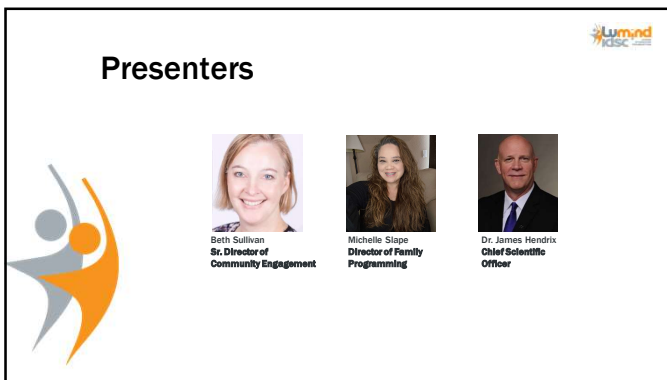
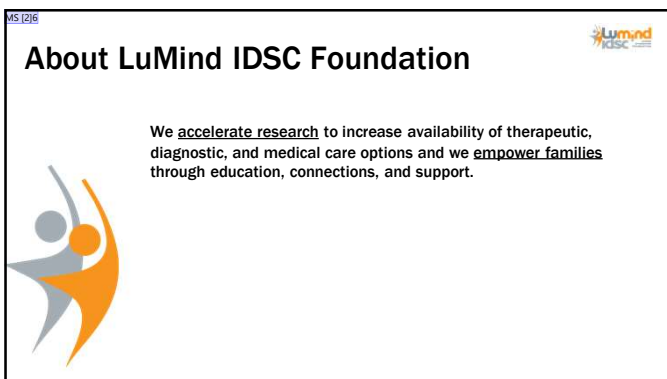




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Slide 3

MS [2]6 Add graphic about merger

Discuss merger


Michelle Slape, 2/2/2021




About LuMind IDSC Foundation

LuMind and IDSC merged in 2019, bringing the research and the community together in one strong organization and creating a symbiotic relationship of the research and community informing each other.

myDSC is a natural extension of this merger where we can bring the community and the research onto one platform.




4



What is **myDSC**?

A free, online library of trusted resources and useful tools for people with Down syndrome and their families that can be personalized to the member's interests



5



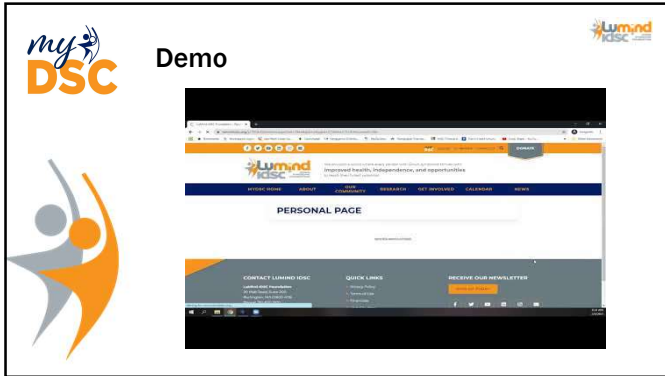
A new platform to access resources, tools, and research opportunities



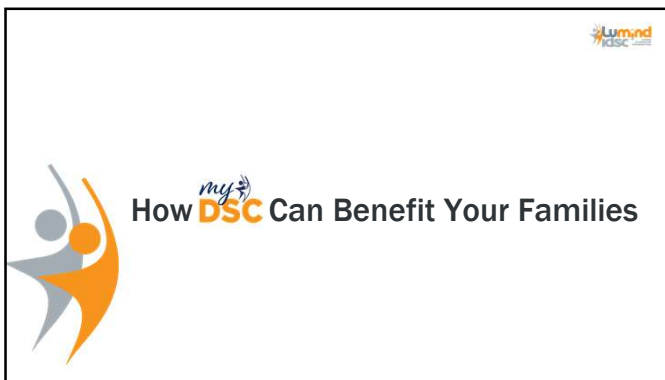


Brief demo!

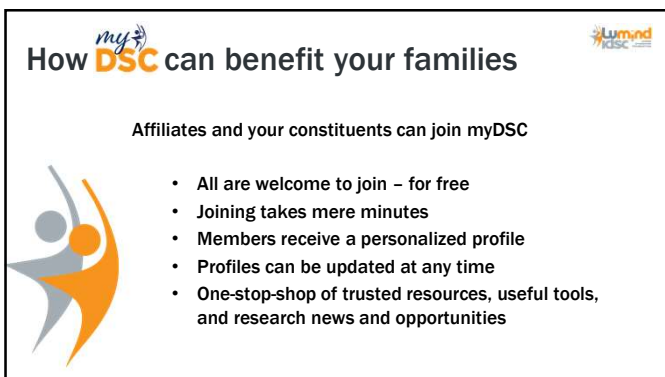
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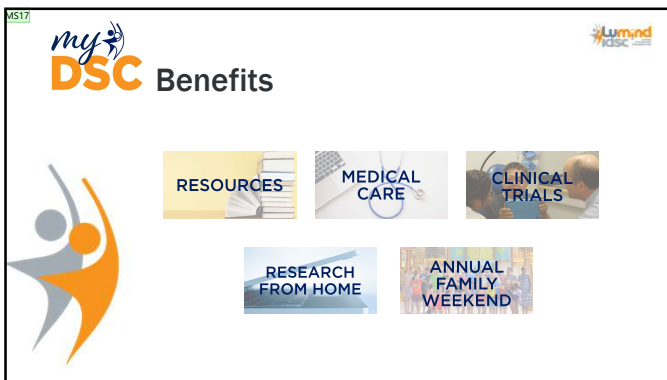
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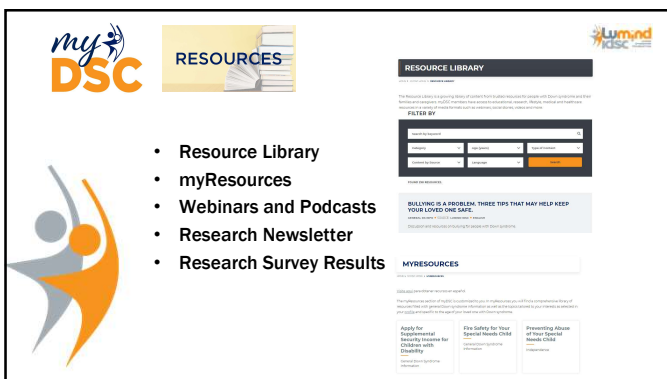
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Slide 11

MS17 This is a very general overview of the benefits. The following slides will go into more detail about the benefits.

Michelle Slape, 1/25/2021




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Ask Dr. Brian Chicoine

- Exclusive benefit for myDSC members
- Dr. Brian Chicoine, Advocate Medical Group Adult Down Syndrome Center
- Accessibility to Dr. Chicoine's expertise



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Down Syndrome Clinic to You (DSC2U) created by Dr. Brian Skotko from the MGH Down Syndrome Program

A personalized care plan for individuals with Down syndrome that can be shared with their primary care provider

- myDSC members receive a \$12 savings when they join myDSC + DSC2U
- **OR** We can help you offer free or discounted DSC2U access to your families

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DSC2U Affiliate Discount

Purchase DSC2U codes in bulk or at a discounted rate

- Gift DSC2U access to your constituents or
- Pass the savings to your constituents

# of Users	Cost per User
0-49	\$49
50-99	\$44
100-249	\$41
250-499	\$39
500-999	\$37
1000+	\$35

Discount Coupons Off Full Price (minimum order of 50)
\$10
\$20
\$30
\$40

DSC2UAffiliates.myDSC.org

Contact: Michelle Slape
mslape@LuMindDSC.org



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ANNUAL FAMILY WEEKEND



- September 17-19, 2021
- Exclusive to myDSC members
- 19 Great Wolf Lodge locations (18 in U.S. and 1 in Canada)
- Over 4,000 people were in attendance in 2019
- Sponsorship opportunities **available now** for each location, **FWSponsorships.myDSC.org**



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Year-Round Savings at Great Wolf Lodge



myDSC BONUS!

Members receive 30% off the best room rates year round at all U.S. Great Wolf Lodge locations



18









Do you care for someone with Down Syndrome who is 25 years of age or above?



MapHabit Helps Individuals with Down Syndrome Increase Their Independence




myGoalNav
myGoalNav.myDSC.org*


MapHabit
MapHabit.myDSC.org*

Surveys - Surveys.myDSC.org
Open surveys and results from past surveys

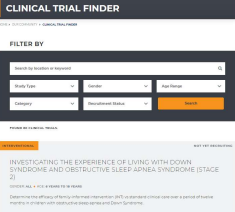
*** NOW RECRUITING**

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List of clinical trials that can be filtered by type, gender, age, category and recruitment status






CLINICAL TRIAL FINDER


Filter by: Study Type, Study Size, Study Phase, Category, Recruitment Status

INVESTIGATING THE EXPERIENCE OF LIVING WITH DOWN SYNDROME AND OBSTRUCTIVE SLEEP APNEA SYNDROME (STAGE 2)

LuMindIDSC.org/ClinicalTrialFinder

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Trials Near Me

TRIALS NEAR ME

Thank you for using Clinical Trials Near Me! Your loved one falls into the **Young Adult (18-30 yrs)** age range and has been matched with active clinical trials currently available in **California** corresponding to that age range. You will see the exact age range of the trial in the list below and can get more details with the links provided.

Visit the Clinical Trial Finder to view the full list of Down Syndrome Clinical Trials.

Safety, Tolerability and Immunogenicity of ACI-24 Vaccine in Adults With Down Syndrome (3 Star)

Age: 25 years to 45 years

The purpose of this study is to test in adults with Down Syndrome the safety, tolerability and immunogenicity of a vaccine, ACI-24.

At-Home Research Study for Patients With Autoimmune, Inflammatory, Genetic, Hematological, Infectious, Neurological, CNS, Oncological, Respiratory, Metabolic Conditions

Age: 25 years and older

This is an observational multi-center longitudinal cohort study to characterize adults with DS ages 25 years and above enrolled at specialized research centers.

Down Syndrome Clinical Trials - Study of Alzheimer's Disease in Down Syndrome (LIFE-DSR)

Age: 25 years and older

This is an observational multi-center longitudinal cohort study to characterize adults with DS ages 25 years and above enrolled at specialized research centers.

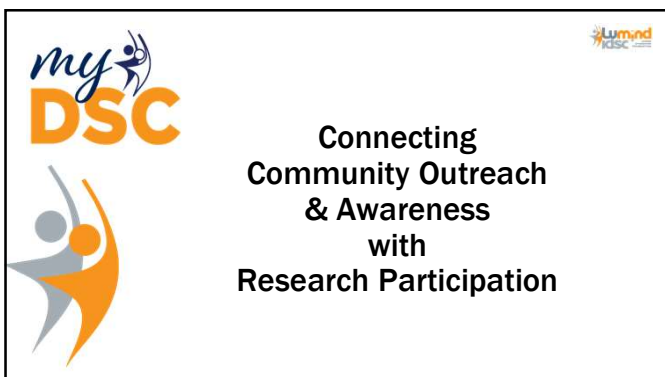
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Big Picture

Why talk about research?

What do we hear from the community?

- Why isn't there a drug for AD?
- Why don't they invent something?



*They can't do anything without trial participation, without **YOU**, without the greater **US**.*

Without participation in clinical trials →

- No drug is approved
- No new treatments get to market
- If new treatments do get to market in DS, most get to market *without ever having been tested in DS.*



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Big Picture



Ultimately, people want to make a difference.

LuMind IDSC is dedicated to creating a patient-centric approach, *facilitating an avenue for the DS community to impact research.*

Increase the potency of collaborations in DS between academia, Industry, and individuals and caregivers with DS.



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Benefits as we raise awareness of **clinical research**:


1. Raise awareness of *concepts*
2. Highlight the *roles* in individuals'
3. Increase *consideration* of a trial when presented

Benefits by bringing the community into early conversations

- An *opportunity* for the community to have a voice!
 - offer individual DS perspective,
 - influence clinical trial protocol development

Recent collaboration with Eli Lilly – Caregiver surveys and focus groups

Benefit to your families: Resource for your constituents



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Thank you!

www.MyDSC.org
