

UP, NOT DOWN SYNDROME

UPLIFTING LESSONS LEARNED FROM
RAISING A SON WITH TRISOMY 21

Up, Not Down Syndrome is a love letter and a map. Experience how it feels to think your life is over after having an unlovable baby. At first the loss seems impossible to overcome. Alex becomes the author's greatest teacher. Love is stronger than fear. Everyone has gifts. The book consists of three parts: the story, the lessons Alex taught the writer and Alex's perspective. *Up, Not Down Syndrome* is a promise to stay positive, no matter what: up, not down. Nancy's journey gets to the core of what it is to be human:

- Explore what it feels like to think life, as you know it, is over.
- Discover the fierce love, joy and peace a baby diagnosed with Trisomy 21 (Down syndrome) brings.
- Learn the lessons this child taught his mom.
- Understand the gift this baby brings to our world.
- Realize the depth of the love this family has for the child.

"A beautiful, honest account of not just accepting—but embracing—the unknown. Nancy shows us the blessing of an unexpected gift and the enormity of love."

— Sara Byala, Ph.D.

"This is a wonderful book to remind you that the joy of love is possible in unexpected places when you open your heart to it."

— Barbara Taylor Bowman,
Irving B. Harris Professor of Child Development

"A moving and wise story of how a family navigates through hope, loss, learning and, most of all, love."

— Rabbi David Wolpe,
Author of *David: The Divided Heart*

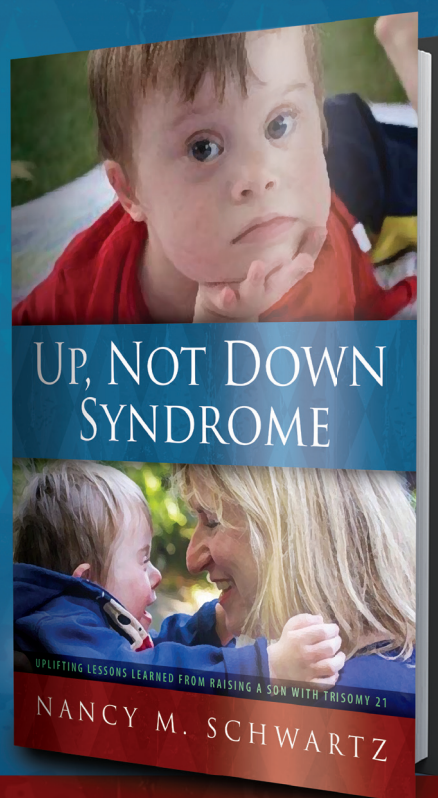
"The truth and beauty of Nancy Schwartz's words tell an ongoing story of love, learning and the power of acceptance. All can learn from this family's boundless hope and from their source of joy and strength: Alex."

— April Beard, Music Educator and Cellist

Up, Not Down Syndrome is available through local and online bookstores including Amazon, Powell's Books, and Blackwell (UK).

Watch Amazon for pre-order details in March 2020

For more information, visit www.UpNotDownBook.com



PUBLICITY CONTACT:

Victor R. Volkman, Senior Ed.
publicity@ModernHistoryPress.com
734-417-4266

Title: *Up, Not Down Syndrome: Uplifting Lessons Learned From Raising a Son With Trisomy 21*

Author: Nancy M. Schwartz

Imprint: Modern History Press

Publisher: Loving Healing Press

PUBLICATION INFO:

Publication Date: April 1st, 2020

Pages: 122

ISBN: 978-1-61599-462-5 paperback /
978-1-61599-463-2 hardcover

Price: \$21.95 paperback / \$32.95 hardcover / \$6.95 eBook

LCCN: 2019980364 (print)

Trim Size: 6.14 x 9.21 in

Category: Family & Relationships / Children with Special Needs

Distributors: INGRAM (USA/CAN/AU), Bertrams (UK),
New Leaf (USA)



NANCY M. SCHWARTZ has taught in Pennsylvania for twenty-six years. She holds certificates as an ESL program specialist, reading specialist, and elementary and early education teacher. Nancy's undergraduate degree came from Temple University, and she attended graduate school at Saint Joseph's University. Nancy spent several summers studying at the Teachers College Columbia University, Reading and Writing Project. She enjoys ballet, reading, writing, art, fashion, animals, music, and, most of all, motherhood. This is her first book.

PRAISE & ENDORSEMENT

“Great read! Here is a ten-year walk down the path of a scary Trisomy birth that leads us to the ‘pure, unadulterated joy these children can bring.’”

— **JOHN WELLS,**
Board Member of L'Arche London, Ontario;
Husband and Father

“This story turns broken into whole, tragedy into joy, and optimism into hope. Nancy is an inspiration for all parents struggling with a child with challenges.”

— **DEBBY ELNATAN,**
Inventor of Upsee, a children's walking device,
and Mom

“Raising a child is an act of faith. Raising a child with a disability requires a fierce kind of love. Nancy Schwartz invites us to share her unique journey of faith, love, and belonging. *Up, Not Down Syndrome* is more than the story of a family. It is a reflection on community, deepening our understanding of what it means to be truly human.”

— **LISA SONNEBORN,** Director,
Media Arts & Culture, Institute on Disabilities,
Temple University

“Nancy's story shines a powerful light on the murky waters of parenting and family dynamics. A required read for any parent navigating the occasionally cloudy and sometimes dark waters of parenthood and family. You will laugh, cry, and love. Enjoy the ride. I'm humbled by this love story.”

— **BETH NORDMAN,** Giving Bean Coffee

“Nancy Schwartz's *Up, Not Down Syndrome* reverberates with such love and care, not just for her son Alex, but for all the friends, family, medical professionals, educators, support staff, physical therapists, and numerous others with whom she has created community. This book shows how a child and a family can impact the world in a powerful, hope-filled way. I felt privileged to read this story.”

— **ELIZABETH CASTIGLIONE,**
Artist and Mother

“Nancy shares personal testimony that can be helpful to a wide range of audiences—from those who can benefit from understanding the wide range of emotions that parents of children with disabilities can face to those who can benefit from the ways Nancy is able to see and develop Alex's abilities; there are lessons in this book that can help any and every reader.”

— **DANIELLE THOMPSON,**
Mom to Porter, Penny, and Paxton, Wife, and CPA

“The truth and beauty of Nancy Schwartz's words tell an ongoing story of love, learning, and the power of acceptance. All can learn from this family's boundless hope and from their source of joy and strength: Alex.”

— **APRIL BEARD,** Music Educator and Cellist

“With indomitable tenderness, *Up, Not Down Syndrome* reveals the unexpected wonder of raising a son with Down's syndrome. Get ready for a brilliant love.”

— **DEIDRE SCHENA,** Historian and Mother

QUESTIONS & ANSWERS

by **NANCY M. SCHWARTZ**

WHAT INSPIRED YOU TO WRITE *UP, NOT DOWN SYNDROME*?

When Alex was born, I thought my life was over. I was devastated. I cried. My husband cried. I wondered what I did to my other two boys, Josh and Sam. I have since realized I love Alex as much as my other two sons. I want the world to know how much I love him. Alex is one of my life's greatest gifts, along with Josh and Sam. I have two graduate degrees, and I have more understanding from Alex than from my advanced degrees.

WHO SHOULD READ THIS BOOK? FOR WHOM WAS IT WRITTEN?

The people that should read my book are parents, doctors, lawyers, teachers, school psychologists, government officials, police, people considering cannabis as a treatment, Down syndrome advocates, people dealing with epilepsy, people with a cancer diagnosis, siblings and any person dealing with a challenge. I believe we can take our struggles and make them triumphs. Challenge is an opportunity to be extraordinary. The book was written for my three boys. I want all three to know how much I love them. It was written for a parent considering this path and for all the professionals that will touch the life of a child.

HOW DOES THE OVERALL STYLE AND STRUCTURE OF THE BOOK RELATE TO ITS CONTENT?

The style and structure of the book is organized with my story of raising Alex, the lessons Alex has taught me and, if he could speak, what he would say. Alex is a person; he is in there, but he has difficulty expressing himself. I wanted the book to allow the reader to understand my story, learn from what I learned and gain insight from Alex's voice. Including his voice was my sister, Susie Garber's, idea. As a writer herself, she thought it would help the reader to feel how Alex feels. My husband, Michael Schwartz, thought I should end each chapter with the lessons I learned from Alex. show a thread of similar sensibility at the crux of it all.

IF YOU COULD ONLY LEAVE READERS WITH ONE LESSON FROM THE BOOK, WHAT WOULD IT BE?

How we live our days is our choice. Each one, while cliché, is a gift. What we choose to do with our day, our relationships, our professions, our children and the world is our choice. While circumstances can seem overwhelming and impossible, there is always hope. Rabbi Wolpe, during a talk in which he recounted a story about a father and son in a concentration camp, said we can live for three days without water and three weeks without food, but we cannot live three minutes without hope.

Joel Osteen reminds us to stand up on the inside, and I do when things seem darkest. My mom, JoAnne Levine, is the ultimate eternal optimist. Mom was a single mom raising three girls (one with mental challenges), she has had breast cancer three times and still she smiles and points to the sun over her morning coffee. My mother-in-law, Sandy Schwartz, is another ultimate eternal optimist. Sandy raised three boys while working at a private investigating firm and would later lose her son, Barry, her husband, Lenny and her mom. Still, she is present and always there for her family with hope, love and warmth to share.

WHAT ADVICE WOULD YOU GIVE YOUNG PARENTS WHOSE CHILD HAS JUST GOTTEN A DIAGNOSIS OF DOWN SYNDROME?

The advice I would give is "Celebrate!" Your baby is a baby. I would say the six words, "Never ever, ever, ever give up." The child is an addition, they are not taking anything away from you. Say the serenity prayer. G-d, grant me the serenity to accept the things I cannot change, courage to change the things I can and wisdom to know the difference. People will respond to your child the way you respond to your child. I will always be grateful to Grace for coming to the hospital when Alex was three days old, in the NICU, to tell me those last three things. I still use them every day.

Be happy, always up, celebrate. Life is what we make it. It is beautiful. Anything worthwhile is hard. My friend, MoonSong, said, "People that matter don't mind, and people that don't matter mind." MoonSong went on to say, "Be comfortable in the skin you are in." I think we have to be prepared for stares and people that may not fully get it. It is okay. It is all part of the lesson our child is here to teach us.



Excerpt from

UP, NOT DOWN SYNDROME

by
NANCY M. SCHWARTZ

Despite its difficulties, this labor was the easiest of all three boys. Well, maybe not the labor. That was hard. But, with Josh and Sam, the delivery was excruciating. It took forever, and the pushing was agonizing. I almost couldn't bear it. With Alex, all that was required were a few pushes, and he was out.

His shoulders were out. He was on my belly.

Internally, I danced. I realized that, externally, something was terribly wrong. The nurses took him from me. Suddenly, a quiet deafening fell over the room...like first snow. Ten years later, as I edit this passage, it is snowing outside. I've come to understand that the tranquility that precedes what we view as a storm can also be nature's quiet acknowledgment of a new, innocent beginning. I've come to understand a lot about the wonder of the unsuspected, and sometimes inconvenient. But we cannot know life's later lessons in the moment. We can only be where we are.

My heart went into freefall. It landed, with a thud, in my gut.

What was going on? I was desperate to know, and, at the same time, I didn't want to. I wanted to keep dancing. I wanted to bask in the accomplished glow of afterbirth.

Dr. Crate reached for my hand. Held it. "His ears, eyes, and neck are characteristic of Down babies."

Down what? As I tried, poorly, to process the word, it felt as if the doctor were speaking from miles away. I strained to listen through the distance. Facts. Figures. Intermittent words. Statistics. A wave of fearful questions.

I wondered about all of those weeks lying there, getting ultrasound after ultrasound. Did the doctor know ahead of time that something was wrong with my third son? If so, why hadn't he told me? I'd thought all the additional monitoring had to do with the fact that I was forty—an advanced maternal

age—and, therefore, needed closer supervision.

Supervision. I would have to look after, a baby who was.... My mind roved its recesses for a way to think about my third son, but I had not yet acquired the language to explain.

Trisomy 21 is Alex's diagnosis. The medical designation refers to a chromosomal anomaly that causes a distinctive set of physical characteristics and lifelong challenges. Trisomy 21 impacts approximately 5,000 of the babies born every year. I didn't know that then. I didn't know so many things. I felt like the only one in the world with a child who would fail to live up to all the hopes and dreams I'd had for him.

How could I love an imperfect child? How did my body produce this unlovable baby? How could we live our lives in the face of this soul-crushing information? I was devastated. I didn't know how to continue living when all my dreams for my youngest were slowly withering within me.

This son would not be cute. He would be the opposite. It must be Michael's fault for using cannabis. That conviction led to our biggest argument. Ridiculous now, thinking back.

It's especially ironic considering that, years later, after Alex was diagnosed with epilepsy, I would fight to get his neurologist to agree to treat him with medical marijuana oil, instead of pharmaceutical drugs.

Sadness was like quicksand, pulling me downward. But then I had a sudden, unexpected, thought. I remembered a boy from my teaching job at Wayne Elementary School. An adorable, intelligent, and amazing young boy who had Down syndrome. The entire previous year, he'd stopped by my room to say, "Hi, Mrs. Schwartz!"

PUBLISHER CONTACT:

Victor Volkman • Modern History Press • 5145 Pontiac Trail, Ann Arbor, MI 48105
Toll free: 888-761-6268 • Fax: 734-663-6861 • Email: publicity@ModernHistoryPress.com