**Newborn Screening: what to do if a family refuses one or more of the newborn screenings**

* *Ensure* that the refusal is an informed decision by reviewing the importance of newborn screening and the serious implications (potentially life threatening for blood and heart screening) of choosing to decline screening.
* *Inform* the baby’s medical home of the refusal.
* *Document* the refusal in a consistent and accessible manner in your organization’s records (i.e. signed refusal of care form in the child’s health record).
* *Report* the refusal to the State Newborn Screening Program.

**Reporting Refusals to the State Newborn Screening Program**

There are two options for reporting information to the State Newborn Screening Program: 1.) on the blood card or 2.) via a Case Add Request in WE-TRAC. Information in WE-TRAC comes directly from the blood card submitted to the State Laboratory of Hygiene when a baby in your care received a newborn blood screening. If the family refuses the newborn blood screening, their information does not enter WE-TRAC automatically. Instead, providers need to manually add the information.

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|  | **Do I need to submit a Case Add Request in**  **WE-TRAC?** | **Can I document refusal on the blood card?** | **Do I have to manually close as refusal in  WE-TRAC?** |
| Refusal of both Blood and Hearing Screenings | Yes | No | Yes |
| Refusal of Blood but Acceptance of Hearing Screening | Yes | No | No |
| Acceptance of Blood but Refusal of Hearing Screening | No | Yes | No (as long as you marked refusal on the blood card) |
| Refusal of screening for Critical Congenital Heart Disease (CCHD) | *Please see special note regarding CCHD Screening* |  |  |

**Refusal of *both* Blood and Hearing Screenings:** If the family refused both blood and hearing screenings, submit a *Case Add Request* in WE-TRAC to document both refusals.

Step 1: Document refusal of Blood Screening

1. Log onto your organization’s WE-TRAC queue
2. Click on the green “Add Case” button on the left-hand side of your organization’s queue
3. Enter all the demographic information for the child
4. Select that the family *Refused* the blood screening
5. Leave the hearing screening results *blank*
6. Click Submit
7. You will receive an email telling you that your case add request has been processed

Step 2: Document refusal of Hearing Screening

* 1. Log onto your organization’s WE-TRAC queue
  2. On the right-hand side of your queue is a Manage Cases drop-down menu
  3. For the case who refused hearing screening, select “Close Case” from the manage cases drop-down menu
  4. Choose “Refusal” from the closed case options
  5. The case will no longer appear on your WE-TRAC queue and you have successfully reported the refusal to the State Newborn Screening Program

**Refusal of Blood but Acceptance of Hearing Screenings:** If the family refused blood but accepted hearing screening, submit a Case Add Request in WE-TRAC to enter hearing screening results and document blood screening refusal.

1. Log onto your organization’s WE-TRAC queue
2. Click on the green “Add Case” button on the left-hand side of your organization’s queue
3. Enter all the demographic information for the child
4. Select that the family *Refused* the blood screening
5. Enter the child’s *Hearing Screening Results*
6. Click Submit
7. You will receive an email telling you that your case add request has been processed
8. If the hearing screening results are pass/pass, the case is archived and will not appear on your WE-TRAC queue
9. If the hearing screening results were not pass/pass, the case will appear on your queue for further follow-up and referrals to service
10. Manage this case as you normally manage other cases that enter your queue

**Acceptance of Blood but Refusal of Hearing Screening:** If the family accepted blood but refused hearing screening, their information will automatically enter WE-TRAC. You *do not* have to submit a Case Add request.

You have two options to document hearing screening refusal (when the child has received a blood screening).

Option 1: Mark “*Refused*” under the Hearing Screening section of the Blood Card, this case will enter WE-TRAC and be archived. This case *will not* appear on your WE-TRAC queue.

Option 2: Manually close the case as “*Refused*” in WE-TRAC

1. Log onto your organization’s WE-TRAC queue
2. On the right-hand side of your queue is a Manage Cases drop-down menu
3. For the case who refused hearing screening, select “Close Case” from the manage cases drop-down menu
4. Choose “Refusal” from the closed case options
5. The case will no longer appear on your WE-TRAC queue and you have successfully reported the refusal to the State Newborn Screening Program

**Refusal of Screening for Critical Congenital Heart Disease (CCHD) by Pulse Oximetry (POX):**

If a family refuses CCHD screening, record “Not Screened” on the newborn blood card. Complete the “Not Screened for CCHD by POX” form and submit to the Wisconsin State Laboratory of Hygiene (WSLH). This form is available online as a fillable form at: [www.wisconsinshine.org/study/Not-Screened-CCHD.docx](http://www.wisconsinshine.org/study/Not-Screened-CCHD.docx). If there is no blood card because blood screening is declined, please submit this form only.

The completed form may be enclosed with blood cards submitted to the WSLH or mailed separately to the following address: Newborn Screening Laboratory

Wisconsin State Laboratory of Hygiene

465 Henry Mall

Madison, WI 53706

Completion of the form should **NEVER** delay submission of blood cards.

**Blood Cards and Birth Certificates**

* If the baby had a blood screening performed, enter the child’s blood card number in the Blood Card ID field in the State Vital Records Information System (SVRIS).
* If the family refused newborn blood screening, enter **X99999** in the Blood Card ID field on the child’s birth certificate worksheet and in SVRIS.

**Accurately documenting the Blood Card number or the refusal code helps the Newborn Screening program ensure that all families who want blood and hearing newborn screenings for their babies receive them and follow-up when necessary.**

(Developed by the Wisconsin Newborn Screening Program July 2014)