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# The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)

November 28, 2025

**Congressional Research Service**
https://crsreports.congress.gov
R48757

**CRS REPORT**
Prepared for Members and
Committees of Congress

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# Introduction

The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) is a committee of experts who have historically advised the Secretary of the U.S. Department of Health and Human Services (HHS; hereinafter, the Secretary) on various aspects of newborn and childhood screening for heritable conditions—genetic disorders that can be passed from parent to child.[1] Generally, newborn screening is conducted 24-48 hours after birth and involves a blood spot screening (or "heel stick") followed by laboratory tests, pulse oximetry screening to assess heart conditions, and a hearing test.

Historically, a key function of ACHDNC was to evaluate heritable conditions that might be added to the Recommended Uniform Screening Panel (RUSP), a standardized list of genetic disorders that the Secretary recommends to state-led newborn screening programs.[2] There has been increased attention on the ACHDNC and the RUSP from policymakers, advocates, and other stakeholders following the committee's termination on April 1, 2025.

This report provides a brief history of the ACHDNC, including relevant laws, major HHS administrative actions, and the ACHDNC's status under the Federal Advisory Committee Act (FACA). This report also describes the ACHDNC's duties and processes as they relate to the RUSP and briefly summarizes actions related to the ACHDNC's termination. Newborn screening processes and programs are discussed in relation to the ACHDNC and the RUSP; however, an in-depth discussion of newborn screening history, research, clinical interventions, and policy debates is beyond the scope of this report.

# Brief History of the ACHDNC

Newborn screening gained momentum as a public health intervention throughout the 1960s and 1970s largely as a result of the development of the first blood test for phenylketonuria (PKU)—a metabolic disorder that can cause brain damage if left untreated—in 1961.[3] As research and laboratory technologies advanced, state public health agencies began implementing newborn screening programs for PKU and other conditions; however, screening guidelines and standards varied widely across states as a result of this decentralized approach.[4]

In 1999, the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA) contracted with the American Academy of Pediatrics (AAP) to form a national Task Force on Newborn Screening (the Task Force).[5] The Task Force was charged with reviewing issues and challenges for state newborn screening programs and developing a set of recommendations. The Task Force outlined the following four recommendations largely focused on the needs and actions of state public health agencies:

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[1] Health Resources and Services Administration, *Advisory Committee on Heritable Disorders in Newborns and Children*, August 2025, https://www.hrsa.gov/advisory-committees/heritable-disorders.

[2] Health Resources and Services Administration, *Recommended Uniform Screening Panel*, July 2024, https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp.

[3] Eunice Kennedy Shriver National Institute of Child Health and Human Development, *Brief History of Newborn Screening*, NICHD and the Early Years of Newborn Screening, September 1, 2017, https://www.nichd.nih.gov/health/topics/newborn/conditioninfo/history.

[4] Michael S. Watson et al., "The Progress and Future of US Newborn Screening," *International Journal of Newborn Screening*, vol. 8, no. 41 (July 18, 2022).

[5] See HRSA/Maternal and Child Health Bureau Contract no. 240-01-0038, *Standardization of Outcomes and Guidelines for Newborn Screening Programs*.

1. Effective newborn screening systems need an adequate public health infrastructure and must be a part of the health care delivery system.
2. Public health agencies must involve health professionals, families, and the general public in the development, operation, and oversight of newborn screening systems.
3. Public health agencies must ensure adequate infrastructure and policies for surveillance and research related to newborn screening.
4. Public health agencies should ensure adequate funding to support a newborn screening program.

With regard to how these four recommendations should be implemented, the Task Force further recommended that

> HRSA should engage in a national process involving government, professionals, and consumers to advance the recommendations of this Task Force and assist in the development and implementation of nationally recognized newborn screening system standards and policies.[6]

With the latter recommendation regarding national standards and policies in mind, HRSA/MCHB contracted with the American College of Medical Genetics (ACMG) in 2001. ACMG was tasked with developing a recommended uniform panel of heritable conditions that state newborn screening programs should screen for.[7] This work, referred to below, led to the first recommended uniform screening panel; however, the Secretary's formal adoption of these recommendations as the official RUSP did not occur until much later (see "Newborn Screening Saves Lives Act of 2007 (P.L. 110-204) and ACHDNC's RUSP Responsibilities").

## Children's Health Act of 2000 (P.L. 106-310) and ACHDNC's Establishment

In 2003, the Children's Health Act of 2000 (P.L. 106-310) enacted a range of provisions relevant to newborn screening. In addition to authorizing federal grant programs and newborn screening demonstration projects,[8] the law also established and codified the ACHDNC (42 U.S.C. §300b-10).[9] According to P.L. 106-310, the ACHDNC was statutorily mandated to "provide advice and recommendations to the [HHS] Secretary" concerning the aforementioned grants and demonstration projects, and to recommend actions to reduce morbidity and mortality from heritable disorders. The law required the Secretary to appoint no fewer than 15 members to the ACHDNC. These members were to include the leaders of four federal agencies and medical, technical, or scientific professionals with expertise in heritable disorders; members of the public with expertise or concern with heritable disorders; and representatives from other public health constituencies, other federal agencies, and medical professional societies. The law did not specify a termination date for the ACHDNC, and the committee was not initially tasked with developing a uniform screening panel; at that time, such work was being undertaken by ACMG (see above).

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[6] "Newborn Screening: A Blueprint for the Future Executive Summary: Newborn Screening Task Force Report," *Pediatrics*, vol. 106, no. 2 (August 1, 2000), pp. 386-387.

[7] Michael S. Watson et al., "Newborn screening: toward a uniform screening panel and system," *Genetics in Medicine*, vol. 8, no. 5 (May 2006), pp. 14S-15S.

[8] Sections1109 and 1110 of the Public Health Service Act (PHSA), respectively, as amended by P.L. 106-310.

[9] PHSA §1111, as amended by P.L. 106-310.

In January 2005, the ACMG published its recommended list of 29 *core* conditions, for which all newborns should be screened, and 25 *secondary* conditions, to be identified after screening for certain core conditions. The ACHDNC reviewed the report and issued a request for public comment. Finding that the scientific evidence was clear and that nearly all comments were supportive of the report, the ACHDNC wrote to HHS Secretary Leavitt,

> In conclusion, the Committee strongly and unanimously recommends that the Secretary initiate appropriate action to facilitate adoption of the ACMG recommended screening panel by every State newborn screening program.[10]

Although this letter was sent in September 2005, a federally recommended newborn screening panel was not established until 2010 (see next section). Specifically, in an October 2008 response to the ACHDNC's recommendation, the HRSA Administrator (writing on behalf of Secretary Leavitt), deferred a decision on the ACMG-recommended screening panel until the completion of President Bush's "President's Council on Bio-ethics."[11] The council was later disbanded by President Obama in June 2009.[12] In November 2009, the ACHDNC wrote to HHS Secretary Sebelius to reaffirm its recommendation of the ACMG-recommended screening panel and to express concern over the council's findings (see below).[13]

## Newborn Screening Saves Lives Act of 2007 (P.L. 110-204) and ACHDNC's RUSP Responsibilities

Enacted in 2008, the Newborn Screening Saves Lives Act of 2007 (P.L. 110-204) expanded the scope of the ACHDNC's responsibilities, in addition to other provisions related to grant programs, research programs, and other newborn-screening activities. Regarding the ACHDNC specifically, the law established a five-year duration of the ACHDNC and authorized annual appropriations for a similar time period (from FY2008 through FY2012). It also required the ACHDNC to provide an annual report to Congress, related committees, state departments of health, and other stakeholders; this report was required to include peer-reviewed newborn screening guidelines, including recommendations related to follow-up and treatment. Relatedly, the law amended Section 1111 of the PHSA to require the ACHDNC to

> (3) make systematic evidence-based and peer-reviewed recommendations that include the heritable disorders that have the potential to significantly impact public health for which all newborns should be screened, including secondary conditions that may be identified as a result of the laboratory methods used for screening.

This provision required the ACHDNC to develop a list of recommended conditions for state newborn screening programs, effectively establishing a recommended uniform screening panel and delegating the responsibility to the ACHDNC in statute. The act also outlined other aspects of newborn screening that the ACHDNC should consider in its development of the recommended list of conditions, such as states' capacity for follow-up care, available treatments, diagnostic

[10] Letter from R. Rodney Howell, Chairperson, Advisory Committee on Heritable Disorders in Newborns and Children, to The Honorable Michael O. Leavitt, Secretary of Health and Human Services, September 9, 2005, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/response-acmg-report-2005-09-09.pdf.

[11] Letter from Elizabeth Duke, HRSA Administrator, to R. Rodney Howell, Chairperson, Advisory Committee on Heritable Disorders in Newborns and Children, October 21, 2008, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/reports-recommendations/adoption-all-state-rusp.pdf.

[12] Nicholas Wade, "Obama Plans to Replace Bush's Bioethics Panel," *The New York Times*, June 17, 2009.

[13] Letter from R. Rodney Howell, Chairperson, Advisory Committee on Heritable Disorders in Newborns and Children, to The Honorable Kathleen Sebelius, Secretary of Health and Human Services, November 22, 2009.

capability, and elements related to quality assurance and oversight.[14] The law also codified a 180-day deadline by which the Secretary must adopt or reject the ACHDNC's recommendations, and added a requirement to make the Secretary's determinations on adopting or rejecting a recommendation publicly available.

As mentioned above, in September 2005, the ACHDNC recommended that the Secretary adopt the list of conditions initially developed by ACMG as the national recommendation for state newborn screening programs. The Secretary deferred this decision until the completion of President' Bush's President's Council on Bio-Ethics; the council was later disbanded by President Obama in June 2009.[15] In November 2009, the ACHDNC requested an update from HHS Secretary Sebelius. In that correspondence, the ACHDNC highlighted the committee's new authority to make uniform screening recommendations with the goal of helping states, as established under the law.[16] The ACHDNC also noted that "one of the central purposes of the Newborn Screening Saves Live Act is to provide federal guidance to help states voluntarily bring their programs into alignment with the most current, evidence based scientific and clinical standards" and recommended, again, that the Secretary adopt the ACMG panel (now renamed as the ACHDNC's recommended uniform screening panel, or RUSP) as the federal guidance. The ACHDNC also expressed concern about some of the findings from the disbanded Council on Bio-Ethics.

In May 2010, Secretary Sebelius formally adopted the RUSP as recommended by the ACHDNC, which evolved into a list of 30 core conditions and 26 secondary conditions.[17]

## Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240) and Expanded ACHDNC Requirements

In 2013, the ACHDNC's statutory authority lapsed, and the HHS Secretary chose to reestablish the entity as a discretionary committee. The Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240) included provisions reauthorizing the ACHDNC as a statutory entity through FY2019 and explicitly allowing the committee to continue as a discretionary committee if a further extension was not enacted after FY2019. This authority to continue as a discretionary committee is discussed below; see the "The ACHDNC's Establishment Under FACA." As with the aforementioned laws, this law also included a range of provisions outside of those related to the ACHDNC.

In addition to reauthorizing the ACHDNC, the law narrowed the Secretary's deadline to adopt or reject ACHDNC's recommendations from 180 to 120 days and implemented a nine-month deadline by which the committee must review and vote on a condition nominated for the RUSP (see "Condition Review and Nomination to the RUSP"). The 2014 reauthorization also added a requirement that the ACHDNC provide technical assistance to the individuals or groups nominating conditions for RUSP consideration and further clarified the considerations the committee should weigh when evaluating whether a condition should be added to the RUSP.

[14] For a full list of additional considerations, see Section 4, part (3) of P.L. 110-204.

[15] Nicholas Wade, "Obama Plans to Replace Bush's Bioethics Panel," *The New York Times*, June 17, 2009.

[16] Letter from R. Rodney Howell, Chairperson, Advisory Committee on Heritable Disorders in Newborns and Children, to The Honorable Kathleen Sebelius, Secretary of Health and Human Services, November 22, 2009.

[17] Letter from Kathleen Sebelius, Secretary of Health and Human Services, to R. Rodney Howell, Chairperson, Advisory Committee on Heritable Disorders in Newborns and Children, May 20, 2010.

## The ACHDNC's Establishment Under FACA

Many federal advisory committees are subject to the Federal Advisory Committee Act (FACA; 5 U.S.C. Chapter 10).[18] Generally, FACA applies to advisory committees that are either established or utilized by the President or an agency and include at least one member—such as a member of the public; business leader; or state, local, or tribal official—who is not a full-time or permanent part-time federal employee or official.[19] Under FACA, advisory committees may be established by one of four methods, which are categorized as either "nondiscretionary" or "discretionary" committees (see the **text box** below on "Federal Advisory Committee Establishment Methods"). These establishment methods have implications for how committees may be terminated, among other procedural aspects of the committee's management and operations. All operational advisory committees subject to FACA must have a charter that is renewed every two years detailing the operations and duration of the committee.[20]

At the ACHDNC's first meeting in June 2004, the committee was established as a nondiscretionary, statutory advisory committee according to FACA (see the **text box** below), given that the committee was authorized in law (P.L. 106-310). ACHDNC continued operating under this designation until its statutory authority expired on April 24, 2013, at which time the HHS Secretary chose to reestablish it as a discretionary advisory committee. Unlike nondiscretionary statutory advisory committees, discretionary advisory committees are established under the authority of an agency head; committee establishment or termination is within the agency head's discretion.[21]

Upon the enactment of the Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240), the ACHDNC was reestablished as a nondiscretionary statutory advisory committee through FY2019. The law also added the following provision:

> (2) **Continuation if not reauthorized**: If at the end of fiscal year 2019 the duration of the Advisory Committee has not been extended by statute, the Advisory Committee may be deemed, for purposes of the Federal Advisory Committee Act, an advisory committee established by the President or an officer of the Federal Government under section 9(a) of such Act.[22]

This provision allowed the ACHDNC to continue its work as a discretionary advisory committee established under *agency authority* (see the **text box** below) in the absence of future statutory reauthorizations.

Despite reauthorization efforts in the 116th (H.R. 2507, S. 2158) and 117th (H.R. 482, S. 350) Congresses, ACHDNC's statutory establishment expired in 2019. Given the aforementioned authority added by P.L. 113-240, HHS had the option to continue ACHDNC's activities as a discretionary advisory committee. HHS renewed ACHDNC for two-year terms in 2020, 2022, and again in 2024, thereby extending ACHDNC's charter through 2026.

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[18] CRS Report R47984, *The Federal Advisory Committee Act (FACA): Overview and Considerations for Congress*.

[19] 5 U.S.C. §1001(2).

[20] 5 U.S.C. §1008.

[21] 41 C.F.R. §§102-3.

[22] P.L. 113-240. The Federal Advisory Committee Act (FACA) was originally enacted in P.L. 92-463, 86 Stat. 770 (1972). In December 2022, P.L. 117-286 (136 Stat. 4197) revised Title 5 of the *U.S. Code* and moved FACA from the Appendix to Chapter 10. Older citations, therefore, may make reference to the Appendix of Title 5. Section 9 is now located at 5 U.S.C. §1008.

According to the ACHDNC's most recent charter, filed on November 10, 2024, the ACHDNC fulfilled the same functions that were undertaken by the ACHDNC when it was a nondiscretionary, statutory advisory committee, effectively continuing the committee's duties and authorities as specified in statute, despite its lack of a statutory reauthorization. As described in the charter:

> ACHDNC is authorized by the Public Health Service (PHS) Act, Titles XI §1111 (42 U.S.C. §300b-10) and II §222 (42 U.S.C. §217a). ACHDNC will fulfill the functions undertaken by the former, congressionally established Advisory Committee on Heritable Disorders in Newborns and Children, under the PHS Act, Title XI §1111 (42 U.S.C. §300b-10.[23]

For more information on FACA, see CRS Report R47984, *The Federal Advisory Committee Act (FACA): Overview and Considerations for Congress*.

**Federal Advisory Committee Establishment Methods**

Federal advisory committees can be created by Congress, Presidents, and executive branch agencies as a platform for gaining expertise and policy advice from individuals outside of the federal government. Since 1972, many federal advisory committees have been subject to the Federal Advisory Committee Act (FACA; 5 U.S.C. Chapter 10). Committees may be established under FACA by one of four methods, which are categorized as either "nondiscretionary" or "discretionary" committees. These categorizations have certain implications for committee termination, among other procedural aspects related to the committee's management or operations.

A nondiscretionary advisory committee is either a

- presidential advisory committee mandated by presidential directive or
- a statutory advisory committee mandated by statute.

A discretionary advisory committee is either

- established under agency authority in cases when nonfederal input might benefit agency decisionmaking or
- authorized by law under specific authorization from Congress.

For more information on federal advisory committees, see CRS Report R47984, *The Federal Advisory Committee Act (FACA): Overview and Considerations for Congress*, and CRS In Focus IF12102, *Federal Advisory Committee Act (FACA): Committee Establishment and Termination*.

# ACHDNC Overview

The following sections describe ACHDNC's most recent structures and processes as implemented prior to the committee's termination in April 2025.

## Membership and Structure

According to the 2024 charter, ACHDNC consisted of up to 10 Secretary-appointed members who were required to have a range of expertise.[24] This included individuals with clinical, scientific, technical, and public health expertise in heritable disorders; individuals with expertise in ethics and infectious disease; members of the public with lived experience with heritable disorders; and representatives from public health agencies, professional societies, or other stakeholders as deemed necessary by the Secretary. ACHDNC also included five ex-officio

[23] Health Resources and Services Administration, *Advisory Committee on Heritable Disorders in Newborns and Children*, Charter, Rockville, MD, November 10, 2024, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/achdnc-charter.pdf. (Hereinafter, HRSA, *Advisory Committee on Heritable Disorders in Newborns and Children*.)

[24] HRSA, *Advisory Committee on Heritable Disorders in Newborns and Children*.

members from other health agencies: the Administrator of HRSA; the Directors of the Centers for Disease Control and Prevention, National Institutes of Health, and the Agency for Healthcare Research and Quality; and the Commissioner of the Food and Drug Administration. Members could serve a maximum of four-year terms, and the total membership was required to be an odd number, with no more than 15 total members.

## Roles and Recommendations

As mentioned in the "Introduction," the ACHDNC was tasked with advising the Secretary on a range of issues related to newborn and child screening. One of its key required functions was to make "systematic evidence-based and peer-reviewed recommendations" on heritable disorders for which "all newborns should be screened." In other words, ACHDNC recommended to the Secretary a list of conditions for inclusion in the RUSP. Although states decide what disorders to screen for, the RUSP functions as a standardized list that is recommended, but not enforced or required, by the Secretary.

### The Recommended Uniform Screening Panel (RUSP)

Prior to the establishment of the ACHDNC and the RUSP, newborn screening guidelines varied widely across states. The RUSP was developed to function as a standardized guideline to assist states in deciding which conditions to include in their newborn screening programs. Some state laws require programs to screen for all conditions added to the RUSP, whereas other states may require screening for fewer or additional conditions beyond those in the RUSP.[25]

As noted above, conditions were historically added to the RUSP following the Secretary's adoption of the ACHDNC's recommendations. The RUSP includes multiple types of heritable disorders, including metabolic, endocrine, hemoglobin, and other disorders, such as hearing loss or congenital heart defects. The RUSP divides conditions into two groups: *core conditions* recommended for every newborn screening program, and *secondary conditions*, which are those that can be detected after the diagnosis of a core condition. As of July 2024, the most recent RUSP recommends screening for 38 core conditions and 26 secondary conditions (see **Table A-1** in **Appendix**).[26]

#### *RUSP and Health Coverage*

The RUSP is referenced in the Health Resources and Services Administration (HRSA)-supported Bright Futures/American Academy of Pediatrics guidelines, which outline recommended pediatric preventive screenings from birth through adolescence.[27] Most private health insurance plans are federally required to cover HRSA-recommended pediatric preventive screenings without cost sharing.[28] As implemented, this includes screenings included in the RUSP, subject to regulations, guidance, and state law.[29]

[25] HRSA, *Newborn Screening in Your State*, https://newbornscreening.hrsa.gov/your-state.

[26] HRSA, *Recommended Uniform Screening Panel*, July 2024, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/rusp/rusp-july-2024.pdf.

[27] HRSA, *Bright Futures*, https://mchb.hrsa.gov/programs-impact/bright-futures.

[28] PHSA §2713.

[29] 45 C.F.R. §147.130. For more information on the Affordable Care Act Preventive Services Coverage Requirement, see CRS In Focus IF13010, *The ACA Preventive Services Coverage Requirement*.

State Medicaid plans may refer to these and other guidelines, subject to state laws, when specifying the periodicity schedules for newborn screenings under Medicaid's Early Periodic, Screening, Diagnostic, and Treatment Services program.[30]

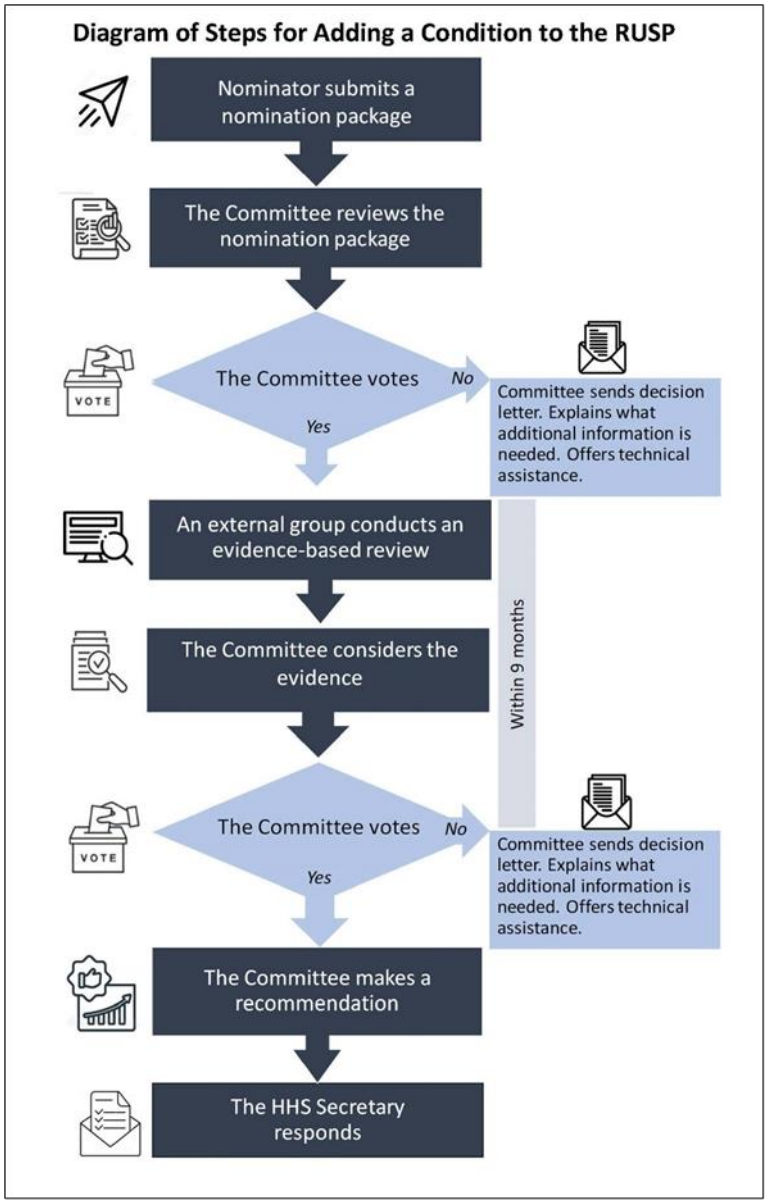
### *Condition Review and Nomination to the RUSP*

Adding conditions to the RUSP typically involved a multistep process beginning with the submission of a nomination package to ACHDNC (see **Figure 1**). Historically, anyone could submit a nomination, though a multidisciplinary team of experts and other stakeholders often worked together. Nominations answered specific questions about the screening and treatment for the nominated condition using scientific evidence, in addition to other requirements. The ACHDNC reviewed the nomination and evaluated whether the condition would move forward for further review. The ACHDNC considered key questions, such as the seriousness of the condition, whether the screening was valid and clinically useful, and whether treatments were available.

If a condition was not chosen for further review, the ACHDNC provided the nominator with feedback. If the ACHDNC voted to move the condition forward, an external, independent group of clinical and technical experts conducted an in-depth, detailed review of the data. The external review group (ERG) prepared a report for ACHDNC that outlined how screening and treatment for the condition could affect newborns, children, and broader public health.

[30] Centers for Medicare & Medicaid Services, *EPSDT - A Guide for States*, Coverage in the Medicaid Benefit for Children and Adolescents, June 2014, https://www.medicaid.gov/medicaid/benefits/downloads/epsdt-coverage-guide.pdf. Section 1905 of the Social Security Act (42 U.S.C. §1396d.).

**Figure 1. Steps for Adding a Condition to the Recommended Uniform Screening Panel (RUSP)**




**Source:** Health Resources and Services Administration (HRSA), *Condition Nomination and Review*, https://www.hrsa.gov/advisory-committees/heritable-disorders/condition-nomination.

**Notes:** HRSA uses the term "Committee" to refer, in short, to the Advisory Committee on Heritable Disorders in Newborns and Children.

When reviewing the ERG report, the ACHDNC used a rating system and decision matrix that (1) considered the overall benefits and harms of screening for the nominated condition and (2) assessed the feasibility and readiness of state newborn screening programs to expand screening for the condition. ACHDNC was statutorily required to vote on whether to recommend adding the condition to the RUSP within nine months of initially accepting the nomination. If a condition was recommended, the ACHDNC Chair sent the Secretary a letter explaining the committee's rationale. The Secretary was required to adopt or reject the recommendation within 120 days after ACHDNC's notice. These timelines, originally established in P.L. 113-240, were maintained and

included in the ACHDNC's charter when the committee transitioned to a discretionary committee (see The ACHDNC's Establishment Under FACA").[31]

# Recent ACHDNC-Related Actions

According to the U.S. General Services Administration, which maintains a database of federal advisory committees, the ACHDNC was terminated on April 1, 2025, citing "2025 Secretary Directive" as the specific termination authority.[32] As previously mentioned, the ACHDNC was operating as a discretionary advisory committee, which may be established, extended, or terminated at the discretion of an agency head.

## HHS Actions

The ACHDNC and RUSP have historically been administered by HRSA, an operating division within HHS, and funded under the "Heritable Disorders" portfolio.[33] On March 27, 2025, HHS announced a proposed restructuring of the department that, in part, would combine HRSA into a proposed new agency, the Administration for a Healthy America (AHA).[34] (As of the date of this report, HRSA has continued as its own operating division within HHS.) Following the April 1 termination of the ACHDNC, the FY2026 Congressional Budget Justification for AHA (released in early June) included the Heritable Disorders portfolio in its list of programs proposed for elimination.[35]

During a June 2025 House Energy and Commerce subcommittee hearing on the HHS FY2026 Budget Request, the HHS Secretary indicated that ACHDNC activities would be undertaken by HRSA, citing the committee's inability to develop new RUSP recommendations over the past two years.[36]

In August 2025, HRSA published separate notices in the *Federal Register* seeking comments on the potential recommendation of two conditions to the RUSP: Duchenne Muscular Dystrophy (DMD) and Metachromatic Leukodystrophy (MLD).[37] According to the *Federal Register* notices,

> HRSA is considering potential ways to continue supporting the RUSP and the overall system of newborn screening. In deciding whether to provide a recommendation to the

[31] For more information on the ACHDNC's procedures, see HRSA, *Advisory Committee on Heritable Disorders in Newborns and Children*.

[32] U.S. General Services Administration, FACA Database, *Advisory Committee on Heritable Disorders in Newborns and Children*, https://www.facadatabase.gov/FACA/s/FACACommittee/a10t0000001gzwVAAQ/com000814.

[33] Department of Health and Human Services, *Health Resources and Services Administration*, FY2025 Justification of Estimates for Appropriations Committees, pp. 228-231, https://www.hrsa.gov/about/budget.

[34] U.S. Department of Health and Human Services, "HHS Announces Transformation to Make America Healthy Again," press release, March 27, 2025, https://www.hhs.gov/press-room/hhs-restructuring-doge.html.

[35] Department of Health and Human Services, *Administration for a Healthy America*, FY2026 Justification of Estimates for Appropriations Committees, p. 365, https://www.hhs.gov/sites/default/files/fy-2026-aha-cj.pdf.

[36] U.S. Congress, House Energy and Commerce Committee, Health Subcommittee, *The Fiscal Year 2026 Department of Health and Human Services Budget*, 119th Cong., 1st sess., June 24, 2025.

[37] Health Resources and Services Administration, Department of Health and Human Services, "Notice With Request for Comment: Consideration of Adding Metachromatic Leukodystrophy to the Recommended Uniform Screening Panel," 90 *Federal Register* 39196-39197, August 14, 2025.

Health Resources and Services Administration, Department of Health and Human Services, "Notice With Request for Comment: Consideration of Adding Duchenne Muscular Dystrophy to the Recommended Uniform Screening Panel," 90 *Federal Register* 39197, August 14, 2025.

> Secretary supporting the addition of DMD to the RUSP, HRSA will consider evidence-based reports and public comments obtained through this notice.[38]

The ACHDNC had previously voted to move both DMD and MLD forward to full external evidence reviews conducted by the ERG (see "Condition Review and Nomination to the RUSP"). However, the ADHDNC had not made a recommendation on whether the condition(s) should be added to the RUSP before the committee's termination occurred. It remains to be seen what processes HRSA may implement, or potentially modify, to manage the RUSP nomination and review process moving forward.

## Congressional Actions by the 119th Congress

Introduced on July 23, 2025, H.R. 4709 proposes to reauthorize the ACHDNC through 2030, thereby reestablishing the ACHDNC as a nondiscretionary, statutory advisory committee. H.R. 4709 would also require the ACHDNC to develop, maintain, and publish publicly accessible, reader-friendly materials about the RUSP process, including how to obtain technical assistance when submitting nominations, in addition to other provisions related to newborn screening programs more broadly. No House action has occurred on this proposal, and similar legislation has not been introduced in the Senate.

The House and Senate appropriations committees each have addressed the Heritable Disorders program through their respective FY2026 appropriations proposals. In the Senate, S.Rept. 119-55 (accompanying S. 2587) allocates $21 million for the program. The committee also includes that allocation in its proposed bill language for the HRSA Maternal and Child Health account.[39] With regard to the RUSP, the committee report includes the following directive:

> *Recommended Uniform Screening Panel [RUSP].*—The Committee recognizes the importance of Federal guidance, including the significant influence of the Recommended Uniform Screening Panel [RUSP], in State decision-making around the detection of chronic illnesses at birth. Within 90 days of enactment of this act, the Committee directs HRSA to provide a briefing on the activities of the Advisory Committee on Heritable Disorders in Newborns and Children [ACHDNC], including efforts to promote universal screening, respond to medical breakthroughs, and any updates to the RUSP.[40]

In the House, H.Rept. 119-271 (accompanying H.R. 5304) allocates the same amount as the Senate for the Heritable Disorders portfolio. (The House Appropriations Committee does not include this allocation in its proposed bill language for HRSA, however.) In its discussion of the Heritable Disorders portfolio, the committee report "recognizes the importance of Federal guidance and support in State decision-making around the detection of chronic illnesses at birth," but does not directly reference the ACHDNC. [41] Rather, the committee "urges HHS to promptly consider the outstanding review of available evidence for Duchenne and requests a plan regarding the new process for future recommendations for conditions for newborn screening."[42] It also

[38] Note that both *Federal Register* notices contained this same text, with DMD replaced by MLD in the MLD-specific notice.

[39] S. 2587 includes language providing that the funds in that account "shall be for the purposes and in the amounts specified" [Missing a quotation mark somewhere. Is this correct?] in the "Committee Recommendation" column for Maternal and Child Health in the "Amounts Recommended in the Bill for Fiscal Year 2026" table in the report accompanying this act. See page 432 of S.Rept. 119-55 for those referenced amounts and purposes, including for the Heritable Disorders program.

[40] S.Rept. 119-55, p. 55.

[41] H.Rept. 119-271, pp. 50-51.

[42] H.Rept. 119-271, pp. 50-51.

requests that HHS provide a status update on the MLD nomination as part of its FY2027 Congressional Budget Justification.[43]

Separately, some Members of Congress have questioned the HHS Secretary about the rationale behind the ACHDNC's termination. In an August 2025 letter to the Secretary, members inquired about the future of the RUSP, plans for future proposals and evidence reviews, and opportunities for future stakeholder engagement in newborn screening.[44]

## Stakeholder Perspectives

In the past, some stakeholders have critiqued the committee's RUSP nomination process, describing it as too burdensome and unable to keep pace with advances in medical research or diagnostics.[45] The termination of the ACHDNC, however, prompted pushback from a range of clinical and nongovernmental organizations, such as those that advocate for individuals with rare disorders.[46] For example, the Newborn Screening Coalition characterized the ACHDNC as a "critical part of the U.S. newborn screening system," and noted there is "no comparable body to carry out this function in its absence."[47] Some observers also have contended that reform of the ACHDNC, rather than its disassembly, could have addressed concerns with the RUSP process.[48]

[43] H.Rept. 119-271, pp. 50-51.

[44] Congresswoman Dr. Kelly Morrison, "U.S. Rep. Kelly Morrison Demands Answers After HHS Disbands Newborn Health Committee," press release, August 1, 2025, https://morrison.house.gov/media/press-releases/us-rep-kelly-morrison-demands-answers-after-hhs-disbands-newborn-health.

[45] Donald B. Bailey et al., "Expert Evaluation of Strategies to Modernize Newborn Screening in the United States," *JAMA Network Open*, vol. 4, no. 12 (December 29, 2021).

[46] Association for Diagnostics & Laboratory Medicine, "ADLM letter to reinstate Secretary's Advisory Committee on Heritable Disorders in Newborns and Children," press release, April 15, 2025, https://myadlm.org/advocacy-and-outreach/comment-letters/2025/adlm-rusp-letter. Letter from Newborn Screening Coalition to Robert F. Kennedy, Jr., Secretary, Department of Health and Human Services, May 5, 2025, https://rarediseases.org/wp-content/uploads/2025/05/Newborn-Screening-Coalition-Letter-FINAL.pdf.

[47] Letter from Newborn Screening Coalition to Robert F. Kennedy, Jr., Secretary, Department of Health and Human Services, May 5, 2025, https://rarediseases.org/wp-content/uploads/2025/05/Newborn-Screening-Coalition-Letter-FINAL.pdf.

[48] Spreeha Choudhury and Richard Hughes IV, "Newborn Screening At Risk: Implications Of Disbanding The Advisory Committee On Heritable Disorders In Newborns And Children," *Health Affairs*, May 1, 2025.

# Appendix. Recommended Uniform Screening Panel (RUSP)

**Table A-1. Recommended Uniform Screening Panel (RUSP)**

As of July 2024

| | Metabolic Disorder: Organic Acid Condition | Metabolic Disorder: Fatty Acid Oxidation Disorder | Metabolic Disorder: Amino Acid Disorder | Endocrine Disorder | Hemoglobin Disorder | Other Disorder |
|---|---|---|---|---|---|---|
| **Core Conditions**[a] | | | | | | |
| 3-Hydroxy-3-Methyglutaric Aciduria | X | — | — | — | — | — |
| 3-Methylcrotonyl-CoA Carboxylase Deficiency | X | — | — | — | — | — |
| ß-Ketothiolase Deficiency | X | — | — | — | — | — |
| Glutaric Acidemia Type I | X | — | — | — | — | — |
| Holocarboxylase Synthase Deficiency | X | — | — | — | — | — |
| Isovaleric Acidemia | X | — | — | — | — | — |
| Methylmalonic Acidemia (Cobalamin disorders) | X | — | — | — | — | — |
| Methylmalonic Acidemia (methylmalonyl-CoA mutase) | X | — | — | — | — | — |
| Propionic Acidemia | X | — | — | — | — | — |
| Carnitine Uptake Defect/Carnitine Transport Defect | — | X | — | — | — | — |
| Long-chain L-3 Hydroxyacyl-CoA Dehydrogenase Deficiency | — | X | — | — | — | — |
| Medium-chain Acyl-CoA Dehydrogenase Deficiency | — | X | — | — | — | — |
| Trifunctional Protein Deficiency | — | X | — | — | — | — |
| Very Long-chain Acyl-CoA Dehydrogenase Deficiency | — | X | — | — | — | — |

| | Metabolic Disorder: Organic Acid Condition | Metabolic Disorder: Fatty Acid Oxidation Disorder | Metabolic Disorder: Amino Acid Disorder | Endocrine Disorder | Hemoglobin Disorder | Other Disorder |
|---|---|---|---|---|---|---|
| Argininosuccinic Aciduria | — | — | X | — | — | — |
| Citrullinemia, Type I | — | — | X | — | — | — |
| Classic Phenylketonuria | — | — | X | — | — | — |
| Homocystinuria | — | — | X | — | — | — |
| Maple Syrup Urine Disease | — | — | X | — | — | — |
| Tyrosinemia, Type I | — | — | X | — | — | — |
| Congenital adrenal hyperplasia | — | — | — | X | — | — |
| Primary Congenital Hypothyroidism | — | — | — | X | — | — |
| S, βeta-Thalassemia | — | — | — | — | X | — |
| S,C Disease | — | — | — | — | X | — |
| S,S Disease (Sickle Cell Anemia) | — | — | — | — | X | — |
| Biotinidase Deficiency | — | — | — | — | — | X |
| Classic Galactosemia | — | — | — | — | — | X |
| Critical Congenital Heart Disease | — | — | — | — | — | X |
| Cystic Fibrosis | — | — | — | — | — | X |
| Glycogen Storage Disease Type II (Pompe) | — | — | — | — | — | X |
| Guanidinoacetate Methyltransferase Deficiency | — | — | — | — | — | X |
| Hearing Loss | — | — | — | — | — | X |
| Infantile Krabbe Disease (low galactocerebrosidase [GALC] and psychosine ≥ 10nM) | — | — | — | — | — | X |
| Mucopolysaccharidosis Type I | — | — | — | — | — | X |
| Mucopolysaccharidosis Type II | — | — | — | — | — | X |
| Severe Combined Immunodeficiencies | — | — | — | — | — | X |

| | Metabolic Disorder: Organic Acid Condition | Metabolic Disorder: Fatty Acid Oxidation Disorder | Metabolic Disorder: Amino Acid Disorder | Endocrine Disorder | Hemoglobin Disorder | Other Disorder |
|---|---|---|---|---|---|---|
| Spinal Muscular Atrophy due to homozygous deletion of exon 7 in SMN1 | — | — | — | — | — | X |
| X-linked Adrenoleukodystrophy | — | — | — | — | — | X |
| **Secondary Conditions**[b] | | | | | | |
| 2-Methyl-3-hydroxybutyric aciduria | X | — | — | — | — | — |
| 2-Methylbutyrylglycinuria | X | — | — | — | — | — |
| 3-Methylglutaconic aciduria | X | — | — | — | — | — |
| Isobutyrylglycinuria | X | — | — | — | — | — |
| Malonic acidemia | X | — | — | — | — | — |
| Methylmalonic acidemia with homocystinuria | X | — | — | — | — | — |
| 2,4 Dienoyl-CoA reductase deficiency | — | X | — | — | — | — |
| Carnitine acylcarnitine translocase deficiency | — | X | — | — | — | — |
| Carnitine palmitoyltransferase type I deficiency | — | X | — | — | — | — |
| Carnitine palmitoyltransferase type II deficiency | — | X | — | — | — | — |
| Glutaric acidemia type II | — | X | — | — | — | — |
| Medium/short-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency | — | X | — | — | — | — |
| Medium-chain ketoacyl-CoA thiolase deficiency | — | X | — | — | — | — |
| Short-chain acyl-CoA dehydrogenase deficiency | — | X | — | — | — | — |
| Argininemia | — | — | X | — | — | — |
| Benign hyperphenylalaninemia | — | — | X | — | — | — |

| | Metabolic Disorder: Organic Acid Condition | Metabolic Disorder: Fatty Acid Oxidation Disorder | Metabolic Disorder: Amino Acid Disorder | Endocrine Disorder | Hemoglobin Disorder | Other Disorder |
|---|---|---|---|---|---|---|
| Biopterin defect in cofactor biosynthesis | — | — | X | — | — | — |
| Biopterin defect in cofactor regeneration | — | — | X | — | — | — |
| Citrullinemia, type II | — | — | X | — | — | — |
| Hypermethioninemia | — | — | X | — | — | — |
| Tyrosinemia, type II | — | — | X | — | — | — |
| Tyrosinemia, type III | — | — | X | — | — | — |
| Various other hemoglobinopathies | — | — | — | — | X | — |
| Galactoepimerase deficiency | — | — | — | — | — | X |
| Galactokinase deficiency | — | — | — | — | — | X |
| T-cell related lymphocyte deficiencies | — | — | — | — | — | X |

**Source:** Adapted from HRSA, *Recommended Uniform Screening Panel*, July 2024, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/rusp/rusp-july-2024.pdf.

**Notes:** "X" indicates condition is in that category; "—" indicates condition is not in that category.

a. Core conditions are conditions that are recommended for all newborn screening programs.

b. Secondary conditions are conditions that can be screened for by a newborn screening program following the diagnosis of a core condition.

## Author Information

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## Disclaimer