



MELORHEOSTOSIS ASSOCIATION

What is Melorheostosis?

Melorheostosis is a rare and progressive bone disorder characterized by significant thickening of the cortical bone. It affects both bone and soft tissue growth and development. On x-rays, the appearance of melorheostosis has been likened to flowing, dripping candle wax.

Our Mission:

The Melorheostosis Association is a 501(c)(3) non-profit organization dedicated to finding the causes, treatments, and cures for melorheostosis. We focus on promoting greater awareness and understanding of this progressive disease and its manifestations through education, research, communication, and advocacy efforts on behalf of those affected by it as well as those dedicated to alleviating it.

Board Governance:

Jen Gordy | President | jen@melorheostosis.org

Kathleen Harper | Chairperson & Founder | kathleen@melorheostosis.org

Katrina Wells-Vardjan | Treasurer | katrina@melorheostosis.org

Amanda Shapiro | Secretary | amanda@melorheostosis.org



Patient Support & Advocacy

Check out our website for details on managing your care, getting involved in our online community, conferences and events, as well as current research.

Add your name to our patient map, or join our private Facebook community to share your story and learn from others. Join our mailing list to keep in touch with the latest advancements, Association news, and ongoing research opportunities.

The Association hosts conferences for patients, supporters, and researchers to share the latest discoveries, promote patient advocacy, and build community.



Medical Professionals

Melorheostosis is a rare, non-hereditary sclerosing bone dysplasia characterized by cortical hyperostosis.

Given its rarity and variable presentation, clinicians play a critical role in early recognition, appropriate management, and coordination of multidisciplinary care.

We have a curated list of research studies and publications identified on our website. Learn more about how to care for patients, attend conferences, and support research on our website.



Research Partnerships

Melorheostosis causes progressive bone thickening, chronic pain, joint deformities, & functional limitations. Patients frequently experience:

- Persistent & debilitating pain
- Reduced mobility & range of motion
- Limb deformities & contractures
- Soft tissue & skin involvement
- Long-term disability impacting quality of life

Despite these profound burdens, there is currently no cure or disease-modifying therapy available. Four genes have been identified as causes - MAP2K1, SMAD3, KRAS, and LEMD3. Learn more about research partnerships and upcoming conferences on our website.

More Information

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 www.melorheostosis.org



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