

SCOPE OF WORK

Article 1 PURPOSE

- 1.1 **Purpose.** The general purpose of this grant is for the Grantee to organize and host the Rare Disease Advisory Council.

Article 2 DEFINITIONS

- 2.1 **Definitions.** In this grant, the following definitions apply:

"RDAC" means the Rare Disease Advisory Council.

"Rare disease" means a disease that affects fewer than 200,000 individuals in the United States.

Article 3 SERVICE REQUIREMENTS

- 3.1 **Services.** The Grantee shall:

- (1) convene the RDAC no less than two times in each 12 month period;
- (2) provide staff and other administrative support to the RDAC;
- (3) coordinate meeting dates and times with the DHHS;
- (4) provide a meeting space that is accessible and meets the Americans with Disabilities Act accessibility standards;
- (5) provide contact email and address for the RDAC and respond to inquiries within five business days;
- (6) provide agenda no later than five days prior to meeting date; and
- (7) facilitate subcommittee meetings of the RDAC.

- 3.2 **Coordinated Responsibilities.** The Grantee, in conjunction with DHHS shall:

- (1) provide a report to the Health and Human Services Interim Committee, due November 30 of every odd numbered year;
- (2) appoint the RDAC chair and members according to Utah Statute 26B-1-402; and
- (3) draft the initial bylaws for the RDAC.

3.3 **DHHS Responsibilities.** DHHS shall:

- 3.3 (1) provide a department representative who will participate in the RDAC; and
- (2) provide website hosting for the RDAC.

3.4 **Reporting.** The Grantee shall submit to DHHS a final report that details the extent to which the Grantee fulfilled the grant's purpose, including the deliverables in Article 3 and the performance metrics described in Article 4.

Article 4 PERFORMANCE METRICS

4.1 **Metrics.** Successful completion of this grant will be measured by:

- (1) at least two RDAC meetings convened by the Grantee;
- (2) the Grantee's provision of administrative support to RDAC; and
- (3) the Grantee's coordination with DHHS.

Article 5 FUNDING

5.1 **Funding:** DHHS agrees to pay the Grantee the amount of \$19,000 upon completion of the grant requirements and following the final RDAC meeting of each fiscal year, for up to five years.

Article 6 BILLING REQUIREMENTS

6.1 **Billing.** The Grantee shall submit one annual invoice to the DHHS designee at uphlfinance@utah.gov that includes:

- (1) Grantee's name, payment address, phone number, and signature;
- (2) agreement number;
- (3) invoice number;
- (4) invoice date; and
- (5) details of services billed including hours worked on this agreement.