

# Deater Foundation, Inc.

## Newsletter

### Years of Research of the “Deater Disease” Continue *Submitted By: Ellen Deater Burns, Medical Liaison*

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#### Reunion

#### Reminder!

Hope to see you  
at the 67th  
Deater Reunion  
on July 18, 2009  
at Butler’s property.

Early in my life my father’s (Harvey Deater) illness was known simply as “the Deater Disease.” I then discovered the designation “Hereditary sensory radicular neuropathy.” This gave way to hereditary sensory neuropathy type 1 (HSN-1), and more recently, hereditary sensory and autonomic neuropathy type 1 (HSAN-1). Even now, there is controversy that the disease might best be labeled “hereditary sensory and motor neuropathy.” As far as we know, Thomas and Henrietta Anthony Deater, my great grandparents, are the founding generation for the disease in the Deater family. People in generation 3 through generation 7 in the Deater family are alive today who have, or are at risk for, the disease.

The Deater family has been engaged in studies over the course of more than 70 years, during which many potential causes of HSAN-1 have been theorized and ruled out. The research by the Day Laboratory involving many Deater family members confirmed the identification of the mutation on Chromosome 9 that is the cause of the disease. The defective gene regulates the production of the sphingolipid serine palmitoyltransferase (SPT). This regulation is faulty in persons with HSAN-1.

Sphingolipids are essential

components of cells in the body. They give cell membranes important structural properties and may play a part in organizing the movement of proteins in and out of cells. Sphingolipids are formed when a fatty acid bonds with a protein. The resulting product is called a metabolite. These metabolites regulate processes within cells. Sphingolipid metabolites are formed when sphingolipids are created or broken down.

Blood samples from Deater family members with HSAN-1 show high levels of certain sphingolipid metabolites. Studies on the HSAN-1 mouse models at Massachusetts General Hospital show high levels of the same metabolites.

The mice were given a supplement of the protein serine in their diet. After two weeks on this special diet, the blood levels of the metabolites decreased. The researchers want to know if dietary supplements of serine will reduce the levels of the metabolites in people with HSN1.

It is not known if the high levels of metabolites that were discovered in the blood of persons with HSAN-1 have any bearing on the nerve destruction seen in the disease. What is known is that people who have the disease have high levels of

*(More on Page 2)*

## In This I Believe

*Submitted By: Ellen Deater Burns*

### *In this I believe...*

National Public Broadcasting sponsored a program for any individual to write an essay on his or her essential belief. Many mornings, as I listened to the beliefs of others I thought of my own story. I believe in the power of family.

I believe that you don't have to like everyone you are related to, but it is still possible to love them. I believe that the sum of the whole is greater than any of its parts. I believe that family gives us a place to be, an identity that becomes more clear with age, a unique niche within the fabric of relationships that would be poorer for the loss of any individual.

I believe that a family includes not only those who are born in, but also those who marry in, and those who stumble in along the way. Family is inclusive, not exclusive.

The Deater Foundation was born of the desire to contribute within the circle of family and friends to support research into the cause and cure of HSN-1. We are a large and caring family. Each one of us biological

family members, at one level or another of our own family tree, had a 50-50 chance of receiving the gene that causes the hereditary neurological disease that results in pain and impaired mobility. Some of us got one genetic mix, some of us got the other. Non-biological family members care about, love, or respect people with the Deater genetic mix. That mix includes steadfastness, determination, good humor, service to others, courage, and faith in something greater than ourselves.

Contributing to the Deater Foundation is a way of responding to the heritage in this family with which we have been blessed. Please consider making regular donations in honor of parents, grandparents, children and grandchildren, neighbors and friends. This family, scattered as we now are, across this continent, continues to care for one another and to support one another, bound by ties that extend through generations.

*In this I do believe.*

—*Ellen Deater Burns*



Ellen Deater Burns

*Medical Liaison*

*Contributing to the Deater Foundation is a way of responding to the heritage in this family with which we have been blessed.*

## Years of Research of the “Deater Disease” Continue

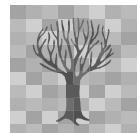
*Submitted By: Ellen Deater Burns, Medical Liaison*

*(Continued from Page 1)*

metabolites, and those without the disease in the same family do not. If the supplements reduce the levels of metabolites in humans, as they do in the mice, there is a chance that this might have some kind of bearing on the pathology of the disease.

We are blessed to be able to participate in a study that may lead us closer to a treatment for this disease. We are hopeful that the supplement of a food product may mean that generation 7 may never know the effects of the “Deater Disease.”

*We are blessed to be able to participate in a study that may lead us closer to a treatment for this disease.*



**DFI**

## Pictures from Last Year's 66th Deater Reunion

*July 12, 2008 Submitted by: Carol Dorward*

Bet you can't guess who headed up the food committee last year? She looked so cute in her lovely apron! And remember how wonderful the food was? Well, somebody else will be heading up the committee this year...but we all know that the food will be great, especially with everyone bringing their favorite side dishes.

And the children always enjoy the games and face painting.

Best of all is the family camaraderie throughout the afternoon.

See you this year on July 18, 2009 on the Butler property again for the 67th Deater Reunion.

*Mark your calendar for  
this year's reunion:  
July 18, 2009*



## Enterprise Rent-A-Car Foundation Grant—Just Ask!

*Submitted by: Jon Ellsworth*

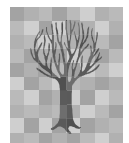
For the third year in a row, we have been able to obtain a grant from the Enterprise Rent-A-Car Foundation to help fund research. I have been with Enterprise for 12 years now, and have had the opportunity to witness their "giving" spirit time and time again. Three years ago I asked if the Deater Foundation qualified to be considered for a grant; and each year since, I have re-applied and been given a "yes." This year they donated \$2000! It's exciting that the company I give to every day is willing to give back and help financially to support this very rare and unique cause. Enterprise has a lot of employees, and is asked for funds constantly. I am privileged to be someone whose cause they feel worthy of supporting.

Having grown up in a family where my mom lives with HSAN-1, and now being one of those "select" few myself, I know first hand the challenges this disease creates. We all live with the inability to do certain basic things and get the opportunity to answer time and time again the question, "Hey, what's wrong with your legs?" The Deater Foundation has made research possible for several decades now, and, combined with other funding sources, is making great strides towards a treatment and ultimately a cure.

You may be someone who is directly affected by the disease--yourself or an immediate family member. Or you may be someone who is a Deater and knows the



Jon Ellsworth



**DFI**

*Continued on Page 6*



## Memories of Mom: “She’s a Tough Act to Follow”

*Submitted By: Louise Adams Hess*

Three things I’ll always remember about my Mom: Her kind heart and love of God; her love for family; and her love of laughter.

One day when I was little (age 4 or 5), a “bum” came to our back porch door and asked for work. I had never seen a “bum” before, and so I watched carefully from the comfort of the nearby grass as Mom told him she didn’t have any work for him but asked if he was hungry; then she brought him a bowl of corned beef and cabbage and some bread. He ate it hungrily as mom talked to him about God. It wasn’t long after that when I observed my mom as she knelt at a chair in our front room. She cried and prayed there often. I wanted to know more about this praying and talking to God, so I tapped her on the shoulder to ask. She led me to Christ that day, right there at that front room chair. *She’s a tough act to follow.*

As she got older, she got bolder. She told everyone she knew about her God: the repair man, the cable guy, the paper boy...anyone who came to her house. I asked her about it one time, and she told me she figured that it was her job. She didn’t get out much so the ones that came to her were the ones she had to tell. *She’s a tough act to follow.*

Mom loved her family. She had a closeness with her siblings that I always envied. I often pondered how, with a family as large as theirs, they all stayed so close. I wondered if the depression years or the fact that they didn’t have much materially or maybe even the disease many of them shared played a big part in it. But I always come back to their shared faith in God as the big key to their closeness.

Mom always found fun things for us kids to do. Not things that cost money or big events but things like: sitting on the front porch swing playing hangman (in our heads); sleeping out on the front porch on a hot summer night; a Halloween party with a “Murder”; or a 4-day monopoly marathon...of course, these were snow days with my best friend snowed in with us! She always made things fun and she continued this with her ten grandchildren. She might not have been able to walk anymore, but she still loved playing with the kids. She was everything from the gas station attendant for all their bikes and “toot-a-pillars” (kiddie cars) to the best caller for a good game of “Sheep, Sheep, Come Home.” She played any game they wanted to play: board games, card games...but her favorite was any word game. She never got the opportunity to play with her eight great grandchildren, but I’m sure she would have done the same for each of them—after she got done hugging and kissing them. *She’s a tough act to follow.*

She was married to my dad, Lloyd Adams, for 39 years. She missed him so much when he passed away that she’d talk to him all the time. I was a little worried for awhile, but I found it was her way of coping with the loss. I really thought she had to come and live with us, but she proved me wrong again. With each little thing that came up,

*More on Page 7*

*This issue of the Deater  
Foundation Newsletter is  
in Memory of*

### *Verna Deater Adams*

*Born November 30, 1928*

*Daughter of*

*Alvin and Ellen Deater*

*Married Lloyd Henry Adams*

*1 Son: Lloyd Russell Adams*

*3 Daughters:*

*Carol Ann Doward*

*Nancy Jean Newcomer*

*Louise Irene Hess*

*10 Grandchildren*

*8 Great Grandchildren*



*Lloyd and Verna Adams*



*Verna, surrounded by children:  
Carol, Bud, Nancy and Louise*

*She’s a tough act  
to follow!*



**DFI**

## Memories of Gram

*Submitted By: Tami Newcomer Murphy*

When it comes to grandmothers, mine was definitely one of the best. My gram was a very special lady, and she had a gift for making all of her grandchildren feel special too. When we were younger, she was always telling us one of her classic fairy tales like Hansel and Gretel or Goldilocks and the Three Bears. Whether it was to entertain us during long car rides home in the backseat of her van or to help us fall asleep while we were spending the night with her, she was always willing to tell us a tale. Even though we had heard them all so many times, she had a way of telling the story that made you feel like you were hearing it for the first time all over again. You could tell that she really loved the stories, but more than that, you could tell that she really loved us.

When my pop-pop died, instead of crumbling under the weight of her loss, my gram showed all of us that life could still go on and gave us an example of what it was like to be strong and independent. She also showed us that living with a disability meant just that...living.

One of my favorite memories of my gram involved a family and

friends Thanksgiving dinner hosted by my girl scout troop when I was about 10 years old. All of the tables were lined up side by side to create a big square around the room so everyone could see each other. My gram was using her scooter chair swiveled around as her seat at the table, so she positioned herself and locked her chair in place. As we were all sitting down to eat, she realized she wasn't close enough to the table, so she asked me to press the lever on her handle bar to move her whole scooter closer to the table. I thought that sounded like something I could handle, but apparently it wasn't. I accidentally pressed the lever too hard and my gram went flying front-first into the table all set with dishes, food, and drinks for the dinner. When I finally let go of the handle, it was way too late...my gram, her scooter, and the table were halfway across the room. The tablecloth and most of what used to be on the table were now on the floor, and my friend's dad was semi-stuck between the table and the wall. Needless to say, everyone saw the whole thing and I had never been so embarrassed in my short life. Everything got really quiet, and I was



waiting for someone to yell at me for slamming my helpless grandmother into a banquet table and ruining the dinner. Instead, I heard my gram start laughing and saying how I gave her one really "wild ride." The tension was broken, everyone laughed, the evening was fun, and I ended up with one great memory. I learned from her that night to try to take life as it comes and not take things too seriously. This is a lesson that I am admittedly still working on, but one that I'm getting better at.

*Continued on Page 7*

## Daily Bread

*—Submitted By: Ellen Deater Burns, Medical Liaison*

I find that I have been pausing and reflecting as I pray that most familiar of all prayers known as "The Lord's Prayer." It is the first request that catches my attention: "Give us this day our daily bread." A simple food supplement, a protein added to the diet, presents a potential for treatment for a debilitating disease or, if not the treatment, further insight into the complex workings of the

chemical make-up of the cells of our bodies. I am thankful for those who are willing to take this food, "for the health and strength of our bodies," as the table prayer goes. I am thankful for the researchers who care about a rare disease and who have devised a study full of promise. I am thankful for the Creator who makes all things possible.



**Ellen Deater Burns**

**LATE BREAKING NEWS!****Clinical Trial of Protein Supplement to Begin in July***Submitted By: Ellen Burns, Medical Liaison*

Members of the Deater family who have been diagnosed with HSAN-1 will have the chance to participate in a remarkable study to determine the pos-

sible effects of a dietary supplement on the effects of the disease.

There are 21 family members known to be diagnosed with HSAN-1.

**Enterprise Rent-A-Car Foundation Grant—Just Ask!***Submitted by: Jon Ellsworth—(Continued from Page 3)*

disease exists but one who doesn't really think about it much. Either way I would encourage EVERY member of our family to look for unique avenues to secure funding. Being able to combat HSAN-1 head on is important and research needs to continue. These uncertain economic times can have an adverse effect on organizations such as the Deater Foundation, but funding has never been more vital.

Ask your company's Human Resources department if there is a fund to draw from for causes like this; or look to see if they have matching programs to charitable organizations. You might be able to double a gift just by asking -- that's what I did, *just asked.*

*The Deater Foundation would like to thank Jon and Enterprise Rent-A-Car Foundation for this generous contribution!*

**Editor's Note:** In addition to working for Enterprise Rent-A-Car, Jon has just recorded a new worship CD.

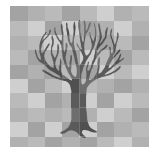
If interested, contact him at: [jkristian99@hotmail.com](mailto:jkristian99@hotmail.com)

**DFI Treasurer's Report (June 1, 2008, to May 31, 2009)***Submitted by: Nancy Newcomer, Treasurer***DFI Statement of Account**

Balance as of 6/1/08	\$45,672.30
<b><u>Income:</u></b>	
Contributions 6/1/08 to 12/31/08	7,510.00
Interest 6/1/08 to 12/31/08	83.70
Contributions 1/1/09 to 5/31/09	2,225.00
Interest 1/1/09 to 5/31/09	11.73
<b><u>Expenses:</u></b>	
September 2008 Mass. General Donation	- 10,000.00
April 2009 Mass. General Donation	- 10,000.00
PayPal Service Charges	- <u>3.90</u>
Balance as of 5/31/09	\$35,498.83



Nancy J. Newcomer  
Treasurer

**DFI**

## She's a Tough Act to Follow"

(Continued from Page 4)

she'd talk to dad and say, "Well, what am I going to do now, Lloyd?" But she always figured something out. *She's a tough act to follow.*

My mom loved to laugh. Everyone that knew her well knew her sense of humor was her most endearing quality. She was a great story-teller, too. She loved to tell stories that made her and everyone else laugh...even if it was at her expense. She told the story of how she tried to put a stamp on a letter she had tapped out on Dad's old electric typewriter. She had used a pencil turned eraser side down to tap out each letter. Then she tried to use the eraser to get a stamp. It worked! She licked it and then it just disappeared. It was stuck on one hand...then the other hand...and then it disappeared again! Just then the doorbell rang. It was a friend of hers from church. They had a nice visit, and when her friend went to leave, she asked politely: "Verna, why do you have a stamp on your forehead?" Mom roared with laughter as she explained. She told that story many times...even in an MD support group meeting...and she roared with laughter each time. She never let her disabilities get her down. Her sense of humor always prevailed. *She's a tough act to follow.*

I find myself really missing her now and many tears have dropped on the keyboard as I've typed this. There is so much more I could say, but take this with you: Mom's life has taught me to keep God first in my life; love my family and friends and keep them close; and never let the things of this life get me down because as she often said: "I am going to run with the angels someday"; and "always, always laugh at yourself 'cause everybody else is already laughing."

*She's a tough act to follow.*

## Gift Certificate Idea

—Submitted by Rory Robb Deater



*For Your Consideration:*

*A gift to Deater Foundation, Inc. may be the perfect gift for someone, to honor someone, to remember someone.*

*Give a donation:*

- \* *To celebrate a birthday*
- \* *In honor of Mother's Day or Father's Day, for the parent with HSN-1 (or without)*
- \* *In appreciation*
- \* *For Christmas, for the hard-to buy-for-person*
- \* *In memoriam*

*You may request a certificate, suitable for gift giving, to present to the recipient. To do so, contact Nancy Newcomer, Treasurer, P. O. Box 255, White Deer, PA 17887 or email her at: njnewcomer@yahoo.com*

## Memories of Gram (Continued from Page 5)

Submitted By: Tami Newcomer Murphy

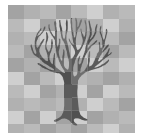
For me personally, even though my gram has been gone for almost 12 years now, the memories still seem so fresh and I definitely find myself thinking about her often. I've taken valuable lessons from the 17 years I spent with her, and I'm sure I will continue to look back at her life and the example she provided for strength and wisdom for years to come. Like I said, my gram was definitely one of the best, and somehow I was one of the lucky ones that got to have her as mine.

**Not on our Mailing List? New Address?**

Notify: Carol Dorward  
at [tcdor34@enter.net](mailto:tcdor34@enter.net)

or [info@deaterfoundation.org](mailto:info@deaterfoundation.org)

of your current home address and/or email address



**DFI**



P. O. Box 255  
White Deer, PA 17887



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We're on the Web!  
[deaterfoundation.org](http://deaterfoundation.org)

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Remember that your  
contributions to DFI are tax  
deductible.

*Mail contributions to:  
Deater Foundation, Inc.  
c/o Mrs. Nancy Newcomer  
P. O. Box 255  
White Deer, PA 17887*

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## LATE BREAKING NEWS! *(Continued from Page 6)*

### Clinical Trial of Protein Supplement to Begin in July

*Submitted By: Ellen Burns, Medical Liaison*

On July 19, 2009, the day following the Deater Family reunion, these family members can gather to give blood and receive a protein supplement to take for a 10-week period. During this time, participants will also be asked to keep a food diary. **The more people who participate in the study, the greater the reliability of the study.** A few people will be asked to continue to participate in a longer-range study.

The premise of this study is that in the disease HSAN-1 cells that should take up the protein serine also bond with other proteins. It is thought that by providing the cells of the body (especially nerve cells) with generous amounts of serine, cells will be more likely to take in this protein. In this way, wrong proteins will be "crowded out" of the cellular connection. There are NO PROMISES that this supplement

will become a treatment or cure. BUT the mice with the HSAN-1 gene defect responded positively to this supplement.

Those with the disease have an opportunity to contribute, as generations have before, to unlock the mystery of the "Deater Disease." Their willing participation may pave the way to eradicate the symptoms of this disease in future generations. Those of us without the disease can contribute support through our prayers and finances to make this study a success!



**DFI**