

Growth-Limiting Interventions for Patients with Developmental Disabilities

POLICY: The consent of parents or legally authorized surrogates is necessary but not sufficient in the case of consent to growth-limiting medical interventions for individuals with developmental disabilities. Where one or more growth-limiting medical interventions are proposed for an individual with a developmental disability, a court order authorization must be obtained before scheduling or otherwise initiating any such growth-limiting medical intervention.

For purposes of this policy, a “growth-limiting medical intervention” means any medical intervention, including surgery or drug therapy, that alters or is intended to alter a patient’s potential for normal physical maturation, such as linear growth. This policy specifically applies to high-dose hormone treatment intended to limit the patient’s normal physical maturation, and breast bud removal undertaken in connection with such high-dose hormone treatment.

PURPOSE: Establishment of guidelines for consent and authorization to growth-limiting medical intervention

PROCEDURE: The **ADDENDUM below** describes the current standards and procedures

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ADDENDUM:

I. Requirement for Court Order for Patient with Developmental Disability

- A. No growth-limiting medical intervention may be scheduled or performed for any individual with a developmental disability, unless a court order specifically authorizing the planned growth-limiting medical intervention has been placed in the patient's medical record, along with an opinion of Children's General Counsel or Associate General Counsel that the court order is valid and that all applicable appeals or appeals periods have concluded.

II. Notification to Washington Protection and Advocacy System

- A. The provisions of this Section II apply during the term, including any extension term, of any "Agreement Between Children's Hospital And Regional Medical Center And The Washington Protection And Advocacy System (Disability Rights Washington) Promoting Protection Of Individuals With Developmental Disabilities" or successor or replacement agreement. Children's General Counsel shall determine whether any such agreement continues in effect.
- B. During any such term, and to the extent permitted under federal and state laws regarding the privacy of health information, Children's, acting through its General Counsel, will inform Disability Rights Washington (formerly known as Washington Protection and Advocacy System), when Children's receives notice that a court order permitting growth-limiting medical intervention for an individual with a developmental disability has been entered.

III. Additional Required Consultations

- A. In addition, except in the case of a medical emergency, any growth-limiting medical intervention must be reviewed by the Ethics Committee, and following such review and receipt and review of any recommendations from the Ethics Committee must be reviewed with and approved by each of the following:
 - 1. The Medical Director
 - 2. Children's General Counsel

IV. Parents or Guardians Bring Petition

- A. A petition for a court order authorizing growth-limiting medical intervention should usually be brought by the parents or legally authorized representative of the patient for whom the intervention is proposed.
- B. Parents or legal guardians should consult with their own counsel in preparing and pursuing the petition.
- C. Parents or legal guardians may, in addition, consult with the Ethics Committee or the Clinical Bioethicist Consult attending on call regarding any such petition.

V. Exceptions to Policy

- A. An exception to the procedures set forth above may be allowed for a surgical or medical procedure where alteration of the patient's normal physical maturation is an unavoidable, unintended, and undesired effect of a medically-indicated procedure that is within the standard of care for the patient's condition. Examples include trauma care, resection of malignant tissue, or chemotherapy or radiation treatment of cancer that causes a limitation of the patient's growth.

- B. Any exception to the procedures set forth above must be reviewed and approved by the Medical Director, in consultation with the Ethics Committee and Children's General Counsel.

VI. Forcing Functions

- A. Children's will implement appropriate forcing functions using its applicable processes and computer systems to prevent scheduling any growth-limiting medical intervention unless the requirements of this policy have been met.

VII. Educational Activities

- A. Following adoption of this policy, Children's will educate its employees and members of its Medical Staff about the provisions of this policy and the legal requirements in the state of Washington for court review and order before growth-limiting medical intervention for an individual with a developmental disability.