Superficial Siderosis Research Tissue Procurement Instructions

This document outlines the standardized procedure for the procurement of fixed slides of siderotic tissue for the Superficial Siderosis Research Alliance (SSRA). The purpose is to ensure tissue samples are collected, preserved, and transported in a timely and consistent manner to the Superficial Siderosis Research Laboratory at Massachusetts General Hospital for research.

1. Tissue Collection Sites

- Required tissue samples: Cerebellum and Brain Stem
- Optional tissue sample: Cervical Spine
- Fixed slides must be prepared from harvested tissue.

2. Timeframe for Procurement

- Tissue samples should be optimally fixed within 12 hours of death.
- The maximum allowable timeframe for fixation is 24 hours post-mortem.

3. Locations for Harvesting

- Samples may be harvested in a hospital setting or a funeral home.
- Funeral homes are equipped with designated rooms suitable for this procedure.

4. Notification Protocol

- Immediate phone notification is required at the time of passing.
- Provide the following details:
  - Exact time of death
  - Funeral home name, address, and contact information

5. Pathologist Involvement

- A local pathologist must be contacted to perform the tissue harvesting. You may plan with the funeral home in advance, or we will try to assist you at the time of passing. It has been our experience that waiting until passing to locate a pathologist sometimes results in the tissue being unusable if passing occurs overnight, weekends, or holidays.

6. Packaging and Transport

- The pathologist is responsible for ensuring proper packaging of the tissue samples.
- Samples must be securely shipped to Massachusetts General Hospital for processing.
- The SSRA will provide detailed instructions to the pathologist for shipping.

7. Expense Coverage

- All expenses related to procurement, packaging, and transport are covered by the SSRA.
- No financial responsibility falls on the family or next of kin.

The SSRA will cover all associated costs for the procedure room, harvesting, packaging, and transport. In the past the funeral home bills the SSRA for the room and the pathologist bills the SSRA for the remainder.

8. Contact Information

For immediate notification and support, contact the SSRA Tissue Donation Coordinator:

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