



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

The MISS Foundation

A Sanctuary for Bereaved Families

January/February 2002

Volume 3, Issue 1

A Message From A Miracle

October 14th marked the two year anniversary of the death of my sweet little son Kody. He truly was the Miracle I had hoped and prayed for.

Kody was born with a rare brain disorder called alobar holoprosencephaly. I remember vividly the doctors telling my husband and I at Kody's birth that it would be a "miracle" if he lived more than a month. But Kody surprised everyone - he lived to be seven and a half.

Though Kody was severely disabled, he could not walk or talk - he had a smile that would light up a room. During his short stay on earth he managed to help hundreds of people with his magical smile and positive attitude. He raised thousands of dollars for United Cerebral Palsy, and Easter Seals - he helped hundreds of other special needs children by promoting programs through California Children's Services and MOVE International just to mention a few.

Our family, through Kody's enthusiasm, started a year round camp (CAN-DO -CAMP)

for children with severe disabilities. That camp continues today with our help and in memory of Kody.

When Kody unexpectedly passed away in his sleep - the grief, sadness and emptiness was unbearable. The MISS foundation provided such a warm arm surrounding me when I needed it most. I was so impressed with Kindness Projects, and how people took the tragedy of losing a child and created something positive to reflect and remember. I even took the advise of Joanne and planted a tree in Kody's memory a couple of months after his passing.

This was not just any tree - this little tangerine tree was planted outside Kody's special education classroom at the base of the wheelchair ramp. This classroom was located on the outskirts of our local elementary school - surrounded only by dirt. Kody's wonderful special education teachers helped to plant the tree and a little garden around it. This little kind-

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Gratitude to MISS from the Pentagon

Dear MISS Foundation,

Thank you for forwarding MISS Foundation Grief Support packets to families suffering as a result of the September 11 attack on the Pentagon.

Your concern for our families' loss—especially as it affects the children related to the Pentagon victims— is deeply appreciated. As the custodian of many Department of Defense Family Programs, it will be my privilege to ensure the packets are delivered promptly.

Please thank all your staff (volunteers) who assisted in this effort. On behalf of the Department of Defense and our families who suffered the greatest loss on September 11, 2001, thank you for your concern and support.

Sincerely,

Meg Falk

Director, Office of Family Policy

Office of the Secretary of Defense

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Take Note:

- New MISS Chapters are forming now! See pages 22 and 23 for Chapter information.
- Peer contact information available in every issue of our newsletter. See page 23
- Kindness Project Ideas Abound! See pages 19

Message from a Miracle *(continued)*

(Continued from page 1)

ness project triggered the over 800 able bodied children at Kody's school who also wanted to do something special in memory of their pal, Kody - so they worked for months planting many gardens - building bird feeders and bird baths surrounding the once depressing classroom for severely disabled children. Today the special education classroom building is the most beautiful place on campus it attracts children that had, in the past, been afraid to get near. Kody I'm sure is smiling as he observes his special friends excitement over the beautiful gardens and trees which have attracted new and beautiful birds, bees and friends.

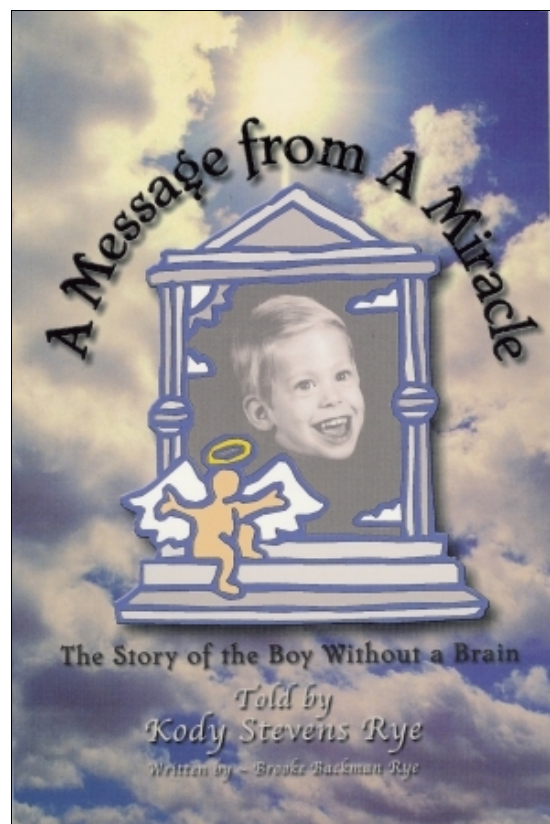
Our 2nd Kindness Project was unveiled on the 1st Year Anniversary of Kody's death. Kody loved to swing. This was very difficult, as he could not sit by himself - we always held him. Knowing that there were many children in our community in wheelchairs with no real way to experience the simple joy of swinging - I set out to raise the needed \$5,000 for a huge specialized wheelchair chair swing.

It's amazing how many people want to help improve the quality of disabled people's lives - especially when you remind them how we take for granted the simple things in life - like swinging.

The swing can hold two children or adults at one time and always has wheelchairs with both adults and children lined up to take their turn at swinging.

This is my 3rd Kindness Project, and I was hoping to have it available on the 2nd Anniversary of my little son's passing, which was October, I missed it by one month - it will be released in November 2001. This project has been my most challenging, but I think will be the most beneficial. It is a book - written though Kody was telling his life story, entitled *A MESSAGE FROM A MIRACLE*. It is a book for families with disabled children. It tells of the joy these miracle children bring - how they turn tragedy into triumphs. I have received grant money to publish the book and all proceeds from the book sales will go to UCP (United Cerebral Palsy) programs and Carter Brain Research Centers throughout the world - in memory of Kody Rye.

I thank all the families in the M.I.S.S. Foundation for inspiring us to remember our son Kody through "Kindness Projects". It not only is healing but gives us such joy to help other disabled children



in the memory of our little miracle Kody.

God Bless you all and all your little Miracles -

Love, Brooke Rye

Study on Newborn Hearing Screening

"Modern screening tests for hearing impairment can improve identification of newborns with PHL [moderate-to-profound bilateral hearing loss], but the efficacy of UNHS [universal newborn hearing screening] to improve long-term language outcomes remains uncertain," state the authors of an article published in the October 24/31 issue of JAMA, The Journal of the American Medical Association. The authors conducted a literature review to identify strengths, weaknesses, and gaps in the evidence supporting UNHS and to compare the additional benefits and harms of UNHS with those of selective screening of high-risk newborns. Each year, approximately 5,000 infants with PHL are born in the United States.

UNHS has been proposed as a way to speed diagnosis and treatment and improve language outcomes in these children. The authors found:

- * Otoacoustic emissions (OAEs) and auditory brain-stem response (ABR) are highly accurate screening tests for congenital PHL.
- * UNHS increases the chance that diagnosis and treatment will occur before 6 months. UNHS increases early identification between 19% and 42% over selective screening in high-risk children.
- * The evidence is for the assumption that identification and treatment prior to 6 months improved language and communication in infants who would not be diag-

nosed that early in a selective, high-risk screening program is inconclusive.

The authors attest to the importance of longitudinal studies and assert that speech, language, and scholastic achievement of deaf and hard-of-hearing children should be followed over time. According to the authors, states that have UNHS should conduct population-based studies to evaluate whether the long-term language outcomes of deaf children improve as the age

Thompson DC, McPhillips H, Davis RL, et al. 2001. Universal newborn hearing screening: Summary of evidence. JAMA 286(16):2000-2010.

My Subsequent Pregnancy: *After* the Pregnancy

I thought my constant companions throughout my pregnancy- anxiety, fear, depression, guilt, self-doubt and pessimism- would end with the safe arrival and delivery into my arms of a healthy child. But it was the beginning of constant fear, constant anxiety. I would wake up every morning knowing that with every step towards the crib, I would find that my child had died in her sleep. Her first illness sent me into a cold sweat at the possibilities. And I became the guard. The guard that stood between death and my child. Maybe I couldn't save my son but I sure was going to do everything I could to keep my daughter safe. I questioned everything and everyone, including myself. I grilled the pediatrician on what to do and when to do it. I fired question after question about any information that was making headlines. Especially about immunizations and their side effects. I searched all over the internet and after reading professional and parental opinions, decided what I thought was the best for all of us. And after each immunization I would cry myself all the way home and be up for days at a time looking for any sign of a severe reaction. I spent hours upon hours making sure that she was safe and alive.

Her first year of life, the most dangerous,

stretched before me like a never-ending highway full of monsters waiting to take her back. I couldn't lose another child.

Now I know some of what I was going through was new, inexperienced, un-knowledgeable, first-time parent jitters. But I would compare thoughts and ideas with "normal", "regular" parents and they thought I was nuts. And they weren't the only ones. My family and friends think I'm nuts too. They think I should be "cured" because I've had a child to "replace" my son. All bereaved parents, whether they've had a subsequent or not, know that you can't replace one child with another. If our mothers and fathers died, we wouldn't go out and get new ones. One human being doesn't replace another human being. But try telling that to my family. I should be healed now. No more grieving allowed. It shocked them when my daughter's first birthday rolled around and they were celebrating with cake, hats and balloons and I was on the bedroom floor crying because I had only ever celebrated memorial birthdays that were sad and painful. I didn't even know how to act. And on Christmas, I was on the same bedroom floor crying because my son would never open a present from Santa.

But there has been happiness too. Much happiness. Having a living child has brought us back to life. A reason to get up in the mornings. If you could have seen my face when my daughter took her first steps, you would have seen the tears of joy in my eyes at her wondrous accomplishment. But those tears were also for my son who would never walk this earth. On the day my daughter was born my heart swelled with love for her, but it swelled around the hole my son's death left, it didn't fill it

A subsequent child brings so much to life-joy, pride and a new-found anticipation for the future, but will never, ever end the grief for the child that has gone before us.

*Margaret Abarr-
^i^ Tyler David's mom and new mom to
Signe Autumn*

For more information on our subsequent pregnancy support group, see page 20 in the newsletter or call Margaret at 623-872-8082 or Anna Kennedy at 602-439-9025.

National Children's Memorial Day: A Night to Remember

It is a day to remember children who lost their lives before their time: National Children's Memorial Day. Now a federal day of memoriam, the second Sunday of every December is set aside for families to openly mourn and remember their beloved children. Some were born too early, some killed by drunk drivers, some born still, some died of unknown natural causes at many various ages...some were murdered, some killed in automobile accidents, some in fires, some in accidental drownings. But this night, these families are woven together in a common thread of sorrow, love, compassion, and remembrance. MISS Foundation chapters across the country banded together to honor these children, and their families who courageously light a candle in the darkness of the night for their child. Many chapters, such as the National Chapter in Arizona, had live music, courtesy of Glorybound, and included the collaborative efforts of the West Compassionate Friends along with special guests, Parents of Murdered Children, Mothers Against Drunk Driving, AGAST, Camp Paz, Survivors of Suicide, and other nonprofit community based organizations. In addition, Phoenix Fire Department Division

Chief Scott Peltin and Phoenix Police Chief Harold Hurtt were present for a special 9-11 Remembrance. Dr Sukie Miller, Author of *Finding Hope When a Child Dies*, calls ritual the "antidote to powerlessness." This beautiful evening of healing is empowering for all the families who attend.



Mark Abarr, with daughter Signe, light a candle to remember son and brother, Tyler David

A Glimpse into a Father's Journal

by Gregg Carder



I miss Alesia Dawn so much and wish I knew what to do to express my sense of loss to others. I look at pictures of Alesia Dawn and I relive her actions of those moments. I can scarcely remember the sound of her voice. That's one of the things that bothers me the most; how time fades the

things about Alesia Dawn that I treasure.

So many things about day to day life are so different now that Alesia is gone. The gray days seem gloomier than before. Sunsets make me sad. Seeing her classmates enjoy things that I know Alesia was looking so forward to, makes me angry that she was denied those opportunities. The way some people seem so oblivious to the loss in our lives and how

"matter-of-fact" they are about Alesia's death, hurts me and makes me angry...I want people to ask me how I'm doing. Call us and check on us. Put their arm around us and say they're thinking about us and not think that by not talking about Alesia somehow make our lives easier. Surely, anyone who knows us must realize that we are consumed with our thoughts of Alesia Dawn. What parents, or sibling, wouldn't be?

Gratitude...From the Pentagon

(Continued from page 1)

Editor's Note: During the month of October, the MISS Foundation asked its members to assist us in an outreach to the children of Washington, D.C., New Jersey, and New York who had suffered from the events of September 11. Our members and supporting corporations responded to our call for help. Within two weeks, thousands of packets were sent to specific aid organizations and have been distributed to the families who so desperately needed them. Thank you to each person who helped us take action. The buildings can be rebuilt, the walls put back together, the land renewed...long before the broken hearts of the grieving families can begin to heal. Our outreach and outpouring of support will help make a difference in the lives of those suffering that immense loss.

The MISS Foundation community has been deeply moved by the tremendous national sharing of the grief that so many thousands of families are now enduring. We are witnessing a transformation in the way that people express grief openly and honestly and in the media's willingness to discuss resultant grief and emotions following such a tragedy. This open acknowledgement of what children and adults experience when death touches their lives will enhance services available to all families affected by death and set the stage for future projects which address the need for increased thanatological education, support, and resources.

That being said, the MISS Foundation Board of Directors would like to offer a Special 911 Project Acknowledgement to those who helped this outreach happen with limited time, money, and resources. We simply could not have done it without the financial support and volunteerism that each of you offered our organization:

Rusty Chepeus

Judi Toth, remembering Christopher

T.W. Lewis Corporation

Pam Binder

Beth Benninghoff

Dave Woolstrum

Juliegh Fullerton

Doris Hicks-Tillman

Holly Wander and the Cactus Pine Girl Scout Troup

MISS Foundation Online and Local Families

Skyview 5th Grade and Indian Bend 6th Grade Elementary Schools

Local 3573 United Sun Cities Firefighters and the Sun City Fire Department

I have seen all souls as my soul, and realized my soul as the soul of all.

Hazrat Inayat Khan

One day
At a time
Is all
That I can bear

If I can make it
Through this day
Then I
Can Look back
Tomorrow
And know

That I am strong
Even in my
Weakness

Because
Sometimes
Being weak
Is the only way
That I can
Be...at all

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Joanne Cacciatore, an excerpt from *Dear Cheyenne*

Kid's Korner



Timmy, MISS Foundation Kids Group member, and Marty, Camp Paz Volunteer play and have fun at the September camp



Drawing by six-year-old, Chase Roper, as he remembers his little brother, Trey



Five-year-old Timmy Dougherty draws a picture to remember his three brothers, Dakotah, who died as a SIDS baby, and Gunnar and River, fullterm twins who died just prior to their birth



Kids work on their grief books at the children's 2001 Passages conference...More than 30 children touched by death attended the two day conference in Scottsdale, Arizona

“Children are the most honest group about death and grief. My daughter is not afraid to say to people, “Sure, I have a brother but he died.” The look on the faces of adults astonishes me— they avoid her and drop the subject— some of her teachers have even asked her not to discuss it at school. Yet, in observing her with other kids, she tells them about her brother and they seem comfortable, even curious about it. They ask questions, they say that they are sorry— that it is sad— that she must feel bad at times. And then, they go about playing together...If you ask me, the latter of the two situations is clearly the most ‘healthy’ of reactions...”

Unsung Heroes

This month's Unsung Hero is **United Parcel Service and their Volunteer Employees**. There are many volunteers employed with UPS, however, they are supported by upper management who realizes the needs of the community and the benefits to everyone when they support employees who volunteer. UPS

Volunteers offered expedient aid to the MISS Foundation's Children's Grief Fund and our 9-11 Outreach. They have attended trainings, conferences, and volunteered at many events. Many have assigned the MISS Foundation as their United Way Agency offering even their personal financial support for our MIS-

Sion. Thank you **United Parcel Service** and the many employees who give, not only to the MISS Foundation, but collectively, to our community! We appreciate all that you do!

Send your nomination along with a brief paragraph to: info@misschildren.org

Conference 2001: Notes from the Heart

Dear MISS Foundation,
I just wanted to write and say thank-you for helping me get to go to the MISS conference. It was absolutely wonderful!!! Since Tyler's death 5 years ago I have talked to many others enduring the same tragedy via e-mail but I have never talked to anyone in person. It was a great feeling to finally be around others who truly understand! I was very emotional which at first really embarrassed me but then after I thought about it I realized that everyone understood and it was okay to cry. It was so special to be to have Tyler honored at the memorial service along with all the other children. And it was also wonderful to have him be a part of the MISS quilt. I left the conference with such peace and comfort. Thank-you so much for that!!! I surely will see you next year! Thanks so much,
Kim Lotz

Dear MISS Foundation,
Thank you so much for affording me the opportunity to attend the Passages 2001 Conference. I am still talking about my moving experiences with the families and I very much enjoyed the workshops I attended. I especially appreciated your presentation which addressed cultural issues to consider when intervening with families in a bereavement crisis. As a professional, I found the information most useful and quite applicable in my work with families. Personally, I was touched by the openness and sharing of feelings and reminded of the grief that I have experienced in my life. I felt very connected. Also, I was very honored and humbled to meet Dr. Elisabeth Kubler-Ross and I would like to extend a special thanks to everyone who worked at the conference. Great Job! I look forward to collaborating with you in the future.
Sincerely,
Desarae Powell, ACSW, LCSW
Lili Claire-UCLA Family Resource Center

Dear MISS,
Thank you so much for the Passages 2001 Conference. It was such an amazing conference. I learned so much and was so deeply touched by the individuals I met there. ...This is the most incredible organization I have ever encountered. You have made an impact on me that will last a lifetime. Thank you again,

Lori Garcia, Tempe Fire Dept.

Dear MISS Foundation,
Thank you so much for a very informative and moving conference. Both Marilyn & I came away feeling very blessed to have been apart of something so significant. Because of this conference, we connected with professionals that are willing to give of their time & talent in helping us.
Judy Lenz
Ascension Preschool

Hi Joanne,
..As I am going through the photos of the conference, I am crying tears of joy, remembering how special an event this conference truly was, and how beautiful all the people are who made it happen.
Jim Nibali, Claire's Father

Hi Joanne:
I just wanted to thank you again for everything. It was so beautiful to be there with so many bereaved who feel just as I do and who understand so well. When I lost my babies Pablo and Santiago I started asking God not Why? but What for? and I think that made all the difference in the world because I got an answer and I could give meaning to my loss. Since I am a Psychologist in South America, I can help women with losses similar to mine, both as a psychologist and as someone who truly understands what they are going through. I would really want to help from here in which ever way I can and you need. Please let me know what I can do to help. I'd be pleased to help you in any way I can. And again thank you for the wonderful experience I had this weekend. I'm really happy I met you.
Yours truly Gina Perroni

Our 2002 Conference is set!! See newsletter for more information! Don't miss it!