

# Guidelines for Pediatric Transplant Survivors

## More than One Year After Transplant

These guidelines are meant to help you and your child prevent post-transplant problems and find post-transplant problems early. Your child's regular provider might make more recommendations based on their specific needs. If you have concerns about healthcare costs, please discuss them with your child's regular provider.

### Medical check-ups

- Growth
  - Measure height and weight at least every 6 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. Delayed puberty can be treated with sex hormones.
  - Adolescents should have regular genitourinary exams appropriate for age and sex.
- Cognitive development
  - Children who were younger than 2 at the time of transplant may have delayed language and motor skills. These children often benefit from speech and occupational therapies.
  - School-age children can attend school after one year following transplant.
- Annual blood pressure and eye exams (cataracts, chronic GVHD).
- DEXA scan (bone density): 1 year after transplant and then annually if abnormal and your child takes prednisone.
- Screening for cancers that occur more often due to transplant:
  - SKIN: Complete skin exam by a provider trained to detect skin cancer.
  - ORAL: Mouth exam by dentist or provider trained to detect oral cancer.
  - BREAST: Breast exam for teenage girls (and counseling about breast self-exams and early mammograms).
- Check for full range of motion at joints and muscle weakness if being treated for chronic GVHD
- Lab tests:
  - Urine sample to test for protein
  - Blood tests (complete blood count, fasting sugar level and cholesterol profile, liver function tests, thyroid panel)
  - If your child had Ph+ Acute Lymphoblastic Leukemia, they will need BCR/ABL blood testing every 3 months during the first year, every 6 months during the second year, and then annually at 3 through 5 years.
  - If your child had Chronic Myeloid Leukemia, they will need BCR/ABL blood testing every 6 months during the first and second years, and then once a year for life.
  - In order to follow BCR/ABL serial result trends, your provider 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 for instructions.

## Dental check-ups

- Your child should brush and floss regularly; your child should have a dental exam every 6 months because they are at higher risk of developing cavities and oral cancers.
- Children younger than 12 who had high-dose total body irradiation before permanent teeth have grown in should have Panorex exams beginning 1 year after transplant to check for teeth.
- Tell your dentist if your child has ever taken medications to strengthen the bones as these medications can cause problems with dental work.

## Pulmonary function tests

- Spirometry is important even without symptoms. Testing may be increased to every 3 to 6 months if your child has lung problems or chronic GVHD.

## Adrenal gland testing

- If your child has taken prednisone for an extended time, their body may not produce enough natural cortisol (a type of steroid). Your child might need a short burst of steroids if they have surgery or a big infection. Your doctor may order a test to see if adrenal glands are working.

## Risk of infections

- If your child has chronic GVHD, they should take antibiotics to prevent infection until at least 6 months after ending all treatments that suppress their immune system.
- Avoid herbals, naturopathic medications and marijuana while on immunosuppression.
- If your child develops fevers, chills, or any signs of infection, seek immediate medical attention.

## Vaccinations

- Most post-transplant vaccinations are given 1 year after transplant. However, your child may receive certain childhood vaccinations beginning as early as 6 months after transplant, if criteria are met. Your doctor can find specific vaccination guidelines at [cutt.ly/mexO9v1](http://cutt.ly/mexO9v1)
- Your child should get the seasonal flu vaccine (get the shot, not Flumist) by October or November every year. Everyone who lives with your child should also get the flu shot (not Flumist).

## Bone health

- Prednisone, low hormone levels and inactivity cause fragile bones. Strengthen bones by:
  - Giving your child calcium and vitamin D supplements as ordered.
  - Helping your child do weight bearing exercises for 20 to 60 minutes every day.

## Subsequent 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.
- Your child should avoid all forms of tobacco, including secondhand smoke.
- Your child should avoid sun exposure. Use sunscreen (SPF 30), especially on your child's face, neck, ears, and lips. Have your child wear a hat, long-sleeve shirt, and full-length pants in the sun.
- Help your child maintain a healthy weight, eat a nutritious diet, and avoid alcohol.

## Online resources

- SCCA Long Term Follow Up Information for Physicians | [cutt.ly/mexO9v1](http://cutt.ly/mexO9v1)
- Be The Match Allo and Auto Transplant Guidelines | [hct.bethematchclinical.org/#/app/home](http://hct.bethematchclinical.org/#/app/home)

**Questions?** Contact LTFU at (206) 667-4415 or [LTFU@seattlecca.org](mailto:LTFU@seattlecca.org)