Perimortem Genetic Testing Policy

Considerations for Genetic Testing in the Perimortem Period

Genetic testing immediately before or after patient death requires consideration of unique issues. The following is intended to function as an appendix to a laboratory test stewardship policy to improve patient care and safety by reviewing laboratory test orders to ensure clinical necessity. This also complements and cross-references the PLUGS Insurance Preauthorization Policy for Genetic Testing.

Genetic testing is not considered medically necessary for a patient when death is imminent. In this situation, genetic testing does not meet clinical utility criteria because the test results will not significantly alter medical management of the patient. (Refer to Appendix I-A of Insurance Preauthorization Policy for Genetic Testing.)

• In many cases the diagnosis has been made reliably based on other testing such as pathology findings, biochemical results, or clinical criteria.
• Genetic testing may be useful to parents in determining whether or not an undiagnosed genetic disease in their child will recur in subsequent pregnancies; however, current policies exclude genetic testing for future reproductive planning (See exclusions in Appendix I-C).
• In these situations, genetic testing may still be performed but the patient’s family will be financially responsible for the cost of such testing.

An exception to this statement is if genetic testing of the patient is needed to confirm a molecular diagnosis to guide informative medically necessary testing of a presymptomatic relative who is at high risk to have inherited the same genetic condition. (Refer to Appendix I-B.1. Medical necessity, Special circumstances.)

• DNA banking is an option for families who wish to defer discussions of genetic testing.

Genetic testing is not considered medically necessary for a patient who has expired. The patient’s family will be financially responsible for the cost of such testing.

In some cases, a family may consider consenting to an autopsy for patients with a suspected genetic condition that was not definitively diagnosed prior to demise. This examination may provide important information about the patient’s health as well as identifying the cause of death. However, genetic testing is not included in a routine autopsy.

• Autopsies may provide additional phenotypic information that can alter the pre-mortem differential diagnosis.
  • If an autopsy is performed and the family wishes to proceed with genetic testing, it is recommended to wait until the final autopsy report is verified before sending out genetic tests. The patient’s family will be financially responsible for the cost of such testing.
• Additional tissues (typically liver) may be sampled at the time of autopsy that may be a sample type for genetic testing. For example, if the patient has had multiple transfusions or has been on ECMO, then other sample types may be preferred.
• Skin can also be collected at autopsy for fibroblast culture.

In this situation, genetic testing does not meet clinical utility criteria because the test results will not significantly alter medical management of the patient. (Refer to Appendix I-A of Insurance Preauthorization Policy for Genetic Testing.)

• Out of pocket advance payment for medically necessary testing.
• DNA banking
• Research options may be available.

Any genetic testing immediately before or after patient death requires consideration of unique issues that have caused confusion amongst Seattle Children’s providers. Background: The Seattle Children’s Hospital Laboratory Stewardship Committee approved a Perimortem Policy addendum to the Lab Test Stewardship Policy in summer 2017. Assessment: The Perimortem Policy provides consistent and fair process for genetic testing of patients in the perimortem period (immediately prior to or after death).

Recommendation: Educate medical teams to be aware of Policy prior to discussions with families regarding genetic testing options to avoid compliance issues and avoid stress for families.

You may choose to use the attached slide deck for this communication. It includes a flow sheet for inpatient genetic test coordination because that is the primary setting in which perimortem genetic testing is considered.

We are very glad to answer any questions or give a short presentation to your team upon request.

With best regards,
The Laboratory Test Stewardship Program