Who We Are
SarcoidosisUK is the UK Sarcoidosis Charity. We’re here to provide support, information and to fund research. The vast majority of our funds go towards researching a cure. We run support groups across the UK – please contact us for information on your nearest group.

How You Can Help:

Donate to fund research: www.sarcoidosisuk.org/donate

Join our registry for the opportunity to participate in medical research: www.sarcoidosisuk.org/patient-register

Thanks to:
Sarcoïdose Belangenvereniging Nederland (SBN), The Dutch Sarcoidosis Society;

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Sarcoidosis and Children

Sarcoidosis is mainly diagnosed in people aged 20 to 40 years. This leaflet examines heredity and other issues surrounding sarcoidosis and children.

Hereditary

If a parent has sarcoidosis, it is understandable to consider the consequences and risks for a newborn child. Hereditary factors may play a role in contracting sarcoidosis; however, this probably occurs in combination with one or more environmental factors. It is not yet known exactly which, if any, genetic factors are involved. In only around 10-20% of sarcoidosis cases, a family member has also suffered from the disease.

Medications and Pregnancy

If you are taking medication and are planning to have children, it is important to discuss this in advance with your doctor. You may need to reduce medication dosages. If anti-inflammatory agents (e.g., methotrexate) or NSAIDs are used, pregnancy is strongly discouraged. This also applies when you yourself are healthy, but your partner has sarcoidosis and is taking this medication. In both cases always consult your doctor.

Fertility

Usually there are no problems caused by sarcoidosis in itself relating to fertility. However, medication may adversely affect fertility - a particularly problematic substance is methotrexate.

Although sarcoidosis in principle can also occur in the genitals, this is fortunately very rare.

Pregnancy

Sarcoidosis does not prevent pregnancy or the birth of a healthy child. During the pregnancy, sarcoidosis symptoms may even reduce in many women. Six months after giving birth, sarcoidosis symptoms in some women can become active again.

Breastfeeding

Women with sarcoidosis may breastfeed as normal.

Medical Analysis

There are no specific tests that can be taken before you become pregnant. It is important to record the medication you (or your partner) may be taking for mapping its risks in discussion with your doctor.

Sarcoidosis in Children

Sarcoidosis in children is very rare; only a few cases have been recorded. Of these, children are mostly in their teens when the disease is diagnosed.

There is no test that can predict whether your child will inherit sarcoidosis. Having sarcoidosis is not a definite predictor that your child will also have the disease.

Menopause

During hormonal changes, in particular relating to oestrogen, sarcoidosis symptoms may increase. It has not been studied scientifically whether the disease gains momentum during these periods. Indeed, sarcoidosis is primarily diagnosed in women aged between 20 and 40 years, before these hormonal changes occur. Those with acute sarcoidosis are likely to have recovered by this time.

Discuss your desire to have children with your doctor!

If you are taking medication for sarcoidosis and are pregnant or are planning a family, it is wise to consult your doctor. This applies even if your partner has sarcoidosis and you are healthy yourself.