TRIO TGA Workshop topic: 
Post-transplant Cancer

Host: 
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2 time liver transplant recipient
TRIO vice-president
web team lead: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)
Today’s workshop agenda

- Background story of TRIO’s PTC focus
- Why this is so important
- Overall project plan & timeline
- Current deliverables
  - PTC educational web site
  - PTC workshops
- Overall message
- Tour of the PTC web site
- Take-away points
- Your personal challenge
- Q&A
Studies show that cancer is one of the leading causes of death post transplant

Transplant recipients are at higher risk for cancer - in some cases more than 50 times higher than the general population

Patients often are not getting long term follow up counseling on this issue which becomes increasingly important with advancing age and years post transplant

With education and proactive follow-up, we can recognize early on and treat/cure cancers, living long, active and healthy lives for those many extended years with a transplant

Why this is **SO VERY** important for you . . .
✓ Raise your awareness of this post-transplant cancer risk issue
✓ Show you how to use a TRIO web based resource to learn and commit to ‘best practices’ actions in dealing with that risk
✓ Provide basic education of the key areas of post-transplant cancer concern that come out of TRIO’s research and findings

*Diagnosing and treating cancer early results in long healthy PT lives!*

Our goals for today . . .
Our PTC project story:
- Where this TRIO PTC focus began

- Steve’s Feb 2014 phone call to Jim:
  “We’ve just lost another San Francisco chapter member to cancer. What are we going to do about that?”

- Jim’s immediate response:
  “Yeah, right! What can we do about cancer!”
  … dismissing Steve’s seemingly impossible question

- Calling Steve back after some thought, Jim challenges:
  “Ok wise guy, if TRIO can’t do it, who is? If you’re game, I’m willing to see what we can do about cancer!”

  … and thus began this TRIO PTC (post-transplant cancer) project
TRIO PTC 5-year Project Plan

2015

Phase 1: Planning/Research
• Flush out full plan & schedule implementation phase
• Obtain grant funding
• Conduct member research
• Develop educational content (i.e. Web site, video, text)
• Phased PTC web site launch

2016

Phase 2: Implementation
• Implementation per plan (i.e. PTC workshop kit)
• Launch behavioral research
• Prepare for phase 3
• Obtain phase 3 grant funding

2017

Phase 3: Evaluation
• User survey evaluations
• Tool refinement based on behavioral research findings
• Prepare for phase 4

2018

Phase 4: & beyond?
• To be determined

2014

Phase 0: Concept Formation
• Research & development of TRIO potential initiatives
• Development of full plan & budget for board review
• Identify grant sources

2015

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2016

Phase 2: Implementation
• Implementation per plan (i.e. PTC workshop kit)
• Launch behavioral research
• Prepare for phase 3
• Obtain phase 3 grant funding
- Background research of need carried out with medical professionals treating transplant recipients and related cancers (all agreed to the need and offered their support)

- Overall 5-year PTC project plan of deliverables by timeline developed

- PTC project plan approved by national board with initial funding from operating budget

- National office began setting out supporting grant requests

- TRIO member PTC support team formed

Where are we today?
- Initial planning and research
Where are we today?

- 1st deliverable: PTC web site

- Overall PTC web site design outsourced to professional web design team
- Video recorded interviews on PTC conducted with medical experts (on-going)
- Video editing of the interviews to match web topics begun
- Recruitment of medical ‘faculty’ for the site solicited
- Content research across 24 topics done with TRIO national team
- Patient video testimonials of life PTC challenges collected/edited
- PTC educational web site launched with 24 place holder topic pages of text, video, action plans and on-line resources
- Content made available as completed with full content still under development
Where are we today?
- 2nd deliverable: PTC workshop

• Framework of PTC workshop developed using as its foundation the PTC educational web site
• First PTC workshop prototype conducted at AAKP conference Sept ‘15 in Nashville (very well received)
• PTC workshop conducted Jun ‘16 at TGA in Cleveland
• Workshop development will continue as the web site becomes fully populated for general use by TRIO chapters and transplant centers
Three key points . . .

1. Understanding the higher cancer risk post transplant
2. Recognizing cancer symptoms
3. Taking action to live with the higher risk of cancer

But . . .

The more important issue is changing human behavior (habits)

**Diagnosing and treating cancer early results in long healthy lives!**
Touring the PTC web site . . .
- 24 text & video topics

- Site address: http://TRIOwebPTC.org
  (note: also linked from TRIO national web site: http://TRIOweb.org)

- Site consists of 24 pages of post-transplant cancer (= PTC) topics

- Organized into four main categories:
  ◦ Learn
  ◦ Look
  ◦ Live
  ◦ Links
Touring the PTC web site . . .
- main educational categories

- Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)

- Four main categories:
  - Learn: the facts of cancer risk by type of organ transplant
  - Look: for cancer symptoms
  - Live: proactively to prevent, diagnose and treat cancer
  - Links: to on-line resources to support further learning about PTC
Site address: http://TRIOwebPTC.org

Touring the PTC web site . . . - a site map ‘big picture’
Touring the PTC web site . . .
- Same topics but more user friendly

Site address: http://TRIOwebPTC.org
Touring the PTC web site . . .
- PTC Home Page: people friendly

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"Elizabeth, 23 years post liver transplant, enjoying life beyond skin cancer."

Elizabeth Rubin, liver recipient 1992, cooking at Gift of Life Family House
Touring the PTC web site . . .
- PTC Home Page: people friendly

"Bob, recipient of two living donor kidneys, in control (train hobbyist) thriving beyond post-transplant cancer."

Bob Kelchner, 13 years and two living family donors later

Site address: http://TRIOwebPTC.org
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Touring the PTC web site . . .
- PTC Home Page: people friendly
Touring the PTC web site . . .

- PTC Home Page: people friendly

Site address: http://TRIOwebPTC.org
Welcome to the TRIO [Transplant Recipients International Organization]/Post-Transplant Cancer (PTC) website.

Here you will find structured educational material and videos to LEARN about and raise your awareness of cancer risks for transplant recipients. Once you are aware of the higher risk, you can learn symptoms to LOOK out for and how to deal and LIVE with cancers that affect the majority of long-term transplant survivors. Finally, you will have LINKS to resources to help you go further in this life-saving learning process. Come, enjoy and live a long cancer-free healthy life with your transplant.

Recent Updates & PTC News:

- The Cancer Conundrum: How should transplant professionals manage their patients in the era of cancer immunotherapy: 3/2016
- A doctor shares the secrets of cancer survivors: 2/2016
- Immunosuppressed Melanoma Patients Have More Aggressive Disease: 7/2015
- Cancer death risk higher for organ transplant patients: 1/2016
- See Sugar & cancer topic under LINKS: INTERACTIVE BLOC: 1/2016

Note: Content is being added as our research progresses, with the more popular topics being expanded first, ie., organ type (kidney: 90% of transplants are kidneys), cancer type (skin/most common cancer by far in post-transplant patients) - since that will serve the greatest number of patients first.

Learn More
- Site address: http://TRIOwebPTC.org

Touring the PTC web site . . .
- PTC Home Page: topic interfaces
Site address: http://TRIOwebPTC.org

Each topic page consists of:
- Introductory text on topic importance
- Videos – both short overview one, and optional 2nd longer presentation by medical professionals
- Supporting paragraphs of textual information
- Suggested follow-on links to on-line learning
- Action items
Touring the PTC web site . . .
- PTC topic pages: LEARN overview

Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)
Imagine this too common scenario: A candidate for organ transplant attends the pre-transplant introduction offered by most transplant programs. Among the overwhelming amount of information explained is the fact that a transplant recipient will be on immunosuppressant medications for the rest of their lives and with that comes a higher risk for cancers. With focus on the transplant process, this is of little note at the time. After the transplant again there is mention of that higher risk for cancer, but with all the other important things that seems of little consequence, especially since those cancers typically don’t arise til years later. Especially for kidney recipients, due to the high volume of transplants at most programs, a patient often transitions back to their local nephrologist after that first year post transplant. Now they are under the care of a kidney doctor who is not a transplant specialist and thus may get little attention to that increasing risk for cancers as the years go on.

How much higher is that risk for a transplant recipient? See more detail in the Overview below these videos.

Watch this introductory video to better understand the post-transplant cancer risk in general, then follow on to your specific type of organ transplant to see what cancers are more common for that type of transplant.
Overview

Many studies now confirm that cancer is a major source of morbidity and mortality following solid organ transplantation and has become one of the three major causes of death after transplantation in the past decade. A recent study supports this issue further. From The Oncology Report: Squamous cell carcinoma (SCC) is the most common cancer to occur after organ transplantation," Dr. Chestnut and his associates noted. "The malignancy is 65-250 times more common, is more than 4 times more likely to metastasize, and has a mortality rate of 5% compared with a rate of less than 1% in immunocompetent patients." Thus, knowledge of post-transplant cancer risks and options for prevention are critically important to all transplant recipients.

Root causes of post-transplant cancers

Touring the PTC web site . . .
- PTC topic topic pages: LEARN videos
Root causes of post-transplant cancers

So you wonder why the cancer risks are different by type of organ transplant? Since most of the higher risk is due to our immunosuppressant medications, one can understand that with different medications and different dosages used for each type of organ transplant, those risks would vary by organ type.

In the topics that follow, cancer risk differences are described by each type of transplanted organ, so read on for your specific organ topic. You heard Dr. Tsai describe the "root causes" of cancer post-transplant in his video above, but medication was just the main contributing factor. There are many others based on such things as certain medications making the patient more sensitive to sunlight, for example, along with age, gene and DNA differences, family and individual life histories, to name just a few more.

Action Plan

Step 1: Read the "Cancer Risk by Organ Type" topic (see organ type icon links below) and understand the higher risks of specific types of cancer post-transplant common to your organ transplant type.

Step 2: … then under LINKS on this PTC site, see the "10 Best Practices" for steps to take to control and deal with your personal PTC risk. Make these your life extending habits.

Site address: http://TRIOwebPTC.org
Touring the PTC web site . . .
- PTC topic pages: LEARN related links

- Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)

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**Action Plan**

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**Related Links**

- View the full PTC site map
- TRIO main site

Choose a transplant organ type:
• Site address: http://TRIOwebPTC.org
And finally . . .

Choose a transplant organ type:

Heart  Kidney  Liver  Lung  Pancreas

. . . To link to risks topic page by specific organ type

Touring the PTC web site . . .
- PTC topic pages: subcategories
Touring the PTC web site . . .
- looking back at the ‘big picture’

Site address: http://TRIOwebPTC.org
Touring the PTC web site . . . - stepping down one level,
Touring the PTC web site . . .
- we have visited the two top topics

Site address: http://TRIOwebPTC.org
Touring the PTC web site . . . LEARN
- next we would step down to learn about the cancer risk topic for our specific organ
Touring the PTC web site . . . LEARN
- next we would step down to learn about the cancer risk topic for our specific organ

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<thead>
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<th>Organ Type</th>
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<td>Heart</td>
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Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)
Heart transplant recipients are at high risk for skin cancers and other less common cancers mainly due to their long-term use of the immunosuppressant drugs required for life. The incidence of cancer rises both with age (as it does in the general population) and with long-term survival post transplant given the increasing years of that drug use. Some lifestyle practices are also contributing factors such as smoking, lack of proper diet and no regular exercise.

The good news is that cancer diagnosis and successful early treatment is improving with each passing year. Our goal then is to recognize and treat cancer early on when it is most treatable, and that is what this TRIO PTC educational web site is all about, helping you meet that early diagnosis and successful treatment.

Most heart transplant programs follow their patients for life and in semi-annual clinic visits, suggest and ask about whether the patient has seen a dermatologist on a regular schedule (usually at least twice a year unless other factors indicate closer surveillance). While skin cancers are the most common, with studies reporting up to 50 times the risk for skin cancers vs. the non-transplant population, cancers types taken together remain the main cause of death in heart transplant patients, something that can be reduced in each individual if proper steps are taken as described below.

But first, watch and listen to the following short videos by transplant medical specialists to gain more understanding of your risk as a heart recipient and what you can do to reduce your risk.
03. PTC: Cancer Types

Each type of organ transplant comes with cancer risks that may be different due to unique biology of that organ, or more commonly, due to the different drug protocols - both drug type and dosage - used for each type of transplant.

In this LOOK section you will find topics related to the most common types of cancer a recipient faces, as described under the various organ risk specific topics in the LEARN section of this educational web site.

Keep in mind that many cancers are non-symptomatic, making it hard for the patient to recognize any external symptoms. In surveys of transplant patients who have experienced those cancers, it is common to learn how coincidental the find was, usually identified in a non-related test or procedure that exposed a tumor that was not the subject of that procedure.
Now that you LEARN about the higher risk of cancer in organ transplant patients and can LOOK for the signs that give early warning to cancer types common to your type of organ transplant, it's time to face and understand how to LIVE through the life cycle of cancer. That will include PREVENTION, DIAGNOSIS, TREATMENT options and finally living through long term RECOVERY hopefully cancer-free.

Note: the following two videos are temporary place holders until we get videos that specifically address this topic of LIFE CYCLES OF CANCER.
Touring the PTC web site . . . LINKS
- from living with the higher risk of cancer we can link to other resources (Patient testimonial videos, 10 best practices, online resources, faculty bio videos, blog, etc.)

- Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)

Choose a resource for more information:

- **Patient Testimonials**
  - Ready for use

- **Interactive Blog**
  - Ready for use

- **10 Best Practices**
  - Ready for use

- **Learning Objectives**
  - Ready for use

- **Behavioral Research**
  - Ready for use

- **Resource Library**
  - Ready for use

- **Medical Faculty**
  - Ready for use
Touring the PTC web site . . .
- so now you can see how the LEARN, LOOK, LIVE and LINK topics all fit together in the 'big picture'

Site address: http://TRIOwebPTC.org
Site address: [http://TRIOwebPTC.org](http://TRIOwebPTC.org)

Touring the PTC web site . . .
- made easier by this user interface to all 24 topics
The PTC web site (http://TRIOwebPTC.org) - is also linked from the TRIO national web site
So what are your key take-away points from those 24 topics & videos?

- As transplant recipients, accept the fact that we ARE at higher risk for cancers
- Main cause: our life-saving daily immunosuppressant meds
- By knowing our risk, watching for signs and following pre-emptive testing (for not all cancers have obvious symptoms), we can find cancers early
- Cancer diagnosed and treated early can be cured!
- Knowledge & ACTION leads to long and healthy lives
Your personal challenge . . .

The more important issue is changing your behavior (forming healthy habits):

Use the TRIO PTC web resource to **Learn, Look, Live** and follow the ‘10 best practices’ under the **Link** section

*Diagnosing and treating cancer early results in long healthy PT lives!*
Practice #1. Understand and acknowledge that with your organ transplant there comes a higher risk - as much as 50 times higher risk - than the normal population of getting cancer. This risk level depends on several factors such as: advancing age, longer years of survival post-transplant, ethnicity, immunosuppressant medications and type of organ transplant.

Practice #2. Being proactive in prevention, early detection and treatment of cancers post-transplant will typically result in minor treatment procedures with high probability of full recovery with minimal pain and inconvenience. The alternative of not being proactive in those steps can dramatically reduce your life expectancy post-transplant.

Practice #3: Know and follow a schedule of regular testing for early symptoms of cancer - i.e. annual tests prescribed by your transplant team (unique to each type of organ transplant), regular self-exams using wellknown processes for skin cancers, etc. adherence to your transplant program’s follow-up visits),

Practice #4. Follow your transplant team's advice in their referrals to cancer specialists with transplant experience - you are special and need the benefit of medical professionals that regularly treat and work with fellow transplant recipients to know how to look for conditions that are more prevalent and faster growing in immune-suppressed transplant recipients.

Practice #5: Write down a few key goals you are willing to commit to from the best practices listed here and track progress against those goals.
Practice #6: Maintain careful full compliance in following your transplant teams directives, especially in taking medications exactly as prescribed in time and dosage.

Practice #7: Stay active both physically and mentally every day, reporting any unusual symptoms promptly to your family doctor and/or transplant team - better safe than sorry!

Practice #8: Keep a regular schedule of appointments and testing.

Practice #9: Maintain an ongoing list of questions for your doctors and bring that list with you as reminders when you see them. Be sure you understand what that team is telling you and if not sure, ask again until it is clear. If you don't fully understand, they are not doing their job right and it's your life that is at stake.

Practice #10: Remember that you are the most important member of your medical team, the only one on-duty 24 hours every day who knows how you are feeling even beyond what testing and your medical team can see and feel. Be open, attentive (some even bring a recorder to insure accurate capture of the meeting), firm and assertive in dealing with all your support resources, including caregivers, family, insurance and medical staff. They are all your 'employees' and if not performing as you need, can be fired or replaced with another who can match your style and needs better.
Let’s chat together . . .
Go to http://TRIOwebPTC.org