

TransplantWorld

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Journal of the



World Transplant Games Federation
Powered by the gift of life

Train Smart, Not Hard!

How training can both help recovery and be fun

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World Transplant Winter
Games 2018

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Train Smart, Not Hard!

Jonas Vanbekbergen is a sports trainer for recreational and elite athletes who is now applying his knowledge to help transplant recipients. Here he explains how a carefully tailored training programme can both help recovery and be fun

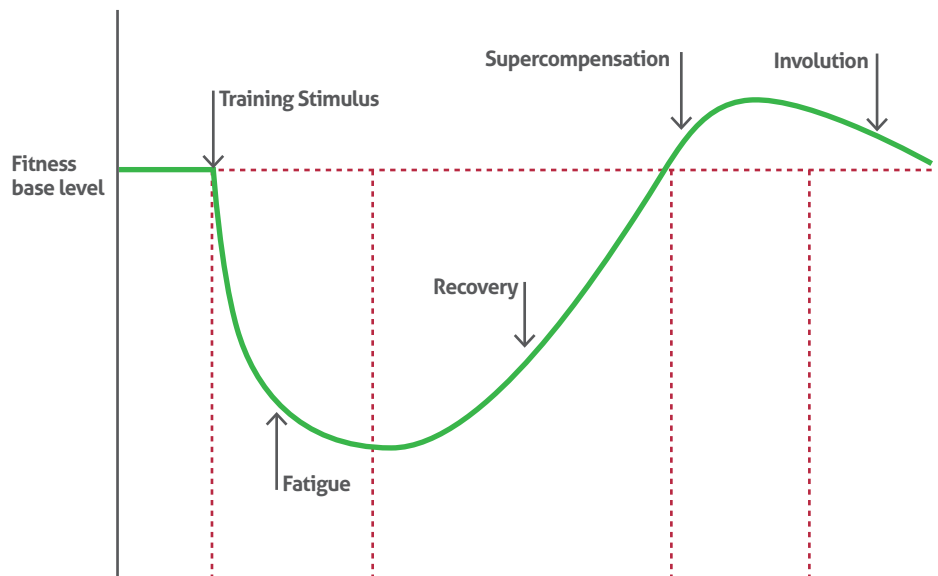


Exercise is fun. And should be fun, for physical activity should become a part of daily life to attenuate side effects of immunosuppression and increase metabolic health. Some transplant recipients take it to the next level and reach physical fitness levels well beyond those of the general population. This is their way to honour their donor and to act as ambassadors of a healthy lifestyle after transplantation. These days an increasing number of sport events are being organized in which both the general population and transplant recipients participate. Just as elite athletes are able to gain great benefit from professional guidance to reach their personal performance goals, so can transplant recipients.

I cannot stress enough the importance of early physical rehabilitation after solid organ transplantation. Starting with a low physical capacity before transplantation, with some usual further deterioration in the early aftermath of the surgical procedure, it is pivotal to implement both aerobic and muscle strengthening exercises early after transplantation. However, here I briefly discuss my training philosophy in those who have already regained normal muscle strength and fitness and who now aim to increase exercise performance.

Many people browse the web

Figure 1: **Supercompensation Model**



Zatsiorsky & Kraemer, 2016

in an attempt to find appropriate training recommendations, only to get overwhelmed by the latest fitness trends. Should I do kettle bell swings to gain explosivity, perform high-intensity interval training for aerobic capacity, eat paleo to stimulate adaptations in body composition? One can't see the forest for the trees anymore. Many ways lead to Rome, none of them are the only way up.

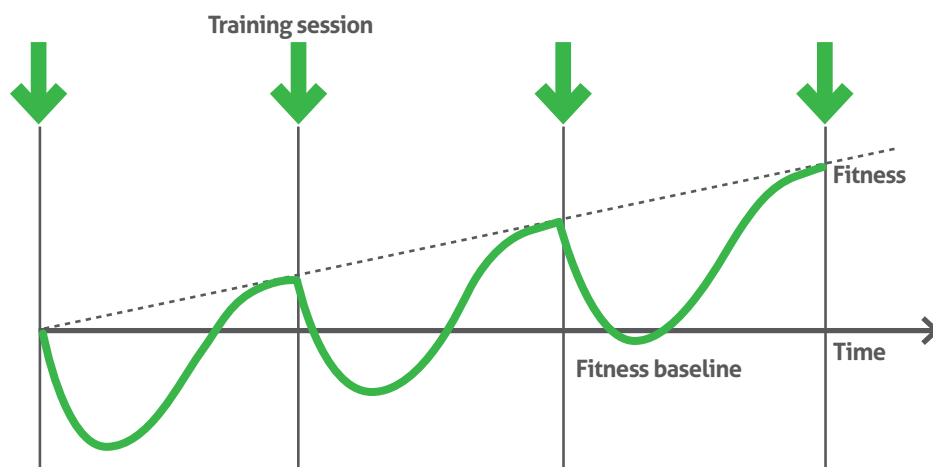
From my personal experience of working with transplant recipients in the last five years, I feel that an effective training programme is a tailored programme carefully balancing training stressors and the capacity to recover from them. The latter not exclusively being influenced by physical factors, but also encompassing psychological aspects.

'Train hard or go home!', a popular quote by wannabe athletes. I prefer to adapt it to 'Train smart or go home'. Get the basics right: train frequently, eat well, sleep well! Understand what you are doing, why you are doing it, what signals your body is giving you both during and after training, and how your body responds to it. Train frequently, but take care of the timing and the load to enable a temporary status of

Many people browse the web in an attempt to find appropriate training recommendations, only to get overwhelmed by the latest fitness trends."

GUEST EDITORIAL continued

Figure 2: How often should you train?

**Normal recovery phase per sport**

- Highly individual different
- Strongly intensity-dependent



Endurance
24h – 48hr ~ 3 à 4x/week



Strength
48h – 72hr ~ 2 à 3x/week



Core stability & flexibility
24h – 36hr ~ 4 à 5x/week

Profile

Jonas Vanbekbergen

Jonas has always been driven by his passion for exercise and sport. After his graduation as Master of Science in Physical Education and Movements Sciences, Jonas worked as an exercise physiologist at KU Leuven for about 8 years. Through his experience, Jonas developed his skills as a trainer of both recreational and elite athletes.

Nowadays, Jonas applies his knowledge to transplant recipients, guiding them in their journey from physically unfit patients to well-trained 'athletes' capable of realising their personal performance goals. Whether this is finishing a 5 km walk or winning a medal at the World Transplant Games, his enthusiastic approach is contagious and brings out the best in everyone with whom he works.

> 'supercompensation' (Figure 1).

This is a phase occurring following recovery from training, in which the body adapted itself to better handle a similar training stressor on a future occasion. You just got stronger! With well-timed successive training sessions, what we call 'progressive overload', step by step your fitness (and performance) level will increase. However, in case the successive training session is planned too early (figure 2), physical fitness might drop due to accumulating fatigue, not per se leading to a greater supercompensation following a long period of recovery. In fact, this is a typical phenomenon observed during for instance the 'Tour de France'. Physical fitness during such stage races progressively decreases over time in most cyclists due to 'overtraining'. Only those with a tremendous capacity to cope with

and recover from successive training days will be able to compete for gold. On the other hand, when successive training stimulus is provided too late, no long-term performance adaptations will be accomplished with physical fitness levels remaining stable at baseline level. Want to get FIT? Get your training frequency, intensity & time right!

Three steps

Making one's training schedule should pass three steps: (1) individual profiling (who are we making a training program for), (2) smart goal setting, and (3) create, implement, and constantly evaluate and adapt the training strategy.

A lot of factors need to be taken into account to gain insights in the profile of the person you are working with. To name a few: medical history (i.e.,

date of transplantation), comorbidities (i.e., musculoskeletal, pulmonary, etc.), medication (i.e. beta-blockers decreasing heart rate), body composition, current physical fitness (how was this assessed?), current (last weeks) and past (last years) training activity, etc. Try also to find out what he or she already knows about training strategies and principles.

Step two, describe exactly your SMART goal! What is the specific goal in the long-term, and can this be divided into multiple goals in the short term? How can we quantify whether the goal was reached? Is the goalsetting realistic and achievable? When do we want to reach this goal?

And finally, step three, built the road towards your goal. Make your periodization, your training plan, which is in fact the structuring of all your sessions taking into account training specificity, intensity, and volume, and of course the personal life/work balance.

And remember, no better feeling as when a plan comes together!

Jonas Vanbekbergen
Belgium

“Only those with a tremendous capacity to cope with and recover from successive training days will be able to compete for gold.”



Understanding the barriers to physical activity

WTGF President Chris Thomas shares his thoughts on the complexities involved in encouraging people to 'get fit'

The consensus was overwhelming. The scene: a conference centre in Leuven, Belgium, where 200 or 300 hundred people interested in exercise after transplantation had gathered. All credit to Professor Diethard Monbaliu from Transplantoux for organising the 'Exercise is Medicine' conference to celebrate 10 years of this exciting organisation.

Throughout the two days speaker after speaker rose to talk of the various benefits of exercise after transplantation.

The conference was 'gold' for the World Transplant Games Federation. It delivered right on message as part of our Fit for Life! campaign.

And the consensus was that all recipients need to be active post-transplant. The majority are not. And it undoubtedly leads to other health complications, possible graft loss and at worse, death.

So, what is the solution? 'Exercise', 'start walking', 'join a gym', went the cries. All makes perfect sense.

Then why do some recipients naturally embrace these messages and some remain glued to their lounge chair, sedentary, refusing to budge?

Re-engaging with sport

I have a theory. It is not rocket science and it is not based on any particular body of evidence. However I believe there is naturally a strong correlation to the sport and physical activity undertaken by people prior to their transplant to the likelihood of them re-engaging with sport after their transplant.

In other words – if you were fit and active before your transplant, it is probably likely you will become fit and active after your transplant. Of course there are exceptions but it is probably a good general rule.

So who are we, as the Federation, here to help? Of course everybody but perhaps less of those who have the

ability to help themselves – that is those who naturally tend to gravitate towards health and fitness.

Our role, like a good classroom teacher, must be to help those who need it the most. To help those who have a fear of movement with their transplant. Those who don't know how to take the first steps? Those who are looking for guidance and social support.

The next stage in our understanding of the complexities of this paradigm is to not just accept that everyone will automatically start walking to get fit. There are many barriers. And we need to understand them.

Community survey

As this journal is being distributed we have a survey out to our community trying to understand the 'barriers to physical activity post-transplant'.

It is all well and good to say to someone 'get fit, go for a walk'. But what if they have other complications such as hypertension or diabetes? Maybe they don't have any feeling in their extremities?

Perhaps they are just too exhausted? Have muscle stiffness, lower back pain or all of the above? These are major barriers and our messages will fall on deaf ears if we don't first understand the root causes of reluctance to begin a program of physical activity.

Perhaps it is the most common of complaints – the cost of participating in sport or going to a gym.

I hope everyone, especially those who are not very active, takes time to complete the survey. The Federation has a lot to learn if we are to achieve our aim of 'more transplant recipients, more active, more often'.

We will continue to offer first class world events focused on sport – such as the Winter and Summer Games. However everywhere across the world the definition of sport and activity is changing. The traditional sports model, where a person joins a club and participates in only that sport, is changing. Some say traditional sport and their clubs are on borrowed time.

Certainly in Australia, people get their physical activity 'fix' from a range of activities – park runs, exercising with the kids, walking the dog, going to the gym. So much of it now is very personally-focused where it is 'me' time.

That's where the traditional sports model still has a strong role to play – its about social inclusion, winning and losing as a team, backing your mates and not letting them down.

Sport has a lot to learn if it is to continue to grow. At the WTGF we are fortunate to have more than just the sports message – our message is one of thanks and encouraging recipients to be their best – not just for themselves but for the donor who gave them that opportunity.

Chris Thomas
President

“ Why do some recipients naturally embrace these messages and some remain glued to their lounge chair, sedentary, refusing to budge? ”

TRANSPLANTOUX SYMPOSIUM

Exercise is Medicine

Diethard Monbaliu and Stefan De Smet report from the Transplantoux Symposium

There is an emerging role for physical activity in attenuating and reversing the process of physical deconditioning and muscle wasting before and after organ transplantation. Indeed, evidence has shown tailored physical training to be feasible, safe, and effective throughout the whole course of organ failure and transplantation. Reconditioning ideally starts before the transplantation, and continues during the early and late post-transplant period. An active lifestyle post-transplant not only enables restoration of physical capacity, but may also contribute to the prevention and treatment of highly prevalent comorbidities such as obesity, diabetes, cardiovascular disease, osteoporosis, chronic fatigue. Moreover, participation in regular physical activity increases mental well-being and quality of life, brings people together, and allows patients to honour their donor's gift by keeping their organ(s) in a healthy condition.

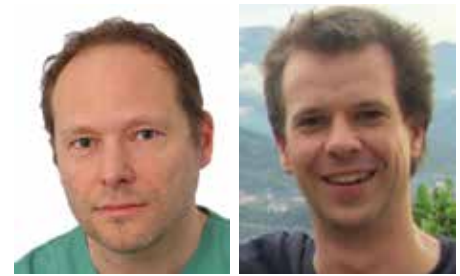
Despite the current evidence, there are still some misconceptions amongst transplant recipients and health care providers. Too often transplant professionals are not aware of the benefits of physical well-being or they dismiss physical training as not feasible or unsafe. Often, recipients who have encountered muscle weakness and physical inactivity before their transplantation underestimate their physical potential or are insecure about exercising after their transplantation. At

the governmental level, policy makers slowly start to realise that physical training as part of routine care not only enhances patients' physical and mental health, but may also be a cost-effective intervention considering the estimated decrease in hospital visits and total health care costs.

It's time for a different mindset!

On the occasion of the 10th anniversary of Transplantoux, we organised for the first time a scientific symposium entitled 'Exercise is medicine'. During this first Transplantoux symposium, with leading experts from seven different countries, we proudly presented a programme, passionately elaborating on evidence, science and practical experiences on physical activity implementation throughout the different phases of transplantation. In the historical city of Leuven, Belgium, more than 150 transplant physicians, physiotherapists, nurses, allied health care professionals, researchers, and transplant recipients from 14 different countries enthusiastically participated to this symposium.

The symposium was gracefully opened by Dr Carella (replacing Prof Costa) who shared the inspiring Italian experience on the active rehabilitation of transplant recipients. Let there be no doubt, supervised physical training following transplantation is feasible, organisable, and effective to increase



What is Transplantoux?



Transplantoux emphasizes the importance of organ donation, raises awareness and motivates people after transplantation to be physically active. It organises sporting activities throughout the year on every level and promotes a healthy lifestyle. Transplantoux also facilitates scientific research to improve outcome after transplantation through physical activity. To find out more visit www.transplantoux.be

patients' physical health when there is a good collaboration among medical doctors, physiotherapists and other allied health care professionals. Dr Oeyen subsequently updated the current evidence regarding the intertwined effects of physical fitness and training on quality of life in chronic organ failure and transplantation. Next, Prof Troosters completed the first session by highlighting the role of physical activity monitoring in the clinical practice.

In the second session 'How to move forward', Dr Van Adrichem identified the most common obstacles to change a sedentary into an active lifestyle. Physical constraints, low energy levels and fear of movement are the most common obstacles for recipients to embrace an active lifestyle. Education and rising awareness followed by early supervised physical training seems the appropriate answer! Subsequently Dr Ried-Larsen elaborated on the beneficial effects of exercise as an effective treatment of type II diabetes.

Continued on page 14



Guest Editorial contributor Jonas Vanbekbergen with Diethard Monbaliu and Stefan De Smet

Introducing the WTGF “Athletes Advisory Commission”

Liam Barnett outlines the aims of the WTGF’s new advisory commission

The start of 2018 ushered in the beginnings of a profound forward step by the WTGF Board towards improving the World Transplant Games with the formation of the Athletes Advisory Commission (ACC).

The focus of the ACC is to attract transplant athletes who have expert skills, knowledge and experience in a particular sport, and give them the opportunity to provide the WTGF Board and Sports Committee with recommendations and guidelines related to technical and organisational issues within a chosen sport.

I heard about the ACC in late 2017 through the WTGF website and Lynne Holt, the GB&NI team manager. I have been a competitive swimmer from an early age and have competed in the swimming event in the past three World Transplant Games. With this involvement, coupled with my experience of managing the GB&NI transplant swimming team, I felt strongly that I could work as part of a team to offer the WTGF fair and realistic recommendations for improving the swimming event, starting with suggestions for the Games in NewcastleGateshead in 2019.

An advisory group was established for each of the sports represented at the World Transplant Games with each group comprising three to four members, all mainly from different countries from around the world. The objective of each group is to serve as a panel in an advisory capacity for their chosen sport, to share their expertise to the WTGF and to provide guidelines to make the Games as professional as possible whilst still serving the needs of the transplant athletes at all levels who will always remain at the heart of the World Transplant Games.

WTGF President Chris Thomas charged

new Trustee Zach Brooks with the job of coordinating the advisory groups for all of the sports and Zach has been a catalyst for its success so far. Zach has set up conference forums for all members, pushed for early engagement between team members and has provided each group with an outline program to stimulate each group to generate, capture and then refine ideas to put forward to the WTGF Sports Committee.

A range of issues

The swimming advisory group consists of myself, Jodie Cox (GB&NI), Hernan Sachero (Argentina) and Donna Hart (Canada). In view of the time zone and language challenges amongst the members, the group has shared ideas mainly using email. Having a range of age, gender, nationality and even transplant type within the team has enabled a range of issues to be addressed by the group. Some of the recommendations put forward by the team so far have

been suggested schedule changes, formalisation of medal ceremony procedure and recommendations on venues and equipment. All advisory groups will produce guidelines and recommendations as we have for swimming. These will then be presented to the WTGF Sports Committee for review and then recommendation to the WTGF Board for implementation into future World Games.

With the World Transplant Games getting bigger and with increasingly more talented and knowledgeable athletes attending each time, the ACC is a great way for the Federation to draw upon the expertise and experience of the athletes who have specific experience of the Games. As such, the AAC has the power to improve organisation and professionalism at the Games, which will lead to wider participation, greater exposure and ultimately more international focus on transplantation and organ donation.

Liam Barnett
UK



Liam Barnett is a member of the commission's swimming advisory group

WORLD TRANSPLANT WINTER GAMES 2018



A Games to remember!

The 10th World Transplant Winter Games 2018 was a huge success. Liz Schick looks back at some of the highlights from Switzerland

Main image, Nicholas Cup winner, Maximilian Off with (back left to right): Liz Schick; Swisstransplant President Pierre-Yves Maillard and WTGF President Chris Thomas
Front left to right: Donor family Sophie and Harvey Layzell from Jemima's Trust

Inset: Four-year-old Isaac O'Kane (with proud Dad) and 74-year-old Eric Monnier

The Winter Games are a much smaller event than the Summer Games and are often considered exclusively for the elite few who are experts at winter sports, but this is not the case, they are for everyone.

The 2018 Games, held for the second time in Anzère, were a transplant family affair. The youngest recipient was four-year-old Isaac O'Kane from the UK who was accompanied by his mother, Michelle, who competed in one of several donor events, and the oldest competitor was Eric Monnier, 74, from Switzerland. These were his first Games and when asked what he thought of the Games back at his transplant centre he declared

that it had been the best week of his life!

Sports including snowshoeing, cross country skiing, curling and alpine skiing were on the schedule although many participants probably burnt the most calories on the dance floor at the gala dinner on Thursday night once the adult competitions were over.

Organising the parallel slalom on two of the evenings during the week was a great success and very exciting for the crowd who enjoyed watching the floodlit competitions as competitors skied against each other simultaneously to the sound of cow bells, dance music and the voice of Philippe Santschi, whose good-humoured commentary accompanied

every competition throughout the week in several languages.

Donor families and living donors were invited to participate in several competitions: snow shoeing, skiing and curling. It was the first time that Kazakhstan had attended the Winter Games and many of the curling participants were beginners creating a great mood of camaraderie on the ice in neighbouring Crans Montana.

A donor family meeting was organized in collaboration with the Etoile de Gael association and Swisstransplant, the national Swiss Foundation for organ donation and transplantation, for both living donors and for the families of

people who had lost loved ones. A private room in the La Crêperie was a perfect place for people to share their experiences and for some of the recipients to say thank you. The meeting, although filled with emotion, was very rewarding for all.

A total of 24 Countries attended the Games including from as far afield as Australia and New Zealand. The largest team was Great Britain and Northern Ireland, followed by the Swiss team and then the Belgian team, many of whom had learned to ski and trained on indoor slopes back in Belgium. The fastest alpine skier was 17-year-old Cameron McGregor Ogden from the Great Britain and Northern Ireland team who had also been training on an indoor slope back home. Some other skiers took several minutes longer but most cleared all the gates and were very happy.

The Nicholas Cup

The Nicholas Cup, which has been part of the Winter Games since 2001, changed format for the 2018. The TACKERS team, that has been running transplant kids camps in Anzère since 2002, lent their experience to run the camp. There were 23 children from 12 countries who stayed together in the same chalet. Activities ranged from skiing and snowboarding to disco, snow shoeing, swimming, arts and crafts and karaoke. Some of the children had skied before, others had never even seen the snow.

Any of the Nicholas Cup participants could have won the cup. The winner was not the fastest, but the participant that most accurately guessed their time compared to LOC chair, Liz Schick's time in the slalom. Liz skied with Dexter, her Parson's Russell terrier, who was more interested in picking up pine cones on the way down than the race!

Several of the volunteers at camp were young transplant recipients who had attended previous TACKERS camps who were perfect role models and who understood what the young campers had been through. Some of the children had even travelled to Geneva airport alone to attend the Games, such as 8-year-old heart recipient, Temperence 'Bob' Reid who travelled from Portugal and Jamin Tamang, 15-year-old kidney recipient from Nepal.

A Special Moment - all the Nicholas Cup kids received a medal and a woven cane heart from the President of

Winter reflections

Chris Thomas, WTGF President

"Many people across the world dedicate their lives to making the lives of our transplant children just that little better. This is patently on display at the Winter Games where Liz Schick shines for a week as she encourages kids of all ages to just have a go.

I sometimes think when helping kids it can seem quite one-sided - all 'take and no give'. But at these Games the kids enrolled in the Nicholas Green Cup camp certainly knew the importance of giving. The way several of them reached out into the audience to give them a specially woven heart was heart-felt, literally. One lady, who had recently lost her own mother, burst into tears at the simple but generous moment.

To all the kids, and to Liz, thanks for making her day, and the days of all those who attended these very special Winter Games."



Left to right: Marco Aymon, President of the Commune of Ayent; Liz Schick, LOC Chair and WTGF Honorary Secretary; Pierre Yves Maillard, President Of the Swisstransplant Foundation; Chris Thomas, WTGF President; Vincent Rebstein President of the Commune of Arbaz

Swisstransplant, Pierre- Yves Maillard, assisted by WTGF President Chris Thomas, and Maximilian Off from Germany, received the Nicholas Cup from Sophy and Harvey Layzell, a UK donor family whose daughter Jemima was an organ donor saving a record eight people. The children then wandered into the crowd to offer their heart to a stranger moving many to tears.

Donor mother, Sophy Layzell, later said, 'Coming to Anzère for the World Winter Transplant Games was the most uplifting event that Harvey and I have been to. On a personal level, it totally confirmed that we had done the right thing donating Jemima's organs. Seeing so many transplanted children together, learning new skills, challenging themselves physically and loving, living and laughing, really brought it all home. It was particularly wonderful meeting Ellie, a liver transplant patient, who Jemima's

Trust were very proud to sponsor."

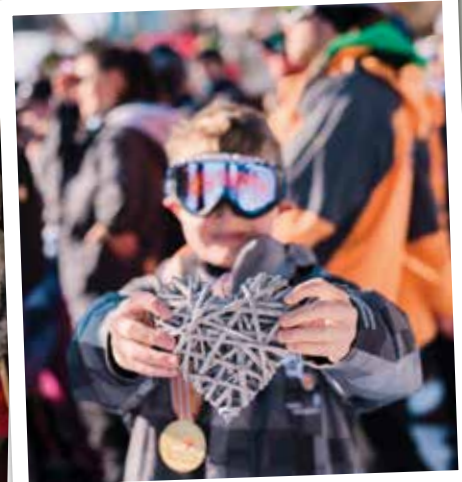
The World Transplant Games Federation decided to hold the WTG 2018 only nine months prior to the Opening Ceremony and it was organised in a new hybrid way – a working partnership between the LOC and the Federation. This new way of organising the Winter Games would not have been possible without our sponsors, the local community, the amazing volunteers, the Local Organising Committee, the Federation staff – Rebecca Phipson, Kim Renyard, Karen Cole and Gary Green - and every one of you who came along and made the World Transplant Winter Games such a memorable event.

Liz Schick

World Transplant Winter Games 2018
LOC Chair
WTGF Honorary Secretary

WORLD TRANSPLANT WINTER GAMES 2018

Our Winter Games Scrapbook



Left: The Opening Ceremony

Above: Give your heart to a stranger

Winter reflections Valentine Pick, France



"My name is Valentine. I'm nine years old and I was delighted to take part in the World Transplant Winter Games in Anzère in January in Switzerland. It was organized like the Olympic Games. I loved the kids camp, we did loads of fun things and I have made many new friends from all over the world.

One of the most exciting parts was carrying the French flag. A huge thank you to Liz and everyone for making this happen."



Taking careful aim at the Biathlon



The 2018 race course



Big cheers from the Nicholas Green Camp kids



Fastest Alpine skier 17-year-old Cameron McGregor Ogden



Happy Curlers!

Winter reflections *Maude Schneider, Canada*



"The World Transplant Winter Games are first and foremost a wonderful occasion for us all to come together. Every time I attend the Games the most important things I take home are the stories and life experiences shared with incredible people. That's what is the most important, far more important than medals and podiums!"

Winter reflections *Jamin Tamang, Nepal*



15-year-old Jamin Tamang from Nepal was pleased to carry his country flag at the Opening Ceremony. The Nicholas Green Camp proved to be an exciting week for Jamin and all the kids.

Jamin: "I like the Ski Games!"

AUSTRALIAN TRANSPLANT GAMES

High performance, incredible fun

Kate Carlyle shares her reflections on Transplant Australia's High Performance Camp

Picture this. A sweltering Gold Coast afternoon in beautiful Australia. Twenty-five recipients who have all been to the brink and contemplated their own mortality – only to be given the gift of life. All assembled for a high performance sports camp. What an opportunity.

First we heard from the Queensland Health Minister, Stephen Miles, who marvelled at the extra years of life at the camp – 266 years, amazing.

Following the official proceedings, we split into our respective sports and hit the track or pool. That first session under the guidance of Coach Stephen Howell was the most alive I have felt in years. Although I've been back in the water for a while, the challenge and absolute thrill of having a go really got my heart pumping!

I sucked in some big breaths with each lap and as I smashed the wall at either end of the pool. I looked around and thought about my fellow transplant athletes. While my body and organs, are now running on someone else's stem

cells, some of them had someone else's heart or lungs helping them reach the end of the pool. Whoa..... I said some silent, but powerful thanks to our donors, their families and our medical teams.

The emotions were running high, but while there was a little rest between sets, there wasn't too much time to lose focus. While Steve pushed us hard, he also had us laughing, like when he nicknamed young Logan 'donkey', as a term of endearment. Steve explained that when he saw real potential in a swimmer he'd ride them like the last donkey in town. Nuff said.

We enjoyed team meals in the dining hall, surrounded by international athletes in town preparing for the upcoming Commonwealth Games (including the Indian basketballers like 'One in a Billion' Satnam Singh, who graciously posed for a pic and hilariously high-fived/low-fived me when we passed between our rooms and training sessions). The vibe was sensational. The conversation covered

everything from heartbreaking transplant wait-list experiences, to inspirational tales of recovery and determination to really live (like they say, 'no-one lives like the dying'). I wished I could bottle this. Not just for my darker moments, but for anyone who might find themselves needing a little light at the end of the proverbial tunnel.

My 'body scans' went from analysing the pain, its severity and what medication I could take to try and control it, to how my muscles were feeling having worked harder than they had in a long, long time. I doubted whether I could keep up, but despite the hurt and exhaustion, was set on living up to the hashtag I started using during my transplant #stillkickin. In this case, I literally was still kicking!!

Expert knowledge

We were imbued with knowledge from experts during Strength and Conditioning (Adsy Gordon), Nutrition (Travis Ronaldson) and Sports Psychology (Craig Pearman) sessions. A lot of us struggle with fatigue just getting through the day, so this lecture format side of things was at times, quite tiring. The information though – so beneficial.

A key point of discussion was internal and external motivation. A room full of people who have survived, and are thriving after transplant, perhaps don't need to be taught about internal motivation. Without it, we all may have rolled over, given up, quit. It's that beautiful combination of internal and external motivation that has created success. I heard so many stories of athletes not wanting to let their family, donor family or doctors down. It's a powerful mix.

Speaking of power...we were gifted a very special insight into world class competitive swimming, with visionary of the sport, Bill Sweetenham. As a mad-keen young swimmer I watched some of his pupils including Tracey Wickham, power to glory on the Olympic stage. Bill's name is synonymous with some of the most successful international teams in history. I was shaking like a leaf when I entered the 'Elite Room' and reached out to shake the hand of greatness. There he sat, in an empty room, just his big hat and dark sunnies and a bucket load of stories to share. I could listen for the rest of my days, but we soon found our way to the pool deck. Holy hell. I was so bloody nervous to strip down



Kate Carlyle



“The emotions were running high, but while there was a little rest between sets, there wasn’t too much time to lose focus.”

to my togs and hop in, I had to go and tell him I was terrified! All of a sudden my head had forgotten how to swim. As Bill took a seat laneside, we all slowly settled into our groove. Before too long, he had us all lined up, hanging onto the side of the pool listening intently to little tweaks we could each make. Teenage transplant recipient Claudia was given the somewhat unenviable task of jumping out to demonstrate getting full reach from a stroke. Whilst manipulating body position in that way, in front of all of us may have been daunting - Claude handled it like a pro, and I winked at her Mum Anna saying “she’ll never forget this.” None of us will.

Bill generously shared more stories with us (as we recovered from a session in the ice baths - another first for some of us!), he detailed the importance of balance and fun. What a way to cap off an unbelievable afternoon!

Some participants opted to sleep in on the final morning (totally cool given the workload and long days), while others

managed a final hit out. I’m happy to say that although my body was screaming with pain - it was great pain - and I was in the water by 6 am. The mental chatter was strong, but there was no way I was missing this last opportunity. Apart from Coach Stephen giving us drills we could test, then take away, he’d also built enough confidence in our group to critique each other. The kindness and positive feedback was palpable. How all of us will grow as a result. I am so excited for the Australian Transplant Games in September!

Fun in the water

I grew up swimming, enjoyed training and loved to compete. I can’t say I ever had fun in the water though. That said, it is my ‘happy place’. I can float on my back for hours. Having been hooked up to machines to keep me alive, I revel in the freedom. The cold rush as I dive in, the swoosh of the water passing my ears, the exhilaration I feel powering along the black line and the absolutely life-

affirming satisfaction at hitting the wall. Fun though? Nope, not really. Until the other day. The last few minutes of our swim session, Coach Steve suggested a Michael Phelps drill for vertical kick training (you’ve gotta watch this!). Ahhhh, yeah, right. Well, getting out into the middle of a lane, dropping till your feet are flat on the bottom, then squatting, pushing up, streamlining and butterfly kicking up out of the water like a rocket is unreal! Such an incredible feeling. And yes, I had FUN!

The reality of organ and tissue donation is very simple - people that were once terminally ill, are now here. And here to stay!

Kate Carlyle
Australia

Kate will be one of hundreds of transplant athletes competing at the Australian Transplant Games on the Gold Coast from September 30 to October 6, 2018. For more information visit www.australiantransplantgames.com

transplant
australia
make the most of life.

TRANSPLANTOUX SYMPOSIUM *Continued from page 6*

In fact, regular physical exercise may enable diabetics to reduce or discontinue glucose-lowering medication! Finally, Prof Hespel presented interesting insights from his experience with elite athletes. Tips and tricks regarding hydration, carbohydrate consumption, weight loss strategies, different training modalities, muscle recovery, and the effects of altitude exposure fascinated the attendees until the end of the final session. After a 'healthy food' lunch and network break, Dr Goetschalckx revealed on the importance of (sports) medical screening before and after transplantation. This field certainly requires more research to address the specific risks and needs of transplant recipients. Prof Calders subsequently summarised the current evidence of the health-related benefits of physical activity pre- and post-transplantation.

After these 'ex cathedra' lectures, the time was right to switch to more practical matters and to stretch body and limbs ourselves. In four interactive seminars, attendees were introduced to tips and tricks from experts in the field on how

to start physical activity in the pre-transplantation period (Dr Greenwood), early after transplantation at the intensive care unit (Mrs Clerckx), after hospital discharge (Dr Gloeckl), or how to 'train smart' when preparing stable transplant recipients for specific sports challenges or goals (Mr Vanbekbergen).

The final session of the symposium was reserved for Dr Masschelein and Mr Thomas. Dr Masschelein shared the experience and research done by Transplantoux. Mr Thomas, President of the World Transplant Games Federation, passionately spoke about his quest to get every transplant recipient in optimal physical and mental health through his mantra: 'More transplant recipients, more active, more often'.

At the end of the day, it was clear that the first edition of our international Transplantoux Symposium "Exercise is Medicine" was a big success as later revealed by the survey which was held at the end of the symposium. If you want to feel the vibes, read the survey or have a look at the presentations, please visit our symposium website [www.transplantoux-](http://www.transplantoux-symposium2018.com)

[symposium2018.com](http://www.transplantoux-symposium2018.com).

How to move forward now? In 2005 Patricia Painter stated that "Regular physical activity should be prescribed and encouraged as a part of the routine (pre and) post Tx care". Now 2018 and thus 13 years later, there is still a lot of work ahead to make this happen. To keep things moving, we are working hard on the 2nd edition of the Transplantoux symposium. Our local and international scientific committee looks forward to present many untouched topics and to organize dedicated sessions for nutritionists, nurses, physiotherapists, physicians, and recipients. Lastly, we invite you to submit your abstract sharing your experience for the next edition.

"Let's move and stay connected, and see you in Leuven, Belgium in February 2019!"

Diethard Monbaliu and Stefan De Smet

On behalf of the Local Organising and International Scientific Committee of Transplantoux Symposium

MEMBER COUNTRY NEWS

SPAIN

Celebrating the 'Party of Life'

News from the 8th Spanish National Transplant Games in Guadalajara

The 8th edition of the Spanish National Transplant Games was held in the beautiful city of Guadalajara, Castilla La Mancha, right in the centre of the peninsula, from 28th April to 2nd May.

The Games were a complete success, mainly due to the support of the local and state authorities – always committed to our mission of organ and tissue donation and the importance of physical activity for transplant recipients.

On this occasion we had 140 participants in attendance, maintaining the numbers for the last three Games.

The opening event was held at the Town Hall and we were very pleased to welcome the



director of the National Transplant Organisation (ONT), Beatriz Domínguez-Gil. It was a huge honour for us to have with us the head of the leading organisation on donation and transplantation worldwide. The collaboration with the ONT is fundamental to our activities and the fulfilment of our values and mission.

The competition began on the afternoon of 28th April with racquet sports - padel, tennis, badminton and table tennis.

The next morning we experienced maybe the most thrilling event of the Games at the cycling route. The rain and the wind on the day provided a hostile environment for the participants. The cyclists decided to proceed with the event, always mindful of the risk of accident. In the end,

the determination and aspirations of the participants made it a clean and successful event.

Another high moment happened on the track with the participation of members of Asociación Española de Ayuda a Niños con Enfermedades Hepáticas y Trasplantados Hepáticos (HEPA), an association dedicated to helping children with liver disease and transplants. The little heroes were part of specific events planned for them such as the 30m run, ball throw and long jump. The parents and siblings participated with them, having a unique moment of joy watching these little warriors enjoying the Gift of Life.

It was an amazing long weekend, a rehearsal for some of our athletes with their sights on the European Games and another opportunity for all of us to celebrate the "Party of Life" and say thank you for our second chance.

Gerardo Reyna
Spain



WTGF Games Review



Kim Renyard looks at the review process for last year's WTGF Games

The World Transplant Games Federation takes great pride in continually improving our offering to the worldwide transplant community. The 2017 World Transplant Games held in Málaga, Spain were a wonderful celebration of the gift of life and many recipients complimented both the Federation and the Local Organising Committee. That said there is always room to review a Games with the aim to continually improve our key event, with particular focus on the conduct of sports, transport, medical services and accommodation.

Previously we have completed these reviews internally, however this time we recognized the benefit in reaching out to key members in our community to ensure we gain a wider perspective. As a result a Games Review Panel was established with an objective to ensure that our Games remain relevant and affordable, and that our community has the opportunity to shape all aspects of future Games.

The Panel was established to incorporate key Federation board members and administrators, as well as key members from our transplant community.

The Federation called for feedback on the 2017 Games from our community through a number of channels including:

- A post Games survey
- Feedback from Team Managers and Country Representatives
- Individual feedback from the community

This feedback was consolidated and divided into 4 areas of operation:

- Logistics – Accommodation, Transport and Catering
- Events – Social and Official
- Medical
- Sports

Insightful and encouraging

The Panel was split to allow key members to focus on the different areas of operation. After several conference calls, the Panel submitted a document to the Federation highlighting recommendations to improve future Games in all these areas. The feedback was insightful and encouraging, and many great ideas and suggestions were put forward.

As a Federation all of these suggestions were reviewed and the relevant WTGF Committees are currently working through these ideas and putting the recommended outcomes into play.

The World Transplant Games Federation Panel consisted of:

Chris Thomas	Australia	WTGF President
Colin White	Ireland	WTGF Treasurer
Liz Schick	Switzerland	WTGF Secretary
Willie Uys	South Africa	WTGF Governance Committee
Andre Lasooij	Netherlands	WTGF Sports Committee
Zachary Brooks	USA	WTGF Sports Committee
Olivier Coustere	France	WTGF Sports Committee
Paul Harden	UK	WTGF Medical Committee
Kim Renyard	South Africa	Executive Manager
Gary Green	USA	Sports Manager

Community Representatives included:

Lynne Holt	UK	2019 WTG LOC Member
Barry Laverick	UK	Transplant Sport
Wouter Schuwirth	Netherlands	Sports & Transplantation Foundation
Teemu Lakkasuo	Finland	Finnish Sports Association
Dr Antony Harding	Australia	Transplant Australia
Dr Mason Porramatikul	Thailand	Transplant Sport Association of Thailand
Andrzej Chmura	Poland	Polskie Stowarzyszenie Sportu po Transplantacji

Over the next couple months, the Federation will announce and share the outcomes of the Games Review.

As a sneak preview, we can share that some insightful recommendations included the simplification of the medical forms, ensuring a more affordable games for all, more public engagement at social events, greater Games visibility, and various suggestions to ensure better seeding at sports events. Whilst these are just a few of the suggestions which were born through our Games Review, they do highlight that this type of review can only be positive for the Federation, future Games and our transplant community.

The WTGF thank the Games Review Panel for their time, commitment and contributions towards making our Games continually improve and grow.

Kim Renyard
WTGF Executive Manager



FIT FOR LIFE! UPDATE

Highlights from the Fit for Life! Ambassadors

Our Fit for Life! Ambassador program now has 26 ambassadors in 18 countries all working hard and enthusiastically to promote an active lifestyle post-transplant. Each Ambassador has been contributing to the spirit of our mantra, "more transplant recipients, more active, more often", and bringing this topic to the forefront of discussions in their own unique way. Below are highlights of some of the great work that has been accomplished by three of our Ambassadors.



Heilie (far right) with members of the South African Transplant Sports Association (SATSA)

Heilie Uys South Africa (Kidney Recipient)

Heilie was recently part of a three-part television series for The Nurse TV channel in South Africa. In the series Heilie positively promotes the Fit for Life! initiatives with a focus on transplantation and donation, the World Transplant Games and the Federation. The series, "Heilie Uys - A life of inspiration and achievement", was uploaded and shared on various social media platforms.

Heilie is very much involved with the medical community, meeting patients to educate them on the benefits of being active post-transplant as well as counselling recipients one on one. 2018 has already been a busy year for Heilie with scheduled presentations at the Livingstone Hospital Transplant Clinic in

Port Elizabeth and for the Eastern Cape Transplant Sports Association. Heilie was also involved in the national South African Step Challenge created by SATSA to encourage more activity amongst the youth as well as their local transplant community. Heilie will be participating in the South African Transplant Games in July this year.

"The first year of being an Ambassador for WTGF came to an end with the realisation that the Fit for Life! Initiative is like a bread with yeast – at first it seems to stay the same size but then slowly it rises out in all directions! The lesson is that it takes time! First to reach people and second to let people realise the importance of the message."



Ronald Grainger Ireland (Kidney recipient)

Ron has been very active in his role over the past six months and is due to publish an article in the Journal of the Irish College Of General Practitioners this year, entitled 'Life After Renal Transplant and being Fit for Life'. Ron will also be attending a new health initiative in Beaumont Hospital in Dublin, supporting the project and highlighting the Fit for Life! program. Ron recently attended the annual conference of the Transplant and Urology Nurses as well as the West Cork Sports Awards dinner. At the end of 2017, Ron spoke at the Cork Branch of The Irish Kidney Association and demonstrated some practical exercises to improve mobility and fitness.



Ron at the Transplant and Urology Nurses meeting - Ron is pictured with a poster of living donor, Vivienne Traynor

Emma Hilton

United Kingdom (Heart Recipient)



Emma at WTG2017

Emma was approached by Trans World Sport to feature in a video commemorating the 50th anniversary of heart transplantation. The video has been shared throughout the transplant world and has helped to reach recipients who hadn't heard of the WTGF or the Fit for Life! initiative before. Because of her participation in this video, Emma receives and responds to feedback from recipients waiting for transplants as well as those wanting to get more involved in exercise and sport. Emma attended a special event at Harefield Hospital where she spoke with young patients on 'Activity as a Tool to Keep Healthy and Being Fit for Life!'.

The Federation wishes to express heartfelt appreciation to all of the amazing Fit for Life! Ambassadors.

Fit for Life! Team
fitforlife@wtgf.org

The Transplantation Society (TTS) Congress

The Fit for Life! program will be launching another initiative at the upcoming TTS International Congress 2018, which will be held in Madrid, Spain from 30th June to 5th July.

The Federation has been working very hard over the past year to create a Fit for Life! Toolkit designed to assist transplant recipients with their first steps towards getting active following their transplant. This rehabilitation program is designed to focus on the importance of exercise, nutrition and mental wellbeing post-transplant.

In constantly working to promote our mantra of "more transplant recipients, more active, more often" we have secured the following activities at the TTS Congress, where we plan to launch and promote the Fit for Life! Toolkit:

WTGF, in conjunction with the TTS Wellness Committee, will host a full day workshop on 30th June. This workshop includes speakers from around the globe on the topic; "Optimizing Recovery after Solid Organ Transplant – the role of physical activity, exercise and sport".

WTGF will also host a 'Wellness' area at the Congress where registrants can pop in during all breaks to revitalise their bodies. There will be different sessions throughout the Congress, including opportunities to participate in various activities including yoga, meditation, relaxation, stretching, breathing and also mindfulness exercises.

More information about the TTS Congress and the workshop can be found at www.tts2018.org

MEMBER COUNTRY NEWS

HONG KONG

Games to launch Community Education Program

Hong Kong is hosting its 4th National Transplant & Dialysis Games on 3rd and 4th November 2018

The Games will be organised by the Hong Kong Transplant Sports Association, a charitable organisation formed and operated by organ transplant recipients to encourage their post-transplant buddies to strive for total rehabilitation through practicing sports. The members also dedicate themselves to promoting organ donation

in the country.

The Games include track & field events, swimming, petanque, table tennis and badminton, while gateball, bowling and darts will be played on respective weekends throughout September 2018. To complement the Games, the Association has launched a community education program where

post-transplant patients, donor family members, medicare and volunteers will be teaming up to give talks and share sessions in the schools and corporations in order to stress the importance of organ donation to the general public.

For more information, please visit: www.hktsa.org and/or follow @hktsa.org on Facebook.

Martin Wong

Chairman, 4th Hong Kong Transplant and Dialysis Games
Fit for Life! Ambassador



UK

Birmingham to welcome over 1,000 athletes this summer

Birmingham, UK, is hosting the 41st British Transplant Games from 2nd to 5th August 2018



Over a thousand transplant athletes will descend on Birmingham this summer when the annual Westfield Health British Transplant Games 2018 come to the city.

The event, which aims to raise awareness of the value of organ donation and help increase numbers on the NHS Organ Donor Register, will take place in Birmingham from the 2-5 August 2018.

Organised on behalf of Transplant Sport, the Games showcase the benefits of transplantation, whilst giving people aged between two and 80 years old, who have had a transplant, the chance to compete in a wide range of sport activities. These include basketball, volleyball, football, snooker, darts, archery, as well as all track and field events, swimming and all racquet sports

The last time the event was held in the city in 1999 it brought a huge boost to the local economy, this year it is estimated the Games will inject around £2.5m into Birmingham and generate a significant national profile.

Birmingham, with a population of 1.1 million people is one of the UK's most vibrant, energetic and diverse cities. The area has excellent transport link and should prove a popular destination for participants and their families in 2018.

Outstanding facilities

The Games will make use of several of the outstanding facilities across the city including the Symphony Hall, the ICC, Alexander Stadium and the recently opened University of Birmingham Sport and Fitness Centre.

The Games will also shine a light on the hard-work, dedication and talent of the doctors and nurses who work in

hospitals across the region who bring hope to families and individuals from all over the UK undergoing transplant surgery, Birmingham performs more Transplants than anywhere else in Europe and recently celebrated its 5,000th Liver Transplant.

British Transplant Games LOC

www.britishtransplantgames.co.uk
www.transplantsport.org.uk



**TRANSPLANT
SPORT**

World Transplant Games 2019: The countdown is on!

In the summer of 2019 thousands of athletes and supporters from around the world will arrive in NewcastleGateshead for the World Transplant Games

Having hosted the British Transplant Games in the summer of 2015, NewcastleGateshead was chosen as the destination for the Games which will take place from Saturday 17th to Saturday 24th August 2019.

NewcastleGateshead has a strong track-record in delivering sporting events and 2019 will also see the region hosting European rugby's showpiece weekend in May, when the European Champions Cup, Challenge Cup and Continental Shield will be held in the city.

The Games will see events taking place at some of the region's most iconic sporting venues, including Gateshead International Stadium, Sport Central at Northumbria University, Close House Golf Club, The Northumberland Club and the Sunderland Aquatic Centre. Sports available at the Games include, athletics, archery, badminton, tennis, bowling,

golf, swimming, table tennis, squash, petanque, basketball, darts and football.

A specially created cultural program bringing together participants, their families, supporters and local residents will ensure that the Games will be the most visible yet. Events and activities for the transplant community will take place in the very heart of the city region, with more details to be announced early in 2019.

Entry is open to those recipients who have been transplanted with a life supporting organ for at least one year, are medically fit and have trained for the events that they have entered. Athletes will compete by gender in various age groups, including juniors, with participation welcomed from those as young as four. There will be sports competition for living donors and donor families – more information to follow.

A revamped website – www.worldtransplantgames.org – is to be launched later this month which will give further information on venues, sports and accommodation in the area. Flexible and affordable accommodation

NewcastleGateshead 2019 FACTFILE



When: 17-24 August 2019

The venues: The games will be hosted at some of the top sports venues in Tyne and Wear, including Gateshead International Stadium, Sport Central at Northumbria University, Newcastle United FC and the Sunderland Aquatic Centre.

Find out more:

www.worldtransplantgames.org

packages will be available to athletes, families and supporters. Registration for this great event will open in December 2018 - participants will be able to register through the website although hard copy registration forms will also be available for team managers, with each registration needing verification to ensure participation is legitimate.

If you would like to know more about the Games please visit the website and sign-up to receive regular e-communications with information on sports, venues and the destination, as well as case studies, news on the teams and their preparations for the Games.

The team in NewcastleGateshead are waiting with a warm welcome for all!

**NewcastleGateshead 2019 Local
Organising Committee**





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Astellas is committed to turning innovative science into medical solutions that bring value and hope to patients worldwide. Every day, we work together to address unmet medical needs with a focus on urology, oncology, immunology, nephrology and neuroscience as prioritized therapeutic areas while advancing new therapeutic areas and discovery research leveraging new technologies/modalities. We remain dedicated to meeting patients' needs, and our support for them will never waver.

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