



**Pro-life Healthcare Alliance**

A Program of Human Life Alliance

**Feb. 19, 2014**

## **PHA Monthly**

*Newsletter for the Pro-Life Healthcare Alliance  
Eighth Edition*

Welcome to the eighth edition of PHA Monthly, the e-newsletter for the Pro-life Healthcare Alliance. This newsletter provides an 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](http://www.prolifehealthcare.org) for more information.

### **The Pro-life Healthcare Alliance, founded in June 2012, is striving to:**

- Establish a support network of healthcare providers, organizations and individuals who subscribe to the "pro-life healthcare philosophy." (See PHA Mission Statement at [www.prolifehealthcare.org](http://www.prolifehealthcare.org).)
- Encourage the growth and availability of pro-life healthcare services for all.
- Respond to persons needing pro-life healthcare or seeking reliable information about medical decision making.
- Educate the public by articulating principles guiding the care, support, and protection of the life and dignity of all human beings, including those who are preborn.

As always, we continually pray for renewal of reverence for life within healthcare. In particular, we have designated Thursday as a special day of prayer for the mission of the Pro-life Healthcare Alliance. St. Paul tells us in Philippians 4 to "not be anxious about anything, but in everything by prayer and petition, with thanksgiving, present your requests to God." We invite you to join us each Thursday by pausing to ask God to guide and bless the PHA and all its members and supporters. Thank you.

**The First National Symposium on  
EUTHANASIA AND ASSISTED SUICIDE**

**Friday and Saturday, May 2-3, 2014  
Minneapolis, Minnesota**

The Euthanasia Prevention Coalition and the Pro-Life Healthcare Alliance are excited to announce this 2-day event hosting a line-up of exceptional speakers covering a wide range of end-of-life topics.



**Alex Schadenberg**, Executive Director, Euthanasia Prevention Coalition, will speak about *Exposing Vulnerable People to Euthanasia and Assisted Suicide* and *Euthanasia World Overview* as well as leading the Coalition Building Workshop.



**Julie Grimstad, LPN**, Executive Director of Life is Worth Living and chair of the Pro-life Healthcare Alliance, will speak on *Medical Futility, Brain Death and Other Threats*. She will also be leading the Patient Advocacy Training.



**Ryan Verret**, Louisiana Right to Life, Center for Medical Ethics, will talk about *Playing Defense and Offense in Medical Ethics: What's Happening in the U.S. and how we took control of the ball in Louisiana!* He will also be leading in the Coalition Building Workshop.



**Tim Rosales**, Vice President, The Wayne Johnson Agency, a public affairs firm. Tim will be participating as a leader in the Coalition Building Workshop.



**John B. Kelly**, New England Regional Director Not Dead Yet, will discuss *Assisted Suicide, Euthanasia and the Massachusetts Experience*. John will also be leading the Coalition Building Workshop.



**Bobby Schindler**, Executive Director of the Terri Schiavo Life and Hope Network, Will speak on *Media Ethics and The Bioethics Movement* and *The Terri Schiavo Case*.



**Cristen M. Krebs, DNP, ANP-BC**, Catholic Hospice Founder/Executive Director, will speak about *Poking Holes in the Darkness: Pro-life Hospice*.



**Nancy Elliott**, State Representative from New Hampshire, Currently serving on the leadership team for Euthanasia Prevention Coalition, International, will discuss, *State Sponsored Suicide: What it really is and how to effectively fight against it*.



**Mary Kellett**, founder and President of Prenatal Partners for Life, will discuss *Prenatal and Infant Euthanasia*.



**Mark Davis Pickup**, Pro-Life speaker, will share about *Grief and the Common Good*

**Schedule:**  
**Friday May 2, 2014**

**1-5pm Coalition Building Workshop\***

Alex Schadenberg, Tim Rosales, John Kelley and Ryan Verret

**1-5pm Patient Advocacy Training\***, Julie Grimstad

**7:00-9:00pm**

Alex Schadenberg-talk **Exposing Vulnerable People to Euthanasia and Assisted Suicide**

8:10-9:00pm Bobby Schindler talk **Media Ethics and The Bioethics Movement**

**Friday-Nursing Continuing Education Units, 2**

**Saturday May 3, 2014 9-5pm**

**Saturday-Nursing Continuing Education Units, 7.8**

Ramada Plaza Minneapolis

1330 Industrial Blvd

Minneapolis, MN 55413

612-331-1900

**Conference \$50.00**

**Coalition building/leadership seminar \$30.00**

**Patient Advocacy Training \$20.00**

**Special room rates for this event**

Room rate \$85.00 per night

Mention Human Life Alliance

Register at [www.imposeddeath.org](http://www.imposeddeath.org) or call 651-484-1040

\*The Coalition Building Workshop will bring together people from around the nation to learn, strategize and organize against legalization of assisted suicide and other pro-euthanasia legislation. Hear from leaders who have effectively fought legislation in their own states.

\*Patient Advocacy-Julie Grimstad has 28 years experience as a volunteer patient advocate. She says, "Being a patient advocate is an awesome privilege and a profound obligation. For some medically vulnerable people, we are their last friends. They need us like a person who is drowning needs a life-preserver."

You will learn:

1. What a volunteer patient advocate is.
2. What a patient advocate does.
3. Why there is an urgent need for an army of pro-life patient advocates

Even if you are not ready to be a patient advocate, you can simply be a friend. Julie will introduce you to the Befriender Program. Learn what you can do to enhance the quality of life of nursing home residents and other people isolated from society.

In the course of examining complex issues such as death with dignity and true mercy, Julie tells heart warming and heart wrenching stories about some of the people she has assisted as a patient advocate.

Come discover how you can safeguard the welfare of a patient in the healthcare system and/or alleviate the suffering of a lonely person whose number one need is a friend.

### **Scholarship Help Needed**

Help us offer scholarships to students and healthcare workers who cannot afford to attend the First National Symposium on Euthanasia and Assisted Suicide.

We want to help people who are eager to learn and cannot afford the registration fees. Could you consider a gift of \$50, \$100, \$75 or more to support our efforts?

Your donation will enable those who cannot afford the conference to attend and share this life-saving information in their own communities.

Please designate donations as "Symposium Scholarship Fund" and mail to Human Life Alliance, 1614 - 93<sup>rd</sup> Lane NE, Blaine, MN 55449 or call 651-484-1040

## The Struggle to Be Born and Live: The Plight of the Child Diagnosed with Special Needs

By Mary Kellett



When I found out I was expecting a baby in the summer of 2010, my thoughts were of things like: How will I ever keep up with the laundry? What bedroom will this little one go in, the boys or the girls? If I could have foreseen the future, I would have known I'd soon be thinking: Why am I being lied to? Why are we being treated like this? Why don't they want to help my baby? But the worst thought would be: How did my child really die? In those early days of blissful ignorance I had a peaceful, happy acceptance of the new little life within me. By my fourth month of pregnancy my happy disposition ended and a journey of uncertainty and sorrow began.

When I was nineteen weeks pregnant, a level two ultrasound was recommended because of my age. I was 43 and had 10 healthy children who were all excited for another baby. The mood turned somber as the doctor explained that he saw some "markers" for a condition called trisomy 18. An immediate amniocentesis was strongly suggested. That way, the doctor explained, we would have more choices - like abortion.

I knew the test carried risks, one of them being miscarriage, and would not chance hurting our son. My husband and I made it clear abortion would never be an option. Instead we named him Peter and vowed to love and care for him as long as God allowed.

Every visit to the doctor brought more pressure to have the amniocentesis. Looking back, I can see that their motives for wanting to know our son's condition were different than ours. We were told there were no survivors beyond two weeks with trisomy 18 and were given very little hope Peter would make it to birth.

Our experience is not unique. Pressure to have prenatal testing is pervasive, often accompanied by strong recommendations to abort babies that don't make the cut of perfection.<sup>[i]</sup> There is a lot of talk about the best use of resources and quality of life, but very little about the joy families can have and the inherent value of these precious lives.

Some parents are made to feel guilty for wanting to carry their babies to term and, despite their health issues, help them reach their full potential. Deceptive and confusing language may be used and the negative aspects of caring for a child with disabilities are overly emphasized.<sup>[ii]</sup>

Statistical evidence backs up the grim and negative environment surrounding babies prenatally diagnosed as having special needs. These babies face huge odds to be born and survive. It is staggering that over 90% of their lives are ended by abortion. <sup>[iii]</sup>

With a false and twisted sense of compassion, abortion is often presented as a moral obligation and urged as the most loving choice for a child who may have special needs. This happens despite overwhelming evidence that people living with disabilities have very happy and fulfilling lives. A recent survey of people with Down syndrome, published in the *American Journal of Genetics*, found that nearly 99% of respondents indicated they were happy with their lives, 97% liked who they are, and 96% liked how they look. Nearly 99% of people with DS expressed love for their families and 97% liked their brothers and sisters.

We knew first hand the unique joy a child with disabilities can bring to a family. Peter was born at 34 weeks by C-section. He was given great care up until day two of his life when test results confirmed he had full trisomy 18. It was recommended that we stop all treatment, "wrap him up in a blanket and hold him as he dies." We were assured Peter would be made comfortable as this

happened. We were told he would lead a life of terrible pain and suffering and would never know us, respond to or interact with us.

Our daughter did some internet research and found many children living with trisomy 18, some in their twenties and thirties. When I confronted the doctor, asking why he had lied to me, he said, "How these children do largely depends on the choices their parents make for them." I responded, "How can parents make decisions when they don't receive accurate information?" He then said, "Well, we have to think about resources and you know Peter will never be able to contribute to society and will be a horrible burden to your family." It was devastating to hear that my son was not worth the money to help him.

One of the most heartbreaking conversations I had was with a woman doctor who advised me, if I wanted to be a good mother, I wouldn't take Peter home. She said I had to let Peter go because he would be a horrible burden to our family and it would not be fair to our other children.

The eugenic and utilitarian mentality of those conversations is now evident to me. At the time, all I could do was cry and wonder why they wouldn't help my son like they would any other child. Peter's first weeks of life were marked by a continuous, ongoing plethora of incomplete, inaccurate information and outright lies. We were afraid for his life in the hospital and brought him home to care for him, weighing only 3lbs 11oz.

Peter thrived at home. He grew and did many things we were told he would never do, like drink from a bottle, roll over, play and eat by mouth. He developed and knew and interacted with us. Our family tremendously loved him. He was not for one moment a burden, only a joy and a blessing. He helped us become better people and taught us so much about love, compassion and empathy for others. He was the best of us and was a joy to have in our family.

Everything was the opposite of what we were told. Sure there were challenges, but we rose to them. We came together as a family to care for Peter. Our children learned the valuable lesson of unconditional love from Peter. They knew we would always love and care for them too, not just if it was easy, convenient or financially expedient, but always. We also received wonderful support from friends and church. Studies show that families do cope and siblings learn important lessons in patience and empathy for others.

A study on children with Trisomy 13 and 18, published in *Pediatrics*, reveals that, despite their severe disabilities, 97% of parents described their child as a happy child. 98% of parents reported these children enriched their family, 89% reported that the overall experience of their child's life was positive and 82% felt that this child had a positive effect on siblings.<sup>[iv]</sup>

The language used by doctors and medical professionals when dealing with children like Peter can mean the difference between life and death. In the article "Lethal Language, Lethal Decisions," the authors say, "Although many of the congenital syndromes that used to be lethal no longer are, they are still routinely referred to as 'lethal anomalies.' But the label is not only inaccurate, it is also dangerous: by portraying as a medical determination what is in fact a judgment about the child's quality of life, it wrests from the parents a decision that only the parents can make."<sup>[v]</sup>

One of the most common and heartbreaking terms used is "Incompatible with Life," despite the fact that there is life in the womb for these children and the possibility of a longer life when born. **Clear, accurate, complete, non-judgmental information offered in a compassionate way is needed and deserved by families.** Doctors also need to be patient and give families time to process the information. Parents are often in shock and tremendous pain when they are told their baby may have health problems. For many, this is the most difficult time of the whole experience. Sincere compassion and a gentle attitude are so helpful to families. If the physician cannot provide that, he or she should refer the family to a doctor who can.

In our journey with Peter, the fight for proper treatment continued his whole life. One example was the aggressive pressure to sign a DNR at hospital visits. A typical attitude was revealed to us during one of these visits. We were asked several times to sign a DNR and several times replied, "No." The doctor said, "Well, if Peter stops breathing, that is him telling us it's his time to go." Peter's father responded, "No, if you help him and if he does not respond, then it's his time, but we want you to try and help him." There was a big difference between our approach to Peter's care and the approach of many medical professionals. We discovered there is even a term, "slow code," which is a deceptive, half-hearted resuscitation effort designed to look like the patient is being helped.[\[vi\]](#)

We always wanted to give Peter a chance and help him reach his full potential. Many of these beautiful kids could live longer if given the proper care and treatment. Instead we have ordinary, routine and medically indicated procedures termed "aggressive" and "futile" for these children. Parents are often pressured to not pursue treatment. Passive euthanasia is commonly called "comfort care," and frequently occurs without parents' knowledge.

Medical students are taught there are no survivors with trisomy 13 and 18. I gave a talk about Peter at a large university when he was a few years old. In the auditorium were many medical and nursing students. I presented a slide show of Peter and many of his friends with trisomy 13 and 18. Numerous students came to talk to me afterwards, expressing surprise at all the living children. They had just had their Genetics class in which they were told these kids did not survive. It is true that many have short lives, but there is a range of severity. Each child needs to be looked at as an individual and given a chance to reach his or her God-given potential. It is intellectually and morally dishonest to promote the lie that there are no survivors. Furthermore, this lie is incredibly disrespectful to the children who are living, their families and the doctors who have helped them.

A recent study backs this up. Children with a postnatal diagnosis, who were treated "as any other children" at birth until the diagnosis, were shown to have been given a survival advantage despite later palliative care. The study's conclusion: Trisomy 13 and 18 are not lethal conditions.[\[vii\]](#) Many of the children who could benefit from interventions are denied or not even offered them and, as a result, have much shorter lives.

We had many quality of life discussions with Peter's doctors over the years. Most doctors see these kids only when they are sick. They do not see them in their homes enjoying life and the love of their families. They make judgments based on what they see and think they know. However, the truth is parents are the real experts and, after being advised of all the options, should be the ones who make the final treatment decisions for their children.

Peter died at age 6 ½ after having an appendectomy. We felt something was terribly wrong after Peter died. We were told that he died from infection caused by appendicitis and his heart couldn't take it, but an independent autopsy we had sought revealed he bled to death. We would later discover the hospital Peter died at had an internal "futility of care" policy. Many, if not all, hospitals have these policies and most of the public is not aware of them.

Was Peter the victim of the hospital's futility of care policy? Did someone decide his care was futile because he could never be "cured?" Did someone make the decision to "let him go" because he wasn't worth the resources? We may never know all the answers, but we feel we were robbed of a peaceful, dignified death for our son and instead are left with questions and the same sad feeling of rejection and sorrow we have felt from the beginning of Peter's life.

We loved Peter and would have gladly taken care of him our whole lives. He brought us a glimpse of God's unconditional love and purity. He was perfect in our eyes and has helped us all to become better people. Peter was a tremendous source of grace, love and happiness for our family. Peter and children like him are "Teachers of Our Souls," and they and their families deserve the same quality and quantity of treatment and care as everyone else. Have our hearts

become so hardened and are we so intent on their destruction that we fail to see the joy and beauty they bring to the world? I am afraid the answer is yes. Until we open our hearts to embrace their lives we will all be the poorer and, in the end, we will all suffer from this gross lack of compassion and love.

About the author: Mary Kellett is founder and executive director of [Prenatal Partners For Life](http://www.prenatalpartnersforlife.org) (PPFL), a group of concerned parents (most of whom have or had a special needs child), medical professionals, legal professionals and clergy whose aim is to support, inform and encourage expectant or new parents. PPFL offers support by connecting parents facing an adverse diagnosis with other parents who have had the same diagnosis. PPFL has many resources, including adoption agencies with clients waiting to adopt and love a special needs child should parents feel they could not care for them. Mary states, "We believe each child is a special gift from God." Mary is also a member of the Pro-life Healthcare Alliance Working Committee. [www.prenatalpartnersforlife.org](http://www.prenatalpartnersforlife.org)

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[i] Allyson J. Peller, MPH, et al., "Trends in Congenital Malformations, 1974-1999: Effect of Prenatal Diagnosis and Elective Termination," *Obstetrics & Gynecology* 104:5, Part 1 (November 2004), 957-964.

[ii] Brian Skotko, MD, "Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers," *American Journal of Obstetrics & Gynecology*, 192(3): 670-677, March 2005.

[iii] An estimated 92 percent of all women who receive a prenatal diagnosis of Down syndrome choose to terminate their pregnancies, according to research reviewed by [Dr. Brian Skotko](#), a pediatric geneticist at Children's Hospital Boston.

[iv] *PEDIATRICS* vol. 130, no. 2, August 2012

[v] Tracy K. Koogler, Ben Wilfond and Lainie Ross, "Lethal Language, Lethal Decisions," *Hastings Center Report* 33, no. 2, 2003

[vi] "Should the 'slow code' be resuscitated?" *The American Journal of Bioethics*, vol. 11, issue 11, 2011

[vii] Jennifer Guon, Benjamin S. Wilfond, Barbara Farlow, Tracy Brazg and Annie Janvier: "Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of Trisomy 13 or 18"

### Case in Point

St. Paul, MN - Sue found the PHA website and called. Her mother, suffering from dehydration, was admitted to the hospital at the home health nurse's suggestion. The hospital took Mom off her antidepressant medication. She was treated and, upon release, was referred to hospice.

During the first visit by the hospice nurse, Mom asked if she would feel better. The nurse said "no" and painted a dire picture of her future. "Well then, I just want to die," Mom declared. The nurse advised her to stop eating and drinking and she would die painlessly in a couple of days. Mom was not experiencing any physical pain, but the nurse wanted to administer morphine.

After speaking with Ann, the PHA member who took her call, Sue was adamantly opposed to stopping food and fluids and did not want morphine used if Mom was not in pain.

Sue was assured they had the right to fire the hospice and hire a new one if they wished. Ann also advised her never to leave her mom alone with the hospice nurse and that she could and should tell the nurse not to speak to her mother about how to kill herself.

Sue called about a week later to notify Ann that her mother had died naturally at home while they were together. Sue thanked Ann for her help.

## Suicide Prevention or Assisted Suicide?

**By Mark Davis Pickup**

In October of 2012, Canada's Parliament gave UNANIMOUS support to a national suicide prevention strategy. The next month, BC Supreme Court "Justice" Lynn Smith ruled in favour of assisted suicide for an incurably ill woman. Now Quebec is about to legalize euthanasia and assisted suicide. They euphemistically call it "medical aid in dying."



So which one is it? Suicide prevention or assisted suicide? Euthanasia proponents will respond, "Both!" Healthy people get suicide prevention while sick and disabled people get assisted suicide.

That's the bad news. The good news is that assisted suicide clinics in Quebec will be fully wheelchair accessible.

*Reprinted with permission from the HumanLifeMatters blog, February 14, 2014.*

*Mark Davis Pickup, a Canadian, developed degenerative and aggressive multiple sclerosis in 1985, after which he shifted much of his energy to working against euthanasia and assisted suicide. Mark says: "As my disability increases, I have become interested in discovering Christian meaning in suffering." Mark has been married to his wife LaRee for 40 years. They have two children and five grandchildren. Mark serves on the PHA Advisory Committee.*

## LORETO ON THE PLAINS:

### The Home that Faith Built

By Julie Grimstad

*"We know what we have here and want to share it with others." - Ed Weber*

Hartley, population 400, sits smack dab in the heart of the upper panhandle of Texas. There on the plains sits a beautiful home, a safe haven for the elderly, the sick and those near death, where "the sanctity of every human life is respected and protected." I recently had the privilege of visiting with Ed and Nan Weber, whose vision became the awesome reality they named Loreto on the Plains Personal Care Home.

My plane touched down in Amarillo a little before noon on Monday, February 3<sup>rd</sup>. Ed and Nan met me at the airport, treated me to lunch and then drove to the hospital where a member of their Loreto "family," Keith, was in the critical care unit after a brush with death. Having extreme difficulty breathing due to pneumonia, Keith was taken by care-flight to the hospital Sunday night. The next day, we found him sitting up in bed eating lunch. A broad smile greeted Nan and Ed. I would soon discover why people who reside at Loreto on the Plains have reason to be joyful.

The drive from Amarillo to Hartley is over an hour with not much to look at but the plains and a few hills, one with a very large cross on top that Ed and Nan had helped erect years before. Nan, quoting scripture, asked, "What did you go out into the desert to see?" I came looking for an answer to an urgent question: What can be done to provide protection and ensure life-enhancing care for the frail elderly who, as their number grows, are increasingly victims of abuse and imposed death? I would leave the next day certain that creating thousands of Loreto-like homes is the answer.

To read the rest of this story: <http://www.prolifehealthcare.org/LoretoOnThePlains.html>



## Announcements

**March 29, 2014, Des Moines, IA--  
Imposed Death: A Conference on Stealth Euthanasia,**

[New Hope Assembly of God](#)

Student Center  
6800 Townsend Ave, Urbandale, IA, 50322  
(515) 254-9094

## Schedule

8-4:30

## Speakers and Topics

Alex Schadenberg, (1) US and Worldwide Overview of Euthanasia Studies (2) Assisted Suicide

Cristen Krebs, (1)Stealth Euthanasia (2) Hospice

Julie Grimstad, (1) Advance Medical Directives and POLST (2) Organ Donation and Patient Advocacy

Mary Kellett, Infant and Prenatal Euthanasia

Registration:\$30/individual or \$50/couple

Registrations by phone: toll free 1.877.595.9406

email:[iowa@iowaRTL.org](mailto:iowa@iowaRTL.org) or through Iowa Right to Life website:[www.iowaRTL.org](http://www.iowaRTL.org)

We can take registrations by credit card payment over the phone or on our "donate" page on the website.

By mail:Iowa Right to Life, 1500 Illinois Street, Des Moines, IA 50314

## Saturday, May 17, 2014

**Location:** Grace Church, 4500 Burbank Road # A , Wooster, Ohio 44691

**Title of conference:** The Healthcare Trojan Horse

**Speakers:** Julie Grimstad, Dr. Cristin Krebs, Dr. Loren Kirchner, Ione Whitlock (Lifetree)

**Tickets \$30.00, Pre-registration will be required**

**More information to follow next month**

DVDs of our first conference, "Imposed Death 2012," held in New Brighton, MN, June 2, 2012, are available from Human Life Alliance. To order, call 651-484-1040.

**NOTE:** The Pro-life Healthcare Alliance wishes to bring conferences to locations in all parts of the United States and Canada, and eventually, the world. We invite you to work with us to make this happen.

[Join the Pro-Life Healthcare Alliance](#)

STAY CONNECTED



Pro-life Healthcare Alliance

a program of [Human Life Alliance](#)  
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