



**State Systems Follow-up Workgroup
Telemeeting Agenda
August 24, 2010 ~ 9 am CT / 10 am ET
1/866/489-0573; *4545164***

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

Meeting Goals: Provide input into state system survey; Provide input on proposed process

Handouts	Handout 4: Nash – comments on IL process
Handout 1: Draft survey questions	Handout 5: Form for CF
Handout 2: Terminology	Handout 6: Sickling Annual Letter
Handout 3: Timeline	Handout 7: Form for all other metabolic

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| I. | Welcome, Introductions by State Roll Call
<i>Please state your name and system representing</i> | Bach |
| II. | Review of Proposed Survey Questions
<i>Handout 1</i>

<i>Samples from Illinois – Handouts 4, 5, 6, 7</i> | Bach/Group |
| III. | Review of Terminology – to be distributed with survey
<i>Handout 2</i> | Bach/Group |
| IV. | Review of Timeline
<i>Handout 3</i> | Bach/Group |
| V. | Next steps | Bach/Group |
| VI. | Announcements/Comments | Group |
| VII. | Adjourn | Bach |