

**GENERAL LONG-TERM FOLLOW-UP RECOMMENDATIONS
FOR PEDIATRIC PATIENTS**

These are some important general recommendations that can help prevent problems after the transplant. Your doctor may have other recommendations that fit the specific health needs of individual patients.

1. **Cancer Prevention:**
 - a) Overall, there is an increased risk of cancer after transplant. The brain, thyroid, skin, mouth and breast are places where cancer can develop after a transplant.
 - b) Sun exposure should be avoided to minimize activation of GVHD and development of skin cancers. Sunscreen cream (SPF-15) should be used to protect the face and neck and any other uncovered skin. Patients should wear a long-sleeve shirt, full-length pants and a hat.
2. **Routine Care:**
 - b) Patients should have annual physician check-ups including blood tests with complete blood count, glucose level, lipid levels, liver function tests, renal function tests, etc.
 - c) Childhood vaccinations should be given beginning one year after the transplant according to specific recommendations that the LTFU office can give to your physician.
 - d) Patients should receive regular dental care. Patients who had a transplant before eruption of secondary teeth should have Panorex examinations beginning one year after the transplant to check for development of secondary teeth. Orthodontic devices should be used with care to avoid damage to the root structure. Please refer to the dental guidelines or call LTFU if you have questions about oral GVHD or about dental procedures during the first year after the transplant or during treatment for GVHD.
 - e) All children should have annual eye examinations.
3. **Development:**
 - a) Patients less than 2 years of age at the time of transplant may have delayed development of language and motor skills. These patients benefit from speech therapy and occupational therapy.
 - b) School age children should have tutors during the first year after the transplant and then attend school after the first year.
4. **Endocrine:**
 - a) **Growth:** Height should be measured every 6 months. Children who received total body irradiation should have growth hormone levels tested at 1 year after transplant and then every year afterwards until the patient is 16 years of age. Patients with documented growth failure (growth hormone deficiency and lack of height growth) benefit from treatment with growth hormone.
 - b) **Thyroid:** All patients should have thyroid function tested every year.
 - c) **Adrenal:** Patients who have been treated with prednisone for more than a month have inadequate natural production of hormones by the adrenal gland. Therefore, when treatment with prednisone is being tapered or discontinued, careful monitoring is needed to avoid complications caused by inadequate levels of adrenal hormones.
 - d) **Puberty:** Patients over 12 years of age with delayed development of secondary sexual characteristics should be evaluated by a pediatric endocrinologist. This problem can be treated by administration of sex hormones. Adolescents should have regular genito-urinary examinations appropriate for age and sex.
5. **Special Tests:**
 - a) **Pulmonary Function Tests:** Children over 6 years of age should have pulmonary function tests every year to check for any damage to the lungs. Children who are being treated for chronic GVHD should be tested every 6 months.
 - b) **Bone Density:** Osteoporosis or loss of calcium in bones can occur after the transplant due to low hormone levels, use of medications like prednisone, and inactivity. The amount of calcium in the bones should be evaluated by an x-ray bone density test at least once, at one year after the transplant. The LTFU office can recommend treatment if the amount of calcium in the bones is low.
 - b) **CML:** Patients who had chronic myeloid leukemia (CML) should have blood tested every year to see if any leukemia cells are still present after the transplant. Your doctor can order the test, but we would prefer to have the blood sent to the FHCRC/SCCA laboratory. The LTFU office will send the results of the test to your doctor. The LTFU office can also make any recommendations needed for treatment.
6. **Risk of Infections:** Patients with chronic GVHD should take antibiotics to prevent infection for at least 6 months after discontinuing all immunosuppressive medications. Patients should not use herbal medications or naturopathic remedies. Patients who develop fevers, chills or any signs of infection should seek immediate medical attention.