donation, with aid from the family of the deceased Mercedes CEO, Helmut Werner, and a group of concerned parents.

The aim of KiO is to assist organ diseased and transplanted children, together with their families, supporting them in social, psychological and financial distress. KiO is a not-for-profit, charitable organization.



The Executive Board Chairman of KiO is former national team table tennis player Hans-Wilhelm Gäb, a liver recipient since 1994. Also on the KiO Board of Directors is Hartwig Gauder, Olympic, World and European Champion (walking) who received a new heart in 1997.

Many elite German sports persons, as well as leading transplant physicians, are on the KiO Committee. In fact, there are more than 100 Olympic, World Cup and European Champions involved in the Association, as well as FC Bayern Munich which has committed formal sponsorship since 2014 and draws media attention to the problems of sick organ and/or transplanted children. Bayern Munich Forward, Thomas Müller is currently an Ambassador of KiO. The oldest and most important charity partner is Victor's Residence Hotels which organises an annual teddy bear collection to support KiO.

In 2005, just one year after the formation of KiO, the first 'experience-educational family free time' could take place and this, together with seminars organized by KiO, is still included in the programme each year. Such retreats enable affected families to interact with each other and for the children and youngsters to gain confidence in their own bodies, to exchange ideas among themselves and of course have fun.

In addition to assisting sick children and their families, KiO was able to support six medical centres (clinics) for organ-transplanted children in 2008 thanks to the generous donations. Just one year after this, KiO received an award from the German Federal Government.

In 2010 KiO made its first appearance on Facebook. Then in 2011, all of the member associations of the German Olympic Sports Confederation (DOSB), with the support of former President, Dr Thomas Bach (now International Olympic Committee President) positioned themselves behind organ donation. A total of 98 member organisations helped with announcements, flyer distribution and internet presence to advocate for organ donation.

The KiO App was launched in December 2013 - a smart phone program that monitors the safe taking of medication. A pillbox integrated in a smart phone! The APP thinks, manages and "monitors" the taking of the vital medicines in a modern way. This can be the way to an independent, normal life for young transplanted people. Of course, older and non-transplanted people can also use the KiO App.

A further development which is designed to accompany transplanted teenagers on their

way to adulthood. A high degree of self-responsibility, self-discipline, the question of career or study choice brings many issues with it. KiO-Phone is a specially addressed to the needs of transplanted youngsters who can receive personal advice from sensitive and competent contacts.

Since 2014, the German Transplant Sport Association, TransDia has also been a partner of KiO. Common goals are the rehabilitation of transplanted children and adolescents and preservation of health through movement and sport. A good example

is 12-year-old Marina Piske, a young member of the German team at the World Transplant Games 2015 in Mar del Plata, who was a gold medal winner in table tennis. There are plans for further exchanges and reciprocal support.

Moving commitment is shown by prominent top athletes, such as Klaus Wolterman, Olympic Javelin Champion, who untiringly organises benefit golf tournaments and represents important support for the KiO relief fund. Other Ambassadors are Rosi Mittermaier, Olympic Alpine Skiing Champion, Matthias Steiner, Olympic Weightlifting Champion... and many, many more.

KiO has become a unique German relief organisation in this long neglected social area.

Gudrun Manuwald-Seemüller
WTGF Councillor

Translated by: Herr Inder Mohan Puri

www.kiohilfe.de



World Transplant Games 2017 Málaga, Spain

Málaga is ready for the WTG in 2017!

With a little more than a year to go before the Games, the Local Organising Committee and the people of Málaga are looking forward to welcoming participants from all over the world to our beautiful city. The athletes and families will enjoy wonderful weather with sunny days and warm temperatures. Great sports facilities and hotel accommodation are waiting for participants at the Games and everyone will love the art of living in Málaga - great gastronomy, beautiful sandy beaches, exciting day and nightlife, a first class shopping area and of course the fascinating ancient pedestrian centre. Also on offer is a vast array of culture with more than 30 museums and ancient monuments.

Since March 2015, Málaga has been the home of the first Georges Pompidou National Center for Art and Culture outside of France, establishing Málaga, the capital of the Costa del Sol, as one of the leading cultural and tourist destinations in the south of Spain. This prestigious French cultural institution occupies the building known as the 'Cubo' on the Mediterranean seafront and exhibits a permanent collection of over 70 famous contemporary works of art. Other unmissable experiences for art lovers are the Picasso Museum and also the house where the painter was born (Casa Natal), as well as the Contemporary Art Centre (CAC). The 19th century is also well represented by the Carmen Thyssen Museum and the renovated Museum of Fine Arts making Malaga one-of-a-kind in Spain, where you can observe how more than a century of artistic creation ties in together.



Ancient Málaga is evident everywhere in the city: the Roman Theatre - the Castle of Gibralfaro - the Alcazaba and much more. The beautiful Málaga Cathedral is a central point for visitors whilst exploring the squares, streets and alleyways of Málaga.

Earlier this year, WTGF President Chris Thomas, Executive Manager Kim Renyard and Sports Manager Gary Green were delighted to be welcomed by the Málaga Local Organising Committee to discuss the preparations being made for 2017. This gave the representatives of WTGF the opportunity to examine the project and see first-hand the great facilities on offer to participants. Later this summer, the WTGF Medical Chair, Dr Ka-foon Chau, will be in Málaga following up on the medical facilities and provisions being made available for athletes next year.

WTGF and the members of the Málaga LOC are committed to providing athletes, their families and supporters a wonderful experience at the amazing 2017 World Transplant Games in Spain!

We are waiting for you!

Francisco Quereda Rodríguez
Málaga 2017 Local Organising Committee

wtgmalaga2017.com

[facebook.com/
officialworldtransplantgames](https://www.facebook.com/officialworldtransplantgames)

All photos © Malaga City Tourist Board







Addison McArthur

A very special four year gives thanks to her donor family.

After weeks of preparation and training back home in Vancouver, it all came down to this moment at the World Transplant Games in Argentina. Standing on the sidelines of the track in Mar del Plata, my heart was bursting with pride and emotion as my beautiful four year old daughter Addison looked over at me and just beamed. She was crouched down in her starting position, waiting for the starting gun, ready to run her little heart out for 25 metres.

When the officials announced that Addison's race was about to begin, the entire track stopped to watch. Fellow athletes halted their own competitions, while spectators crowded along the perimeter, cheering and waving. "Addison! Addison! Addison!" As the youngest competitor at the Games (and the only athlete under five years old), Addison had garnered quite a fan base. The air was electric and the power and beauty of this precious gift of life was palpable. The gold medal was the least important thing. After all, everyone who competes at the WTG has already won the biggest race of their lives.

Addison was just three weeks old when she went into sudden heart failure, leading us down the dramatic road to a heart transplant just a few days later. While she was in hospital recovering, my mind still reeling with what my infant daughter's future would or could hold, I remember hearing about the World Transplant Games. Curious, I looked it up and was intrigued to see children were allowed to compete too. At that moment, I told myself IF we got out of the hospital and somehow got through this bumpy post-transplant rollercoaster, I would find a way to get Addison to a future WTG. It seemed like an impossible goal at the time, more like a pipe dream or one of those things parents tell themselves during a crisis as a lifeline to grasp that teeny bit of hope.

So four and a half years later, there we were in Argentina. The gun went off and Addison pumped her arms, sprinting as fast as her little legs would carry her, right across the finish line into her dad's arms, with a huge ear-to-ear grin. She was overjoyed – really the only way to describe her incredible zest and enthusiasm that day. Plus as the only competitor in her age category, she easily won the gold medal. She posed

for dozens of pictures, high-fived countless people, and that gorgeous smile never left her face.

The next day, Addison stood on the track one more time, ready for her final WTG competition. She was the anchor runner on Team Canada's 4x100metre relay team. We had done a few team practices the day before and Addison was confident the baton pass would go smoothly. We knew this race would not garner Canada any more hardware, but it turned out to be the ultimate gold medal performance. As Addison took the baton for the home stretch, she wasn't alone. The anchor for the Swiss Team Geneviève Anthamatten stayed right next to her, forgoing any hopes of making it to the podium, making sure my little girl stayed on the right track...all the way to the end. Addison and Genevieve crossed the finish line together in what was the most beautiful moment of the Games.

We made many lasting friendships and took home once-in-a-lifetime memories of this ultimate testament to the power of organ donation. More than 1200 people were in Mar del Plata that week – athletes, volunteers, event organizers – and none of them would have been there if not for the incredible generosity of their donors and the ultimate gift of life. We thought often of Addison's donor, Audrey, and her family. Audrey was just six days old when she became the youngest donor in the US state of Nevada in 2011. Her kidneys went to a 38-year old in California. Her heart was gifted to Addison. While there will never be an adequate way to thank Audrey's mom Felicia, we knew ultimately one of Addison's gold medals truly belongs to her.

When Felicia received the medal in the mail, she cried tears of happiness and told us it was an honour to know us and be a part of our lives. But really, every one of Addison's milestones is only possible because of Felicia's selflessness during her darkest hour. And hopefully this will be just the first gold for Addison and Felicia. We are already looking forward to the 2017 World Transplant Games in Spain. Addison has big plans to at least double her medal count.

Elaine Yong
Canada



UPDATE FROM VENEZUELA

There have been many activities enjoyed by transplanted athletes in Venezuela so far this year with participation in training events, competitions and even

mountaineering! These great photos illustrate some of the amazing benefits that sport and physical activity have brought to Venezuelan recipients.



Bici Rock 2016, Caracas, Venezuela



Recipients climbing to 3,600m - Merida State in the Venezuelan Andes

The Venezuelan transplant sport association - Asociación Venezolana Para el Deporte y la Salud del Trasplantado en Situación de Trasplante (AVEDESTRAS) is now busy with preparations for their National Transplant Games this summer.

Ana Sequera of AVEDESTRAS is currently involved in a research project investigating the effects of physical activity and sport on transplanted people as well as continuing her studies in Sports Science which she hopes will enable her to further develop transplant sports in Venezuela.

"We hope, God willing, to participate in the 2017 World Games in Málaga."

Ana Sequera
Venezuela

Greek National Transplant and Dialysis Games

A winning throw from Apostolos Charitonidis in the javelin competition!



15TH AUSTRALIAN TRANSPLANT GAMES

Come along and join in the 15th Australian Transplant Games from 24th September to 1st October 2016, in Western Sydney.

Transplant Australia invite you to participate in the largest Australian Games ever by introducing three new sports: Triathlon, Dragon Boat Race and Football!

The first-ever Transplant Triathlon will be held at Sydney International Regatta Centre, a beautiful native parkland. Kids, transplant athletes, and supporters are invited to compete in the race swimming, cycling and running over set distances to suit all ages.

If you like fast, adrenalin pumping action, participate in the inaugural Dragon Boat Race. Eight boats consisting of a crew made up of two professional dragon boaters, plus 14 team members will face-off in each race. The challenge will be over 2 km with the finish line located directly in front of the grandstand and crowd – an amazing feature of our Opening Ceremony!

For the first time, football is offered at the Australian Transplant Games as our closing day spectacle. Our freshly formed Transplant Australia Football Club will play a match from 1:00 pm.

The Transplant Games are a week-long celebration of the gift of life promoting the necessity of organ and tissue donation, as well as the benefit of transplantation.

We look forward to seeing you at our Games.

The Transplant Australia Team
www.australiantransplantgames.com



'Hola' from the VI National Spanish Games!

29th April
to 2nd May
2016



A wonderful Games in Lorca this year – the Spanish athletes are looking forward to welcoming you all to Málaga in 2017!



A march through Spanish streets during the Games to promote organ donation and give thanks to donors and donor families.

30th Anniversary of the 'Heart Race'

4 Days/4 Nights/750km



From 31st March to 3rd April 2016, with 300 runners and 147 volunteers, an extraordinary race supporting organ donation took place from Paris to Les Arcs in Savoy, France. The Heart Race 2016 featured an entire team of 20 recipients amongst the runners.

At the same time, the scheme "10,000 Hearts for the Hospital" collected paper hearts; made by school children and distributed together with applause and warm support from the villages along the route.

For the 30th anniversary, the Heart Race welcomed many new innovations including:

- A mobile application, SAP, which allowed the results and descriptions of each section of the race to be followed.
- Four recruits focusing specifically on digital communication in order to enhance social media through Twitter and Facebook.

Alison Max

France

www.trans-forme.org

HUNGARIAN TRANSPLANT FEDERATION

The Hungarian Transplant Federation run a busy calendar of sporting events throughout the year. These include training camp, preparation, qualifiers, tournaments and championships in all events. Intensive preparations and training are now taking place for the European Transplant and Dialysis Games in Vantaa Finland.

Judit Berente

Hungary





11th International Austrian Transplant & Dialysis Patient Ski Championships

Schwarzenberg at Hochficht played host to this annual event in March this year welcoming participants from Germany, Poland, Italy, Switzerland and Austria, competing in snowshoeing, giant slalom and cross-country skiing.

A sunny weekend made up for last year's grey and foggy two days. Friday saw a new event – snowshoeing. This was won by Beate Bea from Germany and Austrian Helmut Steigersdorfer. All competitors unanimously agreed to continue with this popular event next year.

Saturday spoiled us with perfect weather conditions for the giant slalom. The women's title was taken by Austrian Ulrike Semrad, who nudged in a small lead over runner-up Chantal Bausch from Germany. The men's event turned into an exciting and close race with competitors from Italy, Poland and Austria tied in the title challenge. After two breathtaking heats, Italian Erminio Rigos

won the title with runners-up Polish Lukasz Bojanowski and Austrian Andreas Wieser.

The final event was the cross-country ski race staged at the Nordic Centre in Schöneben. Austrian Renat Hönlisch won the women's race claiming a superb victory and for the men Elmar Böhler of Vorarlberg, Austria took first place.

The Award Ceremony was held that evening at the local parish house to mark the closing of the 11th Championships. Our guests of honour were the Mayor of Schwarzenberg, Michael Leitner, as well as Abbot Martin of the Schlägl Monastery. After a festive ceremony, the celebrations carried on into the small hours. Each participant is a true winner.

Martin Krimbacher
Austria
www.atsf.at

'Thanks for Life'



A transplant footballing first for Australia! The Transplant Team (orange shirts), consisting of heart, lung, liver and kidney recipients, played a local Terrey Hills/Belrose team in the 'Thanks for Life' 90-minute charity match competing for the Doujon Zammit Shield.

Natasha Chadwick
Transplant Australia



5th Prof R. V. S. Yadav Memorial Oration New Delhi, India

The Raj Vir Singh Yadav Foundation organised the 5th Prof. R.V.S. Yadav Memorial Oration on 4th February, 2016 at the Indraprastha Apollo Hospital in New Delhi. The Foundation has held a biennial memorial ceremony on 4th February since 2008.

The audience heard presentations by several eminent figures in the worldwide Transplant Community. As the keynote address, Mr. Olivier Coustere, the former President of the World Transplant Games Federation, delivered the 5th Prof. R. V. S. Yadav Memorial Oration.

The topic of Mr Coustere's speech was "Transplant Games and Organ Donation". The event was covered by the media and

received very positive reviews. It was well attended and represented by the transplant and other medical fraternity, patients and technical and support staff alike.

The Foundation is committed to continue to support the WTGF in India and aims to organise a Pan-India Transplant Games in collaboration with the Apollo Group of Hospitals and the Chandigarh Kidney Foundation.

Raj Kumar Tiwari
Managing Secretary

Raj Vir Singh Yadav Foundation
raj.kumar@rvsyfoundation.org
www.rvsyfoundation.org



Mr Coustere received a commemorative plaque from Foundation Trustee Dr (Mrs) Krishna Yadav

TACKERS • TACKERS • TACKERS • TACKERS • TACKERS • TACKERS • TACKERS

The “TACKERS” experience for Bradley Stanley, liver recipient, from Australia and mother Katie - 12th to 19th January 2016

It was a surreal moment when Bradley and I were packing our bags on a warm summers day in Canberra, Australia for - a snow trip in Europe!

After a day and a half of travelling we finally arrived in Geneva, Switzerland, where we spent the next 24 hours exploring and recovering from our long haul. The excitement of heading into the Swiss Alps beckoned us the following day with a two hour train trip to Anzère. The TACKERS kids pulled out a deck of cards and got acquainted on the train. It wasn't long before friendships were being formed, the discovery of who had received which organ and laughter filled the train carriage.

A bus took us high into the Alps as the landscape turned white with snow, arriving at twilight to the sight of a full moon over snow-covered chalets. It was breathtaking and a moment no one will ever forget.

The tired but excited TACKERS kids headed for the Chamossaire Chalet reserved for the young recipients and the amazing transplant professionals (comprising of coordinators, doctors and Swisstransplant staff) who volunteer for the event. 'TACKERS friends' (parents and supporters) headed to their own accommodation and a well-earned sleep.

Heading up the gondola for the first day, you could feel the excitement and, as the day wore on, the frustrations of

skills yet to be mastered emerged - but with smiles and cheers of support. These children are inspiring and supported each other through the skill development.

There were activities each afternoon - arts and crafts, swimming and general relaxation. Bradley enjoyed this time, bonding with teenagers that had been through similar experiences and understood the challenges.

In the evenings, parents and children were able to enjoy activities such as karaoke and a fancy dress disco (complete with fireworks). The karaoke saw some children stand up in front of their peers and sing solo - what an amazing achievement for some who would never have done that in their home country.

By the end of the week the TACKERS campers were skiing/snowboarding confidently down the slopes as though they didn't have a care in the world. They were ready for the last day, Race Day, so all boarded buses to a nearby village for the “L'Etoile de Gaël”, named after a five year old donor. Parents, TACKERS friends, sponsors and supporters were there to cheer. Swisstransplant organised their annual seminar at the same time to give transplant professionals the chance to see the results of the wonderful work they do. They usually only see patients in hospital, not having fun on the slopes!

The whole week was about the kids discovering themselves in a safe environment and just learning how to be a kid without the transplant hanging over them. No one at the camp was any different, they had all had very different journeys but shared the gift of receiving a life saving transplant.

Bradley's personal story was following the footsteps of his hero, Scott Bellingham, who had attended TACKERS 13 years ago. On reflection, Bradley's



memories of the week demonstrate not only his excellent snowboarding skills but mentoring skills that he didn't even realise he was displaying. Bradley felt at ease with everyone - he wasn't “the sick kid” and connected with some of those facing some challenges he himself has been through.

For the parents, it was a time to meet other people from around the world and to support each other, also having a little fun letting our hair down. There was adult karaoke and we carved up the dance floor after the kids left the disco.

Bradley and I returned to Australia with new friendships developed and a mission to repeat the trip again next year.

Katie Stanley
Australia

SAVE THE DATE!

**TACKERS 4th-11th
February 2017**

**TACKERS Snow Boot
Camp 4th-11th March 2017**

More info to follow!

www.tackers.org



Bradley with WTGF President Chris Thomas, who was delighted to have the opportunity to visit TACKERS this year.

Paddle Tennis for Málaga 2017!



The Local Organising Committee (LOC) in Málaga, Spain is excited about the new sports at the World Transplant Games next June – Darts, 3 on 3 Basketball and **Paddle Tennis**!

Paddle is a sport that has been played since the eighties. It is a doubles game, and there are three basic elements needed to play: the ball, the racket and the playing ground or court. It has clearly defined rules and is represented by federations and associations.

The sport was invented in Acapulco, Mexico around 1962 and after its growing popularity in various countries in South America and Spain, the game began to spread throughout America and Europe. The English word Paddle, in its meaning of bat or racket,

was Hispanicised as “pádel” and both names are now used worldwide. The warm reception of the sport in areas of Spain such as the Costa del Sol has made it especially popular with tourists from Northern Europe.

A match consists of two sets. The team or pair that is first to win six games with a minimum two-game lead over their opponents is the winner of the set. However, the general rule is that if each pair wins one of the two sets played, in the third set tie-break rules will be applied. Each set is made up of games, with the serve alternating between pairs, and between the players in each team.

The scoring of points in each game is the same as in tennis, although the

court is smaller; one distinguishing feature is that in **Paddle** the ball can bounce off the walls, which makes it a faster and more entertaining game, where the ability to see the ball and the positioning of the player are key.

Any person who plays a racket sport such as tennis, badminton, table tennis or even beach bat-and-ball, will find it easy to take up this sport as it does not require high levels of technique or physical fitness. In Spain **Paddle** has become a very popular sport played by people of all ages. Numerous paddle courts can be found in sports centres and neighbourhood community centres.

There are many examples of **Paddle** being played on YouTube, as well as explanations of the rules and tips for play across the internet, so athletes will be able to do some groundwork and practise their skills well before the Games!

Look out on the Málaga 2017 website and the Official World Transplant Games 2017 Facebook page for further information on our sports preparations – see you all next year!

Málaga 2017 Local Organising Committee

wtgmalaga2017.com

facebook.com/officialworldtransplantgames

12th South African National Transplant Games to be held in Johannesburg, South Africa 2016!

JOHANNESBURG 2016
The People's Transplant Games

6th – 9th October 2016

Please visit:

www.transplantsports.org.za

[www.facebook.com/southafricantransplantgames/](https://facebook.com/southafricantransplantgames/)

Contact: admin@transplantsports.org.za



Blai Signes Fort *Spain*



On the 24th of July of 2005, Blai Signes Fort entered a hospital's emergency room for the first time in his life and his life changed overnight. After several tests, including a bone marrow's biopsy, he was finally diagnosed with a very severe aplastic anemia.

Blai was sick for two and a half years. During that time, he had to fight a hard and arduous war against the disease; both of his treatments and he suffered severe infections from aggressive bacteria, viruses and fungi. Blai was hospitalised many, many times and on some occasions for more than 50 days at a time. Blai had a piece of his left lung removed due to one of these infections and was in the intensive care unit watching the death of many of his roommates and fearing for his life more than once. Doctors treated him with powerful drugs including chemotherapy and other intensive therapy - one of these treatments has left him a severe hip and knee necrosis. He went through countless setbacks, but nevertheless, Blai knew that the illness would also serve to draw very positive things.

Blai learned to love life, to really enjoy the small moments that, at the same time, turn out to be very huge: to walk, to travel, to dream, to smile, to feel in love... It also helped him to understand what he wanted to do when he defeated the illness. He wanted to be a doctor and become a hematologist in order to take care and heal people who suffered a disease as serious as his.

One of the best lessons the disease has taught him is to never lose hope. Although the illness won many battles, Blai never

lost his smile and never stopped fighting for his life. Gradually Blai, with these weapons and with the help of doctors and nurses, went on defeating the disease. However, to defeat it Blai needed the help of donors. During the two and a half years of his disease, Blai needed 244 blood transfusions and a bone marrow transplant of stem cells from an umbilical cord given altruistically in California. Without the help of so many donors Blai wouldn't be alive today and that is why he is eternally grateful to all donors.

When Blai got ill, he was about to catch a flight to the USA in order to finish his studies of Engineering in Computer Science. That trip never took place. He completed his engineering studies between hospital treatments and once healed, he began a new career in Medicine.

Many years after Blai has fulfilled the dream that helped him to cling on to his life when he was ill. He is now a Doctor, and works in a Spanish hospital as an Hematologist taking care of people with leukemia and similar diseases.

Moreover, Blai lectures everywhere to raise awareness of the need for blood and bone marrow donation. Blai also participates in the Spanish, European and World Transplant Sports Games - not only to experience the intense euphoria of a sports competition but also to transmit the message of donation and to give hope to all of those who are suffering a severe disease and to those who require a transplant in order to survive.

FOCUS ON • FOCUS ON • FOCUS ON • FOCUS ON • FOCUS ON • FOCUS ON

FOCUS ON SUIKO CONSULTING



*Suiko Founder and
Principal, Eugenie
Buckley*

Suiko Consulting was founded in early 2010 to provide specialist strategic and business advice exclusively to stakeholders in the major events, sports and event tourism industries. Above all else, we are sports fans. We love the sports industry and we're excited about pulling together the right team to tackle any hard hitting problem or project. We like to think of ourselves as playmakers that create opportunities for our clients to maximise their potential.

We believe that sport can make the world a better place. Sport is the best platform to increase community participation in recreational and physical activity while providing an avenue for broader development in areas such as health promotion, the empowerment of youth and females, equality, leadership, social cohesion and a sense of belonging. Sport has an important role to play as an enabler of social change and sustainable development.

Every project is different, but there are three main ways in which we can help:

- Transformation of events and organisations through best practice structures, strategies and operational efficiencies
- Management of events and projects to deliver priorities within timeframes and on budget
- Communication strategies to align planning and execution initiatives

Our key point of difference is that our consultants have held executive management and board positions in sport at

every level from International Federations, National Sporting Organisation, through to major international events to professional clubs. We understand major events. Recently, we provided strategic host city and venue advice to many recent major international events hosted in Australia, including the Rugby League World Cup 2017, ICC Cricket World Cup 2015 and AFC Asian Cup 2015. Strong leadership with a clear strategic direction facilitates effective operational planning to deliver excellence.

Good governance structures underpin sustainability and success by improving the effectiveness and efficiency of pressured human and financial resources. Suiko has developed strategies and provided recommendations to numerous organisations with clear and prioritised transitional arrangements to manage the change necessary to achieve optimal practice. Collaboration, unity and aggregation with a whole of sport approach will assist to maximise revenue generation. Resultant improved returns can be re-invested back into a community for the future development of the sport and its members. Sports can grow and achieve more through enhanced capability and performance of its members and volunteers.

Suiko Consulting also administers the Suiko Foundation, which leverages the power of sport to deliver education, life skills, social inclusion and development programs to communities. It is through the Suiko Foundation that we were delighted to assist the World Transplant Games Federation with the development of an international bidding and legal framework for its biannual World Transplant Games. This improved process places the health and safety of the athletes at the centre of planning and delivery by committing hosts to minimum standards for sports, venues and sporting infrastructure, medical services, accommodation and transport. It also requires hosts to consider important community engagement and legacy initiatives.

For more information on Suiko and our services, clients and operations, please visit our website www.suiko.com.au or follow us on Twitter [@suikocon](https://twitter.com/suikocon).

Suiko Consulting



"Sport has an important role to play as an enabler of social change and sustainable development."



GAME CHANGERS

TRANSFORM. DELIVER. COMMUNICATE.

Suiko is a specialist sports, major events and tourism consultancy. We believe that sport can make the world a better place.