

Assumptions	Strategies	Outcomes
<p>Adolescents face a range of social-emotional and developmental issues as they transition from childhood to adulthood.</p> <p>Adolescents with genetic conditions face additional issues and greater challenges related to navigating through this developmental stage including</p> <ul style="list-style-type: none"> • Medical management • Health care coordination • Self-advocacy • Communication and partnership with adult health care providers • Reproductive choices • Diet management <p>Adolescents with genetic conditions will experience greater health and well-being if they gradually take responsibility for their own health related needs.</p> <p>Parents play a crucial role their children’s successful transition to adulthood.</p> <p>Appropriate level and type of support from parents throughout adolescence will result in successful transfer of health-related responsibilities from parents to children</p> <p>Parents of children with genetic conditions often feel ill-equipped to support their children’s unique challenges as they transition to the adult healthcare system.</p> <p>Parents of children with genetic conditions will be better equipped to transfer health related responsibilities to their children if they have access to advice and support from other parents who have “been there”</p> <p>Support from other parents can</p> <ul style="list-style-type: none"> • Decrease parent’s anxiety related to “letting go” • Increase a child’s opportunities to gain independence 	<p>Identify Region 4 parents of children with genetic conditions that are interested in learning more about how to support their children’s transition related to</p> <ul style="list-style-type: none"> • Medical management • Care coordination • Self-advocacy • Communication and partnership with adult health care providers • Reproductive choices • Diet management <p>Facilitate opportunities for interaction among parents of children with genetic conditions to give and receive advice and support and share personal experience around the issue of transition (topical phone calls, online support groups, blogging etc.)</p> <p>As opportunities for interaction among parents are established, invite parents from other Regional Collaboratives to participate.</p> <p>Transcribe tips and answers to frequently asked questions shared during conference calls and blogging and publish on the Region 4 website</p>	<p>Parents will have</p> <ul style="list-style-type: none"> • Increased access to resources to help them support their children’s transition to adulthood • Decreased anxiety about their child’s ability to take on more responsibilities for his/her health care (“letting go”) • Increased competence in their ability to support their children’s’ transition to adulthood <p>Adolescents will have Increased knowledge and skills related to:</p> <ul style="list-style-type: none"> • Medical management • Health care coordination • Self-advocacy • Communication and partnership with adult health care providers • Reproductive choices • Diet management <p>Adolescents will have increased opportunities to gain independence</p> <p>Adolescents will demonstrate:</p> <ul style="list-style-type: none"> • Increased participation in making health related decisions • Increased self-confidence • Improved diet management • Increased opportunities to communicate with health care providers/improved communication • Increased skills in self-advocacy • Improved adherence to medical protocols • Increased care coordination skills

