NHS

Screening Programmes

Newborn Blood Spot

When your baby is suspected of being a carrier of cystic fibrosis – communication guidelines

The following guidelines have been developed by the NHS Newborn Blood Spot Screening Programme to support health professionals in their communication of screening results to parents when their baby is suspected of being a carrier of cystic fibrosis.

Guidelines for communicating cystic fibrosis carrier result	Reasoning	Communication should include the following information
• Where possible, a screening nurse specialist will contact the family's health visitor (or other designated health visitor appointed to give screening results) to discuss the screening result • The designated health visitor or alternate (who must be trained to give screening results) will make a visit to the family to inform them that their baby is thought to be a carrier of cystic fibrosis. • Results should not be communicated to parents on a Friday or Saturday or just before a bank holiday	• Health visitors have an ongoing role in supporting families • Information about carrier status should be given to parents by a well-informed health professional • Parents will have questions about their baby's results • Giving results over the phone is not satisfactory, as parents may not have any support or source of further information • Parents should not be left without support over a weekend or bank holiday	• That their baby's screening result suggests that their child is a carrier of the cystic fibrosis gene • That carriers are not affected by the condition • That carriers can pass on their altered gene to any children they may have

Content last updated 2007. Format last updated March 2015

Public Health England is responsible for the NHS Screening Programmes

• Parents should be provided with a copy of the screening results leaflet 'Carrier of cystic fibrosis gene'. This can be downloaded from www.newbornbloodspot.screening.nhs.uk/cf • Parents should be told that occasionally there are uncommon alterations of the CF-gene that are not recognized by the screening test and therefore there is a small chance that the child will have CF. They should contact their health visitor or GP if they have any concerns about their child's health. • Results should be recorded in the Personal Child Health Record and in the baby's notes	• Parents can quickly forget or misunderstand the information they are given about their baby's results. They may also require access to reliable sources of further information and support. • Parents should be aware that the risk that their child has cystic fibrosis has not been eliminated.	• That if they have another child, there is the possibility that this child will have cystic fibrosis. They can ask their GP for an appointment with a genetics centre to discuss this further if they wish. • Most babies who are found, through screening, to have one alteration in a CF-causing gene are carriers who do not have CF. However, there are uncommon alterations of the CF gene that are not recognized by the screening test. It is possible therefore that a baby with this screening result will have a second uncommon alteration and will have CF. This rarely happens. • That if they are worried about their child's health, they should discuss this with their GP who may, if appropriate, refer them to a cystic fibrosis specialist • Where they can get further information and support