Transplant Games

The Gift that Unites

★ Consent Laws – how has Spain led the world in donation ★
★ 40 years of World Transplant Games ★
★ ReFit for Life! Program ★
★ Get ready for 2019! ★
Inside this edition

02 Board of Trustees
03 Guest Editorial
Presumed Consent is not the Key for Success in Deceased Donation
Rosario Marazuela; Beatriz Domínguez-Gil
04 Message from the President
05 Fit for Life! Ambassador Martin Wong
1st Thailand Open Transplant Games
06 ReFit for Life! A WTGF Initiative
07 News from Brazil
08 News from Hungary

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World Transplant Games 2019:
09 Sports Information
10 NewcastleGateshead 2019
12 Count Down to the Games – How Prepared are You?

14 World Transplant Games 2021
15 European Transplant & Dialysis Sports Championships 2018

16 Our Story
Isaac O’Kane and Living Donor Mum Michelle

17 Member Country News
20 Portsmouth, UK 1978 Remembered
Presumed consent is not the key for success in deceased donation

Rosario Marazuela and Beatriz Domínguez-Gil discuss issues surrounding presumed consent for organ donation

Solid organ transplantation is the best and, frequently, the only therapeutic strategy available for patients with end-stage organ failure. According to the Global Observatory on Organ Donation and Transplantation, almost 136,000 solid organ transplants were performed worldwide in 2016.1 Although impressive at first sight, this activity barely covers 10% of the transplantation needs of patients. Shortage of organs is indeed the main obstacle that precludes the full expansion of transplantation therapies. As a result of shortage, thousands of patients die or endure a poor quality of life while waiting for an organ. Desperate patients in need for a transplant may look for solutions in the form of organ trafficking and transplant tourism, practices that violate fundamental human rights and erode the image of ethically sound transplant programmes. Transplant rates are also extremely unequal across countries, ranging from 0 to more than 110 patients transplanted per million population in Spain.2

Although many factors can potentially explain this variable activity across jurisdictions, the type of consent system for posthumous donation has traditionally gathered a lot of attention. Some countries have put in place the so-called opt-out or presumed consent system, whereby persons will only be considered deceased organ donors unless they have specifically expressed their willingness to donate their organs or if their legal representatives authorize organ recovery. In countries with an opt-out or presumed consent policy, all persons are considered deceased organ donors if they have expressed the opposite during their life time. Because, theoretically, presumed consent sets down a more favorable scenario to organ donation, several legal systems have moved on to this type of consent. Recent examples are those of Argentina, Colombia, Scotland or The Netherlands.

Key for success?
But is really presumed consent the key for success? Spain is a world leader in organ donation and has an opt-out system in place since 1979. However, we have never considered that this type of consent explains the Spanish success.1 First, it was not until 1989 – ten years after the legislation was issued – that donation rates started to increase in our country following the implementation of the so-called “Spanish Model on Organ Donation and Transplantation”.4 The presumed consent policy is not strictly enforced either, so the daily practice more closely resembles an opt-in system.5 Donor coordinators must ensure that no opposition to organ donation has been recorded during the life time of potential deceased organ donors, through the Advanced Directive Registries and other means. An interview is always held with relatives of potential organ donors to assess if donation was consistent with the individual’s wishes and values. In the end, relatives have always the final veto and organ recovery does not take place if this is not acceptable to the family. The high rates of deceased donation in Spain are attributed to a model conceived to ensure the systematic identification of opportunities to organ donation and their transition to actual donation. Deceased donation activities have continued to increase in Spain as a result of novel strategies to further progress towards self-sufficiency in transplantation, as intensive care to facilitate organ donation, the transplantation of organs from aged donors, and donation after circulatory death.6

When taking a look at countries that have changed their system towards presumed consent, there is no single example where such modification has derived in increased rates of organ donation, at least in a sustained manner. On occasions, such change has raised negative reactions because it has been seen as an attempt of the government to control individual’s decisions, particularly when a strict implementation of the opt-out system is applied. On the other hand, debates about shifting towards a presumed consent policy may bring the topic of organ shortage to the public attention, but only temporarily.

On a personal note, in a country where every person in need has access to transplantation, a law that assumes the normality of donating organs after death can only be informed positively, as it brings a clear message to the community. But aware that what can make a real difference is a system where the right professionals are in charge of deceased donation, where they receive appropriate guidance and training and are subject to a continuous evaluation of results, one wonders if it is worth to devote so much time, work and attention to such a secondary aspect as the type of consent is. One can only conclude that presumed consent is a big distraction from aspects that are essential to ensure a broader access of patients to organs from the deceased.7

Rosario Marazuela, MD, PhD; Beatriz Domínguez-Gil, MD, PhD
Organización Nacional de Trasplantes, Madrid, Spain

See page 5 for references
MESSAGE FROM THE PRESIDENT

Opt-in or opt-out? The controversy continues

WTGF President Chris Thomas takes a look at the choices governments have to make for their donation systems

Is there any cause more unifying than organ donation? Is there a photo more inspiring than the cover photo of this journal taken in Argentina as the Colombian team readied themselves for the 5k road race?

I feel extremely privileged to visit places like Salta, Argentina for the 9th Latin American Games and, earlier in the year, Sardinia, Italy, for the European Transplant and Dialysis Championships.

It is interesting that at a time when some countries are becoming more insular, and globalism is in retreat, organ donation and transplantation manages to ‘unite the world’. At the World Transplant Games people attend from all walks of life and from all cultural and religious backgrounds. For a week, our differences, sometimes even prejudices, are cast aside as we come together in celebration.

The Games are a wonderful opportunity to say thank you to the donors and their families who opted to save others through such a wonderful legacy. Don’t take your organs to heaven, heaven knows we need them’. One of the older messages but still as true today as it was 20 years ago.

But does everyone feel the need to say thank you?

There was a very interesting observation from one of the organisers in Italy after one of the athletes was deemed to have been out of line in their behaviour in competition. I remarked it was a shame that this isolated incident undermined the overall message of goodwill and the spirit of the games.

The observation alarmed me. ‘You need to remember that 15 of the 23 countries represented here have opt-out donation systems where the recipients receive their organs from the government.’

The clear inference was the role of the donor, and potentially their family, was secondary to the government managing a system to retrieve organs from those citizens who had not opted-out. Of course, in all opt-out countries, families are still asked to confirm the donation but this observation shed a different perspective on the merits of opt-out systems.

The controversy continues in many countries about what legal system – opt-in or opt-out – is best to help increase donation rates? It was for that reason that I asked Beatriz Dominguez-Gil, Director Organización Nacional de Trasplantes, from Spain to pen the Guest Editorial for this issue of TransplantWorld.

Each country has to make its own mind up and the WTGF does not have an official position on what is best in each and every instance. Talking to the doctors in Argentina, they are very pleased with the immediate response to Justina’s Law which was introduced in July making everyone a donor. They were inspired to act after a 12-year-old girl died waiting for a heart transplant.

However in 2015 DonateLife California in a review found a wide disparity within European Presumed Consent countries donation rates, from a high of Spain’s 33.5 nDPM (donors per million head of population normalised) to a low of Greece’s 5.7, with a simple average of 12.5 nDPM. This was insignificantly different from the Explicit Consent average of 12.1 nDPM.

Beatriz gives us some important clues for countries wishing to increase donation. Perhaps 70 per cent of the solution lies within the hospital setting where it is essential to have professional and compassionate donation specialists leading the conversation with the family.

The other 30 per cent relates to inspiring the community to support donation. Is this best achieved by encouraging people to opt-in or just making everyone a donor and those who object can opt-out?

Whatever system a country adopts, I would hope that in all cases the principles of generosity, of compassion, of thanks and a willingness to support our fellow mankind, remain essential values of organ donation.

Chris Thomas
President
The Games organisers did a fantastic job hosting this event. The Opening Ceremony was very well planned with some surprising indoor fireworks, a torch relay, marching and traditional Thai Dance as entertainment. The Mayor of Pattaya City and the Minister of Sports and Tourism of Thailand were the officiating guests, revealing the great support from the Government to the country’s first Open Transplant Games.

I had the honour in representing WTGF as one of the overseas guests to give a presentation on organ donation promotion in Hong Kong. Mr Matty Hempstalk from TransplantAustralia was invited to speak, sharing his experiences of organising a great transplant games.

I was privileged to spend the week with athletes and supporters from China, France, Malaysia and Singapore and the Thai home team in this renowned tourist city, with competitions in petanque, lawn bowls, 10-pin bowling, badminton, table tennis and track & field. There were less than 200 athletes in all, however, the atmosphere was fantastic – everyone was so friendly, getting involved and helping each other, making the event most enjoyable. Sweating and laughter beat off the summer heat on the sports ground, while the indoor games hall was filled with clapping and cheering. I was lucky to earn three Gold and one Silver medal in shot put, long jump, 400m sprint and the 5Km race walk.

The daily schedule was packed as the athletes needed to travel to venues in different locations away from the participants’ hotel. The TSA Thai Council and I actually could not fix a formal meeting due to the busy schedule. However, we spent quality time together on the road exchanging our experiences and ideas for the promotion of post-transplant sport and exercise and organ donation promotion. There are certainly some difficulties in promoting organ donation in any country and in view of the religious concerns in Thailand, the council of TSA Thai are dedicating themselves to helping to shorten the waiting list for an organ. This event was widely reported by local media including both newspaper and TV and followed with social media channeling YouTube and Facebook to keep up the noise and to deliver the message to the general public.

TSA Thai Administrator, Mr. Sunhanut See, and their Secretary, Ms. Thapanee Sophon, both renal transplantees, were the masterminds of this amazing event. Their heartwarming hospitality made our visit so memorable. We mutually agreed to enhance country-level collaboration in the very near future, inviting visiting teams to share the fun and celebrate life together.

Martin Wong
Fit for Life! Ambassador
Hong Kong

References (from page 3)

Would you like to get active post your transplant?

Would you like to improve the function of your whole body?

Would you like to enjoy a greater quality of life?

The Refit toolkit is here to help you take those first steps.

This six-month online rehabilitation programme is aimed directly at transplant recipients with advice, guidance and examples to help you improve not only your fitness and nutrition, but your mental well-being and overall quality of life.

Evidence shows that regular physical activity is highly positive for transplant patients – having beneficial effects for all aspects of your quality of life and yet many people in the transplant community are still not fully aware of the enormous benefits that regular physical activity can have for your health pre and post-transplant. Transplant survival rates are higher than ever before as adopting a physically active lifestyle tends to help the organ work better and longer. The benefits of exercise are only starting to be appreciated and most clinical practice guidelines now recommend exercise as standard care for solid organ transplant recipients, however, most recipients don’t know when, where or how to begin their journey back to life.

As a global sports Federation that promotes sports for all, the World Transplant Games Federation aims to raise awareness and educate the transplant community on the benefits of physical activity and break down the barriers to exercise.

Our goal is to assist all recipients, regardless of age or fitness levels, to get Refit and make the most out of their second chance at a healthy, happy life.

How does it work?

Recipients are directed to log onto to the dedicated website: [www.wtgf.org/refitforlife](http://www.wtgf.org/refitforlife) where they will find a portal of interesting information related to the benefits of exercise, nutrition and mental well-being.

In order to start the program, you are required to first get medical clearance from your Health Care Professional. The program is designed to support, and not replace the relationship that exists between you and your Health Care Professional. Make sure you discuss your fitness and lifestyle goals with your Health Care Professional before you start the program.

It commences with an assessment which captures your current fitness and mental well-being. The assessment can be done with or without the assistance of a sports therapist, making it available and accessible to everyone. Regular assessments are conducted throughout the program.

It runs in a similar style to an online study course. You will be required to complete certain tasks before you can move onto the next phase. The program is made up of four six week exercise programs. These have been designed by qualified specialists and start with very basic exercises to get you moving again. As you progress through the program, the exercises start to build in duration, quantity and intensity. At
the end of the six months, you should be in a position to follow a Fit for Life maintenance program which includes both cardio and strength and toning exercises.

The website provides details on signs and symptoms to be aware of and the importance of listening to your body through this process. The program is fun and interactive and provides a downloadable Health Tracking Journal to help you capture your daily progress and results.

The Refit for Life! Exercise programs

Each of these programs below run for a period of 6 weeks:

Exercise Program 1 – Let’s get Moving
A short and simple walking program to get you moving again. Includes some basic mobility exercises to loosen things up for the upcoming modules.

Exercise Program 2 – Off the Marks!
An interval walking program building your cardiovascular fitness. Includes an introduction to some basic strengthening and toning exercises as well as some stretching exercises.

Exercise Program 3 – Building Blocks
Longer duration walking intervals as we start to increase your cardiovascular fitness. An introduction to full body strengthening and stretches of the major muscle groups.

Exercise Program 4 – Final Straights
Walking program with increased intervals of up to 35 minutes duration. Includes a complex full body strength and toning program, with relevant stretches.

Where will it be promoted?
The long-term aim of the WTGF is to get this program into transplant units around the world. The WTGF has partnered with various associations including the Transplantation Society (TTS) to ensure that Health Care Professionals work alongside us in promoting this program.

Posters will be displayed at transplant units and Health Care Professionals will be given branded prescription pads allowing them to prescribe this program to their patients.

Astellas, as the founding partner in this initiative will utilize their reps to promote the program in all their territories, and must be thanked for their financial contributions which helped make this program a reality.

The WTGF will also provide opportunities to all our member organisations, and any other transplant and organ donation associations to get involved and allow them to promote the program in their territories.

Find out more?
If you would you like to find out more about this program, visit the website www.wtgf.org/refitforlife or send us an email at refitforlife@wtgf.org

Kim Renyard
WTGF Executive Manager

NEWS FROM BRAZIL

An Important Day for Transplant Recipients

Brazil celebrates National Organ Donor Day with a special swimming event

National Organ Donor Day was celebrated in Brazil on 27th September 2018 with an important sports event. The Brazilian Olympic Committee invited transplant recipient athletes and Olympic athletes for a swimming event at the Maria Lenk Aquatics Center in Rio de Janeiro for a 4x50m freestyle relay.

This unprecedented event in Brazil counted on four transplanted triathletes – Patricia Fonseca (heart recipient), Dinael Wolf, Priscilla Pignolatti and Rodrigo Swinka (kidney recipients)--to compete with four Olympic athletes – Ana Marcela Cunha (four-time World Champion – open water swimming), Joanna Maranhão (5th 400m freestyle in Athens, 2004), Matheus Santana (gold medal 100m freestyle at the Summer Youth Olympics in Nanjing – China, 2014) and Virgílio de Castilho (silver medal in the Pan American in Santo Domingo - Dominica Republic, 2003). Dinael and Patricia were both competitors at the World Transplant Games in Málaga, Spain last year.

The main objective of the relay was to encourage organ donation and to show how life keeps on going after a transplant: with lots of health and happiness.

We are pleased to share this moment with you.

Priscilla Pignolatti
Brazil
Happy Birthday, Hungary

Judit Berente reports on celebrations for the Hungarian Transplant Federation’s 20th Anniversary

Everything started with sport. Along with the oath made by our sportsmen who travelled to the XXI World Transplant Games last year, we also celebrated that 30 years ago, in 1987, it was the first time that a small Hungarian team participated in the VIII World Transplant Games in Innsbruck. When the sportsmen returned home, a young and ambitious transplantee, György Székely, established the first sports association for transplanted patients. It was the Hungarian Transplant Sports Association. Hence our organisation celebrates its official birthday with WTGF.

In Hungary the number of organ transplants started to rise rapidly in the late 1980s and early 1990s. In 1987, 58 kidney transplants were carried out. 10 years later in 1997, the number of organ transplants exceeded 300. The number sextupled within 10 years.

With the rise in the number of organ transplants, the membership of the Hungarian Transplant Sports Association also grew nicely, and the organisation became increasingly successful. After 10 years, György Székely realised that a higher structure, a Federation, was needed in order to move forward. Meanwhile county and/or regional associations had been established outside of the capital. In 1998 the circumstances were given for the establishment of the Hungarian Transplant Federation with the unity of 12 organisations, which has now grown to 20. The Statutes have been created in a way that we are not only a sports federation, but we also deal with the protection of the interests of organ transplantees.

We celebrated our 20th anniversary with a three-day weekend in September in Parádfürdő, where 260 transplantees and their families took part. At the Saturday gala conference the Organ Coordination Office, the leaders of the transplant centres and sports leaders, reported on the developments of the past 20 years. The Federation founded an award for the anniversary that was given to the professionals who have selflessly contributed the most to the Federation’s development.

Our key milestones:

1999
The Federation reached its greatest success to date in 1999 with the amendment of the donation law. In 1997 the donation law had been modified so that relatives would be asked whether or not the donor had objected to organ removal during his/her life. This amendment led to a 30% reduction in donations. The Federation began to negotiate with the representatives of all parliamentary parties and succeeded to win them over to the case, so the parliament unanimously voted on the amendment of the law. Therefore from 1999 the principle of presumed consent prevailed once again: tissue or organ removal from the dead may be carried out if the deceased has not made a protesting statement in his/her lifetime. It would be interesting to know how many extra transplantations were carried out due to this amendment in the past 19 years.

2012
In 2012, the Federation organised a very successful scientific conference in the Hungarian Academy of Sciences entitled: Thoughts about the Lives of the Organ Transplantees.

2015
In 2015, the Hungarian Transplant Society, the National Institute for Sports Medicine, the Hungarian Society of Sports Medicine and the Hungarian Transplant Federation jointly organised the Competitive Sports of Transplanted Patients conference - the first occasion where we had the opportunity to talk about this topic in front of such a wide public.

2015
We started our Educated Patient program for new transplanted patients in 2015 – filling in a gap in the health care system, helping with the rehabilitation and social integration of transplantees. Current number of participants – 250.

1999
From 1999 the Federation has organised the travel of the Hungarian team to all World and European Championships and to international championships.

1999, 2002 & 2006
We organised the XII World Transplant Games in Budapest in 1999, the II European Transplant and Dialysis Sports Games in Balatonaliga in 2002 and the IV European Transplant and Dialysis Sports Games in Pécs in 2006.

2001
The Federation also provided great support to the establishment of the European Transplant and Dialysis Sports Federation (ETDSF) in 2001.
The WTGF Sports Committee often receives comments about problems with the organisation of sports in the World Games. After considerable discussion and review, the Committee has expanded the available information and documentation to assist both the athletes and the organisers for future World Games.

The Committee began its work by reviewing its own observations about the sports, the advice contained in the survey of the Málaga Games (which had over 500 responses!) and the input and recommendations of the WTGF’s new Athlete Advisory Commission. The information was reviewed and divided into three groups:

a. General remarks for all sports
b. Recommendations for changes to adopt
c. Recommendations for changes not to adopt

95% of all recommendations from the AAC were adopted. If a suggestion could not be adopted, the AAC sports group was provided with an explanation.

Once completed, the “Rules for the Sports” document was updated. From this, a new “Competitors’ Guide” was created for all athletes which has not only the rules for each sport but also travel information, check-in times, etc – everything that an athlete would need to participate in a sport. This document is designed to be separated so that only the sections related to an athlete’s participation can be printed and kept with the athlete during the Games.

In addition, an “Understanding and Agreement” document was developed for each of the sports of the World Games. This document focuses on the site and venue criteria, setup needs, and procedures to organise and manage each sport. These will be signed by the Sports Coordinator, the LOC Sports Manager and the WTGF Sports Manager.

Now that these documents are completed, they will be adjusted as we gain new insight. Future sport coordinators can know in advance what the WTGF expects from them.

One issue that had many comments was the delay in the start of sports due to numerous athletes with problems with entries, which held things up considerably. To address this, the registration system is being retooled, and team managers will be expected to confirm all of their team’s entries several weeks before the 2019 Games. Also, a registration card is planned for each athlete which will list the events in which s/he is entered. It will be very easy to see if someone is supposed to be entered in an event or not.

Among the changes to the sports rules are the following:

- Additional events for juniors have been added
- A new age group of 80 years and older has been created
- Any allowed entry in the World Games is eligible to win a medal
- Cycling – the time trial lengthened to 10km
- Golf – individual event will be assigned tee times, lowest to highest handicaps in age groups
- Swimming – there is a new 100m breaststroke event for juniors and a new relay event for teams whose combined age is over 200 years
- Tenpin – (tentative) new team event using the Baker format
- The Local Organising Committee has added archery and six-a-side football for 2019
- Track and Field – the implement weights now match World Masters Association weights
- Virtual Triathlon – cycling event for the virtual triathlon will be the time trial, not road race

A goal of WTGF is to have more countries and transplant recipients come to the World Transplant Games but the sports must be ready for the growing number of participants. These range from the well trained athletes to the recipients who were sick and now have a small point of light at the end of the tunnel – to participate at the World Transplant Games. If our Games continue to thrive, we will grow out of our current time limits and we will need to be proactive as we consider the Games’ future.

The Sport Committee appreciates the input of the hundreds of athletes who completed the Málaga survey. Finally, but certainly most importantly, I would like to express my gratitude to all members of the Athlete Advisory Commission groups for their recommendations and advice regarding their sports - helping us to organise better WTG sports events in the future.

I look forward to meeting you all at WTG NewcastleGateshead 2019.

André Lassooij
WTGF Sports Chair

"The Sport Committee appreciates the input of the hundreds of athletes who completed the Málaga survey."

PHOTO: VISIT ENGLAND
A warm Geordie welcome awaits!

NewcastleGateshead is the vibrant capital of North East England. A modern and thriving city, the area’s incredible cultural scene is matched by its thrilling sport, superb shopping, award-winning dining and famously friendly locals, widely known as Geordies!

North East England is a very special place with rolling countryside, an outstanding collection of castles – eight within ten miles – and stunning coastline all easily accessible via road and rail from the city.

There is an unparalleled opportunity to see and do it all. Visitors to NewcastleGateshead can immerse themselves in history with a city walking tour that takes in Newcastle Castle, Bessie Surtees House - a 16th century merchants’ house, the Georgian architectural splendour of Grey Street and Grainger Town, see the iconic seven bridges and Quayside and explore beneath the city at the Victoria Tunnel, a preserved wagonway built in 1842. Culture lovers can take in an art exhibition at the BALTIC Centre for Contemporary Art or the Laing Gallery, enjoy a concert at Sage Gateshead, take in a show at one of the many theatres, unearth the area’s rich heritage at Great North Museum or get up close to the Angel of the North, an awe-inspiring sculpture.

NewcastleGateshead is just a short Metro ride away from the fantastic coastline. Tynemouth has quirky shops and cafes and South Shields offers the traditional British seaside experience with sandy beaches, seafront parks, a funfair and amusements, and treats including ice cream and local culinary favourite, fish and chips.

Foodies will also be spoilt for choice across the city with a huge choice of eateries from pavement cafes to cosy pubs, Michelin starred restaurants - House of Tides and 21 Queen Street - to bistros serving locally sourced produce. For a real local flavour try Pease Pudding, best described as Geordie Hummus, Panhaggerty a slow-cooked bacon, potato and vegetable casserole, Kippers from Craster which are delicious smoked herrings or Lindisfarne Oysters.

For inspiration on things to see and do, itineraries and food and drink go to: www.newcastlegateshead.com

The local communities are very proud and passionate about their city and having hosted many national and international events including Premiership football at the home of Newcastle United at St James Park, the Rugby World Cup 2015 and London 2012 Olympic Football they are sure to roll out the red carpet and provide a warm welcome.

Geordies have a distinctive accent and there are several common words, phrases and saying that visitors are sure to hear.

“Howay man!” meaning ‘Come On’ or ‘Hurry Up’.

“Canny” meaning ‘Good’ or ‘Nice’ – a real expression of approval!

“Why aye man!” meaning a very enthusiastic ‘Yes’.

“Shy bairns get nowt!” meaning ‘If you don’t ask you don’t get!’

Stay up to date with all the news from the NewcastleGateshead WTG 2019 Games by signing up to the newsletter at http://worldtransplantgames.org
Games update

Plans are progressing apace for the World Transplant Games 2019. The NewcastleGateshead Local Organising Committee are currently finalising the Team Managers briefing document which will soon be shared with Team Managers and country representatives and will go online at worldtransplantgames.org - registration is scheduled to open on 3rd December 2018.

Volunteers will be an integral part of what makes the Games a community event that unites, inspires and uplifts. Games organisers are now recruiting for a wide range of roles including event set up, team and hotel liaison, drivers, interpreters and many more.

To coincide with the Games, a Symposium, Life Saver to Life Changer will be staged on 17th August 2019 at Newcastle University. This free event examines the contribution of Newcastle Hospitals and the University to the field of transplantation medicine and the use of exercise and health promotion as part of a healthy lifestyle following organ transplantation.

See you all at the Games!

Michele McCallion
NewcastleGateshead 2019 Local Organising Committee
Count Down to the Games
How Prepared are You?

Sheila Leddington Wright shares some expert advice to help you prepare for the big event

B enjamin Franklin noted “By failing to prepare, you are preparing to fail” and as you are reading this article I trust you are already getting organised and training for the games. NewcastleGateshead are waiting to give you a wonderful experience and are really excited about the Games. However, are you equipped for this challenge? For those that have competed before, you know what to expect and are no doubt already planning and training hard. This article is focused on new competitors to the World Transplant Games (WTG), although there are a few tips for all.

Let’s start with a message from one of our WTG transplanted athletes: “...the most important part of starting out (in transplant sport) is understanding that you are about to embark on an exciting journey of learning and growth over the next 12 months which will be hard work but all worth it.”

This may all feel too much and confusing for you, however, there are many people to help and advise you. It may be worth investing in a medical assessment before starting training and having a full blood count with your medical doctor before embarking on a new training program. When preparing for the Games, remember that you are trying to perform to your best and this means considering what your pre-transplant state was because your age and previous lifestyle may influence your potential outcomes. For example, if you were ill for a long time prior to surgery and still have the disease, such as cystic fibrosis, then your potential will be different to those that have been well, fit and exercising at a high level and then ill for a short period. Please visit our blog which comments on different backgrounds of transplantees.1 Feel free to comment and consider if you identify with any category or indeed suggest another.

One thing is certain, life is a journey and we are constantly learning; this includes me as a Sports Therapist and Physiotherapist. In my experience, it is important to consider when you need to see us for rehabilitation. It may be an injury which first encourages you to consult someone; however the little niggles are worth addressing before you increase training and they become a real problem. One of our roles is to help reduce your risk of injury so consult us before you have a problem! Whichever therapist you choose remember that you the athlete will usually know more about transplant and medication that they do! Precautions are: always to be vigilant with hygiene as all athletes are at risk of infection when training hard.2 This is the basic foundation of all therapists and indicates the quality of the practitioner. A few specific guidelines are: to avoid manipulations (what we call grade V manipulations) as these forced violent manoeuvres which are contraindicated because of the potential overload on the bone structures. Similarly many transplantees have sensitive skin therefore care should be taken with some of the heavy duty tapes. Finally ensure you are not allergic to the oils and creams used for massage. A short massage (5-12 minutes) can be helpful in recovery.3

Things to consider
There are many things to consider for your preparation for the WTG but most importantly, what is your prime sport and what are the components of fitness you require for that sport? Other questions to focus on before starting to train are: what is your specific goal, how realistic is this, where are you right now, what are you strong at, what do you need to improve on most, what help do you need (buddy, coach, kit, equipment, finance, training etc), how committed are you and finally what good /daily habits will help/ stop you achieving your goal? The ‘S’ factors of fitness may help you focus and think about different components you will need in your sport (in no particular order):

- Suppleness
- Stamina
- Strength
- Speed
- Stability
- Skill
- Specificity
- Spirit
- Sensitivity
- Sensorimotor training

Having planned what you need to improve on, how are you measuring these components? If stamina is part of what you require you could use something simple like the Cooper run4 and see how far you can run in 12 minutes. For suppleness you could measure your straight leg raise and shoulder mobility.5 If you consider you are tight maybe some yoga or Pilates would help if you like group activities. Otherwise

Many ‘injuries’ are not actual injuries but are reoccurrences of previous problems or overload issues.”
there are a wealth of stretching exercise you can use, perhaps with a foam roller. For strength training there may be a local gym you can freely use (it is worth asking) as you are representing your country at the WTG. More simply to improve strength you can use bottles filled with water to add or reduce the load you carry. To increase speed sprint training, short burst sprints with periods of recovery are recommended. This is your period of prehabilitation or preparation where you are educating your muscles to protect joints which may be susceptible to injury.

Many ‘injuries’ are not actual injuries but are recurrences of previous problems or overload issues. Therefore prehabilitation enables you to be balanced to achieve the aspects of fitness you require for your sport. Of course in our efforts to perform to our best we set high standards and can be in danger of overtraining. Overtraining is common when athletes keep trying to improve despite their body telling them to slow down and recover. An early warning could be a high resting heart rate of 10 or more beats per minute than is usual for you. Consider taking your pulse regularly or every morning, noticing any significant increases. Other signs of overtraining could be general muscle fatigue, decrease in performance, a low mood or your enthusiasm for training decreases. It will not be a problem to stop or reduce training for a few weeks to see if you improve. When preparing for the WTG you will be training harder and longer than usual in order to improve and perform better, however you still need adequate rest and recovery.

Finally, a few general tips: Be mindful of the potential negative effects of non-steroidal anti-inflammatory medications (NSAIDs e.g. Ibuprofen) which are frequently used to control pain but also have an anti-inflammatory effect. The inflammatory process is a necessary part of the healing process and in acute injuries you only need a pain relief which could be as simple as cryotherapy. Although NSAID’s are generally considered safe for intermittent use, they also have toxic effects on the liver and kidney therefore are best avoided long term by transplantees.

Hydration is really important but that does not mean just drinking water! Isotonic drinks can be used for replenish energy stores, however they are often expensive and can be easily made yourself. Having worked on your plan, always remember recovery between training which means adequate rest, nutrition and fluid intake. Finally, a number of you will require airline travel to the Games and crossing time zones can negatively affect your performance. Consider the disruption of your circadian rhythm, jet lag, sleep deprivation, altitude travel and not forgetting to consider nutrition.

Enjoy the challenge of preparing for the Games and consider the points raised. There are still some months to go so pace yourself and join the transplantees from around the world for the best yet WTG in NewcastleGateshead, UK.

“Enjoy the Games and we look forward to meeting you”.

Sheila Leddington Wright
MCSP SFHEA, Grad Dip Phys. BSc(Hons)
Pgcert (HE) Msc
Principal Lecturer, Faculty of Health & Life Sciences
Coventry University

With thanks to Dr Mike Price, Associate, Faculty Research Centre for Sport, Exercise and Life Sciences, Reader in Exercise Physiology, School of Life Sciences, Coventry University, UK

References
2021 WORLD TRANSPLANT GAMES

Back to America

Houston resident Donna Esposito looks forward to the 21st World Transplant Games coming to her home city and a WTG return to the USA for the first time in 41 years

When the news broke that Houston had been chosen to host the 2021 World Transplant Games, Donna Esposito couldn't help herself. She started dancing around the house, she said, like a fool. Then people reached out asking what they could do to help; how they could volunteer. "I sort of expected it," she said, "because of knowing Houstonians and how they rise to the cause for everything."

For Donna, the manager of Methodist Hospital’s Multi-Organ Transplant Floor, the announcement that the World Games were coming back to the U.S. for the first time in 41 years – and to her hometown – was the culmination of a dream that started more than two decades ago when she took her first team to the U.S. Transplant Games in Atlanta.

It was at that 1994 event where she was team coordinator that she realized the powerful connection between transplant recipients and sports. "It was truly a life-changing experience for me," she said.

One member of her team was a 32-year-old man who needed a heart transplant. He had about 10% of his heart function and could, literally, not get himself out of bed. "We got him transplanted and nine months later we took him to the games in Atlanta and he was running track and playing basketball," she said. "It was amazing. This guy who could not get out of bed, was now running around a basketball court like nothing was ever wrong with him."

Driving force

Stories like those are around every corner on both the national and world levels where donors and recipients compete in a broad range of sports – from basketball to volleyball, swimming and track and field. Houston hosted the 2014 Transplant Games of America and Donna was one of the original driving forces. When she moved to Houston in 2011, she brought the event to the attention of Harris County, Houston Sports Authority CEO Janis Burke who jumped on the idea. The city hosted the 2014 event which was highly successful.

Now she’s ready for 2021. Janis, who was in Newcastle for the announcement, expects the 2021 World Transplant Games will be a record-setter. "We are thrilled to be hosting the 2021 World Transplant Games as it returns to America," Janis said. "Houston has one of the premier transplant programs in the world and the hospitals within the Texas Medical Center were great partners with us when we hosted the Transplant Games of America, so we look forward to working closely with them again."

"It has been a dream of ours to be able to host this international event and bring the transplant world together in our diverse city." One of the initiatives for the 2021 event will be to promote donor awareness because, as Donna said, "without donors there are no transplants."

The initiative was a huge success during the 2014 Games. At the time, Texas had about 4 million people on the donor registry and bettered their goal of 8 million after the event. Texas currently has more than 10.95 million registered donors and 114,591 patients on the transplant waiting list.

Some of those on today’s waiting list will be competing here in 2021 and Janis and Donna know all too well how important that will be. "There’s something that happens to the athletes when they compete," Donna said. "At that point, they really realize they can do anything."

Which brought her back to 1994 and that 32-year old, who is celebrating the 25th anniversary of his transplant.

A picture of herself with him and his medal has had a place of prominence in every office she’s had since 1994. And not just for sentimental reasons. "It reminds me," she said, "of what really is possible in the world of transplantation."

Melanie Hauser
Houston, USA
Cagliari: a positive spirit

Colin White reports on a successful and memorable European Transplant & Dialysis Sports Championship in Sardinia, Italy

This year’s European Transplant & Dialysis Sports Championships were hosted by Forum Sport Italia in Cagliari, Sardinia from June 17th-24th. 25 countries participated and it was particularly pleasing to have teams from Bosnia & Herzegovina, Kazakhstan and Russia taking part. The ever-increasing numbers from Great Britain & Northern Ireland are also adding to the overall experience.

The majority of the competitors were accommodated in one hotel on the outskirts of Cagliari with a number of teams accommodated in other hotels around the beautiful city. It was clear from feedback that people enjoy when all the teams are based together or in very close proximity as it opens more social opportunities and it also encourages a sense of equity.

With the Championships open to people on dialysis as well as transplant recipients, the event brought together a great diversity of people. Whether on dialysis or having received an organ, or bone marrow, transplant, everyone there realised the power of regular physical activity / sport to make a real difference in the quality of life experienced.

The Championships offer the opportunity to set a personal goal. A transplant recipient may wish to use participation in the event as a motivation to return to a sport they love or to take on sports that they were not able to consider prior to transplant. A person on dialysis may be active on a transplant pool or hoping to be listed and they use their participation in the event as a motivation to be as healthy as they can be, or they may simply enjoy the opportunity for continued involvement in organised sport.

The main factor uniting both transplant recipients and people who are on dialysis is the desire to take a proactive role in their own healthcare, whatever the stage of their health journey.

We were delighted to be joined by Chris Thomas, President of the World Transplant Games Federation (WTGF). Chris spoke at the Opening Ceremony, attended many of the sporting events (awarding some medals) and he also took the opportunity to update team managers and country representatives on developments in the WTGF. The cooperation and friendship between both Federations bodes well for the future as we can both learn from and support each other in moving forward and improving how the respective events operate.

A word often used to describe the Championships is, ‘friendly.’ Whether old rivalries are renewed or new rivals are revealed, there is always respect and with that the opportunity for friendship.

Our hosts opened their hearts to all the participants and there was a great sense of common purpose amongst all the team managers to work together to deliver an excellent event for all. Whilst the petanque competition may have taken place in unconventional surroundings, the positive spirit and sense of enjoyment could not have been better.

Cagliari provided a wonderful backdrop to the Championships. An historic city with beautiful beaches and a maze of narrow street in which to lose oneself in the local sounds, smells and culture.

At the gala dinner it was great to see the diversity of winners in the individual best athlete categories and each one of them was celebrated by the entire room. The acknowledgement of our juniors and our over 70’s was also a great spectacle.

There was a great presentation from the Irish promoting Dublin as the hosts of the next European Transplant & Dialysis Sports Championships in August 2020 (check out www.etdsc2020.com). They had a lot of green ducks with them (go figure?!) and have promised to build on the experiences of the very successful Championships in recent years to deliver a memorable event.

Colin White
ETDSF Secretary
www.etdsf.org
As every transplant family knows, it is a triumph in itself to get to the Games. In our day to day lives, we have ongoing and future anxieties. We try to live positively, appreciating the days out of hospital and hope that by living a healthy life our days in hospital will be less.

Isaac has been competing at the British Transplant games for three years following his successful kidney transplant in 2015 at just 21 months old, which he received from me - living donor mum, Michelle.

Isaac was born with Chronic Kidney Disease secondary to Posterior Urethral Valves which had created a blockage and damaged both kidneys. Both dad (James) and I had no reservations to donate and decided that Isaac could have the best matched kidney. Isaac received my kidney in 2015 and now drinks at least 2.1 litres every day to maintain its longevity.

Isaac spent his life as a baby very much in isolation and lived in and out of hospital. It was a battle to get him big enough to have the transplant due to his illness. The next day following transplant was amazing when Isaac sat up and ate his first ever dish of tomato soup! His consultants referred to his kidney as super-kidney, which had cleaned his creatinine from the 600s to 13 in the first day!

Isaac now takes immunosuppressive medicine for the life of his kidney. Although there are side effects, and Isaac still has a lifetime of hospital bloods, stays and check-ups, he is now enjoying the life he has missed out on so much and makes the most of every opportunity. Isaac is a typical boy and has a real zest for life. He wants to climb the highest height and be the fastest skier! He definitely found his feet this year at the Games and we are very proud parents.

As a living donor, I also decided to compete in the World Transplant Winter Games this year. I thought that skiing was something of the past (since having Isaac with his medical needs) until I saw on the Transplant Sport webpage a post inviting living donors and donor families. I immediately contacted the team manager and although I'd never competed in a race before, decided to take part in the Giant Slalom.

What an amazing opportunity for us all. Isaac had a few lessons (and so did I) and we all set off to Switzerland. It was so reassuring for us to be able to ski with a medical team there if we had any concerns. We just kept our fingers crossed that Isaac would be well enough to go.

The World Winter Transplant Games was such a privilege for us, representing Great Britain and meeting others from around the world from the transplant community.

It was such an honour to be a live donor at the Games. It opened my eyes to see all sides of organ transplantation, liaising with recipients, live donors and donor families, who told their heartfelt stories. The gift of life forever prevalent!

It was also a special time for Isaac, taking part in some events with the Nicholas Green Camp for transplant children from around the world. He amazed everyone, completing the Nicholas Green Cup slalom at aged just four. (YouTube: Isaac O’Kane)

The World Transplant Winter Games gave me a real focus to get fit again after donating and enabled me to strive for something greater for us all. It tested my own abilities and although I was exhausted for a long time after, I thoroughly enjoyed the whole experience.

I even managed to win a silver medal, and James a gold! Of course, we hope to return, fortunately it is every two years - so time to recover and prepare!

Someone asked me to define what the Transplant Games means to us. I have pondered often of the right kind of answer and then tried to imagine our lives without the opportunity of the Games.

The answer simply is ‘hope’.

Michelle O’Kane
United Kingdom
What a Celebration of Life we experienced during the 13th South African National Transplant Games (NTG) 2018 in Port Elizabeth!

The excitement ran high when old friends met again on Thursday 12th July during registration and the Welcome function. This function served as a platform to meet new athletes and see old friends again. Councillor Athol Trollip, Honourable Executive Mayor of the Nelson Mandela Bay municipality welcomed all athletes, organisers and supporters to the “Caring City” and pledged his support to the need for organ donation and transplantation.

After weeks of splendid weather, the conditions turned cold and rainy but that did not dampen the spirit of Celebration of New Life! Much needed rain fell in the drought-stricken area for which we were very thankful.

On Friday 13th July, the road runners were the first to participate running next to the breaking waves on the Promenade, while the cyclists took the opposite route following the rocky coastline to Schoemanskop. In the meantime, the golfers teed off at Port Elizabeth Golf Club in cool weather. The swimmers enjoyed the wonderful facilities of the Newton Park Aquatic stadium.

There was much excitement amongst the petanque players as it was the first time ever that this event was played in Port Elizabeth. This can be the start of establishing a petanque club in the area.

The squash and table tennis players enjoyed the courts of the Nelson Mandela University where the competition was tough especially against club league players.

Contagious atmosphere
The atmosphere at the Lighthouse Ten Pin Bowling Club was contagious. Not only did the bowlers enjoy the outstanding facility, but for the first time, darts was part of the National Games.

An organ donation and transplantation awareness walk also took place on Friday in front of Protea Marine Hotel. Athletes, supporters and organisations like Love Life Gift Life, the Organ Donor Foundation, the Sunflower Fund and the Kidney Awareness Network were part of this event to raise awareness for organ donation and transplantation.

On Saturday 14th July, all athletes and supporters gathered at the Nelson Mandela University Athletic Stadium to enjoy a day of track and field events. Between 50% sunshine and 50% rain, the organisers did manage to complete half of the programme. What was outstanding was the warm spirit of support from all the spectators who lifted their voices in song and celebration!

All athletes were rewarded with participation medals at the Gala evening on Saturday. It was clear that new athletes and their families, who arrived on Thursday, became friends and “family” members during three days of Celebration.

As well as Celebrating New Life, the main aim of participating in these Games was to qualify in different sports events to be in contention for selection to the National Team to participate in the World Transplant Games (WTG) that will be hosted in 2019 in Newcastle, UK. Athletes who qualified in their different sporting events will go into a process of re-qualifying and training camps in preparation for the WTG.

The South African Transplant Sports Association would like to thank all institutions who were involved in ensuring the success of these Games, especially the Nelson Mandela University’s Faculty of Health Sciences who embraced this opportunity as a project where all departments participated. They also committed themselves to future development of transplanted athletes.

Hermann Steyn
South Africa

New athletes and their families became friends and “family” members during three days of Celebration.”
USA

Expect the Unexpected

News from the Transplant Games of America, 2nd – 7th August, Salt Lake City, Utah, United States

Expect the unexpected. That’s what I told myself as I was about to begin my sixth US Transplant Games in Salt Lake City, Utah. This year the Games had thousands of athletes, families, friends, donor families, and supporters watching and competing in over 20 athletic events and games.

Every Games brings with it a rush of emotions. The expected emotions are seeing your friends and meeting new friends. The sense of “normal” we feel by being surrounded by other people who have had transplants or who have donated organs (living and deceased) is unmistakably the best part.

You see the first person, then the second, and you suddenly realize you’re there. It’s that feeling that you’ve longed for since the last games. The feeling that you’re normal because your competitors and friends get it.

The parallel of being there is dealing with the logistics of the games. Having participated in five previous US Transplant Games, I knew to expect the unexpected. There are always things that come up unexpectedly…

Thankfully, the best of the human spirit is exhibited at the Games. During my bike race, I took turns at the front to confront the wind with a heart transplant cyclist. There is nothing like being looked after by someone who has faced death and said, “not now.”

The events begin and so does that sensation. Every moment, every step, every finish line is historic. Around 10am the kids started the 50m run and the most cheers and attention were directed to the child in a walker being guided along by his father. A few minutes after the other competitors have crossed the finished line, the 7-year old boy and his family who have been in and out of hospitals more than most medical students, cross the line to a standing ovation. Did he have a heart or liver transplant? Kidney? Was he two, three, four or five years old? It doesn’t matter. He’s here.

There is something so irreplaceable about the look of transplant athletes. It’s a look from beyond the dead because many of us carry a body part that carries a spirit. Running for someone else with someone else’s organ is very special privilege.

The next day we arrive for the volleyball competition. My team, Team SoCal, is typically one of the best teams. When the competition begins, we click. We win every match in straight sets and then wait for the finals to begin. At 12:30am on the following day, we begin the finals match against the home team Utah-Idaho. After losing our first set of the tournament, we warmed up and won the next two sets. Winning a championship with a team creates a deep and everlasting bond. At 1:40am, we lined up to step on the podium. We weren’t in a rush. We were there.

Zachary Brooks
USA

Canada

Champion dragons!

The Toronto Transplant Dragon Boat Team has been in existence for over 20 years, is comprised of individuals who are mostly organ transplant recipients, donors, nurses and they actively promote organ donor registration. The team members are not all from Toronto but travel from their home towns to practices and events. They finished a successful 2018 summer of regattas promoting healthy living after transplant. In September, at the Stratford Rotary Dragon Boat Festival, they were presented with the medal East Division Champs.

Niva Segatto
Canada

Members of Team SoCal: (left to right) Lloyd Tucker, Holly Miyagawa, Lacey Wood, Zach Brooks
SWEDEN

“PGs Prize”

Magnus Pagerup wins an unusual prize at the Swedish Golf Championship...

Magnus Pagerup successfully defended his title in the Swedish Golf Championship - better known as PGs Prize - for transplantees and dialysis patients at Delsjö GK in Gothenburg on the 8th September.

In the very varying weather, from heavy showers to nice sunshine and back again, Magnus posted a very good net score of 74.

PGs Prize is a traditional handicrafted “Dala horse” and the winner will keep, and clean up the stables, until the Championships next year in September when the horse will be up for grabs again. The winner’s prerogative is also to choose the venue for next year’s Swedish Golf Championship.

It was great to see so many entering the tournament however there is always room for more golfers. In total there were 12 players of which eight were transplantees. It was also very positive that several new faces came to Gothenburg to participate in the tournament.

You can only win the Dala horse if you are a Swedish transplant or a dialysis patient but there is also a class for relatives and medical professionals. If any international friends are in Sweden at the time they will be very welcome to participate in the tournament, however the Dala horse can only be won by a Swede!

Deklsjö GK is one of the oldest courses in the Gothenburg area and was opened in 1965. It’s a parkland course, slightly hilly between a couple of holes. It’s very well maintained with good greens and a decent challenge for every golfer, experienced or beginner - well worth a visit if you are in town.

Next PGs Prize will be held sometime in September 2019 although the venue is still a well-kept secret... Or rather Magnus Pagerup is still tasting the sweetness of victory and has yet to decide the course for next year but a good guess is that it will be somewhere close to the Swedish west coast.

CJ Ahl
Sweden

CANADA

Canadian Transplant Games

The 9th Canadian Transplant Games were held from 2nd – 7th July 2018 in Vancouver BC. Canada, is a vast country and most provinces were represented with 158 athletes, in addition to 3 from USA and 3 from Mexico, along with 22 donor families and many supporters.

Numerous athletes participating have attended past World Transplant Games, and many new participants have gotten the Games fever and are looking forward to participating next year in the UK. At these Games many new friendships were made, positive energy, stories and experiences were shared by all. This was a week of friendly competition and celebration of life on Musqueam Territory at the University of British Columbia with panoramic views of the mountains as backdrop.

A donor walk was held to honour living donors and donor families at the Reconciliation Pole. So fitting, the story was given of the Pole’s symbolism and the connection to organ transplantation. The week ended with a gala celebration which included guest speaker Simon Keith, the first professional athlete to return to sport after a heart transplant.

The participants of the Games continued to share their experiences upon returning to their home communities, with social media spreading the message of the benefits of organ donation and healthy active living after transplant.

Niva Segatto
Canada
Forty years ago the first Transplant Games event was conceived by Dr Maurice Slapak. With 99 participants from five countries, the path was set for not only the showcase summer and winter World Transplant Games that we know today but also leading to national and regional Games all around the world.