

Transplant *World*

2015 | Issue 2

Journal of the



World Transplant Games Federation
Powered by the gift of life

Guest Editorial:

The Importance of **Movement** in Post-Transplant Care

Photos, News and Survey
Results from Mar del Plata

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Gudrun Manuwald-Seemuller



Vicente Granados-Cabezas



André Lassooij



Willie Uys



Raymond Van Ryckel



Liz Schick

GUEST EDITORIAL

The Importance of Movement in Post-Transplant Care

Receiving a transplanted organ provides us with an improved opportunity for a quality healthy life. Our transplanted organs need to be looked after the best we possibly can. Movement is important for all people, and the saying “use it or lose it” seems to be true. With advancing age I have noticed that my flexibility during my competitive gymnastics days is now severely restricted. My university work, involving long hours of seated computer work, has resulted in shortened hamstrings which affect my running ability. Positive moves to flexibility in working environments through the use of stand-up desks, walk-and-talk meetings, promotion of stair walking instead of taking lifts or escalators, and the use of health monitoring devices such as accelerometer wrist devices (e.g. iwatch), can help improve our movement ability.

As a biomechanist I study human movement. I cannot help myself when out in public watching people jogging in the streets, walking about the university or shopping malls, qualitatively analysing their movement. My perception is that our movement capability/quality seems to be declining. With the increases in body mass and obesity, there is increased pressure on our joints and musculoskeletal system. There is more functional misalignment of limbs during movement, and worse functional posture - particularly abdominal weakness which is likely to increase back pain. There is evidence that increases in fat mass contribute to cardiovascular health issues resulting in stroke. As transplant patients we are faced with the usual human challenges of trying to keep fit and healthy by regular exercise, good nutrition and sleep habits, and positive social/behavioral interactions. However, we have additional considerations given our immune suppression drugs and other drugs that help keep us alive. Our prescribed medical steroid use can predispose us to putting on weight, however, one advantage is that steroids are good for helping to build muscle mass if we exercise. As a sports scientist on steroids, it has certainly created interesting discussion with athletes, coaches and fellow sport scientists given the no drugs in sport policies we have (unless the drugs are medically prescribed for medical conditions).

As a kidney transplant patient, an ex-New Zealand representative gymnast and coach, and a sport scientist, I did know about progressive rehabilitation exercise to full function after surgery. I wasn't expecting a recreational cycle

session to result in me waking up one morning with my kidney torted (twisted) and across the midline of my stomach instead of in its usual place low in the abdomen. I pushed the kidney back into my lower abdomen, went to the hospital emergency department, and got admitted for relocation surgery. I was told this event is very rare. Fortunately my now lovingly called “gymnastics kidney” survived the trauma and I have been able to continue exercising. I am careful with full hip flexion movements and resistance exercises that increase intra-abdominal pressure – so my rowing ergometer is gathering dust. My cycle seat is now raised higher than I would recommend for a healthy recreational cyclist of my leg length so that I have less hip flexion during cycling. I have found that mowing the lawn is a great exercise for my upper body strength as well as my cardiovascular system challenged. Each of us as transplant patients needs to find the right combination of exercises to provide us with health benefits as well as the social and psychological benefits. What works for one may not work for another. The World Transplant Games are excellent events to participate in as they help provide incentive to train and gain the physical and physiological benefits of exercise and sport.

Movement in post-transplant care is important. The questions that you need to think about are what exercises should I do, when to exercise, how often, and where should I exercise? There are some more non-obvious things to consider. Given our increased risk of skin cancer, the use of sunscreen is important. Given fluid balance challenges, we need to think about our fluid intake for exercise. Those with diabetes need to particularly consider their food intake and exercise levels, and the type of shoes to wear given increased risk of diabetic foot ulcers. For information about exercise and injury prevention you can see the SportSmart information that I led the development of with a great team of sports science and sports medicine experts from Australia and New Zealand (see www.acc.co.nz/preventing-injuries/playing-sport/sportsmart-10-point-plan).

I wish you well in your transplant journey. Remember – Movement Matters!

Patria Hume PhD FISBS

Professor Human Performance

Associate Dean Research, Faculty of Health and Environmental Sciences, Auckland University of Technology

Director, SPRINZ J.E. Lindsay Carter Kinanthropometry Clinic and Archive



Message from the President

And now the work starts...

One of the most important aspects of each World Transplant Games is not the Games themselves but your views on those Games. We should never forget the World Transplant Games belong to the worldwide transplant community. The Council has conducted a formal survey via surveymonkey.com for the past four World Transplant Games and each survey provides a fascinating insight into the performance of each and every Games.

What is even more important is our increasing ability to compare each Games experience now that we have data from four Games sitting on the same survey platform.

Some of the results of this comparison is provided here for your benefit. Direct comparisons are a little difficult as the response rate for completing the surveys varied so much. On the Gold Coast Australia, the first time a survey was undertaken in this format, 283 surveys were completed. In Goteborg Sweden an impressive 583 surveys returned. In Durban, South Africa 381 respondents. Our last survey of Mar del Plata, Argentina, returned 414 surveys. Councillors Liz Schick and André Lassoij detail further in this Transplant World the specific results of Mar del Plata.

Your Council is committed to a process of continual learning and improvement. We should never be defensive about certain results or constructive criticism. Staging the World Transplant Games is a huge undertaking. Bringing 1,000 transplant recipients and an equal number of supporters from 50 countries together for a week of celebration and sport is a mammoth task and all credit to everyone who has been involved in successfully staging these Games over many years.

There will always be a balance between the highlights and the areas that can be improved, hopefully with the good outweighing the 'to be improved'.

In recognising the complexity of running an international sporting event in this day and age, Council has agreed to a review of the entire Games 'lifecycle' so that we examine every facet of our event.

The 'lifecycle' starts obviously with a potential city considering it may wish to submit a bid to host the Games. What are the basic services and infrastructure it should have in place to hold the Games? An athletic track and swimming pool? Well of course. But what of the quality of those venues and others? And of the ancillary facilities such as toilets and areas where food will be consumed?

Just as important is the provision of medical services including first aid, primary health care and an easily understood referral system to more complex transplant services. What type of transport will be provided? Will there be a Games hub where all participants will dine or will they eat in their own hotels?

Our aim is to outline a minimum standard that Council expects if a city wishes to make a bid to host the Games.

The next stage of the 'lifecycle' is how Council helps a potential city to put their best case forward when the review team visits potential cities. Three years prior to a Games Council then receives formal written and verbal presentations from the bidders before voting. Our review will look at whether there is a more structured way for that vote to take place with weightings be given to key aspects of the delivery of the Games?

And finally there is the ongoing communication, close liaison and management of the selected host city

Council over the past few years has already made great improvements in these processes. As well as the formal agreement and protocols, a 73 page Games Manual now serves as a handy guide to running a Games.

This review of the Games 'lifecycle' is just one of the tasks being undertaken by a number of different working groups of Council. The full list is provided so that you can see the length and depth of work being undertaken. All by an amazing group of 13 volunteer Councillors. Welcome to our two new faces, Gudrun Manuwald-Seemüller and Vicente Granados-Cabezas. I am sure they will provide a range of skills and interests to complement a great team.

Chris Thomas



Our Standing Committees and Working Groups

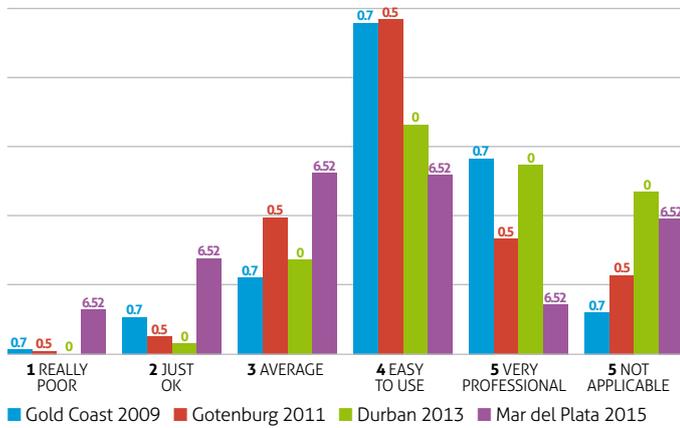
Standing Committees:

- **Sport** (Gary Green, Colin White, Vicente Granados-Cabezas, Andre Lassoij and Sisi Markova)
- **Medical** (Ka-Foon Chau, Won-Hyun Cho, Gudrun Manuwald-Seemüller and Liz Schick)
- **Governance** (Willie Uys, Olivier Coustere and Raymond Van Ryckel)

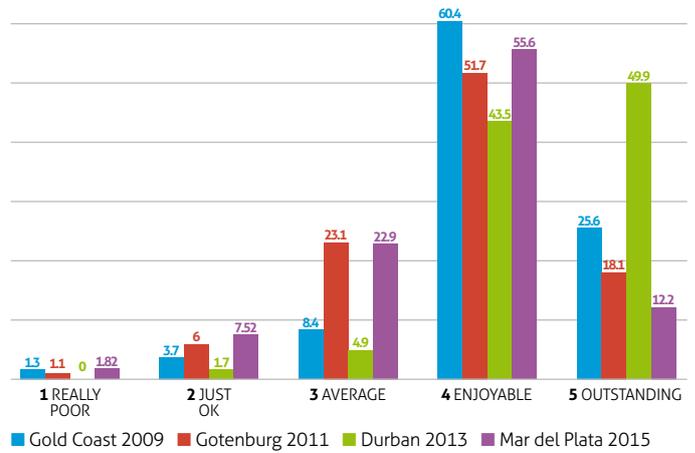
Working Groups (with team leader in brackets) are:

- **Constitutional Reform** (Willie Uys)
- **Games Lifecycle** (Gary Green)
- **Communications Platform** (Colin White)
- **Medical services at WTG** (Ka-Foon Chau)
- **Survey of MDP** (Liz Schick)
- **Lifecycle of the Federation** (Raymond Van Ryckel)
- **How the Council works together** (Chris Thomas)
- **Membership** (Andre Lassoij)
- **Winter Games** (Liz Schick)

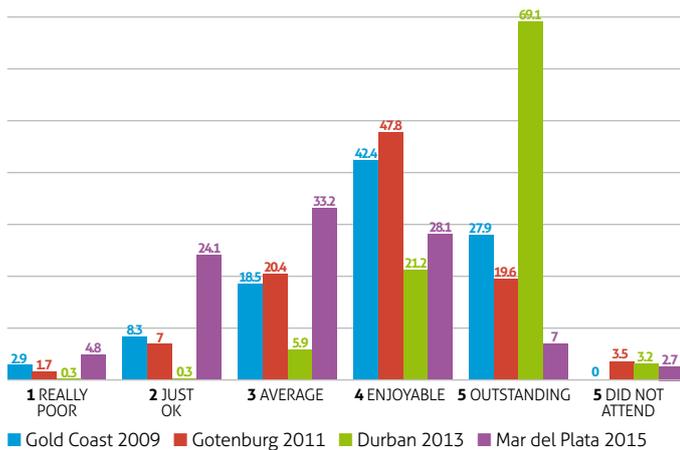
Q1. On a scale of 1 to 5, please rate the online registration system used to complete your registration



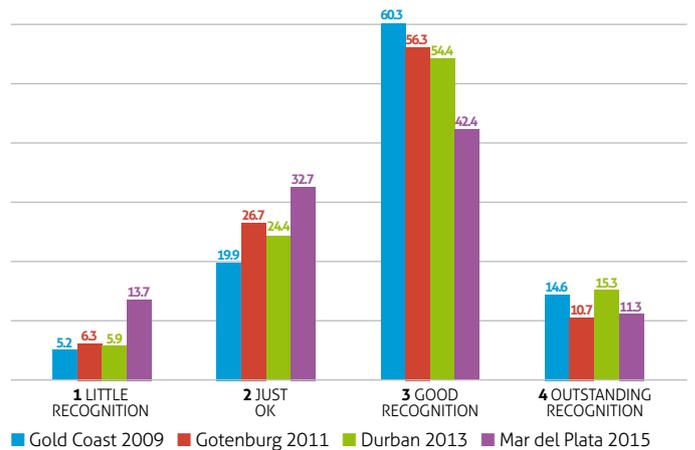
Q2. On a scale of 1 to 5, please rank your overall experience of the Games



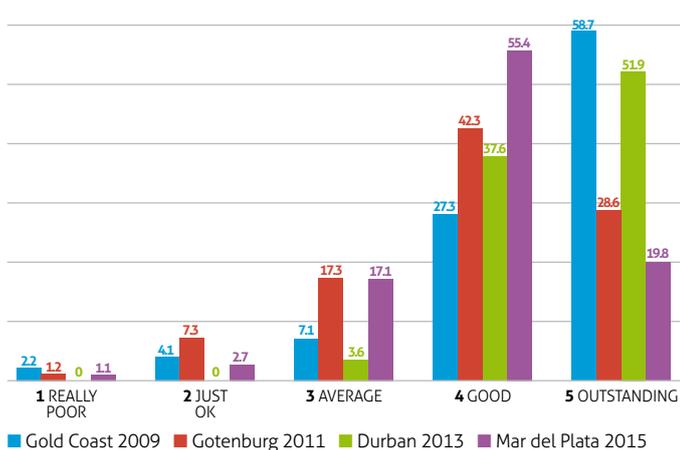
Q3. On a scale of 1 to 5 rank the overall standard of the Opening Ceremony



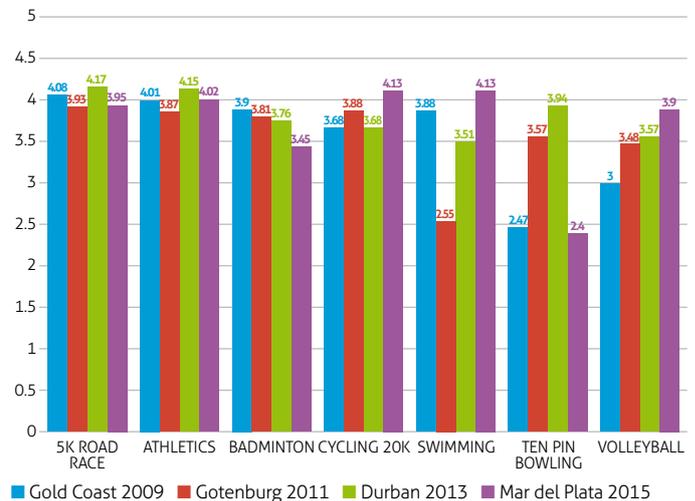
Q5. Please rate the recognition given to donors during the week



Q6. Please rate your overall accommodation experience



A selection of sports and their rankings by athletes





Survey of the 20th World Transplant Games, Mar del Plata



Review by Liz Schick and André Lassoij

The World Transplant Games are staged to provide a unique and tailored environment for transplant recipients to engage in the pursuit of their preferred sports. As two of those athletes, and as Councillors, we are particularly interested in the views of all the participants who attend the Games. The survey of the recent World Transplant Games in Mar del Plata makes fascinating reading.

The Council takes these results very seriously and reviews them carefully to better understand how we can continue to improve the Games. A total of 44 countries took part in the Games with 1121 people registered in all - 749 participating athletes and 372 supporters.

At the outset we should thank all 414 people who took the time to complete the survey. Statistics tell one side of the story but it is the comments provided that really help us understand the performance of a Games in the eyes of the transplant community. A large number, 42% of the respondents, indicated that it was their first Games, 17%, their second Games and 26% indicated that it was the 3rd to 5th whilst 11% had attended

6-10 Games and 17 people, some 4%, had attended 11-20 World Games! Now that's a good testimony for the success of transplantation. *André Lassoij, lung recipient 19 years, has attended 9 WTG and Liz Schick, liver recipient 17 years, has attended 12 WTG.*

It is impossible to record everyone's views in this short summary but it is always encouraging to read these types of comments:

"The friendship forged between athletes and supporters from many different countries was so very rewarding."

"My first time to South America. Really touched by the passion of the team. Volunteers were kind and willing to help."

"For me it was the first time at the Games and it was an amazing experience. I am not a transplant myself and came as a supporter and assistant team manager. It gave me so much joy to see all these people enjoying their lives, being sporty, dancing, singing ... THANK YOU ARGENTINA for this magical week."

"During the competition at the pool, our translator commented that being at the Games had given her a different perspective on life and she was inspired by ALL the athletes at the Games. As a result of this she was going to speak to all her family and friends about carrying a Donor Card. This is what it is all about, getting the message out about considering to carry an Organ Donor Card."

One person summed up what many Councillors were thinking prior to the Games having been involved in the organization with the Local Organising Committee:

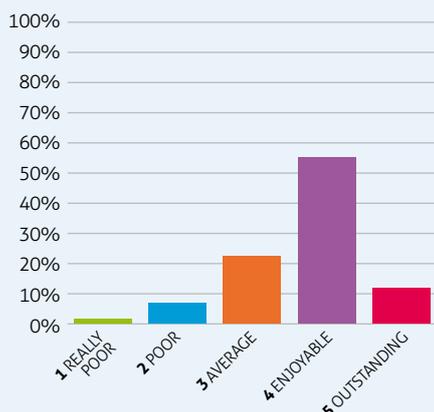
"Overall the Games were thoroughly enjoyable. One just had to go to Argentina with the idea that the Games were going to be organised differently, in the Argentinian way, and to stay focused on why we go there not on our personal comfort and satisfaction."

A constant theme was the lack of communication prior to the Games:

"I would like to congratulate the WTGF and the Argentinian Government for

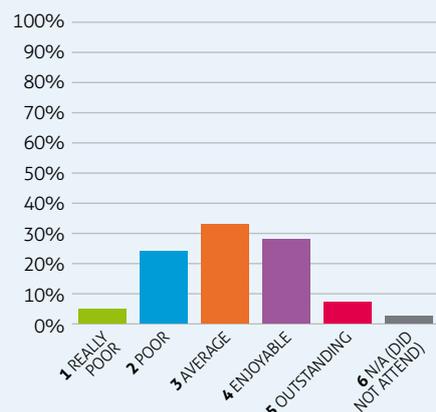
Q7. On a scale of 1 to 5, please rank your overall experience of the Mar Del Plata Games

Answered: 385 Skipped: 29



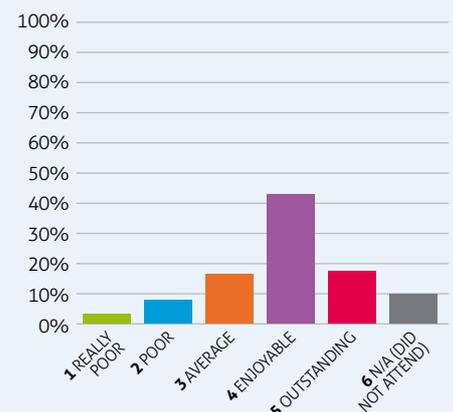
Q10. On a scale of 1 to 5, please rank the overall standard of the Opening Ceremony

Answered: 373 Skipped: 41



Q12. On a scale of 1 to 5, please rank the overall standard of the Gala Closing Dinner

Answered: 373 Skipped: 41



putting on a fantastic Games. I was a bit disappointed with registration as it came out a bit late and information was only slowly forthcoming but in the end the Games took place and a lot of us athletes left happy. I would like to see more promotion/advertising in the city because I felt there wasn't too much interest from the locals in attending our Games - they are the ones we need to promote organ donation more too. In my mind, the Games were generally an outstanding success!"

However if we don't listen we don't learn and some respondents were very honest with their feelings:

"These Games are an amazing testament to the human condition. Feels like these Games were a bit disorganized and very stressful. Focus needs to be on promoting transplant patients and organ donation and not the country."

"As a first-timer I absolutely loved the Games and WTGF did an amazing job. However I did feel Mar del Plata was a bit odd choice due to it being winter - the city clearly lives for summer and felt like they were not able to show us their best. Wrong time of year to visit the city! Local organizers also clearly struggled with managing this huge event."

"I feel that the location was not really suitable for the time of year, given that recipients are on medication that depletes their immune systems."

"This was my second World Transplant Games (WTG) and it would be fair to say

that it did not reach the standards of the last WTG, however this time around I got to know many more people from different countries and formed many new friendships. I liked the Argentinian people. For me these Games were all about the people and I liked it a lot."

A specific section was added to the survey to better understand the health of athletes during and post-Games. Clearly there was a lot of illness suffered

by participants and many people went home with coughs, colds, influenza and chest complaints. The WTGF Medical Committee is looking at this more seriously and has devised a separate medical survey for team managers and doctors.

Here we have included just a selection of the charts on your responses to our questions.

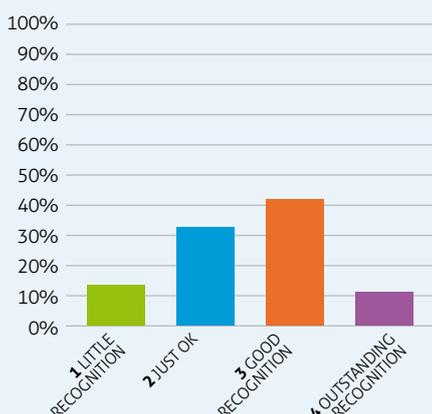
The Council will examine these closely. At first glance the 'take home' messages from these Games were:

1. We need to improve the Communication out to the world before the Games
2. The WTGF must work with the LOC to ensure the sporting facilities including toilets are of an acceptable standard
3. A summer transplant Games must be held in summer
4. We need to minimize the risk of people spreading illnesses. The message – 'if you are sick prior to the Games don't come' – needs to be emphasized
5. Speeches should be shorter, especially when many people don't speak English and they are in a cold Opening Ceremony venue
6. Ancillary events such as the cultural evening will be better supported with early warnings so participants can bring appropriate clothing
7. There is a great opportunity to better recognize donors at the World Transplant Games
8. The distribution of lunches continues to be a challenge especially when it comes to hygiene and keeping them chilled and attention should be paid to their contents ensuring well-balanced meals for our athletes and supporters
9. The registration system for Mar del Plata had significant deficiencies with athletes being wrongly classified into sports and age groups. That said the LOC fixed the problems quickly
10. The transport at Mar del Plata was excellent and provided lessons for the future
11. All athletes should be allowed to march in to the Opening Ceremony
12. Centralising accommodation is greatly appreciated

The summary of the survey will be made available via www.wtgf.org

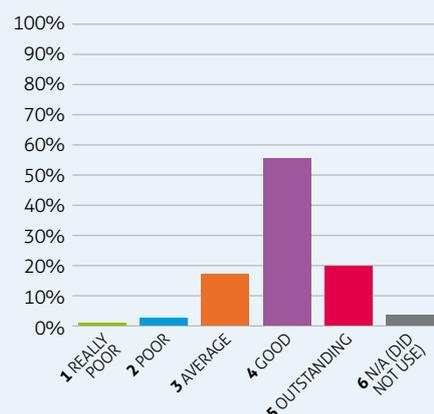
Q13. Please rate the recognition given to donors during the week

Answered: 373 Skipped: 41



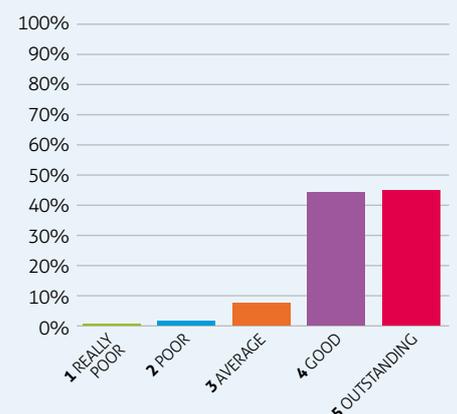
Q21. On a scale of 1 to 5, please rate your overall accommodation experience

Answered: 368 Skipped: 46



Q27. On a scale from 1 to 5, please rate the service given by the volunteers during the Games

Answered: 3495 Skipped: 66



NEW WTGF COUNCILLORS

The World Transplant Games Federation is pleased to introduce two new Councillors who were elected to office in Mar del Plata and who are looking forward to serving in their new roles.

Gudrun Manuwald-Seemueller

Germany

Gudrun Manuwald-Seemueller received her liver transplant in October 2002. She had suffered for more than 20 years with an aggressive chronic Hepatitis C, that had not been diagnosed for a long time. After a long stay in the clinic and a re-infection of the Hepatitis C virus, she could begin her rehabilitation with physical training in February 2003. She will never forget the first few hours in the pool - to be able to move absolutely light-hearted and painless!

In 2005 Gudrun participated in the Open German Championships of Transplant and Dialysis Patients. During the following years she continued her fight against the Hepatitis C virus with a very aggressive therapy. Gudrun attributes perseverance and the success of this therapy, together with her structured physical exercise program to her active lifestyle.

As a "reward" she was first successful in 2008 in Wuerzburg in the European Transplant and Dialysis Sports Championships. Since 2009, when Gudrun took part in the World Transplant Games in Gold Coast, Australia, she has participated successfully in all World Transplant Games both summer and winter.

In 2013 she was elected chairman of TransDia Sport, Germany. To bring home her special concern and commitment to physical sport for children and

youngsters after transplantation, in 2014 Gudrun began to work with Kinderhilfe Organtransplantation (KIO), an organisation for organ transplanted children. Also in 2014, during the European Transplant and Dialysis Sports Championship in Kraków, Poland, she was elected to the Presidential Committee of the European Transplant and Dialysis Sports Federation (ETDSF).

"I am glad to be able to introduce all my experiences as a participant and from my occupation as a physiotherapist, for the good and for the health of all transplanted athletes. As token of the gratitude towards our donors of the organs that protect and preserve our present lives.

My goals are that "sports as remedy" should be offered to as many transplant recipients as possible. I am also convinced that sports can enhance the quality of life of every transplant recipient. Sport and exercise are an important pillar of rehab after transplantation. This has been proven scientifically and need to be promoted.

Last but not least: personally I bear special responsibility towards my own organ donor to protect and preserve the gift of my life."



Vicente Granados-Cabezas

Spain

Vicente is a Doctor and Professor in Economics working at Málaga, University. He obtained his Ph.D. from Birmingham University, UK in 1985 and most importantly he is a renal recipient since 1987 thanks to the Spanish Public System for Transplantation.

Vicente was a sportsman before his renal illness, taking part in rugby and athletics and obtaining some recognition in both of them at regional and national competitions. Vicente first heard of WTGF in 1990 when Maurice Slapak helped to organise the 1st Spanish Games in Pamplona. Vicente was enthused by competing in this event and went on to organise the 2nd Spanish Games the following year in Málaga.

Vicente first attended the World Transplant Games in Manchester 1995 and has participated in all the Games since, with the exception of Gothenburg, winning medals in different disciplines. Now 20 years later he

is delighted to be elected as a member of the Council and is playing a big part in the organisation and planning for Málaga 2017.

Vicente said "I intend to use the successful Málaga 2017 bid to show gratitude to the donor families. Also to the Spanish transplant model for its success and to help to solve some of its deficiencies, such as the lack of doctors' commitment to advise recipients to exercise and practice sport as well as improving the low figures in bone marrow and living donor transplantation. Finally, I am very grateful to the General Assembly for electing me as a Councilor for the next four years. I hope to be worthy of their confidence in me by helping to expand the practice of sport among recipients across the world, to contribute to their health and to make our motto widely heard: Powered by the Gift of Life."





Arena, the Track & Field Stadium, the Aquatic Centre and the Tennis & Padel Centre. Participants will find wonderful hotel facilities and great communications via an enlarged and refurbished International Airport and the high speed train. Málaga is also a dynamic cultural city where participants and their families will enjoy the beach life, food, shopping, nightlife and beautiful walks in the old pedestrian centre. Málaga has more than 320 sunny days a year and the month of June, when the Games will take place, the average temperature will be 24°.

The LOC were very happy to host a visit from the WTGF Executive earlier in the year. This was a great opportunity for us to show off our city and facilities, to exchange ideas and also to receive valuable advice and feedback for Málaga 2017. We are looking forward to building on this relationship over the coming months with the aim of making the World Transplant Games on the Spanish coast a truly great experience.

Francisco Quereda Rodríguez
Málaga, Spain

With around eighteen months until the XXI World Transplant Games, Málaga is ready and our people are happy and excited to give a very warm welcome to athletes and their families from all over the world.

coast of Spain, Málaga has a firmly established cultural heritage. It has maintained, for almost 3,000 years, the reputation of being a city that welcomes visitors.

Located in a privileged location on the banks of the Mediterranean Sea, on the southernmost

The city of Malaga provides an excellent infrastructure for sports and events with modern facilities such as the Martin Carpena

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Awards for Councillors



WTGF Councillor Dr Ka-foon Chau

WTGF Councillor Dr Ka-foon Chau (pictured here, 2nd right), along with five other volunteers, was presented with the Outstanding Volunteer Award by the Agency of Volunteer Service in Hong Kong at an Award Presentation Ceremony on Saturday, 3rd October 2015.

Mrs Regina Leung presenting the Award said: "This Award promotes the spirit of volunteerism that people engage in to serve society without expecting any return. Their selflessness in bringing harmony to the community deserves our recognition."

Adapted from a news release issued by Agency for Volunteer Services 3rd October 2015



WTGF Secretary Gary Green

WTGF Secretary, Gary Green (right), received the prestigious Samuel J. Orenstein Award at the American Association of Kidney Patients (AAKP) 41st Annual Meeting in Nashville, Tennessee, USA. This is presented for 'consistently rendering extraordinary service toward the achievement of AAKP's goals and objectives'.

WTGF President Chris Thomas said: "Gary has clocked up almost 25 years volunteering his time for the World Transplant Games Federation, ensuring the successful staging of many World Transplant Games. We are fortunate to have Gary contributing so tirelessly to the aims and ideals of the Federation. He has provided expert and knowledgeable insights into the professional management of this unique and inspiring sporting event while at all times understanding the needs of transplant recipients and the potential to showcase the importance and success of organ donation to the wider public."

Adapted from a news release issued by World Transplant Games Federation 30th September 2015



WTGF Councillor André Lassoosj

WTGF Councillor André Lassoosj from Netherlands has been honoured with the annual European Lung Foundation Award for 'inspiring others through his achievements' on 26th September 2015 at the European Respiratory Society's International Congress in Amsterdam, Netherlands.

Dan Smyth, Chair of the European Lung Foundation, said: "André's positive attitude to life, his sporting achievements and his tireless efforts to raise awareness of the importance of organ donation are truly inspirational. The 'Take the active option' message of this year's Healthy Lungs for Life campaign aims to draw attention to the benefits of physical activity for everyone, including among people living with a lung condition. There is a level that is right for each individual, whether that be at a highly athletic level like André, or by making smaller day-to-day changes like taking the stairs rather than a lift."

Adapted from news release issued by European Lung Foundation 26th September 2015





World Transplant Games Mar del Plata, Argentina 2015



Golf!



The youngest participant at the Games



Tejo - the sport of choice for WTG2015!



Long jump action!



Racing for the finish!



Handing over the WTGF flag to Málaga for 2017



Smiles from South Africa - the hosting country from 2013!



Table tennis competitors from IR Iran



Time trials!



The fabulous Mar del Plata Opening Ceremony!



Swimming medal winners from USA and France



Cheering on the home team at the volleyball!



World Transplant Games Federation Special Awards – Mar del Plata 2015

The World Transplant Games Federation Special Awards were presented at the Gala Dinner in Mar del Plata, Argentina.

These included the Outstanding Team Award for the team whose athletes won the most medals relative to the team size. Teams with 20 athletes or more were eligible. This Award was new to WTGF in Durban 2013 – it is the second time that it has been presented.



The Hungarian Team Manager, Akos Rideg, receiving the **Team Award** from WTGF President Olivier Coustere

Team Hungary – winners of the **Outstanding Team Award 2015**.

The **WTGF Outstanding Athlete Award** was presented as usual to a man and a woman nominated by their Team Manager and selected by the Judiciary Committee using the following criteria:

- Performance (number of medals won)
- Quality (strength of competition)
- Diversity (achievements in multiple sports)
- Sportsmanship



Outstanding Athletes: Robert Gelencser from Hungary and Simone Bauer from Germany receiving their Awards.

Also the WTGF Outstanding Junior Athlete Awards were presented using the same criteria as the adults.



The **Outstanding Junior Athlete for Boys** was awarded to 16 year old Declan Bennett from Great Britain and Northern Ireland and the **Girls Award** went to 17 year old Ellen Russ, also from Great Britain and Northern Ireland. *Declan and Ellen are pictured here with Lisa Beaumont, GB&NI Junior Team Manager (left), Team Manager Lynne Holt (centre) and Barrie Laverick, Assistant Team Manager.* You can read the life stories of these two amazing young people on pages 18 and 19 of this Journal.

WTGF AWARDS • WTGF AWARDS • WTGF AWARDS



The **Maurice Slapak Award** for the 5km Road Race was won this year by the team from Great Britain and Northern Ireland – John Moore, Phillip Cairnduff, Christos Liaskos (pictured here with all the 5km medal winners from Great Britain and Northern Ireland).



The **Peter Griffin Award** for the Men's Swimming Relay was presented to the Great Britain and Northern Ireland team – Martin Graham, Declan Bennett, Rhys Bonnall and Liam Barnett.



All the 2015 Team Managers were presented with a special certificate on stage, expressing gratitude from the Federation for all their hard work both before and during the Games.

Olivier also presented two very special gifts of thanks and appreciation from the Federation to Gabriel Andreu received on behalf of the 2015 Local Organising Committee and Ariel Barajola, the President of the Argentine Transplant Sport Association, ADETRA.

Finally, President Olivier Coustere received a gift of a painting from the WTGF Council which was presented by incoming Federation President Chris Thomas to show thanks from the Federation and appreciation for over 11 years of service as President. Olivier received a standing ovation and much warmth and love from those in attendance.



The Mar del Plata 2015 Youth Programme

Throughout the week of the 20th World Transplant Games, the Local Organising Committee offered a great range of activities for children and young people, enabling friendships to be formed while trying something new and maybe challenging.

Monday afternoon was spent at the activity centre La Chance in Sierra de los Padres with wall climbing and archery among activities on offer. This was followed the next day by Tango classes attended by around 50 children and parents. The Tango partners were professional dancers from the city who were delighted to show everyone how to move. This enjoyable event was repeated on Thursday, when about 60 young people - and not so young people - danced and had fun joining in with the Tango lessons.

On Wednesday, kids were keen to participate in a circus workshop which was run by a clown from Mar del Plata. This fun event gave the children the opportunity to try some circus skills along with their parents. Finally, the "Brushstrokes for Life" event took place on Friday, allowing the youngsters and their families to enjoy painting with local artists who were pleased to help with tips and advice.

The week of activities passed quickly for the young people who were excited to have such a varied programme of events over the week.

A huge "thank you" to everyone involved in making this happen!



NEW FLAG FOR 2015 • NEW FLAG FOR 2015 • NEW FLAG FOR 2015

Colombia

On Friday 21st of August at 6:30pm, three Colombians, two men and one woman, started a special journey to Mar del Plata Argentina. An experience they had prepared for many months with tenacity and dedication to attend this unique world sporting event, in which every athlete is already a winner, a meeting that celebrates life, regardless of who wins the sports.

The XX World Transplant Games were hosted for the first time in a Latin-American country and there in Mar del Plata, among almost 1,200 participants from 44 different countries was Team Colombia. Two men, Ivan Rojas and Rodolfo Cuervo, 45 and 50 years old respectively and both kidney transplanted, were accompanied by their Team Manager and doctor Alejandra Martin, making them the first Colombians to achieve this dream.

The local organisers in Argentina received us with the warm welcome characterised by Latinos with their unmistakable accent, their hugs and kisses and their famous "mate", making this experience one of the most pleasurable and unforgettable experiences in our lives.

Ivan Rojas participated in the 5k and the virtual triathlon. Rodolfo Cuervo participated in the 5k and 1500 meters. Even though they didn't finish on the podium, they are winners. Like all the athletes in Mar del Plata they had received a second chance in



Rodolfo Cuervo on the track

TM Alejandra Martin with Ivan Rojas

life. There were many positive aspects that we can only smile and be grateful for from attending this event. Thanks to the World Transplant Games Federation for this opportunity and for letting us be a part of this great family.

Our experience makes us even stronger to continue to promote life to those people in Colombia who are transplanted and would like to have the opportunity to do sports and have a happy life again.

Edith Alejandra Martin Pinto
Colombia

COUNTRY NEWS • COUNTRY NEWS • COUNTRY NEWS • COUNTRY NEWS



News and photos from Guatemala!

On 2nd August 2015 transplant recipients, donors, donor families and spectators of all ages gathered in Guatemala City for a competitive 10k run and a fun-run or walk of 5k, organised by the Guatemalan Association of Kidney (AGR).

"We are hoping to form a good team of athletes for the World Transplant Games in Málaga, 2017!"

Rony German Sum Velasquez
Guatemalan Association of Kidney Guatemala



18th Annual Sports Championships of the Association of Dialysis and Transplant Patients (SDaT) at Zelena voda 2015

The SDaT's 18th Games were held, as customary, at Zelena voda in Nove Mesto nad Vahom, Slovakia from 2nd - 4th October 2015. Due to the increasing popularity of the Games, new events have been added to the programme since the 1st Championships and today, not only kidney patients, but also their supporters can actively engage in sports such as tennis, table tennis or darts.

On Friday, the organiser of the games, Dusan Krizko, President of SDaT, welcomed all participants and announced that this year's Championships would be special, as in an effort to promote the event, media were invited to Zelena voda. The President then declared the Games open and wished everyone the best of luck.

Apart from sport, the three-day programme of the Games included a talk from Dr Zuzana Zilinska, PhD, President of the Slovak Transplant Association, launching the second phase of the campaign "Seven Lives". The speech focused on information connected with kidney transplantation, as well as the ongoing campaign aimed at donor support and raising awareness among the general public about the importance of transplantation.

The successful athletes were awarded with diplomas and applause. Afterwards, Robert Kopecky spoke briefly about the achievements of the Slovak team during the World Transplant Games in Mar del Plata, where three Slovak competitors won four medals (gold, silver and two bronze).

Dusan Krizko then stated that it was the intention of SDaT to organise the first Slovak Games of Transplant and Dialysis patients in 2016 - open to all organ transplant recipients (including kidneys, heart, lungs and liver) and of course also our dialysis patients.



All in all, this year's Games were exceptional. Not only when it comes to the number of participants which reached a historic high (80) but also in terms of the educational activities connected to donor support and promotion of transplantation. What is more, the engagement of the media in our event may shed more light on the problems of renal impairment and show that support is much needed in Slovakia. Hopefully, this message will spread also throughout our national and regional authorities which still decline to play any role in supporting our organisation.

Nevertheless, the most important development of the last few months is an agreement reached by Dr. Zilinska with the General Health Insurance Company (GHIC). Based on the experience of our Croatian colleagues and their "miracle", the GHIC committed itself to sponsorship to encourage the process of transplantation. This information coincided with the day when the "Seven Lives" campaign began its second phase. We strongly believe that this development will infuse our dialysis patients with new hope as it may dramatically improve their chances to live a better life.



Spoločnosť Dialyzovaných a Transplantovaných
The Association of Dialysis and Transplant Patients
SLOVAKIA

Dusan Krizko
Slovakia

News from the Philippines

In August 2015 members from the Kidney Transplant Association of the Philippines were excited to make their annual pilgrimage to Baguio City, Philippines.

Manillette F Alcaraz,
Philippines.



Life After Transplant: The Transplant Person

Every day we celebrate life after transplant, the life of a transplant person. A transplant person is a person who has received a transplant organ: heart, liver, kidney, pancreas, kidney-pancreas, small bowel, bone-marrow, and other parts of the body, such as cornea, bones and middle-ear. As you noticed, I mentioned transplant person and not transplant patient. At the time of the pre-transplant evaluation I usually mention to transplant candidates: "If you receive a transplant, you will be a normal person taking pills". As you know, the pills are necessary to prevent rejection and to prevent and treat other complications. Any individual may become a patient when he or she experiences any sickness.

Is life after transplant worthwhile? The answer of a transplant person is YES. Transplant persons have become extremely active and positive to society. Many of you have returned to work, some as early as three months post-transplant. Some of you got married and we were very proud to attend your wedding and share your happiness, and dance with you. Results after transplant have been progressively improving and many of you have celebrated 10, 20 or even more than 30 years after surgery. The cycle of life continues. Many of you had children and many have been able to see their grand-children after transplant. Many have been involved in committees, trying to increase the awareness of transplantation, to raise funds and other activities, most specifically to support each other. An important group has participated in the transplant games, either at a provincial, national or at an international level and interacted with transplant persons from other provinces and from other countries.

The transplant person is an active member of the transplant team. The transplant team is composed of professionals who devote their life to transplantation. For many of us, life includes family, friends, recreation and sports, and work. And work means transplantation. We love our work; we love transplantation. We think and discuss about transplantation throughout the day, even when we are at a restaurant or during our vacation. We think about how to improve results, how to improve the quality of life of a transplant person and we usually do it with your help and interaction. You help us understand the effect of medications, which will subsequently result in an improvement in your care. Many of you participated in research projects, which resulted in advances in the field of transplantation.

The transplant person and the transplant professionals are part of a big family. We are all part of that family, a beautiful multicultural family, and we celebrate and share many aspects of the life of a family on a daily basis. However, as we all know, not everything is perfect in a family. There are good and bad days, discussions and differences in opinion. The important point is that the family remains united by respect and love.

The field of transplantation is increasing and as we all know, there are more transplant candidates than transplant donors. We should continue to work hard, trying to increase the number of transplants so more people could enjoy life. Awareness about transplantation should increase. The involvement of the media should increase. Innovation about awareness should be considered. Information about transplantation should be initiated at elementary and high school. Society must know more about transplantation. It is not science fiction and it might not just happen to someone else. During life, we might be more at risk of receiving a transplant than of becoming organ donors. Society must realize that the use of organs from a deceased donor is a unique and irreplaceable source of health. The health of many people with end-stage organ disease depends on it.

Life must and will go on.

Marcelo Cantarovich, MD
Vice President
The Transplantation Society



"We think about how to improve results, how to improve the quality of life of a transplant person and we usually do it with your help and interaction."

SPORT HEALTH TRAINING

“Heart of a Runner”

A Truly Inspirational and Motivating Story

I had a heart transplant at the Mayo Clinic in Scottsdale, Arizona in October 2012 at the age of 57. Being a lifetime competitive runner, I was quite surprised to learn my heart was failing. I approached the transplant with an aggressive positive attitude, just as I would at the starting line of a 5k. If this was going to beat me, it was going to have a battle on its hands.

Eight days after the transplant I walked out of the hospital and didn't look back. I immediately started walking six miles a day on my treadmill and three months later I began to run again. Slow at first - three ten minute miles once a day. Then I started to run twice a day, three miles at a time. I began to quicken my pace as I started to feel stronger. Fast forward to five months post transplant when I ran a local 5k road race and finished 2nd in my age group (55-59) and ran at a 7:30 mile pace. I was elated but knew my work had just begun when it came to my fitness level.

My new heart was in a good place and it seemed to strive on the aerobic exercise I was giving it. Fast forward to today and I am coming up on my three year anniversary of my transplant as well as celebrating my 60th birthday. Two days after my birthday I ran a local 5k and won my age group (60-69) by over a 1:30. I averaged 7:22 per mile for the 5k distance. Heart transplant or no heart transplant that is a pretty good time for someone 60 years old.



In a recent track workout I ended the work with a 6:35 mile, with the last 800m of the mile in 3:06 and the last 400 was run in 90 seconds! If I stay healthy, I think both of those times can come down to 6:20-6:25 for the mile and under 3:00 for the 800m.

I just checked the winning times for my age group at the recent World Transplant Games, Argentina in the 1500m and 800m races...so look out for me in Málaga, 2017!

Check out the YouTube video “Heart of a Runner”

Don (Heart of a Runner) Salamone
United States of America

COUNTRY NEWS • COUNTRY NEWS

NETHERLANDS NEWS

At the World Transplant Games in Mar del Plata this year, Aris Jan van Ek was pleased to present his hard-won gold medal to Giselle, a volunteer for the Dutch team. Giselle's little sister tragically drowned at a very young age and her parents donated all of their child's organs for transplantation. Giselle was surprised and moved to receive this generous acknowledgement and they were happy to celebrate the moment with the Dutch team.



News from Transplant Sport UK



The familiar face of Lynne Holt is pictured here, surprised and delighted as she is presented with the Peter Griffin Award at the British Transplant Games Gala Dinner.

Peter Griffin was an eminent transplant surgeon who was involved with transplant sport since the start in 1977. This Award was first presented in 2009 in memory of his great dedication to organ donation and transplant sport and can be presented to either a child or an adult. Lynne received this in recognition of her outstanding contribution to promoting organ donation and transplant sport.

Congratulations Lynne!

ANZÈRE, SWITZERLAND



TACKERS (Transplant Adventure Camps for Kids) 23rd - 30th January 2016

- Children age 8-15, alone or unaccompanied
- All levels skiers and snowboarders, all equipment provided

TACKERS Snow Boot Camp, 12th - 19th March 2016

- For recipients, doctors, nurses, carers, donor families and friends and family
- Skiing, snowboarding or snowshoeing, all levels, beginners to racers



www.tackers.org

1st Janet Coleman Classic:

Open to all at the end of Snow Boot Camp. In loving memory of a great friend and supporter.

LIFE STORY • LIFE STORY

Ellen Russ

In August, Ellen went on a trip of a lifetime to Argentina to compete in the World Transplant Games where she won six gold medals and was presented with the Outstanding Junior Athlete Award. This is her story so far...

Ellen was one of triplets born 11 weeks early on 8th April 1998 along with her two brothers Thomas and George. They were all rushed to the special care baby unit requiring support to breathe as their lungs were not yet fully developed. Ellen suffered kidney failure when she was five days old and we were told to expect the worst. Due to excellent medical care she pulled through and she and George came home from hospital aged three months. Unfortunately Thomas was very unwell with other complications and died a month later.

Ellen managed taking only medication for her kidney failure and remained stable for many years due to the care from a specialist team at Bristol Children's hospital. She was tired a lot and struggled at school but managed OK. Her kidney function deteriorated further in 2011 and she was placed on the kidney donor waiting list. She also started dialysis which we did at home overnight; she had to be connected to a machine for 12 hours. The machine meant that often we all had very little sleep as it alarmed a lot.

We had a life changing call on 22nd December 2012 when Ellen was on holiday with her dad. She had to rush to Bristol Children's Hospital and we had an agonising 24 hour wait while tests were undertaken. She had her new kidney on 23rd December. This wonderful gift from an unknown deceased

donor gave Ellen a new lease of life; she has more energy now and managed to catch up with her studies to gain good GCSE grades. She is now studying for A levels at college.

Ellen took part in the British Transplant Games 2013 in Sheffield, eight months after her transplant, alongside other recipients. She won a bronze medal in swimming and after the Games she joined the local swimming club. At the British Transplant Games in 2014 she won silver and bronze medals. In October 2014 we received a letter telling us that she had been selected to represent Great Britain and Northern Ireland in the World Transplant Games in Argentina in August 2015. We had to raise over £4,000 so we made cakes and held a Christmas Fayre. Around the same time Ellen's step dad went to Sierra Leone to nurse people with Ebola as part of the UK response to the crisis. December 2014 turned out to be a very busy time!

We managed to raise the money and Ellen travelled to Argentina in August this year to compete in the Games alongside a team of amazing athletes. She went with her dad and, although it was a long journey, it was a brilliant experience. She won gold medals in all of her individual swimming events competing against athletes from 44 countries from around the world. Ellen's six gold medals are dedicated to her donor and their family. She also won the Outstanding Female Junior Athlete Award which she was over the moon about.

Ellen is planning to go to university next year and is determined to continue to spread the message that organ donation saves and improves lives.

Deborah Chalk
United Kingdom



Ellen (centre) on the podium in Mar del Plata

Declan Bennett

On January 11, 1999, Declan Bennett was born, a seemingly healthy baby weighing in at 7lbs 7oz. Not that he or his parents would know that later in his life he would fall ill with a disease that he was born with.

At the age of seven, Declan seemed like a happy boy living a normal life, however he was on the small side. The reason became apparent in the May of 2006 when his friends asked him to play football. Declan really did not feel up to it, he was laid flat out on his bed, no energy, no effort could have been made. His parents, Guy and Teresa, took Declan to his local hospital, Pilgrim Hospital in Boston, Lincolnshire, UK. Later that day he was discharged with a prescription of Trimethoprim. Despite being subscribed this medication, Declan did not feel any better. He was taken back to Boston and the doctors this time realised the potential problem that caused Declan's illness. This is when a transplant was first mentioned. He was transferred to QMC Nottingham by ambulance in critical condition. A day later, Declan underwent surgery to enable the doctors to investigate what had provoked Declan's downhill of health. It was discovered that he had Posterior Urethral Valves, which in turn caused his lifelong condition of chronic renal failure. It was at that point the doctors discovered that his kidneys were irreparably damaged due to reflux caused by the posterior urethral valves. This is when his family and paediatric team at QMC Nottingham knew that he needed a kidney transplant.

After three years of waiting, his father completed all the procedures to test the compatibility of his kidneys with Declan's body and on April 29th 2009, Declan and Guy went into surgery for the necessary procedures to transfer the kidney from Guy's body into Declan's.

The change in Declan's health post surgery was instantaneous. As someone who has had renal issues since birth, his growth has been impaired but since the transplant he has grown significantly. His appetite has grown immensely, not only due to his calorific output as a sportsman but mainly due to the impairment to taste caused by the condition, which made food in general unpalatable.

Post transplant surgery, in respect of Declan's physical fitness, he returned to the many sporting activities he had enjoyed prior to surgery. Among these were swimming, football and cricket which he played competitively for his village, Woodhall Spa.

Declan's swimming took a change in direction by becoming a member of Lincoln Vulcan's Swimming Club where he was put into a squad for competitive swimming training. Since joining the club, he had become a much stronger and faster swimmer and he attended his first British Transplant Games in 2013 in

Sheffield. Once he qualified for the World Transplant Games, Declan's training regime took a new level. Undertaking a training plan set out by his sport physiotherapist, he began training five times a week in the pool, athletics training twice a week, plus an hour of running every weekend.

In Argentina all his hard work paid off as he won seven gold medals in swimming and achieved five world records, earning him the prestigious award 'Outstanding Junior Male Athlete' of the World Transplant Games.

As his fellow competitors would expect no less he is already training hard towards the World Transplant Games 2017 in Málaga, Spain.

Since Argentina, Declan has featured in many press releases, radio and TV interviews to promote his success but most importantly, promoting the importance and power of the gift of life, transplantation.

Declan Bennett

United Kingdom



Focus On Spain



The Spanish national team, formed from the Deporte & Trasplante España Association, has been competing on the international transplant sports event circuit since Manchester 1995. Like many of the national teams, it began as a group of friends, recipients and friends that wanted to demonstrate that: Trasplante + Deporte = Vida (Transplant + Sports = Life).

The National Transplant Organization (ONT), with 25 years of experience, is a worldwide example as one of the best on the planet. Spain has the highest rate in donation (36 per million) and in 2014 the national public health system performed 4,360 transplants overall. The Spanish Model has been recommended by the World Health Organisation and has been replicated in other countries, accomplishing similar results.

Considering that in Spain we have one of the strongest transplant systems in the world, we have an important weakness in the number of recipients performing any kind of sports or physical activity at all. It is fundamental that the prescription of exercise is given by transplant physicians as a part of the general treatment for all the recipients. In other countries the doctors are really aware of this importance and we want to get into the doctors' offices, in a metaphoric way, to increase this number. This is one of the main concerns of the Deporte & Trasplante España team.



In 2011 we established a legal status with the Spanish Government as a non-profit association. Since that date we have grown at a steady pace and with much more rhythm in the past year. We have developed a new website and social media (Facebook & Instagram), tools that have helped us to reach more recipients, transmitting the message of donation and the quality of life through physical activity and sports.

We have held five national transplant Games in Spain - the last one taking place in May earlier this year. We have again set May for the next national Games in 2016, which will be taking place in the city of Lorca. Also we are forming an important team for the European 2016 Games in Finland. All of this is supported by the participation of our associates in local and national athletic events.

We are redoubling our efforts in every aspect and we are sure important results will be accomplished in the coming years.

The fact that XXI World Transplant Games are going to be held in Málaga is of huge momentum for us. The impact of a global event, attracting the interest of the national media and making an impact on society can boost the message in an exceptional way.

Málaga is one of the most beautiful and important cities in Spain with amazing beaches and great airport and hotel facilities - the perfect size to host this kind of event. The buzz between the recipient athletes is multiplying and we are looking forward to receiving the World Transplant Games family and together spreading the message of organ donation: Transplant + Sports = Life!

Andrea Alanis

Communication Deporte & Trasplante España

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