TransWorld
The Journal of the World Transplant Games Federation

2010

Issue 1

MAIN TOPICS

Chamade 2009:
Second Life in the Heart of the Arctic

Transplant Links:
Sharing Skills for Life

Also:
Photos and reports from Winter World Transplant Games 2010
CONTENTS

Editorial
Message from the President  Page 3
Message from the Secretary  Page 3

Main Topic
Chamade 2009: Second Life in the heart of the Arctic  Page 4
Transplant Links: Sharing skills for Life  Page 5

Profile
Karoon Chau – WTGF Councillor  Page 6

Future WTGF Events
18th World Transplant Games Sweden 2011  Page 7
8th Winter World Transplant Games 2012  Page 7

Report from Terry Mongan – Chairman EHLTF  Page 8

The Nicholas Cup - France 2010  Page 9

7th Winter World Transplant Games  Pages 10-11

WTGF Country Member News  Pages 12-13
TACKERS Ski Camp 2010  Page 14

Sport/Health/Training
Transplant Medications: Forget Me Not!  Page 15
Four Ways to Eat More Healthily  Page 16

Life Story
Shillane Labbett – a moving story from Canada  Page 17

WTGF News  Page 18

Focus On
Middle Eastern Society of Transplantation (MESOT)  Page 19

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Front Cover: Brazilian Balloons at the Opening Ceremony of the Winter World Transplant Games 2010
Official Games Photographer

7th WINTER WORLD TRANSPLANT GAMES 2010 MEDAL TALLY

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MESSAGE FROM THE PRESIDENT

You will now know that at last the WTGF has been recognized as an Olympic organisation. We hope soon to inform our member countries about the benefits of this recognition which will then allow them to be more effective and give them more credibility in the work of rehabilitating transplanted persons through physical activities. It will also help to increase public awareness about organ donation and the success of transplantation. All countries that are members of this Federation will be expected to adopt the values of the International Olympic Committee (IOC), in terms of “taking part” and “doing our best”. Our own values of sport as a tool and a therapy to recover a normal quality of life and to promote the benefits of organ donation and be an ambassador are also very important. We continue to cultivate our relationship with the IOC, particularly on the medical front, and I will be in Lausanne in July to meet their medical director.

In view of our relationship with The Transplantation Society (TTS), our Councillor Prof Daryl Wall will address the transplant community with a message about “the benefits of physical activities after transplantation” at the next TTS Congress in Vancouver, Canada in August. Also, a WTGF booth will be managed there by our Councillor Heather Fisher.

After the successful Winter Games and Nicholas Cup held in France in January 2010 – many thanks to Astellas for their generous support to the transplanted children - I visited the resort of Anzeré in Switzerland and was very impressed by the high level of dedication already shown by the LOC to host some wonderful Winter Games in March 2012.

As a result of the medical symposium held at the 2010 Winter World Transplant Games, we are currently investigating a way to launch and run an international medical “sport & transplant” group. This would define and lead some dedicated medical research and publish some worldwide guidelines to help transplant practitioners prescribe physical activities as a means to recovery after transplantation.

I would like to thank again Paarl Print (Pty) Ltd. and SAPPi Fine Paper Ltd. for their support, and to address a very special thanks to Astellas for our very fruitful ongoing relationship and to Colleen Horan-Green for her great contribution to our Journal.

I wish everyone a very happy summer time.

Friendly yours,

Olivier Coustere, President

MESSAGE FROM THE SECRETARY

Hello Everyone,

By the time you read this, the Intergames Council Meetings will have taken place at the site of the 2011 World Games, Goteborg, Sweden. During these four days, the Councillors of the WTGF will not only have a series of meetings in order to conduct the Federation’s business, but they also have an opportunity to take a look at the current state of preparations for the Games, visit the proposed venues, and meet with key players of the Games Local Organizing Committee.

One of the results of these meetings is an update of the Sports Rules for the Games. There are a number of proposed changes to the Rules, some minor but also a few that are significant. The new Rules will be available on the WTGF web site (www.wtgf.org) by the time you receive this Journal.

In preparation for deciding the site for the next World Games, a three member Site Review Team visited both proposed sites for 2013—Tokyo, Japan and Durban, South Africa. Each member of the Team has extensive experience in directing numerous major Games for recipients at the national and international level. The expertise of the Team, according to both prospective Local Organizing Committees, was extremely helpful in the finetuning of the bids that were presented at the Council meetings in Sweden. By now the 2013 site has been announced; whichever site was selected, without doubt, the selection this time was one of the most difficult in recent memory as both sites were spectacular and both LOCs presented outstanding proposals. Congratulations to both for all your efforts.

The Council is spending the next several months extensively reviewing the operations of the Federation as embodied in the Constitution. If you or your organization has any ideas or suggestions for how the WTGF should be organized and how it should operate, you are encouraged to express your ideas now—we want to hear from you, and now is the time for your suggestions to be heard. Let us know by emailing wtgf@wtgf.org or sending your comments to the WTGF office.

Gary Green, Secretary

“You can never do anything in the world that is really worthwhile unless you are completely devoted to it.”

Mahatma Gandhi
Today hundreds of people are waiting for organ transplants, but the problem is a shortage of suitable organs and this is particularly true in Switzerland. To encourage organ donation and to show that it offers a real and entire “second life” where everything is possible - even adventure, Chamade welcomes transplanted people to sail on the Arctic seas. After a fantastic trip to Spitsberg in 2008 - close to the ice in a wild and deeply isolated area, the Swiss sailing boat Chamade cruised the northern part of Russia in 2009 sailing from Murmansk to St. Petersburg and passing the Gulag Archipelago and through the Belomorsk Canal.

“I left Chamade with a bigger heart, full of emotions and memories.” wrote Sandra, who received a new heart ten years ago, in her diary. “During the crossing I had to do my job taking care of the boat and watching around to avoid any collision.” said Gisèle, who received a new kidney 11 years ago. For Harold, who had a double lung transplant 13 years ago, it was like a dream: “Something I never thought possible.” And Marco, who had a liver transplant just two years ago, will never forget his meeting with Irina, Olga, Anna and Dmitry, four Russian transplant recipients.

Organising a meeting between Swiss and Russian transplanted people was the big goal for this year as it took time to arrange for Russian recipients to meet the Swiss crew. After much effort the meetings eventually took place and were fantastic with friendship and exchanges. The second challenge was to obtain permission for the navigation of the Russian Inland Waterways which are forbidden for foreign vessels. But thanks to the humanitarian aspect of Chamade’s project, after 14 months of talks, we got a special permit signed by the Prime Minister Vladimir Putin.

However, administration was not the only difficulty on this trip. For all of our crew it was sometimes an extremely hard navigation. It is very cold at the beginning of June in the Barents Sea, with high winds and rough seas and passing through the 30 locks spread along the Belomorsk Canal was a tough job. For all of us who took part in this adventure discovering this wild area of Russia was great. Everywhere we went we had a very warm welcome and all of our meetings were fascinating thanks to Tatiana, our young Russian translator, who sailed with us all the way.

We will never forget the wonderful but isolated countryside, the very wild nature and of course the history. At the end of June we stayed for two weeks in the Solovetsky Archipelago in the middle of the White Sea. On the main island stands a “Kremlin” - a fortified monastery which had later been used as a prison. This forbidding place set in beautiful countryside is like hell in paradise.

Last but not least, we organized in cooperation with the Russian Red Cross a “Forum for Transplantation” in St. Petersburg. It was the opportunity for a Swiss medical team to have discussions with Russian colleagues. All of this incredible adventure got a great deal of coverage in the media. Both in Switzerland with newspaper articles, radio and TV reports and also in Russia, where more than ten TV channels reported on the wonderful adventure and the issue of transplantation.

Just to show that organ donation gives life, a great life!

Marc Decrey and Sylvie Cohen
www.chamade.ch
www.editionsaira.ch
Is it fair that parents, family and friends in developed countries can save the life of a much-loved family member by becoming a living kidney donor, whilst in less developed countries this is often impossible because the medical skills are not yet in place?

The UK charity, Transplant Links Community (TLC) was set up three years ago by a group of leading UK kidney doctors and surgeons with a passion for sharing medical skills across the world to help improve the imbalance of medical care.

The key aim of the charity is not just to save the immediate lives of patients with kidney failure in developing countries, (although that is of course a key part of many TLC missions) but most importantly, it is to establish short and long term training and education in those hospitals that are ready to build up living related donor transplant programmes. The objective is to ensure that good communication links are built up between the UK and colleagues abroad, to make sure that transplant programmes will be sustainable over time.

In the past three years, TLC has established strong links between UK hospitals and centres in Nigeria, Ghana, Trinidad and Nepal and demand is rapidly growing from other countries where there is the infrastructure and interest, but not the necessary skills to move forward.

TLC has enabled the first ever paediatric living kidney transplants to take place in both Nigeria and Trinidad and the charity also carried out the first ever adult living kidney transplants in Ghana. There have been a number of visits to each country and doctors have returned to the UK for ongoing training with TLC volunteer doctors.

As Dr. Jennie Jewitt-Harris, Chief Executive of Transplant Links says, “Sharing of skills from centres of excellence in the UK such as University Hospital Birmingham with colleagues in less developed countries is what Transplant Links is all about. The UHB doctors have many years of experience and knowledge which no books can ever teach.”

The TLC missions involve teams of surgeons, kidney doctors, nurses and theatre staff travelling and sharing their experience and skills with their colleagues in local hospitals. Whilst the UK team members give their time voluntarily, TLC has to raise funds constantly to pay for the flights, accommodation and in some cases equipment needed.

The work of the charity is all about innovation, making positive changes and sharing pioneering UK medical skills learned over many years with those in developing countries, so that unnecessary deaths can be prevented.

If you’d like to donate to a mission and the work of Transplant Links, or if you’d just like to find out more about the charity please visit www.transplantlinks.org.

Let’s help as many people as possible around the world benefit from the incredible advances in living related kidney donor transplantation.

Dr. Jennie Jewitt-Harris
Transplant Links
Ka-foon Chau – Consultant Nephrologist
WORLD TRANSPLANT GAMES COUNCILLOR

Ka-foon was born in Hong Kong in the 1950s and at that time Hong Kong was a simple, poor and traditional community where girls did not have a high level of education. As the fourth child of the family, she refused to follow her elder siblings and start working as a teenager. She insisted on continuing her studies through scholarship and money she earned herself by tutoring from the age of 15. After a tough life in secondary school, her vision was greatly broadened when she went to university. While Mainland China was starting to open the door, Hong Kong university students were keen to learn and participate in Hong Kong and Chinese social and political issues. During five years of university life Ka-foon studied medicine and established her life goal to serve the people. Being honest and humble is her rule to herself. To do your best is her attitude towards work. To serve the people, especially her patients, is her commitment.

Ka-foon qualified as a doctor in 1980. Due to her belief in organ donation she started work in this area as a very junior doctor despite great resistance from her seniors. By the early 1980s there was no established system of organ donation in Hong Kong and organ transplant was not a routine treatment. Both the community and the medical profession were not keen on promoting organ donation. Ka-foon was trained as a nephrologist in Oxford and London, UK in 1986 and became the core member in the dialysis and transplant service in Queen Elizabeth Hospital in Hong Kong.

In the 1990s Ka-foon actively served in the Hong Kong Society of Nephrology (HKSN) as Councillor, Treasurer and Secretary. HKSN is a professional body consisting of nephrologists, urologists and renal nurses. It organizes academic conferences, activities promoting organ donation and rehabilitation for dialysis and renal transplant patients.

Coming into the 21st Century Ka-foon has concentrated on her work at the Hong Kong Society of Transplantation (HKST). The Society consists of medical personnel involved in organ or tissue donation and transplantation in Hong Kong. Promoting organ donation is the core target in her work.

In 2007 Ka-foon led the Hong Kong transplant team to participate in the 16th World Transplant Games in Bangkok. In 2008, she led the team to Shanghai for the 3rd Chinese Transplant Games and then in 2009 to the 17th World Transplant Games in Gold Coast. The Hong Kong team members rapidly expanded from 28 in 2007 to 62 in 2009. With help from Ka-foon, the transplant patients soon organized themselves to form the Hong Kong Transplant Sports Association. It has become a rapidly growing army to promote both exercise and organ donation. Apart from organizing sports training and local competitions, they also reach out to schools, organizing fun fairs and play street drama to arouse awareness of organ donation. Ka-foon has also arranged interviews for donor families and patients by various media, including television, radio and newspapers. She is currently in the last stages of publishing a book of articles from donor families, patients and medical staff. Ka-foon is pleased to see that organ donation rate in Hong Kong has jumped from 4.3 in 2007 to 7.0 donors per million of population in 2009 when she stepped down after her two years chairmanship. Ka-foon was elected as a WTGF Councillor in 2007.

Whilst working hard on organ donation and transplantation in the past 25 years, her younger son received a liver transplant in 2001, aged 11. As the mother of a transplanted child and doctor of transplanted patients, it looks as if there is a mysterious link of organ transplantation to Ka-foon’s life - in Chinese terms, HER FATE.

Ka-foon Chau – Consultant Nephrologist
WORLD TRANSPLANT GAMES COUNCILLOR

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18th World Transplant Games

After a tough winter in Sweden, Göteborg is now approaching the best part of the year. Spring and summer are beautiful on the west coast and in the Archipelago - the days get longer and brighter and the trees and flowers are stretching their branches and petals towards the sun. In June 2011 when you arrive summer will be in full bloom. We can’t wait to share the warm and light summer evenings and nights with you all after a day of great competition at the 18th World Transplant Games.

We are currently preparing for the WTGF Councillors’ site visit this June. We are very excited about taking care of the Councillors and also the bidding delegations for the 2013 Games, Japan and South Africa. The Swedish LOC knows how much work goes into these bids. It is like a rollercoaster - a lot of weird and wonderful ideas, arguments and discussions but most of all it is great fun and full of expectations. Good luck Japan and South Africa - may the best bid win! We will know the result by the time you read this.

The Swedish LOC is working hard and is very focused on the 2011 Games. There will soon be only one year left until the gates open and Göteborg welcomes the athletes and their families from all over the world. We are confident that the 2011 Games will be a fantastic experience for everyone, whether you are a competitor, relative, staff, volunteer, Councillor or a citizen of Göteborg.

We are waiting for you with open arms. Welcome to Göteborg in June 2011!

CJ Ahl Göteborg 2011 LOC

8th Winter World Transplant Games and Nicholas Cup 2012

The 8th Winter World Transplant Games and Nicholas Cup will be held from 3rd to 10th March 2012 in the village of Anzére, which sits on a plateau amidst the spectacular Swiss Alps. Anzére is proud of its exceptionally sunny microclimate and sweeping views of the Alps.

Anzére promises to be a wonderful location for the next Winter Games with a central pedestrian village square which will provide an ideal area for people from around the world to meet, make new friends and catch up on the day’s events. All accommodation and ski lifts are easily accessible in this beautiful resort and the heart of the village has restaurants, small shops, cafés and an outdoor skating rink.

Over 50 kilometres of pistes are available for skiers of all abilities and the sports on offer will include Biathlon, Curling, Giant Slalom, Parallel Slalom, Slalom, Snowboarding, Snowshoes and Super Giant Slalom. The Nicholas Cup event, for transplanted children who have not skied before, will run throughout the week and will culminate in a Slalom race on the Friday and the presentation of medals and the Nicholas Cup.

At the beginning of April 2010 the Anzére Local Organizing Committee (LOC) were honoured by a visit from the World Transplant Games Federation President Olivier Coustere. Olivier was extremely impressed by the facilities on offer and WTGF is looking forward to working with the LOC to ensure a great 8th Winter World Transplant Games in 2012!
Terry Mangan, Chairman of the European Heart and Lung Transplant Federation (EHLTF) and a heart recipient himself, was delighted to accept an invitation to speak at the European Conference and World Health Organization (WHO) Global Consultation “Striving to achieve self-sufficiency” in Madrid, Spain.

The European Conference was held on the 23rd March 2010 - a full review was made of the current situation and main challenges in organ donation and transplantation within the European Union, particularly the proposal for a European law on safety and quality aspects and the promotion of cooperation between Member States. Also discussed were the WHO programme relating to the transplantation of organs, cells and tissues as well as the concept of self-sufficiency to increase the availability of organs for transplantation while promoting ethical practices throughout the world. It is the intention of the WHO to issue a Madrid Declaration in due course.

Following the European meeting, the Third World Health Organization Global Consultation on Donation and Transplantation took place over the next two days. This provided the opportunity for sharing experiences and views and constructing a set of recommendations that will make transplantation more accessible to citizens across the world.

Terry quoted Mahatma Ghandi as the theme for his presentation when he used his inspiring quotation “Be the change you want to see in the world”.

Terry represented the EHLTF and spoke on behalf of their 21 National Heart/Lung Transplant Patient Associations. His presentation was “European Organ Donation and Transplantation - A Patient’s Perspective”. Terry compared and discussed the differences in deceased donor rates throughout Europe and urged the need for donor awareness education. He asked the conference to consider if it was now time to challenge the conventional organ donor message and promote organ donation as a moral obligation, a civic duty, an act of communitarian solidarity. Terry said that “If everyone has an equal right to transplantation as a member of a population, then everyone has an equal duty to bear the burden of donation.”

He suggested that too often the emphasis was on deceased donor rates when the real issue was transplant activity arising from donated organs. He went on to graphically illustrate a number of European countries whose deceased donor rates were at the low or middle end of the European table but whose organs transplanted per donor placed them at the top of the table for actual transplant activity. Terry explained the important work of transplant patient groups and their promotion of National, European and the World Transplant Games which he said encouraged fitness and healthy life styles and was vital in the full rehabilitation of patients and which helped to prolong the life and quality of transplanted organs. He also acknowledged the excellent work being done by the European Commission in the area of Organ Donation and Transplantation and the many transplant related research projects being funded by the Commission. Terry ended his presentation with the following reflection from a recipient to his donor.

You are the warm sun on my face
The gentle wind on my back
You are the song in my heart
The music in my soul
You are the promise of spring
And the glory of autumn
You are my future
And my past
You are my Donor
And I am humbled

www.ehltf.info
The 7th Winter World Transplant Games and Nicholas Cup took place in Sainte Foy, Tarentaise, France in January 2010. All participants enjoyed a wonderful and memorable week with competitive skiing, sporting and social events. Please see the centre pages for photos from the Games.

The Nicholas Cup is an event for transplanted children from around the world who have never experienced skiing before and was held throughout the week with skiing lessons, making friends and fun for all.

The Nicholas Cup was awarded on the last day of the Games to Cassandra Lenglet, age 9 from France, who had received her new kidney in May 2009. All the children who attended were awarded medals for their commitment and a race was held on the last day with further medals being won:

- Krzysztof Tragarz, Poland - Gold
- Marine Eraville, France - Silver
- Joska Scherf, France - Bronze

Thoughts on the Nicholas Cup 2010 from Ireland and New Zealand

Eoin Hurley - Ireland

"I was delighted to be asked to go to the Nicholas Cup representing Team Ireland. From the moment Irish Team Manager, Colin White and I met at the airport we had a great time. My first impression of Sainte Foy was thick fog, but when I woke up the following morning the views were spectacular - fresh snow everywhere and tall snow capped mountains. My instructors were very nice and helpful and so were the other children. I found the different languages a small problem but given a few days we all got on fine. I had a great time skiing and the local people were very friendly. I had an absolutely brilliant time at the Nicholas Cup and was made to feel very welcome. I also met many other kids from all over the world and made new friends. I now hope to see some of them in the future and also hope to compete in the World Winter Transplant Games in 2012. I would advise anyone who gets an opportunity to attend the Nicholas Cup to go as you will enjoy all that is offered to you."

Katherine Paton - New Zealand

“I was the only representative from New Zealand at the Winter World Transplant Games and Nicholas Cup in France. My dad and I had a fantastic and very rewarding trip. It was tiring to be travelling for so long but once in France it was beautiful. I was challenged every day to improve and better myself. I received a medal for my contribution and have come home having met some brilliant and very courageous athletes. French television Channel Five was filming all week to make a program about organ donation awareness and I was interviewed for it - that was great fun. I would like to thank everyone who has helped me from the bottom of my heart for their kind words and donations towards my trip. I have been invited to participate in Sweden in 2011, so I had better get myself organized and start to plan my training routine!”

Cassandra Lenglet, winner of the 2010 Nicholas Cup

Eoin speaking at the Opening Ceremony

Katherine with her ski instructors
A wonderful week of snow, sunshine, fun, competition and companionship was experienced by 173 participants from 19 countries at the 7th Winter World Transplant Games and Nicholas Cup in Sainte Foy, Tarentaise, France in January 2010.

The Games included participants from around the world, some from as far afield as Australia, Japan, New Zealand and South Africa. As well as the traditional ski competitions, enjoyed by both competitors and supporters alike, the participants were given the opportunity to experience Snowshoes and Orienteering which were very popular. Courtesy of Astellas’ support, the children were treated to dog sledging, ski-biking and horse ski-joering as well as many other activities. The magnificent 2010 Games will be remembered for many things, but not least of all the friendships made at the beautiful resort. A very big thank you to all the members of the LOC and the brilliant volunteers who worked so hard to make the Winter World Transplant Games 2010 a great success.

Olivier Coustere
Skiing under the blue skies of Sainte Foy

Snowshoes!

Happy medal winners!

Olivier Coutere with the wonderful volunteers - Thank You!

Taking aim at the Biathlon

Three cheers for the Nicholas Cup!
COUNTRY NEWS • COUNTRY NEWS • COUNTRY NEWS • COUNTRY NEWS • COUNTRY NEWS

NEWS FROM SLOVENIA

The Slovenian Transplant Association is a young one, only ten years old. Although we have modernized our organisation, leadership, goals and strategy, we still need to engage our huge energy to make ends meet every month. Our main mandate remains, as always, to improve the quality of life of transplant recipients and their loved ones.

The versatile programme of our association includes sport, cultural, educational and fun events. We do these in the format and way that the money available allows us to - we are enthusiasts and well accepted! On a formal level we take part in legislative procedures as a Non-Governmental Organisation (NGO).

In Slovenia, the media is one of the main tools in the debate regarding a new law referring to organ donation and transplantation.

Our role as a partner has been established and we recognize that a high profile and professional work with the media benefits our efforts.

For the future we hope to participate more fully in the World Transplant Games.

Anastazija Bizjak
Branko MRAK

2nd Polish Transplant Sport SHOOTING CHAMPIONSHIPS

Following the success of the 4th Polish Transplant and Dialysis Games which were held in June in Kozienice, the 2nd Transplant Sport Shooting Championships took place on Friday, 18 October 2009. The Championships were held at Jedlicze Grammar School near Krosno, Poland with 15 transplanted competitors taking part.

The competition included shooting in the following disciplines: 10m pneumatic pistol, 10m pneumatic rifle and 25m sporting rifle. At the end of the day the 2009 shooting champions were Iwona Glazar (kidney transplant), Grzegorz Zimny (liver transplant) and Józef Śliwianka (kidney transplant).

A meeting was organized together with the students from the school to promote organ donation and raise awareness among young people. Gifts of Life Donor forms were distributed to the students.

The event was enjoyed by all those who were involved.

Krystyna Murdzek
Polish Transplant Sport Association

Happy transplant recipients in Slovenia
MIND BOGGLING QUESTION

COULD IT REALLY BE THIS EASY?

If it takes one minute for one person to convince two people to carry an organ donor card – and those two people then convince two more people each in one minute… and then they all carry on convincing two people each in one minute… HOW LONG WOULD IT TAKE FOR THE WHOLE WORLD’S POPULATION (BASED ON AROUND 4 BILLION PEOPLE) TO BE CONVINCED TO CARRY A DONOR CARD?

Answer on Page 18
My name is Claire. I live in Bienne in Switzerland but I’m very lucky because my mother was brought up in Canada and has always spoken to me in English so I can speak French and English. I’m also very lucky because someone said “yes” to organ donation and saved my life. I had a liver transplant when I was three years old. I am ten now and this year was my second time at TACKERS.

There are all kinds of people at TACKERS camp - people that come from all over the world and who take time off to come and help. They are all great fun and make me laugh. I love the fancy dress evening. This year, Meriem, a little girl from Morocco, won the competition. She only spoke Arabic and came to camp all on her own without her mummy.

I have made lots of new friends from around the world. I even saw my surgeon at camp. I told her I did not like her when I was little but I do like her now and she laughed.

We do all sorts of things at camp. I am not very shy so I talk to lots of people and Liz asked me to go and talk to the shy children so they can come and play with us. Liz is the lady who started the camp. She had a liver transplant too.

I don’t know what I like best about camp. I do miss my mummy and I think she misses me but there are so many things to do that I do not cry. Liz’s daughter Zoé organises beauty school. I love beauty school. We have partners and take it in turn to treat our friends. I like to have my friend Emma as my partner. I knew her already as we go to the same hospital in Geneva.

When we played “Stock Exchange” at camp I played with the girls from Israel - it’s lots of fun and you buy things with Monopoly money. At karaoke I sang with everyone. I also won a paragliding jump which was really exciting. I felt like a bird in the sky!

There is so much to do at camp - it’s not just skiing but I am not allowed to forget my school work. Mathieu helped me with my homework. I like the arts and crafts too and the ski race was good. It was lovely weather and I did not fall. We all won a medal too!

Some of the children who came to camp when they were little are older now and come as helpers. I would like to do that when I am older. As I’m only 10 I have to wait a few years.

Hello to any of my friends who might be reading this and thank you everyone who organised the camp. You made us very HAPPY!!!

Claire Steiger
A question for transplant recipients: When is the last time you missed a dose of your medications? Can you remember being late taking your medications? Do you find yourself forgetting to take a dose of your immunosuppressive or other medications?

Most transplant patients are taking between 5 and 15 medications daily, with doses due one to four times daily. This is a very complicated medication regimen! It is not surprising that 20-60% of transplant patients report missing medication doses or non-adherence to their medication regimen. Unfortunately, these missed doses or forgotten medications can lead to serious problems in transplant patients including acute rejection, chronic transplant damage and ultimately the failure of a transplant.

With so much at stake, why is nonadherence to medications so common after transplant? There are many reasons. The most frequent reason given for missing medication doses is “I forgot.” Intense medication regimens required after transplant are difficult to manage and remembering to take pills two or three times a day can be a challenge. Additionally, immunosuppressive medications prevent rejection and transplant patients do not necessarily feel a beneficial effect when they take their medications. In fact, sometimes the side effects of the medications make you feel worse! These medication side effects may include pain or tingling in the hands or feet, tremors, cosmetic changes like weight gain or hair growth or gastrointestinal problems like nausea or diarrhoea. Intolerable side effects are commonly blamed for patients missing doses or stopping medications all together. Another concern is cost. Medications to prevent rejection and treat other complications common in transplant patients often carry a high price tag. Patients may be forced to pick and choose which medications they can afford at their pharmacy.

What can we do to improve compliance with medications?

1. Understand why you are taking each of your medications. It is valuable for transplant patients to work with their clinic pharmacist, nurse or doctors to become educated about their medication regimen. Although immediate symptom relief is not seen with medications for preventing rejection or treating high blood pressure or cholesterol, the long-term benefit of using these medications is very high!

2. Communicate concerns about medicines to your transplant team. This includes reporting problematic side effects, medications with complicated instructions (for example: three or four times daily dosing) or medications that are too expensive for the transplant patient to afford. It may be possible to change medications to alleviate side effects, reduce cost or simplify medication regimens.

3. Develop a reliable system for remembering your medications. Getrefills in advance to prevent running low on pills. Use medication boxes to keep your pills organized and handy. This also makes it easy to see if you’ve taken those morning medications yet or not. Take your pills as a part of your usual morning and evening routine, or set a reminder alarm (cell phones work great!) to alert you when doses are due.

4. Utilize family members and other support systems. The family and friends of transplant patients are invested in your good health (perhaps they donated your organ!). A supportive parent, spouse or child may go a long way in encouraging a transplant recipient to keep up with their complicated medication schedule.

Remember, transplant recipients are the most important player on the post-transplant team. If unable to comply with their medication regimen, outcomes will not be satisfactory for the patient or the health care team. Good communication between the players including your health care providers and social workers can improve patient compliance, outcomes and quality of life.

Tracy Anderson-Haag, Pharm.D
(Published with permission from National Kidney Federation)
1. Protein
Getting the right amount of protein is important to your overall health and how well you feel.

Your body needs the right amount of protein to:
• Build muscles
• Repair tissue
• Fight infections

Your doctor may recommend that you follow a diet that has controlled amounts of protein. This may help decrease the amount of waste in your blood and may help your kidneys to work longer.

Protein comes from two sources.
You will need to get some protein each day from both of these sources:
• Animal sources: eggs, fish, chicken, red meats, milk products and cheese
• Plant sources: vegetables and grains

2. Sodium
Kidney disease, high blood pressure and sodium are often related. Therefore, you may need to limit the amount of sodium in your diet. One tactic to accomplish this is to learn how to read food labels so you can make lower sodium choices when you shop for foods.

Sodium is a mineral found naturally in foods. It is found in large amounts in table salt and in foods that have added salt such as:
• Seasonings like soy sauce, teriyaki sauce and garlic or onion salt
• Canned foods and some frozen foods
• Processed meats like ham, bacon, sausage and cold cuts
• Salted snack foods like chips and crackers
• Most restaurant and take-out foods
• Canned or dehydrated soups (like packaged noodle soup)

3. Potassium
Potassium is an important mineral in the blood that helps your muscles and heart work properly. Too much or too little potassium in the blood can be dangerous. One of the kidney’s jobs is to regulate the amount of potassium in your body and eliminate excess in the urine. When your kidneys begin to lower in function you may need to assist them by monitoring potassium in your diet. Foods that contain higher amounts of potassium are fruits and vegetables.

4. Phosphorus
Your kidneys also have the job of removing excess phosphorus from your blood. A high blood phosphorus level may cause your skin to itch and your bones to lose calcium which increases the risk for breaks. If you have CKD stage 3-5, eating fewer foods that are high in phosphorus, is very important and will help lower the amount of phosphorus in your blood.

Phosphorus is found in large amounts in the following:
• Dairy products such as milk, cheese, pudding, yogurt and ice cream
• Dried beans and peas such as kidney beans, split peas and lentils
• Nuts and peanut butter
• Beverages such as hot chocolate, beer and dark cola drinks

These useful tips regarding healthy eating for those with kidney disease come from the National Kidney Foundation, USA.

IF YOU HAVE KIDNEY DISEASE

Four Ways to Eat More Healthily

IF YOU HAVE KIDNEY DISEASE

Four Ways to Eat More Healthily

IF YOU HAVE KIDNEY DISEASE
My name is Shillane Labbett and I am a 38 year old double lung recipient. I was born with Cystic Fibrosis and was originally given five years to live. With the help of good care and good doctors I was able to get to the age of 33 with my old lungs.

By the time I had reached thirty, my lungs were rapidly deteriorating. On a good day my lung function was 30% and the subject of transplantation was discussed frequently. Talking it over with my husband Simon and my Mom, in time they finally convinced me and I began six monthly assessments.

Then on 25th September 2004 when I was on vacation in Nova Scotia, I developed massive haemoptysis, which is haemorrhaging of the lungs. They estimate that I coughed up two litres of blood before I was rushed to the hospital in Halifax and put on oxygen permanently. Once back in Kingston, after a two week stay in the hospital, the transplant team determined that I should be added to the list. So my Mom, who was my support person, and I moved to Toronto to begin the wait and embark on the exercise rehab program for the six to eight months they said it would take before I would probably get a transplant.

In the first week of waiting, I had another major haemoptysis and I was admitted to the Intensive Care Unit and put on a ventilator. I was given priority on the list and after ten days in Intensive Care, I was given the incredible news that a set of lungs had become available. The first thing I wrote on my notepad was that I felt sorry for the family of the donor. On 24th February 2005, I got my new lungs!

After two years with my new lungs I joined the Ontario East Transplant Support Group, a group who raise awareness and provide support for those pre and post transplant, as well as donor families. Through this group I found out about the Canadian Transplant Games in Edmonton and how it was such an incredible experience. The 2008 Canadian Games were in Windsor, so we decided to go! It was just as they had described; a wonderful experience where everyone had an inspiring story. I competed in Lawn Bowls, Ten Pin Bowling and Table Tennis.

With my experience in Windsor, we figured the World Transplant Games would be great too so we decided to attend the Games on the Gold Coast in 2009. With the help of some local sponsors and the Ontario East Transplant Support Group we headed to Australia for the Games. I only competed in two events this time: no Table Tennis as I had found in Windsor that the calibre of the competitors was much higher than myself – a beginner.

I am hoping to compete in future Games and I have also been training so perhaps I can compete in some more high impact sports. So, Quebec City – Here I come!! I would love to attend the World Transplant Games in Sweden in 2011 as well, although I will have to come up with some capital first.

Shillane Labbett
It is early summer in the UK as I write this – already Karen and I are thinking that this time next year we will be getting ready to travel to Sweden for the Games. Already we are planning and talking to the Swedish LOC and organising the first visit by WTGF Councillors to Gothenburg next month. It seems like Australia 2009 is long gone but not in our memories…

In January 2010 I was lucky to be able to travel to France to experience the Winter World Transplant Games for the first time since I joined WTGF seven years ago. I was very moved by the week that I spent mainly with the children who were preparing for the Nicholas Cup and delighted to have been part of such a lovely, friendly and cheerful week in a beautiful ski resort in the French Alps. Some wonderful photos of the Nicholas Cup and the Winter Games can be seen in this edition.

Here in the WTGF Office, we are in constant communication with all of our members and potential members around the world and we are always pleased to hear your news and to help when we can. There are many countries in the world that we have lost contact with over the years as they have been unable to attend the Games and/or the main contact has disappeared and for this reason, we are conducting a major review of all our contacts in the world – the aim is to increase to 70 attending countries in Sweden 2011 and to increase the numbers attending particularly the smaller teams. We can do this with your help – either by you giving us new contacts in your region of the world or by you making contacts for us and putting us in touch. Please give this some consideration and write to us at wtgf@wtgf.org if you would like to help.

Finally, by the time you read this, the WTGF office will have relocated – for practical reasons we have agreed to move to a better office space nearby……business here will continue as usual.

Till we meet again

Mary and Karen WTGF Secretariat
www.wtgf.org
wtgf@wtgf.org
MESOT was initially founded in Turkey under the leadership of Professor Mehmet A. Haberal in 1987, in compliance with Turkish Civil Code regulations. The Society was subsequently incorporated and registered with the Bern, Switzerland Chamber of Commerce in June 1988 as a nonprofit international scientific Society. The boundaries of the regions defined in the original bylaws were extended to include neighboring mid-Asian countries (Pakistan, Afghanistan and Former Soviet Republics) in accordance with the resolution accepted at the Third General Assembly, which was held in Tunis in December 1992. MESOT became an affiliate member of the Transplantation Society in August 1990 at the General Assembly of the San Francisco Transplantation Society, and in January 1992 became associated with Transplantation Proceedings. The proceedings of MESOT meetings have been published regularly in this Journal since that time.

Briefly, the purpose of MESOT, as stated in the Society’s bylaws, is:

- To promote and encourage education, research and cooperation in the field of organ transplantation between medical centers in Middle Eastern, North African and neighboring mid-Asian countries for the purpose of advancing the art and science of transplantation and to serve the patients of this region through the application of new knowledge and advances in the transplantation of organs for the treatment of human disease.

- To create a scientific forum for discussion of all problems related to the field of transplantation, including medical, social and legal aspects.

- To collaborate with existing public and private organizations to promote and encourage research and clinical applications related to transplantation, and to participate and assist in the coordination of efforts or the formulation of programs by all physicians, agencies, health personnel and scientists which will promote the donation of organs.

- To encourage meetings, symposia and congresses, and to prepare and distribute publications and announcements in order to fulfill the above objectives.

In order to fulfill these goals MESOT has been holding congresses regularly every two years with regional international participation. For example, WTGF President Mr. Olivier Coustere was a guest speaker at our Congress in Shiraz, Iran in November 2008 where he presented a paper on Sport after Transplantation. The next congress will be held on 18th October of this year in Tunisia.

Experimental and Clinical Transplantation (ECT) is the official journal of MESOT which has been issued since 2003 and distributed among its members.

MESOT has also established a Fellowship Program to train and educate young transplant specialists, mostly from underprivileged areas, in centers of excellence in MESOT area. Once trained these young fellows will go back to their countries to establish transplant services which is lacking in many areas of the Middle East.

The positive effects of Transplantation sports are well known in the world and that is why the ME Transplant Games Federation (METGF) was established under the umbrella of MESOT, to encourage organ donation and transplantation in the region. MESOT will be holding its third games in Tunisia in 2010.

And because MESOT regions suffer from organ shortage from deceased donors, the Middle East Transplant Coordinators Organization (METCO) was established in 2009, again under the umbrella of MESOT, in order to promote donation especially from the deceased. This organization has held several courses in different countries.

Like many parts of the world, the Middle East has been affected with unethical practices in the field of organ donation and transplantation. In order to combat transplant tourism and commercialism, MESOT has coordinated its efforts with The Transplantation Society (ITTS), International Society of Nephrology (ISN) and the World Health Organization (WHO). The President and many of the past Presidents of MESOT are still playing an active role in this international fight against illegal practices.

Dr Mustafa Al-Mousawi
Astellas (formerly Fujisawa) has been committed to the European transplant community since the early 1990s. By taking a leadership role in addressing the needs of surgeons, physicians, and patients, we are **CHANGING TOMORROW**.

Through sustained investment in almost 100 European clinical studies, Astellas is continually striving to advance transplant care by developing both new treatment regimens and innovative therapies that target specific pathways.

By partnering with you, and by supporting many of the patient organisations that offer hope for the future, we are all **CHANGING TOMORROW** as we work to fulfil the promise of transplantation.

www.astellas.eu

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