



IsoDicentric 15 Exchange, Advocacy and Support Strategic Plan 2010-2013

IDEAS Mission Statement

IDEAS provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome.

IDEAS offers help and hope for chromosome 15q duplications.

Executive Summary

IDEAS was incorporated as a nonprofit organization in 2004. Since its incorporation, IDEAS has had a two part mission: to provide support to families and to promote awareness, research and targeted treatments for chromosome 15q duplication syndrome.

IDEAS Provides Information, Education and Support to Families Through . . .

Newsletter

The MIRROR is published quarterly to educate families about duplications of chromosome 15q, share family stories, and provide information about treatment options and current research.

Parent Match Program

IDEAS matches parents seeking support with parent mentors who can provide emotional support.

Regional Family Gatherings

IDEAS supports small regional meetings for families to network, share resources and support.

International Conferences

IDEAS Conferences are held every other year and provide families with an opportunity to meet and learn about scientific and treatment advances.

Informative Website

www.dup15q.org

Interactive Message Boards

<https://www.bigtent.com/groups/dup15q>

Promoting Research and Hope for Targeted Treatments Through.....

Scientific Meetings

IDEAS holds national research meetings on chromosome 15q duplications.

Collaboration with Researchers

IDEAS collaborates with researchers to connect our families with research opportunities that may be of interest to them.

Promoting Human Tissue & Cell Line Repositories

Families are encouraged to consider donating cell lines and tissues so that researchers have access to these critical resources.

2010 – 2013 Strategic Goals

The following process was undertaken as the basis for developing the IDEAS strategic plan:

- Review IDEAS mission
- Conduct external analysis
- Conduct internal analysis
- Establish strategic goals
- Develop budget
- Document Strategic Plan
- Implement, monitor and adjust plans

The following goals have been adopted by the IDEAS board of directors to guide the growth of IDEAS from 2010-2013. Some of these goals represent an ongoing commitment to activities that IDEAS already engages in, and the remaining goals represent new initiatives for the organization.

IDEAS will assess and implement an organizational restructuring and strategic succession plan for the purpose of strengthening and maintaining continuity in organizational operations by June, 2010.

IDEAS will help establish research priorities in dup15q syndrome, and will host annual scientific meetings to build multi-disciplinary collaborative efforts to promote research into dup15q.

IDEAS will establish and promote family involvement in an IDEAS research registry.

IDEAS will seek the involvement of a graduate student(s) to develop a “family guide to dup15q” that will assist families in understanding best practices for supporting children with dup15q from birth into adulthood.

IDEAS will establish a targeted awareness campaign with a focus on pediatricians, neurologists, geneticists, parents of children with autism or epilepsy disorders, and early childhood intervention programs.

IDEAS will develop, communicate, and provide quarterly status updates to families on a three year budget that supports the goals in the strategic plan.

IDEAS will encourage and support families in holding fundraising events to help IDEAS exceed each annual operating budget and support continued growth for the organization.

Implementation

A twelve member Board of Directors meets monthly to oversee the programs and services provided by IDEAS, and to ensure adequate resources are available to meet IDEAS mission and purpose. The board delegates responsibility for day-to-day operations to the corporate officers and committees.

The IDEAS Board recognizes that monitoring and evaluating the strategic plan's implementation is as important as identifying strategic issues and goals. The board evaluates progress on the strategic goals at each monthly meeting and will make modifications as necessary.

This plan is subject to approval by the Board of Directors. The plan was approved by the following directors at the November 15, 2009 meeting.

Nicole Cleary
IDEAS Board Chair
Portland, OR

Tom Doyle
IDEAS Finance Officer
Bellevue, WA

Donna Bennett
Co-Founder and Board Member
Thomasville, PA

Rachel Doucette
Board Member
Georgetown, MA

Cindy Johnson
Board Member
Wrightstown, NJ

Michelle Hughes
Board Member
Cincinnati, OH

Kadi Luchsinger
IDEAS Executive Director
Fayetteville, NY

Paula Davis
IDEAS Corporate Secretary
Westford, MA

Frank Kobuszewski
Board Member
Camillus, NY

Len Poore
Board Member
Tewksbury, MA

Karen Sales
Board Member
Ankeny, IA

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