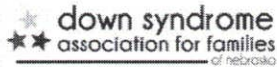


**Keep Up!
Be Down with the Syndrome**

 **down syndrome**
association for families
of nebraska

Overview of Educational Series 2019-2020

Dawna Daily, M.Ed., Program Director
DSAF Nebraska
PO Box 57362
Lincoln, NE 68505
(402) 206-3092
director@dsafnebraska.org

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Outcomes

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

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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

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DSAF Support Programs

- Medical Outreach—Holly Lohmeier
<mailto: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

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DSAF Medical Outreach

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



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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, Kindermusik classes, and more.

Committee Chairs
Tori Attebury - Lil Stars, Co-Chair
Tracy Kadavy - Lil Stars, Co-Chair


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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 swim parties, and more.

Kelly Ekeler - Super Stars, Group Leader




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TEEN/YOUNG ADULT STARS

Provides opportunities for older teens and young adults with Down syndrome to socialize with young adult mentors and peers.
 Events include: Going to the movies, meeting at the mall, touring the State Capitol, cooking classes, sensory friendly Valentine's dance (in coordination with O.N.E. Coalition) and more.

Sydney Ferrara - 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

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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

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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

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Other Offerings/Events

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

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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

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Other DSAF Board and Staff

Liz Echterkamp, President - K-2 Resource Teacher, Hamlow Elementary

DEan Fuelberth, Past President - Project Manager, Ameritas

Tami Urwin, Treasurer - Accounting Specialist - ACTS

Rick Bohaty, Director of IT, CHI Health St. Es

Brandl Benson, Publications Adviser, LPS

Beth Dinneen, M.S., CCC-SLP, Lecturer/Clinical Supervisor UNL

Rick Meyer, Pinnacle Wealth Management

Nikki Hobleman, RN, Center for Maternal and Fetal Care

Scott Neal, Owner Party Inflatables

Mary Sweeney, Marketing and Development Director

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Other Staff and Committees

Committees

Tom Allebury - Lif Stars, Co-Chair

Tracy Kaskavy - Lif Stars, Co-Chair

Holly Lohmeier - Medical Outreach, Chair

Kathryn Brockmeier - Newsletter, Editor

Mary Sweeney - Step Up for Down Syndrome Walk, Co-Chair

Maggie Stuckey - Step Up for Down Syndrome Walk, Co-Chair

Kelly Ekeler - Super Stars, Group Leader

Lexi Wolfe - Super Stars, Group Leader

Sydney Ferrara - Teen/Young Adult Stars, Group Leader

Mary Sweeney - Fundraising Chair

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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

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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

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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

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Other suggestions?

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

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Other suggestions?

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

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Other suggestions?

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

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Other suggestions?

- Inclusion
- Early interventions
- Assistive Technology
- Information on research

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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>

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Resources

- PTI Nebraska (Parent Training and Information)
pti-nebraska.org/
- Nebraska Enable Savings Accounts
<https://www.enableavings.com/>

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Resources

Arc Chapters
<https://thearc.org/find-a-chapter>

MMI Disability Specific Organization
disabilityrightsnebraska.org

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Resources

Munroe-Meyer Institute
unmc.edu/mmi/community-resources/leadership

Special Olympics
<https://www.specialolympics.org/>

Nebraska Legislature:
https://nebraskalegislature.gov/about/sen_qualifications.php

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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/>

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Resources

- National Down Syndrome Congress (NDSC)
<http://www.ndsccenter.org/>
- National Down Syndrome Society
<http://www.ndss.org/>
- Down Syndrome Affiliates in Action (DSAIA)
<http://www.dsaiia.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.dsaiia.org/>

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www.dsafnebraska.org



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