Co-creating a resource for parents of adolescents with achondroplasia

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Introduction

Adolescence is a period of significant physical, emotional and social development, including increasing independence, forming an identity, and building friendships and intimate relationships.[1]
For young people with achondroplasia, the condition may be associated with additional considerations that can affect everyday life and well-being.[2] The aim of this initiative was to produce a practical resource to help parents support children with achondroplasia during this life stage.

Method

A co-creation process was undertaken:

Understanding the adolescent experience
Two roundtable meetings were held with participants from 11 countries across Europe, Turkey, and the US, including parents of adolescents with achondroplasia and representatives of patient organizations. Discussions explored experiences of adolescence with the condition, as well as parents' information needs.

Developing the content
Key themes and priorities identified at the roundtables were used in the development of a resource addressing physical, emotional, and social aspects of adolescence with achondroplasia.

Expert input
A physician and psychologist with expertise in the condition contributed clinical and psychosocial perspectives, complementing the parent-led content.

Review and refinement
The resource was developed and finalized with input from six patient organizations and healthcare professionals.

Results

The roundtable meetings identified a range of factors that may impact the lives and well-being of young people with achondroplasia, including:

- Physical limitations and complications
- Inclusion and accessibility
- Friendships and intimate relationships
- Social media experiences
- Peer pressure
- Societal attitudes
- Parental expectations

To help young people with achondroplasia develop confidence, self-esteem, and resilience, parents highlighted the value of open communication, modeling positive behaviors, and enhancing home and social situations. They also emphasized the importance of working with schools and clubs to improve inclusivity, and encouraging connections with peers with achondroplasia to help develop belonging and widen horizons.

Insights from the roundtables informed the development of *Achondroplasia & Adolescence*, a series of three guides for parents of teens with the condition (Boxes 1 and 2).

Conclusions

This educational series combines the perspectives of families living with achondroplasia with guidance from clinicians with expertise in caring for adolescents with the condition. It is intended to empower parents supporting their child through this life stage and may also help non-specialist healthcare professionals and educators better understand the experiences of young people with achondroplasia. The booklets will be translated and distributed via collaborating patient organizations.

Box 1. What the guides cover



Physical well-being

1. Managing fatigue & energy
2. Managing pain & discomfort
3. Sports & physical activity
4. Nutrition & weight
5. Health monitoring & engagement
6. Physical-emotional link

Emotional well-being

1. Mood, self-esteem & being noticed
2. Belonging & identity

Relationships

3. Forming & sustaining friendships
4. Handling peer pressure
5. Intimate relationships

Social media

6. Navigating social & messaging platforms
7. Building connection & belonging online

Independence & planning for the future

1. The parenting shift
2. Everyday function & environmental adaptations
3. Education & careers
4. Systems & supports

Box 2. Inside each chapter



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