



M.I.S.S.ing Angels ...

The M.I.S.S. Foundation

A Sanctuary for Bereaved Families

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The Loss Dictionary

Because even Grieving People Need a Good Laugh

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One of the things that struck me when reading Dr. Sukie Miller's book "Finding Hope After A Child Dies" was the sense that our American English language has no words to even describe what it is like to be a parent whose child has died. Think about it. If your parents are dead, you are an orphan. If your spouse dies, you are a widow or widower. But where is the word for a parent whose child has died?

While Miller points out that other cultures have language to handle this loss of children, it is not so easy to translate those languages into our daily lives. So my thought was this: I'll make my own darn language. With that in mind, I offer you the first installment (I hope of many) of my dictionary for the loss of a child. Maybe I'll be seriously considered as a

lexicographer someday after all.

You-go-along-and-then-BAM adj. 1. what it feels like to be minding your own business at a coffee shop, enjoying a soy chai, and then suddenly two families sit at the tables surrounding you and put their adorable babies in their carriers up on the tables facing you. 2. what it feels like every year at holiday dinners when your siblings show up with cousins who are the same age your child would have been if he or she were still alive. 3. what it feels like to have your mother-in-law look you in the face at the one year anniversary of your child's birth/death date and tell you that you should "get over it." -BAMinate v.

Cobweb Phenomenon n. 1. comparing your life to a room full of pretty things and happy times, but realizing there are cobwebs in the ceiling corners that never go away. 2. having a perfectly decent life, good job, other children you love, a solid partnership, and still feeling empty because one of your children is dead. 3.

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Baby's Breath: Healthy Baby Campaign

Be Careful not to Overheat Infants

For more information on healthy and safe infant habits, visit our website at www.misschildren.org

Overheating can be a factor in some infant deaths. This occurs when too many blankets are placed on a baby, the room is overheated, or baby is over-dressed. This is an often-overlooked factor in infant deaths in the United States, researchers said on Monday.

The report from the University of Washington School of Medicine called for a "vigorous public campaign warning of heat stress as a preventable risk factor" in some infant deaths. "Although the risk of thermal stress is widely accepted abroad, it has received relatively little attention in the United States," said the study in the April issue of "Pediatrics," published by the American Academy of Pediatrics. "The incidence any infant death, including those

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Take Note:

- Don't miss the First Annual MISS Foundation Golf Tournament! See page 21 for details
- New MISS Chapters are forming now! See page 23 for Chapter information.
- Peer contact information available in every issue of our newsletter. See page 2.

The Loss Dictionary *(continued)*

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going to a party where people are lively and happy and laughing and someone asks how you are, but you know you can't really say how you are. -cobwebbed v. -cobwebified adj.

Space Between The Moments n. 1. those quiet seconds when you stare off wondering what life would have been like. 2. time slows down and between each second it seems there is an eternity of time. 3. moments that catch you off guard when you were otherwise going along with everyday stuff. -momentified adj. -momented v.

Unsuicidal adj. 1. the feeling of wanting to die so you can be with your child but not actually wanting to take action to commit suicide. 2. the feeling you have when the doctor says "are you having suicidal thoughts?" and you know if you tell him you just want to be with your child, he'll commit you for being suicidal even though that really isn't the point. 3. the way you feel when someone tells you your child is "in a better place now" and you're thinking "well it sucks here so I wish I was with my child." 4. the feeling of being undead. -unsuicide n.

The Beast n. 1. grief personified 2. the monkey on your back everyone seems

you think you should "get over" when you know that the loss will be with you for as long as you live. -beasted adj.

The Creeper n. 1. grief anger personified. 2. the anger that resides just under the surface of your skin that may break out at the slightest bump from another human being. -creeper adj.

BaDahBoom v. 1. the verb Sonny used in Godfather Pt. 1 when teasing Michael. 2. the bursting out of The Creeper (see above) that you unleashed on some poor, unsuspecting human being. 3. the smashing of dishes for no "apparent" reason.

taurine excrement, n. 1. cliches used in a futile attempt to comfort grieving parents. e.g. "God needed an angel to tend his garden."

grobs, n. 1. grief snobs 2. others who arrogantly believe that their grief is worse than anyone else's and aren't afraid to say it. -grobish, adj.

grobville, n. 1. the metaphorical place where grobs sequester themselves into a little country clubish group building walls where there should be none.

the contingency theory, n. 1. a false myth perpetrated by society that the depth

of a parent's love or grief can be measured by the child's age -contingency theorist, n.

pop-a-fuse v. 1. what happens inside your head when you visit your child's grave and discover someone has removed or stolen your decorations 2. the ability to make your head spin 360 degrees. pop-a-fuser, n.

Immediate Idiot Syndrome n. 1. what happens to a perfectly nice doctor, teacher, neighbor, friend or other citizen when they hear that your child has died ant. see Immediate Empathy Syndrome

Immediate Empathy Syndrome n. 1. the strange and unexplainable transformation from a complete stranger or person not liked by many to a compassionate and kind comforter upon the news of a child's death.

gremiss adj. 1. cold and indifferent attitude toward the grieving family 2. the grossly remiss behavior by a trained medical professional toward the surviving family members.

We hope you had fun learned the new vernacular of grief. Try them out today! Or if you have new ones, let us know! Maybe we'll even write a book!

Arizona Peer Contacts

If you need one on one support and friendship contact one of our Peer Contacts. Because we understand your pain. Call if you need to talk.

Carl and Heidi Brashears	623-412-3131
Juleigh Fullerton	623-587-1914
Lee Ann Morlan	480-963-9844
Kellie and Nathan Gatewood	602-866-3645
Tom and Traci Johnson	602-789-8068
Alan and Karen Wondra	623-412-9806
Andy Castellanos	623-780-9546
Linda Schmidt	602-548-9333
Todd Beisner	623-825-4341
Cindy Eagle	623-977-5598

Albertson's Partnership with MISS

Do you shop at Albertson's? If so, every time you shop you can raise money for the MISS Foundation. We have partnered with Albertson's to provide a rebate of up to 9% of your shopping bills. This rebate is donated directly to The MISS Foundation's Family Support Programs.

How do you sign up? It's simple, you can do it one of three ways: 1) send us an email; 2) send a self-addressed, stamped envelope (SASE — this saves us money!); 3) or call us and we'll send you your card!

1. To email your request: Joanne@Misschildren.org
2. SASE to: MISS Foundation Albertson's Program, PO Box 5333, Peoria, Az. 85385
3. Call: 623.979.1000

Specify the number of cards you will commit to using and we'll send them off!

Thank you for continuing to support our efforts!

Baby's Breath: Healthy Baby Campaign *(continued)*

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diagnosed, SIDS, in the United States can likely be further reduced by educating the public against the dangers of overheating, as an integral part of the back-to-sleep campaign," it said.

The study concludes that deaths attributed to re-breathing could more logically be attributed to thermal stress. Still, in a program designed to reduce the risks of infant death, both thermal stress and re-breathing should have as common objec-



tives the avoidance of prone sleeping, soft bedding, and covering the head. Exces-

sive sweating, high room temperature, infection with fever and excessive bed-clothes are factors in heat stress.

“It is possible that both thermal stress and re-breathing are interrelated co-factors of a lethal process that could lead to (death) through failure to arouse or respiratory failure,” the study concluded.

“Defects in brain stem function from earlier injuries could increase the susceptibility to either mechanism.”

Special Olympics

A few years ago at the Seattle Special Olympics, nine contestants, all physically or mentally disabled, assembled at the starting line for the 100-yard dash. At the gun, they all started out, not exactly in a dash, but with a relish to run the race to the finish and win.

All, that is, except one boy who stumbled on the asphalt, tumbled over a couple of times and began to cry. The other eight heard the boy cry. They slowed down and

looked back. They all turned around and went back. Every one of them. One girl with Down's Syndrome bent down and kissed him and said, "This will make it better."

All nine linked arms and walked across the finish line together.

Everyone in the stadium stood, and the cheering went on for several minutes. People who were there are still telling the

story. Why? Because deep down we know this one thing: What matters in this life is more than winning for ourselves.

What truly matters in this life is helping others win, even if it means slowing down and changing our course.

Author Unknown



Paradox

by Glen Dickinson

Our time in history is pervaded by paradox. We have taller buildings but shorter tempers; wider freeways, but narrower viewpoints. We spend more, but we have less; we buy more but enjoy less.

We have bigger houses and smaller families, More conveniences, but less time; More degree's, but less sense; More knowledge, but less judgment; More experts, yet more problems, More medicine, but less health. We drink too much, smoke too much, spend too recklessly, laugh too little, drive too fast, get too angry, stay up too late, get too tired, read too little, watch TV too much, and pray too seldom.

We have multiplied our possessions, but reduced our values.

We've added years to life not---life to years. We've been all the way to the moon and back, but have trouble crossing the street to meet a new neighbor. We've conquered outer space but not inner space.

We've cleaned up the air, but polluted the soul. We've conquered the atom, but not our prejudices.

We build more computers to hold more information to produce more copies than ever, but we communicate less and less. These are the times of fast food and slow digestion. Steep profits and shallow relationships. These are the days of two incomes but more divorce, fancier houses but broken homes.

Remember; spend some time with your loved ones, because they are not going to

be around forever.

Remember, say a kind word to someone who looks up to you, because that little person soon will grow up and leave your side. Remember, to give a warm hug to the one next to you, because that is the only treasure you can give with your heart and it doesn't cost a cent. Remember, to say "I Love You" to your partner and your loved ones, but most of all mean it.

A kiss and an embrace will mend hurt when it comes from deep inside of you. Remember to hold hands and cherish the moment for some day that person will not be there anymore. Make time to Love, make time to speak, make time to share the precious thoughts in your mind.

Lili Claire and MISS Founders Finally Meet

by Joanne Cacciatore

More than one-year after first meeting Keith Resnick on the phone, we finally met in Las Vegas at the first annual "Evening with Danny Gans and Friends" event to benefit the UNLV and Lili Claire Foundation's Life Skills Center.

I first 'met' Keith just following a national talk show that I had appeared on sharing about the Kindness Project and the impact of infant death. Keith's young daughter, Lili Claire, died in 1998 at nearly six months of age due to complications from heart surgery. She was born with Williams Syndrome, a neurogenetic birth anomaly. In an effort to help others and to honor their daughter, the Resnick's began to educate and raise awareness for their cause. Keith shared their mission, quite similar to the MISS Foundation, and a long distance friendship blossomed. When the opportunity to meet Keith and his wife, Leslie, came about, I was very excited that I'd finally meet these special people who I had known only from a distance.

The event was incredible. It was held at the Mirage Resort Hotel. Highlights of the evening included special guest ap-

pearances by Jane Kaczmarek (Malcolm in the Middle), Bradley Whitford (The West Wing), Matt LeBlanc (Friends), Marg Helgenberger (C.S.I.), Holly Robinson Peete (For Your Love) and Kevin Sorbo (Andromeda) featured at a cocktail reception and a silent & live auction hosted by Jeff Probst (Survivor).

Danny Gans performed one of the most entertaining acts I've ever seen and at the end of the evening they hosted a reception featuring rock bands Coolio, Big Bad Voodoo Daddy, and The Young Dubliners. I even got a chance to sit and chat with my childhood hero, Angie Dickinson.

While the food was magnificent, the people were beautiful, and the décor was awesome, the most unforgettable part of the evening was finally meeting Keith and Leslie, parents of beautiful Lili Claire. Not only did we have so much in common by experience, but also the Res-



From Left: Leslie Resnick, Keith Resnick, and Joanne Cacciatore-Garard

nick's have done so much to change the world. It was an honor to finally meet them.

With our missions so closely aligned, we are discovering new ways to work together and reach out to more communities and families in need. To the Resnick's, Keith and Leslie- thank you for the wonderful time in Vegas, thank you for your kindness and generosity to MISS, and mostly, thank you for sharing the gift of Lili Claire.

FDA Clears First External Defibrillator for Young Children

FDA has cleared for marketing the first automatic external defibrillator system for use on infants and young children who experience cardiac arrest. AEDs are life saving devices used when the heart is beating irregularly and ineffectively (fibrillating) and the patient will die without treatment. The AED administers an external electric shock through the chest wall to the heart via conductive adhesive pads in an effort to restore normal heart rhythm.

The AEDs currently marketed are restricted to use on adults and children over eight years of age. The new device, made by Agilent Technologies, Inc., of Palo Alto, Calif., can be used on infants and children up to age eight and/or weighing up to 55 lbs.

Agilent's AED was previously cleared by FDA for use on adult and adolescents and has been used thousands of times to save lives. The new version can be equipped with specially designed pediatric defibrillation pads in order to deliver less electrical shock. Standard AEDs deliver 150 joules of energy to the patient; the new product, when equipped with the pediatric pads, delivers 50 joules of energy. FDA cleared the device for young children based on laboratory and animal testing performed by Agilent and on reports in medical literature which showed successful use of AEDs on both adults and young children.

The firm will conduct a follow-up study of up to 50 children worldwide to evalu-

ate how well the device performs in actual use. AEDs are prescription devices and are intended for use by or under the supervision of a physician or by other trained and certified persons.



"When you are fighting for a cause: first they will ignore you; then they will laugh at you; then they will fight you; then you win."

—Mahatma Gandhi

The Story of Shaya

In New York, Chush is a school that caters to learning-disabled children. Some children remain in Chush for their entire school career, while others can be mainstreamed into conventional schools. At a Chush fund-raising dinner, the father of a Chush child delivered a speech that would never be forgotten by all who attended. After extolling the school and its dedicated staff, he cried out, "Where is the perfection in my son Shaya? Everything God does is done with perfection. But my child cannot understand things as other children do. My child cannot remember facts and figures as other children do. Where is God's perfection?"

The audience was shocked by the question, pained by the father's anguish and stilled by the piercing query. "I believe," the father answered, "that when God brings a child like this into the world, the perfection that He seeks is in the way people react to this child."

He then told the following story about his son Shaya: One afternoon Shaya and his father walked past a park where some boys Shaya knew were playing baseball. Shaya asked, "Do you think they will let me play?" Shaya's father knew that his son was not at all athletic and that most boys would not want him on their team. But Shaya's father understood that if his son were chosen to play it would give him a comfortable sense of belonging.

Shaya's father approached one of the boys in the field and asked if Shaya could play. The boy looked around for guidance from his teammates. Getting none, he took matters into his own hands and said, "We are losing by six runs and

the game is in the eighth inning. I guess he can be on our team and we'll try to put him up to bat in the ninth inning."

Shaya's father was ecstatic as Shaya smiled broadly. Shaya was told to put on a glove and go out to play short center field. In the bottom of the eighth inning, Shaya's team scored a few runs but was still behind by three. In the bottom of the ninth inning, Shaya's team scored again and now with two outs and the bases loaded with the potential winning run on base, Shaya was scheduled to be up.

Would the team actually let Shaya bat at this juncture and give away their chance to win the game? Surprisingly, Shaya was given the bat. Everyone knew that it was all but impossible because Shaya didn't even know how to hold the bat properly, let alone hit with it. However, as Shaya stepped up to the plate, the pitcher moved a few steps to lob the ball in softly so Shaya should at least be able to make contact. The first pitch came in and Shaya swung clumsily and missed. One of Shaya's teammates came up to Shaya and together they held the bat and faced the pitcher waiting for the next pitch. The pitcher again took a few steps forward to toss the ball softly toward Shaya.

As the pitch came in, Shaya and his teammate swung the bat and together they hit a slow ground ball to the pitcher. The pitcher picked up the soft grounder and could easily have thrown the ball to the first baseman. Shaya would have been out and that would have ended the game. Instead, the pitcher took the ball and threw it on a high arc to right field,



far beyond reach of the first baseman. Everyone started yelling, "Shaya, run to first. Run to first!" Never in his life had Shaya run to first. He scampered down the baseline wide eyed and startled. By the time he reached first base, the right fielder had the ball. He could have thrown the ball to the second baseman who would tag out Shaya, who was still running. But the right fielder understood what the pitcher's intentions were, so he threw the ball high and far over the third baseman's head. Everyone yelled, "Run to second, run to second." Shaya ran towards second base as the runners ahead of him deliriously circled the bases towards home. As Shaya reached second base, the opposing shortstop ran to him, turned him in the direction of third base and shouted, "Run to third."

As Shaya rounded third, the boys from both teams ran behind him screaming, "Shaya run home!" Shaya ran home, stepped on home plate and all 18 boys lifted him on their shoulders and made him the hero, as he had just hit a "grand slam" and won the game for his team.

"That day," said the father softly with tears now rolling down his face, "those 18 boys reached their level of God's perfection."

Excellence in EMS

The Phoenix Fire Department (PFD) held the "Excellence in EMS" conference in April. The MISS Foundation was able to participate thanks to the foresight and generosity of PFD. Information and education was made available to firefighters

and paramedics from Phoenix, Glendale, Heber-Overgaard, Rural Metro-Scottsdale, Rural Metro-Tucson, Surprise, and Tempe Fire departments. Volunteers from the MISS Foundation were present to offer support and insight at the

information booth. Special thanks to Mary and Tony Orta for their generosity and time! And thank you to the Phoenix Fire Department for continuing to ensure education and awareness to their EMS professionals.