

PHA Monthly
Official Newsletter for the Pro-Life Healthcare Alliance
51st Edition
July 3, 2018



IMPORTANT NOTICE: If you would like to continue to receive the PHA Monthly newsletter or, if you are not currently a subscriber but would like to be, please [click here](#). The PHA is updating its records.

Welcome to the 51st edition of PHA Monthly, the e-newsletter for the Pro-life Healthcare Alliance. This newsletter provides another opportunity for the PHA to share pro-life information about current healthcare issues, PHA events, contributions from members and other relevant information.

Please share your ideas and suggestions with us.

Visit our website at www.prolifehealthcare.org for more information.

PRO-LIFE HEALTHCARE ALLIANCE MISSION STATEMENT

Promoting and developing concrete "pro-life healthcare"* alternatives and advocating for those facing the grave consequences of healthcare rationing and unethical practices, especially those at risk of euthanasia and assisted suicide.

**"Pro-life healthcare" means medical care in which the life and safety of each person comes first, where each person receives medical care across their lifespan based on their need for care, regardless of their abilities or perceived "quality of life."*

MESSAGE FROM THE CHAIR: ARE YOU PREPARED?

By Mary Merritt



Before the take-off of a recent flight to see our grandchildren--newborn twins, my husband and I listened to the attendants giving instructions for emergencies. I noticed one man moving his finger to count the number of rows from his seat to the nearest exit. Nearby passengers could see what he was doing and had the choice to count the rows or to dismiss that precaution. There may have been other passengers who mentally counted the rows without being conspicuous, but it seemed most were not paying attention to the attendants as they pointed out the exits and demonstrated safety measures. Thankfully, there was no emergency, but we were among the seemingly few who paid attention and were prepared.

Studies have shown that the majority of people do not have a medical advance directive. If you, like I was years ago, are not sure what to do and which document to choose, the PHA is here to instruct you regarding the "safety measures" you need to take to make pro-life decisions which are adjustable for various medical conditions, changing times, and advances in treatments. We will happily provide you with educational materials (including a subscription to this newsletter) and speakers. Also, we organize conferences in cooperation with local pro-life groups, churches, etc.

The advance directive that the PHA recommends is the Protective Medical Decisions Document (PMDD), a power of attorney for healthcare available from the Patients Rights Council. (To order PMDD packets, call 740-282-3810.) Some time ago, I ordered PMDD packets for my husband and myself, and also for our children and their spouses. PHA literature and speakers often forewarn, "You never know when a medical situation may require someone else--hopefully someone you've chosen--to make medical decisions for you." By executing a PMDD, you are naming someone you trust (your "agent") to make medical decisions for you if you are ever unable to do so for yourself and you are clearly stating that no one, not even your agent, has the authority to approve the intentional ending of your life.

On a related note, last week, at the National Right to Life Convention, my husband and I attended a breakout session about Simon's Law and the story behind it. This 2017 Kansas legislation ended the practice of placing secret DNR (do not resuscitate orders) in children's medical charts, affirming the right of parents to be informed and involved in such crucial medical decisions for their minor children. Nancy Valko, RN, has written about [Simon's Law](#) and the details of this ground-breaking pro-life law were explained in the [June 2017 PHA Monthly](#).

At the Conference, we met Sheryl Crosier, Simon's mom, who shares her family's powerful story in this newsletter. We are blessed to have another point of view--a mother's. When you read this article, contemplate the need for a Simon's Law in your state. Also, the lessons learned from the Crosier family's tragic experience will help all of us protect and inform future hospital patients and their family members as well as educate our own family members, friends, church members, etc.

Speaking of educating others, I carry a variety of pro-life educational materials in the trunk of our car so that, when the opportunity arises to share information with others, I am prepared. See "OUR SUPER HERO" in this newsletter for another idea about how to be a bearer of life-protective information to your community.

Are you prepared for a life-threatening medical situation for yourself or a loved one? We can help. Call 651-484-1040 and ask to be referred to a Pro-life Healthcare Alliance patient advocate.

TWO MEMBERS OF THE PRO-LIFE HEALTHCARE ALLIANCE SPEAKERS BUREAU WERE PRESENTERS AT THE NATIONAL RIGHT TO LIFE CONFERENCE

Alex Schadenberg, Executive Director of the Euthanasia Prevention Coalition (EPC), and Nancy Valko, RN, Advanced Legal Nurse Consultant, were presenters at the NRL Conference held in Kansas City late last month. The information they shared increased awareness of the perils that euthanasia, assisted suicide, and denial of treatment pose for vulnerable people.

On Friday evening, June 29th, Alex showed the EPC's new documentary "Fatal Flaws" to an attentive crowd. The film features personal stories from people who oppose assisted suicide and interviews with leaders of the death lobbies in the Netherlands and the United States. A lively question and answer period followed the showing and the available "Fatal Flaws" DVDs sold out! More information about this powerful, mind-changing film and how to order it is available at <http://www.epcc.ca/fatal-flaws-legalizing-assisted-death/>.

On June 30th, Nancy had a breakout session: "From 'Choice' to 'No Choice'--Lessons from the Baby Alfie Evans Case." This presentation was very well attended. Nancy's personal experiences and handouts from her blog (<https://nancyvalko.com/>) enhanced an excellent talk. Her handout on the Alfie Evans case will be featured in the next edition of the PHA Monthly.

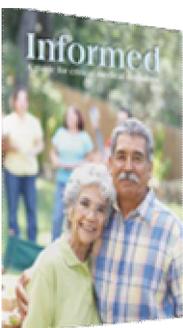
Thank you, Alex and Nancy.



Imposed Death: Euthanasia and Assisted Suicide HLA's 16-page Magazine...

...unveils the tactics and goals of the "right to die" movement; explains the life-threatening attitudes and policies often encountered in various health care settings today; and highlights the experiences and opinions of those most intimately affected by health care policies and laws which endorse imposed death in its various guises. This publication will be an effective educational and life-saving tool only if it reaches people. YOU are a vitally important partner in this work. Please help distribute Imposed Death. To order copies, call 651-484-1040 or email feedback@humanlife.org, or

go to: <https://resources.humanlife.org/imposed-death/>



Informed: A guide for critical medical decisions HLA's 16-page Magazine...

...is an introductory tool to help patients, families and surrogates more fully participate in the interaction with doctors and other health professionals. Topics include: Advanced Directives, POLST, Ventilators, Hospice Care and more. To order copies, call 651-484-1040 or email feedback@humanlife.org, or go to: <https://resources.humanlife.org/informed/>

OUR SUPER HERO "MAGS"

By Jo Tolck

As a new day dawns over the horizon, "Mags" stacks his supplies in the front seat of his "Mags-mobile" and heads out on a mission.

Moving slowly down the side streets of town, Mags lowers the front windows of his trusty vehicle, reaches over to his stack of rolled up materials, and selects two. One is skillfully tossed to land in the driveway to his left, the other to his right. (Being ambidextrous is just one of his super powers.)

Our hero continues on this mission for a of couple hours. All this tossing makes him thirsty, so he heads for the nearest gas station convenience store. Once inside, Mags spots another opportunity. Heading for the restroom, he places materials on the counter by the sink.

After purchasing a nutritious beverage (super heroes don't ingest just anything), Mags decides to feed his Mags-mobile. At the pump--another opportunity! While filling his tank, Mags affixes a not-easily-removed pro-life sticker to the pump for future motorists to enjoy.

By now, you've probably guessed our guy's most impressive super power--EDUCATION! Armed with *Imposed Death* and *Informed magazines*, our hero sets off on yet another mission.

Okay, a little amusing, but our super hero is actually a real-life man who has made it his goal to educate the residents of his state regarding end-of-life issues, one driveway, one bathroom, one gas pump, etc. at a time. AND you can be a pro-life super hero too! Mags can always use a sidekick!

Please contact us if you have used other interesting ways to educate with HLA-PHA publications. Email the editor of the PHA Monthly at crti@sbcglobal.net . We may feature your story next.



THE STORY BEHIND SIMON'S LAW AND PARENTAL RIGHTS OVER DNRS

By Sheryl Crosier

On September 7, 2010, God blessed us with a precious son, Simon. Even with a bilateral cleft lip and weighing only 4 pounds, 3 ounces, he was truly our gift from God.

On Simon's third day of life, he was diagnosed with Trisomy 18, also known as Edward's syndrome. For too long, this condition has been considered a "lethal" anomaly and "incompatible with life" despite evidence of individuals with Edward's syndrome surviving for not only months and years, but even decades.

After that clinical diagnosis, Simon's care and treatment began to be withheld, but the extent of the hospital's denial of care would not be known until much later.

Simon remained in the hospital and our lives revolved around him. Our family and friends spent many hours cuddling Simon and interacting with him.

As Simon neared three months of age, we looked forward to surgery to repair his heart. Tragedy struck just days before the scheduled pre-surgery consult. On December 3, our son's oxygen levels began to fall. Shockingly, we were told, "This is the end. Nothing can be done." Imagine watching your child take his last breaths inside a hospital where he has been a patient for months and no "code blue" resuscitation is engaged!

I pleaded with the medical staff again and again, yet was told, "NOTHING can be done." That morning at 10:45, our sweet baby, Simon, died.

Our sorrow was unimaginable. My agony was soon compounded when the other hospital called to confirm our upcoming consult appointment and I had to tell them that my son was dead.

THE HORRIBLE TRUTH

After Simon's death, we found out the horrible truth: there was a do-not-resuscitate (DNR) instruction in his medical file. This explains why the staff stood around and did nothing. If Simon had been a typical three-month-old, NICU staffers would have been hustling to save him. Because he was a child with one extra chromosome, no one did a thing.

We also discovered--too late--that Simon had only been getting comfort feeds, an insufficient amount of food for growth and development. Simon was being intentionally starved! As an example of that food denial, my husband Scott relayed that he had once been awakened at 4:40 a.m. by a nurse practitioner at the hospital when Simon was fussing and clearly irritated. She firmly asked, "Do you want me to give him morphine?" Scott knew instinctively that giving a powerful narcotic to a tiny infant with severe heart problems was a bad, if not fatal, idea, so he adamantly refused her recommendation. In hindsight, Simon was likely fussy because he was very hungry from being denied sufficient nutrition in the "comfort" feed! Scott gently took Simon in his strong arms and rested him on his chest and our son calmed down immediately.

In spite of the fact that Scott had refused the administration of morphine, on Simon's last day of life he was given a drug which was contraindicated for his apnea, suppressed his respiratory drive, and expedited his death. How would you feel if you discovered your child was given a drug that caused adverse effects to the point of death? Simon's human rights were violated, as he was a victim of genetic discrimination, and our parental rights were completely taken away.

Medical "experts" decided our son's life didn't have value and took a variety of actions to effectuate his demise.

If you have not yet seen it, I encourage you to see the independent documentary film "Labeled." The film interviews many families across the USA who fought for their medically-challenged children to be treated appropriately. It is gut-wrenching to learn it is legal--and common--for a physician to withhold care and place a DNR in a child's chart without parental knowledge or consent. It doesn't matter if the child is one day old or 17 years old, any doctor can unilaterally issue a DNR order to a minor.

Should it be legal to withhold procedures, medications, food and/or water to hasten the death of a child without parental consent? Should it be legal to place a DNR in a child's medical chart without parental consent? Simon's Law says, "NO!"

GOD BLESSED US WITH A SON, NOT A SYNDROME

I can't bring my son, Simon, back, but I want to make sure this doesn't happen to another child, your child or any of my other children. In my opinion, no one loves their child more than their parents. I believe a parent should have the right to make medical decisions for their child.



God did not bless us with a syndrome. He blessed us with a son--Simon. His story will continue to change hearts. I will continue to increase awareness of patient discrimination and help to empower parents to make sure their children are getting the care they deserve.

Unfortunately, Simon was not an isolated incident. Both Scott and I are Chapter Chairs for SOFT (Support Organization for Trisomy). We heard from many families that (1) they will not EVER leave their child alone in a hospital and (2) they monitor medical staff activity with the utmost caution. Scott and I also maintained a vigil at Simon's side and the few times we went out for a dinner "date night," Grandma Lois stayed with Simon in his hospital room.

If ALL children aren't protected, then ALL are at risk! It could be your child or grandchild next. The need for parental permission for DNR orders also extends to children without special needs who have experienced life-threatening accidents or disease.

WE MUST PROTECT ALL CHILDREN, IN EVERY STATE, FROM MEDICAL DISCRIMINATION

All states need to imitate Kansas and pass Simon's Law, which was enacted in April 2017 and is in effect. The law (1) empowers parents to reject DNR orders for their children and, more broadly, (2) enables any interested party to discover which medical facilities have written "futility" policies that dictate when life-saving care will be withheld.

Karye Perez manages Simon's Law pages on social media and is now coordinating Simon's Law nationwide, connecting with families, physicians, pro-life organizations, disability groups and legislatures. Perez is a medical professional, mother of two children with special needs, and former advocate for Charlie Gard. Perez shares her findings about United States hospitals in a recent *Bioethics Report* interview with Bobby Schindler, President of

Terri Schiavo Life and Hope Network:

I called quite a few hospitals. I was grilling them and asking them do they have these futility policies and I was really getting the run around. I was told, "No, we really don't have that. We have an ethics committee that is really patient-oriented." It was constant denial from the facilities with my messages often pawned off on someone else. Nobody would ever give me a clear answer and certainly would not forward any written policies on denial of care.

SIMON'S LEGACY

As for the Crosier family, our grief will never disappear until we hold our little warrior, Simon, again. Simon was, in effect, trying to reach Mount Everest with very little, if any, medical assistance. To memorialize his travails, we have written two books.

My longing to commemorate our journey resulted in a self-published book, *I Am Not a Syndrome--My Name is Simon*. I believe my son provided the title of his first book because our children are not labels and are not defects. No person is disposable and every person has a name and an identity.

Simon's second book, as told by Samuel and Sean, Simon's big brothers, is titled *Hello, My Name is Simon*. It explains their journey and the unconditional love they had for their baby brother. While it is a common saying that children are resilient, the death of a sibling is truly heartbreaking and life changing. Sean testified to the Kansas Senate in support of passage of Simon's Law:

Hello, my name is Sean Crosier, one of Simon's big brothers. I always REALLY wanted to be a big brother. I was young when Simon was born, age 5 to be exact. But my age did not take away any of the hurt of losing him. Looking back, my parents tried to protect me and my older brother, Samuel. But, to this day I still want to know why the doctors did not do what doctors are supposed to do. I loved Simon so much and when he arrived I was finally a big brother. When I think about it, I know they could have done more and truly wish they had. My parents eventually fulfilled my wish and adopted my little sister from China. I am now the big brother of Simon and Sabella.

Simon's legacy lives on. As a family, we will continue making memories in memory of Simon. If it wasn't for Simon, we likely wouldn't have adopted our daughter Sabella. We believe Sabella was "Simon sent."

Please protect our children and parental rights. Please stop the practice of issuing secret DNR's. If all children aren't protected, then all are at risk.

The name Simon means, "To be heard." Let Simon's message be heard! Make your state a Simon State.

CASE IN POINT

What if...?

Don Burnelle, a 64-year-old Windsor, Ontario man, was the passenger in a car involved in a horrific crash on May 26, 2017. After weeks in a medically induced coma and three months of treatment in hospital, Mr. Burnelle returned home to finish healing.

Doctors had told his wife Brenda that they did not expect him to live. "I refused to believe what all the doctors--and I mean all of them--were telling me about how sick he was," she said. "I asked all of that conversation about him not surviving this crash be taken outside of his room." Mr. Burnelle is "very grateful that I'm on the road to getting my life back with all my friends." [1]

Alex Schadenberg, Executive Director of the Euthanasia Prevention Coalition, asks us to consider,

"This is a story of hope, but this story also causes us to question, what if Don had stated, in a legal document, that he would not want to live this way?"[2]

And, Julie Grimstad, a long-time advocate for patients' rights, asks, "What if someone else had decided that Mr. Burnelle 'would not want to live this way' and cut off all his medical care?"

[1] *CBC News*, 8/25/2017: <http://www.cbc.ca/news/canada/windsor/expected-to-die-windsor-man-wakes-from-coma-and-returns-home-1.4263397>

[2] *LifeNews.com*, 8/29/2017: <http://www.lifenews.com/2017/08/29/he-was-comatose-for-weeks-after-a-horrific-crash-and-doctors-expected-him-to-die-now-hes-returned-home/>

REST IN PEACE, JAHİ

Jahi McMath passed away on June 22, 2018.

On December 9, 2013, Jahi McMath, age 13, underwent surgery to remove her tonsils and adenoids at Children's Hospital and Research Center in Oakland, California. While still in the ICU, Jahi started to bleed and suffered cardiac arrest. Three days later, she was declared "brain dead." Her family disagreed and subsequently found themselves in a surreal battle for Jahi's life, which required moving her to New Jersey. Bobby Schindler, President of the Terri Schiavo Life & Hope Network (<https://www.lifeandhope.com/>), explains:

After Jahi was ruled to be brain dead, she and her family found themselves in an incredible situation wherein Jahi was considered legally dead in California, but legally alive in New Jersey due to that state's religious accommodations. Nailah Winkfield [her mother] and Jahi's entire family fought for nearly five years on the grounds that Jahi exhibited behavior inconsistent with the brain death diagnosis. Jahi was not only still alive, but may have benefited from treatment and rehabilitative care.

Various news outlets are now reporting that Jahi McMath has died. Mr. Schindler points out that this "ironically underscores the reality that so many have denied for nearly five years: Jahi was alive."

TAKE ACTION

In spite of heroic and persistent efforts made by pro-life organizations and individuals, the stark reality is that the healthcare system itself has become an ever-increasing threat to the well-being and lives of the preborn, the young, the old and the disabled and ailing of any age. The PHA is dedicated to renewing reverence for life within healthcare. For some excellent information about current and historical issues regarding abortion, contraception, euthanasia, stealth euthanasia, hospice, advance directives and other pertinent topics, please check out these resources.

- [Hospice Patient's Alliance](http://www.hospicepatients.org/)
<http://www.hospicepatients.org/>
- [Euthanasia Prevention Coalition](http://alexschadenberg.blogspot.com/)
<http://alexschadenberg.blogspot.com/>
- [Patient's Rights Council](http://www.patientsrightscouncil.org/site/)
<http://www.patientsrightscouncil.org/site/>
- [Prenatal Partners for Life](http://www.prenatalpartnersforlife.org/)
<http://www.prenatalpartnersforlife.org/>
- [Pro Life Wisconsin](https://www.prolifewi.org/) <https://www.prolifewi.org/>
- [American Life League](http://www.all.org/) <http://www.all.org/>
- [Texas Right to Life](https://www.texasrighttolife.com/) <https://www.texasrighttolife.com/>
- [Read Stealth Euthanasia: Health Care Tyranny in America by Ron Panzer](http://www.hospicepatients.org/this-thing-called-hospice.html) <http://www.hospicepatients.org/this-thing-called-hospice.html>

The Pro-life Healthcare Alliance needs your support.

The suggested PHA membership donation is \$25 per year. Please renew your membership or join today. Be a part of this vitally important work and help the PHA continue and grow.

Pray for renewal of reverence for life. In particular we have designated Thursday as a special day of prayer for the mission of the PHA.



Pro-life Healthcare Alliance

*a program of [Human Life Alliance](#)
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