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Foreword

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Rare disorders by the numbers:
– 7000 to 8000 disorders have been identified, 80 to 85% of them are genetic in origin;
– 5 new disorders are reported every week worldwide;
– 5 to 8% of the world population is affected;
– 1 of the top 5 priorities in public health policy law;
– 900 to 1000 disorders present orofacial symptoms.

Ignored for too long, these disorders were not diagnosed, compromising the health of the patients in the medium to long term, denying them access to specialized care, resulting in major consequences for them and their families and friends whether they be physiological, psychological, socio-economic, or quality of life.
Even if important progress has been made with the creation of 2 national plans for rare disorders since 2004, the diagnostic process and the management of these patients often still turn out to be long and difficult.
We dentists/orthodontists as practitioners and actors for public health have two essential roles:

– **The role of screening: by identifying the signs and by knowing where to refer our patients**

When faced with certain orodental anomalies, (discrepancies in number, or in the structure of dental organs for example), it is our responsibility to look for the related facial and extrafacial clinical symptoms. Muriel De La DURE-MOLLA and Pascal GARREC, illustrate their work with examples, present us with a catalog of these symptoms and support their remarks with supplemental terminology in order to facilitate our exchanges with other medical specialties. Next, we direct our patients to other referral and/or diagnostic and

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treatment centers, or even genetic counseling. There are two Referral Centers for Rare Disorders (RCRD) in Strasbourg and in Paris specifically for treating bucco-dental disorders. We have a valuable tool at our disposal: the ''orphanet'' database, created in 1997, a portal for information and expertise related to rare disorders.

– **Treatment plan for patients who have rare disorders**

Additional information about the treatment responses for these unusual patients will provide us with some answers and make it possible for us to receive and care for these patients by integrating the specificities of their multidisciplinary treatment plan in the course of which each professional collaborates with the other specialists and they all work on behalf of the patient, by constantly exchanging information. Orthodontic treatment for patients with wide-ranging and complex medical problems, is a part of this therapeutic process, and is marked by an extensive demand for esthetic care that has major psychological consequences. By allowing them access to community-based care services, we are working to improve their therapeutic treatment plan and are helping to develop an indispensable ''Open Healthcare Network''.

The significant number and variability of rare disorders both in their form and their evolution have led this group of authors to base their work on targeted examples chosen because of their strong orofacial resonance, that they supplement with a detailed iconography. This 1st issue devoted entirely to rare disorders will guide you through the clinical signs leading to a diagnosis, to orthodontic precautions we cannot ignore and will outline the multidisciplinary treatment plans presented by teams from Lille and Strasbourg.

We would like to thank the two dental referral centers for their cooperation, Ariane BERDAL and Marie Paule VAZQUEZ, RCDM in Paris, Marie-Cécile MANIÈRE, RCDM in Strasbourg, as well as the six diagnostic and treatment centers, in particular the Joël FERRI, RCDM in Lille, and their teams who were always available to help patients and practitioners alike.

Wishing you all an enjoyable reading.

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