

# Stillbirth: What Every Woman Needs to Know

*This pamphlet is being introduced into the Baby's Breath and Family Outreach packets. We hope that this information may reduce some risks associated with stillbirth and that it will be another valuable tool that parents will use to cope with the immeasurable pain in the ensuing years to come.*

## **About Stillbirth:**

Stillbirth is the death of an infant in-utero and past 20 completed gestational weeks. It can happen before or during the onset of labor and can happen to any woman. About 1 in 100 pregnancies will end with the death of a baby to stillbirth or about 30,000 per year in the United States alone. Many full-term stillbirths occur to low risk mothers and **approximately 40% of stillbirths occur with no diagnosable cause of death.** These deaths are called Sudden Antenatal Death Syndrome, or SADS. This means that a baby has died at or near term for no explainable reason.

The most common diagnosable causes for stillbirth include:

- **Placental problems:** Women who smoke cigarettes have a much greater risk of placental abruption. High blood pressure (pre-eclampsia) also increases the risk of abruption. Other problems with the placenta, which prevent it from supplying the infant with enough oxygen and nutrients, may also increase the risk of stillbirth.

- **Birth defects:** Between 5 and 10 percent of stillborn babies have chromosomal anomalies. Others may have structural anomalies which can result from genetic, environmental, or unknown causes.

- **Intra-Uterine Growth Restriction (IUGR):** Infants who are not growing at an appropriate rate for their gestational

age are at an increased risk of stillbirth due to hypoxia (lack of oxygen) both before and during birth.

- **Infections.** Bacterial infections often cause no symptoms in the pregnant woman and may go undiagnosed. These infections increase the likelihood of stillbirth or premature birth.

## **Education + Awareness =Reduction.**

Scientists and physicians do not fully understand the causes of many stillbirths. We do know that at this time, stillbirth cannot be prevented or predicted. However, there are some helpful strategies for pregnant women to follow to help *reduce the risk* of stillbirth:

1. Around 26 weeks of pregnancy, begin doing daily "*kick counts.*" If you count less than 8-10 kicks during a two-hour period or if the baby is moving less than usual and you are concerned, contact your doctor immediately.
2. Do not smoke, drink alcohol, or use drugs (unless prescribed by your physician).
3. Report any vaginal bleeding, leakage, or sharp pain to your health care provider.
4. If you are post-term, be sure to discuss your options and concern with your physician. Pregnancies which last longer than 42 weeks gestation may be at greater risk of stillbirth.
5. It may be necessary to request a second or even a third opinion during your pregnancy to put your mind at ease. Your caregivers should be empathic and respectful of your concerns and you have every right to expect the best care for you and your baby.

**NOTE: This information is not intended to replace you doctor's advice . This is for informational purposes only. Please call your physician if you have any other questions.**

## **The Difficult Questions?**

### **What if it happens to me or someone I know?**

Though the chances of having a stillborn baby are decreasing in most states, it is helpful to know who to call for help. The MISS Foundation has volunteers who can help you or someone that you know who may be going through this tragedy.

### **Will I still have to go through labor if my baby dies?**

Most often, yes. Even if a baby is stillborn before the onset of labor, most women will experience labor and childbirth in the same way as a "live" birth. Having adequate pain control options, supportive family members, and birth assistants or doulas can help ease the overwhelming emotional and physical pain of stillbirth.

### **Will I get to see my baby?**

Yes. We encourage women and their families to see, hold, and touch their baby. You may participate in bathing and caring for your baby after his or her birth. Although it may difficult, most families are very grateful that they had those special moments with their baby. A volunteer with the MISS Foundation can help guide and support you during this time.

### **Will my baby get a birth certificate?**

Yes in certain areas of the country. Several states recently began offering this to parents. Call the Office of Vital Records in your state and tell them you'd like to obtain a "Certificate of Birth resulting in Stillbirth."

*If you can help us get this brochure out to physicians, midwives, and other health professionals, please contact [info@missfoundation.org](mailto:info@missfoundation.org) at the MISS Foundation website or call the MISS Foundation office at 623-979-1000.*

"Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no hope at all."

-Dale Carnegie

# Kids Korner



**“The most honest, truth-telling in this world is done by children.”** Oliver Wendall Holmes

## **Am I Still a Big Sister or Brother? The grief of children**

*By Joanne Cacciatore*

*"How many brothers do you have?" they ask her.*

*"I have three brothers," she says.*

*"Wow! And how many sisters do you have?" they ask again.*

*"I have one sister. But she's in Heaven taking care of us," she replies proudly.*

Those words filled my eyes with tears when I heard them. My daughter, then six years old, has always had a fearless strength that I often envy. Her "matter of fact" attitude about her younger sister's death and her honesty have often surprised me. I have always known that her outlook was healthy, despite the often-astonished looks she would draw from unsuspecting inquisitors. How do you help children through the grief process toward a healthy reconciliation after the death of a sibling?

In retrospect, I try to identify the things I have done 'right' to support my children when their infant sister suddenly died. The most difficult aspect was discussing her death and explaining the concept of "death." I was very cautious about specific terminology. Honesty is the best response. I never associated death with sleeping. I told them that their sister died, explaining that when a person dies, that person won't ever come back on this earth. I told them that they would not see her again. This may be a good opportunity to open dialogue about spiritual beliefs. Use discretion when discussing God and death. Avoid telling the children that God took the baby. It may create feelings of anxiety or anger toward God. Encourage questions and communication. Children may be too frightened to ask without assurance. Keep your answers honest and simple.

We shared an 'open emotion' policy. I allowed myself to cry, wherever and whenever I felt the need to. I set a stan-

dard for them. My openness validated their feelings of loss and despair. It reassured them they could come to me when they felt overwhelmed. I cried many times in front of them: And then I would let them see me laugh again. The expression of sorrow is nothing to be ashamed of. I encouraged them to cry, yell, punch a pillow, and accompany me on a walk or anything else they felt would help them through the difficult time. On several occasions, they were able to draw a picture or write a letter to their sister.

Another helpful idea for siblings is to offer them a 'special' remembrance token of their sibling for them to keep. It is a tangible reminder of a love that will never be forgotten. Every Christmas, our children choose a special ornament in memory of their sister to hang on our tree. It is engraved with her name and the year. They know we have not abandoned her memory, nor will they. Reassure your children they are still a "big brother" or "big sister." Reassure them they always will be. Make time to reminisce together. Cheyenne's pictures still hang on our walls. They are a permanent fixture in our home. She is a significant part of our family. I want them to know their sister. Children have a simple discernment about grief. Everyday, I strive to become more and more like my children.

Note: If your child experiences:

- Extended periods of depression in which he or she loses interest in daily activities and events
- Inability to sleep, loss of appetite, prolonged fear of being alone
- Acting much younger for extended periods of time
- Withdraws from friends at school
- Sharp drop in performance or refusal to attend school

These are warning signs which indicate that professional intervention may be needed. Please seek a therapist who specialized in grief and trauma.

# Meet Our Newest MISS Facilitators



**My name is Tara Pitts.** I like to say I am the Mommy of three sweet boys... two who can run and play, one who can fly. My husband Steve and I are blessed to

the parents of Noah-age 7, Ethan-age 2 and my precious angel, Christian Samuel who was born Aug. 11, 1998. Christian was born a day shy of being 23 weeks. He lived for four wonderful hours. Only the love and comfort of his family's arms was known to him. I found MISS on-line early in my grief and it became a haven for me. I had finally found people who understood what I was experiencing. In early 2001, the DC MISS chapter was formed. Now, as our wonderful facilitator, Jackie Nell, moves out of state, I am taking over as a joint facilitator with Dionna Williams. I take solace in knowing that through this, I can help others. It is important to me to help those who are walking down this road too. I hope I can be a strength to families who need a friend that truly understands. There is no greater loss than that of a child. Christian's life was important – I can share him and honor him through the friends I meet through MISS.

**My name is Gina Carme,** from Arlington, MA. My whole world, and I think the entire world, changed on Sept. 11, 2001. I was 37 weeks pregnant and had 3 weeks to go until my due date. I went to the dr. for my weekly visit and after an ultrasound, she told us Lucia had died. Her heart had stopped. Our daughter, Lucia Francesca, died on Sept. 11, 2001 and was born on Sept. 13, 2001. After Lucia's death, people were so wonderful and supportive. I know there are a lot of families out there with similar stories to mine. Although my grief is still relatively short, I know in my heart I want and have to be a support to mothers, fathers and families that have had similar experiences. Even if it is only to give them a hug and to let them know they are not alone.

**My name is Lynne Barberian.** We live in Medford, MA. Our first child, Rachel, was born and died on Mar. 22, 2000. A few weeks after Rachel's birth and death I called my local city hall to get a birth certificate. I was told that I would not get one because she was stillborn. I was only able to get a "Report of Fetal Death". I was devastated. I felt like I was being told that Rachel was not born. This set me back in my grieving. I gave birth! How could her birth not be acknowledged? Throughout those hazy first months, I somehow stumbled across the MISS website. It quickly became a place for me to find both comfort and valuable information. I ordered "Dear Cheyenne" and read it in one sitting. From that day on, Joanne has been my mentor. She inspired and guided me to lead the way for Massachusetts to be the 4<sup>th</sup> state to pass the MISSing Angels Bill (November 2002). Parents of stillborn children are now eligible to receive a "Certificate of Birth, Resulting in Stillbirth." I also co-founded the Greater Boston Chapter of Project Linus which donates handmade blankets to children in need of comfort ([www.projectlinus.org](http://www.projectlinus.org)). Rachel's birth and death has shaken me to the core. I am a different person now. I am sure some of you can relate. My feeling is that I have to channel all the sadness, anger, love, loss, longing, etc. into something positive. That is how the Massachusetts chapter of MISS came to be. Gina Carme and I are here to share our experiences and help others on their journey.

**Marisela Angel** is the Spanish speaking volunteer for the Merced, California MISS Chapter. Marisela lost her son, Alejandro to stillbirth on August 12, 2002, at 35 weeks of pregnancy. Marisela knows that she could not have gone through the pain of losing a child alone and because of this she tries to help others that might need the support.

**My name is Dionna Williams.** I have experienced the tremendous, and at times overwhelming, loss of a child. We only have our daughter, Alexis Leigh who

was born to her grandparents on January 9, 2001.

Sometimes it is very hard for me to accept so much time has passed. Of course, it all seems like yesterday to me. Please welcome Dionna Williams, new facilitator in the D.C., Virginia Chapter.

**My name is Heather Marvin.** After a series of tests we were told my baby had a fatal birth defect and would not live more than two hours IF she survived delivery. She did and on March 22, 1993, Lara Christine Marsh was born. I had one blessed hour with her before she left my arms for her new home in heaven. My life is so full now and getting fuller all the time. I am still pursuing my education, only now instead of teaching small children I want to counsel them on grief. Besides helping with MISS, I help out in my kids classes, and take care of my husband who is a disabled veteran.

I am delighted to say that I am in the process of establishing a MISS group in London, UK. **I'm Cathie Shipton.** In November 2000 we were delighted to find that we were expecting. Happily, the pregnancy proceeded with all being well and the baby grew larger and larger. Around my due date, we were told that our boy was a very large baby. A whole day in labour was followed by so much constant pain and the knowledge that there was no way that I was going to be able to give birth naturally as I had wanted to. So finally, in the middle of the night we went into theatre for an emergency section. We now know that our son started to lose blood at this point as the obs unavoidably cut a major blood vessel connecting the placenta to the umbilical cord. As our boy was large, it took some minutes to get him out of me and all this time he was losing blood. After he was born, our boy collapsed and was rushed off to be resuscitated, then on to NICU. We called him Ivan as we signed the



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## Meet our Facilitators

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consent forms for surgery to try to stop his internal bleeding for we wanted him to be strong and terrible. He lived for 4 heart-wrenching days - I never expected him to die, even when the prognosis was getting grimmer and grimmer. On his fourth night, we were told that he was dying and we chose to turn off all the equipment and hold him as he died. He was so beautiful and I miss him with all my heart. I have learned subsequently of all the things I could have done for him after death, but didn't and wasn't offered the opportunity to do. I will regret that until I die too. In my grief, I searched the Web in vain for somewhere I could share how I was feeling with other parents in the UK. I found nothing and nobody here. But did come across MISS and finally felt I'd

come home (despite you guys being mostly an ocean away). MISS helped me stay sane through the first months of grief and then through my sub-pregnancy. In Ivan's memory, I am now trying to establish a MISS group in the UK for others, like me, who need something which doesn't appear to exist in the UK currently. Wish me luck!



*Please welcome all our new facilitators to the MISS family. We look forward to getting to know them and in turn, them getting to know and help our newly bereaved families and those families who have been on the journey for a while. If you would like more information about our support groups or facilitators,*

### Quintin

From your tiny head to your tiny toe  
Quintin, we will always love you so.  
And even if you were here just a while,  
We will always remember your smile.  
Words couldn't express how much  
we really cared,  
But we still cherish the  
memories we shared.  
We know its hello, not goodbye,  
So please forgive us if we cry.  
You were only here for a short time,

But your face, laugh, cries echo  
in the back of our minds.  
Remember its not goodbye forever,  
Because someday we will all  
be there together.  
"From your tiny little head,  
to your tiny little toe,  
Quintin we will always love you so."

*This poem was written by Amanda  
Carter, dedicated to  
Quintin Octavien Mathis*



## MISS Foundation's Sacred Hearts Logo Pendant

A beautiful gift representing the eternal love between Mother and Child. This exclusive pendant is custom made of sterling silver and hangs on your choice of 20" or 24" chain. Now available with or without a birthstone. Orders for the Sacred Hearts pendant can be placed online in our store at [www.missfoundation.org](http://www.missfoundation.org)

or use the order form on page 17 of the newsletter. Be sure to indicate your options (i.e. birthstone month, chain size)

<b>Pricing:</b>	<b>Pendant w/20" chain</b>	<b>\$60</b>
	<b>Add birthstone</b>	<b>add \$12</b>
	<b>With 24" chain</b>	<b>add \$5</b>



## Heart Felts

The MISS Foundation would like to thank **Kim St. Laurent** and **Katie Hodge**, two of our MISS California members, for organizing the Amazing World, Amazing Woman Day in Huntington Beach. Thank you to **Enterprise Car Rentals at Sands Chevrolet** for the free mini-van rental for the MISS California trip. We thank **Nicole Dougherty** for her work on the legislation pages of the MISS website. Thank you to **Asena Nicolosi** for her volunteer time answering phones in the MISS office. Thanks to **Lee Ann Morlan** for her work with East Valley funeral homes. A big and ongoing thank you to **Dr. J. Frederick Froen** and **Josie Trejos, MSW** for their guidance and replies to our new "Ask the Expert" forum board. Thank you **Rusty Chepus** and **Dean Synan** for making our newsletter a wonderful reality! Thank you to **Mary Orta** and **Trade Secret Salon** at Arrowhead Mall for your extremely generous product donation. Thank you to **Diane Jackson**, in memory of **Dylan Ryan Jackson**, for her help with the new MISS photo boards. Thank you to **Cynthia Engstrom**, in memory of **Spencer Christian**, for allowing MISS members the use of her home for conference planning. The MISS Foundation would like to thank all of these **MISS members** for the wonderful gift of themselves. We've also received many donations and would like to express our thanks to all of those who have made monetary contributions to our efforts. These are our United Way donors: **Marcia Boettcher** and **anonymous donor**, **Dillard's**, **Samantha Hiatt** and **anonymous donor**, **Phoenix Children's Hospital**, **Lisa Graika** and **anonymous donor**, **Shughart, Thomason**, **Kilroy/Goodwin Raup**, **Jacqueline Mitchell**, **Melissa O'Neal**, **Paradise Valley Hospital**, **Axiom employees**, **Banner Health**, **Susan Thiede**, **Blue Cross-Blue Shield**, **Cindy Barber**, **Capitol Bancorp**, **CIGNA Healthcare**, **Angelina Sparkes**, **City of Phoenix employees**, **Honeywell employees**, **Maricopa County employees**, **Pfizer Corporation**, **G. Milo Caskey**, **UPS employees**, **Pam Binder**, **Robert Callanan**, **John Comerford**, **Geoff Estevez**, **Horace Henning**, **Karen Stafford** and many, many anonymous donors. Thank you for donating through the United Way program.

# Baby's Breath: *Because each breath is a gift*

## AHRQ AND AAP PARTNER TO HELP PREVENT MEDICAL ERRORS RELATED TO CHILDREN

20 Tips to Help Prevent Medical Errors in Children is a fact sheet intended to help parents and their children avoid medical errors. The Agency for Healthcare Research and Quality (AHRQ) and the American Academy of Pediatricians (AAP) are working together to promote the fact sheet and will distribute copies to AAP's 57,000 member pediatricians as well as to groups representing children and parents. The fact sheet offers evidence-based practical tips on avoiding medical errors related to prescription medicines, hospital stays, and surgery. It is available on the **AHRQ Web site at <http://www.arhq.gov/consumer/20tipkid.htm>** or on the **AAP Web site at <http://www.aap.org/visit/qualityimp.htm>**.



## Suboptimal care implicated in many infant deaths in UK— *Mark Pownall, London*

Better care would "probably" or "almost certainly" have made a difference to the outcome in half of the cases of stillbirths and infant deaths in England, Wales, and Northern Ireland, suggested the annual report of the confidential inquiry into stillbirths and deaths in infancy, which was published this week.

The report analyzed the results of detailed investigations into the deaths of 573 infants, randomly selected as a "1 in 10" sample of the stillbirths and neonatal deaths reported to the inquiry in 1996-7. Selected cases were reviewed by a multidisciplinary panel of at least six specialists.

The panel judged that suboptimal care was provided in 28% of the cases and concluded that a different approach "might have made a difference" in the outcome of these cases. For a further 22% of the cases, suboptimal care "would reasonably have been expected to make a difference to the outcome."

The association between death and suboptimal care was found to be strongest for neonatal death, with the link being identified in 61% of the cases reviewed. The link was particularly strong for intrapartum deaths, and 73% of cases reviewed were judged to have been associated with

suboptimal care. The main cause of death was unexplained for 81% of stillbirths, while immaturity, birth related causes, and infection were the most important causes of neonatal deaths.

The panel identified the main problems contributing to the provision of suboptimal care in the cases of stillbirth as a failure to act appropriately, a failure to recognize problems, and a failure of communication. The report's authors warned: "Stillbirth ... is often thought of as 'unavoidable.' A review of these cases has shown that this is often not the case." The authors suggested that the most common shortfall identified by the review panel for stillbirth was in surveillance, in particular the interpretation of cardiotocograms.

The panel noted that poor record keeping had occurred in one third of the cases of stillbirth and neonatal death that they had reviewed.

*Confidential Enquiry into Stillbirths and Deaths in Infancy, 6th Annual Report is available from CESDI, Chiltern Court, 188 Baker Street, London NW1 5SD (tel: 0171 486 1191), price £6.*

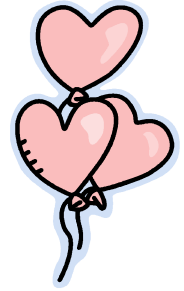


## \$25 Can Save Your Baby's Life

All states require that newborns be tested for three to eight metabolic disorders. A \$25 blood test called tandem mass spectrometry can check newborns for 30 additional inherited disorders not included in the state test. This supplemental screening is important for all babies, since healthy people can carry a hidden defect without realizing it. But it is critical if you or anyone in your family has previously had a baby with one of these conditions. Some researchers believe that up to 3% of deaths attributed to SIDS may actually result from undiagnosed enzyme deficiencies. Women who develop a pregnancy complication called HELLP syndrome (a potentially life-threatening liver disorder) are also at high risk for having a baby with a metabolic disease. If you're pregnant, ask your obstetrician if your state offers tandem mass spectrometry. If not, you can order a free test kit from Baylor University Medical Center by calling 1-800-422-9567. Bring it with you to the hospital, and give it to your doctor, who can take an extra blood sample when she performs the state-required test. For more information, visit [www.baylorhealth.com](http://www.baylorhealth.com).



# Remembering Our May and June Children...



## Happy Birthday

### May

Nicholas Foster Adams  
Tatum Diane Adkins  
Morgan Leigh Armstrong  
Brandon Baker  
Brandon Boddy  
Angela Quanterra Bullard  
Aaron Michael Burley  
Brandon Connor  
Nikolas Kodie Carlson  
Xavier Carter  
Charles Samuel Caskey  
Meredith Lynn Clemensen  
Erica Cohen  
Devin Oscar Craghead  
Jack Harris Crawshaw  
Aiyanna Simone  
Monique Daniels  
Harley M. D'Argenio  
Caitlin Marie Davis  
Tyler John Delgado  
Brock Eller  
Julia Eick  
Mariah Ethington  
Aaron Lee Farrier  
Danielle Farnsworth  
Cody Russ Foote  
Haiden Anthony Freeman  
Gabrial Kaye Fullerton  
Hope Gale  
Cody Shawn Gibson  
Hayden Angel Hall  
Robbie J. Harris  
Madison Brooke Haskett  
Mark Daniel Henderson  
Jacob Dane Hvizdos  
Creay Peter Jackson  
Josephine Mary Jay  
Joshua Nathan Johnson

Marguerite E. Johnson  
Allyson Sabrina Karpus  
Patrick Lanham  
Hattie Ann Lear  
Caleb William Lewis  
Anthony Ian Lewis  
Amanda Lujan-Alvarado  
Lillian Alena Malone  
Nicholas Aaron Mattingly  
Kristina Mary Meyers  
Mikel Moreno  
Josephine Faith Navarro  
Cameron Lee Newburn  
Aaliyah Amari Parker  
Garrett Christopher Pike  
Luke Brian Planert  
Dylan Politte  
Tyler Potts  
Ethan Allen Ralston  
Amy Anahy Renz  
Joshua Darcy Russell  
Nathan Thomas Schmidt  
Elizabeth Margaret Simon  
Lydia Simonson  
Jacob Hunter Smathers  
Tara Janean Smith  
Taylor Jordan Soucie  
Elizabeth Stewart  
Kristin Sunderlin  
Victoria Suttin  
Justin Synan  
Angel Lena-Tecce Hally  
Graham Ross Templeton  
Macy Thomas-Narcia  
Kaycie Shemar Titus  
Timothy Toomey  
Gareth Udall  
Hayden Vanderbloemen  
Angela Rose Villemetz  
Abigail Elizabeth Waden

Jacob James Wesley  
Alexander Williamson  
Ryan Joseph Yancik  
Isiah Daniel Young

### June

Essa Jim Abdallah  
Christian Anderson  
Brianna Janea Baxter  
Vivian Bradley  
Andrew Isaac Burk  
Garrett Allen Carpenter  
Nicholas Collova, III  
Caroline-Marie  
Cooper-De La Cerda  
Amy Nycole Darland  
Hope DiDomenicantonio  
Samantha Amber Dillard  
Cody Dale Elder  
Steven Anthony Endieveri  
Kyle Robert Firstman  
Laura Yudir Fuentes  
Casey Funk  
Ariel Marie Gagliano  
Samantha Grace Gearhart  
Trevor Wayne Gearhart  
Veronica Aurora Glaude  
Benjamin Goedderz  
Duncan Joseph Grant  
Tyler Lee Grissom  
Hailey Faith Haimovitz  
Devin Russell Hession  
Tracey Lee Hudson  
Julia Hurd  
Morgan Anne Hutchinson  
Sabrina Rose Hutterer  
Samuel David Inlow  
Leah Alyssa Johnson  
Shannon Grace Johnston  
Jeret Steven Johnston

Ja'niah Cheyenne Jones  
Jordan David Klapprich  
Noah Jungling-Klein  
Victor Philip Kish  
Madison Louise Kondro  
Michael B. Kurtz  
Riley Ann Lanza  
Gabriel Joseph LeCompte  
Timothy James Lewis  
Jackson Lipari  
Simon de Miguel  
Andrew McBreen  
Makayla McMurtrey  
Carlos Meneses  
Hillary Newton  
Claire Patricia Nibali  
Blake Andrew Nicholls  
Anne Norgard  
Grace O'Hara  
Brandon Keoni Ovalles  
Colt Justice Pechac  
Jesse Quinonez-Perez  
Jesse Peterson  
Bryant Michael Porter  
Kalli Elaine Laray Reed  
Kayla Kamito Robinson  
Mary Elizabeth Rowland  
Jason Michael Saulmon  
Zachary Thomas Schwabe  
Odle Scott  
Allison Shutt  
Maria Sierra  
Quintin Octavien Sly  
Hope Marie Sorrelman  
Naomi Spencer  
Kevin Austin Staggs  
Steven Thomas Terrien  
Madison and Madeline  
Wetterhan  
Colin Edward Witcraft