Pediatric Long-Term Follow-Up Guidelines

These are some important general recommendations that can help prevent or early detect problems after transplant. Your doctor might make other recommendations to fit your child’s specific health needs. Talk to your 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. Cleaning may begin one year after transplant, unless your child is receiving therapy for GVHD. 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 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 one and five years after transplant to find lung problems. If you have lung problems or are being treated for chronic GVHD, get tested every three to six months.

• **Bone density testing:** Low hormone levels, inactivity, and use of medications like prednisone can cause osteoporosis or thin bones. Have bone density tested by a type of x-ray called a DEXA scan one year after transplant and then annually if the test is abnormal or your child continues taking prednisone.

• **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, mychophenolate mofetil, extracorporeal photoforesis 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](http://www.fhcrc.org/content/dam/public/Treatment-Support/Long-Term-Follow-Up/physician.pdf)

• Your child should get the seasonal flu vaccine during 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 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) every year.

• 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: [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. Wear a hat, long-sleeve shirt and full-length pants.

**Resources for additional information:**
The site below contains important post-transplant information for doctors and for all transplant 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)