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Growth attenuation therapy: practice and perspectives of paediatric endocrinologists

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For non-ambulatory children with severe physical and cognitive disabilities (SPCD), being lifted and transported become more challenging with increasing size. Reduction in length and overall size for select children with SPCD can be accomplished by growth attenuation therapy (GAT), which reduces linear growth by administering hormones (eg, oestrogen) that accelerate epiphyseal closure. There are no reliable data describing attitudes and practices of paediatric endocrinologists regarding GAT for children with SPCD.

In collaboration with the Pediatric Endocrine Society (PES), an anonymous questionnaire about GAT was emailed to PES physician members (n=1100, 92% from the USA). Responses were stripped of identifiable information. Consent was implied by responding. The study received institutional review board exemption status at the University of Wisconsin–Madison.

Two hundred and eighty-four PES members responded to the survey (response rate=26%). Ninety-nine respondents had either been asked to prescribe or had prescribed GAT to a child with SPCD. Of these, 92 (94%) said requests came from the patient's family and 34 reported seeking ethics consultation.

Thirty-two respondents had prescribed GAT to a child with SPCD, most recalling doing so one to five times (n=28, 88%), yielding a conservative estimate of at least 65 children with SPCD treated. Oral oestrogen was the most common sex hormone therapy used for GAT (n=21, 66%).

Withholding of interventions that suppress precocious puberty in a child with SPCD in order to reduce ultimate linear growth was reported by 130 respondents (46%). Of these, only seven (5%) sought ethics consultation. Key findings are highlighted in figure 1.

Previous surveys of GAT practices¹² focused on prescriptions of GAT to healthy tall-statured girls, not on treatment of children with SPCD. Results from this present survey

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show, for the first time, that instances of prescribing GAT for children with SPCD are not limited to the single existing case report. There is a need for collaborative investigation of therapeutic growth attenuation strategies, reporting of outcomes, and discussion among stakeholders to develop evidence-based guidance for patients and families. The demonstration here that approximately one in three responding paediatric endocrinologists have been asked about GAT for a child with SPCD provides an opportunity for further investigation regarding efficacy of GAT in length reduction, quality of life improvement and the possible risks of therapy.³

The main limitations of this study were (1) brevity of the questionnaire, which was designed to optimise ease of participation and therefore maximise the response rate and (2) the possibility that respondents may not be representative of paediatric endocrinologists overall.

In conclusion, paediatric endocrinologists are receiving inquiries regarding GAT from families of children with SPCD more commonly than previously realised and at least 65 children with SPCD have received GAT. Most of the responding paediatric endocrinologists view GAT as an appropriate therapeutic modality in certain circumstances. Systematic investigation of risks and benefits of GAT in children with SPCD would enrich paediatric endocrinologists' guidance for families who are already inquiring about GAT and would assist in developing consensus on a responsible and thoughtful approach to GAT within the paediatric endocrinology community.

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Key Findings

Number of respondents who have been asked about GAT for a child with SPCD:	98
Number of respondents who have prescribed GAT for a child with SPCD:	32
Number of children with SPCD treated (minimum calculation):	65
Number of respondents who have withheld treatment of precocious puberty to attenuate growth in a child with SPCD:	130
Percent of respondents who obtained ethics consultation for GAT of children with SPCD:	34%
Percent of respondents who obtained ethics consultation for withholding treatment of precocious puberty in order to attenuate growth in children with SPCD:	5%

Figure 1 Key findings from the study survey. Of note, there were 284 respondents to the questionnaire. GAT, growth attenuation therapy; SPCD, severe physical and cognitive disabilities.

Figure 1.

Key findings from the study survey. Of note, there were 284 respondents to the questionnaire. GAT, growth attenuation therapy; SPCD, severe physical and cognitive disabilities.