JUVENILE XANTHOGRANULOMA

What are the aims of this leaflet?

The aim of this leaflet is to provide patients and their parents with information about juvenile xanthogranuloma (JXG). It tells you what it is, what causes it, what can be done and where you can find out more information.

What is juvenile xanthogranuloma and what causes it?

JXG is a skin lump caused by an excess of cells known as histiocytes. It is rare and occurs mainly in infants and young children, although about 10% occur in adults. It is not known what causes this condition. It is not a type of cancer.

Is juvenile xanthogranuloma hereditary?

It is not hereditary and does not run in families. It is more common in white people than other ethnic groups. More boys than girls are affected. People who have several juvenile xanthogranulomas have a slightly increased chance of having other very uncommon conditions such as chronic myeloid leukaemia, neurofibromatosis type 1 and urticaria pigmentosa (see separate PIL).

What are the symptoms of juvenile xanthogranuloma?

Juvenile xanthogranuloma is a lump in the skin, often on the head, neck or upper body. JXG does not generally cause pain or itch but occasionally the surface can break down to form an ulcer. Rarely JXG can occur in other parts of the body, such as the eye, liver or muscles. It is usually a harmless condition but if it affects the eyes it might be necessary to refer to an eye specialist for advice. Sometimes JXG are present at birth, but can also develop later. Generally there is no effect on the overall health of the person who has a JXG.
What does juvenile xanthogranuloma look like?

JXG are smooth, firm, rubbery, red or yellowish-red dome shaped lumps in the skin that over time may turn more orange or yellow in colour. Sometimes they are scaly. The lump is usually up to 2cm in size and there is usually only one JXG. Rarely, there may be a few JXG present in the skin.

How is juvenile xanthogranuloma diagnosed?

The diagnosis is usually made by the typical appearance of a JXG. A skin biopsy may sometimes be taken (the abnormal skin is removed under a local anaesthetic) and examined under a microscope to confirm the diagnosis.

Can juvenile xanthogranuloma be cured?

For many people JXG disappears by itself over a few years. JXG sometimes leave a slightly darker or paler patch on the skin, or can disappear without leaving a scar if it does not improve, individual lumps can be surgically removed, however this would leave a scar. JXG are less likely to disappear by themselves in adults.

How can juvenile xanthogranuloma be treated?

As it is harmless and tends to clear away on its own in children, treatment is not recommended for those on the skin or in muscles. If JXG affect the eyes; then advice from an eye specialist may be recommended. In extremely rare cases where there are many JXG throughout the body that are causing symptoms, other treatments such as surgery or radiotherapy may be needed.

Self care (What can I do?)

If you have further questions, it may be helpful for you to write them down before the clinic appointments so you don't forget to ask them on the day. Look out for any changes or any new JXG developing. It may be worth telling your child's teacher it is present so the JXG is not mistaken for an infection or a bruise.

If you notice a change in the coloured part of the eye (the iris) tell your doctor as it may be necessary to see an eye specialist for further checks.

Where can I get more information about juvenile xanthogranulomas?
Web links to detailed leaflets:

http://dermnetnz.org/lesions/xanthogranuloma.html

Links to patient support groups:


For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists’ Patient Information Lay Review Panel

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