

# Transplant World

2020 | Issue 2

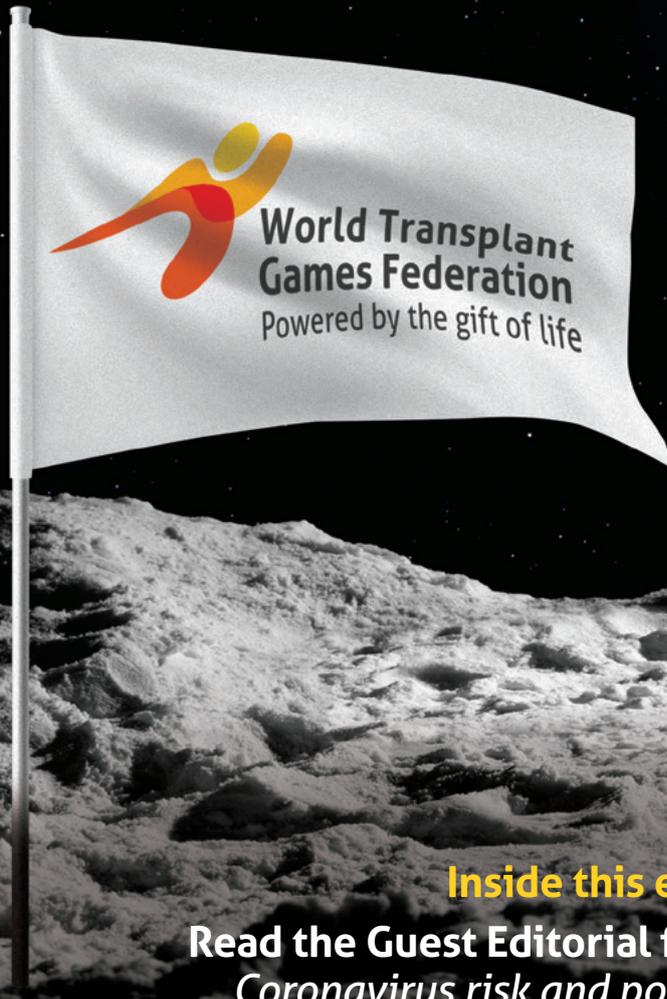
Journal of the



World Transplant Games Federation  
Powered by the gift of life

## To the moon and back

How the Billion Steps Challenge  
inspired a community



### Inside this edition

Read the Guest Editorial from Dr Paul Harden  
*Coronavirus risk and potential vaccination  
in transplant recipients*

Enter the 5K AnyWay 'Share your Story Wall'

# Inside this edition

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MESSAGE FROM THE PRESIDENT

# The marvel of science

A message of hope from WTGF President Chris Thomas



## The Seed

*'When the night has been too lonely and the road has been too long  
And you think that love is only for the lucky and the strong  
Just remember in the winter, far beneath the bitter snows  
Lies the seed, that with the sun's love in the spring becomes... the rose'*

I was never fond of Bette Midler growing up. For those familiar with her work the movie Beaches was just too teary.

However these lyrics, actually written by Amanda McBroom but made famous by Midler in the movie, The Rose, resonate deeply especially when life throws us the usual curveballs.

In a reflective moment it is not hard to imagine the snow on the ground blotting out all life. But high in the sky, the sun's rays slowly gaining strength as spring arrives. And just below the surface, that seed. Ready to bloom as the snow melts and provides the nutrients necessary for life.

It is a wonderful vision that can be applied to many aspects of life. I suppose to believe in that metaphor a degree of faith or confidence is needed that life will turn around and better times are not far off.

I wonder how each of you coped while waiting for your transplant? What was the 'seed' that inspired you to keep going, to keep believing? Perhaps it was the love of family? The desire to see kids grow up? To achieve some of your life's dreams?

Ashleigh, one of our Fit for Life! ambassadors from the USA spoke of keeping her red jogging shoes at the end of her hospital bed as inspiration to get back out running. A simple concept but very powerful.

The world indeed is waiting for that 'seed' to emerge now in the form of an effective vaccine against the Coronavirus. This pandemic has blanketed the world in a way we never thought possible in our lifetimes.

The death toll is unimaginable, the collapse of economies staggering, the blowout of debt mind-blowing. But what is truly shocking has been the politization of the virus in many countries across the world. Somehow the wearing of a mask has become a symbol of weakness. Others have labelled the virus a conspiracy infringing on people's rights.

Goodness, is this is what we have become? What about the rights of everyone not to be infected? What about the rights of the elderly, of the sick, the immune-compromised, to life itself? Isn't that what we should be fighting for?

Fortunately, away from all that noise, dedicated groups of researchers are

committed to finding a solution to this pandemic. A solution not based on rhetoric but one on science and understanding.

To think that a vaccine, perhaps several vaccines, might be developed within a year of the emergence of this pandemic is nothing short of incredible.

The effectiveness of such vaccines in the transplant population is yet to be tested. However we are hopeful that nations will prioritise transplant recipients and those with compromised immune systems, their families and close contacts, such as health care workers in transplant units, as part of their immunisation strategies.

Science – ain't it marvellous! It gave us penicillin, it unwrapped our DNA, it has made many advances improving life across a broad range of disease states. And of course it gave the world immune-suppressive medications.

And now, hopefully it will soon deliver a vaccine. The world, lying far beneath that bitter snow, is waiting for the sun's rays.

**Chris Thomas**  
President

**“To think that a vaccine, perhaps several vaccines, might be developed within a year of the emergence of this pandemic is nothing short of incredible.”**

## GUEST EDITORIAL

# Coronavirus risk and potential vaccination in transplant recipients



An update on Coronavirus from Consultant Transplant Physician **Dr Paul Harden**

It has been a very difficult year for the whole population across the world due to the Coronavirus pandemic, but we know it has been especially difficult for all transplant recipients who are taking maintenance immunosuppression and as such are more vulnerable to infection. This has led to varying measures of lockdown or social / work restrictions across most countries with resultant isolation of many transplant recipients.

Unfortunately this has resulted in an increased risk of depression and mental health problems. Increasingly it is recognised that there is a significant range of risk across the more vulnerable groups such that for example current chemotherapy treated patients are at much greater risk than maintenance transplant recipients on low level immunosuppression without other co-morbidities. In addition serious Coronavirus infection is more common in males than females, Asian and Black individuals and those with multiple other diseases such as diabetes or chronic lung disease.

## Regular exercise

Many of you will be fit and well without other significant illnesses with stable transplant function more

than one year post transplant. In this setting you will be on a stable low dose of immunosuppressive drugs in most cases and are only at a slightly increased risk of Coronavirus infection and its complications. The WTGF would encourage you to maintain a good regular exercise programme including outside activities such as running, cycling, jogging, walking etc. within the allowance of the general population in your country. We believe this is perfectly safe with appropriate measures for social distancing and regular hand washing.

## Successful vaccines

Recently there has been exciting news about three successful vaccines against Coronavirus which have all shown good safety and protection against Coronavirus infection. We know that vaccination may not be quite as effective in transplant recipients due to the suppressed immune system and that live vaccines cannot be used. However there is good evidence that the annual influenza vaccination programme in many countries is effective in the transplant population and we believe that a Coronavirus vaccine will also be effective in transplant recipients. Individuals with HIV infection have a

significant suppression of the immune system but reassuringly early results from the Oxford Coronavirus vaccine trial has shown the vaccine to be effective in HIV positive participants in South Africa.

The three current vaccines are awaiting approval by National Drug Regulatory Authorities with the expectation that all three vaccines are deemed safe and effective and approved for use by early 2021. It will become clear which of these vaccines are best suited for transplant recipients and I anticipate that mass vaccination of transplant recipients will take place in the first 3-6 months of 2021. The vaccines have been shown to be remarkably safe and well tolerated and I will be recommending that our transplant recipients are vaccinated in the UK at the earliest opportunity so that hopefully we can all return to a more normal way of life within the next 6-12 months and get ready for the next WTGF in 2023.

## Dr Paul Harden

WTGF Trustee  
Consultant Transplant Physician  
Oxford University Hospital,  
Oxford UK

**“We know that vaccination may not be quite as effective in transplant recipients due to the suppressed immune system and that live vaccines cannot be used.”**

THE BILLION STEPS CHALLENGE 2020

# The Billion Steps Challenge 2020

United and powered by the Gift of Life – The Billion Steps Challenge, proudly supported by Novartis, returned this year with the ambitious aim to collectively walk one billion steps...to the moon and back!

The call was once again put out to the worldwide transplant community, donors, friends and family to get moving, get active and get fit for life, while raising awareness for organ donation and transplantation.

The Challenge which launched on the 5th October 2020 will run for 10 weeks, ending on the 13th December. The call to action was simple – create teams and contribute your daily steps to our total. Participants sync their fitness devices or manually add their steps using the MoveSpring app. The option to convert other types of exercise; such as cycling, swimming, or fitness classes to steps was incorporated, ensuring that the message of exercise is medicine

was communicated and the challenge was accessible to all. Regular exercise benefits both the body and mind and improves overall feelings of wellbeing – something which we all needed during these strange times.

The response exceeded all our expectations. With over 3200 participants enrolled, representing 60 different countries, and the creation of 700 teams, we saw a growth of 115% participation since we last held the Billion Steps Challenge in 2017. Every participant stepping together to celebrate a life where physical activity and movement have now become the new “normal”. For many, the fears and fatigue faced during these uncertain



times of Covid-19, were conquered through the reinforcement of remaining active and positive, and connecting to a community with a common purpose. Almost everyone who participated saw a degree of increase in their daily steps.

Engagement on the MoveSpring app through the chat forum was brilliant, with over 3200 new friendships being created. Participants took to sharing photos of their cities and parks, rainbows and sunsets, their pets, wildlife and nature – all while getting their steps in and encouraging others. It soon became an opportunity to see the world through other participants eyes – taking in their

*Continued on next page*



**THE BILLION STEPS CHALLENGE 2020**

surroundings and culture.

Weekly mini challenges were held by the WTGF to inspire fun and healthy competition with branded hoodies as giveaways. We received some heartfelt stories in our "What inspired you to enter" competition. Our 'healthy meal' and bake-off competition was a mouth-watering experience, and our Halloween and pet inspired competition showed the diversity and creativity of our participants.

Our Fun Fact Fridays and Motivational Monday inspiring quotes helped to keep participants engaged, while the informational articles and 5 minute indoor daily workout module ensured

there was something for everyone.

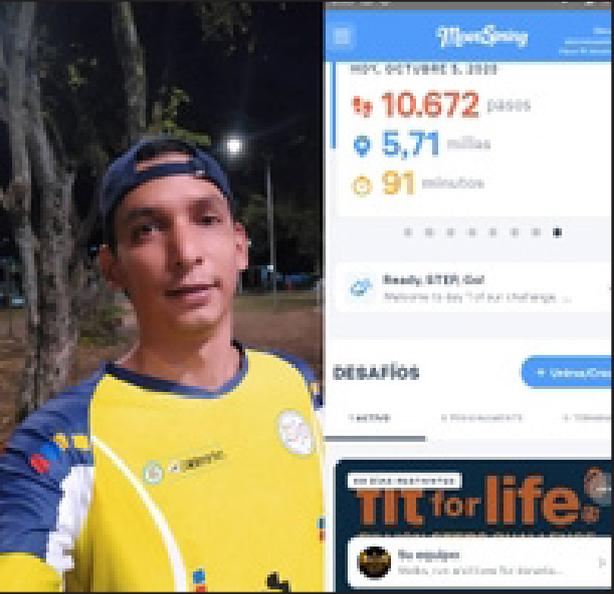
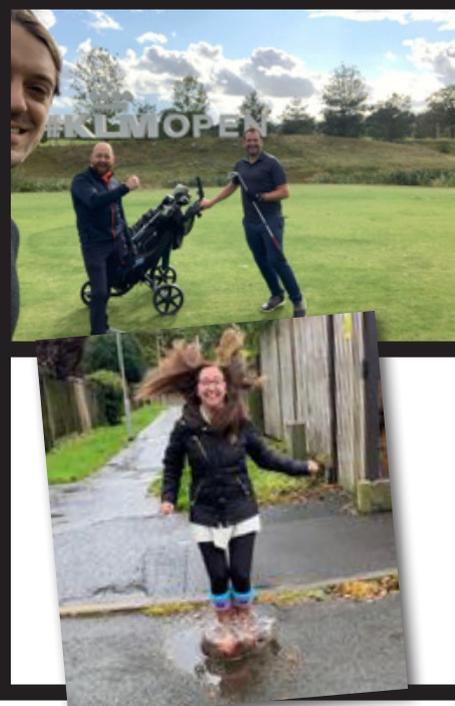
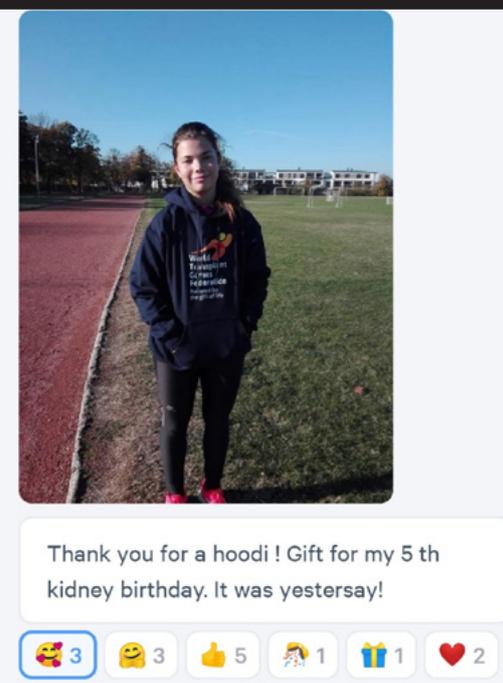
With our participants motoring ahead with this challenge, we reached halfway (the moon) earlier than anticipated and made it back to earth, reaching our target of 1 Billion steps with 24 days still left of the challenge – that's an average of 22 million steps per day! There is no slowing down – we will continue to keep stepping until the end (13 December) and see just how far we can go.

We would like to thank Novartis, our proud sponsor who helped make this challenge possible. With over 90 active Novartis teams participating—their involvement and support not only helped us reach our goal, but ensured

the message of organ donation and transplantation went further, reaching new outreach groups.

We are so proud of what has been achieved and we hope everyone will continue to remain active, celebrating their life and honouring organ donors. The Billion Steps Challenge demonstrates that there is more to the WTGF than the highly successful Summer and Winter Games and we plan to bring more events like this to our community in the near future.

**Kim Renyard**  
WTGF Executive Manager



THE BILLION STEPS CHALLENGE 2020

# Partnering for a great cause

The Billion Steps Challenge was made possible with the support of **Novartis Pharmaceuticals**. Here we asked Novartis about its motivation in working with the worldwide transplant community.

**Novartis has a long history of working in the field of transplantation. How do you rank your contribution to the field of medicine compared to other therapeutic areas?**

At Novartis, we focus on discovering and advancing new treatments for serious patient needs. From the inception of a therapeutic through early clinical development, our disease area teams collaborate across scientific disciplines and organisations in support of our mission to improve and extend peoples' lives. In the area of transplant, Novartis revolutionised transplant medicine 35 years ago and since then we have continued to innovate, changing the lives of patients around the world.

It is worth noting that Novartis is the only company that has had sustained investment in transplant medicine for 35 years. We aim to extend the life of transplanted organs and our ultimate research goal is transplants that last a lifetime. At Novartis, our purpose is to reimagine medicine, to improve and extend people's lives. No matter what our individual roles are, all of us here at Novartis are really passionate about making a positive impact on patients' lives and helping improve health outcomes. This is what we also try to achieve in the field of transplantation.

**Why do you believe it is important for transplant recipients to be active around their transplanted organ?**

Following transplantation, patients are on therapy to prevent organ rejection. It is important for them to maintain a healthy and active lifestyle too.

**“ We aim to extend the life of transplanted organs and our ultimate research goal is transplants that last a lifetime.”**



Proudly supported by  **NOVARTIS**

Regular physical activity is necessary for transplant patients so that they become as healthy and physically fit as possible. Physical activity has also been shown to improve a patient's overall quality of life and long-term outcome.

Also, research shows that if patients remain physically active while listed for transplantation, this will help minimise any further disease-related deconditioning. At Novartis, we believe that our commitment is not only to the patient's organ but also to their broader well-being and we want to show our commitment to transplant patients by joining the One Billion Steps Challenge.

**More broadly why is it important for communities in general to be fit and active?**

A lot of studies show that physical activity and/or exercise can improve our health and reduce the risk of developing a number of diseases. Covid-19 with all the unprecedented challenges that has posed to our lives, has reminded us how important is not to neglect our physical

and mental well-being. As a company, Novartis puts our employees and the broader communities' well-being at heart of what we do and we are always supportive of initiatives that align with that.

**How does a program like the Billion Steps Challenge connect your staff with the people who benefit from Novartis' long-term contribution to the field of transplantation?**

Powered by a shared mission, we are proud to partner with the World Transplant Federation for the 2020 Billion Steps Challenge. Novartis has a long heritage in the organ transplant community, a heritage for which our associates are very proud of. We encourage everyone at Novartis to get involved and show our commitment to the transplant community. It may just be one small step for our associates - but it's a giant leap for the transplant community! Only by working together we can improve outcomes for patients and change the practice of medicine. It has been great to see Novartis associates across the globe embracing and supporting the Billion Steps Challenge.



**FUTURE EVENTS**

# The 2021 5K AnyWay

## Enter the “Share your Story” Wall

Houstonian Sandy Eckles calls it a God thing. Two God things really.

Both were gifts of life that came a little over five years apart.

The first came when her son Jerry, just 15, died instantly in a skiing accident in Colorado. A few months earlier, he had gotten his driver’s license and wanted to put donor on it. He asked his mom and she said yes.

When he died, the call came from the transplant people 1,000 miles away, she didn’t hesitate. His organs weren’t viable, but skin, tissue, eyes and bone were and went to people in need.

A year later, Sandy was diagnosed with lupus and medullary sponge kidney and started undergoing peritoneal dialysis at home. Three years later, a series of ‘godwinks’ led her to San Antonio where she received a kidney in a three-way swap and she was dialysis-free. One of the donors in the swap was her former brother-in-law.

“I have my life back,” she said. “I’m blessed. To this day, I don’t know who donated to me or any of the people whose lives were touched by Jerry’s donation. It doesn’t matter. That the donations happened, does.”

It’s simply amazing what a heart can do. Or a kidney. Or a liver. Or a lung. Or a cornea. Or bone marrow.

Things so many of us take for granted on a daily basis are gifts of life for so many others and stories like Sandy’s drive them home in a very real way.

**The power for transplantation**

Sharing those stories have always been a part of the World Transplant Games. It’s one of those rare times when donors and recipients come together to



**Sandy with husband, Tom**

compete in full complement of sports, tell those stories and show the power for transplantation.

So, when the 2021 World Transplant Games were cancelled due to the pandemic and the Harris County-Houston Sports Authority decided to move forward with the 5K AnyWay – a celebration to unite the world and benefit the World Transplant Games Federation – we went all-out.

The 5K AnyWay is a 5K YOUR way. You can run, swim, row, dribble, walk

a golf course or race 3.1 miles any way you choose as Houston connects you with every time zone, every continent during the week of May 28 through June 4, 2021. And Houston will cap it off with an out-of-this-world Around the World AnyWay Celebration on June 5.

But the Sports Authority also thought it was important to have a place where participants from the transplant community could share those powerful,

*Continued on next page*

**“ You can run, swim, row, dribble, walk a golf course or race 3.1 miles any way you choose.”**

**FUTURE EVENTS**



**Amy**

rich stories with each other and the world.

Enter our Share Your Story Wall on [www.wtg2021.com](http://www.wtg2021.com).

No matter how many times a writer tells a transplant story, it's seldom as powerful as when the one who had the transplant, the donor or a nurse who deals every day with transplantation.

"Sharing those stories not only increases the overall awareness of transplantation but can also has a positive impact on growing the donor registry, which changes lives," said Holly Kesterson, the Sports Authority's VP, Events. "They don't just get the word out. They touch hearts."

**Three Houstonians**

We found three Houstonians to kick off the story wall – Sandy, two-time kidney recipient Amy Frackowiak and Med

surge manager Donna Esposito. Amy and Donna are both nurses and also co-captains of Team Texas.

Amy Frackowiak's story started when she was 15 and found a bite on her foot. Ten years later, she, too, was on peritoneal dialysis and three and a half years later, she received her first kidney. The function wasn't optimal, but she wanted it anyway.

Her deceased donor in 2009? It was Ninghe, an 18-year-old Chinese foreign exchange student. Amy was able to meet Ninghe's best friend at a donor ceremony and eventually communicate with her family via email – and Google translate.

Amy started competing in the Transplant Games of America in 2011 and since then has competed in all the American Games and three World Transplant Games. In November 2018,

that kidney was failing, and she set out to find a living donor. She found one.

She was blessed again with the gift of life.

**Life change**

And finally, there is Donna. Transplantation changed her life.

She was a trauma and surgical ICU nurse who transitioned to organ donor coordinator and Cardiac Transplant Coordinator. That's where she met Derrick.

As they searched for a donor, his condition deteriorated. And when he needed to be transferred to Donna's hospital – Newark (N.J) Beth Israel – doctors weren't sure he would survive the 15-minute helicopter ride.

He did.

A few months later, Donna saw a flyer for the 1994 U.S. Transplant Games and talked Derrick into competing. Donna and Derrick's fiancée Felicia spent five days watching Derrick compete in track and basketball crying tears of joy every day.

Derrick still has the heart and his and Felicia's three children have gone

**“ Amy was able to meet Ninghe's best friend at a donor ceremony and eventually communicate with her family via email – and Google translate. ”**

*Continued on next page*

**FUTURE EVENTS**

through college.

Donna has a picture of herself and Derrick on her office wall. In fact, that picture has been in every office she's had over the last 26 years.

Why?

"It reminds me every day of what is really possible in the world of transplantation."

Powerful stories? We gave you the short versions. You should read them in Sandy, Amy and Donna's words on the story wall. They got it started and, a week after posting their stories, we had 14 more personal stories from transplant recipients from around the world.

We've heard from Belgium, Canada and New Zealand. Liver transplant recipient Marty Maren from Maryland recounted his story of prayers to St. Rita, Saint of the Impossible, and how he got his liver at the eleventh hour, and World Transplant Record holder Stephen Jarvis from Great Britain. From Jennifer Valente Caywood, who received a heart and kidney transplant, and South African Transplant Games gold medalist Hermann Steyn, who had a heart transplant.

**Melanie Hauser**  
Harris County-Houston Sports Authority



*Donna and Derrick*

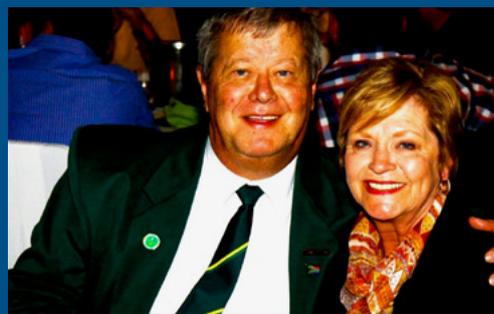
**There's infinite virtual room for more**

We've given you a little peek at some of the stories, but we urge you to click on the page and read how transplantation changed their lives – in their own words.

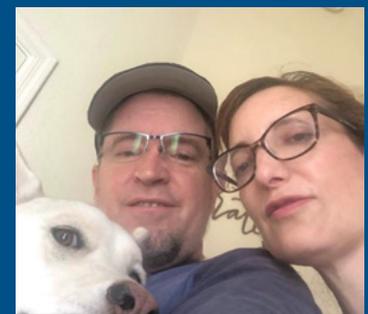
We hope you'll sign up for the 5K AnyWay and we'd love it, too, if you want to share your story. We know it's powerful and unique.

The more we can touch the world, the more people will understand what's possible through gifts of donation and transplantation.

And how powerful it can be to change a life.



*Hermann Steyn, South Africa*



*Jennifer Valente Caywood, USA*



*Marty Maren, USA*



*Steve Jarvis, UK (right)*

## RESEARCH

# Profile: Dr Gareth Wiltshire

School of Sport, Exercise and Health Sciences, Loughborough University, UK

In September 2020 the World Transplant Games Federation held a virtual workshop at The Transplantation Society (TTS) Congress entitled 'How to harness exercise post – transplantation (Impact) and how to measure patient reported outcomes in the Covid-19 Era'.

The Federation was honoured for Dr Gareth Wiltshire to be included on the panel of speakers that was Chaired by Dr Paul Harden and included Chris Thomas, Liz Schick, Dr Ka Foon Chau and Dr Zachary Brooks. Dr Wiltshire's subject was the 'Potential impact of exercise and sport on patient outcomes'.

Dr Wiltshire has produced two research studies relating to the social community of transplant sport and the potential role of physical activity in the recovery of recipients. We are delighted for the opportunity to include summaries of these studies in this Journal.



**Dr Gareth Wiltshire** is lecturer at Loughborough University; a world leading institution for sport and exercise research. As a social scientist, his research attempts to understand how society and culture shapes the ways that we experience and engage with physical activity. This has led to publishing research on the contemporary issues that face physical education in schools and public health initiatives like 'parkrun'. Gareth has published his research in leading academic journals such as Social Science and Medicine, Sociology of Health and Illness and Critical Public Health and well as well as in journals related to sport sociology and sport psychology.

After his wife - Emma Wiltshire - had a liver transplant in 2014 and subsequently participated in the British and World Transplant Games events, Gareth turned his interest towards researching sport and exercise for organ transplant recipients, "There is a growing body of literature that explores the relationship between physical activity and health outcomes for transplant recipients, but little is known about how physical activity might actually have positive benefits for a wider range of social and psychological outcomes. That is, can physical activity help recipients to 'live well' after transplantation? What are the processes that might lead to these benefits? And how can we help new recipients to get there?"

“ Little is known about how physical activity might actually have positive benefits for a wider range of social and psychological outcomes.”

**RESEARCH**

**Background**

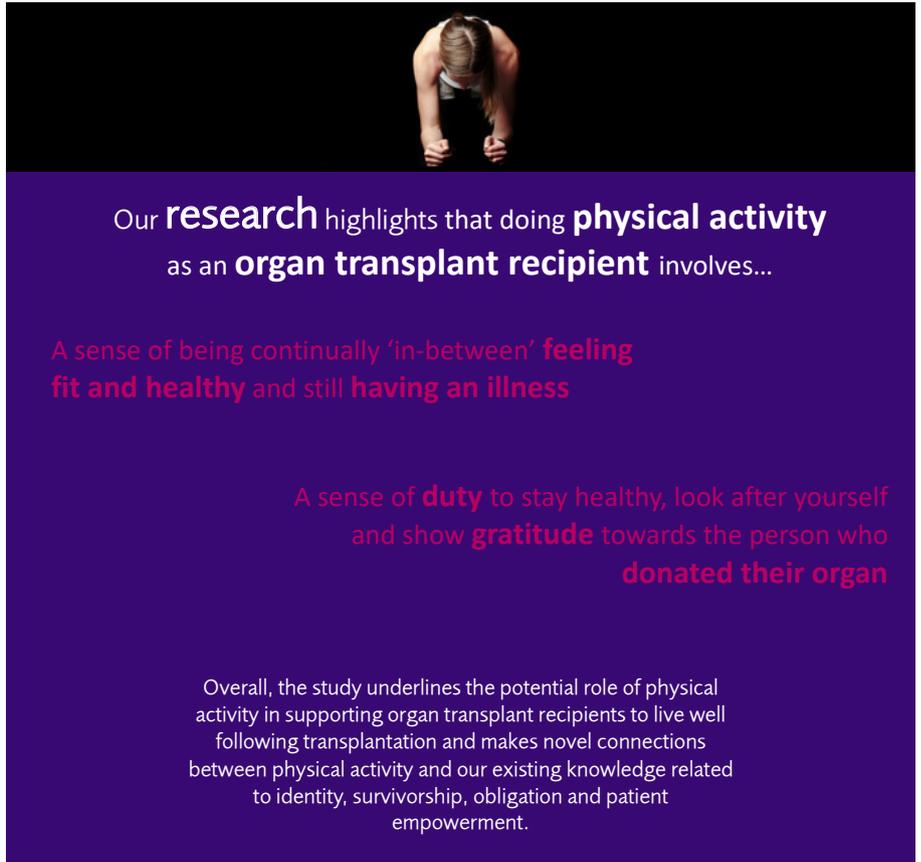
Physical activity is an important lifestyle component of long-term health management for organ transplant recipients, yet little is known about recipients' experiences of physical activity.

The purpose of this study was to shed light on this experience and to investigate the possible implications of physical activity in the context of what is a complex patient journey.

**The study**

We interviewed 14 organ transplant recipients from a range of countries and with a range of transplants, all of whom had successfully engaged with physical activity post-transplantation.

We analysed the interviews by listening carefully to people's personal experiences and focusing on the role that physical activity might have on recipients' illness experience more broadly.



Our **research** highlights that doing **physical activity** as an **organ transplant recipient** involves...

**A sense of being continually 'in-between' feeling fit and healthy and still having an illness**

**A sense of duty to stay healthy, look after yourself and show gratitude towards the person who donated their organ**

Overall, the study underlines the potential role of physical activity in supporting organ transplant recipients to live well following transplantation and makes novel connections between physical activity and our existing knowledge related to identity, survivorship, obligation and patient empowerment.

"I remember when I first got home after the transplant, I walked to the end of the street and back and it took probably 15 minutes or something stupid, you know. It was a real effort."

"I wanted to see what I could do. I wanted to see what was achievable post-transplant – what this, kind of 'new me' could do."

"I felt that golf is good but I wanted to show off my new lungs. I just felt like, playing golf – I can play golf – but wouldn't it be amazing to do something where it's sort of a little bit more cardio-vascular."

"I've never experienced being ill with that side of it. I have just had my heart replaced and just carried on. Whereas, like, people who are ill are more panicked about it, that scary process. Whereas my heart's been, like – it was fine, it was gone, new one in, carry on."

"I don't want to let the disease take over my life. I want to take control over it, and just not let it take over me."

"I owe my life to somebody else...you always feel that you owe somebody something. Somebody has died for me. That somebody has given me a chance."

"I'm always conscious that I've got somebody's organ in me and they always say 'oh that's ridiculous', but I am. I always give it a little tap – I know it's a girl – like "are you okay in there?" "Have I been good to you today?"

**Find out more about the research here**



**RESEARCH**

**Background**

There is a clinical need to better support illness self-management for organ transplant recipients. Research with patients living with other long-term health conditions has shown that social networks play an important role in self-management but little is known about whether this can be applied to organ transplant recipients or whether sociable activities – like sport – can contribute to health-related social network support.

**The study**

We interviewed 14 organ transplant recipients from a range of countries and with a range of transplants, all of whom had taken part in Transplant Games events.

We analysed the interviews by listening carefully to what was said about the community of team mates, friends and acquaintances met through participation at Transplant Games events.



Our **research** illustrates how the **social community of Transplant Sport** provides health-related support in three ways

1. By being a **valued source of knowledge** about **illness symptoms, management strategies** and **medication side-effects**
2. By being available for **emotional support** for both everyday concerns and in times of serious illness
3. By shaping **health expectations** for the future

"It was good to learn from the greater experience and learn from, maybe, from some of the good things that some people have done and probably some of the mistakes that some people have made."

"Yeah, you sort of take it onboard better if it's someone here who has gone through it. And you can be reassured more if it is someone who has maybe been in the same situation as yourself. And it can maybe put your mind at rest if you think how this is happening and this is okay, it's normal."

"From my point of view, it's better for me than my own family because we are not that close. I found it invaluable. I love it. I would be lost without the Games, actually."

"It's kind of like a little group that you can just – whenever someone is ill – it's like you all group together."

"It's good to see that thousands of other people are going through the same thing, and successfully. Yeah, that's probably the main thing [...] it gives you hope that you can keep going and keep living for as long possible."

"You hear 'oh my kidneys are only functioning at 30%' or something. And then it's the reminder of 'I have to be really careful and have got to drink all that water and do all those things'... it's a healthy reminder that it's not all plain sailing."

**Find out more about the research here**



# Social Media Engagement



From 1st Sep 2020, the WTGF embarked on a new social media strategy to bring you, our transplant community, more engagement and widen the message of organ donation and transplantation.

We have seen encouraging growth across all our platforms with a **20% increase** in our followers, and a **100% increase** in post engagements, reach and shares.

The new strategy aims to bring you engaging content such as:

- The Living proof project – Storyboards from our inspiring athletes around the globe
- Regular news from our Member countries
- Exercise videos
- Guidance and tips for improving your sporting skills
- Nutrition tips and advice to help keep you healthy post-transplant
- Youth outreach to inspire our next generation
- Education driven resources
- Surveys and engagement polls
- And regular updates on our programs and events such as the Billion Steps Challenge and 2021 WTG - 5k anyway

Help our message get further – make sure you are following us on all platforms, tell your friends and family and share, share, share...

We welcome your feedback, content and engagement. Feel free to contact us or share content by emailing [wtgf@wtgf.org](mailto:wtgf@wtgf.org)

- WorldTransplantGamesFederation
- worldtransplantgames
- WTGF1
- worldtransplantgames

## Powered by the gift of Life. TRANSPLANT ATHLETE STORYBOARD – The Living Proof Project

Name: Rodrigo Machado Country: BRAZIL  
Transplant: Bone Marrow Age: 48

Since he was a child, Rodrigo has always been passionate about sports. As a teenager he was a very competitive swimmer. He was always very active and always practiced all other sports in a recreational way.

In 2012, at the age of 40, Rodrigo began to feel different signs in his daily life. Tiredness, fatigue and dizziness. So, he was diagnosed with leukemia. The chemotherapy began in the same week and after 6 months he was submitted to an allogeneic bone marrow transplant, his sister being his donor.

After the transplant, he started with physical therapists and physical educators, a hard work of muscle and cardio-respiratory rehabilitation to return to sports activities that he always loved.

### fit for life

BILLION STEPS CHALLENGE

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05 October  
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World Transplant Games Federation  
October 29 at 12:00 PM

Swimming tips: We have 5 tips for you to improve your kicking. Kicking is important to swim a faster freestyle, mostly because it benefits your body position in the water. You want to be high and horizontal in the water to reduce your resistance. A strong kick will benefit your freestyle immensely. <https://youtu.be/3weAYd23GNc>

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World Transplant Games Federation  
April 19

Henk from team South Africa showing us how he uses technology to get in his cycling training. Day by day active challenge #txfamily #worldtransplantgames

@recycledhenk

You and 28 others 1 Comment

COUNTRY NEWS | SWEDEN

# Gustav Wallén, Swedish Golf Champion 2020

There's a new golfer in charge of the Dalahorse...

The 25th Swedish Championship for Transplanted Golfers, PGs Prize, was played at Mariestads Golf Club on the 8th of August and Gustav Wallén from Uppsala came out victorious after a good round of 74 shot net.

A total of 10 golfers showed up with the 'Dalahorse' in their sights.

The competition was played under the best conditions one could wish for, both weather-wise and course-wise. Mariestads Golf Club was well set up with nice fairways and fast greens and Gustav Wallén took full advantage of the course with steady play. He posted the winning score of 74 shots net.

Magnus Pagerup, last three-years' champion, put up a good fight but after the last put was holed, Gustav Wallén came out on top. Gustav is now in charge of the Dalahorse, better known as PGs Prize, and will choose next year's venue for The Swedish Championship.

This year's championship was the 25th and the Dalahorse has been the coveted trophy since the beginning of this century.

PGs Prize is open to be won by all transplant recipients (all organs) and also golfers on dialysis. There is also a class for relatives, friends and people of the transplant profession.

If there are any international transplanted friends who want to play, you are most welcome, however, the Dalahorse can only be won by a Swedish transplanted golfer.

Gustav Wallén will decide during Spring 2021 which course is to be chosen for the next Swedish Championship, PGs Prize. Rest assured, though, it will be an interesting and challenging course somewhere in Sweden.

**CJ Ahl**  
Sweden



*Gustav – the new holder of the Dalahorse*



*Gustav receiving the Dalahorse from Magnus Pagerup*



*The golfers!*

COUNTRY NEWS | COLOMBIA | FRANCE

# Update from Colombia

*Asociación Colombiana de Deportistas Transplantados (ACODET)*

The transplanted population of Colombia intend to break its limits



Just a few months ago we dreamed of the next World Transplant Games in Houston. Our work was focused on this event, however life had a surprise in store which affected all of humanity. This dream has been postponed, but we continue working so that the community of people with transplants in Colombia remains strong. We know that physical activity and sport are tools that we must use daily to make our lives better.

From ACODET we have managed to open more doors so that we can publicise the benefits that staying active brings for a transplant recipient. Today Colombia is a different country with a broader vision of what it means to receive a transplant.

Virtual classes of physical activity, the beginning of research studies and links with transplant doctors have allowed us to reach the lives of those who today live a second chance thanks to a transplant.

We inspire the entire transplanted community not to stop believing that it is possible, to dream big and be the protagonist of dreams come true.

**Dr Alejandra Edith Martin Pinto**  
Colombia



## ANNOUNCEMENT

# The French National Transplant Games will be back for 2021!

Trans-Forme, the French Transplant Sports Federation, are delighted to be organising the 28th National Transplant Games in May 2021.

More than 120 transplanted and dialysed athletes, adults and children, will meet in Narbonne and Gruissan (Aude), France, to compete over three days from the 12th to the 16th of May.

The athletes and their families will be able to run and swim; play table tennis, tennis, petanque and paddle as well as participate in karting, bowling and so much more.

These three days will be the perfect opportunity to raise awareness of the needs and benefits of organ donation by demonstrating the health and fitness that can be achieved post-transplant.



For more information please contact:

[www.jntd.org](http://www.jntd.org)  
[info@trans-forme.org](mailto:info@trans-forme.org)

Trans-Forme, France

**THESIS**

# Physical activity and fitness of transplant recipients

Prepared by Pinja Ekström, Finland



**Pinja Ekström** is a final year physiotherapy student from Finland, who in her Bachelor's thesis focused on the physical activity and fitness of transplant recipients. Being a liver recipient and a sprint runner, Pinja has the personal experience of competing in several national and international transplant sports championships, including WTG 2015 and WTG 2019. She represents track and field in WTGF's Athletes Advisory Commission and transplant sports in the Athlete Commission of her country's Paralympic Committee.

**E**ndurance and resistance training improve the physical fitness and quality of life of organ transplant recipients. Can transplant recipients improve physical fitness through exercise? Is exercise safe? What kind of exercise should one do? Physical activity is generally recommended for all but sometimes these questions are left unanswered. Advice about post-transplant exercise is not routinely given to all, and lack of exercise guidelines has been identified as one of the barriers (1, 2). There is a need for more specific, evidence-based instructions.

A recent literature review found that transplant recipients benefit from regular exercise. Those with a stable health condition may be able to safely perform even high-intensity exercise. The results are encouraging: exercise improves physical fitness and can boost quality of life. Low levels of physical activity, in turn, is shown to have negative effects on transplant recipients' health (3).

The review, conducted for the Finnish Paralympic Committee, aimed to bridge some of the knowledge gap and promote an active lifestyle among the transplant community. The study also sought to identify new exercise recommendations.

## EXERCISE IMPROVES PHYSICAL FITNESS AND QUALITY OF LIFE

15 randomized, controlled trials from the 2010s were reviewed. They included various exercise methods, usually performed three times a week in a supervised setting, lasting from 8 weeks to 12 months. Some studied the effects of endurance exercise, using HIIT (high-intensity interval training), MICT (moderate-intensity continuous training) or light aerobic exercise. Others studied resistance training combined often with endurance training. Sedentary recipients with no exercise typically functioned as controls.

Participants were usually transplanted at least 6 months earlier. In a Norwegian study, however, heart recipients began HIIT or MICT as early as 11 weeks post-op (4). Heart recipients accounted for 44 % of all participants, while 27 % were kidney, 25 % liver, and 4 % lung recipients.

The results were promising: essentially all exercise methods improved cardiorespiratory fitness and the maximal strength or endurance capacity of leg muscles. Training (without diet change) had minimal effects on body weight, but some studies recorded decreased body fat and increased lean body mass. HIIT improved cardiorespiratory fitness more than MICT or light aerobic exercise. Interestingly, HIIT has so far been studied only on heart recipients. Those who started HIIT with a lower

*Continued on next page*

THESIS

## HIIT variations

### BEGINNER

- Intervals: 30-120 seconds
- Total duration of intervals: 5-10 minutes
- Intensity: 80 % of max heart rate
- Active recovery: 1-2 minutes between each interval
- Frequency: twice a month (max once a week)

### INTERMEDIATE

- Intervals: 2-4 minutes
- Total duration of intervals: 10-20 minutes
- Intensity: 80-85% of max HR
- Active recovery: 2-4 minutes between each interval
- Frequency: 3-4 times a month (max once a week)

### ADVANCED

- Intervals: 3-4 minutes
- Total duration of intervals: 16-20 minutes
- Intensity: 80-90% of max HR
- Active recovery: 1-4 minutes between each interval
- Frequency: 4 times a month (once a week)

Intensity can also be based on feeling of exertion. During intervals, aim for 8-9 out of 10 (rate of perceived exertion). Heavy breathing, difficulty to speak more than single words and elevated heart rate are expected bodily signals during high-intensity intervals. Active recovery as light activity, e.g. walking (rate of perceived exertion 2-3 out of 10). Warm-up and cool-down (5-15 minutes each) are highly recommended.

cardiorespiratory fitness level tended to improve the most.

High-load, lower-repetition resistance training significantly improved the maximal strength of leg muscles. Low-load, high-repetition resistance training, in turn, improved the endurance capacity of muscles. As for self-reported quality of life, especially general health perceptions, vitality, physical functioning, and bodily pain improved upon exercise.

### EXERCISE RECOMMENDATIONS – WHAT TO CONSIDER?

Good cardiorespiratory fitness and sufficient muscle strength and mass contribute to health, wellbeing, and functioning. Although considerations exist for exercising post-transplant, WHO's general physical activity recommendations (5) can likely be applied to stable recipients. This includes daily light-intensity activity for many general health benefits but also moderate and vigorous activity, HIIT exemplifying the latter. Short intense interval bouts can be outside of one's comfort zone, and so beginners may benefit from scaled, supervised training. On the other hand, the shorter total duration of HIIT can feel less exhausting than continuous, longer exercise.

Strengthening of major muscle groups is recommended on two or more days each week but beginners can likely start progressing from once a week. Resistance training for muscle mass and strength can be done in sets of 6-12 repetitions at

60-80 % of maximal load.

Training should always be safe and individualized. When considering a new form of exercise or returning after a long break, it is good to talk to a health care professional first. No harmful events were recorded in the reviewed clinical trials, and exercise was concluded safe for those with a stable condition. Most studies were on heart and kidney recipients and there is a need for more studies especially on lung and liver recipients.

### MAKE IT A HABIT!

The effects of exercise cannot be stored. In a Danish trial, a five-month sedentary period after the exercise intervention washed away the positive effects that had been reached (6, 7). Whether starting from one weekly exercise or a more advanced position, regular exercise at sufficient intensity is the best policy.

**Pinja Ekström**  
Finland

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For more information about the World Transplant Games 2021 5K AnyWay, visit [www.wtg2021.com](http://www.wtg2021.com)

