



Examples of outstanding care coordination or team-based care for children and youth with genetic conditions

The National Coordinating Center for the Genetics Regional Collaboratives (NCC)¹ seeks to learn, from real-life examples, how best to coordinate care for children and youth with genetic conditions and/or provide them with team-based care across specialties, disciplines, and settings. Whether accomplished through hard work, innovation, unique personalities, or with apparent ease, we're interested in approaches that result in better communication, collaboration, and satisfaction among patients, families, and healthcare providers. Such practices (meaning what is done and how) might apply to just a few patients or to a large number, and they might be accomplished by a single person, a clinic team, a healthcare system, or other entity.

If you know of an exemplary practice in the realm of coordinating care or providing team-based care, please tell us a little about it and who or what organization is responsible. Your answers below should provide enough information to enable us to compare with other nominations and decide which practices to explore further by contacting the individuals who can fill in the details. This information can be completed and submitted online via: <https://www.surveymonkey.com/s/HRLX723>

1. Please briefly describe the approach to care coordination or team-based care for children with complex conditions or genetic disorders that you feel is exemplary.

2. What kinds of patients/families, group(s) of patients, or population benefit from this practice?

3. What kinds of clinicians, other professionals, organizations, or other entities are involved in this practice or approach?

4. Whom could we contact to learn more about this practice or approach and how can we contact them?

Name: _____

Clinic/Organization: _____

Phone: _____ Email: _____

Address: _____

5. Nominated by: _____

Phone: _____ Email: _____

Please return this nomination form to: Alisha Keehn, akeehn@acmg.net, (301) 718-9604 (Fax)

¹ The NCC (nccrcg.org), managed by the American College of Medical Genetics (acmg.net), coordinates the seven Regional Genetics Collaboratives (RCs), to strengthen and support the genetics and newborn screening capacity of the states, to improve the availability, accessibility, and quality of genetic services and resources for individuals having, or at risk for, genetic conditions and their families across the lifespan. The NCC and the RCs are funded by the Maternal and Child Health Bureau/ Health Resources and Services Administration, Genetic Services Branch.