



Living with Huntington's Disease: A (RE)Introduction to Best Practices

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Presenter Disclosures

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For our time together!

- Understanding & treatment of Huntington's Disease is improving
- The question of whether a cure exists has shifted!
 - Maintain standards of living
- Heterogeneity in onset and progression
 - we will try to cover the spectrum
- This workshop will reintroduce:
 - Standard best practices
 - cognitive, physical, occupational, speech therapy
 - Possibly introduce new suggestions to implement, today!
 - Technology and strategies

Broad Topics:

- 1. A little research (for context)**
- 2. Assistive Technology**
 - **Integrating tech into everyday**
 - **A tour of Durable Medical Equipment (DME)**
- 3. Compensatory Physical Techniques**
 - **Home Exercises**
- 4. “Hacks” for Activities of Daily Living (ADL)**
 - **Simplify to accommodate cognitive change**
 - **Living Positively & Maintaining Optimism!**

A little Research!

Ionis and Roche-Genentech HTRx

- **Huntingtin-lowering drug**
 - **SAFE** in lowering levels of Huntingtin protein
 - **BUT** initial study focused on **SAFETY**, not **EFFICACY**
 - **GOAL** of current Phase 3 clinical trial (underway!)
 - The drug did reach its genetic target
 - **BUT** < 50 participants, which is too small to be sure
 - **Practically promising!** just not yet statistical.
- **When will this be available??**
 - **Difficult to say...** like many things in life... it depends
 - **Lots of steps to take from lab to clinic, but...**
 - **C-Path for FDA (HD-RSC)**

Preliminary Benefits of HTTRx

- **Correlation revealed between:**
- **Reductions in huntingtin and improvements in clinical measures, specifically:**
 - **Cognitive processing measure**
 - **Composite HD symptom scale:**
 - **4 domains of clinical performance and capacity in HD:**
 - » **motor function**
 - » **cognitive function**
 - » **behavioral abnormalities**
 - » **functional capacity**
- **These benefits occurred THREE months after first dose**
 - **maximum effect projected at SIX months**
- **Next stages?**
 - **Shown to be safe**
 - **Next is large-scale studies to demonstrate efficacy!**

A List of “Assistive Technology” that Caregivers have found Extremely Helpful

- 1. Shower nozzles (provide hot water at constant temp.)**
- 2. Automatic gas/electricity/stove/water shut-off (infrared)**
- 3. Automatic refrigerator door closer**
- 4. Simple remote control with large and clear buttons**
- 5. Electronic medication reminders**
- 6. Wristband HR and blood pressure monitors**
- 7. Toilet seat with automatic lift assistance**
- 8. Photo button telephone**
- 9. Verbal prompting devices about essential items before leaving**

Assistive Technology (ATECH/AT)

What is ATECH or AT?

- **Defined** by the **Technology-Related Assistance of Individuals with Disabilities Act of 1998** as...

Equipment, product system, or program:

– “off the shelf,” modified, or customized

That is used TO increase, maintain, or improve function of individuals with disabilities.

- **GOAL:** to match an individual's needs with specific ATEC to **enhance** person's **capabilities** AND **quality of life**.

ATECH to assist in:

1. Computer accessibility

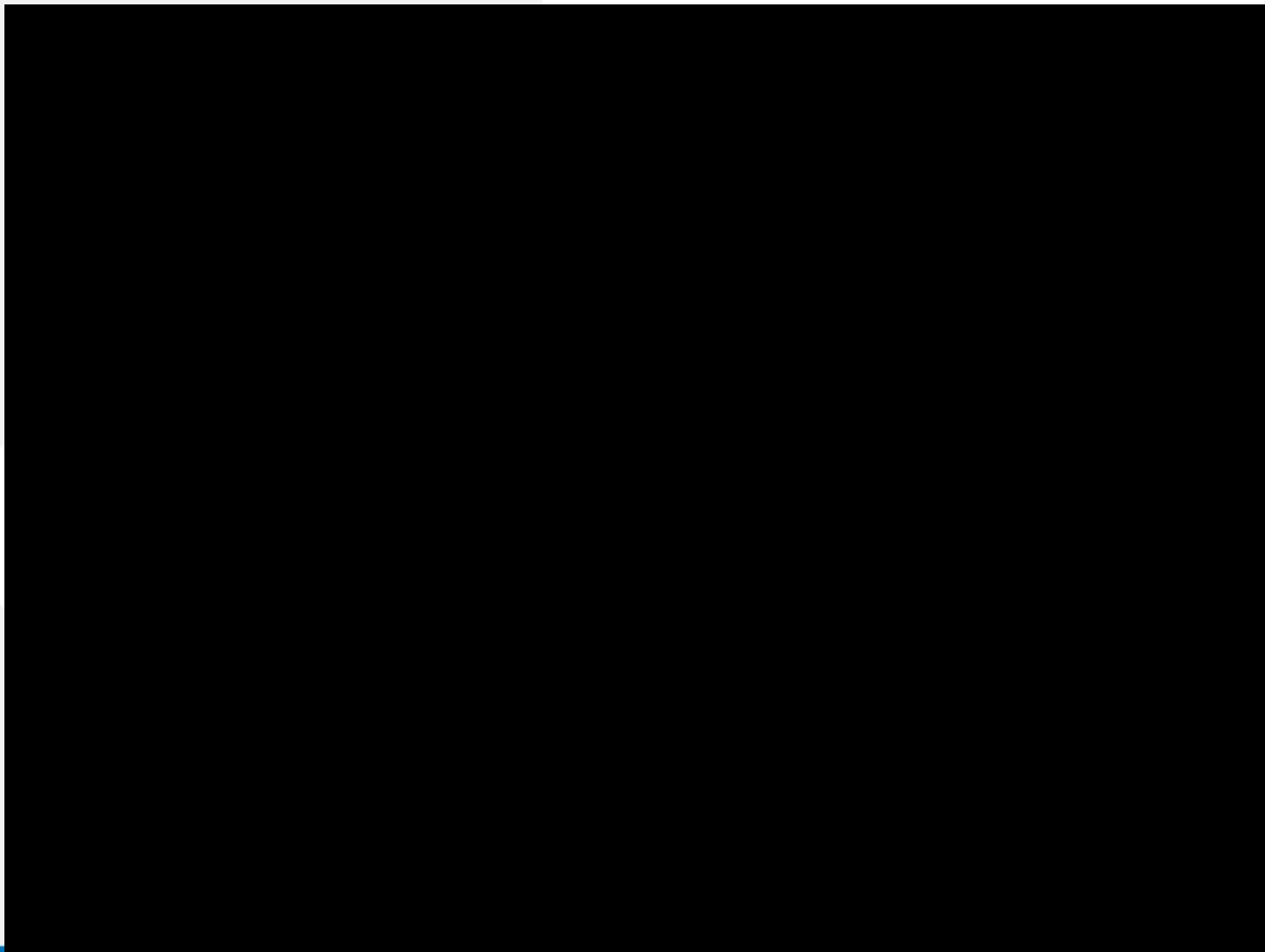
- **a great way to improve:**
 - **connection and communication**

2. Communication

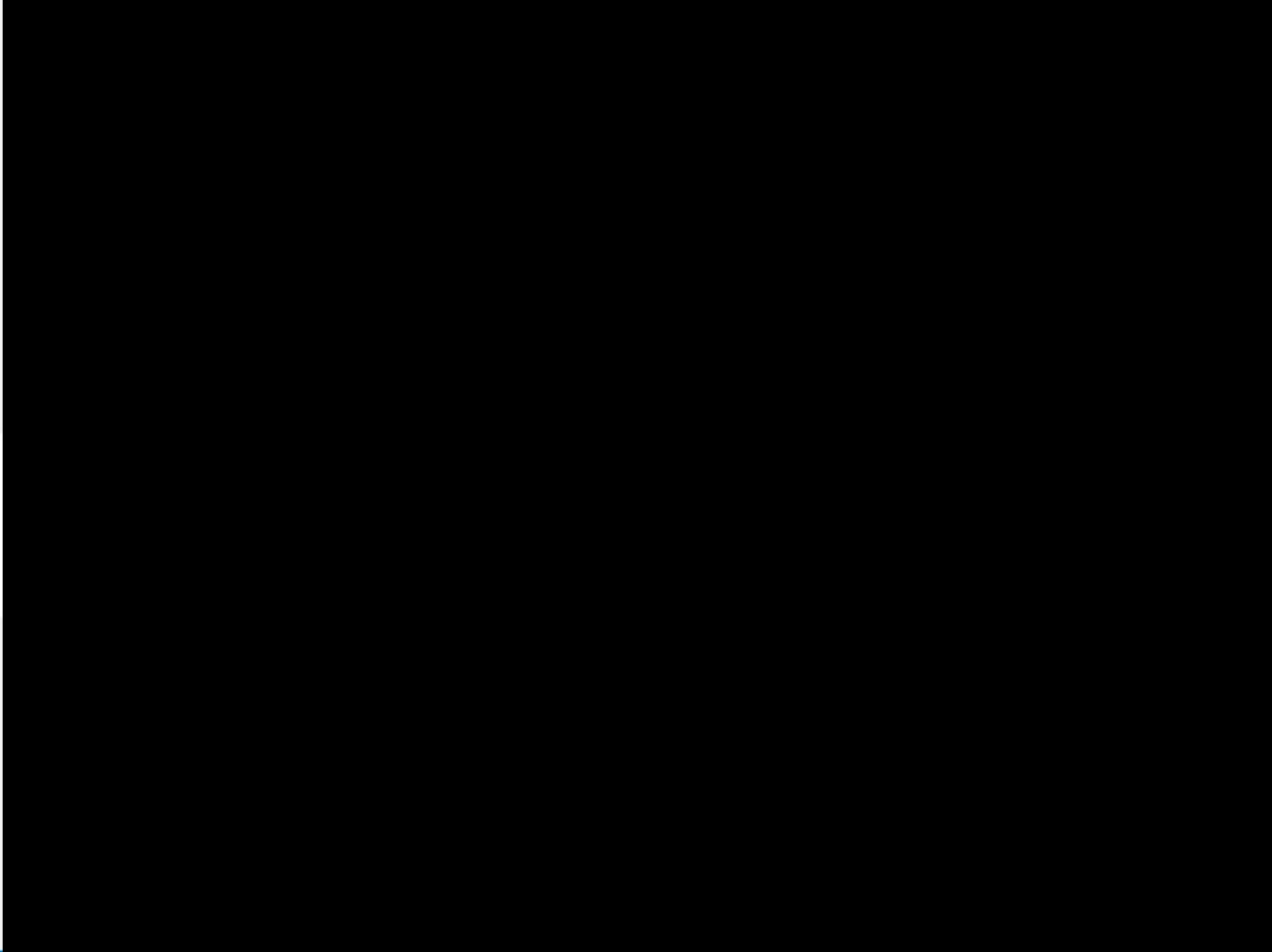
ATEC to Access Computers

- 1. Dictation Programs (free)**
 - **Mac & Windows**
- 2. Eye-tracking devices**
 - **Camera Mouse (free)**
- 3. Foot Mouse & Hands-Free Touchpad**
- 4. The AirBar**

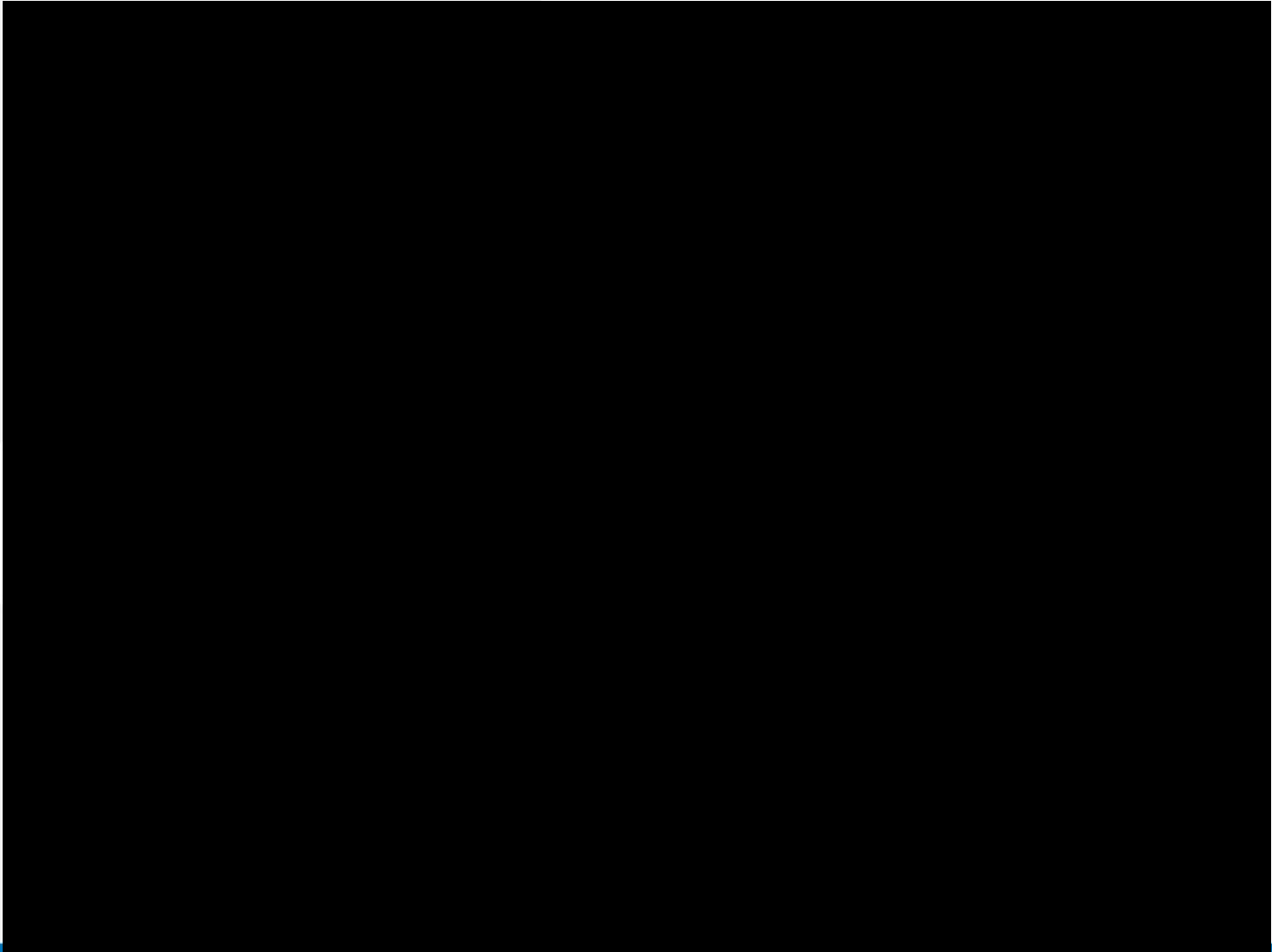
“Accessibility” options for Mac



“Accessibility” options for Mac: Dictation demo



“Ease of Access” options: Windows



Prizmo: Optical Character Recognition (OCR) Software

1. take a photo of a magazine at the doctor's office
2. convert the words to text
3. Use a dictation program on phone to change text-to-speech

www.macupdate.com/Prizmo

Eye Tracking

Pupil and Corneal Reflection is detected to calculate eye gaze

CAMERA MOUSE (FREE)

CAMERAMOUSE.ORG

1. Dwell time

2. Sensitivity

3. Smoothing

reduces the jerkiness if
extrapyramidal tremors

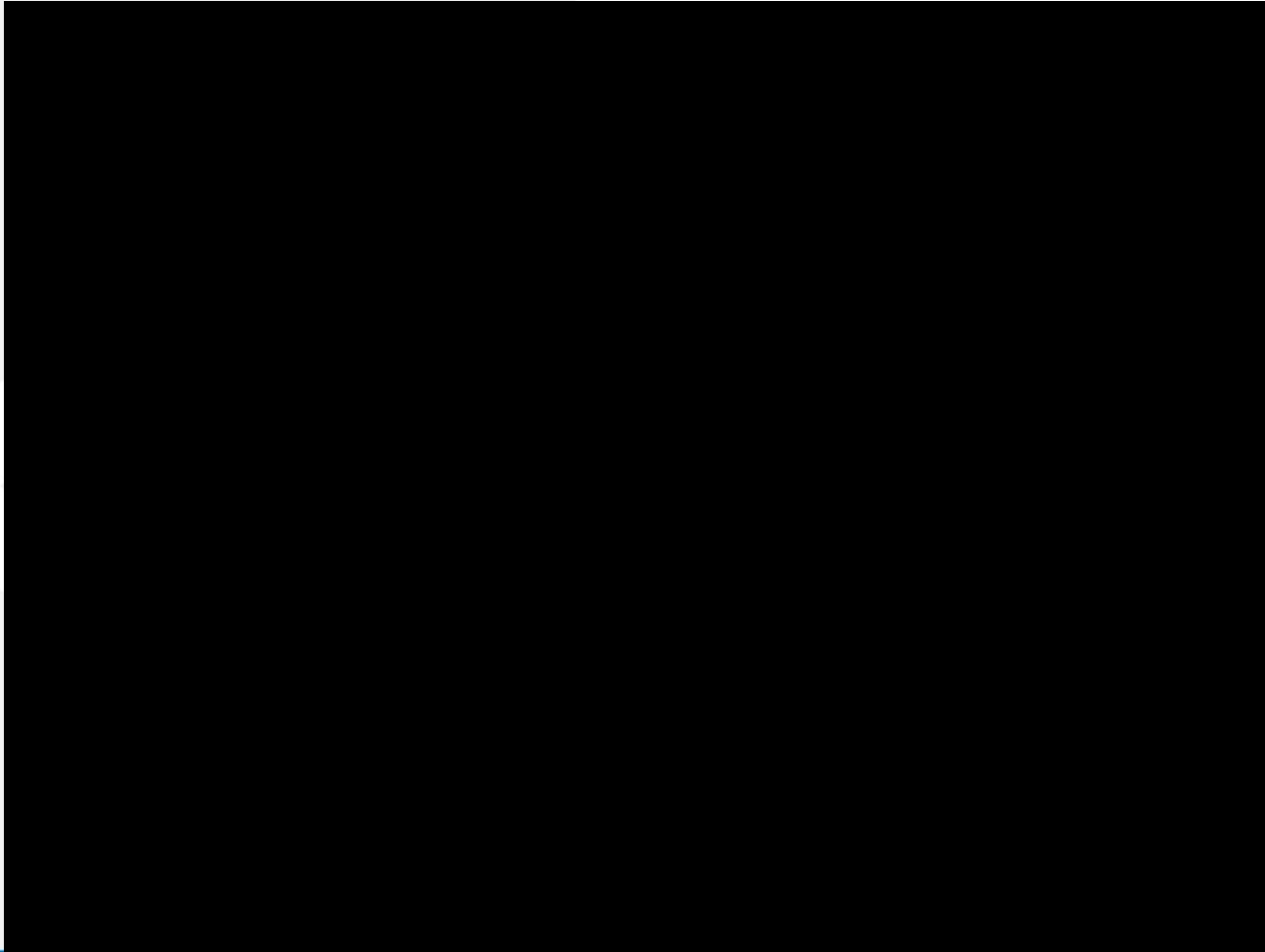
Hands-Free Control of Computer

- The Foot Mouse (~\$139)
 - <http://www.thehumansolution.com/footimemouse.html>



Hands-Free Control of Computer

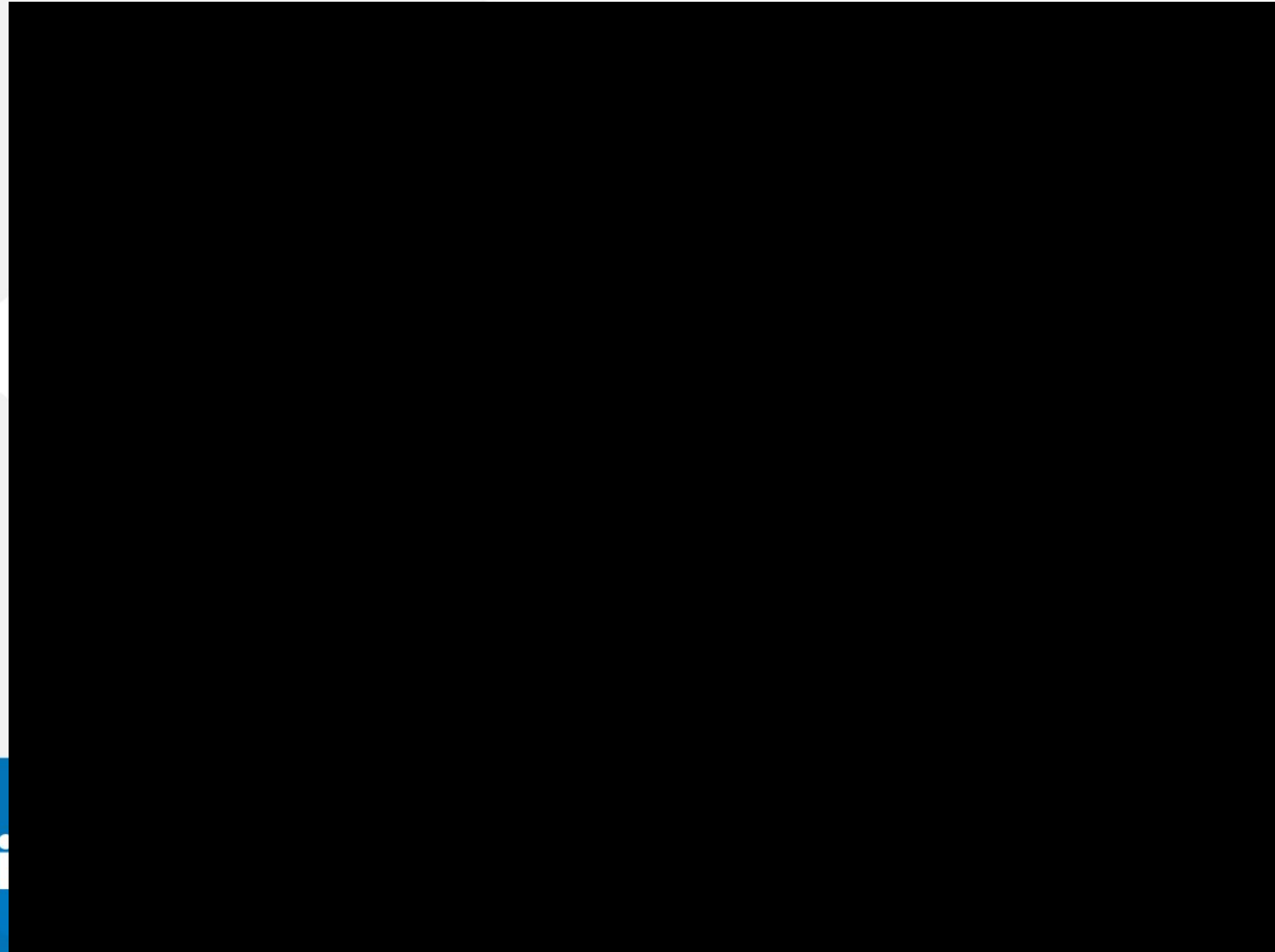
<http://www.handsfreetouchpad.com/>



difficulty using a standard mouse?

Turn any screen into a touchscreen with...

The AirBar – www.air.bar (available for Mac & PC)



**FOR A LIST OF FREE
OR INEXPENSIVE
AAC FOR
APPLE/MAC IOS:**

www.tbioc.org/brain-education

to access this list!

Speech Generating Devices (SGD)

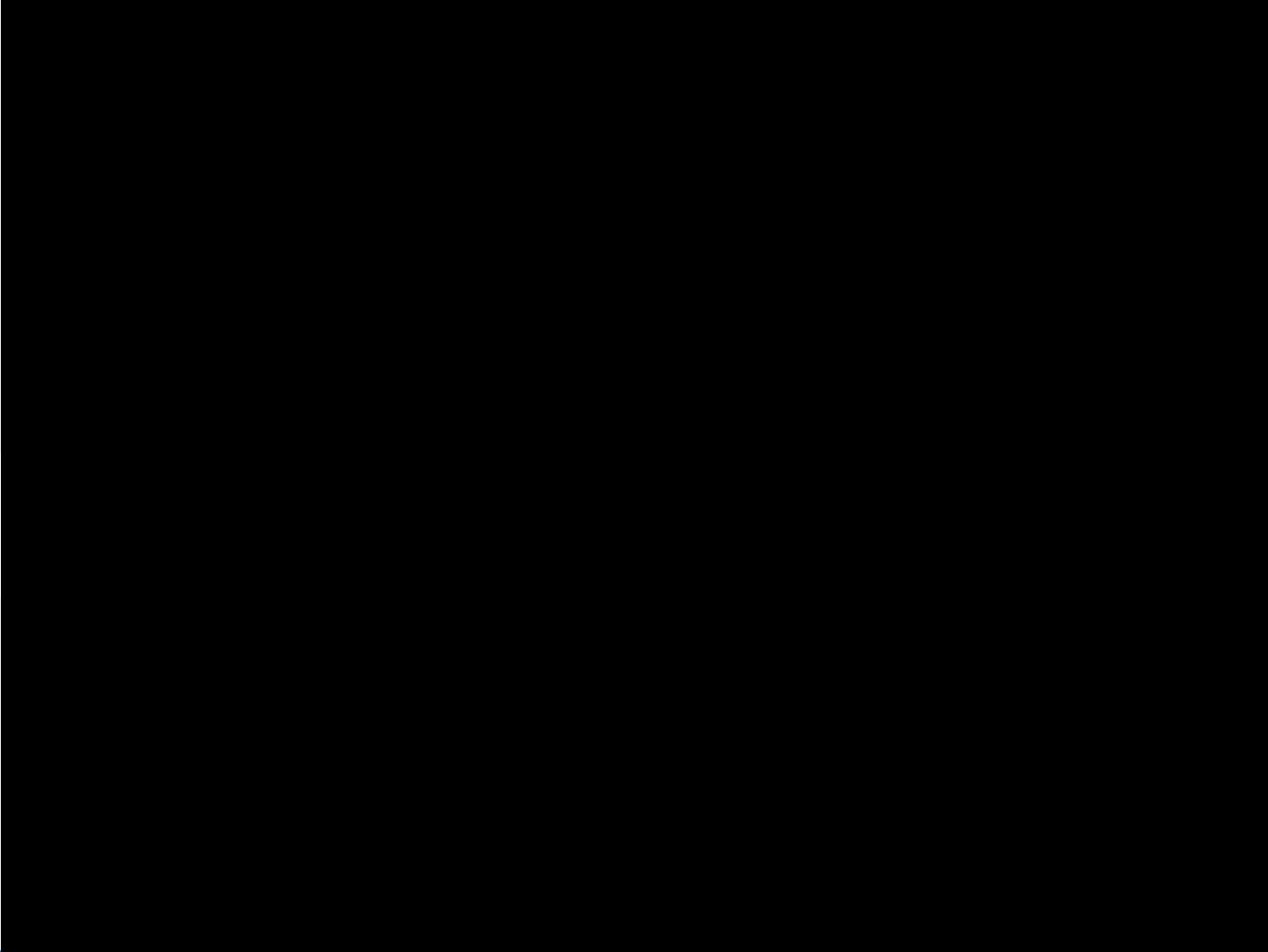
“Higher tech” systems

May be covered by Medicare or other insurance under:

“Durable Medical Equipment (DME)”

- **Tobii I-Series** (eye tracking SGD)
 - » <http://www.tobiidynavox.com/>
- **Eyegaze Edge Talker** (eye tracking SGD)
 - » <http://www.eyegaze.com/>
- **Eye Tribe Tracker** (eye tracking SGD)
 - » <https://theeyetribe.com/>

Tobii Dynavox I-Series (SGD)

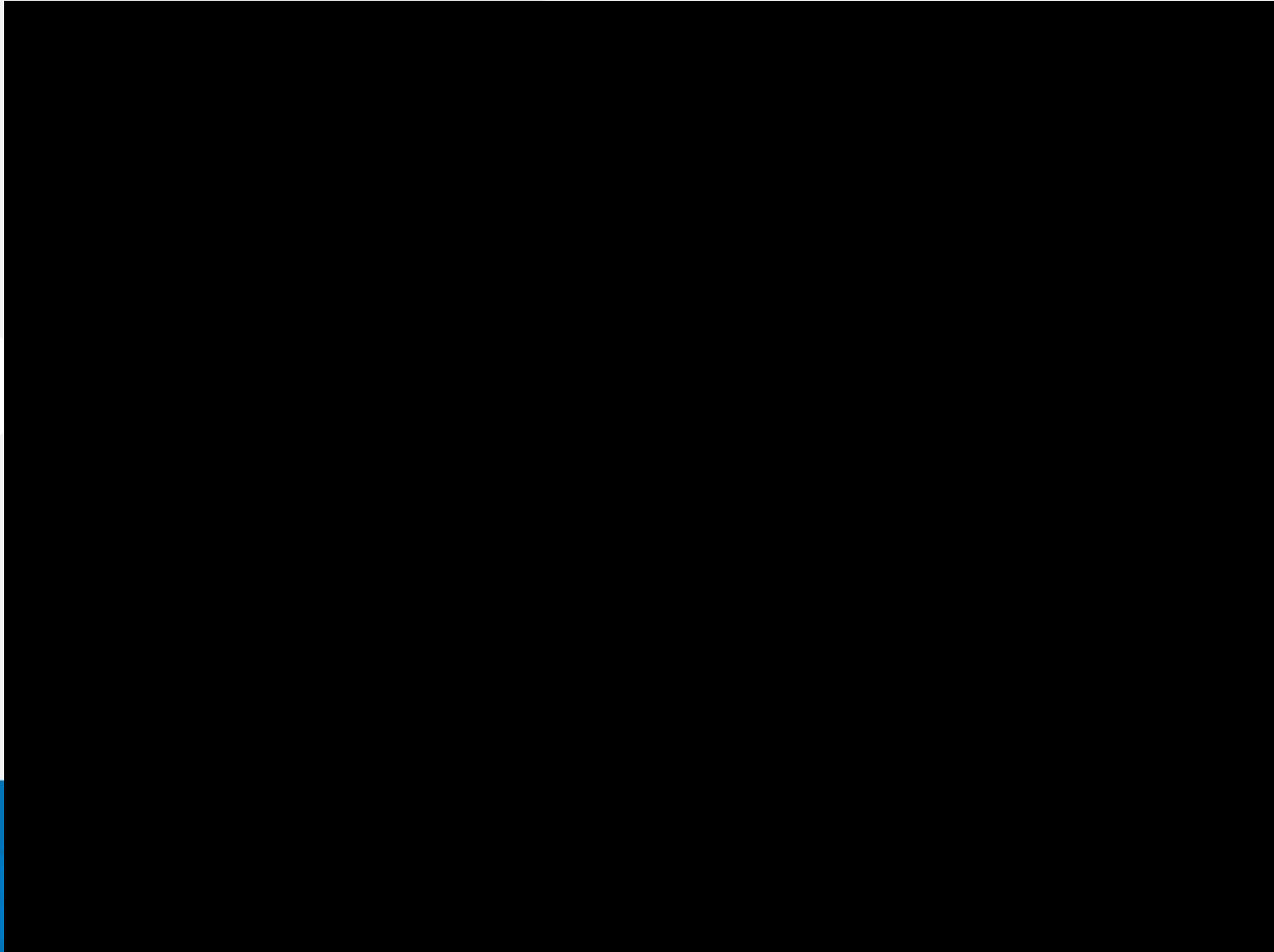


Medicare Compliant Eyegaze Edge Talker

- Physician/speech pathologist must “prescribe”
- Most insurances cover 80% of this device
- Unfunded, the price of the Eyegaze Edge is \$8,700!
 - <http://www.eyegaze.com/>
- LC Technologies
 - Medicare and Medicaid support
 - (703) 385-8800 [Cathy Fahmi]



0:20 – 0:41 to 4:50 – 5:20



The Eye Tribe Tracker

- \$99
- Compatible with the following:
- PC (Windows 7/8)
- Mac (Lion 10.8.4)
- <https://theeyetribe.com/>



Next:

A Tour of Durable Medical Equipment (DME)

Ask your MediCare provider!

Visit www.Medicare.gov

**or call 1-800-MEDICARE
(1-800-633-4227)**

To find a Medicare DME provider near you.

One example in Orange County, CA:

Emporium Home Care (714 224 7474)

150 E Imperial Hwy. Fullerton, CA 92835

DME for Eating



What is the POWER OF RED?

Studies have shown that using red dinnerware increase eating for individuals with Alzheimer's and Dementia.



Shows contrast between the table and food, allowing the user to recognize what they are using and eating.



Ideal for people who cannot tilt their head back due to neck injuries or choking.

Dishwasher and microwave safe.

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DME for Eating



DME for Safety



DME for Safety



DME for Exercise



DME for Movement



The Walk-Bicycle

- Freezing of gait (FOG) is a common Parkinsonian symptom (HD Symptom)
- “Shifting weight laterally” may cause problems with forward stepping movement
- Bicycling avoids this, but not always feasible to ride & dismount.
 - walk-bicycle:
 - no pedals
 - lowered seat
 - may reduce FOG in some
- Elliptical exercise machines take out the high impact and reduces the need to shift weight laterally



“Smarter” Furniture



1. Smarter furniture
 - a. Hard plastic, instead of glass
 - b. Rising furniture
 - c. Chairs with assists



Physical Therapy Techniques

Physical Therapy (physiotherapy) and HD

- **Physical Therapy areas of rehabilitation:**
 - Gait/balance transfers
 - Strengthening/coordination
 - postural stability (keeping still and moving)
 - Transferring body weight from one leg to the other
 - Lateral weight shifting
- **Benefits to seeing a physical therapist:**
 - Prevent falls
 - Promote correct walking/body control
 - Build coordination/flexibility
 - Facilitate confidence in body movement
- Exercises can be adapted for lying down, sitting, or standing.

How can Physical Therapists help HD

1. Teaching how to maintain energy
2. Aerobic exercises
3. Stretching exercises (avoid muscle tightness)
4. Strengthening/Balance exercises (prevent falls)
5. Assist with selecting DMEs and how to use them
6. Teach caregivers how to transfer
 - (e.g., car, bed, bathroom, chair)

“Hacks” for Daily Living

Physical Movements

- Engage in exercises
- Routine
- Safety

Eating

- Sitting up/good posture
- Slow to avoid choking
- DMEs to help chewing/drinking
 - too much water
- Clock technique with caregiver

Sleep

- Good sleep hygiene
 - Low/no light
 - Same time
 - Digestion
 - No loud abrupt sounds

Cognitive Strategies: Simplifying life

Using technology or not!

Common Cognitive Changes in HD

1. Memory & Learning
2. Perception
3. Executive Functioning
4. Language and communication
5. Among many others

Keeping my life organized

1. Minimize clutter
 1. cognitive and physical benefits
2. Determining order of activities for the day
3. Sort and prioritize
4. Maintain “Cognitive Clarity”

“Keeping clarity”

1. Remove distractions
2. Minimize input sources
3. Allow more time for tasks
4. Reduce quantity of information
5. Avoid open ended questions when frustrated
6. Do one thing at a time
 - “multitasking” some would say is a myth
7. Minimize excess stimulation
 - visual and auditory

Remembering tasks

Potential Solutions

1. Calendars
2. To do lists/ task lists
3. Regular routine/schedule
4. Reminder watches/ alarms
5. Set a single place in the home where all “lists” are kept
6. “Tile” is a locating hardware/software you can use
 - Put on your keys, purse, etc.
 - <https://www.thetileapp.com/>
7. Smartphone Apps



Find My Friends

Family Safety Production Social

★★★★☆ 275,785

REVIEWS

4.2



275,785 total

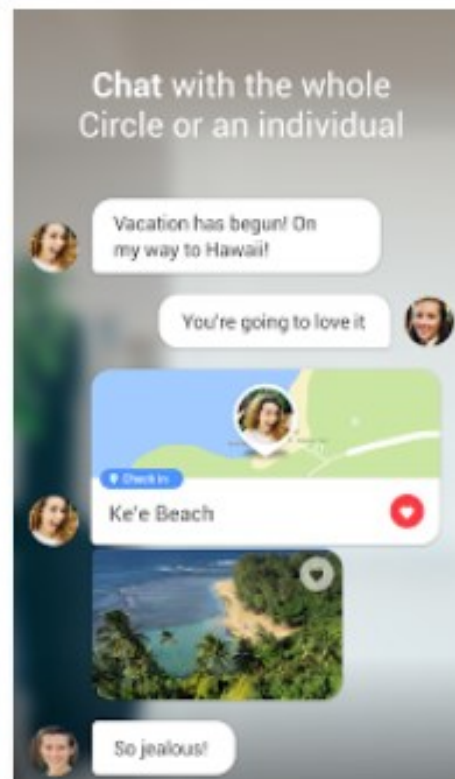
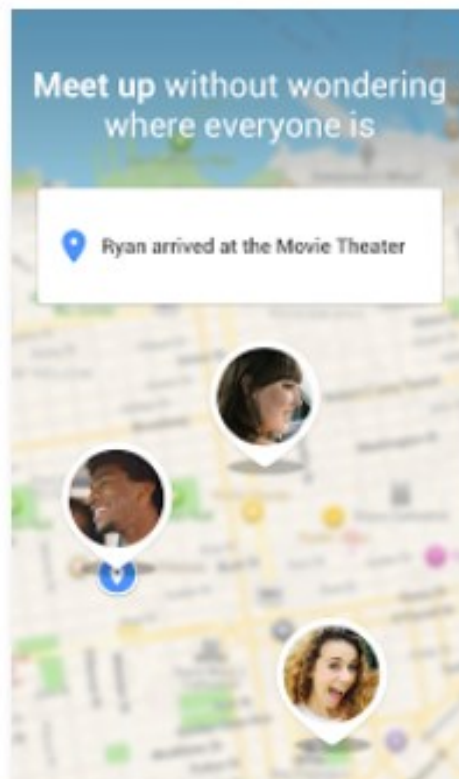
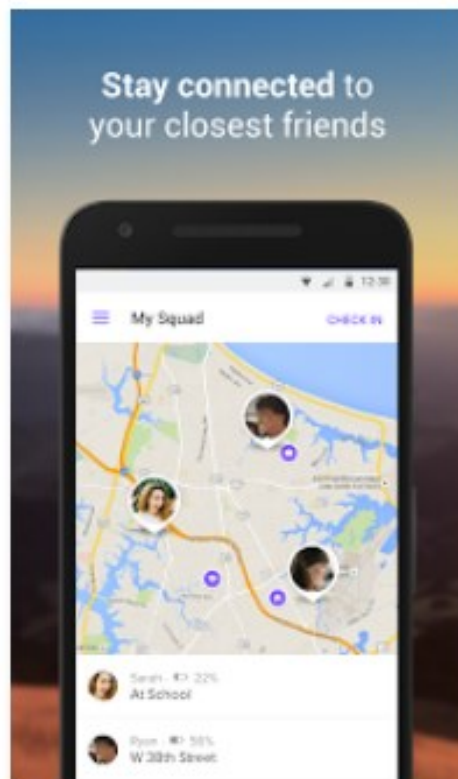
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BEST Suite



*Pace
My Day*



*Reach
My Goals*



*Strategize
My Life*
Coming Soon

Upgrade/Restore

My Reminders

Logout

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Cognitive supplementing apps
for your iPhone & iPad

- Search Best Suite in the app store
- \$9.99 for 3 apps:
 - Pace My Day
 - Reach My Goals
 - Strategize My Life



Task Lists

1. Task lists can be used to supplement memory
2. Can be paired with an alarm
3. Alarms can be set on watches or timers
4. As tasks are completed, crossed off list
5. Create a new list and review it each morning

Reminder Watches

- ❖ Reminder watches can be used as a reminder
- ❖ If you would like to try a Reminder Watch, try:

1. E-Pill Cadex Watches
<http://www.cadexwatch.com/>
2. VibraLite Watches
<http://www.vibralite.com/>
3. WobL Watches
<http://woblwatch.com/>
4. Time Timer Watches
<http://timetimer.com/>

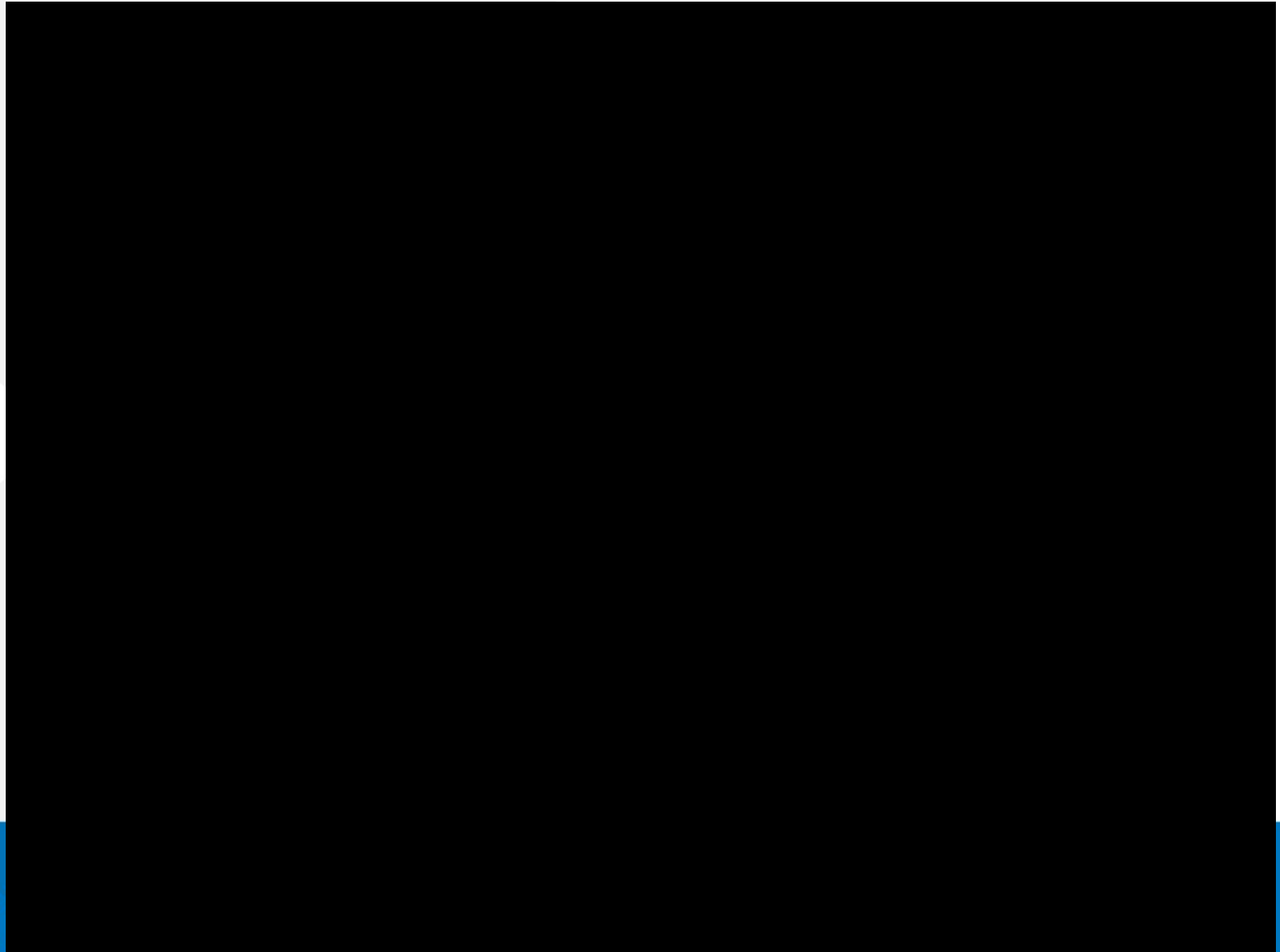
Slowing the decline: cognition apps

Brain Training Apps

Note: these apps have not been through Clinical Trials to cure, treat, or prevent disease

- **NeuroNation**
- **Lumosity**
 - Memory challenge
 - Brain training applications
 - Designed to help memory

NeuroNation and Lumosity App



Affective Neuroscience:

What we can learn and how

- **Neuromechanisms of emotion:**
 - “positive & negative” parts of the brain
- **Neuroplasticity:**
 - brain is malleable based on what we think and do
 - Extend range of mental capabilities
 - Including training our minds to be happy
- **Frequent mental training strategies can produce change**
- **Psychosocial factors** play significant role in the modulating course of cardiovascular disease and asthma
 - Therefore, information from the environment gets “under the skin” and modulates our brain in a significant way

Psychosocial Support Defined

Psychosocial support means:

- a. the support that we get from friends, family, and even ourselves, to help us get and stay healthy.

How can I get it?

Talk therapy

- a. individually or in a **support group** (HDSA.org & HDSAOC.org)

Educating yourself

- a. about what you may be going through, or whatever may be causing stress.

Fun group activities (exercising, games, cooking, & eating!)

Benefits?

1. Reduced stress, depression, and anxiety.
2. Improved problem solving abilities – necessary when dealing with stress.
3. Increased resilience, or ability to adapt to new life changes

Access The Files & Videos
Discussed in this presentation
VISIT:

tbioc.org/brain-education

HDSAOC.org

www.tbioc.org/brain-education



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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.

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