

INTERNATIONAL TRISOMY ALLIANCE

NEWSLETTER

www.internationaltrisomyalliance.com

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Barb Farlow, Jenny Robbins, Siri Fuglem Berg and Debbie Bruns are pleased to announce the launch of International Trisomy Alliance, a volunteer not-for-profit organization focusing on trisomy 13 and trisomy 18, also known as Patau and Edwards syndromes.

Welcome to our ITA newsletter. This first issue is an introduction to our organization with links to our website, and we are pleased to include an article by John Carey MD, our Chief Medical Advisor.



Welcoming Comments: ITA by John C. Carey, MD. MPH

I consider it a true honor to provide a few opening comments for the inaugural newsletter of the **International Trisomy 13/18 Alliance** (ITA). In the last 10 years, largely through my close connection to SOFT (US) and various academic collaborations, I have had the unique opportunity and the remarkable privilege of communicating with clinicians, scientists, families, and support groups on five continents about the experience of caring for persons with these (and related) conditions. Thus I was very pleased to learn of the establishment of an international alliance. This is an idea whose 'Time has come...'

I am reminded of the famous Chinese proverb, "May you live in interesting times". I would suggest to you that in regards to trisomy 13/18, we are living 'in interesting times.' This saying has been regarded by some as a curse, by others as a blessing. I personally have always preferred the notion of a blessing, perhaps better worded as an opportunity. In the context of the complicated, (and often controversial), issues surrounding the care and management of infants and children with the medically complex conditions of trisomy 18 and 13, the current "times" provide an **opportunity**. Let me elaborate: It is my impression that in the last 5 years we have been witnessing in the medical literature, (primarily the pediatrics and bioethics literature), an 'emerging dialogue', i.e., an ongoing

discourse on the issues in the care of newborns with the two conditions. In contrast to little dialogue that followed the appearance of two important papers in 1992 (Bos and colleagues and Paris and coauthors), both suggesting an approach of non-intervention in the care of infants with trisomy 18, there has been a recent proliferation of articles that discuss various views on this theme.

The dialogue likely started-- I would suggest - with the seminal article by Koogler, Ross, and Wilfond in 2003 (just 10 years ago). This paper, published in a leading medical ethics journal, discussed the complicated issues of treatment, (or lack thereof), of infants with serious congenital anomalies, (of which trisomy 18 and trisomy 13 are prototypic); the authors presented a more balanced approach to making decisions regarding treatment. They suggested that in areas of ambiguity, it was prudent to err on the side of following the parental view in making tough decisions. I would suggest that this paper - as well as the ones I will mention below - represents a **landmark** in this recent dialogue of the care of children with these medically complex syndromes.

Let me not underestimate as well the contribution that the support groups, (and their web pages), made during this time in helping to stimulate this dialogue. The Support Organization for Trisomy 18, 13, and Related Disorders of the US and the UK, a number of other US groups, and the advocacy groups in Japan and Australia, (and the many

parents and friends), presented to the world a starkly different view of persons with these conditions than the conventional depiction in most medical textbooks. The family photos and stories on the web pages and newsletters displayed families and children coping with the consequences of the conditions in a clearly positive and genuine light, varying from the stereotype I grew up with as a pediatrician and geneticist in training in the 1970s and 1980s.

This 'dialogue' truly emerged - I would propose - in 2006 in a landmark article by Dr. Tomoki Kosho and his colleagues, at Nagano Children's Hospital in Japan, who described the outcome in 24 newborns with trisomy 18 in whom full medical management was offered and administered. One-year survival in this study, (while the number of cases was relatively small), was 25%, which was significantly higher than survival in any of the previously published population studies, (range 0-8%). Notably, this paper was the first to address the question of what is the outcome if full care is provided to newborns with trisomy 18. It was a crucial landmark in this now ongoing discourse.

Since 2008, a number of other landmark articles have appeared, (and many in the journal *Pediatrics*.) that provide additional input on this discussion: Doctors McGraw and Perlman presented the results of a survey of New York neonatologists and suggested that in recent decision-making, parental autonomy had superseded the 'best interest of the child' standard. Another paper (2011), an 'Ethics Rounds' piece by Janvier and other discussants, (including Barbara Farlow, a founder of ITA), summarized in their discussions all of the important themes in the discourse (e.g., best interest of the child, parental autonomy, quality of life and others). The paper by Merritt and colleagues (2012) also presented a comprehensive review of the issues and additionally provided some practical guidelines; these authors seemed to favor a pure comfort care approach to management.

Recently (2012), Dr Annie Janvier and colleagues, (again including Ms Farlow), authored one of the

only peer-reviewed papers that address the issue of parents' perception of the quality of their life when rearing a child with one of these medically serious conditions; their investigation used social networks to obtain the insights and attitudes of over 300 parents of children with trisomy 13 and 18 and documented an overall highly positive view that emphasized the value of the children. (Note: All of the references mentioned in this piece are cited in the paper that I coauthored with Dr Anna Cereda in 2013 and the 2012 paper in *Current Opinion in Pediatrics*; the former paper is open/ free access on the *Orphanet Journal of Rare Diseases*; the abstract of the other is available on the SOFT web page and the full paper can be obtained from most medical libraries. There are several other important landmark articles published in the last 5 years not mentioned here, including the reports primarily from Japan on outcomes after cardiac surgery in infants with trisomy 13 and 18; I refer the reader to the 2 review papers for those citations. Besides the cited peer-reviewed papers, there is significant amount of documentation of these points on the support group webpages, including SOFT US and UK.)

What then is my message? From my professional and personal experiences working with the families and support groups, and from observing this emerging dialogue, I would propose two:

- It is crucial for families to receive accurate and current information about the outcome of children with trisomy 13 and 18, and for the information to be presented in a balanced manner when making treatment decisions in both the prenatal and postnatal periods.
- The ITA has the opportunity to help lead an international effort to provide a balanced view toward care of children with trisomy 13 and 18.

I look forward to working with the Alliance on this goal.

John C. Carey, MD, MPH

Professor and Vice Chair Department of Pediatrics
Founding Professional and Advisor, SOFT (US)

ITA Professional Advisors

John C. Carey MD. M.P.H.
Siri Fuglem Berg MD. Ph.D. Anesthesiologist
Debbie A. Bruns Ph.D. Associate Professor
Annette Hollingsworth- Moore MD. Obstetrician
Daniela Robbins MBChB. Medical Practitioner

ITA Parent Advisors

Ann M. Barnes United States of America
Daniela Fitzgibbon Italy
Heidi Herdman United Kingdom
Raluca Laura Manea România
Gilianny C. Nickerson Brazil
Tracey and David Pass Australia

www.internationaltrisomyalliance.com/ita-founders

International Trisomy Alliance was founded in 2012 by Barb Farlow, co-author of a survey published in Pediatrics about the lives of children with trisomy 13 and trisomy 18; Jenny Robbins, a founder of SOFT UK; Debbie Bruns, Associate Professor and Principal Investigator of the Tracking Rare Incidence Syndromes project; and Siri Fuglem Berg MD Ph.D. an anesthesiologist who had a prenatal diagnosis of full trisomy 18, and founded a Norwegian web-site, www.trisomi18.com to support other families.

Our mission is to offer trisomy 13 and trisomy 18 support groups, physicians and other professionals, accurate information and resources, and to be a mechanism for sharing between groups. We hope to empower parents to make optimal decisions after a diagnosis of trisomy 13/18, and ITA advisors are a global network of physicians, academics and parents who have an active interest in families and children with these syndromes.



Barb Farlow



Siri Fuglem with her family



Debbie Bruns and Bill



Jenny Robbins

www.internationaltrisomyalliance.com/research-publications

About the research

Publications about infants, children and adults with trisomy 13 and 18 are important because doctors often base the care they provide on research reported in articles in medical journals and textbooks.

www.internationaltrisomyalliance.com/about-the-research

General Topics

These papers below relate to survival, growth, development and parental experience.

www.internationaltrisomyalliance.com/general-topics

Heart Surgery

This is a complete listing of all publications related to cardiac surgery for children with trisomy 13 and 18. When surgery is offered to children whom doctors believe will have a reasonable chance of benefit, survival rates for those children have been shown to increase. www.internationaltrisomyalliance.com/heart-surgery

Commentaries - Ethics

These publications include commentaries, narratives and ethics-related papers about medical care for children with trisomy 13 and 18. As a result of support groups, blogs and websites on the internet that reveal happy, surviving children with these conditions, parents have begun to request consideration of treatment for their children. www.internationaltrisomyalliance.com/commentaries---ethics

www.internationaltrisomyalliance.com/ita-booklets-for-families

The International Trisomy Alliance booklets for families and children are free to download on the ITA website, and the links to other publications include the USA 'Care of the Infant and Child with trisomy 13 or 18'.



A Cherished Pregnancy, Family Dictionary, and booklets for younger and older children



ITA Translations

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Other Publications

Changing Times for Children with Trisomy 13 and 18 in Norway

We are so proud that our co-founder, Dr. Siri Fuglem Berg has successfully initiated a serious discussion in the medical and public sphere in Norway about trisomy 13 and 18.

The following is an editorial by Helge Simonnes that appeared in a leading Norwegian newspaper, Vaart Land on November 1, 2013. This piece was published following a public debate concerning the ethical issues involved in limiting treatment options to a class of patients based on their genotype (genetic label) and not their phenotype (unique characteristics).



Dr Siri Fuglem Berg translated this editorial for ITA

For years distinguished physicians have stated to the public and to our pregnant population that trisomy 13 and trisomy 18 are 'incompatible with life'. Norway's leading fetal medicine physicians have determined that the most reasonable outcome is termination of pregnancy after a diagnosis of an extra chromosome 13 or 18.

When the condition is diagnosed after birth, they do not usually offer medical interventions, or listen to appeals by parents for treatment for their newborn.

Anesthesiologist and mother Siri Fuglem Berg took up the fight. She had a daughter with an extra chromosome number 18 diagnosed in pregnancy, and Siri fought to give her daughter beneficial health care, rather than be put aside to die. She was told that these children do not have the power or will to live, that they do not have the mental ability to be aware of their own existence, that they cannot interact with or notice the people around

them. It was a long fight for Siri. Her daughter lived for three days after birth. Many die in the womb. But some live for years.

Fuglem Berg writes the following on 'verdidebatt.no' (*Vaart Land web debate pages*). "It pains me to know that I was lied to. Perhaps with good intentions. Perhaps. But dangerous." Fuglem Berg's story has led to a lively debate.

The clinical ethics committee at Oslo University Hospital has now authored a commentary on these issues. On one hand the commentary indirectly admits to being wrong in several cases that these conditions were 'incompatible with life'. It must be considered progress that leading communities of physicians now say that some children are compatible with life.

On the other hand: The committee refers to studies that show numbers of survival at around 10 percent. We would like to know whether these children received medical interventions. If ten percent are able to live with no medical help during and after delivery, then we can only speculate what the numbers would be if the children did receive life-saving measures.

It can be a dilemma whether or not to start intensive life-saving interventions. We are in no position to comment, but we do now assume that these children will no longer collectively be referred to as 'incompatible with life,' and termination of pregnancy should no longer be taken for granted.

We appreciate that the committee states that those who choose to carry to term should be treated with great respect, and we need a serious debate concerning health care for those who are born.

Medical personnel should involve those who have challenged the established medical community's standardized death sentence, and learn from their experience.

www.internationaltrisomyalliance.com/ita-booklet-translations

We are grateful to friends of ITA who have translated some of our booklets for families into Italian, Norwegian, Spanish, Finnish and Turkish. If you would like to contribute to the ITA bank of translations, please can you email your details via:

www.internationaltrisomyalliance.com/contact-us

The Tracking Rare Incidence Syndromes (TRIS) Project by Debbie Bruns

Dr Debbie Bruns is a cofounder of ITA, a professor and a researcher of rare syndromes including trisomy 13 and 18. In this piece she describes how she came to be involved in this community and the major research project she has undertaken.



Debbie Bruns

Before I began my doctoral studies and eventual position at a research university, I was an Educational Therapist at the New York Foundling Hospital in New York City.

I was a classroom teacher and during that time, I had the privilege to work with three preschool-aged children with trisomy 18. They had similar medical issues (respiratory, feeding) but very different personalities and temperaments.

When I first researched their condition, I was met with autopsy photos on the fledgling Internet (this was in the early 1990's). Yet, the girls in my classroom interacted with adults, expressed preferences and were able to learn new developmental skills. It was this experience that would lead me to a central part of my work as an academic.

The Tracking Rare Incidence Syndromes (TRIS) project aims to increase awareness and knowledge for families and professionals touched by rare trisomy conditions leading to improved decision making for optimal services and supports for children and their families.

Since the project began in February 2007, approximately 500 families from around the world have enrolled with over 70% completing one or more TRIS project surveys. Trisomy 18 and trisomy 13 are the largest groups represented in the TRIS project database.

Survey data is compiled, analyzed and disseminated via national (U.S.) and international

conference presentations. Specifically, TRIS project results have reached clinical geneticists, neonatal nurses and a range of early intervention professionals working with infants and toddlers with disabilities or developmental delays.

Publications in medical and disability-related journals such as the *American Journal of Medical Genetics*, *Topics in Clinical Nutrition* and *Journal of Intellectual Disability Research* reach additional audiences. Importantly, parent queries guide much of the project's research and dissemination efforts.

Too often, children with trisomy 18 and trisomy 13 are denied medical care. Data from the TRIS project makes an argument for medical interventions that facilitate long-term survival such as cardiac surgery leading to an enhanced quality of life. In this way, the project seeks to change the status quo.

Project data is also being utilized to create a profile of long-term survivors who do not require such intensive medical care. It is no longer sufficient to rely on dated or biased literature to make decisions.

The rise of online information and social media also fuels the project's efforts to change perceptions of this population.

The TRIS project has a website at

<http://web.coehs.siu.edu/Grants/TRIS/>

and a Facebook page at

<https://www.facebook.com/TRIS.Trisomy.project>

Both provide updates on project activities as well as showcase children and adults with rare trisomy conditions.

TRIS project was also invited to prepare a series of blog posts for the Global Genes project - links can be found at:

<http://globalgenes.org/?s=tracking+rare+incidence+syndromes+project>

Passion for the Truth: What the Medical Literature was Missing by Barb Farlow



Barb with Annie

We experienced many problems communicating with providers during my daughter Annie's life. I was informed that one of her physicians asked his colleagues, "Who wants a child like that anyway?"

After years of advocating and telling Annie's story at medical conferences and schools I met Dr. Annie Janvier, a neonatologist and ethicist from Montreal, Canada. She suggested that I undertake a comprehensive review of all the literature related to trisomy 13 and 18. This review included medical journal articles and relevant texts. What I discovered was disturbing but also a revelation to me. Finally, I began to understand why communication problems occur.

Trisomy 13 and 18 were identified in the 1960's and from that time, it seems that survival rates took a downward turn. Large studies in the '60s revealed survival rates that were higher than or similar to what they are quoted to be presently. For example, one large study with 172 children with full trisomy 13, revealed a one-year survival rate of 13.5% (Magenis et al, 1968).

It is important to remember that there was very little that could be done to help sick newborns then compared to now, yet over one-half of the newborns with full trisomy 13 lived beyond one month receiving only basic care. How could that be?

I noticed that through the decades of various publications about trisomy 13 and 18 until recently, no reports sought to identify the characteristics related to survival or to describe treatments or interventions that were beneficial to the children. The quality of the children's lives was implicitly described as poor; there was a repeated emphasis on severe disability and the burden of care on families. The pictures posted of the children always made the children look as if they were suffering and unhappy and significantly malformed.

The texts and journal articles I reviewed were those

that decades of physicians and nurses had been taught with. It was no wonder that everyone came to believe that trisomy 13 and 18 were "incompatible with life." In over 50 years, no study included the parents' description of their child's quality of life.

The Internet fostered parent support groups and parents could connect easily, in a way that was never possible. Parents with a recent diagnosis for their child could find pictures of smiling children and well-adjusted families. Mostly, they found hope and often, information that was starkly in contrast to what their physicians had told them.

In 2010, Dr. Annie Janvier, Dr. Ben Wilfond (Director of Ethics, Seattle Children's Hospital, Washington, USA) and I embarked on a study to obtain the parents experience. These wonderful physicians said, "Everyone has a right to be heard."

Over 350 parents from countries around the world took the time to respond to our survey. The findings were significant in that they contradicted common beliefs and assumptions about the syndrome. Our first article was published in the highest-impact factor pediatric journal in the world (*Pediatrics*) and the editor issued a press release that yielded over 60 media articles in 5 languages. Headlines included, "Parents and doctors see congenital disorders differently," and "Children with trisomy 13 and 18 and their families are happy."

Most importantly, our research revealed that to the parents who responded, the children had immense value to their lives, even if they lived only a short time. Survivors were described as happy and as having an enriching effect on the lives of their families. The full article is available on the Internet: <http://pediatrics.aappublications.org/content/130/2/293.long>

Looking to the future, my greatest hope is that ITA helps to promote the truth about children with trisomy 13 and 18—that some children may benefit from interventions and survive to live a happy life, but when interventions are not desired, available or beneficial, parents and providers alike need to know that those who love these special children are positively transformed by their experience.

25 Years of Advocating and Supporting Parents by Jenny Robbins

Jenny Robbins is a cofounder of ITA and has made a major contribution to the community over the past decades. In this article she provides an insight into a typical example of how she and other advocates support new parents.



Jenny and family with Beth

Twenty-five years ago my daughter Beth was diagnosed with trisomy 13 and I was told it was lethal and extremely rare. Amniocentesis was not widespread, the Internet did not exist, and the only information was in clinical texts that listed the autopsy findings.

Our pediatrician asked, "Do you want to take your baby home to die, or leave her in the hospital."

I found the Support Organization for Trisomy (SOFT USA) half a world away from my British homeland, and they circulated my questionnaire about how to care for a baby like Beth in their newsletter. The many parental responses resulted in the *Your Baby* that was printed by SOFT UK and distributed to parents all over the world. This was the first fruitful international cooperation between two organizations supporting families affected by trisomy 13 and 18. More recently SOFT USA wrote and distributes their resource, *Care of the Infant and Child with Trisomy 13 or Trisomy 18*.

Have things changed over the last twenty-five years? Last week my phone beeped a message:

Hello, I found your support forum/page, I had a little girl just over a week ago and she was diagnosed 2 days ago with Edwards syndrome. I am at my wits end with worry. So many questions that need answering. Doctors really don't know anything so please help.

I was able to text back immediately with the name of a geneticist and practical advice. This included

information about SOFT UK, details of SOFT USA and their Caring booklet and growth charts, and International Trisomy Alliance for sibling booklets and the latest research about trisomy 18.



I put the mom in contact with Heidi, a parent advisors who immediately sent a response. Heidi is a fellow co founder of the 18/13 group:

www.trisomy13-18supportuk.com

and has cared for Saskia who has full T18 for 21 years.

The photograph shows them returning to England after the SOFT USA 2013 Conference.

Heidi wrote:

Congratulations on the birth of your baby girl - such a pretty name. I can imagine your emotions must be all over the place. I had no pre-natal diagnosis with Saskia either, for which I'm actually extremely grateful as I would probably have given in to medical pressure and terminated, based on the very negative information the doctors give. But I would have missed an amazing experience. Saskia is full T18. She has been tube fed since birth and I strongly believe that is one of the reasons she has lived for so long as she has been well nourished and in the early days was able to conserve her energy to fight to survive. The past 21 years have not been easy but they have been amazing years with many positives. So please feel free to contact me.

I feel very privileged to be a part of International Trisomy Alliance. Our aim is to extend this vital support and provision of information to groups caring for families worldwide.

<http://www.internationaltrisomyalliance.com/trisomy-support-groups>

The ITA website lists trisomy support groups and organizations in Australia, France, Germany, Ireland, Italy, Japan, New Zealand, Norway, Romania, United Kingdom, United States of America and Facebook support groups around the world. Please contact us via the website if you belong to an organization that provides support to families affected by trisomy 13 and 18, and you would like your group added to the ITA Trisomy Support Groups or Links pages.

Anaya by Annette Hollingsworth-Moore, MD.



In 2005 I delivered my second child, a daughter who was born with trisomy 18. Anaya.

I knew very little about trisomy 18 at that point in my career.

I was an intern in residency and I was

training to become an obstetrician - gynecologist. Anaya's diagnosis was a complete shock to me. But what was even more shocking was the treatment that the neonatologist offered Anaya soon after she was born.

Once Anaya was born I could see that she had a syndrome, but I was not sure what it was. The doctors knew it also and rushed to get chromosomal analysis. Within 24 hours they told me that she had trisomy 18 and that they were not going to do anything to intervene with the "natural process of the condition". They told me that my daughter would likely die in the first days of her life and that I needed to prepare for this. I was devastated by this information. I stood at her crib watching this 3lb4oz baby struggling to breathe, fighting for her life and I became scared, but mostly I became angry. What did they mean they would not interfere with the "natural process of the condition"? Anaya was born at one of the area's finest hospitals, which boasted of wonderful NICU services, and they would not do anything for Anaya. In fact, they deemed her condition futile and two physicians signed DNR papers for Anaya without even discussing this with her father or me. They claimed that this was their right. They did not have to waste precious resources on a case that they deemed futile. I was devastated, I didn't know what to do but I knew that these doctors were the enemy. The enemy of me taking my daughter home, of my dream of her meeting her older sister and the enemy of Anaya's surviving.

On day 3 of Anaya's life I was allowed to hold her. It was the most amazing experience of my life. I could feel her heart beating next to mine, I could smell her and feel her warmth. I felt unbelievable joy in that moment. However the joy was short lived. The neonatologist, came by at that moment and told me that I should not bond with this baby,

that I should let this baby die as this was natural. He told me that I should consider my career and how this child would affect my career. I was shocked by this. I never knew the extent of prejudice against genetically different individuals that existed in the medical community until that moment. I also was surprised at how ignorant doctors could be. I said nothing. The next day I was afforded another opportunity for kangaroo time with Anaya and I was enjoying it very much when the same neonatologist from before approached me and started to speak. I could tell he was going to replay his previous days' comments to me.

I stopped him cold. I told him it was too late, I had already bonded with my child which happened the moment I found out I was pregnant with her. I told him that as I didn't seem to have much time with my child, I would appreciate it if he wouldn't rob me of these precious moments by coming over with his ridiculous comments. I told him I didn't care about my career. I cared only about my family and Anaya. I asked him to never speak to me again. He told me that I was a doctor and that I needed to be reasonable. He admonished me for acting like these "irrational" parents without medical knowledge. I told him from this point on he could consider me an irrational parent with medical knowledge. I told him he, with his 20 years' experience in medicine and me with my 5 months experience in medicine, probably knew about the same amount about trisomy 18, very little. I explained to him that very little research has been done in the last 20 years regarding this condition. I asked him to never speak to me again and he didn't. I found out later that he wrote in my daughter's chart that I was difficult and irrational.

During the almost 4 weeks that Anaya stayed in that NICU many things happened that surprised me. I was on a 22 hours vigil watch at her bedside. I hardly ever left her. I didn't leave because she had apnea and would often forget to breathe. I was afraid that because of the DNR they would not help her to breathe, that the nurses wouldn't stimulate her or worse that they would let her die without trying to help her. I was not going to let that happen. Anaya was a fighter; she kept living despite all of their predictions. During the second week of life they asked me to start pumping my breast milk so that they could begin feeding it to her via a nasal gastric tube. I was overjoyed. This had to mean that they thought she might survive. Well it

was all a misunderstanding. The resident had thought she should be fed and gave the order; the attending found out about the order and disagreed. This caused an “ethical” dilemma and they came to me and asked if they could stop her feeds to “allow nature to take its course.” They wanted to stop feeding her to allow her to starve to death since she was not dying fast enough. This was very surprising to me. Of course I declined their offer and demanded that her feeds continue. One day I came back to the NICU after being gone for 30 min and I was informed that Anaya had had a seizure and that the nurse was going to give phenobarbital for said seizure. I asked the nurse when the EEG would be done and she said that that was not necessary and that she needed to give the phenobarbital to prevent more seizures. I said I was surprised that Anaya had had a seizure as I had never in the 3 weeks prior witnessed any such activity. The nurse said that she had an order to give phenobarbital and that she was going to give the medicine. I requested that she not give the medicine and that she call the doctor. She said she was giving the medicine. I said if you do I will call the police and charge her with assault. I couldn't believe her insistence on carrying out this order. I also couldn't believe that as a parent I didn't have the autonomy to say what I wanted to have happen to my child. I knew that phenobarbital could cause more apneic spells and I didn't want Anaya to have more of those. I felt powerless, and afraid. Why wouldn't they want to get objective data regarding seizure activity? Maybe she didn't have a seizure and this is a way to hasten her death as she was not starving to death and not dying soon enough? I couldn't help but worry that not only were the doctors at that hospital willing to withhold care they were willing to harm Anaya in the interest of proving their philosophy just. I decided to leave that hospital right then. Anaya left the next day on hospice care.

During the last 8 years I have experienced many battles with medical professionals regarding Anaya and her care. I have become a warrior for her care, an advocate for her right to live a life that is as long as God has intended and not dictated by a doctor's philosophy. I am a champion for her quality of life as well and I will continue to be that. Anaya will be 8 years old this December. She has changed my life for the better. She has taught me how to be strong and how to stand up for what I believe is right and how not to cower and hide from those fights. When I am worried about a battle, I always

remember watching my baby fight for every breath those first weeks of life, with no assistance from anyone, and I know I can continue to fight for Anaya and others.

Advocacy for families with children with trisomy 18 and 13 is so very important. Many times medical professionals withhold lifesaving care from these children in the neonatal period and this alters their life expectancy. This is not done with malice but ignorance. Neonatologists are not fully aware that these children bring such joy to their families. I know that my life would not be the same without Anaya in it. Neonatologists make judgments about the child's quality of life that they are not qualified to make. Only the family can determine the quality of life for the child. It is presumptuous and paternalistic for medical professionals to weigh in on such issues. They remove a family's right to autonomy in deciding what is best for their child. I disagree that this should continue. As a doctor and as a mother of a child with trisomy 18, I want to shed light on what is happening in the neonatal community, I want to advocate for these families and I want to do this by sharing my experience and hopefully this will help others.

There have been major medical advancements in neonatology that allow a 24 weeks premature baby some reasonable life expectancy, yet the medical community has been unwilling to apply these lifesaving advances in technology to those with trisomy 18, or 13. This is unfair and discriminatory. Why is a 24 weeks premature baby more important than a full term baby with trisomy 18 or 13? A child born at 24 weeks has many life challenges ahead, such as cerebral palsy, blindness, and developmental delay and quality of life issues. There is never a question though with all of these issues if this child should receive necessary neonatal care. Why is there even a question for a baby with trisomy 18 or 13?

I am so excited about the International Trisomy 13/18 Alliance. I know that this organization will further shed light on current research in these areas and hopefully change the minds of medical professionals worldwide. This will help to improve the opportunity for children born with this condition to live longer lives. It is my belief that prejudice and ignorance are leading the charge against neonatal treatment of trisomy 18 and 13 and since this organization is poised to change that, I am glad to be a part of it.