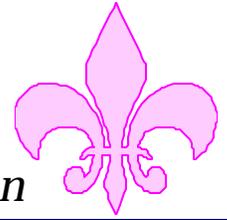


ACDA Notes



From the Alveolar Capillary Dysplasia Association

Volume 4, Issue 3

<http://www.acd-association.com>

Summer 2002

Dear Friends,

This newsletter is dedicated to helping children deal with the loss of a sibling to ACD. Children have the same need as adults to grieve through the loss of a sibling, but have a limited understanding of death. This can be compounded by the fact that parents are in a state of mourning and don't always know what to tell their children. The lead article provides some suggested Do's and Don'ts for discussing death with your children and mentions several books that provide additional information. Our thanks to Victor Parachin for his permission to reprint this article. For additional age specific suggestions, please see the website for Mother's Against Drunk Driving. It has some very good suggestions that we will include in future newsletters. Address is: <http://www.madd.org/victims/0,1056,1982,00.html>.

In an effort to ensure that we are always able to reach all our ACDA families, we urge you to inform us of all new address or e-mail changes. Not only does this allow us to provide you with information about ACDA but we are able to assist the Baylor ACD research team in maintaining contact with you as needs arise during their multi-year study. Thanks for your consideration on this.

*Fondly,
Steve and Donna Hanson
sdhanson@flash.net*

INSIDE THIS ISSUE

- 1 *Talking to Children About Death*
- 2 *Update on Baylor ACD Study*
- 3 *ACDA Website Updated*
- 4 *We Need Your Help!*
- 4 *Help Siblings Find a Pen Pal*
- 4 *Announcements*
- 5 *Remembering Your Baby*
- 5 *New Families, Safe Arrivals*

Talking to Children About Death

Children have the same need as adults to mourn
By Victor Parachin

On most days at four o'clock, Michael and his grandfather could be seen walking down the street, hand in hand, to the corner store. It was a daily ritual for the little boy and the elderly man. Although separated by decades, the two enjoyed a precious common bond. They shared a two-family house in an outlying section of New York City. The grandfather lived in the upstairs unit; Michael and his family lived downstairs. It had been that way since Michael's birth.

When Michael turned seven, his family moved to Long Island, leaving the grandfather back in the city. "See you on Thanksgiving!" they all said. Thanksgiving came and went, however, and they did not see the grandfather. The same thing happened at Christmas.

"Grandpa's away for a while," Michael's parents explained. "Don't worry about it." Months went by and Michael waited. When his birthday came without a card from his grandfather, Michael grew concerned and wondered what he could have done to make the elderly man not love him anymore.

It was nearly two years before Michael's parents told him the truth: his beloved grandfather died shortly after they moved to Long Island. "I know they thought they were doing the right thing," Michael says, "but it was a terrible time for me. They certainly didn't spare me any pain while I was wondering what had happened. And then when they finally told me the truth, I still had to deal with the feeling of losing Grandpa."

This true-but-unfortunate story is reported by funeral director Dan Schaefer and Christine Lyons in their excellent book, *How Do We Tell The Children: A Parents Guide To Helping Children Understand and Cope When Someone Dies*. The fact is that every day of the year, children lose someone they love to death: a parent, grandparent, siblings, friend or relative. Like Michael's family, parents may try to shield the child from the blow. When death is improperly explained and responded to, however, it prevents a child from experiencing the loss, expressing their grief, sharing in the family mourning and moving on toward recovery. Children have the same need as adults to process what has happened and to mourn.

Continued on page 2



Here are some basic do's and don't when talking to children about death.

DO be honest about death. Although you may find it difficult to speak with your child about death, keep in mind that honesty is the best policy. There is nothing worse for a child than being the last to know; accidentally discovering the "secret" and then receiving the excuse: "We thought it was best not to tell you." As soon as you learn about a death, inform your child simply and directly: "Honey, a very sad thing happened this afternoon. Grandmother died." Once you have given your child this information, gently make sure they understand what you have just said.

DON'T use euphemisms. When her aunt died, a six-year-old girl was told, "Aunt Ellen went away on a long trip." Because her aunt never returned from that trip, the little girl was terrified when her family announced that they were all going on a "trip" for their summer vacation. Here is the point: death is not a "long trip;" death is not "sleeping;" death is not "resting;" death is not "passing away."

"When you're talking with your child, avoid euphemisms," say Schaefer and Lyons. "Use simple words like 'dead,' 'stopped working' and 'wore out' - simple words establish the fact that the body is biologically dead." For example, if your child asks, "What does dead mean?" respond simply by stating, "Dead means a person's body has stopped working and won't work anymore." If your child asks, "Is death like sleeping?" a good response is to state simply, "Dying is nothing at all like sleep. When someone dies, their body stops working. It is not resting. Its job is over. DO help Children express their thoughts and feelings.

Encourage children to cry-out their grief and talk out their thoughts, and feelings about the death. Be aware that children are often verbally limited when it comes to stating their feelings and often express their grief in a variety of non-verbal ways such as sleeplessness, nightmares, clinging behavior and school difficulties. Because of their verbal limitations, you, as the parent or important adult, may have to take the initiative to help your children ventilate grief. One effective way of doing this is to pick-up on a child's feelings and say, "I know you miss Daddy very much. I miss him too." A simple statement like that is often enough to help a child open up.

DON'T tell a child how to feel. Some parents unwisely tell children: "Be brave. Be strong, you're the man in the family now," or "Don't cry, it was the will of God." Instead of such statements, let a child experience and express grief in their own way. DO offer continuous love and assurance. "In the early stages of mourning, a child needs reassurance that he is loved. This will make him feel more secure. Parents cannot shield their children from painful feelings, but they can help the child to bear them. So openly express your caring - show him in many ways that you love him," writes psychologist Charles E. Schaefer, Ph.D., in his book *How to Talk To Children About Really Important Things*. Dr. Schaefer also says one of the best ways a parent can show they care is by being readily present and available during the difficult months of grieving.

DON'T hide your grief from your children. Be open with your own

Continued on page 3

Update on ACD Study

By Partha Sen Ph.D and Bassem Bejjani M.D.

The team of researchers at Baylor College of Medicine is now getting ready to embark into another phase of their research. They have been able to isolate DNA from paraffin blocks and now have enough DNA from a few families to start a genome wide screening using the Genotyping technology. They have also written a grant application to National Institute of Health. They are ready to submit their first publication to the Journal of Pediatrics. This is going to be a treatise of clinical aspects of the patients. This will be an exhaustive review of the syndrome with over twenty-five patients. The researchers would like to thank the ACDA and participating parents for their help.

Tear Drops From an Angel by Gayle Clarke

God looked down upon you
and saw you needed him.
So he opened up his arms
and took your baby in.
His eyes began to tear
as he held the baby's head.
But then a smile crossed his face
and this is what he said:
Little child, little child
dry your cryin eyes.
I know it's best for you up here
for I am very wise.
I'll keep you oh so safe
no harm will come to you.
You have to understand
that love's all around here too.
You'll never have to hurt
you'll never have to fear,
so put a smile on your face
and wipe away that tear.
Yes your momma misses you
for she cries right now too.
but in her heart she knows
I'll take good care of you.
She never will forget you
you're in her heart so deep.
So now I tell you baby boy
just close your eyes and sleep.



grief and emotions. It is all right if your children see you crying, or feeling sad. Your open grieving gives a child "permission" to grieve as well. By seeing you grieve, a child will know that it is normal and healthy to cry and feel sad after a death.

"A child takes his cue from the adult," says Sacramento, California, family therapist Jerri Smock, Ph.D. "You need to handle your own emotions - anger, hurt, grieving, tears, whatever - and you need to be vulnerable. You need to be able to express and identify your feelings so a child can do the same with his or her own feelings."

DO invite others to help your children. Enlist the assistance of other family members - uncles, aunts, grandparents, as well as close friends and clergy who can help grieving children. Often, someone outside the family can provide much needed additional comfort, concern and care. Welcome their assistance and aid with open arms.

DON'T assume children will just get "over it." The idea that children are more adaptable, that death is less traumatic to them, is a myth," say authors Candy Lightner and Nancy Hathaway in their book *Giving Sorrow Words*. "The fact is that children are in many ways most affected by a death for, unlike adults whose identities are formed, they must brave a further challenge: growing up in the face of loss. Whether the death takes place during their infancy or their adolescence, whether the person who dies is a relative or a friend, the impact can last for the rest of their lives." Do not assume your child will get over the death naturally and on their own. Be proactive and provide all of the comfort and consolation you can.

DO be a good listener. Like adults, children need to talk about the loss and their feelings connected to it. That means they need adults who will take the time to listen carefully and compassionately. "Listening to the child is an effective way of putting care into action," writes grief authority Alan Wolfelt, Ph.D., in his book *Helping Children Cope With Grief*. "Listening requires hearing not only the content of what the child is saying but also hearing the content of that which is only being hinted. The child may need help in terms of being able to put thoughts and feelings into words. While you will certainly want to listen with your ears and see through your eyes, you will also want to hear and respond with your heart."

DO Nurture faith but DON'T blame God. Death is a profoundly theological issue and children will ask religious questions. Some parents unwittingly create future spiritual problems for children by incorrectly assigning blame to God for a death. This is done when a child hears an adult say, "God needed daddy," "It was God's Will," "God loved your sister so much, He took her," or "God punished him." Rather than speak of God "taking" a loved one, convey to your child that God has "received" a beloved family member and that God is also sad about the tragedy. Remind your child that "God shares our pain and will help us get through the crisis." ∞

ACDA Website Updated

Thanks to Phil Tenney in England the ACDA website was updated in the last few months to reflect several changes and additions.

- The ACDA Spring 2002 newsletter was added in the "Information Library" section;
- A link to Dr. Bassen Bejjani's website was added to the "Latest Research" page to give readers more information on the ACD study being conducted at Baylor College of Medicine in Houston, Texas;
- The medical definition of ACD, previously provided by Dr. Robin Steinhorn, now supplements that layman's definition on the "What is it?" page.

In the near future, we hope to add a section to the website that will address how to donate money to the National Organization for Rare Diseases for ACD research. If you have any other suggestions of things to add, please let us know.

Visit the website at
<http://www.acd-association.com>
and check out Phil's handiwork!

ACDA urges your participation in ACD study

We are grateful to all the families in the ACDA that are participating in the only known ACD study. We hope that your participation in this study, being conducted at Baylor College of Medicine in Houston, will eventually lead to the cause and cure for ACD. However, the success of the study is dependent on the participation of a large number of families. We understand that many families may simply want to move on after such a devastating loss, but the findings of the study can be very important to your living children and your potential grandchildren. We urge everyone to consider participating. If you have any questions or decide to participate, please contact Dr. Bassem Bejjani at 713-798-8704 or e-mail at bbejjani@bcm.tmc.edu. He is the lead doctor at Baylor College of Medicine.

For those families that *are* participating in the study, it is important for you to keep in touch with the team at Baylor to ensure that they have all your information and to answer any questions they may have about your family background or your baby. Please be sure to inform them of any changes to your e-mail address, your home address and your phone number during the study period. ∞

We Need Your Help!!



- **Effective June 2, the National Organization for Rare Disorders changed their mailing address. The new address is:**

**55 Kenosia Avenue
P.O. Box 1968,
Danbury, CT 06813-1968 USA.
Phone Number : (203) 744-0100
Tollfree: (800) 999-6673 (voice
mail only)
Website: www.rarediseases.org**

- **There is approximately \$600 in the ACD research fund at NORD with another \$1200-\$1800 received but not recorded.**

Thank you for your donations!

ACDA is managed by families who have lost children to ACD. They volunteer their time and money to assist in the goal of providing support to other families and finding a cause and cure for ACD. We also try to maintain visibility in the medical community and for that we are asking for your help to update some ACDA materials.

With the help of Dr. Robin Steinhorn, we have two opportunities to introduce ACDA to approximately 4,000 health care professionals. First, in September there will be a conference on Nitric Oxide in San Francisco that is sponsored by ECMO/ELSO. It will be attended by doctors who use Nitric Oxide to treat patients with Persistent Pulmonary Hypertension (PPH), which is often the first symptom of ACD. Second, we want to make all Level III Neonatal Intensive Care Units and ECMO centers aware of ACD and the ACD Association by sending them information about our organization. This will help us reach additional families, thereby improving participation in the Baylor ACD research study.

Specifically, we need your help on the following items.

- Submit an idea(s) for an ACDA logo
- Redesign the ACDA brochure
- Assist in mailing ACDA materials

We would like to complete this effort by the end of August in time for the ECMO/ELSO conference in September. After that, we will also send it to all the Level III Nurseries. If you are interested in helping, please contact Donna or Steve Hanson at 972-414-7722 or sdhanson@flash.net. ∞

Join a Pen Pal Support Group

The Pen Pal Program now includes a support system for brothers and sisters who have lost a sibling. This national organization is a wonderful group that was originally established to connect children with common illnesses together so that they can have a special friend that understands what they are going through. The kids, aged 5 - 17, are given the name of another child as near to them geographically as possible and they are able to exchange letters. This is a no cost matchmaker.

A few years into their program, Pen Pal began including parents of seriously ill kids. There were not ACD parents involved because we had already begun to create our own network. Pen Pal's newest endeavor will now include the siblings of kids who are hurting right along with their families. These kids have feelings too and they need a special person to share them with. Thanks to Pen Pals they now have that person. For more information or a referral card, contact Donna Hanson at sdhanson@flash.net or 972-414-7722 and she can get you on your way to a connection for your child who might be suffering over the loss of a sibling they were barely given the chance to know. ∞

Safe Arrivals

Congratulations to the [REDACTED] family who have been blessed with another baby:



Remembering your baby...

Memorials and mementos help us express our feelings and also honor our baby's importance. Here are two suggestions that you might consider to memorialize your child:

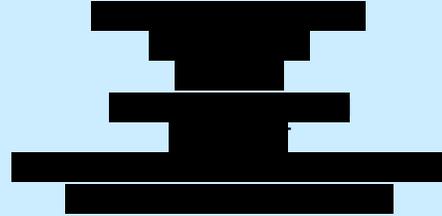


- Make a financial donation to the National Organization for Rare Disorders for ACD research.
- From the [REDACTED] family - "For our son Christopher, I have an entire Garden in the backyard with a slate sign painted with his name on it. We also have his tree in the center of the Garden. We plan on planting a tree for his new little sister who is now 5 months of age and for my husband and myself."

If you have found a unique way to celebrate your child's life and would like to share it with the ACDA, please e-mail us at sdhanson@flash.net. ∞

Please Welcome Our New Families . . .

It is with mixed emotions that we'd like to introduce the families that have joined ACDA since the last newsletter. Please take the time to introduce yourself, offer support and share the story of your child (children). You may find a family in your area.





UPDATE:

The [REDACTED] family recently contacted ACDA with the news that their son's final autopsy report revealed he did not have ACD but had an extreme form of pulmonary maldevelopment which consisted of an extensive but not complete failure to form the terminal respiratory units. This disorder is called Pulmonary Acinar Dysplasia or PAD. They have requested to be removed from the ACDA. We wish them well.

<http://www.acd-association.com>

Searching for Answers, Hoping for a Cure . . .

