For immediate release

[DATE]

Media contact: [FName LName | email@provider.org | Area Phone]

[PROVIDER NAME] Enrolls Adults with Down Syndrome in Nation-Wide Research Study

[Town/State] – [PRACTICE] is now an approved research site in the first clinical trial in the Down Syndrome – Clinical Trials Network (DS-CTN[2]). [PRACTICE] is enrolling adults with Down Syndrome over the age of 25 in the Longitudinal Investigation for Enhancing Down Syndrome Research Study (LIFE-DSR[2]) to better understand the health issues facing people with Down syndrome as they age, particularly their risk for Alzheimer’s disease and dementia.

“In spite of recent advances in medical care, adults with Down syndrome continue to face very significant challenges including a markedly increased risk of Alzheimer disease,” said [CONTACT, FACILITY NAME]. “We are excited to be participating in the LIFE-DSR study and hope that this work will lead to better treatments for older people with Down syndrome.”

Diagnosing Alzheimer’s is complex including in people with Down syndrome. With no single test currently available, diagnosis is based on an individual’s history, physical examination and cognitive testing. The LIFE-DSR study will observe adults with Down syndrome to validate tests of cognition and function designed specifically for adults with Down syndrome. The DS-CTN will also collect blood samples from all study participants to aid in the development of blood tests for Alzheimer disease.

“We believe that the DS-CTN will open up greater access to clinical research for people with Down syndrome and that is why LuMind IDSC is excited to be providing funding and leadership for the first study in the network, the LIFE-DSR study,” said Hampus Hillerstrom, LuMind IDSC chief executive officer.

The LIFE-DSR study is looking to enroll adults over 25 years of age with DS. Health care professionals, families and people with Down syndrome interested in participating should contact a local participating study site, such as [PRACTICE NAME].

The DS-CTN is sponsored by the Alana Foundation and biopharmaceutical companies AC Immune and Lundbeck with $3 million in initial funding and direction is provided by LuMind IDSC.

To learn more about the LIFE DSR Study[2], contact [SITE PRINCIPAL INVESTIGATOR NAME AND TITLE] who serves as the local principal investigator at [FACILITY NAME].

For more information about the DS-CTN visit DS-CTN.org[2].

# # #
**About LuMind IDSC Foundation:**
The LuMind IDSC Foundation envisions a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach his or her fullest potential.

LuMind IDSC accelerates research to increase availability of therapeutic, diagnostic, and medical care options and empowers families through education, connections, and support.

**DS-CTN** launched in 2019 with eleven sites in 9 states ready and coordinated to mobilize trials by 2020 with the supervision of experienced clinicians who are experts at providing medical care for individuals with Down syndrome.

**Media inquiries and interviews contact:**
Marly Chevrette, Director of Marketing at LuMind IDSC Foundation, at mchevrette@lumindrds.org | 781-825-1303

**Local Facility Backgrounder & Logo**
On March 13 in Bethesda, MD, researchers from all 11 sites, the coordinating center, the biobank and LuMind met in person to plan for the upcoming LIFE-DSR study.
©LuMind IDSC Foundation

Inquiries? Contact LuMind IDSC Foundation at 781-825-1303 or mchevrette@LuMindIDSC.org
LIFE-DSR Social Media Posts for IRB Approval

1a. A new natural history study at Advocate Health in Park Ridge, IL is now recruiting adults with Down syndrome over the age of 25 to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer’s disease.

LuMind IDSC’s Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR) is expected to complete in 2021. Want to learn more? Visit http://www.ds-ctn.org/LiFE-DSR.html.

1b. A new natural history study at Barrow Neurological Institute in Phoenix, AZ is now recruiting adults with Down syndrome over the age of 25 to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer’s disease.

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A new natural history study at Duke University in Durham, NC is now recruiting adults with Down syndrome over the age of 25 to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer's disease.

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A new natural history study at Massachusetts General Hospital in Boston, MA is now recruiting adults with Down syndrome over the age of 25 to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer’s disease.

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2a.
The Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR) study is now open for the recruitment of adults with Down syndrome over the age of 25 at our Advocate Health in Park Ridge, IL location. The study is expected to complete in 2021. This will be the first study run in the Down Syndrome Clinical Trial Network (DS-CTN).

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The Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR) study is now open for the recruitment of adults with Down syndrome over the age of 25 at our Barrow Neurological Institute in Phoenix, AZ location. The study is expected to complete in 2021. This will be the first study run in the Down Syndrome Clinical Trial Network (DS-CTN).

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The Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR) study is now open for the recruitment of adults with Down syndrome over the age of 25 at our Case Western Reserve University in Cleveland, OH location. The study is expected to complete in 2021. This will be the first study run in the Down Syndrome Clinical Trial Network (DS-CTN).

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The Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR) study is now open for the recruitment of adults with Down syndrome over the age of 25 at our Rush University in Chicago, IL location. The study is expected to complete in 2021. This will be the first study run in the Down Syndrome Clinical Trial Network (DS-CTN).

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The LIFE-DSR study is an observational investigation with the goal to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer’s disease.

The study is recruiting adults 25 years of age or older and each participant will undergo a baseline evaluation followed by a 1-year then a 2-year follow-up visit. Each participant will undergo a routine health exam including blood collection and will take cognitive and behavioral evaluations at each visit. To learn more, visit http://www.ds-ctn.org/LiFE-DSR.html.

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