## **Lymphatic Malformations**

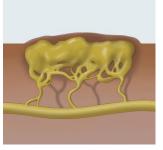


### What are Lymphatic Malformations (LMs)?

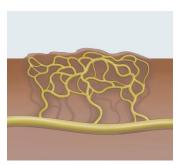
- They are abnormal clusters of lymph nodes (pipes) that do not work to move fluid in the body correctly.
- LMs happen when something goes wrong with the way the pipes form before birth.
- When this happens, the LM acts more like a pool instead of a pipe. The fluid can get in but cannot get out. This makes them swell.
- They can occur anywhere in the body but are most common in the head and neck.

### There are 3 types based on size:

- Macrocysts: Contain large pockets of fluid and can look like a balloon.
- Microcysts: Very small, thin pockets of fluid, like bubbles.
- Mass-Like: When the pockets are too small to see.







Microcystic LM

### What are the Symptoms?

- LMs can be big or small and may cause swelling or too much growth.
- They can feel like a spongy lump.
- They can cause bumps or blisters on the skin that can leak clear liquid or blood that can lead to infection.
- They can cause pain.
- They can cause more serious issues based on where they happen in the body
  - LMs in the mouth/throat can cause difficulty breathing.
  - LMs in the stomach can cause bloody poop or leaking of fluid in the stomach.
  - o LMs in the chest can cause leaking of fluid into the chest and/or lungs.
  - o LMs in the eye can cause the eye to appear popping forward or can cause double vision.
  - LMs in the bone can cause too much growth or bone loss.

# LMs are abnormal clusters of lymph nodes that can cause swelling, pain, and infection.

### How are LMs diagnosed?

The best way to get the correct diagnosis is to get a full history of the patient's symptoms and do a proper exam.

At CHLA, you/your child will meet with our Vascular Anomalies Center team, who will go over the history of the problem, make a diagnosis, and recommend treatments.

#### **Department of Plastic and Maxillofacial Surgery**

Additional testing may be ordered such as:

- Ultrasound: Non-invasive imaging to look at tissues of the body
- Magnetic Resonance Imaging (MRI): Machine that takes detailed pictures of inside the body without radiation.
- Lymphangiography: Special X-ray of lymph nodes and lymph vessels.
- **Genetic testing**: Tests cells and tissue to check for changes in genes.

#### **How are LMs Treated?**

The treatment is based on the unique symptoms of the patient.

Treatment options may include:

- Observation
- **Sclerotherapy**: Injecting a medication with a small needle directly into the abnormal vein to shrink or close it off.
- Laser Therapy: Helps lighten dark marks seen on the skin.
- Surgery: Surgery to remove the abnormal lymph nodes.

#### Medications:

- **Topical Sirolimus**: A medicine rubbed on the skin that can help with bumps on the skin that can drain fluid or blood. It can help prevent skin infections.
- **Oral Sirolimus**: A medicine taken by mouth that may help with pain, swelling, and problems that increase the risk of bleeding and clotting.

### Family Resources

# <u>Lymphangiomatosis & Gorham Disease Alliance</u> (LGDA)

Website: http://www.lgdalliance.org/

# <u>Lymphatic Education & Research Network</u> (<u>LE&RN</u>)

Website: www.lymphaticnetwork.org

# National Organization for Vascular Anomalies (NOVA)

Website: www.novanews.org

#### AboutFace USA

Website: http://www.aboutface.ca/

If you have any questions, please contact the CHLA Vascular Anomalies Center at (323) 361-2154 or fax at (323) 361-4106.