

Baby Badger Network ECHO

Problem of Practice Summary & Recommendations

Session Date: May 14, 2026

Question to consider:

Language Barriers & Genetic Testing in the NICU
How can we be sure families have a good understanding?
How do we best support families through the journey?

Brief Summary:

Baby was initially roomed with mom but transferred to NICU on DOL3 for significant hypotonia, poor feeding and mild hypoxia. The family required an interpreter for a less common dialect. Baby was stable, but not progressing to discharge. On DOL5, Peds Neuro recommended rWGS

The idea of rWGS was introduced on DOL5. Parents were not interested; they didn't see a problem. On DOL6, the reason for rWGS and possible results were discussed. At DOL11, parents agreed baby wasn't progressing to discharge and were curious as to why. It became clear from their questions, parent understanding was changing and they were considering rWGS. Communication was further challenged by use of multiple interpreters, some of whom were more liked by the family - none were in person.

Sample was collected on DOL13 and resulted on DOL17 with a causal pathogenic variant. At the initial results conversation, the parents were frustrated with the continuance of changing explanations for symptoms. Fortunately, parent friendly printed information and clinical guidelines were available in a language the family could speak and read. At subsequent results conversations, it became clear parents had educated themselves.

Discussion Focus :

How can we best support families?

- If possible, have the same neo communicate with the family. The consistency helps with communication and with building trust and rapport.
- Ask if the parents have a preferred interpreter (although may not be able to request a specific interpreter). Ask family if the interpretation is good or lacking
- Have an efficient, hospital approved work-flow for translating printed documents.
- Show curiosity, interest and respect for the family's culture. Greet them using their language!
- Cultural differences may have influenced the family's decision, e.g., wanting the sample destroyed, not wanting to provide parental samples

When testing reveals a rare disorder and you don't know about it

- It happens
- Be honest with family. During consent, explain this may happen. If it does, you may delay delivering results while you: self educate and consult with L4 geneticists to determine if the finding fits with the phenotype and to create a management plan