

TwentyOne

Triangle Down Syndrome Network | Raleigh, NC

WINTER | 2018

nc able

Assisting people with Down Syndrome and their families to save for today's needs and for the future

beautiful souls

Down syndrome through the eyes of the ones we love

 Celebrating
World Down Syndrome Day



TERRI COUWENHOVEN, M.S.
AASET Certified Sexuality Educator

Recognizing your child
is ready to date



KARI ALBERQUE, MSW
Executive Director

Kari's Corner



HEATHER LAURIA
Nurse Practitioner

HealthU
Living a healthy lifestyle

Mission Statement

TDSN is a nonprofit support, resource, advocacy organization serving individuals, families, and professionals. Our Mission is to empower, connect and support parents of children with Down syndrome, their families, and the community.

Vision Statement

TDSN aims to be an effective and comprehensive resource on Down syndrome in the Triangle region and throughout North Carolina. We envision a community where all people with Down syndrome can achieve their full potential, and where individuals with Down syndrome and their families are welcomed with fairness, enthusiasm, and encouragement in the community.

Support

TDSN is funded primarily through individual donations and small grants and we rely on the help of volunteers to carry out activities throughout the year.

While we are a grassroots organization, we look forward to continued growth to support new members and build awareness, understanding, and acceptance in our community.

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Join Us

Are you interested in learning more about TDSN? Would you like to volunteer for an upcoming event or join a committee? Do you have a skill you could use to help TDSN?

To find out how you can become more involved with TDSN, contact Executive Director, Kari Alberque at 984-200-1193 or kari@tdsn.org.



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WHAT IS WORLD DOWN SYNDROME DAY?

World Down Syndrome Day (WSDS), 21 March, is a global awareness day which has been officially observed by the United Nations since 2012.

Why 21 March?

The date for WSDS being the 21st day of the 3rd month, was selected to signify the uniqueness of the triplication (trisomy) of the 21st chromosome which causes Down syndrome .

TDSN's World Down Syndrome Day Outreach Project Providing resources and support to new and expectant families is our most important work. In order to reach these families, we rely heavily on healthcare providers to connect families with TDSN. On March 21, we are saying thank you to area pediatricians and obstetricians with a gift bag full of treats and resources. These resources will include brochures for the Parent's First Call program as well as information on best practices for delivering a diagnosis of Down syndrome.

We need you to make the World Down syndrome Day Outreach Project a success! Volunteer to drop off the gift bags to area doctors. If you would like to volunteer, please email outreach@tdsn.org. For more information on this and other World Down Syndrome Day celebrations in our community, visit tdsn.org/wdsd

(Reproduced from WORLD DOWN SYNDROME DAY website (www.worlddownsyndromeday.org))



KARI'S CORNER

I have received a few inquiries about how families can celebrate World Down Syndrome Day on March 21st. Since WSDS's inception, we have coordinated or promoted several different events and awareness campaigns. There are many easy ways to spread Down syndrome awareness and acceptance in your child's school, your workplace, or the greater community.

For the past several years, we have had a mom who reads a couple of Down syndrome themed children's books to her son's elementary school classmates. There are other ways to share information with middle and high school students. You and your child can do a talk and question and answer session to a few classes in his or her school. If you are up for it, you or your child can request to do a presentation to a larger audience at the school.

Businesses throughout the Triangle have participated in Dress Down for Down syndrome where employees get to dress down on WSDS. You can coordinate a baby item donation drive at work or your church. These items will be used for the Welcome Baby Bags TDSN provides to new families. My favorite activity is Random Acts of Kindness.

One year my children and I left little bags with microwave popcorn and a Down syndrome awareness postcard at local Redbox locations.

Please let me know what you plan to do on WSDS. TDSN can provide a list of books to read, Dress Down flyers for your workplace, Down syndrome awareness postcards, or a copy of Down syndrome 101 presentation.

[More information about World Down Syndrome Day can be found on our website www.tdsn.org/WSDS](http://www.tdsn.org/WSDS)





Dating and Down Syndrome

RECOGNIZING YOUR CHILD IS READY TO ENTER THE DATING SCENE ISN'T ALWAYS EASY. NOTED SEXUALITY EDUCATOR TERRI COUWENHOVEN HELPS BOTH CHILDREN WITH DOWN SYNDROME AND THEIR PARENTS NAVIGATE THESE DIFFICULT WATERS

Article courtesy of the Global Down Syndrome Foundation and appeared in the 2017 Issue 4 of Down Syndrome World TM

RELATIONSHIPS GIVE EVERYONE a chance to love and be loved, avoid loneliness and depression, and gain self-esteem and people with Down syndrome have the same right to these relationships as typical teens and adults. However, “it’s common for people with Down syndrome to experience oppression, denial, and control over the same sexual aspects of being human that typical adults enjoy in their lives,” said Terri Couwenhoven, M.S., AASECT, Certified Sexuality Educator.

“This can lead to a denial of feelings and a reluctance to express themselves.” That denial can perpetuate the myth that people with Down syndrome are asexual, she said. Parents can, and should, take the lead in helping their children develop the foundations of healthy relationships, and Couwenhoven shared three key tips for parents to approach the subject of dating and relationships.

1. ATTITUDE MATTERS.

Parents need to have a positive attitude toward their teenager’s or adult child’s dating. ‘Let’s face it, parents are influential in the dating scene for teens and adults with Down

syndrome,” Couwenhoven said.

“In addition to making sure their children have active social lives so they have access to potential partners, parents often need to coordinate, help plan, transport, chaperone, and coach at least initially.” Parents also serve as role models. Engage in honest and open communication with your own partner, and be attentive to your child’s needs.

2. OFFER CONCRETE INFORMATION ABOUT THE DATING PROCESS.

Look for opportunities to explain dating before your son or daughter is old enough to actually date, Couwenhoven advised. For example, if an older sibling has a partner, explain why people date.

Use specific language, such as “they spend time dating to see if they are a good match for each other.”

If the couple breaks up, you can explain, “not all relationships work out. It takes time to find the right person.” When your child gets older and develops a crush on someone who doesn’t return the affection, remind him or her that a romantic relationship can’t start unless both people have

feelings for or are interested in each other, she added.

3. LET THEM PRACTICE DATING SKILLS.

“Life experience is the greatest teacher of all,” Couwenhoven said. “Chaperoning is an excellent way for inexperienced newbies to practice the rituals of dating in the context of supervision and coaching.” As your teenagers and young adults with Down Syndrome become more mature and gain self-confidence, chaperoning becomes less necessary.

Terri Couwenhoven, M.S., AASECT, Certified Sexuality Educator, hosts sex education workshops and even made a guest appearance on the hit A&E series *Born This Way*, offering sex and dating advice to the young adults on the show. She’s written four books for children who are differently-abled and their parents that cover topics such as puberty and dating. For links to her books and other resources, visit terrificouwenhoven.com.



Terry will be returning to North Carolina to share her knowledge with TDSN families and professionals. Workshops for parents and their adolescent children will address puberty. A session for parents and professionals will address sex education basics for individuals with IDD. www.tdsn.org/puberty

Q&A WITH TERRI COUWENHOVEN

Down Syndrome World™ asked Terri Couwenhoven, M.S., AASECT, Certified Sexuality Educator, to answer some of the most common questions the Global Down Syndrome Foundation receives about sexuality in people with Down syndrome.

DSW: Are children with Down syndrome more at risk for sexual abuse? If so, why?

Couwenhoven: All the data we have suggests this is true. Common reasons reported in literature that apply to people with Down syndrome include:

- Expressive language struggles can make abuse hard to report.
- People with Down syndrome have less information about sexuality than the typical population.
- People with Down syndrome are often dependent on others for help with selfcare and daily living tasks. Throughout their lives, they are also exposed to a larger number of support providers. The dynamic of dependency on others, routine praise, and learned compliance with authority figures can make them more vulnerable to abuse.

What can parents do to educate their children with Down syndrome about protecting themselves from sexual abuse?

Give your child permission to talk openly with you about sexuality. Praise them for asking questions and do your best to answer.

Teach rules about body ownership and touching. With children, for example, “Your body is private, and there are very few times when anyone should be looking at, or touching, your most private parts.” When a child is old enough to date, you can add, “Sometimes dating couples may share their bodies but only if they both agree. No one should ever force you to do things you don’t want to do.”

Encourage assertiveness. Helping your children understand they have a right to say no or leave when something doesn’t feel right is an important skill.

You addressed that people with Down syndrome are not asexual. There is another stereotype that asserts they are actually overly sexual. Is this true?

No. People with Down syndrome have the same range of feelings and emotions as the typical population. I believe this myth stems from others seeing people with Down syndrome exhibit inappropriate sexual behaviors — such as masturbation or genital touching in the presence of others, sharing affection indiscriminately, or overt expression of sexual feelings that you or I might be thinking but keep to ourselves. These behaviors are often related to information deficits, societal attitudes such as infantilization, immaturity, age, and life experience.

BEAUTIFUL SOULS

Down Syndrome Through the Eyes of the Ones We Love

“Beautiful Souls: Down Syndrome Through the Eyes of the Ones We Love” is a compelling, powerful, unforgettable book of portraits and stories that will spread awareness, foster understanding, and inspire you.

We are excited to be wrapping up the production of the book! The book will be published in the spring and available to purchase for \$29.

You can pre-order your copy today by visiting tdsn.org/beautifulsouls.

Local families as well as celebrities are featured in the book.



Celebrities include

Glee star: Lauren Potter

Born This Way cast members:

Elena, Megan, John, Christina and Rocco

Love You More cast members:

Luke, John, Margaret, Casey and Kevin

HealthU Living a Healthy Lifestyle

This spring, Heather Lauria, a Nurse Practitioner student at UNC Chapel Hill, will provide a healthy lifestyle education program for our teenagers and young adults at TDSN.

Heather is a Registered Nurse with a strong interest in nutrition and exercise. She is a fellow at the Carolina Institute for Developmental Disabilities, has volunteered with the Special Olympics and worked in a post-graduate classroom for young adults with developmental disabilities. She will have numerous qualified professionals to assist with the program such as a special education teacher, physical therapist, speech and language pathologist and other nurses.

The program is called **HealthU** and will consist of 6, 2-hour sessions hosted at TDSN. Topics will include learning the My Plate method for healthy eating and participating in various exercises such as dance and other dynamic activities.

The program will be hands-on, using food models, taste tests and interactive take away activities. The final session will include a healthy potluck dinner where all participants and their families are encouraged to attend.

Living a healthy lifestyle is important for all of us and there is a higher incidence of obesity in individuals with Down syndrome due to metabolic and behavioral barriers. Additionally, there are less programs available to meet the needs of individuals with Down syndrome.

This healthy lifestyle program was designed for individuals with intellectual disabilities and has been implemented for teenagers with Down syndrome in other locations.

We encourage you to join us this spring to learn more about making independent, healthy lifestyle choices through this informative and interactive program.

Visit tdsn.org/healthu for more information and to reserve your spot today.



NC ABLE

NC ABLE Accounts Allow People with Down Syndrome and Their Families to Save for Today's Needs and for the Future

The NC Achieving a Better Life Experience (ABLE) Act, passed in 2015, dramatically changed rules that previously limited savings and assets for people with disabilities to just \$2,000. The law, which mirrors the federal ABLE Act of 2014, opened the door to financial freedom for people with disabilities, allowing savings and investments to reach \$100,000 before affecting Social Security Income (SSI) and \$450,000 before affecting Medicaid eligibility.

The NC ABLE Program launched in 2017, and allows qualified individuals — those with a disability that was present prior to age 26 to contribute up to \$15,000 a year. Parents and guardians can open and manage accounts for those who qualify, and family members and friends may direct deposit or gift to NC ABLE accounts, without jeopardizing Medicaid and other supports. As of January 2018, rollovers from 529 college savings accounts are permitted, with some limitations, and NC ABLE account holders who are employed can save up to \$12,060 more per year.

NC ABLE accounts are opened at NC.SaveWithABLE.com with a minimum deposit of just \$25. Earnings on investments are federally tax-deferred and withdrawals are tax-free if used for a wide range of qualified disability expenses (QDEs). QDEs include a broad range of expenses related to living with a disability, including education and work supports, assistive technology, transportation, housing, legal assistance, and many others.

The Department of State Treasurer administers the NC ABLE Program and has joined 15 other states and the District of Columbia, to form the National ABLE Alliance in an effort to provide high-quality plan features and benefits, ensure quality investment options, and offer low participant fees. NC ABLE accounts offer six investment options, to match individual goals and tolerance for investment risk. A checking account option and available debit card provide more independence and flexibility for account owners, parents and guardians.

To learn more or enroll, visit NC.SaveWithABLE.com or call 888-627-7503.



UPCOMING EVENTS

- Feb 6**
How Kindergarten May Look for YOUR Child (Webinar)
- Feb 8**
Mom's Night Out (Fuquay Varina)
- Feb 13**
Setting the Stage Now for Success in Kindergarten (Webinar)
- Feb 17**
IEP Writing Workshop (Greenville)
- Feb 17**
Kindergarten Round Table Discussion (Greenville)
- Feb 18**
0-3 Playgroup (Wake Forest)
- Feb 19**
Inclusive Playgroup (Raleigh)
- Mar 2**
Workshop on puberty (Greenville)
Terri Couwenhoven
(visit tdsn.org/puberty for more information)
- Mar 3**
Workshop on puberty (Triangle Area)
Terri Couwenhoven
(visit tdsn.org/puberty for more information)
- Mar 3**
Parent/Daughter and Parent/Son Puberty Workshop (Triangle)

www.tdsn.org/events

cut along lines



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Empower  Connect  Support

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