

Introducing the Nutrition Management Guideline for VLCAD

Purpose

The Southeast Regional Genetics Network (SERN) and Genetic Metabolic Dietitians International (GMDI) are proud to announce the Nutrition Management Guideline for very long-chain acyl-CoA dehydrogenase deficiency (VLCAD). This is part of a multi-year project to develop evidence and consensus-based guidelines for nutrition management of inborn errors of metabolism (IEM). The VLCAD guideline is now publically available online to all metabolic dietitians, physicians and other clinicians.

Features

- The Management Guideline Portal is a tool for development of guidelines of genetic metabolic disorders for which there is little published scientific evidence.
- SERN and GMDI partnered to develop nutrition management guidelines based on our evidence and consensus DND¹ methodology. The resulting VLCAD guidelines are freely available on this portal.
- Management Guidelines cover the assessment and management of patients known to have a particular metabolic disorder.
- The practice recommendations are an effort to increase standardization of care and enable outcomes studies within and across centers.
- When warranted by developments in VLCAD research and clinical practice, these guidelines will be updated periodically and will be maintained through a dynamic process.

Explore this resource at: https://southeastgenetics.org/ngp/guidelines_vlcad.php

Additional information available at: <http://gmdi.org/Resources/Clinical-Practice-Tools/Nutrition-Guidelines>

Many thanks to the contributors of this guideline, especially the VLCAD Workgroup Chairs, Sandy van Calcar, Ph D, RD and Mary Sowa, MS RD, as well as the workgroup members, web developer, project manager, project coordinators, reference librarian, project consultant, project advisor, evidence analysts, dietitians, physicians, researchers, parents of children with VLCAD, adult patients, and reviewers. This collaborative effort has resulted in guidelines to improve the nutrition management of individuals living with IEMs.

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¹DNDF - Delphi-Nominal Group-Delphi-Field Testing