

# HDAT

THE HUNTINGTON'S DISEASE ASSOC. OF TEXAS

MARCH 2001

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## Scientists Use Jellyfish Protein in Search for Huntington's Drug

Sept. 12, 2000

San Diego, Cal. (Reuters)

- Aurora Biosciences Corporation, helped by a glowing chemical found in some jellyfish, Tuesday said it will collaborate with the Hereditary Disease Foundation in developing tests to help researchers find treatments for HD. Aurora, the San Diego based maker of drug discovery equipment and systems, said it would develop high-speed, industrial scale tests for thousands of potential drug compounds by using the green fluorescent protein (GFP) technology. The protein is used by a species of jellyfish to evade attackers by giving off a green fluorescent flash. Aurora would fuse a new gene with a brighter version of the flash to portions of the defective gene causing Huntington's in the search for a treatment.

The company's research would involve an alliance with the foundation, a non-profit group which led the long period research that culminated in the identification and cloning of the gene behind Huntington's in 1993. The group

has launched a Cure Huntington's initiative to speed up the hunt for a cure. Using GFP and other drug discovery technology, Aurora would help identify compounds with the potential to modify the protein involved in Huntington's disease, a genetic, so far incurable disorder afflicting about 35,000 to 50,000 people in the United States. The inherited disease, which typically appears in adulthood, causes the death of vital nerve cells in a part of the brain, resulting in involuntary movements of the body, coordination loss and cognitive difficulties.

After culling chemicals with potential as drugs, Aurora would figure out their medicinal properties and collaborate with academic researchers to test their efficacy in animal studies, the company said. "We are confident in Aurora's ability to explore new avenues that could lead to an effective treatment in the area of Huntington's disease," said Ethan Signer, Executive Director of the foundation's Cure Huntington's Disease Initiative. "It is our hope that Aurora's cutting-edge technologies and

expertise will further our scientific knowledge not only of this disease, but of other related genetic and neurological disorders," he said.

Aurora said that while the genetics underlying Huntington's disease and related disorders were well-documented, the cellular and molecular biology of these diseases was just beginning to be grasped. Any potential compounds effective against the protein involved in Huntington's were "quite likely to be effective in treating illnesses, such as Parkinson's disease, Alzheimer's disease, schizophrenia and Lou Gehrig's disease," Aurora said.

*HUNTINGTON'S DISEASE ADVOCACY CENTER is an excellent web site that list the most recent HD related articles from newspapers, periodicals and journals.*

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# Networking News: Helpful Insights

*I was excited and deeply honored when Peggy asked me to write something for our HD newsletter! I was diagnosed with Huntington's Disease seven years ago and as a survivor of HD, I would very much like to share some insight that has really been helpful for me . . . and my deepest wish is that it will also help you along this very difficult path we are on.*

*I believe it's so important to live your life in "hope". That's exactly why I've decided to go back to school and finish my degree. Hope is not denial, though. After all, I did watch three of my beloved family members die of HD. So, I would never underestimate the severity of this disease. However, as a result of their tragic demise, as well my own struggles with this disease I've gained a lot of very valuable insight and I thought I would share it with you.*

1.) First of all, be very, very careful with anything that may be harmful to your already fragile health. Things like prescription drugs or alcohol can often do a lot more harm than good.

2.) Eat as healthily as you can. That does not mean count calories or limit your intake in any way . . . because people with HD often need a lot more food. Just eat plenty of things like fruits and vegetables and all-natural products. I truly believe eating well can actually help the body to fight off any disease.

3.) Get plenty of rest . . . the body often heals itself in it's sleep. I know it's not always easy, but

your health will probably quite noticeably decline without it.

4.) I know this one may sound odd, but I have found it to nonetheless true. Watch out for negative thoughts or negative energy of any kind . . . whether they be your own or those of others. You would be surprised at just how much damage they can do! Like the great healers have been trying to tell us, there is a direct connection between the body and the mind. So, I try to meditate whenever I find myself in that situation. That has really helped to re-center me and put me back in a positive direction.

5.) Always keep your hopes and dreams alive no matter how bleak the future may seem. It's that link between the body and mind again that makes this so important. When the mind goes, the body follows. So, if you can, keep your spirits up.

6.) Believe in a higher power, whatever religious affiliation you choose is fine. It just helps so much when we're dealing with issues like death and disability. Knowing that you're not alone and that there is a higher purpose to it all that we're just not yet aware of, can be so helpful.

7.) Set simple achievable goals for yourself and take one small step at a time one day at a time towards achieving them. This gives you a reason to get up every morning. And it can be quite exciting when your seemingly small goals have turned into great, big one's . . . like going back to school was for me!

Start very simple with something like lifting your leg , then build on that achievement to something like walking across the room.

8.) Last, but not least, listen to your heart and your intuition. You will find that you, and perhaps only you, know exactly what's right for you, whether it be health or goal oriented. So, listen to that gut feeling you have and find the path that works for you and follow it somewhat religiously.

All of you who also suffer from this disease are like my extended family and my love goes out to you all!

Katherine R. Edson-Dies

*We are most grateful to Katherine for taking time to share valuable information with us.*

**Don't Forget!  
HDAT plays  
BINGO at  
Treasure Island Bingo**

2400 E. Oltorf  
every Thursday, Friday,  
and Saturday  
at 12 noon.  
Great Cash prizes.  
Come support us  
and have some fun.

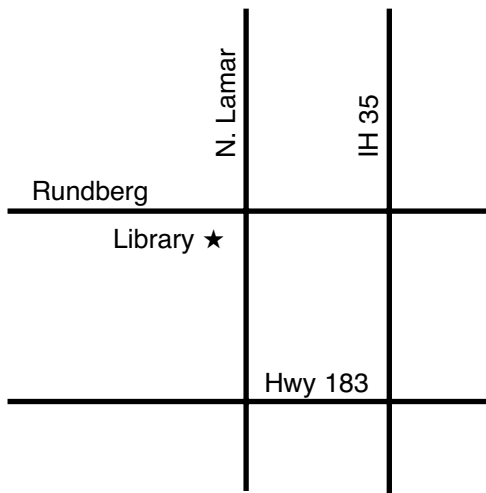
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levels of particular hormones or growth factors, perhaps. If we can identify the specific molecules responsible for running's effects, those molecules should point to new drug strategies to treat A-T and other neurodegenerative diseases."

The current study builds on work directed by Salk Professor and co-author Fred Gage, showing that running leads to increased brain cell numbers in normal adult mice, elderly "senior citizen" mice and a genetically "slow-learning" strain of mice. Gage's studies showing that new cell growth occurs also in human brains suggests the boosting effects of running may occur in people as well.

## Support Group Meetings Scheduled for April 22 and April 29

Our next Support Group Meetings are scheduled for Sundays, April 22 and 29 from 3 - 5:30 pm. We will be sending out reminders next month and announcing our speakers. Little Walnut Library, Lamar at Rundberg. See you there.



### Everyone turned out for the *HDAT Holiday Party* in December



*It was a special time as we all enjoyed greeting the entire families of so many of our friends. Former Board member Nellie Carroll chatted with guests. Lots of laughter and great food was had by all.*

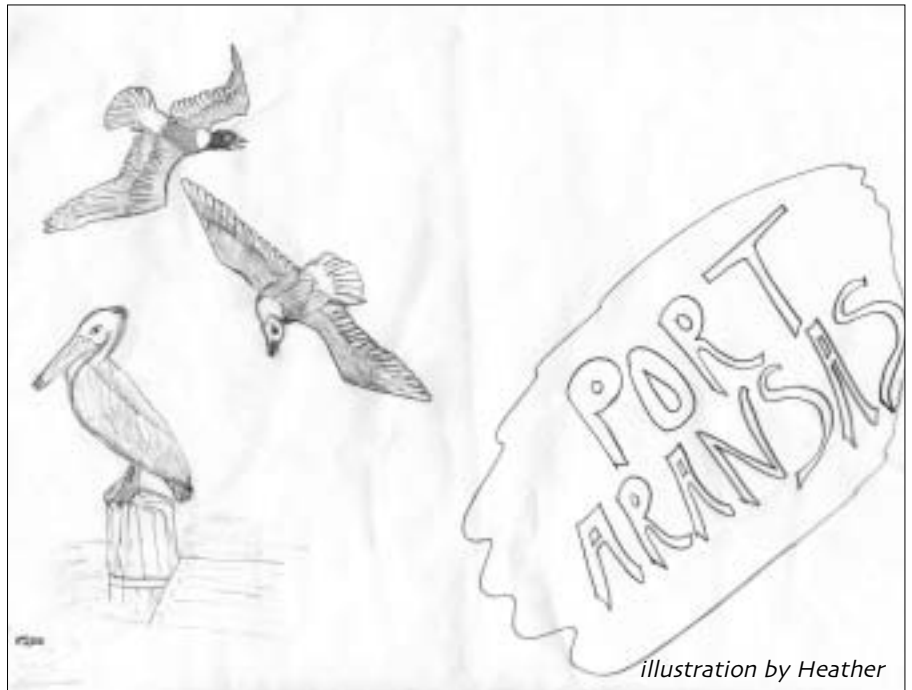
## They Said It Couldn't Be Done!

My husband, Kirk has late stage Huntington's and my 15 yr. old daughter, Heather has Juvenile HD., and my 10 yr. old daughter, Bonnie is at risk. Kirk has always said that he was living with HD, not dying from it. We have done more since Kirk's diagnosis than we've done in years. It is always an adventure when we go out.

Our last big adventure was in July. We went to the coast. Yes, the Stice family went to Port Aransas! As you can imagine we had to take all kinds of things along. The shower chair, suction pump, extra clothes, lots of diapers, a raised potty seat, all of our clothes, a friend to watch the kids, and my brother. Somehow we all fit into our van. it wasn't easy. The rear doors almost didn't close! At last we were off.

A funny thing happened along the way. the kids were watching a movie that had a police siren in it. I didn't realize this and told them to turn down the TV so I could listen for the emergency vehicle. I was looking all around and wondering where it was and if it was behind us. I knew I wasn't speeding. The kids had a good laugh at my expense over that one.

At last we got to Port Aransas. This was amazing in itself. The kids hadn't killed each other, Kirk hadn't had an accident in his pants, we didn't get lost, the van didn't break down, and we were there! It was so hot outside. I wanted Kirk to stay in the a/c and



relax. No, he had to go out to the beach. We had umbrellas, blankets, ice chests, everything you could think of. And yes, his wheelchair. I learned a lesson that day. A wheelchair will get stuck in the sand on the beach. This was quite entertaining for the other beach goers. I can't blame them. We were laughing along with them.

What a site we were! I thought Kirk would be content sitting under the umbrella, enjoying the cool breeze, and watching the kids. No, he had to go in the water. I walked him into the water and went out only as far as I felt safe with him. Which wasn't very far. Was Kirk happy with this? No, he wanted to go out farther. So we did. The waves were so big and strong. I told Kirk to close his mouth whenever a wave came so he

wouldn't swallow water. Did he do this? No, he opened his mouth and laughed at every wave.

Then he saw the kids with these Boogie Boards that they rented. Kirk wanted to try it. I said NO! Did Kirk listen to me? No, he got on a Boogie Board. I tried to hold on to him. Then a huge wave came along and there went Kirk. I was screaming at our friend and the kids to catch Kirk. He traveled pretty far on that wave. Laughing and swallowing water the whole way. When I finally caught up to him, I marched him out of the water. All Kirk could do was laugh and grrr at me for taking him out of the water.

Back at the motel, he wouldn't go to our room until he went for a swim in the pool. UGH! He was going to get all the fun he could

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out of this trip. I was so stressed that I thought I was going to explode. Once in our room, I noticed that Kirk was still beat red and hot even after a shower. Yes, Kirk had a high fever. He was not sunburned, just sick. I knew that our doctor was on call that week, so I called him long distance. Thank goodness for free long distance on the cell phone. He said that Kirk was most likely overheated, and to keep him calm and cool for the rest of the day. Did Kirk do this? No, he insisted on going out to eat for dinner. I just knew that this trip was going to kill Kirk!

All I could think about was all the people that told me we were crazy to even go on the trip. Then I looked at Kirk and the kids. The fun and the memories that this trip was providing were priceless. Kirk was doing better and having the time of his life. We were living with Huntington's. The next three days were so much fun. A lot of work, but a lot of fun. Maybe someday I will finish telling ya'll about our Coastal Adventure.

The thing that I want anyone who reads this to understand is this: Don't let HD or any other disease keep you from living life to it's fullest. It is all too tempting to sit around feeling sorry for yourself or to put your loved one in a "glass bottle" to protect them. With all the odds against Kirk, we still go on "adventures", and love every minute of every one of them. Our next adventure? Kirk wants to see snow! UGH!

## Running Boosts Brain Cell Numbers In Neurodegenerative Disease Model

March 2001

La Jolla, CA - Scientists at The Salk Institute have shown that running can boost brain cell survival in animals with neurodegenerative disease. "The results suggest that exercise might delay the onset and progression of some neurodegenerative disease," said Carolee Barlow, a Salk assistant professor and lead author of the study, published in the current issue of *Genes and Development*.

It also appears that the miles logged correlate directly with the numbers of increased cells. In the study, the Salk team monitored the number of revolutions each mouse lapped on a running wheel placed in its cage. "It's almost as if they were wearing pedometers," said Barlow. "And those that ran more grew more cells." The mice in the study were missing a gene, *Atm*, known to be mutated in the disorder Ataxia-telangiectasia, commonly referred to as A-T. Caused by the death of brain cells, A-T is characterized by a progressive loss of motor control that typically confines patients to wheelchairs by adolescence. The death cell appears first in the cerebellum, the brain region directing movement, but occurs throughout the brain. "A-T is rare," said Barlow, "but at the cellular level it shares properties with more common diseases such as Alzheimer's.

For example, we know that brain cells in both conditions are highly susceptible to oxidative stress, damage from what are commonly

called free radicals." She added that the current study demonstrated running's brain-boosting effects in the hippocampus, a region of the brain linked to learning and memory and known to be affected by Alzheimer's disease. "Therefore, what we can learn from the A-T model mouse may very well be relevant to other neurodegenerative conditions," said Barlow.

In the study, both normal and A-T mice were given running wheels to use for several weeks, at the end of which their brains were monitored for new cells and compared to non-running counterparts. The investigators found that running didn't increase the number of new brain cells in the A-T mice; however, the exercise did have a significant impact on cell survival. "In the sedentary A-T mice," said Barlow, "it appears that most newly born brain cells die. We don't understand that fully, but it probably has something to do with an inability to cope with oxidative stress. "Running appears to 'rescue' many of these cells that would otherwise die. It suggests that staying active may help delay progression of neurodegenerative conditions."

Barlow added that the experiments were carried out in young mice, since A-T mice, like their human counterparts, experience mobility loss as they age. "What we need to do now is figure out what exercise is doing to help these brain cells survive," said Barlow. "It must be altering brain chemistry-altering

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## INFORMATION AND MORE

Stephany Myers is an insurance agent who knows and understands HD. She also know life - health - auto - and homeowners insurance. She can offer special attention to HD families. 248-1998

David Pharis, LMSW-ACP, our HDAT Social Worker is available for case management services, social services referrals and assistance, medical appointments, and home visits. 453-2155.

HDAT has necklaces available for HD persons. These necklaces give vital information such as Doctors name and emergency names and phone numbers. They are available at our office at no charge.

## Two Newest Publications available

Two of the newest publications about HD, published last year, have proved to be very valuable to HD families as well as professionals. *Understanding Behavior in HD* by Jane Paulsen addresses issues relating to the cognitive behavior changes that occur during the different stages of HD. It also includes

information about difficult behaviors, approaches to solving problem behaviors, and common behavior concerns in HD.

*A Caregivers Handbook to Advanced Stage Huntington's Disease* by Jim Pollard, includes information about communication, swallowing difficulties,

preventing falls, exercise and fitness, and medical issues. These books are available through our office at no charge. We also have pamphlets about swallowing, nutrition, therapy, and caregiving. We also have videos on HD for families and facilities.