

TRIO Philadelphia presents:

Mommy Can Play Again



A story for children of families facing transplant - based on a real-life story as illustrated by transplant family children

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Mommy Can Play Again: Based on real-life events, this is a story for children of families facing transplant, illustrated by children of TRIO Philadelphia chapter transplant families; conceived, created and edited by the TRIO Philadelphia chapter.

Summary:

Molly learns about her mother's need for a lung transplant. In time, after that successful transplant, Molly can play in the sandbox with her mother again.

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Testimonials

"A wonderful, realistic story of lung transplant, as seen through the eyes of a child. **Mommy Can Play Again** is a powerful reminder that when major illness strikes a family, both parent and child long to return to happier times."

- Chas Devlin, father, heart/double lung transplant recipient

"As a donor family member, I loved this book and especially the part where they call the new lungs "a gift". I love the illustration of the beautifully wrapped box with a bow. Donor families are happy when they learn their loved one has helped another family so their **Mommy Can Play Again**."

- Diane Milbourne, organ donor spouse

"Upon reading **Mommy Can Play Again**, I realized how important it is to explain to children the complicated world of organ transplant. This book with the artwork by children involved in the process is an excellent example of first hand feelings and art to get a handle on this. As an artist, I too drew many pictures of lungs with butterflies and my three lungs on a clothesline while awaiting transplant."

- Maureen Sweeney, heart/double lung transplant recipient

"I wish I had this book 18 years ago for my children."

- John Clyde, heart transplant recipient, father of three

"The book is very, very good and hits the issue in a non-threatening yet non simplistic way. I think it will benefit a great deal of children and bring comfort to their parents as well."

- Liz Shore, heart transplant program social worker

"Mommy Can Play Again nuzzled my transplanted heart with true-life experiences and encouragement we all need—adults and children alike."

- Cindy Scinto, transplant recipient, author (A Heart Like Mine trilogy) and speaker

"Pictures bring to life a journey of fear to hope to thriving in this stunningly simple yet evocative true story. Children will find healing and their relationships with their ailing parents will be enriched."

- Lynne Samson, Executive Director/CEO HelpHOPELive (formerly NTAF)

"What a wonderful resource for transplant families. We would recommend this book to anyone who wants to explain organ donation and transplantation to children. This book should be in every library."

 Vincent T. Armenti, MD, PhD, Principal Investigator, and Lisa A. Coscia, RN, BSN, CCTC, Transplant Registry Research Coordinator, National Transplantation Pregnancy Registry (NTPR), Thomas Jefferson University, Philadelphia, PA

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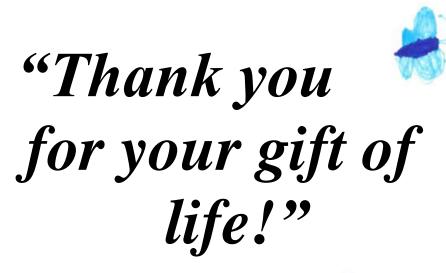
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Dedication

This book would not be possible without those lung, liver, heart, kidney, pancreas, intestine and tissue donors who at their time of tragedy gave life to each of us. Their gifts restored a healthy life that allowed the children in our families to have the care and love that only a parent can give.

Words cannot express enough the gratitude that each of us along with our families offers those deceased and living donors.

We dedicate this book to your memories and families with a heartfelt message from our families:







Special thanks

A very special "thank you" to the families of the TRIO Philadelphia chapter who came together to make this book possible. Each family has lived the experience that is the story in this book in their own way. Whether lung recipient mother, heart recipient father, liver recipient mother, kidney-pancreas mother or donor family, all have had children who lived through family members other than themselves who underwent an organ transplant and thus contributed to the writing and artwork from their unique perspective.

Kathi is the mother to twins, Paul and Sarah. Her lung transplant story (transplanted in 2006 due to complications with Cystic Fibrosis) was the basis for the book's narrative (i.e., Molly's mommy). At ages 7, it was amazing to see those two young children quietly take a part of the story and create their image of how they saw it. (blog site: <u>http://mymommyhadadoublelungtransplant.blogspot.com/</u>)

Dan, a father with two sets of twin girls: Amanda and Tabitha, now 17, and Lucy and Sarah, now 13, who had supported him through his heart transplant in 2005. Each girl volunteered their artwork based on how they saw their artistic skills, one "I do people," another "I do scenes," etc.

Faith, a kidney-pancreas recipient in 1992, gave birth to her two daughters after transplant. Elizabeth, 10, and Erin, 8, enjoyed working on the inside cover together.

Elizabeth, with a liver transplant in 1992, brought her college-aged daughter Isobel, who helped come up with the title and a draft for the cover after declaring herself not an artist, thus finding her own niche of contribution to the team effort.

Jim, a 1994 heart recipient and now donor family member through marriage, did a final piece of artwork and youthful/insightful review and edit with Keira, his 7 year old granddaughter. It was amazing to see her read each page and suggest thoughts that came to her only to find that that thought indeed was in the next page of the draft she was reading, confirming that this book was "spot on" as they say for this intended audience. (blog site: http://gleasonjim.wordpress.com)

And **Susan**, a 1998 kidney-pancreas recipient, who took photos of the book creation event and supplied all the art supplies and guidance for that book creation party.

All in all, this was truly a team effort and we hope you and your family will enjoy the result. It is intended that an adult will come alongside the youthful readers to guide them with the simple interpretation of complex concepts conveyed in the story. There are some surprising insights conveyed in the detail of the children's artwork (e.g., check out the "green ribbon" donor symbol in the carpet on page ten), but young readers will probably catch that better than the adult reader.

We hope that this will be a useful resource for families to explain to their children what is happening when another family member is facing an organ transplant. We have lived it. The support of those young family members can be most welcome and inspirational when things get rough for the patient. Come, enjoy the ride. Check out the team faces at the end of the book.

We are TRIO Philadelphia

In the mid-1980s, a group of transplant patients at the University of Pittsburgh Medical Center saw the need for an organization to help transplant recipients and candidates cope with the challenges they experienced in the transplant process. Out of this group TRIO was established, and in 1987



incorporated as a not-for-profit organization. It was soon determined that TRIO could best serve the transplant community by becoming an international organization and in 1994 moved its headquarters to Washington D.C.

TRIO Philadelphia started as a small group of recipients in the mid-1990s. They first began meeting at the local OPO offices, the Delaware Valley Transplant Program, now called **Gift of Life Donor Program**. The group grew from just five members to over 30, and in 1997 became chartered as **TRIO Philadelphia**. Over the years, TRIO Philadelphia has had over 100 members. Today it's continuing to grow with a new sense of purpose and energy. While most TRIO Philadelphia members are local, many live outside the immediate Philadelphia area of Pennsylvania in neighboring New Jersey and Delaware.

"<u>MOMMY CAN PLAY AGAIN</u>" was conceived and creatively developed by TRIO Philadelphia chapter members and their children, each of whom have lived Molly's story in their own family's lives. It has truly been a labor of love and service on behalf of our TRIO Philadelphia chapter. Through this undertaking we strive to fulfill TRIO's mission of supporting families who may find themselves traveling the same path of organ or tissue transplant while parenting young children who struggle to understand what is happening around them during this time of medical challenge.

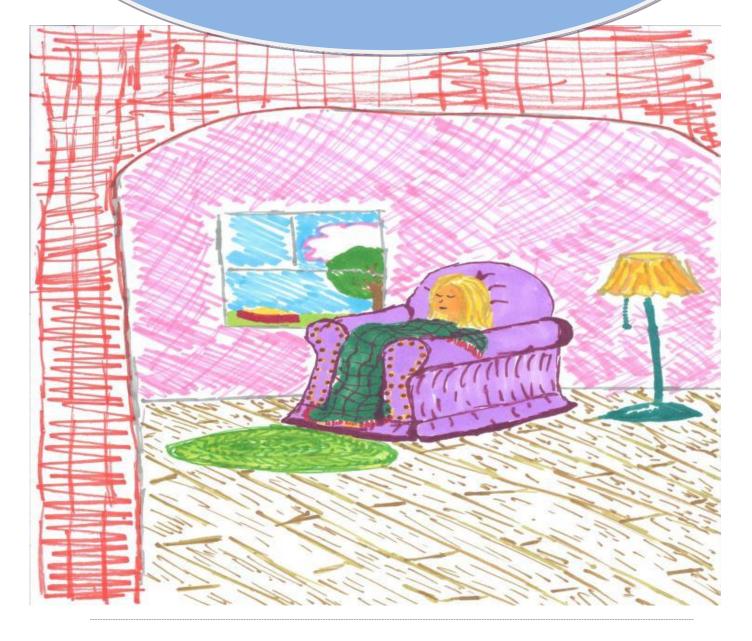


Molly's story

Molly's mommy loved playing in the sandbox with her.

At times, Molly's mommy had to sit back and rest while Molly played in the sand. One day, mommy stopped

coming to the sandbox with Molly. Mommy had to stay home and rest. Molly's dad said that her lungs were tired and that made mommy sleepy.



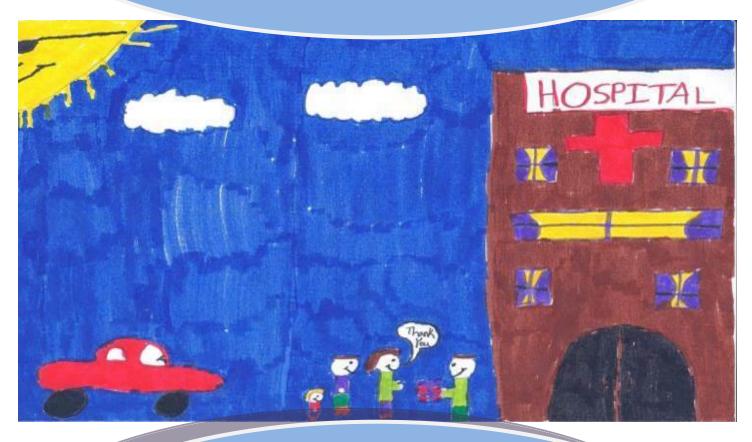
Molly liked to watch her mommy sleep. She didn't seem so tired when she slept.



But Molly wished she could play with her mommy like before. One day, mommy and daddy sat down with Molly and told her they had a surprise.



They told Molly that mommy was going to get an operation that would help her not be so tired and sleepy all the time.



This news made Molly happy. She really wanted her old mommy back. "When are you going to the hospital to get the operation, mommy?" "Well Molly," Daddy said, "that's the thing. mommy doesn't know exactly when she will go."

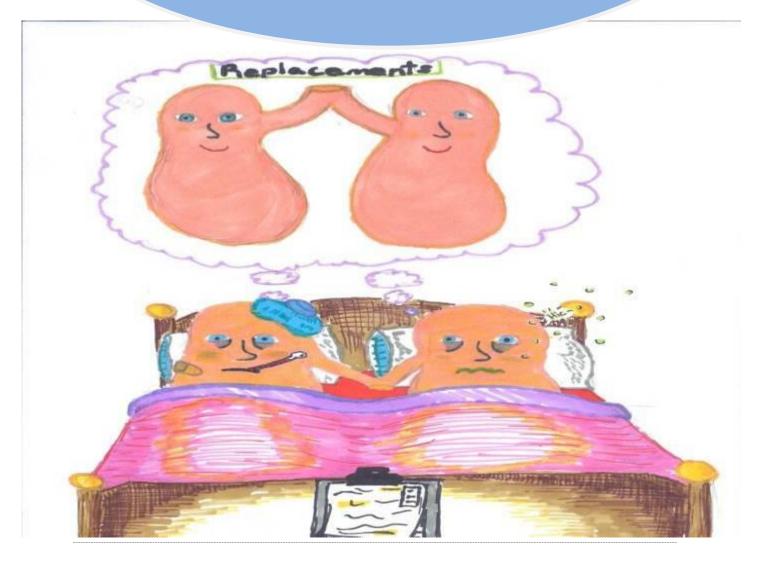
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"But how can that be?" asked Molly. She wondered why mommy

couldn't get better right away!



"You see Molly, mommy has to wait for a phone call telling her there are new lungs for her." "What new lungs? What's the matter with her old lungs? I thought they were going to make her better."

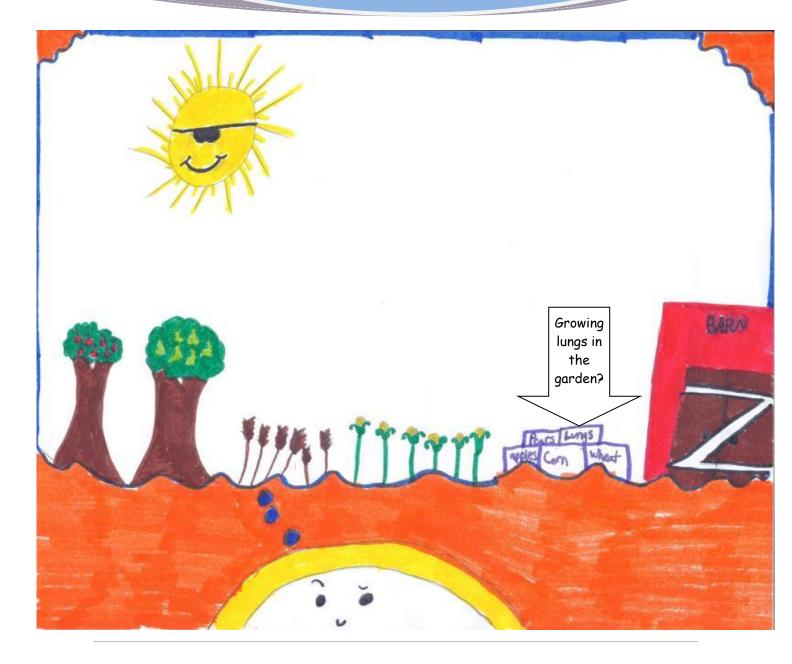


Mommy's old lungs were not working properly anymore.

Molly's dad said that mommy could not breathe with her old lungs. She needed new ones. Then, she would stop coughing and wearing oxygen tubing.



"Oh, WOW, do they grow her new ones?"

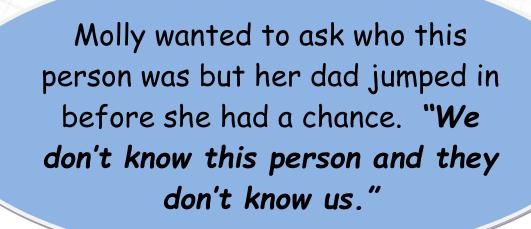


"No Molly. Someone donates their lungs to her."



Molly knew enough about the body to know that you only have one pair of lungs, and you could not give them away without dying. That made Molly sad. "You see Molly, a person who has died had already decided to give their lungs to someone like mommy who is very sick," dad said.

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"We don't know when this will happen; that is why we don't know when mommy will get her new lungs." It was hard for Molly to wait, but one day her mommy went into the hospital to get her gift of new lungs.

She came home feeling much better!



Now Molly can play with her mommy in the sandbox as before, just like she always wanted.

The End

Or rather . . .

A New Beginning

Meet our authors/illustrators

Three sets of twins and a few others from families of transplant recipients gathered at the Gift of Life Donor Program offices to edit and illustrate this story.



Meet our families



(Clockwise from top left . . .) Faith(kidney/ pancreas), Elizabeth (liver);Susan (kidney/ pancreas); (center) Dan (heart), Kathi (double lung), and Jim (heart)



Meet our sponsors

The following organizations have generously provided funding to support the printing and distribution of this book. TRIO Philadelphia offers a very special "thank you" for their support and faith in the project...



Giving Life a Second Chance Through Organ & Tissue Donation

https://www.donors1.org



https://www.caredx.com



http://www.pennmedicine.org

TRIO (Transplant Recipients International Organization)

Transplant Recipients International Organization: Your voice of the transplant community.

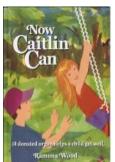


https://www.trioweb.org

Activities for readers

The following are some suggested activities to engage your child in the transplant experience closer to what your family may be going through. You may be able to come up with others that are more appropriate to your own child's age and level of understanding. Don't underestimate a child's ability to understand. In testing this book with children of various ages, it was surprising to hear how they related to, and were able to share their thoughts behind the childlike drawings that may seem too simple to the adult reader. . .

- Read this book aloud with children, letting them read it to you, engaging them in discussion about the story and their family's transplant experience
- Together with children, review many of the story's illustrations for the detail that the child artists on their own incorporated into those pictures, such as lungs growing in the garden on page 19, or the green ribbon in the carpet on page 10, a symbol representing "donate life"
- Have children do their own illustration for their family's experience similar to the children's art work found in this book; have them tell their story that goes with the drawings; use their own family names in the story
- Explore the human body interactively to see what can be donated at <u>http://www.organtransplants.org/understanding/interactivebody/index.html</u>
- Operation: perform a heart transplant in 19 easy steps (an interactive on-line do it yourself surgery): <u>http://www.pbs.org/wgbh/nova/eheart/transplant.html</u>
- Explore other children's books about organ donation and transplantation, such as "<u>Now Caitlin Can</u>" about a young girl's kidney transplant experience. Look into other transplant books with over 100 available (many with reviews) using the On-line Resources links on the following pages
- Explore some of the excellent true life movies for adults and families, such as "Thursday's Child," in the On-line Resources below under "100+ Transplant Movies"
- Finally, share this book with family and friends using the free on-line version available for viewing or downloading at: <u>http://trioweb.org/MommyCanPlayAgain.pdf</u>



On-line resources

- Use the links below (or Ctrl+click on them if reading this on-line) to explore other valuable resources about organ/tissue donation and transplantation:
- But first, if you have not done so already, make your decision, talk to your family about that decision and then register to be an organ donor: <u>http://donatelife.net/register-now/</u>
- TRIO National: <u>http://trioweb.org</u>
- TRIO Facebook: <u>https://facebook.com/TransplantRecipientsInternationalOrganization</u>
- Gift of Life Donor Program: <u>http://donors1.org/</u>
- National Transplantation Pregnancy Registry: <u>http://jefferson.edu/ntpr/</u>
- UNOS (United Network for Organ Sharing): <u>http://unos.org</u>
- Current transplant waiting list numbers: <u>http://unos.org</u>
- Transplant Living (before, during and after): <u>http://transplantliving.org/</u>
- Transplant Experience: <u>http://transplantexperience.com/</u>
- Donate Life America: <u>http://donatelife.net/</u>
- 700+ Transplant related web sites: <u>http://trioweb.org/links</u>

On-line resources (cont'd)

- Stories of Hope: <u>http://donatelife.net/stories-of-hope/</u>
- National Kidney Foundation (NKF): <u>http://kidney.org</u>
- 100+ Transplant books: <u>http://trioweb.org/communications/bookreviewshome.shtml</u>
- 100+ Transplant movies: <u>http://trioweb.org/communications/moviereviewshome.shtml</u>
- Organ facts: <u>http://transplantliving.org/beforethetransplant/organfacts</u>
- Organ allocation: <u>http://transplantliving.org/beforethetransplant/allocation/allocation.aspx</u>
- "What Every Patient Needs to Know" free UNOS 2012 booklet download: <u>http://www.unos.org/docs/WEPNTK.pdf</u>





TO OBTAIN ADDITIONAL COPIES OF "MOMMY CAN PLAY AGAIN" CONTACT THE PHILADELPHIA CHAPTER OF TRIO BY SENDING AN E-MAIL TO <u>INFO@TRIOWEB.ORG</u> PROVIDING YOUR REQUEST (I.E., ONE OR # IF MULTIPLE COPIES) AND CONTACT INFORMATION (MAILING ADDRESS AND PHONE NUMBER). THANKS TO OUR SPONSORS THERE ARE A LIMITED NUMBER OF FREE COPIES AVAILABLE.

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HTTP://TRIOWEB.ORG/MOMMYCANPLAYAGAIN.PDF





Based on a true story:

Donated lungs restore a family

Molly learns her mommy needs new lungs to Make her well, something she comes to Understand through talks with her dad. When Mommy gets her new lungs. She can play with Molly again.



