

HAPPe - News

The Huntington's Asymptomatic Positive People newsheet May 2001

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Website: coming soon



A big month...

Well, exciting news for the Huntington's community from John Hopkins University research over the last month which you can check out in the Research notes. Let's hope things continue to develop.

Speaking of research and developments, I just finished reading *Mapping Fate: A Memoir of Family, Risk and Genetic Research* by Alice Wexler. Alice Wexler's mother and a number of other family members had Huntington's, making Alice and her sister at-risk. Her sister Nancy and her father both become involved in Huntington's research and support and the book tracks the evolution of knowledge about the disease through the discovery of the marker gene in 83 to the discovery of the gene itself in 93 and beyond.

The book is above all a personal story and a very fascinating one but one that also gives insight into the disease. Some sections use complex language to explain the processes and discoveries involved but, overall the book is excellent. It is also available on loan from your state HD Association. Have a read and see what you think.

About this newsheet...

This publication is directed first and foremost at gene-positive people in the Huntington's community. However, it is distributed free of charge by email or by mail on a monthly basis so, if you would like to receive it on a regular basis, please contact Tracey at

Website to Check out...

A Positive View: Yahoo Group

http://groups.yahoo.com/group/a_positive_veiw

This group has only been established since August 2000 and still has an extremely small membership. It is aimed specifically at gene-positive Huntington's people and is intended to help with positive ideas about what to do once you have got your result.

As well as this group, Yahoo also has a carers group, an at-risk group and a couple of other general HD groups all of which are also quite small at the moment.

Instructions on how to join are at the site as are instructions on posting questions etc to the other members of the list.



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SEND US YOUR
RECOMMENDATIONS AND
IDEAS!

A thought...

*A positive attitude
may not solve
all of your problems
but it will annoy enough
people to make it
worth the effort*

Herm Albright

What's new in Research?

On March 22nd 2001, researchers at Johns Hopkins University in Baltimore said they have determined how the gene responsible for the fatal hereditary disease kills nerve cells in a key part of the brain: a mutant protein "hijacks" a key molecule in a cell's survival system

This is very exciting news for sufferers of Huntington Disease as researchers are now looking at ways of managing the disease through this knowledge.

For the full story, please check out:
<http://www.hopkinsmedicine.org/press/2001/MARCH/010322.htm>

Good Ideas...

Attitude Adjustment

Need some tips on how to be or stay positive? Check out the following ideas. If you have your own suggestion, let us know!

- 1) Avoid sugar snacks - you get a high from them which is only temporary and then crave more right afterwards.
- 2) Don't skip breakfast - it gets the day off to a good start, especially if you have a balanced breakfast (cereal, fruit, etc).
- 3) Exercise in moderation - a walk, a swim, anything you like but exercise helps get the body and mind going.
- 4) Drink lots of water - your body needs around 8 glasses a day to flush impurities and keep in top shape.
- 5) Cut down on caffeine - too much caffeine can affect your body as well as your nerves. Try drinking less of them or replacing them with non-caffeine alternatives like herbal tea.
- 6) Soak in a bath - add some Epsom Salts and your favourite bubble bath to the water, light some candles and lie back and relax. Especially in winter, you'll love this!
- 6) Have a massage - If you can't afford to have a professional massage, get your partner to give you one or give yourself one. Foot rubs, hand massages and scalp massages are all wonderful!
- 7) Practice smiling in the mirror - First thing in the morning and last thing at night, and try and make it a habit. Smiles are contagious too!
- 8) Play a game - Twister, Monopoly, Knucklebones, Scrabble, jump rope, the list is endless.
- 9) Try and do something new each month. Sometimes it might

be walking up a new hill, other times it might be buying something new or going somewhere new. You could cycle, get your motorbike license, canoe, windsurf, abseil, go caving, learn to knit, sew, do calligraphy. The choice is yours!

10) Think positive! Don't wonder if your glass is half empty or half full - be glad you have a glass.

Excerpt from Website

Gene tests bring agonizing choices By Richard Willing, USA TODAY

<http://www.usatoday.com/news/acovmon.htm>

The article is mostly about breast cancer testing but also mentions HD:

Stierman's case (breast cancer) offers a glimpse of the complex, deeply personal issues that families across the USA are confronting because of gene testing, which is beginning to live up to its promise of revolutionizing preventive medicine. US labs now do more than 200,000 gene tests a year, compared with just a few a decade ago.

For Stephanie Vogt, the question was whether to be tested for Huntington's disease, which shuts down brain functions and is caused by a single mutation. When she was younger, Vogt says, she had her "head in the sand" about what might be coming. Only about 300 Americans take the Huntington's test each year, says the Huntington's Disease Society of America, which estimates that more than 200,000 people in the USA are at risk for the disease. As she

neared 30, Vogt decided that continuing not to know would be worse than hearing bad news. "I figured if I was gene-positive, knowing or not knowing wouldn't make a difference "I was going to get (Huntington's) anyway," says Vogt, 29. "But I have things I wanted to get done in my life. If I was only going to have so much time, I was determined not to waste it." Vogt tested positive last year meaning she is destined to get the disease but has "not looked back since." The claims adjuster is going to college at night, gives lectures on Huntington's disease and also works as a radio newscaster. Not all patients who take



the Huntington's test react so well, even when the results are negative. In Seattle, a man in his late thirties continued to tell friends he carried the Huntington's mutation three years after testing negative. The man, says genetics counsellor Robin Bennett, had led a partying lifestyle based on the assumption that he would die young. Admitting that he did not carry the mutation would have forced him, in essence, to adjust his values, Bennett says.

Picture and slogan from the HUNT_DIS Mailing List