

Condition Nomination Form for Addition to Newborn Screening Panel

*New Conditions currently under review of the Federal Advisory Committee on Heritable Disorders in the Newborn and Children for addition to the Recommended Uniform Screening Panel (RUSP) will not be reviewed by the Pennsylvania New Condition Nomination Committee. The New Condition Nomination Committee will follow all federal rulings and will not review conditions previously nominated to the RUSP and denied, unless the deficiencies noted by the committee have been resolved.

*All sections of the Nomination Form must be completed. Incomplete forms will be returned to the Nominator. The New Condition Nomination Committee reserves the right to contact the nominator should additional information be required. Please utilize the space provided within the nomination form and avoid sending attachments.

NOMINATOR					
Name	Organization				
Affiliation (i.e., health professional, research	chers, clinician, advocate, relationship with affected individual)				
Address					
Email Address	Phone Number				
CO-SPONSORS (IF ANY)					
Name	Organization				
Affiliation (i.e., health professional, research	chers, clinician, advocate, relationship with affected individual)				
Address					
Email Address	Phone Number				

PLEASE ANSWER THE FOLLOWING QUESTIONS TO THE BEST OF YOUR ABILITY.

CONDITION BACKGROUND				
Date of Nomination				
Nominated Condition				
Symptoms and age of onset:				
How this disorder is currently identified?				
Why should it be screened for at birth?				
How is this disorder treated?				
Proposed Screening Test Method				

PLEASE ANSWER THE FOLLOWING QUESTIONS TO THE BEST OF YOUR ABILITY

PLEASE INDICATE IF THE FOLLOWING STATEMENTS ARE TRUE AND PROVIDE INFORMATION, RESOURCES, OR CONTACTS TO SUPPORT YOUR POSITION

1	. There is support from an appropriate screening facility and the nominated condition is considered feasible to add (i.e., newborn screening lab for blood spot screens and hospitals for point of care screens).	TRUE	UNSURI
2.	Clinical specialist(s) are available in Pennsylvania, or regionally, ready to accept referrals, and willing to manage patients found through screening.		
3.	The nominated condition can be found between 24 and 48 hours of life through screening but cannot be identified clinically in that time frame.		
4.	There is a screening test available now or expected within 12 months that can be done quickly and is successful in finding affected newborns.		

5. There is safe and effective treatment and/or intervention available which	
provides significant improvement in quality of life when administered early	٧.

6. There is an infantile onset form of this condition (a "Infantile onset form" is one in which symptoms develop under one year of age).

NEXT STEPS:

Submit nomination to:

RA-TCNBSAdmin Fax@pa.gov

Or mail to:

Pennsylvania Department of Health Newborn Screening and Follow-up Program Attn: Coordinators of the New Condition Nomination Committee 625 Forster St. 7th Floor Harrisburg, PA 17120

The new condition nomination committee coordinators will confirm receipt of the nomination and may request further information. Submissions will be reviewed by the new condition nomination committee for determination of next steps within 60 days of receipt of the Nomination Form. Nominated conditions that receive initial subcommittee approval will be presented to the Pennsylvania Newborn Screening and Follow-up Technical Advisory Board for review and final approval. The new condition nomination committee coordinators will be in contact with you regarding the outcome of your nomination.

REV 7/28/2023