



Guidelines for Research Recruitment via Helfer Approved by Research Committee 9/6/13

Purpose: Supporting quality research to improve the lives of abused children is a core mission of the Helfer Society. These guidelines are intended to ensure that projects that benefit from the recruitment of Helfer Society members are conducted according to accepted ethical guidelines, and do not unreasonably impact members.

Guidelines

- All studies which solicit participation via the Helfer email list or website should include at least one Helfer member as an investigator.
- It is the responsibility of the study's Principal Investigator, and the participating Helfer member (if the Principal Investigator is not a Helfer member) to ensure that the study conforms to the standards of the IRB for their home institution.
- Protocols that involve the use of patient data, images or information (even if de-identified) carry substantially increased scrutiny relative to protocols involving only data about Helfer members themselves. It is the responsibility of any Helfer member who shares patient information to ensure that the protocol meets the standards of the IRB for their home institution.
- No identifiable patient information, data or images shall be transmitted via the Helfer email list or website.
- Studies that recruit via Helfer will include a statement in all solicitations that they conform to these guidelines, and will include the list of guidelines or a link to them so that any Helfer member with concerns may refer the study for review.
- No more than 2 solicitations per month may be sent via the Helfer email list for any single study.
- Studies posted to the Helfer website should include the period during which recruitment (of Helfer members) is on-going. If this period is more than 1 year, the investigator will be asked to re-new the study annually.

Implementation:

- Guidelines will be posted on the Helfer website along with studies seeking recruitment.
- Investigators that recruit via the Helfer email list should include a statement that their project complies with guidelines, and a link to the guidelines.
- If a Helfer member suspects that a research project may not conform to guidelines, they should forward their concern to Kate Henry (HenryM2@email.chop.edu) or Samantha Schilling (samantha_schilling@med.unc.edu) for initial review.
- If concern remains after initial review, the investigator will be asked to pause enrollment pending review by the full committee.
- If the full committee finds that the project is not consistent with the guidelines, no further enrollment may occur via the Helfer website and no further solicitation may be made via the Helfer list.
- Helfer members may appeal decisions to the executive committee.