

Deater Foundation, Inc.

Newsletter

The Deater Foundation, the Deater Family, and Human Trials

Submitted by: Ellen Deater Burns, Medical Liaison

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The Deater Family has been involved in human research for Hereditary Sensory and Autonomic Neuropathy type 1 (HSAN1) since Harvey and Russell Deater presented themselves for study at the Thomas Jefferson Hospital in Philadelphia in 1937. The research has gone down many paths and some dark alleys since then.

In 2000 there was a major breakthrough in determining the basis of the disease when a specific gene mutation was identified as the cause of HSAN1. The gene was known to encode an enzyme, serine palmitoyl transferase; that is the first step in synthesizing a fatty substance known as ceramide that then is involved in the synthesis of another fatty substance known as sphingolipids. Dr. Garth Nicholson and his team from Australia, and Dr. Robert Brown, Jr. and Dr. Khemissa Bejaoui in Boston published the results of this discovery in 2001. The Deater Foundation supported the work of Drs. Brown and Bejaoui.

In subsequent years, much more has been learned about the cellular pathology of HSAN1. At a Deater Foundation sponsored international conference in 2008, Dr. Thorsten Hornemann proposed that a toxic property, resulting from defective cell receptors, was causing elevations of atypical sphingolipids and the symptoms of HSAN1. Dr. Eichler devised a mouse study that tested this theory. The results were so striking that a human trial followed in 2009, conducted exclusively on members of the Deater family. The results of this trial were also promising.

The researchers then sought to create a study that would prove conclusively, one

way or another, the theory that the serine receptors in the cells of persons with HSAN1 are able to bind with amino acids (building blocks of protein) other than serine, with toxic results. A three-pronged approach was devised: a second international conference with participants who can move the research along—especially researchers working with other HSAN1 families; compiling a “natural history of the disease” with anecdotal reporting and definitive objective testing; and funding to continue and expand the research.

In February 2010 another conference was convened. Dr. Hornemann advocated for action to test the hypothesis. Dr. Brown and Dr. Eichler determined that the prudent approach was to methodically examine volunteer members of the family at specified intervals with a barrage of objective tests. Deater family members began testing in late spring and early summer at both Massachusetts General Hospital (MGH) and at the University of Massachusetts (UMass).

In August, Dr. Eichler met with Dr. Mary Reilly, who works with about 40 HSAN1 patients in England, to enlist her partnership in studies. Collaboration such as this would help overcome the criticism and funding barriers of the National Institutes of Health (NIH), that the current studies involve a small number of patients from only one (Deater) family. Dr. Eichler attended the Clinical Trials Methods



Ellen Deater Burns
Medical Liaison

DFI File Photo

**Reunion
Reminder!**

Hope to see you
at the 69th
Deater Reunion
on July 16, 2011
at
Butler's property.

(Continued on Page 2)

DFI Receives Grant from Enterprise Holdings Foundation

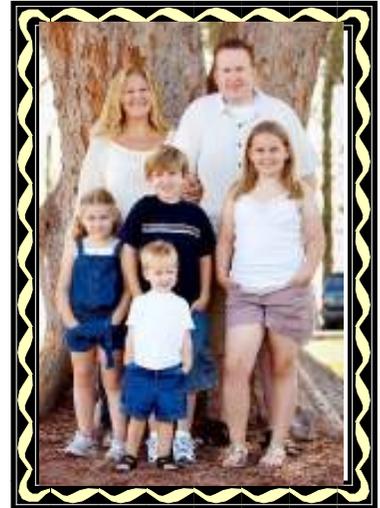
—Submitted by: Carol Dorward

The Deater Foundation, Inc. (DFI) headquartered in northeast Pennsylvania, was recently awarded a \$3,000 grant from Enterprise Holdings Foundation. Deater Foundation, Inc. is a non-profit organization that funds medical research for HSAN1, a hereditary, debilitating, disease that affects the nerves and muscles. HSAN1 has affected families in the United States and other countries for generations.

Jon Ellsworth, who has worked for Enterprise Rent-A-Car for the past fourteen years, submitted the application earlier this year and was notified of the award in late May 2011. This is the fifth time that Jon has filed the application with his company

and the fifth consecutive year that Enterprise has awarded a grant to DFI.

Jon says that he is proud to work for a company that gives back to its employees through generous philanthropic gestures for causes such as the medical research that the Deater Foundation supports. Deater Foundation, Inc. has helped to make HSAN1 research possible for more than twenty years now, and, combined with other funding sources (such as this generous grant from Enterprise Holdings Foundation), is seeing much progress in the quest for finding a viable treatment for HSAN1. For more information about HSAN1 and/or the DFI organization, go to deaterfoundation.org.



*Jon Ellsworth and Family
—Hope, Alexis, Japeth,
Abigail and Josiah—
[Photo used with Permission]*

Editor's Note: Deater Foundation, Inc. is grateful to Jon Ellsworth for continuing to pursue this grant year after year. We applaud you for your efforts. Thank you, Jon!

Deater Foundation, Inc. is equally grateful to Enterprise Rent-A-Car and the Enterprise Holdings Foundation for their support of DFI. Deater Foundation is honored to know that Enterprise Rent-A-Car and the Enterprise Holdings Foundation have considered DFI to be worthy of their support and generosity. Deater Foundation is committed to being good stewards of all gifts in order to expedite the medical research for a treatment/cure for HSAN1.

The Deater Foundation, the Deater Family, and Human Trials

—(Continued from Page 1)—Submitted by: Ellen D. Deater Burns, Medical Liaison

Course where he developed a randomized, double-blind, placebo controlled clinical trial protocol. The protocol was well conceived and well written. Drs. Brown and Eichler were eager to move forward. Dr. Eichler submitted a request to the Deater Foundation for \$30,000 “seed money” for the L-serine supplement and a part time assistant to “jump start” the study and to “enroll first patients without delays.”

The \$30,000 request closely matched the resources of the Deater Foundation. The officers discussed the pros and cons of putting all the financial eggs in one basket and concluded that this proposal was the bold trial we were hoping for. In January, 2011 the Deater Foundation sent a check for the requested amount which Dr. Eichler

“labeled for the serine study” at MGH.

Concurrently, a research group in Belgium published the discovery of another gene mutation seeming to cause a severe, early onset form of HSAN1. Elevations in atypical sphingolipids were found in these patients, consistent with the work of the Boston research team.

In 2011 there has been additional progress:

√The research team submitted and received an IND (investigational new drug) designation for L-serine from the Federal Drug Administration (FDA)

√The team also submitted a grant request to the FDA for the clinical study (expecting a response in July or August).

√Dr. Eichler did get an RO1 (NIH Research Project Grant Program) funding to continue the animal work on HSAN1.

√The human RO1 got a good score but did not get funded. Drs. Brown and Eichler may re-submit in the fall.

√Dr. Eichler presented study data on L-serine in HSAN1 at the American Academy of Neurology in Honolulu; it was chosen for the Scientific Highlights Plenary Session.

Continued on Page 3



DFI

Pictures from Last Year's 68th Deater Reunion

July 19, 2010—Submitted by: Carol Dorward



DFI File Photos

Are you able to name all the individuals that you see in the photos included with this article? If so, you are to be commended. I have not been able to keep up with the names of all of the second and third cousins.

This year, I would like to take some family group photos. Maybe most, if not all of your family, will be attending this year. This opportunity will, of course, be informal and voluntary. If you like this idea, please get your family group together

and let me know when you are ready! I'll do my best to capture your family and will be happy to send you the file(s) via email. Just be sure that I have your email address.

This year's event is the 69th Deater Family Reunion. We'll be meeting at the Butler property again on July 16, 2011. I plan to be there, the Lord willing. How about you?

Mark your calendar for this year's reunion: July 16, 2011



The Deater Foundation, the Deater Family, and Human Trials

—(Continued from Page 2)—Submitted by: Ellen D. Deater Burns, Medical Liaison

√Dr. Eichler continues to work on the natural history of HSAN1 based on the Deater surveys and in collaboration with Dr. Mary Reilly and her group in the UK to better understand the progression of the disease.

√Dr. Eichler will be presenting some of his findings at the Peripheral Neuropathy Society Meeting this summer.

√At this writing, one year follow up studies have been done on some of the participants in the MGH/UMass study. They will be completed in June.

Dr. Eichler's clinical study protocol was based to some extent on NIH funding guidelines. Re-application will need

to be made for that funding and it is not guaranteed. NIH guidelines call for randomization and a placebo (non-treated) group. One member of the 6 person group tested so far has been receiving supplementation. Others are eager to begin. Good baseline data has been established. The original randomized, double-blind, placebo controlled study remains the ideal, but an interim pilot study of the 6 people can be done at a lower cost, with minor modification of the study proposal before the Institutional Review Boards at both MGH and UMass, until the larger, more extensive study can be conducted.

At a meeting on May 29, 2011, Dr. Brown and Dr. Eichler both reaffirmed their commitment to the Deater Family. They believe serine supplementation is

at least part of the answer to the HSAN1 symptoms, although it may not be the whole answer. They believe that the time has come to move forward. We are confident that there are answers at the end of this road.

We are confident that there are answers at the end of this road.
—Ellen D. Burns



DFI

A Tribute to Beulah Deater Womer

—Submitted by: (Reverend) Rick Womer

When I think of my mom and how I will remember her (*as well as how I am certain she would like to be remembered*) it would begin with **happiness**. She saw the potential of good or enjoyment in nearly every situation we confronted, be it in our lives or the lives of friends and relatives. It made for a forgiving atmosphere as well as one that overlooked faults. We laughed a lot, at the simplest of things and many times at more serious happenstances that passed over the great danger point. (*You can ask her about the time when I was learning to drive and fell out of the door turning a corner to fast. Ha, ha, ha, she will laugh!*) Growing up with that influence I never considered our family disease a curse or blessing, but a challenge to be reckoned with. This was very much the same as other challenges she encouraged me (*and many of you, too*) to face.

Music was an integral part of her life. It was one of her spiritual connections to God; it gave way for a camaraderie of family

gatherings and became an encouragement for others to use one's talents. Music was for fun, fellowship, celebration, recovery, reflection, honor and especially worship.

Lastly, I honor her **spiritual dedication** toward prayer and the Word of God (the Bible). She still looks for what God wants, to teach her, change in her, and to better minister encouragement to others. I am still very moved by a scene that was repeated many times of mom in prayer as she was working around the house (*for some reason especially while she was doing dishes*) and becoming greatly burdened and would go to find a place to kneel in prayerful intercession. [Many of us were (*and still are*) the recipients of those prayers, and we may exist because of them.] If I can live like this example my mom set, I will not only be blessed, but I will be a blessing to others as well. Thank you mom!

A Tribute to Gram Womer

—Submitted by: Trisha Womer

Everyone admires a grandmother for her cooking.

Smells of baked goods always fill her home.

Though for mine; that's nothing.

She has a personality of her own.

A God fearing woman from the time she was young,

And a faithful grandmother to me when I was born.

She knows life can be hard and very fun.

I know she is thankful for the sun every morn.

My grandmother is someone I admire.
She knows how to laugh, love, and live.
I won't forget her humor,
Nor the many spirits she could lift.

There are many memories I have of my grandmother. I am pleased to recall them to write her a tribute, but one thing in particular stood out to me. She wasn't one to spoil her grandchildren rotten; rather she taught us many good lessons. Another thing is that she always trusted in God. That faith is something that I believe will be a memory the rest of my life. I love my grandmother, and every memory I have of her.

—Tricia Womer

There are more tributes on Page 5...

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

Beulah Deater Womer



Beulah Deater Womer

*Vintage Photos Courtesy of Becky
Montross Baker and Anita Koziol*

Born

May 18, 1933

*(the 12th child of
Alvin and Ellen Deater)*

Married

Elwood Wayne Womer

October 14, 1951

They had two children:

Richard Wayne Womer

Alvin Elwood Womer



DFI

Grandma's Tribute

—Submitted by: *Melissa Womer Wilbanks*

My Grandma . . .

Christmas cookies! The best molasses cookies in the world! Chocolate cake with white icing—homemade! "Maneggs" [*mayonnaise*] and sugar sandwiches! Cheese! (*Thus my nick-name—Missy Mouse.*) The "trying to get me to be quiet" games! Swimming in the "crick"! Going for walks! D.V.B.S. Sunday School! Playing the piano and keyboard (*despite any handicap*)! Singing church songs and silly songs! Whistling! Bible verses! Family, visiting family, reunions! Games, cards, Sorry, Dominoes! Prayer! Provision! Blessing!

So many wonderful memories and amazingly respectable attributes to be able to sum up in this little slot. She has been through and seen some really intense situations and times. She has endured hardships that would break down and crush many of the strongest men, women, and Christians. Her understanding that no matter the horribleness of the situation you have to keep reaching for God's hope until you can get a hold on it again. She lets God's hope so thrive in her that her positive attitude makes most pale in comparison.



Now, being married and understanding the whole "becoming one flesh" concept, my grandma and grandpa together have been such a strong influence in my life and my family's lives. The testimony of their lives, standing strong for each other and with each other, and working together to get things accomplished have provided us valuable lessons in how to live our lives. Their prayers for us, their encouraging conversations with us, and their help, provision and blessing on us have inspired us greatly.

Grandma and Grandpa, we pray for God's continued blessing on and in your lives! We love you!

—*Shane, Melissa,
Gabriel, Kara, and Chloe Wilbanks*



*DFI Photo Files
Above, Left and Right*



A Tribute to Gram Womer

—Submitted by: *Patrick Womer*

My Grandma is special to me because of the love and care she has given me all my life. She has shown me God's love and the blessings of family. Her joy has always been uplifting, and the passion she has for her family and God is an inspiration to us all!

—*Patrick Womer*

For your information:

This "In Honor of Beulah Deater Womer" section is the final installment of this column in our newsletter. Over the past twelve years, the "in memory/honor of" column has been dedicated to one of the twelve children of Alvin and Ellen Deater. Beulah was the baby of the family or the "caboose" at the end of this family train, bringing this column to closure with this issue.

—*The Editor*

DFI Treasury—On the Road to Recovery

Submitted by: Carol Dorward, President/Secretary

Having depleted our treasury in January 2011, investing \$30,000 to support the medical research for HSAN1 that is being done through Dr. Brown's and Dr. Eichler's efforts as they study the effects of serine supplementation as a viable treatment of HSAN1, I am happy to report that we are on the road to recovery.

As of the end of April 2011, our treasurer, Nancy Newcomer, reported that slightly more than \$5,000 was in our account at that time.

We want to thank each of you who responded to our letter solicitation campaign. We appreciate your willingness to "step up to the plate" at such as time as this. We are committed to continue to support the medical research of HSAN1 as we long for an effective treatment, especially for the sake of future generations.

We are not out of the woods yet, *so to speak*, where our treasury is concerned. So anything that you can do to support our efforts would be appreciated. The Enterprise grant (See Page 2) will certainly give our treasury a nice boost.

Some have asked, "What more can we do to help?" Perhaps, some of you would be interested in holding a fundraiser to benefit DFI—a car

wash, a bake sale, a DFI walk/run, a yard/garage sale, etc. You would need to organize the event, execute it, take out of the profits the expenses you incurred, and send the proceeds to DFI. Send photos and a brief summary of your event so that I can consider an article for our next newsletter about the successes and experiences of our volunteers in this new adventure. Email me at carol_dorward34@yahoo.com.

Something else that our "senior" family members could consider is making **Deater Foundation, Inc.** a beneficiary in your will or estate planning.

It may be that we will soon have a "marketing" flyer about DFI and what it does that may be helpful for you to share with others, especially at events like a yard/sale, bake sale, etc. We are working on it. We plan to include logos, flyers, etc. on our Deater Foundation website in the near future. That way, you'll be able to download and print what you need for upcoming events. Make sure you check out our website over the next few weeks, as we are in the process of updating it.

Thanks again for all that you do to unify our family in supporting the quest for a treatment/cure for HSAN1.



Carol Dorward
President/Secretary

I thank each of you who "stepped up to the plate" and responded to our letter solicitation campaign earlier this year. "
—Carol

DFI Treasurer's Report (June 1, 2010 to May 31, 2011)

Submitted by: Nancy Newcomer, Treasurer

DFI Statement of Account

Balance as of 6/1/10	\$15,212.49
<u>Income:</u>	
Contributions 6/1/10 to 12/31/10	15,555.68
Interest 6/1/10 to 12/31/10	11.41
Contributions 1/1/11 to 5/31/11	7,310.00
Interest 1/1/11 to 5/31/11	2.19
<u>Expenses:</u>	
January 2011 Massachusetts General Donation	- 30,000.00
Postage Stamps	- 50.00
Network for Good Service Charges	- 21.82
PayPal Service Charges	- 10.44
Balance as of 5/31/11	\$8,009.51



Nancy J. Newcomer
Treasurer



DFI

Birth Announcement

Dear Friends and Family,

We are very excited and relieved to announce the arrival of Soren Hugo Eichler.

He was born Thursday evening, January 27th, 2011, weighing a respectable 6 lbs. and 9 oz. He is healthy and vigorous and ready to keep pace with his big brother Kieran. Let us hope his parents can do the same.

—Florian and April



*The Eichler's
--Florian, April, Kieran and Soren*

Recycling of Old Cell Phones and Printer Cartridges to Benefit DFI

—Submitted by: Tami Newcomer Murphy

Help Deater Foundation, Inc. by donating your used cell phones and empty laser and inkjet printer cartridges!

Recycling these unwanted items can help the environment as well as raise money for DFI. You can also check with your local businesses, place of employment, school, church, etc. about donating their unwanted items as well. All brands and models accepted.

Contact Tami Murphy: (610) 873-1310 or newcomert@hotmail.com for more info...and **plan on bringing your items to the reunion in July!** [For those in the Noxen area, items collected throughout the remainder of the year can be dropped off at Boot & Pickle Womer's house at 82 Tulip Road, Noxen PA.]



DFI T-Shirt Fundraiser

—Submitted by: Tami Newcomer Murphy

DFI logo t-shirts are now on sale with proceeds to benefit the Deater Foundation! Cost is \$20, and limited quantities/sizes will be available at the reunion. If interested, contact Tami.Murphy (610) 873-1310.



*Tami N. Murphy, Vice President
and her daughter, Averi*



DFI

Gift Certificate Reminder

—Submitted by Rory Robb Deater



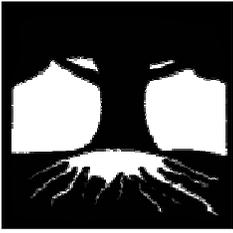
For Your Consideration:

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 HSAN1 (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 by contacting **Nancy Newcomer, Treasurer, P. O. Box 255, White Deer, PA 17887** or email her at: njnewcomer@yahoo.com



DFI

**Deater Foundation, Inc.
P. O. Box 255
White Deer, PA 17887**

*Your contributions
to DFI are
tax deductible.*

*Mail contributions to:
Deater Foundation, Inc.
P. O. Box 255
White Deer, PA 17887*

We are on the Web!
deaterfoundation.org

**Join our Facebook Group and Cause
By searching for Deater Foundation**

Evening Prayer

Submitted by: Ellen Deater Burns, Medical Liaison

Sometimes it is hard to keep the faith when things seem to be at a standstill.

Sometimes it is hard to stay optimistic when symptoms progress.

Sometimes it is hard to always be the “pusher”; the burr under the saddle; the pest.

Sometimes it is hard to endure the pain—real physical pain and anticipated loss.

Sometimes it is hard to look back over the years at failed hopes.

Sometimes it is hard to keep fighting.

Always it is good to know there is something worth fighting for.

Always it is good to be supported by friends.

Always it is good to realize hope survives the darkest moments.

Always it is good to have family by your side—pulling, pushing, lifting.

Always it is good to say no one walks alone.

Always it is good to be surrounded by love.

Not on our Mailing List? New Address?

Notify: Carol Dorward

at carol_dorward34@yahoo.com

or info@deaterfoundation.org

of your current home address and/or email address



DFI