

# Better Days Ahead

NYA Clinical Research Discussion

HDSA, National Youth Association . .and  
Jean Miller!




# Not just the Mouse: Better Days Ahead for People

**The CURE** for Huntington's Disease

*YOU can help. Get INVOLVED in HD Clinical Trials!*

Help CURE Huntington's Disease

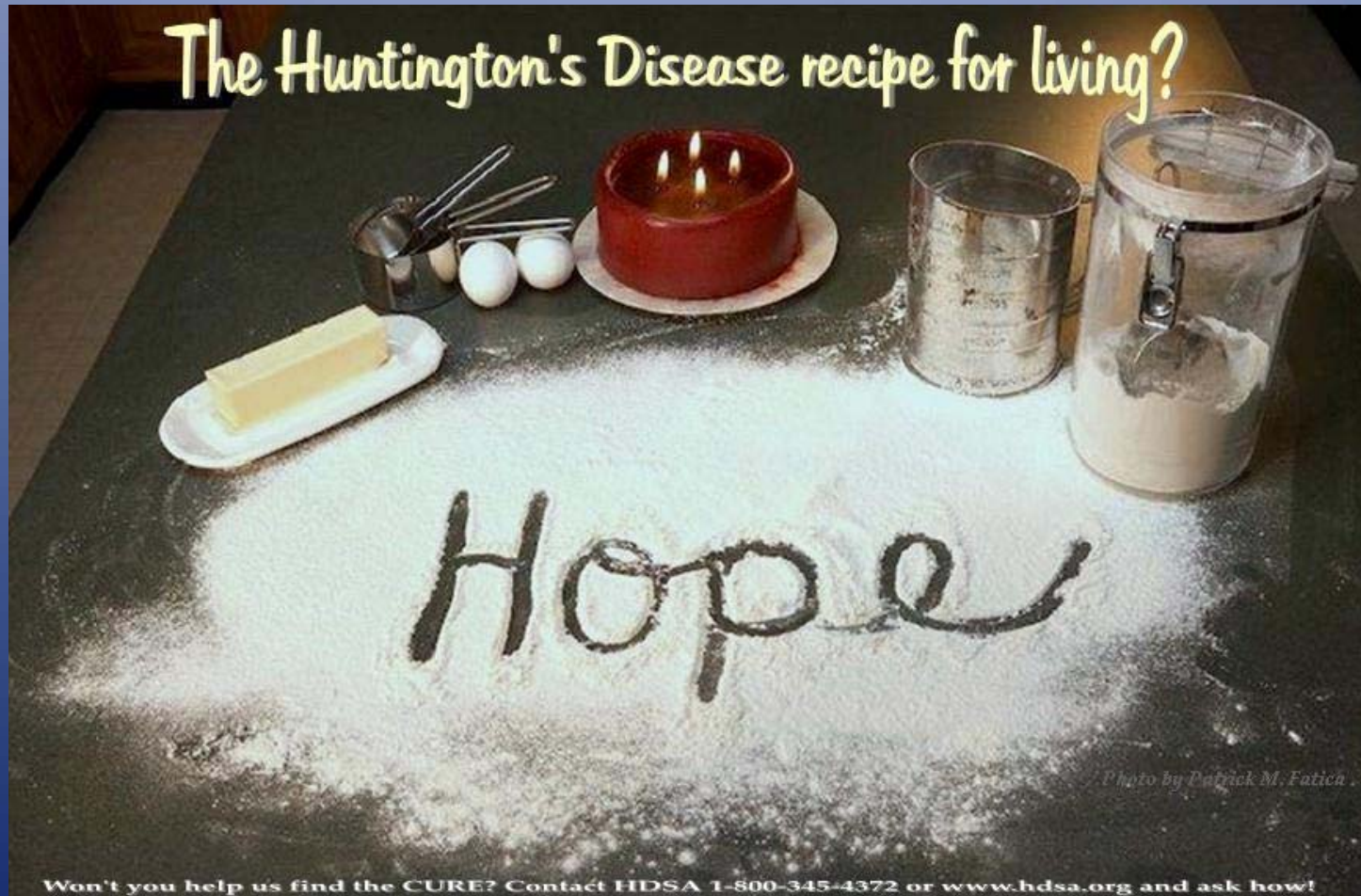
Support HD Research  Save a mouse, find the CURE!

1686 - 2008

**hasn't been found yet.**

Learn more - [www.hdsa.org](http://www.hdsa.org)

# The Most Important Ingredient? Add Clinical Trials



# When Hope becomes Reality

- Hope is translated to treatment only through clinical studies and trials.
- Hefty NYA Participation (and extended families) will be essential.
- But . . . remember it is an opportunity, not an obligation!

# Exciting Things are Happening . .

But we need:

- Large numbers of participants.
- Shorter recruitment times.

# What are the numbers?

Right now:

- 2CARE: 600 participants at 43 study locations
- Precrest: 80 in Boston
- Memantine: 60 participants at 3 study centers
- Citalopram: 36 in Iowa

# And within the next year . .

Another 1000:

- CREST: Will need another 650 participants.
- ACR-16: Another 100
- Will need another 100. Dimabon: May need several hundred more for PHASE 3.



## And more . . .

- First CHDI drugs may be ready for clinical trials in 2 to 5 years, with more coming.

Bottom Line: Long-term ongoing need for lots of people. And you . . .

- Will fit criteria.
- Will likely be needed for several trials.
- Have GINA to protect you.

## Not just numbers . .

- Minocycline: (118) 12 centers, almost 2 years
- Dimebon : (90) 15 centers, 10 months.
- Memantine (60), 3 centers, still recruiting after several (3-4) years.
- Citalopram (36) one center; still going after 3 years.

It takes longer to recruit than to do the trial!

# What can you do to help?

- Get informed . . . And spread the knowledge to friends and family.
- Sign up for *HDTrials.org.*, and encourage others.
- Join a clinical trial and encourage family and friends.
- Other ideas: FDA and PGD advocacy.

So . . . What is a clinical trial?  
Is it really like this?



# Discussion Points

- How to find a clinical trial.
- How to choose one.
- Some words you should know.
- Other things?

# How to choose a Clinical Trial

- Be informed.
- Ask questions.
- Choose the one that fits you best.
- Know your rights.
- Don't allow anyone to pressure you; participation is voluntary.

# Terminology

- Placebo
- Phases
- Informed consent
- Consent form
- Medical care in clinical trials.
- Criteria
- Protocol

# What else can you do?

- PGD
- FDA