PATIENT INFORMATION LEAFLET

# JUVENILE XANTHOGRANULOMA

## WHAT ARE THE AIMS OF THIS LEAFLET?

The aim of this leaflet is to provide patients and their parents/carers with information about juvenile xanthogranuloma (JXG). It explains 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 (which are part of the immune system - see further information below) . 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 males than females, and in white people than other ethnic groups. JXG affects more males than females. People who have several JXGs have a slightly increased chance of having other very uncommon conditions such as chronic myeloid leukaemia, neurofibromatosis type 1 and urticaria pigmentosa (see the patient group information link below).

## WHAT ARE THE SYMPTOMS OF JUVENILE XANTHOGRANULOMA?

JXG is a lump in the skin, often on the scalp, face, neck or upper body. It is usually harmless and has no effect on the overall health of the person affected. JXG does not generally cause pain or itch but occasionally the surface of the lump can break down to form an ulcer. Rarely, JXG can occur at non-skin sites such as deep soft tissue, eyes and other internal organs requiring referrals to relevant specialists, and may or may not be associated with skin lumps.

## WHAT DOES JUVENILE XANTHOGRANULOMA LOOK LIKE?

JXGs are typically smooth, firm, rubbery dome-shaped lumps. In less richly pigmented skin, they may appear red or yellowish-red initially, and may turn more orange or yellow over time. In more richly pigmented skin, the colour of JXG and how it changes over time can be harder to notice and may depend on the person's skin tone. Sometimes they are scaly. They are normally up to 2cm in size. There is usually only one JXG present but rarely, there may be a JXG present in multiple locations at the same time.

## HOW IS JUVENILE XANTHOGRANULOMA DIAGNOSED?

The diagnosis is usually made by a dermatology specialist based on the typical appearance of a JXG. A diagnostic punch biopsy of the lump may sometimes be taken (some of the abnormal skin is removed under a local anaesthetic) and examined under a microscope to confirm the diagnosis. This type of biopsy would leave a small scar.

## 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 mark. If it does not improve, the individual lump can be surgically removed, however this would leave a larger 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. In extremely rare cases where there are many JXG throughout the body that are causing problems, other treatment after consultation with other relevant specialists 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 do not forget to ask them on the day. Look out for any changes e.g. within the iris of the eye (the coloured part of the eye) or any new JXG developing. It may be worth telling the child's teacher or carer of its presence, so the JXG is not mistaken for an infection or a bruise.

## WHERE CAN I GET MORE INFORMATION ABOUT JUVENILE XANTHOGRANULOMAS?

*Web links to detailed leaflets:*
https://dermnetnz.org/topics/juvenile-xanthogranuloma

*Links to patient support groups:*
https://histio.org/histiocytic-disorders/xanthogranuloma/

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*

**BRITISH ASSOCIATION OF DERMATOLOGISTS**

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