THE CRUCIBLE'S FIRE

A STORY OF GOD'S FAITHFULNESS

MATT PARKER

"Matt Parker's book is composed of the authentic, raw material known as suffering. Our resistance to suffering has not removed it from the human experience. This book inspires each of us to walk through our own dark nights of the soul with truth and grace. It allows us the space to feel the weight of our suffering while encouraging us to hang on to faith in the midst of the darkness. No matter how difficult our journeys are, God has promised his presence will be with us, and that transforms suffering into testimony! This book will challenge you, inspire you, encourage you, make you laugh, and make you cry, sometimes on the same page. In the end, you will be grateful for Matt's willingness to share this journey with you."

—Carrie Gurley,
Founder/CEO, ValiantHearts.org

"Parents all agree that something horrible happening to one of their children is terrifying. But this world is broken, and we cannot protect our children from its cracks. Matt Parker's book is a story of how to handle the worst news in light of the Good News. Take up, read, and be encouraged."

—Brandon D. Smith,
Author of *Rooted: Theology for Growing Christians*

"*The Crucible's Fire* takes us on a journey with one family as they travel the dark valleys of trials. Matt Parker peels back the layers, allowing the reader to see the raw feelings, emotions, and questions he and his family grappled with as they walked through the theology of suffering, and then showing the redeeming beauty God birthed on the other side of the fire."

—David Yarbrough,
Pastor, The Bridge Fellowship Church

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LUCIDBOOKS

The Crucible's Fire
A Story of God's Faithfulness

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This book is dedicated to the kids and adults whose daily challenges
teach us so much about the nature and character of God.
Thank you for allowing us to see deeper into his grace as we join him
in the fellowship of his sufferings. You are my superheroes.

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Introduction

The Refiner Sat by the Seven-Fold Fire

Hymn by James M. Gray

The Refiner sat by the seven-fold fire,
As he watched by the precious ore,
And he bent more close with a searching gaze,
As he heated it more and more,
For he knew the ore could stand the test,
And he wanted the finest gold
For to mould as a crown for the King to wear,
Set with gems with a price untold.

Refrain:
He knew he had ore that could stand the test,
And he wanted the finest gold
To mould as a crown for the King to wear,
Set with gems with a price untold.

So he laid our gold in the flaming fire,
Though we fain would have said him nay;
And he watched the dross that we had not seen,
And it melted and passed away,
And the gold grew brighter and yet more bright,

But our eyes were so dim with tears
That we saw but the fire, not the Master's hand,
And we questioned with anxious fears. [Refrain]

Should we think it pleased such a loving heart
For to cause us a moment's pain?
'Tis not so, but that through the present cross
He should see an eternal gain.
So he waited there with a watchful eye,
And a love that is strong and sure;
And his gold did not suffer a bit more heat
Than was needed to make it pure. [Refrain][1]

We believe God is extremely frugal. He wastes nothing—not in the same way your grandmother served you leftovers until they were finally gone, but in the Native American way of using the entire buffalo. They used everything, even the excrement. God uses every single thing that comes our way to mold and shape us into his image, to conform us to his will, for our good and his glory.

This is a story about Brynna, our youngest daughter, and the trials we face raising a child with severe mental and physical difficulties. Brynna has a laundry list of diagnoses, including panhypopituitarism, microcephaly, general developmental delay, diabetes insipidus, autism, gastroesophageal reflux disease (GERD), seizure disorder, and a host of other minor things. She is fed exclusively through a gastrostomy-button (or G-button), and takes 10 medication applications a day when she is well, more when she is sick. Developmentally, she is 24 to 30 months old in a 10-year-old body. She is fun-loving and full of life and personality.

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1. James M. Gray, "The Refiner Sat by the Seven-Fold Fire," *Hymnary.org*. https://hymnary.org/text/the_refiner_sat_by_the_seven_fold_fire.

If someone told us 10 years ago how much we would learn about God, his character, and his nature and how much he loves us, we wouldn't have believed it. Nor would we have believed how much more we would learn to lean on him in times of trial. Now, looking back, we can't help but wonder if it would have been easier to have heard some of these things beforehand. We would like to think so. This book is meant to encourage, to give hope where there seems to be only fear, and to bolster those who seek a righteous king in a very fallen world.

Every workout video I've ever used encourages us to embrace the pain we are inflicting on ourselves. I'm not sure I'm ready to embrace my workout at 5:00 a.m., but Jesus says the same thing to us when suffering comes our way. We don't have to seek it or wish for it since he told us to just sit tight. It will come. When it does, we should embrace it as his will and let it do its full work, let the crucible remove the dross, leaving only a shining reflection of the son.

During Brynna's first couple of years, I kept an e-mail update, chronicling her adventures. What follows are those notes with a bit of commentary. I hope you find them encouraging and helpful and that they leave you hopeful—hopeful that you are not alone and that God cares for you.

1

As Long As It's Healthy

Rejoice always, pray without ceasing, give thanks in all circumstances; for this is the will of God in Christ Jesus for you.

—1 Thessalonians 5:16-18

For those who have children, you know how it is. Everyone starts asking, "What is it, a boy or a girl?" Sometimes people have a preference. If a mother (bless her heart) has four boys, she may really want a girl this time. But most of the time, people give the standard answer—you know the one. "It doesn't matter, as long as it's healthy." Everyone says it. We did. Four times. The answer seemed sufficient. It even seemed holy, like you've actually gotten your priorities together in such a way that they communicate to the world how ready you are to accept whatever God has for you, as long as "it's healthy."

I know the sentiment behind this thought. Believe me, I do. It may be the most sincere retort to date, but think about it for a moment. Here's what we are really saying in that moment: "I'll be happy as long as there's no suffering. I just want the gift, the good stuff." If we really believed what we were saying, we wouldn't say it at all. If we did, we would realize that what we are really saying is this: "I can trust God as long as it isn't too tough. My happiness is predicated on the stipulation that everything is okay." We need to stop saying it.

I don't want to start off on a negative note, so why don't we alter that saying somewhat? What about this? "We are ready for whatever God brings us, but we are really praying for health and a smooth delivery." That works. It's okay to want the best. In fact, God tells us to make our petitions known, to bring our wants to him in prayer. That's a good thing. But I can tell you as a parent of a child for whom this statement wasn't true that it's hard to hear the typical answer. I want to shout at people in a loving Christian tone and say, "You don't mean that! What you mean is that you'll love your baby no matter what. You will accept your child whether it is healthy or unhealthy, pretty or ugly, skinny or fat, frail or robust." What people mean when they say the standard response is that it doesn't matter. At least that's what I hope they mean. That's what I want them to mean. I believe that is what God means and what he wants us to model.

As we roll through this story, I want you to think. Think about what it would be like or is like to have a baby who is not healthy, not whole, or not as expected. The goal is not that you will feel sorry or even sympathetic for them. The goal is to see that God transcends circumstances, even the circumstances of birth, life, death, and suffering. He is what matters, not the conditions of the moment. Now let's look at my story, my family's story.

2

The Breaking

The Lord is near to the brokenhearted
and saves the crushed in spirit.

—Ps. 34:18

The first step in the refining process is gathering raw material. The refiner must first have the correct raw material before it can be processed into fine silver or gold. At the point in our marriage, ministry, and walk with the Lord before Brynna was born, I frankly felt we were beyond being raw material and that in some ways, we had already been refined into decent vessels of honor.

The refining process is a lengthy one, a process of patience and hard work, mostly on the part of the refiner. Once the ore has been located and a desirable treasure has been found inside, the refiner must take a seemingly violent first step to free the valuable cargo. He must break it. The precious metal inside must be exposed, brought into view by brute force, if necessary.

Our journey was about to take a drastic turn that would drive us deeper into the presence and character of God in ways we could not yet fathom. Jeremiah 23:29 says, "Is not my word like fire; declares the Lord, and like a hammer that breaks the rock in pieces?" It was late 2006. We were expecting child number four when the refiner set his hammer to work.

Devastating News

There are moments in life for which you cannot prepare. In fact, there are many moments like that. Might I even say that there are seasons where you are prepared for none of them? I think I can. I remember one moment like it was yesterday. Tammy and I were in the obstetrician's office for a sonogram. It was early on in the pregnancy, and we expected an uneventful day of affirmation and glory. "Have you seen these 4D sonograms?" we joked. They are so cool and show so much detail. But the detail changed our lives forever.

When I saw the doctor's face as he gazed at the screen, I knew something was going on. I'll try not to be dramatic. Long story short, he discovered that our fourth child, Brynna, had something wrong. She had a cleft lip and possibly a cleft palate. "What does that even mean?" we asked. He showed us the pictures and showed us how her upper lip was unformed and split fairly wide open into her nostril. The doctor was astute enough to notice that the cleft was a certain type. They call it a midline cleft because, well, it is in the midline of the body. My question was, "Why does that matter?" His answer was sobering. Apparently, babies form from the middle to the extremities. That means that the farther a deformity is from the center, the better. The farther out it is, the later it happened in the growth process. For us, it was in the midline. That meant it happened early when the brain, the heart, the lungs, and more were being formed. It was, in fact, the worst kind. Off to the specialist we would go.

I want to spend the time I have with you, the reader, being honest. I want to plainly reveal who Tammy and I are, scars and all. I promise to be brutally honest if you will as well. I'll expose our souls if you promise to look deeply into your own.

First and foremost, we were devastated. I remember sitting in the car, crying after the visit. I wasn't crying because our daughter could be really sick. At that point, we were only facing a facial deformity. We didn't yet know what the road would actually look like. I remember crying and thinking to myself, "My kid is going to be ugly." I'd like to say my first thoughts were for her, but they weren't. They were for myself. Sure, I was rocked by what it could mean, but I truly wasn't sure how to go forward with something like this. I had thoughts like this: "It's on her face, and we can't cover that up." I look back in shame on those moments, but they are real, and God was there when I thought them. I'm not proud of it, but I want to communicate how feelings can't really be helped; it's who we are. The difficulty is being prepared to be more like God, not like ourselves. When those times come, our reactions should resemble his kingdom, not our own nature.

I'll also be honest, I don't remember a lot about this early stage. It really is a blur. I'm leaning heavily on my wife to remind me of what happened. We bounced around from doctor to doctor, hearing all sorts of things like she had trisomy 13, she wouldn't live, and she might not even make it to birth. During one sonogram, we saw there were problems in her kidneys. It seemed like there was always something. The most dramatic pre-birth time for me was when we saw an obstetrician in Dallas. It truly was a watershed moment for us on this journey. It turned out to be a formative moment, not just for us as a family but for our theology. Let me explain.

They sent us to have an amniocentesis to check for trisomy 13 and other anomalies detected in the fluid surrounding the baby. We had already decided that whatever they found didn't matter. We were having the baby. Period. During that visit, we were told for the first time that she might not make it. In fact, the tone was more that she *won't* make it. Then something happened for which I was not emotionally prepared. The doctor looked at Tammy, said something about how far along she was, and then asked her what she wanted to do. It took us a minute to register what the doctor was asking. He was asking if Tammy wanted to have an abortion. It was legal at her stage of pregnancy. Let that sink in for a minute. They just asked us if we wanted to kill our baby because having her was going to be really hard—on *us*—as if dying wouldn't be hard on her. I digress.

Without thinking much about how this was going, I simply said, "Oh no, we want to have her!" That's when the reality of the situation hit me, and I could legitimately see myself going to jail for physically assaulting someone. All in one swoosh of a moment, the nurse positioned herself between Tammy and me and the doctor, who looked just at Tammy and said, "It's your decision, Mrs. Parker." Legally speaking, I didn't have the right to answer that question. My Irish temper was blooming at that point. Now, mind you, this is taking place in a matter of seconds. Then someone entered the room and informed us that there was a room ready and waiting for Tammy to decide—to decide whether or not she wanted to abort our baby. In that moment, we—or she—could have decided to avoid the pain and the suffering God had dialed in for us. We chose to trust God.

Frankly, I've never seen Tammy move that fast or get as angry as she was in that moment. In about four nanoseconds, I went from rage, wanting to physically harm the doctor, to thinking, "Oh dang, Tammy is about to kill someone!" We got out of there. Quickly. That visit truly solidified some things for us. Abortion was never on the table. We believed then, as we do now, that whatever God has for us was, well, *for* us. However, in that moment, for whatever reason, and maybe just for me, it was very clear that there was more to this than giving birth to a disabled child. God had plans, and we were truly and deeply resolved to have this baby and love her like she was any "normal" child.

Looking back, I can't believe the abortion option was so easy and open to us. I also can't fathom the hurt we as a society have perpetrated on the unborn and also the mothers. Brynna still carries scars, which I will discuss later, but the emotional and spiritual scars women are carrying around with them is truly a weight too heavy for me to bear. I'll have to leave that with the Lord.

So let's fast forward to the heart of the matter. The following months were riddled with changing stories and new fears. And all the while, no one really knew what we were up against or how severe her issues would be. We also had to wrestle with many emotions. I'll speak more about that later, but at least for my part, suffice it to say that there were many, many moments of *Why us?* and *Why her?* These were rough days.

3

The Crucible

I bear my willing witness that I owe more to the fire, and the hammer,
and the file, than to anything else in my Lord's workshop.
I sometimes question whether I have ever learned anything
except through the rod. When my schoolroom is darkened, I see most.

—Charles Spurgeon

The second phase of refining ore into precious metal is to place the now broken and unrefined material in the crucible. A crucible is a funny thing. It is designed to be heated, designed to destroy what is undesirable within. It is permeable enough to allow heat to pass through yet strong enough to only allow the correct amount of heat—just enough to do its work. In it, the heat will melt away any impurities surrounding and potentially damaging the precious treasure the refiner seeks. The crucible is singular in purpose: expose and remove impurity.

The crucible of God's faithfulness does no less. Instead of a lead pot or a ceramic cylinder, his hands hold us—broken, shattered, bruised, impure, and full of dross. His hands shield us from the fire that is to come but only enough to prevent our complete destruction. He lets enough heat pass through to have its full effect on the ore. Proverbs 17:3 says, "The crucible is for silver, and the furnace for gold, and the Lord tests hearts." It was as if the divine proctor said to the class, "Study time is over. You may begin the test."

We knew enough to know we shouldn't have this baby in Tyler, Texas. We were Dallas-bound. When the time came, we went to the hospital, ready for a new baby but still unsure of what exactly would transpire. Our other children, although they had issues of their own, were all natural births. This one was a planned C-section, traumatic in its own right. I knew we were no longer on the junior varsity team when they took us into the delivery room and we saw a veritable army of people. There were at least 20 people in the room—seriously! Everything began like any normal C-section should. The obstetrician was doing his thing, the anesthesiologist was doing his thing, and the neonatologist stood there waiting.

When Brynna was released from the womb, I was already in shock. I had watched three births, but never a C-section. I wasn't prepared. I remember a few things distinctly from that day, but many other details are simply gone, overshadowed by weightier matters. I remember the doctors pulling up Brynna, who emitted a very small, faint cry. Then it stopped. The next few moments are surreal and horrifyingly cemented in my memory.

The moment Brynna was born, the army of people went into frenzied motion. They rushed her to a heated table and surrounded her, working feverishly. I couldn't see her. Tammy was asking, "Is she okay?" I didn't know. I couldn't tell. I glanced up at the anesthesiologist, whose only job was to monitor Tammy, and he wasn't paying attention. He was watching the baby table. His facial expression didn't reassure me. No one was talking, or at least not that I remember. That was the moment we heard the heaviest words a parent can hear: "Start chest compressions."

I wish I had the literary ability to explain how I felt in that moment, but I simply do not. All the prep, all the fears, all the months of saying out loud that we were okay with whatever happened came to fruition in that very moment. Brynna wasn't breathing and didn't have a pulse. But they brought her back. I was relieved. Then they said it again, "Start chest compressions." I've never experienced emotion like that in my life. I can't even describe it other than to say I could literally feel my soul dying inside of me. Then, I heard the doctor say, "Intubate." I'd watched enough *ER* to know that meant she was at least alive.

Keep in mind that during this time, Tammy is still on the delivery table being put back together, completely helpless. When our other three children had been born, they were placed in Tammy's arms moments after they were born. The pain of childbirth became a mere memory, and the joy of new life overwhelmed the recent struggle. But this was different. I can't imagine how she must have felt. My heart was breaking for Brynna and for Tammy. I didn't know whether to pay attention to the baby or to Tammy. I was, as the prophet Isaiah said, "undone" (Isa. 6:5 KJV). My stupor was broken by the doctor saying—forcefully, I might add—"Dad! Follow me." In those few short moments, Brynna had coded twice, been intubated, and been placed in an incubator. The good doctor was now squeezing rhythmically on the Ambu Bag, breathing for her through the armhole of the clear plastic box she was in. When I saw his eyes, I knew I had to go with him. We ran.

We ran down the hall, past rooms, back and forth—I think. All I remember is running. We had to get her to the NICU (neonatal intensive care unit), and we needed to do it fast. Her life literally depended on it. I remember going by the waiting room, not able to stop, and someone—a faceless, nameless memory—asking, "How is she?" I replied, "We don't know yet." Turns out that was Erika, our then nine-year-old daughter. The kids were as nervous as we were.

One thing I do remember is seeing Brynna's little face when she came from the womb. I honestly wasn't prepared for the cleft. It was large. Later, I described it to someone as a golf-ball-sized gap just under her left nostril. No gums, no lips in that area. Just a hole. No matter how much you prepare yourself, no matter how much you think you are ready, you aren't. It was the heaviest time of my life—heavier than watching Austin get checked for tumors, heavier than having Erika checked for leukemia. It was even heavier than waiting to see if Shaun had a rare neurological condition. All of those were maybes. Good news or bad news, we didn't know. This day, it was bad news, plain and simple. Heavy and thick. It is what I call the dark night of the soul.

After Brynna was born, we knew there were many people praying and wondering how things were going. There was no way to keep everyone in the loop, so we decided on an e-mail chain for updates. What follows are those updates. I have no idea how to put them into paragraphs or chapters, or to know which ones people might need or want to read. Some will speak for themselves, while others will need introductions, interjections, and some commentary.

If this were a storybook, we would be standing at this moment looking deeply into the wardrobe, wondering if Mr. Tumnus would come out to meet us. We would be preparing to enter another world, only this world isn't filled with whimsical characters, exciting adventure, or unbelievable creatures. This world is peppered with moments of dark doubt, unsearchable fear, and loads of uncertainty. It's also filled with wellsprings of joy, hope, and divine provision on an unprecedented scale. This is a story of how God taught us to love deeply and to trust him. He showed us our theology was sound, his love was pure, his sovereignty intact, and his mercy as abundant as ever. Into the wardrobe we go.

May 10, 2007
Day 1

6.3 pounds, 17 inches, 9:50 a.m. After all the waiting, she's finally here. I know you all have been as apprehensive as we have. It is very *late, and I am very tired, but I promised I'd get some pictures out to you tonight. I also wanted to let you know where we are and what we are facing.*

First of all, Brynna's brain is smaller than it ought to be. The ramifications of this are unknown at this time. Also, there is a piece just above the place where the optic nerves converge that is simply missing. I can't remember what this is supposed to do. There is also a small part directly under this, just behind the eyes and in front of the pituitary gland, that is underdeveloped. The pituitary appears to be structurally ok, but we are concerned about its functionality in secreting hormones to regulate things such as blood pressure. Her eyes are structurally a little small. An ophthalmologist will look at this to evaluate any damage that may be there. The palate is cleft all the way back. She still has kidney issues, but they appear to be functioning. At present, her blood pressure is the issue. Her blood pressure is low, but the blood pressure in her lungs is high. Imbalance in pressure equals problems exchanging oxygen and carbon dioxide. At this moment, we are in approximately hour two of trying to stabilize this issue. It is looking good, and it is working. We will know more tomorrow. We are just now embarking on the investigation for our little sweetie.

After a pause in writing this, I have returned. It is 1:00 a.m. on Friday, and Brynna is doing better, blood pressure-wise. It could take a couple of days to completely see the results of the procedure. She gets cranky from time to time with all the tubes and such. Tonight, she slept while I sang to her. What a moment. In the immortal words of a pastor friend of mine, "I have turned into a slug." I am going to get some sleep before our busy day tomorrow.

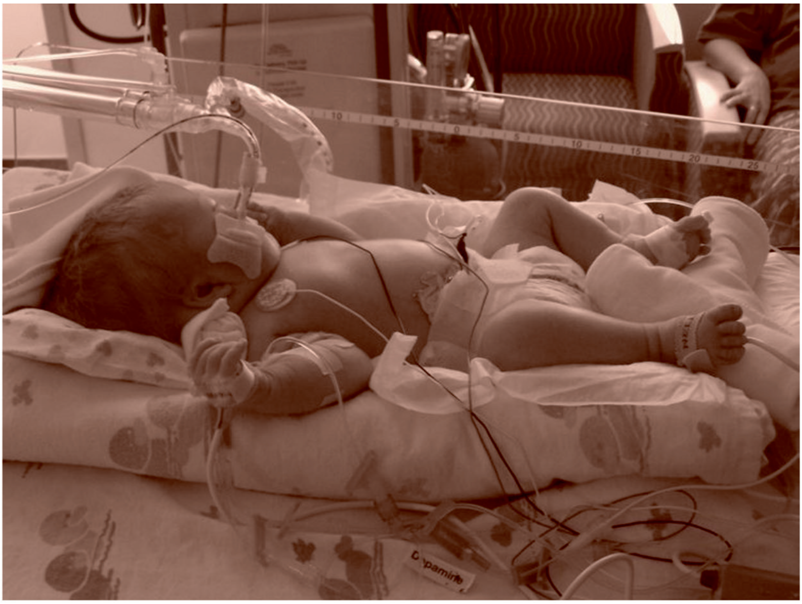
Thanks for your prayers.

This day was such a weird mix of emotions. We were overjoyed to finally have Brynna here and still in shock over what having her here actually meant. The little bit that we knew was bleak and overwhelming. You've heard the saying about drinking from a firehose, right? Try drinking from Niagara Falls. It was sort of like that.

May 12, 2007
Day 3

Good morning. It is about 7:30 on Day 3. Brynna is doing great. Thursday night we had a little issue with her blood pressure. The long and short is that she isn't exchanging carbon dioxide and oxygen as she should. This is affecting everything else at the time. They have her on a heavy duty ventilator and several IVs. Through last night, she is improving. This condition is temporary and should not return when addressed completely. Our little bundle of happiness has a long road to travel.

We met with the neurologists yesterday. We have learned that her brain is significantly underdeveloped overall and that several key areas are affected. We will not know for some time exactly what the developmental ramifications are but will cross that bridge when we get there.



To date she has a neonatologist, neurologist, geneticist, ophthalmologist, urologist, surgeon, speech pathologist, cardiologist, and who knows what else. She is well cared for, to say the least. She also has some eye issues. They are a bit small, and we don't know exactly what the damage is. The ophthalmologists will come on Monday. Her palate is cleft all the way back and into the nasal passage, but we will worry about that later.

We aren't able to spend a lot of time with her as the attention agitates her and excites her. I have that effect on people! In true Brynna fashion, however, she is 180 degrees the opposite of normal. When most babies get excited, their blood pressure goes up. With Brynna, it goes down. Go figure. Just like her mother, backwards from everyone! So, we spend a few minutes at a time.

It occurred to me this morning that in eternity past, God looked up and saw me. My soul was, shall we say, not as I would like it to be. There were imperfections, marks of a fallen nature. However, the scriptures tell me he loved me anyway and counted me as one of his own. This is agape, unconditional love. As I looked down and whispered to Brynna last night, I truly began, and I mean began, to understand what agape really means. Her little body is not, shall we say, as we would like it to be. However, it is exactly as it should be for she is fearfully and wonderfully made! We love her and call her our own with unconditional love. Thank you all for loving her, too! We are about to go see her after breakfast. We can't wait.

With children, those first few days are so sweet. The snuggles, the feeding times, the visits, that new baby smell (no, not that one—the good one). So many of the things we longed for when we learned we were expecting had vanished before our eyes. I can't tell you how difficult it is on a mother, even an experienced one, when she isn't able to hold her baby. What's worse, Tammy had undergone a C-section and didn't get to see her right away, much less hold her in those precious moments. Knowing that our mere presence in the room put her at significant risk weighed heavily on us. We wanted to touch her, hold her, love on her so badly, but it was not yet to be.

The other issue impacting us those first few days was simply the unknown. We were learning and hearing new words every day, every hour sometimes. We became experts at looking up terms and diagnoses. One thing the doctors told us early on was to stay off the Internet. It was clear we needed a crash course in how to be a nurse, so they gave us some websites we could trust. We started reading and learning. I often wonder if we should get some sort of honorary nursing degree. I think we should.

May 14, 2007
Day 5

Brynna continues much as she has for the past 72 hours. She is still on the ventilator and all but one of the machines. The itric oxide machine is gone. Praise God for little victories! She has increased her feeding to 5ml every six hours. The endocrinologist is running tests, the geneticist is running tests, and we are basically treating the moment. We have no prognosis or time frame for her to come home. Her brain development is what it is and will affect her in ways we do not yet know. Please continue to pray.

May 15, 2007
Day 6

Today was a good day. Brynna opened her eyes for a brief moment today. Her color is better. Her swelling is down. Tammy says she looks good. They have taken her off of dopamine, and she had her first dirty diaper. She is feisty and spirited. Today, she cried and her blood pressure stayed stable. We are so excited. Thanks for praying.

I honestly started to leave these two days out of the book. They're boring. Nothing happened. No drama, no near-death experience, nothing to tell really. So I read them again and realized that simply isn't true. There's a line in the movie *Jerry McGuire* (I don't recommend the movie, but the quote illustrates my point) where Jerry says, "I'm good in the living room." What he meant was that he was gifted in sitting down with the families of his clients and closing the deal. He won their trust and loyalty in the living room. I don't know about the living room, but I'm good in the hospital. I do fairly well when things are big, ugly, and out of control. It's the days like this, the simple ones, the mundane ones, that are the problem. It's constant. Every. Single. Day. These are the days I struggle. I often miss the meticulous details of God's provision in the stillness of nothing spectacular. Reread my posts. Did you see them? The little things God was doing?

She increased her feeds. That was a big deal, a really big deal. One less machine, another milestone. That meant she was stronger, doing better, needed less help. They were running tests. That meant more answers were on the way. In this game, knowledge is power. Test results can mean the world.

She pooped. Yes, pooping is a big deal for a baby in her condition. Among other things, it means her bowels are waking up, starting to function ever so slowly. She opened her eyes. I nearly missed that one altogether. If you have kids, you will understand. Remember that feeling when you looked into their eyes and they saw you? They responded to your voice, your touch, your presence, your heartbeat? Those moments are special. In this report, Brynna opened her eyes. We got to look into her soul. What's the takeaway? Looking back, I see that we were learning how to see God in the little things. We were learning to bask in the glow of the everyday, mundane, boring gifts from God. In them, we truly see his majesty.

May 16, 2007
Day 7

Today, Brynna is about the same. She continues breathing on the ventilator and taking a myriad of medications. Her blood pressure seems to be getting better. She threw a good ol' fashioned red-haired temper tantrum today for quite some time, and her blood pressure stayed up where it should be. That was great to see. She looks so wonderful and precious. She had her eye exam today. By the way, when a doctor says they are going to do a procedure on your child's eyes, like Shaun's surgery or Brynna's exam, DO NOT, I repeat DO NOT ask them what they are going to do. Just trust them and pray. Learn from our mistakes. You don't want to know. With that said, her eyes seem to be structurally ok. No visible damage noted. This does not speak to their functionality, but at least they appear intact.

Tammy and I are both home tonight. Brynna is in good hands, and our other children need us, too. We will return on Friday. We have trusted her to God thus far and can do so in our absence. Besides, our constant presence agitates her some, it seems. I was really not ok at first with one of us not being there, but I think of a couple of scriptures in a new light.

Psalms 10:14 [KJV]: thou art the helper of the fatherless.

Psalms 68:5 [KJV]: A father of the fatherless, and a judge of the widows, is God in his holy habitation.

I have always seen these verses in the light of orphans who do not have earthly fathers at all, and truly their context may bear out that application. However, for the next 36 hours or so, at least in physical manifestation, Brynna will need God to stand in for us. I believe he will and has already. Your kindness is overwhelming, and your love and concern keep us going.

At this stage, we started to realize how much our absence was impacting our other kids. Don't get me wrong, they were great, but they, too, needed their parents. We were starting to really see and learn what it meant to trust in the Lord with all our hearts. He would have to be there for us because we absolutely could not be there ourselves. Look at 1 Corinthians 10:13, one of the most misinterpreted and misapplied scriptures in all the Bible.

> *No temptation has overtaken you that is not common to man. God is faithful, and he will not let you be tempted beyond your ability, but with the temptation he will also provide the way of escape, that you may be able to endure it.*

People often use this verse to tell themselves, "God will not give you more than you can handle." That isn't what this verse is saying. It is saying you can always avoid the sin you are being invited into. We can choose not to sin. It doesn't mean he won't give you more than you can handle. In fact, scripture and experience would bear out that he does quite the opposite. He puts more on us every day than we can handle. That's sort of the point. He wants us to be so dependent on him that we can't possibly come out on the other side, thinking, "Man, I'm glad I was so strong or that deal would've done me in!" No. Just no. He often wants us to simply recognize the fact that without him, we can do nothing. Everything is more than we can handle.

May 18, 2007
Day 9

We visited with Brynna again today. This morning, they turned her ventilator down to 20 respirations per minute from 30. She is off of her blood pressure meds, and her eating has been increased to 20cc every three hours. She is rapidly getting stronger. We are definitely moving in the right direction. We have, in the past 48 to 72 hours, seen two machines leave her room and some others cease to be used. She is so beautiful. We can't wait to get her home.

Through this all, we have been asked over and over again, "How can you guys stay so positive?" I think that is a good and fair question, a question with a good and fair answer. Our faith helps, but it isn't what makes it all happen necessarily. Underneath that faith is the unimaginable grace and mercy of God. Underneath his mercy is his ever-specific, meticulously planned will. He knew long, long ago where we, and she, would be right now. He knew it all. He has orchestrated our lives to bring us to this place to experience his grace and his love. That is what feeds our faith. Jesus is alive. He is real, and he cares about us. Brynna has touched so many already, I can't wait to see how he uses her further. We will undoubtedly have many more rough roads ahead, but we know that God will be with us the entire way. Thanks for your prayers, again. And keep it up, it's working.

If you happen to be the type of believer who doesn't like theology, who thinks it's too academic or too boring, you won't like this part. As I said in the e-mail, our faith is certainly a central part of how we put one foot in front of the other, but our faith isn't a completely blind faith. Our theology informs our faith, undergirds our decisions, holds us up when we are about to fall.

The single most important piece of theology during this time was the plain and simple sovereignty of God. Nothing—*nothing*—comes to the believer that has not passed through either the directive or permissive hand of God. Our weirded-out religious culture has convinced itself that to be in tune with God, to be obedient to his voice, means everything is going to be fine. When that paradigm fails, we don't know what to do. We see it all the time. Something good happens, a prayer is answered affirmatively, an accident is narrowly missed, a death is postponed, a bill is paid. What do we do? We say, "Oh, man, God was looking out for me today." So when all hell breaks loose in our lives, does that mean that he missed one? Did he drop the ball, go to sleep, get distracted? Worse yet, could he simply not care as much for us as we thought he did? These are all bunk, and deep down, we know it. We, as a culture, aren't accustomed to thinking in these terms anymore.

The truth is, God is sovereign. Let me say that again. God. Is. Sovereign. That doesn't mean he is in charge only when we let him. It doesn't mean he is in control over only the good things. It doesn't mean he only gets the credit when things go our way. It means he *is* sovereign. He is in charge. End of story. He can make it rain or not rain. He can make the sun come up or stand still. Here is the kicker, the one that pierced me deep in parts of my soul I don't like to talk about at parties. Ready? He could heal Brynna. Any time. Any day. At his word. Remember, we believe in the same Jesus who told Lazarus he wasn't allowed to be dead anymore. He could have done it. The fact is, he didn't. Does that mean that by some act of human strength we were able to handle this terribly heavy load? Not at all. Just the opposite. It meant that we couldn't carry it.

Looking back, I'm faced with this very hard truth. The fact is that I *did* think I was strong enough to handle it. I mean, for crying out loud, I'd been serving the Lord for years. I grew up in a Christian home and knew the Bible. I was faithful. Faithful. A spiritual giant, so I thought. I was also a proud and self-centered fool. The truth is that God could heal Brynna, but he didn't because he didn't want to. Let that settle in for a moment. He always accomplishes his will. Always. It was not, still is not, in his will to heal her. He simply had work for her to do, mostly in my dark and twisted heart. We'll talk more about that later, but suffice it to say for now that he loved me and our family enough to let her remain as she was.

Our belief in the absolute sovereignty of God, coupled with an undying and unwavering faith in the goodness and purity of his character and nature, helped us begin to accept his plan over ours. These were certainly formative days. In fact, they would prove to be some of the most formative in my life to date. He had work to do in my heart.

4

The Dross

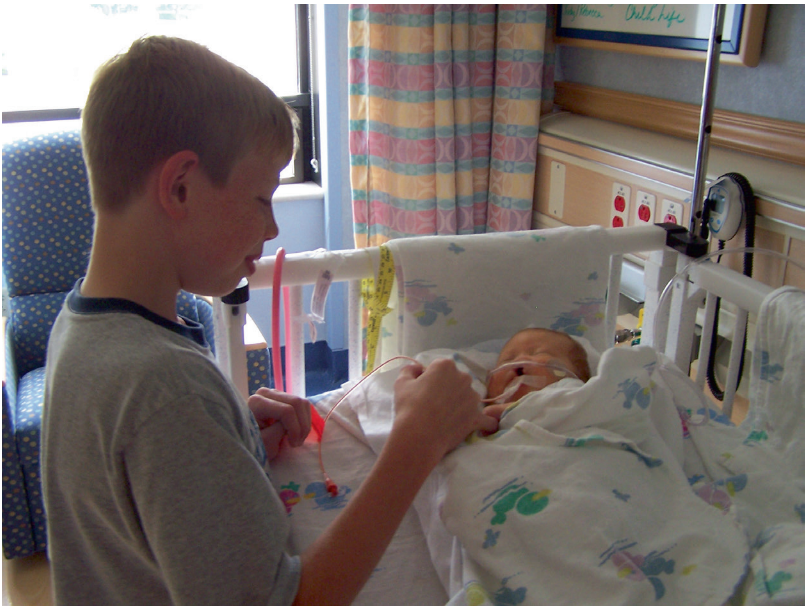
Oh, that God would purge away my dross,
and take away my tin, and refine me seven times.

—David Brainerd

After the crucible is heated and the ore begins to melt, something amazing happens. The dross, all the impurities, all the junk and gunk that is mixed in with the precious cargo, begins to rise to the surface so it can be removed. During that stage, the refiner has a very watchful eye on the entire process. He is not detached, absent, or disinterested in this methodical step. His eye is ever on the smelting pot. In fact, everything is considered with the end in mind. How hot? How long? When to remove the first bit of dross? All under his insightful and experienced hand.

Our culture is busy removing itself, protecting itself, from suffering and pain. However, the pain and suffering of progressive sanctification is often the only path to a purified heart that longs for nothing else but to be used by the master. In Proverbs 25:4, we learn, "Take away the dross from the silver, and the smith has material for a vessel." Many might think that the goal of refining is simply to remove impurities. But while it is a necessary part of the process, the goal is to create a finished product, a product ready and worthy to be fashioned into something beautiful, into a vessel of honor.

I'd really like to say that for us, this process was one of merely continual strengthening of our faith. And it was, mostly, but hindsight has shown me that there was also a very significant dross removal process going on, mostly in my own heart. As I said earlier, I honestly felt I was doing pretty well. What the Lord would reveal in my life during this trial was the selfish attitude I had and still struggle with today.



The oldest child in any family is always the guinea pig. Young parents haven't a clue about how to raise children, and yet they are sent home from the hospital with a tiny human totally dependent on them. We figure it out and do the best we can. As a redhead, my temper has always been a problem, especially when my son Austin turned out to be just like me. I can honestly say my intentions were good, but I dealt with him far more strictly than I should have, often lording my authority over him, far more concerned about his compliance than about the development of his heart.

Our relationship was strained, to say the least. He was 11 when Brynna was born, and we were already butting heads. By the time she had coded in the delivery room twice, taken a couple of helicopter rides, and been at death's door a few times, my heart was changing, getting softer. The biggest change was an appreciation for the brevity of life and for the sovereignty of God. So many things I once dubbed extremely important were no longer even on the radar. I know Austin struggled with the changes, with how to interact with us. I struggled, too. It is a harsh realization to appreciate the frailty and mortality of humanity while also knowing you've squandered away years with poor leadership and fatherhood. The root of our struggles was often my very own pride, the pride that God was crushing and removing. I'm by no means a humble man today as I would like to be, but I do have a healthy reverence for my own limitations and God's incredible mercy and grace to take the time to reach out to someone like me.

Erika was a bit younger and Daddy's little girl. She was handled more gently, for sure, and little Shaun had his own troubles. So Austin seemed to get the short end of the stick. I couldn't see I was crushing his heart and breaking his spirit under the cloak of making him a man. Just because there is no physical altercation doesn't mean you're doing it all right. For me, I was focused too much on how his behavior impacted my reputation, my ministry, and my appearance before men. I needed to see him like God saw me—fearfully and wonderfully made, a gift like I was now seeing Brynna.

One of the final crushing blows during this time, and maybe one of the most formative moments, was a phone call from the parent of a student. I was teaching and received word that a father wanted to pull his son from my class. I had never had this student before, so I was perplexed. I called and asked what was going on. It turns out that the dad had seen me coach Little Dribblers basketball. He'd seen me yelling at referees, throwing my hat on the bench, basically acting like a fool in front of God and everybody. It is true that some of that could be pawned off on the need to raise your voice in a gym full of loud spectators and children, but the truth was, I wasn't in control, and I knew it. Something had to change.

The Sermon on the Mount isn't just a filler in scripture. Jesus really meant those things. Brynna's journey was grinding home the truth that I must relinquish control, not just of her future but of my own. I was living under an illusion of control, a false one. I can't control anything. Not one hair on my head can be added, not one inch of stature can I change. That meant I needed to turn my whole existence over to Jesus. I had a ton of apologies to make. They would take time and still do.

The removal of the dross—the sin—in our lives can be a painful process, one in which our obstinance finds us in need of repeated applications of the refining fire. God the Father was about to turn up the heat. I had lots of dross to remove.

May 22, 2007
Day 13

At approximately 10:00 a.m. today, the doctors turned Brynna's ventilator down to zero. She is breathing on her own, 100% at this time. We rushed up to see her this afternoon. The doctor told us her facial cleft does not permit them to put the little prongs for oxygen in her nose to assist her, so it was all or nothing for Brynna. She is doing fine as of this evening. She is maxed out on her feeding at this time until she gains more weight. She has been given a diagnosis of SOD, or septo-optic dysplasia. Thank you for your continued prayer!

We were settling into a groove, if that's possible, of going to work and one or both of us scooting up to Dallas to see her. It was an hour-and-a-half drive. This day was particularly special because of the ventilator. She had to come off of it to come home. So far so good. It was also good to finally have a name for what she had, for her condition. We read so much about SOD, and all of it was terrifying. No one had even heard of it where we lived. We would experience that often over the coming years and still do from time to time, nurses and medical professionals who know nothing of SOD or its dangers. Remember that honorary RN license I was talking about earlier? This started to feel like grad school.

The next two days were big days. There was a great deal going on with Brynna and in our hearts. It was a very stressful time, a time where we grew leaps and bounds. We learned to trust, we began to grieve, and I think it was during this stretch that I had my first meltdown with God. My problem is that I remember things vividly, but I sometimes get them out of order. I'll share what happened and why after this next post.

May 23, 2007
Day 14

What a day! I understand that there has been some confusion regarding the events of the day, so here goes.

Today they took Brynna off of all her support to see how she would do. No more arterial line, no more respirator. She had to have a small bit of oxygen as a boost shortly after removing her from the ventilator. However, we did get to hold her, and that was wonderful. The neonatologist came in and talked with us regarding her options. They still say that with the level of defect she has in the brain, she will be like an infant the rest of her life. They also said she had trisomy 13 once before and they blew that one, so we take that with a grain of salt. Basically, we are beginning discussions of how to transition Brynna home. The big *question today was whether or not she could maintain her blood oxygen levels apart from the machine. As of 11:30 p.m., so far so good. Had she needed to go back on the machine, our options would be different, such as bringing her home with a breathing machine. As it stands now, we will need to have oxygen at the house. What else we will need remains to be seen. We are calling the feeding specialist tomorrow to discuss feeding options. We are living day by day. Please continue to pray.*

This evening, we discussed all of the special things that all of you have done for us. You have laughed with us, you have cried with us, rejoiced with us, sometimes all in the same day. We cannot express how much each of you means to us, really. As the doctors tried today to prepare us for possibly letting Brynna go, we were upset and somewhat discouraged, but we reminded each other something even the doctors forget. Her life is in the Lord's hands, not theirs, not ours. We are prepared for any outcome that the Lord brings our way but remain resolved that things are not as grim as they believe. Brynna has changed our lives in so many ways. We look forward to seeing how she changes them even more.

I don't really have the words to describe all the emotions of these days. There were too many to even list, and they seemed to hit all at once. I can't explain how difficult it was and still is at times, sitting down with the doctors and having very open and honest conversations about the prognosis. It has always been our position that we wanted to know everything, no sugarcoating. I've always been comfortable with having honest discussions with people, if necessary, even if they are hard or awkward, but these were different. The medical staff tried, the best they knew how, to prepare us for Brynna's death. Did you catch that in the second paragraph? I said, "As the doctors today tried to prepare us for possibly letting Brynna go." I remember one night sitting in the living room, knowing we faced the real possibility of needing to do Brynna's funeral. I knew I should be the one to do it but also knew I would not be able to put the service together in the moment. I sat down in my chair. It was really late, and I penned the sermon I hoped to never preach. So far, I haven't had to, but I keep it in a folder in my closet, a reminder of God's provision. He gave me the words. He gave me the verses. I haven't read it since that night. This was crunch time. These are deep, deep waters. It was truly another dark night of the soul.

We needed people more than we ever knew at this point. Here's a little secret. Tammy and I are pretty self-reliant people. We don't ask for help, and truthfully, we don't need a ton of it. This was different. We were empty. We were scared. People poured into our lives over and over again with prayer, encouragement, the occasional gift card for food or gas money, and constant encouragement. People pointed us to Jesus because that was the only place we could find hope. Thinking about losing her was more than we could bear. Even though we had put all our eggs in the basket of God's sovereignty, this was hard. I don't know another word. It was just hard, and I was mad about it.

There were a couple of times I really let things get to me. I don't exactly recall the timeline, whether this was "the time" or just a precursor, so I'll just tell this part of the story and let the timeline stand as is. Like I said, I was mad. I was mad at God. Really, really mad. We didn't deserve this. We had been faithful to serve in ministry for over a decade at this point. We'd left our home and been dirt poor for the ministry. We had lost friends, family, and church members. We'd given ourselves over to serving God. That was supposed to bring blessings, right? This wasn't a blessing. This sucked. I'm sorry for the raw language, but that's where I was. I remember one time walking down to the pasture and sobbing uncontrollably. I was so angry. It hit me that God could heal her and didn't want to. I had come to this conclusion before, but this time I wasn't buying it. I was tired and exhausted—physically, emotionally, and spiritually. I told God everything I could think to tell him, loudly.

What sort of God would possess the power to heal her, to make her well, and then refuse to do so? This was reminiscent of another time in my life when I was super angry with God. I had resigned my first church, and a mentoring pastor wrote me an eight-page letter telling me that since I left the church, God would harm my firstborn child. I told God that if this was what Christianity was, he could keep it. I walked away from the faith for about three months. Thankfully, he dispatched the legions of heaven to bring me back.

This time felt much the same. We had towed the line and been faithful. We prayed, we believed, and still he didn't help us, so it seemed. I began to understand how Mary and Martha felt when Lazarus died. They knew Jesus could heal him if he had only been there. What was worse, he tarried two days to make sure Lazarus died. I was personally wrestling with the question, "Why did you let this happen?" His answer to me was the same as his answer to the sisters of Lazarus—so the glory of the Lord could be known. Looking back, I take comfort in knowing that even though Jesus knew he would soon raise Lazarus from the dead, he still wept with the family. He felt their pain. He hurt with them. He felt their grief. He felt mine, too. I'm sure he wept with me that day. Many people worry that God can't handle their doubt, fear, and anger. Let me assure you, he is fine. It was during these dark days that I learned what it meant to really walk by faith, what it meant to have a relationship with God the Father so deep and intimate that I could tell him anything I wanted. He loved me, still. He picked me up, dusted me off, and whispered, "Trust me." We did just that.

May 24, 2007
Day 15

Well, another day is done. Another day that we are not promised but God makes wonderful! We got to spend a great day with her. She continues *to breathe on her own, and her blood gases are good. We heard her cry yesterday for the first time, except for a tiny squeak in the delivery room just before she stopped breathing. Today she cooed and oodled much of the day. What a great sound. We had an echocardiogram today to check for PDA, or patent ductus arteriosus, as if we didn't have enough to worry about. They can fix this in most infants. However, we don't yet know if they will wish to treat her with the other issues she is facing with her breathing. It could be a real setback. We will talk with them tomorrow by phone about the options before us.*

On the way home today, after being steamed about some of the medical staff's inability to understand that Brynna is in God's hands, not ours, and that she is not necessarily bound by what the medical evidence says she can't do, Tammy read me an article by a mother with a child with septo-optic dysplasia. She reminded us of John 9:1–3, which tells us that sometimes what we view as a physical defect is actually being used so God can receive glory. This did a lot for me today. Pray for me that I keep my temper and witness with this particular doctor as we progress forward. She is trying us! :) What a kick in the pants if Brynna could be used to lead her to the Lord!

Thanks again for your prayers.

By the way, Brady B., the little boy who came in the same day as Brynna with a heart condition, is doing well. They hope to be in a regular room by Saturday. Mom and Dad are holding up ok, as much as you can living in the hospital. They thank you all for your prayers. They profess to be believers, and we take them at their word, so don't forget these family members as you continue to pray daily.

There are several things happening in this e-mail. First, let me introduce Brady B. As you can see, he came in the same time as Brynna and was in the NICU with us. When he arrived by helicopter, his mother was still at the birthing hospital in West Texas. I remember feeling heartbroken for them in the waiting room where we all learned to live. My dad was with me there that night. I went over to the family, introduced myself, and after exchanging brief versions of our stories, I asked if I could pray for them. They obliged, and we prayed there together. It was a sweet time in the Lord.

Crying Babies

Remember when the kids were babies and you longed for times when they would just stop crying? You needed sleep, or at least a few minutes of quiet and a cup of coffee. Me, too. This was different. We were on Day 15, and Brynna had been sedated much of the time because she had large rigid tubes going down her throat into her lungs. She couldn't cry. She had now been taken off the ventilator and was breathing room air, which meant she could finally cry a little and make those baby noises you long to hear. It really was a precious sound.

PDA and Bartimaeus

The heart condition mentioned above, the PDA, was particularly troubling. I was seriously in this what's-next place. I was starting to lose patience with the medical staff. I was having the same struggles as they were. It was a roller coaster. When Tammy read me the article on John 9, it did its work in my heart. Since Brynna was born, we've been asked by well-meaning people if we thought this happened because of sin in our lives. That was really hard to deal with. But what I really wrestled with was why. Why didn't God heal her? Why was Brynna this way? To be more honest, I was really asking, "Why was I being asked to go through this?" It didn't seem fair. Not at all. However, the truth of John 9 is that God knew exactly what he was doing. He had glory to gain, and we were privileged—and so was Brynna—to be tools in the building of that glory. It wasn't about us. It wasn't about her. It was, and always has been, about glorifying God the Father, just like Jesus did. Always.

May 27, 2007
Day 17

Today is Brynna's 17th day with us. Today, she looked good. She sat and looked at me for some time, or at least she appeared to. There is a good chance with her condition that she will be partially or completely blind. She appears to follow shapes, but only time will really tell. We are learning a lot about septo-optic dysplasia and have found some support groups and online communities with a wealth of information. Brynna continues to have two heart issues: (1) the PDA not closing and (2) there is low pressure in the right side due to it being slightly enlarged. She is still on her oxygen tube. They tried her without it today, and that was a no-go. She needed it back. This little lady is very attitudinal and does not like to be held very much. She isn't accustomed to being passed around, like most babies. She lies by herself in the crib most of the time, except when we can get up there or a nurse is doing a procedure. We expect to have her in the hospital for at least two more weeks, maybe more, until they can regulate her meds and get her stable for a period of days.

We can't wait to get her home and figure out where to put all her stuff. Just like a woman, she comes with baggage! :)

May 31, 2007
Day 20

First, let me apologize for not updating in several days. Things have been crazy the last few days. Yesterday, at 2:00 p.m., Brynna was taken off of her oxygen tube. As of this evening, she is doing fine without it. The only thing she has left is the gavage tube for feeding and lots of meds. The tentative plan is for us to continue to learn how to care for her and to room in with her on Saturday night. Rooming in is where we stay with Brynna in a regular room, outside the NICU, with all the stuff we will need to care for her at home. We will stay through Sunday with nursing support close by. If all goes well, we will come home Sunday night or Monday a.m. We are so excited, yet very nervous. Thank you again for all your *prayers and support. Truly, though, this has been a rough go. There are so many ways that this has been a very rewarding and nice experience. We have forged friendships that will last forever, built bonds that can't be broken, and seen the side of God that few of us ever really get to see.*

We have learned many new words, diagnosis terms, skills, and much about ourselves. Thank you for sharing this journey with us so far. . . . This little girl continues to defy the odds. She is God's tool, after all.

Today, Tammy put in the feeding tube. That was an experience. Tomorrow is my turn. I'm nervous, but Tammy, the pro, says it's not a big deal. We'll see! Brynna sucked on the nurse's finger today, and we found out that pacifiers are out. This sucking completely cut off her airway, and she turned blue. Blue = bad. Pinkish beige = good. We will not do this again, for now. In two weeks we will see the craniofacial surgical team. They are wonderful. Then, we will discuss doing feeding/swallowing studies to see if she can start to wean off of the tube. We will see. Please pray. We will update as things change.

WOOOOHOOOOOO! She's coming home!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

These were good days, encouraging days. We felt like things were really beginning to get somewhere. One of the greatest things to come out of this ordeal was the bond with friends and family. People stepped up, sometimes people we didn't know, and supported and served us. For this, we will be forever grateful. Putting her nasal feeding tube in was also one of those things we will never forget. It goes against all parental instincts to shove something up your kid's nose and down their throat while they gag and fight you. I will say, though, that we became experts over time. Tammy could throw that sucker in with one hand while talking on the phone with the other. She's a ninja. Then, things changed. Again.

5

The Heat

In this you rejoice, though now for a little while, if necessary, you have been grieved by various trials, so that the tested genuineness of your faith—more precious than gold that perishes though it is tested by fire—may be found to result in praise and glory and honor at the revelation of Jesus Christ.

—1 Pet. 1:6–7

After the dross has begun to be removed and the material is starting to look more and more like its pure end product, many people think the refining process is over. The material no longer looks like dirty, raw ore but actually has a shine to it. It's sort of pretty. The problem is, it isn't. There are still impurities that need to come out, and many are hidden. For us, these come in the form of hidden agendas, secret sins, bitter attitudes, and things we love but shouldn't—idolatry, blind spots, you get the idea.

For the refiner, this is all part of the process. He knew this day would come when he started. He knows there is more dross in there, and he wants it gone. To do this, he has to heat the material even more. More heat. Back in the fire. Some impurities only come out at extreme temperatures. In our own lives, sometimes maturity only comes out of deep valleys. These dark nights of the soul often bring about the deepest changes in our walk with Jesus. Psalm 12:6 says, "The words of the Lord are pure words, like silver refined in a furnace on the ground, purified seven times."

Every time I thought we were out of the woods, something else would happen. There were honestly days I would ask God, "How much more do you think we can take? How long? How many times must we stand at the precipice of losing her before you help us?" These are all thoughts we had and sometimes still do. Every time, he held us in his hands, protecting us as he thrust us back into the fire, whispering, "Trust me. Just trust me." Trust is hard. Total trust is even harder, but sometimes it's the only way for us to be transformed into what he has for us. The fire had been stoked. We were going back in.

June 2, 2007
Day 22

Well, if we've learned anything, we've learned that things change. We went to the hospital today to prepare for bringing Brynna home. We spent all afternoon arranging oxygen, supplies, and machines. While we were there, they did an echocardiogram of her heart to check her PDA, the valve in her heart that was supposed to close after birth and didn't. As we were preparing to leave, and the transition home was planned, they brought us the results from the test. The original plan was to wait until Brynna was 10 pounds and then fix the PDA laparoscopically. It appears that the PDA is taxing her little heart. Unfortunately, the repair can't wait. So, plans have changed. Brynna is not going to come home on Sunday, just yet. Early next week, either Wednesday or before, she will undergo surgery to perform the repair. Afterwards, she will go back on the ventilator, and that process will begin again. Tammy and I both feel a very strange peace about this.

Through this entire ordeal, at each stage, we have had peace from God about all of our decisions and Brynna's turns. Neither one of us was confident about bringing her home, yet we both feel that the surgery is *the thing to do, even though we wished to avoid it. It is true. The Lord knows what he is doing! Please continue to pray.*

A bit of good news. Brady, the boy we've been praying for, is home and, as far as we know, doing well.

Tammy and I are appreciating the importance of Matthew 6:34 [KJV]. "Take therefore no thought for the morrow: for the morrow shall take thought for the things of itself. Sufficient unto the day is the evil thereof." Don't worry about tomorrow, because it may not be the tomorrow you planned! God is good, all the time. I am reminded that he never promised us an easy ride. In fact, he promised we would have trouble in this present world. We have heard several stories from some of you regarding how Brynna has touched someone's life. You can't imagine how much hearing and knowing this helps us each day. Some of you have also asked if it is ok to forward the updates to friends and family. Absolutely! We don't mind a bit. I am going to spend Saturday in Longview in school, and the rest of the family is going to spend the day at the house (laundry, mowing, family time, etc.). We will return to the hospital on Sunday to finalize plans for the surgery. We will update again when we know more. Adios, for now.

This was a tough day, especially as we learned they would be going in from the back through her rib cage to do the repair. I was back on track, trying to trust and know God. He was extremely faithful during this time. By this time, the impact Brynna was having in our lives, drawing us closer to the Father, molding us in the image of his Son, was becoming apparent. We had a profound sense that he was with us and things were as they should be. His peace was with us.

June 5, 2007
Day 25

We awoke this morning after a restful night to find our little jewel with a heart rate of 135–150, blood pressure of 55, and blood sugar of about 150. Her sugar was 360 after the surgery, steroid induced. She looks *great and is ready to start eating and get those tubes out of her mouth. Thanks for praying her through.*

I have attached a devotional written by a very special lady. It was given to us here in the NICU by the family therapist, also a special lady. It is the book of Philippians from the eyes of a special needs child. Get out your Kleenex. Tammy and my mom had to take it in chunks—too much for one sitting.

Throughout Brynna's ordeal, we have hoped and prayed that God would be glorified through her struggle, and he has. We have prayed that he would teach us, and he has. We have prayed that people would understand how we feel and not think that our faith is just words, but that it is real. We want people to know that God is good, real, and truly a very present help in the time of trouble. Read this attachment, cry with me, and give praise to our Savior!

Thanks, Kelly Beller. What a story! Hug your kids. Love them like they are, and thank God for every little thing they get to do.

Good days. Bad days. Unexpected days. This was the pattern. I'm not going to lie. There were days, even when God's peace was heavy and thick, that I wondered, "What else? What more can we endure?" During these really sketchy days, and the sketchy ones to come, we began to really learn about trust. We began to see portions of the bigger picture. The devotional I spoke of in this post was very formative, at least for me. It sat on our souls and came at a time when we really needed it. I have included it at the end of the book with permission from the author. As noted, you may need a Kleenex when you read it.

June 7, 2007
Day 27

Momma said there would be days like this. First rattle out of the box today, we were elated to learn that Brynna was coming off of the *ventilator. She was doing well all on her own, and her sodium levels had come down and her urine was "normal," or at least more normal than expected. We were on cloud nine—then it thundered. When they pulled her off the ventilator, it was obvious that things were not what we expected. Her airways were swollen and constricted from the tubes. She was trying but wasn't moving much air at all. She turned several undesirable colors and was working hard to get air in. They began to do breathing treatments to open her airways. After the first one, she just looked up at me, not fussing, not crying, just looking, but working so hard to breathe that I almost cried. There just isn't a drop of quit in this little girl. It's like when she gets another setback, she just says, "Ok, here we go" and just does it. As parents, we would take her hurt away and put it on ourselves in a heartbeat, but I'm not sure we could handle it.*

I must interject here. This post doesn't do justice to how hard this little lady was working. Imagine with me for a moment a solid hour of watching your tiny little baby struggling so hard to breathe. She simply couldn't pull in enough air. We knew in our hearts that this might be the moment when we would say goodbye to her. In the moment described below, she was struggling so hard to suck in air that the only thing touching the bed was the back of her head and one of her heels, her back arched, straining for breath. Our souls were dying inside. Then, this:

Finally, after an hour and one final breathing treatment, she calmed down and began to breathe. Hmmmm, ok. Then, I noticed her convulsing and blinking rhythmically. We knew this was a possibility, but today she had her first seizure. It lasted about 3.5 to 4 minutes. She is now on meds for this. We called at about 9 tonight, and all her stats were wonderful.

She was peaceful and sleeping, responsive to stimulus and just plain pleasant, said the nurse. After her day today, I hope she sleeps all night *long. We are going back up on Saturday, Tammy is going tomorrow to let the kids see her. Keep praying. It is definitely working.*

By the way, this isn't right, but the doctors are still amazed that she is doing as well as she is. Ain't God good?

I felt compelled to write more later that day. In the dark night of the soul, God always reminds us that joy comes in the morning.

June 7, 2007

Day 27 (continued)

"You need to understand that Brynna will never be able to eat, swallow, suck on a pacifier, tell you when she's hungry, or wet. She will just lie there like this forever. She may not be able to breathe on her own and will most likely need oxygen, suction, and very complicated meds," said the doctor.

Tonight, we called to check on Brynna. At 9:45 p.m., she is lying on her stomach breathing room air with no oxygen. She makes an incredible fuss when she is the least bit wet, and everyone on the floor knows when she is hungry. Her nurse tonight told us that not only has she figured out how to suck on a pacifier and still breathe, with no good airways mind you, but it has become an obsession with her to have it.

Every time they say she can't, she just backs up and says, "Watch me." She is the embodiment of "I can do all things through Christ which strengtheneth me" (Phil. 4:13 KJV).

Our doctor will be out until next weekend and said today that if she continues like this, there is no reason Brynna should be in Dallas when she comes back. Thank you for your prayers. The other night, I received an e-mail from a lady on the SOD support group list. She is 36 years old, blind, and has SOD like Brynna. She is married, lives with her blind husband, and has a Master's degree. Matthew 19:26 [KJV] says, "But Jesus beheld them, and said unto them, With men this is impossible; but with God all things are possible." I am so glad that *today this is still true. I will update again as things progress. I just had to share this with you all!*

As I said, joy comes in the morning. The peace of God was so strong during these days, sometimes I forget how strong. I tell people all the time that walking through the valley of the shadow of death, deep in the dark night of the soul, is not the first time to begin to think of God and attempt to rely on his goodness. We need to settle ourselves and resolve our hearts to the reality and merciful goodness of his sovereignty, for when we enter this valley, we will need it. I'm thankful for faith. I'm thankful for experiences that prepare us to walk this road. He gave us many days like this next one to see us through.

June 14, 2007
Day 34

I'm sorry for the delay in the update. It has been a very busy week. The latest on the little peach is great, great news. She is doing wonderfully, and as of 10:30 p.m. tonight, they have stopped checking her for diabetes insipidus. Her sodium is a bit high tonight, but not in the problem range. She seems to be holding up just fine. Her calcium is also right on. She is up much during the day and is sleeping at night, so long as she is on her stomach, has her pacifier, and has the radio playing. Can anyone say "high maintenance"? From early on, we knew she had a condition called hydronephrosis (that's water on the kidney). Basically, her kidneys were swollen and distended and had what could be characterized as reflux in the kidney. Yesterday, the doctor came in and told us that after a sonogram of her kidneys, the hydronephrosis in the left kidney is completely gone, and the right one is almost gone. I love it!

Also, the cardiologist came in and examined her and said we could take her cardiac problems off the table. They are way on the back burner, and her heart is doing fine.

Tonight at Bible study, we discussed the story of the pool of Bethesda in John 5. Great story! After 38 years of being crippled, the man truly understood what it meant to be whole, and by his example, we better understand the sovereignty of God. He was part of God's plan from the beginning. Just because he spent 38 years disabled does not mean God didn't know about it, didn't care about it, or was unable to do anything about it. It simply means the moment at the pool was all part of the plan.

Brynna's struggle is no different. She is part of his wonderful plan. I must say, we are a bit nervous to be bringing her home soon (possibly this weekend or the first of next week). The fears that we will do something wrong haunt us daily, but we continually remind each other that we will have her as long as we are supposed to have her, and she will develop as she is supposed to develop. We will do our best, we will care for her with all diligence, and all the while trust her to his mighty hand.

If you are reading this and your child, children, or grandchildren are whole, as the man at the pool was after meeting Jesus, then hug them, squeeze them, and thank God that they are not facing tough days every day. Thank God that they can run, play, speak, see, eat, and all those things we take for granted.

If you are reading this and your child, children, or grandchildren seem to have it more difficult than others, maybe they have trouble seeing, speaking, walking, or understanding the world around them, hug them, too. Hug them hard, and hug them long. Thank God that he has shown you a side of his love that we only see once in a while. Lay your head down tonight knowing that things are just the way they are supposed to be, to his honor and glory and by his good pleasure. Amen.

Thank you all for your support. We will continue to update you all on her progress as she grows.

This was a really, really good day. Happy birthday and happy Father's Day to me.

June 17, 2007
Day 37

I am very sorry that we have not brought everyone up to speed as of late. Brynna has continued to improve over the past several days and the last week, really. Yesterday, Saturday the 16th, we finally got to bring her home. I can't even begin to imagine a better Father's Day present than having Brynna home with us. Now the real work begins. She has to be fed every three hours along with meds, temperature check, diaper weigh-in, and more. This takes about an hour each round as she is still on the feeding tube. Sleep is a thing of the past—but a mere memory of days of yore. Sorry, I digress. Now we begin the myriad of doctor follow-ups and related visits. Please continue to pray, and thank you.

Week One at Home

The next few posts were relatively uneventful as we learned and adjusted to caring for Brynna. During this stretch, our lives were packed with equipment, new terminology, new schedules, and new responsibilities. We truly saw the hand of God resting on us.

Over the following weeks, Brynna had a swallow study, got more meds, grew, ate, and had a million doctor visits. We began to settle into some semblance of rhythm. On July 13, I offhandedly said something to her doctors about their expectations in the NICU that she wouldn't make it. I sort of expected them to disagree with me, say something reassuring like, "Nah, Mr. Parker, we knew all along." They didn't say that. They pursed their lips, nodded gently, and agreed with us, saying, "You're right, we didn't. She was really sick." Tammy and I had truly been alone in our optimism about Brynna. Our endocrinologist confirmed the same thing on our first visit to see him. He looked at the medications they sent Brynna home on and commented, "These aren't home-type medications. They didn't expect her to make it." We knew this, yet here we were.

We rocked along all summer, learned a great deal about Brynna and ourselves, tweaked meds, did procedures, and so on. She was still having trouble eating, and we knew we needed a G-tube. The surgeon was a great guy, a believer who made no bones about it. I was in the hospital with Brynna the night Tammy graduated from college. They simulcast the event on the Internet, and I got to watch. It was on when the doctor came for his rounds. He sat down and watched the graduation with me. He was very proud of Tammy, as was I.

At our pre-op with the surgeon, we found out that Brynna had another problem: malrotated intestines. This would have to be fixed during the G-tube placement. She would also get a Nissen, a stomach wrap around the esophagus to stop reflux. During the surgery, they found out her appendix was on the wrong side, so they just took that out. Apparently, you don't need it anyway. They were worried the appendix would inflame and the doctors wouldn't know it because the pain would be on the wrong side. It's always something with this one. It seems our faith needed stretching again.

September 30, 2007

When Brynna was born, one of the hardest things was leaving her in the hospital and then coming home to take care of business. Fortunately, in the hospital lobby was a Frulatti stand that sold the most magnificent, chewy 6-inch chocolate chip cookies ever. We considered it comfort food. Some days, the good ones were just one-cookie days. The bad days were those two-cookie days. Yesterday was definitely a two-cookie day.

Last Tuesday, Brynna traded her G-tube for a Mic-Key button in the stomach. Ever since, she has been very gassy and would scream out every so often in intense pain. Needless to say, that disturbed us, and her. Saturday morning, her pain seemed exceptionally intense, and we called the surgeon. He wanted us to come in to the Medical City ER and do a G-tube X-ray study to make sure everything was ok. So we got ready, *put Brynna in her car seat, and were on the way out the door when she began to have her second seizure. The first one came when they took her off the ventilator after heart surgery and she had trouble breathing. We were not too alarmed as we had seen this before and knew it would end and all would be well. After all, Monday we have an appointment to discuss her seizure meds and evaluate their potency. After several minutes of the seizure not subsiding, we called 9-1-1 since we live about an hour and a half from the hospital. They dispatched an ambulance to come and see Brynna. While en route and as the seizure went on and on, they went ahead and dispatched the Flight for Life helicopter. All said and done, her seizure lasted almost 15 minutes with fixed eyes, very rigid limbs, and mild convulsions. This was a long seizure, at least for her. We loaded her into the helicopter, strapped Mom in, and off we went. It is a rough drive to make alone when your wife and daughter are being airlifted to the ER. After hours of trying to get IVs in, they finally got enough blood to determine that her level of seizure meds was too low. She has been doing really great lately, and has really grown. She is now just about 10 pounds. She simply outgrew her meds. They loaded her dose up, increased her maintenance dose, and sent us home.*

Today, all is well. We made it to church this morning for a good time in the Lord. Brynna has been much better and is back on schedule, working toward getting back to bolus feeding instead of continuous feeding. She continues to take her meds by mouth, drinks water from a syringe, and even has an occasional mini popsicle. Her eyesight seems to be fine. She tracks and watches movement all the time. She smiles, talks, laughs, and is working on rolling over. Not bad, if I do say so myself, for a baby said to be an invalid in a vegetative state the rest of her life. I guess God had other plans.

Thank you all for your prayers and concern. I hope none of you EVER have to see your baby, or anyone else, loaded into a helicopter and flown away. But if you do, remember that God is in charge. He knows all about it, and according to Romans 8:28 [KJV], "All things work together for *good to them that love God, to them who are the called according to his purpose."*

Along this journey, there have been what I call watershed moments in which our faith seemed to grow leaps and bounds. This was one of those times. We had seen a seizure before in the hospital but not for this long and certainly not out here in the boonies where we live. I remember the helicopter pilot asking about her conditions, and after the first few lines of diagnosis review, we knew one of us needed to be on the chopper. This was strictly against policy. We decided Tammy would go. The pilot looked her in the eye, talking a bit loudly as the blades roared behind us, and said, "If you go hysterical on me, I swear, I will set this thing down wherever we are, put you out, and continue." Tammy nodded in agreement and pensively got in the front of the cockpit.

I watched them fly away. I had an enormous lump in my throat. As I remember, Brynna's seizure had subsided when they took off, but I couldn't help but run the worst-case scenarios through my mind. I went back in the house, gathered a couple of things, and headed out on the hour-and-a-half drive to Medical City, Dallas. I was all by myself in the car. My wife and daughter were in the air, and I was scared. I had no idea what I would find when I got there. I was afraid Brynna wasn't going to make it.

One of the weirdest things I remember going through my mind was wondering what to do on the drive. Is it ok to listen to music? Or should I just sit and think? What's more, I actually had another round of that peace that passes understanding. Not peace that everything would be fine when I got there, but that God would sustain, whatever happened. My heart was simultaneously breaking and mending at the same time. I know no other way to describe it. I began to pray, play worship music, and sing. That's when it happened. I broke. I started weeping. It wasn't from fear but from sweet fellowship and worship with our creator. I really don't have command enough of the language to express it. I have subsequently described this hour-and-a-half block of time as some of the sweetest worship I've ever had, all the while not sure if Brynna was dead, alive, or what. It was weird—and wonderful. This time, everything turned out just fine. In God's world, no matter how things turn out, they are just fine.

As I write this now, it is almost Thanksgiving 2017. I'm looking back over where I am in the chronology of e-mails and blog posts and find that the last one is dated November 21, 2007, almost Thanksgiving of Brynna's first year. It was a time of reflection and gratitude. Brynna was doing quite well, all things considered, and the family was really learning to adjust.

December 21, 2007

I am reminded in the book of Hebrews, Chapter 11, that it is by his word that the worlds are framed. Our faith helps us realize that what we see is not made of the sort of things that they appear to be. In other words, God knows the behind-the-scenes story. What we can see and take in with our senses is only the tip of the iceberg. There is an entire plan out there with us in it. When the doctors saw Brynna would not thrive, they only saw the tip of the iceberg. She truly is making her own way, according to God's plan. We are so grateful to be blessed with such a gift. We are also grateful to be blessed with three other amazing children whom we love just as much and who are as much of a blessing and gift as Brynna. We could lose everything tomorrow, and life would still have been, would still be, fantastic.

One of the things our family has learned over the past decade, and we learned it the first year at a rapid rate, is to appreciate and value each and every moment. We are not guaranteed any more moments. Tomorrow is fleeting, and yesterday is gone. We can only affect change in the here and now. Just last week, I went to a pastor's conference and listened to Lisa and Francis Chan talk about being married and living life in the light of eternity. Francis said something that stuck with me. "Why live protecting this 50 to 70 years at the expense of the next 50 million."[1] That was profound.

The basic idea is that we must live this life, right now, for God's kingdom. We will someday stand before the one who spoke and the sun happened. All we will be able to show him is how obedient we were, how committed to his cause we were, how much we loved him and loved others, and how much we poured ourselves out for others. At first, my mind was focused on surviving at all costs, and that's practical and good. At the same time, we found we need to be focused on God, not on outcomes, even while we work diligently for them. He may not grant them. He certainly would lead us in paths we could not imagine, paths we apparently needed to travel.

Our path was about to take another turn. A couple of years before, our youngest son, Shaun, woke up with his eyes suddenly crossed. It was determined at the time that he had a nerve palsy in his left eye that was causing the problem. It was finally corrected, and we moved on, not thinking much more about it until January 2008. All was quiet on the Brynna front. We were cruising on a form of autopilot with her.

January 25, 2008

As for Shaun, our youngest boy, his eyes have crossed again. After a doctor's visit yesterday, we found out that the nerve palsy in his left eye has returned, causing the right eye to overcompensate and cross to the middle. They will do another MRI to determine there is no damage that they have missed, then go to pediatric neurology to rule out a neuromuscular disease. We are patching and praying. Shaun is a little scared, so please

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1. Francis Chan (speech at RightNow Pastor's Conference, Dallas, TX, 2017).

pray for him. Last night, he said he doesn't want to go blind. Tammy had a good talk with him regarding the sovereignty of God. We will pray for healing, but he understands that we must accept what the Lord has for us, at least that is what we are reinforcing as we ask God to heal him. Please pray. He doesn't want to have eye surgery again, but that may be a possibility. To me, that is better than neuromuscular disease, but we shall see. Thank you all very much for your prayers.

During that talk with Shaun, it really did occur to me that God was stepping us through a process. When someone starts lifting weights, they don't start with the heaviest weights. They start low and build up. I was starting to feel like a spiritual weight lifter, and God just added a plate to the bar. Watching my wife skillfully and adeptly navigate the corridors of God's sovereign will with a six-year-old amazes me to this day. This lady is something else. She is quiet and reserved in public but possesses a strength of faith and grit that many people only dream of in their lifetime. Shaun understood as much as he could at the time. Hearing him cry and reveal his fear of blindness and knowing it could actually happen makes for another two-cookie day.

February 1, 2008

Tammy just called. The neurologist thinks Shaun has an autoimmune disorder called ocular myasthenia gravis. Basically, the body produces a rogue antibody that attacks one of the body's own members. There are two versions. One attacks everything, and one just the eyes. It appears that Shaun only has the eye version. They have medicine that can address this. Right now he is in getting a CT scan to check his thymus. This little fellow produces T cells that feed the autoimmune system. They want to see if it is ok. Typically, ocular myasthenia is accompanied by problems with the thymus. We will keep you posted. Thanks for your prayers.

We had become adept Internet scavengers and were able to find plenty of terrifying news about myasthenia gravis. It turns out he did have it, and everything we read was awful. This thing could attack the nerves in the ears, causing deafness, and progress to the limbs, making them useless, and on to really significant things like the heart and lungs. It is typically found in males in their 20s, not in little boys. Once again, we were dealt a card that doctors would call a rare case. He was put on medicine, which seemed to help, and round two of the waiting and watching game began.

Between February and April, we didn't update much, just rolling with life as school teachers, doing extracurricular activities and such. It was now April 2008, and I was at a one-act play competition. Brynna now had a Mic-Key button through which she received all her feedings. For those who aren't aware, a Mic-Key button is a feeding port that is surgically implanted through the stomach wall so we can inject formula straight into the stomach and bypass the throat. It truly saved Brynna's life. A small hole called a stoma is punched in the abdominal wall, and a little T-shaped item is put in, like a really big earring. Then 5 milliliters of water are injected into the side, inflating a balloon on the inside of the stomach wall to just larger than a nickel. The hole is only about 1/8 of an inch in diameter. This balloon holds it in place quite nicely—most of the time.

While I was at the competition, Brynna managed to pull her button out. Inflated. This caused the stoma to basically slam shut, and Tammy couldn't get the button back in. Parents of special needs children learn some interesting skills along the way. It took six hours in the ER progressively widening the stoma until the button could get back in. All was well, right? Well, in the days that followed, Brynna started throwing up everything. Remember that Nissen (stomach wrap) I talked about earlier that stopped her reflux? Yeah, she busted that dude open. April 23 would be an unscheduled surgery to fix that. We asked for prayers because the incision would be large, breast bone to belly button. All the fears we had learned to keep at bay were flooding back—again.

We rocked along for a while, once again adjusting, living, learning, trusting. The Nissen procedure is designed to control vomiting by pinching off the esophagus. When we put Brynna in the car to go home from the procedure, she threw up the moment we put her in the car seat. We believed the Nissen had blown. We weren't even out of the parking lot yet. The surgeons were trying to schedule her palate repair, but the now uncontrolled reflux and vomiting just wouldn't allow it. Stomach acid is apparently hard on stitches and open wounds. Her repair had been scheduled for June 23 but was now postponed to July.

June 23 found us back at the doctor's office getting an upper GI to look for issues behind the now chronic vomiting. It revealed that the Nissen was okay, but there was still no reason for the vomiting. Brynna was throwing up, not spitting up, I mean stomach-emptying vomiting, 20 to 25 times a day. Besides the obvious discomfort, this made it really hard to keep her electrolytes in check, which for her could be fatal if they spiraled out of control. In the June 23 post, I added this blurb:

I just returned from a mission trip to Mexico this past week. My heart was broken by the poverty and the hopelessness I saw on the faces in the children's home in Galeana, Nuevo Leon. There is a level of darkness, spiritual darkness, in this country that I have never seen here in the Bible Belt. I realized just how blessed our family is. Brynna has been a source of inspiration and faith for us as we minister to people. I had the opportunity to share her incredible story in another country (I tried it in Spanish ☺) and was able to see her continue to be a blessing to others in the name of Christ. What a privilege to have your child used as a tool for the gospel of Christ! We are truly blessed.

I was serious about the level of poverty we had seen. It was the worst thing I had ever encountered, surpassed only by the poverty we found in Nicaragua a few years later. Sharing her story in Spanish to a small church in the mountains of Nuevo Leon is one of the high points of my walk with the Lord. It doesn't take much to figure out that people are people everywhere. As I spoke of her struggles in very broken Spanish, I watched mothers and fathers, grandparents, and family friends break down in tears. The privilege of living in a place with so much readily available medical care sat heavily on my heart. Had Brynna been in this village, she would have never made it past birth, which would have happened at home, alone. No neonatologist, no neurologist, no staff, no NICU. She would have died in minutes. God is so good. His plans are amazing. I was in awe once again.

During the GI, they did a biopsy and found that Brynna had yet another diagnosis. She was allergic to cow milk protein, not just milk, not just lactose. She was allergic to the whole stinking protein chain. Conceivably, anything with this protein chain in it would cause her to have a reaction. Our formula was killing her. They put her on an amino acid–based peptide formula and that helped some, but now she was having copious amounts of belly gas, which was incredibly painful. Every 30 minutes or so, we had to vent her button, basically burping her through her stomach. If we didn't, you guessed it, it was all coming up, and it hurt. It hurt bad. She cried. We cried. Truly, it was a pretty rough season.

July 14, 2008

In church on Sunday, our Sunday school teacher reminded us of the story of the man blind from birth. The disciples asked Jesus who had sinned to bring this about, him or his parents. Jesus replied, "No one has sinned." He then told the disciples that this man was made this way so that God could receive glory at that time. Then he healed the man.

We have always known that Brynna was made just as intended by God. We were reminded that she is here to be a blessing to people and bring God glory. That she has done well. We are proud to be her parents. We are thankful that we only have to deal with the issues she has. There are so many people with far worse situations. God be praised for her testimony of grace.

Throughout this entire ordeal, and still today a decade later, I'm continually amazed at how God brings the right people, message, and words into our lives at just the right time. Blind Bartimaeus came up all the time. Brynna wasn't broken because we had sinned. She wasn't broken because God was angry. She was just the way she was supposed to be. The entire time she was in the NICU, we had Brynna's verses—Psalm 139:13–16—and a poem over her little bed. We really did want the world to know she was just as she should be, not broken, but a tool for God's glory. Here are the verses and the poem:

> *For you formed my inward parts;*
> *you knitted me together in my mother's womb.*
> *I praise you, for I am fearfully and wonderfully made.*
> *Wonderful are your works;*
> *my soul knows it very well.*
> *My frame was not hidden from you,*
> *when I was being made in secret,*
> *intricately woven in the depths of the earth.*
> *Your eyes saw my unformed substance;*
> *in your book were written, every one of them,*
> *the days that were formed for me,*
> *when as yet there was none of them.*
>
> —Ps. 139:13–16

This child is a child of God
and born a full soul,
completely formed . . .
This child is guarded by
a Guardian Angel
who sees God
and intercedes directly
for the newborn life . . .
This child has come to sing
God's praises in ways given only to her.
You were chosen to be her family
for the gifts you bring to her.
May your family receive rich blessings
and many healings because of her.
Amen.[2]

I honestly think one of the weightier kingdom lessons we've learned from Brynna is that God is totally, completely, utterly, sovereign. We want him—no, we need him—to be no other way. If he isn't all powerful and is incapable of controlling situations like this, we are men and women most miserable and utterly lost before the ravages of this world. Those words—"You knitted me together in my mother's womb" (Ps. 139:13)—would jar me each and every time I read them.

Remember that day when we had the sonogram and saw the cleft? He, God the Father, the creator God of the universe, was knitting her together in Tammy's womb. Nah, you might say, something happened, something went wrong. God didn't do this. Whether he did it or simply allowed it, he is responsible for what happens

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[2] "Natalia's Prayer," ThereseAnn Siegle. Used with permission. For more information, go to www.livingwithtrisomy13.org.

in the womb, according to the scriptures. Every deformity, every misaligned something, every broken, busted, twisted, malfunctioning part of Brynna's physical and mental development passed through the sovereign hands of a holy, righteous, good, merciful, kind, and gentle father. Romans 8:28 doesn't just mean everything will turn out okay. It means that he will take what is there—anything Satan meant for evil as an extension of the fall of man, anything purposefully brought on us by the enemy, anything allowed to befall us as children of the most high God redeemed through Jesus on the cross—for our good and for his glory.

Brynna's struggles, our struggles, her pain, our pain, everyone's pain—redeemed! Purchased! We have only the choice to wallow in pity and victimization or choose to get up and shout to the Lord for his goodness. Shout to him for his kindness and his restoration. I believe our broken little girl will be made whole one day when all things are made new. I know, I know, that brings up some very heavy theological questions I can answer in another venue, but suffice it to say that I believe beyond a doubt that she is being used—used to mold our lives into the image of Jesus. She's being used to mold others, used to point people to the miracles and goodness of God, not through healing but through suffering. She is getting to know Jesus through suffering in a way few of us ever understand or experience. She is blessed.

And to think that she has angels watching over her, interceding with the father on her behalf, just blows my mind. I have more to say about that later, but I'll just say this. Brynna has boosted our belief in the interaction of the supernatural with the natural. Those aren't just distant Bible stories fit only for elementary Sunday school lessons.

The week of July 26, 2008, proved once again to be an eventful week. I was away at summer camp with the youth. Brynna was still throwing up all the time. Sometimes, it was the color of egg yolks, and sometimes it was green and foul like bile.

July 26, 2008

Friday, Tammy took Brynna to Children's Hospital to see a motility specialist regarding her eating issues. While there, they did a lab workup and found that her electrolytes were in the critical zone. About the time Tammy got to Canton, she received a call from Dallas, and they told her to get to the ER right away. At this point I was in Tulsa, Oklahoma. Brynna was admitted in Tyler for stabilization. She was down to 16 lbs. 9 oz and severely dehydrated, which were causing the problems. Her chronic issue is that her bowels aren't moving food through, and she isn't thriving. So we are going tomorrow, Monday, to Children's to check in and stay put until they figure out the problem. While there, they will likely put in a TPN port, This will allow us to supplement her feeding through an IV at night until we get it all worked out. Just another chapter in her blessed little life.

I guess there is someone at Children's who needs to see what God's grace looks like, so he is sending Brynna over! Keep us in your prayers.

I read this post, and at the end, I thought to myself, "Man, that sounds so trite," but that is really how we were living our lives during that season. Everywhere we turned, Brynna was struggling with something new, and we were being put in front of people whom she would touch, whom the gospel would reach, and through whom God would be glorified. It sounds weird to read, but it really is how we've learned to live and frankly how we've learned to accept and endure the roller coaster that has been Brynna Parker's journey.

August 10, 2008

Well, it has been a wild two weeks. Brynna has been in the hospital for most of it, coming home last Sunday only to return on Monday. She is finally home as of Thursday this week and doing well. She has been diagnosed with cyclical vomiting syndrome, has a GJ button that puts *food directly into the small intestine, and is on another medication and a new formula. Finally, after five months of this, she has been doing well.*

That stint in the hospital, two solid weeks, was trying for us all. When we got there, the phlebotomist came in and tried to put in the IV. At Children's Hospital, the nurses don't do blood draws. They have specialists for that. Brynna has squiggly veins. They roll, and they are tough, and it's almost impossible to get a good blood draw from them. Two hours. That's how long they worked on her the first round. The phlebotomist would not relent. I was about to cause a nasty scene when we finally called it off. She became angry and threatened to discharge us AMA (against medical advice), but we weren't having it. Thankfully, one of the doctors came in and ripped the lady up one side and down the other for traumatizing Brynna. He brushed her aside, grabbed a huge needle, and quickly plunged it into her neck—yes, her neck! Apparently only doctors can do that. I sat fairly stunned, but thankful, as he harvested the sample.

The GJ button is a thing in and of itself. It was huge. It passed through the stomach and into the small intestines. That meant that we could only feed her in very small amounts. To give some perspective, 5cc is about one teaspoon. So we increased her feeds to 25cc, or 1½ tablespoons, per hour around the clock, dripping from a feeding pump. Tammy and I had learned by now that sleep was something we would only do in heaven.

May 23, 2009

Well, as you know, the more things change, the more they stay the same. Just as we celebrate Brynna's great successes lately, tonight I write you with a somewhat heavy heart. Last Tuesday, Brynna was very fussy at night. Wednesday, she started running a fever. She was diagnosed with a viral infection and had a fever between 102 and 104 all week. Thursday, she started bleeding in her stomach. Her breaths were very *shallow and rapid. We took her to the ER for the abdominal bleeding but could not figure out what happened. We came home, and Friday night her breathing continued to be labored and her fever persisted. Her lungs also began to rattle considerably. This morning, we took her to the doctor again, and she was diagnosed with pneumonia. She was sent immediately to the hospital and admitted. She is there now with Tammy, on antibiotics and oxygen. Her pulse* O_2 *is hanging in around the mid to upper 80s with a cannula in her nose and a blow by mask. Please pray for her as she recovers.*

Just another day in the life! I was especially touched today by the care and concern shown to Brynna by her brothers and sister. They have grown to really love her for who and what she is, a tool in God's hands. In our attention to her needs, I know that sometimes our other children feel the strain and pressure of the time a special needs child takes from the family and the parents. But they have stepped over this obstacle with ease. They are blessings from God.

Over the past decade, we've seen our children grow and become accustomed to dealing with Brynna and her needs. And our family has grown. In 2014, we completed the training to become foster parents. The following year, we adopted 15-year-old Eli. He assimilated into the family fairly quickly. We have recently taken on three foster sons, all 11 years old. It has been heartwarming to see all our children learn to cope with all that Brynna brings to the table.

I am writing this on a Monday after Thanksgiving 2017. Over the school holidays, we took our three foster children and two older boys to watch the movie *Wonder*. As I noted in the previous post, the pressure our children have been under as we all care for Brynna is enormous. While watching the movie, I was shaken. Deeply. Here is my blog post from the night we returned. I am placing this here in the story to communicate what the other kids were going through during all of this. It is out of order, so bear with me.

The Others

November 23, 2017

I've written a ton of e-mails, updates, and blog posts about Brynna and how she has touched our lives, about how we've learned some great lessons, about how amazing she is. This one is different.

Tonight, we took the little boys to see Wonder, *a story of a boy with Treacher Collins Syndrome, which causes major craniofacial deformities. As the parent of a child born with a serious and profound facial deformity, I fully expected to identify with this movie and with Auggie, the main character. I did. I cried during the whole movie. Sometimes big, ugly crying. But not for the reasons I expected.*

The movie started, and I cried in the opening scene. I won't spoil it for you, but we've done exactly what happened there. I recovered and did ok until the story focused on Via, the big sister. The point of the film that touched me the most was how it addressed the impact Auggie had on his sister. Suffer me a few minutes to indulge.

Tammy and I are very familiar with the impact the stares of others have on parents. Before her lip repair, we've had people run up to the baby carrier in Walmart only to recoil in horror. We've fielded awkward comments, condescension, and gawking. We forget that our other kids have endured it, too.

It's true that the child with the needs is the sun, and everyone else are the planets. There have been so many times our kids have necessarily been served the leftovers of our time and attention, yet they march on like champs. We can't go to restaurants like others or jump in the car on a whim and do things. And let's not get started about how many nights they've spent with others while we've been in the hospital.

Then there was that time Austin got in a fight at school because a classmate made fun of his sister. Erika is by far the best nurse we've ever *had (and we've always had great nurses). She's even taken Brynna on dates!*

They can give meds, do tube feedings, and know when we need a break. They've never complained, ever. Seriously. They have embraced her differences and grown as a result. They love her and love others better because of how she loves them.

Parents of special needs kids are often called superheroes. The real superheroes are their siblings. I love you guys. You rock. Here's my shout out to Austin, Erika, Eli, Shaun, and even the littles [our three foster boys]. *I love you guys for loving Brynna the way you do.*

As Brynna has gotten older, all the special things we have to do for her that define her have become part of our everyday lives. Most of the time, things have gone swimmingly. Others, not so much.

August 5, 2009

It's been a little bit since we did an update but thought this story was worth sharing. As most of you know, Brynna is fed via a Mic-Key Button in her stomach. It is held in place by a little balloon on the inside of her stomach that holds about 5cc's of water. There is a special syringe that comes with it that will let you pull the water out, check its level, replace the button, and so on. Well, last night we were appliance shopping in Tyler. When we got in the car, I was loading Brynna and somehow got her tube caught on the stroller. I thought I was clear. Tammy looked at me and said, "You pulled out the whole thing!"

Sure enough, there on the stroller was her G Button, inflated balloon and all. I was waiting for her to scream in pain, but she never made a peep. The only real consequence was that her dinner was now coming out like Old Faithful. We knew we had to get it back in quickly before the stoma, or hole, closed up. So, we dutifully reached into the bag to get the special syringe to fix it. But it wasn't there. Somehow it got pulled *out of the bag. We knew from past experience that a 1cc syringe will fit in the hole, or a Lur-Lock tip.*

So we looked around, spied the quick clinic nearby, and off we went. I took the button in, thrust it through the little clerk window and said, "My daughter's button came out, do you have a 1cc syringe I can have to put it back in?" She stared at the button with horror. You know, the "What in the world is that, and why is it in your daughter's stomach?" look. She was not a nurse.

After they called someone to see if they had permission to give me a syringe, the stoma was steadily closing tighter and tighter. Finally, they came out, gave me a syringe, which I tested on the button. It worked. I then asked for some "jelly" packets and went on my way. Button went in, dinner was on! No trip to ER or Dallas! Brynna clapped and laughed.

Austin, our 13-year-old, said, "Man, how many families can say they can do that?" True! It was like an episode of ER in the car. "Hand me the button. . . .syringe. . .need more water. . .button is in. . .got it."

Just another day in the life!

What I didn't say in the post was that our concerns were based on our first experience with this when Brynna was in the ER for hours. We didn't want the stoma to close up this time. We didn't have anything to put in it to keep it open, except a finger. We needed someone to volunteer. Austin took the hit. He rode to the emergency clinic and waited for me to return, with the tip of his pinky stuck inside the stoma to keep it open. That boy was a trooper. He would soon learn how much.

A couple of weeks later while swimming in a friend's pond, Austin impaled his foot with a half-inch bolt. The doctor said the only thing remaining was one layer of skin before it was a complete, through-and-through puncture just behind his toes. It was awful. That happened on a Tuesday, the week before school, as I recall. By Friday, Austin's foot was swollen up like a cantaloupe. I thought he was being too ginger on it but finally took him to the doctor for a follow-up. The pediatrician looked it over, felt Austin's legs for some reason, smiled, said hmm, and then left. He said he'd be right back. We had been in the hospital enough to know something was wrong.

He returned with a surgeon. The surgeon calmly told us Austin would need surgery to get the infection out. No big deal. We could do that. It was Friday, though, so I asked what time Monday we should have him there. He looked at me and said, "Oh, no, he will be in surgery within the hour. The infection is in his blood and has moved up toward his waist. We need to get it cleaned up right away." So, just like that, we were on the path for another surgery, another door to walk through.

Surgery went well, and Austin spent the first week of his eighth grade school year in the hospital on IV antibiotics while they tried to figure out what kind of bug had gotten inside of him. He was a trooper. I don't really know how hard it was since the nurses kept him fairly well stocked with snacks and plenty of attention.

If God didn't continually put things in our paths to cause us to trust him, we wouldn't need him. We would be utterly self-reliant and prone to committing the original sin over and over and over again. It is the crucible that James speaks of in his epistle. The trying and the testing will perform its perfect work in us to transform us into the image of the Son, if we allow it.

Fast forward to January 2010. Brynna was doing great. She was growing and developing some, having a healthy year. We watched her laugh, play, try to talk, walk, and love on us all the time. Then, on January 4, my brother-in-law suddenly passed away. He was 34 years old. It hit me hard for two reasons. First, we were exactly the same age, born on the same day, the same year. Exactly. Second, I performed CPR on him for almost 40 minutes while we waited for the paramedics to arrive. It was not like the training. Not at all. I was exhausted. He was most likely already gone when I got there, but I knew I had to try. In the blur of the moment after the first responders arrived, I recall sitting on the kitchen floor stunned, winded, and in shock. My own mortality began to set in.

In all of this mess, we managed to get in touch with my dearest friend Josh. By this time, Brynna was getting growth hormone injections to sustain her blood sugar and other vital systems. No one could give the shots but us. Josh came over to watch the kids for us without hesitation. Erika walked him through how to do the shot, and she gave Brynna all her other meds. Erika was 12. In this time of crisis, God provided Elijah's ravens, the widow's oil, and Hannah's son for us. Those two helpers were all those things in that moment.

When we got to the hospital, we visited with Diane, my sister-in-law. It was gut-wrenching. Her first husband, a dear friend of mine as well, had been killed years earlier in a motorcycle accident. His was the first funeral I ever preached. Now I knew I would need to perform a second one for her with Allen. I had the privilege of leading Allen's parents to the Lord some years before. At this time, they were home in Minnesota. The crossing of our paths is a story for another day. Suffice it to say, Diane asked me to call his folks and tell them. I had to tell them that their 34-year-old son and cancer survivor had died suddenly. I had no experience on how to make that call, no knowledge from which to draw. I prayed. I dialed. I spoke, and we cried. The crucible's fire was getting hotter.

Over the holidays every year, I take time to reflect and ponder the year gone by. Where have we been, where are we going, what is God doing, what do we see him doing next? You know, the usual. This time I couldn't help but ponder the literal juxtaposition of these two events—Allen's death and Brynna's flourishing. On the one hand, there is despair, discouragement, fear, doubt, grief, unbelief, and all the trappings that come with sudden tragedy. On the other is the joy that Brynna lives and prospers in her own way. Our suffering was replaced with joy. Our angst was replaced with comfort. That truly paints a picture of the grace God has for us.

On the night Allen died, a friend told me that God knows what he is doing. That stunned me. I'm a pastor. I should know this, but I needed to be reminded again in my pain, in the crucible. I needed to hear that God loved us and that he was in control. That is why we constantly must preach the gospel, not only to ourselves but to each other. We need to hear it, and hear it often. The gospel is simple. Jesus took the tragedy of our sin and rebellion on himself and replaced it with the joy of salvation.

God knows why my brother-in-law died. He knows why Brynna lives. He knows what milestone, or even tragedy, awaits her. Nothing ever surprises him, and it shouldn't surprise us how he will and does provide for our comfort, our joy, and our lives in the very moments of defeat and tragedy.

As a pastor, God's sovereignty was sometimes seen as my hobby horse. I spoke of it all the time, no matter the passage, no matter the message. The gospel and God's sovereignty. We learn to trust him in times of tragedy, loss, and despair. I suppose it came out so often because in the past decade, we have walked through the depths of some serious tragedy, through the very valley of the shadow of death. These times are *not* the times to learn about theology. They are the times to *practice* theology. But often, they are the only times we are prepared and ready to learn theology, to learn who God is—his nature and his character—and learn about his son and his kingdom.

No one can successfully go to the bank to withdraw funds from an account that has no money in it. Nor should anyone expect to withdraw from their spiritual bank when there is no faith there. When we have invested in knowing God and the power of his resurrection during peaceful times, then we can withdraw at will from that account when we are summoned to know him in the fellowship of suffering. It is an important account to keep current.

Have you ever watched a good superhero movie, or maybe you are nerdy enough to remember *The Matrix*. In those movies, there are always those special moments—those moments of clarity. The hero is embroiled in some sort of battle, a flurry of activity all around with bullets, fire, and robots. You get the idea. Then it happens. Suddenly, the action slows down, every move is deliberate, all action is paused, and every detail is clear. The hero slowly looks around, understands his surroundings, and acts accordingly with this recently illuminated information.

In those cinematic moments, we always learn something. We learn how the hero operates and how he can move so fast. We see things from his perspective and understand how he can dodge bullets, escape falling debris, and grab the good guys before the bad guys even know he is there. On May 10, 2010, Brynna's third birthday, I wrote a post illuminating our lives in just this way, at least for me. You see, we need moments like this to bring clarity to an ever-blurring landscape of chaos around us. It is so easy to get caught up in the everyday moments that we miss the ones that show God's grace and mercy. For us, it has often come with some profound feeling of loss, but it is in loss that we feel the grace of our heavenly father like a warm blanket in winter.

May 10, 2010

Our family had gone to Jerry's Pizza for dinner, not an uncommon experience. While there, the other kids were doing what they do, playing games in the game room. Tammy and I sat at the table with Brynna at the end in her usual place. For the past few weeks, Brynna has been sick with another pretty severe sinus infection. You see, that seems to be the pattern on this strange planet we live on. Brynna is well for about six weeks, then she begins to have drainage, vomiting, infection, fever, sickness, and antibiotics. Then wellness, six weeks of health. Then drainage, vomiting—you get the idea. For the past week, we have come out of one *of the down cycles, and Brynna has been wonderful—active, playful, full of life. Good times.*

While we sat there at the table, a little girl walked up and asked us what had happened to Brynna's face. We get that a lot from little ones. As a cleft-affected child, you can tell that something, by the standards of society, is just not quite right with her facial presentation. So we dutifully explained that she had a boo boo when she was a baby and it had to be fixed by the doctors. "How old is she?" the little girl asked. "Almost three," we replied. As this beautiful cherub of a little girl stood there twisting her dress in her hands and swaying side to side, she replied, "I'm three, too." That's when it sank in.

You see, we don't notice all the differences all the time between Brynna and other three-year-olds until they are presented side by side. This little girl stood there next to Brynna, who is unable to speak, to stand, to run, to eat by mouth, to do all those things that other three-year-olds do. I'll be honest, a little piece of me dies each time this happens. I feel sadness, not for us but for Brynna. This feeling is almost immediately followed by the overspreading joy that comes from knowing that she doesn't really know there is a difference. She is just being Brynna. That is where this defining moment I spoke of earlier comes in.

Later that night, maybe the next, I can't remember, and it really doesn't matter, Brynna broke out at about 2:00 a.m. in one of her early morning concerts. She does this from time to time when she feels good. She wakes up and sings at the top of her lungs the most joyful noise you could ever imagine, all the while clapping for herself as if she had just won a Grammy. I thought she would finally settle down, so I dozed off, only to hear her shout in a screeching rendition of "Daddy" and some other unintelligible words. It startled me to the point of wakefulness that could only be matched by hers. So, like most parents, we took her out of bed, brought her to our room, and put her in bed with us to see if she would drift away to dreamland and take us with her. However, in the immortal words of Beaver Cleaver, "Nothin' doin'."

In our bed, she crawled from Tammy to me, from me to Tammy, and back again. Over and over and over. She would crawl up, grab our faces, hug and squeeze, kiss and hug. She didn't want to sleep, and she didn't really even want to play. She just wanted to be loved. That's when it hit me. She just wants to love and to be loved. That's it. That is her goal in her little life. To love and to be loved. That may sound trite or cliché, but not for Brynna. They told us many things in the hospital when she was born, that she would die at birth and we should prepare to hold her as long as we can. Then, we prepared ourselves for her not to make it when coming off of the vent. Then, when it looked like she would come home, they told us she would be a vegetable. She would never be able to show love or to appreciate being loved.

Why relive this now? Well, this is a very unique and wonderful day. It is Mother's Day for Tammy, and tomorrow is Brynna's third birthday. Three years into this journey, and the one thing they said she couldn't do is the one thing she wants to do the most, and that happens to be the most important thing of all. She has taught us a great deal, to be dependent on God, to love no matter what, to appreciate each day. But this, this is the best of all. She has taught us to love and to be loved. This is the picture of the church Christ paints for us in scripture—to love and to be loved.

This Mother's Day is special because I remember watching my wife stand by the bed in the NICU in all the strength that the Lord can give, being the mother God had equipped her to be. She has done this, or something like it, with all four of our kids. MRIs looking for tumors, blood tests looking for leukemia, crossed eyes, and nerve disorders. She is my Proverbs 31 woman. I love her, and she is to be praised.

We don't know what this year will bring. We may get to celebrate a fourth birthday, a 15th, a 13th, and a ninth. And then again, we may not. Either way, we have lived well, we have loved often, and we hope to live each day for what it is—a gift. Thanks, kiddos, for teaching us to appreciate each one. Thanks, Tammy, for showing what strength looks like, what it feels like to be loved.

There is a song called "What It Means to Be Loved" by Mark Shultz that nearly wrecks me every time I hear it. I used it as a backdrop for a video of Brynna not long before this post was written. It really and truly is our story. You should look it up online and give it a listen. It will do your heart good.

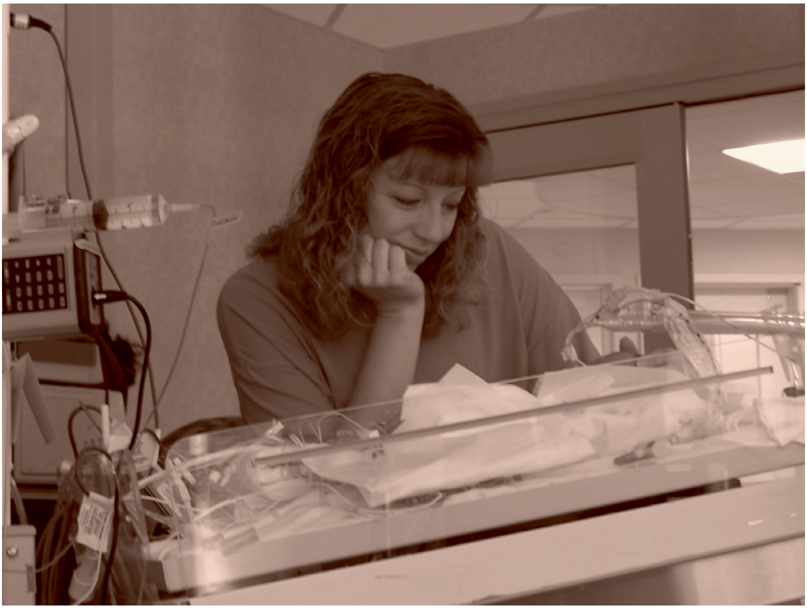
As I said, the strength my wife has exhibited through this has always amazed me. She really is a rock. People often misunderstand this lady. Some think she is aloof or sullen. Some people are scared of her honesty. If asked, she will tell you the truth. Straight. No fluff, usually. Just truth. The fact is, we need these people in our lives. They are the ones who keep us grounded. I'm a dreamer. I emote everything. Tammy keeps me firmly planted where I need to be in order to be an effective husband and father.

The thing is, Tammy is really none of the things people think she is. She is a giver of life in the truest sense of the concept. Yes, God is the ultimate giver of life by creating life at its genesis. But a mother gives and speaks life every day into the children she loves and cherishes, into her husband, into her world. Because of her, things get done and love is felt by a wide variety of children and adults every day. Sometimes, that love comes in a direct outlay of truth, sometimes in the form of a sandwich or a hug, a story at night, a surprise trip to get frozen yogurt, or a cuddle on the couch.

On May 16, 2010, I posted something we've learned to just accept: sleeping lightly. Brynna was pretty sick. About 2:00 a.m., we were up changing sheets after she had thrown up. We sleep lightly during these times because we know it is probably going to happen again, and she is at high risk of aspiration, which leads to pneumonia, which can be critical for her. We were up most of the night, exhausted.

The next day, I went to church. Tammy stayed home to watch after Brynna, who was still pretty sick. When I came home, this is what I found.

After church, I came home to a beautiful picture. As I stepped onto the front porch, I looked through Brynna's window to see Tammy sitting on the floor with Brynna in her lap, rocking back and forth. I knew she was helping her through another spell. "That's a mother's love," I thought. I continue to be amazed at the strength my wife continues to show. I love them both so much. Later tonight, Brynna had another tough moment, and after it passed, she grabbed Tammy by the face and kissed and hugged her as if to say, "I know you are doing your best." We would all take our kids' "sick" from them if we could. Brynna is sleeping now. Quieter. Better than last night so far.



I love this picture I snapped in the NICU when Brynna was born because it captures the strength of which I speak. This strength, patience, and love inspires me to be a better father, husband, and follower of Jesus. No one would blame Tammy if she was battle-worn to the point of cynicism, if she was somewhat bitter and sad, but she isn't. She has a seemingly endless river of love and compassion that pours out day after day after day. There is a side to this lady that no one really sees. It's hard parenting a special needs child. It's hard for many reasons. They can be physically as well as emotionally tough on you. Tammy has been poked, scratched, and pinched. She has had her hair pulled and who knows what else for years. Still, every day, she knows Brynna doesn't really mean it. She's just reacting to some stimulus of the moment, dealing with her world the only way she knows how. It takes a great woman to love through this. Tammy is that woman. She is my Proverbs 31 woman.

Fast forward several years. Brynna has rocked along and done as well as she can. The updates have come less and less as the years have gone by, not that we are learning less, but we have just settled into our rhythm, our shalom. Brynna is a part of that rhythm, as are her meds, her supplies, her limitations, her wails, her surgeries, her love, and her spirit. In November 2014, Brynna turned seven years old, and I wrote the following blog:

If you have children, you remember the times. You know the ones, when they were little and everything was fun? Every experience was new. Snowflakes, raindrops, blanket forts—you know, milestones. The first time they took a step, when they started eating food for real, the first day of school, and birthday parties. Those were good times.

When Brynna was born, we weren't sure about any of those things. Would she even live to see those milestones, to have all these experiences? Who knew? Life with Brynna is hard, for sure. She is seven now. She has never run through the park or really run at all. She doesn't speak to us with words but, like Dory, speaks fluent whale. She doesn't really eat anything by mouth except French fries, Doritos, and cheddar popcorn. Her med list looks like CVS exploded. She pokes me in my eye when I don't pay attention, and sometimes we wake up to poop-ocalypse early in the morning.

However, for all the hardships and all the struggles, every single day seems like another milestone, another chance to celebrate God's goodness, mercy, and provision. She is seven now, and last May, she began attending a special school near our home, a school built for kids like her. She is seven now, and last week, she used the potty. (I still use the word potty because my wife teaches three- and four-year-olds, and it's part of our vocabulary). She used the potty for the first time! Remember, she is seven now. We were elated.

She is seven now, and about a month ago, she proved to us at parents' day that she could now match things. Bowl to bowl, cup to cup. Every. Single. Time. She is seven now, and she is finally walking unassisted, most of the time. She is seven now and asks for popcorn using an iPad that has pictures on it. She is seven now, and she still sleeps like an infant, bottom hiked in the air and covers all over the place. She is seven now and cuddles with me every morning and loves hugs. She is seven now and plays with her See 'N Say for hours. Surely they can make those things silent, right?

For all the hardship and all the stress, we are privy to some unforeseen joy. We have set our shoulders for a lifetime of caring for an adult child, a real adult child. Not a child who has become an adult, but an adult-sized child. That's different. The unforeseen joy is this: When she is 25, who knows what advances she will have made? Who knows what she will be able to do? But it is likely that we will be blessed to have an adult child who still marvels at the Fresh Beat Band, who loves reruns of Blues Clues, who wants hugs every morning, who loves to spin in circles outside in the sun, who continues to have milestones that other people stop celebrating after a few years.

It will be hard, but it will also be joyful. She is seven now, and the good news is that she may be "seven" forever. God is good.

Over the past decade, Brynna has taken two helicopter rides, one airplane ride, and an ambulance trip. She has spent countless days in the hospital between illnesses and surgeries and more days than we like in critical condition. In April 2014, we took our most recent helicopter ride to Dallas. She went to the ER with a blood oxygen level of 72. She had pneumonia, RSV (respiratory syncytial virus), and rhinovirus all at once. It didn't look good. She was in really bad shape when we got there. The doctors didn't have a great deal of hope. After two weeks in ICU, she made the turn and got to come home. In all this, God really is good. He is unwaveringly amazing and steadfast.

On October 28, 2017, I had one of those experiences with Brynna that shook my soul. Here we are, 10 years into this life God has chosen for us, and it still impresses me each and every time. Here were my thoughts:

Pinned Down

I never get used to it—that moment the doctor comes in with a syringe, a scalpel, a utensil of some sort, and Brynna starts her battle to escape. Last night was no different.

We've spent more than our fair share of nights in the ER or in hospital rooms. We took Brynna last night because of a serious infection in her ear that would not relent. Her pain tolerance is higher than most men's, so when she can't stand the pain, it's time to do something.

I can handle the waiting, I can handle trying to keep her occupied, I can even handle lack of sleep and exorbitant costs. What I never get used to is helping—helping them hold her down while they do whatever it is they must do in order to help her, to make her well.

Brynna is 10 years old and strong as an ox. She pushed back on me with all her might as I gave her the necessary bear hug it took to hold her still. Mom had her legs. Brynna was crying, I was crying, and I tried not to let her see my face as I whispered, "It's ok, baby. I love you. We have to do this to make you well. I love you so much." That's when I caught a glimpse of her eyes.

Those little blue eyes. They were filled with huge crocodile tears set beneath a furrowed brow that spoke a clear message, "Why, Daddy? Why *don't you stop this? Why are you letting this happen?" I whispered to her as I held her that we had to do it, we had to make her well. I assured her that I loved her and that this was for her good in the long run.*

How many times has Jesus held me in a similarly strong bear hug in the middle of my hurt, my chastisement, my pain, and my sorrow, gently whispering, "I love you. We have to do it this way, it's for your good in the long run, to make you well"? The answer is many times.

I'm also certain that, just like me and Brynna, his eyes also well up with tears, feeling my hurt, experiencing every ounce of my sorrow. But his great and surpassing love for me occasionally keeps me pinned to the table so I can learn of him, so I may be more like him.

Why do I think he weeps for us? Look at Lazarus and his family. Jesus waited to arrive, and Lazarus died. The whole family was pinned to the table. The sisters even approached Jesus asking why, just as Brynna's eyes said to me, just like I say to him so often.

His response to Lazarus's family? He wept. He wept for Lazarus. He wept for the sisters, whom he loved. He wept because weeping was appropriate. He knew he was about to raise Lazarus, and he wept anyway.

Next time you are pinned to the table, weeping, know that your savior weeps with you and has your sanctification in mind. Trust him. Yield to him. He knows better.

When it was all over last night, Brynna sat up and, through tears, began to hug and kiss us while she cried. It was as if to say, "I know you love me. I know you can't help it, it just hurts. I'm not mad at you. Thank you for making me better."

Right now, she is sitting and playing with her reflection, just like always. She seemingly has no memory of last night's pain and sorrow. She is better. We are better, but the pain was necessary to get there. I want to be like her when I grow up.

6

Purification and Reflections

Since we have these promises, beloved, let us cleanse ourselves from every defilement of body and spirit, bringing holiness to completion in the fear of God.

—2 Cor. 7:1

Purification

In the process of refining precious metals, the final stage is where the purified gold or silver truly becomes what the refiner seeks. He repeats the heating process over and over as many times as necessary. He does this with skill and patience, with grace and love. The process can't be rushed as he painstakingly creates what is only a starting place, a beginning. The silver can now be used to make jewelry, dishes, and crowns.

When does he know it is finished? When the refiner reaches this stage, he watches closely. He gauges his progress by peering into the crucible as he looks for his own reflection. The more the dross is removed, the clearer the reflection of himself. So it is with us. All of our affliction, all of Brynna's affliction, anyone's affliction, is to bring joy and praise as a response to being transformed into his image, reflecting his nature and character. There is joy and praise because these are the fires by which we are purified. From eternity, God had it in mind that we would be changed—changed from our sinful, impure natural self into the image of his son (Rom. 8:29).

Our culture has convinced itself that the absence of pain equates to the blessing of God. In contrast, our father intently and mercifully holds us in his hands through a lifetime of heating and melting to remove impurities, whether overt sin, hidden attitudes of the heart, or simply to bring us closer to him. He watches closely. He is eternally engaged in the process. Whether we are delivered or asked to continue in the pain, he watches with a gracious eye, moving us closer to his vision of us. He is willing to sacrifice himself and asks us to sacrifice all that *is* in favor of what *can be*. Job 23:10 says, "He knows the way that I take; when he has tried me, I shall come out as gold."

Through this, I've been asked, "What would you say to someone going through a trial?" The answer is twofold. First, I would say, "Trust him. He knows what he is doing." Second, I would echo James 1:4, which says, "Let steadfastness have its full effect, that you may be perfect and complete, lacking in nothing." Don't just persevere, but persevere with purpose. The end goal is our progressive sanctification and ultimately his glory in it. He knows the fires of our afflictions. He understands and is poised to love us through it.

Reflections

I've never written a book before. When I started this project, I had to ask myself this question: "What is my purpose?" I'm not sure I know the answer to that yet. Why would we share our experiences? Why would we expose our story, our fears, our heartaches? The short answer is because I feel the Lord wants us to. A more practical response may be because I believe someone needs to hear it. Someone needs encouragement. Someone needs to be reminded that God is good, God is sovereign, God is holy and righteous, and his attributes are not defined or limited by our circumstances.

He is often putting us in the crucible of his refining fire to make something desirable out of our mess.

The point of a crucible is to take something raw and nearly useless, but something that contains a treasure and turn it into something not just of utility but of desire—something beautiful. This is the purpose behind God's refining fire. First, his word takes the raw material of our sinful lives and pounds it down, grinds it, and refines it into a workable medium.

The past decade of our lives has found us in the crucible of God's faithful hands as he protected us through the fires of his sanctification. As the fires heated up, some of the dross, the undesirable characteristics of the mixture, were melted away and removed, all under the watchful eye of the refiner.

As image bearers of the king, we will repeatedly be thrust into the refining fire of trial and tribulation, protected by the crucible of his hands, until he can look on us and see his perfect reflection, until we look like him. We call it sanctification. The refiner's fire is hot but worth it. The purpose of refining the treasure isn't just for the sake of the treasure. The purpose is to make something—something new, something wonderful. In our case, the purpose is to make sons and daughters of God who walk, talk, and act like Jesus—precious stones in the crown of his glory.

We have felt the hands of Jesus protecting us while letting just enough heat pass through to refine us. Unfortunately, when he looks on us, he doesn't yet see himself as he should. That means we will one day go back into the fire, heated, protected, melted, and then poured out and fashioned into a vessel of honor. May he be pleased with our lives as he molds us into his image.

At the end of the day, there are four things we must remember in order to pursue joy in our times of suffering, in our seasons in the crucible.

1. God is sovereign.

Lamentations 3:37 says, "Who has spoken and it came to pass, unless the Lord has commanded it?" Nothing, even the tragic moments, the dark nights of the soul, comes to us unless it has first passed through the fingers of his will and power. We must trust him and his goodness, even in these difficult days. Proverbs 19:21 tells us, "Many are the plans in the mind of a man, but it is the purpose of the LORD that will stand."

2. Our pain has purpose.

The trials of the believer are not meant to destroy us. They are designed to mold us into a clearer reflection of him. They are meant to prepare us as James 1:12 promises, "Blessed is the man who remains steadfast under trial, for when he has stood the test he will receive the crown of life, which God has promised to those who love him."

3. The refiner is always watching.

The refiner is not distant. He is a very present help in times of trouble (Ps. 46:1). He knows our pain and weeps with us. When he came to Lazarus, he saw the people crying and had compassion. He, the creative voice of the universe, knowing he was about to raise Lazarus from the dead, wept. He wept with them because he loved them, because he loved Lazarus. Just because we are in pain and the pain may even be his design, he is not detached from our sadness and sorrow. Malachi 3:2–3 reassures us that he watches and sits as a refiner so we may bring offerings of righteousness to the Lord.

4. He will sustain us.

Isaiah 43:2–3 says this:

> *When you pass through the waters, I will be with you; and through the rivers, they shall not overwhelm you; when you walk through the fire*

> *you shall not be burned, and the flame shall not consume you. For I am the* L*ORD* *your God, the Holy One of Israel, your Savior.*

We will not be consumed because his hands stand between us and the fires of affliction. Notice the reason for this is not because we are awesome, not because we have done well, not because we are in control. This is only true because he is the Lord, our savior. It is his nature, his character, his goodness, his righteousness, his grace, and his mercy that assure us we will pass through. I'm reminded of the passage in 2 Corinthians 4:16–18:

> *So we do not lose heart. Though our outer self is wasting away, our inner self is being renewed day by day. For this light momentary affliction is preparing for us an eternal weight of glory beyond all comparison, as we look not to the things that are seen but to the things that are unseen. For the things that are seen are transient, but the things that are unseen are eternal.*

May the blessings of Numbers 6:24–26 echo in your heart and soul:

> *The* L*ORD* *bless you and keep you;*
> *the* L*ORD* *make his face to shine upon you and be gracious to you;*
> *the* L*ORD* *lift up his countenance upon you and give you peace.*

7

Devotion on Philippians – Through the Eyes of a Special Needs Child[1]

by Kelly Beller

God opened up the book of Philippians to me in a whole new way.
One day when looking up a verse for a Bible study,
I just saw Philippians as if our son, Sam, had written it to my husband,
David and me. Sam is truly God's extraordinary servant
and an example of God's power made perfect in weakness.
Through Sam, the Lord has forever changed us and blessed us.

—Kelley Beller

Philippians 1

1 My Parents, workers for Jesus:
2 May God our Father and the Lord Jesus Christ bless you with grace and peace.

Thanksgiving and Prayer

3 I thank God every time I think of you.

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[1] Used by permission. Kelly Beller, "Devotion on Philippians – Through the Eyes of a Special Needs Child" (unpublished manuscript).

4 In all my prayers for you, I always pray with joy

5 because of the work you do every day for the Lord,

6 and I know that God you will carry your work on to completion.

7 I have you in my heart; and whether I am unable or able to speak the gospel to others in my life, you share in God's grace with me.

8 God can testify that I love you almost as much as Jesus does.

9 And this is my prayer: that your love may grow more and that your knowledge and insight will deepen,

10 so that you may be able to discern what is best and may be pure and blameless until the day of Christ,

11 filled with the fruit of righteousness that comes through Jesus Christ—praise God!

My Bondage Advances the Gospel

12 Now I want you to know, Mom and Dad, that what has happened to me has really served to spread the love of Jesus to others.

13 I see the message is getting to all those around me through my bondage, that glorifies Jesus.

14 Because of my limitations, most of the believers in the Lord have been encouraged to speak the word of God more courageously and fearlessly.

15–17 Some preach Christ out of good will and do so in love, knowing that I am put here to defend the good news that Jesus brought.

18 The important thing is that in every way, Christ is preached. And because of this I am so happy.

19 Yes, and I will continue to be full of joy, for I know that through your prayers and the help given by the Holy Spirit, what has happened to me will turn out for my salvation.

20 I eagerly expect and hope that I will in no way be ashamed, but will have sufficient courage so that now as always Christ will be exalted in my body, whether by life or by death.

21 For to me, to live is all about sharing Christ and to die is a blessing because I will be with my Lord.

22 If I am to go on living in the body, this will mean more people will pray to the Lord on my behalf and therefore, commune with our Father. Sometimes, I'm not sure what I want more!

23 I am torn between the two: I long to leave this world and be with Christ, which will be the best thing that will ever happen to me;

24 but it is more necessary for you that I remain in my body.

25 And I am sure of this, I know that I will remain, and I will continue with you for your spiritual journey,

26 so that through my being with you, your joy in Christ Jesus will overflow simply because of me.

27 Whatever happens, live your lives honoring the good news of Jesus. Then, even when I am not with you any more, I will know that you stand firm in faith together, fighting for the gospel

28 without being scared of Satan who attacks you constantly. Satan will see his final defeat is coming when he sees your victory that the Lord our God will bring you.

29 You see, we are asked not only to believe in Jesus, but also to suffer for him,

30 as you are finding out as you go through this struggle with me.

Philippians 2

Imitating Christ's Humility

1 Mom and Dad, if you have any encouragement from giving your life to Christ or experienced any comfort, tenderness, compassion or love from the Spirit,

2 then make me totally happy by together being of the same mind, having the same love, being one in spirit and purpose.

3 Do nothing out of selfish ambition or vain conceit, but in humility consider each other better than yourself.

4 Each of you should look not only to your own interests, but also to the interests of each other.

5 Your attitude should be the same as that of Christ Jesus:

6 Who, being in very nature God,
did not consider equality with God something to be grasped,
7 but made himself nothing,
taking the very nature of a servant,
being made in human likeness.
8 And being found in appearance as a man,
he humbled himself
and became obedient to death—
even death on a cross!
9 Therefore God exalted him to the highest place
and gave him the name that is above every name,
10 that at the name of Jesus every knee should bow,
in heaven and on earth and under the earth,
11 and every tongue confess that Jesus Christ is Lord,
to the glory of God the Father.

Shining as Stars

12 My dear parents, you have been so obedient when I have been in your life, but do much more when I am gone—continue to work out your salvation with fear and trembling,

13 for it is God who works in you according to his good purpose.

14 Do everything without complaining or arguing with each other,

15 so that you may become pure in a crazy and confused world, where you lead others

16 holding out the word of life—when I see this I know that I did not suffer great pain for nothing.

17 But even if I am a sacrifice for your faith, I am happy.

18 So be happy too and don't feel sorry for me.

Philippians 3

No Confidence in the Flesh

1 Finally, Mom and Dad, rejoice in the Lord! It is no trouble for me to pray for the same things for you again and again and you need it!

2 Watch out for those bad people, those who try to fill you with doubt and lead you away from Jesus.

3–7 Because you know by now that we live to glorify Christ Jesus, and we can't concern ourselves with the flesh.

8 This world cannot offer me anything valuable compared to knowing Christ Jesus my Lord, for whose sake I give up all. I consider my losses to have helped me know Christ

9 so that I could live in him. Of course, there is nothing I can do on my own to earn righteousness, but I love Christ—and this is righteousness that comes from God and is by faith.

10 I want to know Jesus and see his power and share in his sufferings, becoming like him in his death,

11 and so, somehow, live again.

Pressing On toward the Goal

12 You know, I don't have everything figured out and am certainly not perfect, but I will endure so that I may know Jesus and let him fully take hold of me.

13 Mom and Dad, I do understand one thing: Forgetting what is behind in my life, what others see as lost in me, what I may lose even more in days to come and, instead, I am focusing on what is ahead,

14 I seek the goal to win the prize for which God has called me heavenward in Christ Jesus.

15 We all focus on heaven. And if on some point you think differently, don't worry, God will straighten you out.

16 Now let's live up to the victorious struggles we have already gone through together.

17 Stay with me and follow Christ's example, Mom and Dad, and imitate others who live faithfully.

18 For, you know, many live as enemies of the cross of Christ.

19 Their shameful destiny is their own death and destruction. Their mind is on earthly things.

20 But what we long for is in heaven. And we eagerly await our Savior,

21 who controls everything and will transform our lowly bodies so that they will be like his glorious body.

Philippians 4

1 So, my dear parents, that is how you should stand firm in the Lord! I love you; you are my joy.

Exhortations

2–4 Rejoice in the Lord always. I will say it again: Rejoice!

5 Be gentle to all. The Lord is near.

6 Don't be worried about anything, just pray for everything over and over, be thankful and bring your desires to God.

7 And the peace of God, which is above all understanding, will surround your hearts and your minds in Christ Jesus.

8 Finally, Mom and Dad, whatever is true, whatever is noble, whatever is right, whatever is pure, whatever is lovely, whatever is admirable—if anything is excellent or praiseworthy—think about such things.

9 Whatever you have learned or received or gleaned from me, or seen in me—put it into practice. And the God of peace will be with you.

Thanks for Their Gifts

10 I rejoice greatly in the Lord that you love me. You have always been concerned about me and I am thankful.

11 I am not saying this because I am so needy, you see, I have learned to be content whatever kind of day I'm having.

12 I know what it is to be really needy, and I have seen what it is to have your needs met. I have learned the secret of being content in any and every situation, whether healthy or sick, whether lacking in abilities or being able, whether lonely or surrounded by friends, whether in pain or comforted, whether living fully or barely hanging on.

13 I can continue on through him who gives me strength.

14 Mom and Dad, thank you for sharing in my struggles every day.

15 Sometimes it felt as though you were the only ones who cared for me and really loved me;

16 even when I've needed you day and night, without ceasing, you helped me in so many ways.

17 These acts of love will be remembered by the Lord.

18 I have received over and over again from you—gifts of a pure love. They are pleasing to God.

19 And don't worry, my God will meet all your needs according to his glorious riches in Christ Jesus—he is our treasure.

20–23 To our God and Father be glory for ever and ever. Amen.

Acknowledgments

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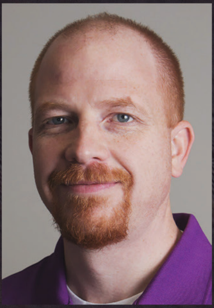
After having several children, parents often feel well-equipped to take on the challenges of another child. When Matt and Tammy Parker decided to add a child to their family, they had little idea of the blessings and struggles God had in store for them. *The Crucible's Fire* paints a picture of God's steadfast love through trials as he holds one family in the loving and protective crucible of his faithfulness. Readers will learn:

- The raw emotion of unexpected hardship
- How to rely on God for strength
- The beauty of God's faithfulness when it seems all hope is lost
- How to trust in God through their own dark night of the soul
- The sanctification that comes only through the refining fire of trials

Strengthen your own trust in God's refining faithfulness as you join this family through the joys and pains of raising a special needs child.



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Their youngest daughter, Brynna, was born with severe physical and developmental delays. Over the past decade, Matt has kept friends and family updated on her condition, progress, and their sanctification through email and his ministry blog at www.thecruciblesfire.org.

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