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BREAKING NEWS AND OPINION

Patient Story: When Your Baby Gets Burned

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I live in San Francisco with my husband and our four wonderful kids. Our story starts a year ago, when our youngest was 13 months old, and was burned by a cup of tea. I hope that by sharing our story I can help people understand how damaging scald burns can be, how to prevent them, and how to deal with them when they occur. As I will show, even a relatively small burn can be a big deal, involve a lengthy recovery, and affect the whole family.

December 28th had been a busy day. My two older kids were on winter break and we had a fun day of shopping for winter coats and getting my oldest daughter Avalon's ears pierced for her upcoming birthday three days later. We were catsitting for my husband John's mother, and dinner was almost ready. John had just poured two cups of tea, and was getting the pizza out of the oven. I had been walking around after our 13-month-old son Cyprian, and was sitting down to relax and wait for John to bring me my tea. Cyprian was fine - happily walking around while the other kids played together. The tea was poured, and sitting on the kitchen table.

I looked up to hear my husband saying "Oh my God!" and I saw Cyprian start to flail around the floor. He had reached up to grab the cup of tea on the table, and it had fallen on him, and spilled all down his face and front. My husband leapt in to action and ripped off his clothes in 2 seconds flat. (I will always be grateful that my husband's instincts were to ACT!) Then he said, "Let's get him in cold water." I grabbed Cyprian and practically jumped in the cold shower holding him.

John put Cyprian's diaper on; I held him in a towel and took him out to the car. John wasn't sure we needed to take him to the ER. I was.

In wet clothes, I grabbed my cell phone and keys, and with Cyprian screaming in my arms, I told my husband I would call him from the hospital. The other three kids were freaked out, but I didn't so much as tell them goodbye on my way out. It was pouring rain that night, and I didn't notice that I was still wet until after we had arrived at the hospital.

I drove across town to the ER with the baby and me both screaming and crying the whole way there.

We got to the hospital, I parked in the taxi zone (and did a terrible job parking but I didn't care) and we ran in to the super busy ER. I remember everyone staring at me as I ran in with my screaming baby in a towel. The woman at the window I ran up to asked for his Kaiser number and I said I don't know, he's been burned and I don't have it with me. (I was a wreck, but trying to hold it together.) She said, "Okay; just go on back through the doors."

It seemed like every doctor and nurse in the ER came in to our room. I sat on a chair with Cyprian's back on me. The doctors put some kind of gauze-like material on his chest and face, and poured cold liquid on him. They did this continually, asking me questions while an ambulance got ready to take us to Saint Francis Memorial Hospital where The Bothin Burn Center is located.

When the ambulance got there they made me put him on a stretcher for safety and his little swollen face was looking at me while he tried to get me to hold him. As hard as it was, with my body screaming PICK UP YOUR HURT BABY, I had to let them do what they needed to do, so I held his hand as we rode quickly to the burn unit. My husband was with our other 3 kids, and I called my parents to meet me at Saint Francis.

We were taken right up to the burn center, where I spoke with the expert Dr. Grossman. He told me we had a choice of putting a bio-skin on his chest and torso or putting only bandages on and continuing to change them. He explained the risks of both and I chose the bio-skin.

They took Cyprian into a room with a big metal tub and other scary equipment, and then asked me to leave while they performed surgery. It was so hard to walk out of that room while Cyprian was screaming for me!

The Treatment

When I got Cyprian back, he was unrecognizable. He had white bandages covering his chest and a bandage wrapped around his face and head. His face was swollen and burned, and I didn't know whether he would ever look like himself

again. His lips looked like they had been burned off, and I was told that the inside of his mouth had been burned as well. Even his hands had been wrapped up into little balls of gauze so that he couldn't pull off his other bandages.

I went to our room with him, still in shock, shaking uncontrollably. I was so grateful to have Cyprian back in my arms. He was on heavy medication, so he was no longer screaming and was apparently more comfortable than he looked. Before I knew it he was asleep in my arms, and I was still shaking.

We spent the first night, just the two of us, in the hospital. My husband was back at home taking care of our other three kids, who had witnessed his burn and our reactions, and were completely freaked out. Cyprian and I went on to spend the next eight days at that hospital - the longest eight days of my life!

Two other families shared our room, which was reserved for children in the burn ward. The first family was there over a month with a four year old boy who had been burned by soup. I don't remember what he looked like, but I do remember him screaming for his mom to hold him. She was sitting with him, but could not hold him because it hurt his burns. So she had to sit next to her little boy and listen to him cry for her while not being allowed to hold him. It must have been just terrible to experience.

When they finally got to go home, about three days after we got there, all the staff came to say goodbye and good luck, and to bring him gifts. It was a happy and hopeful day, and I just pray that everything is going well for him and his family.

Our doctor was cautiously optimistic. I was not. My beautiful, happy 13-month-old baby who looked like an angel now looked like someone out of a scary movie. The days all ran together - a string of nearly 200 hours, during which I barely slept and I couldn't distract myself with anything.

Nurses came in to take Cyprian's stats, complete their rounds, and give him his medicine around the clock. I love all the nurses at Saint Francis Memorial Hospital, and will always believe they are saints themselves to do what they do every single day. Cyprian, however, felt differently. To him, nurses were scary people who poked and prodded. He screamed whenever he saw them come in the room and although his face was bandaged up, you could still see the fear in his eyes.

It was so hard, and the time at the hospital all blurred together. Every moment felt like we were fighting for a chance at a somewhat normal life in the future. I had no real idea what this was going to look like in the long run, beyond the fact that he was going to live. I was thoroughly grateful, thoroughly angry, and thoroughly scared.

The swelling on Cyprian's face started to go down (just like the doctor told me it would) and after about the fifth day, I started to recognize a bit of the old Cyprian again. He would have moments of happiness. I would sing to him, and he'd calm down a bit until I'd stop. Since his hands were wrapped in balls of gauze no one could hold his hand, but he would allow people he knew to blow raspberries on the bottoms of his feet and make him laugh. The physical therapy room had a huge red ball he'd play with, and he loved the balloons people would send - with his little wrapped-up hands, he treated each balloon as a punching bag.

Despite this new positive direction we seemed to be going in, we had one more obstacle to deal with: his lips were very badly burned. Even though Cyprian had begun to look more like himself, he was losing weight. Before he could be discharged, Cyp needed to be seen gaining weight. He was hungry, and it was very frustrating to try to feed him or nurse him, and not to be able to, due to the pain in his lips and mouth. Despite our best efforts, I finally had to let the nurses give him a feeding tube.

After a day or two of Cyprian having the feeding tube in his nose and pulling it out repeatedly, we were eventually told he was doing better. He was starting to nurse, bit by bit, and we were on the mend. After 48 hours or so of Cyp doing better on his own, they told us we'd probably be able to go home. On the eighth day the doctor said we could take him home, but would need to come back on Monday.

As we left the hospital, we said goodbye to all the wonderful people who had helped save my baby. I felt a rush of gratitude and optimism as we left the burn ward. We stepped outside, and that feeling quickly went away. We were coming out of our bubble for the first time, and I realized that I now had to deal with the outside world. It hadn't occurred to me that we'd have to deal with looks from people on the street, not to mention what felt like potential danger lurking around every corner. I held my baby close to me as we headed out to the car.

The Recovery

We got home to my other kids, who I had missed like crazy while in the hospital. I had spoken to them on the phone, but only for short periods of time. I had never been away from them for this long before, and it felt great to have my little family back under one roof.

Cyprian was so happy to be home and see the family that he seemed to light up, but it took me a while to calm down. The immediate recovery was really intense. I had lotions to rub on his scars, and bandages to keep on his face and head. I had to keep him from pulling his bandages off as he got back into the swing of things with the other three. We went back to the hospital every few days for various check-ups for the first month after being discharged from the hospital. After the first month I got a call, and Kaiser wanted us to return to them for care from that point forward. St. Francis had become almost like a second home to us, and we had got to know the staff so well that I was not looking forward to the switch. When it was time for our last appointment, we said goodbye to Dr. Grossman and told him that we would be back to visit soon.

Our transition to Dr. Ikeda went a lot smoother than I expected. I was prepared to put up a fight to keep receiving treatment at St. Francis, but I was pleasantly surprised to find how much I really liked Dr. Ikeda. He was nice to Cyprian, explained everything in detail, and asked me if I had any questions. He never tried to rush us out of the room, and it turned out that Dr. Ikeda used to head the St. Francis Burn Ward and everyone there new and liked him. Six weeks after the burn, with a new doctor, I hoped we were on our way to a smooth and swift recovery.

Dr. Ikeda told us that the main trouble spots were where the third degree burns had been, and that these spots needed to be watched closely.

Cyprian's third-degree burns were on his chest and under his chin. The scar under his chin was the hardest to treat. We thought about a tight fitting garment, but it couldn't be made tight enough to make a big difference. Also, since Cyprian was so young there was a chance that wearing a garment might affect how his jaw grew. The alternative we opted for was to stick something called Silicon Skin underneath his chin.

Over time the burns on Cyprian's face kept fading away until they were gone. What was left were the ones on his chest and under his chin. Silicon skin is a great thing. Unfortunately, Cyprian did not agree. I would massage the spot under his chin with cream to reduce the scarring and to keep him feeling comfortable with people touching under his chin. I went online to the website the doctor recommended and bought silicon skin strips in bulk. Each strip is supposed to last two weeks, and I was ready! I had them shipped by two day delivery so we could get started right away. My goal: for Cyprian to not need to wear a head garment.

The silicon skin sheets came in the mail and that evening I gave him a bath, got him in his pajamas and carefully pulled out the strip. I placed it carefully under his chin and said "There!" No sooner was the word out of my mouth than Cyprian ripped the strip off his face. I put the strip back on his chin many, many times that night and he eventually he left it on. I felt like I had conquered the world.

When we woke up the next day, the strip was gone. I looked everywhere and couldn't find it. Over the next few weeks, I struggled to keep the silicon skin strips on Cyprian's chin. I'd fight him to keep them on, watch him like a hawk, turn my head for a second and find that he'd taken them off again. I ordered new batch after new batch. After months of battling, I eventually gave up. In hindsight, I should have kept on fighting that particular battle but at the time it seemed frustrating and pointless.

What I did do was keep on rubbing cream on his scars and massaging the spot to prevent keloid scarring and keep him accustomed to people touching his face. At this point his chest and stomach were looking really good. The third degree burns on his chest were easier to take care of, and they flattened out a lot and faded. He will always have visible scars there, but I was not worried about it at this point. I think if it was one of my daughters I would feel that it was a bigger deal, but since Cyprian is a boy, I am hoping he thinks his chest scars are kind of cool.

Since the burn, Cyprian has had a lot of freakouts, and been very clingy. I love him and it's great to be with him all the time, but I think the other kids resent it slightly - they understand, but they still miss me.

Recovery has been a rollercoaster. I'd feel nervous about taking him in to his appointments, afraid the doctor would say his scars are not getting better, or excited and delighted by the hope that they would. The doctor's word wasn't good enough - I needed to see his scars getting better. I needed to believe it inside my traumatized mom heart.

The Forward

One great source of support has been Alisa Ann Ruch Burn Foundation in California. If your child is burned, a burn foundation for support is the first call you should make after you are discharged from the hospital. It's when you most need help that's the hardest to reach out, and it's so important to call and follow through anyway. We have been to AARBF support groups, met some wonderful people, and attended some great local events.

The burn survivor events were not just for Cyprian, but for the whole family. When something like this happens, the whole family is affected, and it's important to make sure they are all involved in the recovery process.

When December 28th came around again this year, it was a big deal for me. I don't think anyone else noticed, but to me it felt huge. We spent that evening at a family Christmas party in Arizona. It was a big party, with tons of people, and I was surprised by how nervous I was. All of these unattended beverages - were they hot? How hot were they? Where was Cyprian? Very cute that the teenage cousins wanted to play with him, but did they know what to look out for? I'd better tell them, but would they take it seriously? I spent most of the party following him around.

At Cyprian's one-year appointment, we got some bad news: the scar on Cyprian's chin is getting worse, and there are no perfect solutions. I discussed options with the doctor: staying the course with scar cream and silicon strips (which isn't really working); getting fitted for a garment (which could affect the growth of his jaw); painful regular topical steroid injections; risky surgery. The visit had started off happy and hopeful, and getting this news nearly brought me to tears. What would we do next?

John and I discussed our options, and settled on hybrid approach that seemed best to us. Cyprian may still need surgery in a few years - that's a reality I have to face. For now, all I can do is fight the scarring today. It will never be totally gone. Even in the best case scenario, Cyprian will have scars for the rest of his life. Is it the end of the world? No, but it has certainly changed our world. Our hope is that telling our story may help other families.

First, be aware of the dangers. Everyday things that seem harmless - tea, coffee, food cooking on the stove, firecrackers, and hot pans - can change your life forever in a moment.

Second, react quickly and correctly. When a child is burned, get the hot material off them immediately. Every second counts! Strip the child of soaked clothing, and get them under cold water immediately. Call an ambulance to get the child treated as quickly as possible.

Third, get support! Burn recovery is a long term process. There's the initial hospital stay, the follow up appointments and treatment, and the long term learning to deal with and live with scarring. Burns and scars will change your life in big ways and small ways, and it's important to talk to people who understand and can teach you how to deal with the questions, the staring, and the well-intentioned comments, not to mention the intense mix of emotions that flow from the trauma of the burn itself and the slow recovery process. Ask your doctor to refer you to local burn support groups, or contact the [Alisa Ann Ruch Burn Foundation at www.aarbf.org](#).

http://www.huffingtonpost.com/melissa-lamming/when-your-baby-gets-burned_b_4620131.html

www.saintfrancismemorial.org

Bothin Burn Center: http://www.saintfrancismemorial.org/Medical_Services/195214