

Florida's
Brain Bank Program

Presented by

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Brain Bank Coordinator

Alzheimer's & Dementia Resource Center

- Local, Non-profit Organization Serving Caregivers Since 1984
- Orange, Seminole & Osceola Counties for Face-to-Face Consultations
- Support Groups
- Information & Referral Services
- Educational Programs
- Brain Bank - Covering a 20 County Area

Facts

- Nearly 1,000 People are Diagnosed with Alzheimer's Disease Every Day in the US
- 1 EVERY 7 seconds is newly diagnosed
- In Central Florida there are close to 50,000 People Struggling with Alzheimer's disease

Facts

There are Approximately 30 Different Reversible Dementias
There are Approximately 150 Different Irreversible Dementias

1. Vascular Dementia
2. Mixed Dementia
3. Dementia with Lewy Bodies (DLB)
4. Parkinson's Disease Dementia (PDD)
5. Frontotemporal Dementia
6. Creutzfeldt-Jacob Dementia (CJD)
7. Normal Pressure Hydrocephalus (NPH)
8. Huntington's Disease
9. Wernicke-Korsakoff Syndrome
10. Mild Cognitive Impairment (MCI)

The Alzheimer's Disease Initiative

- Established in 1985 by the Florida Legislature and ADRC for the Purpose of:
 - Providing Support Services to Alleviate the Suffering of Persons with dementia and Their Caregivers
 - To Offer an Aggressive Research and Advisory Component to Identify Causes and Develop Treatment Strategies

The Alzheimer's Disease Initiative

Program is Based on Five Components:

- An Advisory Committee
- Memory Disorder Clinics (MDC's)
- Model Day Care Programs
- Respite Service
- Brain Bank & Research Database

Highest Priorities for the Brain Bank Program

- Find A Cure



Highest Priorities for the Brain Bank Program

- Develop Simple,
less invasive
Diagnostic tests



Highest Priorities for the Brain Bank Program

Find More
Advanced
Therapeutic
Interventions



Highest Priorities
for the
Brain Bank Program



Halt Functional

AND

Intellectual

Declines

*Who is Eligible to Enroll
in the Brain Bank?*

Individuals over 18 with a Diagnosis
of dementia **are** Eligible

Requirements for Acceptance

- Full Neurological Work-Up
- A local funeral home identified
- Acceptance by the Regional Neuropathologist





What is a Full Neurological Work-Up?

A Medical History Including:

- Interviews with the Patient and/or Close Family Members
- Gather Patient's Past & Present Health Condition
- Gather Patient's Family History
- Determine the Patient's Symptoms and when they First Appeared

Neuro Work-Up

A Mental Status Evaluation:

Determines Orientation

Evaluates Cognitive Abilities

Tests Short Term Memory

Tests Ability to Perform Simple
Calculations



Neuro Work-Up

A Physical Exam Including:

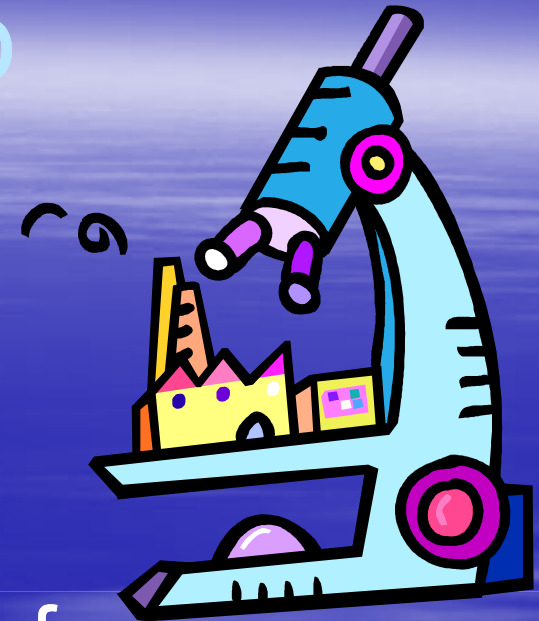


- General Condition including blood pressure and pulse
- Checks for Heart Conditions, Hardening of the Arteries, Kidney Disorders, Diabetes, Nutritional Deficiencies, & Abnormal Hormone Levels

Neuro Work-Up

Laboratory Tests:

- Blood & Urine Testing
- Determining the Presence of Infections, Anemia, Liver or Kidney Disorders, Diabetes, Nutritional Deficiencies, & Abnormal Hormone Levels



Neuro Work-Up

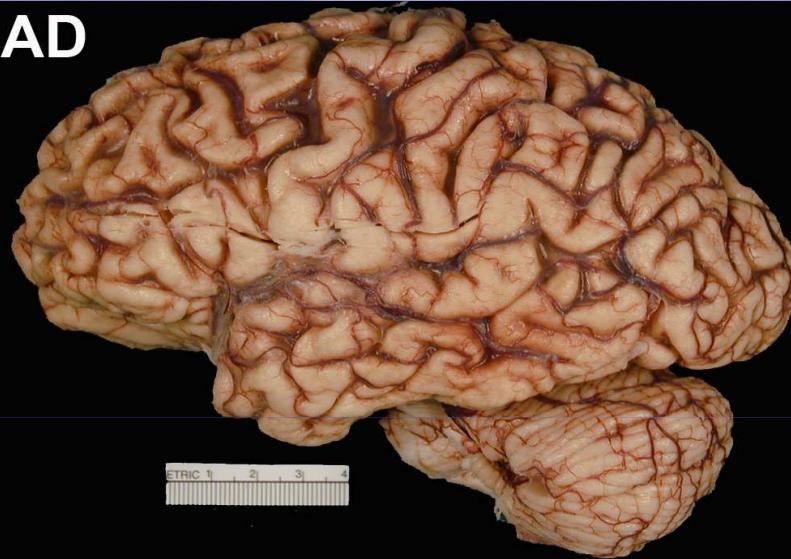
Brain Activity and Imaging:

- CT Scan or MRI can show Brain Atrophy, (Shrinkage), Tumors, Strokes, previous head injuries, or Blood Clots

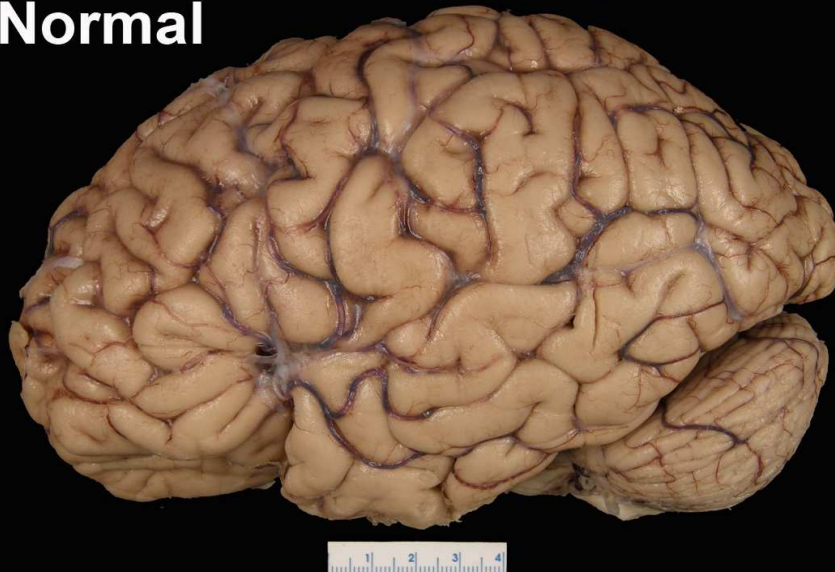


Notice the shrinkage (Atrophy)

AD



Normal

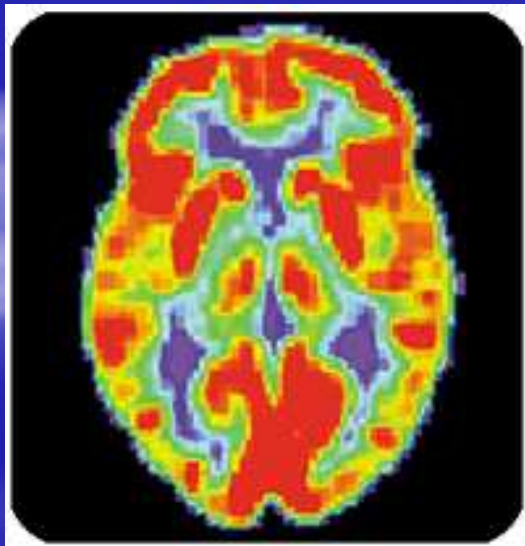


Neuro Work-up

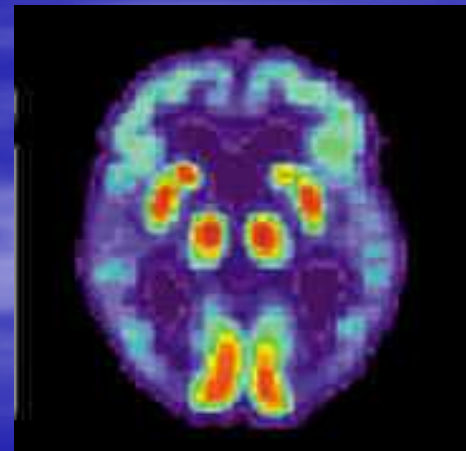
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PET or SPECT Scans Allow Brain
Functioning to be Evaluated

Normal

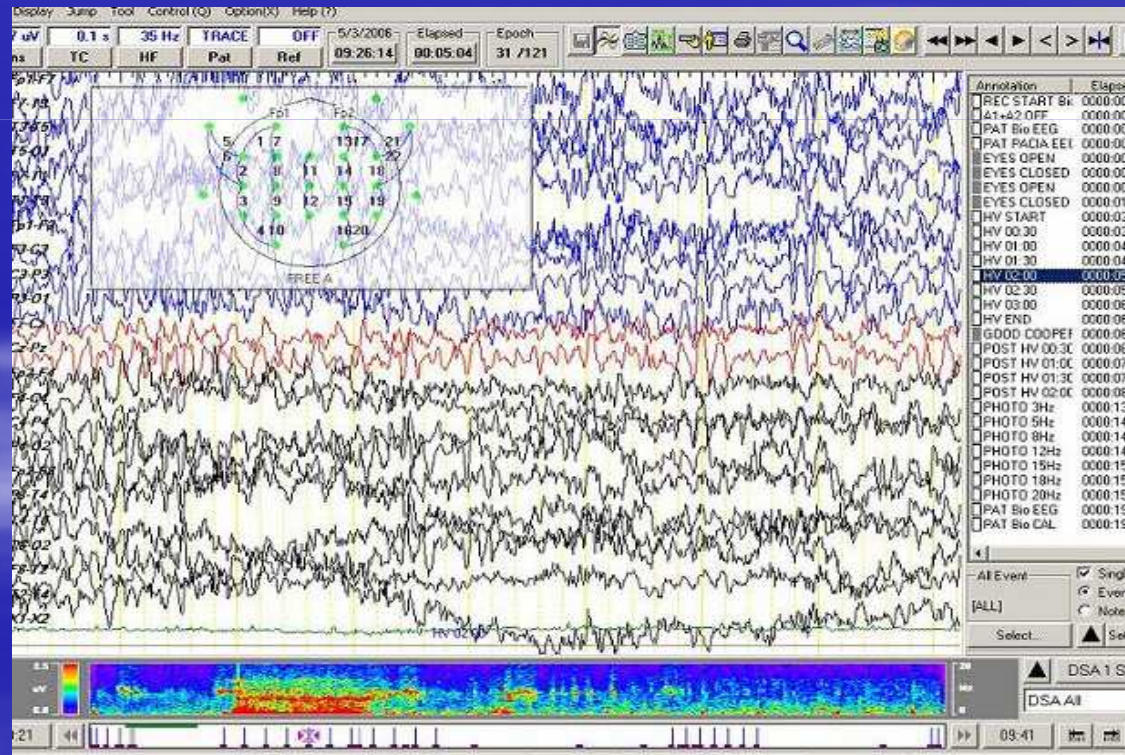


Diseased



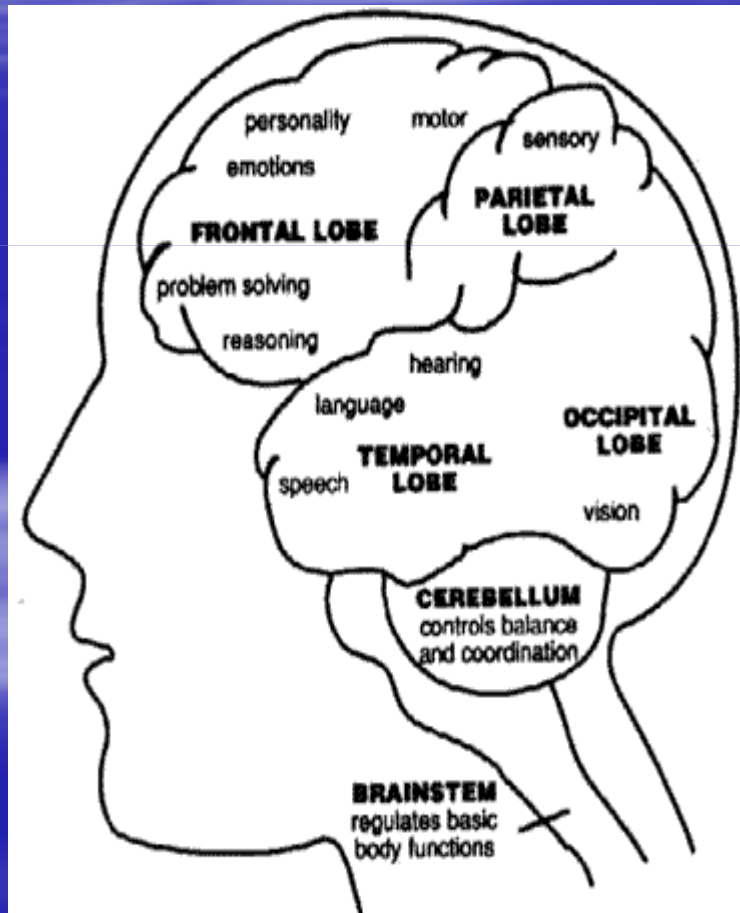
Neuro Work-up continue

- EEG Shows Brain Wave Activity



Areas of the Brain & Function

■ Areas of the Brain



Frontal Lobe:

- Plans, organizes & carries out
- Responds to situations
- Controls emotional response
- Problem-solve & decision making

Parietal Lobe:

- Visual-spatial perception
- Integrates signals from all senses

Temporal Lobe:

- Controls hearing
- Manages memory acquisition/storage
- Categorizes objects

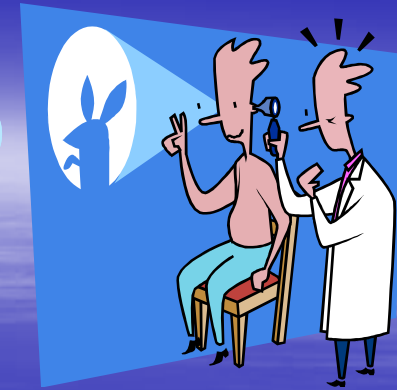
Cerebellum:

- Coordinates voluntary muscles
- Maintains balance

Brain Stem:

- Controls reflexes
- Affects alertness
- Affects sense of balance

Neuro Work-Up



Psychological and Psychiatric Assessments:

- Tests Ability to Remember, Write, Reason, and Express Thoughts
- Rules Out Clinical Depression and Other Psychiatric Disorders

Neuro Work- up continued

Neurological Evaluation:

- Testing of the Nervous System
- Evaluates Coordination, Sensory Abilities,
- Speech, Eye Movement, Muscle Tone & Strength
- Rules Out Parkinson's Disease, Stroke, & Brain Tumors

Why are Brain Autopsies so Important?

- Comparison of the patient's clinical symptoms (medical records) with changes found in the brain tissue can lead researchers to a better understanding of memory loss and other problems experienced by patients

Why Have an Autopsy?

Comments by **Jamie Humphries PhD,**
A Researcher at Roskamp Institute

- “Autopsies Provide Valuable Information that can Educate and Enlighten Families, Physicians, and Researchers”
- “Ultimately, this Research will Uncover the Chain of Events that Leads to AD”

Why Have an Autopsy?

- Tissue Harvested within a Few Hours of Death Still Contains Active Molecules Involved in the Disease Process Providing a Unique Resource for Researchers
- From this Tissue they have Validated New Possible Therapeutic Targets for AD

How Will an Autopsy Benefit the Family?

- Softens the helpless feelings of the caregiver by doing something positive for research
- Learning the precise illnesses maybe a tremendous relief to the family, helping them to close this chapter in their live.
- Very **rarely** will a report come back with a **single** diagnosis.

How will an Autopsy Benefit the Family?

- In the event that more than one family member has a similar illness, the autopsy provides vital information to the family and their doctor about possible genetic implications.

Funeral Arrangements

- Removal of the brain does not leave any visible marks so that it is still possible to have an open-casket viewing and funeral.
- The procedure is a 35 to 45 minutes and therefore will not interfere with any funeral plans the family wishes to make.

Once Accepted

Coordinator Notifies:

- Family
- Place of Patient's Residence
- Funeral Home
- Doctors

Who may request an autopsy?



- The spouse and/or the Durable Power of Attorney for Healthcare or a guardian.

Educating & Enlightening Families



- About the *Exact* Cause of Death.
- About their personal risk of developing AD or other types of dementia
- About Helping families attach meaning & purpose to the suffering that occurs with these insidious diseases.

Educating & Enlightening

Researchers & the Medical Community

- Doctors are Provided with the Neuro-pathological Report so they can compare pre- & post morbid diagnoses.

So What Have They Found?



- The Discovery of many new Dementias
- The Identification of Different Chromosomes and Genes that are Genetic Indicators for the Development of Alzheimer's Disease and other dementias

Plan Ahead

The time to start thinking and discussing a brain autopsy is **NOW**, even though the patient's death maybe years away!

Often the patient wants to participate in the application process. Is the patient an organ donor? The brain is the only organ they can donate!

Planning Ahead allows Family Members Time to Research, discuss, and make this difficult Decision and then Prepare the Needed Paperwork.

Barriers to Brain Donations

- Religious or Cultural Factors:

Families may have difficulty making a decision of this nature due to the belief that their religion does not support organ donations. However, this practice is accepted by most religions, but if concerned please consult your spiritual leader

Frequently Asked Questions

- Is it important for Children of dementia Parents to get a definitive diagnosis? **Yes.**
- Do some types of AD and other dementias run in families? **Yes but less than 1%**

Frequently asked questions

- Is a complete body autopsy performed? **NO**
- Can I have an open casket? **Yes! Harvesting the brain leaves no disfigurement.**
- Are there other ways to get a definitive diagnosis? **Currently there is no other way.**

*The Central Florida Brain
Bank is coordinating autopsies
for Researchers at:*



The Alzheimer Disease Research Center at
the Johnny Byrd Institute –Tampa - Healthy
brains and Mild Cognitively Impaired brains

Indiana University – At least 2 Living Blood
Relatives With Dementia

Johns Hopkins Brain Bank in Baltimore, MD

Other Research Partners

Mayo Clinic-Jacksonville - Lewy Body Disease Brain Bank

Mt. Sinai Medical Center – Full Blood Siblings One With & One Without AD

ORMC – MDC

UCF - NanoScience Technology Center

Has the Patient ALREADY TOLD YOU what they want?

- If they are already an organ donor, the only organ they can donate is the brain, once they have a dementia diagnosis.
- If they have mild impairment, encourage them to discuss their feelings about donating their brain in an effort to rid the world of these dreaded diseases.

Caregiver Quotes

- “Participating in the Brain Bank is the **ONLY** thing I felt I could do that might bring something positive from my family member’s suffering.”
- “Thank you for giving my mother her last **HOORAH**, a gift to science, a gift to our future.”

Florida's Brain Bank Program

For More Information

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