



# Research for Busy People

Incorporating Down syndrome research into your existing programs and channels

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*VP, Marketing &  
Community Engagement*

# SESSION OUTLINE



- I. Why is Down syndrome research so important right now?
- II. You don't have to do everything - choose a role or two for your org to play in accelerating research
- III. Sharing research information & education
  - a) in SOCIAL MEDIA
  - b) in COMMUNICATIONS
  - c) via PROGRAMS & EVENTS
- IV. Vetting INVITATIONS
- V. Considering RESEARCH ADVISORY COMMITTEES
- VI. Making friends with your LOCAL CLINICS

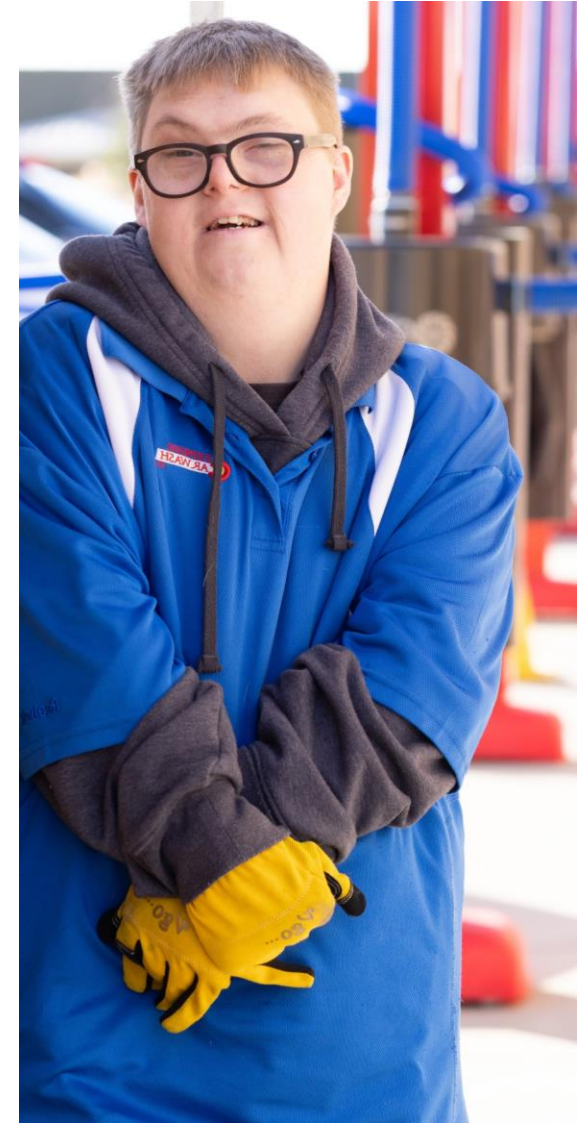
# Hi. We're LuMind IDSC!



We envision a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential.

To realize our vision, we...

- **accelerate research** to increase availability of therapeutic, diagnostic, and medical care options
- **provide resources and support** to a dynamic community of individuals with Down syndrome and their caregivers
- **serve as a connector, a bridge** between the Down syndrome community and the research community



# Our Community



278,000

followers on 5 social media platforms



6,600

digital survey participants & clinical research studies

4,300+

people from 50 states and 18 countries are members of myDSC, our free digital resource library


1500+

Participants in 21 observational studies and interventional clinical trials

130

scientists at 32 institutions conduct research for LuMind IDSC

# Why We Accelerate Research & Promote Research Awareness



95%

risk of Down syndrome-associated Alzheimer's disease at age 65. It is the leading cause of death for adults with DS.

100%

of adults with DS experience obstructive sleep apnea. 60% of kids with DS experience abnormal sleep by age 4.

97%

of families report lack of independence as a critical concern for their loved one.

99%

almost all children and adults with Down syndrome have speech and cognitive delays.

# Why is research info more important than ever before?



- This is the first generation of people with Down syndrome to live to retirement age and experience elder medical issues.
- Parents, siblings, and caregivers are aging along with their loved one. Everyone needs more support, info, and solutions.
- New treatments and therapies for Alzheimer's disease, sleep apnea, and other conditions associate with Down syndrome are on the near horizon.
- As new treatments are made available, people with Down syndrome should be able to access the latest medical advancements.
- **But first, doctors need to know those treatments are safe to prescribe to people with Down syndrome. Participation is key!**



# Research Participation is Needed

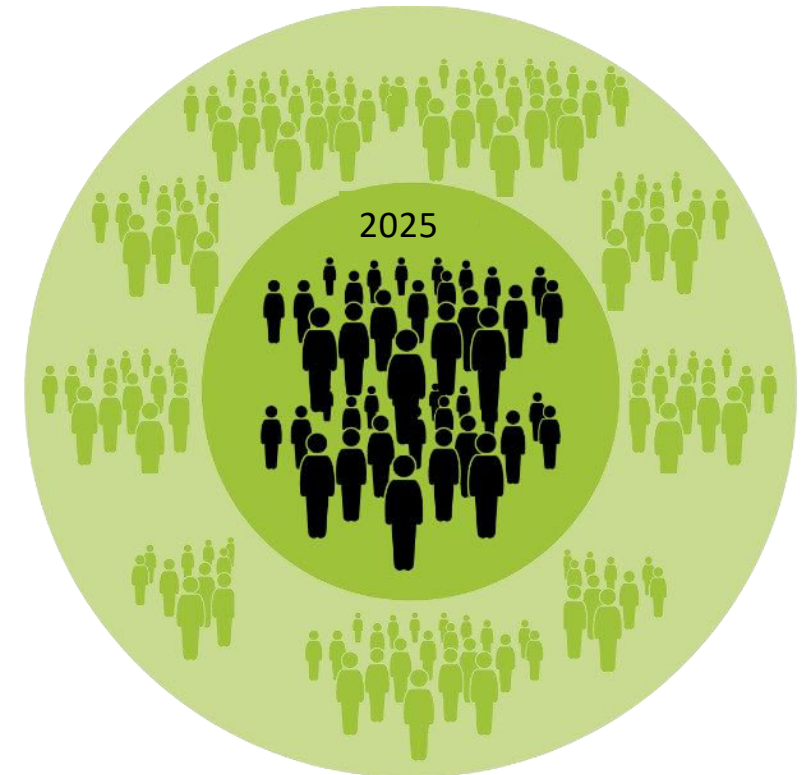
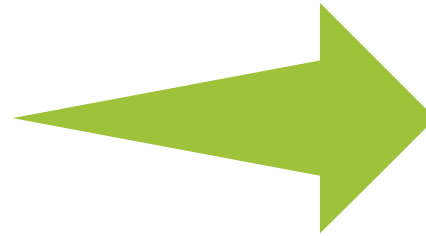


The number of clinical trials and observational studies in adults with Down syndrome grew from one trial in 2016 to four in 2021.

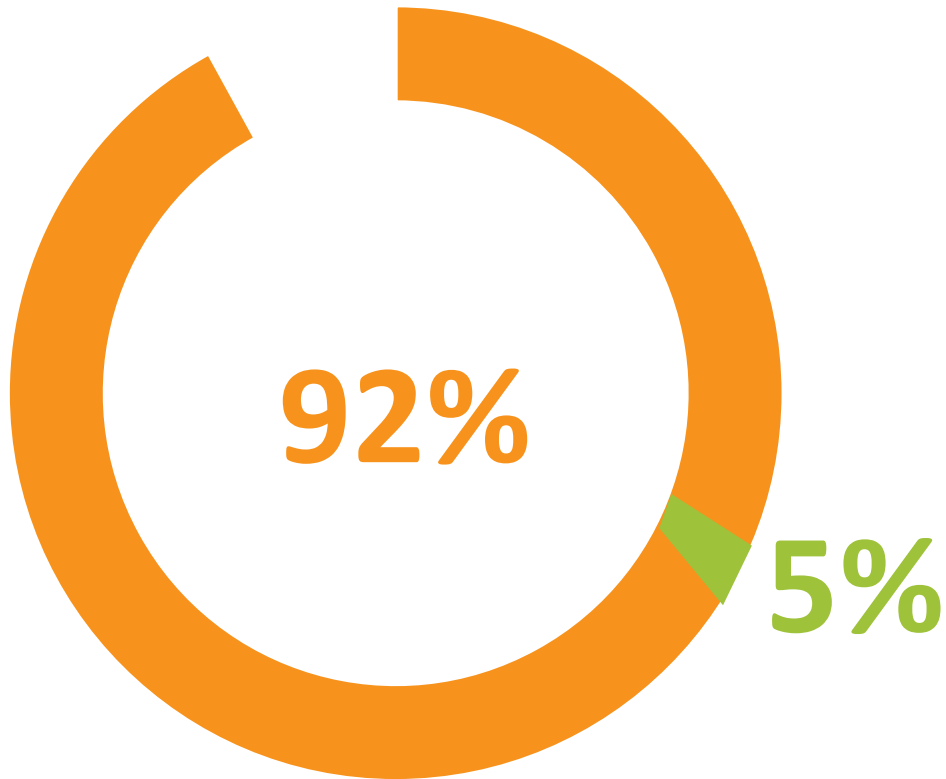
5-10 studies are expected by **2025**

**2016**

**2021**



# The Research Participation Disparity



**92%** of families surveyed by LuMind IDSC indicated they wanted clinical trials to focus on the health care needs of people with Down syndrome.

Fewer than **5%** of families said they had ever participated in a clinical trial. N.White, 2021

**CONCLUSION:** We need to raise awareness of research opportunities, and de-mystify research for our families.





# What role can local/regional org play in explaining/promoting research?



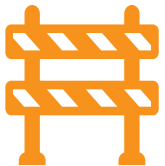
**Be a conduit.** Help facilitate conversations and information sharing about the importance of Down syndrome research by connecting with content providers.



**Be a teacher.** Offer your community existing resources to help de-mystify research and introduce them to education and awareness tools.



**Be a promoter.** Advertise research opportunities to your community, or invite researchers to engage



**Be a gatekeeper.** Establish processes or use available tools to vet incoming research opportunities for value, impact, and legitimacy.





# CONNECTING via Social Media



Be a conduit. Help facilitate conversations and information sharing about the importance of Down syndrome research by connecting with content and resource providers.

## Sharing research information, tools, & education via social media

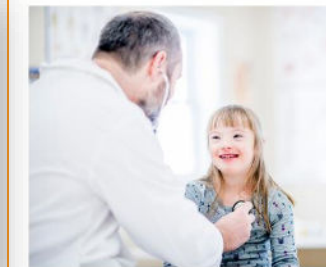
- Borrow content from national orgs, hospitals, clinics
- Create a series for scientific vocab or key statistics
- Use “awareness” months to promote a certain condition (February is Heart ♥ Health, for example)
- Ask a question of your community
- Get some first-person “testimonials”

### RESEARCH GLOSSARY #9

**What are “clinical trials” and how can they benefit people with Down syndrome?**

#TheyDidICanWeWill

myDSmoment



February is American Heart Month, a time to bring awareness to heart conditions. Congenital heart defects affect approximately 50% of babies born with Down syndrome—compared to 1% of neurotypical children.

Learn more here: [link](#)

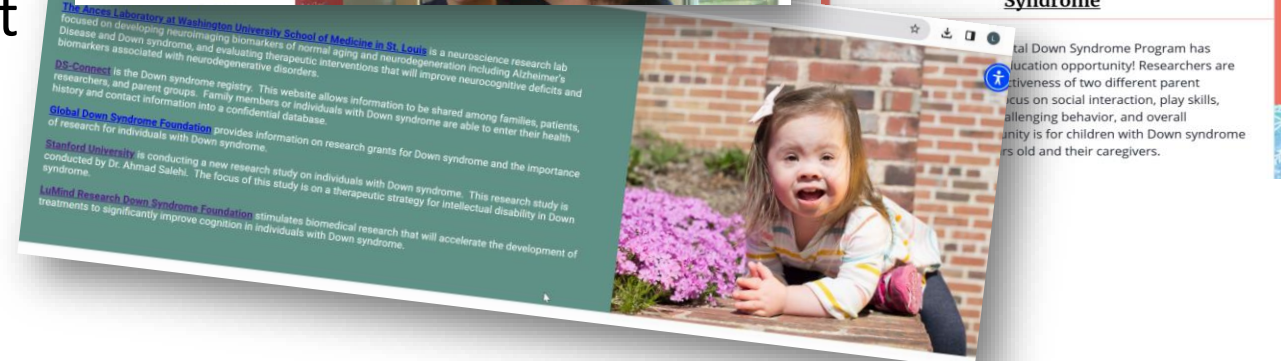
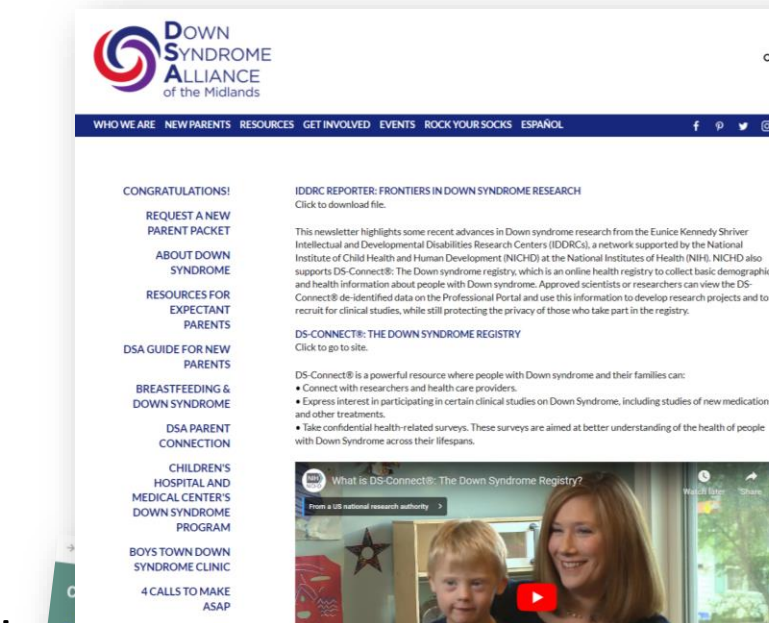


# CONNECTING via communications



## Sharing research information, tools, & education in your communications

- Include a “research corner” in your monthly newsletter
- Send a research-specific newsletter at specific times of year
- Host a research info web page with resource links
- Invite researchers or scientists to submit a column to your blog (free content!)
- Add a “research interested” checkbox to your intake form





# CONNECTING via programs & events



- Invite local clinics and researchers to table at your Walk
- Ask families who have participated in research to speak about their experiences, mentor the research-curious
- Include research info, myDSC, and/or other in your new families packet or orientation
- Invite scientists/researchers to present a webinar, or presentation. Free programming!





# Where to find research info?



Resources other than LuMind IDSC or myDSC:

[Clinical Trials.gov](https://clinicaltrials.gov)

[DS Connect](#)

[ABC-DS](#)

[Advocate Health Adult DS Clinic](#) (their fb page, too!)

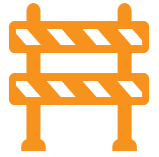
[DS Medical Interest Group](#)

[Global Down Syndrome Foundation](#)

[Jerome Lejeune Foundation](#)

[The National Task Group on Intellectual Disabilities & Dementia](#)





# Being a gatekeeper



## How Do I Know if a Study is “Good”?

When considering a research participation opportunity, we suggest you make sure the recruitment flyer, web page, etc. contains, in clear and family-friendly language:

- The contact information and credentials of the requestor or the individual who will be the main point of contact for questions
- A thorough description of the study/trial/survey
- Proof of regulatory oversight (IRB, ERB, etc.)
- Outline of participant inclusion parameters
- Timeline components of the request (project anticipated start or end date), and any other relevant information



We can help! LuMind IDSC is always a resource!

# Key things to consider

- Is the language around the study/trial/survey factual and not sensational?
- Does the study promise anything outrageous or improbable?
- Are the study materials and outreach collateral written with Down syndrome-related language that aligns to your community values?
- Is participant information de-identified and aggregated? If not, what is the reasoning?
- Is compensation for participation commensurate with the time invested?

Download Guidelines & Checklist at  
[www.LuMindIDSC.org/affiliates](http://www.LuMindIDSC.org/affiliates)



# What do “family-friendly,” “person-centric” materials look like?



**LIFE-DSR**  
**PARTICIPANT GUIDE**

**Preparing for a Lumbar Puncture**

The cover of a participant guide titled 'LIFE-DSR PARTICIPANT GUIDE'. It features a green leaf icon with a molecular structure, a portrait of a woman, and the Lumind IDSC Down Syndrome Foundation logo at the bottom.

The doctor will touch my back. The doctor is looking for the place where the fluid is in my back.

The doctor will clean my back. It might feel cold but it will not hurt.

The doctor will put a cloth over my back to keep it clean.

The doctor will give me a shot to make my back numb.

I have probably had shots before. I might feel a pinch but it will not last long.

We will all wait a few minutes for the numbing medicine to work.

This block contains three panels of text and images. The first panel shows a doctor's hands touching a patient's back. The second panel shows a doctor cleaning a patient's back. The third panel shows a doctor giving a patient a shot. Each panel includes a short video transcript snippet.

**WHEN WE ARRIVE AT THE HOSPITAL, I WILL CHECK IN TO A NEW OFFICE AND MEET SOME NEW PEOPLE.**

Getting Ready for a PET Scan

Unlisted

LuMind IDSC 124 subscribers

Analytics Edit video

0 0 Share Download

This block shows a video thumbnail with a red play button. The video title is 'WHEN WE ARRIVE AT THE HOSPITAL, I WILL CHECK IN TO A NEW OFFICE AND MEET SOME NEW PEOPLE.' Below the video, there is a title 'Getting Ready for a PET Scan', a 'Unlisted' status, the channel name 'LuMind IDSC' with 124 subscribers, and buttons for 'Analytics' and 'Edit video'. At the bottom, there are social media icons for likes, comments, shares, and downloads.

**SPEECH ACCESSIBILITY PROJECT**

**Share your voice with the Speech Accessibility Project!**

Now recruiting U.S. adults with Down syndrome (18+ years) to help commercial speech recognition tools understand different types of voices, including those of people with Down syndrome.

All personal information safeguarded at the University of Illinois Urbana-Champaign. Project funded by Amazon, Apple, Google, Meta, and Microsoft.

Record your speech from the comfort of your home, with caregiver support as needed.

Mentors from UIUC are ready to walk you through the participation process.

Participants can earn up to \$180. Caregivers, if needed, can earn up to \$90, as well.

[go.illinois.edu/SAPregistration](http://go.illinois.edu/SAPregistration)

Questions? [speechaccessibility@beckman.illinois.edu](mailto:speechaccessibility@beckman.illinois.edu)  
Phone #: 217-244-7700  
Email: [DSspeechaccess@illinois.edu](mailto:DSspeechaccess@illinois.edu)

The block is a flyer for the 'Speech Accessibility Project'. It features a photo of two women looking at a tablet. The text describes the project's goal of recruiting U.S. adults with Down syndrome to help improve speech recognition tools. It provides contact information for questions and a QR code for registration. The Beckman Institute logo is at the bottom.



# Study 1: Reading Among Young Adults



## What is this research project about?

This research project aims to investigate the everyday reading habits of young people and adults with Down syndrome. The survey was designed with the help of people with Down syndrome who have given their input on the research aims for the project.



If the person is over the age of 16 and has Down syndrome, they are invited to participate. Participants who are under 18 will need access parent/guardian consent before participating.

Questions within the survey will be a mix of tick box questions and text box questions. The survey is in Easy Read format. Some questions ask about previous educational history, so we recommend that participants fill out the survey with some help to remember those parts.

The data collected will help researchers to gain information about what young people and adults with Down syndrome read on a daily basis. It will also help researchers understand how adults with Down syndrome feel about reading such as ..What makes it hard? What makes it easy?

All answers will be anonymous and there is no reward for participating in this research. Ethical approval has been given by University College Cork's Social Research Ethical Committee.

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If you have any questions please email: [maryjolley@uicoll.ucc.ie](mailto:maryjolley@uicoll.ucc.ie)

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Link to the survey: [https://ucc.qualtrics.com/jfe/form/SV\\_ekxkt76qk33WOP4](https://ucc.qualtrics.com/jfe/form/SV_ekxkt76qk33WOP4). If you have any questions please email: [maryjolley@uicoll.ucc.ie](mailto:maryjolley@uicoll.ucc.ie)

# Study 2: Brain & Sleep in Kids





**ATTENTION:**  
Researchers are seeking child participants for a research study on brain function and sleep in children with Down syndrome or typical development

**To qualify...**

Participants with Down syndrome must	Participants with typical development must
<ul style="list-style-type: none"> <li>• Be between 5 &amp; 12 years of age</li> <li>• Have a confirmed medical diagnosis of Down syndrome</li> <li>• Be free of traumatic brain injuries, seizure disorders, or other neurological disorders</li> <li>• Not be taking medication for emotional, behavioral, or neurological concerns</li> <li>• Speak English</li> </ul>	<ul style="list-style-type: none"> <li>• Be between 3 &amp; 12 years of age</li> <li>• Be free of developmental, learning, psychiatric, or neurological disorders as well as traumatic brain injury</li> <li>• Not be taking medication for emotional, behavioral, or neurological concerns</li> <li>• Speak English</li> </ul>

Child and parent participants will each be compensated \$40.



The Drexel University Institutional Review Board has approved this research study.

our child for one week

- Participating in a ~2 hour session in which the child will complete tests to examine thinking and learning skills while wearing a band to monitor brain function
- Completing questionnaires about your child's health, behavior, and sleep and your family's background information

**If you are interested in this research study, please contact Dr. Nancy Raitano Lee at (215) 553-7164.**  
This research is conducted by a researcher who is a member of Drexel University

**ATTENTION:** Researchers are seeking child participants for a research study on brain function and sleep in children with Down syndrome or typical development. This research is conducted by a researcher who is a member of Drexel University. Child and parent participants will each be compensated \$40.

- Participants with Down syndrome must**
- Be between 5 & 12 years of age
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  - Not be taking medication for emotional, behavioral, or neurological concerns
  - Speak English

- Participants with typical development must**
- Be between 3 & 12 years of age
  - Be free of developmental, learning, psychiatric, or neurological disorders as well as traumatic brain injury
  - Be free of traumatic brain injuries, seizure disorders, or other neurological disorders
  - Not be taking medication for emotional, behavioral, or neurological concerns
  - Speak English

**Participation involves the following...For child**

- Wearing a 'watch' to monitor sleep and activity for one week
- Participating in a ~2 hour session in which the child will complete tests to examine thinking and learning skills while wearing a band to monitor brain function

**Participation involves the following...For Parents**

- Completing a sleep diary for child for one week
- Completing questionnaires about your child's health, behavior, and sleep and your family's background information

If you are interested in this research study, please contact Dr. Nancy Raitano Lee at phone #

# Study 3: Sleep Apnea Drug Study



**Does your child have Down syndrome?**

**Is your child 6-17 years old?**

**Your child may be eligible to participate in a Sleep Apnea Research Study**

**What is this study about?**

This project will study the use of two medications, atomoxetine (an ADHD medicine) and oxybutynin (a bladder medication) for the treatment of obstructive sleep apnea in children with Down syndrome.

**What will participation look like?**

- taking medication
- completing questionnaires
- three on-site sleep studies over a period of 3 months
- participants will be

If you would like more information about the study, please contact Silvia Lopez at [slopez1@arizona.edu](mailto:slopez1@arizona.edu) for further information. Participants will be compensated for their time. This study has been approved by the University of Arizona Institutional Review Board.

**Does your child have Down syndrome? Is your child 6-17 years old?**

This study will investigate the use a combination of atomoxetine (a medication approved by the FDA in children for the treatment of ADHD) and oxybutynin (a medication approved by the FDA in children for overactive bladder). These medications, which have been shown to treat obstructive sleep apnea in a small study of adults without Down syndrome, are thought to treat obstructive sleep apnea by increasing airway muscle strength, which is known to be lower in children with Down syndrome.

The clinical trial will involve completing a total of 3 sleep studies over 3 months and taking study medications for a total of 2 months. Participants should be within driving distance of the University of Arizona in Tucson.

Children may be eligible if they have a diagnosis of Down syndrome (trisomy 21, but not translocation or mosaicism) and do not have any of the following:

- currently using and unable to discontinue PAP therapy
- premature birth < 37 weeks estimated gestational age
- seizure disorder requiring current use of medications
- untreated or inadequately treated hypothyroidism
- history of current, untreated depression
- history of liver disease

# Research Advisory Committees



- Have a research champion on your board
- Talk to local clinicians, or university contacts
- Start small and build – growing slowly is better than nothing
- Keep the scope of work narrow to be efficient
- Use/adapt existing tools rather than re-create the wheel
- Capitalize on expertise of your committee
- Committee can be a great entry point to your org



# Why we're hopeful



- 1** Pharma companies & government are more invested than ever
- 2** Federal regulators are hearing DS concerns
- 3** More families interested in research participation
- 4** Infrastructure is ready for clinical trials
- 5** Growing public and media interest in inequities



# Thanks to our DSA sources & partners for info & advice



Download free content, guidelines, more info at  
[www.LuMindIDSC.org/affiliates](http://www.LuMindIDSC.org/affiliates)

Kate O'Neill [koneill@lumindidsc.org](mailto:koneill@lumindidsc.org)

Christina Reaves [creaves@lumindidsc.org](mailto:creaves@lumindidsc.org)

