



Storm 5 years old rubbing his hands from the chronic pain

Storm's Story

By Georgia Peschel

WHEW! Delivering this kid was like delivering a hurricane!" When our son was born, those were our doctor's words! Storm was an emergency breech C-section. It was the best day of my (our) life!

From the very beginning, we had a special bond. Looking back, I believe I know why now. Moms know. Storm was an amazing baby! He was the cutest baby ever! Clever and advanced — **well advanced, happy, curious, and loving, but something was just not right. Storm cried every night.** Yes, many babies cry a lot, and it lasts a while — with Storm it lasted until he was 14. That was how old he was when I introduced him to cannabis.

Gasp! A mother giving her child cannabis at 14!? The horror!! I am



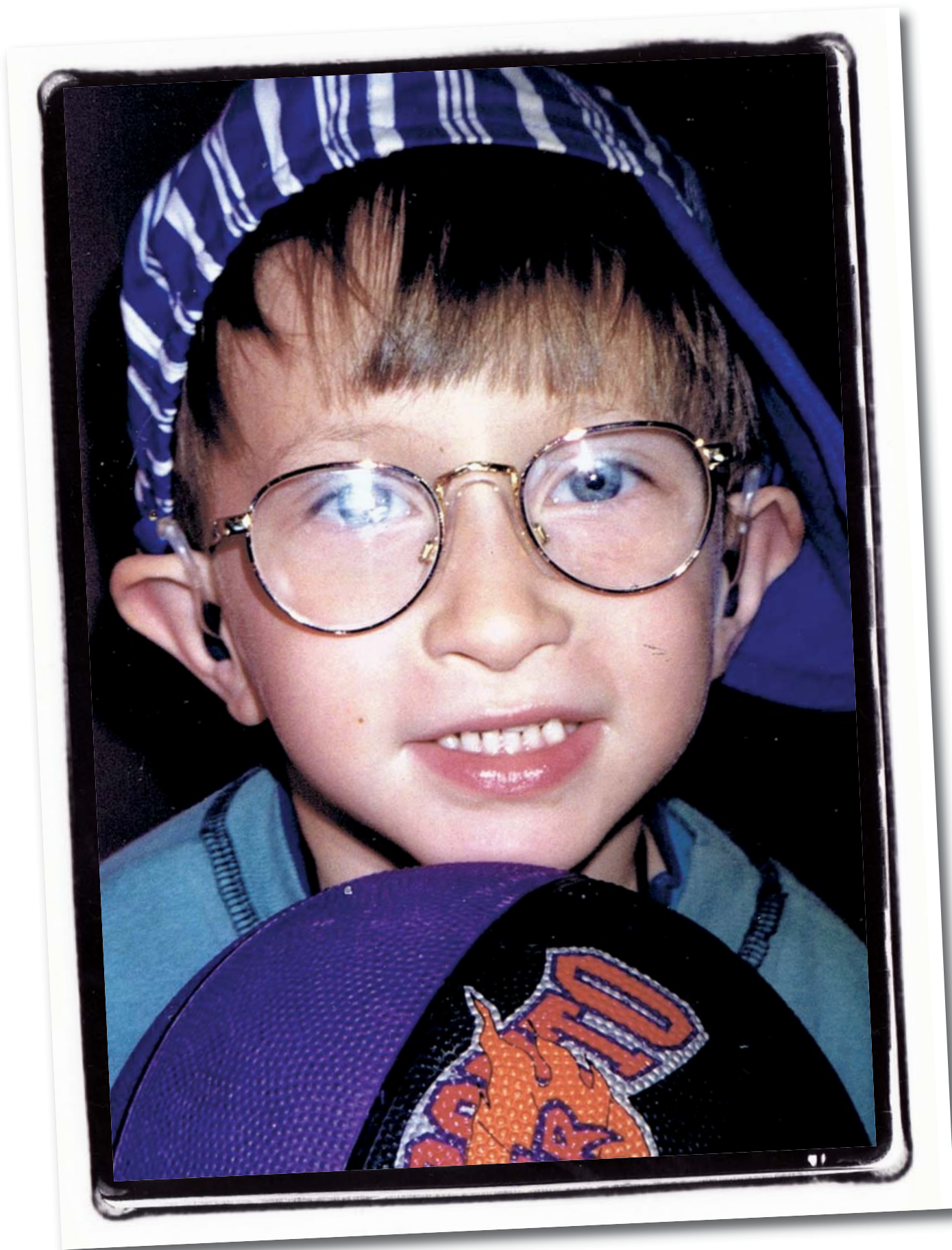
sure many people did and will continue to think that way. Horror? NO.

Horror is watching your baby, your child, scream in agony day after day, week after week, year after year, and know that there is nothing that can be done. Ask any mother. From the time our son was born, he would scream. Not cry — SCREAM. It would continue for hours, usually until he would pass out from exhaus-

tion, and nothing was able to soothe him — we tried everything! It was so fierce, the screaming, many times my husband and I would panic and undress Storm, thinking he must have been bit by a bug or jabbed with a pin. Something physically sticking him to cause him to scream like that! Several trips to the emergency room, only to be told, "There is nothing wrong that we can see." Only to turn around and come home to have it happen over and over again.

There were also many other little things that Storm did. **He would constantly rub his hands and feet, even in the infant stage.** He was not happy when he could not see me. I remember crying to my doctor, telling him, "I swear I can't even leave the room... and every night. SCREAMING." I was exhausted.

I was blessed that I was able to stay▷



home with Storm — my husband worked and supported us financially, so Storm and I were very close. I worried about what was going on, but I was told time and time again — it's probably growing — there was always a reason. Unless you witness it firsthand, you might think the same. Part of the problem was that Storm did not speak. Many people shared their opinions on this also. The fact was that Storm could not hear. Storm was such an amazing, little, alert baby who was advanced in most ways that doctors thought nothing of it, not realizing he was deaf, only that he was just going to speak late. It was not until he was almost three, when a fire alarm went off in his room, that we realized he was hearing impaired.

How could we not know!? Trust me, no one did — again, because he was so smart. He knew how to ask me for things and his dad and grandma and a few others. After many tests and x-rays (thank God for those x-rays), Storm was diagnosed as being moderately to severely hearing impaired. Every time a parent finds out that there is something wrong with a child, it is devastating.

Heartbreaking. We only want the best for our children. No one wants to hear there is anything wrong with a child.

Hearing impaired; we can deal with this! I remember at the time someone close to me saying, "It could be worse...." I have come to the conclusion that you should not say that, ever. Storm got his first hearing aids, went to a special school earlier than most children, and I bought all I could find on sign language, place-mats, books, toys, etc. We were ready to adjust to a life with hearing aids. Storm took to them instantly! He could hear!! He started to learn and speak words! I still laugh at his fascination, as many little boys have, with trucks! The 'T' could not be sounded out, and when he saw a big truck go by, he would yell out, "FUCK!!" "FUCK!!" The looks we would get! It still makes me giggle. We learned early — hearing aids are not always noticed, and people make ASSumptions. So be it. There is so much to learn when someone you love can't hear. Mostly patience. We were never ashamed that our son wore hearing aids and we wanted to

teach him the same.

From the start, I let him make decisions — he was the one, after all, wearing them! He usually liked to choose blue or green ear molds and often took them out and handed them to people to try when they asked about them! I remember a mom saying to me, "You should be ashamed of yourself letting your kid stick candy in his ears! What example is he setting to the other children?" REALLY!! It was at a Boy Scout function. A friend of mine also heard the comment and quickly put this mom in place before I had the chance. People would also stare. Not much you can do about it. I would ask them if they had any questions or sometimes, I admit it, I would just GLARE.

Soon I could spell in sign and was teaching Storm and my husband. We knew many words and were going to be OK.

The pain and screaming never stopped, though. Night and day. All I could do was hold Storm and try to calm him down. Sometimes I would ▷



Left: Storm 5 years old, a typical happy little boy.
Above: Mom and Storm (11 months) at the zoo before he was diagnosed
Right: Storm always curious



Storm already in school at an early age to try to catch up with his speech

be so tired, Norm and I would take turns, rotate nights, but Storm usually wanted me, and I always went. Many nights it would start around 10 and then again at 3. Always the same: Storm screaming. He could hardly talk and usually did NOT want to even be touched. He did not know the words to describe what was happening to him. He did not have to. We could see the physical anguish in his face and body language with every episode of pain he endured.

This is when I was introduced to cannabis again — I had smoked from time to time over the years, but was never really big on it. I usually preferred to consume alcohol. I had a very close and good friend that was always telling me — you have to get some sleep or you're going to get sick. Easier said than done. How could I sleep through it — sleeping pills were NOT an option. I had to be there for Storm. Long before the screaming, he would become restless. I could hear him toss and turn and

start to moan in his sleep and knew what was soon to follow.

My friend (someone I never would have ever expected to use cannabis) offered me a joint to help me sleep. It worked. The next day, I woke up alert and refreshed to the day ahead. I used cannabis on and off to help me sleep and sometimes just to unwind. My life was not about getting high. It was about my son

and husband. At the time I was freelancing — painting murals in schools and offices, and teaching kids cartooning from time to time to help with the bills. I was on Cityline (a popular television show here in Canada) with a few murals and was getting busy. We considered putting Storm into daycare with a neighbor who lived a few doors away. I took him to see how he would like it, and he wanted some juice. I explained to the woman, "He wants juice." She turned and said, "Well, when he's here, unless he asks for it properly — he's not getting it." I took Storm home and never returned. The murals and all else could wait.

The pain was not just in the evening. Storm wanted to be carried everywhere. I thought it was normal and never minded, so I just did it. As he got bigger and heavier, it became harder. Whenever we went anywhere, the visits were always cut short from Storm expressing that he could not walk anymore as his feet hurt. Feet and hands mostly. This was at the mall, Wonderland, parks, everywhere. Followed by screaming and crying and passing out to sleep. I

knew there was something wrong and had to find out what.

As time went on, at night we could not even touch Storm. He would scream even louder if we tried to comfort him. It was like his body would react with pain to touch. We were afraid to hold him; we really thought that we were hurting him. I cannot tell you how many times he fell asleep in my arms after crying. I would lie there and cry too. Norm also. We could not stand it! We could not understand it. All we were told was to give him Tylenol. We gave him Tylenol daily. For years. I still pray that we did not cause him any internal damage. This too was a chore as HE HATED medicine, as most kids do, unless it was bubblegum flavor, and even that was a task getting him to take. It became such a battle, we decided we were hurting him more by forcing him to take medicine that never seemed to help much anyway.

I took Storm to his doctor again, but this time I was not my usual friendly self. I told the doctor, "There is SOMETHING wrong. I want tests done. This is NOT normal." Our doctor has always been patient and caring. Looking back now, I understand. Storm did LOOK normal. Nothing that could be seen, and unless you witnessed firsthand the screaming, you just figured I was a sensitive mom, I guess. My doctor said OK, I'll book some tests. We were soon at the Hospital for Sick Children in Toronto, and the tests started. Weeks. I still do not like to remember all the tests and Storm having to go through it all on top of everything he dealt with. One time, it took four adults to hold him down, him begging me not to let them hurt him anymore. After a few days, I had one doctor ask me if I knew what "Munchausen by proxy" was. I did not, but when I found out, I FREAKED! I was so angry, it still raises the hackles on the back of my neck. All just part of the lesson, looking back now. A couple of weeks later and the results were in. This is when

"...it could be worse..." got worse.

Thank GOD for the x-rays taken when he was two! It was one of the first clues. Doctors could see how the bones had fused since the last x-ray! They had something to compare. I was not crazy! It just kept getting worse the following days. I remember telling my husband I did not want to hear any more. Every appointment was accompanied with more bad news.

Storm's hearing loss would progress.

He was losing his vision and had to get his first pair of glasses.

Some symptoms of multiple synostosis syndrome:

Fusion of nasal bone and frontal process of the maxilla, Short philtrum. Multiple fusion of midphalangeal joints. Fusion of elbow bones. Fusion of carpal bones. Fusion of tarsal bones. Clinodactyly. Brachydactyly. Distal phalangeal bone hypoplasia. Aplasia of distal bone phalanges. Aplasia of fingernails. Aplasia of toenails. Limited forearm pronation. Limited forearm supination. Limited rotation of hips.

Abduction of shoulders. Vertebral anomalies. Fusion of middle ear ossicles. Conductive deafness. Sunken chest. Prominent costochondral junction.



ing.medscape.com/p/med/&kb/pediatrics_genetics/941088-941723-480.jpg

All his bones in his body were slowly fusing together, starting with the smallest, which included his hands and feet and spine.

He would continue to suffer with chronic pain every day of his life.

Progressive to terminal. No treatment; no cure.

At the time, the doctors told us they expected he would be completely deaf around the age of 10 and possibly in a wheelchair at 12 and not expected to live long after that. No treatment; no cure.

Sitting here now, the tears pour from my eyes. It still hurts as if it was yesterday. I remember coming home and being physically ill. It was the worst thing they could have said. My head spinning, my heart breaking. How are we to continue to watch our son suffer like this every day?? Not to mention what we were learning about multiple synostosis syndrome. NOT MUCH! At the time, it was considered an ORPHAN disease because it was so rare. There were no known cases in Canada or the U.S.A.

We met with more doctors. Some explained and some just talked; of course, a child psychiatrist, genetic doctors, and more. This was also one

of my first rude awakenings. The genetic doctor explained a life lesson to my husband and me. Our son's disease was "so rare, no one would be putting any money into research for a disease that only one kid has." REALITY. It was like a final slap.

We also met with the pain clinic and discussed a future of prescribed drugs to help ease our son's pain. The future was not looking very bright at the time. Doctors suggested some more tests "to learn," but we said No. Storm had been through enough tests and pain and would continue to do so. I was not going to put him through anything else unless they said it would help him — but of course, it couldn't.

I went into a sort of shock, I think, after all that. I cried a lot and I was angry. I was angry with the hospital, the doctors..., myself, my husband, and GOD. I had one thing that kept me going — Storm. He was and always will be the love of my life, and along with all the pain and suffering, he was our little GIFT from God! When not in pain, he was a happy, normal little boy! He made us laugh all the time, and the one thing that instantly happened — as with anyone — when you are faced with a fact that you could lose someone you cherish — you LOVE him even more!

I cherish every second to this day. What does not kill us makes us stronger. Many parents separate when they have a child with such serious medical issues. My husband and I grew closer over the years. We were the only ones that could completely understand what each was going through. To this day, my husband has a difficult time talking about Storm's pain.

I started to search online and found nothing. Today, I still do not find more than I knew then. I became obsessed, looking for a cure! Making myself crazy. I wrote to doctors in Canada and the U.S.A No one could help. I did not stop there, of course. We did go to the Shriners Hospital in Montreal to do it all over again, only to come out with the same conclusions. Storm's fingers started to fuse, so sign language was no longer an option. Again looking back, I was so angry. I know now that it was not the hospital's fault or any of the doctors' (don't shoot the messenger) that they could not do anything. I guess they have to prepare you for the worst-case scenario. No treatment; no cure. No hope.

What did I do? What would you do? I learned to PRAY. We had been attending mass every Sunday since we moved to our small town. Storm▷

was just one year old when we moved here. I love the community and was blessed to live here with so many wonderful people that have become our friends over the years. There was a fundraiser for Storm, and he was granted his wish from the Starlight Foundation. It was all so bittersweet. We had an amazing time and were able to provide Storm with a few things that financially we would not have been able to do otherwise, including new hearing aids! I am thankful for such organizations that provide sunshine in such times for families who already are dealing with so much. I wish there were more.

What were our options? I prayed all the time. Still do. I'm not sure if you would call it praying or begging. I did a lot of both. Still do. To date, God has answered my prayers. Storm is here with us. He is the love of my life and our inspiration. His condition is slower than doctors guessed it would be. Thank God! I still pray that they were wrong. I pray for a miracle every day.

Over the years, we get x-rays, and they continue to confirm what we already know. Storm's disease is progressing. We don't need the x-rays to tell us this. As the years continued, so did the pain. I can tell you it became worse as Storm got older. He learned to express with more words, words that no parent wants to hear. He started to understand what was happening to him. The pain continued and became stronger. Night and day. We could not go anywhere without planning and medication, but eventually the pain would kick in and our life was ruled by it. As Storm got older, we had many conversations about all of this. Most of them very sad.

What do you say? What do you say to your child when he is screaming with pain night after night and begs you to take it away? Asks you WHY??? To make it stop! WHAT do you say or DO?? The problems with prescribed medications were many. They took too long to work. They caused upset stomach, constipation or diarrhea, sleepiness, and depression. Often he would vomit up what we gave him right after. Storm hated taking medicine.



Storm and his favorite dog Tequila.
She got a little too curious about the hamster ball!

He did not like how it made him feel, and it was a battle. One I did not want to push because I had looked into the side effects of a life on medication, and they were as grim as the bone disease. This was not something he would be taking occasionally. He needed to control his pain, and in order to do that, he had to take it all the time. Every day, every few hours, for the rest of his life. The talks that Storm and I have had over the years are very personal and heart-wrenching. Too much to even share. Talks that I pray parents do not have

to have with their children ever.

At the age of 12, Storm had mentioned how he did not know how we were going to live this life of pain and pharmaceuticals. Suffer or be drugged out and sit on the sofa. Storm has always been so interested in everything. He did not want to sit on the sofa and play video games all day. We encouraged Storm to do whatever he wanted!! Knowing all too well life is short and we wanted him to experience all that life had to offer — that we were able to provide. The problem was that whenever he did do anything fun, he paid for it later. A day at Wonderland usually meant two days of severe pain. Imagine watching your child walk, and each step looks like he is walking on glass. It hurts that much to put his feet on the ground. See his fingers fusing together, knowing as time goes on, it will only get worse. Time for something drastic.

Although I have told people over the years how bad it was — it was never really anything you could see. Still cannot. If he was in pain, he was at home, and we would try to make him comfortable. A few times when family or friends have slept over, they have witnessed it firsthand. I remember my cousin almost in tears when he stayed with us, after seeing Storm night after night and how we were dealing so well.

What were our options? My parents were the only ones I would trust with Storm for a long period of time, and they have shed a few tears themselves over the years with what their grandson has had to endure. I never trusted anyone with sleepovers. It was difficult enough for us to help him through it. I have shared with a few people what it is really like, but they

find it very sad, and I have even lost a few friends because they have a hard time dealing with it. I used to stress over such things, but I don't anymore. My concern for my son comes above all else — especially others' feelings.

I started to do some research online. Pain control. Cannabis kept coming up. I had smoked it myself and knew that I had not seen dragons or had any strange hallucinations or anything else, for that matter. I did not see the munchies, giggling, or wanting to take a nap as serious side effects. I knew you did not have a hangover the next day or did anything so stupid like when you consume too much alcohol. What I was reading seemed almost too good to be true. I continually read that no one had ever died from cannabis use — unlike what I was reading about some of our other medicine options. I spoke with my husband. We talked a long time about it, going over all the what ifs. There

were many! Weeks later and we both agreed we should let him try cannabis.

A few days later, we had purchased a bong (I read it was one of the better ways to use cannabis — not as harmful as smoking). I'll admit I had no clue then about edibles (I wish I did!) and I'm not much of a cook or baker! WE are also a family of NON-smokers. Never have.

I called Storm upstairs and told him I

wanted to talk to him and show him something. When I showed him the cannabis and bong and told him we wanted him to try it, he immediately asked us, "IS this a TEST?!! I don't smoke drugs!" Clearly, while he was growing up, we had asked him not to try drugs, and he had not. PROOF that Norman and I had been doing a great job raising our son.

I explained all I had found out about helping people with pain and just thought it was a more natural reme-

again usually at bedtime. Within minutes he would feel better. No one knew; no one could tell. My son was not stoned; he was medicated.

His attitude started to change. His mood was better — as was ours! Do you know what it is like to watch your child suffer such agonizing pain for hours on end and you have no control whatsoever!? I pray you never do. We could not get over it. Several symptoms stopped completely! Now what? Storm knew he could not tell anyone because we

could all get into serious trouble. At that point, I already did not care. It was a miracle medicine. It eased our son's pain, and we did not have to watch him suffer, so it eased our pain also. In my mind, there was no turning back. Legally or illegally, cannabis was his medicine.

The next step was to approach the doctor. I had no idea what the doctor would say. He has known of Storm's condition since he was diagnosed and has wit-

nessed firsthand some of the things we have had to deal with over the years. He told Storm, "Prove to me why you think this would directly help your condition." I thought that was great! Don't forget: Storm was only 14.

He did exactly that. The next week, we went back with all the research Storm himself had done. After going over it, the doctor agreed. He also told us Storm was his first patient that he was granting medicinal mari- ➤



Storm and Hunny, mom Georgia and dad Norman the summer Storm became a legal cannabis patient.

dy and we thought he should at least try it. He did. Keep in mind we made sure he had nothing else in his system for a few days — this was easy. As I've said a million times before, he hated medicine! The results were almost INSTANT. He said he felt great. That night again, he tried a bit more and slept the night through!!! DO you understand the meaning of that!? I still am amazed myself when I think about it. For the next couple of weeks, he would come and ask when he said he was sore and



**Mom and son at 1st Treating Yourself Expo 2010! Our education to a better day.
Storm and his dream Volcano! ha ha ha**

next page:

A cartoon by Goergia each drawn and inspired by LOVE.

juana to and might be the only one, but he was willing to see how it helped Storm.

At 15, his papers came back in the mail from Health Canada, and Storm was legal to smoke cannabis! The hard part over — so we thought! Well, the hard part was over. From the first puff, we saw the results, and that is what mattered most to US! Results we had not ever seen with any other medication. Not to mention we did not have a fear of overdoses or liver damage or organs shutting down! From a PLANT! Again, God had answered my prayers. Believe in God or not, that is up to you. When I pray to God for a miracle every day, I figure the least I can do is show my respect and share with others what we know to be true. See it to BELIEVE IT. I say many times I am amazed where this path has taken us, but I am not one to question it. My son is here and he is pain free... well, NOT pain free, but pain controlled.

Storm being only 15, we kept it hush-

hush. The first two compassion clubs I contacted did not take me seriously. One could not believe a 15 year old had his license, and the other never returned my calls. One finally did: C.A.L.M. I believe everything and everyone happens for a reason. C.A.L.M. took the time, taught us so much, explained the different strains, and more. I will be forever grateful to them for helping us on this journey. They made a difficult time easier and fun!

It has been just four years. Storm is now 18! We see how cannabis has changed our lives for the better. We started to feel an obligation to others. TELL them how cannabis has helped. I tell every doctor I meet that Storm uses cannabis with fantastic results for his pain. We are NOT ashamed of our son's medicine. Would I be ashamed if he was using morphine to help him? NO. Why? Because morphine is socially acceptable in this society — cannabis is not!? The more I learn every day, the more passionate I become. STORM is living PROOF. Like MANY others.

I want other parents to know cannabis is an option. HAD I known what I know now, I would have been baking brownies when he was four!!!

When you see your child suffer, you will do whatever it takes to stop the pain. If you doubt this, wait until the next time your baby cries because he hurt himself. Then think about our situation.

HOW amazing will it be for parents who want to try cannabis for seriously ill children to have doctors support them and perhaps even educate them so they know where to start!

If we can ease some child's pain, especially children with terminal illness — and not just that! I pay close attention to cannabis in the news. There are children all over now benefiting from cannabis! A 2 1/2 year old with a brain tumor, children with OCD, autism, and more! Not to mention countless adults who have finally found relief. More moms like myself are standing up and demanding research, having courage in a time when cannabis is NOT yet fully



appreciated for what it is and still has a silly negative stigma attached to it.

I do feel the truth can only be kept hidden for so long before all realize how we have been misled and lied to about cannabis. I don't want you to trust me on that — I want you to EDUCATE yourself. Once you do look into it, it is hard to deny. Research from all around the world is coming in. I am not a scholar or doctor, and my grammar sucks. I am a mother who loves her child with every breath I take. We did not ask to be on this path but we are and we will not lie or keep quiet. That would be a sin. I have no intentions of purposely pissing off the Big Guy! He placed the plant here. **God makes NO mistakes.**

Cartooning. I have always wanted to be a cartoonist for as long as I can remember. I went to Sheridan College for animation. I drew and painted to keep my mind elsewhere. To keep my sanity. My favorite distraction. For our son, a side effect of cannabis had been laughter! What a FANTASTIC

side effect to have! Inspired, the ideas started to come. I got a phone call one night from Mike Peters (creator of Mother Goose & Grimm). He called to tell me to keep it up! During our conversation, I mentioned I was thinking about drawing some strips about medicinal marijuana. He said GO FOR IT! Draw what you know! It was what we knew!

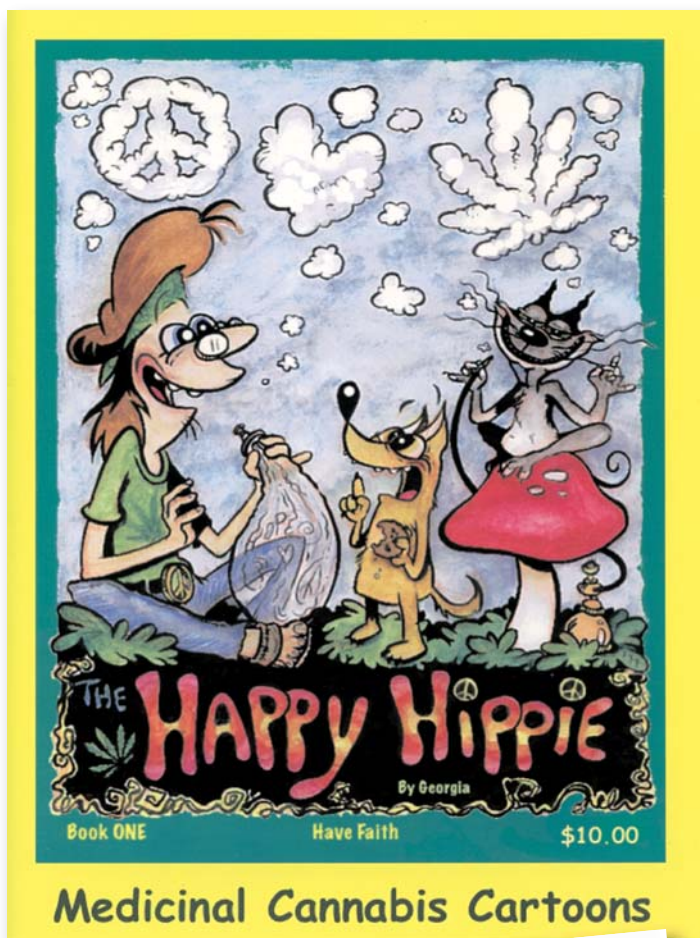
Before I knew it, The Happy Hippie was published in a medicinal magazine called Treating Yourself! Another blessing! I did not contact Treating Yourself directly. I contacted another artist who was featured in the magazine to tell him how inspired I was by his drawings. As fate would have it, he liked my cartoons too. The Happy Hippie appeared in the magazine soon after our initial e-mail. Before the strip was in the magazine, we had purchased several issues. It was soon our favorite, educating us on several levels. So when I saw my strip in it, I could not believe it! I am honored to this date.

I did not tell people right away that it is based on a true story. As I continue

to learn, my strip has become somewhat more serious. I have realized the problem surrounding cannabis and the terrible way patients are being treated. Like criminals. I have no intentions of stopping my cartooning and want cannabis legalized so that I do not have to worry about a future where my son might have difficulty getting what he needs: MEDICINE to control his pain.

I still have many days where I worry. I still see the pain and am well aware of the diagnoses and prognoses. I wish I could forget the years of pain and not worry about what the future might bring. I am a MOM. Moms worry. Some days I don't feel like drawing, but God soon gives me a little push... the next thing I know, I'm at my desk. Hopefully with a smile, I just might make someone curious enough to research for himself! I am now currently in six different publications, all of them great, and all I am proud to be a part of.

My son at 18 is an amazing young ▷



The Happy Hippie book
for more info check out:
www.georgiatoons.com

Mom and Storm, prom
night. A proud moment!



man. He is much more educated on the subject of cannabis than I am. He continues to teach me daily. He works very hard. Never sleeps in. He works out with his body and pushes himself beyond his pain. He became an honor student shortly after starting cannabis! Free to focus on education and not pain! Determined not to let his bone disease rob him of one moment of this precious life. People are always commenting on how well spoken he is and how he seems much older than he is. What he has endured has made him more mature for his years. Should you get to know him, you can't help but be impressed! He is also very funny and handsome, if I do say so myself! (HUGE pride grin.)

I truly believe Storm is here for a reason! To teach us all about cannabis. Living proof. He wants to work with plants, horticulture, botany. Whatever he does, he does it well, and his dad and I are confident he will not only contribute to this world but make it a better place in the process. When I get down, he reminds me of how much he loves me, and everything seems better. Not one day has gone by where we have neglected to say I LOVE you.

So time to speak up! I do it best with my cartoons, my son with his words. This is not a story to us, but our life. As parents, we still struggle and worry. For now, we take it one day at a time. With love, we cannot fail. Even my comic book! I never thought four years ago I'd have a comic book! It is so much more to me than that. It is my way of spreading the word! Even after several proofreaders, it has a few typos, but I figure people will see the LOVE and get past the few mistakes. God keeping me humble. Please share this story with others, Be the change you want to see. It should be about CHOICE.

The problems with cannabis have been going on for far too long, from what I have been learning.

I still do not like to talk about our son's bone disease. I tear up instantly. I hope I can change minds and hearts with my drawing. I thank all who have supported me to date and the amazing people I have met along this journey. For the record: they are not criminals; they are some of the most compassionate people I have had the pleasure of knowing. Time to work together. We all make mistakes. I do not judge anyone. I have not walked in their shoes. I am grateful that God has me on this path. I feel blessed to have been educated, finally! 🍀