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The Achondroplasia Roadmap: Connecting With the Community

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INTRODUCTION

- Achondroplasia is **a rare** skeletal dysplasia that occurs in 1 in 25,000 births and affects the length and shape of bones, particularly in the arms, legs, and head[1–3]
- Many parents, healthcare professionals, and others **still** lack resources to support children in navigating the emotional, social, and health challenges they face growing up
- The **Achondroplasia Roadmap** is an interactive and visual resource for parents and children with achondroplasia that was co-created by 11 leaders from achondroplasia organizations from Europe and Latin America. It aims to help parents prepare for challenges they or their children may face from infancy to adolescence, and to educate different stakeholders about the condition

OBJECTIVE

- To understand **how** the organizations involved in the development of the Roadmap **are sharing it i**n their communities and to obtain feedback on its utility

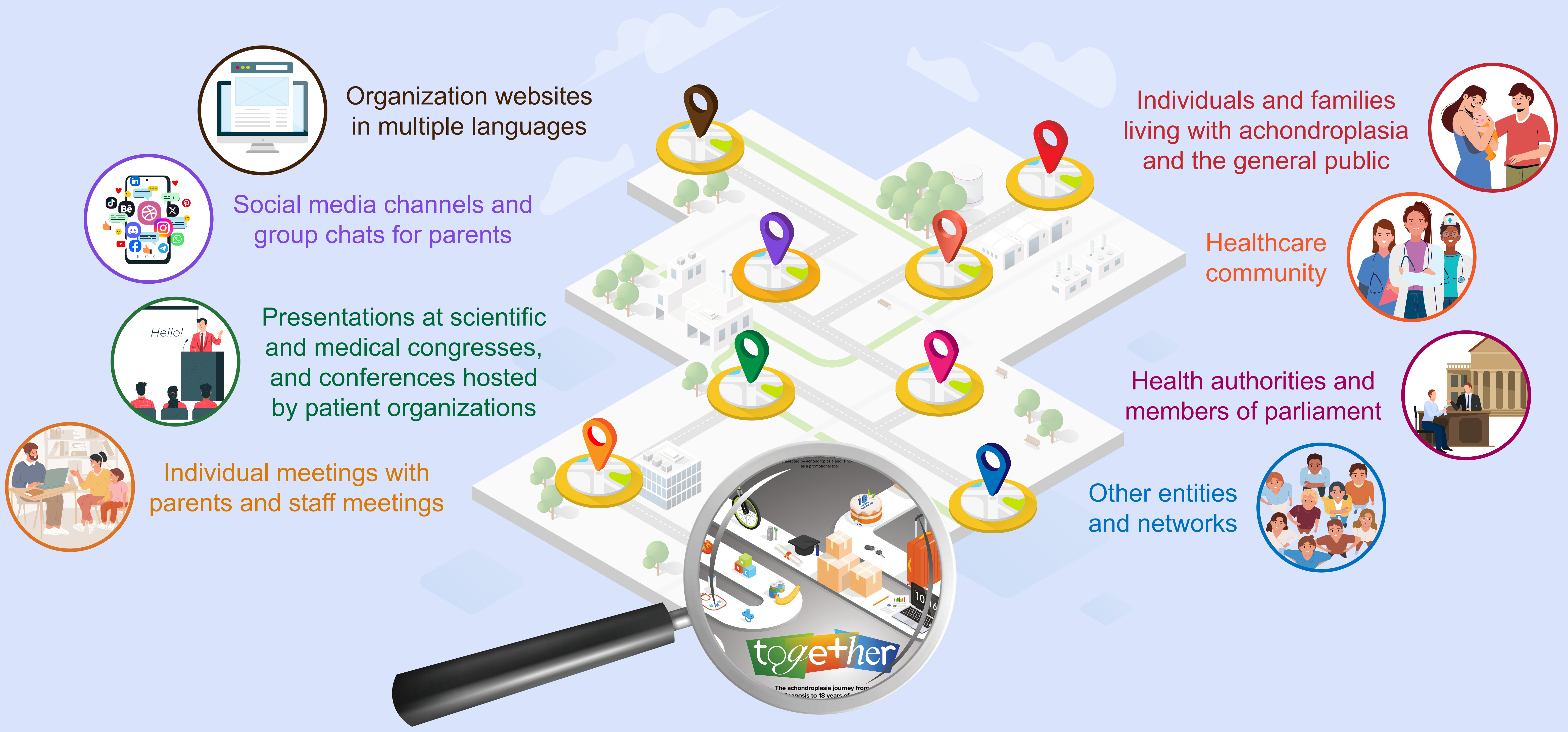
METHODOLOGY

- Approximately 12 months after the launch of the Achondroplasia Roadmap, **the 11 patient representatives involved in its development, were asked if and how the roadmap had been used throughout the year**
- A survey was conducted and included open-ended questions that aimed to understand how the Roadmap was disseminated

RESULTS

The Roadmap has been disseminated by Patient Associations in Europe and Latin America through various channels:

Patient Association leaders reported on opportunities for sharing the Roadmap with diverse audiences across events:



Organization websites in multiple languages

Social media channels and group chats for parents

Presentations at scientific and medical congresses, and conferences hosted by patient organizations

Individual meetings with parents and staff meetings

Individuals and families living with achondroplasia and the general public

Healthcare community

Health authorities and members of parliament

Other entities and networks

CONCLUSIONS

The Roadmap is a **comprehensive resource for families of children with achondroplasia** to help improve parents' knowledge of the condition

It **can be used globally and be a tool for** facilitating conversations with healthcare professionals, teachers, peers, and the collaboration between achondroplasia organizations allowed the creation of this tool

ABOUT THE ROADMAP

About the development of the Roadmap: Leaders from 11 achondroplasia patient organizations in Europe and Latin America, including parents and individuals with the condition, participated in guided discussions to define the life milestones and related medical, emotional, and social issues families and children often face. Based on these discussions, content was developed, with leaders consulted throughout the process. The Roadmap was made available to the participating organizations in seven languages, including English, Portuguese, Spanish, French, Italian, Polish, and Swedish.

Use of the Roadmap: The primary target audience of the Roadmap is parents who have or will have a child with achondroplasia. It is also a resource for informing and educating others about the condition and its potential impact on children and families.

How the Roadmap is organized: The Roadmap is organized into key phases of childhood development: prenatal, birth – 2 years, 3–6 years, 7–12 years, and 13–18 years. At each stage, information is provided on what to expect, how parents can support their child's healthcare, and how families can discuss achondroplasia within their close network and the social environment.

Topics included: Diagnosis, genetic counseling, pregnancy, birth and postpartum, learning how to care for a child with achondroplasia, the child's development of self-awareness, medical issues, navigating the social environment, and promoting independence.

References

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