Title:   San Francisco (SF) Bay Area Spina Bifida Registry

IRB# 2011-063
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Synopsis:
The overall goal of this demonstration project is to establish the National Spina Bifida Registry as an approach to improving quality of care. As one of the participating sites in the registry project, the Greater San Francisco Bay Area Spina Bifida Partnership will meet the following aims:

- Recruit and collect data on at least 125 spina bifida patients for each of three years of the project using standard forms provided by the CDC.
- Submit the de-identified data to a central repository using a web-based electronic medical record (EMR) system.
- Adopt the EMR for regular, ongoing use at both clinic sites.
- Participate in the national Coordinating Committee with other participants to standardize processes, promote improvements to the registry, propose research questions, and develop an analytical plan.
- Propose changes to clinical practice standards based on data findings, and promote the integration of these standards into clinical practice.