



# NBS Unity Quilt

*A Celebration of Rarity*

## THE IDEA AND MISSION

---

Quilts are beautiful works of art that provide warmth and comfort as well as allowing people to unite together in making them. Many cultures have a tradition of quilting. The quilting groups of the past would share stories, memories and hopes for the future - overall enjoying one another's company. It is hoped that the NBS Unity quilt will allow the families and friends of today to enjoy this tradition of yesterday.

The NBS Unity Quilt will allow families to celebrate and share the lives of their children who were born with disorders detectable through newborn screening, including children spared, children lost and children damaged or otherwise hurt.

The mission of the NBS Unity Quilt is to create a visual testimony of the most compelling symbol of newborn screening - the children touched by it.

## THE DISPLAY

---

The Quilt can be a heartfelt tool in the fight for proper NBS. The quilt panels will be displayed each year during the month of September, which has been declared as Newborn Screening Awareness Month.

The first unveiling was in September 2001 at Virtua West Jersey Hospital in Voorhees, New Jersey at a ceremony recognizing New Jersey Governor, Donald DiFrancesco, and Virtua Health for their proactive efforts and commitment to better newborn screening. The initial unveiling on the quilt contained approximately 30 quilt panels, representing more than 14 disorders.

For more information about the NBS Unity Quilt project, please send an email to the project director at [quilt@savebabies.org](mailto:quilt@savebabies.org) or by calling (816) 640-0127.

## SAVE BABIES THROUGH SCREENING FOUNDATION, INC.

---

Save Babies Through Screening Foundation, Inc. is a non-profit volunteer organization whose mission is to improve the life of babies by preventing mental retardation and death resulting from disorders detectable through newborn screening.

The Foundation was created in 1998 by a family in Georgia who lost their infant son, Tyler Wayne, to galactosemia, a completely treatable condition that can be detected through the newborn screening test. It is their hope that the foundation will help to prevent other families from having to endure the pain of losing a child needlessly, maybe even yours.



*SAVE BABIES THROUGH SCREENING*

4 Manor View Circle • Malvern, PA 19355  
Phone 1-888-4LIFE-83 • Fax 610-993-0545 • [www.savebabies.org](http://www.savebabies.org)

**NEWBORN SCREENING: *Saves Babies One Foot At A Time***®

# HOW TO PARTICIPATE IN THE UNITY QUILT PROJECT

## CREATING THE PANEL

---

- Include the name of the person being honored or remembered
- Include the person's disorder name (abbreviations acceptable)
- Include the person's date of birth and death (if applicable)
- Include the person's hometown

You can create one panel for each person you would like to remember/honor, or you may include all the affected siblings of one family on the same panel. Panels with more than one celebrated person should all be of the same family (siblings). Participation is open to families with children or individuals with disorders currently detectable through newborn screening. \*\*See list at bottom of submission form for disorder listing.

## PANEL SPECIFICS

---

Durability of each panel is crucial since the Quilt will be folded, unfolded and transported all over the country many times. It is recommended that glue not be used on the panels, since it deteriorates with time. It is requested that all items attached to the panels be solidly sewn in place. Please use a medium-weight, non-stretch fabric to create your panel.

## SIZE SPECIFICS

---

Create panels to be placed horizontally (long ways) on the finished quilt. It should be 3 feet by 6 feet (90 cm x 180 cm)—no more and no less—in size. To help facilitate the complete quilt, edges should be hemmed. If you are unable to hem the edges, please send the panel anyway—we will hem the edges when necessary. Remember when you cut your fabric for the panel to leave an extra 2-3 inches on each side for the hem. It is not necessary to place batting inside the panels. However, a backing is recommended to help keep the panels clean when they are displayed across the flooring or ground.

## DESIGN IDEAS

---

There are many techniques you can use in constructing your panel. Here are just a few ideas:

- **Photos**  
Photos can be easily used in the panel design by printing them onto iron-on transfers. This can be done using your personal computer and color printer. You can iron the transfer onto a separate piece of fabric and then attach the piece of fabric on the panel.
- **Paint**  
You may choose to paint items on the panel. You may use textile paint, colorfast dye, or indelible ink pens. You can also use sponges to apply the paint. Another idea is to use stencils to paint the designs on the panel. Please don't use "puffy" paint as it remains sticky even after drying and may smudge or stick together when folded.
- **Appliqué**  
You may choose to sew fabric, letters and small mementos onto the background fabric. Please do not use glue to attach these items, as it will not endure the frequent folding and unfolding of the quilt.

- Collage  
You can place almost any type of item on the panel; however, please make sure that the materials you use won't tear the fabric and will remain in place when the quilt is transported. Please avoid using glass and sequins, as they will tear the fabric over time. Bulky items should also be avoided.

---

## **INCLUDE A LETTER WITH YOUR PANEL**

---

Please include a one-page letter about the person you are celebrating along with your panel. If possible, please also include a photo of the celebrated person along with the letter. These will be kept at our offices and may be displayed along with the quilt from time to time.

---

## **FILL OUT PANEL SUBMISSION FORM**

---

This form provides vital information we need about you and your panel. Please fill out the form below and return it with your panel.

---

## **WHERE TO SEND THE PANEL**

---

Finished panels should be sent to:

Kelly Peters  
22440 County Road M  
Weston, MO 64098

Please send your panel via registered mail or with a courier service, such as UPS, FedEx or Airborne Express, so that you can track the package and ensure its delivery.

Be sure to include a completed panel submission form with your panel.

Once a completed panel arrives at our office, it will be examined for durability and all your information logged into our quilt database. If required, all adjustments, repairs, and/or reinforcements will occur at this time.

Panels will be sorted by state and region. Once eight panels of the same region are collected, they will be sewn together to make the complete quilt. Each panel will be numbered and recorded as to its placement in the quilt and logged appropriately. The submitting family will be notified of the location of the panel (serial number) and supplied with information on how to request the quilt containing your panel for display. A quarterly display schedule will be included in the Save Babies Through Screening newsletter.

---

## **HELPING WITH FINANCIAL COST OF THE PROJECT**

---

Save Babies Through Screening depends on the support of the families who submit panels for the quilt to keep the project going. Costs to create, transport, repair and maintain the quilt will continuously occur. If you are able, please make a donation to the project to help cover the expense to keep the project going. A minimum donation of \$25.00 per panel is requested to help cover these costs; however, all submitted panels will be included in the quilt, with or without a donation.

Some families have solicited donations from families, friends, and local businesses in memory of or in honor of the celebrated individual. Or they make a yearly contribution to the project in celebration of the affected person's birthday, holiday, or special occasions.

Any amount is appreciated and will be used solely for this project.

All donations should be made payable to Save Babies Through Screening Foundation, Inc., with "NBS Unity Quilt" in the memo line of the check.

