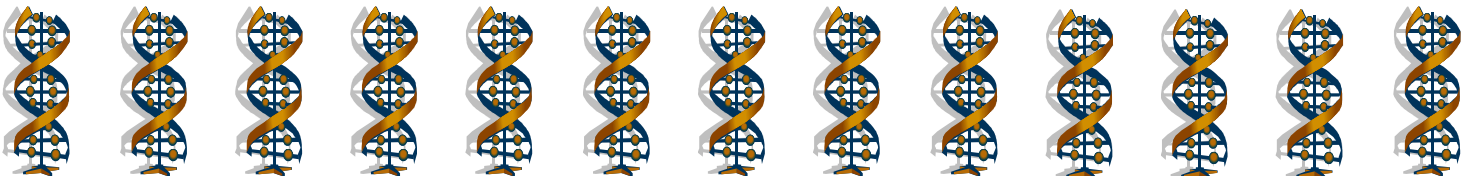


# Finding the “New Normal”



We are the Smith family, we would like to share our story of how we arrived at our new normal in our life.



My name is Chad Smith, also known as “Chad the Dad”. My wife, Becky, and I are the proud parents of two wonderful children, Aleah who is eight years old, and Blake, who is five years old. Blake has a long list of medical challenges which continue to plague his life. Throughout the past five years our family has grown and learned many different tricks in dealing with the trials that come with being Parents of a Medically Challenged Kid.

During our journey I have written two different articles. The first one is titled, “8 Things You Don’t Know About the Smith Family”. This was written when Blake was almost 3 years old. At this point in our life everything seemed overwhelming, stressful, and frustrating. Writing these issues down is the way I was able to express my frustrations of day to day challenges. The second article is my most recent article. It describes our life now and how it has transformed into what I have started to call a “New Normal.”

The purpose of this packet is to share our family’s life experiences with other people and families. Becky and I feel we have gained a wealth of knowledge throughout the years. We believe we have nearly everything Blake needs in his life to live a healthy, normal life and even thrive while battling the problems associated with his unknown neuromuscular condition. We want to share what we know with you and others like us. We want to help answer the scary questions such as: Will our life ever be normal? Can we do the same things we were doing before? We want to share our life experiences, to let people know what it is like after living these past five years with ongoing medical challenges. We want to start a support group of likeminded parents who can come together and help each other with the little tricks they have learned raising and enriching the lives of their children.

Eventually, we want to start play dates for the siblings of special needs kids. These are the super stars of the family. At such a young age Aleah and many other children like her are asked to accept responsibilities much greater than can ever be expected from their peers. They are the ones who really know what it is like living in a home with a medically challenged child.

We want to help other people to reach the “New Normal” in their life. We have adapted and learned to ask and advocate for nothing but the best for our family. We want to help you advocate and get the very best for you and your family. We have included pictures of adaptive items for Blake as well as our organizational style in setting up his room. Please call, write, email, or text us. We are here for you.

So, to explain this first article I wrote. Let me tell you a bit about our family. When Blake was about 8 months old we learned that our son has bilateral vocal cord paralysis. Since that time his condition and our family’s lives have evolved into a complicated medical challenge.

Blake was 3 years old and was living with the following: tracheostomy dependent, ventilator dependent, atelectasis, chronic respiratory failure, dysphagia, oropharyngeal phase, GERD (gastroesophageal reflux disease), hypotonia, sialorrhea, bilateral vocal cord paralysis, type 1-A minor laryngeal cleft, aerophagia, and a minor gastric ulcer. That’s 13 different issues with no answers.

Here is where the frustration comes. Now, 3 years into this, six Life Flights later, with an uncountable number of visits to the pediatric intensive care unit, pediatrician visits, specialists of every kind and other hospital visits, there seems to be no explanation to tie all of this together. What is wrong with my child? Can it be cured? How long will this affect him? Are there long-term side effects? What is the treatment plan? When do you usually see improvement? Are we doing something that could adversely affect Blake? There has been no forward movement or progress in a diagnosis or time frame.

It feels good being able to talk about what most people bottle up. After introducing this article to people I have received many different responses. Some say I am yelling at people, some say I am whining, some are grateful to have read an informative article. Please do not take offense to anything I share in this article. Instead, just take in the thoughts of a parent. Thoughts often not put onto paper.

## **8 Things You Don't Know About The Smith Family**

**1. We are tired.** Parenting is already an exhausting endeavor. But parenting a special needs child takes things to another level of fatigue. Sleep deprivation due to obnoxious ventilator alarms, water in the vent lines, and listening to our son's breathing or sleeping restlessly over the baby monitor. I am so tired; I do not want to hear it's like having a newborn, when in fact newborns do eventually let you sleep at night. Even if we had gotten a good night's sleep, or have had some time off, there is a level of emotional and physical tiredness that is always there, that simply comes from the weight of tending to those needs. Hospital and doctor visits are not just a few times a year; they may be a few times a month. Paperwork and bills stack up. Add to that the emotional toll of raising a special needs child, since the peaks and valleys seem so much more extreme for us (listen to Hannah Montana's song "The Climb"). I am always appreciative of any amount of grace or help from friends to make our life easier, no matter how small, including arranging plans around our schedule and location. With what little spare time we have, we try to allocate this time to his super star older sister. She has learned at a very young age how to be patient and understanding. God has blessed Aleah with some special attributes.

**2. We feel alone.** It's lonely parenting a special needs child. I can feel like an outsider around parents of typical kids. Others do not know what it's like to leave church meetings, sporting events, or public events to suction your child; or to have to take him home because he is not maintaining his oxygen; or his work of breathing has increased. It's been a sanity saver to connect with other special needs parents with whom it's not so uncomfortable or shocking to swap stories about trach decanulation (pulling the trach out), suction, medications, feeding tubes, communication devices, and therapies. Even within this community, though, there is such variation in how every child is affected. Only we understand Blake's unique makeup and challenges. With this honor of caring for him comes the solitude of the role. We often feel really lonely in raising him.

**3. We are jealous.** It's a hard one for me to come out and say, but it's true. When I see a 2 or 3 year old boy do what my son can't (like walk without issue or run and play), I feel a pang of jealousy. It hurts when I see my son struggling so hard to learn to do something that comes naturally to a typical kid. It can be hard to hear about the accomplishments of my friends' kids. Sometimes, I just mourn inside for Blake, "It's not fair". A life without the sound of a child's voice, Blake will cry with tears but all we hear is heavy breathing. Hearing words of any kind is a special treat. His laugh and cry have not been heard for over 3 years now. Weirdly enough, I can even feel jealous of other special needs kids who seem to have an answer as to what their issues are; diseases, disorders, or syndromes (like Downs or Autism), which are more mainstream and understood by the public and have a belonging. They seem to offer more support and resources than for Blake's rare condition. All we have is the Blake Smith Foundation which is what ever help we can find. It sounds petty, and yet it doesn't diminish all my joy and pride in my son's accomplishments.

**4. We are scared.** I worry that I'm not doing enough. What if I missed a treatment or a diagnosis and that window of optimal time to treat it has passed? That means another Life Flight. I worry about Blake's future, whether he will ever be able to be baptized, have fun with the other children on the playground, play sports, hunt, or get married, or live independently. I am scared thinking of the hurts he will experience being "different" in what's often a harsh world (not to mention that I fear for the physical safety of the person who inflicts any pain upon my son). I am scared about finances, and finding a way to provide my family with what they need. How are we ever going to afford the new equipment as he is given new aids and freedom, such as his power chair? A van to accommodate this can cost up to \$65,000.00. Who can afford this with the wages my wife and I make? Finally, I fear what will happen to Blake if anything were to happen to me. In spite of this, my fears have subsided greatly over the years because of my faith in God, and because of exposure to other kids, teenagers, and adults living with Blake's disorder or at least something similar to it.

**5. Sometimes I wish you would stop asking, "How is your son?" or "How is the little one?"...** We seem to give the answer that he is ok or he is maintaining, when we really want to let people know we struggle every day to cope. Blake is an ever changing child. Do you really want the 15-20 minute explanation? Yes, Blake is well, he is still with us. I know people usually don't mean to be rude by not really wanting to know how he is. But whenever we are asked we feel a pang of hurt, because we want to share but feel that you only want to hear "Good", "Fine" or "Ok". During the explanation people have drifted off because it was more information than they wanted to hear. I want to talk about my son but it can be hard to talk about him. My son is the most awe-inspiring thing to happen to our life. Some days I want to shout from the top of the Empire State Building how funny and cute he is, or how he accomplished something in therapy. Sometimes, when I'm having a rough day, or have been made aware of yet another health or developmental issue, I might not say much. I don't often share with others, even close friends and family, the depths of what I go through when it comes to my son Blake. One thing I always

appreciate is whenever people ask me a more specific question about my son, like, “How did Blake like the zoo?” or “How’s Blake’s sign language coming along?”, rather than a more generalized, “How’s Blake?”, which can make me feel so overwhelmed that I usually just respond, “Good.” Starting with the small and specific things gives me a chance to start sharing. And if I’m not sharing, don’t think that there isn’t a lot going on underneath, or that I don’t want to.

**6. We have to fight too much.** Countless times insurance has denied prescriptions, medical equipment, and medical charges. We have had to spend hours on the phone and on hold to explain why something was billed wrong. Our doctors are the best, they fight for us. Doctors have called in a peer to peer conference to explain why our son needs a cough assist machine, power wheelchair, and medication. Why should we have to explain why lifesaving equipment and medication is needed? The fighting only seems to slow down his recovery; this causes undue stress and is extremely frustrating. Once we have finished one fight another seems to appear. It is hard being your child’s only advocate.

**7. We are human.** We have been challenged and pushed beyond many limits in raising our son. We’ve grown tremendously as a family, and developed a soft heart and empathy for others in a way I never would have without him. But I’m just like the next parent in some ways. Sometimes I get cranky, my kids irritate me, and sometimes I just want to flee or go away and have some me time, or court my wife. Sometimes it’s nice to escape and talk about other everyday things. Thank you to our family and friends who have helped us to unplug.

**8. The Family.** Becky is the greatest reason this family can operate. How do you describe the perfect Mother? Dependable, intelligent, generous with her time, believes in doing the right thing, the list can seem to go on forever. After everything noted above she still finds the time and energy to do things beyond the best that can be expected. Aleah, Blake’s older sister, is the biggest six year old I know. She is able to be put on the back burner while we deal with Blake’s different issues, emergencies, and appointments. Who can ask for a better big sister than Aleah? Blake has somehow blessed our home with all these challenges and sleep deprivation. Strangely, I cannot imagine I would want my family any different (perhaps less with the medical visits) than the way we are.

# The New Normal

---

*The story of the Chad and Becky Smith family and how we found our New Normal*

---

I was on Facebook the other day looking at a post from a new trach parent. Reading and understanding the fears she felt, I knew what she worried about, having just gotten home with her new medically challenged child. She was scared and did not know what to do. I wanted to share some experiences in my life with her, and with others going through the same challenge. I want to share how our family arrived at what I call the New Normal. The New Normal is a point in life I hope many of us find sooner rather than later. Below are a few highlights in my family's life. It's a little story about how we came to our new life, our New Normal.

**The Scariest Day of My Life:** The scariest day of my life was in February of 2010, when I received a call at work telling me that my 6 month old son was going to be air lifted to Salt Lake City because he was having severe breathing issues. My wife Becky and I later learned our son had RSV (which is an intense cold in most children) combined with a little rhino virus. This was easily treated with some medication and deep suctioning. However, he also had distinct whistle, called a stridor. A stridor is an abnormal, high-pitched, musical breathing sound. It is caused by a blockage in the throat or voice box (larynx). It is most often heard when taking in a breath, like when he was upset and cried. We would soon learn that his stridor was a symptom of a more serious, long-term, condition than his RSV. Primary Children's Hospital medical staff advised us to schedule an appointment with an ENT to have this stridor looked at. They had us schedule for 4-6 weeks out to allow him to fully recover from the RSV before this examination.

**The Worst News Ever:** On April 5<sup>th</sup> 2010, we went in to see Dr. Park, one of the best ENT's in the nation. He pushed a camera down Blake's nose into his throat and all the way down to his vocal cords. They sure did look fascinating to me on the monitor. Dr. Park then withdrew the camera and told our family that Blake had bilateral vocalcord paralysis and would need a tracheostomy. As you can imagine, this was extremely shocking for us to hear. The only thing we could think of was to ask if there was a less invasive procedure to avoid permanently cutting a hole into our child's throat. Dr. Park said we could try a Botox injection into the vocal cord allowing separation and in turn allowing Blake to breathe. Initially, we did opt to start with an injection to see if we could avoid the tracheostomy.

**The Hospital:** On April 8<sup>th</sup> 2010, Blake was admitted to Primary Children's Hospital for surgery. Any parent who has handed their child off to doctors or nurses and had to watch their baby go off to a place you were not allowed to follow, knows the devastation and pain one goes through. We prayed and cried our way through the minutes that turned into hours that turned into what seemed an eternity before we got the call that we were allowed to reunite with our son. There he was peacefully sleeping, but not like we had ever seen him before. He had tubes and cords all over his body and going into his nose and mouth. What had they done to our baby? Blake recovered from this surgery and was smiling in his mother's arms by the end of the day.

**The Next Day:** The next day Blake started going downhill again. He was doing what we learned to call “crashing”, his oxygen was dropping lower and lower no matter how much oxygen they gave him. We were in the PICU where the best doctors, nurses, and respiratory therapists were. These were the people we had quickly learned to trust. It was determined that they would need to intubate Blake and prepare him for trach surgery since the Botox injection was beginning to have adverse effects. Becky and I were invited to leave our son’s room. I did not want to leave him again. I told the doctor I had been an EMT for some time a while ago and I wanted to stay. She advised me that parents did not normally do this but she would let me if I could remain calm. I watched as the room filled with medical professionals, and I found myself backed way back into a corner to give them all the room they needed. As they tried to intubate my son, I watched his vital signs drop and drop. They started to bag my son with the bag valve mask, the same kind we now carry with us every day called an Ambu bag. His vitals would go up and they would try and intubate again. Again his vitals dropped and I watched his oxygen drop to 0. At that point Dr. Kathleen Ventre, whom we still to this day hold on the highest pedestal possible, called for another doctor to come and back her up; this scared me. Dr. Ventre was the best and brightest doctor who had ever taken care of him so far and to hear her ask for help really scared me more than I can express. Again they started to bag him with the mask and again his vitals and pulse came back up. They tried to intubate again, again they were unsuccessful. It wasn’t until a different ENT tried and finally got the breathing tube properly placed that Blake was able to stabilize.

**Chris Hartling:** Then, as our son slept calmly on a vent and in a medically induced coma, we met the most incredible respiratory therapist we will ever meet. Her name is Chris Hartling. She walked into the room holding a PVC pipe with a trach hanging out of it with its ties securely holding it to the pipe. She was there to teach us what a tracheostomy was, show us what they looked like, and how they worked. Chris was ready to spend all day and night with us until we had no more possible questions for her. She spent as much time as we needed teaching and talking with us knowing our life was taking a drastic turn, and as we made the decision to trach our little boy.

**Training:** As we prepared for our son to receive his trach, the staff at Primary Children’s Hospital put us through some serious training. We learned everything from suctioning, to trach changes, to monitoring oxygen. The day came when we let our son go again to surgery. This time he was pulled off the vent and a kind old man who was going to be Blake’s anesthesiologist pushed our son away in his hospital bed while he was calmly bagging him at the same time. Again, we as parents felt our child had been ripped away. Waiting on pins and needles started again.

**He is Back and Training Continues:** Our son has returned safely to us with a small Shiley trach in his chubby little neck. The training continued and we started practicing on Blake. We were now responsible for suctioning and trach care. We also learned how to place an NG-tube (a feeding tube which goes down a child’s nose) since he was now unable to pass a swallow study.

Chris wanted us to know everything and be able to perform everything at 110%. We lived in Ely, Nevada, a little over 250 miles from a hospital capable of dealing with our son's conditions. Eventually, we completed our training and we were almost ready to go home.

**DME:** DME is an acronym for Durable Medical Equipment. DME providers are the suppliers for all the medical supplies needed at home. Due to the distance from a major city we had been denied by every DME company the hospital could find. A small oxygen company, Aero Care, heard about our family who could not come home because we had no one to be our supplier. Aero Care got their certification for respiratory supplies and provided us with the equipment necessary to bring our son Blake home. Thank you Aero Care!

**Home:** We finally got to go home after a few weeks away from home. All the doctors, nurses, respiratory therapists, and the other medical staff did their best to teach us as we were learning about our new life. This was a scary reality. But, we did it, with a lot of sacrifices and sleepless nights. But then, Blake's breathing began to get worse and was becoming faster and faster. We knew something was wrong. We called Primary Children's Hospital and they wanted us to take him to our local hospital again. And, another emergency trip to Salt Lake City. He was immediately admitted to Primary Children's Hospital and placed on a ventilator.

**The Vent:** It was decided that Blake needed a vent to assist with his breathing. However, no one really knew why. More training; this time Fred and Maurine Fisher, Blake's grandparents, were there to help and learn about the vent, how to adjust the settings, and how to operate it. Again, we were trained at 110% before we were released to our home. And again, we waited for approval for a ventilator to take home. But after a couple of months this time, we were able to return home.

**All Alone:** It was scary knowing there were only 4 people (Mom, Dad, Grandma, and Grandpa) in town trained well enough to care for our child. Home health nursing was not available in Ely, Nevada, for pediatrics. Blake's vent was just too complicated for our local hospital to handle. If we had a problem they would just call for a life flight and send us to Salt Lake City. This went on for two years until we met Dan with Maximum Health Care in Las Vegas, Nevada. Dan, along with Maximum, fought for us. They went out of their way to fight and get a license to be a home health provider for my son in Ely. They were able to get the license but had a very hard time finding nurses to care for our child for the hours we needed.

**As We Grew:** Time went on and trips to the doctor were more frequent, simple sickness turned into a life flight to the hospital, pneumonia and more time at Primary Children's Hospital. We went through more surgeries and had a feeding tube placed into Blake's little belly. Every 6 months we attended a trach/vent clinic. We even traveled to Cincinnati in an attempt to try and learn why our son was going through these issues. As time went on we noticed Blake not meeting his physical milestones and that anything muscle related was a struggle for him. To this day, we still have no idea what is the cause of Blake's issues. We simply care for all of his



symptoms and conditions: tracheostomy dependent, ventilator dependent, atelectasis, chronic respiratory failure, dysphagia, oropharyngeal phase, GERD (gastroesophageal reflux disease), hypotonia, sialorrhea, bilateral vocal cord paralysis, type 1-A minor laryngeal cleft, aerophagia, and a minor gastric ulcer. That's 13 different issues with no answers. No explanation for why God was putting our family through these trials. But we are grateful for Blake's life and the lessons that he teaches others.

**Recovery Time:** Dictionaries say 'Recovery' Time is a noun defined as "the time required for a material or piece of equipment to resume its former or usual condition following an action." Sports people use a formula to describe ideal athletic recovery as Hard Work + Good Recovery = Best Performance. Athletes need time to adapt to training. Parents need this same time to adapt to their new lifestyle of living with a special needs child. Recovery is maximized when fatigue is reduced as parents learn to cope more effectively. Although there is no real training program a parent can use to train for the daunting task of being a super hero with the super power of keeping up with the daily stresses of living with these new changes, time can be our friend. With each additional doctor appointment we as parents learn more about our children and how they respond to different situations. Often we are told that we are the professionals and know the most about our child. With this intense training of living with multiple doctor and hospital visits comes a wealth of knowledge. This knowledge can be used to adapt to your new life. Hard Work + Good Recovery = Best Performance? In our life Knowledge + Experience = Good Recovery and Best Performance.

As you can imagine, a non-sports guy like myself has a hard time recovering from any type of exercise. A bit over a year ago I weighed just less than 350 lbs. I tried to be active by walking and attempted running. At that time I could only run from street light to street light, a distance about 25 yards. I was winded, worn out, tired, and needed to walk for about a half mile before attempting it again. Over the past year my recovery time between these runs improved. My distance got longer and I was able to do more and more. Now, over a year later I weigh 225 and will be running my first ½ marathon in two weeks.

The point is, when life has been turned upside down and as you grow with your child and get used to things such as suctioning, changing a trach, adapting to your new life, your recovery time will also improve. Soon a visit to the doctor will become routine. Hooking your child up to all that equipment just to take a nap or sleep will become your new normal.

**Listening to Others:** So, my wife can tell you that listening to other people can help you, but it can also scare you to death. Becky met a mother of a trach vent kiddo while we were in the hospital. She told my wife that her life was over. She said you will never have any time for yourself, no sex, no more dating, that is even if you stay married, nothing, your life is consumed by taking care of your child. We have since learned that this is simply not true. Life is going to be what you make of it. We have chosen to fight for nothing but the best for our family. Now when I say fight I am a full believer that you do catch more flies with honey than with vinegar. I

work at a prison for a living as a caseworker and I have to yell at and deal with bad guys 8 hours a day, 5 days a week. But when advocating for my child and my family I have never raised my voice, been rude or been disrespectful even once. Our house is loaded with medical supplies, the best medical supplies we can get, all because we choose to do our best and live life to the fullest.

Chris Hartling told us to not change our life, continue with what you're doing now, all you have to do is adapt to live with the new accessories you now have in your life: a trach, suction machine and whatever else is required for keeping your child happy.

**The New Normal:** Our church does a fathers and sons outing once a year. It's an overnight camp. I have looked forward to taking my son on this camp out for years. Even before he was born I so wanted to enjoy this camp out with him. I knew one day my son and I would go scouting, hunting, fishing, and camping. But when our life was turned upside down, I thought that would never become a reality.

Well, now that our life has reached its "New Normal", this year we found a friend with a portable generator to run Blake's vent, humidification, and pulse ox. We loaded up Blake's feeding supplies and medical supplies, and went on our first camp out. I was the proudest daddy up there and he had a permanent smile burned on his face watching that campfire all night. Ya know what? Both of us made it. In fact, nothing happened, nothing changed, he had a good night sleep and so did I.

With everything we have experienced, with all the close calls and scary sleepless nights, our family has evolved into a New Normal. This is a point where we are starting to feel like our life is normal. In the beginning we had no nursing support, no real help. Now after we relocated our family to a larger city, Las Vegas, we are closer to medical help and medical amenities, life has begun to work out for our family.

It has been 5 years since we were first trusted to care for our son. As the doctor appointments seem to spread out further and the knowledge of medical equipment gets stronger, we seem to fall into a new normal life. Putting our two children to bed is a very different experience. Blake's older sister requires a book or a bed time story prior to going to bed. Blake requires meds, breathing treatments, trach and g-tube stoma care, ventilation, oxygen, pulse ox, cameras to watch, but as time goes on it has developed into just a new normal. Please remember God has a plan for everyone. We may never know His plan or what part we or our children may play in it. Like a ripple in the water we affect those closest to us as the waves are strongest there, but how far away will the waves travel? How much will the life we currently live affect others? No one knows.

The idea of Blake starting kindergarten this year excites me. Our son is a mostly healthy 5 year old boy going to normal mainstream school (with a normal nurse), with normal regular kids as friends, and we just learned about a girlfriend he may have. I asked him if he was checking out the girls in his class and he told me, just one. He is currently undiagnosed. Bilateral vocal

paralysis was the beginning of our journey and we love meeting people with similar symptoms. We have been there, done that, and prayed for our child's life just like you have.

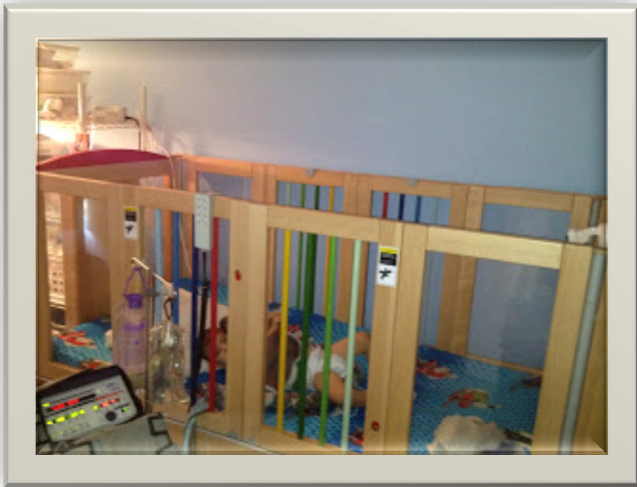
We have recently returned from a Global Gene Rare Disease Advocacy Summit in California. There my wife and I realized we are doing all that we can do as parents of an undiagnosed child. We feel our life is pretty normal considering all that we go through every day. How can we help you reach the NEW NORMAL in your life?

Chad and Becky Smith  
3621 Cedartown St.  
Las Vegas, NV 89129  
[smith5708@yahoo.com](mailto:smith5708@yahoo.com)  
C 775-293-3728 (Chad)  
C 775-293-0144 (Becky)



*"Promise me you'll always remember: You're braver than you believe, and stronger than you seem, and smarter than you think."*

— A.A. Milne



### **Kayser Betten IDA Bed:**

**This is a versatile bed, ideal for the patient who is non-ambulatory and needs a secure safe bed to sleep in and receive care. The safety rail height stays consistent when the bed is raised and lowered. IDA is the caregiver's friend with height adjustment, easy access.**



### **Cough Assist:**

**The Cough Assist noninvasively helps patients' clear bronchial secretions when they can't cough for themselves**

### **Hill-Rom The Vest®:**

**The vest is a medical device that assists children and adults with mobilizing secretions that may contribute to, or complicate, their respiratory conditions. If not removed, retained secretions may lead to increased rates of respiratory infections, hospitalizations, and reduced lung function.**



### **Permobil K450:**

The all-wheel suspension system of the K450 MX provides a smooth ride, whether cruising the halls at school or heading out to the playground. The power seat-to-floor function lets children get down on the ground, perfect for story time, transfers and playing with others. The seat-to-floor height ranges from 3" to 26," making it easy to sit at a table or counter and even to reach things down low.



### **AmTryke:**

This is a therapeutic tricycles featuring the combination of hand/foot motion are available in a variety of sizes: AM-9, AM-12, AM-16. Many accessories allow these trykes to adapt to a wide variety of sizes and abilities.

### **EZCare™ (Neoprene)**

Tracheostomy tube holder made of Neoprene® technology and offer multiple color choices. Moisture resistant material allows patient to be bathed without removing holder. Colorful straps help resist staining. Stretchable material allows for cough reflex. Reduces chance for accidental dislodgement. Soft neoprene material won't irritate the skin.



### **Convaid Cruiser Wheelchair:**

A solid, durable and convenient compact-folding make it the best choice for active children and young adults. An array of positioning options help you achieve optimal positioning, and most options need not be removed when folding the lightweight wheelchair.





## Vent Circuit Covers:

**Rain out, is a problem we all deal with when it comes to vents. We have created insulated sleeves to cover the vent hoses. Not to mention the good looking colors and patterns.**

Working with our DME provider we have created our own order sheet. One that fits all of Blake's needs and has all the supplies he needs to survive and thrive.

| Requested<br>(Auto Populate Date)<br>E-Signature  |                    | Blake Smith<br>3621 Cedartown Street<br>Las, Vegas, NV 89129<br>702-778-6624 |        | Received<br>(Auto Populate Date)<br>E-Signature |  |
|---|--------------------|--|--------|---|--|
| <b>Order: November</b>  |                    |  |        |   |  |
| ITEM  | Preferred Item #   | QUANTITY ORDERED   | #      | QUANTITY RECEIVED                               |  |
| Q-TIPS - (PREFERRED STERILE)  | 60202000           | 0  | Each   | 0   |  |
| OXYGEN TUBING REF 2050 (50 FOOT)  | SA 2050            | 0  | Each   | 0   |  |
| OXYGEN TUBING REF 0013005 (25 FOOT)   | 55001305           | 0  | Each   | 0   |  |
| HUMID VENT (PORTABLE HME)   |                    | 0  | Each   | 0   |  |
| THERMOVENT (HME - STYLE 1)  | SF570016           | 30   | Each   | 30  |  |
| HYGROSCOPIC CONDENSER HUMIDIFIER (HME - STYLE 2)  |                    | 0  | Each   | 0   |  |
| NEONATAL/ADULT SPO2 ADHESIVE SENSOR   | JD2329EA           | 4  | Each   | 4   |  |
| REPLACEMENT TAPES (PULSE OX REPLACEMENT TAPES)  | JD2308             | 0  | Roll   | 0   |  |
| NON CONDUCTIVE CONNECTING TUBING (10 FEET SUCTION)  |                    | 0  | Each   | 0   |  |
| OXY-VENT WITH TUBE (OXYGEN TUBING TO CONNECT HME)   |                    | 0  | Each   | 0   |  |
| SMALL VOLUME NEBULIZER UNIT   | 60HCS4483H         | 2  | Each   | 2   |  |
| STRAIGHT SET (ACCORDAINS)   | SMA 662504         | 0  | Each   | 0   |  |
| DRAIN SPONGES TRACH 2 X 2 INCHES  | 60256001/ZG2206SPK | 2  | Box/es | 2   |  |
| AIRLIFE (FILTER FOR COUGH ASSIST AND VENT)  |                    | 2  | Each   | 2   |  |
| SUCTION INLET FILTER (DISC)   | TATBF250S05        | 0  | Each   | 0   |  |
| SUCTION CONNECTION TUBE 3/16" X 10"   | TATRP30210         | 2  | Each   | 2   |  |
| SUCTION CANISTERS 800MLS  | IA61012            | 2  | Each   | 2   |  |
| SUCTION CANISTERS 800MLS - KIT  | 7305D-632          | 0  | Each   | 0   |  |
| SALINE BULLETS 0.9% NS 3ML (100 PER BOX)  | 555257             | 2  | Box/es | 2   |  |
| WATER BOWLS HUMIDIFIER UNIT ON THE VENT   | FPMR290VEA         | 4  | Each   | 4   |  |
| STERILE WATER FOR INHALATION 1000MLS INFUSION BAG   | 552D0735X          | 30   | Each   | 30  |  |
| LARGE TEE ADAPTER WITH VALVE (FOR VENT NEBULIZER)   |                    | 0  | Each   | 0   |  |
| UNIVERSAL CUFF ADAPTOR (FOR VENT) 15mm  | 921422             | 4  | Each   | 4   |  |
| BBG NASAL ASPIRATOR   | RE93032S           | 0  | Each   | 0   |  |
| MINIATURE FLEXTUB 2" (22MM X 15MM) VENT CONNECTION  | RE1006043          | 2  | Each   | 2   |  |
| DISPOSABLE ADULT PASSIVE CIRCUIT NO WATER TRAP  | RES 1073236        | 4  | Each   | 4   |  |
| EZCARE NEOPRENE TRACH TIES  | NGN910BL           | 2  | Each   | 2   |  |
| <b>Notes:</b>   |                    |  |        |   |  |
|   |                    |  |        |   |  |
|   |                    |  |        |   |  |
|   |                    |  |        |   |  |
|   |                    |  |        |   |  |
|   |                    |  |        |   |  |
| <b>Email Distribution List</b><br>Chad (Dad): smith5708@yahoo.com<br>Becky (Mom): b1fisher@sbcglobal.net<br>Pam (DME): @preferredhomecare.com<br>Scott (Nurse): @gmail.com<br>Carmelyn (Nurse): @yahoo.com<br>Elwanda (Nurse): @yahoo.com |                    |  |        |   |  |



### **Oxygen:**

**O2 concentrators are loud and hot. We like to keep Blake's O2 in another room or an adjacent closet.**

**We run the tubing along the wall and door frame to avoid tripping hazards. In another setting, we drilled a hole in the closet and kept the concentrator in the next room.**

**Every phone number you get, keep it. Write down little secrets you learn when talking with providers like “Press #2 then 00 then #” to skip past all the insurance voice prompts. This gets me straight to a live person with my insurance company.**

|                                |                         |      |
|--------------------------------|-------------------------|------|
| BriovaRx                       |                         | 866- |
| Brivoa                         | RX                      | 855- |
| Catalyst RX                    |                         | 800- |
| Catalyst RX                    | Christy Kamata          | 702- |
| CCSD Nurse                     | Jennifer                | 405- |
| CCSD Nurse Director            | Linda                   | 702- |
| CCSD Nurse Trans               | Cindy Koziol            | 702- |
| CCSD SPED Director             | Katrina                 | 702- |
| CCSD Supervisor                | Debra Potter (cell)     | 702- |
| CCSD Supervisor                | Debra Potter (5351)     | 702- |
| CCSD Trans                     |                         | 702- |
| Children's Clinic              | Blair Duddy             | 702- |
| Childrens Lung Specialist      | Craig Nakamura          | 702- |
| Eileen Connors Elementary      |                         | 702- |
| ENT Clinic                     | Albert Park             | 801- |
| Gastroenterology               | Howard Barron           | 702- |
| Health Scope                   | Press #2 then 00 then # | 888- |
| Healthtown Health              | Pam                     | 775- |
| Logisticare                    |                         | 888- |
| Maxium Health Care             |                         | 702- |
| National Seating & Mobi        | Jeff Murphy             | 702- |
| National Seating & Mobi        | Lisa                    | 702- |
| NV Medicaid                    | Melinda Summer          | 702- |
| NV Medicaid hours              | Aderian Naverro         | 775- |
| Orthopedic                     | Dr. Stewart             | 702- |
| Preferred Homecare             | Nichole                 | 702- |
| Preferred Homecare             |                         | 702- |
| Primary Children's             | Chris Hartling          | 801- |
| School ID                      | Blake                   |      |
| Spring View Home Health        |                         | 702- |
| Spring View Nurse              | Carmalyn                | 702- |
| Spring View Nurse              | Scott                   | 801- |
| Total Wellness Family Medicine | Dr. Kimberly Adams      | 702- |
| University Dept of Nuro        | Tara/Sam                | 801- |
| University Dept of Peds.       | Caroline Hagedorn       | 801- |
| W S & S Medical                |                         | 702- |



## **Labeling and**

### **Storage Bins:**

**We have found it can be very helpful to label and number bins. This helps to find items for use and also helps when reordering.**



### **Cameras:**

**There are a lot of different cameras available on the market. These have been a life saver for us to enjoy a date, or even sleep in the next room and still be able to see our son.**



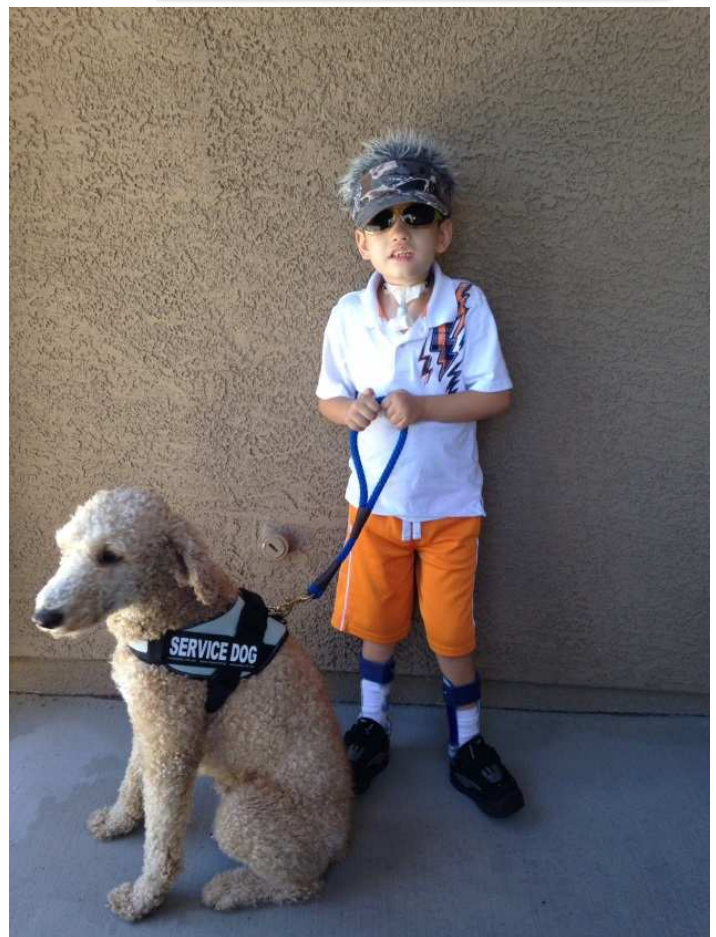


**MOUTH WASH:**

**IF YOU PUT  
MOUTHWASH  
INTO YOUR  
SUCTION  
CANISTER IT  
WILL KILL THE  
BACTERIA IN THE  
BOWL WHICH  
CAUSES THAT  
AWFUL SMELL.**

**SERVICE DOG:**

**MILO, BLAKE'S  
SERVICE DOG CAN  
BE A BIG HELP. HE  
WAS TRAINED  
MOSTLY BY  
ALEAH, BLAKE'S  
BIG SISTER.**



### **Vent Stands:**

**Most Vents come with stands. These help keep everything in one easy spot to manage. If you use water bags a simple door hanger attached to the bed is a great place. We like to keep the humidification low allowing excess rain out in the vent tubing to drain back to the water chamber.**



It's a kids room, keep it looking like one.

