Hairy Cell Leukemia (HCL)

The UCSF Patient and Family Cancer Support Center is the hub of support, information and resources for people with cancer at the Helen Diller Family Comprehensive Cancer Center. Learn more about UCSF’s supportive care programs at https://cancer.ucsf.edu/support/crc/patient-support-center

The Cancer Support Center at Mission Bay is located at 1825 4th St., 1st Floor, Room M-1210. The Cancer Support Center at Mt. Zion is located at 1600 Divisadero St., 1st Floor, Room B-101.

The complete list of Patient Education Resource Pages is available to view at http://cancer.ucsf.edu/support/crc/patient-education-resources

Overview

Hairy cell Leukemia (HCL) is a rare, slow-growing disease that responds to initial treatment. Chemotherapy with purine nucleoside analogues given either alone or with rituximab are the mainstay therapy for newly diagnosed symptomatic patients leading to five-year survival rates in excess of 90% of patients. Despite this progress, our important work continues because there is still no cure for HCL, some patients do not respond to treatment at all, and many patients relapse at some point after treatment. Therefore, LLS is committed to funding research to help find better treatments for initial disease as well as relapsed cases. Fortunately, with the discovery new drug technologies as well as molecular defects specifically found in HCL patients, alternative therapies have been identified. Website: https://tlls.org/research/hcl-research-funded-by-lls

UCSF Resources

UCSF Hematology and Oncology

The faculty of the Divisions of Hematology & Medical Oncology - managed separately at the UCSF Medical Center at Parnassus, the UCSF Helen Diller Family Comprehensive Cancer Center at Mount Zion, Zuckerberg San Francisco General Hospital Medical Center, and the San Francisco VA Health Care System - are leaders in the fields of cancer care and blood disorders. For over thirty years, our faculty has passionately pursued its mission to enhance individual lives around the world by improving the treatment of cancer and blood disorders. For patients suffering from these conditions, we discover and implement medical advances that have improved survival rates and quality of life. Website: https://hemonc.ucsf.edu/ | Phone Number: (415) 353-2421
Publications
American Society of Hematology (ASH Blood): Consensus guidelines for the diagnosis and management of patients with classic hairy cell leukemia
Website: https://ashpublications.org/blood/article/129/5/553/36153/Consensus-guidelines-for-the-diagnosis-and

Leukemia & Lymphoma Society Education Resources
LLS provides excellent patient education materials, videos, webcasts, and drug information, as well as books on caregiving. Materials can be ordered for free or viewed online. (Available in various foreign languages) Website: http://www.lls.org/education-resources

NIH: National Library of Medicine, Hairy Cell Leukemia
Website: https://www.ncbi.nlm.nih.gov/books/NBK586203/

The Lancet Oncology: Advances in the treatment of hairy-cell leukemia
Website: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(03)00980-X/fulltext

Organizations
American Cancer Society (ACS) – Hairy Cell Leukemia (HCL)
At the American Cancer Society, we are on a mission to free the world from cancer. Until we do, we'll be funding and conducting research, sharing expert information, supporting patients, and spreading the word about prevention. All so you can live longer — and better.

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Cancer.Net : Leukemia - B-cell Prolymphocytic Leukemia and Hairy Cell Leukemia: Introduction
Comprehensive information for people with cancer, families, and caregivers, from the American Society of Clinical Oncology (ASCO), the voice of the world’s oncology professionals.
Hairy Cell Leukemia Foundation
Network of leading researchers, cancer research centers, and hematologists from around the world working to advance understanding and treatment of hairy cell leukemia. We encourage patients to seek medical consultation and treatment for hairy cell leukemia at these centers, and we frequently turn to the HCL experts at these centers for assistance in providing patients with the most current information about this rare disease.
Website: https://www.hairycellleukemia.org/centers-of-excellence

Leukemia Research Foundation – Hairy Cell Leukemia (HCL)
In 1946, the Leukemia Research Foundation was established to memorialize 12-year-old Sherwin Pessin. Leukemia was a well-known but not well-understood disease. For Sherwin and thousands of other children and adults, there was no hope and no possibility for a cure. Website: https://leukemiarf.org/leukemia/chronic-lymphocytic-leukemia/hairy-cell-leukemia/

Leukemia & Lymphoma Society – Hairy Cell Leukemia (HCL)
Dedicated to curing leukemia, lymphoma, myeloma, and other blood cancers, we are now The Leukemia & Lymphoma Society (LLS), the world's largest voluntary (nonprofit) health organization dedicated to funding blood cancer research and providing education and patient services. Website: https://tlls.org/research/hcl-research-funded-by-lls

National Cancer Institute – Hairy Cell Leukemia (HCL)
The National Cancer Institute (NCI) is the federal government's principal agency for cancer research and training. NCI is deeply committed to the core values of equity, diversity, and inclusion that allow all staff to reach their potential and fully contribute to the Institute’s cancer mission. Website: https://www.cancer.gov/types/leukemia/patient/hairy-cell-treatment-pdq

National LGBTQI+ Cancer Network
The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk by: EDUCATING the LGBT community about our increased cancer risks and the importance of screening and early detection; TRAINING health care providers to offer more culturally-competent, safe and welcoming care; and ADVOCATING for LGBT survivors in mainstream cancer organizations, the media and research.
Website: https://cancer-network.org/about/ | Phone Number: 212-675-2633

This information is intended to offer credible and reliable education resources for patients who want to learn more about their diagnosis. It is not intended to be a comprehensive list of all resources available.