सत्यमेव जयते

Department of Biotechnology
Ministry of Science & Technology
Government of India

Call for proposals under the DBT-UMMID Initiative

(Unique Methods of Management of Inherited Disorders Initiative)

Congenital and hereditary genetic diseases are a significant health burden in India. Therefore, there is a need for adequate and effective genetic testing and counseling services. The diagnostic tests for many of the genetic disorders available in India are at a relatively nascent stage. While antenatal diagnostics for a few genetic diseases are available, these are available in very few hospitals. Considering these facts, the Department, in the year 2019, launched the DBT-UMMID initiative with the objectives of establishing Genetic Diagnostic Units (NIDAN Kendras) in Government Hospitals, producing skilled clinicians in the area of Human Genetics (Biochemical Genetics, Cytogenetics, Molecular Genetics, Clinical Genetics and Comprehensive Clinical Care), and screening of pregnant women and newborn babies for diagnosis of inherited genetic diseases in aspirational districts to provide comprehensive clinical care.

Now, the Department of Biotechnology, in the next phase of UMMID initiative, is desirous of expansion of the program across the country. Under the present call, the Department invites R&D proposals in the following areas:

1. **Establishment of DBT-NIDAN Kendras**
2. **Screening of pregnant women and newborns in Aspirational Districts**
3. **Establishment of Training Centres on Clinical Genetics**

Scope of the present Call for Proposals under these three components are as follows:

1. Establishment of DBT-NIDAN Kendras

The NIDAN Kendras are envisaged to undertake the following activities:

A. Prenatal testing for genetic disorders such as:

i. Beta thalassemia, sickle cell disease, and other hemoglobinopathies
ii. Down syndrome and other aneuploidies
iii. Congenital malformations such as neural tube defects
iv. Other genetic disorders prevalent at a relatively higher rate in the region where the proposed NIDAN Kendra would be situated.

B. Newborn Screening for relatively common treatable genetic metabolic disorders including:

i. Congenital hypothyroidism
ii. Congenital adrenal hyperplasia
iii. Galactosemia
iv. Biotinidase deficiency
v. Glucose-6-phosphate dehydrogenase (G6PD) deficiency
vi. Other treatable genetic metabolic disorders prevalent at a relatively higher rate in the region

C. Genetic Counseling

Genetic Counseling of pregnant mothers carrying fetuses with high risk of genetic disorders

Eligibility: A Government Medical College / Government Hospital or SIRO recognized not-for-profit Medical College/Hospital desirous of establishing genetic laboratories (NIDAN Kendras) can submit proposals against this call by nominating Clinician(s)/Scientist(s) working in regular capacity with sound relevant clinical/scientific and technical backgrounds and relevant publications as the Principal Investigator. The host hospital/medical college should undertake the overall responsibility of implementing the project and should be willing to provide basic infrastructure including dedicated space and equipments for the establishment of the NIDAN Kendras. **Involvement of all relevant stakeholders is compulsory. Host Institution has to also provide undertaking that once the DBT support is over, host institute will take over the responsibility for continuation of these NIDAN Kendras.**

2. Screening of pregnant women and newborns in Aspirational Districts

In this component of the DBT-UMMID initiative, institutions with the requisite infrastructure and expertise to carry out genetic screening of pregnant mothers and newborns would adopt aspirational district(s) in collaboration with the concerned district hospital(s) to undertake the following activities:

A. Screening of pregnant women for genetic disorders such as:

i. Beta thalassemia, sickle cell disease, and other hemoglobinopathies
ii. Other genetic disorders prevalent at a relatively higher rate in the region for which antenatal testing methods are available

B. Newborn Screening for relatively common treatable genetic metabolic disorders including:

i. Congenital hypothyroidism
ii. Congenital adrenal hyperplasia
iii. Galactosemia
iv. Biotinidase deficiency
v. Glucose-6-phosphate dehydrogenase (G6PD) deficiency
vi. Other treatable genetic metabolic disorders prevalent at a relatively higher rate in the region

C. **Genetic Counselling:** Genetic Counselling of pregnant mothers carrying fetuses with high risk of genetic disorders.
D. **Training to paramedical health workers:** Training on identification of families and children with a high risk of genetic disorder to paramedical health workers including nurses posted in neonatal/pediatric and maternity wards.

Eligibility: Medical Colleges / Hospitals or recognized Research Institutions/Academic Institutions desirous of undertaking Genetic Screening and Counseling activities as enumerated above at one or more Aspirational District(s) can submit proposals against this call by nominating Clinician(s)/Scientist(s)/Researcher(s) working in regular capacity with sound relevant clinical/scientific and technical backgrounds and relevant publications as the Principal Investigator. For non-government institutions, SIRO-recognition is a must. The host institution should undertake the overall responsibility of implementing the project. The concerned district hospital/medical college and the host institution should be willing to provide basic infrastructure including dedicated space and equipment for the UMMID centre. **Involvement of all relevant stakeholders such as concerned District Hospital (s) of the Aspirational District (s) and the State Government etc. is compulsory.**

3. Establishment of Training Centres on Clinical Genetics

This component of the UMMID initiative envisages supporting establishment of training centres for providing training to the clinicians working in hospitals in Biochemical Genetics, Cytogenetics, Molecular Genetics, Clinical Genetics and Comprehensive clinical care.

Eligibility: Medical Colleges / Hospitals or recognized Research Institutions/Academic Institutions (having minimum 10 years of experience in research and training in clinical genetics) desirous of establishing training Centres on clinical Genetics submit proposals against this call by nominating Clinician(s)/Scientist(s) working in regular capacity with sound relevant clinical/scientific and technical backgrounds and relevant publications as the Principal Investigator. The host hospital/medical college should undertake the overall responsibility of implementing the project and should be willing to provide basic infrastructure including dedicated space and equipments for the establishment of the training centres.

Evaluation Criteria: All the proposals will be evaluated based on the scientific and technical merit including expertise of the project investigator(s) in the relevant areas, availability of relevant facilities at the host institution, need for initiation of such program in particular

region/ location, involvement of stakeholders, etc. Department also reserves the right to select or reject the proposals based on the priority and other factors.

Note: Project proposals may be submitted by an Institution for one or more components of the UMMID initiative (i.e. NIDAN Kendras, Training Centres and Screening at Aspirational Districts). However, eligibility for each component would be assessed separately. If an Institution is applying for more than one component of the program, then in eProMIS please select single institution multicomponent option before filling further details.

Mode of Submission: Interested institutions should submit project proposals online by nominating Project Coordinator and Principal Investigator(s)/Co-Principal Investigator(s)/ Co-investigator(s) who can submit proposals through DBT electronic project management system 'eProMIS' (http://dbtepromis.nic.in/Login.aspx) under the Programme **'Human Genetics and Genome Analysis'. In addition to submitting the proposal in the R&D project format available on the DBT e-ProMIS portal, the format at Annexure –I should also be also completed, duly endorsed and submitted by uploading on the e-ProMIS portal as a PDF file.**

The Consolidated PDF and MS Word files of the proposal with all the enclosures and the Annexure-I (duly completed and endorsed) must also be sent via email on the email IDs: amitkr.tripathi@dbt.nic.in with a copy to onkar.dbt@nic.in within last date of submission.

Contact for furher information: Dr. Onkar N. Tiwari, Scientist 'E', DBT, New Delhi (Email ID: onkar.dbt@nic.in Tel.: +91-11-24361290) or **Dr. Amit K. Tripathi, Scientist 'C', DBT, New Delhi** (Email ID: amitkr.tripathi@dbt.nic.in)

Last Date for Submission: 31st July, 2020.

Annexure -I

Format for additional information for projects under the DBT-UMMID Initiative

General Information

1. **Title of the Proposal:**
   [*The title should reflect the components of the DBT-UMMID initiative for which the proposal is being submitted. Please refer item no. 7 below.*]
2. **Name and Address of the Institution:**

3. **Details of the Project Coordinator/ Principal Investigator (s):**
   Name:
   Address:
   Telephone and Mobile:
   Email:

   [*The Institute is expected to nominate one Project Coordinator and one or more Principal Investigators (PIs)/Co-PIs/Investigators. The overall responsibility of the implementation of the project would lie with the Project Coordinator and the host institution.]*

4. **Total Requested Budget:**

5. **Proposed Durations**

6. **About your Institution:**
   [Mention about:
   a. *Clinical, Scientific, and Technical Expertise available in your institution with respect to inherited disorders.*
   b. *Facilities, Infrastructure and Equipment pertaining to inherited disorders testing/Diagnosis already available in your institution***]**

7. **Components of the UMMID initiative for which the proposal is being submitted: [Please strike out whichever of the following is not applicable]**

   A. Establishment of DBT-NIDAN Kendras
   B. Screening of pregnant women and newborns in Aspirational Districts
   C. Establishment of Training Centres on Clinical Genetics

   [*An institution can submit proposals for **any or all the components** of the UMMID initiative (i.e. NIDAN Kendras, Aspirational Districts, and Training Centres). In case the institution is not submitting the proposal for a particular*

component, please write "Not Applicable" in the corresponding section (Part-A, B, or C, as applicable) of the Application Form].

8. **Overall and Component wise objectives:**
[*In Bullet points. Should include the components for which the proposal is being submitted (in separate objectives) and their respective details, against which the progress may be monitored***]**

9. **Component Specific Details of the Proposal**
(*Please complete the following parts of the Application i.e. Part-A, B and C, as applicable***)**

Part 'A'

Establishment of DBT-NIDAN Kendras

1. **Details of Principal Investigators/ Co-investigators for the DBT-NIDAN Kendra Program:**
Name:
Address:
Telephone:
Email:
Brief Bio-data of all the investigators with relevant details: (To be attached)
2. **Proposed Duration:**

3. **Details of the plan of work**

[*Should include the names of disorders for which diagnostic facilities would be provided at the NIDAN Kendra and the detailed methodology for diagnosis of each of them and relevant details pertaining to the proposed Genetic Counseling activity. Should also include an estimated no. of pregnant women/newborns which are likely to undergo genetic diagnosis and estimated number of families who are likely to be enrolled for Counseling*]

4. **Present activities of your institution (in brief) that merits seeking this grant:**

5. **Facilities, Infrastructure and Equipment available for implementing Genetic Testing at the host institute:**
6. **Proposed fund requirement from DBT [***Year-wise details may be given under different subheads (Equipment, Consumable, Manpower, Travel, Contingency, Overhead etc.***)]**

7. **Proposed plan for sustainability of the proposed NIDAN Kendra after the support from the DBT would end (upon completion of the project duration): (***e.g. takeover plan by Hospital Authority/State Government; and supporting documents may be enclosed, if any***)**

8. **The following documents should be annexed with the application:**

   a. Undertaking indicating that the existing infrastructure for the proposed genetic diagnostic unit (NIDAN Kendra) in terms of dedicated space; electrical set-up, including voltage and back-up requirements; annual maintenance of the facility; and back-up plans to ensure continued functioning of NIDAN Kendra at all times etc. will be ensured.

   b. Undertaking stating that prior informed consent of the subjects/patients involved will be obtained and the proposed NIDAN Kendra will obtain necessary approval of institutional ethical committee on all matters wherein such approvals are needed. Also enclose the details of the Institutional Ethical Committee and its Registration number with National Ethics Committee Registry for Biomedical and Health Research, Department of Health Research, Govt. of India.

PART 'B'

Screening of pregnant women and newborns in Aspirational Districts

1. **Details of Principal Investigators/ Co-investigators for the Aspirational District Component**
   Name:
   Address:
   Telephone and Mobile:
   Email:
   Brief Bio-data of all the investigators: (To be attached)
2. **Details of the concerned District Hospital / Medical College of the Aspirational District** (*Including name and address of the concerned clinician(s) from the District Hospital/Medical College; brief Bio-data to be enclosed. He/ she may also be included as Co-PI/ Co- Investigator in the proposal)*

3. **Proposed duration:**

4. **Details of the plan of work**

   [*Should include the name of the aspirational district, the rationale for selecting a particular aspirational district for undertaking the screening program; the genetic disorders for which pregnant women and newborn screening would be carried out and the detailed methodology for screening for each of the disorders.*

Please also include methodological details pertaining to collection, processing and shipment (wherever required) of biological specimens.

Relevant details pertaining to proposed Genetic Counseling and training to paramedical health workers should also be provided. Estimated no. of pregnant women/newborns which are likely to be screened per year and estimated number of families who are likely to be enrolled for Counseling should also be given.]

5. **Present activities of your institution (in brief) that merits seeking this grant:**

6. **Facilities, Infrastructure and Equipment available for implementing Genetic Testing/Screening at the host institute/district hospital/district medical college:**

7. **Proposed plan for sustainability of the initiative after the support from the DBT would end (upon completion of the project duration):**

8. **Proposed fund requirement from DBT** *Year-wise details may be given under different subheads (Equipment, Consumable, Manpower, Travel, Contingency, Overhead etc.***)]**

9. **The following documents should be annexed with the application:**

a. Undertaking stating that the existing infrastructure in terms of the dedicated space; electrical set-up, including voltage and back-up requirements; annual maintenance of the facility; and backup plans to ensure continued functioning at all times etc. will be ensured. This should be submitted separately for the host institution and the concerned district hospital/medical college of the Aspirational District.

b. Undertaking stating that prior informed consent of the subjects/patients will be obtained and the host institution and the concerned district hospital/medical college will obtain necessary approval of institutional ethical committee on all matters wherein such approvals are needed. Also enclose the details of the Institutional Ethical Committee and its Registration number with National Ethics Committee Registry for Biomedical and Health Research, Department of Health Research, Govt. of India.

PART 'C'

Establishment of Training Centres on Clinical Genetics

1. **Details of Coordinator/Principal Investigators/ Co-investigators for the Training Program:**

   Name:
   Address:

Telephone and Mobile.
Email:
Brief Bio-data: (To be attached)

2. **Proposed duration:**

3. **Present activities of your institution (in brief) that merits seeking this grant:**

4. **Facilities, Infrastructure and Equipment available for implementing the training program:**

5. **Available expertise [name of experts (3-5) who will actually be involved in training program and their brief Bio-data to be attached]**
6. **Present and previous (last 10 years) training activities of the institution in the area of clinical genetics (in brief) that merits seeking this grant:**

7. **Training Module Details [***in terms of specific areas of Clinical Genetics; training structure; duration of training (3-6 months, preferable duration may be specified); number of batches/year and total number of trainees/ year (the number of trainees envisaged from your own institution and from outside may clearly be stated)***]**
8. **Proposed fund requirement from DBT [***details may be given under different subheads (Equipment, Consumable, Manpower, Travel, Contingency, Overhead etc.***)]**

Signature and seal of Project Coordinator (If applicable)

Signature and seal of all Principal Investigator(s)/ Co- PI (s)

Signature and seal of all Co-Investigator (s)

Signature and seal of Executive Authority of Institute/ University forwarding the proposal

Date:

Place: