

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

On September 7, 2010, God blessed us with a beautiful baby boy named Simon. His name means, "To be heard." Even with a bilateral cleft lip, he was absolutely perfect to our family.



SIMON with parents

Did you know that having one extra chromosome could lead to denial of treatment and care withheld? On Simon's third day of life, he was diagnosed with trisomy 18. Many doctors declare that trisomy 18 is "incompatible with life," despite evidence of the contrary in those who survive for months, years and even decades.

On December 3, Simon's oxygen saturation levels began to fall. We were told this is the end, nothing could be done. Simon drew his last breaths, **I asked again what could be done and I was told "nothing."** At 10:45am December 3, 2010, Simon died.

Imagine watching your child take their last breaths, his oxygen saturation levels plummet and the medical professionals do nothing. **Later, we found out there was a Do Not Resuscitate (DNR) in his medical file** which explains why the medical professionals stood around and did nothing.

On top of that we found out Simon was only getting comfort feeds-the least amount of food, not intended for nourishment. It means they starve you to death. If Simon hadn't stopped breathing, he might have starved to death.

It was a battle we fought to defend our son's life and dignity. Not only were Simon's human rights violated, as he was a victim of genetic discrimination, but also our parental rights were taken away. When our son, Simon was a living, breathing human being, who brought incredible joy to his family; and he experienced love and joy from us...did he NOT deserve the right to live?

Someone else decided our son's life didn't have value. Care was withheld and a DNR order was placed in our son's chart, without our knowledge or consent as Simon's parents. Ultimately, our wishes were ignored and Simon's death was expedited.

I can't bring my son back. But, I want to make sure this doesn't happen to another child, your child and my other children. In my opinion, no one loves their child more than their parent. Do not let this happen to your child.

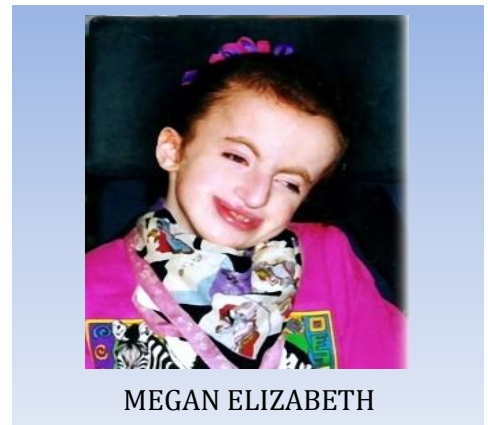
More details here: <https://globalgenes.org/raredaily/our-labeled-childs-name-is-simon-fighting-for-treatment/>

Full story in [I'm Not a Syndrome-My Name is Simon](#)

Sheryl Crosier
1155 Hawken Place
St. Louis, MO 63119
314-443-3770
smcrosier@sbcglobal.net



Proponent, SIMON'S LAW
SB 437
Kansas Legislature



Our youngest and sweetest child, Megan, was born with a **chromosomal disorder** that causes mental delays and physical disability. We adapted our lives to meet her needs, loved her unconditionally and she lived into her teens.

On her last Christmas day she was hospitalized for dehydration caused by a virus and when she died 4 days later we were devastated. She was in a pediatric intensive care unit at a major teaching hospital but it was not until we requested and read her records from that final hospitalization that we finally understood why she died.

We learned that our wishes for life support intervention had been **over-ruled by a verbal order from the Attending physician** to his staff. We know this because we found the words "DNR per ATTENDING" written by the resident in her chart. But no one told us that our daughter had been made a DNR. She was made a Do Not Resuscitate (**DNR**) **without our knowledge or consent**. Had there been a requirement for a parent signature on a life support order in that hospital, this would not have happened.

It added so much **more pain to our grief to learn that our daughter died because we trusted the wrong physician**. Instead of providing needed intervention, he misled us about what was happening, allowed her condition to decline and then said there was nothing that could be done.

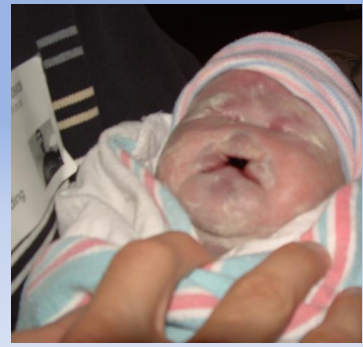
Our daughter was a teacher who gently guided hearts. Her final lesson is about the vulnerability of parents and their children when the child is hospitalized.

Parent-physician trust requires **transparency and respect**. A physician (or hospital, medical society or hospital association) opposed to the signature requirement on a life support order as proposed in Simon's Law, has something to hide and in some cases wants to control the outcome due to personal views about a particular disability or illness. How **much easier the loss of our beloved daughter would be on our hearts, if we knew she had been given every chance to get well**.

ANN & FRANK BARNES
113 Autumn Lane
Chapel Hill, NC 27516
919-933-9981
fbarnes@nc.rr.com

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

My name is Adele Lam **and I am an emergency room doctor in Camden, New Jersey.** Simon's story pulled up many sweet yet sorrowful memories of my own and I was compelled to share.



MADELINE

We had a daughter named Madeline. She was diagnosed at her 20 week ultrasound as having **Trisomy 13**. She was also our third child and my husband and I as you have, refused an abortion.

The day we were told her diagnosis by the radiologist, he started the conversation with, "horrible things happen to good people". I barely remember what else he said because all I thought was **how could he call my baby "horrible"** or how did he know if I was "good" or not. Sounds silly but once I got past that in my head I finally heard what he was telling me. I **felt like he was scaring me into an abortion.** Pushing me to do "what needs to be done". He told me I only had two weeks to decide by Pennsylvania law so I needed to hurry.

There were no other options given to me. There was no longer a life within me. There was nothing but death that was discussed.

I left that day feeling very alone. I felt betrayed and misunderstood by my profession. I wondered how we were trained to heal yet here I was with a sick baby and I was being treated like some weird renegade, someone going against the scientific norm. My head was swimming.

Thankfully God never left my side. For the next 12 weeks I didn't see a doctor (although I was supposed to). I did my best to continue my life as a mom and a doctor and a wife and I carried her sweet little life within me waiting for the "inevitable still born" that I was told would happen.

Well I could go on forever but Madeline was not a still born. In fact she lived for a full 3 1/2 hours on Nov. 10, 2008. Those three hours for us brought us **great joy in hearing her cry and great despair** when I had to continuously stimulate her myself to keep her breathing.

I finally asked for a NICU attending to come and evaluate her and help her but she walked into the room and without ever looking at my baby touched my face and told me to "stop being a doctor and start being a mother." She told me i was making my baby suffer by stimulating her to keep her breathing and that I should naturally let her stop on her own. She offered I take her to the NICU and give her morphine to make her "comfortable".

I was irate. I informed her that she and the rest of the **medical world has been trying to kill my baby since before she was born and now she is trying to once again kill her.**

After she left (was kicked out), my husband and I held our baby in our arms and I no longer stimulated her. She stopped breathing on her own and her heart slowly stopped beating.

I know The Lord was holding our hand but I can't help but think sometimes, did we fight hard enough? I feel terrible for the moms who have no medical background and truly feel like they are **at the mercy of what their doctors say**. Imagine if we and others like us were actually supported through what is already a tremendously difficult journey.

ADELE LAM

112 Forest Rd.

Moorestown N.J., 08057

215-913-4945

adeletayoun@yahoo.com

Proponent, SIMON'S LAW SB 437 Kansas Legislature

I am writing in support of Senate Bill No. 437 (Simon's Law). I am a pediatrician from Denver, Colorado, and did my pediatric residency at St. Louis Children's Hospital. I strongly support the 2 sections mentioned in the paragraphs to follow.



DR. SCOTT SHOWALTER

Related to Section 1. (b) of Bill 437 , patients and guardians should have the right to know written policies of a hospital or medical provider concerning life-sustaining or nonbeneficial treatment. Often a patient who is critically sick can be facing life-threatening or disabling events that require complicated medical decisions whether to intervene or withhold treatments. By the same token a parent of a sick child often faces the same situation. Hospitals and medical providers, in such critical situations, should have an obligation, if requested, to inform patients and parents of any written policies that might relate to how they approach life-sustaining treatments and how they determine a treatment might be beneficial or not. If a treatment is considered futile, a patient or parent should have the right to know how this was determined and by what process.

Just as hospitals and medical providers of health care are now required to inform patients of advance directive procedures, I feel being transparent about the information outlined above is just as critical. It would also require very little administrative burden as the policies would only need to be provided if requested.

Section 1. (d) deals with do-not-resuscitate orders and I fully support the provisions of this section. In my practice and experience I know of several instances where parents or guardians were not informed of do-not-resuscitate orders and only found out after a death that those orders were in place. This should never happen and Simon's law would prevent this, whether it occurs because of miscommunication or intent. I also feel that in a life-threatening and changing clinical situation a parent should always have the right to expect resuscitation of their child. This does not mean that such a decision is final. When the clinical situation becomes more clear a parent or guardian could still decide to institute a do-not-resuscitate order or agree to a withhold treatment order.

I believe the arguments presented above support an environment that allows medical decisions to be made in an ethical and transparent way. Parents and patients deserve to operate in a system where their values and concerns are heard, and whenever possible, where decisions are made with a philosophy of shared decision making.

Scott Showalter, MD

CURRICULUM VITAE

Name: David Scott Showalter, M.D.

Date and Place of Birth: December 14, 1945, Lancaster, S.C.

Marital Status: Married (Vivian Parcels Showalter)

Home Address and Phone: 8155 E. Fairmount Dr. Apt. 626

Denver, Co. 80230

Ph. 720-324-8213 Cell: 720-581-4324

Degrees: 1. Emory University, Atlanta, Ga. Bachelor of Arts, Biology, 1968

2, Emory University School of Medicine, M.D., 1973

3. University of California School of Public Health, M.P.H., 1975-76

Internship and Residency:

Internship, St. Louis Children's Hospital, Straight Pediatrics 1973-74

Pediatric Resident (PL-2), St. Louis Children's Hospital 1974-75

Pediatric Resident (PL-3) and Pediatric Ambulatory Fellow, Univ. of Colorado Medical Center, 1976-77

Certification: American Board of Pediatrics, 1980

Licensure: Colorado

Organizations: American Academy of Pediatrics, Fellow

S.O.F.T. (Support Organization for Families with Trisomy 13,18 and Related Disorders)

Professional History: General pediatrician for Colorado Permanente Medical Group, majority of time at the Kaiser Permanente East Medical Facility, Denver, Co., 1978-2014
Retired 2014

Past Responsibilities: Chief of Pediatrics for 7 years at the Kaiser Permanente East Medical Facility, Denver, Co.

Other Medical Interests: Professional Advisory Committee for S.O.F.T. (Support Organization for Trisomy 13, 18, and Related Disorders)

Served on local community board that provided services for the disabled (for 6 years)

Medical ethics

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

Lane Hauber is 7 years old living with Full Trisomy 18.

We didn't get his diagnosis until he was 3 days old.

Prior to receiving the diagnosis, a Cardiologist had discussed performing heart surgery to repair his VSD and an ASD.



LANE

When we visited Lane in the NICU **on his diagnosis day, we found a DNR** attached to his crib. When we asked why it was there, we were told by the doctor that his diagnosis is considered 'incompatible with life'. We told the doctor and medical staff that no matter what his diagnosis is, they had no right to put a DNR on our child. The hospital staff told us that they can make that decision without the parents' approval.

Lane was discharged from the hospital at 9 days old into hospice care with zero resources on how to care for him at home. However, Lane continued to grow stronger and thrive. He was let go from hospice at 10 months old because insurance said he was in too good of health to remain on it.

We searched hospitals all over the U.S. looking for a surgeon to repair his heart. By a year old, however, he had already developed pulmonary hypertension, which made it unsafe to do surgery. Lane is currently in his 7th year of not only surviving this 'incompatible with life' diagnosis, but he's also living with an un-repaired heart!!

As Lane's parents, we feel like our human rights and our son's were taken away from us based on **a diagnosis that shouldn't even be labeled 'incompatible with life'**. How old does our son have to be before he receives the same rights as anyone else in the world? Why did someone else make the decision on his health?

We now wonder how long he would have lived had he been given the heart surgery!
Please give other parents the choice! **Please make a hospital disclose to parents whether they will treat their child.** Give the parents back their voice and their rights to be able to go through any journey with their children so that they can live with no regret.

Alex and Alisha Hauber
5621 Blanca Court;
Fort Worth, TX 76179
(817) 694-5223
leesleashaboo@juno.com

Proponent, SIMON'S LAW SB 437 Kansas Legislature

I am a Missouri resident of district 157 who fully supports "Simon's Law," and I would greatly appreciate it if you would take a moment to read and share my story.



JAJSA

Having no concerns during pregnancy, I delivered Jaisa Precious Green on November 22, 2013. She was full term, however, weighed only 3lbs 4oz. Concerned there may be something wrong, she was transferred to a larger Missouri hospital with a NICU. This hospital began immediate action for care and sought the necessary treatments. Soon, finding she had holes in her heart, the **cardiologist stressed the importance of her heart surgery** and discussed the great success rate.

However, 11 days after birth **the diagnosis of Trisomy 18 was discovered and Everything changed:**

- My husband, mother, & I were told there was Nothing that could be done for Jaisa.
- In a consultation they told us they do not treat Trisomy 18 babies.
- They said to take her home and let nature take its course.
- After we had been given statistics on trisomy children I questioned this particular doctor if they had ever seen my daughter. This doctor had not; only reviewed her chart with the diagnosis, and even went as far to say **if it were their daughter they wouldn't bother** giving her the heart medication.
- When Jaisa's oxygen would decrease they lowered her parameters on the monitor so it wouldn't alarm as often.
- When she had breathing issues they stopped her feedings stating her stomach wouldn't process it anyway.
- **We had to strongly request we be sent home with ALL the appropriate equipment and monitors** to take care of her and monitor her condition at home.
- They discharged her at 3lbs 12oz. We were told **had she not had this diagnosis, they would have kept her** until she reached a healthier weight..

As time passed, I began to research her diagnosis and gained knowledge from people who had been in similar situations. It was then that I discovered a hospital that treats children with genetic disorders. The doctors at this hospital wasted no time on my daughter's diagnosis but instead chose to treat her symptoms.

I am proud to say Jaisa is currently 2 years old and is healthy and thriving, despite what the "literature" may say.

KELLY GREEN

214 W Clay St

Mt Vernon, MO 65712

(202) 321-6713

kelly.green.ghlr@gmail.com

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

When my daughter, Angela was diagnosed with anencephaly, doctors told us that no sophisticated interventions were needed for **anencephalic babies**.



ANGELA with mom

Unfortunately, I believed them and brought my baby home two days after birth on hospice care. The only care medical professionals provided was covering her head with dressing. However, that was because of my persistent request.

According to the doctors and medical staff, Angela was going to die and only comfort measures were necessary. In my opinion, none of us has a guarantee for another day, only God knows. At two months old, Angela was still alive, so surgery was successfully performed to close her skull.

A few months ago, I **requested her medical records and I couldn't believe what I found! I was shocked!**

There was a DNR Do Not Resuscitate and NO tube feedings in my daughter's chart.

To the best of my knowledge, I never signed for a DNR or withholding of tube feedings. I made myself clear on several occasions that I wanted to do everything for my child. My daughter deserved to live and I wanted to give her every opportunity to thrive.

Today, I'm proud to say that Angela is twenty two months old. Obviously, she **is defying the odds. My daughter is not incompatible with life!** She is a living human being who deserves to be treated with dignity and respect.

Sadly, it's a daily battle with some doctors. Their argument is that my daughter, Angela never will be a typical child, so palliative care is the only option given to me. I disagree, Angela deserves the right to live like any other child.

In addition, **recently Angela was overdosed with dilantin.** Her medical record stated, "accidental overdose." Imagine catching two nurses administering high doses of medication to your baby! I was livid!

I will keep fighting and be strong for my precious daughter. I will continue to advocate for all children with anencephaly and other similar conditions.

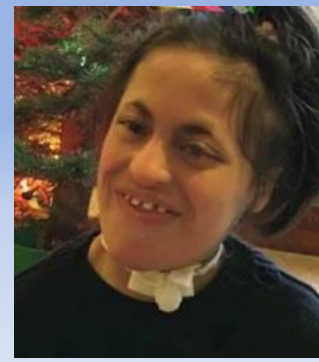
I am in support of Simon's Law because I have personally **experienced a violation of my parental decision making rights**. In addition, my daughter, Angela has been discriminated against because of her medical condition.

SONYA MORALES ALDANA

Sonia-aldana@sdcenterri.org
22 Ruggles St
Providence RI 02908
401-286-6874
Sonia-aldana@sdcenterri.org

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

Our daughter Kristina was diagnosed prenatally with Trisomy 18. At the time they confirmed the diagnosis via amniocentesis they let us know that although we were at 22 weeks it would still be acceptable to "interrupt" the pregnancy, i.e. terminate, because the fetus was still smaller than a typical "20 week fetus" but we would need to decide quickly. We declined.



KRISTINA

Later in our pregnancy we began preparing for our daughter's birth. In our discussion with the doctors we were very clear that we would do whatever it took to get our daughter into this world alive. We didn't know how much time we would get but it was important to us to give her life if at all possible. The doctor refused to consider c-section as she said it was a non-viable pregnancy and even **refused to monitor my daughter during labor because, and I quote, "I don't want you to know if she dies or not."**

This doctor was fired.

A new doctor agreed to the c-section if necessary. We scheduled a day to induce (at 39 weeks) so that this doctor would be guaranteed to be there as he was the only one we trusted to give our daughter a chance. We were very clear that our birth plan was to get her into this world alive and from there decide --based on her actual overall health and medical needs-- what to do each step of the way. Never could anyone have interpreted our desires to include a Do Not Resuscitate order.

Labor began and our baby's heart rate dropped with each contraction. It was decided a c-section was necessary. Our daughter was born soon after. She presented with Apgar scores of 5 and 8 and needed only a small amount of "blow by" oxygen. We spent time together and she was taken to the intermediate care NICU for more evaluation and monitoring. She did fine, we went home 5 days later with our tiny 3lb 8oz little girl.

This was almost 15 years ago. Today **Krissy is 14 years old and a freshman in high school.** While she's had a handful of medical issues, Kristina has done well.

Two years ago I was looking through the medical records from Kristina's birth and found that-- **unbeknownst to us-- the hospital had placed a DNR on Kristina prior to her birth.** This DNR was not our choice or decision and if I hadn't looked back at the records, we never would have known.

To this day, every time Kristina is hospitalized we get challenged over the fact that we have her listed as a full code. We were once told, "you've had 10 good years with her, isn't that enough?" Krissy has a happy, healthy, full quality of life. When that changes, our decisions might change. But either way it should always be our choice.

Terre Krotzer
1820 216th Avenue Ct East
Lake Tapps, WA 98391
253-862-2235
terre@trisomytalk.com
www.trisomytalk.com

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**

I, Lori Hinton support Simon's Law. I have 3 children.
My youngest daughter is Danica Hope Hinton.
She was born with Trisomy 18.



DANICA HOPE

There is no way I would want any other person to
make a decision for my children. This should never be acceptable. A DNR should only be a
choice for the parents to decide.

Lori Hinton
42 Ledger Stone ln
Greensboro NC 27407
Phone 336-601-5489
lah108122@hotmail.com

Proponent, SIMON'S LAW SB 437 Kansas Legislature

In September 1982, I gave birth to a beautiful baby girl we named Karen. Karen was born with both **Down Syndrome and a severe heart defect** called a complete endocardial cushion defect.



KAREN with big sister Marie

A pediatric cardiologist was called in and even before I left the recovery room, he gave me the bad news about our Karen's heart defect and even said that it was inoperable. He said to take Karen home where she would **die in 2 weeks to 2 months**.

This doctor turned out to be wrong. Further testing revealed that Karen's heart defect could be fixed with one open heart operation and she had a 90% chance of survival.

My husband (a doctor) and I (an ICU nurse) were **determined that our daughter receive the best medical care possible for her heart condition and without bias** because she had Down Syndrome. We knew about the recent Baby Doe case where the parents of baby boy with Down Syndrome and an easily correctable tracheoesophageal fistula refused surgery so that their baby would die. The case went to court and a judge ruled that the parents could make that lethal choice. As medical professionals, we were appalled by this case but at least we could make sure that our daughter would have her chance at life. Or so I thought.

The **bias against children** like Karen soon became apparent when the cardiologist said he **would support us "100%" if we chose to let our Karen die without surgery**. I had to insist that Karen be treated for her heart defect the same way any other child would be treated for the same heart defect. To do otherwise was medical discrimination and illegal.

Then, the surgeon recommended for Karen's pre-op heart catheterization was overheard questioning the wisdom of even treating "all these little mongoloids"! Another doctor sympathetically told us that "people like you shouldn't be saddled with a child like this." We were stunned by this negative view of children with Down Syndrome.

Later on when Karen developed a pneumonia that was being successfully treated in the hospital, I found out that **my trusted pediatrician had even made Karen a "Do Not Resuscitate" behind my back because I "was too emotionally involved with that retarded baby."** The DNR was rescinded and we took Karen home but I found it hard to trust any doctor after that.

Unfortunately, Karen developed another bout of pneumonia and died of complications just before her scheduled open-heart surgery. But even at the very end, when Karen was apparently dying, a young resident **physician “offered” to pull all her tubes so that she would die** as soon as possible. I reported this young man to the chief of pediatric cardiology who was furious with the resident. (This chief of cardiology later started a clinic for children with Down Syndrome to meet their special health needs)

Unfortunately, our Karen died of complications after a series of pneumonia just before her scheduled open-heart surgery. Karen was 5 ½ months old. I still treasure my time with her and because of her, I became an advocate and volunteer for people with disabilities.

I wish I could say that my story is unique but **I have seen many similar situations over the last over three decades involving people of all ages with disabilities.**

Therefore, I beg you to approve Simon’s Law. It will potentially save lives as well as send a **strong message that medical discrimination against the disabled** based on subjective judgements of “medical futility” and/or predicted “poor quality of life” is wrong.

NANCY VALKO, RN ALNC (Advanced Legal Nurse Consultant)

1740 Seven Pines Dr.

St. Louis, Mo. 63146

PH: [314-434-5208](tel:314-434-5208)

Email: nancyvalko@sbcglobal.net

**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**



As a physician, I was unaware that a DNR could be placed on a child's chart without the consent or knowledge of the parent until it **happened to my 3 year daughter during a routine hospitalization in 2007.**

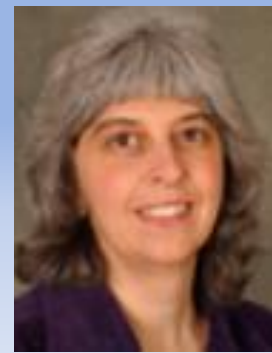
Since that time, in making the documentary '*Labeled*', my family and I have traveled 25,000 miles interviewing expert physicians (Harvard, University of Washington, Cleveland Clinic, University of Utah and Loma Linda) nursing faculty, parents and historians. I asked some of the parents we interviewed to request their child's medical records. **I personally reviewed the files of children from Missouri as well as other states and found DNR orders in their charts. The parents of these children had been previously unaware that a DNR order had been placed in their child's chart.**

As a practicing physician, I believe that in this day and age where there is a push for more transparency in health care that **Simon's Law should be passed to insure transparency of DNR policies at hospitals.**

Dawn S. Allison M.D and Rex Allison
18790 Hakamore Dr
Bend Oregon 97701
541-390-3979
alisonderm@gmail.com



**Proponent, SIMON'S LAW
SB 437
Kansas Legislature**



PROF. DEBORA BRUNS

I am the Principal Investigator of the Tracking Rare Incidence Syndromes (TRIS) project. Began in 2007, the TRIS project seeks to raise awareness of genetic conditions including trisomy 18 and trisomy 13. Project participants represent most states in the United States and across the continents of North America, Europe, and Australia. Of particular note is the project's focus on dissemination of research findings on longevity due to medical interventions such as placement of a tracheotomy and cardiac surgery to correct common defects (for a listing of project presentations and publications, see <http://web.coehs.siu.edu/Grants/TRIS/publicationsandpresentations.html>]

I fully support Simon's Law as a professional researcher and also as one with **direct contact with families with children with trisomy 18**. It is striking how many parents have had experiences similar to Mrs. Crosier. It is no less than **genetic discrimination** and must be stopped. Each child must be seen as an individual not a diagnosis. Treatment decisions during delivery, immediately post-birth and beyond must meet medical needs not be dictated by a diagnosis. Hospital policies must be reviewed to eliminate this practice around the country.

The children's voices deserve to be heard. They are individuals first, not their diagnosis of trisomy 18 or other genetic conditions.

DEBORA BRUNS,, Ph.D.,
Professor and Coordinator, Special Education Program
Department of Counseling, Quantitative Methods and Special Education
SIU Vita available upon request (27 pages)

Southern Illinois University Carbondale
Mailcode 4618
Carbondale, IL 62901

Phone: (618) 453-2311
Fax: (618) 453-7110
E-mail: dabruns@siu.edu
Web: <http://ehs.siu.edu/cqmse/undergraduate/>
<http://ehs.siu.edu/cqmse/graduate/special-education/>
TRIS project: <http://tris.siu.edu>

Proponent, SIMON'S LAW
SB 437
Kansas Legislature



ANDY KNEF, editor

My name is Andy Knef and I'm the editor of [I'm Not a Syndrome – My Name is Simon](#). In the course of working on this book with author Sheryl Crosier I interviewed dozens of health care professionals, including nurses who cared for Simon personally on the neonatal floor where he lived for his short life. While some nurses were more adamant than others in their convictions about the lack of urgency attached to saving Simon's precarious existence by some physicians responsible for his care plan, **all agreed that more could have and should have been done to offer this special infant a fighting chance to survive.**

Whether it was the issue of a Do Not Resuscitate directive that was unknown to his parents, comfort care feedings in place of nutritionally necessary sustenance or prescriptive medications that were potentially life threatening to infants with compromised pulmonary functions, the nurses shared their concerns about Simon's care with me. Individually and as a group, these experienced professionals portrayed **systematic care plan decisions that were not consistent with a priority on prolonging Simon's life** and viability outside of the hospital.

Based on these observations and my experience meeting and sharing life with the many wonderful Trisomy survivors and families I've encountered, I urge **Missouri** Lawmakers to adopt Simon's Law and to do everything in their power to protect the innocent lives of our most vulnerable citizens. Surely, the existence of these wonderful people is one of the ways our Maker enters the word to ensure that we are doing all we can to care for those who cannot care for themselves.

Andy Knef, Editor [I'm Not a Syndrome – My Name is Simon](#)
400 Shadow Creek Drive
Apartment 301
Oxford, Mississippi 38655
662-816-0253
Knef.andy@yahoo.com

PROPONENTS - SB 437, SIMON'S LAW

I worked for 15 years as a social worker for a local hospice organization. My wife is an RN working for 20 years in pediatric home care in Topeka.

Our work experience leads us to strongly support the passage of Senate Bill 437. The parents and guardians (and other involved family as appropriate) must always be consulted about the DNR status of a minor and about about the issue of withholding life-sustaining treatment.

Neither health care facility policies or physicians must be allowed to override the basic authority of the parents. This is a fundamental protection that needs to be in place, especially in this era when there is so much emphasis on saving money and when there exists a growing tendency among some to deny or minimize the God-given sanctity of all human life, including that of disabled children.

Tim Brandyberry, LSCSW & Patricia Brandyberry RN/BSN

6615 SW Scathelock Rd.

Topeka, KS 66614

785-478-0857

on2pella@gmail.com

Although this is the first I have heard of this I must say this is troubling. There is absolutely no entity who should have discretion over the care of children which preempts a parent's rights. This has horrible implications and needs to be stopped. I urge all of Kansas' legislators to vote in favor of this legislation which will assure parents of their control of what medical care their children should receive.

Rose Koggie

Associate Broker, HomeLand Realty & Auction

1112 Main Street

Goodland, KS 67735

785-899-3060 Office, 785-821-1179 Cell

rkoggie@homelandre.com

I support Simon's Law and am a registered voter. Thank You.

Charlene McFerson

1507 E. Carolyn St.

Derby, Ks 67037

316-788-3799

cmcferson@usd263.org

It has only recently been brought to my attention that a DNR (Do-not-resuscitate) note can be placed on any minor child's medical chart WITHOUT the consent of a parent. I can't help but feel a little irresponsible as a parent for not knowing this before now, but I think we are all generally under the impression that doctors are ALWAYS practicing with the goal of saving lives. We don't tend to question that idea. Now that my eyes have been opened and I am better informed as a parent, I am furious.

I have recently watched the medical care of a family member decline during pregnancy once a diagnosis was given to the baby. The care given was even below what a healthy pregnancy would be given and this particular pregnancy should have been given even more care, considering the diagnosis.

Though I have not personally been affected by the specific need for Simon's Law, I can see how the need can arise for any parent at any time, unexpectedly and it's an immediate need. Watching this person's journey has lit a fire in my heart and opened my eyes wider to do some research in order to better understand what is happening right here at our hospitals in Missouri. I personally feel very naive and uncomfortably vulnerable, having 3 kids and not knowing until recently that this could happen. That at any moment, one of my children could be in critical condition, needing medical attention and be fighting for their life and a doctor can decide FOR ME that it is my child's time to pass away. For the doctor to do nothing. Is that what we pay so much for them to do? Nothing? That thought is both terrifying and infuriating.

I have read that the main reason why Simon's Law is being opposed is because they believe that parents are too emotional in these situations to make the decision for their own child and that it is actually a courtesy to the parents to relieve them of that burden. And to that I say, how dare you? How dare you take that choice away from a parent, the person who loves and cherishes that child more than anything in this world. The person who values that child's life more than their own, the person who spends every waking moment considering that child's well being. Allow me to make a suggestion. If at any moment a parent feels that making that choice is too difficult and that they aren't emotionally capable of handling the weight of that decision, how about that parent then asks for a professional medical opinion and gives verbal and written permission for a doctor to make that decision in their place? That should be the ONLY scenario in which a stranger is making the call. Assuming that parents are incapable of making that decision for someone they love so dearly is both offensive and incorrect. Simon's Law is desperately needed. Our children deserve better and the families of these children deserve better.

Stephanie Gerhard
116 Spruce Ave.
Clever, MO 65631
417-834-2675
sgerhard5286@gmail.com

I can't imagine why any state would allow a DNR order on children 18 or under to be placed on a child or anyone else. I suspect some medical personnel would actually do this.

Our society more and more seems to think that some people are not worth keeping and their solution is to let them die. I don't even like it when doctors or nurses ask me if I want that kind of order placed on my door when I am in the hospital. I would like to think that they would have enough sense to do all they can to keep me alive unless they are absolutely sure that I am already brain dead.

Fr. Earl Dekat
11010 Myers Valley Road
St. George KS 66535
785-494-8245
earld@carsoncomm.com

As a business owner, as an educated and informed individual, as a logical thinker, as one who sees the big picture, as a person who has not been personally affected by the policy that needs changing, but mostly as a mom of five children, I am writing to state my support of Simon's Law.

Currently, hospital policy states that doctors have the right to make life changing and life ending decisions for a minor child based on their medical expertise, irregardless of the desires of the parents, and even without the knowledge of the parents.

When I heard about this policy, I was honestly blown away. It sounded to me like a policy that would be in a communist country, not in a country that values the freedom of the individual. As I learned more, I began to see that there are two distinct sides and opinions regarding this hospital policy.

The side against Simon's law says that parents are too emotional to make a decision to end their child's life if that's what's best in those critical situations. The side for Simon's Law state that it is the parent and only the parent that has the right to make those calls.

My have two very distinct reasons that I personally am in support of Simon's Law. The first is obvious and felt by anyone that has ever been a parent. There is no one on earth that loves and cares for that child more than a parent. Every day as parents we make decisions that affect our children. We tell them to buckle up, we make them wear a helmet, we ground them if they are making poor choices, we praise them when they do well in school. Each day, it's the parents that shape the child's future. Imagine if a stranger were allowed to come in and make any of those decisions for us. Every one of us would fight

them tooth and nail. Why? Because we want to raise our children to be the very best they can be. That is our job! Why then should a doctor be allowed to make the most precarious decision of a child's entire life? No truly good parent would want that choice taken away from them, because they alone know how best to give them that life.

Secondly, a policy of this sort is too fluid. There is no black and white. It comes down to a doctor that often is a stranger to the family. And that doctor's decision is going to be based on a variety of probably instinctual beliefs that may not even be part of the conscious decision making process. That doctor may be having a bad day, or a busy day. Maybe they have been there a long time and are exhausted and not thinking straight. Possibly the doctor has different beliefs and views about how those with disabilities should be handled. It could be that the doctor is being influenced by others that lack knowledge of the child in question. Maybe the doctor just simply wants to move on to the next case! Now please don't think I am assuming that doctors are evil people with bad motives. No, I think probably this is the hardest decision a doctor would ever have to make. But that doctor and that parent may have totally different ideas of care and health and life goals and morality and religion and even politics!

So if we have a difference in opinion about what should be the treatment plan for a child, the burden of decision making should fall to the parents. Even if they are emotional and incapable of making a choice, there are friends and family that are usually available to help calm those emotions and participate in making those hard choices. Ultimately, it is the doctor's obligation and responsibility to give the parents every piece of medical evidence and advice they have, and then allow the parents, who gave this child life to begin with, the final decision in choices of life and death.

Please take this matter into your consideration, and look at it with your heart, but also with your head. You will see as I have that the logical reasoning matching the parents emotional pleas for their rights.

VALERY FAZIO
987 S. Hedge Dr
Nixa, MO 65714
417-540-6019 cell
valery_fazio@yahoo.com
