Langerhans Cell Histiocytosis

CONTACT US

For patient referrals and non-urgent consultation during business hours, contact the program directly at:

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cincinnatichildrens.org

BEST CHILDREN'S HOSPITALS
U.S.News & WORLD REPORT
HONOR ROLL
2022-23

Cincinnati Children's is ranked #3 in the nation among Honor Roll hospitals.

Specialists at Cincinnati Children's Hospital Medical Center have devised an innovative therapy for patients with Langerhans Cell Histiocytosis (LCH), and are the first in the world to offer it as a first-line treatment. Patient response to this targeted treatment has been better than or the same as the response to standard chemotherapy, without side effects.

Our multidisciplinary team of specialists cares for children, adolescents, young adults and—in some cases—older patients with LCH and non-LCH forms of the disease.

ABOUT LCH

Langerhans Cell Histiocytosis is a rare, cancer-like condition caused by a mutation in the MAP kinase pathway, most commonly BRAF. Up to 15% of patients who undergo chemotherapy do not respond to treatment. Among patients who do respond to treatment, the relapse rate at the one-year mark is as high as 40%.

Not all patients with LCH need treatment. If a patient's symptoms are limited to an isolated bone lesion with no sign of disease elsewhere, it is likely that the disease will resolve on its own. When a patient does need treatment, our team offers the choice of chemotherapy or the new, targeted therapy.

ONE-OF-A-KIND TREATMENT PROTOCOL

In 2016, Ashish Kumar, MD, PhD, a physician-scientist at Cincinnati Children's, began exploring a new treatment approach based on the fact that LCH and melanoma are both caused by a BRAF gene mutation. He hypothesized that the kinase inhibitors used to treat melanoma (Dabrafenib and Trametinib) could be effective in treating LCH.

Dr. Kumar used one of the agents on two patients who had failed multiple chemotherapy drugs. Both patients made a full recovery. Dr. Kumar began offering the novel protocol as a first-line treatment to patients with LCH, with identical results.

In the first six years of using this therapy, the team observed a 100% response rate, with no instance of disease recurrence. The children who have received this therapy at Cincinnati Children's have not experienced any significant side effects, and are growing and developing normally. This is significant when comparing the regimen to chemotherapy and its associated side effects and long-term effects. Most importantly, all of the children treated with BRAF or MEK inhibitors remain well without disease reactivation.

TREATMENT TEAM

Leadership

Ashish Kumar, MD, PhD
Co-Director, Histiocytosis Center

Jennifer Picarsic, MD
Co-Director, Histiocytosis Center

Hematology

Allison Bartlett, MD

Michael Jordan, MD

Pathology

Robert Lorsbach, MD, PhD

Somak Roy, MD

Dermatology

Kalyani S. Marathe, MD, MPH

Psychology

Naomi Joffe, PhD

Radiology

Arnold Carlson Merrow Jr., MD

Nurse Practitioner

Jennifer Detzel, MSN, APRN, CFNP

Rachael Mohr, MSN, RN, CPNP-PC/AC

Care Manager

Kristen Coleman, RN, BSN

For urgent issues, or to speak with the specialist on call 24/7, call the Physician Priority Link® at 1-888-987-7997.

For international inquiries, call +1-513-636-3100 or email international@cchmc.org.

www.cincinnatichildrens.org

MULTIDISCIPLINARY, COMPREHENSIVE CARE

Our core team includes pediatric hematologists/oncologists, pathologists who specialize in histiocyte diseases, a care manager, nurse practitioners and a psychologist. They collaborate with other specialists at Cincinnati Children's to ensure that patients receive comprehensive, personalized care.

Many children seeking care from the LCH Center have experienced extensive damage to the liver due to uncontrolled LCH. We collaborate with pediatric hepatologists at Cincinnati Children's to address their specific concerns. Our team recently treated a child with end-stage liver disease who had been turned down for a liver transplant elsewhere. Once we brought the LCH under control with the help of Dabrafenib, the child underwent transplant surgery at Cincinnati Children's and is doing well.

ADVANCED GENETIC TESTING

Advanced diagnostic testing, including molecular testing, is essential to identify the specific mutation of the BRAF or other genes, which helps guide treatment decisions. The Cincinnati Children's Division of Pathology and Laboratory Medicine provides molecular testing and test interpretation. The team developed Histio-Track, droplet-digital PCR for BRAV-V600E, the most common mutation found in LCH. HistioTrak allows the team to make more accurate treatment decisions because it detects minimal residual disease that is not picked up by imaging or real-time PCR. This allows therapy decisions to be made based on evidence, rather than just clinical judgment or the fear of relapse.

Working with pathologists, we continue to identify novel mutations in histocytoses (LCH, JXG, RDD et.al.) This has furthered our understanding of this rare disease.

RESEARCH TO ADVANCE CLINICAL CARE

The team is preparing a new clinical research study to evaluate the safety and efficacy of using targeted therapies to treat LCH. Complementing this work, basic science researchers at Cincinnati Children's have created a new mouse model of LCH to develop and test the novel therapies.

The LCH Center cares for patients from our local area, across the nation and around the world. Our team of clinicians and pathologists can provide consultation to help local physicians appropriately diagnose and choose the best therapy for the

082022_BRV163493