

Things to Know

- ❖ Blood spot cards are the easiest way to make a quick diagnosis. There are usually two bloodspot cards per baby taken routinely; one soon after birth, and the other after death during autopsy. Your personal circumstances will determine which card you are able to obtain.
- ❖ When the card is no longer available OR you would like to find the genetic markers of the disorder, other samples will be needed. Many samples are taken during autopsy and then kept by the medical investigator. Depending on the type of sample, they are kept for varying time periods. Post-mortem bloodspot cards are usually kept for a few years. Our son's card was still available three years after his death.
- ❖ If your circumstances require contacting the Office of the Medical Investigator, keep in mind that these offices are extremely busy. Many times one facility performs all the autopsies for an entire state. The employees there primarily deal with funeral homes, police departments, hospitals, and legal issues. They rarely interact directly with families, and will appreciate respectful direction from you.
- ❖ Remember: All samples taken from your child are yours. YOU legally own them. Do not be afraid to ask for or demand what you feel needs to be done.

State by State – Newborn Screening Cards

AL.....3-6 Months	LA.....Under 3 Months	OH.....Under 3 Months
AK.....7-12 Months	ME.....Indefinitely	OK.....Under 3 Months
AZ.....3-6 Months	MD.....13 Mos. -23 Yrs.	OR.....7-12 Months
AR.....7-12 Months	MA.....Indefinitely	PA.....3-6 Months
CA.....Indefinitely	MI.....13 Mos. -23Yrs.	RI.....13 Mos. -23 Yrs.
CO.....3-6 Months	MN.....13 Mos. -23 Yrs.	SC.....Indefinitely
CT.....3-6 Months	MS.....3-6 Months	SD.....Under 3 Months
DE.....Under 3 Months	MO.....3-6 Months	TN.....3-6 Months
FL.....13 Mos. - 23 Yrs.	MT.....Under 3 Months	TX.....3-6 Months
GA.....Under 3 Months	NE.....Under 3 Months	UT.....3-6 Months
HI.....7-12 Months	NV.....7-12 Months	VT.....13 Mos. -23 Yrs.
ID.....7-12 Months	NH.....13 Mos. -23Yrs.	VA.....13 Mos. -23 Yrs.
IL.....3-6 Months	NJ.....13 Mos. -23 Yrs.	WA.....Indefinitely
IN.....13 Mos. -23 Yrs.	NM.....3-6 Months	WV.....3-6 Months
IA.....Under 3 Months	NY.....3-6 Months	WI (S. ½).....7-12 Months
KS.....Under 3 Months	NC.....13 Mos. -23 Yrs.	WI (N. ½) 13 Mos.-23Yrs.
KY.....3-6 Months	ND.....Under 3 Months	WY.....3-6 Months

Provided By:

Save Babies Through Screening Foundation, Inc.

Toll Free: 888-454-3383

www.savebabies.org

GETTING ANSWERS

A Parent's Guide For Metabolic Screening After Your Child's Death

Trying to get answers and understand the cause of your child's death is extremely exhausting; mentally and emotionally. During this most stressful time in your life, the last thing you should have to do is fight for answers. I assure you the peace from knowing is well worth your efforts.

My husband and I have lost two infant sons to *Very Long Chain Acyl-CoA Dehydrogenase Deficiency* (VLCAD), a detectable but not yet routinely tested for metabolic disorder. Both boys were born seemingly healthy, both scoring 8 at one minute and 9 at five minutes on the APGAR. Our first son, Storm Tyler Hall, died at 28 hours old in 1996. His cause of death was misdiagnosed as a heart defect. Three years later in 1999 our second son, Tiger Jordan Hall, also died at just 28 hours old. We were told that our son's deaths were not related since Tiger's extensive heart testing after birth was normal, and Storm's death was thought to be a heart defect. We knew that the cause was the same. After learning about metabolic disorders, we were confident it could be the answer, and requested the testing. However, it was more than six months later, after a great deal of pressure on our part, when the test was performed and the diagnosis was finally made for our second son. It took additional time and effort to get our first son's case re-opened and his cause of death amended to show the same cause of death as his brother, VLCAD.

Since my experience with the Office of the Medical Investigator (OMI), I have had many bereaved parents ask for advise on metabolic screening for their child. For this reason, I have compiled information for parents in the same position. I hope that you will find this helpful in your efforts, and give you hope that you CAN get the answers you need. It will not be easy, but you have already experienced the worst – your child has died. Remember, only you have the authority to demand the answers you and your child deserve.

By Kileen Hall

Select a Screening Lab

There are two major labs which provide this screening. Each screens for different disorders. Call or go online to see their options.

Baylor Medical Center: 1-800-4-BAYLOR
www.baylorhealth.com/newbornscreening

NeoGen Screening: 1-866-4-NEOGEN
www.neogenscreening.com

Contact the Lab

Once you have selected a lab, you need to contact them. Make a note of the person you speak with. Be sure they understand that your child has died.

- a. Verify specific shipping instructions, have them e-mail or fax the instructions to you to avoid confusion and save time. *(Although this is usually very simple; just put in an envelope and mail.)*
- b. Ask to be contacted personally with the results, give phone, address, e-mail etc.
- c. Verify who to contact to inform when the samples are enroute.

Locate bloodspot card

Hospital bloodspot card:

At approximately 24 hours old, every baby is pricked on the heel and a few drops of blood are put on a special filter paper. Depending on which state you live in, the card will be tested for 3-8 disorders. After testing, some states keep their newborn screening bloodspot cards for varying time periods. Others keep them indefinitely. Please see the list on the back cover for your state's procedures. To obtain this card you would need to contact your local Department of Health.

Post-mortem bloodspot card:

It is standard procedure for the Office of the Medical Investigator (OMI) to take this sample during autopsy. This card is available ONLY if your child has had an autopsy, and may be located by contacting OMI.

Depending on how far you live from OMI, you may want to go in person. I realize that this can be difficult considering that just doing everyday things isn't easy right now. But it is usually more effective and you are less likely to be put-off. Definitely make an appointment if you don't live close by or want to talk to the specific pathologist that was involved in your child's case.

Type an Agenda

Make a clear concise outline with your objectives, bring extra copies to give to anyone you speak with. Having an agenda to follow will help you stay focused and feel more in control during an emotional time. Giving them something in writing eliminates any misunderstanding as to the purpose of your visit. It also provides you with dated, written proof of your meeting and requests.

The Agenda Needs to Include:

- **The Date of the meeting**
- **Your contact info:** Name, Phone, Address, E-mail
- **Objective:**
 - Tandem Mass Spectrometry Screening (MS/MS) for your child.
- **Lab Info:**
 - Name of person you contacted
 - Address, Phone Number, E-mail
 - Shipping Instructions, include copy of fax or email sent from lab to you.

Optional to Include:

- **Requests:**
 - Print out showing ALL remaining samples of your child.
 - Retain remaining samples indefinitely. (Or until you feel confident of the findings.)
 - Addendum to the autopsy and correction to the death certificate upon new findings.
 - Copy of the autopsy report upon completion. (It is not routinely sent to the family)