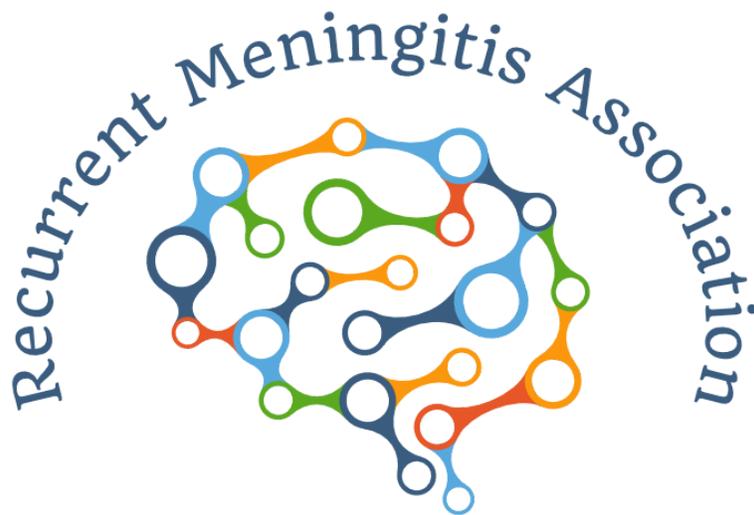


Recurrent Meningitis Association

PATIENT INFORMATION

Recurrent Viral Meningitis (Mollaret's)



Information for Patients

Thank you for looking to the Recurrent Meningitis Association for information.

All information contained in this document is provided as information only and is not a substitute for medical advice from a medical professional.

At the Recurrent Meningitis Association (RMA), we understand that recurrent meningitis is a poorly researched rare disease, and therefore we believe that patient experiences are our

best source of information. Please understand that you are not alone: we are all in this together and together we can find answers. In fact, RMA is working on further research for recurrent viral meningitis (Mollaret's) through the development of a patient registry. However, it is important to remember that although we share a common illness, our bodies react differently to medications, supplements, foods etc. **Please consult with your doctor before taking any medications or supplements.**

We have noticed that it is common for patients to report the condition getting worse with age. Because pain lacks visible evidence, some doctors have difficulty understanding a patient's pain. Patients can be told that their symptoms are all in their heads, which is another reason we need more research to substantiate these experiences. Pain management is important with this disease. Being in pain causes an increase in blood pressure and intracranial pressure as well as stress to the body. Anecdotal evidence seems to support that stress alone can bring on an episode for many patients.

Lumbar punctures can be an important diagnostic tool. The lumbar puncture will reveal what disease-causing agents may be in the spinal fluid, and it is the only way to definitively tell what is causing your active meningitis episode. It is believed by some patients that multiple lumbar punctures can cause serious problems, this is why many patients only consider additional lumbar punctures after diagnosis if the symptom profile is different than usual. Lumbar punctures may continue to be recommended by some medical professionals to rule out other causes of a meningitis episode, however a new cause may be unlikely. These are concerns you need to address with your healthcare professional.

Due to its rare nature and lack of research on the topic, some doctors have never heard of recurrent viral meningitis (Mollaret's). There is also a common misconception in the medical community that one cannot be diagnosed with meningitis twice. Initial research found that most recovered from this illness. Unfortunately, we do not have any evidence of this in our association. Most of our members has suffered for years, and some have experienced episodes after long periods of relative calm.

It is recommended before seeing your healthcare professional to write down all your symptoms and allergies to medications. It is also important to take your current supplements and medications, including over the counter medications, with you to each

appointment. This is because, in rare instances, some medications are found to be responsible for a patient's recurrent meningitis, referred to as "drug-induced" meningitis.

Patient Reported Information

The information provided here is from surveys conducted by the Recurrent Meningitis Association of its members. We hope to provide more comprehensive information from our patient registry once that information is available.

Most Commonly Reported Patient Symptoms

(Top 10 from most to least common)

1. Memory Problems
2. Fatigue
3. Headache
4. Concentration Issues
5. Brain Fog
6. Balance Issues
7. Sensitivity to Sound
8. Eyesight Changes
9. Dizziness
10. Nerve Pain in Extremities

Most Commonly Reported Treatments

(WARNING! DO NOT TAKE ANY OF THESE MEDICATIONS WITHOUT DOCTOR CONSULTATION)

Medications

(Most to least common)

1. Acyclovir
2. Valacyclovir

Supplements

(Most to least common)

1. Lysine
2. Magnesium
3. Vitamin C
4. B12

Natural Treatments

(Most to least common)

1. Avoid Stress
2. Extra Sleep
3. Massage

For additional information visit <https://recurrentmeningitis.org>.