Introduction
Around 30 million people in Europe are affected by a rare disease. Approximately 80% of all known rare diseases are of genetic origin and around 15% can become manifest in the orofacial region\(^1\), e.g. craniofacial dysplasia such as cleft lip and palate, dysgnathia, and hypodontia. Orthodontics forms a major field in rare diseases, and orthodontists are often the first ones to come in contact with young patients who are affected by a rare disease. There is little knowledge in dentistry about how to treat patients with rare diseases and that an orofacial manifestation can help to find the diagnosis. Our aim is to establish a “database for orofacial manifestations in people with rare diseases-ROMSE”\(^3\) and to concentrate the little knowledge on rare diseases in order to improve the diagnosis and treatment of patients with rare diseases. To allow a standardised documentation of orthodontic cases, it is necessary to unify the classifications of dysgnathia.

Material and Methods
Since 2011 material from various databases like Orphanet, OMIM, and Pubmed, was evaluated. Starting in 2013 the gathered information has been incorporated into a web-based, freely accessible database at http://romse.org. The dysmorphological classification of “Ehmer”\(^4\) shall be the guideline for orthodontists to classify the dysgnathia and to standardise the documentation of people with rare diseases. The classification form is freely available at the ROMSE website.

Results
So far 531 rare diseases with orofacial manifestations have been listed in the ROMSE database. Up to now, 10 global categories for orofacial manifestations such as dental anomalies, dysgnathia or orofacial clefts which are subdivided into 100 subcategories have been set up. About one third of those diseases or syndromes show dysgnathia. Especially the sub-classification of dysgnathia seems to be difficult since most of the patients were not analysed according to a standardised classification. Wrong or double assignments are the result. To unify the classifications of dysgnathia, a modified version of the “Dysmorphological Classification by Ehmer”\(^4\) adapted for rare diseases was developed (Fig. 1).

Conclusions
Rare diseases and their symptoms come with difficult challenges regarding their therapy. More than 900 rare diseases with a genetic genesis can be demonstrated to have a dental, oral, or maxillofacial involvement. Since publications on rare diseases and data on possible care strategies in dental medicine are scant, there is an urgent need to provide the limited available information on a central and accessible platform. By setting up a “database for orofacial manifestations in people with rare diseases-ROMSE”, a platform is provided for dentists and orthodontists to work interdisciplinarily on treatment strategies. A consistent and beyond dentistry classification of dysgnathia can prospectively avoid wrong assignments.

Literature: