



Case Report

# Parental knowledge reduces long term anxiety induced by false-positive test results after newborn screening for cystic fibrosis<sup>☆</sup>



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## ABSTRACT

**Background:** False-positive screening results in newborn screening for cystic fibrosis may lead to parental stress, family relationship problems and a changed perception of the child's health.

**Aim of the study:** To evaluate whether parental anxiety induced by a false positive screening result disappears after six months and to assess whether a special program to inform parents prior and during the screening procedure prevents or diminishes parental anxiety.

**Methods:** Prospective controlled study assessing the long term effects of false-positive test results of newborn screening for cystic fibrosis (NBSCF) on parental anxiety and stress by means of questionnaires sent to parents of 106 infants with a false positive newborn screening

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test and 318 randomly selected infants with a true negative screening test. Additionally we interviewed 25 parents of the false-positive group.

*Results:* Parents showed negative feelings after being informed about the positive screening test result. After confirmation that their child was healthy and not suffering from CF, most parents felt reassured. After six months no difference in anxiety levels between both groups of parents was found. Well-informed parents in the false positive group experienced less stress.

*Conclusions:* A positive screening test result induces parental anxiety but false positive test results in NBSCF do not seem to cause long-term anxiety. Well-informed parents show lower stress and anxiety levels.

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## 1. Introduction

Newborn screening for cystic fibrosis (NBSCF) is implemented in many countries worldwide with a variety of screening programs [1,2]. False-positive newborn screening results may lead to parental stress, family relationship problems and a changed perception of the child's health [3–5].

Long-lasting parental stress after false-positive results in newborn screening has been described for various screening programs [3,5–8]. Only two of these studies were controlled. In the first study mothers who had received a false-positive result, showed more anxiety and stress than the control group. Children with a false-positive result were also twice as often admitted to the hospital. However, in this study the age of the infants in both groups differed which may have had a substantial effect on the results [8]. Another controlled study found that false-positive results after newborn hearing screening did not cause long-term parental anxiety in the majority of the parents [6]. During a study comparing two novel strategies for NBSCF we investigated whether or not increased parental anxiety induced by a false-positive screening test persisted after six months [9]. A secondary aim was to assess if a special education program to inform health care workers and parents prior and during the screening program could prevent or diminish parental anxiety.

## 2. Methods

### 2.1. Screening program

This study was part of a larger study investigating the effectiveness of two novel screening strategies in the Netherlands [9]. In only one of these strategies false-positive screening tests were found. This strategy consisted of a measurement of immunoreactive trypsinogen (IRT) followed by determination of pancreas-associated protein (PAP). The second strategy consisted of IRT analysis, and DNA mutation analysis (35 mutations) when  $IRT \geq 60 \mu\text{g/l}$  followed by DNA sequencing when a single mutation was found.

All newborns with a positive screening test were referred to a Cystic Fibrosis (CF)-centre for a sweat test to confirm or to exclude the diagnosis. The general practitioner (GP), or pediatrician, informed the parents about the positive test and the sweat test appointment (24 to 48 h later). The sweat test was performed at a gestational age of 38 weeks or more and a minimum weight of 2000 g. Sweat test results were given to the parents the same day or the day after, mostly by telephone by one of the staff members of the CF centre.

### 2.2. Educational material

An information leaflet about NBSCF was developed and pre-tested by eight pregnant women at their appointment with their midwife in a practice in Zoetermeer, the Netherlands. Parents were asked to read

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