LYMPHOMA
RESEARCH • FOUNDATION

Getting the Facts

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Lymphomatous Meningitis

Overview

Lymphoma is the most common blood cancer. The two main forms of lymphoma are Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). Lymphoma occurs when cells of the immune system called lymphocytes, a type of white blood cell, grow and multiply uncontrollably. Cancerous lymphocytes can travel to many parts of the body, including the lymph nodes, spleen, bone marrow, blood, or other organs, and form a mass called a tumor. The body has two main types of lymphocytes that can develop into lymphomas: B lymphocytes (B cells) and T lymphocytes (T cells).

Lymphomatous meningitis, also called lymphomatous leptomeningitis, is a complication of lymphoma that occurs when lymphoma cells travel to and affect the meninges (thin layers of tissue that cover and protect the brain and spinal cord). Lymphomatous meningitis is estimated to occur in approximately five percent of patients but can vary based on a patient's age, type of lymphoma, and stage of disease, among other risk factors. The true incidence of the disease may be higher due to under-recognition/reporting.

Once the disease affects the cerebrospinal fluid (CSF), it can cause many widespread symptoms including pain in the neck, back, or that radiates along nerves (e.g., similar to sciatica); seizures (the most common patient-reported symptoms); headaches (usually associated with nausea, vomiting, and lightheadedness); difficulty walking from weakness; facial weakness; memory problems; incontinence; and abnormalities of the senses (sight, hearing, etc.)

Treatment Options

The goals for treatment of patients with lymphomatous meningitis are to stabilize or improve neurologic function and prolong survival. There is no standard treatment for lymphomatous meningitis; however, radiation is a common treatment used to relieve the symptoms and improve the flow of CSF, which can be impaired by tumor formation. Intrathecal chemotherapy (delivered directly to the CSF) is a treatment option for patients who are able to tolerate the toxicity of various chemotherapy agents. These agents can either be delivered through a lumbar puncture (in which a needle is inserted into the lower back and the drug is delivered directly into the CSF) or through an Ommaya reservoir (a device placed directly in the skull that can provide long-term treatment directly to the CSF and central nervous system). Methotrexate and cytarabine liposome (Depocyt) are commonly used for the intrathecal treatment of lymphomatous meningitis. Therapy with high-dose intravenous methotrexate is another treatment option for lymphomatous meningitis because the drug crosses the blood–brain barrier and enters the central nervous system.

Treatments Under Investigation

Several treatments at various stages of drug development are currently being tested in clinical trials for lymphomatous meningitis, including intrathecal chemotherapy with bevacizumab (Avastin), rituximab (Rituxan), and LMB-7 Immunotoxin and targeted drugs such as ibrutinib (Imbruvica).

It is critical to remember that today's scientific research is continuously evolving. Treatment options may change as new treatments are discovered and current treatments are improved. Therefore, it is important that patients check with their physician or with the Lymphoma Research Foundation (LRF) for any treatment updates that may have recently emerged.

Clinical Trials

Clinical trials are crucial for identifying effective drugs and determining optimal doses for patients with lymphoma. In many of the rare subtypes of lymphoma, no standard of care is established. Clinical trial enrollment is critical for establishing more effective, less toxic treatments. In rare diseases, novel treatments are also often only available through clinical trials. Patients interested in participating in a clinical trial should talk to their physician or contact the LRF Helpline for an individualized clinical trial search by calling (800) 500-9976 or emailing helpline@lymphoma.org. For more information on clinical trials, view the *Understanding Clinical Trials* fact sheet on LRF's website at www.lymphoma.org.

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Follow-up

Patients in remission should have regular visits with a physician who is familiar with their medical history and the treatments they have received. Medical tests (such as blood tests and computed axial tomography [CAT] scans) may be required at various times during remission to evaluate the need for additional treatment.

Patients and their caregivers are encouraged to keep copies of all medical records and test results as well as information on the types, amounts, and duration of all treatments received. This documentation will be important for keeping track of any effects resulting from treatment or potential disease recurrences.

Support

A lymphoma diagnosis often triggers a range of feelings and raises concerns. In addition, cancer treatment can cause physical and emotional discomfort. Support groups and online message boards can help patients connect with other people who have lymphoma. One-to-one peer support programs, such as the LRF Lymphoma Support Network, match lymphoma patients (or caregivers) with volunteers who have gone through similar experiences.

Resources

LRF offers a wide range of resources that address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma, including our award-winning mobile app. LRF also provides many educational activities, from in-person meetings to teleconferences and webcasts, as well as disease-specific websites, videos, and eNewsletters for current lymphoma information and treatment options. To learn more about any of these resources, visit our website at www.lymphoma.org, or contact the LRF Helpline at (800) 500-9976 or helpline@lymphoma.org.