What You Should Know about Clinical Trials for Alzheimer’s Disease

Information for and from Families

Brighter Futures Workshop – Friday March 27, 1.30-3.00pm

national down syndrome society
ndss®

Presentation Agenda

I. Introductions

II. Clinical research in Down Syndrome-associated Alzheimer's disease

III. Community survey insights – attitudes toward research participation

IV. Interacting with a study team

V. First-Person Experience – Insights from a clinical trial participant and study partner

VI. Question & answer

NDSS is creating a world where individuals with Down syndrome thrive.

NDSS Core Pillars

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:

- Resources & Support
- Research
- Advocacy & Policy
- Community Engagement

NDSS Core Pillars

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving, and more


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Down Syndrome Regression Disorder

Down Syndrome Regression Disorder

Down syndrome regression disorder (DSRD), also referred to as regression, is a rare but serious disorder that occurs in some adolescents and young adults with Down syndrome. Regression is used to describe the loss of skills an individual has previously learned. These skills can be daily living, language, movement, or social skills. The loss is often sudden and occurs over a period of weeks to months. Since DSRD may be caused by a variety of factors, the first priority is to determine the most likely cause. Individuals who are younger than 10 years or older than 30 years are very rarely diagnosed with DSRD. If these individuals are experiencing regression-like symptoms, a close look at all other factors must be taken before giving the diagnosis of DSRD.

In 2022, a group of medical experts with experience treating regression in patients with Down syndrome gathered to create the first criteria for diagnosing DSRD. These criteria provide guidance to physicians and families who do not have access to specialists in DSRD. There are eight clusters of symptoms linked to regression, and some are broken down into specific examples. Individuals who are experiencing four or more of the eight symptom clusters are considered "possible" cases of DSRD, meaning further investigation is needed. Individuals who have seven or eight of the eight symptom clusters are considered "probable" cases, meaning they are likely to receive a diagnosis of DSRD if no other cause can be found.

Testing

If you or your loved one are experiencing symptoms in the checklist (see page 3), it is recommended that you make an appointment with your primary care doctor or neurologist as soon as possible. The diagnosis of DSRD is mostly based on symptoms, but your doctor may order some of the following medical tests as part of the evaluation:

- Imaging of the brain with an MRI
- Blood work
- Urine tests (if necessary)
- Lumbar puncture (also known as a spinal tap)
- Electroencephalogram (EEG)
- Genetic or metabolic testing (if necessary)
- Polysomnogram (sleep study)

For more detailed testing recommendations, you and your doctor can read the *Assessment and Diagnosis of Regression in Down Syndrome* (Santoro et al., Front Neurol. 2022). https://www.frontiersin.org/articles/10.3389/fneur.2022.846175/full

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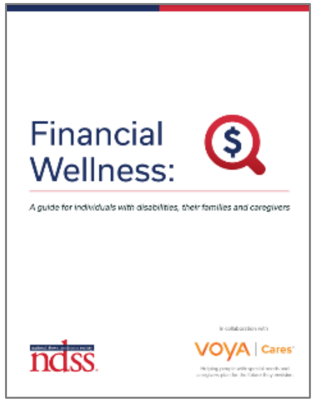
DOWN SYNDROME
Guidelines for Inclusive Education
DECEMBER 2021
ndss
down syndrome education international
discovering potential · transforming lives


Financial Wellness:
A guide for individuals with disabilities, their families and caregivers
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In collaboration with
VOYA | Cares

NDSS Core Pillars

Research

- Bridge between research and our community
- Coordinating research projects
- Preparing scientific industry companies for clinical trials
- Sharing research opportunities with families
- Expanding access to clinical trials, treatments, and diagnostics

NDSS Core Pillars

Advocacy & Public Policy

- Federal, state, and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome

NDSS Core Pillars

Community Events

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video Presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!

Upcoming NDSS Events

national down syndrome society®
Down Syndrome
Advocacy
Conference

[Down Syndrome Advocacy Conference](#)
May 11-13, 2026
Washington D.C.

NEW YORK CITY
BUDDYWALK®
national down syndrome society
EDUCATE | ADVOCATE | CELEBRATE

New York City Buddy Walk
September 12, 2026
New York City, NY

Research specific! www.NDSS.org/pfdd

Two important dates:

- **Monday, April 6:** community webinar to prepare for PFDD meeting
- **Tuesday, June 2:** Externally-led Patient-focused Drug Development Meeting, streaming online, all day

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Clinical Trials in Down Syndrome-associated Alzheimer’s Disease

Introduction to clinical research in Down Syndrome-associated Alzheimer’s disease

ABL
Ances Bioimaging Laboratory

WASHINGTON UNIVERSITY IN ST. LOUIS · 1853 ·

ABC-DS

Beau M. Ances, MD, PhD, MSc, FANA, FANA

- Daniel J Brennan Professor of Neurology
- Vice Chair of Academic Affairs
- Department of Neurology

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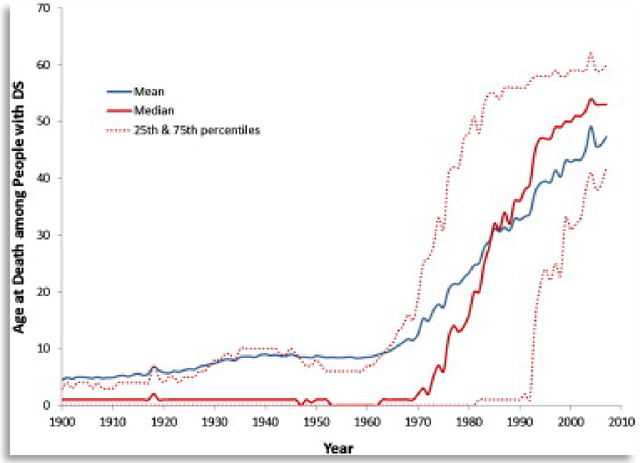
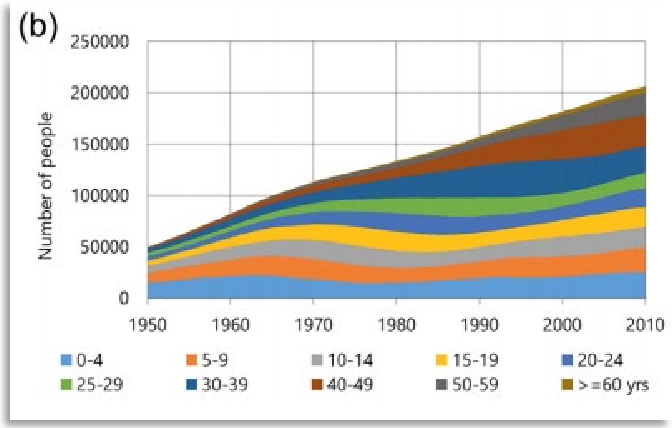
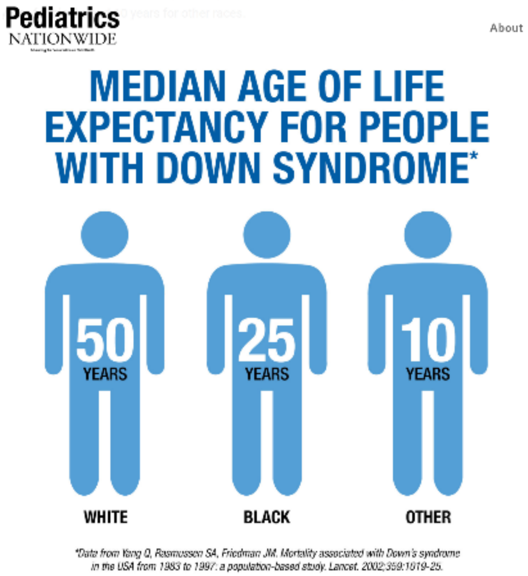
People with Down syndrome are living longer, but differences exist



A 3.75-fold increase in average life expectancy since 1970 (Presson et al., J Peds., 2013).

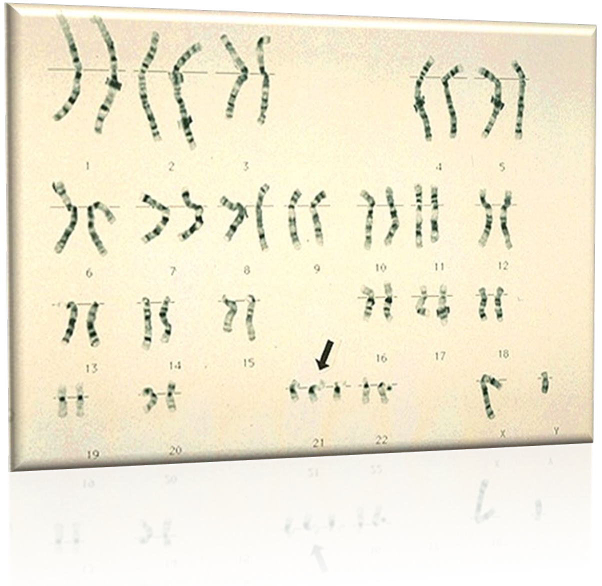


Fastest growing segment is 40-49 years of age (Hithersay et al., 2019)

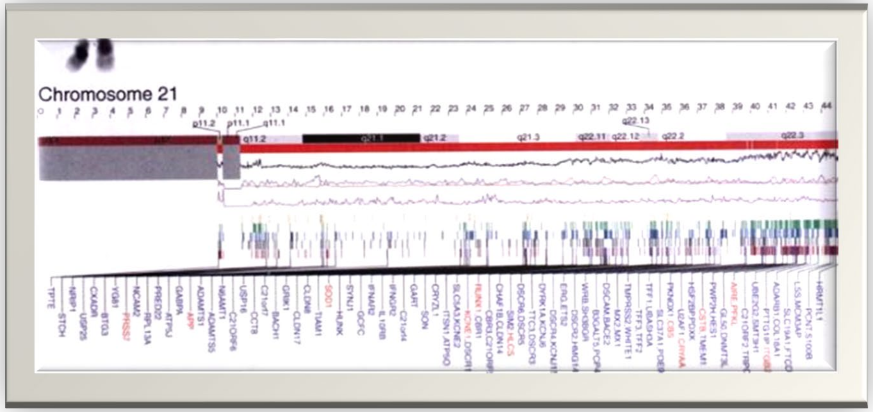


*Data from Yang Q, Rasmussen SA, Friedman JM. Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population-based study. Lancet. 2002;359:1019-25.

Aging people with Down syndrome are vulnerable to Alzheimer’s disease



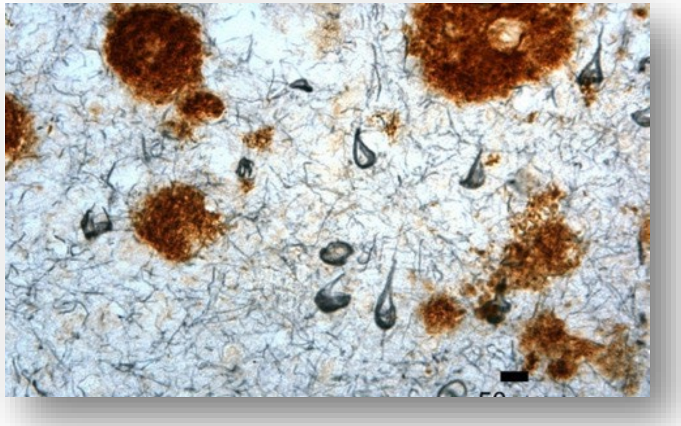
People with Down syndrome are living longer and age is the biggest risk factor for Alzheimer’s disease



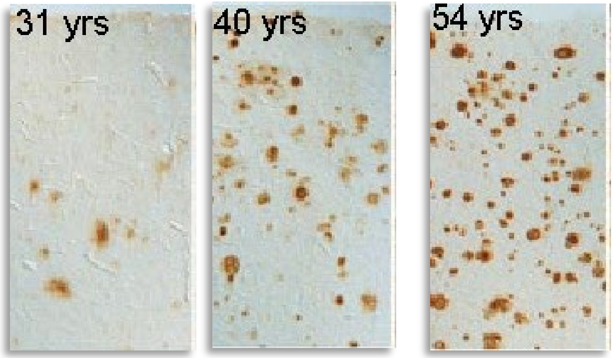
Amyloid precursor protein is present at 1.5 higher levels – overproduction of Aβ

What is Alzheimer’s disease?

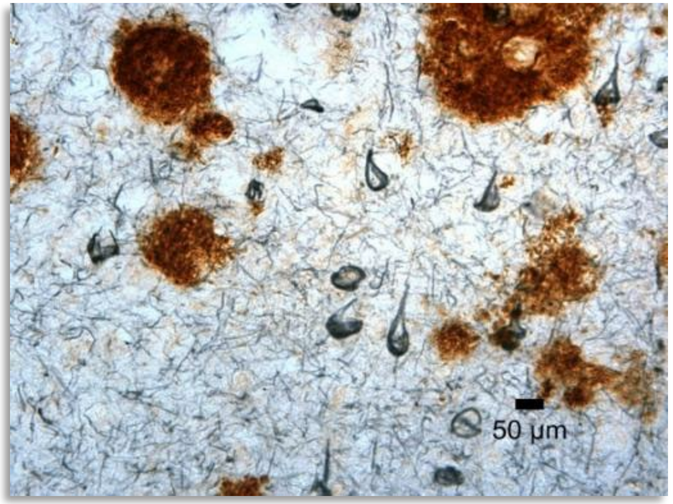
- Described by Alois Alzheimer in 1906
- The most common cause of dementia in the elderly
- Associated with a change in cognition and function that interferes with activities of daily living
- Diagnosed as possible or probable Alzheimer's disease in the clinic
- Verified at autopsy – beta-amyloid plaques and neurofibrillary tangles



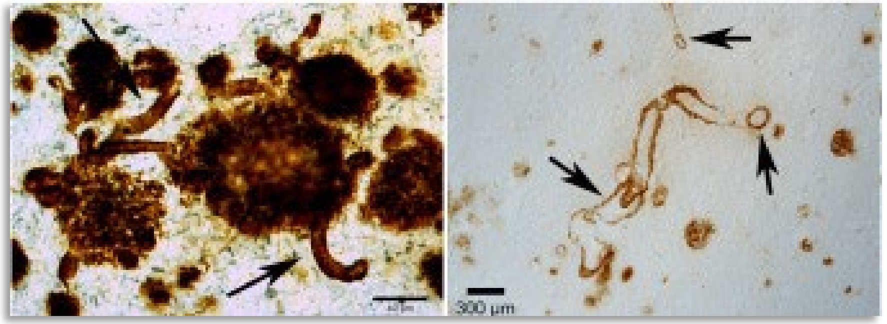
People with Down syndrome develop Alzheimer's disease at an earlier age of onset



Head, Azizeh, Lott, Tenner, Cotman & Cribbs, 2001



Head & Lott, 2019



Clinical Diagnosis of AD in Individuals with Down syndrome Can Be Difficult

- Duration of the disorder from first symptoms to death is 8 years (range, 6-11 years), and the duration from diagnosis to death is 5 years (range, 5-12 years) (Raffi et al., 2020)
- The main clinical symptoms are memory loss, confusion, disorientation, and wandering.

- ✓ Social withdrawal / apathy
- ✓ Disorientation
- ✓ Loss of daily living skills
- ✓ Changes in personality
- ✓ Loss of speech
- ✓ Aggressive behaviors
- ✓ Development of seizures
- ✓ Changes in sleep patterns
- ✓ Major weight change
- ✓ Persistent forgetfulness

Evaluation of Dementia in DS Individuals

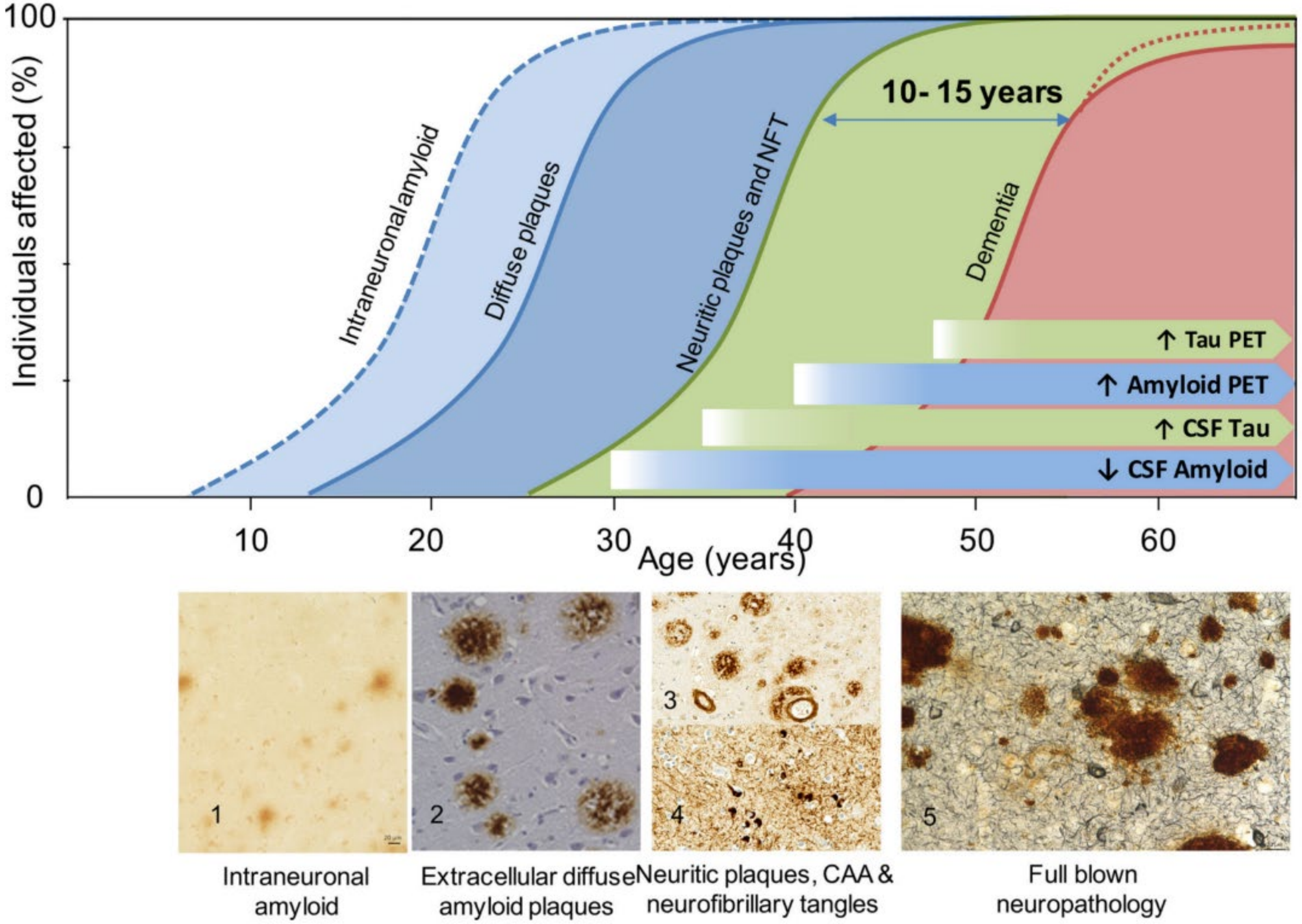
Differential Diagnosis

- *Depression, Anxiety, Psychosis*
- *Medical disorders* (e.g. hypothyroidism)
- *Sensory problems* (cataracts)
- *Medication*: Polypharmacy- potential role for deprescribing

Evaluation

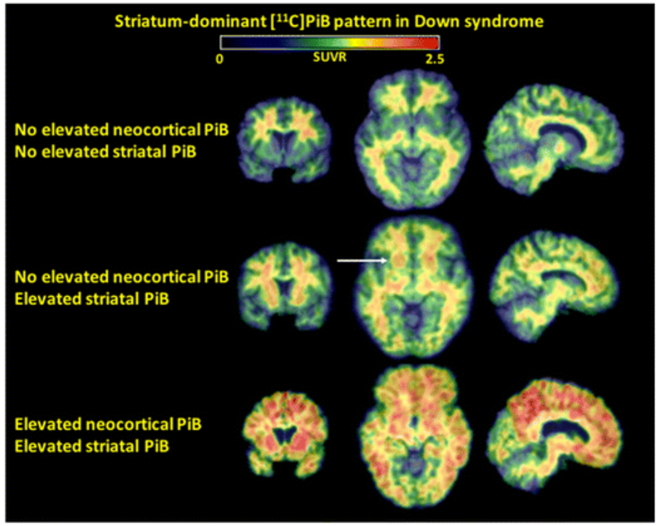
- Annual thyroid screening (TSH and T4)
- Ophthalmologic evaluation every two years (looking especially for cataracts)
- Fasting glucose, B12, and lipid panel
- Hashimoto’s encephalopathy-anti-thyroglobulin, anti-thyroid peroxidase
- Cognitive testing- especially if change from premorbid functioning at 35 years old
- Brain imaging- can consider brain volumetrics to help track trajectories

Hypothesized Timeline of AD Changes in DS

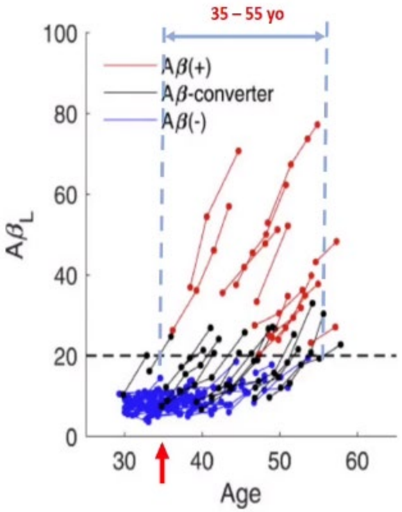


Fortea et al., *Lancet Neurol.*, 2021
Head and Ances, *Lancet*, 2020
Lott and Head, *Nat Rev Neurol*, 2019

Amyloid Deposits Quickly Accumulate in the Brain



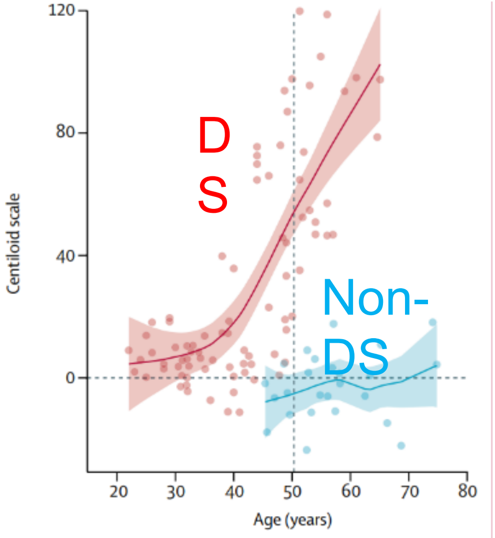
Lao et al., *Brain Imaging and Behavior*, 2019



$A\beta_L$ metric = Global outcome measure of Aβ burden. Calculated by the linear least squares method between the SUVr image and population-derived templates.

Converters = AB_L 13.3

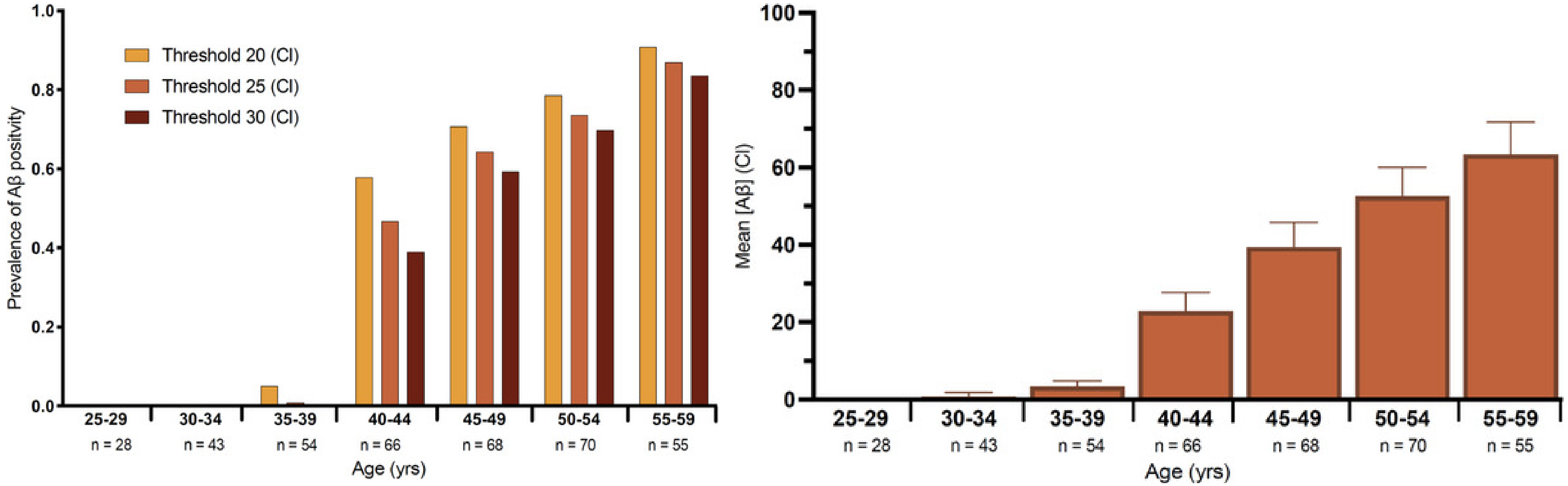
Zammit et al., *DADM*, 2020



Fortea et al., *Lancet*, 2020

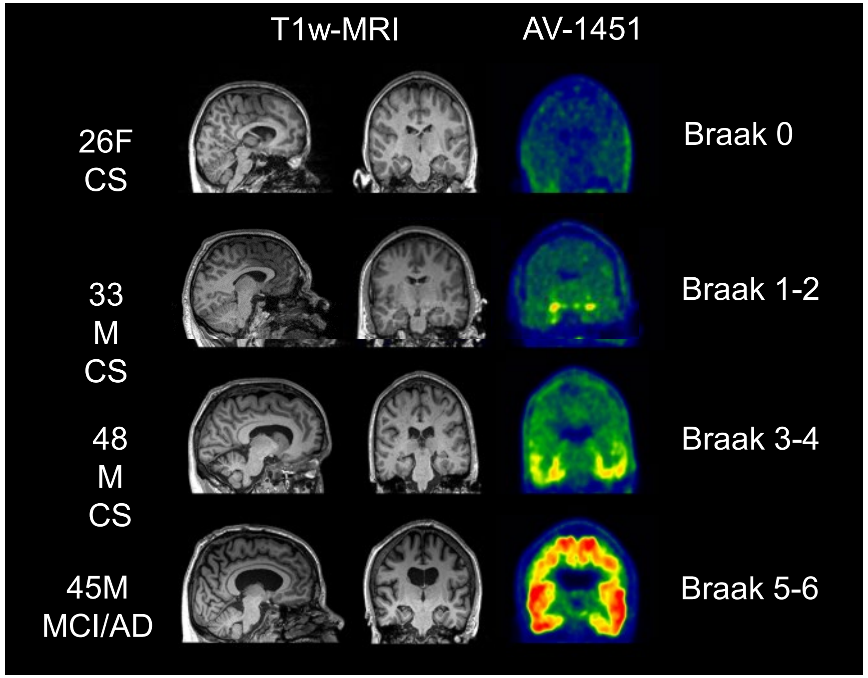
- **Rates of amyloid accumulation is greater in DSAD compared to late onset AD**

Amyloid Increases with Age in Down syndrome

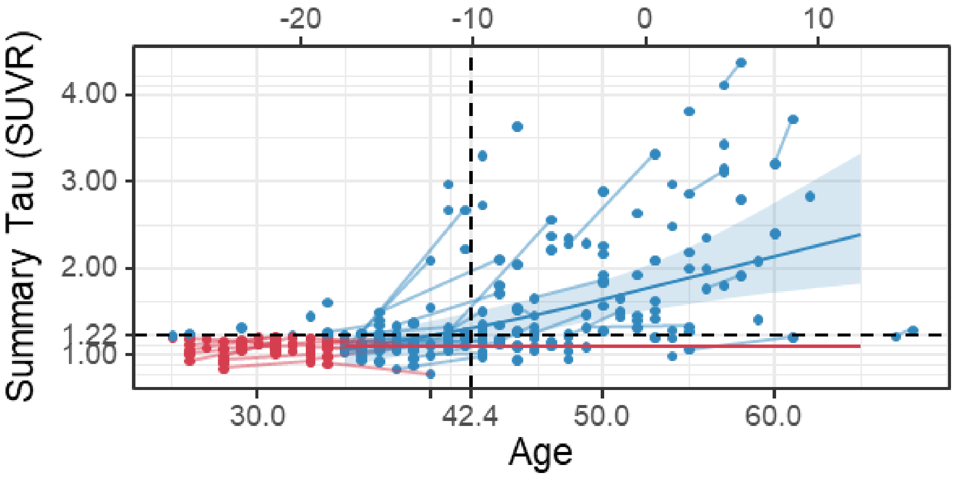


Krasny et al., *Alz Dem,* 2024

Tau Changes Soon After Amyloid



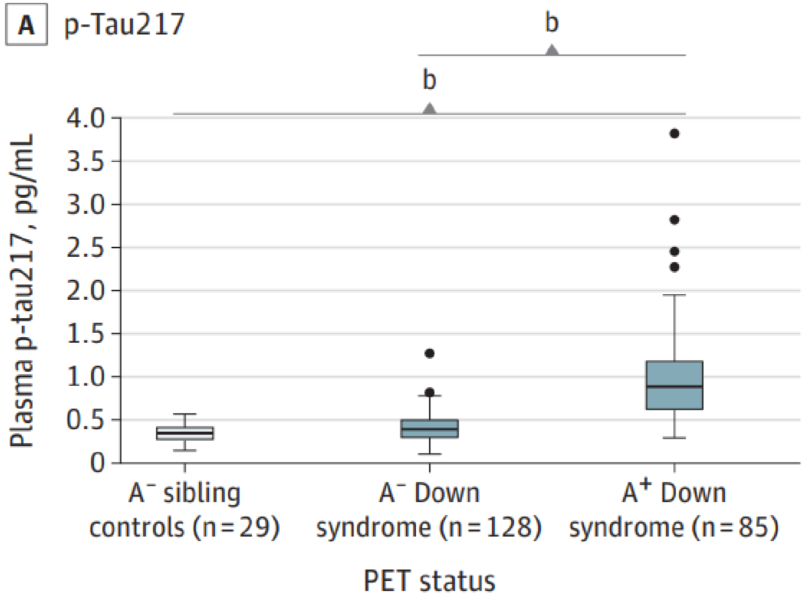
Rafii et al., 2017; Zammit et al., 2020

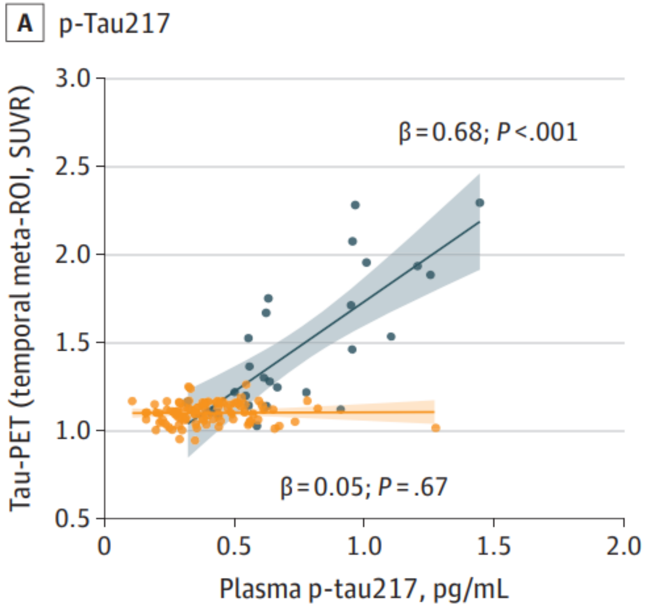


Wisch et al., *Brain*, 2025

Tau is elevated in adults with Down syndrome adults who have amyloid

Plasma P-Tau217 Detects Both Amyloid and Tau Pathology in Down syndrome

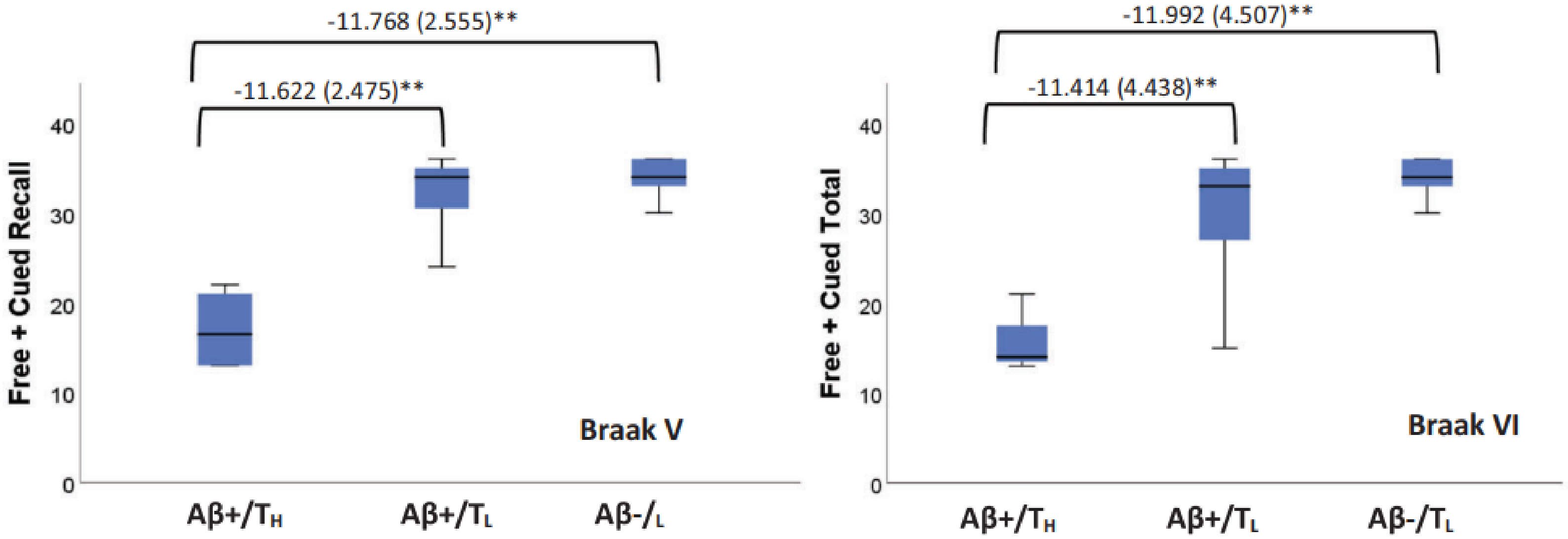




● Aβ-PET positive
● Aβ-PET negative

Janelidze et al., *JAMA Neurol.*, 2022

Changes in Tau Are Associated With Worse Cognitive Performance

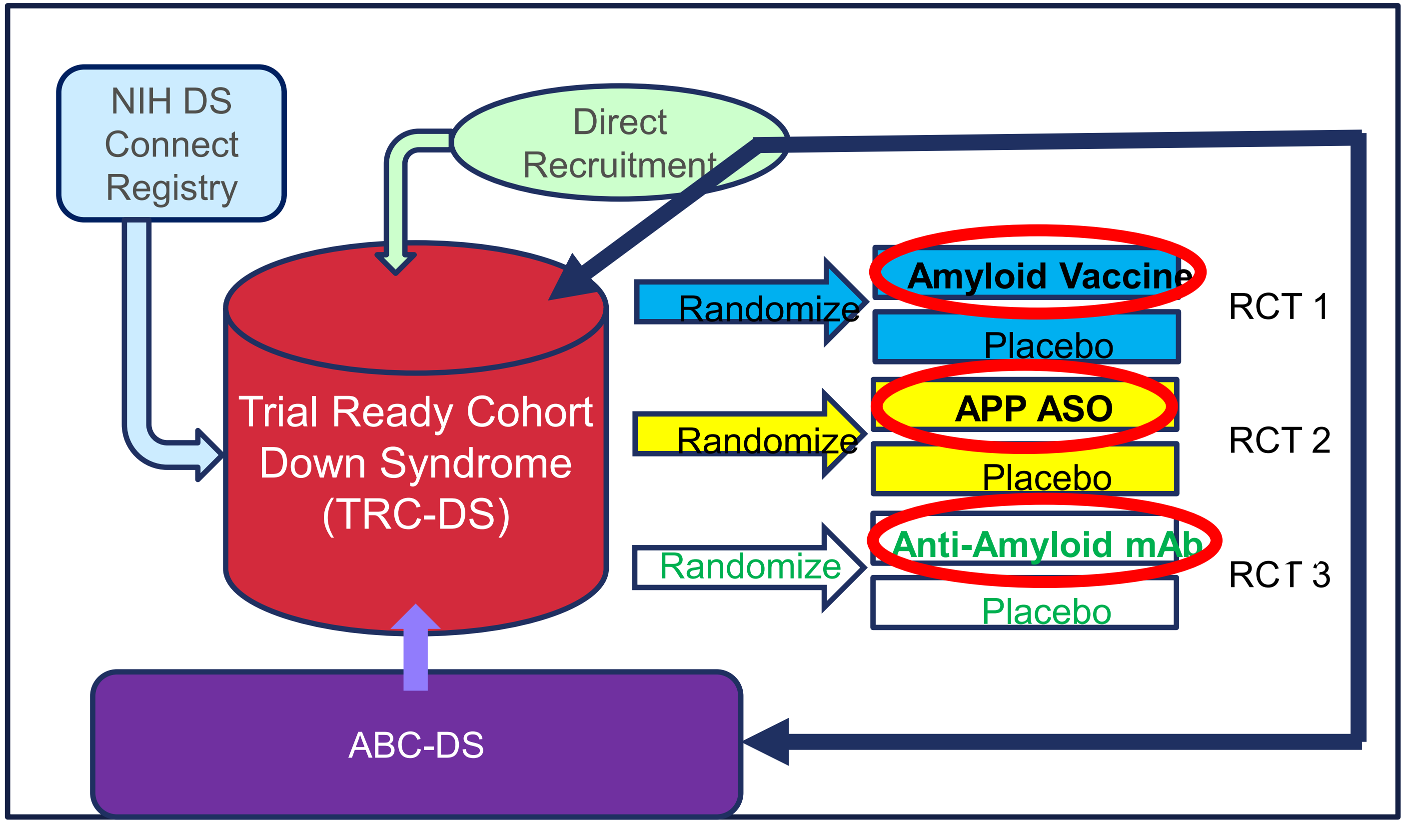


Hartley et al., *DADM*, 2021

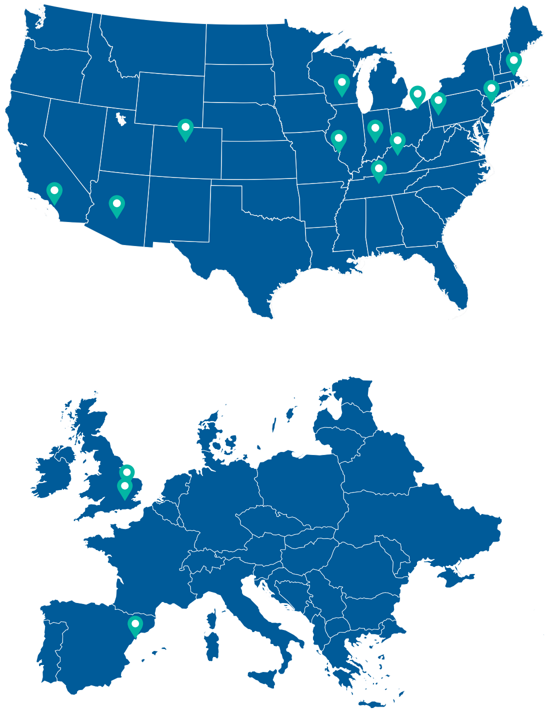
- Higher Amounts of Tau are associated with worse cognitive performance

Trial Ready Cohort (TRC) for Down Syndrome

TRC DS
Trial-Ready Cohort-Down Syndrome

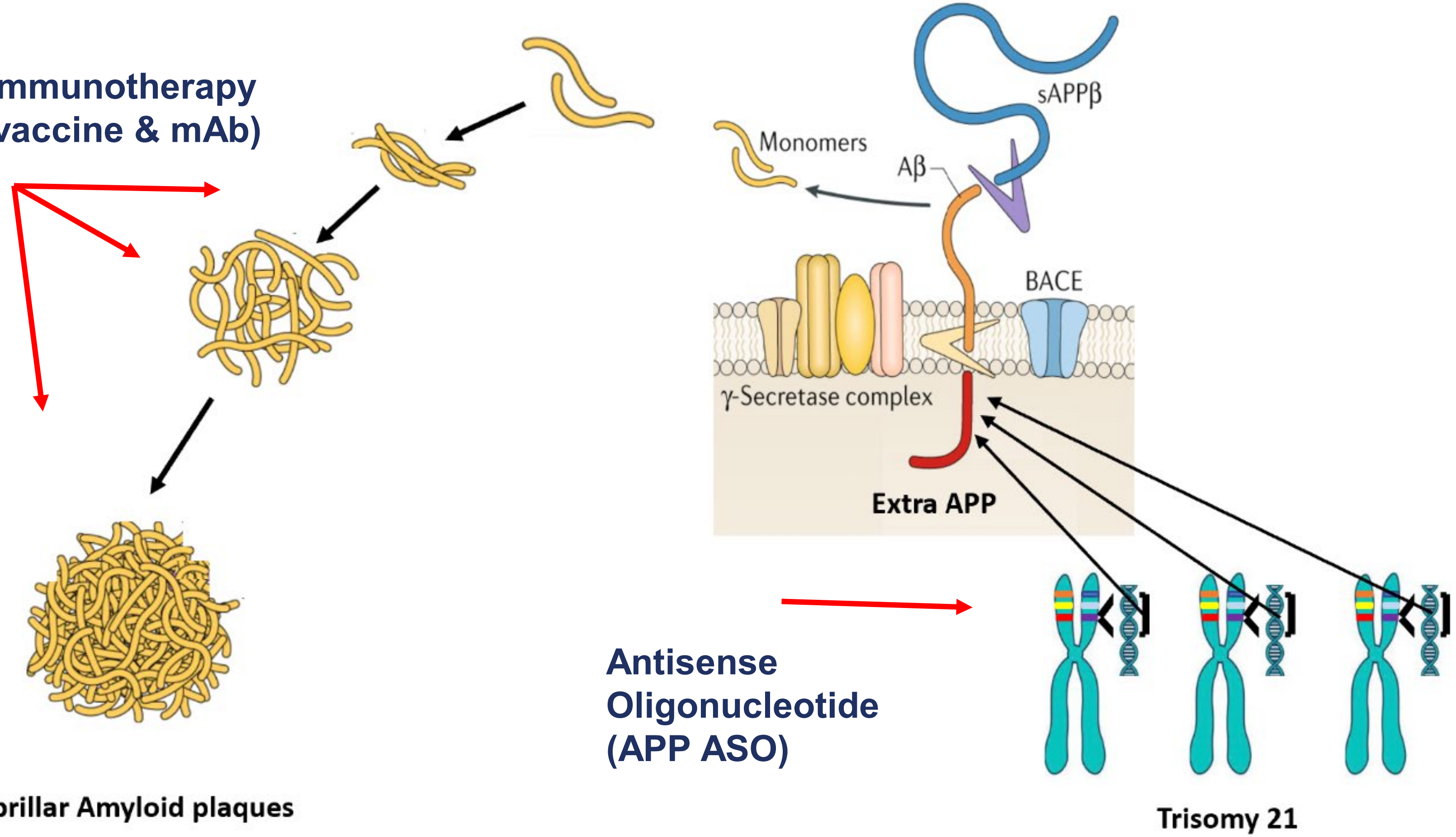


Sites



Healthy adults with Down sydnrome between 25-55 years old- **we need more volunteers**

New Therapeutic Targets for DS-AD Include Beta-Amyloid and APP



Immunotherapy (vaccine & mAb)

Antisense Oligonucleotide (APP ASO)

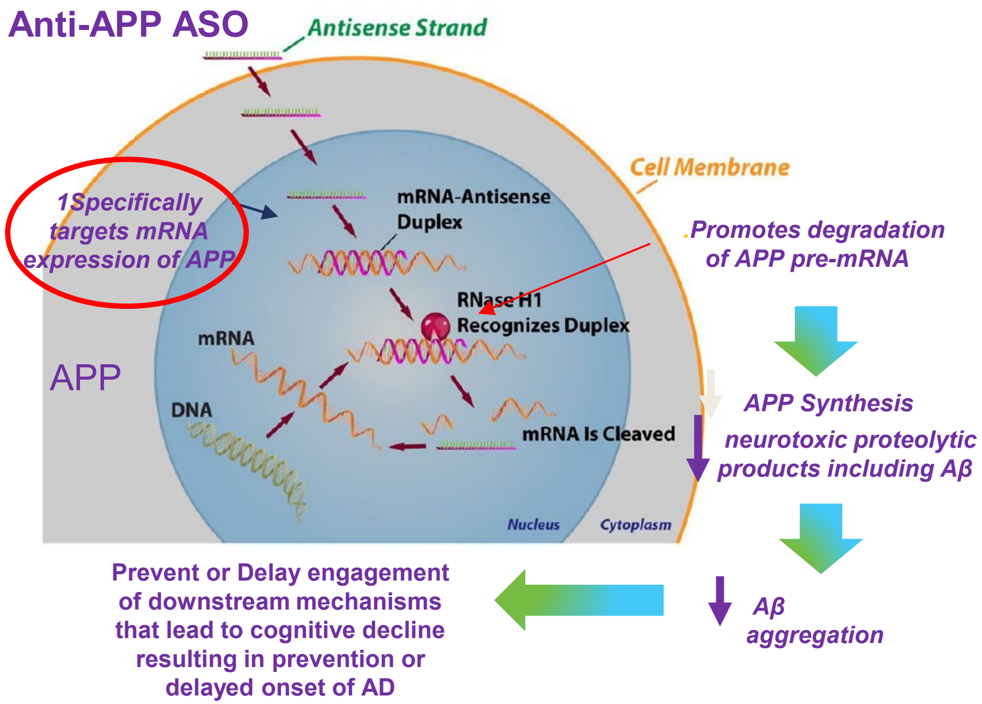
Vaccination for Amyloid Clinical Trial

www.abate-study.com

- A phase 1b/2, multicenter, double-blind, randomized, placebo-controlled study to assess the safety, tolerability, immunogenicity, and pharmacodynamic effects of ACI-24.060 in participants with prodromal Alzheimer’s disease and in adults with Down syndrome (ABATE)
- A total of 35 participants worldwide will be enrolled
- 35-50 years old persons with DS who are cognitively stable and have elevated brain amyloid
- Six intramuscular injections over 74 weeks with 26 weeks of observational follow-up
- 14 sites (7 US and 7 Europe)
- Launched end of December 2023 - it will soon be completed

Antisense Oligonucleotide (ASO) Targeting APP in Down syndrome

- Participants 35-55 years old with Down syndrome at risk for AD
- The study is specifically designed for people with DS before they have clinical symptoms of AD
- Main goals:
  - To learn about the study treatment's safety
  - To learn about how well the study treatment reduces levels of APP
- Study was stopped due to poor enrollment



Anti-APP ASO

1Specifically targets mRNA expression of APP

APP

.Promotes degradation of APP pre-mRNA

APP Synthesis

neurotoxic proteolytic products including Aβ

Aβ aggregation

Prevent or Delay engagement of downstream mechanisms that lead to cognitive decline resulting in prevention or delayed onset of AD

HERO

ALADDIN – **A**myloid **L**owering for **A**lzheimer’s in **D**own’s **D**onanemab **IN**vestigation

ALADDIN STUDY

- The study is specifically designed for people with DS and is testing the FDA-approved drug donanemab.
- We want to confirm its effect in people with DS so that it can be prescribed safely in this population.
- Adults with Down syndrome have been excluded from current clinical trials for late onset AD
- Will be enrolling in the end of 2026.

Take Home Messages

1. DSAD is a genetic form of AD with nearly all adults developing dementia due to AD
2. Biomarkers of amyloid and tau can help stage adults with DS
3. AD process is more compact in Down syndrome compare to late onset AD
4. Adults with Down syndrome have been excluded from clinical trials. New therapies are now being investigated for adults with DS.
   We need more volunteers!
5. Adults with Down syndrome are potentially the ideal population to understand AD. Results will not only help adults with Down syndrome but also the general population.

Acknowledgements

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Thanks to all of our amazing participants and families

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  - Michael Yassa PhD

ABC-DS

- Funding Support
  - NIA
  - NICHD
  - Bright Focus
  - Alzheimer Association

Ances Bioimaging Laboratory Is Committed to Giving Back to the Community

Vaccination Clinics

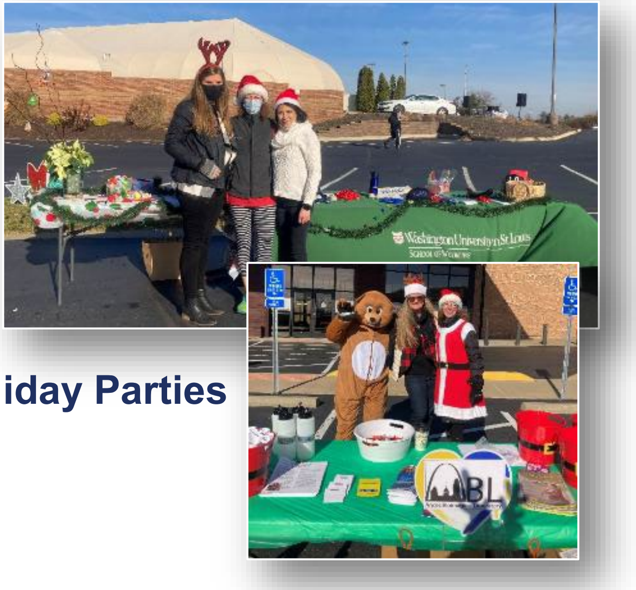
Bowling Night

Trivia Night

Artists Wall

Step Up for DS

Participant Breakfasts- we just had 6th Annual



Holiday Parties

ADDORE Core

How to Contact the Ances Lab

Ances Bioimaging Laboratory

@anceslaboratory

@anceslaboratory

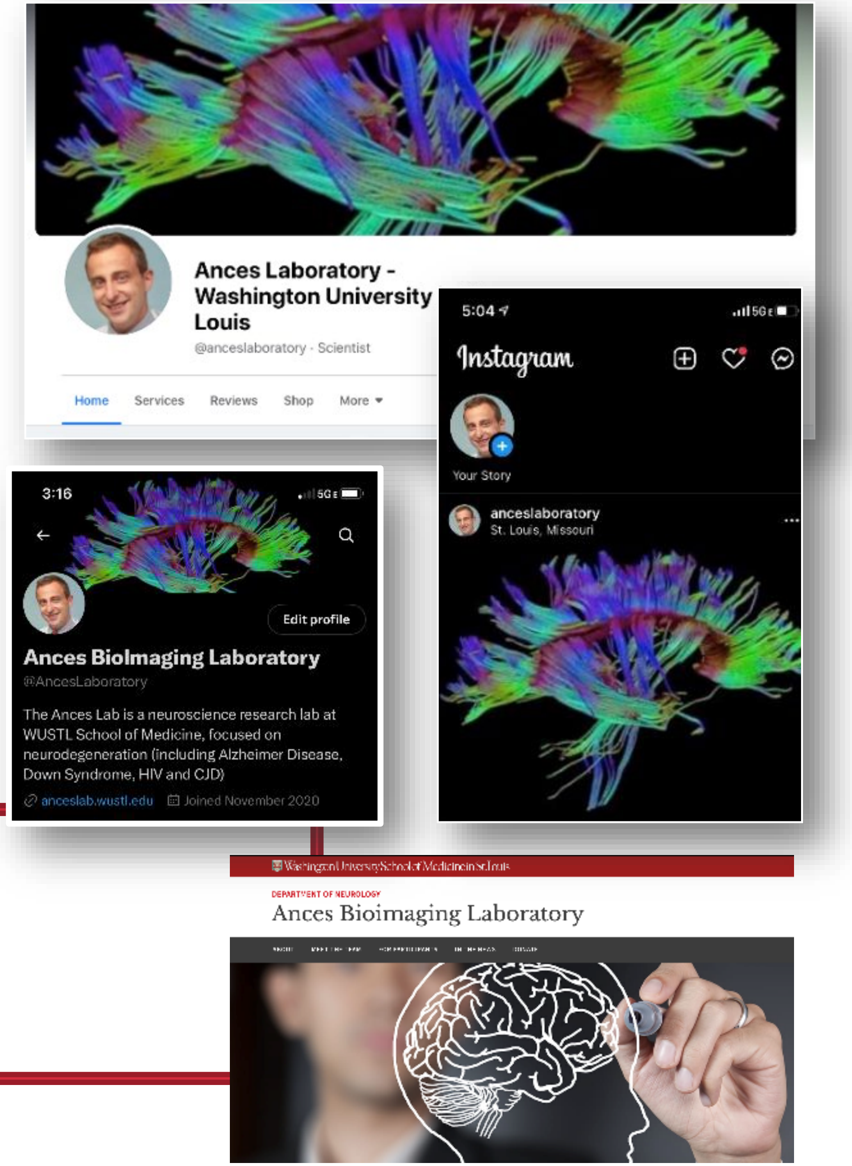
anceslaboratory

nceslab.wustl.edu

If you have questions or are interested in being seen for research or clinical evaluation

Contact Info

Beau Ances MD, PhD
bances@wustl.edu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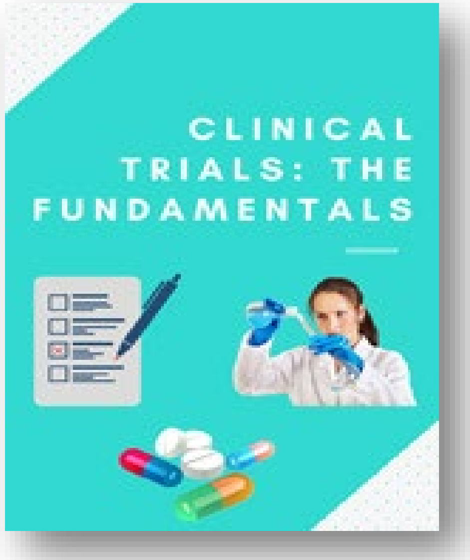
St. Louis, Missouri

Ances BioImaging Laboratory
@AncesLaboratory
The Ances Lab is a neuroscience research lab at WUSTL School of Medicine, focused on neurodegeneration (including Alzheimer Disease, Down Syndrome, HIV and CJD)
anceslab.wustl.edu Joined November 2020
Washington University School of Medicine in St. Louis
DEPARTMENT OF NEUROLOGY
Ances Bioimaging Laboratory

What You Should Know About Interacting with a Study Team

What are Clinical Trials?

Clinical trials are the engine of medical progress!



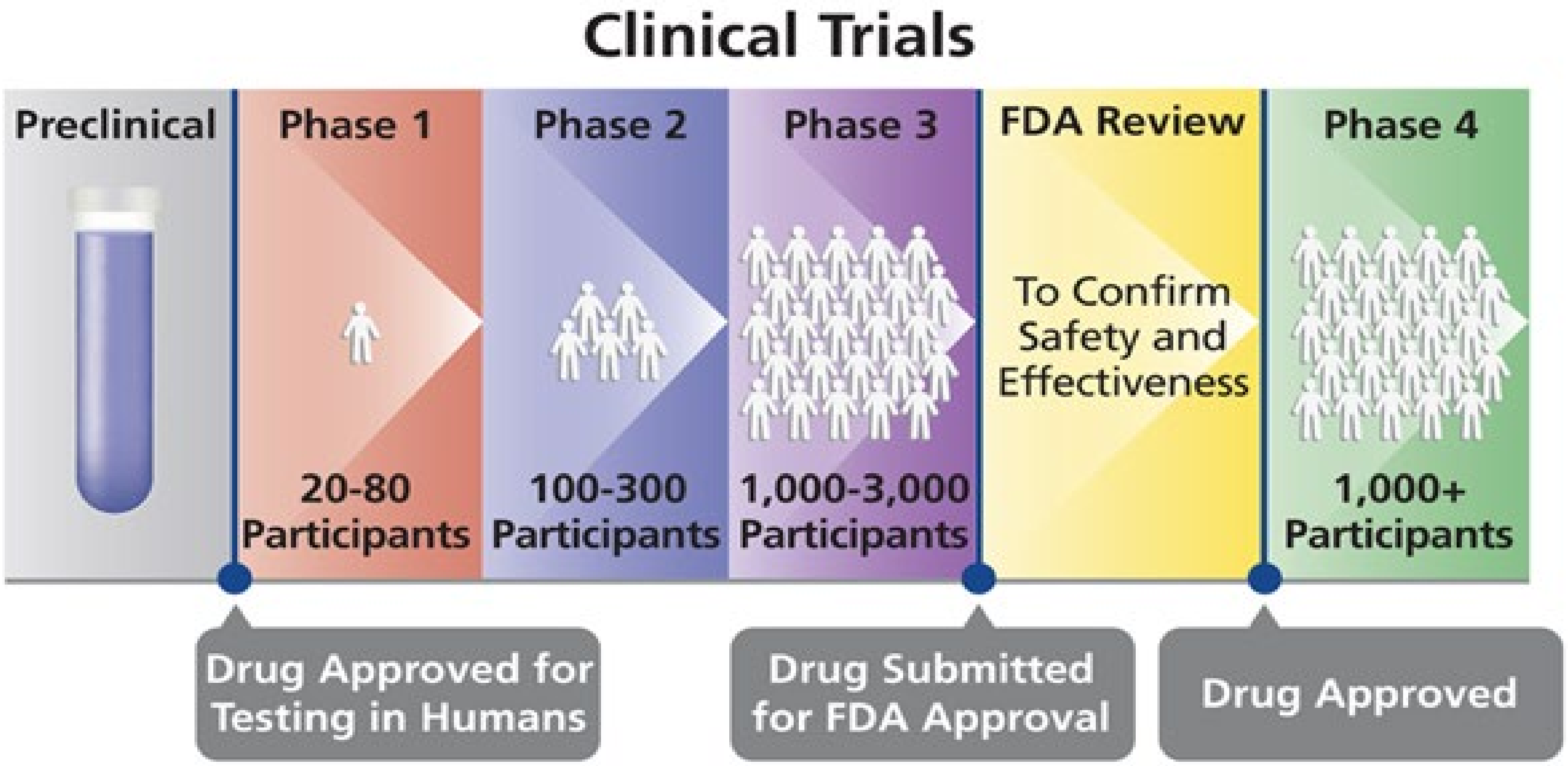
The primary goals are to:

- Determine whether a treatment is **safe and effective**, and to
- Gather data on **dosage, side effects, and overall impact on health**.

Clinical trials are **essential for advancing medical knowledge** and **improving patient care.**

Is a clinical research study right for me?

Phases of Clinical Trials



Clinical Trials

Preclinical

Phase 1

20-80 Participants

Phase 2

100-300 Participants

Phase 3

1,000-3,000 Participants

FDA Review

To Confirm Safety and Effectiveness

Phase 4

1,000+ Participants

Drug Approved for Testing in Humans

Drug Submitted for FDA Approval

Drug Approved

Inclusion and Exclusion Criteria

WHAT IT IS:
The filters that help researchers determine who can or cannot participate in a study.

- Set before the study starts
- Based on the specific research question

THE PURPOSE:
To ensure that the study is fair and the study results can be trusted. As these are experimental drugs, it helps protect the safety and well-being of the study participants.

  - **Inclusion Criteria**: The characteristics that participants *must* have to qualify for the study.

  - **Exclusion Criteria**: The specified criteria to indicate who will not qualify for the study.

Informed Consent & Assent

- **Informed consent** is the process by which researchers ensure that individuals understand a study and voluntarily agree to participate.
  - Every participant consents freely and with full information before any data is collected.
  - This involves **providing potential participants with clear details** about the study's purpose, procedures, duration, potential benefits, and any risks or discomfort that might be involved.
  - True informed consent also **requires that participants have the capacity to consent** (e.g. they are of sound mind or appropriate age) and that their agreement is given without any form of coercion or undue influence.
- **Assent is the agreement of individuals who are not legally able to provide informed consent**, such as children or cognitively impaired individuals, to participate in research.
  - **Assent is a vital component** of the informed consent process, particularly in research involving vulnerable populations.
  - It emphasizes the importance of **respecting the autonomy of participants** who may not be able to provide legal consent, ensuring that they are informed and willing to participate in the research activities.

Understanding Assent

WHAT IT IS:
Assent refers to the agreement of a participant who is unable to give legal consent due to age or cognitive ability.

For Example:

- Children aged 7-17 may provide assent, while their parents or legal guardians provide the necessary consent for participation in research.

THE PURPOSE:
Obtaining assent is crucial as it respects the autonomy of the participant, allowing them to express their willingness to participate in the research, even if they cannot legally consent.

- This process acknowledges their developing capacity to understand and make decisions about their involvement.

Being an Informed Participant or Caregiver/Study Partner

- Understand the study
- Ask questions
- Make informed decisions
- Leave the study at any time
- Seek second opinions
- Understand the costs
- Understand safety measures
- The Informed Consent will be a great resource for you.

Interacting with a Research Study Team

- Depending on where the clinical trial is being held, the experience of the study team who are interacting with individuals with Down syndrome may vary.
- As more clinical trials are being developed that include individuals with Down syndrome, there is a chance that site study teams may be less experienced with individuals with Down syndrome.

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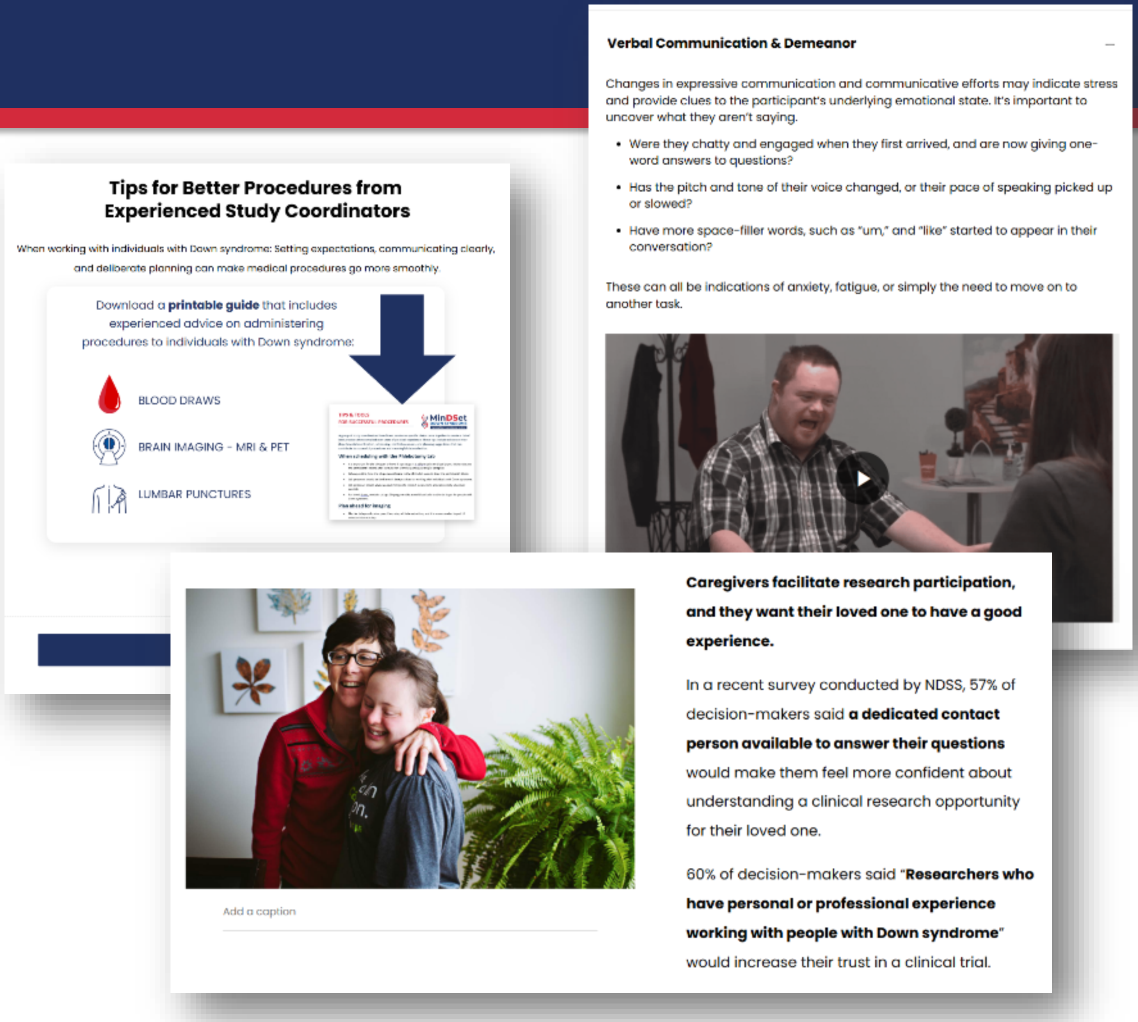
MinDSet – Training Researchers to Work with Individuals With Down Syndrome

MinDSet
DOWN SYNDROME
national down syndrome society

The MinDSet training is designed for **researchers** who are experienced in research, but **who do not have familiarity working with individuals with Down syndrome**.

By taking the MinDSet training, researchers can **feel more confident and competent** in welcoming individuals with Down syndrome to their clinical research site.



Verbal Communication & Demeanor

Changes in expressive communication and communicative efforts may indicate stress and provide clues to the participant's underlying emotional state. It's important to uncover what they aren't saying.

- Were they chatty and engaged when they first arrived, and are now giving one-word answers to questions?
- Has the pitch and tone of their voice changed, or their pace of speaking picked up or slowed?
- Have more space-filler words, such as "um," and "like" started to appear in their conversation?

These can all be indications of anxiety, fatigue, or simply the need to move on to another task.

Tips for Better Procedures from Experienced Study Coordinators

When working with individuals with Down syndrome: Setting expectations, communicating clearly, and deliberate planning can make medical procedures go more smoothly.

Download a **printable guide** that includes experienced advice on administering procedures to individuals with Down syndrome:

Caregivers facilitate research participation, and they want their loved one to have a good experience.

In a recent survey conducted by NDSS, 57% of decision-makers said **a dedicated contact person available to answer their questions** would make them feel more confident about understanding a clinical research opportunity for their loved one.

60% of decision-makers said "**Researchers who have personal or professional experience working with people with Down syndrome**" would increase their trust in a clinical trial.

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Patient-focused Drug Development Meeting (PFDD)

Patient-Focused Drug Development (PFDD) helps ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.

In June, NDSS will produce a scheduled meeting with the FDA where members of the FDA will hear directly from self-advocates with Down syndrome, and their families and caregivers on their lived experience with Down syndrome-associated Alzheimer's Disease.

www.NDSS.org/pfdd

Two important dates:

- **Monday, April 6:** community webinar to prepare for PFDD meeting
- **Tuesday, June 2:** Externally-led Patient-focused Drug Development Meeting, streaming online, all day

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Caregiver Perspectives on DS-AD and Clinical Trials in Down Syndrome

Recent Survey of Caregivers of Adults with Down Syndrome

CONIFER
RESEARCH

Current clinical trials to prevent DS-AD represent a critically relevant opportunity for the Down syndrome community; however, participation in these studies has been limited, leading trials to be discontinued.

To better understand what is driving low participation—and **how engagement can be strengthened before this opportunity window closes**—the National Down Syndrome Society partnered with Conifer Research to conduct a mixed-method study.

Researchers designed a framework that combined **qualitative in-depth interviews (n=18)** with a **quantitative online survey (n=200)** to understand decision-makers' awareness of the connection between Down syndrome and Alzheimer's disease (DS-AD), their experiences with research participation, and the barriers influencing DS-AD clinical trial engagement.

Special thanks to all those who completed the survey or took part in an interview!

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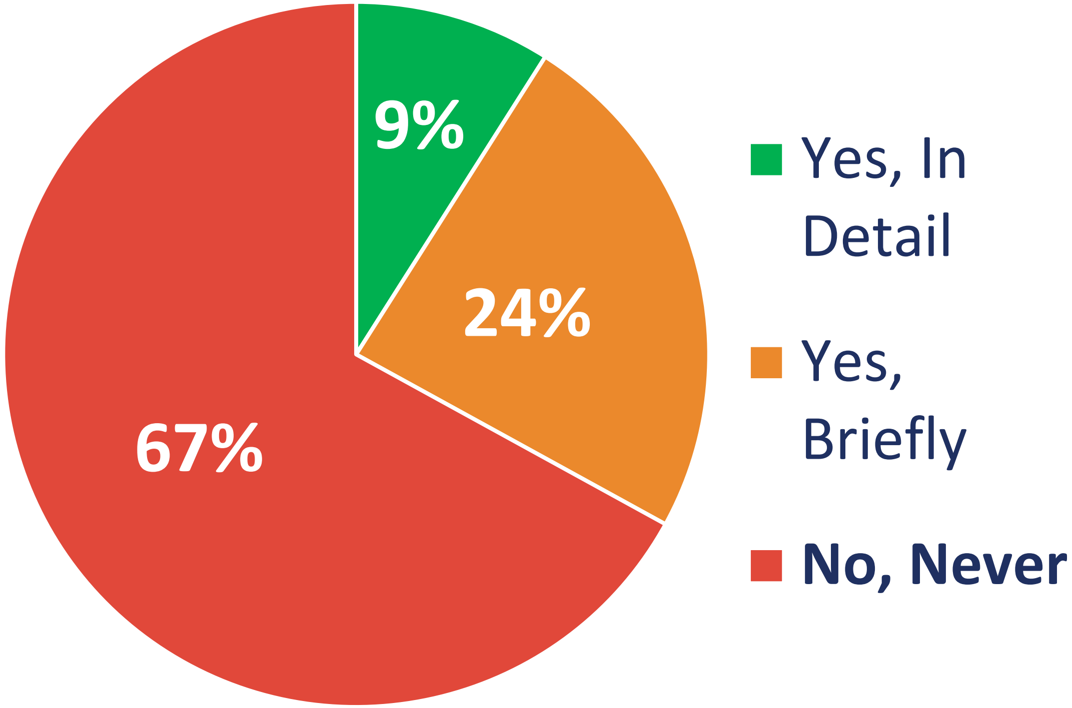
Decision Makers Lack Understanding and Support related to DS-AD

	"Somewhat" or "Very Familiar" with the connection N=133 (76%)	"Not Very" or "Not at all Familiar" with the connection N=41 (24%)
DON'T HAVE a good understanding of how to care for someone with Alzheimer's disease.	54%	73%
DON'T HAVE adequate support for understanding and addressing the risk of their loved one developing DS-AD.	56%	78%

DS-AD Risk Rarely Discussed with a Medical Professional

"Has a healthcare provider ever discussed with you the risks of Alzheimer's disease in relation to the person you care for?"



The most common ways that decision-makers learn about the connection are:

65% Personal research online

53% Advocacy organizations

36% Conference, workshop, or educational event

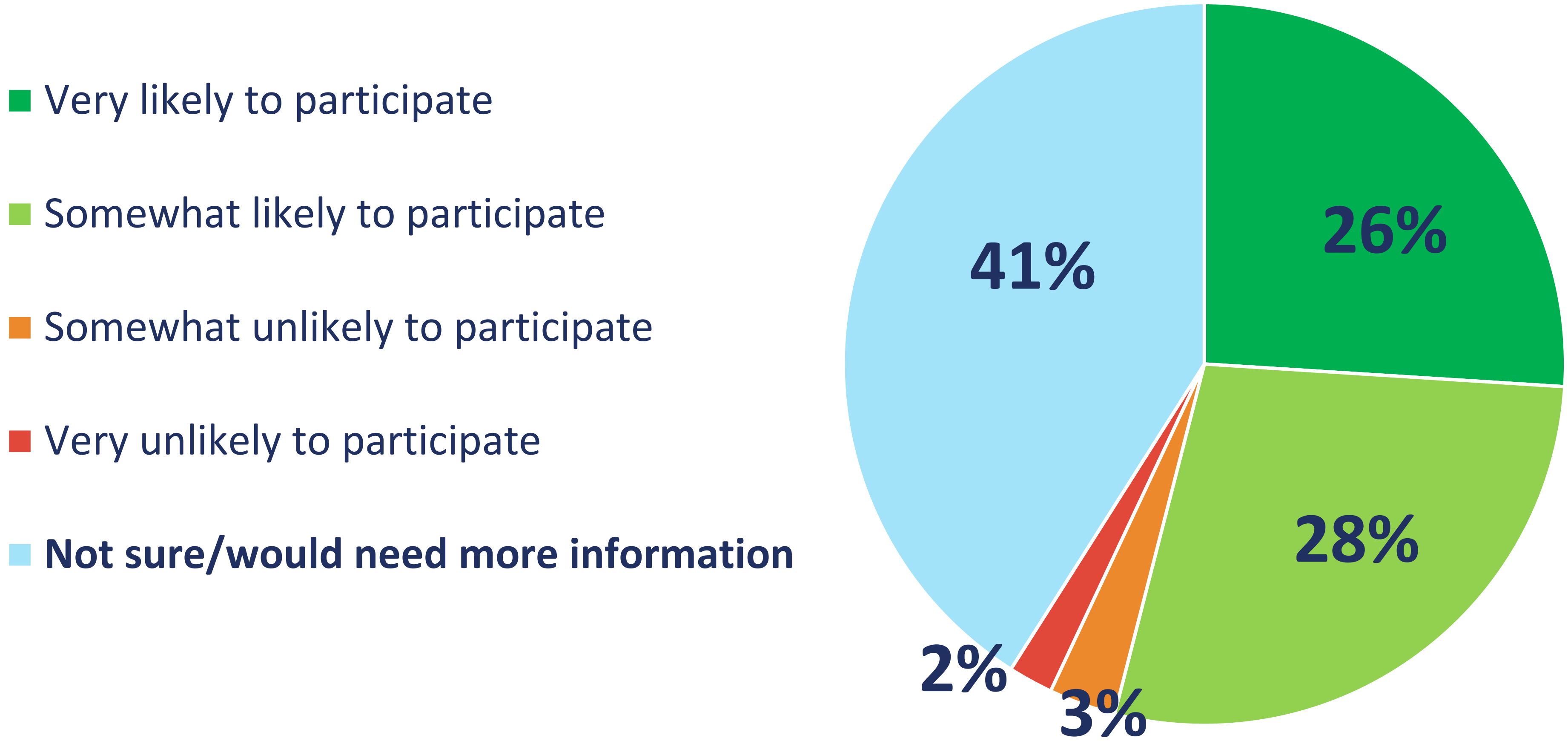
32% Doctor or other healthcare

Discussions about DS-AD with Healthcare Professionals leads to better preparedness and confidence

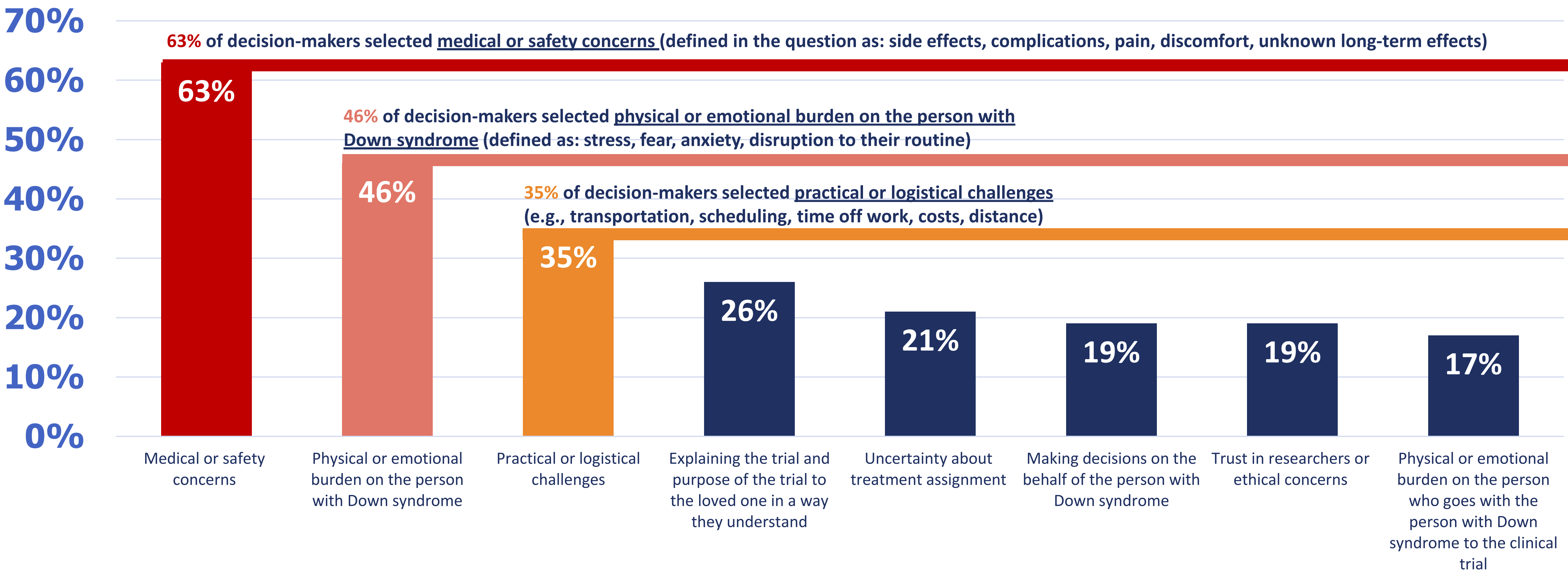
	Have discussed DS-AD with a healthcare professional **N=57**	**Have NOT discussed** DS-AD with a healthcare professional **N=117**
Confident in **distinguishing normal aging vs early signs** of Alzheimer's disease	**74%**	**54%**
Have a good **understanding of treatment and support services**	**40%**	**21%**
Feel **adequately supported** to address DS-AD risk	**53%**	**39%**
Have at least **some plans in place** for how they would manage care for their loved one	**46%**	**29%**

Almost half of Decision Makers need more information before they would enroll their loved one in a clinical trial.

If your loved one with Down syndrome was eligible to participate in a clinical trial aimed at improving the lives of people with Down syndrome, you would be…?



Top three concerns of decision-makers need to be addressed to increase clinical trial participation



63% of decision-makers selected medical or safety concerns (defined in the question as: side effects, complications, pain, discomfort, unknown long-term effects)

46% of decision-makers selected physical or emotional burden on the person with Down syndrome (defined as: stress, fear, anxiety, disruption to their routine)

35% of decision-makers selected practical or logistical challenges (e.g., transportation, scheduling, time off work, costs, distance)

Unclear or outdated information on the procedure and its risks fuel anxiety of lumbar puncture.

Only 22% of decision-makers feel comfortable with their loved one having a lumbar puncture as part of a clinical trial.

*Source: Survey Question "How would you feel about this person with Down syndrome undergoing a lumbar puncture as part of a clinical trial studying Down syndrome and Alzheimer's disease?" (n=174, excluding those who have a DS-AD diagnosis)

Familiarity with lumbar punctures:

68% I know what a lumbar puncture is

26% I have heard of a lumbar puncture but don't know anything about the procedure

6% I have never heard of a lumbar puncture

*Source: Survey Question "How familiar are you with a procedure called a lumbar puncture, otherwise known as a spinal tap?" (n=174, excluding those who have a DS-AD diagnosis)

82%

of decision-makers whose loved one has not been diagnosed with Alzheimer's disease, are **unaware that lumbar punctures may be part of the diagnostic process** to detect Alzheimer's disease and/or are used to provide a drug treatment.

*Source: Survey Question "Before now, were you aware that a lumbar puncture may be used as part of the diagnostic process to detect Alzheimer's disease biomarkers and/or to provide an investigational drug treatment?" *(n=174, excluding those who have a DS-AD diagnosis)*

Many issues factor into a caregiver's decision about trial participation

Communication & Comprehension

- Pain or discomfort may be **difficult to describe clearly** or consistently.
- **High pain tolerance** can delay recognition of adverse effects.
- **Distress may not present in ways clinicians expect** or immediately notice.

Routines & Environment

- **Unfamiliar medical settings** can feel unpredictable or overwhelming.
- **Changes to routine** can affect emotional regulation and behavior.
- **Sensory demands** (noise, pacing, rotating staff) can add strain before procedures begin.

Structure & Expectations

- Trials may require staying still for long periods or completing activities in highly regimented ways, with **limited flexibility in timing or pacing**.
- **Expectations can be misaligned** with how individuals with Down syndrome process or engage.

51% I'm not sure they understand what's happening

45% I worry about making the wrong decision for them

**Source: Top 2 answers to Survey Question: "What concerns do you have about making decisions regarding clinical trials on behalf of this person with Down syndrome? Please select up to three." (n=174, excluding those who have a DS-AD diagnosis)*

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Evaluating Trial Participation: Multiple, Compounding Challenges

- Differing levels of understanding of DS-AD (probability, signs and symptoms, disease trajectory)
- Lack of education, guidance, and validation from medical professionals regarding DS-AD and research
- Ongoing emotional burden of confronting and accepting the potential for DS-AD to impact their loved one.
- Ethics of balancing loved one's autonomy, personal comfort, and safety vs. altruistic service to the Down syndrome community
- Trial requirements introduce new, practical burdens for decision-makers—on top of existing responsibilities

The complex, interwoven nature of these challenges makes it difficult for decision-makers to confidently assess if trial participation would be a good fit for their loved one and themselves.

Impacting Strategy, Messaging, and Research Design

The data uncovered several key opportunities for NDSS, healthcare professionals, and researchers to make DS-AD research more accessible, understandable, and possible for caregivers and self-advocates:

Unify the data, information, and messaging around DS-AD awareness, trials, and prevention

- New information hub on NDSS.org, new resources for families
- Collaborating across organizations and disciplines to increase awareness and education
- Work to standardize language, stats, and calls-to-action

De-mystify the logistical and practical burdens of trial participation

- Continue dialogue with researchers and clinical trial designers, raise up family voices
- Find new ways to deliver information, and hear from the community about clinical trials

Ensure that participants have a good and meaningful research experience

- Prepare clinical trial teams to welcome individuals with Down syndrome and their families to their study sites
- Empower families with tools and resources they need when interacting with study teams

Voices & Perspectives from our recent survey and interviews

"His primary [care provider has] never said anything. We've never had one of his medical doctors say anything about [DS-AD]."
— Melissa (60), mother of Mark (28), NC

"My dad...had a [lumbar puncture] done [when I was a kid]... I have never seen my dad cry before, ever. And he came back from that thing just so distraught."
—Keith (32), paid caregiver for Patrick (55), FL

"After I saw 'lumbar punctures,' and then I read the second line where it said: 'drug injection,' I will be honest with you, I didn't read that last line because at that point, those two, study drug injection and lumbar punctures, scare me."
— Daria (60), mother of Justin (29), CA

There aren't a lot of services out there for folks who are developmentally disabled and going through Alzheimer's."

— Elaine (82), mother of Mick (60), CA

"I don't think they [doctors] have a clue. They should be up to date on that kind of thing. He should have mentioned it at some point just as a, 'Hey, just a heads up, keep your eye open for changes and things so we can address them or we can talk about it.' But he doesn't ever ask about things like that."
— Rebecca (59), sister of Donald (57), OH

"They're going to have to be cognizant of the fact that this is not general population.

They are going to have to know not everybody is going to be the same and how they react... My daughter will be like, 'Here, take my blood, this is cool. Where's my lollipop? Whatever.' Another may have to be hogtied practically in order to get that blood test… And they need to be able to listen to the parent... because we've been there, we've seen it, we know exactly how our kid's going to react if you don't do xyz."
— Jenny (49), mother of Abigail (23), TX

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Voices of Experience

Welcome to Benjamin & Kristi Golden, from California