

## Transition to Adult Health Care ACT Sheet

*Transition is an ongoing process that does not end with transfer of care. The goal of transition of adolescents with chronic medical conditions is to provide uninterrupted, comprehensive, culturally sensitive, coordinated, and developmentally appropriate healthcare. The transition team includes at least the patient and family, and the pediatric, adult PCP, and specialty care providers. For the general principles of transition, refer to the [2011 AAP/AAFP/ACP transition clinical report](#), which includes the recommendation that transition planning begin no later than age 12 and includes a patient readiness assessment.*

## Congenital Hypothyroidism

**Condition Description:** Congenital hypothyroidism (CH) is predominately a non-genetic condition identified by newborn screening. In both the primary (generally thyroid agenesis or ectopia) and secondary (panhypopituitarism) forms, there is a lack of adequate thyroid hormone production.

**Clinical Considerations:** Most individuals with adequately controlled congenital hypothyroidism do not manifest intellectual disability, growth impairment, or delay in bone maturation is seen in individuals with delayed diagnosis and treatment or discontinued therapy. Inadequate treatment may result in delayed puberty and impaired fertility. Pregnancies should be considered high risk. Offspring of mothers with untreated low thyroid function during pregnancy (maternal hypothyroidism) may have reduced cognitive function and learning difficulties.

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### **THE TRANSITION TEAM SHOULD TAKE THE FOLLOWING ACTIONS:**

- Initiate a dialogue among transition team members and establish an adult medical home.
  - Facilitate consistency and coordination of care among multiple health care providers as the patient transitions to independent living (to include college, relocation, employment).
  - Consult with an endocrinologist, if appropriate.
  - Review the medical record and previous laboratory studies.
  - Order laboratory studies, including thyroid function tests - routine TSH and, if indicated, free T<sub>4</sub>.
  - Develop and implement a comprehensive care plan that includes:
    - Continuation of appropriate thyroid therapy
    - Preconception counseling - discuss potential increase of thyroid hormone dose as soon as a woman knows she is pregnant (maternal hypothyroidism, especially in the first trimester, may be associated with cognitive loss in offspring)
    - Referral of pregnant CH patient for management of potentially high risk pregnancy
  - Identify the patient's health care coverage (including insurance) and access to care.
  - Assess and address the patient's psychological, behavioral, and social service needs.
  - Offer health education and genetic counseling concerning future reproductive decisions.
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### Additional Information:

[AAP/AAFP/ACP Transition Clinical Report](#)  
[Transition Toolkit](#) (New England Consortium of Metabolic Programs)  
[Got Transition](#)  
[American Association of Clinical Endocrinologists](#)  
[Endocrine Society](#)  
[American Thyroid Association](#)

### Referral (local, state, regional and national):

[Clinical Services](#)  
[Find Genetic Services](#)

Disclaimer: This guideline is designed primarily as an educational resource for clinicians to help them provide quality medical care. It should not be considered inclusive of all proper procedures and tests or exclusive of other procedures and tests that are reasonably directed to obtaining the same results. Adherence to this guideline does not necessarily ensure a successful medical outcome. In determining the propriety of any specific procedure or test, the clinician should apply his or her own professional judgment to the specific clinical circumstances presented by the individual patient or specimen. Clinicians are encouraged to document the reasons for the use of a particular procedure or test, whether or not it is in conformance with this guideline. Clinicians also are advised to take notice of the date this guideline was adopted, and to consider other medical and scientific information that become available after that date.

LOCAL RESOURCES: Insert State program web site links

State Resource site (insert program information)

Name	<input type="text"/>
URL	<input type="text"/>
Comments	<input type="text"/>

APPENDIX: Resources with Full URL Addresses

*Additional Information:*

AAP/AAFP/ACP Transition Clinical Report

<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;128/1/182.pdf>

New England Consortium of Metabolic Programs Transition Toolkit

<http://newenglandconsortium.org/for-families/transition-toolkit/>

Got Transition

<http://www.gottransition.org>

American Association of Clinical Endocrinologists

<https://www.aace.com/>

Endocrine Society

<http://www.endo-society.org/>

American Thyroid Association

<http://www.thyroid.org/>

*Referral (local, state, regional and national):*

Clinical Services

<http://www.ncbi.nlm.nih.gov/sites/GeneTests/clinic?db=GeneTests>

Find Genetic Services

<http://www.acmg.net/GIS/Disclaimer.aspx>

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