

## SouthSeq Provider Live Training

**Purpose:** Equip healthcare providers with the knowledge and skills needed to be able to understand genome sequencing results and discuss results with patients and families in a NICU setting.

**Background:** A major goal of the SouthSeq study is to test a hypothesis that with adequate training and support, genome sequencing can be deployed in a NICU setting without the direct involvement of genetic specialists. Babies receiving genome sequencing will be randomized to either receive results from a genetic specialist (i.e. genetic counselor) or a NICU provider (i.e. neonatologist or neonatal nurse practitioner). Results will be discussed with the participant family in-person (ideally) or over the phone. Following result disclosure, the participant family will complete questionnaires to help the SouthSeq research team understand their experience and outcomes allowing us to test the stated hypothesis.

**Description:** Live training of participating SouthSeq healthcare providers will occur at each study site and will in total last approximately 4 hours. The study team will work with each NICU to determine the structure of the training to best meet provider's needs. The training may take place in one session or be broken up into multiple sessions over several days. The training will incorporate didactic learning, hands-on learning, and small group discussions to achieve the desired learning objectives. In addition to live training, materials from the training will be stored in the online Genome Gateway education platform for providers to review as needed throughout the study.

### Learning Objectives:

1. Explain the benefits and limitations of genome sequencing and how it compares to other types of genetic tests
2. State the purpose of the SouthSeq study and the hypothesis being tested through result disclosure
3. Identify the role of the non-genetics NICU provider in the SouthSeq study
4. Demonstrate familiarity and proficiency completing provider tasks in the online Genome Gateway platform
5. Interpret a SouthSeq genome sequencing result letter and report
6. Develop a plan for disclosing various types of genome sequencing results (positive, negative, uncertain) including key points and next steps
7. Describe common questions among patients receiving genome sequencing results
8. Attend to psychosocial needs of families surrounding genome sequencing result disclosure
9. Identify and critique patient support resources relevant to genome sequencing results

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**Tentative Schedule** (order and timing to be modified per site):

15 minutes	Meet and greet; Get refreshments	
15 minutes	Introductions; Overview of the SouthSeq study <i>Didactic</i>	Candice Finnila (Project Manager)
15 minutes	Logistics of return of results in SouthSeq <i>Didactic</i>	Kelly East (Genetic Counselor)
10 minutes	Q/A	Kelly East
15 minutes	Logistics of the trial <i>Didactic</i>	Liz Rahn (Clinical Trial Team)
45 minutes	Genome Gateway training <i>Hands-on</i>	Kelly East
15 minutes	Whole genome sequencing (WGS) <i>Didactic</i>	Meagan Cochran (Genetic Counselor)
60 minutes	Returning WGS results <i>Didactic; Hands-on; Small group discussion</i>	Overview: Kelly East Role Plays: All GCs
60 minutes	Psychosocial skills <i>Didactic; Simulation</i>	Whitley Kelley Veronica Greve (Genetic Counselors)
30 minutes	Wrap up; Q/A	Kelly East

### Description of non-didactic portions of training:

- Genome Gateway Training:** providers will use their own device (tablet, laptop) or a provided device to log into the Genome Gateway system. They will be led through a series of step by step instructions to learn how to 1) review patient information, 2) view files, 3) review educational materials, and 4) answer questionnaires.
- Returning WGS results:** this session will begin with a brief didactic overview of what SouthSeq results look like. Next providers will be given 6 example reports to review. As they review these reports they will be asked to answer questions about each result on a written table. The goal of this activity is to become familiar with reports and know where to find information. Following this activity, attendees will break into smaller groups for a discussion facilitated by a genetic counselor. Genetic counselors will have a discussion guide to scaffold conversations, highlighting important take home messages and nuances of each example result.
- Psychosocial skills:** this session will begin with a brief didactic presentation where genetic counselors will share their experiences giving genome results to patients and the possible range of psychosocial responses. We will also discuss strategies for assessing patient understanding and avoiding information overload when presenting genomic information. The final activity of the training includes a one-on-one simulation between each participating provider and a genetic counselor. The provider will be given the opportunity to practice describing an example result to the genetic counselor as well as responding to some typical (and not so typical) patient questions.