



The Journey...

Creating a Legacy for Your Baby

Please know our thoughts are with you and your family at this time. We appreciate your desire to donate and are happy to partner with you in creating a legacy for your baby. You may have already met with your local organ procurement organization. They may have discussed donation options with you. If you have not yet met with your organ procurement organization, we can help you get in contact with them.

As you will learn, human transplantation allows for donated gifts such as livers, kidneys or hearts to save lives. However, transplantation is not an option in every circumstance. In those cases and upon passing, your baby may be able to donate gifts to medical research and education which can benefit many, many lives.

The International Institute for the Advancement of Medicine (IIAM) is a non-profit medical research organization that works with researchers and medical education organizations in the U.S. and abroad.

We guide families who wish to consider organ/tissue donation to find ways for their baby's gifts to help others. We will work very closely with you, your doctor, your delivery hospital, and your local organ procurement organization in hopes of providing an opportunity to add another layer of meaning to a precious and brief life.

Thoughts you may have

Will I be able to hold and see my baby after he or she is born?

Yes, your care team will work very closely with you so that you will have bonding time with your baby. You and the medical team will be made aware prior to delivery of any critical timelines for consideration to ensure donation of your baby's gifts remains possible. Your care team will support you to help balance personal time without compromising the recovery of the gifts.

You may also arrange time after organ recovery to hold your baby and proceed with any additional personal plans if you wish. Otherwise, we suggest you make arrangements with a funeral home and communicate this with your care team.

Will there be any expense to my family as a result of donation?

IIAM will incur all expenses related to the donation of organs and tissue for medical research to our organization. We recommend you discuss any hospital or customary delivery expenses with your caregivers so you have clear expectations.

What do I need to do?

- **Consent/Authorization:** You will need to complete a form with the local organ procurement organization.
- **Blood Work:** Blood work will be obtained to determine blood type and Rh factor of the mom. The blood will also be evaluated for standard infectious disease screening.
- **Medical-Social History:** Completion of a questionnaire will provide the organ procurement organization with an understanding of important past medical history and social behaviors of the mom.

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What donation options can we consider?

All organs/tissue are evaluated at the time of referral. While every effort will be made to make donation for research happen, unforeseen events may occur to prevent this. It's important that you are aware of this possibility and have considered alternate plans.

What happens to my baby when the donation has been completed?

Upon completion of the organ recovery, the hospital team will return your baby to you unless other arrangements have been made. Arrangements with a funeral home will need to be specified and will proceed accordingly.

Is there someone I can contact for more information?

- You can communicate with a Family Services Coordinator at IIAM with any additional questions or needs you may have: 800-486-IIAM (4426).
- Once this process begins, we will pair you with one of IIAM's team members who will partner with you and guide you through the donation process.
- Attached is a list of other resources you may find helpful as you go through your journey.

Please know our thoughts will remain with you and your family. We deeply appreciate your desire to donate.

Internet Resources



www.purposefulgift.com

Purposeful Gift promotes organ and tissue donation among expectant families who have received a terminal diagnosis.



www.sustaininggrace.org

Sustaining Grace is a non-profit organization whose mission is to provide free 3D/4D ultrasounds to families who have received a terminal diagnosis during pregnancy. The goal is to give families special bonding time with their child.



www.prenatalpartnersforlife.org

Prenatal Partners for Life is a non-profit whose goal is to encourage families to carry babies to term after receiving a negative diagnosis. They provide information, stories and support aids on the website. They also provide free "gifts of love" care boxes for families upon request.



www.perinatalhospice.org

Perinatal Hospice and Palliative Care is another organization that provides resources for families who have received terminal diagnoses. Among their many resources, they highlight a book: *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief* which is a leading book on coping with a life limiting diagnosis.



www.stringofpearlsonline.org

String of Pearls is another non-profit whose goal is to support families after receiving a terminal diagnosis. They provide a free "care/memory kit" to use at the hospital to help families create memories with their baby.



www.nowilaymedowntosleep.org

Now I Lay Me Down To Sleep is a group of photographers who donate time and services to families. All photographers in this group have been trained in assisting families facing infant loss, and provide services free of charge.

Anencephaly Specific Resources



www.anencephalie-info.org



www.anencephaly.net

These are two of the most helpful websites for families carrying babies diagnosed with Anencephaly. Both have extensive information, stories, and in-depth resources (including birth plans, memory making ideas, grief counseling info, and TONS more).