

**PAS-003 - (21SPP-11484) - GLOBAL ACHONDROPLASIA CAREGIVER SURVEY – PERSPECTIVES FROM 660 CARERS OF CHILDREN WITH ACHONDROPLASIA**

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**Introdução e Objectivos**

Achondroplasia (ACH), the most common skeletal dysplasia, is associated with multiple serious complications. We aimed to understand diagnostic pathways, availability of healthcare management plans (HMPs) and social/psychological support (SPS) received by parents/caregivers (carers) of children with ACH.

**Metodologia**

A cross-sectional bespoke survey was distributed by patient advocacy groups in Japan, Europe [EU] and Latin America [LATAM]) between June–October 2019.

**Resultados**

660 carers completed the survey: Japan N=233; EU N=190 [Spain: n=128; France: n=40; Italy: n=22]; LATAM N=237 [Brazil: n=170; Argentina: n=36; Colombia: n=31].

ACH diagnosis generally occurred after birth (85% Japan, 64% EU, 74% LATAM). Typically (>50%) HMPs included information on specialists, further assessments and expected complications; fewer plans (<30%) included SPS. HMPs were established after diagnosis in 41% (EU/LATAM) to 81% (Japan).

In EU and LATAM, two-thirds of children with ACH had a primary physician (usually geneticist/paediatrician/orthopedist) with visits every 6 months (54% EU, 79% LATAM), often requiring travel >60 miles (~30% EU /LATAM). Frequency of medical appointments reduced with increasing age: >90% of 0–2 yr-olds in EU/LATAM were seen more than once/yr vs. 41% [US] to 71% [LATAM] of 12–18 year-olds. Children were seen by multiple specialists, most often orthopedists/ENT specialists (~70%). Over 50% of carers reported impacted emotional well-being, yet only <40% were offered SPS.

**Conclusões**

ACH management can be complex and is inconsistent between countries/regions. Guidelines can help improve consistency of care globally.

**Palavras-chave :** achondroplasia, skeletal dysplasia, healthcare management