



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Notice of a Maternal and Child Health Bureau-Initiated Supplemental Award to the Immune Deficiency Foundation for the Severe Combined Immunodeficiency Screening and Education program.**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice of a Supplemental Award.

**SUMMARY:** HRSA announces the award of a supplement of approximately \$3,000,000 to the Immune Deficiency Foundation (IDF) for the Severe Combined Immunodeficiency (SCID) Screening and Education program for fiscal year (FY) 2020. The supplement will add another year of funding to the current recipient, during the period of 08/01/2020-07/31/2021, to allow the recipient to provide increased implementation, education, and awareness of newborn screening for SCID.

**FOR FURTHER INFORMATION CONTACT:** Debi Sarkar, Division of Children with Special Health Needs, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W65, Rockville, MD 20857 E-mail: [DSarkar@hrsa.gov](mailto:DSarkar@hrsa.gov) or Phone: (301) 443-0959

#### **SUPPLEMENTARY INFORMATION:**

Intended Recipient of Award: Immune Deficiency Foundation

Amount of Non-Competitive Award: Approximately \$3,000,000 for fiscal year FY 2020

Period of Supplemental Funding: 08/01/2020- 07/31/2021

CFDA Number: 93.110

Authority: Public Health Service Act, § 1109 (42 U.S.C. § 300b-8)

**JUSTIFICATION:** The Explanatory Statement accompanying the Further Consolidated Appropriations Act, 2020 indicated that: “Within the total for the Heritable Disorders Program, the agreement includes no less than \$3,000,000 for the third year of a grant to support implementation, education, and awareness of newborn screening for Severe Combined Immunodeficiency and related disorders.” Therefore, following an objective review, HRSA awarded \$3,000,000 to the Immune Deficiency Foundation and extended the 2-year period of performance to a third year, so that IDF can provide increased implementation, education, and awareness of newborn screening for SCID

Although all 50 states have legislation to screen for SCID, access to pediatric immunology and infectious disease specialists for SCID diagnosis and treatment is mostly found in urban areas, posing access challenges for families in rural and other medically underserved areas. SCID education and awareness resources that are linguistically and culturally sensitive are critical for diverse and medically underserved families. In addition, long-term follow-up of infants identified through SCID newborn screening is critical to obtain clinical outcomes data and inform future treatment options. Furthermore, many infants detected through newborn screening do not have classical SCID but have one of a number of other immune deficiency disorders, so information is needed for families and providers on other detected conditions. Within the scope of the Notice of Opportunity (HRSA 18-188), proposed activities include:

- Develop and implement a plan to engage families and treatment centers to obtain follow-

up information;

- Develop and disseminate linguistically and culturally appropriate education and awareness materials about SCID and other immune deficiencies that are identified when screening for SCID;
- Connect families with SCID to pediatric immunology and infectious disease specialists, and pediatricians in urban areas;
- Implement telehealth/telemedicine outreach to families residing in rural and medically underserved areas; and
- Support an annual SCID meeting that includes state newborn screening staff, pediatricians, immunology and infectious diseases specialists, and families.

| Grantee/Organization Name    | Grant Number | State | FY 2020 Funding |
|------------------------------|--------------|-------|-----------------|
| Immune Deficiency Foundation | SC1MC31881   | MD    | \$3,000,000     |

**Thomas J. Engels,**

*Administrator.*

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