

With belief in
Research,
Education,
Scientific accomplishment,
Energy, and
Advocacy aimed at
Rewarding
Collaboration and
Hope

We established

Melorheostosis.org

- The largest database of melorheostosis patients in the world
- A community of melorheostosis patients and their families joined to share information, offer support, and seek answers together
- A resource for treating physicians, researchers and other professionals



Please Visit Our Website

For additional information, resources and a short video (with statement by Dr. Frederick S. Kaplan, Medical Panel Chair Emeritus) please go to www.melorheostosis.org.

We welcome your questions and comments.

How You Can Help

100% of all gifts are used to support our mission and are tax deductible

Please make your donation by:

- Check payable to the Melorheostosis Association
- With PayPal via our website



Melorheostosis Association



Melorheostosis Association

410 East 50th Street
New York, NY 10022
www.melorheostosis.org
Contact us: Info@melorheostosis.org



Who We Are



Dr. Geert Mortier



Dr. Frederick S. Kaplan



Medical Advisory Panel

Our world renowned Scientific and Medical Advisory Panel is led by

Dr. Michael P. Whyte

Professor of Medicine, Pediatrics, and Genetics,
Division of Bone and Mineral Diseases,
Department of Internal Medicine,
Washington University School of Medicine; and
Medical-Scientific Director, Center for
Metabolic Bone Disease and Molecular Research
Shriners Hospital for Children; St. Louis, MO

For a full list of Medical Panel members:
www.melorheostosis.org

Board of Directors

Jennifer Gordy	President
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The Melorheostosis Association is a 501(c)(3) not-for-profit organization dedicated to finding the cause, treatments and cure for melorheostosis. Our focus is 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.

What Is Melorheostosis?

Melorheostosis is a rare and progressive disease characterized by hyperostosis (thickening) of cortical bone. It affects both bone and soft tissue growth and development. While the disorder is benign (non-cancerous), it often results in severe functional limitation, extensive pain, soft tissue contractures (malformed and/or immobilized muscles, tendons, ligaments), and limb, hand and/or foot deformity.

X-rays are the most common diagnostic tool and the appearance of melorheostosis on x-rays can resemble flowing, melted candle wax. The age of diagnosis is typically based on the severity of onset and symptoms.

Melorheostotic bone and soft tissue often do **not** react as unaffected bone and tissue would to traditional surgical interventions.



Areas of the body affected

Melorheostosis is usually found in the arms and hands (upper quadrant) or legs and feet (lower quadrant). It can present in one extremity of either the upper or lower quadrant, can be bilateral upper or lower, or present in all quadrants. The disease can affect the pelvis, hips, sternum, ribs and, more rarely, the spine and skull.

Related Conditions

Diseases associated with melorheostosis include, Osteopoikilosis, Osteopathia Striata, Buschke-Ollendorff Syndrome, Tuberos Sclerosis, Neurofibromatosis, Linear Scleroderma, Hemangiomas, and Scoliosis.