

Transplant World

2021 | Issue 2

Journal of the



World Transplant Games Federation
Powered by the gift of life

CLOSER THAN EVER

Sharing the dream through the love of sport

INSIDE THIS EDITION

Golf goes virtual!

Transplant Next sneak preview

Postcards from Perth

National Events back on



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MESSAGE FROM THE PRESIDENT

Our community – a click away



WTGF President **Chris Thomas** on the importance of maintaining a close community

Our ability to communicate with one another has been transformed immeasurably in the last 20 years. Although our everyday social media tools are less than 20 years old (Facebook 2004, Twitter 2006, Instagram 2010 and WhatsApp 2009) it seems like they have been with us forever.

I have been around long enough (don't laugh) to remember the Telex machine which was used to send our newspaper stories from country NSW to Sydney head office. We even worked on hot metal printing presses. Google that some time.

Our first company policy at the Australian Medical Association was for one standard email address for all staff because no-one would want one of their own! But we got a fax machine which revolutionised our communication.

Fast forward 30 years and our first task waking up each morning might be to check to see who has WhatsApped us overnight or what our worldwide transplant community is up to on Facebook or Instagram?

With the click of a button we can see what all our good friends are up to in their pursuit of sport, raising monies for charity or just loving life!

The MoveSpring App allowed more than 2,000 people in our community to come together and step their way to more than 1.2 billion steps. We could

follow them on their journey, encourage each other, share pictures and create a little friendly rivalry.

Our community, hopefully, has never felt closer and this has been especially important over the last two years of the Covid-19 pandemic. It has been an exceptionally difficult time as we have waited out this pandemic wary of contact and crowds. And sadly, too many of our community are no longer with us. We will remember them in a special way soon.

Covid information

The WTGF has tried to help with information about Covid and how to protect yourself. Transplant Hub created a safe online platform to connect. We sent out hundreds of Transplant Tx Teddy Bears to kids waiting for a transplant. Our community challenged each other in a virtual golf tournament and our transplant cycle group conducted regular zoom rides. And of course, to top it off, our Billion Steps Challenge.

All very modern, all very instant. One click on your mobile and you are part of a worldwide community.

It is probably why the Australian local organising committee opted for some nostalgia and reverted to the old postcard to promote the World Transplant Games to more than 1,000 members of the international transplant community. It was a great concept from

the Games Communications Manager, Jo O'Farrell. The local transplant community sent in their favourite pictures of Perth and surrounds, the postcards were produced and what followed was a fun day of the community getting together and writing personal messages on each of the postcards.

And in recent weeks 'old' has met 'new' with some of the people who received the postcards posting selfies online. Just a lovely way to connect our people. Brilliant.

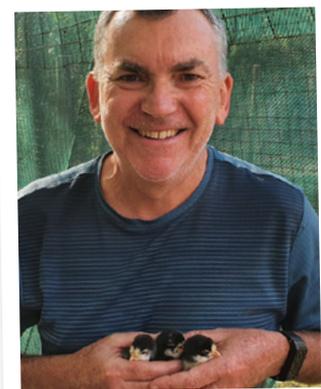
The WTGF remains committed to helping our global community. We are blessed with some fine trustees and staff all dedicated to supporting recipients.

I remember at the end of 2020 many people praised its end looking forward to 2021. Hmm, 2021 actually looked a lot like the previous year. However there has to be a 'morning after' sooner or later. The pandemic will not last forever.

But until then, stay safe. Look after each other. And start your training for Perth 2023. It is going to be one heck of a party!

Kind regards and Seasons Greetings and Happy New Year!

Chris Thomas
WTGF President



Chris with new life at the farm

“The Australian local organising committee opted for some nostalgia and reverted to the old postcard to promote the World Transplant Games.”

Turn the page for some of the postcard selfies

MESSAGE FROM THE PRESIDENT

Postcard selfies!

Postcards of Perth were produced using the local transplant community's favourite pictures. Here are selfies from some of the postcard recipients.



Gabriella Szabo – Hungary



Jean Christophe Voise – France



Marco Mestriner – Italy



Tamás Mihálovits – Hungary

VIRTUAL GOLF CHALLENGE

Golf goes virtual!

The WTGF successfully hosts the first ever World Transplant Virtual Golf Challenge



Golf has been one of the largest represented sports at the World Transplant Games for the last 30+ years. Transplant athletes from around the world, of all ages and abilities, traditionally come together to celebrate life through the game of golf.

After a worldwide pandemic halted the opportunity for our transplant community to come together in the usual way, the World Transplant Games Federation launched its first ever World Transplant Virtual Golf Challenge.

The Virtual Golf Challenge, open to both transplant recipients and the extended transplant community (living donor, donor family, health professional, family, friends) brought keen and new golfers from around the world to compete against each other in a Strokeplay Medal Competition format. All handicap bands were welcomed, with golfers encouraged to 'Swing into action and play' and once again celebrate the gift of life.

Teeing off at the beginning of August, the challenge ran for 3 months allowing golfers to play on their preferred local 18-hole golf course, and submit multiple scores during the challenge period, with their best score being added to the weekly Leaderboard.

The challenge was well received by our global community with participation



from 53 golfers, representing 14 countries with a total of 167 rounds of golf played during the challenge period.

Adding some fun to the Challenge was the addition of a Pitch & Putt category, fun prize giveaways, most rounds played and a best averages competition for golfers playing 5 rounds or more.

Great prizes were on offer with branded WTGF gold, silver and bronze medals awarded to the top 3 positions in each category and handicap band. Additional prizes included signed Lee Westwood caps, WTGF branded polo shirts and luxury golf gift boxes.

We saw some impressive scores being submitted with some golfers reporting having played their best rounds of golf in their life.

Player feedback



"Thanking you for all you do for us transplanted athletes"

Charles Dyson – United Kingdom



"I have found it a very good initiative to have organized the World Transplant Virtual Golf Challenge, something that in my opinion should continue to be done"

Fabiano and Valérie Paratore - Switzerland



"Thank you for the wonderful golf event, it was good fun"

Carlos Iglesias Souto - Spain



"Such a great event seeing scores come in from around the world week by week, I really enjoyed it!"

Lloyd Perry - South Africa

The WTGF plan to host more virtual golf challenges, and other virtual sports challenges in the near future.

Visit <https://wtgf.org/leaderboard/> to view the final Leaderboards for all categories and handicap bands

BILLION STEPS CHALLENGE 2021



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Fit for Life! Billion Steps Challenge 2021

The highly anticipated Billion Steps Challenge, proudly supported by Novartis, was back with a message to encourage our global community to STEP their way to better health

The Fit for Life! Billion Steps Challenge, proudly supported by Novartis was once again back for the 3rd edition of this successful community centred stepping challenge. Being one of our favourite virtual events at the Federation, the call was put out to our global community to step up to the challenge, join together to reach as many steps as possible, while focussing on the holistic benefits of walking and staying active.

Exercise is the best way to remain positive during challenging times and working together towards a common goal increases morale and boosts feelings of connectivity to others. This is especially important during this period of Covid-19. A good walk can do wonders for your mental wellbeing. It improves self-perception and self-esteem, mood, sleep quality, reduces stress and anxiety.

The Challenge launched on 20th

September and ran for 70 days using the online fitness platform MoveSpring. Everyone was invited to join and sign up into teams of between 2 – 10 people, making up various combinations of transplant recipients, medical professionals, living donors and donor families, friends, family, colleagues, neighbours, sports groups, community organisations, and transplant units across the world.

A total of 2,082 participants representing 58 countries registered for the challenge, reaching an overall group total of an incredible 1,226,440,954 steps! Each step recognising the importance of organ donation, the success of transplantation and celebrating the gift of life.

All physical activities were recognised and could be converted to steps.

Continued on next page

Quotes

"Thank you to WTGF for having all of us stay very active. We are grateful for a way to be connected." Pepi Fernández, Spain

"I feel so very grateful and blessed to be motivated by so many of you to keep on going even when I been seriously sick. You are all amazing at advocating organ donor awareness" Melanie Moffat, Canada

"Thank you for organizing this exciting challenge which helped not only to appreciate every day and stay active but also to meet wonderful people from different countries and share important moments" Liliia Ozbilen, Russia

fit for life
BILLION STEPS CHALLENGE

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CONGRATUALIONS TO ALL OUR DEDICATED STEPPERS!!!

We've reached
1 226 440 954
STEPS!!!

Thank you to everyone for your contribution

STEP your way 2 better health
10 weeks to reach 2 billion steps
20th September – 28th November 2021

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BILLION STEPS CHALLENGE 2021

Participants were encouraged to convert their non-stepping activities using easy conversion tools, which saw a variety of sport disciplines being counted towards the overall group target. Field hockey, pickleball, kayaking, table tennis, open water swimming, yoga, ice hockey, cycling, ultimate frisbee, netball and volleyball where some of the ways our participants accumulated their steps, along with our usual entries of walkers and runners.

New feature

A new feature to this year's challenge was the unlocking of Milestones at every 200,000,000 steps. A total of 6 Milestones were unlocked during the challenge. Each Milestone delivered information on various health-related topics, motivational tips and mindfulness techniques, aimed to encourage participants to learn more about the benefits of staying active. Prize giveaways were also unlocked at each Milestone with active participants

bagging themselves some great prizes, such as Garmin fitness watches, stretching kits, GoPro, Nutribullet and WTGF Earpods.

The Legacy of the TX Teddy Bear originally launched during the 5K AnyWay virtual event in June 2021 was continued during the Billion Steps Challenge. For every country that participated, one TX Teddy was unlocked and a further 10 Teddys unlocked at each Milestone. A grand total of 118 Teddies were unlocked for transplant youth around the world. These will be distributed around the world through our exciting new Youth program: Transplant Next.

Another great addition to the 2021 Challenge was the Donate Your Steps campaign which called on sporting clubs and group events to make a once off donation of their steps or physical activity to the Billion Steps Challenge. This campaign allowed our message for

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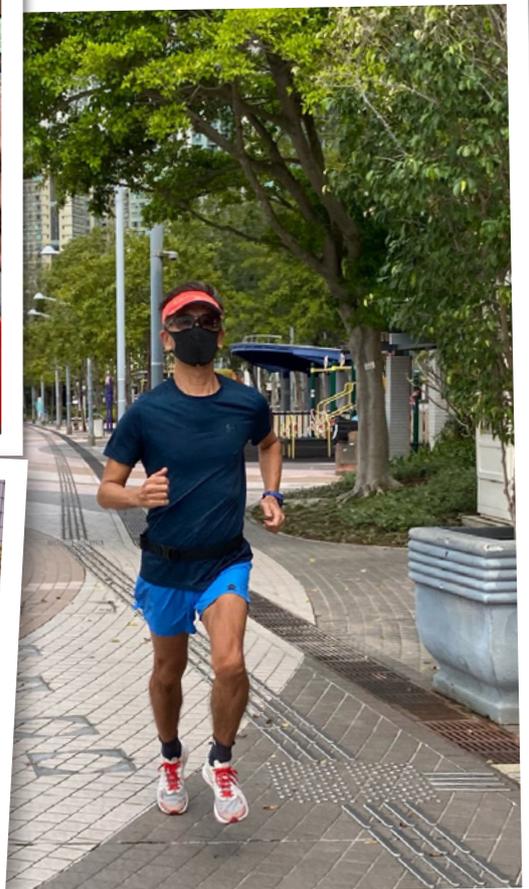
Quotes



"Thanks to all participants around the world. We are stronger together! Hope to see you all in Perth 2023" Teoman Erdoğan, Turkey

"I am grateful for 13 colleagues-liver tx and family members, who have taken part in the Billion Steps Challenge for a third time. The event has led us to improve physical and mental health by making us Stay Connected, Stay in good shape, Stay young and Stay fun, even during the pandemic." Yong-Hwan Han, Korea

"Thanks to our donors we can connect in this beautiful challenge and enjoy from different parts of the world, celebrating life and second opportunities" Maria Medina, Argentina



BILLION STEPS CHALLENGE 2021

raising awareness on Organ Donation to reach new audiences. 25 groups pledged their steps to the Billion Steps Challenge, bringing in a total of 79,521,151 additional steps.

Our global steppers were kept entertained and engaged with weekly competitions which motivated participants to get out stepping while taking photos of new weekly themes. Our target challenges encouraged steppers to increase their daily step count. The WTGF gave away new and exciting prizes to thank our supporters for their dedication and creativity. WTGF branded hoodies, socks, travel coffee mugs, water bottles and caps were some of the prizes given away to winning participants.

Most registered steppers showed a notable increase in their daily step

counts with many reporting that being accountable to their team members and striving towards a common goal, motivated them to step up to the challenge and push themselves beyond their normal boundaries, improving their fitness and overall wellbeing.

We would like to thank Novartis, our proud sponsor who helped make this challenge possible once again and all our supporting partners from our Member Countries and Organisations for promoting our message across the world.

As we head into 2022, we hope our global community remain inspired and motivated to continue to STEP their way to better health.

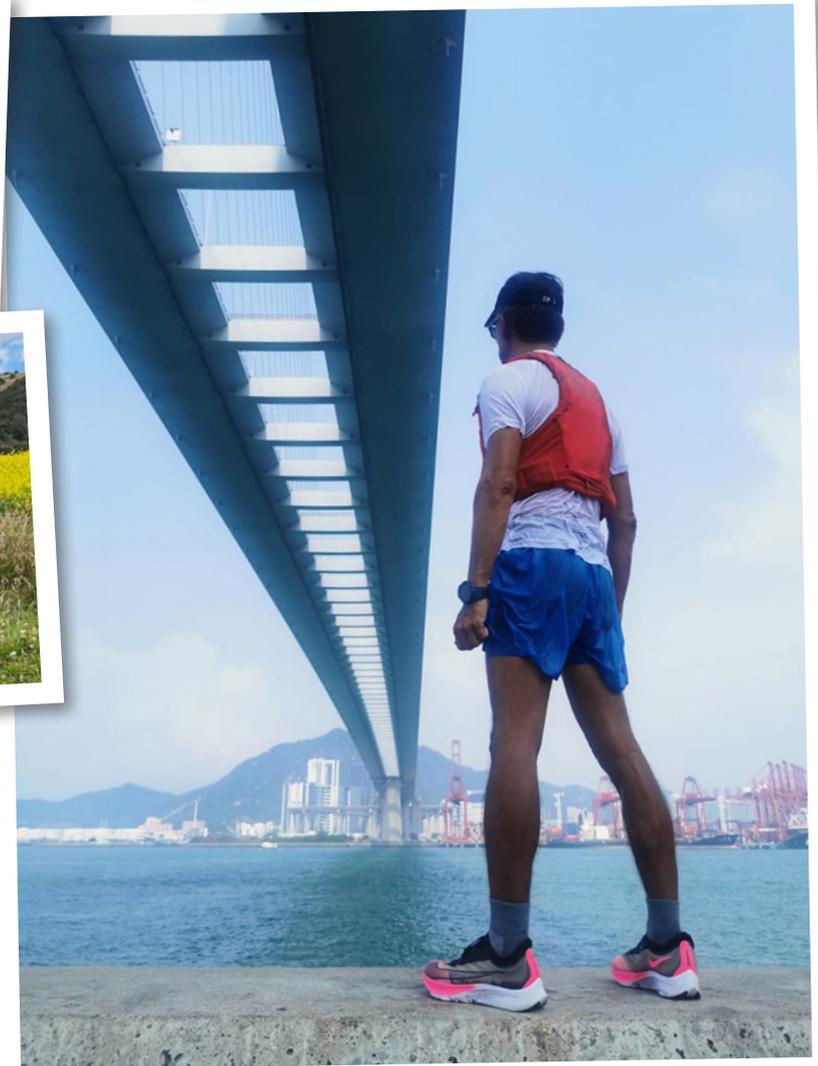
Fit for Life! Team

Quotes



"We have 2 groups at Kings College Hospital in London, and we are going to really miss this fabulous challenge. It has been so inclusive & got so many people moving! We have so enjoyed it. Please do it again soon!" Donna Barrington, Great Britain

"It has been very interesting to participate in this challenge. Each photo and chat message was a precious learning, the personal stories, the value and quality of life. For a while I felt that anything is possible if we organise ourselves with clear objectives and enjoy with others" Lourdes, Uruguay



The World Reunites

 PERTH 2023



REGISTRATIONS
OPEN APRIL 2022

15 April - 21 April 2023
worldtransplantgames.org

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Perth

 **Perth** 2023
AUSTRALIA
World Transplant Games



Perth 2023

World Transplant Games

“We’re closer than ever”



Troy and Julie Scudds are active members of the Local Executive Committee hosting the 2023 World Transplant Games in Perth. They share their journey from transplant to triathlons as they prepare for Troy’s tenth solo half Ironman since receiving a liver transplant 8 years ago and Julie’s second event since taking up the sport earlier this year.

TROY

We met through a friend playing basketball while at university. I thought Julie was very attractive from the first time I laid my eyes on her. We had a lot in common and just enjoyed having fun together. She is caring, super smart and pretty good at Trivial Pursuit as well. I’m a lucky guy!

Julie has supported my sporting aspirations since my transplant. I’m so happy that this year Julie has also taken up triathlon and now we get to train together. We have developed some wonderful friendships and triathlon has become a way of life for us.

I was diagnosed with a liver disease just before the birth of our twin daughters in 2000. Following a decade of regular bloods tests and medication,

Continued on next page

PERTH 2023

I was diagnosed with primary sclerosing cholangitis (PSC) in 2010. In late 2012, I was put on the liver transplant wait list and eight months later, I was fortunate to be given the gift of life.

For about 12 months prior to transplant all I could manage was work and sleep. Julie gave up a career role and carried a huge load in managing the family and caring for me. Post-transplant, I had a really difficult time with complications and Julie was the one that spent twelve hours a day for 38 days by my side while I recovered.

The experience of having the transplant has been the best thing to happen to me. This is because it showed me what is important in life, how Julie is my best friend and she's there for me in the good times and the bad.

Post-transplant I started walking as the doctors told me that the anti-rejection drugs can impact on bone density. I could hardly walk the five metres from the front door to the letterbox. But 14 months post-transplant, I was asked by a close friend to do a 21km run leg of a half Ironman. After completing two events in teams and watching others race, I wanted to give it a go myself.

I have competed in nine individual 70.3 Ironman races and three team events. I achieved a silver medal in

triathlon at the 2019 World Transplant Games in Newcastle. The Transplant Games are such a rewarding experience. I love to compete and stay active but it's the friendships and support that make it unique. I would encourage any first timers to embrace the spirit of the Games, get out of your comfort zone and meet some new people. Celebrate your efforts in preparing for the Games and remember to support your fellow competitors.

I love triathlon. I never get bored as there are three sports to try and master. I have a coach that prepares a weekly plan. A typical week includes two or three swims, a strength session, two rides and runs and then a longer rides and runs on the weekend. Consistency is key to training; some days are better than others. If you are moving, then you are winning! But sleep, eating well and recovery are just as important as the training and competing.

I greatly admire how Julie has taken up triathlon in her late forties. She is so strong and committed. Training together we encourage each other to higher performance and a sense of accomplishment. It's great to have a training partner that pushes you when you don't want to train or you're having a bit of a down day.



Post-transplant, I had a really difficult time with complications and Julie was the one that spent twelve hours a day for 38 days by my side while I recovered."

JULIE

What I admire most about Troy is his strong desire to achieve his best, whether it's work or sport. He never gives up and achieves amazing things whilst being gracious and humble. Learning to live within his health limitations was frustrating for Troy both before and immediately after his transplant, when he was struggling to get well enough to get out of hospital.

Troy was first diagnosed with autoimmune liver disease when I was pregnant with the twins, and we were told that sometime down the track he may need a liver transplant. That was a bit of a shock, given we had a 6-year-old and two babies about to be born.

Three weeks post-transplant, he was just skin and bone, his muscles had all but wasted away. But once he got home, he started walking to the mailbox, then the end of the street, and further and then graduated to running. Next year, to celebrate his 9-year transplant anniversary, he aims to compete in his first full Ironman event in Cairns.

With Troy training 9 times a week I would barely see him, so I decided to start swimming as well and after I while got on a bike too. Then I opened my big mouth and said I'd like to do a half Ironman when I turn 50! Troy gave me a coaching package for Christmas and in



Continued on next page

PERTH 2023



A training run in the outback!

“ Make the most of every opportunity, and don’t sweat the little stuff. Happiness and health are precious things to cherish.”

April I completed my first half Ironman three weeks after my 50th birthday.

Now we spend a lot more time together, we are both healthy and active and we even plan our holidays to include triathlon events. Before I was doing triathlons, I didn’t really understand why Troy was off to bed at 8:30pm, and not wanting to go out on weekends. Now that we both have the same goals, and the same exercise and training mentality, we are closer than ever! Last month, I did the ladies-only triathlon, so Troy got the

chance to be the spectator and I know how great it is to have your partner cheering you on from the sidelines.

One of the biggest things we have both learnt after the whole experience is to appreciate every minute you have. Every minute is one that would not have happened if it wasn’t for the generosity of his donor and their family. Make the most of every opportunity, and don’t sweat the little stuff. Happiness and health are precious things to cherish.

We first got involved with Transplant

Australia when we went with our kids to the 2016 Australian Transplant Games in Sydney, and we had a wonderful time meeting other transplant recipients and their families. Since then, I have been arranging sporting and exercise activities for our local transplant community, initiating weekly walking groups, and teams for larger community events. The support from our members is wonderful. Even if they don’t participate in an event, there are many who are willing to come and support our competitors. It was our transplant friends who helped me through that last lap of running for my first half ironman. We are all really excited to be hosting the first stand-alone triathlon event at the 2023 World Transplant Games and we can’t wait to cheer on every participant who comes to Perth.

Julie and Troy share some local travel tips:

Perth: There’s a great network of cycle and walk paths around the city. You can hire a bike and take the 10km loop around the Swan River from the city to the South Perth foreshore and back or you can cut across on the zoo ferry. Kings Park is great for running and cycling with flat or hilly options. And a beach sunset is a must - maybe with some fish ‘n chips!

Day Trip: Take a ferry to Rottnest Island for a day trip or longer - you can cycle around the whole island and stop off at the beaches along the way. And the quokkas are so cute!

Road Trip: Drive a few hours north or south of Perth to explore forests, caves, ancient stromatolites, and the Pinnacles. Margaret River is a favourite for its wineries, beaches, and galleries.

Fly: Exmouth for snorkelling over Ningaloo Reef right off the beach, scuba diving, or swimming with whale sharks.

KIDNEY DONORS

Living donor Mark Scotch is on “The Organ Trail”!

A Journey to Heighten Awareness of Kidney Disease and the Need for Kidney Donors



Hugh, Mark and Mark's wife Lynn back at Cane River Brewing where they first met

Looking back:

Early in 2020, Mark Scotch, retired from a career of selling diagnostic equipment in the paper mill industry, met Hugh Smith, a 56-year-old former professional horse jockey, at “Cane River Brewing” in Hugh’s hometown of Natchitoches, Louisiana. Although neither had ever seen the other before, both men can be described as “guys who never met a stranger”. They soon began to talk and here’s what Mark learned about Hugh..

During his days as a jockey, Hugh suffered frequent bangs and bruises. To combat the aches and pains he took ibuprofen. And more ibuprofen. And lots more ibuprofen. That was decades ago when consumers were not effectively warned about the dangers of taking too much of that drug. Consequently, Hugh’s kidneys were damaged and over the years became progressively worse. Renal

failure hit hard in 2019 and for ten hours every night, Hugh was on peritoneal dialysis - a type of dialysis that uses the peritoneum in a person’s abdomen as a membrane through which fluid and dissolved substances are exchanged with the blood.

Hugh had been accepted on the waitlist for a kidney transplant from a deceased donor and became one of nearly 100,000 Americans waiting for a life-saving kidney. By the time we each wake up tomorrow morning, 13 of those patients will have died for lack of a donor.

Just the day before, the two men had been strangers. That day, in a bar in Louisiana, Mark Scotch knew what he wanted to do: give one of his kidneys to Hugh Smith. It was one of those extraordinary times in life when a decision is instantly clear. The fact that

Hugh had not been known to Mark more than an hour earlier did not matter. It was the thing to do. By mid-August, 2020, Mark and Hugh had both gone through extensive medical testing and screening.

Through the National Kidney Registry Voucher Program Mark became a “voucher donor” where he would be matched with a recipient somewhere in the country. Once the kidney donation was complete, Mark could also name Hugh as the person he wanted to benefit, which would give the former jockey higher priority on the National Kidney Registry transplant list.

By using the voucher program through the National Kidney Registry, Mark being a match with Hugh wasn’t necessary. It also allows donors and recipients to complete transplantations

Continued on next page

KIDNEY DONORS

with the highest degree of compatibility, thereby greatly reducing the chances of rejection.

Mark said, "The voucher system let me do everything at my local hospital in Madison, Wisconsin while Hugh went to his local hospital in Jackson, Mississippi, and was given higher priority on the transplant list."

In September 2020, Mark Scotch was matched with a compatible individual in New York and successfully donated his kidney. In February 2021, Hugh Smith received his much-needed kidney from Southern California. Both men are healthy and have resumed normal lifestyles.

The Organ Trail:

In May 2021, Mark completed his first Organ Trail journey of 1,500 miles from Madison, Wisconsin to Natchitoches, Louisiana. On 19 September 2021, Mark Scotch, age 65, once again hit "The Organ Trail," cycling his way 1,600 miles to promote kidney disease awareness, living donor need, and post-donation functionality, this time with a marathon bike ride from Martha's Vineyard, Massachusetts to his home in Plover, Wisconsin.

Mark said, "The Organ Trail is all about generating awareness of the need for kidney donors, especially living kidney donors; but it's also about showing people that even with one kidney, you can still lead a life full of activities, even if those activities are sustained and vigorous."

Mark & Hugh



fit for life
BILLION STEPS CHALLENGE

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STEPS DONATION 4 935 744 STEPS!

Thank you to
The Organ Trail: A Kidney Donation Journey
for donating your steps!



Your contribution is going to help us reach our goal of
2 BILLION STEPS

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STEP your way 2 better health
10 weeks to reach 2 billion steps
20th September – 28th November 2021

The WTGF Billion Steps Challenge was delighted to be in receipt of The Organ Trail's donation of 4,935,744 steps for the group target of 2 billion steps.

Mark was joined along the route by Steve Wilson who donated his cycle of 304 miles and Jeff Lange who added another 421 miles.

With 3,000 new patients added monthly to the kidney waiting list, and 13 people dying every day because of a shortage of kidneys, Mark Scotch, the cyclist-turned-kidney donor plans to continue raising awareness about living kidney donation through The Organ Trail.

Coming up for Mark:

Mark has also been named as a Finalist in the USA Today Best Humankind Triumph of the Year. Voting is over with winners to be announced in December.

Mark will also compete in 2 winter Ultra- Marathons in January 2022. The first is the Tuscobia 160 (miles) and the 2nd is the Arrowhead 135 (miles) and is recognized in the book "The World's

Toughest Endurance Challenges" by Richard Hoad and Paul Moore as one of the 50 toughest races in the world. Mark has competed in both of these events before and wants to demonstrate once again that one can donate a kidney to potentially save someone else's life and still return to pre-donation activities with no ill effects.

In the spring of 2022 Mark will embark on another OrganTrail, following the route of the kidney his voucher recipient Hugh Smith received, traveling from southern California to Louisiana. The first leg of the ride will be 1200 miles from Los Angeles to Denver City, Texas. The second leg will take place in December of 2022 from Denver City, Texas to New Orleans, Louisiana, another 1200 miles.

Read more about The Organ Trail here: <https://theorgantrailhm.wordpress.com/>

REFIT FOR LIFE!

Free online rehabilitation programs relaunched



Announcement of the exciting relaunch of the WTGF Refit for Life! Toolkit in 2022!

First launched at the end of 2018, the WTGF **Refit for Life! Toolkit** was created to provide free online rehabilitation programs available to all transplant recipients. This functional resource was designed to provide a motivational tool for taking those first steps towards getting active, and to offer practical guidance in the areas of physical activity, mental wellbeing, and nutrition.

As we continue to elevate the importance of physical activity at all levels in the long-term management and wellbeing of transplant recipients, we are excited to announce relaunch of the WTGF Refit for Life! Toolkit which will be rolled out early 2022 in an improved and expanded format.

After detailed consultation with those recipients who enrolled in the pilot program, we were able to develop a program more aligned to the needs of our global transplant community.

What's coming in our Rehabilitation Program:

- A simple and short sign-up process with very basic assessment tools
- 4 levels of progressive exercises with a mixture of warm up's, conditioning, cardio and warm down exercises
- Downloadable exercise program for each level
- Ability to choose your own starting level based on your current fitness levels
- Short exercise videos clearing showing how to do each exercise properly

“We were able to develop a program more aligned to the needs of our global transplant community.”

Wellness Series

Our new Wellness Series is aimed at everyone post-transplant looking to try something new and improve their fitness and wellbeing. This series will be rolled out gradually starting early in 2022 and will include a range of on-demand video classes in the areas of:

Mental Wellbeing

- 10 week Somatic Therapies course
- 8 week Mindfulness course

Nutrition

- 8 week course on achieving better nutrition post-transplant

Exercise

- 8 progressive videos on Pilates
- 8 progressive videos on Yoga
- 8 progressive videos on Stretching & Flexibility
- 8 progressive videos on Cardio Workouts

Both our Rehabilitation Program and Wellness Series are free of charge for anyone, and available anywhere in the world.

Coupled with the revamp will be an extensive promotion program across social media and targeted at transplant units around the world. Member countries will all be offered the opportunity to promote the program on their own websites and social media, ensuring we help reach more transplant recipients around the world.

Subject to funding we hope to translate this program into various languages over the next year.

With our new revamped Refit for Life! Toolkit, both the Rehabilitation Program and Wellness Series hope to offer guidance which will improve not only transplant recipients' fitness and nutrition but their mental wellbeing and overall quality of life.

Refit for Life Team

www.wtgf.org/refitforlife

Continued on next page

Meet some of our Wellness Series Facilitators:



Grey Brett

"In 2005 I was diagnosed with Primary Sclerosing Cholangitis, an untreatable and progressive autoimmune disease. I decided at that time, to relentlessly pursue my dreams as much as possible while the disease afforded me the ability to. I lived and worked in Bermuda and then Grand Cayman for several years at which time my daughter was born.

Eventually, in 2015 and back home in Toronto, my liver failed and a month later on 20 June 2015, I received a new liver from a selfless deceased donor. Since that time, I have dedicated a large portion of my life to the cause that has saved mine. Speaking at numerous school and corporate events while trying to lead as an example of what transplant sport can do for recipients, I've been able to showcase people's ability to overcome at all odds. I'm a member of the Canadian Transplant Swim Team where I've represented Canada at two World Transplant Games in Malaga, Spain and Newcastle, England and won numerous medals and have set 7 world records. Movement and physical activity are huge components of my life and I'm looking forward to sharing my perspective on physical and mental fitness and what it can do for transplant recipients".

Guided - Stretching & Flexibility

The Guided series of videos are follow-along routines with voiceovers to guide you through Form and Technique all done from home with no equipment required. This series will allow you to increase your body's range of motion, flexibility, and mobility all while allowing you to develop strength that is useable in daily life.

“Movement and physical activity are huge components of my life and I'm looking forward to sharing my perspective on physical and mental fitness.”



Simplicity Coaching

Liz Witherspoon and Julie Elliott first met in June 2008 and realised their mutual passion for supporting people to slow down, reflect and reconnect with who they are. Their love of learning, personal development and compassion for people is the reason Simplicity Coaching was created. "As Mindfulness Teachers, we aim to inspire and support the growth of both individuals and teams. We believe in taking the time to reflect and to simplify our lives by clearing the 'clutter' of thoughts, behaviours and distractions that are not aligned to living an authentic, mindful and wholehearted life. By living mindfully, we savour each moment to connect with those things and relationships that are important to us."

Julie Elliott and Liz Witherspoon have completed their Post-Graduate Certificates in Mindfulness-Based-Interventions through Stellenbosch University and the Institute for Mindfulness South Africa (IMISA). They have also completed their Mindfulness Educators Essential Program through Mindful Schools and have been working as Facilitators and Life Coaches for the past fifteen years. They are currently qualifying as Mindfulness-Based supervisors.

Simplicity Coaching Mindfulness Course

The aim of this 8-week online Mindfulness program is to help you to develop your own mindfulness practice that fits into your lifestyle and soon becomes a habit. The course provides the groundwork to observe your own mind and body, life, and work, and whatever else may arise for you. You have an opportunity over this eight-week journey to befriend yourself and to reclaim your life, living it more fully, moment by moment. This commitment is ultimately a radical act of trust and faith in yourself.

“By living mindfully, we savour each moment to connect with those things and relationships that are important to us.”

**fit
for life!**

Refit for **Life!**
A World Transplant Games Federation Initiative

**World
Transplant
Games
Federation**

The Refit for Life Toolkit - Relaunching in 2022

Brought to you by the World Transplant Games Federation, our global Fit For Life! initiative 'The Refit for Life Toolkit' offers a free online program available to all transplant recipients.

Our soon to be relaunched toolkit, offers our core Rehabilitation Program to newly transplanted recipients, and our new Wellness Series for recipients at various stages of their transplant journey.

Both programs aim to encourage all recipients to stay active and motivated by offering guidance in the areas of various physical activities, mental wellbeing and nutrition.

Would you like to get active post your transplant?

Our Rehabilitation Program is aimed as a starting point to help new transplant recipients take the first steps to get active. The program offers 4 progressive levels with a mixture of warm up's, conditioning, cardio and warm down exercises, allowing you to progress at your own pace.

REHABILITATION PROGRAM

- Guidance on Exercise, Nutrition, Mental Wellbeing
- 4 Levels of Exercise Videos
- Downloadable Workout Plans
- Assessment & Tracking Tools

EXERCISE LEVELS

- Level 1: Let's Get Moving (I've just had my transplant)
- Level 2: Off The Marks (Beginner)
- Level 3: Building Blocks (Moderate)
- Level 4: Final Straights (Intermediate)

Are you ready to try something new?

Our new Wellness Series is aimed at everyone post-transplant who is ready to try something new. Improve your fitness and wellbeing by exploring our new range of on-demand video classes from Instructors around the world.

WELLNESS SERIES

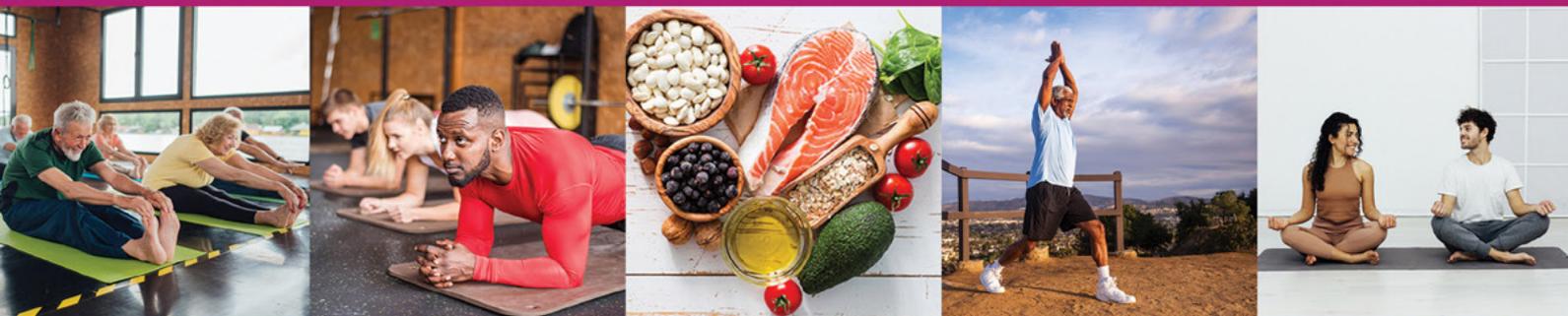
- On Demand Video Classes
- 8 - 10 classes in each series
- Guidance on Exercise, Nutrition and Mental Wellbeing
- Access to core Rehabilitation Program

CLASSES

- Stretching & Flexibility
- Cardio Workouts
- Pilates
- Yoga
- Somatic Therapy Practice
- Mindfulness & Meditation
- Nutrition
- Motivation

MORE INFORMATION COMING SOON

Refit Reinspired Refocused



TRANSPLANT NEXT

WTGF will launch their new Youth Initiative early in 2022...



A youth initiative of the World Transplant Games Federation featuring:

- ▶ **Webinars and Coffee chats aimed at Transplant Youth and their families**
- ▶ **Education**
- ▶ **Life skills**
- ▶ **TACKERS camps**
- ▶ **TX Transplant Teddy Bear**

The WTGF Youth Committee have been working hard at delivering this new initiative with some great webinars and coffee chats lined up to kick off early next year. These will include a range of topics offering support and advice for both youth transplant recipients, youth on the transplant waiting list and their parents, caregivers and families.

Joined with this will be a global online distribution platform for sending TX the Transplant Teddy Bear to children on the waiting list or recently transplanted. The system will allow families around the world to apply for a TX teddy and track "where in the world TX is" on a creative world map.

Between the 2021 World Transplant Games 5K AnyWay event and the more recent Billion Steps Challenge – over 640 TX Teddy Bears have been unlocked.

The WTGF thanks everyone who fundraised during the 2021 WTGF 5K AnyWay to help make this new Youth Initiative come to life.

WTGF Youth Committee



"I am very excited to be a part of the development of Transplant Next! I am looking forward to the delivery of youth products and providing resources to support our transplant community with the focus on our next generation."

Ashleigh Duran
WTGF Youth Committee



"After over 20 years of organising our TACKERS camps it felt like we should offer more opportunities to more young recipients around the globe to help them and their families on the transplant journey. I have met so many children over the years, heard the hopes and fears of parents, had the joy of seeing so many of these kids gain confidence, live their dreams, become parents themselves.

The way forward was evident, TACKERS needed to become part of the WTGF Youth Initiative and therefore part of Transplant Next. Led by Ashleigh, who is a mother of two young children and a liver recipient herself, we are excited to go into 2022 and help more transparent kids and more families, more often! This is especially important with the situations people have seen during the pandemic. We are not alone. We are here!"

Liz Schick
WTGF Honorary Secretary
WTGF Youth Committee



Kayla Kander from South Africa – a new kidney



Tanesha from United Kingdom - waiting for a new heart

Three children from Hong Kong with their bears!



Tung-sun Ho – waiting for a new heart



Sing-Yu Poon – liver recipient



Nga-lam Lam – kidney recipient

MY STORY

My Story So Far... Jillian Best, Canada

How Jillian Best made her transplant comeback with her health and started the Move for Life Foundation



Jillian in training

I think we all dream and wonder when we're young, what we might end up doing with our lives. Who will I be? What will I do with my life? I sure didn't imagine needing a liver transplant to survive at the age of 29, or that I'd find such a passion for swimming and use it to fundraise and make an impact on the transplant community and transplant program that saved my life.

My journey to having a liver transplant began when I was just 15 years old. In 2004, my mom was sick and needed a liver transplant to survive. It was at this time that our family discovered a hereditary disease that causes abnormal blood vessels and affects blood flow in different organs of the body. This is when I was diagnosed, believing that if I had issues from this disease, I'd likely be my mom's age when it happened. I was wrong, only 7 years later in my early 20's I began experiencing pain and liver failure.

Months went by, I was in and out of the hospital, endured seizures, muscle loss, in and out of a coma, and was put

on all sorts of medicine galore. I had just begun my career as a hairstylist and I was unable to work for about 18 months. In fact, I was put on an experimental drug in hopes that it would prevent me from needing a liver transplant at such a young age.

I was finally able to return to work, and it got me by for about four years. When the medication stopped working, I began feeling the symptoms of liver failure return. Except this time, it was worse. Not only was I accumulating fluid on my abdomen (ascites), and bleeding internally, but my mom began to feel ill again too.

In May of 2015, my mom and I found ourselves on the waitlist for liver transplants. Our health was declining fast. We waited almost a whole painful year before matching organs became available for us, and miraculously, our transplants happened just two weeks apart, in February and March of 2016.

As you can imagine, my transplant completely changed my outlook on life. I hadn't been well for such a long time, so

I was dreaming of becoming healthy and fit again. The timing couldn't have been better, when I was laying in my hospital bed recovering from my transplant, when a volunteer walked in. He handed me a brochure, and I read all about the World Transplant Games that were to take place in Malaga, Spain in 2017.

Standing on the podium

I realized I could compete in these games as a transplanted swimmer. It was then and there that I imagined myself standing on the podium at these games in 2017, and I was strong, happy and healthy. Just two months after my transplant, I joined the YMCA and I got back in the pool. Swimming was my life until I was a teenager. You could always find me in my bathing suit anywhere that we went, always ready to hop in a pool or the lake at the beach. I stopped swimming in my early teen years because of depression; my mom being sick took a real toll on my mental health. I found swimming as an adult was like a new medicine for me. It helped me gain back my confidence, strength, and I found it meditative to swim. I was focused on my goal, to compete at the Transplant Games and make a comeback with my health.

My experience at the World Transplant Games was incredible. Aside from realizing my goal, standing on the podium just over a year after my transplant and accepting two silver medals in the pool for the 200m and 400m freestyle event, I had my health back. I have met some really incredible people at the games as well.

I trained extremely hard for the following World Games in 2019 in



20 Minutes post 'Lake Ontario' - Jillian with her proud parents

Continued on next page

MY STORY

Newcastle-Gateshead, UK, and my hard work paid off when I won all gold in each swimming event I entered, and set all new World Records in my age group! I was positively overwhelmed with my experience, and the confidence gained from working hard towards these goals... something I couldn't have imagined being able to do, just three short years prior.

So, you could imagine my disappointment when the pandemic hit and the 2021 World Transplant Games in Houston were cancelled. I had been on a roll - setting goals, swimming and feeling really good about creating awareness about the importance of organ donation. So, I decided I wasn't going to sit back all year and wait for the world to return to some kind of normal where we could compete. I called up my friends that I had met at the games, and told them about my big idea to swim across one of the 5 Great Lakes here in Ontario.

What we ended up doing was creating a foundation where we could funnel our energy and ambition to give back to the transplant community. We decided on the name "Move for Life Foundation". This encapsulated the passion and gratitude we have to be able to move our bodies for optimal health and wellness, while honouring our organ donors, and also because we hope to inspire others to move, and to save lives by raising funds using our sport challenges to see our mission to shorten the wait list for an organ transplant come true.

“What we ended up doing was creating a foundation where we could funnel our energy and ambition to give back to the transplant community.”



Jillian, straight of out Lake Ontario, with the Move for Life team

2020 was actually an incredible year for me. I began my training for the swim across Lake Ontario. The route I had decided on has some pretty cool history. It begins in Niagara-on-the-Lake, Ontario, and I continuously swam 52km (32.5 miles) across to the other side of the lake, to Marilyn Bell Park in Toronto. Marilyn Bell was the first person to have ever swam across Lake Ontario in 1954. I was the 66th person to have followed her path, and the first transplant recipient to have ever swam across a great lake! The swim itself took 18 hours and 36 minutes to complete, so as you can imagine, my training for this marathon was astronomical! I swam anywhere from 20-65km a week, 3-25km a day, and challenged myself as much as I could by swimming in all conditions, so I could be as prepared as possible for whatever mother nature gave me on the day I had decided to swim across the lake.

Ultimate goal

Aside from a gruelling but successful swim across Lake Ontario, my Move for Life team and I have raised \$180,000! Our ultimate goal is to raise \$250,000 to implement a new program for my local hospital, by purchasing a new piece of equipment called ARP (Abdominal Regional Perfusion). The London Health Sciences Center (LHSC) will be the first hospital in Canada to implement ARP! Instead of transporting organs on ice, which aims to delay the death of viable organs, this new technology will keep

organs warm, oxygenated, and alive. This means that donated organs can stay viable for a longer time before being transplanted, resulting in more successful transplants thanks to fewer post-transplant complications and reduced wait times.

To raise the remaining \$70,000, we're planning another epic event for 2022. We're also excited to be selling merchandise on our website, with all profits going towards our mission! The commemorative Lake Ontario swim merchandise can be viewed and purchased right through the move for life website. Bookmark the website so you can stay up to date on the details of our next event and to discover how you can help our mission!

It's been incredibly rewarding to give back to the transplant community and help others in the dire situation that I was once in, while honouring my organ donor, and living life to the fullest!

I'll be over here in London, Canada, planning Move for Life's next event and training for the 2023 World Transplant Games in Perth Australia! I hope to see you there. You'll find me on the pool deck...

Jillian Best
Canada

If you'd like to read in more detail about my swim across Lake Ontario, you can visit the foundations website and read my blog: <https://www.moveforlifefoundation.com/blog/the-journey-to-the-other-side>

COVID-IMMUNO



COVID-IMMUNO: A research project part of the Projet Laurent research program investigating mental health and healthy lifestyles of immunosuppressed individuals and their relatives in the context of COVID-19

Authors and affiliations

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Introduction

The context COVID-19 pandemic has led to unprecedented efforts to institute the practice of physical and social distancing (PSD) in countries all over the world. The PSD measures instigated in Canada have led to major changes in lifestyle habits and social relationships among the general population. These changes were even more important among populations whose immune system is suppressed or compromised. These immunosuppressed or immunocompromised populations include patients taking immunosuppressive drugs (transplant recipients, cancer patients, patients suffering from rheumatic/ autoimmune diseases) and other vulnerable populations with compromised immune systems such as people with chronic kidney disease and HIV (Brooks et al., 2020; Lupi et al., 2020; Williams et al., 2020).

The current project was derived from a larger project, *Projet Laurent*, following the onset of the COVID-19 pandemic. *Projet Laurent* (projetlaurent.org) is a pan Canadian one-health project, initiated and co-developed by patient partners, researchers and health professionals from multiple disciplines. Their vision is to enable immunosuppressed patients to safely own pets in order to reap a multitude of benefits, all while minimizing the risks of infection. The COVID-IMMUNO subproject aims to provide a better understanding of the impact of COVID-19 and the PSD measures on lifestyle and mental health indicators of immunosuppressed individuals and their relatives. Impact of pet ownership on lifestyle and mental health indicators during this pandemic context will also be evaluated.

Methodology

Participants were recruited through the Canadian Donation and Transplantation Research Program (CDTRP) network, other organisations including the Kidney Foundation of Canada, Canadian Society of Transplantation, Lupus Canada, Crohn's and Colitis Canada, Canadian Liver Foundation and social media. Two online questionnaires were administered to participants: a first baseline questionnaire in May-August 2020 (T1) and a second follow-up questionnaire in May-September 2021 (T2). Both online questionnaires were presented in several sections and covered various topics.



Figure 1. Topics covered by the COVID-IMMUNO project

A total of 138 and 218 participants completed, respectively, the T1 and T2 questionnaires and 93 participants completed both T1 (2020) and T2 (2021) questionnaires (Figure 2).



Figure 2. Total number of participants at T1 (2020) and T2 (2021)

Preliminary results from 2021 (T2) questionnaire

Participant profiles

Three quarters of participants were women (76%) and 81% were English speaking. All participants were over 18 years old and distributed through various age groups (Figure 3). 54% were transplant, tissue or stem cell recipients whilst 33% were immunosuppressed, but not transplanted. The sample was also consisted of organ, tissue or stem cell donors (2%) and family members or relatives of transplant recipients or donors (8%) (Figure 4).

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COVID-IMMUNO

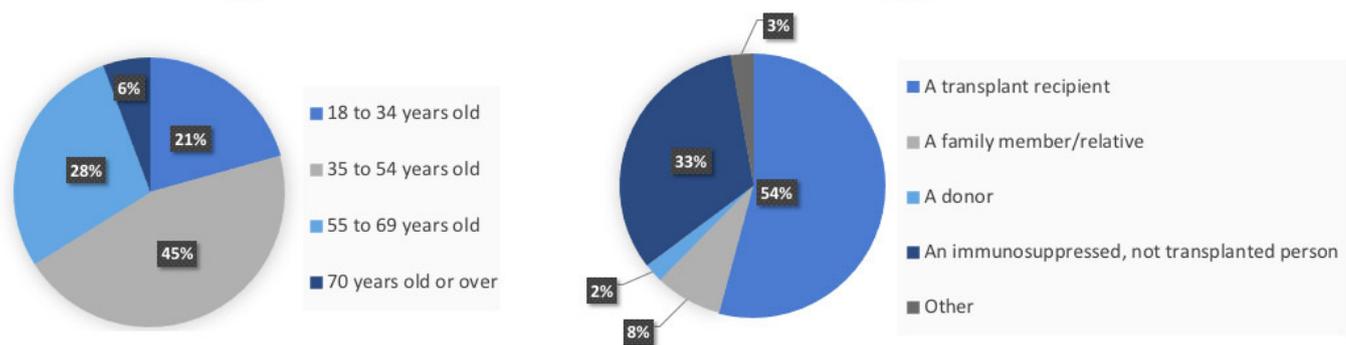


Figure 3. Participant age (Left panel) and status (Right panel)

Physical activity

Vigorous physical activities (VPA), such as aerobics and fast cycling, refer to activities that take hard physical effort and make individuals breathe much harder than normal. In 2021 (T2), on average, participants reported practicing VPA for at least 10 min for 1.4 days during the past 7 days. When asking participants whether their VPA practice changed since the onset of the COVID-19 pandemic, 43% reported a slight or substantial decrease, whilst 19% reported an increase in their VPA practice. Similar outcomes were reported for **moderate physical activities (MPA)** in 2021 (T2). MPA refers to physical activity that take moderate physical efforts and include activities such as jogging or cycling at a regular pace or doubles tennis. Participants report practicing MPA for at least 10 min for 2.1 days during the past 7 days. 39% reported a decrease in their MPA practice and 24% reported an increase following the onset of the COVID-19 pandemic.

However, the reported walking frequency was on average 5.1 days/week (this includes walking at work and at home, walking to travel from place to place, and any other walking that individuals did solely for recreation, sport, exercise or leisure). In 2021, nearly half of participants indicated that their walking frequency increased (42%), although 29% reported a decrease in number of days walking when they were asked whether their walking practice has changed since the onset of COVID-19.

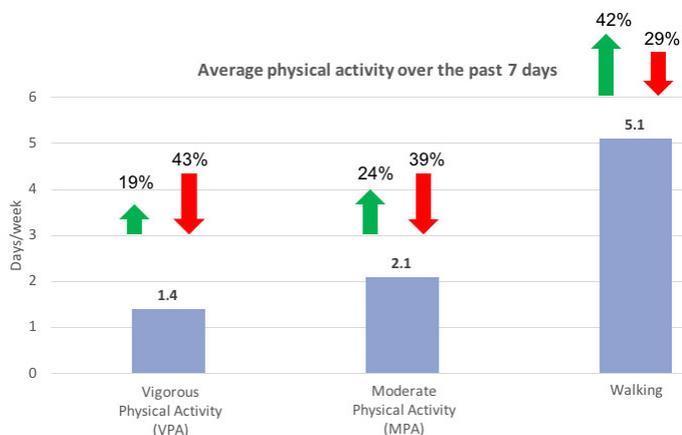


Figure 4. Number of days per week practicing vigorous and moderate intensity physical activity as well as walking (blue stripes) and perceived change in these movement behaviors (red and green arrows) reported in 2021.

Eating behaviors

In 2021, when they were asked about changes in their eating behaviors since the onset of COVID-19, participants reported an increase in snacking frequency (64%), drinking alcohol (22%) and eating meals in front of a screen (39%). Changes were also reported in food consumption; 14% reported a decrease in their consumption of fruits and vegetables, whilst 34% reported an increase in fast food consumption.

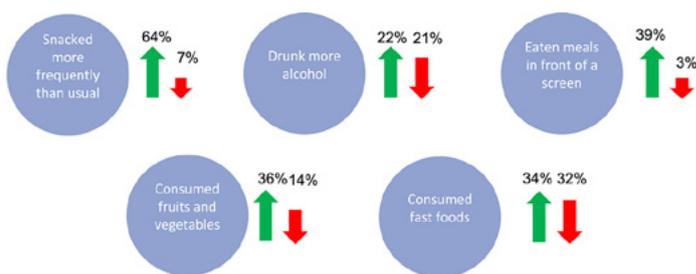


Figure 5. Perceived change in eating behaviors (red and green arrows) reported in 2021.

Conclusion

In conclusion, our preliminary results suggest that the COVID-19 pandemic left its trace on immunosuppressed populations yet in 2021, a year after its onset. Its impact was observed on lifestyle behaviors, including physical activity practice and eating behaviors. Further analyses will be performed, and more comprehensive results provide a granular understanding of these impacts. This project will provide new scientific knowledge and will inform the development of evidence-based tools (including physical activity practice and healthy eating behaviors) to adequately support immunosuppressed populations and their relatives during stressful contexts such as the COVID-19 pandemic.

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Iran's friendly competition

National Athletics event for transplanted patients held with 130 participants

I.R. Iran Specific Patients and Transplant Sports Federation once again started its yearly routine of holding a national event after following about two years of absence due to Covid-19 pandemic. Only this year, instead of one huge event containing every sport, national events are being held as several smaller events.

This year, Athletics for transplanted patients ignited the torch of the Iranian National Games in Shiraz, Fars, Iran, which is the fifth most populated city of Iran and without a doubt one of the most historical and beautiful.

130 athletes (35 females and 95 males) from 22 of the 32 cities of Iran participated in this friendly competition from 30th November 2021 until 3rd December 2021.

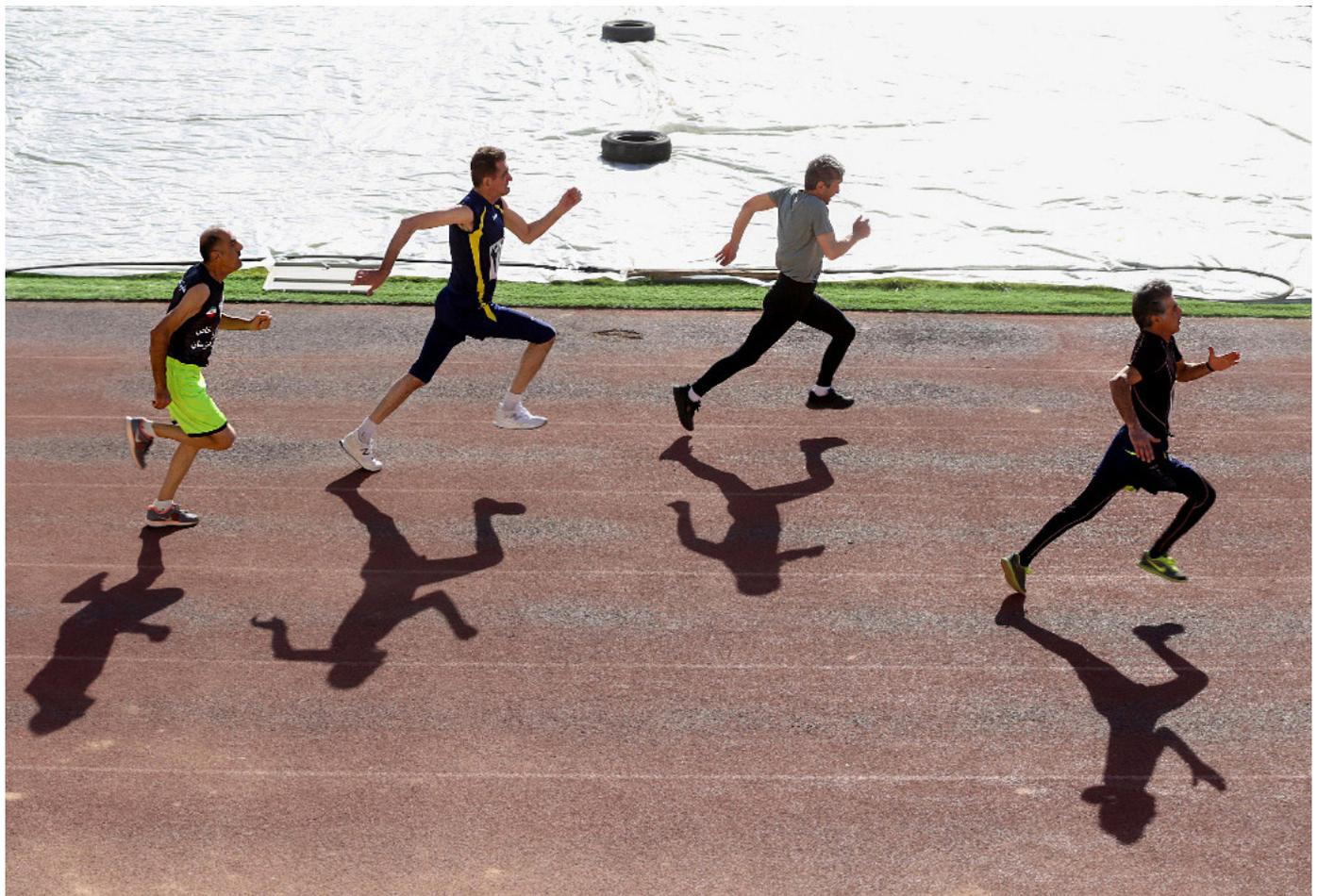
This year's event, like previous ones, was held for everyone according to their age range (just like World Transplant Games events).

During the games, participants were given the option to do some sightseeing. Shah-e-Cheragh and Hafeziye were some of the options which both hold a lot of historical and cultural value.

The top three athletes in every field received a certificate and a medal.

The I.R. Iran Specific Patients and Transplant Sports Federation have Table Tennis, Squash, Petanque, Darts and Badminton national events coming up over the next two weeks.

Seyed Mohsen Mousawi
Iran



COUNTRY MEMBER NEWS

Hungary's eagerly awaited games



The City of Kings hosts Hungarian Transplant Games and the Hungarian Transplant Federation's lifestyle camp

The first Hungarian Transplant Games and the Hungarian Transplant Federation's lifestyle camp organized by the Hungarian Transplant Federation (HTF) were held in Székesfehérvár, the city of Hungarian kings, between August 25 - 28, 2021.

We were eagerly awaiting this event, as we could only keep in touch electronically during the pandemic. The event was held with maximum adherence to safety regulations. Transplant recipients, those who are on dialysis, donor families and the family members could participate only after two vaccinations with a certificate of protection issued by the Hungarian Health Organization.

Unfortunately, the pandemic negatively affected not only our health but also our mental state, many of us went through the disease and we lost some to our deep sorrow.

But the great day had come and in the beautiful lakeside hotel, in beautiful surroundings we have finally been able to meet our fellow transplantees, embrace each other for a very long time, talk, laugh big ones, and forget about everyday life. We could try different kinds of sport and compare our strength in ours.

The opening ceremony took place not far from the hotel in a sports centre,

where Attila Mészáros, Deputy Mayor of Székesfehérvár, Judit Berente, President of the Hungarian Transplant Federation, and Irma Csikósné Kiss, a representative of organ donor families, gave a speech that was followed by a traditional folk-dance performance.

Sports conference

The next morning the official program continued by a sports conference for mainly the athletes, on which we were able to follow presentations on the effects of exercise and sports on transplant recipients, interaction of nutrition and sports, on sports psychology and weight management as well. The presentations were interpreted by famous professionals as nephrologist, cardiologist, aftercare doctor, dietitian, and sports psychologist.

The national and international competition system for organ transplants and the "Million Steps for Life" challenge developed by the Hungarian Transplant Federation were also presented.

The Hungarian Transplant Games competitions began in the afternoon, with the sport of badminton and darts, and then continued in the following days with tennis, bowling, athletics, swimming, petanque and table tennis.

In addition to the competitors, all participants of the 4-day event could

try out not only the sports included in the federation's competition calendar but streetball, teqball, football, ground golf and laser run as well. The bicycle tour around the nearby Lake Venice, the daily Nordic walking and senior- and folk-dance exercises were very popular.

Anyone who wished had the possibility to attend psychologists' spiritual immune-boosting sessions, or have a portrait photo taken of themselves to be seen on the weekly television news of the Organ Coordination Office on the M1 TV screen.

The series of events closed with a gala dinner, after which we were dancing until dawn. It was a week full of very well-organized programs, very useful presentations spiced with lots of sports, in a very good mood and wonderful sunny weather.

I think that on behalf of the Hungarian athletes, I can say that the Hungarian Transplant Games, organized for the first time this year in the model of the European and World Games, partially compensated us for the missed Dublin European and Houston World Games.

But of course, there is nothing to give back their feeling. Thanks to the organizers, the volunteers, I hope to see you again soon.

Gabriella Szabó

Athletes' Advisory Committee member
Hungary

COUNTRY MEMBER NEWS

Germany holds TransDia Sports Weekend

A great response to 'exercise meeting' for vaccinated athletes



The pandemic demanded a lot of sacrifices from our members. For the second time, our national championships for transplanted and dialysis patients had to be cancelled in May 2021 for well-known reasons.

Over the summer, the idea arose to make a "exercise meeting" possible for all fully vaccinated athletes. After many considerations and intensive preparations, we were able to hold the sports weekend from 1-3 October 2021.

All participants, active and passive, were fully vaccinated and tested negative for Covid-19 on the day. All hygiene rules, such as distancing, wearing masks and hand sanitising were communicated for the indoor areas as well as for the sports facilities and made visible by posters and controlled by volunteers.

The response to our invitation was

great, it corresponded to the frequently mentioned wishes of our members, which had been communicated via WhatsApp or Signal groups. 95% of those registered took part in this sports weekend and spent pleasant days in familiar fellowship. Nobody was infected by Covid-19 after the weekend.

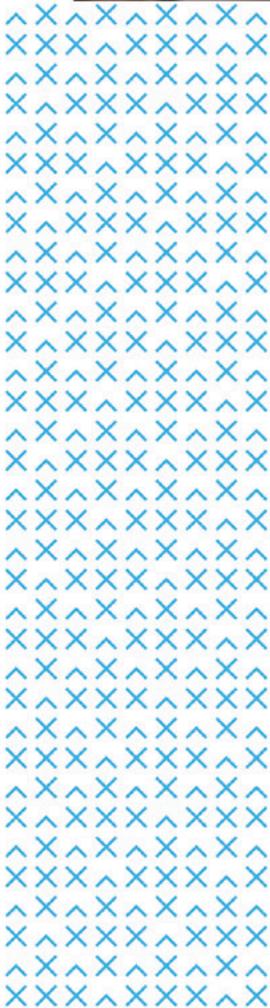
We are confident that we will be able to hold our German Championships for transplant and dialysis patients again at the usual date in May 2022.

Gudrun Manuwald-Seemüller
TransDia Sport Deutschland e. V.
Germany





Novartis



Novartis is proud to support World Transplant Games Federation

At Novartis, we harness the innovation power of science to address some of society's most challenging healthcare issues. Our researchers work to push the boundaries of science, broaden our understanding of diseases and develop novel products in areas of great unmet medical need. We are passionate about discovering new ways to improve and extend people's lives.

