

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

Happy Holidays and all our best for a happy and prosperous 2007! We hope that all of you have created holiday traditions for your family and found a way to include the memory of your baby that you have so tragically lost to ACD. Again this year, we chose a 9 year old "angel" from the Salvation Army Angel Tree - the same age that Eric would have been. It is important to us that Stephanie and Jennifer always remember that they have an older brother.

A goal of the ACDA in 2007 is to raise enough money to award another grant for ACDA research. This brings to mind a story we've heard. "A pastor got up one Sunday and announced to his congregation: "I have good news and bad news. The good news is, we have enough money to pay for our new building program. The bad news is that it's still out there in your pockets." This story also applies to finding the cure for ACD. The money is out there for funding the research required to meet our goal. We just have to find out who has it and introduce them to our cause. They say that there are only six degrees of separation between everyone on Earth. We're sure you know the people or you know the people who know the people.

As we close out 2006, we give thanks to all of you that have contributed to the efforts of the ACDA and to the research to find a cause and cure for ACD.

Fondly,

Donna & Steve Hanson, ACDA Executive Directors

Family Holds Fundraiser for ACD Research

The [REDACTED] family of New York recently held a golf outing in honor of their son, [REDACTED], who died of ACD in 2005. [REDACTED] and [REDACTED] raised \$1,800 that they sent to the ACD Research Fund at the National Organization of Rare Diseases. Their first fundraiser was so successful that they are already planning another one for the upcoming summer.

Thank you to the [REDACTED] for their efforts!



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Carrying Our Babies with Us - Always

ACDA Mom, [REDACTED], sent us a web link on some information that indicates that a baby's fetal cells remain in a mom's blood for many years. While there is still research to be done in this area before it is determined if these cells are beneficial or not, we thought that knowing that our babies cells are within us may bring some small comfort to some of you. So, we wanted to pass along this article. Thanks to [REDACTED] for sharing this with the ACDA!

Behind the Fetal Cell Research by Robert Krulwich

NPR's Robert Krulwich provides a behind-the-scenes look at the research on fetal cells and mothers -- and some of his own thoughts on what the science means.

For those of you who want to know a little more about these fetal cells, I should say, first: Dr. Kirby Johnson works at the Tupper Research Center (supported by Mr. Tupper of Tupperware fame, for those of you who like sealed plastic containers) at Tufts University.

He works very closely with Diana Bianchi, chief of genetics at the New England Medical Center in Boston. Bianchi did some of the pioneering research that discovered that moms carry fetal cells in their blood for years and years.

Carol Artlett has a lab at Thomas Jefferson University in Philadelphia and works with Sergio Jimenez there.

There's another fellow, Lee Nelson at the Fred Hutchinson Cancer Research Center in Seattle, who has also studied these cells.

Also, just to be honest and fair, there are more than two hypotheses being investigated by all these scientists.

Yes, there is the "Good Hypothesis": that the cells stay in the mom and try to protect her for the rest of her life.

And yes, there is the "Bad Hypothesis": that the cells gather at inflammation sites and contribute to mom's autoimmune diseases.

But there is also a third hypothesis: that the cells stay in mom all her life and do... nothing. This is the "Bystander Hypothesis": that the cells float around, hang out, rubberneck when at sites where mom gets ill, but neither help or hurt. This third hypothesis has not been disproved, meaning it's still in contention.

Finally, the big question right now is, can scientists find evidence that fetal cells are actually doing repairs when mom is stricken?

It's not a far-fetched idea. These cells may behave like those famous embryonic cells: They can turn themselves into any cell mom needs.

If she's got a bad heart, they can be healthy heart cells.

Bad lungs? No problem, they can be lung cells. Fetal cells may be the ultimate repairmen (or repairwomen).

A cautionary note: The anecdote I mention in the story, about the 30-year-old woman who has liver trouble and seems to heal herself, is *not* proof of the Good Hypothesis. There are no published studies that definitively show baby cells floating to, say, a liver cancer site and then turning themselves into healthy liver cells. That's the hunch. That's the theory. But we have no hard data -- not yet.

But everybody I talked to is whispering that something like repair is what they are seeing in mice and in humans. Carol Artlett comes right out and says so in our story.

But so far, it's very, very preliminary, and in her mind -- and everybody else's I talked to -- it's too early to know if baby cells are really repairing moms. They hope so. But hope is not proof and these folks are too professional to get ahead of their evidence.

And finally, I want to thank my friend Jonah Lehrer for suggesting this idea to me; he's a wonderful science reporter and a font of fascinating ideas, which he (stupidly) shares with me. And -- since we're all here sharing -- here's what I'd like to know:

If fetal cells really are helping moms, I wonder if women who have babies (and abortions and miscarriages) tend to live longer than women who do not conceive. After all, the Conceivers have an extra gang (the more conceptions, the bigger the gang) of helpful cells inside.

Maybe there's some measurable consequence. And if the Good Hypothesis turns out to be true and every child leaves a posse of good soldiers in their mothers, then no matter how crummy we are to our moms, we are, willingly or unwillingly, still doing something nice for her -- on the inside.

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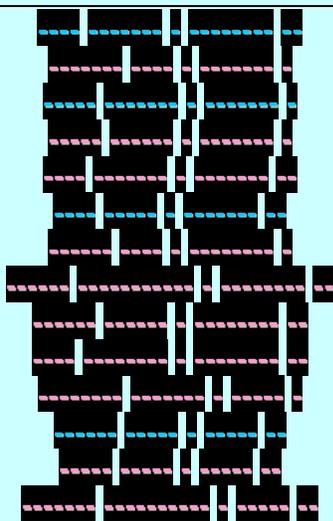
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Memorial Garden

We are dedicated to remembering the birth dates of our member's babies who are not here to share our lives. Please pause to remember them.

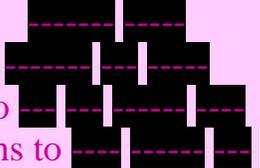
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Update on ACD Study

Partha Sen, Ph.D. at Baylor College of Medicine in Houston reports that the ACD research team has completed their work on immunohistochemical studies on the ACD lung samples. They will begin summarizing the results early next month and authoring a paper for publication. A frequent requirement for publication in medical journals is that the information has not been previously published anywhere. As soon as the article is published, we will provide the details in an upcoming newsletter.

SAFE ARRIVAL

To  Congratulations to !

