

## Foreword

It's not very often one gets to help one's nineteen-month-old child write about his experiences with bone marrow transplants. God willing, it will continue to be a rare occurrence.

Anyone who knows anything about this family knows that it has been through much. Since Loren's birth, our lives have been turned upside down. Just when we think we can finally relax, Loren comes up with a new disease. His most recent is also the most devastating.

Loren has been in hospitals in three states and has gained a reputation for doing the unexpected. In the process of building that reputation, he and this family have experienced things no family should ever experience. It is these experiences, mainly from Loren's viewpoint, that are set down in this book.

Although Loren uses humor to get his point across, the subject matter is deadly serious. The subject of a child with a terminal illness that affects out of every 100,000 children can't help but be so.

While Loren still fights for his life, we hope his story will be a help to those experiencing the same things we are.

This book describes Loren's experiences with his bone marrow transplant, but this is not just a book about transplants. This book is intended for anyone who has ever experienced loss, fear or uncertainty of any kind. Whether it is the loss of a loved one, fear of being alone, uncertainty with one's job, the truth of God's grace in the face of adversity applies to us all equally. We hope Loren's courage in the face of adversity, and his continued faith, will be a light to others.

I first wrote this foreword in November 1999. Since that time, we have been through Loren's second transplant and are fighting to make it successful. In the process of rereading this book, I have thought often about whether I would change anything said here about Loren's experiences or our relationship to God. I think I can honestly say that I would not.

Without doubt, the road thus far has been long and it has been hard on us all. Equally without doubt, God has been with us all of the way. His loving kindness and guidance have been our constant companions and I thank Him daily for His grace.

There is another family we keep up with that posts regular updates via e-mail. At varying times, they have used standard closings. The most recent closing is what we hope you will take with you from reading this book: "Never stop believing!"

Jim McClelland  
June 20, 2000

*" For all have sinned, and come short of the glory of God." -Romans 3 :23*

*"The LORD is my shepherd,. I shall not want. He maketh me to lie down in green pastures: he leadeth me beside the still waters. He restoreth my soul: he leadeth me in the paths of righteousness for his name's sake. Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me,. thy rod and thy staff they comfort me. Thou preparest a table before me in the presence of mine enemies: thou anointest my head with oil, my cup runneth over. Surely, goodness and mercy shall follow me all the days of my life: and I will dwell in the house of the LORD for ever. "*  
*- Psalm 23*

October 5, 1999

Hi every person!

Guess who? Ya got it. It's me, the amazin " the fantastic, the huggable, lovable Loren!

I had to say that 'cause I been a bit fussy the last few days and I wanted Mommy and Daddy to 'member how great I am.

Now, before ya start sayin' "You shudn't be fussy," let me tell ya what's been happenin'.

Basikally, I'm still in jail and I'm gettin' bored. I know I said it before, but adults is the hardest peeples to keep entertained. That's speshully true when part of the entertainment is doin' stuff to me.

Oh, I know, they always say "This'll make you feel better" or "This is for your own gud. " Well, let them feel better and let them be gud! I want to be left alone.

For instance, I almost got out of jail on Munday, but they made me stay 'cause I had a 101.5 feevers. I got rid of'em, but they came back later that nite. I got rid of 'em again, but then they came back again in the mornin'. Feevers is stubborn.

So what do the silly adults do? They decide to test me sum more. Now I ask you, who likes to take tests when they are feelin' bad? Not this baby.

Anyway, they decided to take an x-ray of my chest and ultrasound (Daddy helped me spell ultrasound) in my tummy.

I never really have figured out how they can see inside without openin' me up. Maybe I got a secret window that opens when they take piktures of my insides. It must open and close awful fast 'cause I can't ever see it.

They didn't see any problem with my tummy, but my lungs had gotten a little worse. I thawt I was better there, but then Daddy decided he wud give me a chest cold. At least that's what I think. Why do they call it a cold? I'm not the least bit chilly.

Still, the chest cold shudn't have caused my feever from what Mommy and the doctor say.

That was the easy stuff. They also wanted to test my peepee. Have you ever seen how they get the peepee? Man, I wudn't wish that on my worstest enemy. That's gud ' cause I wud have to find an enemy first 'cause I don't know of any rite now. Instead of makin ' me feel better, they make me feel worse in an entirely different part of my body.

Then they stuck this thing up my nose to get a sample from there. That wasn't enuff, so they gave my nose a real big cleanin '.

See, adults always say they are tryin' to make you feel better when they are hurtin' you. They're crazy.

I keep tellin' 'em the feevers is gone today and I told 'em not to come back, but these peeples don't listen.

Personally, I think that the donor marrow stuff is growin , and fightin' with the rest of me. That wud make me have a feevers.

This stuff is bad when you go to clinic, but I been stuck here for a week. I'm tired of seein ' the same walls all the time, tired of the food (not that I've eaten much), tired of the same old videos and same old toys. I WANT OUT!

There, I said it. I want out! Problem is, no one listens to babies. Ah well, what's a baby to do. I'll stop complainin' and start 'splainin' 'bout the verses I picked.

Oh! I forgot to tell ya. The latest DNA test showed I had 25% donor marrow. Comin' up from 10%, that's pretty gud. We are all excited 'bout this and you know who is to blame - Jresus. He keeps listenin' and helpin'.

The first one is part of what Daddy says peeples call the Roman Road. I don't know why, 'cause it's in a book, not on a road. He says peeples use it to help other peeples realize they need Jesus in their lives as their Lord.

Well, I hope everyone duz accept Jesus as their Lord 'cause He's a pretty neat guy, but that's not why I used it.

Layin' around all the time, a baby gets a chance to think a lot. One of the things I think 'bout is how bad I got it.

Then I think, "Maybe I don't got it as bad as other babies." For example, my Hurler friend at Duke University (Maddy) who had a transperson after me really has problems. Here is part of her update last nite.

*"Maddy is in the PICU and is stable but in extremely critical condition. Today was a terrible day. I have to get some sleep so this will be short. Maddy was doing great today. She was taking a nap around noon but need sum blood pressure medicine. They gave it to her and she got very upset and started choking. She was coughing up blood again but this time she couldn't clear it. She was not getting any air. She was suffocating. It was extremely scary. They got her stabilized fairly quickly and decided she should go to PICU for monitoring. After a chest x-ray which showed substantial fluid in her right lung, they decided to do the brochostomy and a upper GI scope. They found that there was blood in her lungs but everything else looked pretty good. Her upper GI looked good. She was stable and we were just waiting for them to put an arterial line in to monitor her blood pressure better.*

*The bronch requires her to be on a ventilator and they have to give her drugs to paralyze her. Moving would cause damage to her airway. This is where things got bad.*

*Her lungs were continuing to bleed and were filling up with blood. She would drown in her own blood. It got very, very bad. She was losing blood faster than they could put it in. They were suctioning it out as fast as possible.*

*They put a few central lines into her groin area to allow them to get more in. They were finally able to get her stabilized. Then they took us in to be with her.*

*We have never known the kind of pain we felt when we first saw her. She was all sprawled out, comatose, blood all over and shaking like crazy. We couldn't believe it. How could this be happening? She is on a oscillatory ventilator which keeps her lungs inflated and just gives her short quick breaths - that's what makes her shake. The ventilator also keeps pressure in her lungs to help stop the bleeding. Her blood pressure was 200/100 (normal-100/60). This was making the bleeding worse.*

*She is stable now - her blood pressure is okay and they have been able to lower the oxygen level on the ventilator.*

*She is still very critical. The next 48 hours are critical. If she does okay, she should be able to recover okay.*

*She will need to be on the ventilator for probably a month or more. That means they will need to keep her paralyzed for all that time. We can't believe it. It all happened so fast. We won't be able to even hold her for all that time.*

*Maddy is very strong. It is good that her white count is high and that she has been healthy otherwise. We know she will be strong enough to overcome this. It is so very hard to see her this way but all we want is for her to get better.*

*Tragically, our little friend Katie died last night. She was occupying one of the 2 isolation rooms in the PICU. Our hearts hurt for her family. We are*

*thankful that Maddy is in an isolation room even though it is a terrible way to get it. "*

See, there are two kids that got it worse than I do. Maddy is real sick, so please pray real hard for her. The other little girl died. Please pray for her mommy and daddy. It's gotta be hard to lose your kid.

So then I think 'bout all those babies that don't got it bad. You know, the ones that are healthy with no real physical or mental problems. I get jealous. But I bet they got problems I don't know 'bout. A lot of 'em probably have diaper rash, or colds or sumthin' else. This duzn't seem like a big deal, but to baby that diaper rash stuff can be a big problem. I know.

What I'm gettin' at, is the Roman Road verse tells me that every person gets their problems. Sum can be worser than others, but everyone has problems. Cents that's true, I really shouldn't keep thinkin' 'bout all my problems all the time. Maybe I should forget 'bout 'em from time to time and thank Jesus for what I do have.

The sekund thing I picked is pretty clear. I think God's been gud shepherd to me so far. I really don't want to lay down in the grass rite now, though. Here is a Loren translashun of the Psalm:

*The Lord is my Doctor,  
I shall not want to see Him a whole lot more ('cept if we're just gonna visit and talk and stuff).  
He maketh me to lie down on plastic covered hospital beds :  
He leadeth me beside the X-Ray machines and CT Scanner thingies.  
He fills me up with new bone marrow.  
He leadeth me thru the Hospital 'cause He knows where He is goin' .  
Yes, even though I'm carried to operatin' rooms and other scary places, I will fear nothin' : 'Cause He's there.  
His nurses and his medical staff, they comfort me.  
He prepares lots of yummy food and gives them to me on trays. (Hah! You want to buy a bridge in Brooklyn? )  
He sends priests, deacons and Mommy to put oil on my head (I wish I knew why)  
Surely, gudness and mercy will follow me all the days of my life and I will dwell in the Hospital forever -NOT!*

I know that sum of you may not like the translashun, but I think God duzn't mind so much. He knows how bored I get. Besides, He knows I love Him and I'm really glad He loves me. After all, it's him who is keepin' me goin'.

Anyway, I love all of ya.

Nite, nite.

Love, Loren and Family