



CIP 2016

March 3-6, 2016 | Xi'an - China

The 5th Global Congress for
Consensus in Pediatrics & Child Health



Distinct Features of Children with a Rare Disease in Preventive Child Health Care

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Background:

Dutch Preventive child health (PCH) care is regulated under a Public Health Law. The goals of the PCH program are to monitor growth and development, to detect health and social risk factors, to perform neonatal screening and to deliver the national vaccination programme. A national digital child record has been developed which is designed to document the national standard preventive child health scheme. The file contains information about health and other relevant issues about each child between 0-18 years.

Rare diseases often present in childhood with a specific history or with specific features.

Objective:

To present identified features of 10 different rare disorders on the basis of data collected in preventive child health care.

Methods:

The 10 different disorders were selected on the basis of their diversity of presentations in childhood and the support of an active patient organization.

The national standard preventive child data set was evaluated upon items that could reveal a sign of one of these rare diseases. The patient organizations and their supporting professionals were asked to contribute to the process based on their experience. Features were categorized. The diseases and their features were provided with international codes.

Results:

The features and codes will be presented as well as how they are applicable internationally in electronic child health records.

Conclusion:

Our data illustrate that rare diseases present themselves with more or less specific features in preventive child health care. Our results can be implemented in global child health preventive programs.