

FOR IMMEDIATE RELEASE:

A New Year, a New Care Center for Erdheim-Chester Patients in the Netherlands

Erasmus University Medical Center in Rotterdam joins a network of hospitals skilled in treating Erdheim-Chester disease patients.

DeRidder, LA, - January 15, 2021 – The Erdheim-Chester Disease (ECD) Global Alliance welcomes Erasmus University Medical Center in Rotterdam, Netherlands into its Referral Care Center Network to help Erdheim-Chester disease patients.

Leading this ECD-knowledgeable team is Dr. Jan Am van Laar, Associate Professor Clinical Immunology, Department of Internal Medicine, Erasmus MC University Medical Center, in Rotterdam, the Netherlands. The group of 14 specialists representing this center has seen six patients fighting the rare blood cancer thus far.

The center will be part of the recent push to improve rare cancer care in this region. The Dutch Cancer Society (KWF) has invested five million euros into rare cancer research starting in 2021.

"We see that the survival rates for many common forms of cancer have increased considerably over the years, but patients with a rare form of cancer benefit even less from new developments," says KWF director Johan van de Gronden.

"Knowledge about rare tumors is still widely spread across different hospitals."

Researchers and practitioners from UMC Groningen, UMC Utrecht, Erasmus MC, Amsterdam UMC and Maxima Medical Center will therefore share more internally information about rare forms of blood cancer, for example. This data collection and the development of ultra-sensitive blood tests make it possible to better determine which traces rare tumors leave behind in the blood and organs.

With this, KWF hopes to improve the prospects for a large group of patients in the coming years.

(cited from recent article written in Dutch)

Just this month, Dr. van Laar and cohorts published the [article *Spectrum of histiocytic neoplasms associated with diverse haematological malignancies bearing the same oncogenic mutation*](#). Emerging centers such as these help to bring more knowledge and access to care for ECD patients around the world.

The Clinical Immunology section of the Department of Internal Medicine is based at the Erasmus University Medical Center (EMC) in Rotterdam. The EMC represents the largest hospital in the Netherlands and is a referral center for many patients with (rare) diseases such as the histiocytosis. They are recognized as a national referral center for various immunological and hematological diseases and also participate in the European Reference Network in the subgroups of RITA and ReCONNET.

Dr. van Laar is a clinical immunologist and leading a dedicated team of specialists in the field of histiocytosis like Erdheim-Chester Disease. He and members of this team visit the annual meetings of the International Histiocyte Society and are actively involved in the consensus workgroups and (inter)national studies on adult patients with histiocytic disorders. They have treated and evaluated about 200 patients with hemophagocytosis or HLH, more than 120 with LCH and so far, at least six with ECD.

Dr. van Laar shares more about their center and the new partnership. *"It is our goal to recognize and treat patients with rare diseases as swiftly as possible with up-to-date and state of the art techniques and medication. It is also our goal to increase awareness on histiocytic diseases. Therefore, we publish frequently peer-reviewed papers, including the histiocytic disorders in our educational program for residents of the internal medicine and organize and hold lectures for*



Dr. Jan Am van Laar

other specialists in the Netherlands. We are therefore extremely pleased to be part of the ECD Referral Care Center consortium to be able to learn more and to improve cooperation with specialists in the field.”

The ECD Global Alliance created the ECD Referral Care Center Network in 2015 in order to serve this patient group with a broader reach, encouraging an expert, higher standard of care and regular consults to aid local physicians. Including the Netherlands hospital, there are now 34 centers serving the ECD population worldwide.

Notable institutes within the group include Memorial Sloan-Kettering Cancer Center in New York, NY, The University of Texas/MD Anderson Cancer Center in Houston, and University of California, San Diego.

Learn more about the ECD Referral Care Center network at www.erdheim-chester.org/care-centers.

[Erdheim-Chester Disease](#) is a rare multi-systemic non-Langerhans histiocytic neoplasm (type of blood cancer) with no known cause, which is challenging to diagnosis and treat. Unless successful treatment is found, organ failure can occur.

The [ECD Global Alliance](#) is a 501(c)(3) non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester Disease.

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