

## Proponent, SB 85 SIMON'S LAW

February 16, 2017

**Senate Federal & State Affairs Committee.**  
Chairman LaTurner and committee members,

Today you are learning about very distressing situations of denial of life-sustaining treatment to children, sometimes with their **parents present at the bedside-- yet unaware of the true extent of the threat** to their beloved offspring.

**The traditional presumption in favor of life is in jeopardy.** While we respect the expertise of health care personnel, there are far too many victims of value-judgment-based unilateral DNR placements to ignore the issue. A poll of pediatricians last year showed that, depending on the scenario, as many as 75% believed they had the right to issue DNRs without notice or permission by parents. [Murray PD, Esserman D, and Mercurio MR. In what circumstances will a neonatologist decide a patient is not a resuscitation candidate? J Med Ethics. 2016 Mar 17]

The need for parental permission for DNRs also extends to children *without* special needs who have experienced life-threatening accidents or disease.

In our attached packet are instances that reflect **medical discrimination toward children with special needs.** These "horror stories" were collected after Simon's mom, conferee Sheryl Crosier, began a crusade (and self-published a book) to protect other parents from the tragedy she and her husband, Scott, experienced five years ago. These are compelling stories. Some of the children died—as did Simon—and a few escaped death. Some highlights:

Pg.1- Simon's story: in which a baby with **Trisomy 18** dies when a DNR without parental consultation was placed in his chart.

Pg.3- A mom mourns her daughter with **Trisomy 18** who lived to age 19 only to die due to a secret DNR effectuated during hospitalization for pneumonia.

Pg.5- An ER doctor tells of how the medical world had been trying to kill her **Trisomy 13** daughter since before she was born.

Pg.7- A pediatrician aligned with S.O.F.T. [Support Organization for Families with Trisomy 13, 18 and Related Disorders] believes sections (b) & (d) of Simon's Law can produce "an environment that allows medical decisions to be made in an ethical and transparent way."

[1]

Senate Fed and State Committee  
Date 2-16-17  
Attachment # 6

Pg.9- A mom describes how her now-7-yr old son is living with an unrepaired heart due to a dismissive assessment that his **Trisomy 18** condition was “incompatible with life.”

Pg.11- A mom tells of a newborn being scheduled for heart surgery UNTIL a diagnosis of **Trisomy 18**, after which the infant was denied sustenance and sent home too early.

Pg.13- A mom discusses her now-22-months-old daughter, born with **anencephaly**, who was not properly treated, overdosed and given a DNR order in secret.

Pg.15- A mom tells of discovering that a secret DNR was placed in the medical files of her 14-yr-old daughter with **Trisomy 18**; the mom reports she continually has to argue with medical personnel that her daughter is to receive full resuscitation.

Pg.17- A mom insists on the parental right to decide about a DNR, and worries about her youngest daughter with **Trisomy 18**.

Pg.19- A nurse recalls the discrimination she fought to get proper care for her daughter born with a heart problem and **Down Syndrome**, and how it set her on a career of caring for the medically vulnerable.

Pg.21- A doctor has become involved in verifying medical charts that had secret DNRs placed in them, after it happened to her daughter with a **rare chromosomal diagnosis**.

Pg.23- A professional researcher with direct contact with families with children with **Trisomy 18** urges that medical needs should *not* be dictated by a diagnosis and hospital policies be reviewed to eliminate this practice around the country.

Pg. 25- The editor of Sheryl Crosier’s book, *I’m Not a Syndrome – My Name is Simon*, tells of numerous interviews verifying the lack of urgency attached to saving Simon’s precarious existence by some physicians responsible for his care plan.

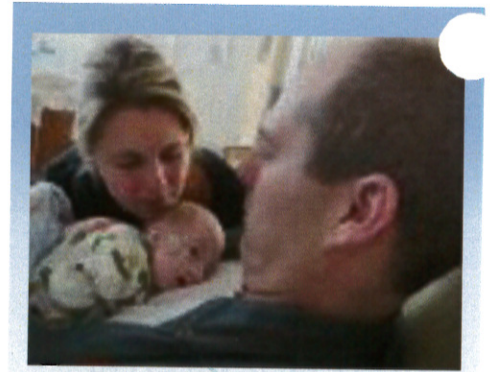
The technology for saving lives in the NICU continues to improve. I have attached a new paper published this week in the prestigious Journal of the American Medical Association (JAMA) which examines the evolving way children with chromosomal disorders and their families *should* be treated. This paper promotes ending the old assumptions that diagnoses of Trisomy 13 and 18 are “fatal,” “untreatable,” and yield a low quality of life. The comparison is made to the way that the medical establishment has evolved/improved over the past century in their treatment of individuals with Trisomy21 (Down Syndrome).

There is a great public outcry that parental permission is *not* required for DNR placement. This bill passed 37-3 in last year’s Senate and we hope this committee supports passage again.

Kathy Ostrowski, Kansans for Life Legislative Director

## Proponent, SIMON'S LAW SB 85 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

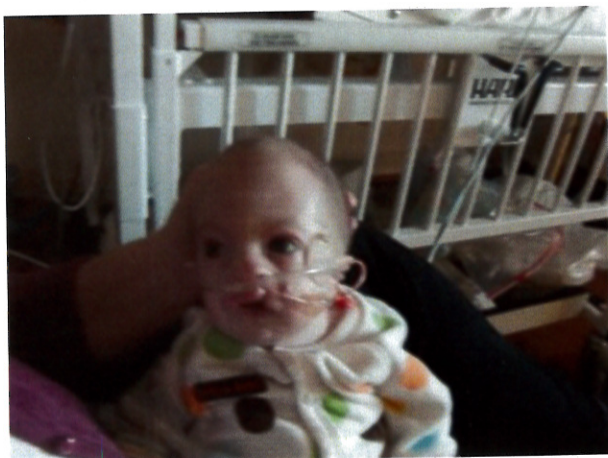
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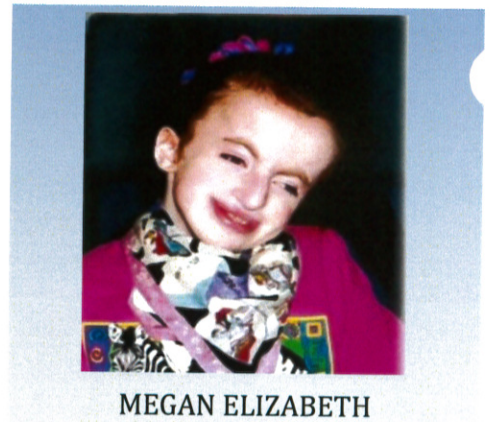
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**SB 437**  
**Kansas Legislature**



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**.

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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.

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.**



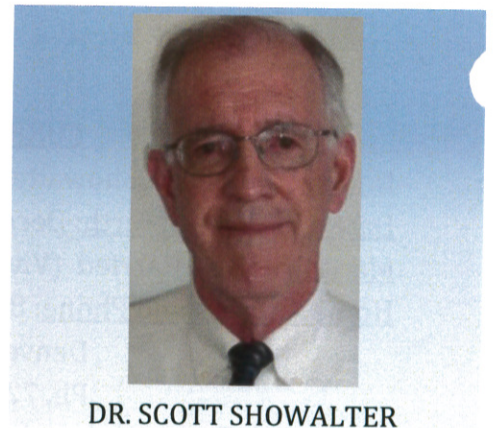
After she left (was kicked out), my husband and I held our baby in our arms and I no longer stimulated her. She stopped breathing on her own and her heart slowly stopped beating.

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.

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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.



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.

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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.

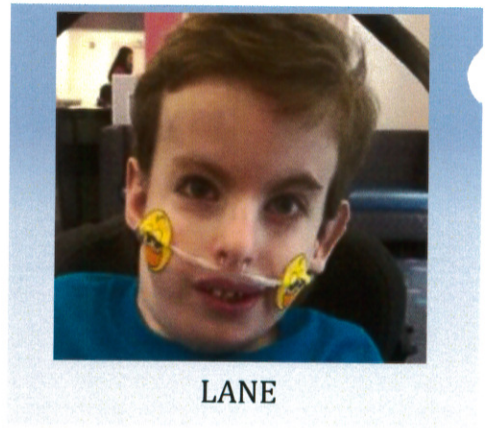
Other Medical Interests: Professional Advisory Committee for S.O.F.T. (Support Organization for Trisomy 13, 18, and Related Disorders)

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

Medical ethics



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LANE

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.

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.

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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.

Having no concerns during pregnancy, I delivered Jaisha 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 Jaisha.
- 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 Jaisha'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..



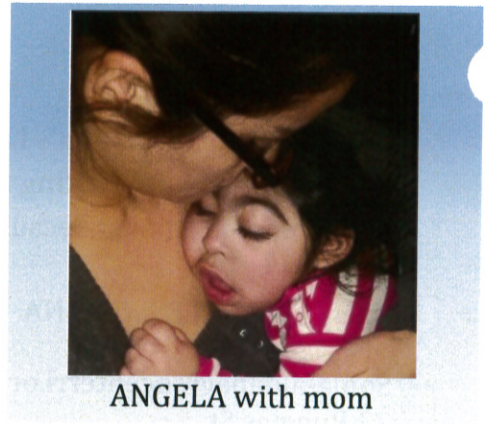
As time passed, I began to research her diagnosis and gained knowledge from people who had been in similar situations. It was then that I discovered a hospital that treats children with genetic disorders. The doctors at this hospital wasted no time on my daughter's diagnosis but instead chose to treat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

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

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



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.

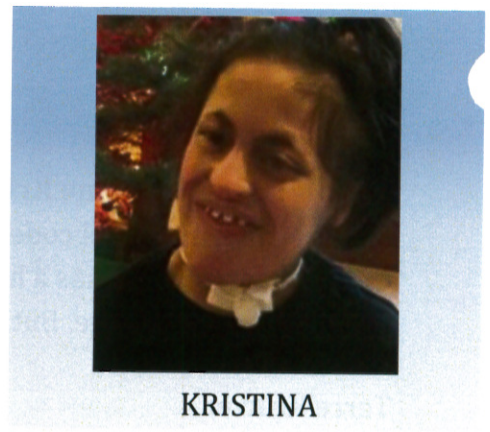
I am in support of Simon's Law because I have personally **experienced a violation of my parental decision making rights**. In addition, my daughter, Angela has been discriminated against because of her medical condition.

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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.

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.

6-15

**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.

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

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.

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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.

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Kansas Legislature**



DR. DAWN ALLISON

**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.**

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**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)

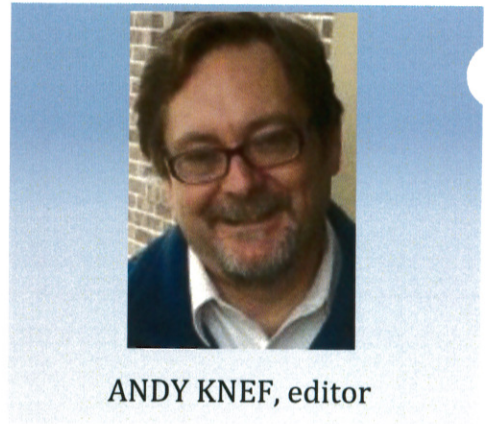
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**Proponent, SIMON'S LAW**  
**SB 437**  
**Kansas Legislature**



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.

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## **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.

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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.

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

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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.

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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.

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JAMA Pediatrics | Review

# Using Patient-Centered Care After a Prenatal Diagnosis of Trisomy 18 or Trisomy 13

## A Review

Shelly Haug, MD; Mitchell Goldstein, MD; Denise Cummins, DNP, WHBP-BC; Elba Fayard, MD; T. Allen Merritt, MD



Editorial

**IMPORTANCE** Patient-centered care (PCC) has been advocated by the Institute of Medicine to improve health care in the United States. Four concepts of PCC align with clinical ethics principles and are associated with enhanced patient/parent satisfaction. These concepts are dignity and respect, information sharing, participation, and collaboration. The objective of this article is to use the PCC approach as a framework for an extensive literature review evaluating the current status of counseling regarding prenatal diagnosis of trisomy 18 (T18) or trisomy 13 (T13) and to advocate PCC in the care of these infants.

**OBSERVATIONS** Extensive availability of prenatal screening and diagnostic testing has led to increased detection of chromosomal anomalies early in pregnancy. After diagnosis of T18 or T13, counseling and care have traditionally been based on assumptions that these aneuploidies are lethal or associated with poor quality of life, a view that is now being challenged. Recent evidence suggests that there is variability in outcomes that may be improved by postnatal interventions, and that quality-of-life assumptions are subjective. Parental advocacy for their infant's best interest mimics this variability as requests for resuscitation, neonatal intensive care, and surgical intervention are becoming more frequent.

**CONCLUSIONS AND RELEVANCE** With new knowledge and increased parental advocacy, physicians face ethical decisions in formulating recommendations including interruption vs continuation of pregnancy, interventions to prolong life, and choices to offer medical or surgical procedures. We advocate a PCC approach, which has the potential to reduce harm when inadequate care and counseling strategies create conflicting values and uncertain outcomes between parents and caregivers in the treatment of infants with T18 and T13.

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**P**atient satisfaction with health care is an increasingly significant concern. In 2001, the Institute of Medicine introduced a comprehensive strategy to improve health care in the United States. A key aim of this proposal is patient-centered care (PCC), defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."<sup>1(p6)</sup> Based on a comprehensive analysis of patient focus group data, 4 core concepts (dignity and respect, information sharing, participation, and collaboration) have been established to define quality in health care delivery (Table).<sup>2</sup> These concepts harmonize with the clinical ethical principles of beneficence, nonmaleficence, justice, and respect for autonomy.<sup>3</sup>

Previous reports suggest dissatisfaction among patient families and growing debate among clinicians regarding care after trisomy 18 (T18) or trisomy 13 (T13) diagnosis.<sup>4,5</sup> Our objective was to use PCC concepts to develop a framework that more fully evaluates sources of dissatisfaction and debate regarding shared decision making and clinical care of infants with T18 and T13. We outline

key recommendations for a balanced approach to joint decision making regarding care that has application in other areas of challenging patient treatment.

### Background

Trisomy 18 and T13 are chromosomal aneuploidies first identified in the 1960s. These syndromes have high mortality and morbidity and are characterized by growth deficiency, cognitive disability, psychomotor disability, and recognizable patterns of physical anomalies.<sup>6-8</sup> Together, they affect 1 in 1800 US pregnancies; thus, approximately 2000 women will carry a fetus to term with T18 or T13 annually.<sup>8,9</sup>

Trisomy 18 and T13 were historically designated as lethal or incompatible with life<sup>10</sup> and families had traditionally been counseled from this perspective.<sup>6,11,12</sup> Approximately 1:6000 to 1:8000 live births are complicated by T18 and 1:10 000 to 1:20 000 by T13.<sup>6,13</sup> There is increasing evidence of variable outcomes of these infants that may be improved by postnatal interventions.<sup>12,14-17</sup>

Table. Application of Patient-Centered Care Approach

Characteristic	Approach
Dignity and respect	<ul style="list-style-type: none"> <li>Promote research and dialogue about the influence of patient values, beliefs, and culture on decisions and outcomes after a prenatal diagnosis of trisomy 18 or trisomy 13.<sup>4,12,17</sup></li> <li>Assess and communicate patient values, beliefs, and preferences at diagnosis and throughout the continuum of care.<sup>21,45,46</sup></li> <li>Support parents in making decisions that fit with their values.<sup>8,15,27,67</sup></li> <li>Defer to patient wishes when the prognosis or best interest of the child is unclear.<sup>8,20</sup></li> <li>Support the development of best practice models and guidelines for perinatal palliative care.<sup>45,46</sup></li> <li>Create opportunities for providers to listen to the health care experiences of patients with trisomy 18 or trisomy 13 pregnancies or children.<sup>2,12,17,41</sup></li> </ul>
Information sharing	<ul style="list-style-type: none"> <li>Present accurate figures for survival and outcome that take into consideration the individual clinical features of the fetus or child.<sup>8,24</sup></li> <li>Avoid the unmodified use of <i>lethal, fatal, or incompatible with life</i> in describing potential outcomes,<sup>8</sup> particularly during pregnancy when the condition and prognosis of the fetus are ambiguous.</li> <li>Provide information about a variety of educational resources, including Internet websites and support groups.<sup>45</sup></li> <li>Consider offering "a positive viewpoint" and "erring on the side of life" within the framework of the Convention of the Rights of the Child and Convention on the Rights of Persons with Disabilities.<sup>61</sup></li> <li>Advocate a willingness to do whatever it takes to fully inform and understand the perspectives of patients/parents.<sup>8,15</sup></li> </ul>
Participation	<ul style="list-style-type: none"> <li>Avoid coercion and use good communication to resolve conflicts between patients and health care professionals about pregnancy decisions; arrange for second or third opinions, if necessary, and ethics or legal consultations; allow parents time to consider options on "their own turf" with time-limited goals.<sup>3</sup></li> <li>Reduce variability in physician approaches to intervention/nonintervention to prolong fetal viability in pregnancy.<sup>59</sup></li> <li>Petition professional organizations to establish ethical, patient-centered guidelines for care of women with pregnancies complicated by "severe, not uniformly lethal anomalies."<sup>4,17</sup></li> </ul>
Collaboration	<ul style="list-style-type: none"> <li>Create interdisciplinary teams that can assess and care for the complex needs of patients/parents throughout the continuum of care.<sup>21,36,45,46</sup></li> <li>Arrange for ethics consultation for professionals and families with ethical concerns about newborn care to identify potential solutions to conflicts.<sup>8,18,22,49</sup></li> <li>Establish partnerships with specialist providers and institutions that offer broader options or resources for prenatal or neonatal care, and with agencies that offer ongoing care or support for patients and families.<sup>18</sup></li> <li>Promote the establishment of centers of excellence for pregnancies complicated by "severe, not uniformly lethal anomalies," and for care of newborns and children with these conditions.<sup>12,17</sup></li> </ul>

Lantos<sup>18</sup> recently addressed the history and evolution of management regarding infants with trisomy 21 that sheds light on the current evolving approach toward infants with T18 and T13. Recommendations to limit treatment for infants with trisomy 21 were previously commonplace; however, it is now impermissible to withhold surgery in such cases (with rare exceptions in complicated circumstances). Lantos explains that ethical decisions regarding treatment futility must include consideration of "survival, neurocognitive deficits, and the burdens of treatment."<sup>18(p397)</sup> He goes on to emphasize that trisomy 18 and 13 once belonged in the category that recommended limited treatment.

There is also increasing debate about quality-of-life (QOL) assumptions.<sup>19-23</sup> Quality of life is subjective and physicians rarely understand the criteria that family use in determining their percep-

tion or what the infant might experience. The term *quality of life* is often misused for perceived physical or neurologic impairments; however, some infants can have severe impairments and still have an excellent QOL.<sup>24</sup> Nelson and colleagues<sup>25</sup> recently described improved survival with surgery (primarily cardiac) in a cohort of 428 infants with T18 or T13 over a 21-year period. The median survival time of the 254 children with T18 was 9 days, and the median survival time of the 174 infants with T13 was 12.5 days.<sup>25</sup> Of infants with T18, 13.8% underwent surgery with a 1-year survival rate of 68.6%, and, of infants with T13, 23.6% underwent surgery with a 1-year survival of 70.7%. These results provide a rationale for reconsidering previous recommendations regarding care limitations for these infants. However, Graham<sup>26</sup> questions whether these aggressive interventions have improved survival or the quality of life while using resources at increased cost.

## Discussion

### Dignity and Respect

Dignity and respect in PCC hold that health care professionals should honor patient perspectives, values, and decisions when implementing care.<sup>27</sup> There is a paucity of literature addressing the influence of particular values and cultural heritage within families on decision making and outcomes after diagnosis of T18 and T13.<sup>28</sup> Physician attitudes accrue from scientific knowledge and experience, yet are influenced by ethical principles and personal beliefs. Patient perspectives are strongly influenced by societal, familial, religious, and cultural factors. The often-required immediacy of medical decision making can make inquiry into a family's values and beliefs clinically impractical. Given the strong spiritual and cultural beliefs that encompass birth and death, both of which may be imminent after diagnosis in T18 or T13, decision making may be difficult. In such situations, individuals have a heightened need for information relevant to their values.

Advances in genetic testing, especially noninvasive prenatal testing and chorionic villus sampling, have led to diagnosis as early as the first trimester of pregnancy. A study of the natural history of fetal T18 found high rates of fetal demise and stillbirth.<sup>29</sup> Pregnancy termination may be offered after T18 or T13 diagnosis; however, availability may be affected by gestational age limitations or cultural confines. The difference between the number of pregnancies affected by T18 or T13 and the live birth rate suggests that fetal demise or pregnancy termination is common. Few studies have assessed cultural differences in attitudes toward prenatal testing and pregnancy termination for broad categories of fetal anomalies,<sup>30,31</sup> and there is inadequate literature addressing the needs or preferences of women who choose this option.

There has been increased acknowledgment of patient preferences in the care of women who choose to continue pregnancies affected by severe or lethal fetal anomalies. The concepts of perinatal palliative care and prenatal advanced birth care planning have been evolving since the theory of perinatal hospice was introduced.<sup>32-40</sup> Wool and colleagues<sup>41-43</sup> published research in developing quality indicators in perinatal palliative care. Perinatal palliative care initiatives are now increasingly supported by clinicians, parents, and professional entities.<sup>21,44</sup> Perinatal palliative care that focuses on interdisciplinary team and family involvement of

fers a valuable framework for providing PCC after T18 or T13 diagnosis. Merritt et al<sup>45</sup> provide guidelines for perinatal palliative care in this context. English and Hessler,<sup>46</sup> Wool and Dudek,<sup>47</sup> and Wool<sup>48</sup> offer guidance in outlining steps for assessing patient perspectives and preferences, a shared decision-making process for palliative care, components of a written birth plan, roles of interdisciplinary team members, perspectives of perinatal palliative care barriers, and other valuable guides.

Typical perinatal palliative care after diagnosis of T18 or T13 has 2 important limitations. First, it generally offers limited services to women who opt for pregnancy termination, and second, the common emphasis is on comfort care (which assumes poor neonatal outcome) or providing a compassionate environment to adjust expectations and choose to limit interventions.<sup>45,49</sup> This approach may be hollow if not aligned with patient preferences. van de Eijk et al<sup>50</sup> propose that PCC requires more than just a respectful attitude or a personalized approach to assessment and care; rather, it requires engaging patients to become active participants and decision makers.

Influential parent support groups, such as the Support Organization for Trisomy 18, 13 and Related Disorders (SOFT)<sup>12</sup> and the Trisomy 18 Foundation,<sup>17</sup> have had a significant effect on the dignity and respect afforded patients and families affected by these syndromes. The parent-professional collaborations resulting from the advocacy of parent support groups have vocally advocated over the last decade owing to increased visibility via the internet and additional information in medical and ethical literature. These websites offer contextual information to promote respect for patients and families and provide testimonials of adverse medical experiences while offering videos of children who have overcome the odds of perinatal mortality. Such websites appear, however, to spark controversy among health care professionals, who claim that the sites may promote unrealistic expectations about outcomes due to selection bias toward children who have generally survived for longer than 1 year. However, a survey by Janvier et al<sup>51</sup> of parents of children with T18 or T13 recruited from these social networks emphasizes that parent goals were "to meet their child, be discharged home, and be a family."

#### Information Sharing

Information sharing requires health care professionals to offer accurate, complete, and unbiased information to patients so that they may make well-informed decisions even when there is controversy regarding management strategies.<sup>52,53</sup> Although patients do not universally appreciate patient-centered information sharing, the ethical principles of respect for autonomy, beneficence, and nonmaleficence support the importance of accurate information disclosure.

Parents are commonly counseled from the perspective that T18 and T13 are "incompatible with life."<sup>54</sup> Population-based studies indicate that mean survival time is between 3 and 14.5 days and 1-year survival is 0 to 10%.<sup>13,55</sup> The length of survival time decreased after T18 and T13 were identified as discrete syndromes, possibly as a result of less aggressive treatment being offered owing to expectation of death.<sup>56</sup> Although recent studies show that mortality remains high, there is increasing evidence of outcome variability and mortality reduction through postnatal interventions. Rasmussen et al<sup>54</sup> agree that aggressive intervention, such as cardiac surgery, may be necessary to prolong the lives of some infants; however, long-term T18 survivors may not need particularly aggressive or extraor-

inary treatment. According to Niedrist et al, "if children with trisomy 18 are brought beyond the first critical phase of life when postnatal adaptation of cardiorespiratory function is still very poor, the subsequent survival chance is enhanced,"<sup>55(p957)</sup> and the recent report by Nelson et al<sup>25</sup> supports this concept.

Recent studies on T18 and T13 outcomes acknowledged that these aneuploidies are not universally lethal. In a review of genetic screening challenges, Coughlin<sup>57</sup> evaluated surveys of genetic professionals in an attempt to rank the seriousness of genetic disorders. The study confirmed a consensus about which conditions were considered lethal, serious but not lethal, or not serious.<sup>58</sup> In a survey among members of the Society for Maternal-Fetal Medicine, Heuser et al<sup>59</sup> distinguished T18 and T13 as severe, commonly lethal anomalies as opposed to uniformly lethal anomalies, such as anencephaly and bilateral renal agenesis. Despite such variability, specialists routinely use the term *lethal* in counseling the parents of fetuses or infants with T18 or T13 and perpetuate QOL assumptions that promote withholding interventions.<sup>48</sup>

In an international survey of 272 parents of children with T18 or T13 (76% within the United States), parents reported being told by a health care professional that their child's condition was incompatible with life (87%), the child would have a life of suffering (57%), or that care of the child would ruin their family (23%).<sup>4</sup> Of the respondents, more than 25% had a child with T18 or T13 still living, with a median age of 4 years. Although 50% reported that care of a disabled child was more difficult than expected, 97% reported that their child was happy. These study results may be limited by selection bias because the survey did not include women who terminated the pregnancy or experienced fetal loss, or those whose infants died shortly after birth. Parents responding to the survey were identified through T18 and T13 support groups and so may have been more likely to have a living child, be happier with the current status of their child and family, or be more dissatisfied with the information that they received because it proved to be inconsistent with their child's outcomes. Follow-up studies among parents who are not members of support groups may offer a broader perspective on parental perceptions. Janvier et al<sup>4</sup> theorize that increasing disparities in patient and provider perspectives may be due to the aforementioned internet support groups. These testimonials challenge the incompatible-with-life and life-of-suffering perspectives. Mercurio and coworkers<sup>60</sup> observed that physician arguments for withholding treatment have lost credibility owing to insufficient corroborating evidence.

Current approaches to information sharing after diagnosis of T18 and T13 may not be as accurate, complete, and unbiased as they should be.<sup>60</sup> One factor in these limitations may be pressure to make decisions about pregnancy termination before narrow gestational age time frames expire. McGraw and Perlman<sup>19</sup> suggest that parents exposed to support group websites may develop expectations that interventions to prolong life are "reasonable." The context of the comment suggests that physicians may consider parental expectations of prolonging life to be unreasonable. The American Congress of Obstetricians and Gynecologists explicitly states, "it is unethical for a physician to deny patients important information in order to avoid physician-patient interactions that are difficult or uncomfortable."<sup>23(p1025)</sup> Religious, family, and cultural beliefs often influence parental decisions. These decisions are not merely of weighing potential risks vs benefits; they may, in fact, represent significant spiritual or ethical dilemmas. We advocate a more bal-

anced approach to information shared in the counseling process, including use of up-to-date survival figures taking into consideration individual clinical findings of the child. This approach should include potential surgical interventions and avoidance of the terms *lethal* or *poor quality of life* without presupposition of the family's perceptions. Health care professionals have an obligation to "present prognostic information in a frank and balanced way without coercion."<sup>21(p402)</sup> As proposed by Bruns,<sup>61</sup> they also have an obligation to offer "a positive viewpoint" and "err on the side of life" within the framework of the Convention of the Rights of the Child and Convention on the Rights of Persons with Disabilities.<sup>16,61,62</sup>

### Participation

This concept of PCC includes patients' ability to participate in and make decisions about their care at the level they choose.<sup>63</sup> Heuser et al<sup>59</sup> showed that, for women wishing to continue the pregnancy, 99% of physicians would adhere to a patient's wish not to intervene on the fetus's behalf. Five percent would discourage nonintervention, but would adhere to the patient's decision. In contrast, 82% of physicians would adhere to the patient's wish to intervene to prolong the fetus's life (eg, by cesarean section) and 66% would discourage intervention, but adhere to the patient's decision. The perspective appears to be that intervention puts the mother at risk with no clear benefit to a fetus with severe anomalies.

The variability noted in physician approaches raises the ethical principle of justice. Distributive justice assumes that patients with similar conditions are treated alike.<sup>64</sup> In discussions regarding inequity in treatment, the lives of both the fetus with T18 or T13 and the mother may be at stake. Injustice in prenatal management of T18 and T13 may go beyond individual variation in provider approaches to cesarean section. It also involves the broader question of how much personal risk a woman should be allowed to assume to prolong the life of her child. Individuals are often allowed or even encouraged to assume personal risk, such as living organ transplantation, to increase the length or QOL of a seriously ill family member or stranger with no guarantee of positive outcomes. Denying this opportunity for women who wish to assume a similar risk to ensure the live birth of a child with an uncertain prognosis could be considered unjust to both fetus and mother.

If it is known that nonintervention is likely to result in fetal morbidity or mortality, failure to intervene may violate the ethical principle of beneficence, particularly when the mother is requesting the intervention. Although physician approaches vary widely to maternal requests for late trimester pregnancy termination or nonaggressive intrapartum management, Spinnato et al suggest that physicians are obligated to respect maternal autonomy. Spinnato et al<sup>65</sup> explain, "When a patient's desire to avoid an intrapartum stillbirth is strong enough that substantial psychological harm might result from one, the physician's beneficence-based obligation to her and respect for maternal autonomy justify selectively aggressive intrapartum therapy, even if no beneficence-based obligation to the fetus exists."<sup>65(p89)</sup>

### Collaboration

Patient-centered care collaboration focuses on involvement of all health care constituents in the development of health care policies.<sup>63</sup> After the birth of a child with T18 or T13, the role of the mother shifts from participant to collaborator in conjunction with other family mem-

bers and health care professionals. Perceived collaboration in decision making has been described as the most important determinant of parental satisfaction with end-of-life care.<sup>66</sup> Too often collaboration between physicians and parents is compromised by contention. In a survey of 54 pediatricians, 44% indicated that they would be willing to make resuscitative efforts on behalf of an infant with T18 who has known congenital heart disease (present in >90% of T18 cases).<sup>19</sup> The authors characterize the pediatricians' willingness to intervene as adoption of an "'ethic of abdication' in their approach to difficult treatment/nontreatment decisions" as a result of the "strong emphasis bioethics has placed on patient autonomy."<sup>19(p1108)</sup> Physicians frequently center their perception on the best interest of the child, futility of treatment, and waste of resources. Resistance of pediatric specialists to intervene is apparent in a survey of 859 physicians regarding their attitudes toward cardiac palliations in infants with T18 or T13. Neonatologists were least likely (7%) to recommend intervention on heart lesions compared with geneticists (20%) and cardiologists (32%); however, there was a 3-fold increase in willingness to intervene among all specialists if intervention is requested by parents.<sup>53</sup>

Disparate perspectives between parents and clinicians on the best interest of the child, futility of treatment, and allocation of resources may create tension and set the stage for adversarial relationships. Janvier and colleagues<sup>67</sup> illustrate the deep divisions between parents and clinicians caring for infants with T18 or T13. In this case, the parents wanted maximal intervention for their 1-year-old child with T18, including cardiac surgery, and were unmoved by discussions about poor outcomes, risks of surgery, and futility of treatment. It may be difficult for parents to accept that nonintervention is in the best interest of the child when it is likely to hasten the child's death. Finding consensus with parents about futility of treatment may be even more problematic, as medical futility is a poorly defined, highly subjective, and conflict-ridden concept.<sup>68</sup> In the case cited above, the child did well after surgery, which suggests that the parents' request was reasonable and not futile. The variability in outcomes and intensity of interventions for infants with T18 and T13 suggests that it may be difficult to clearly establish the futility of treatment.

In considering allocation of resources, Janvier et al emphasize that "the principle of justice demands similar patients be treated similarly."<sup>67(p758)</sup> They assert that, among other classes of patients who are expected to die or have severe neurodevelopmental compromise, such as those with brain trauma, the general standard is to defer to the wishes of the patient's family. The authors argue that it is unjust to impose restrictions specifically for children with T18 (and, by extension, T13) that are nonexistent for other patients with similarly severe limitations. Furthermore, concerns about wasting resources may be dispelled by the low incidence of live T18 or T13 births and the infrequency of parental requests for maximal intervention.<sup>7</sup>

Collaboration among health care professionals is a particularly important consideration in providing care after diagnosis of T18 or T13. The interdisciplinary structure of models such as perinatal palliative care can provide valuable support for the complex needs of patients and families, particularly if the scope of care is broadened to address the needs of women who choose termination of pregnancy. Such teams may be composed of neonatologists, geneticists, palliative care specialists, social workers, ethicists, and nurses—all of whom should have sufficient collective expertise to address the physical, psychosocial, practical, and spiritual needs of the child and family.<sup>21</sup> An ethics consultation may be valuable in cases un-



settled by perinatal and neonatal management teams.<sup>21</sup> Such consultations offer a forum for exploration of the family's values and the moral context in which decisions are being made and may result in consideration of a wider range of satisfactory options for care. Lantos suggests that "yesterday's moral gray zones disappear as more data elucidate that treatment is either clearly beneficial or ineffective."<sup>18(p397)</sup> He emphasizes that decisions about aggressive treatment of infants with T18 and T13 are in a "'stable gray zone' in which treatment decisions are unlikely to become more clear"<sup>18(p397)</sup> and align with a shared decision-making approach.<sup>69</sup>

## Conclusions

Patient-centered care facilitates decision making after diagnosis of T18 or T13 and other perinatal conditions in which there are conflicting values and uncertainty of outcomes based on patterns of variability of care. Patient-centered care focuses on the parent and child's best interest,<sup>70</sup> offers an ethically sound approach that considers the well-being of all involved, and can be applied in cases of T18, T13, or other conditions requiring complex perinatal decisions.

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