

NOTICE OF FUNDING OPPORTUNITY INFORMATIONAL WEBINAR

Long-term Health Outcomes of People Living with Spina Bifida

Opportunity number: CDC-RFA-DD-26-0222 | Assistance Listing 93.073

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Infant Disorders

September 17, 2026



Centers for Disease Control and Prevention



Today's session

WELCOME

Goal: help potential applicants understand the opportunity, major requirements, review criteria, and deadlines.

Agenda

- Opportunity overview and funding
- Program approach: Components A and B
- Eligibility and responsiveness
- Application package and scoring
- Submission, review, and post-award expectations
- Questions and answers

Important

- Participation is voluntary.
- Attendance does not affect eligibility, scoring, or award selection.
- This presentation summarizes the NOFO; refer to the published NOFO for further details.

[Long-Term Health Outcomes of People Living With Spina Bifida \(NOFO\)](#) | [National Center on Birth Defects and Developmental Disabilities \(NCBDDD\)](#) | [CDC](#)

Opportunity at a glance

OVERVIEW

Component A — National Spina Bifida Patient Registry (NSBPR)

Collect high-quality longitudinal data on children and adults with spina bifida receiving care in specialized clinics participating in the National Spina Bifida Patient Registry.

Component B — Urologic Management to Preserve Initial Renal Function (UMPIRE) Protocol

Carry out and evaluate the iterative UMPIRE protocol in infants and young children with myelomeningocele to preserve initial renal function.

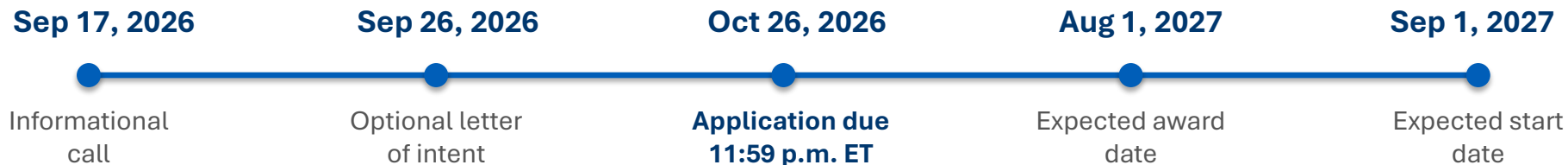
Applicants may apply to Component A, Component B, or both. A separate application is required for each component.

Overall purpose

- Collect longitudinal data from spina bifida specialty clinics to describe key outcomes.
- Identify healthcare and clinic practices associated with the best outcomes.
- Improve health and quality of life for people of all ages living with spina bifida.

Key dates

OVERVIEW



Start SAM.gov and Grants.gov registration now if needed; registration can take days to weeks.

Funding details

OVERVIEW

Component A — NSBPR

- Expected awards: 8–11
- 3-year period of performance
- Total program funding: \$2.4M–\$6.6M
- Estimated award/applicant over 3 years: \$300K–\$600K
- Expected per 12-month budget period: \$100K–\$200K

Component B — UMPIRE

- Expected awards: 6–9
- 3-year period of performance
- Total program funding: \$900K–\$2.7M
- Estimated award/applicant over 3 years: \$150K–\$300K
- Expected per 12-month budget period: \$50K–\$100K

Cooperative agreement • No cost-sharing requirement • Awards subject to available funds and program priorities

Program approach

What recipients will do and what success looks like



Why this work matters

PROGRAM APPROACH

National Spina Bifida Patient Registry

- Established by CDC in 2008.
- Tracks health status of children and adults with SB who receive care in specialized SB clinics.
- More than 12,000 participants enrolled as of September 2024.

UMPIRE protocol

- Established in 2014.
- Standardized monitoring and testing of the urinary system intended to preserve kidney function among infants and young children with myelomeningocele.
- More than 600 infants and young children enrolled, with >4,000 encounters as of October 2024.

What is needed now

- More longitudinal analyses to identify healthcare and clinic practices associated with better outcomes.
- Additional years of follow-up to understand long-term outcomes.
- Continued evaluation and refinement of the UMPIRE surveillance protocol.

Three core strategies

PROGRAM APPROACH

1 Collect longitudinal data

- Follow enrolled participants.
- Reduce loss to follow-up.
- For NSBPR, approach eligible individuals for enrollment.

2 Manage & report data

- Use CDC data collection tools and systems.
- Submit standardized, validated data with limited identifiers monthly.
- Conduct data-quality checks and resolve errors.

3 Analyze & share findings

- Collaborate with CDC and other recipients on pooled analyses.
- Participate in meetings, committees, and workgroups.
- Share findings through presentations and publications.

Component A — NSBPR: key activities

PROGRAM APPROACH

Longitudinal follow-up

- Collect follow-up visit data on children and adults already enrolled.
- Enhance retention and collect information on participants lost to follow-up.
- Approach all eligible individuals and collect data after consent.

Additional data activities

- Report minimal non-identifiable data on eligible non-enrollees annually.
- Describe capacity for optional data collection efforts.
- Link with state death records or National Death Index to identify deaths.

Analysis & dissemination

- Develop proposals and analytic plans using pooled NSBPR data.
- Analyze and interpret pooled data.
- At least one presentation to a key audience each year; contribute to publications.

Component B — UMPIRE: key activities

PROGRAM APPROACH

Protocol follow-up

- Collect longitudinal data for currently enrolled UMPIRE participants.
- Enhance retention and report on participants lost to follow-up.
- Document protocol deviations and reasons.

Data management

- Use CDC forms and data system.
- Submit standardized, validated data with limited identifiers monthly.
- Conduct data-quality checks and participate in CDC training.

Evaluate & refine UMPIRE

- Collaborate on analytic plans and pooled analyses.
- Use results to inform evaluation and potential revision of the surveillance protocol.
- Share findings with key audiences at least annually.

Expected outcomes and performance

PROGRAM APPROACH

During the 3-year period

- Improved longitudinal data quality and increased information for clinical decision-making.
- Improved science base of spina bifida care among key audiences.
- Increased awareness of findings among key audiences.

Examples of draft targets

- Decrease by 5% the number not seen in the last 3 years.
- Increase by 5% non-deceased enrollees with a visit in past 12 months.
- 80% of data extracts submitted on time; 100% validated before export.
- At least one manuscript and one presentation each funding year.

Performance measures are draft and may be refined with recipients before reporting is required.

Work plan, evaluation, and data management



PROGRAM APPROACH

Work plan

- Detailed first-year work plan.
- High-level plan for subsequent years.
- Connect activities, measures, outcomes, responsible positions, and completion dates.

Evaluation & performance

- Submit a plan aligned with the logic model and required measures.
- Include personnel, timeline, expected outcomes, and use of findings for improvement.
- CDC expects approximately 5–10% of project funding for monitoring, reporting, and evaluation.

Data management plan

- Required for public health data collected.
- Address sources, access/protection, standards, preservation, sharing limitations, and updates.
- Draft due with application; more detailed evaluation/performance plan due within 6 months after award.

Eligibility & responsiveness

Requirements that determine whether an application moves forward



Who may apply

ELIGIBILITY

Eligible organization types

- State, county, city/township, and special district governments
- Independent school districts
- Public/state-controlled and private institutions of higher education
- Federally recognized Native American tribal governments and other tribal organizations
- Public/Indian housing authorities
- Nonprofit organizations, with or without 501(c)(3) status
- For-profit organizations and small businesses
- Bona fide agents for eligible government organizations

Application limit: one application per component per organization/UEI — up to two applications total.

Responsiveness criteria — do not miss these

ELIGIBILITY

All applications

- Applicant must meet eligibility requirements.
- Application must be submitted on time.
- Submit a document labeled “Responsiveness criteria” for each component.

Component A

- Number of current NSBPR enrollees with ≥ 1 registry visit Jan 2020–Aug 2024
- Proportion of participants seen Jan 2020–Aug 2024 who have >5 registry visits.
- At least one clinic/hospital commitment letter documenting access to spina bifida patients and collection of data elements included in the NSBPR.

Component B

- Number previously enrolled in UMPIRE with myelomeningocele and ≥ 1 visit Jan 2020–Aug 2024.
- CV of a pediatric urologist on the study team.
- At least one clinic/hospital commitment letter documenting access to spina bifida patients and collection of data elements included in the UMPIRE.

Build a competitive application

Required content, format, and how applications are scored



Application package checklist

APPLICATION

Narratives

- Project summary — 1 page
- Project narrative — 20 pages; responsiveness factor
- Budget narrative — no page limit; responsiveness factor

Attachments

- Table of contents
- Responsiveness criteria
- Indirect cost agreement, if applicable
- Resumes/job descriptions
- Organizational chart
- Letter(s) of commitment
- Report on overlap, if applicable
- Data management plan

Standard forms

- SF-424 — responsiveness factor
- SF-424A — responsiveness factor
- SF-LLL, if applicable

Project narrative: 100 points

APPLICATION

40 points

Background and approach

25 points

Evaluation and performance measurement plan

35 points

Organizational capacity

Use the exact headings, subheadings, and order specified in the NOFO.

Required narrative format

- Calibri 12-point; graphics/footnotes may be 10-point
- Single-spaced, black text, 1-inch margins, page numbers
- Submit as PDF
- Separate application for each component

Background & approach: what reviewers emphasize

APPLICATION

Component A — high-value items

- Number of individuals with clinical SB surveillance data, 2020–2024: up to 10 points ($\geq 300 = 10$).
- Proportion with >5 total visits: up to 10 points ($\geq 50\% = 10$).
- Longitudinal data experience, secure data transfer, and aligned work plan are also substantial scoring elements.

Component B — high-value items

- At least 20 individuals with myelomeningocele and recorded clinical data, 2020–2024: 12 points.
- Longitudinal data experience: 8 points.
- Secure data transfer and aligned work plan are also substantial scoring elements.

Evaluation & organizational capacity scoring

APPLICATION

Evaluation & performance — 25 points

- Ability to collect data for specified process/outcome measures — 10
- Ability to report measures and demonstrate outcomes — 8
- Use findings to demonstrate outcomes and support continuous improvement — 7

Organizational capacity — 35 points

- Relevant management, administrative, and technical experience — 10
- Evaluation capacity and committed specialist relationships — 10
- Staffing plan — 8
- Organizational chart — 2
- Collaborations that add value — 5

Staffing and collaboration expectations

APPLICATION

Both components

- Clearly define roles, level of effort, and whether staff are existing or planned hires.
- Include a data coordinator capable of timely data management and submission.
- Demonstrate relationships with specialists and access to patients/data.
- Show capacity to develop peer-reviewed scientific manuscripts.

Component-specific

- Component A: include data-analysis capacity and a data analyst.
- Component B: include a pediatric urologist; show close connection with the initial hospital/clinic where affected newborns present.
- Maintain/establish partnerships with clinicians and patient support groups; collaborate with CDC and other recipients.

Budget and funding limitations

APPLICATION

Budget narrative

- Explain and justify each cost and the basis for calculations.
- Use the required categories in the NOFO.
- Indirect costs: approved negotiated rate, or up to 15% de minimis MTDC if eligible.
- Salary rate limitation stated in NOFO: \$228,000 as of January 2026.

Key limitations

- Funds may not be used for clinical care except as allowed by law.
- Pre-award costs require authorization.
- Federal anti-lobbying and cost principles apply.
- Support beyond year 1 depends on appropriations, satisfactory progress, and government priorities.

Agency priorities and compliance



APPLICATION

Required alignment

- Funded activities must align with applicable CDC priorities, laws, regulations, and award terms.
- The NOFO emphasizes gold-standard science, transparency, evidence-based practice, data modernization, integrity, accountability, and compliance.
- Applicants should review the full CDC Priorities statement linked in the NOFO.

Selection priority

- Before final funding decisions, CDC leadership reviews potential awards for legal compliance and alignment with agency priorities.
- Applications demonstrating capacity to contribute high-quality longitudinal data and advance evidence-based understanding of long-term spina bifida outcomes may receive funding priority, to the extent permitted by law.

Submit, review & award

What happens after the application is complete



Submission requirements

SUBMIT & REVIEW

Submit through Grants.gov

- Deadline: Monday, October 26, 2026 at 11:59 p.m. ET.
- Authorized official must certify the application.
- Do not encrypt, zip, or password-protect files.
- Make sure the submission passes Grants.gov validation checks.
- If resubmitting, CDC accepts the last on-time submission.

Before submission

- Maintain active SAM.gov registration and UEI.
- Maintain active Grants.gov registration.
- Use the correct application package for CDC-RFA-DD-26-0222.
- Subscribe to the Grants.gov opportunity for updates.

How applications are reviewed and selected

SUBMIT & REVIEW

1 Initial review

- CDC checks responsiveness criteria.
- Nonresponsive applications do not advance.
- Pages over the stated page limit are not reviewed.

2 Merit & risk review

- Panel scores responsive applications using the published criteria.
- CDC conducts a pre-award risk review, including SAM.gov responsibility/qualification information.

3 Selection & award

- Applications are generally funded in rank order, subject to appropriations and priorities.
- CDC may fund in whole or part, at a lower amount, or make no awards.
- The Notice of Award is the only official award document.

After award: cooperative agreement expectations

SUBMIT & REVIEW

Recipient reporting

- Detailed evaluation/performance measurement plan — 6 months into award
- Annual Performance Report — no later than 120 days before each budget period ends
- Annual Federal Financial Report — 90 days after each budget period
- Final performance and financial reports — 120 days after period of performance

CDC substantial involvement

- Technical assistance for longitudinal data collection and data quality
- Data dictionary and reporting guidance
- Timelines for data transmission
- Storage/management of limited-identifier data
- Facilitation of multi-site analysis proposals
- Technical assistance for analysis, dissemination, and evaluation

Applicant takeaways

CLOSING

1

Choose the component(s) that match your existing patient population, expertise, and capacity.

2

Treat responsiveness criteria as a gate: assemble the required counts, CV, and commitment letter(s) early.

3

Build the narrative around the published scoring criteria, especially longitudinal data capacity and work-plan alignment.

4

Plan for monthly data submission, data quality work, pooled analyses, dissemination, and evaluation from day one.

5

Register early, follow formatting rules, validate Grants.gov submission, and submit before the deadline.

Contacts and support



CLOSING

Program

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Grants management

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Systems support

Grants.gov: 1-800-518-4726
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SAM.gov: 866-606-8220

For application materials and updates, search Grants.gov for CDC-RFA-DD-26-0222.

Questions? - Please submit in writing to vgx3@cdc.gov

[Long-Term Health Outcomes of People Living With Spina Bifida \(NOFO\) | National Center on Birth Defects and Developmental Disabilities \(NCBDDD\) | CDC](#)