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## How a baby's brief life had a 'positive impact'

After her infant son Thomas died, Sarah Gray donated his organs and tissues to medical research. Finding meaning in Thomas' death has helped Sarah cope with the loss of her son



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**PUBLISHED** Dec. 6, 2016 n 2009, Sarah Gray and her husband Ross were excited at the prospect of welcoming identical twins into the world. Three months into the pregnancy, however, the Washington, D.C., couple found that one of the boys had a rare condition called anencephaly – a birth defect restricting brain and skull growth.

The doctors predicted that the baby, whom the Grays named Thomas, would die during childbirth or live only a few hours or days. Hearing this, Sarah asked the medical staff if



Sarah Gray, author of A Life Everlasting: The Extraordinary Story of One Boy's Gift to Medical Science

'Being able to see that his tissues could be studied to help people that are still alive has been helpful while going through the grief,' Sarah Gray says. she could donate Thomas' body for transplant purposes. They put her in touch with the Washington Regional Transplant Community, an organ procurement organization.

On March 23, 2010, Thomas and his brother Callum were born. Six days later, Thomas passed away.

"I wanted to find a way for Thomas' brief life to have some kind of positive impact," Sarah said during a recent interview. She wanted to see the tragedy less as a loss and more as an opportunity.

"We asked our local organ procurement organization if we could donate for transplant, but they said he would probably be too small, but he would be able to donate to medical research. I said, 'Sure, whatever you want, you can have.' And so they were able to match the tissue he had to offer with a few different things."

Thomas' tissues went to four different places:

- His core blood was donated to Duke University.
- His liver was sent to a cell company called Cytonet, in Durham, N.C.
- His retinas were donated to the University of Pennsylvania's medical school in Philadelphia.
  His corneas were donated to Schepens Eye
- Research Institute, an affiliate of Harvard Medical School.

Finding meaning in Thomas' death has helped Sarah cope with the loss of her son.

"There's something that really takes away the loss," she said. "It's sad no matter what, and that's OK. But being able to see that his tissues could be studied to help people that are still alive has been helpful while going through the grief."



At home in D.C. last September: Sarah Gray with her son Callum, then 6, and infant daughter Jocelyn.

To Sarah, it was great to hear that her son's tissues had been successfully donated, but she still had a few questions on her mind: What happened next? Was the donation worth it?

She decided to take action and find the answers. Sarah started her journey by contacting her local procurement group in Washington, DC. They put her in contact with Old Dominion Eye Foundation in Richmond. This was the eye bank that received Thomas' corneas in March 2010.

The first person to handle Sarah's request of information was Christina Jenkins, the eye foundation's associate director.

"She wanted to know what type of research was done with the tissue," Jenkins said. "I never had that request before. I didn't know how to handle it; a lot of times we know what the research project is and sometimes we don't.

"I pulled the chart and discovered that it went to Schepens Eye Research Institute. I emailed that to her, and she emailed me right back and said, 'Oh wow, I can say my son went to Harvard.' To me, for someone to have such a positive outlook just on that little piece of information she had, it was really touching – especially as a parent."

In the years since her son's death, Sarah Gray has been one of the nation's leading advocates for organ donations. She has written a memoir, *A Life Everlasting: The Extraordinary Story of One Boy's Gift to Medical Science*, and given an inspiring TED Talk that has been viewed nearly 1.4 million times.

Sarah often jokes about how Thomas got into different schools.

"Thomas got into Harvard, Duke and Penn, and he has a job at Cytonet, and he has colleagues

'When you really break it down and look at all of the potential diseases that they may be able to cure or treat that directly relate back to Thomas, it's pretty powerful.' and coworkers, and they need him in order to do their job," she said in her TED Talk.

In October, Sarah returned to Richmond to visit the Old Dominion Eye Foundation, which was a turning point in her quest to learn about what happened to Thomas' body. This was the organization that pointed her in the right direction and guided her through the organ donation and organ research process.

The nonprofit foundation, which was formed in 1962, helps thousands of people each year. Its slogan is simple yet profound: "Imagine a gift that could be opened 1,000 times a day and see a lifetime of smiles."

The Old Dominion Eye Foundation is led by William Proctor, the group's chief executive officer, and Jenkins. They have dedicated their lives to advocating for organ transplant and research.

"One of the most powerful parts of my job is working with the donor families," Jenkins said. "That is something that's really dear to me – being able to provide them some light in a very dark time. It's my pleasure to do that, and my honor to be a part of that, and that's the piece of the job that really kept me here."

Many people don't realize the potential benefit of donating organs to the scientific community. Sometimes, the donation can be to a specific person. But even when it's not, an organ donated to research can help millions of people.

"The research is not just about helping thousands now but into the future," Proctor said.

"With Thomas, they still have his cells that they will use ongoing. When you really break it down and look at all of the potential diseases that they

## Want to be an organ donor? Here's how

An important part of becoming a donor is having a conversation with your family. It's critical to let them know that you want to help people by donating; that will make it an easier transition when the time comes.

To register as an organ, eye and tissue donor, visit <u>www.DonateLife.net</u>. That is the website of a Richmond-based nonprofit group called Donate Life America.

One person can save up to eight lives through organ donation, restore sight to two people through cornea donation and heal up to 75 people through tissue donation, the website says. may be able to cure or treat that directly relate back to Thomas, it's pretty powerful."

Nobody knows that more than Thomas' mother.

Sarah Gray has since had a daughter – Jocelyn – and serves as the director of communications for the American Association of Tissue Banks in McLean, Virginia. Her story shows the true potential of a mother's strength and its benefits to the community. The donation of Thomas' tissues has had a monumental impact on families, organ donors and researchers.

"For grieving families that are about to face a loss, and they have a choice to make and they want to think about donating, I would recommend it," Sarah said. "I can't guarantee every experience is going to be like mine. But I did it, and I had a good experience, and I recommend it." •

This article also was published on Dec. 6, 2016, by RVAHub.com, a news portal for the Richmond area.