The NIH INCLUDE Project

Investing in Inclusive Research That Matters to You and Your Family

July 22, 2023

NDSC 51st Annual Convention

Orlando, Florida

NATIONAL DOWN SYNDROME CONGRESS

NIH National Institutes of Health
Turning Discovery Into Health

Today's Presenters

Dr. Melissa A. Parisi

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development

Dr. Marishka K. Brown

NIH National Heart, Lung, and Blood Institute

Miah and her Mom, Linda Roan

Research Participants

Dr. Jonathan D. Santoro

Children's Hospital LOS ANGELES

Linda Garcia

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development

Outline

- The National Institutes of Health & The INCLUDE Project
- Sleep Apnea
- Down Syndrome Regression Disorder
  - Perspectives from a research participant
- DS-Connect® Registry & Community Outreach

The National Institutes of Health

National Institutes of Health
Turning Discovery Into Health

The NIH

- The U.S.'s national medical research agency based in Bethesda, Maryland
- The world's largest funder of biomedical research
- Made up of 27 separate research institutes and centers
- 90% of funds go to university research institutions based on peer review of grant applications

NIH National Institutes of Health
Turning Discovery Into Health

The INCLUDE PROJECT

INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE

The INCLUDE Project Goals

- Launched in 2018 under a Congressional Directive to address **critical health and quality of life needs for those with DS**.
- INCLUDE is investigating **conditions** that affect individuals with DS and the general population, such as Alzheimer's disease, autism, cataracts, celiac disease, congenital heart disease, and diabetes.
- The project will also **increase the number of investigators/trainees** studying DS.
- The project will engage with those with DS and their families from **diverse backgrounds**.

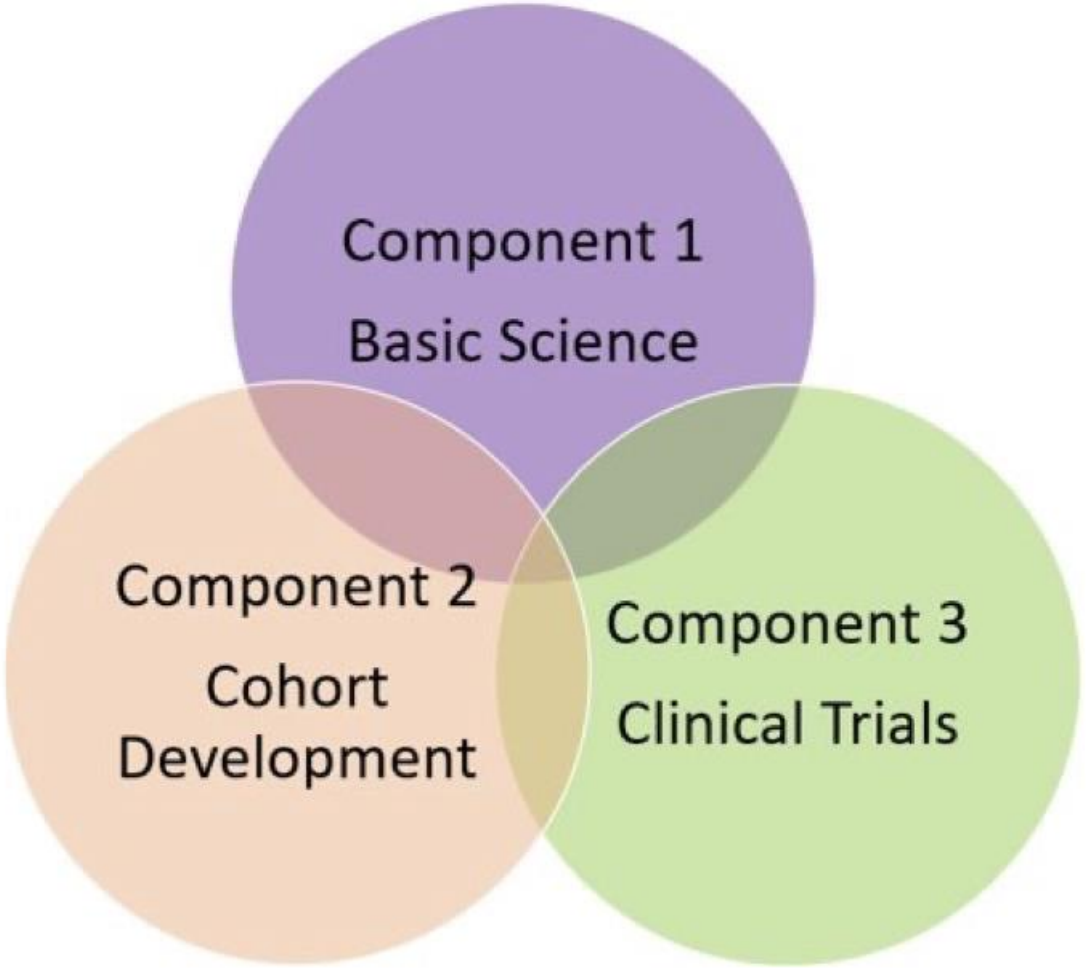
INCLUDE Project

Three components:

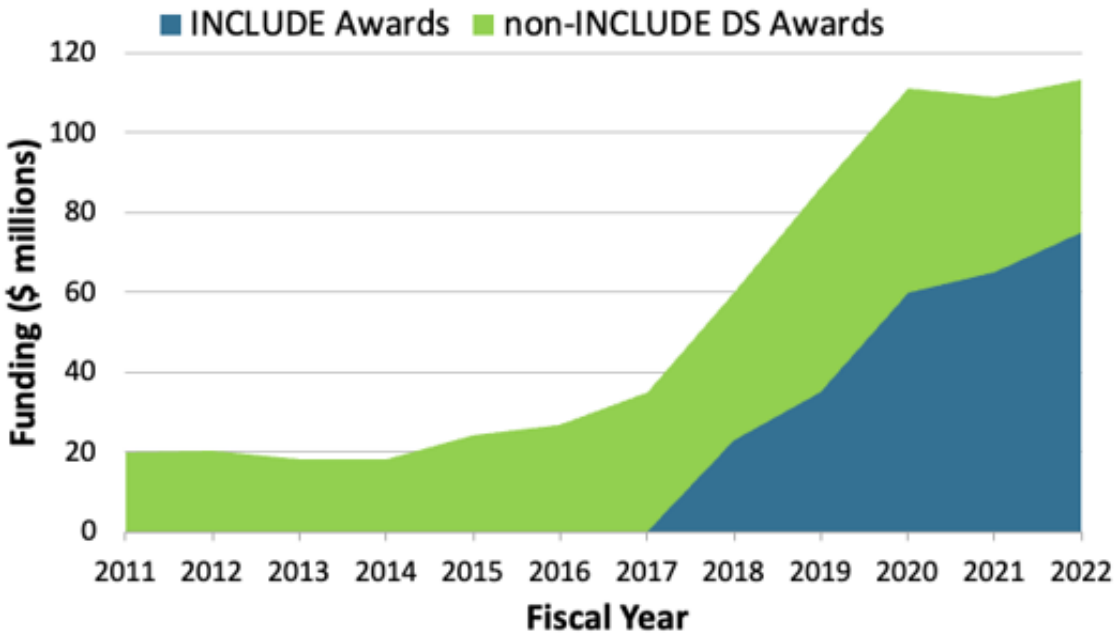
1. Conduct targeted, high-risk, high-reward **basic science** studies on chromosome 21.

2. Build a **large cohort** of individuals with Down syndrome for comprehensive analysis and biomarker evaluation.

3. Include individuals with Down syndrome in existing and future **clinical trials**.



Down Syndrome Funding at NIH, 2011-2022



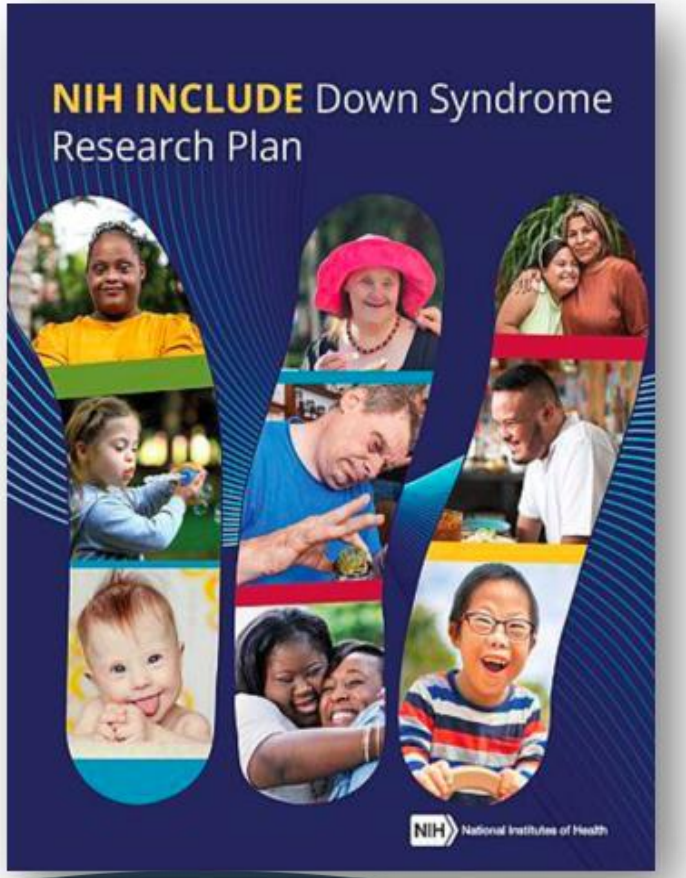
FY	INCLUDE ($M)	Non-INCLUDE DS ($M)	Total DS ($M)
2018	23	37	60
2019	35	51	86
2020	60	51	111
2021	65	44	109
2022	75	38	113

The NIH has invested **$258 million** in the past **5 years** on **270** new projects for **INCLUDE**

What has INCLUDE done so far?

- Study the causes of acute lymphoblastic leukemia in children with DS
- Study hearing loss across the lifespan in those with DS
- Study language acquisition and articulation in children with DS
- Develop and validate cognitive measures in the NIH Toolbox for children with DS.
- Develop a Behavior Inventory for Down Syndrome (BIDS) for children and adolescents with DS in English and Spanish.
- Study the causes of congenital heart disease in infants with DS, and whether heart surgery impacts their neurodevelopment and behavior
- Study a cohort of adults with DS to identify biomarkers of neurodegeneration and risk and resilience factors for Alzheimer's disease

New NIH Research Plan for Down Syndrome



NIH finalized the Research Plan for its **INCLUDE Project** and related DS research.

Highlights of the plan include the following:

- Public and DS community input in the new and revised goals and objectives
- Emphasis on increasing diversity of researchers and research participants
- New information about DS research training
- Detailed review of NIH research projects conducted between 2014 and 2020, and a bibliography with 590+ scientific articles
- Findings from research on COVID-19 in individuals with DS

Available for download on the INCLUDE Project website: nih.gov/include-project/include-project-down-syndrome-ds-research-plan

IncludeDCC.org

INCLUDE
Data Coordinating Center

Funded by the NIH

Improving the quality of life of people with Down syndrome

The INCLUDE Data Coordinating Center (DCC) is making it easier for scientists and the Down syndrome community to work together. Matching the latest technology with shareable resources, researchers use the Data Hub to enhance healthcare and change lives.

Learn More Contact us

Resnick

Children's Hospital of Philadelphia
Center for Data Driven Discovery in Biomedicine

DATA PORTAL CORE

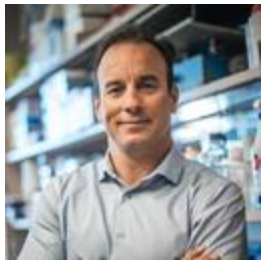
Facilitate access to and analysis of data via web portal

O'Connor

SageBionetworks

DATA MANAGEMENT CORE

Manage data collection, processing and harmonization



Espinosa

LINDA CRNIC INSTITUTE for DOWN SYNDROME

ADMINISTRATIVE & OUTREACH CORE

Provide program management, outreach, education and support

Thirteen Clinical Trials Funded by INCLUDE

Sleep & Apnea (OSA)

- Medications for OSA to improve cognition in children with DS
- Effects of hypoglossal nerve stimulation on cognition and language in DS
- Positive airway pressure for OSA in children with DS
- Home Sleep Apnea Testing Compared to In-lab Polysomnography for the Evaluation of OSA in Children with DS
- Self-Supporting Nasopharyngeal Airway Treating Upper Airway Obstruction in Hypotonia
- A Personalized Surgical Approach for the Treatment of Children with Obstructive Sleep Apnea and Small Tonsils
- Randomized Controlled Trial of Oxygen Therapy in Children and Adolescents with DS and OSA

Alzheimer's Disease & Aging

- Clinical trials to prevent Alzheimer's Disease in DS
- Addition of GM-CSF/sargramostim treatment to improve cognition in DS
- The Impact of Weight Loss on Alzheimer's Disease Risk in Adults with DS

Immune System Dysregulation

- JAK inhibition for treatment of DS skin conditions

Neurodevelopment

- Mechanistic investigation of therapies for Down Syndrome Regression Disorder
- Evaluating assessment and medication treatment of ADHD in children with DS

Sleep and Sleep-disordered Breathing in People with Down Syndrome

Marishka K. Brown, Ph.D.

Director
National Center on Sleep Disorders Research
National Heart, Lung, and Blood Institute
National Institutes of Health

51st National Down Syndrome Congress Annual Convention

July 22, 2023

National Heart, Lung, and Blood Institute

Overview: Sleep and Sleep Disorders in People with Down Syndrome (DS)

- Sleep in DS
- Obstructive Sleep Apnea (OSA)
  - Consequences of OSA
- Sleep Clinical Trials supported by INCLUDE DS
- Research Gaps and Potential Opportunities in sleep and DS research

Image Source: https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/children-families-and-education/

Sleep is Required for Optimal Health and Well-being

- Sleep is required for:
  - Neurodevelopment and cognitive processes.
  - Maintaining a healthy weight.
  - Optimal health and performance trajectories.
- Deeper stages of sleep play an important role in learning by promoting the consolidation and integration of memory and significantly affect behavior.
- Undermining development could be a burden for life.

Image Source: https://downsyndromealabama.org/

Sleep in People with Down Syndrome

Pediatric

- Research has found that sleep problems were significantly greater in the children with DS compared to the general population.

- Sleep problems included:
  - difficulty settling at bedtime
  - resistance to going to bed
  - nighttime awakenings
  - co-sleeping with parents or siblings
  - insomnia
  - parasomnias

Adult

- In adults with DS, with DS, the prevalence of *behavioral sleep disturbances* ranges from 13 to 86%.

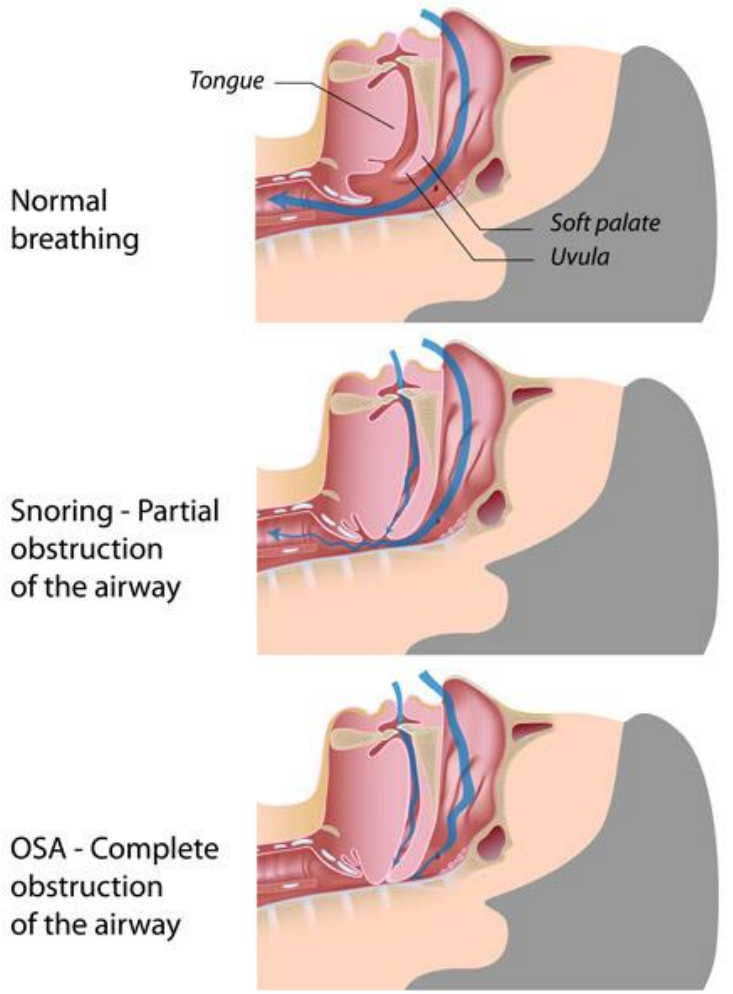
- Studies have found that adults with DS have less rapid eye movement (REM) sleep.

- About a third of adults living with DS experience difficulties initiating sleep, frequent night-time awakenings, talking in sleep, and/or restless sleep.

Sleep-disordered breathing is the most reported sleep disorder in people living with DS

Sleep-Related Disordered Breathing (SDB)

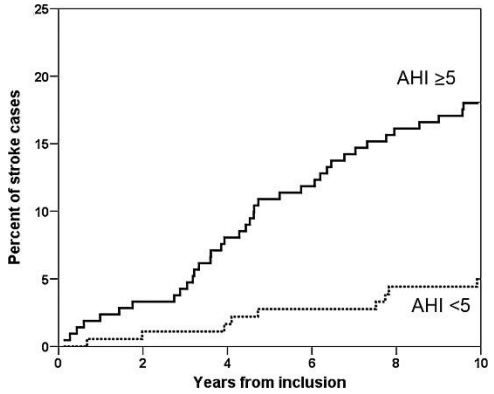
- SDB has a spectrum of severity from primary snoring to obstructive sleep apnea (OSA).
- Characterized by abnormal respiration during sleep.
- Most common form is OSA.
- OSA is a common co-occurring condition of DS.
  - Prevalence of OSA in people with DS ranges from ~ 54 – 90%.
  - Difficult to diagnose because early subtle signs can be missed, and sleep studies can be challenging.
  - Primary treatments are adenotonsillectomy and continuous positive airway pressure (CPAP), which are not cures.



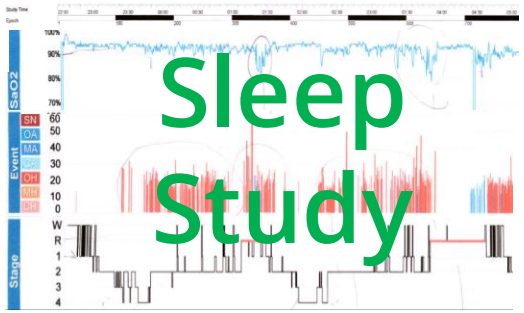
https://mdadental.com/Sleep-Dentistry/Obstructive-Sleep-Apnea

Sleep Disorders Increase Medical Risks

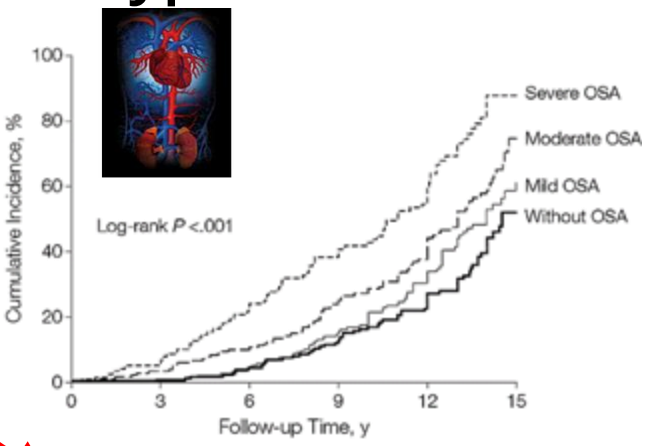
Stroke ⇧



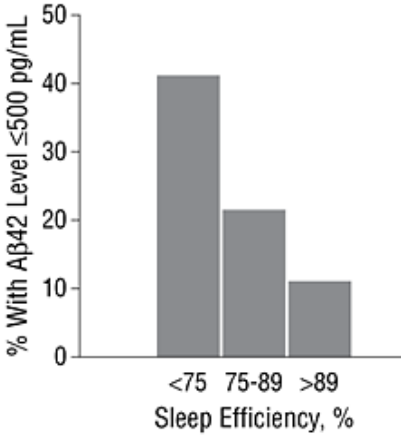
Sleep Disorders



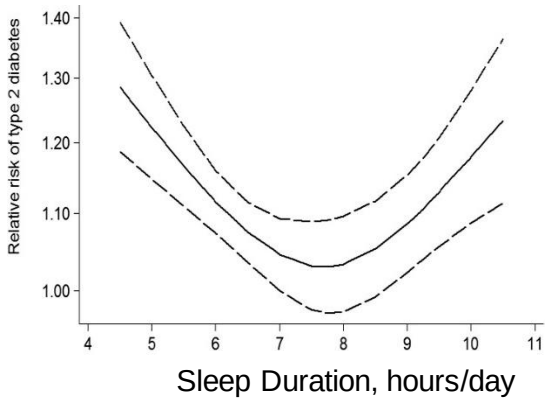
Hypertension ⇧



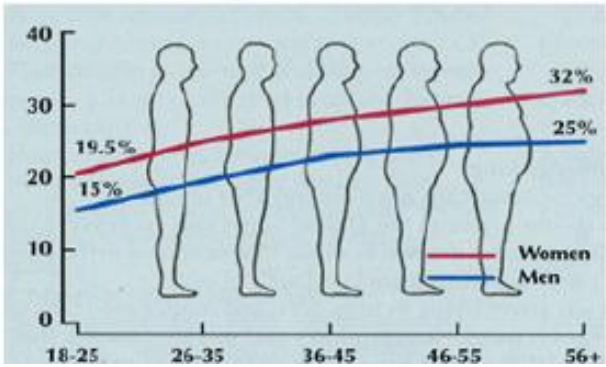
Dementia



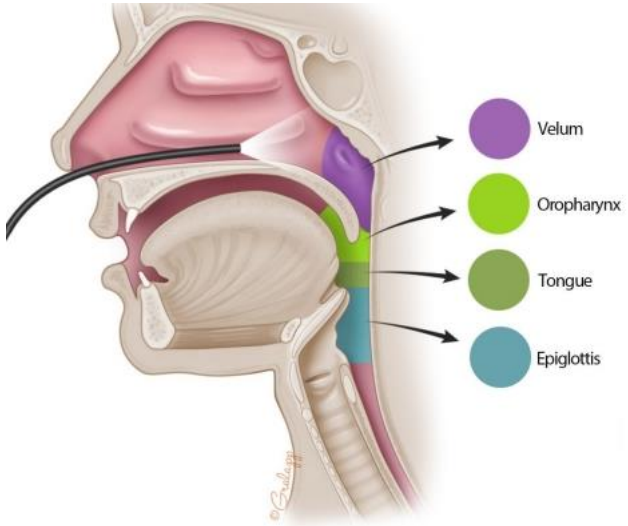
Diabetes ⇧

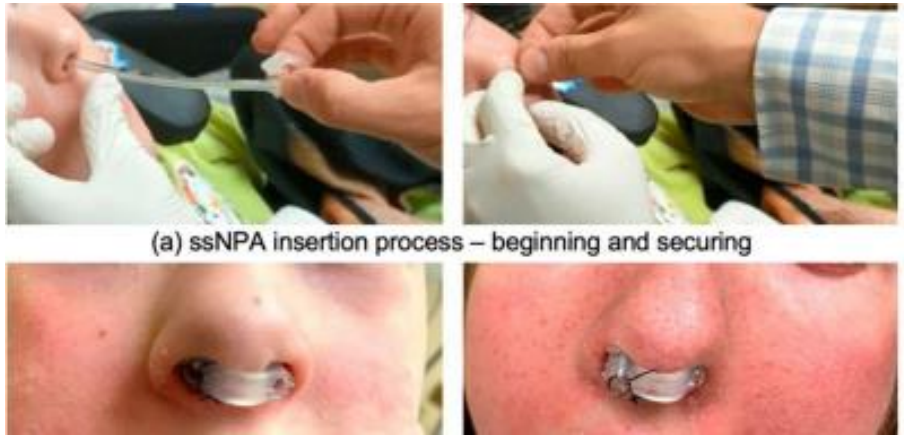


Obesity risk ⇧



INCLUDE DS: Clinical Trials to Treat Sleep Disordered Breathing





Updates: Early Findings and New Multi-site Clinical Trials

Sleep Medicine 107 (2023) 179–186

Contents lists available at ScienceDirect

Sleep Medicine

journal homepage: www.elsevier.com/locate/sleep

Caregiver experiences helping children with Down syndrome use positive airway pressure to treat obstructive sleep apnea

Melissa S. Xanthopoulos [a, b, c, *], Maria N. Nelson [d], Whitney Eriksen [d], Frances K. Barg [d], Kelly C. Byars [e, f], Stacey L. Ishman [e, g, h, i], Anna J. Esbensen [e, j], Jareen Meinzen-Derr [e, k], Christine H. Heubi [e, g, h, i], Neepa S. Gurbani [e, i], Ruth Bradford [a], Suzanna Hicks [i], Ignacio E. Tapia [a, l]

ClinicalTrials.gov Identifier: NCT04132999

TOPS-DS A SURGICAL TRIAL FOR SLEEP APNEA

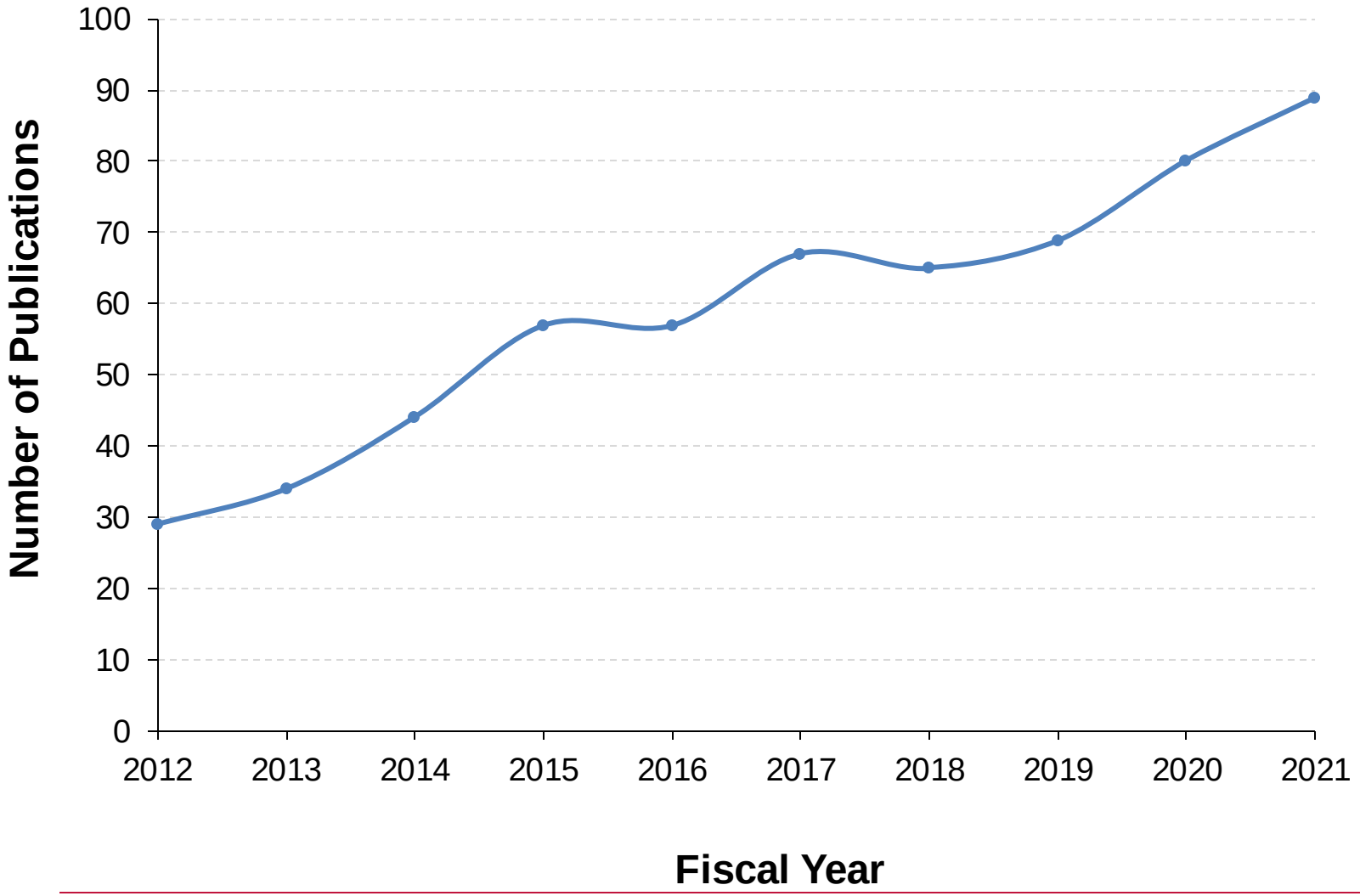
Enrollment expected to begin Late Summer/ Early Fall of 2023

dosa

NIH National Heart, Lung, and Blood Institute

ClinicalTrials.gov Identifier: NCT05508971

Sleep Research Gaps and *Select* Future Opportunities



- **Research Gaps:**
  - Research needed to study sleep health in persons living with DS across the lifespan.
  - Limited data on adults with DS outside of OSA.
  - Sex and/or gender differences in sleep and sleep disorders.
  - Further research into the study of circadian rhythms in DS.

Perspectives from a Research Participant

Linda Roan and her daughter, Miah

Down Syndrome Regression Disorder (DSRD):

A Race Accelerated by the INCLUDE Project

Jonathan D. Santoro, M.D.

Director of Neuroimmunology

Director of Research, Neurologic Institute

Associate Professor of Neurology and Pediatrics

Children's Hospital Los Angeles

Keck School of Medicine of USC

Children's Hospital LOS ANGELES

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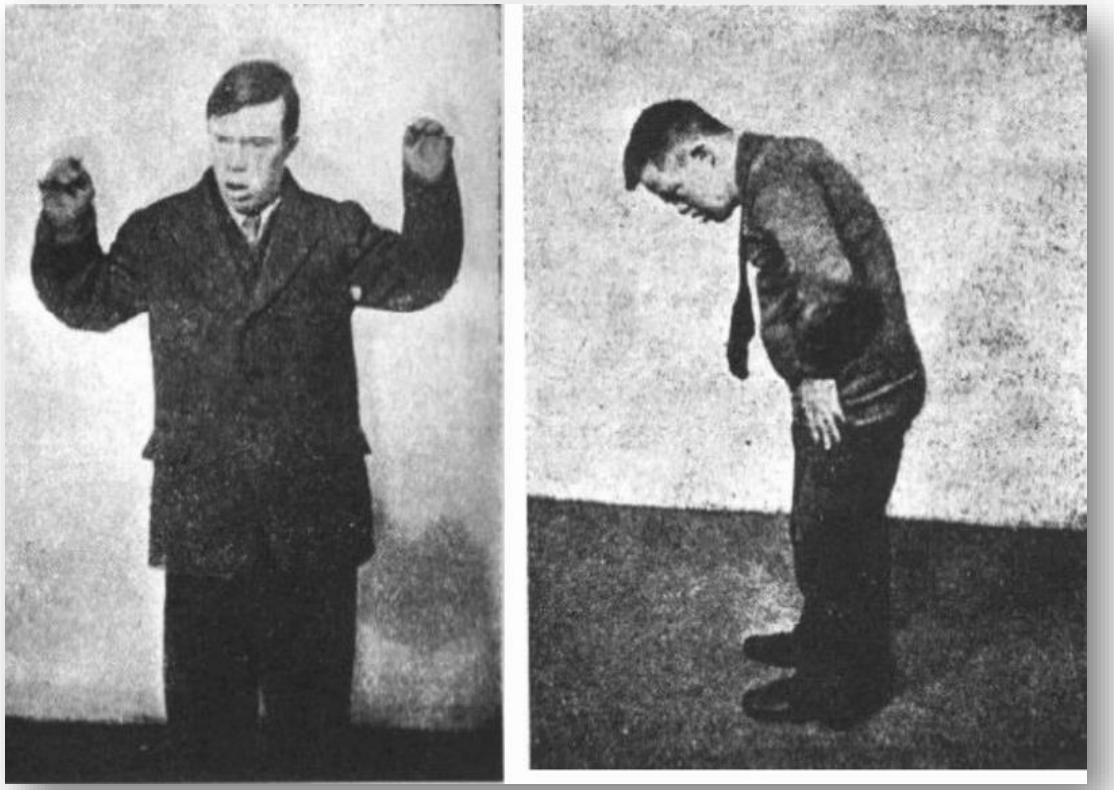
History of Down Syndrome Regression Disorder (DSRD)

- First report by Rollin (1946) where he described a condition called "**catatonic psychosis**" in institutionalized adolescents with Down syndrome.
- Individuals had "appropriate" development and then experienced an unexplained behavioral change
- Symptoms reported as: *agitation, aggression, incontinence, apathy, mutism, social withdrawal, psychosis and catatonia*

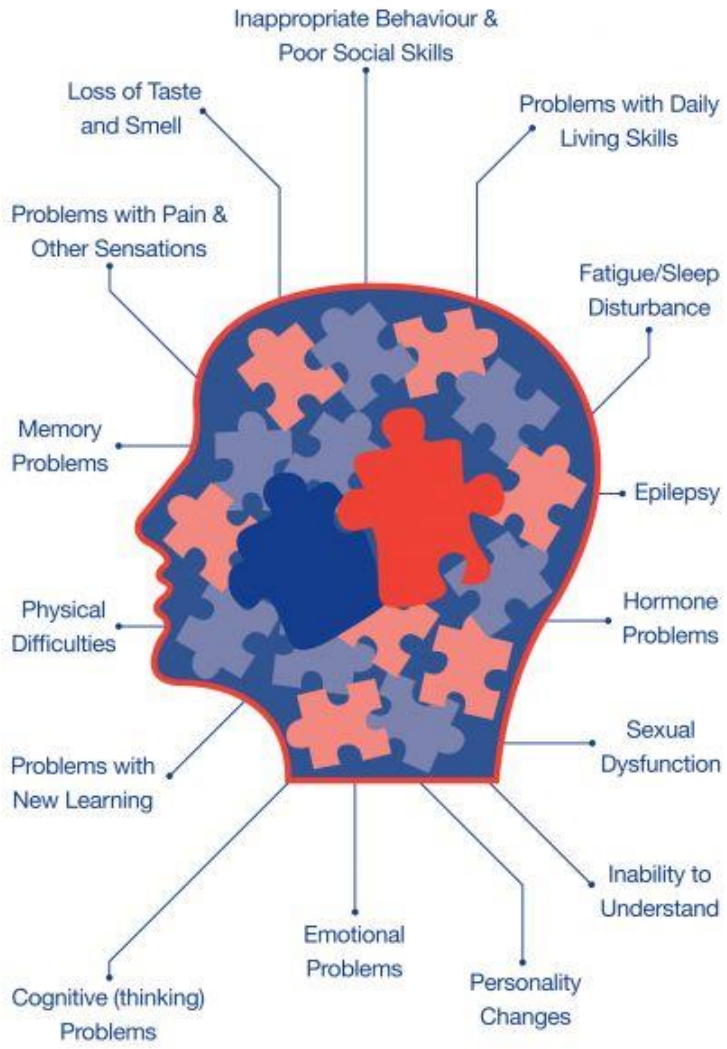


History of DSRD, continued

- In 2000, Kerbeshian and Burd described “autistic-like regression” in an 8-year-old girl with DS. She had loss of social and communication skills, loss of cognitive functions, and a rapid-onset insomnia.

- Several other case reports were reported, all with similar features.

- Subsequently, Worley (2015) and Mircher (2017) presented similar case series and characterized DSRD as onset of “autistic regression,” cognitive decline resulting in a dementia-like state, occurring at an older age than autistic regression, and no other established diagnosis to explain the condition.



Worley G, et al. Down syndrome disintegrative disorder: new-onset autistic regression, dementia, and insomnia in older children and adolescents with Down syndrome. J Child Neurol. 2015;30(9):1147–1152; Mircher C et al. Acute regression in young people with Down syndrome. Brain Sci. 2017;7(6):E57
Kerbeshian J et al. Comorbid Down’s syndrome, Tourette syndrome and intellectual disability: registry prevalence and developmental course. J Intellect Disabil Res. 2000;44(pt 1):60–67

From Phenotyping to intervention

- Cardinale et al., reported on four patients with DSRD responding to a variety of immunotherapies in 2019.

- This rapidly advanced to two larger studies (Santoro JD, et al. (2022) and Santoro SL, et al (2022)) of 72 and 55 patients identifying a variety of potential therapeutic options.

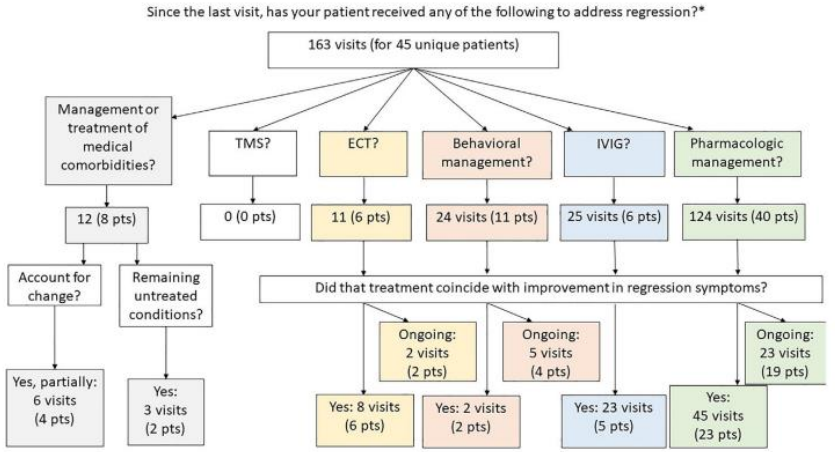


FIGURE 2 Management of patients with unexplained regression in Down syndrome (URDS), and if that management coincided with improvement in symptoms. Patients = pts; *Patients could receive more than one type of management at a single visit.

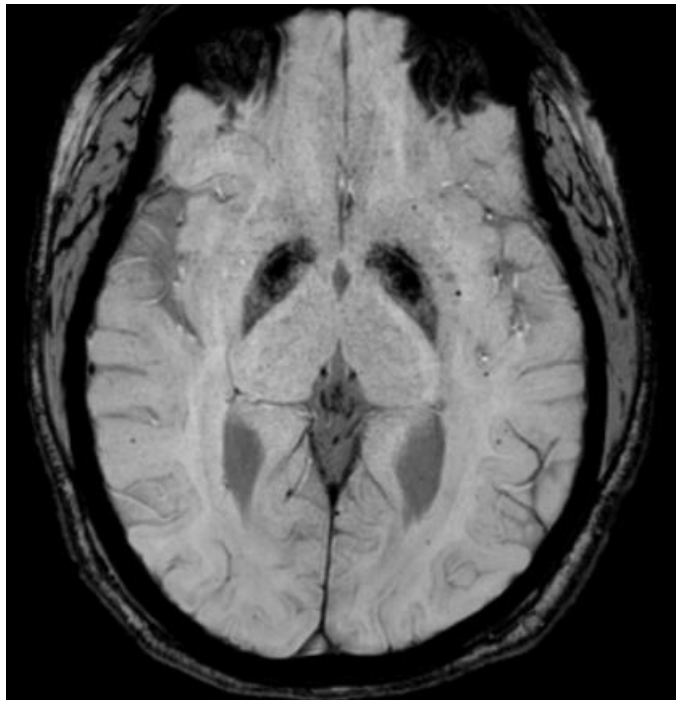
Table 3 Therapeutic responses

Therapy type[a]	Utilization (*n* (%))	Effectiveness (*n* (%))			Any neurodiagnostic abnormality vs normal workup		
		All patients (*n* = 72)	Any neurodiagnostic abnormality (*n* = 29)	EEG/MRI/CSF normal (*n* = 43)	X^2 value	*p* value	Odds ratio (95%CI)
Antidepressant	45 (63%)	22 (49%)	4/16 (25%)	18/29 (62%)	5.67	**0.02**	**0.20 (0.05–0.79)**
Antipsychotic	52 (72%)	32 (61%)	9/19 (47%)	23/33 (70%)	2.54	0.12	0.39 (0.12–1.26)
Benzodiazepines	63 (87%)	49 (77%)	18/24 (75%)	31/39 (79%)	0.17	0.42	0.77 (0.23–2.59)
ECT	49 (68%)	36 (74%)	6/15 (40%)	30/34 (88%)	12.42	**0.01**	**0.09 (0.02–0.39)**
Nutritional therapy	29 (40%)	0 (0%)	0/13 (0%)	0/10 (0%)	0	1.0	n/a
Immunotherapy	43 (59%)	74/120 (62%)	55/74 (74%)	19/46 (41%)	10.04	**< 0.001**	**4.11 (1.88–9.02)**
Steroids	39 (54%)	14/39 (36%)	10/24 (42%)	4/15 (27%)	0.90	0.34	1.96 (0.48–7.99)
IVIg	43 (59%)	38/43 (88%)	24/26 (92%)	14/17 (82%)	0.05	0.33	2.57 (0.38–17.31)
Anti-CD20	19 (26%)	9/19 (47%)	9/11 (81%)	0/8 (0%)	9.89	**0.01**	**49.5 (3.84–638.43)**
MMF/AZ	19 (26%)	13/19 (68%)	12/13 (92%)	1/6 (17%)	12.17	**0.01**	**60.0 (3.10–1159.84)**

AZ Azathioprine, *CSF* cerebrospinal fluid, *EEG* electroencephalogram, *ECT* electroconvulsive therapy, *MRI* magnetic resonance imaging, *MMF* mycophenolate mofetil

[a] Patients may have received multiple therapeutic interventions creating a higher "*n*" with regard to the treatment interventions by class

Biomarkers of Disease and Response?



- Arriving at the most likely reason for regression in a person with Down syndrome is very important as the available therapies vary widely depending on the explanation.
  - *Remember, mimics of DSRD can occur!*

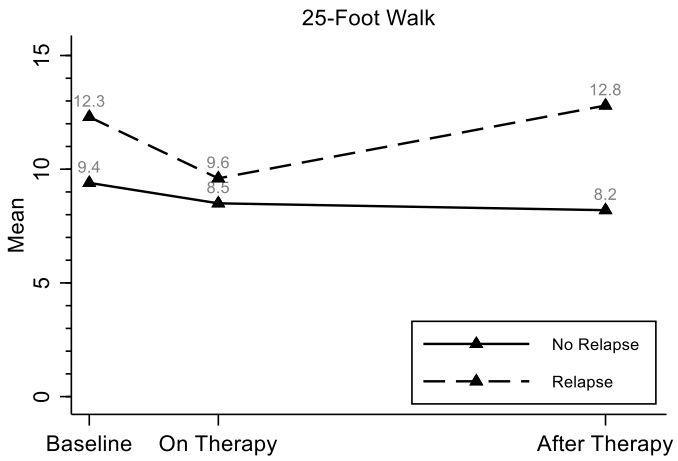
- Emerging evidence supports that neuroimaging (**MRI**) and cerebrospinal fluid (**CSF**) biomarkers are likely to aid in the prediction of who is most likely to respond to immunotherapy

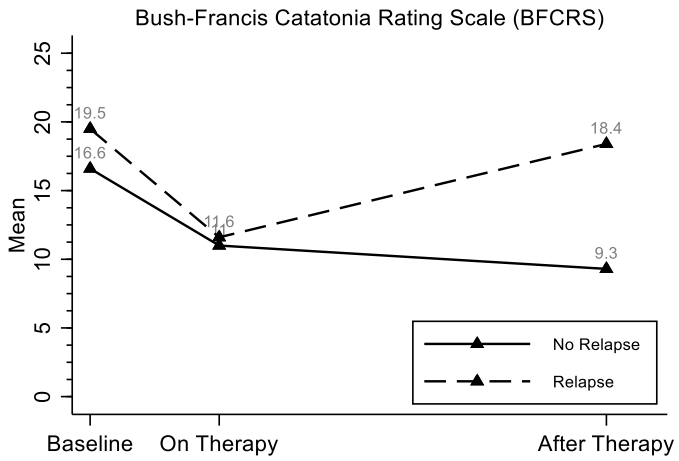
Up to 30% of individuals with DSRD compared to 8% in age-matched controls (n= 233) have SWI imaging abnormalities. The odds of response to immunotherapy with these findings is up to 9x higher than when not present.

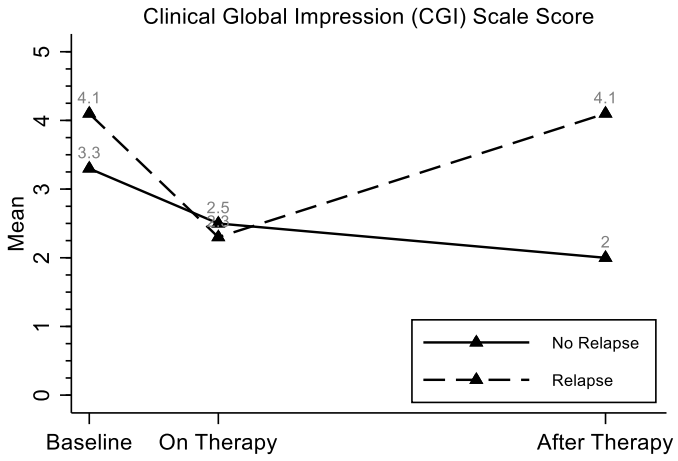
CSF abnormalities, when present, similarly result in a 12x higher rate of response to immunotherapy

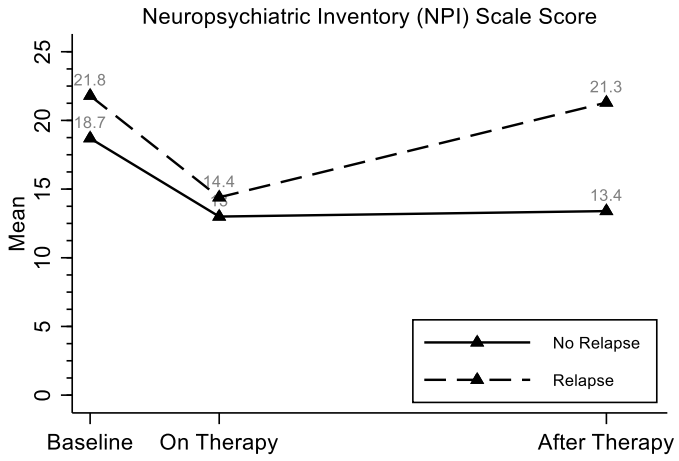
Immunotherapy Responsiveness!

- Prospective studies have verified the efficacy (does it work) of IVIg in individuals with DSRD with over 75% of patients responding to treatment after three months
- After one year of therapy, about 50% of individuals continue to have benefit even after the medication is stopped.
- Yet the other 50% continue to need treatment…. why?



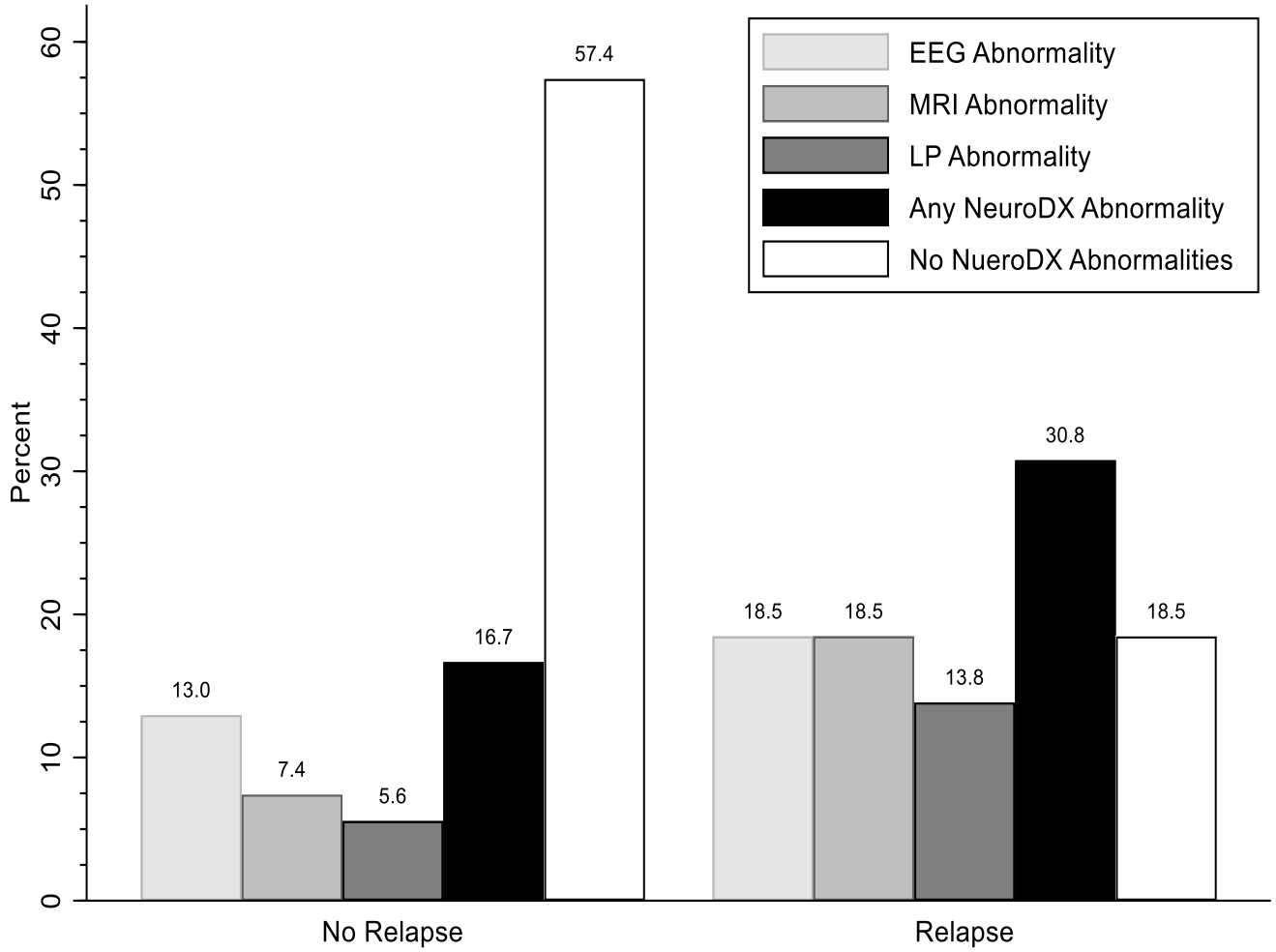




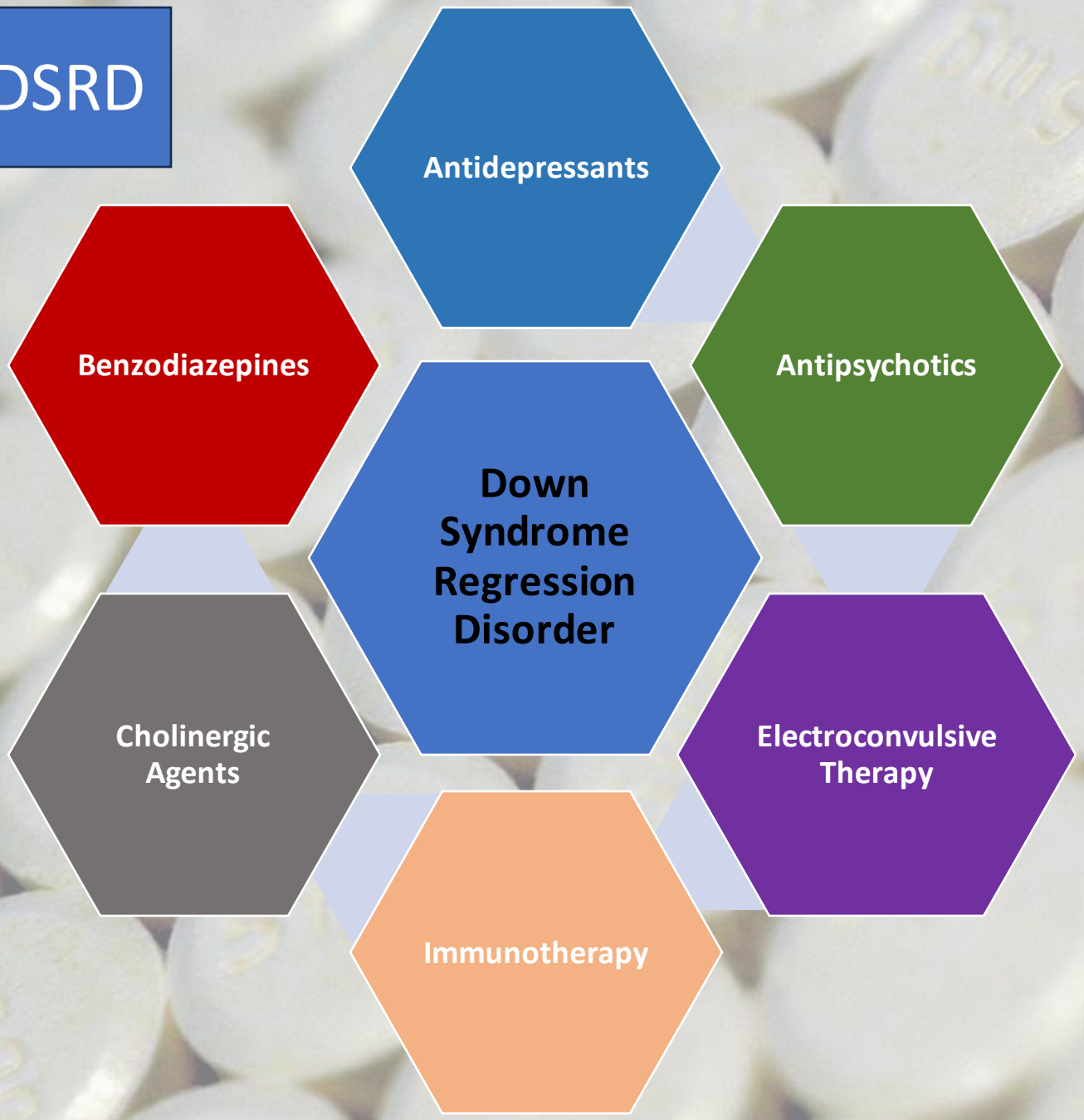


Biomarker Importance

- The risk of relapse when IVIg is stopped is highest in patients who have neurodiagnostic abnormalities.
- These were also the same patients that were more likely to respond to therapy in the first place.
- This may indicate that patients with neurodiagnostic abnormalities are more likely to be experiencing chronic immune dysregulation causing the symptoms.



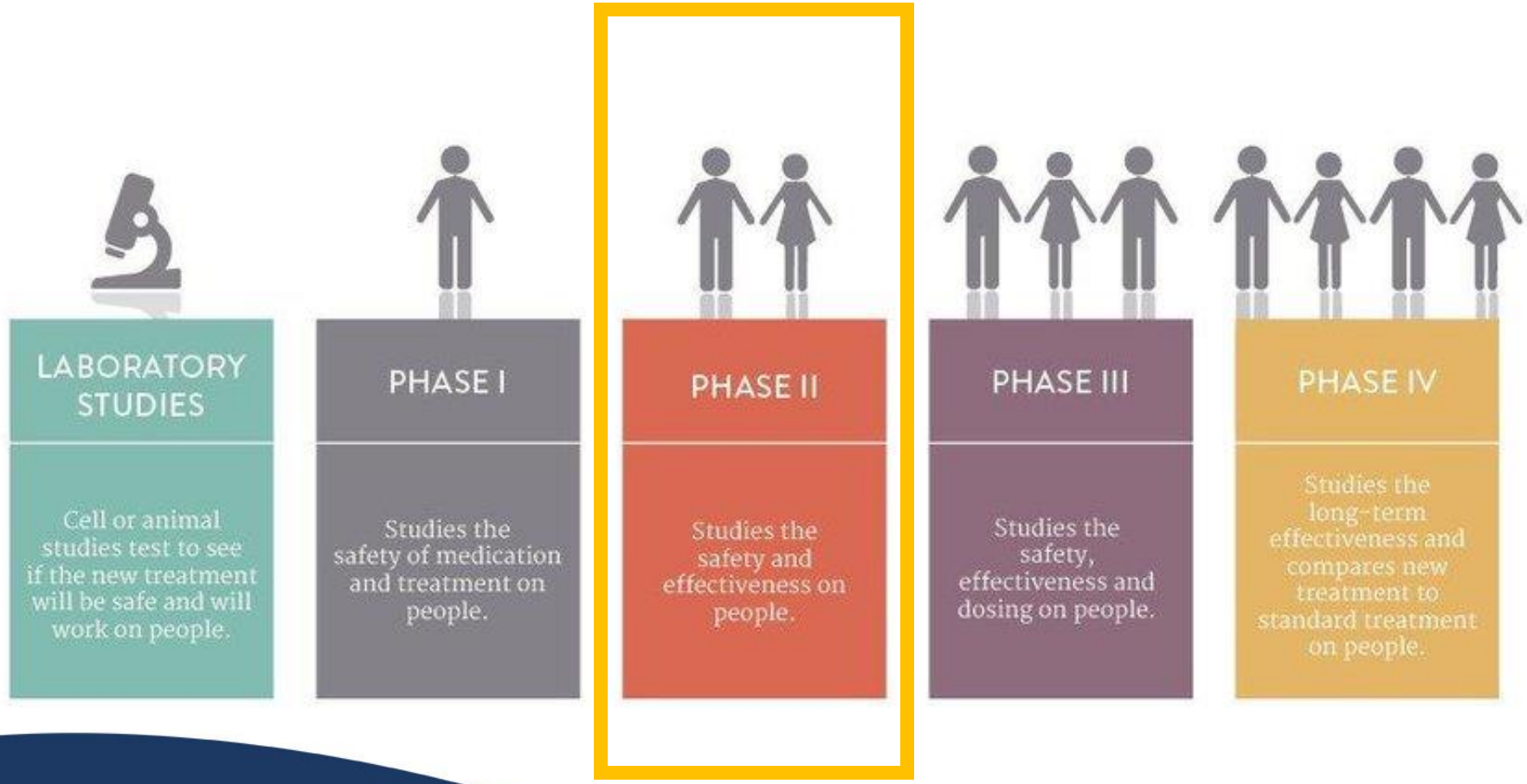
Treatments for DSRD



Knowledge Gaps

- What is the cause of DSRD, and does it differ in each individual?
- Are there easy to obtain biomarkers that can help identify the best treatments for those with DSRD?
- Is there a way to prevent DSRD?

How is the INCLUDE Project moving DSRD Research forward?



Clinical Trial for mechanistic investigation of therapies for DSRD

Three goals:

1. To define the relative **safety** profile of Lorazepam, IVIG, and Tofacitinib in DSRD.

2. To compare the **efficacy** of Lorazepam, IVIG, and Tofacitinib in DSRD.

3. To investigate potential **mechanisms** underlying DSRD and its response to therapies.

Is it safe?

Is it effective?

What is the mechanism?

Multi-Center Collaboration

A collaboration between

The Linda Crnic Institute, Children's Hospital Colorado, and Children's Hospital Los Angeles

Principal Investigators:

Dr. Santoro

Dr. Sannar

Dr. Espinosa

Co-Investigators:

Rachubinski

Patel

Kammeyer

Galbraith

Consultants:

Sanders

Tartaglia

Charoensook

Funded by:

NIH National Institutes of Health
Turning Discovery Into Health

THE INCLUDE PROJECT

Summary of Study Design

University of Colorado Anschutz Medical Campus

Children's Hospital LOS ANGELES

- Only individuals with Down Syndrome Regression Disorder (DSRD)
- Ages 8-30 years
- 12 weeks (3 months) of treatment with one medicine
- 60 participants total, 20 on each medicine
- Two sites, Denver and Los Angeles, 30 participants each

A Phase II, three-arm, open-label, research intensive trial

Lorazepam
Brand name: Ativan
Benzodiazepine

IVIG
Brand name: Gammagard
Intravenous Immune Globulin

Tofacitinib
Brand name: Xeljanz
JAK inhibitor

All three medicines studied in this trial are already FDA-approved for **other** medical conditions

The power of 'drug repurposing': this study benefits from extensive available data for all three drugs

Open label: participants will know which medicine they are taking

No placebo arm

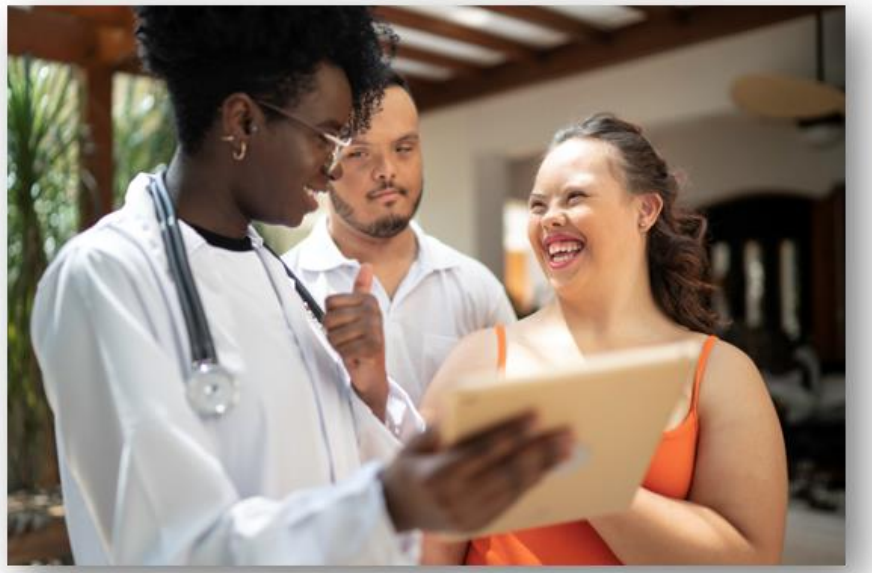
Why compare these three medicines?

A subset of DSRD cases are associated with signs of immune dysregulation affecting the central nervous system (CNS).

Is DSRD an autoimmune condition, like autoimmune encephalitis or alopecia? Is there a shared mechanism behind multiple autoimmune diseases in persons with Down syndrome?

What is the value of immune therapies relative to psychiatric medicines?

Why compare these three medicines?



- Who would benefit the most from which medicine?
- What are the diagnostic characteristics that could predict a good response?
- Are there ‘biomarkers’ in the blood or spinal fluid that could match each participant to their best therapeutic option?
- **Developing a personalized medicine approach for the treatment of DSRD**

A research-intensive clinical trial

• Blood samples and cerebrospinal fluid samples will be collected for deep analysis using cutting-edge technologies.

• Each participant will undergo significant testing to monitor for potential improvements in diverse areas of brain function.

• A multidisciplinary team with expertise in psychiatry, neurology, psychology, immunology, genetics, and molecular biology will analyze the data.

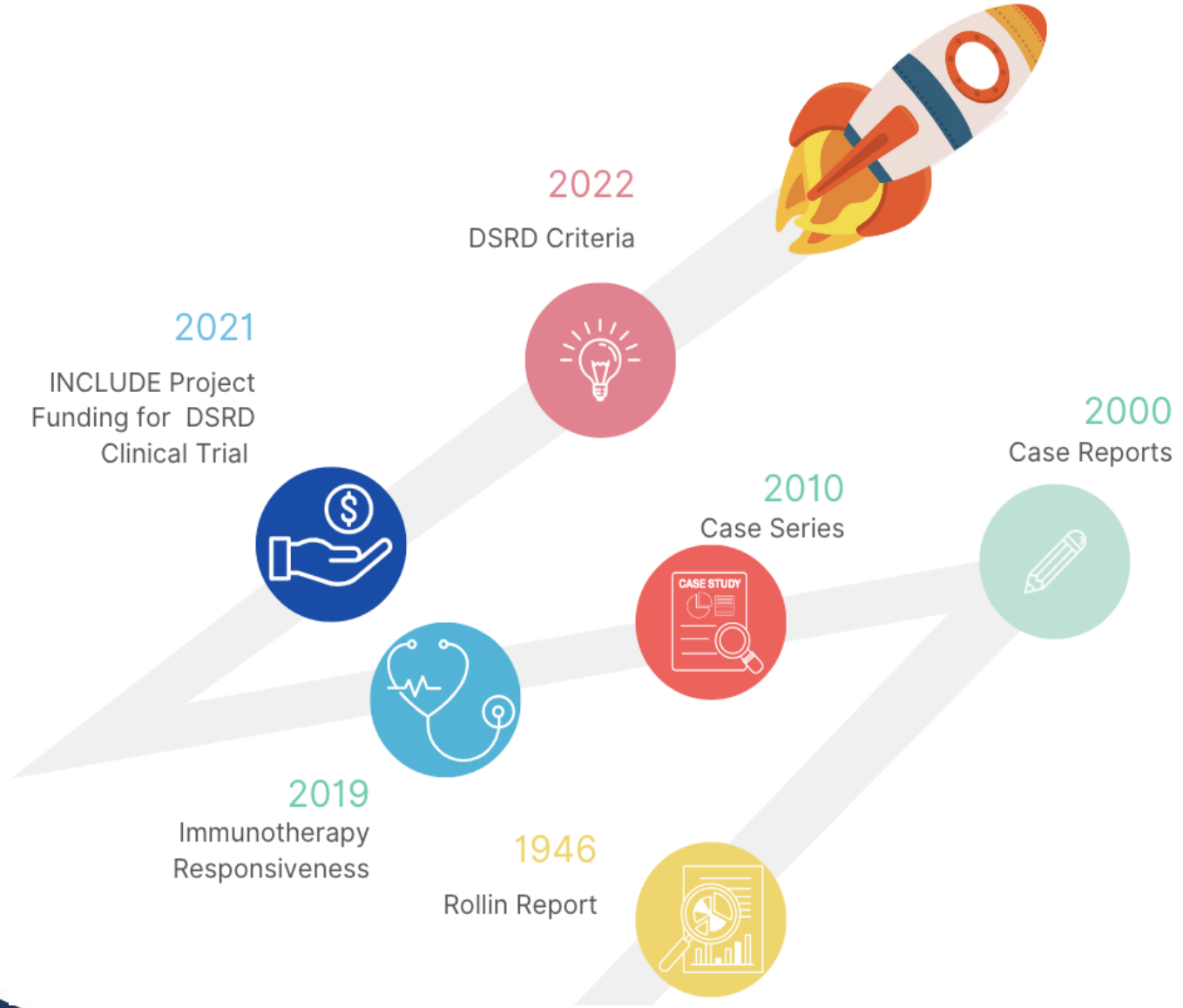
Important Facts

- **Recruitment** is ACTIVE right now! Our first patient enrolled in June 2023.
- **An interim analysis** will be completed **after recruitment** of the **first ~20 participants**, before scaling up to **~60 participants.**
- **Travel** and **lodging assistance** will be provided.
- Participation in the trial **will not prevent** participants from receiving other medicines (including those tested in the trial) after the trial.

dsresearch@chla.usc.edu
dsresearch@cuanschutz.edu

The DSRD Timeline

- The last four years have resulted in remarkable progress on the diagnosis and treatment of DSRD!
- Multiple INCLUDE initiatives have helped CHLA investigate neurologic conditions including stroke and moyamoya disease in addition to DSRD.
- Through multi-center collaborations, investigation into the shared mechanisms causing these conditions and how to treat them is now underway.



Thank you!

Children's Hospital Colorado

GLOBAL DOWN SYNDROME FOUNDATION

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Keck Medicine of USC

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DSMIG-USA Down Syndrome Medical Interest Group-USA

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DS-Connect®
The DS Registry

Community Engagement & Outreach

National Institutes of Health
Turning Discovery Into Health












DS-Connect®: The Down Syndrome Registry

A secure, confidential, online survey tool to collect basic information about people with Down syndrome

Available in Spanish

- Join DS-Connect and encourage other families to sign up!

Help us reach our goal:

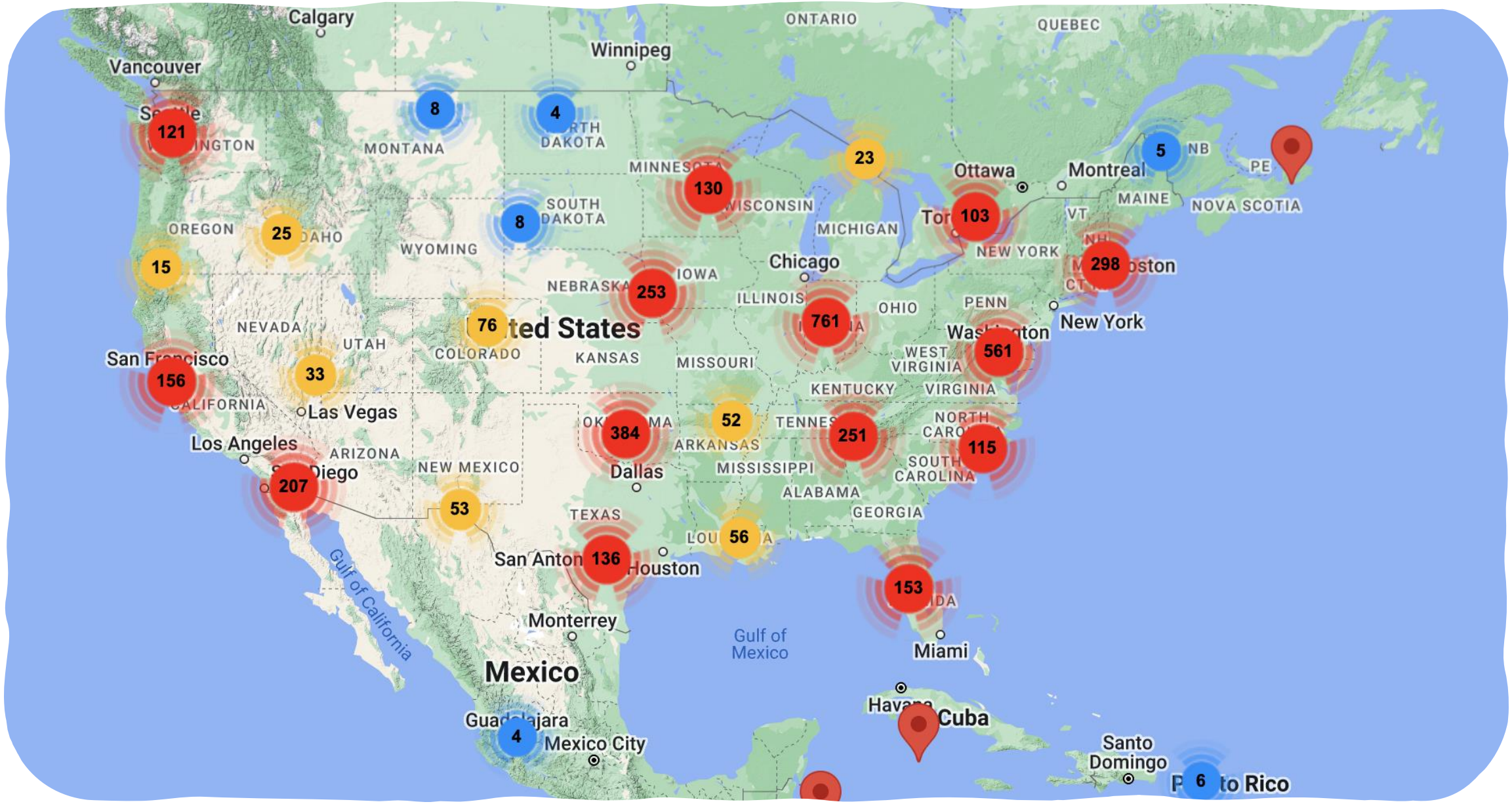
- 10,000 participants by September 2023, the 10-year anniversary of the Registry

SCAN ME

dsconnect.nih.gov

Launched 2013:
~5,804 registrants globally as of June 2023

Participants in the DS-Connect® Registry

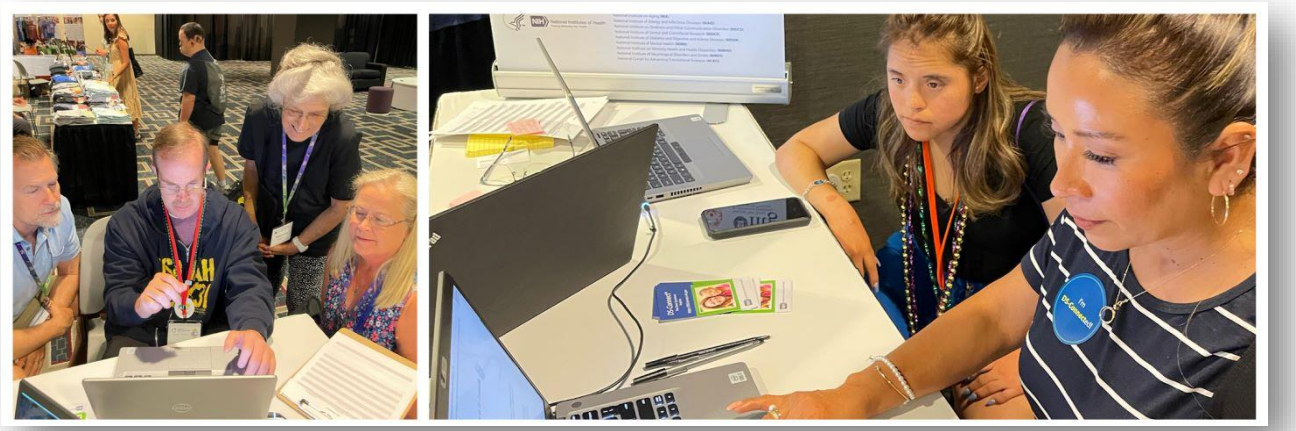


How secure is it?

- **Meets stringent data security requirements to protect personally identifiable information**
  - ~ 250 security controls are checked regularly (FISMA moderate level)
  - Information is encrypted
  - Password requirements (at least 8 characters long, 1 upper case, 1 lower case, 1 symbol, 1 number)
  - Example: P@ssword3
  - Passwords must be changed every 10 months
  - No social security info is collected
  - No personal bank account info is collected

Multiple Survey Modules

Basic Health Survey with "Trigger Questions" that lead to other surveys →



- ✓ Basic Health Survey
- ✓ Sibling Survey
- ✓ Thyroid Survey
- ✓ Heart Survey
- ✓ Sleep Survey
- ✓ Skeletal Survey
- ✓ Gastrointestinal Survey
- ✓ Diabetes Survey
- ✓ Celiac Disease Survey
- ✓ Leukemia Survey
- ✓ Development Survey
- ✓ Prenatal and Birth Survey

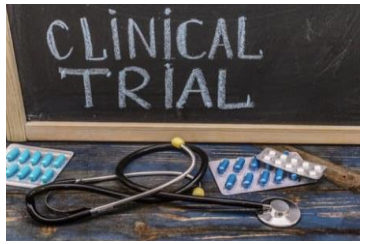
Available to adults →

- ✓ Adulthood Survey
- ✓ Men's Health Survey
- ✓ Women's Health Survey

Survey for 12-30 yo →

- ✓ Transition to Adulthood Survey

What does it mean to participate in research?

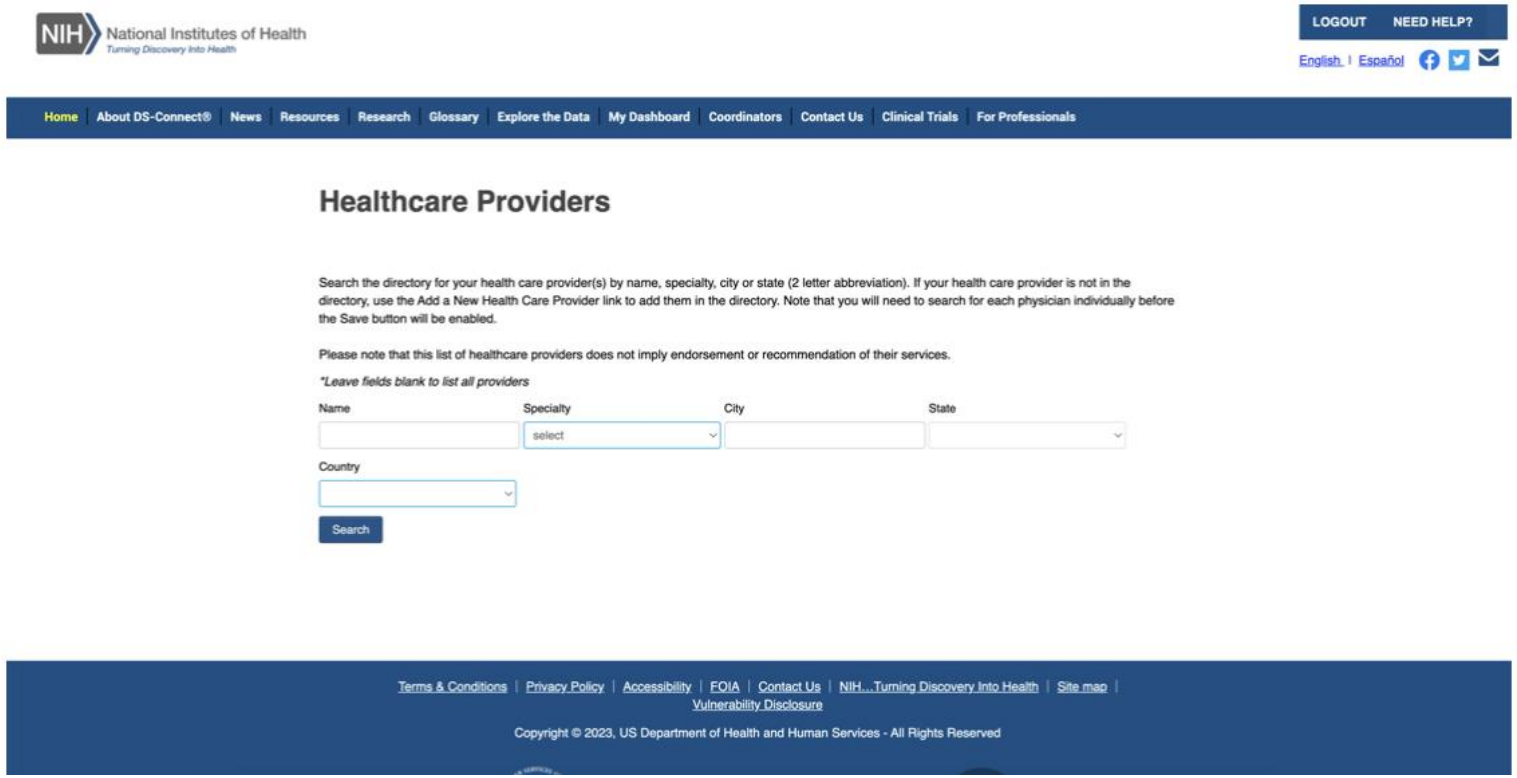


- ❑ Take a survey of your experiences
- ❑ Answer a questionnaire about health issues
- ❑ Record data from an activity tracker or watch
- ❑ Participate in a clinical study of an intervention
- ❑ Be in a clinical trial for a new drug or medication
- ❑ Participate in an “INCLUDE” study
- ☑ Any of the above! It’s your choice

Resources on DS-Connect® Registry

Access the health care provider list

~864 now listed



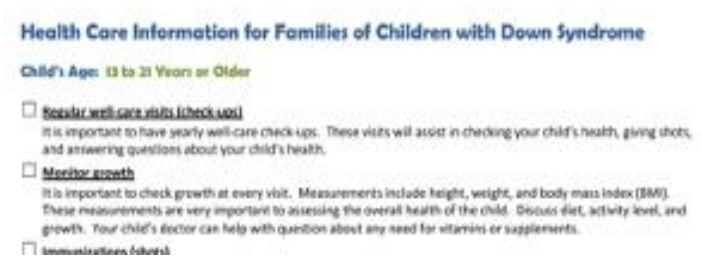
dsconnect.nih.gov

Access the Health Care Recommendations personalized for the person with DS

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

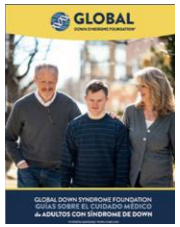
Children with Down Syndrome:
Health Care Information for Families (AAP)
Links to AAP checklists

healthychildren.org
Powered by pediatricians. Trusted by parents.
from the American Academy of Pediatrics


Health Care Information for Families of Children with Down Syndrome

Child's Age: 13 to 21 Years or Older

- Regular well-care visits (check ups)
  It is important to have yearly well-care check-ups. These visits will assist in checking your child's health, giving shots, and answering questions about your child's health.
- Monitor growth
  It is important to check growth at every visit. Measurements include height, weight, and body mass index (BMI). These measurements are very important to assessing the overall health of the child. Discuss diet, activity level, and growth. Your child's doctor can help with question about any need for vitamins or supplements.
- Immunizations (shots)



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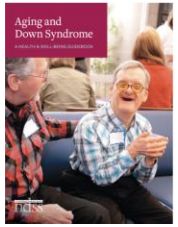
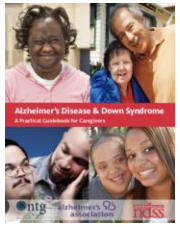
Medical Care Guidelines for Adults with Down Syndrome



national down syndrome society
ndss

Aging and Down Syndrome: A Health & Well-being Guidebook (NDSS)



national down syndrome society
ndss

Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers (NDSS)

Find Clinical Trials

NIH National Institutes of Health
Turning Discovery Into Health

Home | About DS-Connect® | News | Resources | Research | Glossary | For Professionals | Contact Us | Clinical Trials

Find Down Syndrome Clinical Trials

Search for NIH-funded clinical trials related to Down Syndrome

Filter by:

Location: Age

Search Clear See all NIH-funded Down Syndrome clinical trials

To search all clinical trials, visit clinicaltrials.gov

Community Engagement & Outreach

2023

2024

Investigator Workshop

Advancing Chicanos/Hispanics & Native Americans in Science

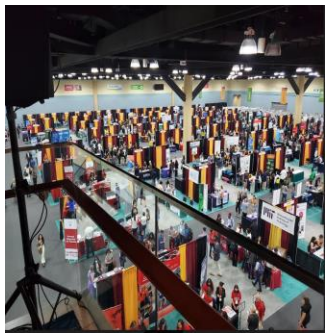
Diversity, Equity, Inclusion, and Accessibility (DEIA)

First INCLUDE Project DEIA Webinar held last month!

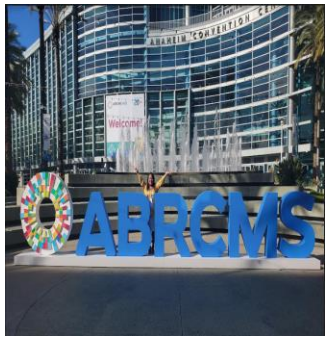
Visit the NIH INCLUDE Website to access the recording: nih.gov/include-project

Building trust and establishing positive relationships between researchers and the DS community

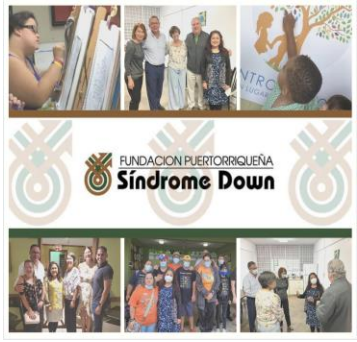
Society for the Advancement of Chicanos/Hispanics & Native Americans in Science (SACNAS) 2022



Annual Biomedical Research Conference for Minoritized Scientists (ABRCMS) 2022



Fundación Puertorriqueña Síndrome de Down—Puerto Rico



VI Iberoamerican Down Syndrome Congress (FIADOWN) Costa Rica, 2023

Acknowledgements

- Miah and her Mom, Linda Roan
- The NIH-wide Down Syndrome INCLUDE Working Group
- Investigators
- Children and adults with Down syndrome and their families

Thank You!