

Press release

One month's salary and thousands of kilometres by car every year

EFCNI parent study shows the financial burden placed on parents of children born prematurely

Munich, 18 April 2008 – The emotional and psychological burden that parents of children born prematurely feel is hard to put into words or figures. However, the huge economic burden they have to meet can be quantified. To acknowledge this issue, the European Foundation for the Care of Newborn Infants (EFCNI) has carried out a study in cooperation with the Medical University of Innsbruck and the European research consortium, Neobrain.

Aims and questions

EFCNI surveyed 588 parents from the German-speaking countries in the period from September 2007 to March 2008. The aim of the questionnaire was to find the long-term costs for parents of children born prematurely, including costs not covered by the state. These include costs for clinic visits for readmission and outpatient care, as well as costs that parents incur to secure care for their child after this, such as childcare costs for other children, or for unpaid leave.

Parents involved in the study were able to participate via the homepage of Bundesverband "Das Frühgeborene Kind" e.V, or were told about the survey by their paediatrician. The study questions focused on the following subjects:

- Problems for the child because of premature birth
- Costs met by the parents themselves for treatment, medicines and resources
- Number and duration of stays in hospital
- Number of treatment courses and examinations required
- Kilometres travelled to hospitals, doctors, and therapists
- Children's academic problems and resulting tutoring costs
- Problems for the parents in the workplace

The highest burden: treatment and childcare

A baby born before 32 weeks gestational age spends an average of three months in hospital after birth. The earlier the birth, the higher the probability of readmission to hospital after the initial discharge. Up to 65 percent of children born prematurely are readmitted to hospital because of respiratory infections, or problems resulting from their disrupted neurological development. In the first two years of their life, these premature infants require six examinations a year on average.



One of the highest costs that parents have to meet themselves is treatment fees. In the first two years, a premature infant born before 32 weeks gestational age requires about 90 hours of treatment. Furthermore, general developmental difficulties, sight defects, eating disorders and dyspraxia (motor disruption) are among the most frequent neurological issues for children born prematurely. Other problems include muscle weakness and speech development disorders. Three-quarters of the children born prematurely will therefore require physiotherapy, 40% will require occupational therapy, and about a third will require speech therapy. The most intensive treatment period for all affected children is in the pre-school age between the age of three and five. On average, the parents will have spent EUR 1,180 on treatment and EUR 410 on medicines before their child's fifth birthday.

Treatment often continues at home. Almost half the families affected have to buy an inhalation device, or a home monitor to check the heart frequency and breathing pattern of the child. The list of the required resources ranges from glasses or special shoes, to sitting supports and wheelchairs. In addition, premature infants are not the only ones that need special attention - the infant's siblings also need to be supervised and cared for. Parents spend an average of EUR 450 on the care of siblings in the first two years of life.

Costs continue into primary school age

Unfortunately, the financial strain is not lessened when the child reaches primary school age. Almost 40 percent of children born before 32 weeks gestational age enrol in school late and have learning problems. One in six of these children suffer from reading and writing difficulties, counting difficulties or integration problems. 45 percent of prematurely born children between the ages of 6 and 10, therefore attend a specialised school, special needs schools, or Waldorf (Rudolf Steiner) schools. The total cost for school support is around EUR 550 each year.

Annual costs equivalent to one month's salary

According to the study, parents travel more than 5,000 km by car on average to visit their prematurely born child in hospital during the first five years. This distance is more than once across the USA from the Atlantic to the Pacific coast.

Many parents also encounter problems at their workplace, since they have to take unpaid leave to care for their a prematurely born child. This applies to 18 percent of the mothers in the study, and almost a quarter of the fathers, and represents a loss of revenue of around EUR 460 or EUR 1,220, respectively. In isolated cases, these problems may even lead to salary reductions and dismissals, thus the financial difficulties resulting from this are serious.

Taking into consideration all the costs incurred for the care of a child born prematurely, including hospital visits after birth, hospital readmission, outpatient examinations, treatment, equipment, medication, travel costs and childcare, the EFCNI study found that parents must expect to spend an average of EUR 6,613 in total before the child's fifth birthday.



