

## A Story of Fatherhood

Bryan Stubblefield is a big ruddy man with the gentlest manner you could imagine. This is the story of his little boy, who's overcoming almost insurmountable problems, and of the man who has learned from him what it really means to be a father.

### The First Years

Flynn Stubblefield is only five, but he's already had a lifetime of troubles. In addition to type 1 diabetes, he has kidney disease and has been on a gastrointestinal (GI) tube most of his young life. His physical traumas have caused developmental delays, and he cannot yet speak in words.

But he's thirty pounds of stalwart little fellow: He determinedly clammers up the stairs all by himself, and he tries to cooperate when Bryan changes his diaper and gives him his insulin shot. Most importantly, he feels good these days. Watched over by his father's loving eyes, he chortles and murmurs happily like a contented little bird. But the journey he and Bryan have taken to reach this point has been long and hard.

Flynn was born five weeks prematurely and weighed only four pounds, eleven ounces. Three weeks after his birth, kidney disease was discovered and a lengthy hospitalization ensued. He'll need a kidney transplant eventually, perhaps within the year, and his father has been going through testing for the past six months to make sure that one of his kidneys will work for Flynn. A big kidney and a big operation for such a little guy, comments Bryan.

Flynn has not eaten food by mouth for over four years. Among the side effects of his kidney disease are severe reflux problems and slow motility; food moves through Flynn's body really slowly. During his first years, he used to vomit dozens of times every day. When he first started learning to eat, it was accompanied by such pain that he developed a deep antipathy to food. In his first year, he underwent a second lengthy hospitalization during which a GI tube was implemented in an attempt to keep him healthy and growing. He'll drink water by mouth, but all his nutrition is provided through the GI tube.

### The Diagnosis of Type 1 Diabetes

Initially the doctors recommended forcing a lot of food into Flynn through the GI tube, especially at night, in an attempt to help him grow. But his system couldn't take it, and he vomited constantly and urinated all the time. Bryan recalls, One night when he was about a year old, I was up with him all night long. He had been screaming for hours, red in the face.

I had a tank top on and he would grab my chest hair and pull it out by the handfuls, and I thought, something's deeply wrong. I may have never been a dad before, but something's wrong. That morning we took him in to the emergency room and refused to leave until they told us what was the matter, and it was diabetes. At that point, I think his blood sugar was 900.

Bryan thinks that Flynn may have had diabetes for a considerable time before it was discovered, but that it was camouflaged by all his other problems. He believes that many of Flynn's struggles during his first year may have been due to undiagnosed diabetes.

### Changing the Initial Routine

When Flynn came home after his hospitalization for diabetes, he was receiving relatively large doses of food through the GI tube, even at night, in an attempt to help him grow. He was on a large dose of Lantus as well, twelve units daily, because the doctors thought it would correlate well with the slow feeds he was getting. It didn't quite work out that way. The Lantus burned somewhat irregularly, and Flynn's blood sugar was extremely sensitive.

Flynn was also vomiting constantly. Consequently, Bryan was unable to measure how much food Flynn was really getting through the GI tube. In managing type 1 diabetes, the dose of insulin depends upon the amount of food taken in. If, after the insulin is administered, the food comes back up, it's impossible to know how many calories have been retained. Those issues arose daily, and it was very complicated and very frightening for Flynn's parents. There was a lot of guesswork, and they never knew if he was going to come crashing down. The high and low blood sugars left him feeling even sicker and vomiting even more.

Bryan recalls, At first we followed the doctors' advice, their best bets at the time. Eventually, however, we as parents had to discover what was going to work for him through trial and error, and ultimately we dialed back the Lantus and the amount of food. There was a lot of fear in changing the routine because it was what had been handed to us, and we believed it.

Going out on a limb to change that, cutting the nighttime feedings, cutting the Lantus dose by more than half, introducing the Humalog, going with the more traditional diabetes management routine, took time and courage. It was a scary thing to do, but it paid huge dividends for Flynn's health in the long run. He is out of the woods now, and well on his way. He's much more stable, and he just keeps improving. No one expected him to be doing as well as he is, walking around, climbing the stairs independently - and happy. Most important of all, he's comfortable and happy.

#### Flynn's Routine These Days

Now Flynn gets four daily feeds. Because of his motility issues, he can take in only a little food at a time. Usually he gets a base feed of 170 mls (2/3 cup) of formula that's specially compounded to go easy on his kidneys, and then he has two follow-up feeds of about 70 mls (about cup) each. He also receives a slow continuous feed throughout the night.

Flynn currently gets 1-1/2 units of Humalog four times a day, usually at 8:00 am, noon, 4:00 pm and 8:00 pm, and then five units of long-acting Lantus at bedtime, around 8:30 or 9:00 pm. The combination of the Humalog and the Lantus has allowed him to achieve a fairly consistent blood sugar level. Any time he's low, it's easy to give him some fruit juice through his GI tube.

Up until recently, it was extremely difficult to give Flynn his insulin injections. Recalls Bryan, He fought us tooth and nail every shot for three years, with all of his might, and that was another difficulty because sometimes you would feel like you had only managed a partial injection. He would flex the muscles in his rear end, this little fifteen-pound person, so we couldn't give him a good sub-cutaneous shot.

Ultimately we found a method in which we put his legs around our lap and then bend him over so he is not capable of flexing his buttocks. It takes a lot of direct face-to-face communication, in which I ask him to be still and explain to him that I only want to do it once; a lot of time, patience, and communication prior to giving him a shot, allowing him to calm down and not forcing it. With that ritual he has slowly become more and more inclined to participate in helping us administer his insulin.

Because Flynn can't talk yet, it's hard to know how much he gets and how much he doesn't. No one knows how much of his inability to communicate verbally is neurological and how much is due to the physical trauma he's suffered. He was experiencing very turbulent times with his diabetes and his kidneys right through important learning stages, and Bryan thinks that many of his delays are due to his missing the normal experiences of those stages.

Bryan spends a lot of time communicating with Flynn, letting him know what's going on and why, and trying to incorporate sign and other forms of language so that he knows what to expect and can participate. And there's been a lot of progress, amazing progress over the past year.

Bryan adds, We're going to have a more difficult time managing his diabetes after he gets a new kidney. A lot of steroids will be introduced, making the insulin management routine more difficult. They'll continuously adjust those steroid levels, which will continuously tweak his insulin routine, so we will have our work cut out for us.

#### In His Own Words: Bryan's Story

##### About Finding Financial Aid

Flynn was born with Blue Cross, and because he was on so many different medicines and there were so many doctor visits every week those first few years, the deductibles were murderous. The co-pays alone were enough to financially bury us. With time, we figured out that we needed not just Blue Cross, but also MediCal (California's low-income insurance). We also needed help from California Children's Services, who helped eventually with the co-pays and the therapy sessions, and from Golden Gate Regional Center, which is a local organization.

At the age of five, Flynn is still in diapers, and they provided us with free diapers. Flynn qualifies for over 250 hours a month of nursing care from In-Home Support Services because of all his physical illnesses, and they were able to help compensate us because we were taking on all the nursing. Although it was a very small wage, it helped us to focus more as caregivers and parents, and it provided us with health and dental for ourselves.

None of the programs was easy to apply for, and nobody told us that they were there and that we needed to apply for them. Flynn was three years old before we had MediCal and California Children's Services. No one told us, hey, if you work five fewer hours a week you might qualify for MediCal. Those are things that we had to figure out through trial and error over a period of years. Navigating all the intricacies of the bureaucracies on two hours sleep, it was a difficult time.

When something like this happens with an infant, the first thing you need to find is a social worker who has experience with such a situation and with its economic repercussions. If the social worker doesn't have that experience, you're going to need to find an alternative resource. Even so, you cannot rely on your social worker to answer all of your questions. Chances are that even the most knowledgeable social worker has never had experience with your type of situation.

### The Community of Help

We've been very fortunate to have Dr. Marty Ernster in Mill Valley as Flynn's pediatrician. He's been a great advocate for Flynn, such a caring individual that I consider him to be Flynn's fairy godparent. He used to look in on Flynn twice a week, check on how we were holding up, and visit us at the hospital. He protected Flynn, making sure that he got everything he needed and seeing to it that Flynn's various medical teams were communicating with one another.

He gave us the encouragement to go out and find what was going to work for Flynn, saying, "You have to do something different, and it's your job to figure it out. He was neither a family member nor a social worker, but he believed that if Flynn were to survive, he needed an abundance of participation. The same level of devotion has characterized Flynn's special needs teacher, Laura Becker, who has been unbelievably supportive and helpful.

### The Isolation at the Beginning

When we brought Flynn home after the diabetes diagnosis, it was a very difficult time and we felt really alone. We were trying with all of our effort and all of our might, and we were up with the vomiting every night; we never slept for more than two hours at a time, and there wasn't anybody to help. No one could give us an answer, and when we did get advice, it was often wrong.

We couldn't find anyone for in-home support who was willing to take on such a difficult case that also involved changing diapers and nurturing an infant. And family members struggled too, out of fear, I think, because Flynn's blood sugars were so sensitive and there was so much that could go wrong. Family members did try, but after a couple times they were in tears and scared to death that they would hurt Flynn or be responsible for something bad happening, so no one wanted to be with him unsupervised. His mother and I were left to our own devices.

It took a really big emotional toll and put an enormous stress on our relationship, a stress that the relationship ultimately could not survive. There's trauma that's suffered just due to having a child that's not 100 percent healthy. There's also trauma that results because he requires such a significant health management routine, one that forever changes the lives of his parents. And those traumas have consequences for a couple and a relationship. We had only each other to rely on, and we were both so emotionally affected by what had happened that we couldn't support each other. We both needed help, and neither of us was able to help the other.

If I had it to do again, I'd find help. At all costs, you have to find help. You can't leave it up to a couple to do; it takes a village, and you have to call out that village when something like this happens, because no one is going to come running to you; everybody's going to go the other way. It's a great lesson in life.

What ended up happening is we separated. Now we both take care of Flynn separately, and that's allowed a minor respite to each of us. It's come at a great cost to Flynn and a great cost to each of us too. But that period of rest was necessary to us both. After just two days a week of sleeping eight hours, I felt like a completely different individual.

Once I was able to get a little rest, I began to incorporate much different routines in order to be able to take better care of Flynn and have a good quality of life. The two of us, Flynn and I, go out and exercise every day. I'll take him on a long walk or he'll get in the stroller and I'll go on a run. Exercise has made a tremendous difference in being able to manage the stress of this routine. In Flynn's first few years, I was still working fifty or sixty hours a week and then taking care of him when I came home.

I had to learn how to manage my life and work differently, delegate better, become a more efficient businessperson. I cut my schedule in half and began to work thirty hours a week so that I could do the things to take care of myself that would allow me to take better care of Flynn. And with the rest, with the sleep, with the exercise, came more clarity and a lot of breakthroughs regarding how we needed to change Flynn's health management routine.

Ultimately it's very sad that it took the separation from Flynn's mother to allow us to reach the point of changing the way we did everything and for me

to take a larger part in Flynn's life. It's just unfortunate that it took a really humbling moment for that to occur. You think you're doing everything you can, but it is so hard for parents in this situation. They do need breaks, they do need sleep. For several years I had worked every day and cared for Flynn every hour I wasn't working. It took just a few nights rest, and I could think again.

Over time, I've also found that therapy has been a huge part of being healthy. After a year of not being with Flynn's mother, we started couples therapy to work on our relationship so that we could make sure that his rituals and his routines were similar. Raising a child with these health conditions is a challenge in itself, and we want to ensure that we're independently providing a very positive environment for him. I just think we both regret that we couldn't have gone through the process at an earlier time.

### The New Routine

As an individual, therapy has helped me to realize that as isolated as I have been, I am challenged to get out there and not live an isolated life. Flynn and I take the ferry to San Francisco and explore the neighborhoods every week. We spend a lot of time at the park with all the other kids and all the other families. We've gone backpacking! I've found ways to keep the insulin cool and to keep Flynn's GI pump charged, and we've headed out into safe situations in the wilderness.

Those were always my lifelong dreams for my child, to take him to the baseball games, take him backpacking and hiking, and teach him about this really rich life. I think that for a few years I kind of gave up on that. But as I grew up with Flynn, I realized that I just needed to work twice as hard to make those things happen. And when they finally did happen, they were ten times richer than I could ever have imagined, for him and for me.

And they've had such an amazing effect on his life. When he was younger, he wouldn't touch sand, grass, or cold water. By the end of our first backpacking trip, with several friends who have been very supportive and their kids, he was playing in the sand, walking through the grass, and walking into the stream on his own. The same things that help every child, nature and being out in the wild, make an impact on him as well.

It took a lot more effort to figure out how to get there, but it was NOT impossible, and once we did it, it paid such huge dividends. And it made me realize that, you know what, I need to do this more. I need to call the Giants and see if I can find handicapped seating. I need to find park rangers who are willing to pitch in, and people who are willing to figure out how to make things happen for this kid.

Although I felt isolated, what I realized is that once you put it out there, and once you're not afraid or ashamed that your child has these problems, there's really a strong community that wants to help any child succeed and will put their heads together to make it happen. That's what we've found. We can go to the baseball games, we can go backpacking, we can do exciting things, and people will make it happen because they want to see a child achieve those things. You just have to ask. It's very gratifying. But first you have to realize that you're not just a nurse and you're not just a caregiver. It's time to move on to bigger things. You are a father.

In the future, I see Flynn and me doing everything we possibly can. Whether it's world travel or outdoor adventures, we'll tackle any environment that we feel we can get control of. You have to use your imagination to take that safe environment on the road, but it's doable.

### How Bryan Has Changed

I'm a completely different person than I was five years ago. Flynn has forced me to realize the importance of being with your family. The typical American work-week of fifty or sixty hours for a father is not a good situation for a child. With a lot of will and determination you can decrease your work schedule, because a child with special needs really requires the support of both parents. And it's a much greater reward being a parent who really participates in your child's upbringing than it is just being a breadwinner.

It's made me realize that I have to take very good care of my mind and body long-term because that's the only way that I can take care of Flynn. It took him to force me to realize that I needed to lose thirty pounds and that I needed to exercise, eat healthy food, and figure out ways to keep up with a very difficult and challenging routine.

Knowing that you might live longer than your child makes you realize how important your time with him is. You come to understand how important it is to live every moment with him, just making sure that you're present every day and that you're paying attention to him and enjoying his company. Those are lessons that I'm sure all parents go through, but it seemed just a little more dramatic for me. It really stared me right in the face. The process of becoming a parent was intensified by Flynn's special needs and the level of devotion that he needs to survive and flourish.

## The Road to Maturity

During the first couple of years of Flynn's life, I felt like I had lost a lot, that life was very difficult and that I had been dealt a bad hand of cards. I wasted a lot of time and energy trying to mature to the point that I could realize that I was fortunate to have my son, that he was grateful to have me, that I wasn't a victim, and that I had a huge opportunity. I had to take ownership of that, give up all my preconceptions, and create a healthy situation. It is my responsibility to myself and it is my responsibility to my son, to create that reality.

I don't think I had the maturity to do it until I was faced with the challenge. You start out with standard preconceptions: you're throwing the baseball around, and your child is talking to you. One of the most difficult things for me, and this is very difficult for his diabetic routine too, is my son cannot talk to me. He cannot tell me when he's not feeling well, when he thinks his sugar's high or low, or when he's about to get sick. Those are expectations that we all take for granted. So living in the moment, coming to understand how fortunate you are to be wherever you are, has been a great realization.

I spent a lot of time on the pediatric ward in UCSF, where there are children on kidney dialysis, children newly diagnosed with diabetes, children with cancer and other serious health concerns. And the majority of them, as long as they're not in extreme physical pain at that moment, are happier than your neighbor or the other children you know. They've realized what the real difference is between a good day and a bad day. They understand that if you're feeling okay, or even if you're not, take it while you can get it. It was very humbling and a great lesson to realize that while you're going around complaining that you're tired or busy, here these little beings are, chirping and happy and making the most of it. You just kind of feel like a fool. And you learn.

## Calling Out the Community

Sometime within the next few years, I'll be faced with a kidney transplant. They'll put Flynn and me side by side on the operating table and remove one of my kidneys and put it in him, and after that I won't even be able to pick him up for several weeks. And my challenge, the next stage, is figuring out how to find help during that time.

In fact, I don't even have someone to take care of myself after the operation. And so that is the next growth challenge that I'm faced with right now: how do I find more help. I've developed a healthy routine for him and me, and his mother and I have found ways to give each other a respite, but that's not enough. The kidney operation that I have to undertake, just to help Flynn continue to survive, is going to break that apart. So it's really important that there are more than just two healthy parents to take care of a child with these types of needs, and I don't have that right now. I have to find people who will be able to take care of me and take care of him, because it's too much for one person. I have to do that - and I have to do it yesterday.

## Hope For the Future

I was fortunate enough to grow up in this community, and I've been in business for myself for ten years now, so I have a lot of friends and family. They can't take care of me independently, but I think as a community, they can. As far as who's going to help take care of Flynn, again, I think that several people are going to have to step up. It's time for people to learn from the past few years and take responsibility for the fact that his mother and I, and most importantly Flynn himself, need them to step up and learn his healthcare management routine. Just because it wasn't done in the past doesn't mean it can't be done in the future. And moving forward and asking again, with time having passed, is what needs to be done now. It's going to take courage, but I live with a very brave person, much braver than I.

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