



# MISS Foundation

A COMMUNITY OF COMPASSION AND HOPE FOR GRIEVING FAMILIES

Each newsletter issue will feature one of the MISS Foundation's many important volunteers. Our dedicated volunteers are the lifeblood of MISS. In this issue, meet Robyn DelReal.

## Volunteer Spotlight

Hello mamas & papas!

My name is Robyn DelReal: woman~warrior~mother, who has buried two children in three years.

My beautiful daughter Samantha, my youngest of three, left those who love her so very much on July 11, 2004 at twenty years old in San Francisco by hanging, after an eleven-day dosage of anti-depressants and anti-psychotics.

A little more than a year later in the fall of 2005 I journeyed home to Boston, broken heart in tow, to live with my sweet, kind, loving son, Ryan. He was seventeen months older to the day from Sam! (I always loved that about those two!) I settled in with my grief and the love of my son. I was grateful for his love and kindness. We tried to carve out a life without Samantha.

On September 29, 2007-two years and two weeks after my return home-my precious devoted child, keeper of my broken heart, Ryan, was killed while riding his motorcycle on a country road. He died in his brother's arms, those of my oldest child David. He is now my only child...an only child...

The second time death knocked on my door, stealing another one of my children!

Fade to black...the darkness...

*Missing them ...*

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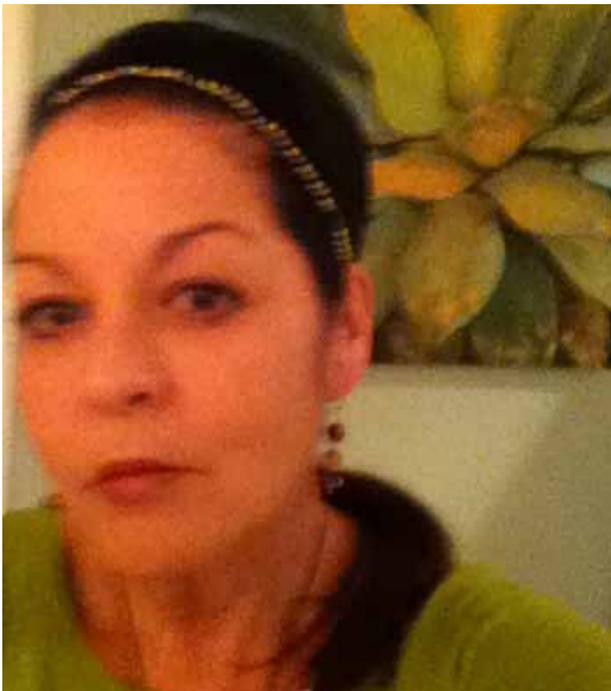
**Contact Us**

*submission guidelines*

Want to contribute to the MISSing newsletter?  
Send submissions to [info@missfoundation.org](mailto:info@missfoundation.org) for consideration. Thank you.

**Issue 05, Vol. 17, February/March  
2013**

**BI-MONTHLY NEWSLETTER FROM  
MISSFOUNDATION.ORG**



## Loving Relentlessly

*Mara Hill is a mother, wife, and author of Brona: a memoir, a story chronicling the short but sacred life of her son. It can be purchased at <http://missfoundation.org/book/brona>. Fifty percent of proceeds go to the MISS Foundation and twenty-five percent to Now I Lay Me Down to Sleep. Here is an excerpt from her memoir.*

His death did not stop me from loving him.

We all know this, don't we? No. It doesn't stop. I think it is quite possible that it grows bigger, picking up momentum in every tear, filling up our insides, and making us explode with un-given affection?

Personally, my love was so huge it overtook any other sense I knew. I had to see his face everywhere, in photographs, personally-made photo charms, necklaces, holiday ornaments. I wrote his name in the condensed water vapor in my shower door. I wrote him silly songs that made me cry so hard I couldn't get out the first verse before bursting into tears. I drew his name on lanyards, name tags, on balloons going up to explode in the sky.

I got a tattoo. I wrote a book even. I dreamed of him, spoke of him, breathed in my few, yet potent memories of him, every moment of every day.

Far beyond his death, I loved him. Boldly. Unmistakably. With a defiant shout that screamed, "I have a right to love my son as long as I want to!" I need to. I don't ever have to stop loving him and out loud. I do not have to hide this grand affection that burst forth from my heart like an undeniable sunrise, coming with fire, whether we want it to or not: bright, burning, beautiful, blinding, unrelenting, ever-present, undying...our love.

I challenge any of us bereaved to be allowed to love our lost children as long as we want to and not hold it in our heart like a secret, one we are not supposed to mention after the first year or two or three, or ten, or forty. We don't want to make people uncomfortable, do we? We know that most of them have no clue what to say and are probably tired of hearing about it.

Well...I say, let our love grow, blossom, grow wings and fly, sprinkle the earth with drops of kindness, compassion and a deeper understanding of the human condition than before. That isn't bad. That is pure goodness, and I bet our children gave it to us.

The cruelty of burying my children, the journey through darkness, brought me to the MISS foundation, Dr. Jo, and my service to bereaved community. Because my daughter experienced a medication-induced suicide, I am a HOPE Mentor for parents whose children also ended their lives after forgetting how much they are loved. I am blessed to serve. Thank you for having me.

Robyn DelReal  
Lost Lake  
Groton, MA



*Special thanks to The 2Bandits who raised money for The Leo Project in memory of Maura and Ari Feingold's son Leo, who died on May 17, 2012. These funds are being donated to the MISS Foundation in honor of Leo. Leo's parents are "so thankful for the support MISS Foundation has provided." We extend a special expression of gratitude to Leo's parents and baby sister, Noa Love Feingold.*

## Support Through Design: The 2Bandits' Leo Project



We'll jump on any opportunity to admire the rustic-cool jewelry of Tamar Wider's line The 2Bandits. Need proof? Her recent lookbook had us practically falling over each other to nab the fun pieces. Her latest venture, though, is about much more than just gorgeous bips and bops: The Leo Project is an homage to Wider's close friends who recently lost their beloved son, Leo.

Wider has designed bracelets (prices ranging from \$55 to \$118) for the project, simply called Leo's Sticks, pieces that are not only a beautiful remembrance of a loved one, but of our persevering human empathy. Every purchase will include a personal note from Leo's parents, and 20% of all proceeds will be donated to the MISS Foundation, which provides a compassionate community for grieving parents. Maura and Ari Feingold added, "We are so honored to be working with The 2Bandits to help keep Leo's memory alive, support The MISS Foundation, and to bring healing and support to families that are grieving. Being in touch with others who understand the intense grieving process after losing a child — at any age — has been incredibly important in our healing process." Gorgeous jewelry and a good cause — we'll take it.

Photos: Courtesy of The 2Bandits

**The lovely artwork below was created by Esme Regimbal, sister to Toren. She created it spontaneously with the simple explanation, "Toren died."**

**Andrea is Toren's and Esme's mother. She says, "Esme is super excited that her drawing is going into [the] newsletter! She asked why you wanted it, all big eyes and fat cheeks, and we talked about how it can show how kids can express their feelings through art. She knows [Dr. Joanne] work[s] with many families whose children have died and that this could help them. Cue the happy dance! I'm astounded how she can feel the joy that we can't always feel...I want Esme to understand that we're sad because we love [Toren]. Love doesn't stop just because someone dies."**



## On Fingernails and the X

**Weston Max Yoder lived from July 7 to July 28, 2012. In the piece below, Shauna Bryant Yoder, his mother, reflects on an aspect of their too-short life together.**



Something that has always caught my attention in Weston's post-death pictures is the length of my fingernails:

They were so much longer than usual. As time has continued, I have finally realized the reason for such a seemingly trivial detail to consume my thoughts.

The moment a woman becomes pregnant, her body is no longer hers alone. She shares it for nine months, longer if the baby breastfeeds. Pregnant women usually radiate life, health, and vitality. People talk about that pregnancy glow.

Perhaps a more appropriate word than "share" is "surrender." The pregnant woman surrenders her body. When the baby is born, she surrenders her time. And, at some point between surrendering her body and her time, she surrenders her heart.

The pregnant mother radiates life because she is literally growing a baby. The growth is invisible, except for belly size and ultrasound pictures, until she gives birth.

My pregnancy with Weston was vastly different. I became unhealthier than I have ever been to give him life. Believe it or not, spending months in bed takes a huge physical toll, not to mention the mental, emotional, and spiritual aspects.

Toward the end of my pregnancy, my muscles had atrophied. I would lift up my leg and see sagging skin. Although my belly grew, I actually lost weight. Weeks in a hospital bed began to cause excruciating back pain to the point where I needed physical therapy. I couldn't sleep. I wasn't allowed to walk except to the shower. Lying down posed a danger of blood clots, so I had to wear compression socks whenever I was in bed.

And, of course, the blood. I lost this life-giving substance continually for three months. Blood loss was the root of my anxiety. More blood loss meant a higher likelihood of early labor, which, at that time, would mean certain death for Weston. I could often feel blood coursing out of me; it felt like life leaving my body. Too much blood loss inevitably led to invasive and traumatic exams, always in the middle of the night.

But, while I experienced this physical decay and emotional prison, Weston grew and thrived inside of me. Every week he grew. The ultrasounds confirmed it, but I could tell by the way my pajama pants grew tighter, even as I lost weight. Toward the end of my too-short pregnancy, his kicks grew stronger. He'd fight to get away from the Doppler every time. And that heartbeat was music to my ears, twice a day. It was so strong, so constant.

Until July 7, 2012, when my physical decline caught up with him and left him literally gasping for air. We both could have died that night. I was no longer enough. I was sawed in half so that he could be rescued from the tomb that my body had become.

At that moment, the tables turned. In an instant, this thriving 24-week-old baby became a micro-preemie on a ventilator, fighting for his life. As for me, I was stitched up and began to grow stronger immediately.

My one-pound six-ounce baby dropped down to one pound two ounces. I was told this is normal, but there's not a whole lot of wiggle room there. He was always connected to at least four tubes, with two down his throat. His lungs started deteriorating as soon as he was born. When he finally started gaining weight, his lungs were so bad that he had to use an oscillator: the highest level of breathing assistance. He hated the oscillator so much that he had to be sedated. As he got older, his list of medical issues grew longer. The list became too long and overcame his fragile body on July 28, 2012.

On the other hand, my physical strength returned. I could finally walk again. I stopped bleeding. My incision started to heal as soon as it was stitched up. Without the constant blood loss, my nutrient levels returned to normal. The color in my face returned. I got to go home and sleep in my own bed. My muscle strength returned.

My milk came in: the very definition of life and vitality. I pumped an entire freezer full of milk, and Weston consumed maybe an ounce of it.

And, my fingernails. I had been on prenatal vitamins for months, and I continued taking them because I was "breastfeeding." The vitamins make my fingernails stronger in general, but they really started growing after Weston was born. You can see the result in the pictures. And that is why my fingernails capture my attention in the photos every time. There is a dead baby, my dead baby. They are, quite literally, pictures of death. Yet the hands that hold that baby are stronger and healthier than they had been in months. The contrast is stark.

Perhaps the body cannot always fully distinguish between love and grief. Actually, there is nothing to distinguish: grief comes from love. After Weston died, my milk supply multiplied exponentially because I had held him all day. My body did not know that the baby no longer needed the milk. I became a literal fountain of life. For nothing.

Grief takes an unbelievable toll on the physical body. But I started running again anyway, about a month after Weston died. And the physical capabilities of my body just increased from there. Less than six months later, I ran my first half marathon in about five years, only slightly slower than my fastest time ever.

It takes multiple systems of the human body working together to successfully run a half marathon. As I crested the final hill in that race, with the entire valley before my eyes, I marveled at the central players of my ability at that moment: my lungs. Weston's lungs were not enough. Somehow, mine had become enough to power me through 13.1 fast miles, and so I breathed for both of us.

Our physical trajectories met in the middle like an X, ever so briefly, that hot July. As a result, Weston's DNA will be in my body for the rest of my life. I continue to carry his heart in my heart. They both inhabit the middle of that X.

Don't run or leave the room  
when I speak her name  
Hold my hand and  
share her memory  
And remember:  
**Love does  
not end with death...**

Joanne Cacciatore "Dear Cheyenne"

## Poetry

Dear Families of the MISS Foundation,

We would like to introduce you to a special collection of poetry written by mothers who have suffered the death of a baby. The poems would touch any grieving parent or grandparent, brother or sister, or anyone who wants to connect with the internal unspeakable intimacy which comes with deep loss and suffering.

We have permission to share the foreword of this beautiful piece of work, written by Dr. Joanne Cacciatore, and which has received accolades from countless scholars, writers, and, most importantly, grieving mothers. You can purchase this beautiful collection on Amazon: <http://www.amazon.com/linger-hot-coals-collected-grieving/dp/1628575654/>

Foreword by Dr. Joanne Cacciatore

"I cannot live if she does not live."

Death. Death came. Death came into my body. Death came into my body and took my child. Death came into my body and took my child, leaving me in its carnage.

It was 1994. For ten long months we waited, all eyes turned toward me for the greatest performance of my life. Our bags were packed; laid across the top was her organic cotton

sleeper with shiny silver snaps, embroidered in mint green thread, "Going Home."

I was no novice at pregnancy and birth, feeling overambitious bravado after three lip-splitting naturalis partus. Still, a quiescent sense of unease tugged at my arm. Dare I say it aloud? "Something doesn't feel right." The obstetrician advised me well: put your feet up, take a bath, and relax. I put my worry in a box, neatly, on the shelf in the closet next to my high school yearbook and old Peter Frampton concert tickets. "Everything will be okay." It was searingly hot that summer day, my ankle bones hidden beneath swollen tissue, when labor pangs struck...

And then, Death kicked in the door, right there, on the clean white sheets that smelled of bleach and teddy bears. He didn't kiss me. Or ask permission. Or even warn me. He just held me down and took her, the most precious and inviolable piece of me. Just like in the movies of near-death phenomena, I left my body. I floated on the ceiling, watching the slow-motion movements of men in white, frame by frame, as they put her lifeless eight-ebony-pounds-of-well-nourished-baby into my arms. I was stunned and disoriented. Three hours later, I crawled past the nursery toward the exit, empty-wombed and empty armed, a shamed outcast. She would not be 'going home' with me at all. The doctor lied. Her sleeper lied. I lied.

I wandered the aisles of the 24-hour Walgreens at 3 am looking for a pump to ease my gorging breasts, hot with fury. My uterus collapsed on itself, pregnant with unspeakable shock, grief, and despair. Her death became a blockbuster horror film I watched over and over-sounds, sights, smells, glances. The kind of terror-inducing movie you cannot possibly watch but from which you are unable to avert your gaze. I listened to the burning rationalizations of ministers and counselors and UPS drivers, like sage on the altar: "All things happen for a reason," "You're young, you'll have more," "She just wasn't meant to be," "At least it wasn't one of your older children," "God has a plan for you," and "Maybe something was wrong with her." The world had shattered, language had no meaning, and my heart was eviscerated. I paced the hallways at night seeking her like a wild animal in captivity or an amputee searching for a missing limb. Every cell in my body craved her. I could not eat. Sleep. Think. Defend myself against an unsympathetic world. I could not care. I opened the russet envelope stamped "Office of Vital Records" that held her death certificate as proof of my failed performance. My Judas-body had not brought forth life. "I cannot live if she does not live." I was amongst the walking dead.

## Birthdays & Death Days

**Bi-monthly Birthdays and Death Days are now online on the MISS website.**

[Click here to see the Birthdays](#)

[Click here to see Death Days](#)

## Our Donors & Sponsors

**We'd like to thank all of you who give so much to support the MISS Foundation. All donor, memorial messages and sponsor listings are currently being updated on the website.**

[Click here to see the Sponsors list.](#)

[Click here to see the Donors list.](#)



Indeed, in cultures around the world, childbirth is revered and celebrated as one of the most anticipated, emotionally charged of all human experiences. But sometimes, about one in 120 births, the baby dies. And this death is the ultimate paradox: primal messages of birth, bonding, and maternal love coalesce with messages of death, departure, and insufferably traumatic grief.

Still, perhaps because of the systemic paternalization in childbirth, the process of recognition for babies who died of stillbirth has been a long and winding road. Two decades ago, these children were the dirty family secret, that which we dared not speak. Only one book, written nearly a decade earlier, would reach through the hands of time and provide a framework for this peculiarly painful state of Hades: *Stillborn*, *The Invisible Death* by Dr John DeFrain. But in 1994, the death of a baby to stillbirth was considered a reproductive or pregnancy loss, even a mere “adverse pregnancy outcome.” Society dislikes truth: A baby, a loved and wanted child, died. Instead, these babies were dismissed as an asterisk, and grieving mothers’ – and fathers’- experiences of loss were minimized and dismissed. These babies were not counted in infant mortality data (and still aren’t), they were issued death certificates but not birth certificates (we started the movement to change this 1998 and now more than three dozen states offer the option for a birth certificate), a dearth of research explored the lived experiences of families after baby death, what research did exist lumped stillbirth into studies about abortion and miscarriage rather than infant/child death, federal health funding initiatives did not include stillbirth in their funding agenda (we changed this in 2003), and these babies’ lives were quickly glossed over as if they’d never existed, as if they’d never mattered. We lingered on hot coals.

But the unified voices of mothers and fathers and sisters and brothers and grandparents and caring professionals over the past two decades have shifted the tide for babies stillborn and their families. And the pressure for recognition, research, and competent psychosocial care has come full circle. We are silent no more. Rather, we are their voices. We are the voices that sing: It is our time, it is their time. It is time to speak their truth. It is time to speak grief’s truth. It is time to speak love’s truth, one which never dies and which will no longer be quelled.

To Linger on Hot Coals...yes, to linger is to burn, ravage, blister. And this collection of poetry, save the *joie de vivre*, is faithful to its title. It sings their songs with all the sharp notes of bitter verity. It is a collective purging, pleading, pardoning.

It is anguish spilled onto many keyboards, contractions long into night hours, pangs until the poem is born, words created from each letter, giving form to that which is invisible, that which is the unmendable, albeit beautiful, wound. It will move you. It will seduce you into its darkness. It will take away your breath.

It invites you into the space between self and other as Stephanie Cole's piece *For My Mother* does:

you did not touch  
you did not move  
you did not weep, though your heart must have shattered  
your granddaughter dead  
your own daughter dying before your eyes  
and you, unable to move the mountains between  
what we needed and  
what we had

Or Angie Yingst's honest portrayal of death avoidance in *Of This We Shall Not Speak*:

You came into my home,  
and did not speak of death.  
But death was what we were doing...  
You said that death talk made you uncomfortable.  
And besides, you said, you wouldn't want to talk of death,  
if your baby died.  
I thought that I would call you again  
when I could speak of something other than death.  
I still think that some days.

Then, there is the longest journey back into one's self, into the place of unanswered questions, unreachable destinations, elusive concordance, and lurid acrimony as in the way Catherine Bayley's *Stillborn* adj. captures sublime anguish:

there, I found a moth pressed  
between the pages, like its own  
little translucent, ephemeral leaf,  
with veins for words, and blood  
drained out, and more years dead  
than living, and through its forewing  
I read (of an infant) born dead.

In what kind of world do children die before their parents? In what kind of world do children die before their birth? Anne Morris, in *The Physics of Losing You*, challenges a universe where babies can- and do- die.

An object at rest stays at rest.  
The tiny circle of your heart, so still.  
So still and silent that not even the force  
of our prayers, our screams, our love,  
our labor  
could move you again.  
Dear baby, breaking the laws of our universe.

And Hannah Logan Morris speaks of maternal love and remembrance "Every Morning" with her precious Joseph:

I  
rubbed circles of lotion into my belly,  
caressed my belly,  
held it,  
hugged it,  
rested my hands on it,  
gazed at it,  
watched my profile in the mirror  
growing...  
I cradled you in one arm at night as I fell asleep.  
And I sang to you every morning.

\*\*

In a furor sanandi (rage to cure) world, intolerant of grief and its manifestations, we journey into the imminence and unpredictability of grief after a baby's death with Stephanie Cole's Untitled II and her own unrhyming:

and then  
five years later  
you will sit in your car  
in the dark  
in the parking lot of Barnes & Noble  
and you will put your forehead on the steering wheel  
and you will cry  
and you will cry  
and you will cry

\*\*

And cry we do.

Our children are stories waiting to be told. Our children are hearts waiting to be opened. Our children are great teachers waiting to be heard. Our children are poems waiting to be born. Our children are deserts waiting to be crossed. From Kara LC Jones, it's all an experiment in free form:

These are the things we find in the desert.  
These are the ingredients of a life lived till death.  
These are the frames in which we hang ourselves...  
These are the boundaries we push by simply cheating death each wide eyed morning.

\*\*

Nearly two decades after I watched as they lowered her pink satin casket into the red earth, I feel her inhalations, resurrected in the songs of my sisters in mourning. I feel her exhalations, reborn in the movement toward recognition of these precious children. Stillbirth is a fundamental contradiction: a moment when life and death meet at the edge. And all these years later, I remember, well, those words "I cannot live if she does not live."

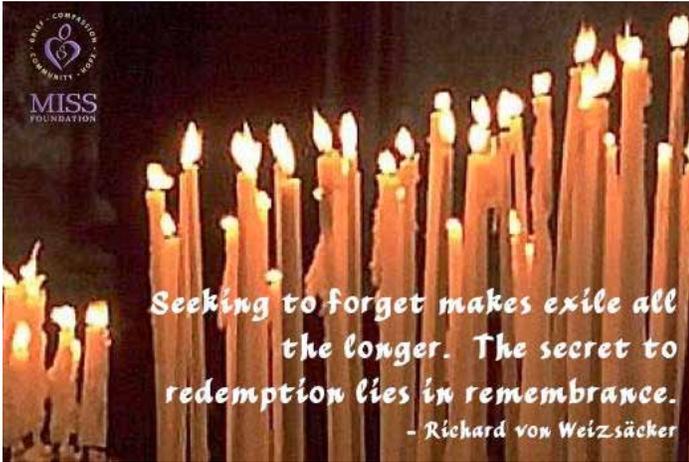
Indeed, I did not live, not in the same way. I, like the mother-poets in this collection, was irreparably changed that fateful day. But in some small and meaningful way, To Linger on Hot Coals is their breath, their beating hearts, their mark in the world. And perhaps this is one step toward rebirth, for me, for her, for us, for them. And so, I live, she lives, we live. They live.

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If it is possible to sum up the need for, and the important work done by, the MISS Foundation, it is done here.

<http://www.missfoundation.org/sites/default/files/60%20miss.mp3>





## 'A Pill for Every Ill'

By John Ericson / February 6, 2014 / Newsweek

If there were fewer possible psychiatric diagnoses, would fewer people consider themselves ill? A growing number of health experts suspect that psychiatric care is drifting toward "diagnostic inflation," in which the rate of mental disorders balloons as a result of new diagnoses - and not due to an increasingly troubled population. What's worse is that this process may be fueled by the very document that is supposed to control it.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a 1,000-page behemoth that is now in its fifth edition, gives researchers and clinicians across the country a common language for discussing the ins and outs of a mind that is not well, ideally allowing everyone to agree on who is and isn't ill. The manual is produced by the American Psychiatric Association (APA).

Although the APA has insisted that its signature document should not be read as a rulebook, with definitions set in stone, a publication of this scope and caliber inevitably shapes the field. If the DSM-5 says your pain doesn't align with its definition of pain, you can be certain that, in the eyes of most psychiatrists, lawyers and policy makers, you're not in pain.

Now consider the opposite: What if the DSM-5's definition of pain illuminates a problem you didn't know you had - a pain you didn't know was even considered a real issue?

When the APA released the fifth edition of its manual in May 2013, it was instantly criticized by several researchers and clinicians, who claimed that some of the revisions and modifications reflected the agenda of an editorial panel that did not have the public's best interest in mind. For example, many therapists and parents denounced the decision to define Asperger's syndrome as a part of the autism spectrum rather than a stand-alone diagnosis. Some said it would skew statistics. Others said it would mess with identities.

"I personally continue to believe that Asperger's stands alone from autism," Andy Novis, a 50-year-old artist, handyman and personal trainer who received his Asperger's diagnosis shortly before the publication of the DSM-5, wrote in an email to Newsweek. Save for a few social anxieties, Novis navigates the world with ease, communicates about his experiences with aplomb, and prides himself on independence as he awaits the right time to start a family of his own. "While I accept that Asperger's may be part of the autism spectrum as a whole.... I personally do not see myself as autistic in any way."

That, however, wasn't the biggest concern. Other experts, including Sheldon Krinsky, professor of Urban & Environmental Policy & Planning at Tufts University, have pointed out that changes to the DSM can also be big business, with lots of downstream profit for everyone involved. If, for example, the DSM-5 finds a new "indication" for a particular drug, the developer can renew its patent and keep generic competitors off the market for another three years. For most industries, this would have a pretty modest impact on revenue. But in the business of curing ills, in which price tags can be very high and demand is often buoyed by nature, those three years can make a huge difference.

Take, for example, the drug Cymbalta - one of a group of drugs referred to by the industry as "blockbusters" - drugs that rake in at least \$1 billion in annual revenue. Cymbalta, which is prescribed for major depressive disorder and generalized anxiety disorder, earned its blockbuster title almost five times over in 2012, bringing in nearly \$5 billion to developer Eli Lilly. Lilly's patent on Cymbalta expired in December 2013, and the developer should soon begin to lose revenue to generics.

But thanks to the changes made by the APA to the DSM, the money will likely keep rolling in.

In past editions of the DSM, a so-called bereavement exclusion from major depressive disorder recommended that actively grieving individuals not be diagnosed with depression. In the DSM-5, this recommendation has been erased, giving rise to "bereavement-related depression" - a subset of major depressive disorder that is treatable by all the standard methods (and drugs) that ease depression. But if you didn't need to treat the loss of a loved one with medication in 2000, is it really necessary in 2014?

Companies like Lilly certainly want it to be - and they may just get their way. Public records regarding clinical investigations show that Lilly's expired patent on Cymbalta will in all likelihood be renewed, as it is currently the focus of a new trial for the pharmacological treatment of bereavement-related depression. In other words, it's going to end up being the drug of choice for treating what was merely called "grief" at the time of Lilly's original patent filing.

Changes like the bereavement-related depression clause are a cause for concern, Krinsky told Newsweek. After all, the APA is made up of professionals whose diagnostic preferences shape not only the psychiatric landscape, but also the revenue and stock profile of the pharmaceutical industry. The problem is that a striking number of key decision makers within the APA openly profit from this industry.

"In such sensitive areas, where new clinical indications are introduced for behavioral conditions, even the appearance of conflict of interest can affect public confidence," said Krinsky, whose new study -- conducted at the lab of Dr. Lisa Cosgrove, lead author and researcher at the Ethics Center of Harvard -- takes a closer look at 13 ongoing drug trials for broad, newly introduced diagnoses like bereavement-related depression. "The absence of biological markers - there are no blood tests or scanning techniques to determine the presence of binge eating disorder' or even 'major depressive disorder' - makes the risk of subjective bias stronger and the opportunity for the DSM to play hand-aid to industry even greater."

The DSM-5, like all scientific publications, comes with something called a "disclosure statement." In it, everyone involved in the publication discloses his or her affiliations with potentially conflicting entities (such as, say, a pharmaceutical company). A staple of good research, these statements serve to boost transparency and public confidence.



The APA's disclosures regarding the DSM-5 include several instances that appear to support the contention that the public's best interest has fallen in the shadow of financial gains. Take, for example, the Cymbalta trial: Of the 43 APA panel members involved in the implementation of this new diagnosis, 20 had disclosed financial conflicts of interest with drug manufacturer Lilly. These disclosures, which range from stock holdings and consultancies to honoraria and research funding, suggest that more diagnoses ultimately means more money for everyone involved. So, has the U.S. psychiatric authority been reduced to an intellectual grift, or does Cosgrove and Krinsky's study illuminate a more complex issue that warrants a second opinion?

"The issue that they are raising is completely legitimate and worth worrying about," says Dr. Allen Frances, a psychiatrist and former DSM chairman whose book *Saving Normal* takes a closer look at a public health landscape that has come to rely on a pill for everything. "But I know the people working on the DSM-5, and I think they've made simply terrible decisions, but that they've done it with pure heart."

Frances believes that while pharmaceutical companies may indeed pounce at every opportunity to drive revenue and retain exclusivity, the panel members themselves have also been blinded by their desire to help "the missed patient" - the individual in pain who, for one reason or another, disappears through cracks in the system. "The experts on the DSM-5 were given a tremendous amount of freedom, and what this resulted in was a kind of dream list of new diagnoses that turned the everyday problems of life into mental disorders," he tells Newsweek. "They are naive about how something that may work in their hands will be misused in the average practice."

The Cymbalta trial isn't the only case involving financially conflicted APA decision-makers. Cosgrove and Krimsky's new study identifies similar conflicts of interest across its entire sample, with board members as well as principal investigators disclosing ties to Lilly, Forest, Cephalon and many others. But Frances is quick to point out that greed is not the only thing coaxing panel members towards a broader view on mental illness.

"The biggest risk is not financial conflict of interest, but intellectual conflict of interest," he says. "The pressure of experts is always to expand their area."

What makes this prospect of diagnostic inflation so unsettling is that, from some distance, the development looks like a service to those in pain, a panacea from the tippy top of the system. Judging by Frances's thoughts on the matter, that's what it looks like to many high-ranking APA members, too. But as both he and Krimsky point out, a "pill for every ill" is an unsustainable dream that may ultimately do more harm than good.

"We have more deaths in emergency rooms now for prescribed psychiatric medication than we do for street drugs," Frances explains. And, as broad diagnoses will have psychiatrists and primary-care providers prescribe these pills to younger and younger patients, hospitals across the country may soon face a patient generation that has come to think of the pains of everyday life as treatable ills.

Historians have noted that when the Austrian philosopher Ludwig Wittgenstein worked as a hospital porter tasked with delivering psychiatric medication to World War I veterans, he would tell his patients not to take the drugs he brought them - supposedly out of a belief that, once illness becomes the norm, no one is really sick anymore. Although the strategy is a bit extreme, the idea behind it goes to the very core of the problem at hand: If there is a pill to cure all ills, will there no longer be such a thing as a healthy mind?

*The story has been clarified to reflect that Dr. Lisa Cosgrove and Sheldon Krimsky conducted a study exploring 13 ongoing drug trials for newly introduced diagnoses like bereavement-related depression.*

## Become a Certified Provider

Reminder: The MISS Foundation is partnering with the Elisabeth Kubler-Ross Family Trust to train providers to be better prepared to help families whose babies and children are dying or have died (doctors, nurses, social workers, funeral directors, psychologists, first responders, and others). Please share this information in your community. We are weary of hearing 'nightmarish' stories from our families about their experiences with providers' lack of compassion and training. <http://certification.missfoundation.org/>



### Become a Certified Provider

Are you a medical or mental health provider looking to specialize in the area of traumatic grief? Do you want to truly be a solace to parents who have lost babies and children, or to others who have experienced traumatic losses? Obtain your certification in beautiful Sedona, Arizona at one of our upcoming trainings.

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## Volunteers Needed

**Because in helping others, we help ourselves and in helping ourselves, we help others...**

Volunteers needed: help us help another bereaved parent through their darkest days... Our HOPE Mentors volunteers provide one-on-one peer mentoring to families who are seeking bereavement support from the MISS Foundation. If you are interested in volunteering, please apply through: [https://docs.google.com/a/missfoundation.org/spreadsheet/viewform?usp=drive\\_web&formkey=dFp2VDdTTXAtUUpvalF6V2w2U2l4VWc6MQ#gid=0](https://docs.google.com/a/missfoundation.org/spreadsheet/viewform?usp=drive_web&formkey=dFp2VDdTTXAtUUpvalF6V2w2U2l4VWc6MQ#gid=0)

# Woman held in psych ward testifies at hearing

**Christina Schumacher was held involuntarily for 5 1/2 weeks after learning about the killing of her teenage son by her estranged husband, who then killed himself.**

**USA Today January 31, 2014**

MONTPELIER, Vt. -- Christina Schumacher, who a judge determined was improperly held against her will for more than five weeks in a psychiatric unit, told Vermont legislators she opposes involuntarily hospitalization.

Schumacher, 48, of Essex said she had gone through hell the day she was admitted to Fletcher Allen Health Care in Burlington after learning about the killing of her teenage son by her estranged husband, who then killed himself.

"The bottom line is nobody should have to endure the death of their son and the death of their husband and then be put into the situation," Schumacher said as she summarized for lawmakers her life on Dec. 18-19.

She made the remarks Thursday during a two-hour joint session of the Legislature. The Senate is considering a measure to update laws regarding involuntary hospitalization and medication.

Schumacher said she was fortunate to have a lot of support from friends after the bodies were found Dec. 18, and she decided to keep her therapy appointment the following afternoon.

"I thought it would be a logical thing to do, to actually go to that therapy appointment," she said. "So I made a choice to go."

Schumacher said she was surprised to find that her therapist had been joined by the director of the counseling program, another doctor and two guards.

"They all made a decision before I even arrived that they were going to check me in. Check me into a mental health facility. A woman that just experienced the hell of her life," she said.

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"That night I went through the fires of hell just dealing with what I dealt with," Schumacher said.

Schumacher said in an interview prior to the Senate hearing that she went public with her story in the Burlington Free Press while she was hospitalized to try to ensure nobody ever again has to endure what happened to her and also to be released so she could support her teenage daughter. Schumacher said her visit to the Legislature is a continuation of her fight.

Disability Rights Vermont, a Montpelier-based nonprofit advocacy group, asked her to testify at the joint hearing, Schumacher said. The group helped her in the fight to gain freedom, which came last week when her case finally went before a judge.

Vermont Superior Court Judge Kevin Griffin ruled Jan. 24 that he could not find "by clear and convincing evidence" that Schumacher was in need of treatment when she was admitted Dec. 19 or when he held a three-hour hearing Jan. 22. about her possible continued hospitalization.

Schumacher told the nine senators that although she was not crying Thursday night, she shed "so many tears in the psych ward by myself for ... 5 1/2 weeks. Locked up."

"My family turned against me. They are sitting in the room right now," she said about sister Louise Lynch and brothers Matthew and Mark Fitzgerald. "Instead they wanted me to be locked up and put on medication."

The three siblings opted not to testify at the hearing. They have declined comment during the course of the case.

"I had patients throw chairs at me. I had this woman sit outside my room who was mentally ill and needed more help then she was getting," Schumacher told the senators. She said the woman would scream obscene comments.

Schumacher said she walked the halls at night as she couldn't sleep because of nightmares she had about how her son was killed.

"I would wake up all night long and get in trouble with the doctors for not sleeping all night. Would you sleep having nightmares about that? Would you want to go to sleep?"

The doctors told Schumacher they wanted her to take stronger drugs, she told lawmakers.

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Once Lindsey Owen of Disability Rights explained to Schumacher her legal rights while she was hospitalized, she said she began to fight.

"I started standing up to the doctors," Schumacher said. "They did not know whether to kick me out or lock me up forever. So guess what? I fought for my rights, and I'm out of there.

"And no one should ever have to endure what I have gone through," she added. "It has been hell. I will not stop fighting this fight."

Essex police said Thursday they continue to investigate the homicide-suicide.

Gunnar Schumacher, 14, was strangled, and his father, Ludwig "Sonny" Schumacher Jr., 49, later hanged himself, police have said. The bodies were found Dec. 18 in an apartment in Essex. Sonny Schumacher rented the apartment after Christina Schumacher obtained a relief-from-abuse order regarding her husband during the summer, records show. She later filed for divorce.

At the counseling appointment the day after the bodies were found, Christina Schumacher's doctor and mental-health workers were unsuccessful in persuading her to sign herself into the hospital, court records show. The staff then tried to have her admitted against her will, but University of Vermont police refused to transport her to Fletcher Allen, saying the required paperwork was not in order.

A few hours later, when the mental-health workers and doctors obtained the proper documents, UVM police took Schumacher to the psychiatric unit, where she remained until the judge ordered her release.

## Rush to prescribe: Study questions speed in giving antidepressants to grieving parents

Some doctors are too quick to prescribe antidepressants to parents who have suffered the death of a child either during pregnancy or within the first month of life, according to a study conducted by Florida State University researcher Jeffrey R. Lacasse.

In a study of 235 bereaved parents participating in an online support community, Lacasse found that 88—or 37.4 percent—of them were prescribed a psychiatric medication to help them cope. Some women received prescriptions with a week of losing their children.

"This is simply too soon after the loss to reasonably conclude that these women need long-term treatment with antidepressants," said Lacasse, an assistant professor in the College of Social Work. "Even though our sample is select, the data raise disturbing questions about prescribing practices for grieving parents."

The study, "Prescribing of Psychiatric Medication to Bereaved Parents Following Perinatal/Neonatal Death: An Observational Study," conducted with Joanne Cacciatore, a professor of social work at Arizona State University, has been published in the journal *Death Studies*.

Of the 88 parents, the study found that 79.5 percent were written prescriptions for antidepressants and 19.5 percent were only prescribed sedatives or sleep aids. Prescriptions were written shortly after the loss in many cases: 32.2 percent within 48 hours; 43.87 percent within a week; and 74.7 percent within a month. Most women prescribed antidepressants took them long term, some for years.

The research revealed that the clinicians doing the bulk of the prescribing were obstetrician/gynecologists.

"We did not see the same pattern of prescribing from psychiatrists or general practitioners," said Lacasse, who suggests that OB/GYNs should refer their patients to mental health practitioners in such tragic and highly emotional situations.

The effectiveness of antidepressants, which were highly touted in the 1990s and 2000s, has been called into question in recent years.

“It is pretty well accepted at this point that antidepressants are not as effective as it was hoped they would be, and thus should be used carefully,” he said.

Common sense dictates that grief is not a mental illness. By the very act of prescribing an antidepressant, clinicians are tacitly labeling a patient as mentally ill, according to Lacasse.

“If it’s only been 48 hours since a mother lost a child, it would be normal for her to experience an extreme state of grief,” he said. “This is a natural reaction to tragic circumstances, not a mental disorder. To treat it as a mental disorder so soon is contrary to the concept of evidence-based medicine.”

There is no evidence that says giving antidepressants to parents who have lost a child will help them get over the loss faster than through a grieving process that does not include psychiatric medication, he said.

The usefulness of prescribing antidepressants in this situation is questionable given the time it takes for them to take effect—two to four weeks, in some cases.

“We also don’t know how prescribing a psychotropic drug so soon after a bereavement affects the normal process of grieving,” Lacasse said. “The assumption is that it helps, but we don’t know that.”

These concerns should cause medical practitioners to hesitate before they write a newly bereaved parent a prescription for an antidepressant.

“Nowhere in our paper do we say that people should never be prescribed antidepressants,” Lacasse said. “But there are other options that should be tried first. Given the lack of evidence to support the efficacy of antidepressants in bereavement, physicians should take a conservative approach in prescribing to avoid overtreatment.”

The researchers suggest first using psychosocial interventions such as peer support or psychotherapy with social workers, psychologists and mental health specialists.

“If these options do not work, and it’s clear that something beyond normal grieving is going on, then we can have a conversation about psychiatric treatment,” he said.

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