

TransplantWorld

2021 | Issue 1

Journal of the



World Transplant Games Federation
Powered by the gift of life

INSIDE THIS EDITION

Virtual Golf tees off

The facts about vaccination

5K AnyWay wrap-up



Sharing The Love

TX the Teddy Bear providing hope for
kids waiting for a transplant

Inside this edition

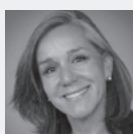
- 03** A message from WTGF President
Chris Thomas
- 05** Guest Editorial *Dr Gareth Wiltshire*
- 06** Introducing the new WTGF Trustees
- 08** Future events: Perth, Australia 2023
- 10** Future events: WTGF 2021 virtual Golf event
- 11** 5K AnyWay
- 12** A legacy has started...
- 13** Transplant Pregnancy Registry International (TPRI)
- 17** From TACKERS to TRIE CIC
- 19** Transplant Hub Conversations
- 20** Refit for Life! Mental Well-Being - Embodying Your Transplant
- 23** HeroKi Kidney Shield

Officers and Trustees

Executive:



Chris Thomas
President



Liz Schick
Honorary Secretary



Colin White
Treasurer

Trustees:



Judit Berente



Anders Billström



Ka-foon Chau



Ashleigh Duran



Paul Harden



Yuhji Marui



**Edith Alejandra
Martin Pinto**



Gerardo Reyna

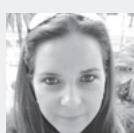


**Gudrun Manuwald-
Seemuller**



Willie Uys

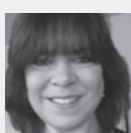
Staff:



Kim Renyard
Executive Manager



Gary Green
Sports Manager



Karen Cole
Office Administrator

Acknowledgements

Editor: Chris Thomas

Sub Editor: Colleen Horan-Green

Content/Article Coordinator:
Karen Cole

Artwork: Inkcap Design, Bath, UK
www.inkcapdesign.co.uk

Front cover: 'TX the Teddy Bear'
by Kim Reynard



Powered by
the gift of life

WTGF

Basepoint Business Centre
1 Winnall Valley Road
Winchester
SO23 0LD United Kingdom

Tel: +44 1962 832560

Email: wtgf@wtgf.org

Website: www.wtgf.org

*Registered Address: World Transplant Games
Federation, Basepoint Business Centre,
1 Winnall Valley Road, Winchester, Hampshire,
SO23 0LD, UK
Registered Charity No.1179470
Company limited by guarantee No.10323481
Registered in England*

MESSAGE FROM THE PRESIDENT

Let the facts speak for themselves

WTGF President **Chris Thomas** on vaccination advice



In the United Kingdom it's singer Elton John and actor Michael Caine who have been recruited to promote vaccination. In Berlin, it is an elderly woman 'flipping the bird' (lifting her middle finger) against people who don't wear masks. In Singapore it's disco music. And in New Jersey it is the promise of a free beer for anyone aged 21 plus who gets a shot.

Across the world governments have adopted different tactics to encourage populations to be vaccinated against COVID. Some are amusing, some serious, all attempt to address the new buzz term of the year – vaccine hesitancy.

Without attempting to lighten the seriousness of this subject, thank goodness those under four didn't express vaccine hesitancy when their mums and dads took them to the doctors to be vaccinated for life-threatening illness such as measles, rubella, mumps, polio, chicken pox and whooping cough. Imagine a world where these horrible diseases were still prevalent.

But what about the transplant population? Do recipients need campaigns to get vaccinated or is their faith in medicine and science so great that getting the jab comes naturally?

Recipients are, of course, listed as one of the potentially vulnerable groups that has had to be protected these past 18 months. Anyone immune-suppressed has been included in government arguments as to why whole societies have shut down to slow the spread of the disease. And with good reason. But of course, the arguments are really not that simple.

Personal choice is paramount in these decisions although we all notionally support the concept of the 'greater good'. However, when it comes to our own body, and what we allow to be injected into it, it is understandable we want a say.

So, while Rocketman may have his place in convincing the British public to be vaccinated, I suspect recipients want just a little more information.

On June 30 the NHS Blood and Transplant and the British Transplantation Society released its latest advice on COVID-19 Vaccination in Transplant Recipients and Patients Waiting for a Transplant.

If you wanted proof as to the benefits of vaccination, I suggest this advice be read by every recipient across the world. You see it wasn't a doctor espousing the

virtues of vaccination, it was, for the first time, the facts speaking.

Here's a snapshot of the proof they have released after careful analysis of COVID cases in recipients:

Between 8th Dec 2020 – 24th of June 2021:

- Of approximately 6,700 transplant recipients who had not received even one vaccine dose, 7% (466) contracted COVID-19. Of these, 40% (189) died within 28 days of a positive COVID test.
- Of approximately 39,000 transplant recipients who had received both vaccine doses, less than 1% (76) contracted COVID-19 two weeks or more after second vaccine dose. Of these 8% (6) died within 28 days of a positive COVID-19 test.
- Of approximately 650 patients on the transplant waiting list who had not received even one vaccine dose, 8% (51) contracted COVID-19. Of these 17% (8) died within 28 days of the positive test.

Continued on next page

“Do recipients need campaigns to get vaccinated or is their faith in medicine and science so great that getting the jab comes naturally?”

MESSAGE FROM THE PRESIDENT

- Of approximately 3100 patients on the transplant waiting list who received both vaccine doses, less than 1% (5) contracted COVID-19 two weeks or more after the second vaccine dose and none died within 28 days of the positive test.

Let us just emphasise these figures for a moment.

- The unvaccinated transplant population got COVID at 7 times the rate (7% compared to 1%) of the vaccinated population.
- Once you got COVID unvaccinated recipients had a 40% chance of dying compared to just 8% if you were vaccinated.
- The results were similar for those on the waiting list.

Before moving on to the obvious conclusion of this President's report let's spare a moment for the families and recipients behind these statistics. A significant number of deaths from COVID and this is just one country!

I think it would be fair to say that the facts speak for themselves. Please, if you haven't already done so, get vaccinated now. And if you can't get access to vaccines, raise hell. Write to your government, your health authorities, tell them the urgency.

Yes, there is light at the end of the tunnel. It's a jab, a jab on the path back to freedom. In the meantime, stay safe.

Chris Thomas
WTGF President



Please, if you haven't already done so, get vaccinated now."



Introducing TX the Teddy Bear

Across the world TX the Teddy Bear has been greeted in the last month or so by the open arms of kids waiting for a transplant. The idea came about with the World Transplant Games due to be held in Houston, Texas. The Games were not to be but, in its place, came the 5K Anyway Celebration.

A brilliant legacy from that event is TX the Teddy Bear and it is a beautiful way for the transplant community to think about and help the next generation of transplant recipients. Even more important is the hope it instils in the mums and dads of these kids waiting – and for them to know there are recipients out there thinking of them.

At the WTGF we have great plans for TX the Teddy Bear. Stay tuned.

GUEST EDITORIAL

Research is essential



Research into physical activity after transplant has been a key objective of the WTGF for some years. The appointment of **Gareth Wiltshire** to co-chair the Research Committee alongside Trustee Anders Billström should ensure we get the answers to help validate the underlying belief that, when it comes to transplantation, exercise is indeed medicine.

Research is essential to saving and sustaining the lives of organ transplant recipients. This is already well understood. Most people in the transplant community are rightly in awe of the medical research that has allowed clinical teams to do the amazing things that they do. However, with more recipients living longer and healthier lives than ever it is important to broaden the remit of research to include aims that look beyond survival.

Fortunately, there is a growing number of researchers, recipients and clinicians interested in investigating how recipients can live healthy, fulfilling and meaningful lives after surviving an organ transplant. A vast array of exciting research topics opens up when we think about such aims. Life after transplantation is, of course, reliant on the physiological functioning of the body. Yet, if recipients are to live well after transplantation it would be wise to pay attention to the importance of psychological experiences, social support, life opportunities, healthcare systems and supportive policies and regulations.

Across all of these areas, there are gaps in knowledge and curious questions to be answered. Like many other researchers, I believe that sport and exercise can have enormous benefits for transplant recipients and should be considered an important area

of future research.

Research that I have been involved in focuses on the personal and social aspects of sport and exercise after organ transplantation. After my wife, Emma, had a liver transplant in 2014 and subsequently participated in the World Transplant Games, it was clear to me that sport and exercise had a significant impact on her and other recipients that she met and became friends with. Yet, participating in sport and exercise came with challenges. Many of these challenges appeared to be common to other recipients and therefore something to learn about in order to inform how future recipients are supported.

One of our initial research studies found that organ transplant recipients experience exercise in unique ways. The participants that we interviewed spoke about a sense of feeling continually 'in-between' feeling fit and healthy and still having an illness. They also told us that doing exercise involved a sense of duty to stay healthy, look after themselves and show gratitude towards the person who donated their organ. Our research showed that Transplant Games events are not only part of a personal journey but can be a collective experience and a source of community. People widen their social network after attending Transplant Games events and then use this network to exchange knowledge,

seek emotional support and gauge health expectations for the future based on the health of other recipients.

It is encouraging to know that many other researchers are working hard on seeking answers to important questions across a range of disciplines and specialities. For example: Is there a relationship between exercise and mental health? Does fitness improve long-term health after transplantation? What are the limits to sporting performance for people on immunosuppressive drugs? Does intensive exercise impact immune function? What can healthcare professionals do to help recipients become more physically active?

Proactively showing support for this research, the World Transplant Games Federation has set up an initiative to accelerate, facilitate and coordinate research activities that are taking place internationally. I know that I speak for other researchers when I say that this initiative is incredibly welcome news and is a sign that research into sport and exercise for organ transplant recipients has a healthy future.

Dr Gareth Wiltshire

Lecturer in the School of Sport, Exercise and Health Sciences
Loughborough University (UK)

“Many of these challenges appeared to be common to other recipients and therefore something to learn about in order to inform how future recipients are supported.”

NEW TRUSTEES

World Transplant Games Federation welcomes new Trustees

Meet the three new trustees joining the Federation's governing board

Judit Berente Hungary



Judit became a kidney transplant recipient in 1995, after 19 years of chronic kidney failure. She started transplant sports six months after her operation and since then she participated successfully in all the World Transplant Games (12 summer and nine winter Games) and all the European Games and Championships up until now. Judit herself felt the benefits of sport after transplantation and committed herself to transplant sport at both national and international level - not just as an athlete but also working for the National Government Organisations (NGOs).

Judit is the president of the European Transplant and Dialysis Sports Federation (ETDSF) as well as the Hungarian Transplant Federation. The ETDSF coordinate the organisation of the European Transplant and Dialysis Sports Championships, which has been organised every two years since 2000 with increasing number of participants. The Hungarian Transplant Federation operates sports programs in 11 different sports, not just for transplant recipients but also for dialysed patients, and also run a patients' education programme, called Be Educated and Empowered Patient (BEEP).

Judit served the WTGF as a Councillor between 2005-2009 and is delighted to be returned to the Board again.

Ashleigh Duran USA



Ashleigh is a liver transplant recipient and received her gift of life because of the selfless act from her youngest sister Maurisa, who donated a portion of her liver to save her sister's life 6 years ago. Ashleigh resides in the Chicagoland area of Illinois and is a Co-Owner of Flight Club Power Tumbling & Trampoline, where she coaches tumbling & trampoline to youth athletes ranging in ages from 3-18 years of age for both recreational classes and competitive team athletes.

Ashleigh is also a Fit for Life Ambassador of the World Transplant Games Federation and volunteers with Donate Life Colorado as an advocate for organ and tissue donation. Ashleigh participates in the World Transplant Games as a member of Team USA for volleyball and athletics track & field. Ashleigh is a wife, mom of two young kids (Emma seven years old and Lucas one year old), a homeschool teacher, and an athlete. She stays active by exercising, coaching sports, playing volleyball, and stays busy keeping up with her children.

Outside of coaching, Ashleigh enjoys spending time and relaxing with her family and friends, cooking, crafting, attending Broadway theater and ballets, reading suspense novels, is a very big Harry Potter fan, a big movie geek, and loves living life to the fullest.

Chris Thomas, the President of the World Transplant Games Federation, has welcomed three new trustees to the governing Board of the Federation while acknowledging the contributions of those who had served the worldwide transplant community recently.

At the General Assembly of the WTGF on 17 June 2021 the outcome of the recent trustee elections was announced.

Newly-elected on to the Board were Judit Berente from Hungary, Ashleigh Duran from the United States of America and Gerardo Reyna from Spain.

Chris gave his thanks to the outgoing trustees for their work - Andre Lassooij, from the Netherlands, Dr Won Hyun-Cho from Korea and Dr Zach Brooks from the United States of America.

Gerardo Reyna Spain



Gerardo was born in Mexico City in January 1981. He has a degree in Audio-visual Communication and Journalism; is fluent in Spanish and English and speaks and understands Italian.

Gerardo began having liver problems from a young age but it was not until 2011 that he was diagnosed with an autoimmune hepatitis. Gerardo received his transplant in March 2012 when he was living in Madrid.

Since the beginning of life as a recipient, Gerardo has understood the importance of emotional and psychological aspects to well-being. Gerardo's life changed when he met a small group of friends at the assembly of the Asociación Deporte y Trasplante España. With a great deal of work from this group the project grew culminating in the World Transplant Games in Malaga in 2017 with Gerardo leading the Spanish team as team manager.

Gerardo: "Finding people who have experienced the same as you, that understand your fears, your concerns, joys and successes was life changing. Since then, we have collaborated with the Association, I say 'we' because my wife, Andrea, has always been by my side in this beautiful and challenging battle known as transplant life."

Fill your heart



PERTH 2023

The
Greatest
Gift
for All

15 April – 21 April 2023
worldtransplantgames.org

Proudly supported by



Perth





Perth 2023

World Transplant Games

Make it Count Down Under in 2023

Meet swimmer **Bryan Williams** from Perth, Western Australia, host city of the 2023 World Transplant Games

Hi, I'm Bryan Williams, I'm 47 years old and 15 years post my heart transplant. I live in beautiful Perth, Western Australia, host city of the 2023 World Transplant Games.

Perth has a population of approximately two million people and is located on the West Coast of Australia. It has the most fantastic beaches and climate, which feeds my passion for open water swimming. I regularly swim at Cottesloe Beach, one of Perth's iconic tourist locations, located a short drive from the city.

From Cottesloe Beach, you can gaze your eyes over the Indian Ocean to Rottnest Island, situated 20km off the coast. Rottnest Island is a tourist mecca and an oasis with white sandy beaches and sparkling aqua water. Rottnest is famous for a cute little creature called a quokka, part of the kangaroo family, that inhabits the island.

One of my favourite events of the year is the Rottnest Channel Swim, held on the last weekend in February. Over 2,000 people participate, swimming from Cottesloe across the channel to



Bryan at Rottnest Island

Rottnest Island in a team of four, a duo (2) or the crazy solo swimmers.

Since my heart transplant I have completed three 20km marathon open water solo crossings of the Rottnest Channel Swim, two duo crossings, as well as four team swims.

The swim is a massive mental and

Continued on next page



*Cottesloe Beach, Perth
(Tourism Western Australia)*

PERTH 2023

physical challenge, which takes me over six hours to complete. Swimmers face many challenges along the way, including jellyfish stings and hypothermia. But the sheer satisfaction of touching the sand at Rottnest after all that training and commitment is well worth it. A beer in the pub and an ice cream at Simmo's on Rottnest never taste better!

Initially, I took up swimming as part of my rehabilitation after my heart transplant. I competed at my first Australian Transplant Games only 11 months post-transplant, winning five gold medals in the pool. This gave me the bug, and I have since competed at five Australian National Games. Swimming is my passion and I use this platform to honour my donor and to advocate for the importance of organ and tissue donation as often as I can.

I have also been fortunate to compete at four World Transplant Games (Thailand, Sweden, Australia and South Africa) and made many friends around the world. Most recently, I competed in the 5K AnyWay virtual event, in lieu of the Houston Texas Games, winning a gold medal in the swimming for my 5k open water swim.

I am now fit and healthy and living life to the fullest, thanks to my hero donor and donor family, to whom I will be forever grateful. However, I have had



Bryan & family

“Perth, Australia is my hometown and my favourite place in the world. It has many fantastic sites that I would love to show off to my fellow recipients during the 2023 WTG.”

to overcome adversity all my life, setting me in good stead for the many athletic endeavours that I now embark on!

At just one year old, I was diagnosed with childhood cancer (Rhabdomyosarcoma of the bladder). Two years of intensive chemotherapy and radiotherapy saved my life – but the treatment took its toll. At nine years old I

was diagnosed with avascular necrosis (a bone disease), leading to 12 operations on my left hip during my teenage years. A few years later I was diagnosed with dilated cardiomyopathy (heart failure), a problem I fought for more than a decade before end stage heart failure. A heart transplant in 2005 gave me a second (or is that third) chance at life. My hip problems culminated in requiring a total hip replacement during 2010. Since my heart transplant my wife and I have celebrated the birth of three miracle daughters who bring us enormous joy.

Perth, Australia is my hometown and my favourite place in the world. It has many fantastic sites that I would love to show off to my fellow recipients during the 2023 WTG. There's the amazing Kings Park with views over the city and Swan River, Elizabeth Quay, historical Fremantle, Cottesloe Beach and of course Rottnest Island. Come join me for a selfie with a quokka over at Rottnest!

You can follow my journey to the WTG Perth 2023 on Instagram @htx_swimmer.

See you in '23.
Bryan Williams



A quokka selfie!

WORLD TRANSPLANT VIRTUAL GOLF CHALLENGE

You are invited to join our first
WORLD TRANSPLANT VIRTUAL GOLF CHALLENGE
and compete against golfers from around the world!

ABOUT THE CHALLENGE:

- Challenge runs from 01 August – 30 September 2021
- \$10 per registration
- Challenge is a Net Score Competition (ie: Play until you sink the ball and deduct your handicap to determine the outcome)
- Strokeplay Medal Competition format applies, where one plays every hole complete
- Win medals and prizes in your category
- Leaderboard updated weekly

CATEGORIES:

- Transplant Recipients
- Transplant Community and Supporters
- Male & Female Participation Categories

HANDICAP BANDS:

- 0 - 8 handicap
- 9 – 16 handicap
- 17 and Over handicap
- Male: Max. handicap 28 / Female: Max. handicap 36

HOW TO PLAY:

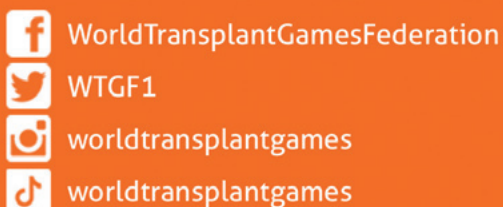
- Register for the Challenge **HERE** in your category and handicap band
- Select an 18-hole golf course in your area with a recognised course rating
- Play as many rounds of golf as you like during the challenge period, submit multiple scores
- You must play on the same golf course throughout the challenge
- Take a picture of yourself (selfie) playing on course
- Complete your scorecard showing Gross Score and Nett Score, course rating and handicap
- Verify your score by your local Pro Shop
- Submit your score online
- Your best score will always override your previous scores

REQUIREMENTS:

- You are required to have an official World Golf Handicap in order to participate
- It must be verified by a recognized authority in your Country

PLAY FOR YOUR CHANCE TO WIN!

For more information and to register – visit www.wtgf.org/golf/



LET'S SWING INTO ACTION & PLAY!

www.wtgf.org

5K ANYWAY

The 5K AnyWay – the largest global transplant event in history!

How Houston planned the record-breaking 5K AnyWay – virtually

Houston was set to host the 2021 World Transplant Games in the United States for the first time in 41 years, when a global pandemic rocked the world and brought virtually everything in it to a screeching halt. The key word in that opening sentence is of course *virtually*, because The Harris County – Houston Sports Authority was not going to give in and decided to find a way to bring the world and the transplant community together *virtually*, **Any Way** they could.

The idea was simple but the goals were monumental. The simple part was to just do it AnyWay. A virtual 5K, any way you wanted. Run it, walk it, bike it, swim it, bowl it or hula hoop it, just get out and do it AnyWay. The goals, however, were lofty and not for the faint at heart. Make this the largest global transplant event in history, have at least 20% of the participants be first time competitors in a World Games, log enough kilometers to go around the world, and leave a lasting legacy.

But as it turns out, that was just the beginning. America showed up like never before with more than 1,700 participants representing all 50 states. Worldwide 52 Countries from Andorra to Venezuela logged in their 5K's, and that goal of 20% new participants, well it was shattered with 81% signing up

for the first time ever. Add to that Global Coffee Chats, 96 supporting partners, more than 70 ways of participation, a mining team, a celebration including NASA, the International Space Station, multiple celebrities and Disney's EPCOT Center, not to mention a social media campaign that engaged more than 8 million, and it turns out the 2021 World Transplant Games exceeded ALL goals and indeed finished as the largest global transplant event in history.

But what about leaving that lasting legacy. Well, as it turns out, that just might be the best part. With an amazing partnership between Build-a-Bear, the Texas Medical Center and the World Transplant Games Federation, TX (pronounced Tex) the Teddy Bear was created and made with love and special wishes for children who are either on the transplant waiting list or have recently recovered.

TX wears a cape to represent the hero in all of us and truly made these kids feel like the superheroes that they are. In fact, Kit, a precious four-year old from the UK, not only received a bear, but wore his own cape, started his own team, walked his 5K around the hospital while visiting other kids and ended up receiving the first ever World Transplant Games Heart Award at the celebration, reminding us all, what the Games are all about. To date



Kit and TX participating in the 5K AnyWay!

over 500 bears have been shipped all over the world and we are just getting started! For more information on how to help put another bear in the hands of a special child or to see some photos of the kiddos that have received them, you can visit [WTG2021.com](https://www.wtg2021.com).

Holly Kesterson

WTG2021 5K AnyWay LOC
Harris County - Houston Sports Authority

“A virtual 5K, any way you wanted. Run it, walk it, bike it, swim it, bowl it or hula hoop it, just get out and do it AnyWay.”

TX TEDDY

A Legacy has started...

The 2021 WTG 5K AnyWay started the legacy of TX (Tex) the Teddy Bear

Children from all around the world have started to receive their TX Teddy while they are on the transplant waiting list or have recently received their gift of life.

The following children have all received their bears from teams competing around the world who unlocked TX during the 5K AnyWay event.

Through the WTGF Transplant Next Youth Program we plan to continue to spread awareness and hope by continuing the legacy of TX. We will be implementing strategies and initiatives to continue to get TX around the world to children on the transplant waiting list.



Ellie
Dublin, Ireland
Awaiting Kidney Transplant



Mohammed
United Kingdom
Awaiting Heart Transplant



Maddie
United Kingdom
Small Bowel Transplant



Yahya
Syrian Refugee
Received Kidney Transplant



Dinah-Rose
United Kingdom
Awaiting Liver Transplant

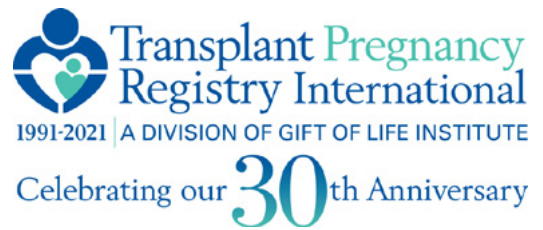


Giorgio
USA
Bone Marrow Transplant



Grace
United Kingdom
Awaiting Heart Transplant

TPRI



Parenthood after transplantation

Lisa A. Coscia on Transplant Pregnancy Registry International (TPRI)

The story of the Transplant Pregnancy Registry International (TPRI) begins with a compassionate doctor and his quest to help transplant recipients who wanted to start a family. When speaking with a patient in 1991, Dr. Vincent Armenti realized there was almost no information available about the possibilities for pregnancy after an organ transplant. He then established the National Transplantation Registry (NTPR) at Thomas Jefferson University in Philadelphia, Pa. to study pregnancy after solid organ transplant.

In 2016, the NTPR became the Transplant Pregnancy Registry International (TPRI) to reflect the need for our Registry to expand to include eligible recipients from around the world. The TPRI was started because no single transplant center would have enough outcomes to adequately study pregnancy after transplantation. The TPRI now has enrolled more than 2,880 transplant recipients with 4,900 pregnancies (includes multiple births) enrolled. The TPRI has now reached recipients in more than 27 countries.

“It is important to know that following a successful transplant, pregnancy is possible.”

The TPRI includes all types of transplant recipients including men who have fathered pregnancies and women who have had pregnancies. We collect all different types of pregnancy outcomes including live births, miscarriages, terminations, ectopic and stillbirths. Each recipient has a unique story that enriches our research, which in turn will also help other transplant recipients in the future.

In addition to gathering data, every year the TPRI fields hundreds of questions from transplant recipients and healthcare providers worldwide who are seeking answers to post-transplant parenthood questions. Each request is personally answered by our team. With help from their own healthcare team and with information provided by the TPRI, recipients can make the best decision about parenthood for them. Our database has pregnancy information that we have collected over decades. This helps us to provide vital data to those considering parenthood after a transplant. We continue to study pregnancies in all transplant recipients, now including uterus transplant recipients.

Voluntary pregnancy registry

The TPRI is a voluntary pregnancy registry. It not only seeks to include new post-transplant pregnancies, but also continues ongoing follow up with our recipients over the long term. Key questions that we have asked are – How might pregnancy affect the mother, her transplanted organ, and her baby? Our goal is to call recipients every 2 two years for this follow-up, to see how the recipient, their child(ren) and their transplant are doing over time.

Based on TPRI studies we have observed that it is especially important to have a planned pregnancy, as there may need to be changes in some medications prior to conception and for establishing stable transplant function. It is important to know that following a successful transplant, pregnancy is possible. Based on TPRI research and other studies, there are general

Advertisement



Continued on next page

TPRI

recommendations for women who have had a transplant to follow prior to planning a pregnancy. These general recommendations include:

- good general health for at least 1 year post transplant, to allow for sufficient time for transplant function to stabilize
- immunosuppression at maintenance levels
- low risk of infectious complications
- no rejection in the last year prior to pregnancy
- no high blood pressure or high blood pressure that is well-controlled
- no or minimal protein in urine

The babies born to women after transplant are generally born about 4 weeks early and weigh approximately 5 1/2 pounds. Mothers are at greater risk for high blood pressure and preeclampsia during pregnancy. During pregnancy there is not a great risk of transplant problems when pregnancy is started with a well-functioning organ. However, each organ recipient (kidney, liver, heart, lung, etc.) faces different challenges and to reiterate careful planning is encouraged and needed. Regarding fathered pregnancies based on TPRI studies, the overall outcomes appear to have outcomes similar to the general population.

The TPRI staff and collaborators have participated in more than 500 professional presentations around the world. Additionally, we are pleased to say that we have written more than 200 professional publications based on our study data. Each year, the TPRI also publishes an annual report that

How to participate:

Participation is easy and you can do it from anywhere in the world! Anyone who has had a transplant and then had a pregnancy or fathered a pregnancy can enroll. There is a 2-step process: first complete a short questionnaire to tell us about you and your transplant. Then we will call you if you are in North America or if you are elsewhere, we send another survey for you to complete. We also follow-up with recipients every 1 -2 years! We want to see how you, your child, and your transplant are doing long-term. We look forward to hearing from you!

The link to register can be found here:

www.transplantpregnancyregistry.org/participation

Our website link:

www.transplantpregnancyregistry.org

provides an overview of our pregnancy data, as well as the latest information from the studies we have conducted over the previous year. This report and our professional publications are available by request by emailing the TPRI team.

The TPRI currently stands as the longest-running voluntary pregnancy registry of its type in the world. Some of our early participants have now even become grandparents! We encourage all recipients to participate (see the box on how to participate). It is easy and it will help other transplant recipients in the future!

Lisa A. Coscia, RN, BSN, CCTC

Transplant Pregnancy Registry International



The TPRI Team

TPRI

Meet Erin

I'm so grateful for the Transplant Pregnancy Registry International (TPRI). I don't think we would have our precious son if I had not found out about the organization.

To start my story, I was diagnosed with kidney disease when I was in junior high school. I had lived so long with kidney disease, that I never thought I would need a transplant. But after almost 20 years, the slow steady damage from the disease caught up with me and I was shocked to hear the doctor say that I needed a transplant. At the time, I was just engaged, planning my wedding and my future, so I felt like I had been hit by a freight train.

I was beyond blessed that my amazing husband Ken was an excellent match. We always knew we were meant to be together, but him giving me his kidney and saving my life was a miracle. I received his kidney in 2014, a couple months before my 33rd birthday.

The recovery was tough, but I was soon in the best health of my entire life. We wanted to have a baby someday but were very concerned with putting my body through a pregnancy especially while taking immunosuppressants. We decided to speak to my doctors and look into if it was realistic to have a baby of our own. My doctors are wonderful, and they all said it was possible, they have had pregnant transplant recipients, and that they were there to help us through. But I needed to know more about the risks that could be associated with pregnancy after transplant, and I wasn't getting many confident answers.

I had always thought pregnancy after transplant would be too dangerous. I thought it would be highly likely that my child could have health problems from the medications I was taking. I needed to know what the probability of having a child with a birth defect was? I'd heard pregnancy is hard on your kidneys, would I lose my new kidney? Or worse, what was the chance my baby or I wouldn't make it at all?

I tried to find answers, but it wasn't until I found the TPRI that I finally had real answers to my questions. They sent me the most recent study and charts with information.

I had additional questions about some of the data, so I decided to call them. I was surprised at how easily I was able to speak with someone from the TPRI. One of the nurse coordinators, Lisa, answered all my questions. I remember tearing up on the phone because I was so relieved to finally have the information that I needed to make an informed decision. Additionally, I found out that the percentages of risks were much smaller than I had ever imagined. TPRI had so much valuable information and Lisa even gave me some post-transplant emotional support that I desperately needed.

After speaking with Lisa about



Erin and family

the TPRI data, we had the confidence to faithfully pursue having a baby.

My husband and I experienced several years of unexplained infertility, in part due to me running a high stress business. We wanted to get pregnant without IVF because of the expense and from wanting to have the extra assurance that my body was ready on its own. But months of trying turned into years and years of waiting. Ken turned 41 and I was almost 39, and we were very close to giving up our hopes of getting pregnant. But as soon as we made the decision to close my business and focus on me living a more peaceful life, I finally got pregnant!

Being pregnant and delivering during the Covid 19 pandemic had enough uncertainties, and since I was of advanced maternal age, it was wonderful being able to see the TPRI stats broken out by maternal age to give me confidence that even at almost 40, we still had a wonderful likelihood to have a healthy baby. We had our son in October 2020, and he is our healthy and happy little miracle.

The day I was able to contact Lisa again and add my own pregnancy experience to the TPRI database was a very special day. I was so happy to know that my information might help another recipient who has questions about parenthood after transplant. I encourage anyone who has had a pregnancy to contact the TPRI.



Erin and baby

TPRI

Meet Lisbeth

My name is Lisbeth, I am 35 years old, and I live in Denmark. My husband, Tobias, and I have two children; Eva who is 3 years old and Alfred, that was born a month ago. Both were born after my kidney transplant which is why it was never a matter of course that we would be able to have our own, biological children.

Here is more of my story, in 1999, when I was 14 years old, I was diagnosed with an autoimmune kidney disease. I was able to have a normal childhood until the day came, when the love of my life and high school boyfriend Tobias and I wished to start a family.

At that time in 2013 my kidney function, even though stable, had decreased to a point where my nephrologist strongly advised against pregnancy. Furthermore, we found out that my fertility was very poor (which is common in women suffering from kidney disease). We were told that it was very unlikely if not impossible - even if my kidney function improved - that I would ever get pregnant. This was a great, great sorrow for us.

However, six years ago, in 2015, my kidneys failed due to an infection and I had to start dialysis. This period of my life is a blur. I knew all along that I would probably need a kidney transplant one day, but still it came as a shock when the time actually came to have a transplant. It suddenly dawned on me that I was critically ill. I was fortunate to have Tobias by my side during this entire time, but I couldn't help but feel that I had put his life on standby as well. The uncertainty about his, mine and our common future numbed me.

On May 27th, 2016, I received my dad's left kidney and with that a whole new life. Even though I had some issues with regulating the immunosuppressive medications, frequent infections, and hospital admissions in the first month's post-transplant, I soon felt energy that I hadn't felt for years rushing through me.

In 2017 Tobias and I celebrated my new life by getting married. And then the honeymoon came. I consulted with my doctors and with that, out of the blue (well, not entirely out of the blue...!) and against all odds I got pregnant. I delivered a healthy baby girl!

Well, here we are three years later. I was able to get pregnant a second time! This time I had a baby boy. Both pregnancies resulted in healthy, beautiful children. We have become what we always dreamed to be: nothing more than an average Danish family.

“ Out of the blue (well, not entirely out of the blue...!) and against all odds I got pregnant.”



Lisbeth and family



Eva and Alfred

TRIE

From TACKERS to TRIE CIC



Meet the transplantee-led sustainability enterprise!

The Creators of TRIE

TRIE was founded by Cynthia Guillemain and Andrea Barrett in February 2021, after Cynthia posted on social media lamenting about the lack of sustainable ways to dispose of pill packaging and Andrea contacted her with a proposal. Linking the two is Baebhen Schüttke, now the inaugural Ambassador of TRIE. The creators of TRIE all have something special in common: they all had transplants as children.

These ladies all belong to the Platinum Club, meaning they are 20 years post-transplant: Cynthia received a kidney aged five; Andrea received a heart aged seven; and Baebhen received a liver as a baby. In the last two decades they met at the Transplant Adventure Camp for Kids (TACKERS) and the World Transplant Games, as both participants and volunteers. They are each multi-national, between them having links to England, Ireland, France, Austria, Germany and the USA.

Cynthia now works in a school as a Special Educational Needs Teaching Assistant. Andrea juggles managing

financial accounts for a charity supporting homeless people and undertaking postgraduate research in the medical humanities and Baebhen is training to be a lawyer. They share the desire and drive to want to make a positive impact in the world. And to make TRIE CIC a success, they need your help!

The Importance of Consistent Immunosuppression

As many transplantees know well, especially since the pandemic, #transplantlife involves both ups and downs. It is important that we both celebrate the good times fully as well as face tricky truths in the hard times. Only from embracing both may we continue on an 'onwards and upwards' trajectory. One of the tricky truths is that sometimes, immunosuppression non-compliance happens. Statistics show that there is higher incidence in adolescent transplant recipients. This can have tragic outcomes, and further research in the sphere of transplantation is needed.



Andrea Barrett & Baebhen Schüttke with their Skiing Awards at TACKERS circa 2006

We all want the gift of life to last a lifetime, and for that lifetime to include a giving back to the world. TRIE shares in this vision and seeks to promote sustainability post-transplant, both in the environmental sense of reducing waste, as well as the individual sense of sustaining health both physically and psychologically.

To achieve this, TRIE is developing a pill packaging recycling service, which will also help raise awareness about the importance of maintaining consistent immunosuppression post-transplant.

Instead of pill packaging polluting the planet and leaving a legacy of waste, the millions of pill packaging transplantees get through will have a way to be returned back into the chain of reusable materials. We hope to encourage members of the transplant community to develop further positive associations with their drugs. By taking drugs consistently it will be possible to send us a parcel of pill packaging sooner.



Cynthia Guillemain & Andrea Barrett representing #TeamTRIE in WTGF's 5K AnyWay



Cynthia Guillemain & Baebhen Schüttke as TACKERS Volunteers circa 2017

Continued on next page



TRIE

FAQs

What does the acronym TRIE stand for?

Transplant Recycling Initiative for the Environment. TRIE is a social enterprise and in the process of gaining status as a Community Interest Company.

What is TRIE's mission?

To enable the immediate and wider environment to become more sustainable, by enabling the recycling and repurposing of currently unrecycled medical waste both in the transplant community and more widely too. The philosophy of TRIE shares its spirit with that of the endeavor of transplantation itself: to extend lives and reuse valuable materials which would otherwise go to waste.

What is TRIE's current project?

Phase 1 of TRIE, planned for the next few years, is focused on transforming pill packaging into planet-friendly products. We are raising funds for a workshop, industrial shredder and other machinery

required to transform the pill packaging plastic-metals.

Before this big endeavor, the first project within Phase 1 is a Postal Delivery Scheme, designed to enable those taking medication to safely send on their pill packaging to be recycled by an external partner organization.

We are in the process of deciding the first city to roll this out to. So far, Winchester in England (the country where the World Transplant Games Federation happened to be founded and the city of its central office) is a big contender.

So far TRIE has begun meetings with interested financial backers, built a team of volunteer specialists to consult, and competed in the World Transplant Games' #5KAnyway as #TeamTRIE.

How can you help and get involved?

Keep your leftover pill packaging for when we roll out official collection later this year! Tell your transplant pals, continuing care centre nurses and

family about the initiative. Consider contributing to the TRIE GoFundMe. And most importantly, follow the official TRIE social media accounts on Instagram and Facebook. Likewise, please feel free to email trieworkshop@gmail.com, for the latest news and future opportunities to become part of the TRIE team.

Andrea Barrett

(with peer review by Cynthia Guillemin)



After 20 amazing years the TACKERS legacy passed from Swisstransplant to the World Transplant Games Federation in March 2021

Seeing Beyond Limits

New Frontiers in Transplant Diagnostics



The Immucor LIFECODES products increase your ability to find acceptable donors and provide new beginnings for more transplant patients.¹

LIFECODES®

Compatibility Solutions for a Lifetime

Visit www.immucor.com to learn more.



¹Ravindranath M.H., et al. Monitoring native HLA-I trimer specific antibodies in Luminesx multiplex single antigen bead assay: Evaluation of beads from different manufacturers. J. Immunol. Methods (2017) 450:79-90.

VIRTUAL VIDEOS

The WTGF launches Transplant Hub Conversations

The World Transplant Games Federation has recently introduced a new series of virtual video interviews called "Transplant Hub Conversations"

The interviews are being led by the fond and familiar face (or rather voice) of kidney recipient and keen cricketer - Lewis Daniels, who currently runs his own Podcast called Transplant Take on Sports.

At the Federation, we are continuously inspired by the journey of recipients in our transplant family. Our first three aspirants, all transplant recipients, share their stories with us and demonstrate how they have applied their experience

· Learn · Be Inspired · Give Hope · Learn · Be Inspired · Give Hope

Join us for...

TRANSPLANT HUB
Conversations

with Lewis Daniels

VIRTUAL VIDEO CHATS

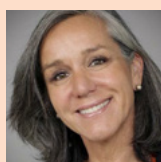
brought to you by the
World Transplant Games Federation



of transplant to teach and uplift others in their community. Each story is unique and we have enjoyed capturing their enthusiasm for life, and learning about how they overcame the challenges of transplantation.

In sharing these stories with our audience, we aim to inspire, give hope and offer encouragement to those who are at various stages in their transplant journey.

We are excited to introduce:



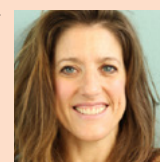
Liz Schick

Liz received her liver transplant in 1998 after being diagnosed with a rare cancer called Epithelioid Haemangioendothelioma (EHE). Liz has spent the last 23 years volunteering for everything and anything transplant related. Her journey led to her formation of TACKERS (Transplant Adventure Camps for children), working for Swisstransplant and serving as Honorary Secretary on the WTGF board. Liz has attended 10 summer games and six winter games, which she describes as a feeling of 'going home' each time. In her interview, Liz shares insight into the handover of TACKERS to the WTGF, how she forgave her body for letting her down and her advice for preparing physically and mentally for transplantation. As Liz would say – "When you are feeling down – get moving!"



Darren Cawley

"Have a goal - Get up, get out, get active and get involved" is the motto Darren Cawley lives and teaches. At 20 years old, Darren went from a healthy Sports & Fitness student, to being diagnosed with serious long term kidney disease. He subsequently underwent 11 years of dialyses, two kidney transplant and over 1800 hospital visits. During our interview, Darren talks about the lessons he has learned while overcoming all the highs and lows of transplant, and how to find growth through adversity. He shares his experience of attending various Transplant Games, the importance of Role Models and the vital role physical activity plays in living well. Darren now shares his tools in public speaking work, an eBook and online course where he tackles the mental, emotional, and social side of chronic illness.



Tina Clarke

Tina was diagnosed with Cystic Fibrosis at 4 months old, at a time when the disease was very rare and individuals didn't make it past childhood. Throughout her adult life, Tina searched for ways to compliment her current treatment, which led her to explore and train in a variety of holistic therapies. After receiving a lung transplant 7 years ago, she now specialises in working with chronic disease and transplant recipients. In the interview, Tina talks about how movement is essential, particularly after transplant. She explains various techniques that help to heal from a life altering event, by using therapies that not only work with the body, but the emotions and mental trauma that go along with this. Tina believes that we need to be kind to ourselves, and try to gain self-empowerment in one's journey to health and wellness.

REFIT FOR LIFE!

Mental Well-Being Classes Embodying Your Transplant



Introducing new classes as part of the WTGF Refit for Life! Toolkit

We recognise that mental well-being is a crucial element in rehabilitation post-transplant, and that dealing with trauma and stress can be a challenging experience.

As part of our Refit for Life! brand, the WTGF is committed to providing mental well-being resources which help recipients deal with the emotional elements that come with having a transplant.

A transplant is not a cure in itself, but a chance to start again. Transplantation is an area of medicine that falls outside of traditional care models. Recipients are given back their health but must strive to regain fitness to re-enter the workforce and learn about living with a transplant. They need to regain their confidence and overcome many physical and well-being issues.

Together with Tina Clarke Wellness, we are currently offering an 'Embodying Your Transplant' mental well-being live class series which started on the 26th May and will run for 8 weeks.

The classes have been offered to everyone over the age of 18 years old, who are at least 4 months post-transplant, with the aim to introduce recipients to the benefits of complimentary holistic therapy, alongside their usual physical sport and exercise routines. This Somatic practice / or body centred therapy looks at the connection of both the mind and the body when healing from a life altering experience, such as a transplant.

During the Embodying Your Transplant series, recipients will learn practical tools to help process what they have been through and safely explore the story held within their body after receiving a transplant. The live classes offer a series of gentle techniques: breath work, touch, sound, movement, and meditation, to build inner awareness, bring calm and balance to one's life, and rebuild a friendship with your body again.

These classes will form part of the WTGF Refit for Life! Toolkit and will be made available to everyone in the rehabilitation program after the series has ended.

The response to the classes has been extremely positive:

Noreen from South Africa:

"It's good to know that I'm not alone in the emotions and feelings I did and do experience. And it's made me realise that I need to 'focus on the moment' when I am exercising, so I am very grateful that you awakened that again for me today."

Dr Kin from Hong Kong:

"Thank you for the wonderful lesson. I did enjoy it and followed your instructions. The experience was great. Thank you for your time and effort."

Randy from USA:

"I very much enjoyed the discussion of somatic awareness. I do think that all of us transplant recipients carry the trauma of past operations within our mind-body selves. I look forward to learning more about accessing (and hopefully healing) this part of me."

The WTGF hopes to launch more mental well-being classes in the areas of motivational and clinical support in the near future.

Refit for Life! Team

World Transplant Games Federation

Continued on next page

REFIT FOR LIFE!

About Tina Clarke:

Tina has Cystic Fibrosis and received a double lung transplant 7 years ago. She has worked for over 20 years as a wellness & body orientated therapist specialising in working with people who have chronic disease and those who have received an organ transplant.

After years of gathering, exploring and experimenting, Tina believes that knowledge and tools are a fantastic way to feel empowered even with chronic conditions, where you can often feel so defeated or lost.



'EMBODYING YOUR TRANSPLANT' LIVE CLASSES

PRESENTED BY **TINA CLARKE**
wellness

WE INVITE YOU TO JOIN OUR MINDFUL BODY-BASED CLASSES AND DISCOVER A GENTLE AND HOLISTIC APPROACH TO MENTAL & PHYSICAL WELL-BEING POST TRANSPLANT

WHAT: SOMATIC PRACTICES
USING BREATH WORK, SOUND, TOUCH & MOVEMENT
BUILDING INNER AWARENESS

WHEN: 26 MAY - 14 JULY 2021
8 WEEK ONLINE COURSE - ONE CLASS PER WEEK

WHO: OPEN TO EVERYONE
AT LEAST 4 MONTHS POST TRANSPLANT

WHY: LEARN TECHNIQUES TO HELP PROCESS WHAT
YOU HAVE BEEN THROUGH
SAFELY REBUILD YOUR FRIENDSHIP
WITH YOUR BODY AGAIN

HOW: ONLINE VIA ZOOM, NO REGISTRATION FEE
LIMITED SPACE AVAILABLE

INFO: EMAIL FITFORLIFE@WTGF.ORG



INNOVATION



The HeroKi "Kidney Shield"

An innovation for the protection of the transplanted kidney

Five years ago, Alon Magal, a young civil engineering student received a kidney transplant after a long year of waiting on dialysis.

After his transplant, the doctors told him that a hard shock to his transplanted kidney could be fatal. It was then that he realized that he would not be able to regain his life as before and would have to be extra careful to avoid any trauma to the graft placed in the front lower abdomen. Alon was more determined than ever to keep himself safe and created his own safety belt. This is how the start-up HeroKi (www.heroki.co) was born.

In a study conducted by Prof. Dorien M. Zelle from the Department of Nephrology at the University of Groningen in Holland, it has been shown that cardiovascular mortality is estimated to be four to six times higher in kidney transplant recipients than in the general population. Regular physical exertion is recommended to reduce this risk. However, it is clear that a large majority of recipients change their sports practices, or even abstain for fear of an accident.

HeroKi is proud to be able to actively contribute to the rehabilitation of kidney transplant recipients with its innovation, the Kidney Shield.

Created by Alon Magal and his wife Fiona Choppe, HeroKi aims to improve the lives of kidney transplant recipients and inspire millions of dialysis patients around the world. Its founder Alon Magal is also the first user and client of the start-up HeroKi.

The Kidney Shield has been designed to act as a "bodyguard" to protect the precious transplanted kidney. Unlike other products on the market, HeroKi's Kidney Shield is a medically approved, patented, and

**Alon Magal, HeroKi
"Kidney Shield"**



Keen cricketer from the United Kingdom, who received his new kidney from his mum in 2019



Three times kidney recipient, football player and golfer from the Netherlands

class 1 certified solution by the European Medical Devices Directive.

The belt is able to absorb any impact by instantly forming a comfortable protective shell, impact after impact. The protective belt with its ergonomic back support adapts perfectly to every movement of the body. With its elegant design and superior quality, the Kidney Shield is designed to be durable, washable, breathable and for maximum comfort in any climate and whatever the activities practiced.

The HeroKi Kidney



Alexandra Funk - Athlete from Germany who received her kidney in 2015



Paul de Smalen - Active sportsman from the Netherlands who received his kidney 10 years ago

Shield is intended for all kidney transplant recipients who choose safety in their daily life. Kidney recipients can go out on their daily activities or play sports with peace of mind, fully enjoying outdoor activities with family or friends.

The WTGF partnered with HeroKi in March 2021, to offer our transplant community the opportunity to test and review their innovative belt.

A competition ran over social media for one month, after which five lucky participants were selected to review and keep the kidney shield. The winners were Lewis Daniels, Steve Donald, Alexandra Funk, Paul de Smalen and Margherita Mazzantini.

If you would like to purchase your own HeroKi Kidney Shield, use promo code WTGF022021GY for great discounts and follow this link <http://bit.ly/HeroKipromocode>

World Transplant Games Federation

A photograph of a woman in a grey tank top high-fiving another person in a gym setting. The woman is smiling and looking towards the other person. In the background, there are other people sitting on a bench.

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.