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Charles O. Strickler
Transplant Center

Box 800265
University of Virginia Health System
Charlottesville, VA 22908

Phone: 800-543-8814
Fax 434-924-0017

Let's Talk Transplant

Getting Started

By Winsor Simmons, RN, CCTC

Greetings! Welcome to our first, quarterly newsletter hot off the press from the Strickler Transplant Center at the University of Virginia. I hope this finds you well and feeling healthy as the summer months are fast approaching.

Our goal will be to distribute this newsletter on a quarterly basis to patients awaiting liver, kidney, and pancreas transplantation as well as transplant recipients. Our global idea is for this letter to serve as a forum to help distribute information, provide education and transplant tips for healthy living while also keeping you abreast of the latest happenings in transplantation and at the Strickler Transplant Center.

Of special interest in June is the Women's Transplant Symposium. This meeting is an all day conference on Friday June 17th targeted specifically for women who are awaiting or who have received a transplant. This year marks our 4th annual conference and each year we have had a full house! To accommodate our growing numbers, the symposium will be held at the Omni Hotel in Charlottesville this year. Our keynote speaker will be Dr. Dearing Johns, who will discuss cardiovascular disease in women.



Other topics to look forward to include: diabetes education, patient testimonials, a mini yoga session, a food recipe makeover, pharmacy trivia, and the Transplant Olympics, not to mention a scrumptious lunch, door prizes, and the opportunity to meet and network with other transplant women! Hopefully, you have received this invitation in the mail however, we have inserted a copy of the invitation in this newsletter if you have not already received one. We hope to see many of you there!

Lastly, if you have information, upcoming events, or ideas for future topics that you would like to see in an upcoming edition, I encourage you to call our toll free number 1-800-543-8814 and speak with your transplant coordinator or send an email to the transplant inbox at transplant@virginia.edu.

Suggestions for topics that we may publish include transplant support group meetings, fundraising events, National Kidney Foundation (NKF) happenings and other established organizational group events. Perhaps you might be interested in submitting an article about how transplant has touched your life! Remember, we will need at least two month's notice and we won't be able to print everything, but we want to hear from you.

Best wishes for a safe and enjoyable summer!

Fun and Safety in the Sun

Nan Carroll, RN, CCTC

Many of us will find ourselves outdoors this summer enjoying our favorite activities. Gardening, swimming, going to the ballgame and the beach all mean more exposure to the sun's rays. The medicines you are taking to prevent rejection of your transplanted organ along with sun exposure will make your risk higher for developing a skin cancer.

What Causes Skin Cancer?

Sunburn and UV light can damage your skin and this damage can lead to skin cancer. Other determining factors that influence your risk of developing skin cancer include: family history, environment, and an altered immune system. Both the total amount of sun received over the years, and overexposure resulting in sunburn can cause skin cancer.

What are the characteristics of sun sensitive skin?

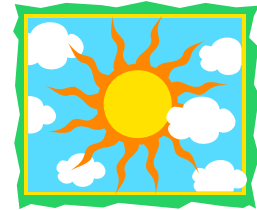
- ★ Skin is fair and freckles easily. Although, all skin tones can be susceptible to skin cancer.
- ★ Light-colored hair and eyes.
- ★ Large number of moles, or moles of unusual size or shape.
- ★ Family history of skin cancer or a personal history of blistering sunburn.
- ★ Primarily working or playing outdoors.

How is skin cancer treated?

Most skin cancers are removed surgically. Cryosurgery, or freezing the cancer cells is another method for removing the skin cancer. Radiation therapy (using x-rays) or topical chemotherapy (anti-cancer drugs applied to the skin) have also been used. Mohs surgery, is a special procedure in which the cancer is shaved off one layer at a time. If you develop a skin cancer

your doctor can help you decide which treatment is best for you.

Always notify your transplant coordinator if you have been diagnosed with a skin cancer. The transplant team may make changes to your anti-rejection medicine to help prevent the skin cancer from recurring.



How do I protect myself from the harmful sun's rays?

There are a number of steps you can take to protect yourself from the harmful UV sun's rays. First, avoid unnecessary sun exposure, especially between 10:00 a.m. and 4:00 p.m., the peak hours for harmful ultraviolet (UV) radiation. When you are outdoors, use sunscreens rated SPF 15 or higher. Apply them liberally, uniformly, and frequently. When exposed to sunlight, wear protective clothing such as long pants, long-sleeved shirts, broad-brimmed hats to cover your nose and top of your ears, and wear UV-protective sunglasses.

How do I use sunscreen?

- ★ Use SPF 15 or higher
- ★ Apply 30 minutes before sun exposure.
- ★ Apply liberally and re-apply after swimming or heavy perspiration.
- ★ Use lip balm with sunscreen.
- ★ Use make-up or after shave with sunscreen.
- ★ Protect eyes with sunglasses designed to screen UV light.

Have fun and enjoy summer!

Introducing Leah Wayner, RN, CCTN



Hello, my name is Leah and I am the newest coordinator here at UVA. I work in the pre-kidney transplant area. I graduated from Calvin College, in Grand Rapids, MI, in 2002 with my bachelors of nursing degree. My husband and I moved to Charlottesville in 2002 when I began working at UVA on the inpatient transplant unit, caring for transplant patients while they were in the hospital.

As I began to learn more and more about transplant from my experiences as a nurse and from being in the graduate nurse practitioner program here at UVA, I began to really like working in transplant. I began working as a coordinator in March 2005, and I have enjoyed getting to know my transplant patients and learning more every day.

Surfing the Transplant Websites

Leah Wayner, RN, CCTN

After donating or receiving an organ transplant, you and your family may have many questions, concerns, or needs that must be addressed. There are many resources available on the internet to answer questions, provide information, or to meet others in similar situations, and also to help you to provide education to others about your experiences with transplant. Please also remember as you do internet searches for transplant to use discernment—not all websites are safe or honest! The sites listed here may help you as you continue in your transplant journey.

Support groups and memberships:

<http://www.aakp.org/> Kidney disease support organization for those on the waiting list as well as organ recipients, with local chapters and support groups.
http://www.transweb.org/reference/maps/sg_guide/sg_virginia.html a list of support groups in Virginia, including Lynchburg, Washington DC, Roanoke area, and Virginia Beach.
<http://www.trioweb.org/> transplant recipients' international organization: online bulletin board, transplantation and organ donation information and

resources for candidates, donors, recipients and families.
<http://www.tppp.net/> the transplant patient partnering program: provides pt education material for all organs and support for recipients and families
<http://www.ikidney.com/iKidney/home.htm> online resource that brings together people with kidney disease, their family members, and renal care professionals to improve quality of life. Contains patient education material about kidney disease, lifestyle education, newsletters, and more.
<http://www.wildirisdesign.com/tso/links.html> transplant support organization with memberships available.



Websites related to organ donation information:

www.unos.org is an organization designed to coordinate organ donation and transplantation, provide education to the public, and encourage organ donation.
<http://www.lifenet.org/> provides basic information for transplant recipients and donors, as well as potential donors.
<http://www.transweb.org/> sets the record straight on “top ten myths” of organ donation.

H.O.P.E. Clinic

Brandy Yowell, RN, CCTC

You may have noticed the flyers around clinic, or maybe you have even attended Dr. Ross Isaacs' new H.O.P.E. Clinic.

H Healthy
O Options
P Patient
E Education

This new clinic is held one Friday a month and it is designed to help patients before and after transplantation with weight related issues.

All patients attend a one hour class that includes easy to follow and practical diet and exercise tips. After the class, patients have the opportunity to meet individually with a physical therapist and behavioral psychologist. Patients may also request phone call follow-up with the physical therapist or the behavioral psychologist after you have attended the H.O.P.E. Clinic.

Even minimal amounts of weight loss can improve blood pressure, blood sugars and lower cholesterol, as well as help you feel better.

To schedule an appointment in the H.O.P.E. Clinic, please call 1-800-543-8814 and ask for the appointment secretary.





Fourth Annual Living Well After Transplantation: A Female Perspective

Please join us for a one-day seminar dedicated to the special needs of women who have undergone organ transplantation. Life after organ transplantation requires a strong commitment to good health and for women, recognition of specialized needs. Our seminar draws upon the expertise of female health care providers who have expertise in caring for transplant recipients. This seminar is for women transplant recipients presented by women dedicated to their care.

Meet other female organ transplant recipients and ask regional experts in the field of transplantation questions about your health. Take the opportunity to meet and share and get the latest updates in female transplant care.

Friday June 17, 2005

Continental Breakfast from 8:30-9:00

8 am – 5pm

OMNI HOTEL

Charlottesville, Virginia

Registration Deadline: Friday June 3rd.

Cost: \$10.00 per person includes continental breakfast and lunch buffet.

***Registration is open to females only. Scholarships for registration are available.**

Please, no male guests.

For more information, call 1-800-257-0757

Cut here

**Return this section with check or money order to: University of Virginia Health System
C/O Cardiopulmonary Transplant Box 800191 Charlottesville, VA 22908**

Name: _____

Address: _____

Phone: _____

Date of Transplant: _____

Type of Transplant: _____

Number of participants: _____ **@ \$10.00 per person Total:\$** _____



The Waiting Room

Barbara Shephard, RN, CCTC

Funk and Wagnalls Standard Desk Dictionary defines to **wait** as 1) to stay or remain in expectation, 2) to be or remain in a state of readiness and 3) to remain temporarily neglected or undone. All of these definitions fit for an individual waiting for an organ transplant. The anticipated wait time for an organ from a deceased donor is difficult to predict and the Strickler Transplant Center asks that you be ready at any moment for the call telling you that an organ is available for you. You may feel neglected between visits to the clinic and communications from the transplant staff and wonder, "Have they forgotten about me?"



There are specific things that you can do while you wait for your transplant that will help to ensure that when an organ becomes available, you are ready.

- We need to know how to reach you day or night. That means we need a current home number, cellular phone number or a pager number, as well as phone numbers of other family members that might know where you are if we can't reach you.
- We need a current home address in case we need to send someone to your home if your phone is out of order.
- You should also make sure that you keep our financial coordinator updated regarding any changes in your insurance so that at the time of transplant you are ready to go financially when an organ becomes available for you.
- If you are waiting on the kidney or pancreas transplant list, you are responsible for making sure that we have a sample of your blood each month to perform a crossmatch with any potential donors that may become available. If our lab does not have a current blood sample, a kidney cannot be offered to you for transplantation. Please check with your dialysis unit staff or doctor's office to make certain this specimen arrives monthly. You can confirm that your sample has arrived by contacting the Tissue Typing Lab directly at 434-924-5086.

- You should remain current with regular health maintenance tests. Women should have pap smears and mammograms done each year in addition to any studies that we request to update your transplant evaluation. Colonoscopies are necessary for any patient over the age of 50.
- Please let us know when you have seen your local doctor or ask that he or she send us records from your visit. Also, please contact us if you develop new medical problems. It is important that we maintain an accurate and current record of all of your medical issues. Changes in your medical condition may change your status on the UNOS waiting list for transplantation.
- Contact the Transplant Office if you do not hear from us to update your evaluation each year.

You may have several "false alarms" before we find the organ that is right for you. You might be asked to be a "back up" to a patient ahead of you on the list. That means that should the first patient be unable to receive the kidney for some reason, it would be offered to you. The Transplant Coordinator will discuss this with you if you are asked to be a "back up."

The most important thing that you can do while you wait is to take good care of yourself. Follow your doctor's recommendations regarding taking care of yourself so that when the time comes, you are as healthy as you can be when "the call" comes.

Welcome Amy Roman, RN, BSN

I am so pleased to have joined the transplant team as a post-liver transplant coordinator. I have been a nurse since 1988 (here at UVA since 1995), working in the critical care units and caring for many transplant patients both before and after transplantation. The new opportunity of following patients' care as they incorporate their transplant experience into their life is a wonderful challenge and I am enjoying getting to know all of my patients. I have been in my new position since October and have met many of my patients, but continue to look forward to meeting all of them as they come to clinic....don't forget, we need to see you at least once a year!



United Network for Organ Sharing (UNOS) Patient Waiting Lists for Transplantation
May 2005

Kidney	61,947
Liver	17,379
Pancreas	1,708
Kidney/Pancreas	2,463
Heart	3,146
Lung	3,673
Heart/Lung	164
Intestine	<u>202</u>
Total	90,682



Laboratory Monitoring and Follow-up after Transplantation

Laura Healy, RN, FNP

After receiving your transplant, it is crucial to the life of your new organ that you receive routine laboratory monitoring, regular visits to the transplant clinic and follow-up with your primary care physician. Routine lab values help the transplant team gauge how your new organ is functioning in the context of its new environment. Such monitoring can be easily done by having your blood work and urine tests as directed by the transplant team, and making sure that you are compliant with all of your transplant clinic appointments. In addition to visits with your transplant coordinators and physicians, you will be instructed to return to your regular doctor at some point. This can include an internal medicine or family practice

doctor, a nephrologist for kidney transplant recipients, and a gynecologist for women, and other specialists when required.

Points to remember about laboratory testing:



1. Labs should be drawn first thing in the morning between 8:00 and 9:00 AM.
2. Do not eat or drink before having your labs drawn.
3. Do not take your medicine before having your labs drawn.
4. Cyclosporine and Prograf levels should be obtained 12 hours after the last dose of the medication for an accurate reading.

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ADDRESS CORRECTION REQUESTED

