

# The LITE Program:

Long-term  
Information  
Treatment Effects  
Evaluation



“The Lighthouse”  
A Beacon of Life

## ABOUT THE LITE PROGRAM:

The **LITE** Program, at The Cancer Institute of New Jersey, provides long-term evaluation, support, and health education for the growing population of childhood cancer survivors. The successes in the treatment of childhood cancer have led to increasing survival rates.

Survivors may be at risk for developing problems (late effects) from the life-saving cancer treatments they received (chemotherapy, radiation, and surgery) since the treatment not only gets rid of the cancer, but also damages healthy tissues/cells.

Long-lasting and late-appearing damage can disrupt health, normal growth and development, well being, and the quality of life. Our goal is to provide the on-going care needed to meet the needs of childhood cancer survivors.

With medical advances, many more children and teenagers will survive the diagnosis of cancer. The health needs of these survivors are different from those receiving therapy. They need follow-up (routine check-ups, bloodwork, tests, and teaching) by doctors and nurses who know the late effects of cancer treatments. The **LITE** Program is designed to meet the needs of these long-term survivors and their families.

## WHO WE ARE?

We are a comprehensive team of specialists with years of experience in caring for children. We are interested in the late effects of therapy, finding problems early, and providing the appropriate follow-up care to meet the special needs of survivors. Our goal is to enable the survivors of childhood cancer to experience the best quality of life by addressing their individual late effects and providing the necessary support, education, and intervention. The **LITE** team will make appropriate referrals to genetics, endocrinology, cardiology, neurology, or nephrology.

- Genetics: doctors that counsel families about problems dealing with genes and traits passed from parents to their children
- Endocrinology: doctors that see patients for problems with glands such as thyroid or adrenal
- Cardiology: doctors that see patients for heart problems
- Neurology: doctors that see patients for problems with the nerve tissues, such as seizures
- Nephrology: doctors that see patients for problems pertaining to the kidneys, such as hypertension, bladder problems

Dawn M. Carey RN, MSN, APN  
LITE Program Director/Coordinator  
Pediatric Nurse Practitioner

Margaret Masterson, MD  
Medical Director of the LITE Program  
Associate Professor of Pediatrics  
Department of Pediatric Hematology/Oncology

Judy Twardos, RD, CSP, CNSD  
Pediatric Nutritionist

Carl J. Hochhauser, Psy.D.  
Pediatric Psychology Post-Doctoral Fellow  
Institute for the Study of Child Development

Christine Call-Sternberg, MTC, MAT  
Director of Educational Services  
Patient Management Liaison/Counselor

Priscilla Scheiner, MA  
Patient Management Liaison/Counselor

Marilyn Mundy, RN, CPON  
Pediatric Nurse

Pat Evans, RN, CPON  
Pediatric Nurse

#### **THE GOALS OF THE LITE PROGRAM:**

- To provide survivors of childhood cancer with a complete evaluation from our LITE Team
- To provide guidelines for follow-up in regards to the late effects of therapy and promotion of a healthy lifestyle
- To provide up-to-date information and support to survivors and their families
- To identify late effects of therapy and provide the necessary education, support, treatment, and referral to other health care providers or community agencies
- Provide educational programs and support groups for survivors

#### **WHO IS ELIGIBLE?**

Any child treated for childhood cancer that is now 2 years off treatment and without evidence of disease.

#### **CONTACT INFORMATION:**

You can reach us at (732)-235-KIDS. Follow the prompt for the pediatric clinic.

We used the LIGHTHOUSE as our symbol for the program because it is a strong beacon that shines a light and guides you in the right direction. It will provide a sense of security and light the path into the future for our cancer survivors. This program focuses on survivorship.

## Late Effects of Childhood Cancer:

**There are a wide range of possible late effects. It is important to make you aware of all the potential late effects, but that does not mean your child will be affected by any of them.**

### What are late effects?

Childhood cancer survivors are living longer, and their long-term health has come into focus within recent years. The treatment may affect the survivor's health many years later. This is known as "**Late Effects.**" Late effects are the long-term effects of treatment.

Just as treatment of childhood cancer requires a very specialized approach, so does the post treatment and monitoring for late effects. Careful follow-up after cancer treatment allows for early detection of and attention to the after-effects of treatment.

### What causes late effects?

They are caused by damage to the healthy cells as a result of cancer therapy. The late effects may be a result of surgery, radiation therapy, some chemotherapy medications, or bone marrow transplantation.

### Who is at risk for the late effects?

The late effects depend largely on the type of therapy received as well as the doses of that therapy. The very young child may be at the greatest risk. Children who received the following are at risk:

- Chemotherapy
- Radiation
- Surgery

### How specific parts of the body react?

**Brain:** Chemotherapy delivered to the spinal column (intrathecal therapy, or IT) has been associated with learning problems in children. They are more common in children who are treated under the age of five. They usually appear within two to five years of ending treatment. Learning disabilities are more common with children who receive both IT chemotherapy and radiation therapy to the brain. Brain surgery, depending on the area of the brain affected, may create a wide range of late effects.

These problems are often referred to as cognitive impairments, such as a decline in IQ and in academic achievement scores. In addition, there may be problems with memory and attention issues.

**Eyesight and Hearing:** Vision may be affected in a number of ways from treatment if the tumor was on or near the eye. Certain medications can be toxic to the eye and lead to problems such as blurred vision, double vision, and glaucoma. Radiation in the area of the eye can cause cataracts. Radiation to the bones near the eye may slow bone growth and cause facial changes.

Some chemotherapy and antibiotics may cause hearing loss. Radiation therapy to the brain or ear can lead to hearing loss. Careful monitoring during and after therapy will help to identify and manage these issues. Treatments such as cataract removal, eyeglasses, or hearing aids may be needed.

**Growth and Development:** Decreased growth during childhood cancer therapy is a common problem. Catch-up growth may occur, but in some cases, short stature may be permanent. Chemotherapy may cause a slow-down in growth if given alone without radiation. Many patients will catch-up to a normal growth pattern.

Radiation has a direct effect on the growth of bones that are within the radiation area. Cranial radiation, or radiation to the head, may lead to a delay in growth.

**Thyroid:** Thyroid function may be at risk when head and neck radiation is given. Hypothyroidism occurs when the thyroid in the neck no longer produces enough thyroid hormone. Some of the signs and symptoms are extreme tiredness, dry skin, and thinning hair. Hyperthyroidism is caused by too much of the thyroid hormone being made. Annual thyroid evaluations are useful after therapy for up to 10 years or longer to find such problems.

### **Sexual Development:**

**Males:** Radiation therapy and chemotherapy may cause a reduced sperm production. The lack of sperm production affects the patient's ability to father children. This is an important concern prior to starting cancer treatments in the older child. Sperm banking may be offered prior to treatment so that the patient can still father children through alternative means later in life.

Other effects that may occur as a result of radiation damage to the brain include changes in testosterone (male hormone) levels leading to the failure to complete puberty, or rapid onset of puberty; decreased sexual drive/desire; and impotence.

**Females:** Both chemotherapy and abdominal radiation can affect how the ovaries work. This is less common in girls who have not been through puberty. There is a risk of delayed periods, as well as early menopause.

Radiation therapy to the head can cause changes with the hormones necessary for ovarian function. These changes may lead to irregular menstrual bleeding, problems with the release of eggs, and early puberty.

Radiation to the chest (mantle region) may result in breast cancer.

**Reproduction:** Many childhood cancer survivors have concerns about being able to parent a child in the future. Though risks do exist, most survivors can go on to produce healthy children. Decreased fertility issues, early menopause, and other treatment related problems could cause problems with pregnancy. Genetic counseling may be helpful. Early referral to a fertility specialist may also be beneficial.

**Heart/Cardiovascular System:** A class of chemotherapy drugs used for childhood cancers called anthracyclines have been linked with decreased heart function in survivors. Radiation to the chest may also cause problems with the heart. The total dose given, and age of the patient at the time of treatment may affect the heart problems. With routine physical examinations and cardiac monitoring any changes in the heart function may be found early.

**Respiratory:** The lungs may also be affected by cancer therapy. Respiratory problems, such as trouble breathing and scarring of the lung tissue, are most common in children who have received radiation therapy to the chest wall. Other respiratory problems may include pneumonitis. This is an inflammation of the lung tissue, causing problems with breathing and exercise, or a dry cough. Certain chemotherapy drugs, such as bleomycin, may also lead to these problems.

**Muscle and bone:** Radiation therapy can affect the normal growth of bone and muscle. Very young children can have slow growth related to radiation. Bones, soft tissue, muscle and blood vessels may be damaged by radiation during times of rapid growth. Children under the age of six or children going through puberty are more at risk. In addition, stunted bone growth, osteoporosis, and joint problems may occur. Certain medications such as steroids (dexamethasone, prednisone) may have an impact on bones.

**Teeth:** Radiation therapy given to an area that involves teeth may cause problems such as:

1. reduction in saliva
2. dry mouth
3. cavities
4. delayed tooth development.

**Secondary Cancers:** Childhood cancer survivors have a small, but increased risk of developing a second type of cancer during their lifetime. Many factors affect the risk, such as type of original cancer, types of treatments received, and genetics.

## **LONG TERM EFFECTS OF CHEMOTHERAPY AND RADIATION**

**Long Term Effect of Chemotherapy to:**

- Ears/Hearing
- Heart/Cardiac
- Lungs/Pulmonary
- Liver/Gastrointestinal tract
- Bladder/Renal system
- Ovaries/Testes/Reproductive system
- Brain

**Long Term Effects of Radiation to:**

- Eyes/Vision
- Ears/Hearing
- Salivary Glands/Teeth/Mouth
- Head and Neck
- Bone
- Heart/Cardiac
- Lungs/Pulmonary
- Breast
- Liver/Gastrointestinal tract
- Bladder/Renal system
- Ovaries/Testes/Reproductive system
- Bone/Muscle/Musculoskeletal system
- Nerves/Brain/Nervous System
- Thyroid/Endocrine System
- Skin

## **Nutrition After Treatment Ends**

Most eating-related side effects of cancer treatments go away after the treatment ends. Sometimes, side effects such as poor appetite, dry mouth, change in taste or smell, difficulty swallowing, or weight loss may persist. If this happens to you, talk to your LITE team and work out a plan together to address the problem. As you begin to feel better, you may have questions about eating a healthier diet.

Just as you wanted to go into treatment with the necessary nutrients that your diet could give you, you'll want to do the best for yourself after therapy. Eating well will help you regain your strength, rebuild tissues, and feel better overall.

### **Suggestions For Healthy Eating After Cancer**

- Check with your doctor for any food or diet restrictions
- Ask your dietitian to help you create a nutritious, balanced eating plan
- Choose a variety of foods from all the food groups. Use the Food Guide Pyramid to help choose foods for a well-balanced meal plan
- Try to eat at least 5 to 7 servings a day of fruits and vegetable, including citrus fruits and dark-green and deep-yellow vegetable
- Eat plenty of high-fiber foods, such as whole grain breads and cereal
- Choose a new fruit, vegetable, low-fat food, or whole-grain product each time you shop for groceries
- Decrease the amount of fat in your meals by baking or broiling foods
- Choose low-fat milk and dairy products
- Avoid salt-cured, smoked, and pickled foods
- Try to avoid alcohol
- Consider exercise. Choose activities you enjoy and check with your doctor before starting any exercise program

## **NUTRITION GUIDELINES**

### **Eat 5 or more servings of fruit and vegetables each day:**

- Include vegetables or fruits in every meal and for snacks
- If you drink fruit or vegetable juice, choose one that contains 100% fruit juice
- Avoid french fries, snack chips and other fried vegetable products

### **Choose whole grain starches instead of processed starches and refined sugar:**

- Choose whole grain breads and cereals, whole-wheat pasta, brown rice, and beans instead of white bread, white rice and regular pasta
- Limit intake of refined sugars, including regular soft drinks, sweetened cereals, cookies, cakes, pies, doughnuts and candy

### **Limit intake of red meats, especially processed red meats:**

- Choose fish, poultry, or beans as an alternative to beef, pork, and lamb.
- Trim visible fat from meat

- Select lean cuts like skinless poultry, fish and loin cuts of beef or pork
- Avoid unhealthy meats such as bacon, sausage and hot dogs
- Bake, broil and poach rather than frying or charbroiling

**Choose small portions of fats and oils:**

- Choose healthy oils such as olive or canola
- Limit intake of butter and margarine, mayonnaise, and salad dressings
- Choose low fat dairy foods such as low fat milk and reduced fat cheese
- Limit fried foods, snack chips, ice cream and candy

**Avoid alcoholic beverages or limit consumption:**

- No more than two drinks per day for men
- No more than two drinks per day for women

Recommendations adapted from the American Cancer Society nutrition guidelines.

## **Education Programs**

The **LITE Program** offers a number of programs aimed at providing education and consultation for children who have received treatment for childhood cancers.

**Our Services:**

- Educating families and school personnel on the cognitive/learning effects of cancer treatments
- Neurodevelopmental testing of patients
- Consulting with parents and schools in the educational planning for children
- Review of Individual Education Plan (IEP)

For further information, please contact:

- Christine Call-Sternberg at (732)-235-6454
- Carl Hochhauser, PsyD at (732)-235-7166

**What Can Parents Expect?**

- Initial classroom observation and visit with school team, if necessary
- Follow-up visits and neuropsychological testing
- Review of Individual Education Plans
- Telephone consultation
- Education of the school team and family

## **Psychology:**

The Cancer Institute of New Jersey is offering four psychological services for survivors of pediatric cancer in collaboration with The Institute for the Study of Child Development.

These services are being provided by:

- Carl Hochhauser, Psy.D., Psychology Fellow for the Pediatric Hematology/Oncology Clinic
- Michael Lewis, Ph.D., University Distinguished Professor and Director of The Institute for the Study of Child Development.

The programs that are offered include:

- **Assessment:** Neuropsychological evaluations are an important part of screening children and adolescents during treatment and after it has been completed. A complete neuropsychological evaluation will take several hours and will assess a broad range of functioning, looking at areas such as intelligence (IQ), fine motor skills, attention, behavior, and social skills. The results of this evaluation will be presented in a face-to-face feedback session for the parents and will be followed by a written report. It will include detailed guidelines and may be shared with the school to assist in educational planning.
- **Outpatient psychotherapy:** For children or adolescents experiencing difficulties coping with their experience or some of the effects.
- **Math Remediation Programs:** Those individuals with school difficulties in the area of mathematics and attention. The math remediation program will be overseen by Dr. Hochhauser and taught by a teacher specialized in mathematics. It strives to target key areas of weakness, teach the necessary skills and practice until mastery is achieved.
- **Cognitive Remediation Program:** This program for attention uses activities as well as games and fun to help kids improve their concentration ability, attention span, and their school performance in general.

If you or your child is interested in any of these programs, please speak with the LITE team or contact Dr. Hochhauser directly at (732)-235-7166. Dr. Hochhauser's office is at the Institute for the Study of Child Development, located on the third floor of the Robert Wood Johnson Professional Center, 97 Paterson Street, New Brunswick, NJ 08903.

## **Cognitive Late Effects To The Brain**

Childhood cancer and its treatments can leave cancer survivors with unique educational needs. The treatments may affect school performance. Changes in the way children or teenagers think, remember, and learn are called cognitive late effects.

Studies have shown that children treated for ALL (Acute Lymphoblastic Leukemia) and other cancers are at risk for certain cognitive/learning and memory difficulties, especially if they received treatment to their central nervous system (e.g. intrathecal Methotrexate, cranial radiation). Research has shown that these deficits do not appear until several years after treatment has been completed.

**Signs of possible learning disabilities are problems with:**

- Handwriting
- Spelling

- Reading or reading comprehension
- Understanding math concepts, remembering math facts, understanding math symbols, sequencing, and working with columns and graphs
- Remembering and copying shapes
- Learning to ride bike or tie shoes
- Hearing or visual language processing (trouble with vocabulary, blending sounds)
- Attention deficits (trouble with attention or are hyperactive or both)
- Short-term memory (trouble following instructions that are multiple part)
- Information retrieval/long-term memory
- Social maturity and social skills
- Recognizing faces and understanding facial expressions or gestures
- Planning and organizational skills

Psychologists who specialize in evaluating how children learn and think may administer neuropsychological tests. These tests usually take four to six hours, and are done over two days for younger or very fatigued children. The psychologist gives a series of general tests appropriate for age level. Some parents have this testing done through the schools, while others have it done by experts at the treating institution. Neuropsychological tests are very different from tests that measure educational level.

### **The Individual Education Plan (IEP):**

Parents or teachers can make a referral by writing the school principal to request special education testing. School systems should automatically set up an IEP for any child who has had radiation to the head. It is best for the parent or physician to send a written request stating that the child is "health impaired" due to treatment for cancer, list his problems, and request assessments and an IEP meeting.

Once the referral is made, an evaluation is necessary to find out if the school district agrees that the child needs additional help and what type of help would be most beneficial. Children with a history of chemotherapy and/or radiation to the brain, as well as surgery to the brain usually require thorough neuropsychological testing.

After the evaluation, a conference is usually held to discuss the results and reach conclusions about what actions will be necessary in the future.

The IEP describes the special education program and any other related services specifically designed to meet the individual's needs of your child with learning differences.

Some examples of things parents may include in the child's IEP:

- School provides a keyboard for children who have difficulty writing
- A second set of books to keep at home for children who tire easily carrying books or for those with attention difficulties who forget to bring books home
- A day planner for homework assignments
- One-to-one resource room to help organize large assignments into manageable pieces
- Social skills training for children with social difficulties
- A classmate to take notes and copy them for students who have difficulty writing

## **Early Intervention services for preschoolers:**

Federal law mandates early intervention services for disabled infants and toddlers, and in some cases, children at risk of having developmental delays. Infants, toddlers or preschoolers with cancer may be eligible for these services in order to avoid developmental delays caused by cancer treatments. The special education director for your school district will be able to assist you. The law requires services, not only for the infant or preschooler, but for the family as well. Therefore, instead of an IEP, an Individualized Family Service Plan (IFSP) is developed.

## **Services for middle and high-schoolers:**

Transition planning should begin in the early years of middle school, when the student's peers begin to gain work skills and collect credits toward high school graduation. For some survivors, extra support will be needed to make the transition from high school to adulthood go smoothly. The transition programs should address the move from high school to trade school, community college, or a four-year college program. Students are eligible for a publicly funded education and/or services until age 22 if needed. Special education services and help for students with learning disabilities are available on campus and in dorms at many colleges.

## **Your legal rights:**

The Individuals with Disabilities Act requires that every public school must provide free and appropriate education to all handicapped individuals between the ages of 3 and 21 years. That means providing, free of charge, special education programs, speech therapy, occupational therapy, physical therapy, psychiatric services, augmentative communication techniques such as tape recorders and special computers and technology, and other interventions that are needed to help children learn. The Individuals with Disabilities in Education Act (IDEA) have improved these laws. These laws cover survivors of cancer whose medical problems affect their educational performance under the categories known as "other health impaired" (OHI).

Many survivors do not need special help in school, but those who do have the legal right to it. See <http://www.ed.gov/offices/OSERS/IDEA/> for the full text of IDEA and related information and updates.

There are also special accommodations that a child may need to successfully perform in school such as reduced homework, additional time to get to class, getting rid of timed tests, more time to finish writing assignments, etc.

You can also write to your state Superintendent of Public Instruction to obtain a copy of the state rules governing special education. For further information contact Christine Call-Sternberg.

As parents, you are the advocate for your child and you can help them obtain the necessary resources available to help them perform in school. The steps that will be taken are referral, evaluation, eligibility, developing an individual education plan (IEP), and annual review.

## **Your Employment Rights As A Cancer Survivor:**

Work may be very fulfilling. It fills a critical financial and emotional need for most cancer survivors. In addition, it provides income and important benefits such as health insurance, employment, and retirement benefits. It can also improve self-esteem. Cancer may create barriers to finding and keeping a job. Most employers treat cancer survivors fairly.

**How employment discrimination laws protect the cancer survivor:**

Under federal and state laws, an employer cannot treat you differently from other workers in job related activities because of your cancer history as long as you are qualified for the job. You may be protected by these laws only if:

1. You are qualified for the job (you have the necessary skills, experience and education) and you can do the essential duties of the job
2. Your employer treated you differently from other workers in job related activities because of your cancer treatment or history
3. At some time your cancer substantially limited your ability to do everyday activities or your employer thought that your cancer limited you

**If you are looking for a new job, you can take several steps to lessen the chance that you will face discrimination because of your cancer history:**

- Do not say that you have or have had cancer unless it directly affects your qualifications for the job
- Do not lie on a job or insurance application
- Keep in mind your legal rights
- Keep the focus on your current ability to do the job
- Apply only for jobs that you are able to do
- Emphasize that you are in good health and you are expected to remain healthy
- Offer your employer a letter from your doctor that explains your current health status, prognosis, and ability to work
- Seek help from a job counselor or social worker with resume preparation and job interviewing skills
- Always maintain a positive attitude

**Where to turn for help and information:**

State laws: (1-800-669-4000) can help you locate appropriate state enforcement agencies. Also check your local telephone book under state government.

Candlelighters Childhood Cancer Foundation <http://www.candlelighters.org>

Cancer Survival Tool Box [www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org)

What Cancer Survivors Need to Know About Health Insurance

Written by Kimberly J. Calder, MPS & Karen Pollitz, MPP

Working It Out: Your Employment Rights As A Cancer Survivor

Written by Barbara Hoffman, JD