



## Why Merge?

Merging IDSC and LuMind RDS brings together the largest social media voice in the Down syndrome community with the leading organization supporting translational research for Down syndrome. Together, our combined resources can significantly empower families and create more opportunities for improved health and independence for all people with Down syndrome.

As two separate organizations, each was working diligently to meet emerging needs of the Down syndrome community. LuMind RDS was striving to reach families who were unaware of the significant research progress that needs their support to be translated to medicines and interventions. IDSC was tackling a growing interest for quality research and medical care content and education for their followers. Realizing the similarity in our goals, we began collaborating in 2018 on a survey initiative to identify the informational needs and priorities of families with loved ones who have Down syndrome. In February 2019 we partnered to launch a Facebook support group - [IDSC LuMind Research and Medical Care Group](#) - with exclusive webinars led by researchers, curated medical articles and Q&As with clinicians. Rapid growth of the group membership confirmed the importance of meeting this need within the community. It was clear that we could have a bigger impact as one organization.

## What is your new vision and mission statement?

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 will accelerate research to increase availability of therapeutic, diagnostic, and medical care options and will empower families through education, connections, and support.

## What does the merger mean to our family?

We believe that we can serve your family better as one organization. This merger brings together the largest social media voice in the Down syndrome community with the leading organization supporting translational research for Down syndrome. Together, our combined resources can significantly:



- accelerate research to increase availability of therapeutic, diagnostic, and medical care options for your loved one.
- empower you through education, connections, and support.

## **Who is leading the new organization?**

The merger combines the teams and volunteer leadership of both organizations. Hampus Hillerstrom will lead LuMind IDSC as President and CEO. Beth Sullivan is the Senior Director of Community Engagement and former Chairman of the IDSC. Michelle Slape is the Director of Great Wolf Lodge Events and Special Projects and former Executive Director of IDSC. In addition, IDSC Board members and volunteers Linda Nargi, Maria Dellapina and Jennifer Smolka join the LuMind IDSC Board of Directors.

## **What does the merger mean to researchers?**

LuMind IDSC is strongly committed to quality, high impact research to improve health and independence for all people with Down syndrome. As a merged organization, LuMind IDSC will greatly expand our worldwide reach to 250,000 family members through social media to increase the awareness of DS research, educate families on the best medical practices and help promote high quality and ethical medical science.

Increased research awareness will lead to a more informed community of DS families who can be stronger supporters and advocates for research. Researchers will have a connection to both families and the people with DS who their research is intended to benefit and will be able to hear what families need and value from new research. This merger is a game-changer for DS research.

## **What does the merger mean to DS Affiliates?**

The new merged organization, LuMind IDSC, is strongly committed to increasing opportunities for collaboration with and support for DS affiliates and your families. As a merged organization, we will provide online support groups, research webinars, better support for local participation in research, and regional community events including our Family Weekend at Great Wolf Lodge to accelerate research and empower families to improve health, independence and opportunities for all people with Down syndrome.