

Care Network Serves Australian Rare Disease Patients

The Erdheim-Chester Disease Global Alliance is proud to announce the first ECD Referral Care Center to be located in Australia

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Erdheim-Chester Disease Global Alliance (ECDGA) is pleased to introduce the newest addition to the ECD Referral Care Center network, **Peter MacCallum Cancer Center and Royal Melbourne Hospital**, located in Melbourne, Australia. The lead physician at this center is Dr. Michael Dickinson who specializes in hematology. Having an Erdheim-Chester Disease (ECD) referral center located in Melbourne will not only be beneficial to the 13 Australian patients currently registered with ECDGA, but also will allow access for more patients seeking a possible ECD diagnosis in the future. Forming this partnership ensures collaboration, education, improving early diagnosis, providing effective treatments, and offers support for the ECD patients in this part of the world.



Dr. Dickinson explains why becoming an ECD Care Center is important for ECD patients in Australia. “ECD is rare and in my experience no two patients have the same symptoms. Our centre has a number of haematologists and pathologists with a special interest in ECD. I believe the best way of achieving a high quality diagnosis and good treatment outcome for rare diseases such as ECD is to see as much of it as possible. I hope our genomics and clinical service will be a useful resource for patients and clinicians in Australia who want to collaborate on diagnosis and treatment of this condition.”

The ECDGA recognizes 22 referral centers and 7 emerging centers across the globe. A Referral Care Center is defined as having consulted and treated more than five cases of ECD in their practice. Emerging Care Centers are capable of and willing to treat ECD patients, but have seen less than five cases. All institutions are required to communicate and collaborate with one another to ensure patients are receiving the most up-to-date treatment options and best care available. Another vital aspect of the ECD Referral Care Center network is making certain that in the event a patient cannot travel due to their illness, the ECD physicians at these centers can consult on the patient’s case with their local doctor.

For more information on the ECD Referral Care Center network and how to contact them, please visit www.erdheim-chester.org/care-centers/.

[Erdheim-Chester Disease](#) is a rare multi-systemic histiocytic neoplasm with no known cause that 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.

FOR IMMEDIATE RELEASE

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