

# Screening Programmes

## Newborn Blood Spot

### When cystic fibrosis is suspected – 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 cystic fibrosis is suspected.

Guidelines for communicating screening results indicating that cystic fibrosis is suspected	Reasoning	Communication should include the following information
<ul style="list-style-type: none"> <li>• A health professional working at a designated local cystic fibrosis clinic will discuss the positive screening result with the health visitor or other appropriate health professional, and co-ordinate the first joint contact with the family. A joint appointment with a cystic fibrosis nurse specialist or a screening nurse specialist could be arranged if appropriate</li> <li>• Parents should be provided with:               <ul style="list-style-type: none"> <li>(a) a copy of the screening results leaflet entitled 'Cystic fibrosis is suspected', which can be downloaded from <a href="http://www.newbornbloodspot.screening.nhs.uk/cf">www.newbornbloodspot.screening.nhs.uk/cf</a></li> <li>(b) contact numbers for the designated clinician or nurse and details of parent support group</li> <li>(c) details of the time and location of an appointment at the designated cystic fibrosis specialist centre</li> </ul> </li> <li>• Parents should be offered an appointment with the designated local cystic fibrosis team on the following day</li> <li>• Screening results indicating cystic fibrosis is suspected should not be communicated to parents on a Friday or Saturday, Sunday or just before a bank holiday. Ideally, Thursday should be avoided as well</li> <li>• Results should be recorded in the Personal Child Health Record and in the baby's notes</li> </ul>	<ul style="list-style-type: none"> <li>• Health visitors have an ongoing role in supporting families</li> <li>• Information about positive screening results should be given to parents by a well-informed health professional</li> <li>• Parents will have questions about their baby's results</li> <li>• Giving results over the phone is not satisfactory, as parents may not have any support or source of further information</li> <li>• 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 (also provided in the results leaflet)</li> <li>• Delays in confirming results and starting treatment can only add to parents' anxiety</li> <li>• Parents should not be left without support over a weekend or bank holiday</li> </ul>	<ul style="list-style-type: none"> <li>• That the screening result suggests that their baby may be affected by cystic fibrosis</li> <li>• That their baby will need further tests to confirm this result</li> <li>• That their baby does not need any urgent treatment now; they will receive advice about treatment from the specialist cystic fibrosis team over the next few days</li> <li>• The time and place of the appointment to see the specialist team and the name of the consultant</li> <li>• That they will be able to discuss the screening result and treatment for their baby with the specialist cystic fibrosis team</li> <li>• Where they can get further information and support</li> </ul>

