

A  
*Love*  
LIKE NO  
OTHER

*Grandmothers Share  
Experiences with  
Grandchildren that  
have Special Needs*

*Written and edited by*  
DR. SUE SCHWARTZ

outskirtspress  
DENVER, COLORADO

The opinions expressed in this manuscript are solely the opinions of the author and do not represent the opinions or thoughts of the publisher. The author has represented and warranted full ownership and/or legal right to publish all the materials in this book.

A Love Like No Other  
Grandmothers Share Experiences with Grandchildren that have Special Needs  
All Rights Reserved.  
Copyright © 2013 Dr. Sue Schwartz  
v2.0

Cover Image © 2013 Dr. Sue Schwartz. All rights reserved - used with permission.

This book may not be reproduced, transmitted, or stored in whole or in part by any means, including graphic, electronic, or mechanical without the express written consent of the publisher except in the case of brief quotations embodied in critical articles and reviews.

Outskirts Press, Inc.  
<http://www.outskirtspress.com>

ISBN: 978-1-4787-0039-5

Outskirts Press and the “OP” logo are trademarks belonging to Outskirts Press, Inc.

PRINTED IN THE UNITED STATES OF AMERICA

*One cannot know how profound love can be until one becomes a grandparent. The joy is boundless. And when a "difference" appears in any one of those precious grandchildren, we learn to love in a unique way. I dedicate this book to the Grandmas who opened their hearts to reach out to unknown grandparents who will experience the heartbreak of learning that their darling grandchild will be faced with many challenges. Each Grandma story is unique and will give hope to grandparents who are learning of a diagnosis of difference. I have cherished the experience of putting this book together, and have come to know some very special people.*



# Contents

How The Journey Began .....	i
An Introduction	
Impact of Disabilities on Families .....	iii
A Pediatrician’s Perspective	
The Love Story of Anita Sarah Jane Murphy.....	1
Contributed by Joan Widdowson	
For the Love of Grace .....	5
Contributed by Kathy Foy	
What’s A Grandma For? .....	11
Contributed by Chris Strother	
My Journey With Sarah Elizabeth Ginsburg .....	17
Contributed by Rayna Katz	
Noah—Our First Grandchild .....	21
Contributed by Joan Wilbricht	
The Mighty Hudson.....	27
Contributed by Katy Wirt	
My Very Dearest Grandson .....	33
Contributed by Audra Brown	
The Best Christmas Present Ever.....	37
Contributed by Tara Proffitt	
Our Super Math Whiz .....	39
Contributed by a loving grandma	
The Gift of our First Grandson! .....	43
Contributed by Bonnie Seigfried	
A Child’s Grandmother Remembers.....	47
Contributed by an adoring grandma	
Johnathan’s Amazing Journey .....	55
Contributed by Roxy Bell	

Connor Thomas Lee.....	65
Contributed by Terri Brooks	
Jonathan, The Eagle Scout.....	71
Contributed by Rita Frydman	
The Road Not Taken .....	79
Contributed by Wendy Schneider	
Life is full of Surprises (Breah’s Story).....	85
Contributed by Alicia Schomaker	
Our Darling Simran .....	93
Contributed by Rup Navyar	
The Dirty Green Dump Truck.....	99
Contributed by Barbara Singleton	
Acknowledgements .....	102
About the Author .....	103
Brief Descriptions of Each of the .....	105
Special Needs encountered in the Book .....	105
Resource Guide.....	117

# How The Journey Began

## *An Introduction*

THE JOURNEY TO the development of this book actually began eleven years ago. On September 11, 2001, I became a first time grandma. As we all know, the day was fraught with anguish, but joy lay just ahead. At 2:56 that afternoon, the first of my grandchildren arrived amidst the chaos and confusion of the day. Of course, she was magnificent and over eleven years has become even more so. As the other grandchildren came along in short sequence, my joy was unbounded. Each brought his and her own unique qualities and as so happens, each is gorgeous, smart and sweet to the core. This gig of grandparenting is just my cup of tea.

Within a few months of the birth of the first grandchild, I retired from my career as a family counselor in a program for children who are deaf and hard of hearing. I haven't looked back. Soccer games, football games, manicures, and shopping with the grandchildren are just right for me.

Several years ago, a very dear friend gave me a book titled *Eye of My Heart*, edited by Barbara Graham. It contained 27 essays written by grandparents of typically developing grandchildren that told about their relationships, both positive and negative. Above all, the stories were suffused with love throughout. After reading this book, I knew immediately that we needed such a book for grandparents of atypically developing grandchildren.

Although I had published two previous titles resulting in

three editions each, I was not able to find a publisher interested in this project. With a lot of searching, I was able to find Outskirts Press with a wonderful team of professionals who have the skills to make this book come to fruition. I am indebted to this group for their expertise. Then came the task of finding the grandparents to write their essays. As you will see, I have found eighteen delightful grandparents who have reached deeply into their hearts and found the courage to write about the life-changing diagnoses of their grandchildren. Although I ended up with fewer stories and less diversity than I had planned, I definitely have the quality that I wanted. Each story is unique and filled to the brim with unconditional love for the grandchild and guided support for the grandparent's own child. I know that each reader will come to these stories from a different perspective, but I also know that all readers will emerge from this book with hope for the future of their grandchild who has special needs.

# Impact of Disabilities on Families

## *A Pediatrician's Perspective*

AS A PEDIATRIC cardiac physician in the intensive care unit, I stand in awe of the families of children with disabilities. I am privileged to meet these families every day, as they take on the herculean job of advocating for their children—managing medical, social and educational challenges—while at the same time carving out time for those children to enjoy the normalcy of play, love, and laughter.

Families faced with the gift and challenge of children with disabilities have the same struggles of families everywhere: work/life balance, sibling issues, budgeting, family disagreements, as well as marital stress. These everyday ups and downs are at the same time dwarfed and amplified by the diagnosis of disability. Family arguments about tantrums or who is longest in the bathroom seem a lot less important when bigger and lifelong issues are at hand—while at the same time, these ‘mundane’ issues can suddenly be magnified by the added complexity of the atypically developing child. Parents and caregivers can find strength and resilience they didn’t know they had when working to create an environment of advocacy and normalcy for their child who has a disability. It is this strength that awes me; I find that these families are a source of energy and fortitude – and that they often provide inspiration to the caregivers whose job it is to support them.

Grandparents serve a special role in this effort. They are a

source of unconditional love for the children and parents. They celebrate successes and provide support. They are a constant for the parents and the children – a steady and nurturing source of strength. This book gives grandparents of children with special needs the opportunity to share their experiences and to reach out to grandparents everywhere to give them hope for their grandchild's future. These stories will amaze you with their candor and unconditional love.

Jamie McElrath Schwartz, MD  
Attending Physician  
Cardiac Intensive Care Unit and Cardiac Anesthesiology  
The Children's National Medical Center  
Washington, DC

# The Love Story of Anita Sarah Jane Murphy

*Contributed by Joan Widdowson*

THE STORY OF Anita Murphy, born on March 9, 2009, is a tale of courage, fear, tenacity, and love. This beautiful little girl was born to a mother, my daughter, who at the time was struggling with her own life, fighting hard to overcome challenges that have consumed others' lives who have not been able to win the battle.

Anita's birth was a bittersweet combination of joy and angst. Would this dear baby, about to be welcomed into the world, have complications too great to overcome? Would she go home to a stable, supportive home, and thrive? Our immediate concerns were assuaged when Anita was born; she was beautiful, and looked healthy. Her first Apgar score was not impressive, but we were too caught up in the happiness to pay much attention. Anita was with us; she seemed healthy, and we were overjoyed.

For the first year of her life, the challenges for Anita's mom continued to plague her. At a few months of age, Anita was not gaining weight, and her coloring was pale. Admitted to the hospital for "failure to thrive", Anita received a battery of tests designed to protect and help her. Through the course of this testing, it was determined that Anita had Chromosome 18 Distal Q Deletion. Due to this condition, Anita's body was not absorbing adequate nutrition. Other effects of this condition indicated

## ✧ A LOVE LIKE NO OTHER

developmental delays, a heart murmur, and hearing loss. (It was later determined that Meghan has the exact Chromosome deletion that her daughter has, a condition that had not yet been identified by the medical community during Meghan's childhood years.)

Although Anita's hearing loss was of great concern to my husband and me, I have always had the "glass half-full" approach to life, and believed that this was a condition we could work with.

My background as a special education teacher also helped me to realize that, no matter how extensive the hearing loss, Anita would have the opportunity to live a full and productive life. Extensive testing revealed that Anita's conductive hearing loss was relatively mild, and with the use of a BAHA, a bone activated hearing aid, her hearing levels would be close to normal. Anita's conductive hearing loss is due to the fact that both ear canals are filled with a dense, cartilage, almost bone-like, tissue that allows for very little sound to pass from her outer to inner ear. Fortunately, Anita's hearing nerve works very well. The BAHA she wears allows the hearing nerve to be activated. (Keeping the BAHA on Anita's head, and in one piece, was a great challenge that originally meant many periods of reduced hearing.)

The plus side to Meghan's struggles during Anita's first year of life, is that Anita began to receive a multitude of services, including hearing, speech, and occupational therapy. When Meghan, through incredible strength and love for her daughter, was able to regain full custody and care of Anita, she persevered to gain the assurance of Anita's well-being with a determination never before evident in her life. At a pediatric neurologist appointment, when Anita was eighteen months of age, the program at a school for Hearing and Speech was mentioned. No

sooner were we in the car, following the doctor appointment, than Anita's mom was on the phone, contacting this school. The school was enthusiastic about meeting Anita, and an initial interview was arranged. Since that first appointment, there has been no turning back. Anita began services at the school at eighteen months of age, in a two-morning, then three-morning a week program. When Anita celebrated her third birthday, the provision for her services transitioned from Alliance for Infants to the Public School District. The district, through meetings with us and assessments of Anita, determined that she would benefit most by continuing in the program established for her at this school. Now a full-fledged preschooler, Anita attends school Monday thru Friday for a full school day. It was evident at a recent Open House that there is mutual love and excitement for the school and each other from staff and students. Anita continues to make progress with the sounds and simple words that will soon develop into normal speech. Her receptive language skills have increased significantly. The goal of this school is to transition students to a general education program as soon as possible. It is evident that Anita is making progress toward this goal.

The use of sign language was never a real consideration for Anita, although there were some who felt she should be learning sign. It is easy to be overcome with worry when speech is not progressing at a rate expected by many, and a fear that a child will lose the ability to communicate with others without some method of manual communication. This is where education is invaluable. Knowledge of the oral language program for the hearing impaired leads to an understanding of the process, and recognition of progress that is not assessed at the same rate as that of a hearing child.

Life with Anita is a true gift for all of us who love her. Her

## ✧ A LOVE LIKE NO OTHER

hearing loss, and the other challenges Anita faces, have not daunted her spirit and her obvious joy for life. As she grows physically, so does she grow cognitively, and her personality assures all who know her that hers is a life that will flourish. A little girl whose life began in less-than-ideal conditions, Anita is proof that the power of love can overcome many of life's obstacles. Anita and her mom are taking life head on, and there is no standing in their way! Theirs is a story of strength, determination, and unconditional love.