Inherited Metabolic Disease Service
Patient Information
Alpha mannosidosis

You may find it helpful to contact your patient support group.

MPS society
Tel: 0345 3899901
Email: mps@mpssociety.org.uk
https://www.mpssociety.org.uk/

Contact us
LDU Box 135, Addenbrooke’s Hospital, Hills Road, Cambridge. CB2 0QQ
Tel: 01223 274634
Email: lducambridge@nhs.net

Please note the department is open Monday to Friday 08:30-17:00.

If you are unwell outside of these hours you should seek medical advice from your local healthcare team.

If your emergency doctor needs specific advice they should call the hospital switchboard on 01223 245151 and ask for the metabolic consultant on call.

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk
For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Authors
Liz Morris/ Patrick Deegan

Pharmacist
N/A

Department
Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ
www.cuh.org.uk

Contact no.
01223 274634

Publish/Review date
December 2019/December 2022

Filename
Alpha_mannosidosis.doc

Version no.
1

Reference
101423
What is Alpha mannosidosis?

Alpha mannosidosis is a lysosomal storage disorder. Your body is made up of trillions of individual cells and each cell contains a small part called the lysosome. This is primarily responsible for breaking down and recycling worn out cell components. Inside the lysosome are enzymes which perform this very important housekeeping role. In alpha mannosidosis the necessary enzymes are not working effectively allowing these products to build up and become stored in very specific areas of your body. There are many different enzymes in your lysosomes, and deficiencies of each enzyme will cause a different disease. All of these different diseases together are called lysosomal storage disorders.

How will this affect me?

In alpha mannosidosis the cells most commonly affected can be found in the joints, brain, immune system and bones. This means you may experience or be at risk of the following:

- Hearing loss
- Cataracts
- Muscle weakness
- Increased risk of infections
- Difficulty with walking
- Memory impairment

- Cognitive decline
- Swallowing difficulties
- Communication difficulties
- Joint pain
- Anxiety/depression

The progress of the disease in adults is extremely variable with some people not really noticing any symptoms whilst others are more severely affected.

If you have any questions about the effects and progression of the disease please do ask your doctor or specialist nurse

Is there any treatment?

At the moment there is no specific treatment for alpha mannosidosis available on the NHS in the UK. We work very closely with colleagues from around the world to keep up to date/participate in research in this field.

How did I get alpha mannosidosis?

Your disease is a genetic condition which means that you inherited it from your parents.

There are instructions in your genes for making lysosomal enzymes and a small change in the DNA can be enough to stop the enzyme from working properly.

You have two copies of every gene, having received one from each parent. To be affected by alpha mannosidosis you need to have two copies of the gene with the DNA change on it – one from each parent. Only receiving one affected copy means you are a carrier and will not be affected. Please do talk to your doctor or specialist nurse who can explain this in more detail.

What do I need to do next?

- Do ask your doctor or nurse for more information.
- Do attend your regular appointments with the lysosomal disorders team so that we can ensure you receive the most appropriate care for your current difficulties and can keep you informed of any new developments.
- Do maintain a healthy lifestyle
  - avoid smoking
  - keep alcohol consumption to a minimum
  - maintain a healthy weight
  - take some regular exercise
- Do report any difficulties you may encounter when eating or drinking.