Supporting Conversations with Your Healthcare Team

A Family Guide to the UK Consensus Guidelines for Children and Young People with Achondroplasia

Why this guide?

Most healthcare professionals will see very few people with achondroplasia during their careers.
This guide has been developed by FEST to help families understand the key recommendations within the UK Consensus Guidelines and support conversations with healthcare professionals. It is designed to accompany the published guideline and should not replace clinical advice or individualised care. ***All Children with achondroplasia should have access to a specialist multidisciplinary team (MDT) alongside local healthcare services.***



After diagnosis

□ Have we been referred to a specialist multidisciplinary achondroplasia team?
□ Do we know which specialist centre is coordinating our child's care?
□ Have we received advice about safe handling, positioning and appropriate equipment?
□ Have we been introduced to patient support organisations?

During infancy

□ Have we discussed the age-appropriate monitoring recommended in the UK Consensus Guideline (including MRI and sleep studies where appropriate)?
□ Are achondroplasia-specific growth charts being used?
□ Is development being assessed using achondroplasia-specific developmental milestones?

Therapy & local healthcare

The UK Consensus Guideline includes specific recommendations about positioning, handling and motor development.
□ Is our physiotherapist or occupational therapist familiar with the achondroplasia-specific guidance?
□ Have we discussed safe positioning and handling, including avoiding early supported sitting and using appropriate equipment, in line with the UK Consensus Guideline?
□ Is therapy based on achondroplasia-specific development rather than average stature?
□ If local professionals have limited experience of achondroplasia, have they contacted the specialist MDT?



As my child grows

□ Are referrals being made at the appropriate time?
□ Is care shared between our local healthcare professionals and the specialist MDT?
□ Do we know which symptoms require urgent review?

Important! Before surgery or anaesthesia

□ Does the surgical and anaesthetic team know my child has achondroplasia?
□ Have they reviewed the achondroplasia-specific recommendations within the UK Consensus Guideline?

Scan this QR code to share with your local medical team and ask:

- Is my child's care following the UK Consensus Guideline?
- Are there any referrals or investigations still outstanding?
- Would it help for my local healthcare team to discuss my child's care with the specialist MDT?

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