Long-Term Follow-Up Guidelines for Adults

These are some important recommendations that can help prevent or early detect problems after transplant. Your doctor might make other recommendations to fit your specific health needs. Talk to your doctor if you have concerns about the costs of recommended medical tests.

Minimum Monitoring:

- **Self-examinations:** You should routinely do skin self-exams (looking for new or changing moles or other skin lesions) and mouth self-evaluations (for ulcers, red patches, or white patches). Women should do monthly breast self-exams and men should do testicular self-exams to check for any abnormal lumps. Discuss any unusual findings with your primary care doctor.

- **Key points at annual medical check-ups include:** height, weight, blood pressure, complete skin exam to screen for skin cancers, mouth exam to check for oral cancer; neck and thyroid exam to check for lumps; breast exam; annual Pap smear; and annual mammogram for all women over 35 years old. Female patients who received prior chest radiation should begin annual screening mammograms at age 25, or eight years after radiation but no later than age 35. Women who are taking estrogen should discuss the risks, benefits and alternatives with their gynecologist annually. Men over 45 years old should have a digital prostate exam annually. Screening colonoscopy is recommended at age 50 years (earlier if a first-degree relative was diagnosed with colorectal cancer before age 60). If you are being treated for chronic GVHD, check mouth for GVHD, joint range of motion and muscle weakness. Use “GVHD Tips & Forms” found at www.fhcrc.org/en/treatment/long-term-follow-up/information-for-physicians.html.

- **Recommended lab tests at annual medical check up include:** urine sample to test for protein, three stool samples to test for blood (age 50 or above), blood tests (complete blood count, fasting sugar level, fasting cholesterol profile, liver function tests, etc.), thyroid panel, and other tests as indicated by the history and physical findings.

- **Special disease monitoring blood tests:** If you had a transplant for Philadelphia chromosome positive acute lymphocytic leukemia (Ph+ ALL), the minimum frequency of BCR/ABL PCR testing in blood is every three months during the first year, every six months during the second year, then once a year for five years. If you had chronic myeloid leukemia (CML), BCR/ABL PCR testing in blood is recommended every six months during the first and second year after transplant, then every year for life. In order to follow serial BCR/ABL PCR trends, your doctor may want to continue this clinical testing at our UW Hematopathology Lab. Please have your doctor to contact the LTFU office at (206) 667-4415 or at LTFU@seattlecca.org for information regarding the size and type of tube and shipping instructions.

- **Dental check-ups:** Daily brushing and flossing are very important. See your dentist every six months to check your teeth, screen for oral cancers and, if you had an allogeneic transplant, to look for chronic GVHD. Remind your dentist that long-term transplant survivors have an increased risk of cancer in the mouth. Dental cleaning may begin one year after transplant, unless you are receiving therapy for GVHD. Use “GVHD Tips & Forms,” found at www.fhcrc.org/en/treatment/long-term-follow-up/information-for-physicians.html. Contact the LTFU office (206) 667-4415 or email LTFU@seattlecca.org if you have questions about dental care during treatment for GVHD. Tell your dentist if you are taking a bisphosphonate medication to improve bone density. This medication can cause a rare problem in jaw bones, including problems with healing if you have a tooth removed.

- **Eye exam:** Have annual eye exams to check for cataracts or problems caused by GVHD.
• **Pulmonary function tests:** Testing is done one and five years after transplant to check for lung problems. Testing may be increased to every three to six months if you have lung problems or are being treated for chronic GVHD.

• **Bone density testing:** Low hormone levels, inactivity, and medications such as prednisone can cause osteoporosis (thin bones). Have bone density tested by a type of x-ray called a DEXA scan at one year after the transplant, and then annually if the test is abnormal or you continue taking prednisone.

• **Adrenal gland testing:** Patients who have been treated with prednisone for more than a month may not produce enough natural cortisol from the adrenal glands. Therefore, when prednisone is being tapered or discontinued, a test of adrenal gland function may be indicated to avoid complications caused by inadequate cortisol levels.

**Risk of Infections**

- If you have chronic GVHD, take antibiotics to prevent infection for at least six months after ending all treatment with medications or treatments that suppress the immune system. These include prednisone, tacrolimus, cyclosporine, sirolimus, mycophenolate mofetil, extracorporeal photopheresis, etc.
- Avoid herbal medications or naturopathic remedies.
- If you develop fevers, chills or any signs of infection, seek immediate medical attention.

**Vaccinations**

- Most post-transplant vaccinations are given one year after the transplant. However, you may receive certain childhood vaccinations (Prevnar, haemophilus influenzae type B (HiB) and Menactra) starting as early as six months after transplant, if you meet requirements. Specific vaccination guidelines can be found at: [www.fhrc.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/physician.pdf](http://www.fhrc.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/physician.pdf).
- You should get the seasonal flu vaccine in October or November every year.

**Bone Health**

**Prednisone therapy causes loss of calcium in bones.** There are some ways to minimize this problem.

- If your diet does not contain at least 1500 mg of calcium per day, take a calcium supplement. You should not get more than 2,000 mg total calcium per day.
- If your diet does not contain at least 800 I.U. of vitamin D every day, take a vitamin D supplement.
- Do weight bearing exercises for 20-60 minutes every day, like walking, golf, or tennis.
- Have DEXA scan (bone density test) every year if you are taking prednisone-type medication.
- Medications like Fosamax, Actonel, Boniva, Pamidronate, Reclast or Zometa might prevent loss of bone density during treatment with prednisone.
- Hormone replacement therapy, such as estrogen or testosterone, might be helpful.

**Cancer Risk and Prevention**

- **The risk of cancer** is increased after transplant. The skin, mouth, breast, thyroid, esophagus and brain are the most common places where cancer may develop. See above for recommended cancer screenings.
- **Avoid tobacco products.** Contact Living Tobacco-Free Services for support: [www.seattlecca.org/smoke-free-life.cfm](http://www.seattlecca.org/smoke-free-life.cfm).
- **Avoid sun exposure** to minimize activation of GVHD and development of skin cancers. Sunscreen (SPF-30) should be used to protect skin, especially on your face, neck and ears, and lip balm with SPF. Wear a hat, long-sleeve shirt and full-length pants year-round.

The following web sites have additional information:

The site below contains important post-transplant information for doctors, and for patients.

Allogeneic (donor) Transplant:
[http://marrow.org/Patient/You_and_Survivorship/Working_with_Doctors/allo_post_transplant.aspx](http://marrow.org/Patient/You_and_Survivorship/Working_with_Doctors/allo_post_transplant.aspx)

Autologous (self) Transplant:
[http://marrow.org/Patient/You_and_Survivorship/Working_with_Doctors/auto_post_transplant.aspx](http://marrow.org/Patient/You_and_Survivorship/Working_with_Doctors/auto_post_transplant.aspx)