

BUILDING AWARENESS & BRIGHT FUTURES FOR INDIVIDUALS WITH DOWN SYNDROME & THEIR FAMILIES

DESIGNER GENES NEWSLETTER

Spring 2020



DESIGNER GENES HITS THE BALLPARK AT LARK'S OPENER

Watch for an announcement soon as Designer Genes is joining the Lark's at the ballpark this spring!

We'll soon provide information on how to get tickets for a Designer Genes group outing at the opening game of the Bismarck Lark's 3rd season on Tuesday, May 26, 2020.

Tickets will be available for \$7.00 a person and will include a Larks baseball cap. Mark your calendars and watch for more information.

FAMILY SUPPER & GET TOGETHER

Join us Thursday, April 16 at Juniper Workantile for supper and an informal discussion on Down syndrome health guidelines. We're working on a guest speaker and will have child care. Watch for more information to come.

WORLD DOWN SYNDROME DAY COME JOIN THE CELEBRATION - MARCH 20 & 21

Mark your calendars for a one-of-a-kind World Down Syndrome Day celebration! Learn more below and get excited!

MARCH 20 – AN EVENING WITH BRIAN DONOVAN

Friday, March 20th from 7 p.m. – 9:30 p.m. Century High School Auditorium

Brian is the director of the award winning documentary, Kelly's Hollywood (Showtime Networks),



about the relationship he had with his spectacular sister who was born with Down syndrome (www.kellyshollywood.com). Brian has toured internationally speaking about inclusion, equality and how imperative it is for everyone to be given the chance to pursue their dreams.

MARCH 21 – SIBLING CELEBRATION

Friday, March 21st from 9 a.m. - 12 noon at HIT, Inc. 2640 Sunset Dr., Mandan

Saturday morning kicks off with a sibling workshop specifically for our best support partners – teen brothers and sisters who support individuals with Down Syndrome! Brian Donovan will be joining us, along with expert speakers to help in the morning of learning.

MARCH 21 – BIKERS 4 BIKERS FAMILY FUN DAY

Saturday, March 21st from 12 noon to 3 p.m. at HIT, Inc. 2640 Sunset Dr., Mandan

Our pals from Our Place Motorcycle Club will be holding their 6th annual Bikers for Bikers "fun"raiser for the Designer Genes iCan Bike Camp. There will be bingo, lunch,



face painting, games, drawings for motorcycle rides for the 2020 Walk for Down syndrome, and a silent auction! Get ready for fun!

PEANUT BUTTER FALCON STAR SHARES EMPLOYMENT INSIGHTS

Zack Gottsagen from The Peanut Butter Falcon shares important insights about employment for people with intellectual disabilities at the Down syndrome Affiliates in Action conference last month. Read below to find out what we learned from the 34-year-old actor with Down syndrome:

- He started developing his talent as an actor at a very young when he had a role as a frog in a school play at 3-years-old. He continued to take acting classes, go to acting camps, and auditioned for plays and films for three decades before starring in a movie. Lessons for us: Start developing talents early.
- 2. He worked at a paid job in high school at a grocery store and also worked at many other jobs and at a movie theater throughout his adult life before starring in a movie. Zack says people with disabilities should work for pay and receive at least minimum wage. Lessons for us: Get a paid job as soon as possible.
- 3. Zack told film directors he met at an acting camp that he wanted to star in a movie. When they said there were not starring roles for people with Down syndrome, he told them to make one. The writers and directors decided to go for it and lived in tents to afford to film the movie and refused film companies who them to replace Zack with another actor without Down syndrome. Lessons for us: Find advocates who believe in us and will help us follow our dream.

4. Zack said he met some of his best friends at acting camp and then made more friends during the movie. In fact, his friendship was profoundly influential in helping his co-star, Shia Lebeouf, become sober.

"The morning he got out of jail, LaBeouf attended a small party for the cast and crew, and no one brought up what had happened. 'Everybody was pussyfooting around it,' he says. As soon as Gottsagen arrived, he beelined for LaBeouf and sat on the floor, and there LaBeouf joined him. They talked for twenty minutes. Gottsagen told him, 'You're already famous. This is my chance. And you're ruining it.'

'To hear him say that he was disappointed in me probably changed the course of my life,' LaBeouf says.

... When LaBeouf first checked into rehab, he was asked about the pop—the moment your head gets pulled out of your ass and clarity washes over you. "For me," he says, "it was Zack."

Lessons for us: Work can build important and influential relationships that benefit everyone, not just the person with a disability.

5. Zack's said, "Follow your dreams." Lesson for us: Talk to your child or student with disabilities to find out their dreams and help them follow those dreams!

Reprinted with permission from the author, Stephanie Hall Meredith, who wrote this for KentuckyWorks, whose resources on promoting employment for individuals with disabilities are available to the general public at kentuckyworks.org.

UPCOMING CONFERENCE OPPORTUNITIES & WHERE TO LEARN MORE

International Division of Early Childhood Conference

October 20 – 23, Minneapolis, MN www.decconference.org
Registration waivers will be available for parents attending with children under the age of 8.
Two \$750 scholarships will be awarded and the applications will available April 1.

Power Up Conference

September 13, Bismarck, ND www.facebook.com/PowerUpHealthConference

National Down Syndrome Congress Conference

June 25 – 28, New Orleans, LA www.ndsccenter.org/annual-convention/about-the-convention

One Able Body Conference

April 18, Bismarck, ND www.eventbright.com - search One Able Body Conference 2020

YOUTH EMPOWERING SOCIAL STATUS (Y.E.S.S.) EVENTS

Designer Genes has been collaborating with Y.E.S.S. since it started in January 2019 after receiving a grant from the North Dakota Department of Public Instruction. Y.E.S.S. is hosted by Dakota Center for Independent Living and is a gathering of youth and young adults both with and without disabilities (ages 14-30). Since starting, they have hosted a mocktail event, held a game night, formed a working advisory board, and put on a youth conference in June of last year. Please consider checking out some of their upcoming events:

March 28 - Mocktail Mixer

▶ 6 p.m. - 9 p.m. - Hillside Aquatic Community Center Live music, snacks, games and networking.

April 20 – Voting Training with Judy Dewitz

6:15 p.m. − Dakota Center for Independent Living 3111 E. Broadway Ave., Bismarck

July 23 – Joint celebration for the 30th

Anniversary of the Americans with Disabilities Act Baymont Inn, Mandan



Stay tuned to upcoming Y.E.S.S. events by following them on Facebook: Facebook.com/YouthEmpoweringSocialStatus



THANK YOU TO ALL OUR GIVING HEARTS IN 2020

Designer Genes was blessed along with other great non-profits for to participate for the third year in Giving Heart's Day. We continued to say "Yes #COUNTME!". We're excited to report that Giving Heart's Day provided about \$11,000 to assist with Designer Genes programming and family support this year. Thank you to all those who gave from the heart.

Thank you once again to the Schmid Family for donating the annual membership fee for Designer Genes to participate and all those who donated to help us meet our \$4,000 match. Our membership in Giving Hearts, through its creators – Impact Institute, continues to provide Designer Genes with learning opportunities, the ability to network with other Giving Heart's organizations, and participation in the Giving Heart's Day event.

PARTNERING FOR Babies Across North Dakota

Designer Genes is partnering with the North Dakota Department of Health to assure that birthing hospitals in Williston, Minot, Belcourt, Dickinson, Hettinger, Devils Lake, and Jamestown have information packets for families whose babies are diagnosed with Down syndrome at birth. In addition, the North Dakota Department of Health, through their Newborn Screening division, facilitated a webinar on Prenatal Diagnosis (Difficult Conversations) presented by Dr. Ana Tobiasz, maternal and fetal physician, Arielle Flynn, genetic counselor, and Roxane Romanick. The webinar is available on the Newborn Screening website at www.nbs.health.nd.gov.



MARK YOUR CALENDARS IMPORTANT UPCOMING DESIGNER GENES DATES

WORLD DOWN SYNDROME DAY CELEBRATION Mar. 20 - Celebrating with Brian Donovan

Screening Kelly's Hollywood at Century High School

Mar. 21 - World Down Syndrome Day -

Morning - Sibling Celebration

Afternoon - Family Activity & Our Place Motorcycle Club Fundraiser

Apr. 16 | Family Supper & Discussion on Medical Guidelines

More information coming soon. Juniper Workantile

Apr. 18 | One Able Body Conference

New Song Church

Apr. 21 | DG Board Meeting

6 p.m. - 8:30 p.m. at Juniper Workantile

May 26 | Designer Genes Celebrates Opening Night with the Bismarck Larks

Watch for more information coming soon!

July 21 | DG Board Meeting

6 p.m. - 8:30 p.m. at Juniper Workantile

Aug. 23 | DG Annual Picnic

Sept. II | 2020 Power Up Conference - Bismarck

Sept. 26 | Annual Walk for Down Syndrome

10 a.m. Registration - 11 a.m. Walk Bismarck State Capitol Grounds

Oct. 20 | DG Board Meeting

6 p.m. - 8:30 p.m. at Juniper Workantile

Dec. 14 | Supper with Santa & DG Annual Meeting

A LITTLE INCLUSION AT THE OSCARS

Zack Gottsagen became the first actor with Down syndrome to announce the the Oscars, reading the selections for best live action short. Gottsagen presented alongside Shia LaBeouf who co-starred with him in "The Peanut Butter Falcon," which came out last year. Congratulations to Zack!



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