Iransplant World

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Journal of the

World Transplant Games Federation
Powered by the gift of life

Suddenly we are very small in the scheme of things

SPECIAL DIGITAL-ONLY EDITION

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MESSAGE FROM THE PRESIDENT

Suddenly we are very small in the scheme of things



A heartfelt message from WTGF President Chris Thomas

he theme of this online journal, 'suddenly we are very small in the scheme of things' seems appropriate for the world in which we current live.

Rewind just to January and no one could have predicted the impact and devastation the COVID-19 Pandemic would wreak on our populations, our economies and our way of living. Well, when I say no one, if you have five minutes spare Google Bill Gates' TED Talk on pandemics and you will realise that some people have been warning our governments for years.

Still, this is where we find ourselves. Very small in the scheme of things.

And unfortunately, no one, no activity or no event is immune. By now you will know that the World Transplant Games for 2021 in Houston has been cancelled. It takes years of planning and building towards a Games and it would be fair to say this pandemic took the wind out of Houston's sails.

We appreciate their honesty in letting us know the challenges of bringing the Games to fruition. Equally we appreciate the advice of our medical committee that concluded a Games in 12 months' time in the USA was extremely doubtful. Our recipients on the Board also expressed their concern for the health and safety of their fellow recipients.

But most of all I have appreciated the genuine and honest feedback from the members of the transplant community themselves. Overall, the advice has been justified disappointment but understanding. A few have questioned whether we made the call too early. And, yes, that plays on my mind as well. We volunteer our time with the Federation to 'stage' the Games not 'not stage' the Games. There is no pleasure in cancelling an event.

But when faced with the facts, when realizing that all the advice is

unequivocal, well really there is no other option. And it gives our community certainty. It is normally about now, 12 months out, plans are made, team managers are selected, holidays are applied for and travel is booked. We stand behind the decision. We stand behind putting the health and safety of our community first.

My first Games were in Thailand. As an honorary team member of the Australian team I took a photo of every athlete with their medals. Occasionally I look back through that file of the smiling faces of that team. It saddens me that too many of those faces are no longer with us. The time we have on this small speck in the universe is precious. We need to care for all those around us.

But let's also put into perspective the reality of cancelling a sporting event celebrating the gift of life. This pandemic has killed hundreds of thousands of people. Across the world transplant programs have been suspended, those waiting have faced an additional burden and recipients have sought safety in isolation. Rewinding just back to January, no one could have predicted it.

Unexpected outcomes

Still amongst the gloom there are some unexpected outcomes shining.

The shutdown has provided many people with a time for reflection. A time to slow down, take it all in and reevaluate. I wouldn't be surprised if many people change careers when they emerge from this pandemic slumber.

We have connected with family and friends in ways like never before. Zoom meetings have become a daily fixture.

We held a Zoom meeting with country representatives and team managers to discuss the cancellation and it was wonderful to connect with so many people I am privileged to call friends.

And I have taken up a hobby I

never thought I would get time for – photographing the night sky - our cover shot.

The photography gets me, and Raf, the English Springer Spaniel, up in the middle of the night and lets me focus on nothing other than the galaxies above us. The photos could still do with some improvement but I am in awe of what's up there and all around us. The Southern Cross in particular is a wonderful celestial mark in our night sky. And of course, the Milky Way.

Yes, we certainly are small in the scheme of things. But small things matter. They give us purpose, enjoyment, satisfaction. And looking after our mental health is as important as our physical health.

So, to all the hobbyists out there, whether you are sewing, baking, clicking or crafting. Enjoy this time. Rediscover yourself. And see you soon.

Chris ThomasPresident



Magnificent mountains and a lot of hard work

Brenda Brown on a succesful Winter Games in Banff





Banff, Alberta
CANADA 2020

hey said build it and they would come. Or at least that's what Dave Smith, the past President of the Canadian Transplant Association (CTA) had advised the Board in early 2018 after he returned from the World Transplant Winter Games in Anzére, Switzerland. While the CTA Board and Games Project Team were busy preparing for the 2018 CTA Vancouver Transplant Games, Dave was already envisioning the World Transplant Winter Games coming to Canada in 2020.

After the Games in Vancouver came to an end, and the dust settled, it was time for a new President to take over the CTA Board. In early 2019, as Brenda Brown was assuming her new role as President of CTA, Dave's dream to host the 2020 World Winter Games in Canada was turning into more of a real opportunity. The World Transplant Games Federation approached the CTA and asked if we would host the World Transplant Winter Games in Banff, AB. Ouick discussions were had with the Board, Banff Tourism, as well as SkiBig3 and the dream soon turned into reality. With visions of snow dust, ice, magnificent mountains combined with a whole lot of hard work, the CTA Board and the World Transplant Games Federation, thanks to the commitment and partnerships built with the local organizing committee, brought a very successful World Transplant

Winter Games to Canada.

Build it and they did come - to Banff in February 2020. The Games saw 122 transplant athletes and donor athletes come together to the magnificent Rocky Mountains. They came to compete in alpine, Nordic, snowshoe and curling events. The competitors brought close to 100 supporters and another 60 volunteers, ensuring the Games were a successful celebration. Over 17 countries were represented and participants were eager to demonstrate that nothing, not even the looming threat of COVID-19, could keep them from celebrating their second chance at life. And celebrate they did, by way of friendly competition in the mountains, snow and ice. The Games illustrate how transplant and the selflessness of others provided these individuals the rare gift to live anew. Athletes demonstrated to their donors, donor families and themselves what a gift being here together to compete in these events is.

Nicholas Cup

An extra special part of the Games were the children and youth competing in Nicholas Cup as well as the young teenagers trying out snowboarding for their first time. In addition to celebrating new leases on life, the Games also

encourage and build confidence. Some participants have been living with illness their whole lives and never were able to play or compete in sports. To stand in the mountains and fly down their hills, are freedoms they never thought they would experience, while they were fighting for their lives, waiting for that much needed heart, lungs, or kidney.

Young or old, the joy of the Games is the same. Building new friendships, learning new languages and celebrating the life through sport were key themes for the week. The Games culminated in the Gala Dinner at Buffalo Bill's with dancing and singing. It was topped only by the final event of the Nicholas Cup the following morning when the children raced and closed the Games after their week of lessons culminated in one final head to head fun, timed event. They were so inspiring to watch. They skied with heart and passion, and the audience cheered them all on. It was a fabulous end to a glorious week in Banff, Canada - something the CTA is thrilled to have been a part of creating.

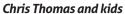
Brenda Brown

President Canadian Transplant Association Chair Banff 2020











Medal winners



Team Canada curling





PICTURE SPECIAL #2







Father and son for Team Ireland

Team Ireland (Luke & Shane) at the World Transplant Winter Games, Banff 2020

ow to begin? This was our second WTWG competing in a father and son duo as Team Ireland! Banff was a long way to travel from Dublin, but boy was it worth it. What a truly magical event at a beautiful and friendly destination. It was great to see so many old friends there and have the opportunity to make several new ones. Jet lag was quickly dispelled as we marched down Banff Avenue in the fresh snow to kick off the Games at the Opening Ceremony. Looking back now in the current new reality of living in the midst of a global pandemic, how truly fortunate we all were to be able to celebrate the Gift of Life before the world went into lockdown.

Day 1 of the competition kicked off nice and early as Luke got settled into his Nicholas Green Camp under the fantastic care and leadership of Amanda and Maggie, as I got the skis on for the first round of the Giant Slalom competition where I was racing as a living donor. Luke received my left kidney three years ago, and has not looked back since. First run done and I was leading, could I keep it up for the second and final round? Thankfully my second run went flawlessly, and I was able to bag Ireland's first gold medal from the Winter Games! Meanwhile Luke was busy inner tubing down Mt Norquay with his Nicholas Green camp buddies in one of his highlights of the

Luke with donor Dad Shane

week. What a thrill it was to stand up on the podium for the medal ceremony. I'm not that active on social media, but a post on my LinkedIn account celebrating and passing on the message about organ donation received 17,000 hits. I guess people aren't used to reading about an Irish guy winning gold in an alpine event! My teenage upbringing on skis in upstate New York probably helped the cause!

Best Games and holiday ever!

The rest of the week was a huge amount of fun for both Luke and I as he added rock climbing and horse sleigh riding to his skiing adventures. Luke summed the week up as his best Games and holiday ever! I spent the time hanging out with friends on the mountain and in the lodge and squeezing in some fun runs in the Parallel Slalom and Super-G. Team Ireland were adopted by Canada, USA and GB, so we really enjoyed

socialising amongst everyone during the week sharing stories and revelling in the incredibly warm camaraderie that is prevalent at World Transplant Games. It is abundantly obvious how humble and gracious all transplant recipients are to have had a second chance at life, thanks to the unbelievable generosity of donors and donor families.

Huge congratulations are due to the organising committee, who put on a fantastic week for everyone to enjoy. Sadly, the Games had to end, but not before Luke won the Nicholas Green Cup and we caught up with good friends living in Alberta who showed us the sights at Lake Louise, where Luke even learned to play ice hockey!

We look forward to seeing everyone again at the next Games! Stay safe everyone - we will all get to hug again!

Luke & Shane Herlihy Ireland



Shane and Luke in the fabulous Rockies

MEDICAL UPDATE

Information on Coronavirus COVID-19



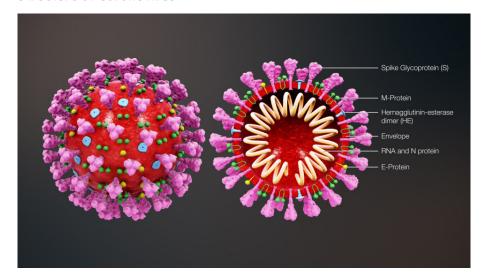
Prepared by Dr Ka Foon Chau, WTGF Medical Committee Chair

Information summary of Coronaviral (SARS-CoV-2) Pneumonia

Note: Our knowledge of the disease and the guidelines for good practise change every day. All of the information quoted here is as at 30 April 2020. To read Dr Chau's full report with statistics and graphs with data up to 30 April 2020, please contact wtgf@wtgf.org.

Coronavirus is a group of viruses associated with respiratory infection which may affect both humans and animals.

Structure of Coronavirus



Statistics: Top 10 affected countries of the world (up to 29 April 2020)

| Country | Total confirmed cases | Confirmed new cases (on 29 April 2020) | Total deaths | New deaths |
|---------|-----------------------|--|-----------------|---------------|
| USA | 983457 | 22541 | 50492 | 1322 |
| Spain | 210773 | 1308 | 23822 | 632 |
| Italy | 201505 | 2091 | 27359 | 382 |
| UK | 161149 | 3996 | 21678 | 586 |
| Germany | 157641 | 1304 | 6115 | 202 |
| France | 125464 | 3729 (28 April) | 23627 | 366 |
| Turkey | 114653 | 2392 | 2992 | 92 |
| Russia | 99399 | 5841 | 972 | 105 |
| Iran | 92584 | 1112 | 5877 | 71 |
| China | 84369 | 22 | 4643 | 0 |
| Global | 3018952 | 66276 | 207973 | 5376 |

The Trend is currently showing that China and Korea have plateaued off with the European countries' trends variable, in North America, South America and Africa the trends are increasing rapidly.

Symptoms

The majority of cases have mild symptoms with fever, tiredness, dry cough and sore throat; some have a running nose, diarrhea and loss of smell. Less than 20% of patients experience shortness of breath and less than 2% of cases are critical. The most susceptible are the elderly; those with underlying medical problems e.g. hypertension, diabetes mellitus, heart and problems; immunocompromised patients (transplant recipients).

MEDICAL UPDATE

Continued from previous page

Natural history

May recover at any stage, can transmit disease even before symptoms

| Incubation period | 7- 14 days, maybe up to 24 days |
|-------------------|---|
| 1st week | Mild symptoms, maybe even no fever |
| 2nd week | Deteriorating with cough and difficulty in breathing - lung damage may already be present |
| 3rd week | Rapid deterioration with respiratory/multi-organ failure, death |
| Discharge | Clinical and radiological improvement, fever down for at least three days, diagnostic testing twice at least 24 hours apart |
| Follow up | Some patients - severe damage and fibrosis of lung after recovery from acute stage |

Transmission

| Droplets formed during sneezing or coughing - entering | |
|--|--|
| through nose, mouth, eyes due to direct encounter or | |
| contaminated hands | |
| Close contact with infected people | |
| Contact with contaminated items | |
| Faecal-oral route | |
| Aerosol - generated during invasive medical procedures | |

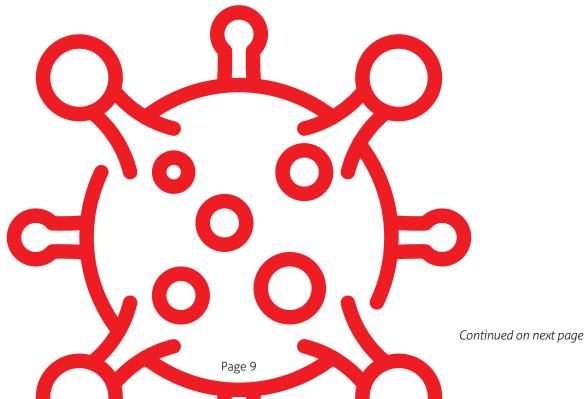
How to kill the virus

| Soap – 20 seconds |
|--|
| Heat - 56° for 30 minutes |
| Chlorine containing disinfectants |
| Hydrogen Peroxide (H ₂ O ₂) |

Unfortunately, there is no effective treatment so far however a search for a vaccine is in process worldwide.

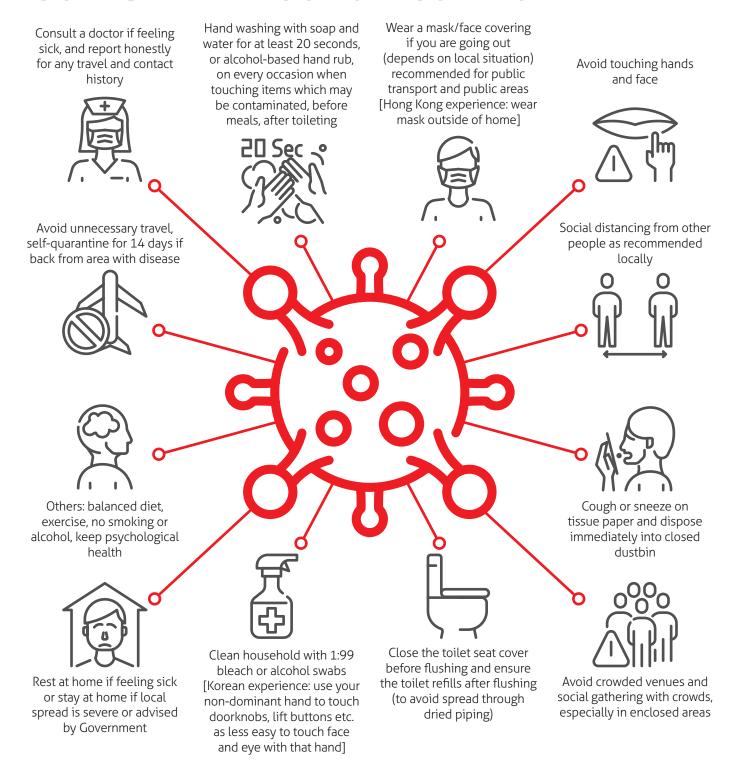
Dr Ka Foon Chau

WTGF Medical Chair Hong Kong



MEDICAL UPDATE

COVID-19 Infection Control



Infection control by Health Authorities:

- Early detection and testing, quarantine policy, medical surveillance and effective case tracing
 Triage of cases according to symptom and need for treatment
 Training of medical staff and ensuring adequate protective equipment
 Infection control infrastructure (zoning and fever clinic) and working protocols
 - O Government policy to prevent crowding

Arriving Home with Coronavirus COVID-19



William Bonnaud Dowell on testing positive for COVID-19

s I fell into bed back in Chamonix (France) on 2nd March, following the long trip back via Amsterdam and Geneva airports, I must confess to feeling a little smug: I had successfully made it to and back from the World Transplant Winter Games in Banff. As important as the skiing, I had been surrounded by a huge number of truly fantastic and inspiring people. Somehow, I had avoided catching influenza from four of the ten in the French team who had symptoms and the nearest thing I had to experiencing issues with COVID-19 was finding out the factory in China was shut so couldn't make our medals! I felt invincible. Perhaps, I thought, it is because I had paced myself - going a few days early and forced myself to bed every night before 9pm.

Within 48 hours, however, I had a fever and could barely get out of bed. It seemed I hadn't escaped the influenza after all. But by this point I had to get back to Marseille, so the half unpacked suitcase was closed back up and I made my way down in a state which, I confess, can only be described as reckless. My nose wouldn't stop running, I was dripping with sweat, and my vision was blurred and my legs weak. I also couldn't smell anything and the sandwich I tried to eat tasted like cardboard.

I managed to type out a mangled email to my nephrologist explaining that my wonderful teammates had confirmed cases of influenza, didn't feel great, do I need to bring forward my blood test? The reply was admirably swift "The problem is that you've been in Haute Savoie" where there had been cases of Corona.

"Call the '15' to get tested. Don't go to hospital!" Having not been to northern Italy or Asia, the '15' were disinterested. I must admit to wanting to point them to a map given the proximity of both Geneva airport, and Chamonix in particular, but they were 'following the directives' and so I gave it little thought and spent the next days in bed doing very little other than sleeping or watching the wave of news on my phone about the horrors in Italy and see countries all wake up to the reality that they were next. But I wasn't coughing. It couldn't be. Or could it? It did feel worse than any flu I had experienced previously.

So, now what?

Fast forward nine days since the first symptoms, and I started throwing up incessantly to the point I couldn't even sip water let alone swallow any medication. My transplant unit took me in on the premise that I was probably dehydrated and likely had some sort of post-flu acute kidney injury. They tested me for flu, which came back negative and 48 hours later a nervous looking doctor, dressed up for a trip to the moon, came into my room and announced I'd tested positive for COVID-19. I. After a few seconds of silence, "so, now what" was my immediate question. He didn't know - I was their first but it didn't seem sensible to keep me in a unit with other transplant patients. I was eventually moved to the IHU, the infectious disease institute across the road where I was given intravenous azithromycin. There was some discussion of participating in a clinical trial but, as my nephrologists seemed less than keen, given their reservations, I held back.

Thankfully I didn't get any worse and after various negative, swab results (for some reason, carried out daily at 3am. Not the nicest way to be woken up!) I was on the verge of going home to recover there, until the next test returned positive again...before returning negative again and getting out 48 hours later. Somehow, I had avoided any issues with my lungs — a CT scan was done and not a trace, I hadn't coughed once, and I came back home feeling like I'd dodged a ginormous bullet.

Continued on next page



Continued from previous page

But again, within 48 hours I seemed to get worse again exhausted and throwing up at home and within days returned, this time back to the renal unit. I kept testing negative for the virus but there's much debate over the validity of nasal swabs, especially as I appeared to be having some sort of gastrointestinal variant. And, to boot, five days in, a fever kicked off, shivering etc. and I found myself with Clostridium difficile and with it, yet another course of antibiotics commenced. But eventually I got back home where I am now under pseudo house-arrest like everybody else.

Two months on...

I write all this now almost two months on from the first symptoms, and though my kidney function has still not returned to how it was 'pre-Corona' (will it ever?), it is evident that I have been very fortunate. Many transplant patients - and even more so dialysis patients - have sadly suffered greatly and too many have sadly passed away, and my thoughts are with them and their loved-ones.

My hope that as the entire transplant community - the recipients, but equally

Though my kidney function has still not returned to have it not returned to how it was 'pre-Corona' (will it ever?), it is evident that I have been very fortunate"

the medical community around the world - grapple with all the consequences of this virus and knock in impacts for our usual care, testing becomes easier, and effective treatments emerge for those who need it. And my cautionary tale is simple: it's becoming clearer by the day, even in a relatively mild form, is not solely a respiratory illness. The virus appears to, directly or indirectly, affect kidneys, the neurological system, the heart and potentially the liver in many cases. Coughing as an initial symptom, it seems in some reports, appears to be in about 70% of cases – quite a lot don't - and the other symptoms are far and wild. It need not be said, the members of the transplant community are particularly vulnerable to its impacts to the virus but also indirectly with routine appointments curtailed and transplant themselves suspended procedures

in many cases too having untold consequences on those in need. Oh, and who yet knows how we fare where it comes to building up effective and/or durable antibodies after an infection or even a vaccine?

Thankfully was incredibly as demonstrable in Banff and around the world, the transplant community is united in its resilience and compassion to one another. We've all faced lifechanging challenges and it's in that vein we'll hopefully get through this and meet again stronger, more knowledgeable and healthier than ever.

Above all, keep well, and look forward to seeing you all on the slopes in Italy in 2022

William Bonnaud Dowell

France

21 years kidney transplanted

SOCIAL MEDIA

Staying Connected During Lockdown

Kim Reynard on WTGF's social media campaigns









Transplant Bears in Victory

ransplant recipients from around the world sent us pictures of their teddy bears dressed in medals to celebrate their victories, create awareness and show solidarity during this time of isolation. We received loads of pictures from all around the world, reminding each other that we are all winners – and will meet again soon.











SOCIAL MEDIA



Day by Day Active Challenge

e called out to our community to show us how they are all keeping active during lockdown. What a tremendous response! We received close to 150 different videos / pictures, from 32 countries over a period of just 7 days, and were left incredibly encouraged.

The range of lockdown exercise activities varied from cardio, toning exercises, stretching, yoga, treadmills, home cycling trainers, daily walks, spinning classes, at home golf practise, to wall tennis exercises and Pilates.

We were encouraged to see how many of our member associations were conducting online training classes and ensuring their members remain active. Keep sharing your videos with us so others can be encouraged during this time.



WTGF Executive Manager

















ATHLETE ADVISORY COMMISSION

Athlete Advisory Commission Begins New Term

A select group of transplant athletes from around the world has been appointed to the World Transplant Games Federation's Athlete Advisory Commission, Federation President Chris Thomas of Australia, recently announced.

hirty-three individuals, all experienced athletes and competent in their chosen sport, have been appointed to the Commission for a two-year term. These individuals will advise the Federation, through the WTGF Sport Committee, on matters pertaining to their sport and on future Summer Transplant Games.

The Commission was formed in 2017 to provide a more direct route to incorporate the recommendations of athletes participating in the World Transplant Games into the planning and staging of future events. The Commission had an important role in recommending changes to the rules and competition formats of many of the sports of the Games, evidenced by the tremendous success of the 2019 World Transplant Games in NewcastleGateshead, United Kingdom,, in which the sports are regarded as the best managed since the beginning of the Games in 1979. Post-event surveys show that almost 92% of athletes felt that the sports of the NewcastleGateshead Games were good or excellent (47% rating them as excellent).

The AAC members are looking forward with great enthusiasm to continuing the work of the Commission. Members stated:

"I am very much honored and delighted being appointed as a member of the AAC for the next two-years term. Thanks a lot for your confidence. I will do my best to contribute well to the further development of the transplant sports." Rainer Weckeck, Germany

"I proudly accept your invitation. I will do my best to provide my knowledge, experience and ideas to the improvement of the Games."

Peter van Maurik, Netherlands

"I am looking forward to discussing ideas, questions, proposals that arise to support transplant sport and to keep "GIFT OF LIFE" long lasting. Wish us a fruitful cooperation." Gabriella Szabó, Hungary

WTGF President, Chris Thomas, said the Commission helped to ensure the Games continued to deliver for the most important people at the Games – the athletes themselves.

"In the first two years of the AAC we had some brilliant input and no doubt this led to a superbly-run World Transplant Games in NewcastleGateshead. The entire Board of Trustees was gratified with the input from the athletes and the outcomes achieved."

Continued on next page





ATHLETE ADVISORY COMMISSION

Continued from previous page

The complete list of Athlete Advisory Commission members with their country and sport follows:

| Christopher Bagley | USA | Swimming |
|--------------------|---------------------------------------|-----------------|
| Liam Barnett | Great Britain and Northern Ireland | Swimming |
| Jodie Cox | Great Britain and Northern Ireland | Swimming |
| Laurent Desormeaux | France | Badminton |
| Pinja Ekström | Finland | Athletics |
| Simon Elmore | Great Britain and | Attiteties |
| Simon Euriore | Northern Ireland | Ten Pin Bowling |
| Deirdre Faul | Ireland | Squash |
| Lucas Ferrini | Argentina | Swimming |
| Bruce Giles | Australia | Cycling |
| Andrzej Haj | Poland | Athletics |
| Donna Hart | Canada | Swimming |
| Karen Hoyt | USA | Road Race |
| Alexandra Humeau | France | Road Race |
| Jennifer Irwin | Canada | Ten Pin Bowling |
| Jen Klouse | USA | Volleyball |
| René Leeflang | Netherlands | Volleyball |
| Markus Malter | Germany | Tennis |
| Margaret Martin | Australia | Petanque |
| Peter van Maurik | Netherlands | Swimming |
| David Miller | USA | Ten Pin Bowling |
| Tatiana Narvaez | Colombia | Triathlon |
| Ross Owens | USA | Basketball |
| Erik Paalvast | Netherlands | Athletics |
| Reena Raju | India | Athletics |
| Paul Rakoski | USA | Golf |
| Bart Rienties | Netherlands | Cycling |
| Dennis Segatto | Canada | Athletics |
| Gabriella Szabo | Hungary | Table Tennis |
| Amar Nath Tanwar | India | Badminton |
| Ruurd Valkenburg | Netherlands | Golf |
| John van Vliet | Netherlands | Table Tennis |
| Rainer Weckeck | Germany | Petanque |
| Ben Wilson | USA | Tennis |









Keeping fit but staying apart

