European Cystic Fibrosis Society

Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

Cystic Fibrosis Research News

Title:

NEWBORN SCREENING FOR CYSTIC FIBROSIS–THE PARENT PERSPECTIVE

Authors:

Corina S. Rueegg[1,2] , Jürg Barben[3] , Gaudenz M. Hafen[4], Alexander Moeller[5], Maja Jurca[1], Ralph Fingerhut[6], Claudia E. Kuehni[1], and the Swiss Cystic Fibrosis Screening Group

Affiliations:

[1] Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland
[2] Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland
[3] Division of Pediatric Pulmonology, Children's Hospital of Eastern Switzerland, St.Gallen, Switzerland
[4] Department of Pediatrics, Respiratory Unit, University Hospital of Lausanne (CHUV), Lausanne, Switzerland
[5] Division of Respiratory Medicine, University Children's Hospital of Zurich, Zurich, Switzerland
[6] Swiss Newborn Screening Laboratory, University Children's Hospital Zurich, Zurich, Switzerland.

What was your research question?

We asked parents of children with a positive newborn screening result for CF:

- how satisfied they were with the information they received during the screening process:
- how they felt about screening: and
- if they approved of screening overall?

Why is this important?

Newborn screening for CF using the heel prick test results in a quick diagnosis and early treatment of affected children, which helps them to grow and develop better. In Switzerland, such a national newborn screening program was introduced in January 2011. One disadvantage of such a newborn screening program is that there are false positive results (test suggests that the child has CF, but in fact it doesn't) which can cause anxiety and distress in parents while they wait for the definite diagnosis. It is therefore important to

assess the opinion of affected parents after starting such a program, in order to improve it if necessary.

What did you do?

In Switzerland, parents are told about newborn screening before and immediately after a baby is born with a brochure and a conversation. A heel-prick test in the newborn baby is then done and the blood sent to the national screening centre. If the result is positive, which means a high risk of the child having CF, the nearest CF clinic calls the parents and invites them for further diagnostic tests to confirm or rule out CF. During this visit (usually on the day after the phone call), the parents are told about the test results and what it all means. In addition, all parents received a questionnaire at this visit, to allow them to comment on the screening procedure.

What did you find?

From 2011-2013, 246 families received the questionnaire and 138 (56%) replied. Of these, 77 (60%) found the information given at the birth clinic was satisfactory; 100 (74%) found the phone call from the CF clinic satisfactory; and 124 (91%) were happy with the information provided in the CF clinic. Ninety-eight parents (78%) felt troubled or anxious when the CF clinic called, 51 (38%) remained anxious after the visit (22% of families without CF and 67% of families with CF). Most (122) parents (88%) were satisfied with the screening program overall, 4 (3%) were not, and 12 (9%) were unsure.

What does this mean and reasons for caution?

The large majority of families were glad that their babies had been screened, independent of the final CF diagnosis, and their suggestions have been used to improve the screening procedure. The smooth organisation of the screening process, with a personal phone call by a specialist from a CF clinic, and a minimum of time between this call and the diagnostic confirmation, might have helped reduce parents' anxiety. CF specialists should be aware of the importance of the information given by phone and in the CF clinics, because this information can either reassure or cause anxiety in parents.

What's next?

To improve newborn screening for CF, the screening brochure should be handed out more systematically and the staff talking to parents at birth clinics might benefit from special training. In addition, the reduction of false-positive screening results will also help to avoid unnecessary stress among parents.

Cystic Fibrosis Research News

Original manuscript citation in PubMed

http://www.ncbi.nlm.nih.gov/pubmed/?term=NEWBORN+SCREENING+FOR+CYSTIC+FIBROSIS%E2%80%93THE+PARENT+PERSPECTIVE

cfresearchnews@gmail.com