All parents hope that their new born baby will be entirely healthy. Words can not easily express the initial distress and shock of being told you have a collodion baby especially as parents receive little information about the condition in the first few days after birth. This article attempts to provide such information and answer some of the most frequently asked questions about collodion babies:

The term ‘collodion baby’ does not refer to a medical condition but to the baby's appearance. Collodion babies appear to have an extra skin – parents have described it as being like a sausage skin or a shiny film, as if they had covered the baby in Vaseline®. The skin is tight, and this may make the eyelids and lips look as if they are being forced open. Unfortunately, collodion skin is only rarely detected during pregnancy; the first thing that usually happens for the parents is either a doctor or midwife explaining that something is wrong and actually seeing the baby themselves with abnormal looking skin.

Collodion babies are rare, so it is quite likely that the midwife and other medical professionals present at your baby’s birth know very little about this condition. This can be very distressing for parents, who naturally have lots of questions and want to know what can be done to help their child.

**What causes the collodion skin?**
We do not know the exact cause but the collodion skin is usually due to an inherited or genetic abnormality in normal skin shedding. Usually, surface skin cells rub away in the course of daily life (even in the womb) and are replaced with new ones. There are a number of genetic faults (also known as gene mutations) that can prevent this from happening. These are usually associated with a group of skin conditions which together are known as ‘ichthyosis’ (from the Greek word meaning ‘fish’). This is a condition in which the skin is dry and scaly.

**Will the collodion skin go away?**
Yes. The outer skin layer will usually be shed within a few days; occasionally this process may take longer – perhaps 1-2 weeks. The shedding process may reveal normal skin in about 1 in 10 collodion babies or in the majority one of the forms of ichthyosis – most probably Lamellar ichthyosis or Non-bullous ichthyosiform erythroderma, but very rarely one of the ichthyosis syndromes associated with other organ involvement. Frustratingly we can’t predict which of the above will happen.

**Is my baby likely to have internal problems too?**
No, in the vast majority of cases the problem is confined to the skin.

**Is my baby in pain?**
Specialists in ichthyosis think that the collodion skin does not cause pain or distress to the baby but it is necessary to keep the skin moist, because otherwise heat and fluid can be lost through the abnormal skin, which will affect the baby’s general health. For this reason the medical team may want your baby to spend a few days in a humidified incubator and they will also apply appropriate moisturisers to keep your baby comfortable.
What happens next?
Very soon after the birth, the midwife will have referred you and your baby on to a paediatrician (a doctor specialising in the treatment of children). It is likely that you will also see a dermatologist (skin specialist) within the first few days. Even dermatologists do not see this condition very frequently, however, and so they may choose to refer you on to a paediatric dermatologist (who specialises in children’s skin conditions) for assessment. It may be that this expertise is not available locally and you will have to travel some distance to appointments. The dermatologist will arrange for tests to make a complete diagnosis of your child’s condition and will advise you on how to care for them.

I’m not sure I can cope – where can I find help?
Collodion skin is rare, and because the doctors and nurses around you may not recognise and understand it, you could feel that you are having to cope on your own. The Ichthyosis Support Group (ISG) exists to provide you with psychological support and practical information. This in many ways is the best advice as it comes from people who have asked the same questions and experienced the same emotions that you are currently experiencing.
We have other leaflets about congenital (inherited) ichthyosis and its treatment and leaflets that help you to explain the condition to your child, other children, doctors and other people who look after your child that you can download. You can also use the website or facebook to ask questions about ichthyosis and to share suggestions and tips that work for your child and to find out about events for families of children with ichthyosis so that you (and your child) will know that you are not alone and that there are other people who understand what you are going through and can help you.

To find out more about the ISG or become a member please get in touch in one of the following ways:

By Phone or Fax:
Tel: 0845 602 9202 Fax: 0560 343 8046 (on request)

By Email:
isg@ichthyosis.org.uk

By Post:
Ichthyosis Support Group
PO Box 1242, Yateley GU47 7FL

Facebook:
facebook.com/ichthyosisupportgroup

Twitter:
twitter.com/ISG_Charity