LEUKEMIA & LYMPHOMA SOCIETY OF CANADA®

JMML
Juvenile Myelomonocytic Leukemia

WHAT YOU NEED TO KNOW

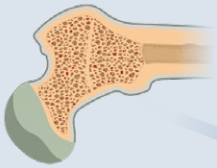
Your child has been diagnosed with juvenile myelomonocytic leukemia (JMML). What does it mean and how will it affect them?

This fact sheet will help you:

- Learn about JMML and how it is diagnosed
- Get an overview of treatment options
- Understand what happens next

What is leukemia?

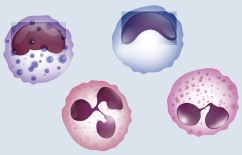
Leukemia is a cancer of the blood and bone marrow. Bone marrow is the soft, spongy material inside bones. Blood cells are formed in the bone marrow. There are three kinds of blood cells:



Bone marrow

Red blood cells
(carry oxygen)

Platelets
(allow blood to clot)



White blood cells
(fight infection)

When you have leukemia, cancerous blood cells form and push out healthy blood cells.

What is juvenile myelomonocytic leukemia?

JMML is a blood cancer of young children. It has features of two other diseases: myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs). This may mean that:

- The bone marrow – the soft, spongy material inside bones – does not produce enough healthy blood cells
- Immature blood cells in the bone marrow (blast cells) do not turn into healthy blood cells
- The bone marrow makes too many red blood cells, certain white blood cells, or platelets

JMML affects the normal development of a white blood cell type called a monocyte.

About JMML

- JMML is an uncommon type of blood cancer
- It is a clonal disease, where cells multiply uncontrollably
- Too many stem cells become monocytes
- Some stem cells never mature: these are called blasts
- It interferes with the normal production of red blood cells (which carry oxygen) and platelets (which stop bleeding)
- It is sometimes known by other names, such as juvenile chronic myeloid leukemia or CMML of childhood (CMML is chronic myelomonocytic leukemia)
- It occurs most often in infants and children under age 6
- It is more common in boys than in girls

Signs and symptoms

Most children with JMML have no obvious signs or symptoms. The disease is uncovered during a visit to the doctor and through follow-up testing. The signs and symptoms can be similar to other less serious diseases. With JMML, your child may experience:

- A feeling of fullness below the ribs
  - When the spleen and liver are enlarged, causing the abdomen to swell
- Large masses in the neck or abdomen and/or painless swelling in one or more lymph nodes
  - When the lymph nodes are enlarged or swollen
- Fever and returning infections
  - When they have a low white blood cell count and are fighting infections
- Dry cough, irritability, and rash
  - This is a response from the immune system
- Pale appearance, weakness, and fatigue
  - When they have a low red blood cell count (anemia)
- Decrease in appetite and weight loss
  - When they are eating less or using more energy
- Bone and joint pain
  - When the white blood cells accumulate, causing the bone marrow to expand
- Developmental delays
  - When they have congenital syndromes that are associated with genetic mutations that cause JMML

After your diagnosis

With your child's diagnosis, the doctor can determine the right treatment. Test results help the doctor predict how JMML will likely progress and how your child may respond to treatment.

Name of test	Description
Medical history and physical exam	The doctor reviews past illnesses, injuries, and symptoms. They examine your child's lungs, heart, and other organs.
Peripheral blood smear	This test looks at blood cells under a microscope to see the number, size, shape, type, and pattern of cells. It also looks for blast cells (immature blood cells), which are not usually present in healthy people.
Complete blood count (CBC)	This test measures the number of red blood cells, white blood cells, and platelets in your child's blood.
Bone marrow aspiration and biopsy	These two tests look for the presence and number of abnormal cells. The tests are usually done at the same time.
Cytogenetics	These tests may be done to clarify the diagnosis or help with risk stratification in some circumstances.

JMML treatment

JMML is an aggressive disease for most individuals, an allogeneic hematopoietic stem cell transplantation (HCT) remains the only curative treatment. Without HCT, average survival is 10-12 months.

Types of treatment

Treatment is individualized and may include:

- **Allogeneic stem cell transplantation** transfers a healthy person's (donor) blood-making stem cells to your child's body. Many, but not all, children with JMML are treated with blood stem cell transplant from a healthy donor. The transplant process includes high doses of chemotherapy.
- **Chemotherapy**
- **Supportive care**
- **Clinical trials**

Find out if your child can take part in clinical trials of treatments. Clinical trials test new drugs and treatments before they are approved. Talk to your doctor for more information.

Other treatment options being studied are:

- **Molecular-targeted therapies:** These therapies slow the growth of cancer cells by blocking certain molecules or proteins that help cancer cells grow.
- **Immunotherapy:** These medicines use the body's immune system to target cancer cells and remove them from the body.

Factors that affect treatment

Discuss your child's treatment options with the doctor to make sure you understand the benefits and risks of each approach. Your child's treatment plan is based on:

- JMML subtype
- Severity of symptoms
- How quickly the cancer needs to be controlled
- Eligibility for stem cell transplantation

Treatment side effects

When your child begins treatment for JMML, they may experience mild to severe side effects, depending on their age, their overall health, and their treatment plan. New drugs and therapies can help control side effects.

Common side effects	Side effects of common treatments would include low blood counts and associated risks (fever, infection, bleeding, fatigue, etc.), need for transfusions. Talk to your doctor for specific side effects of your treatment.
Medical follow-up	Medical follow-up is important. Your child may need blood tests, bone marrow tests, or molecular tests after treatment for JMML. Your child's medical team should provide you with a care plan listing the frequency of follow-up visits and the tests your child will have at those visits.

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