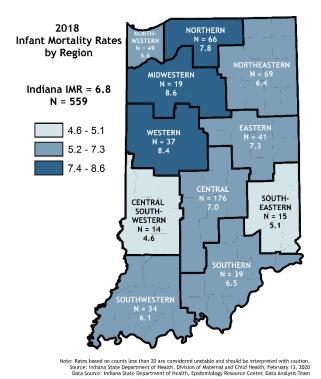
Indiana State Department of Health Division of Maternal and Child Health Genomics and Newborn Screening Program

Request for Applications (RFA) – Krabbe, Pompe and MPS-I / Lysosomal Storage Disorders

Application Deadline	April 13 th , 2020
Submit applications via email to:	MCHBusinessUnit@isdh.IN.gov

EXECUTIVE SUMMARY

A key health initiative for Indiana is collaborating with community partners to reduce infant mortality and morbidity rates across the state. The goal of the Genomics and Newborn Screening Program within the Maternal and Child Health Division at the Indiana State Department of Health is to ensure all babies born in Indiana receive timely newborn screens in order to identify potential life threatening conditions early. Prevention and early detection of problems in infants are vital to reduce the magnitude of financial, personal and emotional burdens associated with adverse health outcomes. the Genomics and Newborn Screening Program is seeking community partners able to provide services focused on the confirmation of disease and connection to resources for children 0 through 3 years of age diagnosed with Krabbe, Pompe and MPS-I.



TECHNICAL ASSISTANCE

To ensure fair and equitable consideration to all applicants, questions about the requirements or the application process must be emailed to ISDHNBS@isdh.IN.gov.

Applicant questions should be submitted by the designated due date of 3:00 p.m. Eastern Standard Time on March 16th, 2020. All submitted questions will be compiled into a single document, answered, and posted online for all applicants to view by close of business day on March 20th, 2020.

SUMMARY OF TIMELINE

Event	Date
Posting of Request for Applications	March 6 nd , 2020
Deadline to Submit Written Questions	March 16 th at 3pm EST
Response to Written Questions	March 20 th at 3pm EST
Application Due Date	April 13 th at 3pm EST
Length of Project Period	1 year due to current grant
	cycle alignment.

I. FUNDING OPPORTUNITY DESCRIPTION

The Indiana State Department of Health (ISDH) Genomics and Newborn Screening (GNBS) program announces the availability of funds to satisfy the need for early intervention and follow-up services from a community partner in order to reduce infant morbidity and mortality rates within the state of Indiana. Services included in this opportunity are focused on confirmation of disease and connection to resources for children 0 through 3 years of age diagnosed with Krabbe, Pompe and MPS-I. Services will be for state fiscal year 2021, beginning July 1, 2020 through June 30, 2021.

Applicants, at a minimum, must provide services for the following:

- Provide services to patients with Indiana residency who screened positive for Krabbe,
 Pompe and MPS-I and fall within the 0 through 3 year age-range within the state of
 Indiana including:
 - Ensure early contact to primary care provider (PCP) and families of children with abnormal newborn screening results
 - Confirmatory testing as defined by the Perinatal Genetics and Genomics advisory committee of the Indiana Perinatal Quality Improvement Collaborative.
 - Ensure treatment, intervention services, and management of diagnosed condition.
 - Evaluation and counseling to patients and families, including genetic counseling as appropriate.
 - Other consultations as necessary
- 2. Address access to care concerns with patients and families (e.g. other care/providers, transportation needs, funding and other available resources).

- 3. Refer families of children with special care needs to appropriate resources, including Children's Special Health Care Services, Women with Infants and Children (WIC) clinic, and First Steps (for infants under age 3).
- 4. Provide appropriate education to patients regarding the proactive effects of prenatal care and family planning, as well as referral to MCH programs as needed.
- 5. Provide educational presentations to health care professionals, students, and general population. Alert ISDH GNBS of each planned presentation.
- 6. Applicants must be willing to work directly with ISDH GNBS leadership and team to ensure compliance to program requirements outlined in the funding opportunity description. Applicants will provide:
 - Reports and documents for all children who screened positive and receive direct and/or telehealth services and consultations. Reports will be sent securely via email to ISDHNBS@isdh.in.gov.
 - Community partner is required to participate in meetings as indicated by ISDH GNBS team (annually at a minimum).
 - Community partner will contact the Newborn Screening Follow-up Care
 Coordinator via email ISDHNBS@isdh.in.gov regarding any lost to follow-up
 cases as they occur.
 - Community partner is expected to work alongside ISDH through technology enhancement initiatives including an INSTEP application rebuild.

II. AWARD INFORMATION

AWARD AMOUNT

It is expected that up to \$75,000 will be available to fund in FY 2021 for children diagnosed with Krabbe, Pompe and MPS-I ages 0 through 3 years.

III. ELIGIBILITY INFORMATION

ELIGIBLE APPLICANTS

Due to the complexity of healthcare navigation and coordination of services, ISDH GNBS determined that it is the most cost-effective and efficient to limit eligibility to one community

partner. Eligibility for this competitive supplemental funding opportunity is limited to FY 2021 July 1, 2020 to June 30, 2021. ISDH GNBS is providing supplemental funding for this program in order to better address the full range of care and treatment of individuals 0 through 3 years of age who are diagnosed with Krabbe, Pompe, and MPS-I. The selected community partner must possesses the necessary infrastructure in place to immediately implement activities under this supplemental funding announcement. The Community partner must also have a team including (at a minimum) a licensed/board-certified medical geneticist, genetic counselor(s), and social worker/case manager.

IV. APPLICATION AND SUBMISSION INFORMATION

BUDGET AND GRANT APPLICATION SUBMISSION

Applications are due by <u>03:00 PM (Eastern Standard Time)</u> on <u>April 13th</u>, <u>2020</u>. Your application must be submitted via email to <u>MCHBusinessUnit@isdh.IN.gov</u>

INSTRUCTIONS FOR BUDGET FORM

Using the Excel template provided, create a budget for Fiscal Year 2021 (July 1, 2020 through June 30, 2021). Budget forms are to be attached as a separate Microsoft Excel workbook. The budget is an estimate of what the project will cost. Include basic business costs and income from patient care or other funding sources depicting ability to maintain daily business practices outside the scope of NBS grant funding project. Be sure to demonstrate that all expenses are directly related to the project and the relationship between budget and project objectives are clear, provide budget narrative inside worksheet if necessary for clarification.

EXAMPLES OF EXPENDITURE ITEMS THAT WILL BE ALLOWED:

Allowable expenditure items are only valid for children with Indiana residency who screened positive for Krabbe, Pompe or MPS-I on their newborn screen.

- Patient visit fees
- Patient transportation (when all other resources are not available)
- Medical supplies/treatment supplies
- In-state staff travel for patient care (if/when necessary) Note: All staff listed in the budget must be included. In-state travel information must include miles, mileage reimbursement rate, and reason for travel. Travel reimbursement may not exceed state rates. Currently,

the in-state travel reimbursement is \$0.38 per mile, \$32 per day per diem, and \$94 plus tax per night of lodging.

- Confirmatory testing fees
- Fees associated with case management, patient communication and outreach services
- Medical courier service
- Other costs associated with providing patient care

EXAMPLES OF EXPENDITURE ITEMS THAT WILL NOT BE ALLOWED:

- Personnel salaries
- Construction of buildings, existing building renovations
- Contributions, gifts, donations
- Entertainment and/or food
- Automobile purchase
- Bad debts and/or interest
- Overhead costs such as internet, electric, utilities, etc.
- Costs for in-hospital patient care
- Fines and penalties
- Accounting expenses
- Contingency funds
- Executive expenses such as car rental and unrelated travel expenses
- Fundraising expenses
- Legal fees
- Legislative lobbying
- Equipment (over \$5,000 per unit)
- Dues to societies, organizations, or federations
- Incentives

REQUIRED APPLICATION COMPONENTS/ INSTRUCTIONS

Applications cannot exceed 30 pages with one inch margins using Times New Roman 12-point font. Applications must include the following required components:

Section A: Forms A, B-1, B-2, and Budget Worksheet (15 points)

Ensure all of the attached forms are complete and comprehensive. Problems to be addressed are identified and align with the grant opportunity. *Forms A, B-1 and B-2 are not included in the 30 page count.*

- Form A Application cover page Provided with RFA posting.
- Form B-1 Project Description Provided with RFA posting.
- Form B-2 Facilities Provided with RFA posting.
- **Budget Excel template** Provided with RFA posting.

Section B: Application Narrative (35 points)

Created by applicant and must discuss the following:

- Current services provided by your program for the targeted population. Include the impact of your current services shown through data and community reach.
- Process map of your proposed program's lysosomal storage disorder follow-up. Begin from the time of notification from the NBS lab and continue through patient diagnosis, treatment, and continued care.
- Ability to reach patients statewide through your individual network, outside networks, other community partners and telehealth solutions.
- Describe your statement of need. Include specific problems or needs to be addressed by this
 project. Include documentation such as current data, research, local surveys, reports from
 professional local and national health organizations, and other reliable resources. Please be
 sure to include a reference page for sources of documentation.

Section C: Proposed SMART Goals and Activities (35 points)

SMART Goals and Activities

Community Partner is expected to fulfill the requirements of Indiana's Newborn Screening Law (Indiana Code 16-41-17, available at http://iga.in.gov/legislative/laws/2017/ic/titles/016/) Created by applicant and must discuss the following:

- Five SMART goals and defined performance measures to track the progress toward each goal.
- Planned activities including: implementation of follow-up process and how SMART goals will be met.

- Plans to expand or enhance your existing program in order to allow implementation of lysosomal storage disorder follow-up services.
- Description of activities that will be supported with the supplemental grant funds.
- Plans for collaboration and enhancement of the Indiana Perinatal Quality Improvement Collaborative Perinatal Genetics and Genomics Committee.
- Type of data and method of data collection to be shared monthly or as requested by GNBS.
- Describe proposed educational outreach activities

Section D: Staffing Plan and Shortened CVs (5 points)

Include the two content sections below:

- Staffing Plan: List the names, roles and contact information of all staff that will work on this project. Indicate who will be the designated newborn screening coordinator. The newborn screening coordinator will be the main point of contact between the community partner, newborn screening laboratory and ISDH. A weekend staffing plan should also be discussed. This should include: who will be the point of contact for the lab and/or ISDH GNBS if the need arises on during a weekend or evening.
- Staff Credentials: Demonstrate that staff is both qualified to participate and can adequately manage project requirements and objectives. Submit shortened curriculum vitae (CV) for key staff, highlighting pertinent experience and publications *Note: this will be included in the 30 page count*. Copies of current professional licenses and certifications must be on file at your organization. Copies of current professional licenses and certifications do not need to be submitted with the application, only include the license number on the appropriate CV.

Section E: Endorsement (10 points)

• Endorsements – Each application must include at least three letters of support from relevant agencies outside of the applicant's healthcare network. All letters of support should show evidence that the applicant has the necessary staff, equipment, and expertise to perform the timely follow-up of lysosomal storage disorders. Letters of support must demonstrate a commitment to collaboration between applicant agency and other relevant organizations within the proposed follow-up process. A strong partnership among the applicant, other health care agencies, the newborn screening lab, and ISDH is vital to

ensure best outcomes for children screened positive for lysosomal storage disorders. *Note: These will not be included in the 30 page count.*

V. APPLICATION REVIEW INFORMATION

EVALUATION CRITERIA

All proposals will be reviewed on the quality, clarity, and completeness of the application.

- Section A: Forms A, B-1, B-2, and Budget Worksheet 15 points
- Section B: Application Narrative 35 points
- Section C: Proposed Performance Objectives and Goals 35 points
- Section D: Staffing Plan and Shortened CVs 5 points
- Section E: Endorsement 10 points

Discuss the following items within your responses:

- SMART goals contribute to the early detection of conditions and improvement of healthcare for Indiana children ages 0 through 3 years who are diagnosed with Krabbe, Pompe or MPS-1.
- Responsiveness to program objectives for activities for which grant dollars are being made available.
- Identification of target population who experience a disproportionate burden of the health condition and explains the root causes of disparities.
- SMART (Specific, Measurable, Attainable, Relevant, Time-based) objectives, activities, performance targets and outcomes with respect to timelines and resources.
- Evaluation plan and/or data source(s) that will be used to determine the level of success for the project.
- The role that fostering a partnership with ISDH plays in decreasing infant mortality.
- Demonstration of past performance in areas related to programmatic and financial stewardship with program personnel that are qualified for their roles.

REVIEW AND SELECTION PROCESS

Applications are reviewed by ISDH agency staff according to the evaluation criteria listed above. If multiple applications are received for this funding opportunity, the highest scored applicant will be awarded.

VI. ADMINISTRATION INFORMATION

AWARD NOTICES

You will receive a letter from ISDH GNBS program via email that describes the general results of the review of your application, including the score that your application received.

If you are approved for funding, you will receive an **additional** notice through email, the Notice of Award, signed by ISDH Grants Management Officer. The Notice of Award is the sole obligating document that allows you to receive state funding for work on the grant project. If you are not funded, you will receive notification from ISDH GNBS.

ADMINISTRATIVE POLICY REQUIREMENTS

- If you are awarded you must comply with all terms and conditions of the grant contract.
- Depending on the scope of work within your proposed project, ISDH GNBS may negotiate additional terms and conditions with you prior to grant award. These may include:
 - Actions required to be in compliance with confidentiality and participant protection/human subjects requirements
 - o Requirements relating to additional data collection and reporting
 - Requirements to amend proposed project approach
 - Revised budget
- If you are awarded you will be held accountable for the information provided in the application relating to performance targets. ISDH GNBS program officials will consider your progress in meeting goals and objectives, as well as your failures and strategies for overcoming them, when making an annual recommendation to continue the grant and the amount of any continuation award. Failure to meet stated goals and objectives may result in withholding opportunity for continuation awards.
- Grant funds cannot be used to supplant current funding of existing activities.

VII. AGENCY CONTACTS

For questions about application process contact:

Eden Bezy

Indiana State Department of Health

Director of Maternal and Child Health

2 Meridian St

Indianapolis, IN 46204

317-233-1252

EBezy@isdh.IN.gov

For questions about grants management contact:

Michael Mendyk

Indiana State Department of Health

Director of Grants and Contracts

2 Meridian St

Indianapolis, IN 46204

317-234-6874

MMendyk@isdh.IN.gov

VIII. DEFINITIONS

- Client/ patient: A recipient of services that are supported by program expenses funded in whole or in part by ISDH GNBS dollars
- **INSTEP**: Indiana Newborn Screening Tracking and Education Program (INSTEP) is a webbased application developed by the Indiana State Department of Health Newborn Screening (NBS) Program in order to help ensure that all children in Indiana receive the best care related to newborn screening.
- IPQIC: Indiana Perinatal Quality Improvement Committee
- ISDH: Indiana State Department of Health
- **GNBS**: Genomics and Newborn Screening program within the Indiana State Department of Health
- NBS (newborn screening) supported services:
 - Direct medical and dental care: family planning, prenatal care, child health (infant, child adolescent), women's health
 - Enabling services: prenatal care coordination, family care coordination.
- PGG sub-committee: IPQIC Perinatal Genetics and Genomics sub-committee
- **Program expense**: Any expense included in the budget to be funded by NBS (supplies, space costs, etc.)
- **SMART goals**: SMART is an acronym for <u>Specific</u>, <u>Measurable</u>, <u>Attainable</u>, <u>Relevant</u>, and <u>Time-based</u>. SMART goals take each of these into account. Example of a SMART goal:
 - Specific: Detailed
 - Measurable: Metrics are provided and tracked
 - Attainable: Reasonable and realistic
 - Relevant: Pertains to activities outlined in this grant application packet
 - Time-based: Includes specific timeframes
- **Supplant**: Replacing funding of a recipient's existing program with funds from a federal grant.
- **Telehealth**: the provision of healthcare remotely by means of telecommunications technology.

LYSOSOMAL STORAGE DISORDER GRANT APPLICATION FY 2021

Title of Project:		
Federal ID Number:	Medicaid Provider Nur	nber:
Legal Agency/ Organization Name:		
Address: Street	Zip Code	City
Phone	Fax	
Project Director (Printed)	Title	Email
Project Director Signature*		Date
Agency CEO or Official Custodian of	Funds Title	Email
Agency CEO/Custodian of Funds Sign	nature*	Date
Date registered with Secretary of State		e considered for funding

FY 2021 Project Description

Project Name:		Project Number:	
Address:	City, State, Zip	-	
Telephone Number:	Fax Number:	E-Mail Address:	
Counties Served:			
Type of Organization: State \Box	Local	Private Non-Profit □	
Requested Funds: \$	(Amount should reflect total	for FY 2021)	
Sponsoring Agency:			
Summarize identified needs to be addressed by this projection	ect.		
Summarize proposed performance objectives and goals.			

FY 2021 Facilities

NBS Project Name:		Project Number:		# Clinic Sites
Clinic Site Address:	Clinic Schedule (days & NBS I times):		NBS Budg	get for Site:
Counties Served:	Services Provided in NBS Budget for site:			
Target Population and estimated number to be served with NBS funds:	Other services provided at site (non-NBS):		BS):	
Clinic Site Address:	Clinic Schedule (day times):	ys &	NBS Budg	get for Site:
Counties Served:	Services Provided in NBS Budget for site:			
Target Population and estimated number to be served with NBS funds:	Other services provided at site (non-NBS):		BS):	
Clinic Site Address:	Clinic Schedule (day times):	ys &	NBS Budg	get for Site:
Counties Served:	Services Provided in	n NBS	Budget for s	site:
Target Population and estimated number to be served with NBS funds:	Other services provided at site (non-NBS):		BS):	
Clinic Site Address:	Clinic Schedule (day times):	ys &	NBS Budg	get for Site:
Counties Served:	Services Provided in NBS Budget for site:			
Target Population and estimated number to be served with NBS funds:	Other services provi	ided at	site (non-NI	BS):

Clinic Site Address:	Clinic Schedule (days &	NBS Budget for Site:
	times):	
Counties Served:	Services Provided in NBS	Budget for site:
Target Population and estimated number to be served with NBS funds:	Other services provided at	site (non-NBS):

Account Codes

	Account Codes	
111.000 Physicians		
Clinical Geneticist	Medical Geneticist	Pediatrician
Family Practice Physician	OB/GYN	Resident/ Intern
General Family Physician	Other Physician	Neonatologist
Genetic Fellow		
111.200 Other Service Pro	viders	
Audiologist	Genetic Counselor (M.S.)	Psychologist
Child Development Specialist	Health Educator/ Teacher	Psychometrist
Community Educator	Outreach Worker	Speech Pathologist
Community Health Worker	Physical Therapist	Occupational Therapist
Family Planning Counselor	Physician Assistant	Respiratory Therapist
1		
111.350 Care Coordination		
111.350 Care Coordination Licensed Clinical Social Worker(L.C.S.W.)	Registered Dietician	Social Worker (M.S.W.)
Licensed Clinical Social		Social Worker (M.S.W.) Registered Nurse
Licensed Clinical Social Worker(L.C.S.W.) Licensed Social Worker	Registered Dietician	,
Licensed Clinical Social Worker(L.C.S.W.) Licensed Social Worker (L.S.W.)	Registered Dietician	,
Licensed Clinical Social Worker(L.C.S.W.) Licensed Social Worker (L.S.W.) Physician	Registered Dietician	,
Licensed Clinical Social Worker(L.C.S.W.) Licensed Social Worker (L.S.W.) Physician 111.400 Nurses	Registered Dietician Social Worker (B.S.W.)	Registered Nurse Pediatric Nurse
Licensed Clinical Social Worker(L.C.S.W.) Licensed Social Worker (L.S.W.) Physician 111.400 Nurses Clinic Coordinator	Registered Dietician Social Worker (B.S.W.) Licensed Midwife	Registered Nurse Pediatric Nurse Practitioner

111.600 Social Service Providers				
Caseworker	Counselor (M.S.)	Social Worker (M.S.W.)		
Licensed Clinical Social Worker(L.C.S.W.)	Social Worker (B.S.W.)	Counselor		
Licensed Social Worker (L.S.W.)				
111.700 Nutritionists/ Dieti	tians			
Dietitian (R.D. Eligible)	Registered Dietitian	Nutritionist (Master's Degree)		
Nutrition Educator				
111.800 Medical/ Dental Pr	oject Director			
Dental Director	Medical Director	Project Director		
111.825 Project Coordinate	or			
111.850 Other Administrat	ion			
Accountant/ Finance/ Bookkeeper	Data Entry Clerk	Nurse Aid		
Administrator/ General Manager	Evaluator	Other Administration		
Clinic Aide	Laboratory Assistant	Programmer/ Systems Analyst		
Clinic Coordinator (Administration)	Laboratory Technician	Secretary/ Clerk/ Medical Record		
Communications Coordinator	Maintenance/ Housekeeping	Genetic Associate/ Assistant		
115.000 Fringe Benefits				
200.000 Contractual Service	ces			
Insurance and Bonding	Equipment Leases	Licensing		
(insurance premiums for fire, theft, liability, fidelity	Maintenance Agreements			

bonds, etc.; malpractice insurance premiums cannot be paid with grant funds)

200.700 Travel

Conference Registrations In-State Staff Travel

200.800 Rental and Utilities

Janitorial Services Utilities Rental of Space

200.850 Communications

Postage (including UPS) Publications Subscriptions

Printing Costs Reports Telephone

200.900 Other Expenditures

Approved items not otherwise classified above

Consultants

<u>Individuals</u> not directly employed by your organization, but with whom you want to contract to perform services under this grant. (If you are contracting with an <u>organization</u> for services, you should list the organization under 200.00 Contractual Services.)