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Early care services for babies born with cleft lip and/or palate

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English Version

Early care services for babies born with cleft lip and/or palate

Services de prise en charge précoce des bébés nés avec une fente labiale et/ou palatine

Fürsorgedienstleistungen für Babies mit Lippen-, Kiefer- und Gaumenspalten

This Technical Report was approved by CEN on 7 March 2015. It has been drawn up by the Technical Committee CEN/TC 424.

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EUROPEAN COMMITTEE FOR STANDARDIZATION
COMITÉ EUROPÉEN DE NORMALISATION
EUROPÄISCHES KOMITEE FÜR NORMUNG

CEN-CENELEC Management Centre: Avenue Marnix 17, B-1000 Brussels

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Contents

Foreword

This document (CEN/TR 16824:2015) has been prepared by Technical Committee CEN/TC 424 “Project Committee - Care services for cleft lip and/or palate”, the secretariat of which is held by ASI.

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Introduction

In Europe around 1 in 700 babies is born with cleft lip and/or palate, the most common congenital anomaly of the head and neck region. The incidence is approximately 1,6 per 1 000 live births, but there is some variance across Europe [1]. Estimates indicate there are over 900 000 individuals (babies, children and adults) with clefts in Europe [2] - a significant figure, especially when one considers that not only the patients but also their families are affected in terms of psychosocial adjustment and having to endure the burden of a long treatment pathway.

In round figures the incidence by type of cleft may be summarized as follows [3]:

Table 1 — Incidence of Type of Cleft [1)]

Type of Cleft	**Percent of Total**
Cleft palate only	50 %
Cleft lip (±alveolus) only	20 %
Cleft lip and palate	20 %
Bilateral cleft lip and palate	10 %

In some cases the cleft may be associated with other problems which need specialist management and these need to be identified early [4]. Accurate diagnosis (antenatal or post natal), the provision of appropriate information and support for the family, and the establishment of a structured care pathway, especially in the early months, will ensure that these infants thrive and develop like all other children. Access to good treatment varies widely throughout Europe, meaning that many children born with clefts are never given the opportunity to realize their full potential. The concept of a comprehensive specialist-team approach to care is not universal. Furthermore babies with clefts are still institutionalized in some countries in Europe [5].

The aim of this report is to provide an informative document which can be used by those countries where national protocols need to be established.

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1) For further information on different types of cleft see Annex A.

1 Scope

This Technical Report specifies recommendations for the care of babies born with cleft lip and/or cleft palate at time of diagnosis (ante- and/or postnatal) and the year following birth or diagnosis (whichever is later), including referral processes, establishment of feeding, parental support and care pathways.

Recommendations on all aspects of surgery, including timing and the use of pre surgical orthopaedics is excluded.