Keep Up!
Be Down with the Syndrome

Overview of Educational Series 2019-2020

Dawna Daily, M.Ed., Program Director
DSAF Nebraska
PO Box 57362
Lincoln, NE 68505
(402) 206-3002
director@dsafnebraska.org

Outcomes
- Following tonight's presentation the attendee should:
  Become familiar with the new program director's background and
  role within DSAF
  Learn information about the new educational series revamp to non
  attendees
  Give input on future educational programming via survey and verbal
  input.

What is DSAF?
- Down Syndrome Association for Families of Nebraska
- Established over 20 years ago
- Created to provide a support system for parents of children with Down
  syndrome
- One of the hundreds of local support groups across the United States
**DSAF Support Programs**

- Medical Outreach - medicaloutreach@dsafnebraska.org
- Responsible for providing physicians with accurate, up-to-date and balanced information when delivering a Down syndrome diagnosis
- First Call Parents
  - Trained parents that meet with new parents to offer support and answer questions

**DSAF Medical Outreach**

- Ensures medical professionals have balanced, accurate resources available to present to families at the time of diagnosis by providing them resources.

**LiL Stars**

(Birth - 5)
This group organizes social events, especially for our member families with very young children and their siblings.
Events include: Private Swim Parties, outings to My Gym, play dates in the park, Kindermusic classes, and more.

Committee Chairs:
- Tracy Hammer - LiL Stars, Co-Chair
- Kelly Hammer - LiL Stars, Co-Chair
SUPER STARS

(Kindergarten-High School)

Meaningful social events for school-aged children focus on fostering peer relationships for the individual with Down syndrome.

Events include: Outings to Champions Fun Center and Urban Air, going to the movies, private event parties, and more.

Sally Easter - Super Stars Group Leader

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TEEN/YOUNG ADULT STARS

Provides opportunities for older teens and young adults with Down syndrome to associate with young adult mentors and peers.

Events include: Going to the movies, meeting at the mall, touring the State Capitol, science classes, sensory friendly Valentine's dance (in coordination with D.A.I.E Coalition) and more.

Sydney Fantas - Teen/Young Adult Committee Chair

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Other Events/Offerings

- New Parents Resource guide
- DSAF Medical Outreach team
- Parent's First Call program-New Parents brunch
- Step Up for Down Syndrome Walk
- World Down Syndrome Day Celebration/Awareness
- One Coalition Husker Heroes event
Other Offerings

- Book bundles with membership
- Newsletters
- Family networking events
- Mom's Night out
- Annual Reporting
- Chairs Brunches
- Picnic and Pool Party
- Christmas brunch family networking

Other Offerings

Annual Zoo family networking event
YA Social Book Club
Ice Cream Social
Dad's Night
Just you and me sibling events
Give to Lincoln involvement

Other Offerings/Events

Board Retreat/Strategic Planning sessions
Teen Stars Events (monthly)
Sibling workshops
National Affiliates in Action (AA) conference
Super Stars quarterly events
Lit Stars quarterly events
Calendar
Annual Pumpkin Patch family networking
Inclusive schools week teacher recognition program
About Me

- Wife, Mother of 2 boys, DIL, grandmother of 2
- Undergrad UNO - Education
- Graduate - M.Ed. - Special Education
- Special Education teacher 15 yrs.
- Endorsements in Transition and
- Work Experience Training
- Dog lover
- Business owner
- Independent Service Provider
  (DHHS Respite and Residential)

Hired by DSAF - Part time April 2019

Other DSAF Board and Staff

- Liz Eichmell, President - K-2 Resource Teacher, Hamlin Elementary
- Dean Fuhrerth, Past President - Project Manager, Ameritas
- Tamra Unwin, Treasurer - Accounting Specialist - ACTS
- Rick Bochaty, Director of IT, CH Health St. Ets
- Brandi Berson, Publications Adviser, LPS
- Beth Dismann, M.S., CCC-SLP, Lecturer/Clinical Supervisor UNL
- Rick Meyer, Pinnacle Wealth Management
- Niki Holmberg, RN, Center for Maternal and Fetal Care
- Scott Neal, Owner Party Initiator's
- Mary Sweeney, Marketing and Development Director

Other Staff and Committees

Committees
- Tori Altenbury - LIF Staff, Co-Chair
- Tracy Salley - LIF Staff, Co-Chair
- Holly Johnsen - Medical Outreach, Chair
- Kathryn Stroemaker - Newsletter Editor
- Mary Sweeney - Step Up for Down Syndrome Walk, Co-Chair
- Maggie Studley - Step Up for Down Syndrome Walk, Co-Chair
- Katy Baxter - Super Slam, Group Leader
- Let's Cook - Super Slam, Group Leader
- Sandy James - Teens Young Adult Slam, Group Leader
- Mary Sweeney - Fundraising Chair
Educational Series Revamp
- Series Topics collected and will run each month
- August - Connection Series Kickoff
- September - IEP 101 - Jenn Miller PTI Nebraska
- October - Toilet training and other behavior management - Matt McNiff, ESU #5 and Enable Savings Plan - Diane Stewart, First National Bank

Educational Revamp
- November - Advocacy and Social Inclusion - Edison McDonald, The Arc of Nebraska
- Behavior and sleep routines - Matt McNiff, ESU #5
- December - Tips for Successful Transitions - Jenn Miller, PTI Nebraska
- More upcoming trainings:
  - Guardianship
  - Legislative advocacy
  - Self Advocacy training - Rights - Age of Majority
  - Person centered planning
  - Social/Sexual relationships
  - Voting
  - Transition - applying for services, VR, DD, SSI, Medicaid

Education Revamp Cont.
- Other upcoming educational series
- People first language
- Down Syndrome awareness
- Independent Living
- State Waivers for adult services
- Voting rights
- Be SAFE - first responder trainings
- Circles Curriculum - teaching boundaries for abuse prevention
Other suggestions?

Building Blocks of Communication through DSSAA
Collaborative events with Omaha and Lincoln Down syndrome groups
Peer Presentations
Grandparents program/brunch/book club
Member director
New Parent Orienatation
First Contact Parent Orientation
S.E.A.S. Program
Bike Camp
Running Club
Down to Box
Parent retreat
Sibling workshop

Other suggestions?

IEP assistance
Scholarship opportunities
Hospital stay assistance (long term)
Webinars?
Family One out events
Special Olympics involvement
Civic engagement opportunities

Other suggestions?

Therapy programs/Clinical (SLP, PT, OT)
Dentist/Dr. referrals
Daycare/school referral program
Call center for Qs, related questions
Aging and Dis
Parent to Parent connections
Advocacy/Parent conference stipends
Post Secondary Education/Employment
Tutoring
Other suggestions?

Inclusion
Early interventions
Assistive Technology
Information on research

Resources

People First of Nebraska
https://www.peoplefirstnebraska.com/
The Arc of Nebraska
https://www.arc-nebraska.org/
DHHS
dhhs.ne.gov/Pages/Down-Syndrome.aspx
APSE (Association Supporting People in Employment)
https://apse.org/chapter/nebraska/
Ollie Webb Center Omaha
https://www.olliewebbinc.org

Resources

PTI Nebraska (Parent Training and Information)
pti-nebraska.org/
Nebraska Enable Savings Accounts
https://www.enableavings.com/
Resources
Arc Chapters
https://thearc.org/find-a-chapter
MMI Disability Specific Organization
disabilityrightsnbraska.org

Resources
Munroe-Meyer Institute
unmc.edu/mmi/community-resources/leadership
Special Olympics
https://www.specialolympics.org/
Nebraska Legislature:
https://nebraskalegislature.gov/about/se n_qualifications.php

Resources
• Developmental Disabilities Advisory Council: http://dhhs.ne.gov/Pages/DD- Advisory-Committee.aspx
• National Down Syndrome Society (NDSS)
  https://www.ndss.org/
  Down Syndrome Alliance of the Midlands - Omaha
  https://www.dsamidlands.org/
Resources

National Down Syndrome Congress (NOSC)
http://www.ndsccenter.org/

National Down Syndrome Society
http://www.ndss.org/

Down Syndrome Affiliates in Action (DSAIA)
http://www.dsaia.org/

Global Down Syndrome Foundation
https://www.globaldownsyndrome.org/

National Association for Down Syndrome
https://www.nads.org/

Down Syndrome Affiliates in Action - Lincoln
https://www.dsalo.org/

www.dsafnebraska.org

down syndrome
association for families
dsafnebraska.org