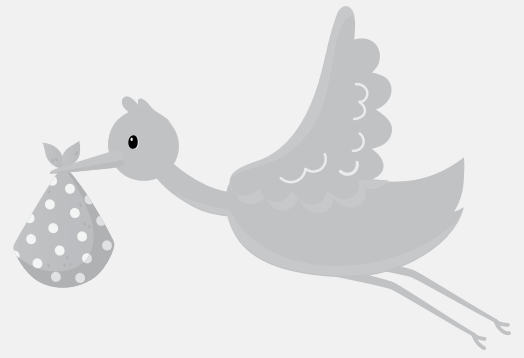


# LIVING WITH LAM:

## LAM AND PREGNANCY



LAM affects women almost exclusively. Since there is evidence to suggest that the hormone oestrogen might affect LAM adversely, women are advised to avoid treatments containing oestrogen, including the combined oral contraceptive pill and hormone replacement therapy. This raises questions about pregnancy since oestrogen levels are raised during pregnancy.

Many women have completed their family before LAM is diagnosed but others will not have done so, and may wish to become pregnant. The decision as to whether to become pregnant or not can be a difficult one and this leaflet discusses the information that has been collected from studying women with LAM during pregnancy. If LAM is associated with tuberous sclerosis complex there are further considerations to bear in mind, detailed below.

### FOR WOMEN CONSIDERING PREGNANCY

When deciding whether to become pregnant or not, women with LAM often ask about the possible effects of pregnancy on their LAM, and also on the effects of having LAM on their pregnancy and their baby. A further question is how sirolimus (Rapamycin) treatment might affect the management of pregnancy.

We discuss these points below.

### The effects of pregnancy on LAM

Women with LAM may have no significant problems during pregnancy but there is an increased incidence of complications from LAM during pregnancy, which may be harder to deal with, particularly in women with poorer lung function. Whilst these complications are usually manageable with good care, they can make pregnancy more difficult for women with LAM.

The effects noted during pregnancy in patients with LAM are:

- An increase in breathlessness in nearly all women as the baby increases in size
- A pneumothorax (collapsed lung) in roughly seven out of ten women, and these have often been difficult to manage
- A pleural effusion (fluid around the lungs) has occurred occasionally, or worsened during pregnancy
- A rapid increase in the size of angiomyolipomas, which are then more likely to bleed

There is also some evidence to suggest that lung function may be lower after pregnancy than it would be after the same period of time if the mother had not been pregnant. This is particularly important for women with poorer lung function prior to pregnancy, or whose lung function is deteriorating more rapidly than average.

*(continued over)*

## **The effects of having LAM on the pregnancy and baby**

Women with LAM are more likely to have a premature birth but, reassuringly, the outcome for the baby appears to be similar to that in women not affected by LAM.

## **The effects of sirolimus on pregnancy and its management**

The effect of taking sirolimus (Rapamycin) during pregnancy has not been studied in women with LAM. At present therefore patients are advised not to take sirolimus if they are pregnant, are planning pregnancy or are breast feeding. Women are advised to use effective contraception whilst taking sirolimus and for 12 weeks after stopping sirolimus, (but avoiding the combined oral contraceptive pill, which contains oestrogen). This should be discussed with the doctor prescribing sirolimus.

## **WOMEN WITH LAM AND TUBEROUS SCLEROSIS COMPLEX**

Women with LAM associated with the separate condition tuberous sclerosis need to be aware that tuberous sclerosis, unlike sporadic LAM, is inherited. This means that there is a 50% chance that the baby will inherit tuberous sclerosis. It is also important to consider that the manifestations of tuberous sclerosis are life-long and the child may be more seriously affected than the mother. If there is any doubt, a genetic test can be arranged for the mother.

## **CONCLUSIONS**

The decision for women with LAM as to whether to become pregnant or not is a very personal and individual one. The risks will vary between women depending on several factors but particularly their lung function and the rate at which their lung function is declining, since this varies considerably between women. Women with relatively well-preserved lung function and where lung function has shown only limited deterioration over the last few years are less likely to have chest problems, whilst women with small or no angiomyolipomas are less likely to have problems from bleeding. Talking to a consultant with experience of managing women with LAM and who knows the individual's medical history means that the pros and cons of pregnancy can be discussed on a personal basis. In the case of tuberous sclerosis, discussion with a consultant with experience of managing women with tuberous sclerosis would also be appropriate.

## **FURTHER INFORMATION**

In the recorded presentation below, Professor Johnson discusses pregnancy and LAM:

<https://www.thelamfoundation.org/LAM-Patients-Family-Friends-Resources-Video-Library/Article/185/Exploring-Women-s-Health-and-LAM>