MISSFoundation
A COMMUNITY OF COMPASSION AND HOPE FOR GRIEVING FAMILIES

"That'll do"

"Do parents who've lost a child parent differently?"

By Steve Larsen

A month after joining the board of the MISS Foundation and three minutes into my first video conference with Kelli Montgomery, its executive director, I was startled. A four-year-old blond child in a bright red sun dress clambered up on the chair behind her mother. She began to thrust a ribbon into her mother's hair with all the skill of the average four year old, and sent fleeting glances toward the computer screen which projected my voice and image.

Prior to the start of our call, Alaina had played quietly in another area of the house. Realizing her mother was on the phone and may no longer be immediately accessible to her every whim, she sprang to action. As Kelli and I talked though a variety of operational issues related to the MISS Foundation, Alaina climbed around her mother, played with her mother's hair and shot quick looks toward the camera so as to catch my eye.

Unable to ignore her, I soon asked Kelli if she would introduce me to this beautiful young princess. After a few minutes of introductions that included my holding our less-than-enthusiastic kitty, Gilda, up to the camera, we returned to our discussion. Alaina continued to make occasional, benign efforts to intrude, but mostly settled down and played quietly in an overstuffed chair behind her mother but in the same room.

Not until the next day did it began to sink in. I'd recently seen this same behavior – parents responding to the demands of a child in an unexpected and non-customary way. Kelli, typical of many who work with the MISS

Continued on page 3…

MISSing them…

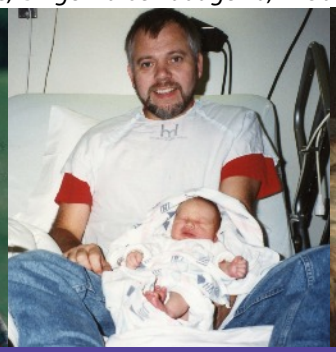
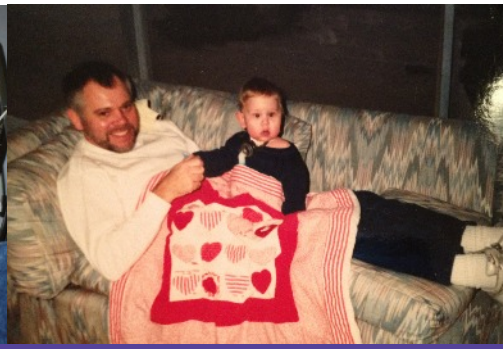
Table of Contents

- That'll do
- News
- Birth & Death Days
- Donors
- Research
- Silence
- Pathologizing Grief
- Honor Thonors
- Poetry
- Noah's Jar
- FMLA

Submission Guidelines

Want to contribute to MISSing Them newsletter? Send submissions to info@missfoundation.org for consideration. Thank you.

Photos left to right: Eric M. Larsen; Eric Larsen with nurse; Ginger Larsen at age 10; Eric and Steve Larsen

News

San Antonio Kindness Walk 2013

Postponed!

2013 MISS Foundation Kindness Walk for the San Antonio Chapter has been postponed until May 19th to avoid a new construction project at the park. The new date will make the event a memorial event rather than a walk, in honor of Bereaved Parents Day which is being celebrated Nationally.

If you have questions or would like to be on the planning committee, please contact Jennifer.

Bereaved Parent Day In Phoenix 2013

May 19th Bereaved Parent Day, contact Jennifer Blain Christen, Event Organizer, Phoenix Chapter, if you want to help with event planning in AZ.

Call for Participants

If you lost a beloved child from a terminal illness, you may be interested in becoming a participant in our latest research. Click here to find out more.

LA Support Group adds a second meeting each month!

Our LA area group is growing, and so we've added a second support group meeting each month. Click here for full info.

MISS Foundation named one of the top 10 grief resources online!

Click here for the full article.

When a Child Dies: A Critical Analysis of Grief-Related Controversies in DSM-5

"... This article critically analyzes research and debate regarding these two changes and considers the likely implications for bereaved parents and other traumatically bereaved groups, who may be especially vulnerable to consequences of the two proposed changes." Click here for link to full publication.

Do we have your most current information?

It is very important to us to have the correct information regarding your precious child(ren), including his/her full name, DOB, DOD, mom and dad's names, surviving siblings, etc.

If you have not filled out our Request of MISS Foundation Services Form, we ask that all members please do.

The form also allows you to request more support from MISS by means of a HOPE Mentor, Counseling referral, Newsletter subscription and Family Support Packet.

Join us in the Boycott

The MISS Foundation opposes the medicalization of grief and we invite you to join us in this boycott.

Please sign and share this petition to boycott the DSM5 for its position that significant grief symptoms, common amongst bereaved parents, beyond two weeks can be diagnosed as a mental illness.

Click here to sign and share.

Let's send a message to the APA that bereaved parents are not mentally ill, and that the death of a baby/child presents unique circumstances for most families which causes enduring and profound psychological distress which is not mental illness.

What bereaved parents need is a compassionate community. What this move will do is further abnormalize and mystify society's already- strained- understanding of a parent's grief.

Thank you.

…cont' from page 1
Foundation, has lost a child. The loss of Madeleine, her firstborn daughter, impacts how she interacts with Alaina, her living child.

I remembered watching children and parents at the MISS Foundation conference in Tempe, AZ the week before. The children didn't behave any differently from children anywhere else but their parents did. I observed no frustrated parental outbursts directed at rambunctious children. Parents seemed to automatically drop to their knees, look into the eyes of wayward or misbehaving children and mindfully listen to find the cause of the child's frustration.

Perhaps bereaved parents, those who have had children die, view their living children differently. Do standards of behavior change? Are they now more forgiving? Do expectations for their living children evolve? Are they now more likely to think, "You don't need to be on the winning soccer team any more, get the best grade in the class, score the winning homerun or get into the best college: you just need to live."

When Eric, our two-year old son died, our daughter lost her only brother and had a huge part of her life was stolen from her. In retrospect, I see that my sometimes overly-critical approach to a lot of what she did fizzled out like a defective firecracker. It wasn't long before I began to alter my interactions with her.

As a family, we were shell-shocked for several years. We eventually began to stabilize, individually finding our footing as we emerged from a long, dark tunnel of anguish. Our daughter, Ginger, had been locked by Eric's death into terrible guilt and grief. All the normal resentments she'd felt about a new child in the family, a sick child who'd harvested 100% of our attention, had come down on her after his passing like a heavy, impenetrable cloud.

We finally located help for her in a marvelous therapist, Dr. Collette Geary. It was she who brought Ginger slowly and beautifully back, not only back from talk of suicide, but back to us. Each slowly emerging glimmer of light, like a tiny miracle, allowed us to begin to heal. Joy and laughter slowly began to find a place alongside the loss and loneliness we all felt.

As she entered her pre-teen and teen years, the time when everyone expects girls, especially girls, to become major problems, I found few things intolerable. Ginger and, more likely, her mother, may recall events slightly differently, but there weren't major issues for me – at least not with her. At 14, she announced she'd decided to become a vegetarian. Her mother appealed with me to talk her out of it. I never made the attempt. "Vegetarian? Hell, I thought, she could be a Presbyterian for all I care."

In tenth grade, she asked me to construct 11 fish tanks, each one a precise size, built to hold a different and exact amount of water, and a specific number of fish for a Science Fair experiment. Out of scope for my handyman skills, I elicited help from my cousin Ron to build what she needed. Ron and I both agreed that what we were doing was crazy, but far be it from me to be unsupportive. She'd made up her mind to do this experiment and I'd made up mine: "I'm here for you."

The next year, the private school in which she was enrolled informed her they would be unable to accommodate her desire to up the ante and conduct a variation on her Science Fair experiment, this time with 40 white rats. We then learned that if she raised them at home -- her first choice, incidentally -- the experiment would not qualify for Science Fair competition. Hearing the public high school may be better equipped, she visited there and found a science lab with the space to house her rats. After assurances that her rats would not be used to feed a large snake in one corner of the lab, she learned only students of the school were allowed to use the lab. With no fanfare, she announced her intention of transferring schools and then did so, mostly accomplished on her own. Five months later, her experiment complete, she arranged to return to her private school. What high school student does this? What parents allow for this sort of to and fro? I can answer the second question: parents who are desperately thrilled every day that their child is alive.

As it turned out, both science experiments were successful. Unusual and creative, her efforts received many awards. Her rat experiment took her to the International Science Fair competition in Palo Alto, California and this success played a part in her receiving invitations and scholarships to attend several exceptional universities. She had her own equally direct and focused ideas about college as well, but that is a different story.

After college and in her twenties, Ginger told me, "None of my friends have parents as supportive as you. I can't recall anything I've ever wanted to do that you didn't try to accommodate. Sure, when I told you I wanted to major in sexuality studies, you weren't overly enthusiastic but, after a few months, I was getting emails from you with attachments saying, 'This article applies to your research. Check it out, quite interesting."

I now believe that parents who lose a child change the way they relate to their living children. Research in this space is inadequate. I've heard some speculation that parents make one of two mistakes: 1) withdrawal from the remaining children, or 2) holding them too close. I think we need to consider a third option, which is not a mistake. There is the possibility that they become incredibly effective parents – loving their living children with intensity and passion and with an acceptance and appreciation that every parent can learn from – even those who've never lost a child.

We've all seen parents show visible disappointment when their child's little league team loses a game. Some parents let kids think that their love and approval is tied to an SAT score or their performance at a swim meet. I've heard parents berate kids for not getting the best score, the top grade or winning the highest achievement award. As a parent who's lost a child, trust me, I'd take the runner up, the second best, the guys who are eliminated in the hockey tournament first round. Hell, give me my son back and put him in last place; I'll take that in a heartbeat. I'd hold him

Continued on page 4…

…cont' from page 3

and never let him go. Give me my son back and I promise to not let a day go by without telling him I love him. I'd even build him fish tanks.

In Mandy Patinkin's role as Inigo Montoya in my favorite movie, The Princess Bride, he approaches his climatic confrontation with the six-fingered villain, Count Rugen, repeating the line, "Hello. My name is Inigo Montoya. You killed my father. Prepare to die." Once he has the upper hand, he commands Rugen to "Offer me money," then "Power, too. Promise me that," and finally, "Offer me everything I ask for!" Rugen repeatedly acquiesces and finally desperately responds with "Yes, anything you want." Inigo runs his sword into Rugen's stomach and says, "I want my father back, you son of a bitch." I'm unable to watch this delightful movie without tears at this scene as the feeling Patinkin conveys is one I know far too well. My anger at the doctor who countered specific written and emphatic verbal instructions from Eric's heart doctor, his surgeon and his mother to not initiate a post-surgery procedure on our son, but then did so anyway, in the middle of the night, on an unconscious and defenseless 2-year old, causing his death, has never left me.

There is another line with which I identify, a bit later, after Rugen is dead. His longest-held ambition now met, Montoya confesses: "I have been in the revenge business so long, now that's over, I do not know what to do with the rest of my life."

Most parents who've lost children struggle to find reasons to continue living and not all of them do. A study, "Increased mortality in parents bereaved in the first year of their child's life" by Mairi Harper at the University of York in the UK,* revealed that parents are twice as likely to die in the first 15 years following their child's death as parents who have not lost a child. Among bereaved mothers in England and Wales, the risk of early demise was four times higher than non-bereaved parents. But if and when they make it through, and most do, they may very well address parenting differently.

After a year in the hospital, a time when Eric had spent 350 days in pediatric intensive care and survived two "do or die" heart surgeries, he was home and on the road to full recovery. Eric's progress was rapid and remarkable after this incredibly rough start. He had started to crawl on the living room floor but, according to his mother and her friends, his crawling was "not right."

Off we went to an orthopedic specialist, who, after a series of tests, called us in for a consultation. "Eric," he explained somberly, "would need braces." He went on to explain that while he hoped the braces would cause his bones to grow into the right configuration, he could make no promise of that, and we needed to understand that it was possible Eric would spend the rest of his life in a wheelchair. I can imagine the impression on that doctor as we grinned and said, "That's it? That's the downside? He might live his life in a chair? NO BIG DEAL! We can deal with that. Hell, we thought you might have had really bad news for us."

There is no doubt in my mind most parents would be devastated by such news. But we weren't most parents. This doctor had no idea he was talking to parents who'd had, over the first year of Eric's life, countless meetings and repeatedly heard statements such as, "We don't think he'll make it through the weekend; this is an exceptionally risky procedure, he's failing – do you want us to call someone to perform last rites?; We're worried, you may want to let your daughter say goodbye to her brother."

They said all this and more. But Eric always came through. His will to live was phenomenal. He repeatedly survived situations where every single one of his caregivers – doctors, nurses, surgeons – had written him off, except his parents. One time they even accidently poisoned him with a 10X overdose of his antibiotic, another near-death experience, but he recovered and thrived.

We never gave up hope. Parents don't. We never stopped believing he'd come home and live a normal life. And Eric did come home and he did almost make it to the point of living a long and normal life. He got so close.

Having him home was a relief, even with supplemental nursing care. Eric found security in his braces; he used them to push himself into almost a genuine crawl. He looked kind of funny moving crablike and noisily across the floor. The braces helped him sit upright and he especially liked doing so in his wagon. At the same time, the braces caused him to need help getting turned over in his crib, although he rarely complained. Less than six months into the braces odyssey, he had another series of X-rays. The doctor now recommended taking them off. The bones were growing correctly now. Eric should be able to run and play as any normal boy – no wheelchair in his future.

Were we thrilled? Of course! What parent wouldn't be overjoyed at this news? While not having to wear braces made Eric and all of us delightfully happy, don't forget the real lesson here. We would have been perfectly happy if he'd been in a wheel chair the rest of his life – and still would be – if only we could have him alive.

If your children are alive, be happy. Feel lucky! Don't worry so much on how they measure up to a mass of artificial standards that mean next to nothing. Do you really need to be the one to push your children farther and faster than they are ready to go? Most likely, they'll push themselves when the time is right, when they find the thing that ignites the fire deep inside. When they do, they'll succeed because deep down, they have something to push off from: the unconditional love and support of their parents.

(1) Reference: 'Increased mortality in parents bereaved in the first year of their child's life': statistical points and possible extensions. BMJ Support Palliat Care 2012;2:1 7

About the author: Steve Larsen splits his time between advising young entrepreneurs at the Thunderbird School of Global Management and riding and writing about motorcycles. His free-lance articles appear in national cycle magazines such as RIDER and Motorcycle Consumer News and international adventure magazines like the Overland Journal. This is the first time he's written publicly about his son. He can be reached at: steve@stevelarsen.net. A sampling of his motorcycle stories can be found here: http://stevelarsen.net/blog/

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 on the MISS website now.

Click here to see the Sponsors list.
Click here to see the Donors list.

Silence

Written by Shauna Bryant Yoder

We didn't talk often. He was a premature baby, weighing barely over a pound and with a tube shoved down his throat, so he was not expected to say much. But parents are supposed to talk to their babies from the moment of conception, practically. Mom, baby will hear your voice constantly and come to recognize it. Dad, you are not physically attached, so talk to Mom's belly. Play classical music at your uterus to gain some bonus IQ points. Read to your baby in utero so he will be an early reader.

If your baby, still within you or having arrived in the outside world, is sick, talk to him. Tell her to fight and hang on. It will help.

I am an extrovert, and I used to talk for a living. This is advice I could have followed in my sleep. But I didn't.

Two months of bed rest at home provided plenty of quiet, down time to talk to my baby, defying the odds and growing normally despite my continually disintegrating placenta. A third month of bed rest in the hospital provided more time: often panicked, but time, just the same. But it just didn't occur to me to speak audibly to my baby.

For one thing, I didn't know his name yet, because I didn't know his gender until he was born (even though I "knew" from the very beginning). I would have felt terrible calling him by the wrong name.

But I never felt the urge or the need to speak out loud. I would sit there and stare at my tiny belly and wonder if it was growing, and I would whisper in my head, "Come on, baby. What's going on in there?" There were thoughts I couldn't (and still can't) put into words-thoughts of love, hopeful pleadings, and fear-but I would transfer them to him anyway.

I was alone so often that he actually did not hear my voice constantly. But he had plenty to listen to. There was the fetal heart rate monitor that I am convinced sounded like a freight train to him. He hated that thing; he would move away every time. It made me smile: he was my feisty one!

And there was my heartbeat. It has been said that our babies are the only ones who know the sound of our hearts from the inside. Given the chaos my body was stirring up, my heartbeat was the only physical steadiness he ever had from me. I didn't have to say a word. And what could I have possibly said, anyway? What words could transcend the comfort of my heartbeat? It was his lullaby, his metronome indicating that the rhythm of his world was still steady. It was an audible reminder to him that he was part of me. Until it wasn't. The sound of my heartbeat was replaced with the

Continued on page 6…

…cont' from page 5

sound of beeping monitors and constant medical-speak. We were hopeful. We spent many hours at his side, of course, but our faces were mostly separated by a wall of plexi-glass. There were holes for our arms, so we could touch him. Mostly, I would stand or sit there, just staring. Maybe I subconsciously knew he was hearing way too much noise already; after all, he should still be listening to my heartbeat. So I kept quiet. The blanket over his bed, when folded a certain way, provided perfect padding for my forehead, so I could relax a bit when becoming stiff after hours of cocking my arm at a weird angle in order to put my hand around him. And I would talk to him, silently: tell him how perfect and beautiful he is, how tiny, how tenacious, how much I wished his lungs would strengthen, how many people love him, and how much I love him. He "heard" me every time: his vital signs would improve almost immediately upon my touch. One author, writing about her premature baby in the NICU, would walk away from her baby's bedside whenever the doctors wanted to talk to her. She wanted to be strong for her baby, not cry in front of him. Not me. My son became an old soul quickly: I didn't spare him any emotions. When medical staff gave me bad news from time to time, I stayed at his bedside. Then, I would put my forehead back on that blanket, vision blurred by tears, and plead to him, silently again, to please defy the odds.

Before he died, I had never really seen death. I had seen death in the movies or read about it in books. When people die on the screen or on the pages of a book, their parents or other loved ones inevitably let out a scream, a noise, or some other indescribable sound upon the discovery that their loved one is dead. And the loved ones, if they are there, talk to them, comforting them as they leave this world. When I walked into the NICU that hot July morning to see my son, my flesh and blood, non-responsive to full resuscitation efforts, I knew what it meant immediately. Yet I did not scream. I did not cry. When they handed him to me for only the second time ever, knowing it would be last time I would hold my living baby, even then I stayed quiet. There was activity around us. Medical staff wanted to make sure the three of us were physically comfortable, and then they moved us to a private room. People continued to filter in and out: the physician to check his heartbeat periodically to determine the time of death, the nurses, some family members. I have a vague memory of the activity, but mostly I remember my son's weight in my arms, his smell, his peaceful face, finally unencumbered by tubes and wires, as he took his last breaths. And still, I was silent. For the first and only time, I rocked my baby. They happened to seat me in a rocking chair, and I rocked him for hours in that chair, long after he had passed. Silently. And I held him close to my chest. Maybe he heard that reassuring thump-thump-thump of my heartbeat then: the audible reminder of my steadfast, perpetual love for him. It was, perhaps, the first and last sound he heard on this earth.

Later, I would learn that hearing is one of the last bodily functions to cease. For a while, I cursed myself for not talking to him as he was leaving this earth.

But he and I should have had a lifetime to communicate. I should have had daily opportunities to live my love for him. How could I possibly sum up all we would miss in the forty-five minutes from when he was placed in my arms until he breathed his last?

And what could I have said to an extension of myself? What words would I speak, for example, to my heart or my brain? They ARE me, they embody me; what words of explanation or affection would enlighten them further?

No, I have never talked to myself, at least not out loud. My monologues take place internally. So it stands to reason that my son, an extension of me, needs no audible sound to hear me. He is loved beyond description, and he knows it.

He was physically wrenched from me long before he should have been. My body felt, and still feels, the wrenching, and his body felt it so profoundly that it ceased to function.

But a mother's love, it transcends the body. Which means that it transcends the five senses. And a mother's love transcends language. Ever silent, my love is with him even now. Of this I am certain.

heARTwork by Kara LC Jones/MotherHenna at GriefAndCreativity.com

Pathologizing Grief

Feeling, Relating, Existing
On emotion and the human dimension
Reprinted with permission by Robert D. Stolorow, Ph.D.

Pathologizing Grief
Pain is not pathology.
Psychology Today, Published on February 24, 2012

Psychiatry's Diagnostic and Statistical Manual's pathologizing of grief is but the latest installment of a lamentable tradition in Western civilization aptly chronicled by Philip Fisher in his book, The Vehement Passions (Princeton Univ. Press, 2002): "[T]he twin ideas of Christianity's eternal life and Stoicism's nature have for two thousand years ... pressed against the legitimacy of mourning and against the strong imagination of personal loss and mortality that grief sets in front of us, not as an idea, but as a profound physical and emotional experience " (p. 202). "Pain is not pathology," I wrote in my book, Trauma and Human Existence (Routledge, 2007, p. 10. Click here for access to full article.

The traumatizing impact of human finiteness, as disclosed in the loss of a loved one, is not an illness from which one can or should recover.

Remembering Evan Nathaniel Nasky, Beloved son, brother and friend
Dec. 13, 1990 - March 3, 2012

HonorThonors

Stephanie Mondino ran 100 miles over 6 weeks for the MISS Foundation as part of our Honor Thonors program last fall. She raised $1200 on behalf of her son Dillon. "I was extremely honored to help MISS. They helped me so much when I needed them and I will always be grateful. I can't think of a better way to show my appreciation to MISS. There are times when I'm training and the physical pain takes hold and all I want to do is stop. Then I remind myself that I've survived the worst pain imaginable.

I am so grateful to MISS for teaching me how to be a survivor. I miss my son Dillon terribly and not a day goes by that I don't think of him. But I can now thank him for making me a stronger woman; emotionally, intellectually, and physically. I know he is with me and everyday I vow to make him proud of me."

If you would like to participate in a program like "Honor Thonors" to help support the MISS Foundation and our bereaved families, please contact MISS Foundation Director Kelli Montgomery.

Poetry

Circling Caverns

—for Shauna

By Natalie Bryant Rizzieri

Savage skies hurl against
your wakefulness. Desert sun

beats down your hollow
and autumn soldiers you further

from his brief crest between
birth and death. I know nothing

except I am no further
from his eyes that opened

the day I met him. I looked
hard into his stormed clouds,

choked by the weight of breath.
And your hands on his body,

tending his flawless form,
unafraid to love. There is only

one picture of tenderness—
it is your eyes only for him

in that maze of machinery
clanging, picc procedures,

new vocabulary to measure lungs
and each drop of milk you leaked.

I know only one hour of his breath—
but the rise and fall of his chest,

his silent cries, and finally sleep
under the wings of your hands

I will never forget.
It is not enough.

The valleys of July choked—
walls of heat, dust.

Mountains were swallowed whole
and I too struggled against blindness.

You circle stark caves.
Is the perimeter still shrinking?

I watch from narrow ficus shadows,
knowing I cannot tourniquet loss.

I wait. Sun strikes last the worn
grass bending under your feet.

When

when does that moment come?

the one when i think of you
and it is okay you are not beside me.
the one where i understand fate brought you to me
but keeps us apart.
the one where i hear your name
and my eyes don't search for "you".
the one when i see and hold you (in my dreams)
and it comforts me.
when does that moment come?
how long is the wait?
Are you waiting too.

By Paige Ricci
In Memory of Samantha Paige Ricci 1/26/03

Noah's Jar

Join us in Noah's campaign for change. Spread the word, start a jar and post your picture. All money collected will be donated to the MISS Foundation in May,as we remember all children gone too soon and support the families navigating this life without their beloved children. This is our jar.

-- Rae Ann Wood & Sarah Toig

MISS Foundation CEO Barry Kluger (pictured on the right) and MISS Advisory Board Member Kelly Farley (on the left), authors of the Farley-Kluger Initiative to Amend the FMLA, were in Washington D.C. the week of February 5th to watch their efforts become a reality with the introduction in the House and Senate of "The Parental Bereavement Act of 2013." Karla Helbert (in the middle), MISS Foundation's Richmond Chapter Leader, and (not pictured) Jim Boyle, of Boyle Public Affairs, joined them.

GRIEF • COMPASSION • COMMUNITY • HOPE

MISS FOUNDATION

Credits

Newsletter is edited by Shauna Bryant Yoder in memory of Weston; with creative design by Kara Jones in memory of her two sons, Kota and Zuzu.

www.MISSFoundation.org

Thank you for your continued donations and support of our work!

Donate Now

Contact Us
1-602-279-MISS (6477)
1-888-455-MISS (6477)

Physical Address
77 E Thomas Rd #112
Phoenix, AZ 85012

Donations/Billing Address
Kelli Montgomery
c/o MISS Foundation
1700 Alcove Ct.
Austin TX 78757

Please note: Snail mail donations should be made to "MISS Foundation."

Email Contact
info@missfoundation.org