What is an IgM MGUS?

MGUS stands for monoclonal gammopathy of unknown significance. It is a non-cancerous condition where the body makes an abnormal antibody, called a 'monoclonal (abbreviated as M)' protein or paraprotein.

MGUS is named according to the type of the backbone the paraprotein has:

• IgM MGUS

• Non-IgM MGUS – i.e. IgG, IgA, IgD or IgE

• Light chain MGUS – where there are no heavy chain backbone at all, only smaller so-called light chains (fragments of antibodies)

People with MGUS have an increased risk of developing other conditions such as low-grade lymphomas from IgM MGUS and multiple myeloma from other MGUS

The risk of progression among patients with IgM MGUS is around 2% per year in the first 10 years after diagnosis and 1% per year thereafter

For this reason, patients need to be monitored over the time

What does monitoring consist of?

Monitoring consists of simple blood tests, often repeated once a year.

These should include:

- Quantification of the M-protein on serum electrophoresis and immunoglobulin levels;
- Full blood count;
- Renal and liver function;
- Bone profile;
- LDH.

Occasionally other blood tests might be required

What happens if my paraprotein levels are rising?

Over time, your paraprotein levels might increase. It is not necessarily the numerical levels that trigger further investigations but signs or symptoms which may be caused by a developing underlying medical condition, for example, rapid weight loss or feeling breathless and fatigued from a new anaemia. If your paraprotein increases and you have symptoms, you may be asked to have

more frequent monitoring or to undergo a CT scan or bone marrow test. A bone marrow test is a relatively quick routine procedure where liquid bone marrow and a very small core of bone is removed from the back of your pelvic bone using local anaesthetic.

Will I have any symptoms with an IgM MGUS?

Generally, having an IgM MGUS will not cause any symptoms. If you have unexplained symptoms they are likely to need further investigations as you may be developing an underlying low-grade lymphoma or you may have a form of IgM M-protein which has a clinical significance (as opposed to unknown significance). This has been termed monoclonal gammopathy of clinical significance (MGCS). For example, you may have IgM related neuropathy, causing numbness in your hands or feet, or balance problems; you may have an IgM related autoimmune condition such as cold agglutin disease or an IgM gammopathy of renal (affecting the kidney) significance. Also, there is a separate condition where the protein is deposited in organs such as your heart, kidney and nerves, called Amyloidosis. Further specialised tests and examinations will help to determine these types of conditions. These conditions may have additional signs and symptoms such as enlarged organs or abnormal hormone levels or skin abnormalities. It is important to let your clinician know if you have any symptoms that you are concerned about.

What type of low-grade lymphoma might an IgM MGUS this develop into?

A very small number of patients with an IgM MGUS can go on to develop a low-grade (slow-growing) lymphoma, such as Waldenstrom's Lymphoma or a Marginal Zone Lymphoma. Less likely, a chronic lymphocytic leukaemia (CLL), or a very rare type of Myeloma. If diagnosied with a low-grade Lymphoma, you may not need treatment but you will require closer monitoring in case treatment is required in the future. If the low-grade Lymphoma is causing symptoms, a course of treatment will be recommended. Treatment will generally consist of a combination of intravenous antibody treatment and chemotherapy given on our day unit as a day case or sometimes it can be in tablet form.

The Rory Morrison WMUK Registry

Working with centres across the UK, The Rory Morrison WMUK Registry gathers data from patients with IgM MGUS and related disorders.

If you are under the care of one the participating centres, your clinical data might be automatically included in the registry. All data is uploaded on our secure online database by local clinicians and data managers, and is anonymised.

If your centre isn't participating, you can request a referral to one of the listed centres for the purposes of capturing your data.

How can I find out more information?

You can find out more from Lymphoma Action at lymphoma-action.org.uk and Waldenstrom's UK at wmuk.org.uk