Guidelines for Pediatrics
Long Term Follow Up

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

Minimum Monitoring:
- **Growth**: Height should be measured at least every six months. Short children who received radiation to the head and/or total body should see an endocrinologist to check for growth hormone deficiency.
- **Puberty**: Children age 12 years and older with delayed signs of puberty should be evaluated by a pediatric endocrinologist. This problem can be treated with sex hormones. Adolescents should have regular genitourinary exams appropriate for age and sex.
- **Cognitive development**: Children who were younger than two at the time of transplant may have delayed language and motor skills. These children often benefit from speech and occupational therapies. School-age children should have tutors during the first year after the transplant. After the first year post-transplant, they can attend school.
- **Key points at annual medical check-up include** height, weight, blood pressure, a complete skin exam to screen for skin cancers, a mouth exam for cancer and a neck exam for thyroid lumps. Check for full range of motion at joints and muscle weakness if being treated for chronic GVHD (a simple “GVHD Tips & forms” can be found at [www.fhcrc.org/en/treatment/long-term-follow-up/information-for-physicians.html](http://www.fhcrc.org/en/treatment/long-term-follow-up/information-for-physicians.html). Breast exam for teenage girls (and counseling about breast self-exams).
- **Recommended lab tests at annual medical check-ups**: urine sample to test for protein, complete blood count, fasting glucose and cholesterol/triglyceride panel, liver and kidney function panel, thyroid hormone levels, and other tests directed by the history and doctor findings.
- **Special disease monitoring blood tests for**:
  - Transplant for Philadelphia positive acute lymphocytic leukemia (ALL): The minimum frequency of BCR/ABL by PCR testing in blood is every 3 months during the first year, every six months during the second year and then annually at three through five years.
  - Chronic myeloid leukemia (CML): BCR/ABL by PCR testing is every six months during the first and second years, and then once a year for life. In order to follow BCR/ABL serial result trends, your doctor may prefer to continue this clinical testing at our UW Hematopathology Laboratory. If that is the case, please ask your doctor to contact our LTFU office at (206) 667-4415 or by email at LTFU@seattlecca.org for instructions on sample shipment and other information for testing here.
- **Dental check-ups**: Daily brushing and flossing are very important. Your child should have a dental exam every six months. Dental cleaning may begin 6 months after transplant if your child’s absolute neutrophil count (ANC) is >1000, platelets are >30K, and the total daily dose of prednisone is equal to or lower than 0.5mg/kg.. Call LTFU if you have questions about dental care during treatment for GVHD at (206) 667-4415 or email at LTFU@seattlecca.org. Children younger than 12 who had high-dose total body irradiation before eruption of secondary teeth should have Panorex exams beginning one year after transplant to check for secondary teeth. Remind your dentist that long-term transplant survivors have an increased risk of cancer in the mouth. Tell your dentist if your child is taking or has a history of taking a bisphosphonate medication to improve bone density (see below under **Bone Health**). This type of medication can cause a rare problem in the bones that hold teeth, especially if your child has tooth removed.
Eye exams are recommended to check for cataracts or problems caused by GVHD.

Pulmonary function tests are recommended at 6 months, one and five years after transplant to find lung problems even if your child is symptom free. If your child has lung problems or is being treated for chronic GVHD, get tested every three to six months.

Adrenal gland testing: Taking prednisone for more than a month may lower the production of natural cortisol from the adrenal gland. When prednisone is being tapered or discontinued, monitoring is needed to avoid complications caused by inadequate levels of adrenal hormones.

Risk of Infections

- Chronic GVHD should be treated with antibiotics to prevent infection for at least 6 months, after ending all treatment with medications that suppress the immune system (such as prednisone, tacrolimus, cyclosporine, sirolimus, mycophenolate mofetil, extracorporeal photophoresis and others).
- Avoid using herbal medications or naturopathic remedies to treat infection.
- Seek immediate medical attention if fever, chills or any signs of infection develop.

Childhood Vaccinations

- Most post-transplant vaccinations are given one year after the transplant. However, your child may receive certain childhood vaccinations (Prevnar, Hib and Menactra) beginning as early as six months after transplant, if your child meets certain criteria. Your doctor can find specific vaccination guidelines at www.fhcrc.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/physician.pdf
- Your child should get the seasonal flu vaccine (get the shot, NOT Flumist) during October or November every year. Everyone who lives with your child should also get the flu shot.

Bone Health

Prednisone therapy, low hormone levels and inactivity causes loss of calcium in bones. There are some ways to minimize this problem.

- If your child’s diet does not contain at least 1500 mg of calcium per day, take a calcium supplement.
- If your child’s diet does not contain at least 800 I.U. of vitamin D every day, take a vitamin D supplement.
- Your child should do weight bearing exercises for 20-60 minutes every day.
- Your child should have a DEXA scan (bone density test) one year after transplant and then annually if your child continues taking prednisone.
- Medications such as Fosamax, Actonel, Pamidronate, Reclast or Zometa might also help to prevent loss of bone density during treatment with prednisone. Hormone replacement therapy might be helpful for certain people.

Cancer Risk and Prevention

- The risk of cancer is increased after transplant. The skin, mouth, breast, thyroid gland, esophagus, and brain are the most common places where cancer can develop after a transplant.
- Avoid tobacco products. Contact Living Tobacco-Free Services for support: https://www.seattlecca.org/diseases/lung-cancer/treatment-options/living-tobacco-free
- 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, ears, and lips (balm with SPF). Wear a hat, long-sleeve shirt and full-length pants.

The following web sites have additional information:

The sites below contain important post-transplant information for doctors, and for patients.