



Inclusion Body Myositis (IBM) In Focus

- Inclusion Body Myositis (IBM), also called sporadic inclusion body myositis (sIBM), one of the Idiopathic Inflammatory Myopathies (IIM), is a complex and rare autoimmune **and** degenerative muscle disease with an unclear cause and no cure.
- IBM is the most common acquired muscle disorder in those over age 50, with symptoms sometimes starting in the 30's and 40's for some. IBM is somewhat more common in men.
- IBM is a slowly progressing muscle disease that causes muscle weakness and wasting over months and years. Unexplained frequent falls, difficulty standing up from a chair, difficulty swallowing, and a weak handgrip may be early signs of IBM.
- Muscle weakness is often asymmetric (greater on one side of the body) and affects the distal muscles (furthest from the body's core). Muscle weakness in the hands affects abilities of pinching, gripping, buttoning, and holding items. Weakened neck muscles can cause the head to drop and rest on the chest. Leg muscle weakness can cause difficulty rising from a chair and walking up stairs.
- Other symptoms /complications include fatigue, a weakened diaphragm, and trouble swallowing (dysphagia), which can cause choking and aspiration and can lead to dangerous pneumonias.
- IBM is often misdiagnosed. "Normal aging" is a very common misdiagnosis, but symptoms associated with IBM are not normally expected aspects of aging. Misdiagnosis of motor neuron disease (ALS) or polymyositis (PM), another of the inflammatory myopathies, is not uncommon.
- Diagnosing IBM can often take many years. Patient history, physical exam, Myositis-Specific antibodies (MSA), Myositis-Associated antibodies (MAA), anti-NT5C1A antibodies, other blood tests (muscle enzymes, inflammatory and autoimmune markers, and other antibodies), MRI, EMG, nerve conduction studies, and a muscle biopsy can assist in making a diagnosis. Finding a doctor with experience is essential.
- Findings of IBM on muscle biopsy largely depend upon disease progression. Presence of "rimmed vacuoles" can help confirm a diagnosis, however, lack of these does not rule out IBM.
- There are no available or approved medications to treat IBM. Immunosuppressive drugs used to treat other forms of the inflammatory myopathies have been tried, however, many treated with these drugs have reported worse outcomes, even if there was short-term improvement.
- Exercise, in coordination with a doctor and physical therapist, is recommended for IBM patients.
- Caregivers become an essential, and invaluable, part of the IBM patient's life. Assistance is often needed with activities of daily living (ADL's) such as feeding, dressing, bathing, and toileting. Having support in place can also help with the emotional aspects of life with IBM. Adapting to changing abilities and limitations is a large part of life with IBM.

IBM is different from person-to-person, as is the progression of the disease. Overall, within 5 years patients require assistive devices for mobility (cane, walker, rollator) and within 10 years, patients require a wheelchair or power chair. IBM is not "normal aging." Adapting to changing abilities is difficult physically and emotionally. Look closer and put #MyositisInFocus and learn more about IBM at <http://www.UnderstandingMyositis.org/sibm>

There is an urgent need for therapies to treat IBM. There are several clinical trials underway. Find your clinical trial match at www.UnderstandingMyositis.org/clinical-trials