

Bridging Discovery and Practice

How Research and Education Drive Clinical Excellence at the Adult Down Syndrome Center

March 10, 2026



Presenters

- Brian Chicoine, MD
- Katie Frank, PhD, OTR/L
- Hannah Graham, MD

Agenda

- Introduction, History
- Clinical Care
- Educational Groups & Presentations
- Resources & Social Media
- Research



Introduction

ADSC Team

Physicians



Brian Chicoine, MD



Erin Dominiak, MD



Hannah Graham, MD



Farah Chaus, MD



Shelly Verma, DO, MSGPH



Katie Frank, PhD, OTR/L

OT

Clinical Staff



Pat Zidek, RN, BSN
Registered Nurse



Giselle Rodriguez
Medical Assistant



Ana Appelman
Medical Assistant

Front Desk Staff



Shirley Lange



Sandy Schumacher

Social Work



Brittany Anderson, LCSW

ADSC Team

Patient Advocates



Ann Garcia, PhD



Jenny Lutes, MS, CCLS

Research & Education



Laura Krohn, BA
Project Manager,
Research & Education



Angie Figueroa, MS, CCRP
Research Coordinator,
Clinical Trials

Practice Manager



Ruben Santiago

Volunteer



Julie Halfen

Foundation Team



Ally Regnier, CFRE
Vice President, Development
Near North Chicago & West
Suburbs



Kerry Neville, BA
Development Manager
Advocate Lutheran
General Hospital

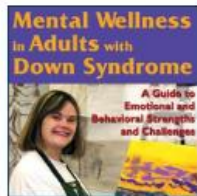
History

The Adult Down Syndrome Center opened on January 17.



1992

Mental Wellness book (1st edition) was published.



2006

The Adult Down Syndrome Center moved to a newly constructed building designed specifically for adults with Down syndrome.



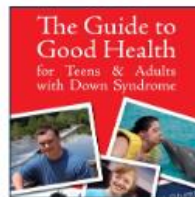
2012

1999



The Adult Down Syndrome Center moved into its own building on the campus of Advocate Lutheran General Hospital.

2010



The Guide to Good Health book was published.

2015



The Research and Education Initiative was launched.

History

Occupational therapy services (including sensory evaluations and expanded social skills groups) started at the ADSC.

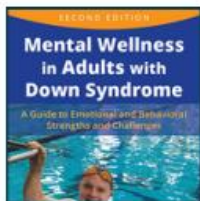
ADSC invited to participate in the LIFE-DSR study, a multi-site study to better understand aging in people with Down syndrome.

Dr. Chicoine invited to contribute to Trisomy 21 Research Society's COVID-19 research efforts.



History

Mental Wellness (2nd edition) was published.



2021

Success of At the Center of It All campaign enabled the ADSC to hire an LCSW and expand mental health services.



2022

NDSS published "The Primary Care Provider's Guide to Women's Health and Down Syndrome." Dr. Graham was the lead author.



2024



Launched the At the Center of It All fundraising campaign in support of research and education at the ADSC.

2021



Led by Dr. Chicoine, DSMIG-USA launched Project ECHO to support healthcare professionals of people with Down syndrome.

2023



NDSS launched CARE Down Syndrome. Dr. Chicoine was the lead author and continues to contribute significantly to the project.

2025



Clinical care in 2025

- **Patients seen:** 1,895
- **Appointments:** 3,875
- **Other encounters:** 14,456
 - Phone/portal messages, refills, forms, etc.



Education for Healthcare Professionals

Professionals in training

- **Medical students**

- Dr. Graham is the Assistant Education Director of Family Medicine at Chicago Medical School at Rosalind Franklin University of Medicine and Science.
- Dr. Chicoine is a Clinical Associate Professor at University of Illinois Chicago College of Medicine and lecturer at Chicago Medical School.

- **Family Medicine residents**

- Our physicians are on the faculty of the Advocate Lutheran General Hospital Family Medicine Residency.

- **Occupational therapy students**

- Dr. Frank lectures for the Occupational Therapy departments at University of Illinois Chicago and Rush University.
- She also mentors OTD Capstone students.

DSMIG-USA

- **Down Syndrome Medical Interest Group-USA**
 - Dr. Chicoine is on the Board of Directors, chairs the Education Committee, and facilitates Down Syndrome Project ECHO.
 - Dr. Frank has been on the Board of Directors and served as the President. She is the current co-chair of the Annual Symposium Committee.
 - Dr. Graham presented at the Annual Symposium in July 2025.
 - Pat Zidek presented a webinar for the Speaker Series in August 2025.



CARE Down Syndrome

- Free clinical education and resource hub developed by the National Down Syndrome Society to support healthcare professionals of adults with Down syndrome.
- Accredited by Penn State. Endorsed by DSMIG-USA and AADMD.
- Launched October 2025
- ADSC contributions
 - Brian Chicoine, MD – lead author and reviewer
 - Hannah Graham, MD – author and reviewer
 - Katie Frank, PhD, OTR/L - author



CARE DS

Share resources

Down Syndrome Medical Interest Group-USA

[Website](#)

[General Flyer](#)

[Project ECHO Flyer for Professionals](#)

[Project ECHO Flyer for Families](#)

CARE Down Syndrome (National Down Syndrome Society)

[Website](#)

[Flyer](#)

[Email Template](#)



Do you have patients with Down syndrome?

Whether you're seeing one adult with Down syndrome or many, CARE Down Syndrome gives you the knowledge and resources to deliver informed, respectful, and individualized care starting today.

Elevating Primary Care for Adults with Down Syndrome

A Clinical Education and Resource Hub for Healthcare Professionals

Only an estimated 5% of adults with Down syndrome have access to specialty Down syndrome clinics.¹



That means **95% rely on you**—their primary care professional.



Learn More at
careds.org



What is CARE Down Syndrome?



Self-Paced eLearning Course

Earn free continuing medical education (CME) credits while gaining practical strategies for managing health conditions in adults with Down syndrome.



Clinical Reference Articles

Explore our collection of in-depth articles, designed to enhance understanding and provide deeper insight into key healthcare topics related to adults with Down syndrome.

Review articles on:

- Alzheimer's disease
- Common conditions
- Down Syndrome Regression Disorder
- Mental health



Resource Library

Access our resource library for downloadable patient education materials and tools to help healthcare professionals deliver exceptional care to adults with Down syndrome.

**Designed for Primary Care.
Backed by Expertise.**

¹Santoro SL, Campbell A, Balasubramanian A, Haugen K, Schuller K, Hobbey W. Specialty Clinics for adults with Down syndrome: A clinic survey. *Am J Med Genet A*. 2021;186(5):1767-1775. doi:10.1002/ajmg.a.42989



Advocate Health Care

Education

Education efforts



People with Down syndrome

- Visuals & videos
- Groups



Families and caregivers

- Articles
- Webinars



Healthcare professionals

- DSMIG
- CARE Down Syndrome

Resources



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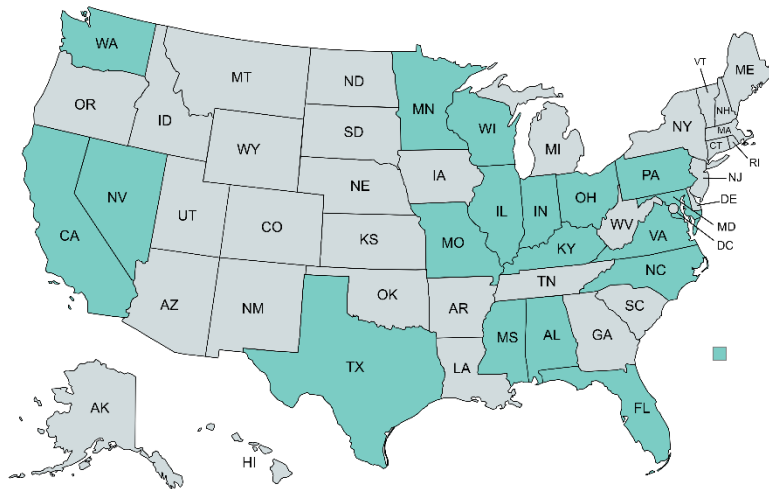
Groups

- Learn and practice social skills
- Promote health
- Interact with other participants with Down syndrome
- Have fun



Group Participants in 2025

- **Total group participants: 129**
 - Illinois: 98
 - Non-Illinois: 31
- **Total participant interactions: 910**



17 states

Group Sessions in 2025

Total group sessions: 108

- **Virtual**

- Healthy Living
- Conversation Skills
- Dating
- Music

- **In-person**

- Art
- Conversation Skills
- Summer Wellness
- Skills for Successful Social Interactions
- Games



ADSC webinars in 2025

The *Recipe* for Health: How to Nourish Your Mind, Body, & Soul

Thursday, January 9, 2025 at 10:30 a.m. CST

Learn practical ways to encourage individuals with Down syndrome to be active participants in promoting their health.



Presenter: Brian Chicoine, MD



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Adapting Activities for Older Adults with Down Syndrome

Thursday, March 13, 2025 at 11:00 a.m. CDT

Learn strategies for modifying or adapting tasks as a person ages to promote safe and successful completion of daily activities including:

- dressing
- bathing
- eating
- participating in leisure & social activities



Presenter: Katie Frank, PhD, OTR/L



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Gastrointestinal (GI) Health of People with Down Syndrome

From a Primary Care Perspective

Presenter: Brian Chicoine, MD



TWO-PART WEBINAR SERIES

Part 1 Thursday, May 15 at 11:00 a.m. CDT

Part 2 Thursday, May 29 at 11:00 a.m. CDT

▶ Can't attend live? The webinars will be recorded!



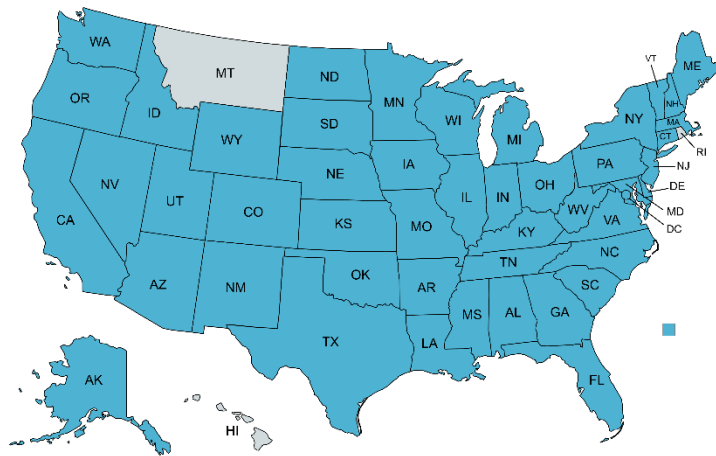
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ADSC webinars in 2025

	Recipe for Health	Adapting Activities	GI Part 1	GI Part 2
Registrants	552	464	598	629
Live attendees	150	142	140	138
YouTube views (as of 3/1/2026)	139	510	622	198
Feedback	“Dr. Chicoine and the ADSC are my number one source of information about Down syndrome.” “You all are amazing! Thank you for sharing and making all the resources available to help out our loved ones with Down syndrome! You are appreciated!” “I am so grateful for your teaching us parents what you’ve learned!!! There is so little we humans know about Down syndrome, therefore, your sharing is INVALUABLE!!”			



47 states



18 countries

Other presentations

ADSC staff presented 44 additional webinars or presentations in 2025.

- **Organizations included:**

- Down Syndrome Medical Interest Group-USA
- National Down Syndrome Society
- National Down Syndrome Congress
- European Down Syndrome Association
- Alzheimer's Association
- Down's Syndrome Association (UK)
- GiGi's Playhouse
- And others

- **Topics included:**

- Common and uncommon health conditions
- Aging and Alzheimer's disease
- Health promotion
- Healthy sexuality
- Women's health
- Decline in skills and regression
- Sensory



Resource Library

- **New resources:** 24
- **Updated resources:** 37

Heart Rates of Adults With Down Syndrome While Exercising

- Many adults with Down syndrome have lower resting and maximum heart rates.
- Thus, target heart rates for moderate and vigorous exercise are also lower for adults with Down syndrome.
- This is important to consider when supporting adults with Down syndrome in setting exercise goals.

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Stories About Period Symptoms



Printable versions available in our Resource Library

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The Autonomic Nervous System in People with Down Syndrome

The autonomic nervous system is part of the nervous system. It functions "automatically" without us needing to think about it.

It consists of 2 parts:

- sympathetic ("fight or flight")
- parasympathetic ("rest and digest")

People with Down syndrome tend to have reduced sympathetic and increased parasympathetic activity.

These differences can affect other body functions including blood pressure, heart rate, temperature regulation, and the digestive and urinary systems.

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FATIGUE

What can contribute to fatigue in people with Down syndrome?

Lifestyle factors

Diet, exercise, sleep, hydration, and stress.

Health conditions

- Sleep apnea
- Thyroid conditions
- Diabetes
- Kidney dysfunction
- Celiac disease
- Addison's disease
- Anemia
- Autoimmune conditions
- Vitamin deficiencies
- Depression & anxiety
- Alzheimer's disease
- And others

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Social media



Facebook

- **Views:** 7,006,108
- **New follows:** 6,975



Instagram

- **Views:** 255,417
- **New follows:** 369

"I can't thank you enough for all of this valuable information. We are a bit isolated in Florida. There are no local doctors or clinics that focus on DS. The information has been invaluable."

"I cannot thank you enough for your resources! We are in Missouri, and I wish we had an organization that is half as great as yours! Your resources are excellent. I have learned so much from your posts and share them as often as possible! Thank you for all you do!"

"This is amazing information! I shared with my daughter. We're loving your site!"



Research

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graph TD; Research[Research] --> Data[Data/EMR]; Research --> Trials[Clinical Trials];
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Research

Data/EMR

Clinical
Trials

Publications

The ADSC has contributed to studies on a range of topics related to health of people with Down syndrome:

- Alzheimer's disease
- Cancer
- COVID-19
- Down syndrome regression disorder
- Endocrine disorders
- Heart disease
- Mental health
- Parents as primary sexuality educators
- Pneumonia

*See Appendix for complete list of publications.



Data/EMR

- Co-occurring conditions in people with Down syndrome
- Articles published in 2021 and 2022 are read and cited frequently.

Article	Downloads	Citations
Prevalence of Common Disease Conditions (Chicoine et al.)	3,577	83
Prevalence of Infectious Diseases (Fitzpatrick et al.)	1,058	13
Prevalence of Endocrine Disorders (Rivelli et al.)	1,435	17
Prevalence of Mental Health Conditions (Rivelli et al.)	2,354	42

Clinical trials

- LIFE-DSR
 - Longitudinal Investigation for the Enhancement of Down Syndrome Research
 - Multi-year, multi-site study that ended in 2024
 - ADSC was 1 of 14 sites and recruited 1/3 of the total participants



Article

Cross-Sectional Exploration of Plasma Biomarkers of Alzheimer's Disease in Down Syndrome: Early Data from the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) Study

James A. Hendrix ^{1,*}, David C. Airey ², Angela Britton ¹, Anna D. Burke ³, George T. Capone ⁴, Ronelyn Chavez ⁵, Jacqueline Chen ⁶, Brian Chicoine ⁷, Alberto C. S. Costa ⁸, Jeffrey L. Dage ², Eric Doran ⁹, Anna Esbensen ^{10,11}, Casey L. Evans ¹², Kelley M. Faber ¹³, Tatiana M. Foroud ¹³, Sarah Hart ¹⁴, Kelsey Haugen ¹⁵, Elizabeth Head ¹⁶, Suzanne Hendrix ¹⁷, Hampus Hillerstrom ¹, Priya S. Kishnani ¹⁴, Kavita Krell ¹⁵, Duvia Lara Ledesma ⁵, Florence Lai ¹⁸, Ira Lott ⁹, Cesar Ochoa-Lubinoff ⁹, Jennifer Mason ⁵, Jessie Nicodemus-Johnson ¹⁷, Nicholas Kyle Proctor ², Margaret B. Pulsifer ¹², Carolyn Revta ⁹, H. Diana Rosas ¹⁸, Tracie C. Rosser ¹⁹, Stephanie Santoro ^{15,20}, Kim Schafer ⁵, Thomas Scheidemantel ²¹, Frederick Schmitt ²², Brian G. Skotko ^{15,20}, Melissa R. Stasko ²¹, Amy Talbot ²³, Amy Torres ¹⁵, Kristi Wilmes ¹³, Jason Woodward ^{10,11}, Jennifer A. Zimmer ², Howard H. Feldman ⁵ and William Mobley ²⁴

Knox et al. *Journal of Patient-Reported Outcomes* (2021) 5:5
<https://doi.org/10.1186/s41687-020-00278-7>

Journal of Patient-Reported Outcomes

RESEARCHOpen Access

Development of a symptom menu to facilitate Goal Attainment Scaling in adults with Down syndrome-associated Alzheimer's disease: a qualitative study to identify meaningful symptoms

Kari Knox¹, Justin Stanley¹, James A. Hendrix², Hampus Hillerstrom², Taylor Dunn¹, Jillian Achenbach³, Brian A. Chicoine⁴, Florence Lai⁵, Ira Lott⁶, Sanja Stanojevic¹, Susan E. Howlett^{1,3*} and Kenneth Rockwood^{1,3*}

Upcoming clinical trials

- [Sleep apnea](#)
- [Trial-Ready Cohort – Down Syndrome \(TRC-DS\)](#)
- [ALADDIN](#)

Upcoming clinical trials

- [Sleep apnea](#)
 - Studying alternative therapies for treating sleep apnea
 - Led by Daniel Combs, MD, at the University of Arizona
 - Anticipate starting at the ADSC in spring 2026

Upcoming clinical trials

- [Trial-Ready Cohort – Down Syndrome \(TRC-DS\)](#)
 - Longitudinal study to prepare participants for Alzheimer's disease clinical trials
 - Led by Michael Rafii, MD, PhD, at the University of Southern California
 - Anticipate starting at the ADSC in summer 2026
- [ALADDIN](#)
 - Studying an amyloid-reducing treatment (donanemab) in people with Down syndrome
 - Led by Michael Rafii, MD, PhD, at the University of Southern California
 - Planning stages



Learn more & get updates!

Adult Down Syndrome Center



[Resource Library](https://adsresources.advocatehealth.com/)

[https://adsresources.
advocatehealth.com/](https://adsresources.advocatehealth.com/)



[@adultdownsyndromecenter](https://www.facebook.com/adultdownsyndromecenter)



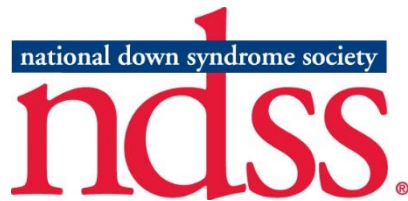
[Email List](http://eepurl.com/c7uV1v)

<http://eepurl.com/c7uV1v>



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Research Opportunities



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Support our mission

We are able to offer services like our resource library, groups, and educational webinars free of charge through the generosity of donors. If you would like to support the Adult Down Syndrome Center's Research and Education Program, please see our [Giving Page](#).



Questions?

Adult Down Syndrome Center



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Join us at our next webinar!



[Register](#)

▶ UPCOMING WEBINAR

From Heart Rate to Digestion

Autonomic Nervous System
Function in People with
Down Syndrome

Wednesday, April 29, 2026
12:00 to 1:00 p.m. CDT



Presenter: Brian Chicoine, MD
Medical Director
Adult Down Syndrome Center

*Can't attend live? Register to
receive a link to the recording!*



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Appendix

Publications 2020-2025

Publications

2020

Co-Occurring Medical Conditions in Adults with Down Syndrome: A Systematic Review Toward the Development of Health Care Guidelines. Part II (Capone et al.)

Challenges of Pediatric Disease in Adulthood (Baumgardner & Chicoine)

Heart Disease in Adults with Down Syndrome Between 1996 and 2016 (Fitzpatrick et al.)

Medical Care of Adults with Down Syndrome: A Clinical Guideline (Tsou et al.)

A Randomized Controlled Trial of an Online Health Tool about Down Syndrome (Chung et al.)

2021

Pneumonia and Respiratory Infections in Down Syndrome: A Scoping Review of the Literature (Santoro et al.)

Development of a Symptom Menu to Facilitate the Goal Attainment Scaling in Adults with Down Syndrome-Associated Alzheimer's Disease: A Qualitative Study to Identify Meaningful Symptoms (Knox et al.)



Publications

2021

Parents as Primary Sexuality Educators for Adolescents and Adults with Down Syndrome: A Mixed Methods Examination of the *Home B.A.S.E. for Intellectual Disabilities* Workshop
(Frank & Sandman)

Medical Vulnerability of Individuals with Down Syndrome to Severe COVID-19: Data from the Trisomy 21 Research Society and the UK ISARIC4C Survey (Huls et al.)

Opportunities, Barriers, and Recommendations in Down Syndrome Research (Hendrix et al.)

Prevalence of Common Disease Conditions in a Large Cohort of Individuals with Down Syndrome in the United States (Chicoine et al.)

Cross-Sectional Exploration of Plasma Biomarkers of Alzheimer's Disease in Down Syndrome: Early Data from the Longitudinal Investigation for Enhancing Down Syndrome Research Study (Hendrix et al.)

COVID-19 in Children with Down Syndrome: Data from the Trisomy 21 Research Society Survey (Emes et al.)



Publications

2022

Prevalence of Mental Health Conditions Among 6,078 Individuals with Down Syndrome in the United States (Rivelli et al.)

Prevalence of Infectious Diseases Among 6,078 Individuals with Down Syndrome in the United States (Fitzpatrick et al.)

Prevalence of Endocrine Disorders Among 6,078 Individuals with Down Syndrome in the United States (Rivelli et al.)

COVID-19 Vaccination of Individuals with Down Syndrome: Data from the Trisomy 21 Research Society Survey on Safety, Efficacy, and Factors Associated with the Decision to be Vaccinated (Huls et al.)

Ableism at the Bedside: People with Intellectual Disabilities and COVID-19 (Chicoine et al.)

Assessment and Diagnosis of Down Syndrome Regression Disorder: International Expert Consensus (Santoro et al.)

Considering Dignity of Risk in the Care of People with Intellectual Disabilities: A Clinical Perspective (Chicoine & Kirschner)



Publications

2022

Differences in Clinical Presentation, Severity, and Treatment of COVID-19 Among Individuals with Down Syndrome from India and High-Income Countries: Data from the Trisomy 21 Research Society Survey (Pinku et al.)

The Feasibility of Goal Attainment Scaling in Adults with Down Syndrome: Early Results from the LIFE-DSR-GAS Sub-Study (Dunn et al.)

2023

Cardiovascular Complications of Down Syndrome: Scoping Review and Expert Consensus (Dimopoulos et al.)

2024

Retrospective Review of the Code Status of Individuals with Down Syndrome during the COVID-19 Era (Jett et al.)

Adapting Prescribing Criteria for Amyloid-Targeted Antibodies for Adults with Down Syndrome (Hillerstrom et al.)