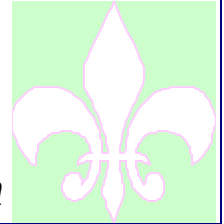


ACDA Notes



From the Alveolar Capillary Dysplasia Association

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

Spring 2003

Dear Friends,

We continue to be amazed about the wonderful stories that you are sending us about your efforts to make a difference in honor of your child. We have some exciting fundraising news in this newsletter as well as some information on a new family that has offered to provide some much-needed help designing an ACDA logo, brochure and letterhead.

We are extremely appreciative of those families that stay in touch and/or provide feedback to us. We realize that not all of our families are active in the ACDA as it may be a painful reminder of your loss. But we hope that you will eventually find the strength to join us in our efforts so that our surviving children will not have to suffer as we have.

Fondly,
Steve and Donna Hanson
sdhanson@flash.net

In Memory of Isabella

In February 2003, [REDACTED] lost their daughter, [REDACTED], to a suspected case of ACD. In their grief, they have found the need to do something tangible in memory of [REDACTED].

[REDACTED] own an advertising agency, [REDACTED], and currently, their biggest client is the Texas Department of Health promoting childhood immunizations and breastfeeding. [REDACTED] have offered to use their expertise to design a logo, create a new brochure and print letterhead for ACDA. Like other families who have lost a child to ACD, the [REDACTED] find some comfort in being able to make a difference. ACDA is extremely grateful for their efforts.

"A Tribute to [REDACTED]"

On March 28, 2003 [REDACTED] held a fundraiser in memory of their son, [REDACTED], who died in 1999 from ACD. "A Tribute to [REDACTED]" was the brainchild of the [REDACTED]'s neighbor, Cynthia Nichols, President of 2bQ Productions in Allen, Texas. Cynthia's company specializes in fundraisers for non-profit organizations and suggested that the [REDACTED] have a fundraiser for ACD research. The outcome was a wine and hors d'oeuvres reception with a silent auction at the Art Center of Plano. Generous artists, including Chanan Mock who is a Program Manager for 2bQ and [REDACTED] ([REDACTED]'s older sister), donated art for this special event. Over 80 people

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attended the reception including family, friends, a nurse and doctor who treated [REDACTED]. The guest speaker was Dr. Partha Sen from Baylor College of Medicine in Houston who discussed ACD and provided an overview of Baylor's ongoing genetic research program on ACD. The [REDACTED]'s were overwhelmed by the support and generosity of the family and friends that supported this special event. Thank you to 2bQ Productions, the artists and friends who donated items for the auction and to all those people who made a donation to ACD research. Approximately \$3,000 was raised for ACD research!!



"Tribute to [REDACTED]" Fundraiser
(left to right: Steve and Donna Hanson, Dr. Partha Sen, [REDACTED])

**** Watch the website for a copy of Dr. Sen's Presentation ****

Safe Arrival

Congratulations to the [REDACTED] family who has been blessed with another baby. [REDACTED] was born to [REDACTED] and big sister, [REDACTED], on May 6, 2003.

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

On February 19, 2003, [REDACTED] died from a suspected case of ACD. Her father, [REDACTED], wrote the following tribute to his daughter for her rosary and also sent it to family and friends that were so touched by [REDACTED]'s short life. [REDACTED] asked that they keep [REDACTED] alive in their hearts.

[REDACTED]'s Beach
By [REDACTED]

Life is full of miracles we cannot understand. Milagros. Just like [REDACTED].

All we have to do is stand on a beach and gaze across the ocean to feel the peace that comes with accepting that we are but a small part of something so great it is unfathomable. Something so immense and timeless it is a miracle we can hardly hope to grasp and comprehend.

[REDACTED] is such a miracle. She was made of pure love. She grew for nine glorious months within the warmth and comfort of her mother's womb. And she fought for five long weeks to stay with us here on Earth. Those weeks seemed eternal. And in a sense they were. For while to some it might seem like a fleeting moment, to Isabella and those who loved her, they were a lifetime.

[REDACTED] was a beautiful baby girl. She gazed at us - her parents, her sister, her grandparents, her nurses and her doctors - with an incredible range of emotions. And she captivated us. For in her big blue eyes we could see our own humanity reflected: love, happiness, comfort...curiosity, frustration, pain...and most of all...awe. An awe that we would come to share as she took us on a most unexpected journey, a journey filled with yearning, hope, and even despair, for all of us at her side longed for those precious eyes to see more of our world.

After many days of support from machines that prevented her from moving much or making sounds, her final days were ones filled with hope and tiny joys that will always be remembered. We'll never forget the strong grasp of her fingers, her tiny smile, her soft cry. And now quickly she was comforted by a loving embrace, by the soothing sounds of lullabies, by her mother's milk. These were simple things. But [REDACTED] taught us that simple things are what matter most.

During our time at the hospital we once told her nurse, we couldn't believe how many lives had touched her. And she so wisely responded: "No, what's amazing is how many lives SHE's touched."

And it was true: [REDACTED] brought out the best in those who knew her. Hundreds, if not thousands, of people prayed for her fervently throughout the globe, as family, friends and colleagues passed the word: in person, on phone and via the Internet. The doctors and nurses that nurtured her, granted us the opportunity to share those five weeks, for without their knowledge and skills, she might not have survived her first days. So many great minds came to her aid. But in the end, it was not the minds that prevailed; it was the hearts. For when all of the science and technology failed to help her heal, only love could ease her suffering and her passage to a better place. And everyone around her allowed their love to flow freely upon her, accepting the sorrow that comes with such a bittersweet devotion.

And from that sorrow, we can only hope that her legacy will be one of learning, beauty and celebration. For her gifts to us were many:

- She taught us that when we call a baby into this world, we may think we're signing up for the perfect child. While in fact, we're truly signing up for whatever we shall receive. And we must love and accept that gift for all its beauty and grace, and for all its flaws and imperfections as well.
- She restored our faith, understanding towards the end, that we were praying not simply for her survival, but for the peaceful, dignified and righteous completion of her destiny.
- She exposed us to a world from which we had been sheltered, a world where parents and families are suffering every day in NICUs, praying for miracles and hoping for the best, needing help, support, love and understanding.
- She convinced us that being parents is not a right; it is a gift that we should cherish and honor.
- She brought us closer to God, because we know that only by being close to Him can we remain close to her, for she is now at His side as an angel that will protect us.
- And she gave us something to look forward to when our own time comes, for one day our souls will be reunited with hers in Heaven.

With that in mind our thoughts drift back like a gentle breeze over that sandy shore on which there is so much peace to be found. And as we gaze across the waves to the horizon, we can ponder:

If there is a forever, and we have to believe there is a forever, these few years we have on Earth are but a grain of sand on an endless beach. In losing [REDACTED], we have lost just a part of her. We have lost that grain of sand, but we still have the beach. And that's part of her miracle: We believe...we still have the beach...with [REDACTED].

Olivia's Circle Update

In last month's newsletter, we introduced Olivia's Circle, a women's fitness center started by the [REDACTED] family of New York to honor their daughter, Olivia. A portion of each monthly membership to Olivia's Circle is being donated to NORD for ACD research. [REDACTED] has reported that \$747 has been sent to NORD and another \$250 will be sent in at the end of May. The gym is successful and members have been touched by Olivia's story. Some members have even made an additional donation to NORD, and [REDACTED] has received offers to participate in other fundraisers. [REDACTED]'s endeavors were the focus of an article in "The Business Review," New York's Capital Region business journal. You can find out more about Olivia's Circle at oliviacircle.com. The [REDACTED]'s have added a spot on the website that tells how much money they have raised and what their goal is.

[REDACTED] said, "This endeavor has really helped us keep Olivia alive in our hearts and every day I hear people say her name and each day I look at her picture as I enter the building. She may not be here with us on earth but she is very much a part of our life." What a wonderful tribute to Olivia!

Announcements

- There is approximately \$5,552 in the ACD research fund at NORD as of April 24, 2003.
- Did you know that the ACD Study at Baylor College of Medicine would like to include blood samples from all the healthy siblings? Contact Bassem Bejjani at Office Phone: (509) 368-6717, Fax: (509) 358-7627, or E-Mail: bejjani@wsu.edu for more information.
- If you live in the UK and are interested in joining an ACD support group in that country, please contact:

[REDACTED] [REDACTED]
or
[REDACTED] ([REDACTED])

- [REDACTED] has recently updated the ACDA website with the following changes or additions:
 - Changed the contact address for ADCA from Madonna Myers to Steve and Donna Hanson
 - Added a section on common ACD medical terms
 - Added the Winter 2003 ACDA Newsletter
 - Sorted out the problem with the guest book
 - Prepared the web pages for the update on research
 - Prepared a link for Frequently Asked Questions

If you have any changes or additions to the website that you would find helpful, please let us know. Many thanks to [REDACTED] for maintaining the website for ACDA. It is through the website that many new families find our support group.



COPING WITH GRIEF

(From www.about.com)

It takes time to heal after a great loss. There is no formula to follow or timetable to keep. As you grieve you will find yourself returning again and again to images, feelings and memories of your loved one.

No one can know your grief or tell you in what ways or how long you should grieve. Everyone's process is unique.

Along the way you will find that your loss will become more bearable as your experience of everyday life changes to accommodate the absence of the person you miss the most.

Your initial response to the loss of your loved one may be shock, numbness, anger, and sadness, all running together in an overwhelming series of waves that pulls you deep inside yourself, like the undertow of riptides that keep coming.

Grief is often a mixture of raw emotions such as sorrow, anger, guilt, regret, emptiness, abandonment, desolation, despair, and longing. This loss may bring up other losses you've experienced over the course of your life. You don't need to explain away any of these feelings or push away your grief; Just be gentle with yourself, allowing yourself to feel whatever comes.

Unexpressed grief can cause you to misplace anger onto others and emotionally withdraw to hide your feelings from others you are close to. You may not feel like eating. You may be unable to sleep or want to retreat from life's demands altogether. This is natural. Bouts of grief will come again and again, but over time they will come less often and not last as long.

Creating times of solitude can give you the time and space needed to help you get in touch with your feelings. You can express them in the privacy of these intimate moments with yourself and your loved one, in the spirit of the relationship that existed between you.

You might want to create a sacred ritual to celebrate the life of your loved one, a ritual that helps you bring closure and meaning to your loved one's life and the relationship you shared. Some people light candles near a picture of their loved one, or write poems about that person, keeping flowers near the picture, all to express the love that is still very much alive.

Above all, know that your loved one has moved on carrying the love that existed between you. And you will always have the love, memories, and gifts

Searching for Answers, Hoping for a Cure . . .



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your loved shared with you. They have shaped who you are and that alone makes them very special. Moving on does not mean that you have forgotten, or that you are neglecting your loved one's memory. It means only that you have grown from the gift of love that this one left with you and the sharing of another's passing from this world.

If you find yourself overeating, sleeping too much, even drinking or using drugs - prescription or recreational - you may want to get help. While some people drink under stress, or overeat to fill the emptiness they feel inside, maintaining these ways of coping can harm your health. Confiding in a family member who can help may be wise.

The Generosity Continues

██████████ of England have a friend, ██████████, who is a member of a group called the *Sworland Singers*. ██████████'s group travels around singing and raising money for various charities and on one occasion nominated ██████████'s daughter, ██████████, and the ACD fund at NORD to be the beneficiary of their efforts. The amount donated was £50 (sterling). Thank you to both the ██████████ and the *Sworland Singers*!

For those families who want to make a contribution to NORD using foreign currency:

We asked Linda Cataldo at NORD for the best way for someone who lives outside the US to donate money to our ACD research fund at NORD. Linda informed us that the best way (most economical) to contribute with foreign currency is to do so with a credit card. The credit card bank will do the conversion much cheaper than NORD's account bank. This can be done on-line or through the mail. The donor MUST be sure to indicate that the contribution is for Restricted Research Fund for Alveolar Capillary Dysplasia. Otherwise, the gift will be accepted as a general contribution.

NORD indicated that £ sterling cheques are accepted but not the most preferable method.

General Guidelines for Contributions:

Send the contribution to the following address:

National Organization for Rare Disorders (NORD)
Attn. Mrs. Linda Cataldo
PO Box 1968
Danbury, CT 06813-1968
USA

You should send the following information to NORD with your contribution:

- 1) Make any checks payable to "NORD Restricted Research Fund - Alveolar Capillary Dysplasia"
- 2) The name of the person who your gift is given in memory of. NORD will include their details in the memorial section of the next NORD newsletter.
- 3) The name and address of the person(s) who you would like an acknowledgement card sent to.