



The Australasian Mastocytosis Society



7th Annual Conference 2019 - CANBERRA, ACT



AUSTRALASIAN MASTOCYTOSIS SOCIETY

TAMS is a non-profit organisation, founded in 2011 to:

- **Provide a network** of support for patients living with mast cell disorders including Systemic Mastocytosis, Cutaneous Mastocytosis and Mast Cell Activation Syndrome (MCAS) and their carers.
- **Connect patients** to medical practitioners and specialists with knowledge of Mastocytosis and MCAS.
- **Link with worldwide associations** to collectively gather research data, share resources and knowledge for greater understanding, treatment practices, medications and improved health outcomes.

We support you - Support Groups

Support, education and research are provided through our website, newsletters, annual conferences and online and offline support groups.

Join one of our Facebook support groups:

Mastocytosis Australasia (support)
Mastocytosis Australasia Carers (support)

Or like our TAMS Facebook page:

The Australasian Mastocytosis Society

Education, Support and Networking

The seventh annual Mastocytosis conference will be a wonderful opportunity for patients, carers, masto kids, families and medical professionals to connect, share knowledge, resources and support with the goal of better health management outcomes for those living with a Mast Cell Disorder.

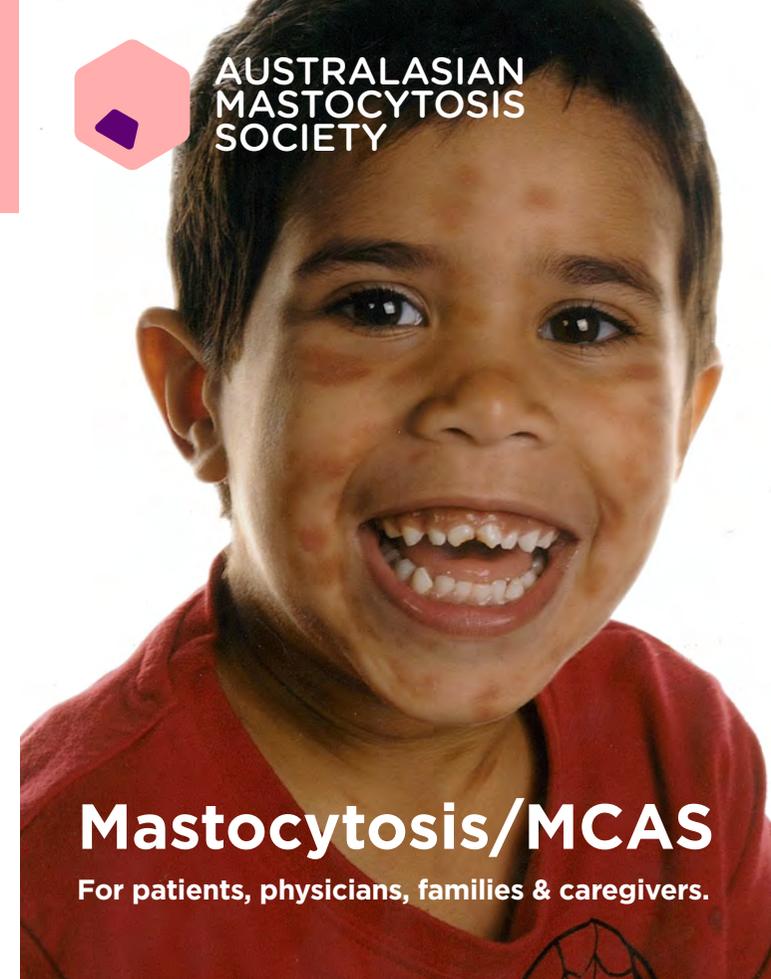
Delegates will learn from leading medical professionals about Mastocytosis and Mast Cell Activation Syndrome (MCAS), managing symptoms, latest research and treatments.

It also helps to meet others who understand what life is like with a rare, chronic health condition:

- **For caregivers:** how to support your patient
- **For patients:** how to support your carer.



AUSTRALASIAN MASTOCYTOSIS SOCIETY



Mastocytosis/MCAS

For patients, physicians, families & caregivers.

Become a TAMS Member

Member benefits include:

- Discounted registration fees for the Annual Conference.
- Regular TAMS e-newsletters.
- Membership of online and face to face support groups.
- Advocacy, research and more.

The annual fee of \$25 provides membership to an individual + \$5 per additional family member.

Visit mastocytosis.org.au

Make a Donation

Your donation makes a difference. Help raise awareness of and support people with mast cell activation disorders and fund future research projects.

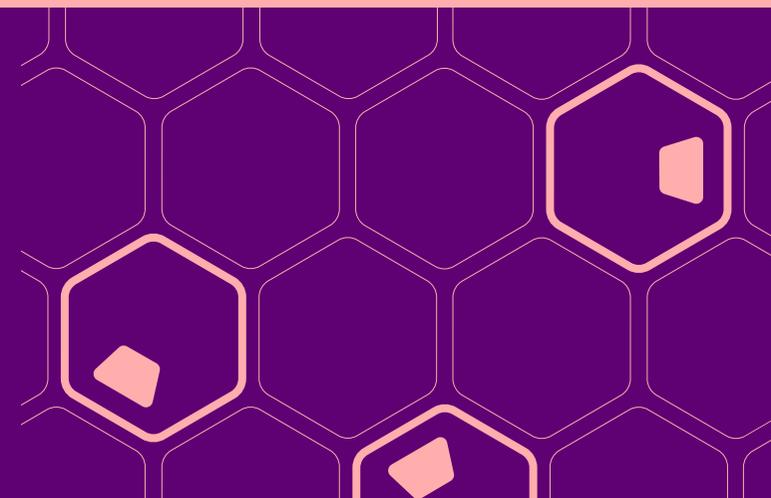
Visit mastocytosis.org.au to donate and get further information or contact us:

The Australasian Mastocytosis Society
PO Box 865 Port Macquarie NSW 2444
info@mastocytosis.org.au

Or donate via EFT:
The Holiday Coast Credit Union
BSB 721-000, Account Number 132471



EDUCATION RESEARCH ADVOCACY SUPPORT





What are Mast Cell Disorders?

Mast cell disorders are caused by the proliferation and accumulation of genetically altered mast cells and/or the inappropriate release of mast cell mediators, creating symptoms in multiple organ systems. The two major forms of mast cell disorders are Mastocytosis and Mast Cell Activation Syndrome (MCAS).

Mast cell disorders can cause tremendous suffering and disability due to symptomatology from daily mast cell mediator release, and/or symptoms arising from infiltration and accumulation of mast cells in major organ systems.

WHAT ARE MAST CELLS?

Mast cells are immune system cells that live in the bone marrow and in body tissues, such as the gastrointestinal tract, the lining of the airway and the skin. Everyone has mast cells in their body and they play many complex and critical roles in keeping us healthy. They help to protect us from infection and participate in the inflammatory process. However, mast cells are also involved in allergic reactions, from the tiny swelling appearing after a mosquito bite, to a life threatening full-blown anaphylaxis.

Mast cells have within them small sacs, or granules, surrounded by membranes. The sacs contain many different kinds of substances called mediators, which participate in all of the roles above, including allergic response and anaphylaxis.

MASTOCYTOSIS

Mastocytosis has been defined as an abnormal accumulation of mast cells in one or more organ systems. Previously classified by the World Health Organization (WHO) as a myeloproliferative neoplasm, mastocytosis is now classified in its own category under myeloid neoplasms. Broadly separated into three categories, cutaneous mastocytosis (CM), systemic mastocytosis (SM) and mast cell sarcoma. These diseases occur in both children and adults.

CHILDREN WITH MASTOCYTOSIS

The most common form of mastocytosis in children is cutaneous mastocytosis (CM), accounting for approximately 90 percent of mastocytosis cases in this age group. The prognosis is excellent for children with CM who have onset of skin lesions within the first two years of life (most children) as spontaneous resolution or improvement is common after several years. CM that develops after the age of two years tends to persist.

MAST CELL ACTIVATION SYNDROME (MCAS)

There is an existence of a subset of mast cell disorder patients who experience episodes of mast cell activation without detectable evidence of a proliferative mast cell disorder. Some patients who exhibit symptoms of mast cell mediator release do not fulfil the criteria for SM. Diagnosis requires consistent symptoms, reported benefit with medications and diagnostic evidence of excess mast cells in tissue biopsies or abnormal mast cell mediators in blood or urine tests. This is referred to as Mast Cell Activation Syndrome (MCAS).

SYMPTOMS

People with mast cell disorders may experience the following symptoms or signs. Sometimes these symptoms may not be apparent or may be caused by another medical condition. This list is by no means complete and serves as an example. If you are concerned about a symptom or sign on this list, please talk with your GP, Immunologist or Dermatologist.

- Anaphylaxis
- Skin lesion
- Urticaria pigmentosa
- Facial flushing
- Itching
- Nausea
- Vomiting
- Diarrhea
- Abdominal pain
- Ulcers in the stomach and duodenum (small intestine)
- Headache
- Light-headedness
- Heart palpitations (an irregular or unusually rapid beating of the heart)
- Bone pain
- Anaemia (low red blood cell count, which can cause fatigue)
- Psychological changes (for example, irritability and inability to concentrate)
- Lack of cognitive function (brain fog)

Symptoms of mast cell disorders can sometimes occur as "attacks or events," where multiple symptoms appear all at once. Following an attack, the person may feel fatigued and lethargic. If a mast cell disorder is diagnosed, relieving symptoms and side effects remains an important part of your care and treatment. This may also be called symptom management or supportive care. Be sure to talk with your health care team about symptoms you experience, including any new symptoms or a change in symptoms.

COMMON TRIGGERS

Certain medication, substances or environmental factors can be mast cell triggers and can differ for each patient.

Possible triggers, unique to each patient, can include but are not limited to:

- **Unknown trigger** - idiopathic anaphylaxis
- **Bee and wasp stings and other venoms** such as ants and other insects, snakes and jellyfish
- **Some medications** - please discuss with your GP
- **Some anaesthetic drugs**
- **Radiocontrast dyes**
- **Food or beverages**, including alcohol
- **Emotional stress, anxiety and fatigue**
- **Physical stress** - heat, cold, change in temperature
- **Friction of skin, lesions or vibration**
- **Exercise**
- **Odours/perfumes**

ANAPHYLAXIS

Anaphylaxis is an acute, life-threatening, systemic reaction resulting from the **sudden, rapid, systemic** release of mediators from mast cells and basophils.

Anaphylaxis-like symptoms present as new or worsening symptoms, and **may** include some or all of the following:

- **Mouth:** itching, swelling of lips and/or tongue.
- **Throat:** itching, tightness, closure, hoarseness.
- **Skin:** itching, hives, redness, swelling, flushing.
- **Gut:** nausea, vomiting, diarrhoea, cramps.
- **Lung:** shortness of breath, cough, wheeze.
- **Heart:** weak pulse, dizziness, passing out.
- **Psychological:** feeling of dread, agitation.

Only a few symptoms may be present. Severity of symptoms can change quickly.

Some symptoms can be life-threatening. ACT FAST! Use your anaphylaxis action plan! Discuss this further with your GP and specialists.

Thank you to our friends at TMS for this information.