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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.
Presenter Disclosures

Roy Nierenberg

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list
living well with HD
Roy Nierenberg
meet
Roy Nierenberg
living well with HD

eat well

help out

try meds

do what you love

sleep a lot

exercise
living well with HD

eat well

help out

exercise

try meds

do what you love

sleep a lot
breakfast smoothie:
• almonds
• coconut flakes
• blueberries, frozen ok
• greens, like kale or beet greens
• protein powder
• orange juice
lunch:
sandwich—
• whole grain bread
• salmon, broiled
• roasted beets
• mayonnaise
• horseradish!
• (keep it moist)
....with a salad—

• red peppers
• cold, sautéed beet greens
lots of snacks!
• protein drink
• almonds (again!)
• energy bars
• fruit
• red peppers
• juice
• sorbet
dinner:
• whatever she gives me!
living well with HD

- eat well
- exercise
- help out
- try meds
- sleep a lot
- do what you love
biking helps with—

- strength
- balance
- my brain
- independence
- 28 gears—I do hills!
- saddle bags
- I fetch a few groceries
- it’s ok to walk when I need to
qi gong:
- good for balance
- part of a flock
- if I can’t sleep!
- meditative
- 2x / wk +
living well with HD

- eat well
- exercise
- help out
- try meds
- do what you love
- sleep a lot
I sleep a lot!
• 10+ hours a night!
• melatonin helps me sleep
• less apathy / more energy
• neuroprotective
• I use my Jawbone UP to monitor my sleep
living well with HD

eat well

help out

try meds

do what you love

exercise

sleep a lot
I sing in a community chorus
• we learn new music
• sometimes in other languages!
build community:
• I walk with my best friend Ed
• joined an HD support group
• go to therapy
• attend science lectures
• visit the Maker Faire!
advocate!

- I appeared before FDA on HD
- contacted my congressman about the HD parity act
participate in HD research:
• whole genome analysis in HD to find new therapeutic targets (Finkbeiner)
• Enroll-HD
• helps everyone!
• keeps me informed
• arranged donation of my father’s brain to HD research
• mine will be available too!
Living well with HD

- Eat well
- Exercise
- Sleep a lot
- Do what you love
- Try meds
- Help out
try things!
consult your neurologist or general practitioner!
...besides some of the standardly prescribed drugs, here’s what’s worked for me—
Verapamil —
• a calcium channel blocker, usually prescribed for high blood pressure or migraines
• promotes autophagy in animals with HD
• helped restore my creative thinking and reduced apathy
Memantine (Namenda)
• usually for Alzheimer's
• makes me sharper
melatonin
• a supplement, not Rx
• regulates sleep
• take it regularly at bedtime
• HD patients are naturally deficient in it
living well with HD

- eat well
- exercise
- try meds
- help out
- sleep a lot
- do what you love
- a lot
trust your caregiver!
caregiving is hard—  
• how can you help?
questions?
resources

Heros:
Sara Riggare
http://www.riggare.se/1-vs-8765/
https://www.youtube.com/watch?v=0vG_ZyI5Wko

Exercise:
The best exercise for aging muscles:
https://www.nytimes.com/2017/03/23/well/move/the-best-exercise-for-aging-muscles.html?_r=0

Qi Gong:
http://www.wenwuschool.com/
Health benefits of Qi Gong:
www.nga.org/assets/docs/Know-the-Evidence-FINAL-1.pdf

Berkeley Community Chorus:
http://storychorus.org/spirit-of-bcco/
http://storychorus.org/community-brain-science-power-of-music/
http://storychorus.org/my-philosophy-of-choral-singing/

Sleep:
Jill Bolte Taylor, My stroke of insight
https://www.ted.com/talks/jill_bolte_taylor_s_powerful_stroke_of_insight

Meds:
Verapamil
http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/verapamil/

Where to donate your brain:
http://www.nybb.hs.columbia.edu/