10 Signs of AD

1. Memory loss
2. Difficulty performing familiar tasks
3. Problems with language
4. Disorientation to time and place
5. Poor or impaired judgment
6. Problems with abstract thinking
7. Misplacing things
8. Changes in personality
9. Changes in mood or behavior
10. Loss of initiative

For more information, call the Alzheimer’s Association at (800) 272-3900.

Sources for Information and Support

The Association for Frontotemporal Dementias (AFTD)
Tel: 267-514-7221 or 866-507-7222
http://www.theaftd.org

Dementias (AFTD)
The Association for Frontotemporal
Tel: 415-434-3388 or 800-445-8106
http://www.associationfrontotemporal.org

Alzheimer’s Association at Indianapolis, IN 46202-3002
410 West 10th Street • HS 4000
National Cell Repository for Alzheimer’s Disease (NCRAD)
Website: www.ncrad.org
Phone: 1-800-526-2839
e-mail: alzstudy@iu.edu

NCRAD Patients
Tel: 954-704-0519 or 305-891-7579
http://cjdfoundation.org

Creutzfeldt- Jakob Disease (CJD)
Tel: 800-311-3435
http://www.cdc.gov

National Organization for Rare Disorders (NORD)
Tel: 212-751-0000 or 800-NORD-2U (6673)
http://www.rarediseases.org

The National Cell Repository for Alzheimer’s Disease Hereditary Genomics Division
Health Information and Translational Sciences Building
412 West 10th Street • HS 6903
Indianapolis, IN 46202-3002
Phone: 1-312-335-8700 or 800-272-3900
Website: www.pdf.org

The Alzheimer’s Biomarker Consortium-Down Syndrome (ABC-DS)
By Drs. Nicole Schupf and Ben Handen — By the time they reach 40 years of age virtually all individuals with Down Syndrome (DS) have neuropathological changes consistent with a diagnosis of Alzheimer’s disease (AD), including diffuse and neuritic plaques, and most will develop dementia by the end of their seventh decade. The increased risk for AD in DS is due to overexpression of APP, leading to elevated levels of Aβ peptides. However, there are large individual differences in Aβ peptide level, and there is a wide range of age at onset of dementia. Thus, there are more complex underlying mechanisms which are not well understood and which influence risk for cognitive decline and age of onset of dementia.
NIA (National Institute on Aging) and NICHD (National Institute of Child Health & Human Development) have recently funded two large, multicenter projects that seek to identify biomarkers that can predict the risk of developing Alzheimer’s disease in adults with Down syndrome. Together they will enroll over 650 adults with DS, ranging from 25 to 85 years of age. The project focuses on longitudinal and multivariate determination of key biomarkers that are likely to define the progression from normal aging to onset of dementia, including levels and ratio of change in blood-based biomarkers such as Aβ peptides, protein, inflammatory and lipid profiles, measures of amyloid and tau, concentrations in cerebrospinal fluid, neuroimaging-based beta-amyloid peptides, protein, inflammatory and lipid profiles, measures of amyloid and tau, concentration in cerebrospinal fluid, neuroimaging-based changes, PET studies of brain amyloid and tau and genetic polymorphisms.
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Adapted from Alzheimer’s Association brochure —

Amyloid Scanning Study. In this study, scientists want to learn how images of the brain may be able to help doctors treat dementia patients, and if that treatment may lead to better results.

The IDEAS Study will focus on brain images called amyloid PET scans. PET stands for Positron Emission Tomography. These scans can show if amyloid plaques are building up in the brain. Amyloid plaques are sticky clumps of protein in the brain. Plaques are associated with Alzheimer’s disease, but can also be seen with aging and other brain disorders. The presence or absence of amyloid plaques will help doctors determine if the likelihood that dementia related symptoms are caused by Alzheimer’s disease.

If the subject is eligible, a radiopharmaceutical, which is also called a radioactive tracer, will stick to the plaques for a short time, allowing PET scanning to determine the likelihood that dementia related symptoms are caused by Alzheimer’s disease, but can also be seen with aging and other brain disorders. While the study is ongoing, PET scanning will highlight them. A radiopharmaceutical, which is also called a radioactive tracer, will stick to the plaques for a short time, allowing PET scanning to determine the likelihood that dementia related symptoms are caused by Alzheimer’s disease.

Subjects participating in the IDEAS Study are also offered the opportunity to participate in additional related add-on projects. One of these projects is based out of the National Cell Repository for Alzheimer’s Disease (NCRAD) and is called the Alzheimer’s Disease Genetics Initiative (the purpose of the study is to pair the clinical information and brain imaging findings of subjects used in IDEAS, or related studies, with DNA obtained from a saliva sample). DNA is the genetic material in each of us that makes us unique. It contains all of the genetic instructions that support the development, growth, functions, and characteristics of each individual. DNA is the blueprint for all that we are. Genetic information can be acquired and altered (e.g., through exposure to environmental stressors) and passed to future generations. Genetic information can also be altered during the process of cell division and is part of the cell’s genetic makeup.

To learn more, go to: www.IDEAS-Study.org/patients

Meet the newest members of our NCRAD staff

Madeline Potter, BA has been with the Department of Medical and Molecular Genetics since January 2015 and is new to the NCRAD team. Madeline works as a research coordinator and her duties include data validation, sample accessioning, data validation and work with study subjects to ensure efficiency.

To reach Madeline directly, please email mpotter@indiana.edu or call (317)278-1546.

Kris Wilmes, MS is a new member to NCRAD and has been with the Department of Medical and Molecular Genetics since 2015. Kristi has a Master of Science in Clinical Research Administration. Her duties include coordinating studies within NCRAD, data validation and working with study subjects to ensure efficiency.

To reach Kristi directly, please email wwilmes@indiana.edu or call (317)278-7546.

Kaci Lacy, BS is new to the Department of Medical and Molecular Genetics. She graduated from Indiana University in 2015 with a BS in Biology. Kaci’s research coordinator and her duties include sample accessioning, preparing sample kits, and data validation.

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If the plaques are present, PET imaging will show how much amyloid PET scanning upon physician request. This could be at a hospital or an outpatient center. After the amyloid PET scan, subjects complete a follow-up visit with the dementia care team. The information and DNA samples that are collected through the IDEAS Study are used in IDEAS, or other related studies, with DNA obtained through other collaborative efforts.

Meet the newest members of our NCRRAD staff

Madeline Potter
Madeline Potter, BA has been with the Department of Medical and Molecular Genetics since January 2015 and is a new member to NCRRAD. Madeline was a research coordinator and her duties include database maintenance, data collection, preparation of medical documents, and scheduling and tracking of samples. She also helps complete annual chart reviews.

To reach Madeline directly, please email mapotter@indiana.edu or call (317) 278-9546.

Katie Lacy
Katie Lacy, BSN has a new member status with NCRRAD and has been with the Department of Medical and Molecular Genetics since 2015. Katie has a Master of Science in Clinical Research Administration. Her duties include coordinating studies within NCRRAD, data validation and working with study sites to ensure efficiency.

To reach Katie directly, please email ktlacy@indiana.edu or call (317) 278-7546.

Research Opportunities

4 Repeat Neuroimaging in Alzheimer’s Disease (4RNDA-2)

Purpose: To identify the most reliable methods of analysis for tracking CSF, MRI and PET over time. The results from this study may be used in the future to calculate statistical power for clinical drug trials. This study will also provide information about the relative validity of novel imaging techniques versus testing of CSF, urine and cerebrospinal fluid biomarkers.

Eligibility: Males and females age 18 and older, with a diagnosis of Alzheimer’s disease or at-risk for AD

Contact: Dr. Tad M.公布的地址或电话

Dominated by Inherited Alzheimer’s Disease (DiNA)

Purpose: To study brain changes in people with Alzheimer’s disease mutations in order to determine how the disease process develops in the absence of amyloid plaques.

Eligibility: Males and females age 55 or older, diagnosis of mild to moderate Alzheimer’s disease, good general health and medically stable

Contact: Dr. Zhao and the DIANA webpage

Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS)

Purpose: To model the rates of decline in clinical function of those suffering from Frontotemporal Lobar Degeneration (FTLD) and identify potential biomarkers for use in clinical drug trials.

Eligibility: Males and females age 18 and older, diagnosis of FTLD

Contact: PH: 314-286-2683 or DIAN webpage: https://www.rarediseasesnetwork.org/ARTFL/index.htm

Longitudinal Evaluations of People with Cognitive Impairment (LEPCI)

Purpose: To model the rates of change in clinical function of those suffering from Mild Cognitive Impairment (MCI) and identify potential biomarkers for use in clinical drug trials.

Eligibility: Males and females age 18 and older, diagnosis of MCI

Contact: PH: 314-286-2683 or DIAN webpage: https://www.rarediseasesnetwork.org/ARTFL/index.htm

Contact:

Phone: 1-800-536-2839
Email: abotkin@dir.niddk.nih.gov
Website: www.nicrd.org
Meet the newest members of our NCRAF staff

Madeline Potter, MD
Madeline Potter, BA has been with the Department of Medical and Molecular Genetics since January 2023 and is a new recruit to NCRAF. Madeline was a research coordinator and her duties include data validation, sample processing, and sample requests. She also helps complete annual chart reviews.

To reach Madeline directly, please email mpotter@ukyd.edu or call (317)278-9546.

Katie Lacy
Katie Lacy is a new member to the Department of Medical and Molecular Genetics. She graduated from Indiana University in 2013 with a BS in Biology. Katie leads a research coordinator and her duties include sample processing, preparing sample kits, and data validation.

To reach Katie directly, please email klacy@ukyd.edu or call (317)278-7170.

The IDEAS and ANGI Studies

Adopted from Alzheimer's Association brochure

A new four-year research study, conducted by the Alzheimer’s Association and the University of California, San Francisco, is designed to help doctors better treat those individuals with dementia. The study will be conducted through the University of California, San Francisco, and involves the use of PET scans to identify new treatments and improve the health of those affected by dementia.

Subjects To be part of the study, subjects will need to be evaluated by a specialist in dementia. Subjects are eligible to participate in the IDEAS study if they:

• Are a Medicare beneficiary
• Are a U.S. citizen
• Are 65 years of age or older
• Have ongoing memory problems or confusion and the subject or friend has found it cause a problem
• Have a medical history of dementia or other cognitive impairment, but the cause is unclear

To be part of the study, subjects will need to be evaluated by a doctor who is an IDEAS Study dementia specialist. Subjects will also visit an IDEAS Study PET facility for a brain

anatomical PET scan under physician receipt. This could be at a hospital or an outpatient center. The anatomical PET scans, subject complete a follow-up visit and receive the scans. The scans can be used to identify plaques and help doctors better treat dementia. The presence of amyloid plaques has been shown to cause Alzheimer’s disease, but the signs and symptoms of this disease can be difficult to diagnose. The information and DNA samples that are collected will be used to help scientists identify genetic and biofluid factors that modify these rates.

Purpose: To model the rates of decline in clinical function of those suffering from Frontotemporal Lobar Degeneration (FTLD) and identify genetic and biofluid factors that modify these rates.

Contact: PH: 415-476-9578 or 4RTNI2 webpage: Locations: CA

Eligibility: Men and women ages 40 to 80, diagnosis of Progressive Supranuclear Palsy or Corticobasal Degeneration (CBD)

Purpose: To study brain changes in people who carry an Alzheimer’s disease mutation in order to determine how the disease process develops before the onset of symptoms.

Contact: Mayo Clinic in Jacksonville, University of Pennsylvania, Northwestern University, University of Toronto, University of British Columbia, and Mayo Clinic, Jacksonville, FL, United Kingdom; Australia

Email: info@ncraf.org
Website: www.ncraf.org

Research Opportunities 4 Repeat Sympathetic Nerve Imaging Initiative - Cycle 2 (4RNSI-II)

• Purpose: To identify the most reliable methods of imaging for tracking OFD (SFN and OFN) over time. The results from this trial may be used in the future to calculate statistical power for clinical drug trials. This study will also provide information about the relative value of imaging technologies, specifically for SFN, in the imaging of OA using traditional clinical trial methodology.

• Eligibility: Men and women ages 18 to 80, diagnosis of Progressive Superficial Polyarthritis (COPA) or Disseminated Arthritis (CDA)

Dominantly Inherited Alzheimer Network (DIAN)

• Purpose: To study brain changes in people who carry mutations that cause Alzheimer’s disease in order to determine how the disease process develops before the onset of symptoms.

• Eligibility: Men and women ages 55 to 85 years, diagnosis of familial Alzheimer’s disease, good general health and medically able to undergo imaging.

Locations: CA, CO, CT, EU, NE, UK, Australia

Contact: DIAN: 1-216-714-2400 or DIAN@ukyd.edu

Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL)

• Purpose: New therapies targeting some of the molecular causes of FTLD are rapidly becoming available for testing in human clinical trials. The ARTFL study is a preclinical study for clinical trials of these new therapies and is designed to be comparable to large, randomized, controlled clinical trials to provide a foundation for the development of new treatments.

• Locations: Mayo Clinic, Rochester

Contact: Mayo Clinic in Jacksonville, University of California in San Diego, University of California in San Francisco, Harvard/Massachusetts General Hospital, Johns Hopkins Hospital, University of North Carolina, Mayo Clinic Jacksonville, University of Southern California, University of Washington, University of California, San Francisco.

Email: info@artfl.org
Website: www.artfl.org

Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects to UFDIPS

• Purpose: To model the rates of decline in clinical function of those suffering from Frontotemporal Lobar Degeneration (FTLD) and identify genetic and biofluid factors that modify these rates.

• Eligibility: Must be a member of a family with an autosomal dominant, a rare variant of a common variant, or a carrier with an unrelated phenotype and provide at least one parent or sibling with a known familial variant. The subject must be willing to undergo yearly evaluations for a period of three years.

• Contact: Mayo Clinic in Jacksonville

Email: info@artfl.org
Website: www.artfl.org

North Carolina Alzheimer’s Disease Research Center (NCADRC)

• Purpose: To develop and implement methods for the efficient and effective analysis of research data. Data analysts will work closely with investigators to ensure that data are collected and analyzed accurately and efficiently.

• Eligibility: Must be a member of a family with a known familial variant, a rare variant of a common variant, or a carrier with an unrelated phenotype and provide at least one parent or sibling with a known familial variant. The subject must be willing to undergo yearly evaluations and provide information about the disease process.
Sources for Information and Support

**National Cell Repository for Alzheimer's Disease Hereditary Genomics Division**

Health Information and Translational Sciences Building
410 West 10th Street • HS 4000
Indianapolis, IN 46202-3002

Phone: 1-800-526-2839
e-mail: alzstudy@iu.edu
Website: www.ncrad.org

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Hereditary Genomics Division

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\*A peek at the list of 10 Signs of Alzheimer's Disease:

1. Memory loss
2. Difficulty performing familiar tasks
3. Problems with language
4. Disorientation to time and place
5. Poor or unexplained weight loss
6. Problems with abstract thinking
7. Misplacing things
8. Changes in personality
9. Change in mood or behavior
10. Loss of initiative

\*The Alzheimer's Association is a registry of federally supported Alzheimer's disease centers. The association provides information about the disease and its impact on families.

\*Research Match is a free service for researchers interested in participating in research projects supported by the NIH and other sources, including private foundations.

\*The National Cell Repository for Alzheimer's Disease Hereditary Genomics Division is a data and resource initiative, Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS), that collects blood and brain tissue samples from families with Alzheimer's disease (AD) or Down syndrome (DS) to study the underlying mechanisms of AD. The grant for this prospective study is part of a National Institutes of Health (NIH) initiative to combat AD in DS, augmented by biomarker outcomes. This information should be used in the context of a scientific study conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details.

\*These are good sources for research opportunities and resources for information and support:

1. Alzheimer's Association
2. Alzheimer's Association at the Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS)
3. For more information, call the Alzheimer's Association at (800) 272-3900

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\*10 Signs of Alzheimer's Disease

**Problems with language**

Changes in personality

Misplacing things

Changes in mood or behavior

Difficulty performing familiar tasks

1. Memory loss
2. Difficulty performing familiar tasks
3. Problems with language
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Sources for Information and Support

1. National Alzheimer's Association
   - Phone: 1-800-272-3900
   - Website: www.alz.org
2. Alzheimer’s Disease Education and Referral Center (ADEAR)
   - Phone: 800-272-3900
   - Website: www.alz.org
3. The Association for Frontotemporal Dementias (AFTD)
   - Phone: 203-746-6518
   - Website: www.aftd.org
4. National Organization for Rare Disorders (NORD)
   - Phone: 1-800-999-NORD (6673)
5. Creutzfeldt-Jakob Disease Center
   - Phone: 1-800-445-8106
   - Website: www.cdc.gov
6. The Association for Frontotemporal Dementias
   - Phone: 312-335-8700
   - Website: www.aftd.org
7. The Association for Frontotemporal Dementias (AFTD)
   - Phone: 203-746-6518
   - Website: www.aftd.org
8. National Society of Genetic Counselors
   - Phone: 800-311-3435
   - Website: www.nsgc.org
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National Cell Repository for Alzheimer’s Disease

Indiana University Health Information and TRANSLATION Center on Aging
410 West 10th Street • HS 4000
Indianapolis, IN 46202-3002

Phone: 1-800-526-2839
E-mail: alzstudy@iu.edu
Website: www.ncrad.org

The National Cell Repository for Alzheimer’s Disease (NCRAD) is a tissue bank with a mission to pool specimens collected from families with Alzheimer’s disease (AD) or other related diseases. Our hope is that through the efforts of our partners, we will one day unravel the mystery of Alzheimer’s disease and help us move forward to a world free of AD.

By Dr. Nicole Schiff and Ben Handen – By the time they reach 40 years of age virtually all individuals with Down Syndrome (DS) have neuropathological changes consistent with a diagnosis of Alzheimer’s disease (AD), including amyloid deposition in diffuse and neuritic plaques, and most will develop dementia by the end of their second decade. The cumulative risk for AD in adults with DS is as high as 90% for those with DS born after 1980, and in infants born in 2000 this risk increases to 100%. Despite the high risk of AD in DS, there is limited information on the longitudinal and multidisciplinary determination of key biomarkers that are likely to define the progression from normal aging to onset of dementia, including levels and ratios of change in blood-based biomarkers such as amyloid, tau, and phosphorylation levels in AD-related proteins with DS.

NIA (National Institute on Aging) and NICHD (National Institute of Child Health & Human Development) have recently funded two large, multicenter projects that seek to identify biomarkers that can predict the risk of developing Alzheimer’s disease in adults with Down syndrome. Together they will enroll over 650 adults with DS, ranging from 25 to 85 years of age. The project focuses on longitudinal and multidisciplinary determination of key biomarkers that are likely to define the progression from normal aging to onset of dementia, including levels and ratios of change in blood-based biomarkers such as amyloid, tau, and phosphorylation levels in AD-related proteins with DS. These biomarkers will be combined to develop the most valid indicators of synchonal and early stages of Alzheimer’s. All of the blood-based biomarker for this study will be banked at National Cell Repository for Alzheimer’s Disease. It is expected that AD-related proteins with DS will be used to develop a model for predicting risk that may allow for future therapeutic interventions before irreversible cognitive deterioration has occurred. The goal of this study is to understand biomarker relationships and the pathways implicated in AD pathogenesis, to identify critical factors that link central AD deposition to neurodegeneration, and develop a model for predicting risk that may allow for future therapeutic interventions before irreversible cognitive deterioration has occurred. It will be a foundation for an efficient transition from this biomarker study to a therapeutic trial to combat AD in DS, augmented by biomarker outcomes.

This grant for this prospective study is part of a National Institute of Health initiative, Alzheimer’s Biomarker Consortium-Down Syndrome (ABC-DS), that...