



## State Systems Follow-up Workgroup –Work Plan

**Charge:** Identify model state systems that assure linking/referral to services, facilitate surveillance and support communication among programs for children with heritable conditions and their families.

**Outcome:** An integrated follow-up system that increases access to genetic services for those identified with a genetic condition and their families.

Objective	Who	What	When
1. Develop shared understanding of WG purpose	SSFU WG	Provide input on charge	June 2010
	SSFU WG	Identify outcomes of a model state system	June 2010
2. Delineate different models	SSFU WG	Identify information needed	June 2010
	MPHI	Develop and disseminate survey	July 2010
	SSFU WG	Complete survey	
	MPHI	Compile and summarize survey responses	
SSFU WG	Discuss state system follow-up models Disseminate summary of state systems in Region 4	August 2010	
3. Identify promising practices	SSFU WG	Identify models/protocols for assuring follow-up, surveillance, and communication	July 2010
	MPHI	Collect protocols	August 2010
	SSFU WG	Consider protocols for adaptation	
4. Compare and contrast models	SSFU WG	Select 2 conditions to work through – 1 NBS and one BDR	August 2010
		Identify information needed	
	MPHI	Develop template to collect information about surveillance, follow-up, communication	
	SSFU WG	Track fake patients through each state system	September 2010
	MPHI	Summarize results	October 2010
5. Develop systems model	SSFU WG	Formulate recommendations/select strategies	October 2010
	MPHI	Develop protocol	November 2010
	SSFU	Test protocol	

