fect of pregnancy on the disease. However, women with diffuse scleroderma in pregnancy may have problems with high blood pressure and some develop kidney disease. Further, some patients with scleroderma and lung disease deteriorate after delivery. It is therefore wise for each patient contemplating pregnancy to discuss their case individually with their doctor, so that the best advice can be obtained.

Conclusion

There is a lot of hearsay and very little hard information on the relationship between pregnancy and scleroderma. There are some intriguing suggestions that pregnancy prior to disease onset might provide hints to understanding why women have an increased risk of this disorder. There is no evidence that reproductive loss through miscarriage and related factors is importantly increased either before or after the development of the disease. There are some suggestions however, that there is a slightly increased risk of prematurity, and that the birth weight of babies born from mothers with scleroderma might be lower. In some women who have scleroderma, pregnancy does not cause a problem although it is important to carefully monitor blood pressure, function of the kidneys and lung function during pregnancy and there is a need to attend regularly for specialist appraisal during this period.

Scleroderma Society
Supporting people with Scleroderma for over 25 years

The Scleroderma Society supports people with scleroderma and their families by providing:

- educational literature
- a telephone helpline
- a comprehensive website & forum
- a newsletter with research information
- member contact
- informal group meetings
- an annual conference

We also work to promote awareness of scleroderma among the medical profession and general public in order to improve early diagnosis and prognosis. We fund medical & scientific research in the UK and are a founder member of FESCA (Federation of European Scleroderma Associations), working to forward the cause of people with scleroderma throughout Europe.

PO Box 581
Chichester
PO19 9EW
020 7000 1925
info@sclerodermasociety.co.uk
Helpline 0800 311 2756
www.sclerodermasociety.co.uk

UK Registered Charity No. 286736
Revised March 2010

Scleroderma Society
Supporting people with Scleroderma for over 25 years

Scleroderma and Pregnancy

The production costs of this leaflet have been supported by Actelion Pharmaceuticals UK Ltd and Pfizer Ltd

Scleroderma and Pregnancy

Scleroderma is an umbrella term used to indicate a spectrum of disorders. There are two main types of scleroderma— localised and systemic. Often medical professionals use the term "scleroderma" when they talk about systemic sclerosis.

The inter-relations between systemic sclerosis and pregnancy are of considerable interest, particularly since scleroderma is a disease which affects markedly more females than males and does seem to have a peak of onset during the reproductive period. There are three questions of interest to those researching in the field.

These are:

Do women who are going to develop scleroderma have any difference in their pregnancy history prior to the development of the disease?

Does the presence of scleroderma affect the outcome of pregnancy in any way?

Does having a pregnancy affect the course or the outcome of scleroderma and its severity?

Pregnancy Experience Before the Onset of Scleroderma

There does seem to be a number of studies suggesting that previous difficulty in conceiving is increased among women who are going to develop scleroderma. In some women this difficulty is such that they have no recorded successful conception prior to the disease. Further, information also suggests that the size of babies born to women who are going to develop scleroderma are actually smaller than might be expected. It is difficult to know what these findings all mean, although there is some suggestion that Raynaud's phenomenon, which is part of the scleroderma process, causes in some women a small reduction in blood flow to the uterus which can have these effects.

Recent studies have suggested that during a normal pregnancy cells from the baby can cross the placenta and circulate in the mother's bloodstream. In women who develop scleroderma, the baby's cells survive for longer and the reason for the development of the disease may be a response to these cells. Thus in the same way that a person who receives a transplanted kidney may react and become ill following the transplant, then the mother's scleroderma may be a very long delayed reaction to the persistence of these "foreign" cells.

What is the Pregnancy Experience After the Onset of Disease?

It used to be said that women who had developed scleroderma and then became pregnant, normally had a very poor experience with their pregnancy with a high rate of miscarriage and other pregnancy problems. However, more recent and more carefully done studies have actually shown that in women who have scleroderma and who become pregnant, the pregnancy loss rates are really only slightly higher than expected from normal population. Indeed, the best study would suggest that there is no increase in miscarriage rates between women with scleroderma and the normal population of women. As with pregnancies occurring before the onset of the disease, pregnancies after the onset of the disease are also associated with the risk of prematurity and slightly smaller babies. This does not appear to be a major problem in regard to the babies' health, but it is of interest to those investigating the disease.

The Effect of Pregnancy on Scleroderma

It is often recommended that women who had scleroderma should not become pregnant because this might cause deterioration in their disease. One of the problems for medical researchers is that when people have a bad experience, it tends to get published in the medical press, where in reality, one needs to answer whether this might have happened even if the women had not become pregnant. When carefully observed groups of women with scleroderma have been followed up and compared with what happened when they were not pregnant, the picture is much happier for the milder disease. The conclusions would be that for patients with limited scleroderma, there is no ef-