Virginia Newborn Screening Advisory Committee Workgroup:

Review of X-ALD as an Addition to Virginia’s Newborn Screening Panel

Date: June 7, 2018

Location: DCLS –600 North 5th St.

Richmond, VA 23219

Schedule: 1:30 PM Workgroup convenes session

3:30 PM Workgroup concludes session

Webinar Link:

Call-in information: 8668425779; passcode 8046484480

Agenda

*1:30 PM – 2:30 PM*

1. Introductions--*All*

2. Background of Review--*Jen Macdonald*

3. Defining X-ALD—*Christen Crews*

*a. Pathophysiology*

*b. Incidence*

*c. Screening*

*d. Diagnostics*

*d. Treatment*

4. Other State NBS Program perspectives*—Chris Nixon, Richard Haughton, Jen Macdonald*

*a. Review of States Currently Screening*

*b. Specific State Information*

*c. Methodologies*

5. Anticipated Programmatic Costs--- *Willie Andrews, Jen Macdonald*

*2:30 PM BREAK*

*2:35 PM-3:30 PM*

6. Discussion—*All (Facilitated by NBS staff)*

a. Review of Scientific Literature

b. Define Risks and Benefits

7. Recommendations—All (*Facilitated by NBS staff)*

8. Next steps—*Jen Macdonald*