

Zachary Johnson was born a preemie and in need of extensive medical support. This is a story of his incredible fight for survival and the day-to-day insights that his parents experienced during the process.

A View From Bed 15

**Buy The Complete Version of This Book at
Booklocker.com:**

<http://www.booklocker.com/p/books/3760.html?s=pdf>

A View From Bed 15

A P a r e n t ' s P e r s p e c t i v e

The Story of an Organ Transplant
for Zachary Johnson

by Brian K. Johnson

A View From Bed 15

Copyright 2008 © by Brian K. Johnson

All Rights Reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any information and retrieving system, without permission in writing from the copyright holder/publisher, except in the case of brief quotations embodied in critical article reviews.

Cover art and interior design by: Brian K. Johnson

ISBN 978-1-60145-681-6

www.booklocker.com

Printed in the United States of America

Table of Contents

THE BEGINNING	1
THE TWINS ENTER THIS WORLD	5
AIDAN COMES HOME	9
ZACHARY'S INTRODUCTION TO SURGERY.....	11
THE SURGICAL WAITING ROOM	14
ADJUSTING TO MARYLAND	17
WEB BASED SUPPORT.....	20
THE ENDLESS WAIT	22
ATTEMPT AT NORMALCY.....	25
THE OMEGAVEN FACTOR.....	28
THE LIVER, WORKHORSE OF THE BODY	33
ZACHARY COMES HOME	35
Blog: Together At Last	39
Blog: Life Imitated	40
Blog: Yellow Hospital Gowns	41
GETTING ON WITH OUR LIVES.....	43
Blog: Debating Skills	48
Blog: A Few More Bottles	49
Blog: Waiting for a Bed	50
Blog: Bag of Bananas	51
THE FLIGHT TO PITTSBURGH.....	52
WELCOME TO CHILDREN'S HOSPITAL OF PITTSBURGH.....	54
Blog: Mass Transit	60
Blog: Mannerisms	61
Blog: Confuse the Doctors	63

Blog: Behavior Psychiatrist	64
Blog: City Slickers	66
Blog: Asking Questions	67
Blog: An International Team	68
Blog: Steeler Sunday	69
Blog: Second Hand Smoke	70
Blog: Rigel 7	72
Blog: How Much?	73
Blog: Lost in Translation	74
Blog: Starbucks Factor	76
Blog: Doctor Parent Bonding	78
Blog: "The Intimidator"starring Deanna Johnson	79
Blog: Scrubs	81
Blog: Patience	82
Blog: Groundhog Day	84
Blog: Half Full	85
Blog: Eye Contact	86
Blog: Third Time's a Charm	87
Blog: Trending North	89
Blog: Reality Programs	90
Blog: Crusin' 7 North	93
Blog: A Good Night's Sleep	94
Blog: Sometimes Y	96
Blog: Mr. Johnson	97
Blog: Time To Reboot	99
Blog: CNN	100
Blog: Whack A Mole	102

Blog: Facial Expressions	103
Blog: Pair Of Threes	105
Blog: Trial Run	107
Blog: Persona Upgrade	108
Blog: A Good Closing	110
Blog: Blood Type	112
Blog: The Next 24 Hours	113
Blog: The Past 24 Hours	115
Blog: Turn the Band	116
Blog: Youth and Maturity	118
Blog: Lottery Prediction	120
Blog: Dream of a Life	121
Blog: Around the Bend	123
Blog: Hence the Bleeding	125
Blog: Perspective	127
Blog: Shades of Gray	129
Blog: One More Day	130
HOW TRANSPLANTATION WORKS	132
FUNDRAISING	137
INSURANCE.....	142
THE CALL	146
Blog: Transplant Call	150
Blog: Transplant Update	151
Blog: Which Leads To ...	153
Blog: The Hike Downhill	155
Blog: The Math	157
Blog: 1968 Plymouth Satellite	159

Blog: Sun Block Factor 400	161
Blog: Chess Match	162
Blog: Wingman	163
Blog: The Glass Door Incident	164
Blog: 2nd Year Birthday Party, by Deanna	166
Blog: Columbus Marathon	168
Blog: Sisyphus	170
BEYOND CHILDREN'S HOSPITAL.....	173
Blog: Madeline Kate Johnson	178
THE CHILDREN'S HOME	180
Blog: Pods	183
Blog: Dejohnsonfication	184
Blog: Halloween Gourds	185
Blog: The Fish Hook Story	187
Blog: Thousands of Footprints	189
CLOSURE	192

Chapter 1

The Beginning

Zachary Mason Johnson was born July 2, 2006 at the University Of Maryland Medical Center in Baltimore. He, along with twin brother Aidan, came into this world a few months earlier than we had planned – apparently setting the tone for what was going to be a very long childhood. A few hours prior to the birth I pulled into the hospital parking lot and enjoyed the warm and comforting feeling that the sun applied on my face.

“This is a good day to become a dad,” I thought. With Deanna’s overnight luggage in one hand and a cup of coffee in the other I was ready to take this monumental walk past the front entrance’s rotating glass doors and into the maternity ward. These were steps that I wanted to savor for a few moments. All of our parenting plans came down to this. Parenthood was soon upon us.

But this story doesn’t really start here. It actually started several years back in Seattle, Washington. The Pacific Northwest is a great place to live if you like nature, water ferries, and a big volcano looming over the horizon. Throughout our stay we took advantage of everything this area provided. We hiked. We kayaked. We slept in tents deep within Mt. Rainier National Park. Our lives were full of excitement in this city of rain, technology, and coffee.

Deanna and I had put off the “kid conversation” until she finished her studies and obtained her Master’s degree in Physical Therapy from the University of Puget Sound in Tacoma, Washington. During this time I worked as a database developer for a national real estate company up the road in the nearby community of SeaTac. It’s not that we didn’t want children. It’s just that they didn’t factor into our lives at this point in time. After

Deanna's graduation we sort of threw caution to the wind and embarked on a two month backpacking trip around Europe. Prior to our trip we had sold our house in Seattle and put all of our belongings in a 10x10 foot storage bin. Nothing like knowing that your whole life can be stored away in a small cubical protected from the evils of the world by a \$4 padlock. Still, the world was ours for the taking...provided that the price was low enough.

Now it is important to note that we are adults of...shall I



Deanna & Brian in Seattle

say...a frugal nature? Perhaps it is our modest Midwest raising or the fact that our careers took us along a lower paying route. Either way, we didn't have a ton of money to spend when hiking around some of Europe's most beautiful cities. We chose picnics instead of pricy restaurants, we opted to stay in hostels instead of hotels, and when a cheap hostel wasn't available, we actually spent the night in a barn. Okay, so that only happened once but hopefully this shows some insight into our budget-minded spending habits.

Our story actually gains some momentum on the final leg of our backpacking trip. At

this time we found ourselves smack dab in the middle of Paris, France. It was a very beautiful day as we sat in the park overlooking the Eiffel Tower. With a picnic lunch spread out before us we confessed that our lives were pretty good. We were newly married, young, and had no responsibilities.

It was at that moment that everything seemed clear. The life that we led was a prelude to the life that we would lead. Our knowledge and experience were stepping-stones to a future of prosperity and happiness. Everything was falling in line. Life was becoming simpler. It was time to take the next step in our relationship. The obvious was staring us in the face.

Lose the birth control.

And thus our destiny was set in motion.

That defining moment was July 2, 2001 and from that point on nothing had gone according to plan. Conception never occurred and pregnancy never developed. Throughout this ordeal we adopted a nomadic approach to living and moved several times resembling some sort of bizarre witness relocation episode. To be fair, most of the moves were job related which took us from Seattle to Cleveland to San Francisco back to Seattle and finally to Maryland. But throughout most of this endeavor the pregnancy thing never took. Maybe it was bad timing on the ovulation front. Maybe my underwear was too tight. Maybe we just weren't doing it right. Who knows?

Sometime in Seattle (the second time around that is) we decided to pry open the checkbook and invest in Invitro Fertilization (IVF). Consider this approach a combination of nature, test tubes, Petri dishes

and a squadron of trained medical personnel. It seems the last resort and dare I say the most expensive. Not exactly the preferred path of frugal people. But after a handful of appointments and



Deanna in Eiffel Park, Paris

tests it all came down to a positive blood test. Deanna was pregnant...with twins.

We logged a lot of miles from that day in Paris to delivery day in Baltimore. In the end it took us exactly five years to the day, thousands of dollars of our own money and the help of IVF doctors to make our joys of parenthood a reality. Not exactly the time frame that we were looking for but dwelling on the past was never our style.

We have always enjoyed the proximity of living near water and thus it wasn't any surprise that we sought out coastal Maryland as an ideal location for our new lives. Now we live in Severna Park, Maryland - a small bedroom community located just upstream from the Chesapeake Bay. It is a beautiful place to live and very close to historic Annapolis. As the pregnancy progressed we kind of developed this fantasy of hanging out in an Annapolis coffee shop on a Sunday morning with our dog and twin boys. Just like on the cover of an LL Bean catalog.

Chapter 5

The Surgical Waiting Room

The University of Maryland Medical Center has one of the nicer places to pass time than any other hospital that I have seen.

It is a balcony of sorts with trees and surprisingly very comfortable chairs, couches and benches. In fact, if this balcony were located anywhere else it would make an ideal setting for a prom or a great spot for an Olive Garden. This waiting area has plenty of today's newspapers strewn about – probably by other surgery related relatives in the same position as Deanna and myself. You can only read so many articles about the Iraq War, the governor or the mayor before you crave a magazine by Martha Stewart or if desperate enough - Teen Beat.



UMMC waiting room

After a few hours of waiting around with no additional information you naturally start to get a little nervous. You start to wonder just how things are going and contemplate sticking your head into the Operating Room door just to get a little information. Thankfully, the OR liaison told us that if we had questions to consult with the waiting room personnel located at the front of the area. "Just have her call the OR for updates", she said. Since I have never been in an Operating Room during an operation I really had no preconception on how this worked. Was it the doctor's duty to

pick up the phone for the update? Was there a nurse whose sole job was to simply answer the phone? Perhaps a Bluetooth head set on the surgeon's assistant for such an occasion. Perhaps this was more of a Bat Phone setup where the waiting room attendant simply picked up her phone (bypassing Commissioner Gordon in the process) and automatically made the phone ring in the Operating Room.

After all of this heavy and intense mental pondering I decided to just go up and ask. Let the powers at large handle all of the complicated communication engineering feats. As I stood by with my half empty cold cup of coffee I watched the waiting room attendant call the operating room with a simple four number code and heard the following: "I'm calling about Zachary Johnson's status"... "Yes"... "Okay"... "Sure"... "Uh-huh"... "Uh-huh"... "How long?"... "Really?"... "I'll tell him. Thank you".

She then hangs up the phone, turns to me and says, "He's fine". "What? That's it?" I asked. "Cause it sounded like they said a lot more than that". "Nope", He's fine," she mumbled. Apparently parents are on a medical need-to-know basis when it comes to information on your child.

Not to be deterred, I then rattled off several key questions relating to Zachary's medical condition and drug related issues. Shortly after I began this rapid fire of questions I realized that this lady had as much interest in my affairs as a vegetarian at a butcher's shop. She nodded politely and gave me the same answer: "Your son is doing fine". Not quite the data retrieving adventure that I had hoped. It was a long walk back to the bench where Deanna was sitting. "He's fine" I said with the confidence only an award winning actor could portray.

A few hours (and several hundred feet of pacing) later the surgeon emerged from the double doors near the waiting room. He approached with his surgical scrubs still in place. "All went well", he immediately stated. Whew! Time to take a good deep breath and let the lungs continue their course of action. The surgeon went on

to describe how he had to cut away several centimeters of bowel that had essentially been killed off by the disease. Of course, I am not a Metrics kinda guy and was diverting valuable brain processing power trying to convert his measurement into inches. Then it dawned on me that I really had no idea just how many inches of bowel a baby has in his belly anyway.

At this time the conversion really didn't matter. The surgery was done. Zachary was doing fine and life would resume in a normal fashion a few months later than expected.

Zachary Johnson was born a preemie and in need of extensive medical support. This is a story of his incredible fight for survival and the day-to-day insights that his parents experienced during the process.

A View From Bed 15

**Buy The Complete Version of This Book at
Booklocker.com:**

<http://www.booklocker.com/p/books/3760.html?s=pdf>