



NDAD

helping others to help themselves

Fall Edition 2017

Insider

NDAD'S MISSION:
Enhance the quality of lives
of individuals facing health challenges.



Everly's 'village'

*Grand Forks tyke's
daunting health care
challenges faced with
assists from NDAD*

2

Count me, count you

*February's Giving
Hearts Day 2018
among ways to join
in NDAD's mission*

4

Positive thoughts

*Williston teen hopes
NDAD-assisted chemo
treatment trips help her
walk beyond cancer*

5

*PLUS: Haley at the
lanes; latest Faye
Gibbens grant award*

Everly Peterson

NDAD part of caring village for child with rare disorder

Complex daily medical regimen sustains little Grand Forks girl's life

Everly Peterson is 2 years old. For this very social, highly curious, frequently singing Grand Forks tyke, that one simple but marvelous statement became fact on Sept. 22.

Fact layered in oodles of love, family and community support. NDAD has contributed charitable support, because it's also fact that Everly's

How NDAD has helped Everly

- Sponsored 2015 community fundraiser and served as fund custodian
- Provided lodging assistance for a medical trip to Sioux Falls, S.D.
- Assisted with gas for several medical trips to Sioux Falls

“It takes a village, and we are blessed to have NDAD a part of our village, helping to ensure Everly receives the best care possible. Thank you!”

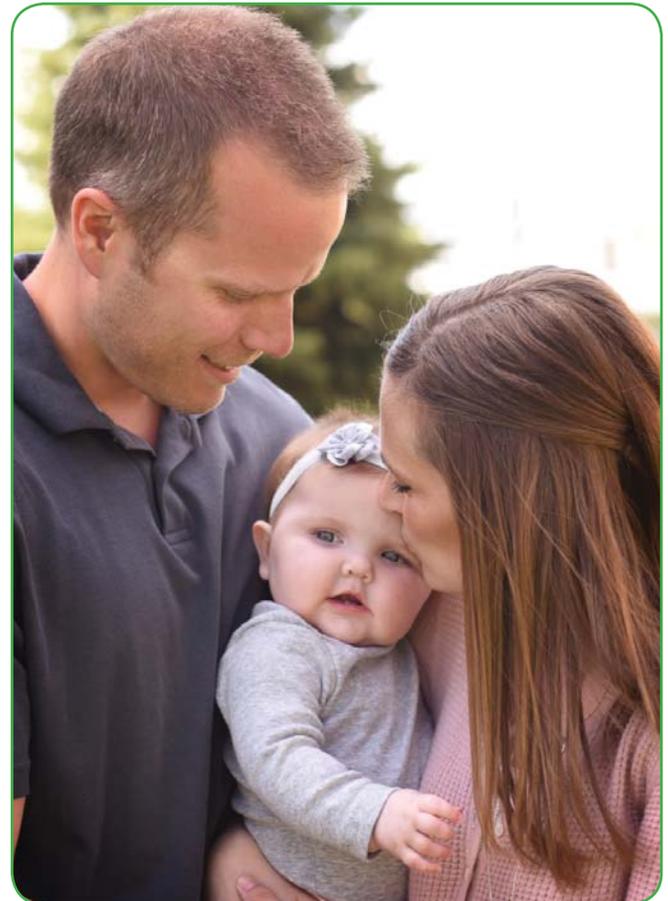
Erin Peterson
Everly's mom

entire life has been challenged throughout by daunting daily medical complexities.

“Everly has spent 150-plus days in hospitals and has been airlifted three times,” said Erin Peterson, her mom. “Everly’s life depends on existing in an environment that limits her exposure to much that could be detrimental to her health.”

A syndrome called megacystis microcolon intestinal hypoperistalsis (MMIHS) has jeopardized Evie all the days of her life.

MMIHS (see MMIHS.org) is an extremely rare disorder that affects the bladder and gastrointestinal



Everly, at 7 months, with her parents in 2016. Brody and Erin married in August 2012.

Cover and Page 2 photos: Farrah Spivey Photography

For more about this syndrome, visit MMIHS.org, a website created by Erin Peterson's sister.

ABOUT NDAD INSIDER

Mike Brue - Editor - mbrue@ndad.org
Stories by Mike Brue

Sign up for the on-line version of the Insider at NDAD.org

tract and can lead to failure of up to eight organs. To date, there's no cure; MMIHS often is fatal during childhood, or early adulthood. Still, Erin said, medical advances, plus improved management awareness and understanding, are changing life expectancy for the better.

Working with medical teams in Fargo, Milwaukee, Sioux Falls and Grand Forks, and fulfilling numerous daily and weekly life-sustaining procedures, medications and medical appointments themselves, Erin and husband Brody Peterson are doing all they can to allow Everly — not MMIHS — to define her life.

"Everly has certainly given us a rich perspective on life," said Erin, who took a leave from teaching in order to care for Everly. Brody is a service manager at Butler Machinery. "We take it one day at a time," Erin said, "and do our best to enjoy every moment."

With NDAD's help, the Petersons have taken Everly to several key medical appointments with their Sioux Falls, S.D., children's hospital medical team, including a surgeon, urologist and gastrointestinal specialist. NDAD helped pay for lodging for one of those trips, too.

In late 2015, NDAD sponsored community fundraising on the Petersons' behalf, and NDAD also provided free custodial support for funds raised from several benefits.

Erin Peterson says NDAD has been a valued part of a caring village of assistance for the family at a time they've needed it most.

"We have been so grateful for the assistance we have received through NDAD," Erin said. Lora Machart, NDAD's client service representative in Grand Forks, "has been

nothing short of exceptional to work with, and we thank you all from the bottom of our hearts."

Everly requires around-the-clock care and monitoring. Her young body must be completely nourished and hydrated intravenously by being connected to three separate bags and tubing, grandmother Nancy Sullivan explained on a recent CaringBridge.org website post about Everly. "She is given experiences in taste and texture through just licking and sucking on some specific foods," Sullivan wrote. "She will tell you, 'No bite!'"

The family's weekly costs for total parenteral nutrition (TPN) alone can run around \$3,000. Everly also requires urinary catheterizations and "tummy ventings," which help minimize and sometimes prevent retching. "If her body starts to retch," Sullivan wrote, "she will cuddle in her mom's lap, wipe her mouth afterward and say, 'Little sick.'"

When feeling well, Everly gets around almost always with support of attached backpacks containing needed nutritional and hydrating fluids, plus someone to follow her and hold them as she moves.

But get around she does, to places ranging from parks to preschool to the local library. Everly's overall quality of life is good, one of her medical teams has said.

Though clinical appointments and pharmacy runs occur on a weekly and sometimes daily basis, she's not needed a hospital admission since spring. More joy.

Everly "is the perfect mix of sweet and spunky and is the greatest fighter I have ever known," Erin said. "She has taught us more about life than we could have ever imagined." ■



Photo: Erin Peterson

Two-year old Everly dressed as a kitty cat for Halloween 2017, walking around several inside Grand Forks locations and interacting with the community.

How to help

A donation to NDAD is a humanitarian act and a wise investment in people with disabilities and serious health concerns who live in North Dakota and in border cities in neighbor states.

Many of us need help to live a more mobile and independent life that's as healthful as possible.

To help our charitable nonprofit's valued mission of helping people live more satisfying, productive lives, NDAD offers a variety of avenues to help:

- Giving Hearts Day
- General donation
- Community fundraisers
- Memorial
- Equipment donation
- Planned giving
- AmazonSmile

We invite you to contact us at (800) 532-NDAD, or visit NDAD.org or one of our four offices for more information about these giving opportunities.

'#COUNTME' in

Giving Hearts Day 2018 arrives Feb. 8

Back in February 2017, NDAD was heartened by our region of Giving Hearts.

Your spirit of generosity buoyed our charitable nonprofit's first-ever participation in Giving Hearts Day. The annual regional fundraising event, a 24-hour give-a-thon of goodwill, includes hundreds of charities and is organized by Dakota Medical Foundation, Impact Foundation and Alex Stern Family Foundation. The impact is profound. Giving Hearts count. Especially when they beat together.

NDAD is part of 2018's Giving Hearts Day, using the slogan #COUNTME and set for Feb. 8. It's a terrific chance for you to be a partner in NDAD's giving mission. By donating to NDAD on Giving Hearts Day, you support people with disabilities and health issues throughout North Dakota and neighboring state's border cities.

This newsletter features Everly Peterson, Katlyn Calhoun and Haley Brossart, three examples from among thousands of our area's children and adults who NDAD has helped through our programs over the decades (see "How NDAD helps," below).

Please say #COUNTME on Feb. 8.

Go to givingheartstoday.org and give online to NDAD.

Or, mail or drop off a check at any NDAD office by Feb. 8.

Please make sure your check is payable to NDAD, date the check Feb. 8, 2018, and write "Giving Hearts Day" on the memo line.

It's **AMAZING** what people can do when there's help from NDAD – and your giving heart. ■



How NDAD helps

* Direct financial assistance (prescription medications, medical equipment, out-of-town medical travel expenses, home and vehicle accessibility, personal attendant care expenses, in-town accessible transportation fees, adaptive recreational activities).

* Free healthcare equipment loans for up to 90 days * Information and referral

* Community fundraising support * Financial loans for assistive devices

We invite you to contact us to learn more about our multiple programs and guidelines.

NDAD. Helping Others to Help Themselves.

Katlyn Calhoun

Williston teen focuses on 'positive things' during cancer challenge

■ NDAD gas assistance helps her get to chemotherapy treatments

There's no denying a "monster" lives among the Calhoun family in Williston — and even comes along on family road trips.

Katlyn Calhoun says as much, but she's not at all referring to her bout with cancer. No one would blame her if she did.

Ewing's sarcoma, a malignancy, led to the

How NDAD has helped Katlyn

- Assistance with gas for 2017 travel from Williston to Bismarck for chemotherapy treatments
- Assistance with gas for one of several trips to Mayo Clinic in southeast Minnesota

amputation of roughly half of this 19-year-old's right foot in March.

Katlyn is undergoing chemotherapy treatments, 14 in all, scheduled two weeks apart at Bismarck's Sanford Health. Gas cards from

NDAD have covered part of the fuel costs for those trips since spring.

Katlyn travels to treatments with her mom, Tiffany, and youngest sister, Charlotte, 2 — "Charlie," as she's usually called by her five siblings and parents.

It was Katlyn who tagged the tyke with a second nickname.

Charlie's "not a terrible kid," Katlyn said, chuckling. Yet, the little girl's so-called "terrible 2s" inspired Katlyn to dub Charlotte the "Monster Baby."

Soon, the child committed another



Katlyn Calhoun

rowdy act, then looked mischievously at Katlyn and proclaimed, "Monster Baby strikes again!"

Humor and smiles are especially welcomed these days in the Calhoun household. Prayer and faith already have a family stronghold; dad Michael Calhoun is pastor of Williston's Calvary Baptist Church. Community support and multiple acts of charity, such as NDAD's assistance, further help the Calhoun family keep a positive outlook on Katlyn's behalf. She's also trying to help herself.

"I just try not to think about the negative side of it," Katlyn said. She keeps her head shaved and usually wears baseball-style caps since

her hair began falling out in clumps after her first chemo treatment early this year. "When we go out, I don't like to sit and (think), 'I'm going to get chemo so I'm

Top photo, Page 6 photo: Norie & Bubs Photography



Katlyn "selfie" with sister Charlotte, 2



The Calhoun family: (clockwise, from left) Jordan, Chase, Samantha, dad Michael, Katlyn, Megan and mom Tiffany, holding Charlotte.

going to feel sick,' or 'I'm not going to be able to do this,'" Katlyn said. "I'm trying to think about the positive things."

During the Calhoun's first Sanford Health visit, a case worker urged them to call NDAD about getting some charitable help. "With the amputation and the amount of testing (Katlyn) was going through, our medical costs were piling up," Tiffany said.

The added expense of lodging, hotels, food and gas alone grew into "an amount of debt that was going to be very difficult to get out of," so the NDAD gas cards helped to lighten some of that burden, Tiffany said. She would recommend NDAD to others in similar need.

Marsha Dupré, NDAD's Minot client services representative, stays in contact and keeps the Calhouns up to date "to make sure everything is going well," Tiffany said. That helps, since Tiffany doesn't make plans "past today, because I don't know what's going to happen tomorrow to Katlyn."

After completing several chemo trips to Bismarck with few problems, Katlyn's returns to Williston were followed several days later with a fever, headache and backache. She had neutropenia, an abnormally low level of certain white blood cells, called neutrophils, that attack bacteria and other organisms should

they invade the body. As a result, Katlyn required several emergency ambulance trips to Bismarck, where she received round-the-clock antibiotics and sometimes platelet and blood transfusions.

"We've gotten to the point now that we know when (neutropenia) is going to hit," Tiffany said. At the first sign of symptoms, the Calhouns head for Bismarck.

In late December, the Calhouns are scheduled to return to Mayo Clinic in Rochester, Minn., for new scans and, the Calhouns hope, good news. Mayo doctors confirmed Katlyn had cancer early this year and also performed the amputation — several months and multiple North Dakota medical appointments after the teen first began experiencing pain around her right toe.

"For the longest time," Katlyn said, "I thought we were just covering all the bases" with the multiple doctor visits. Even after learning she could expect losing two toes, Katlyn was unprepared to be told the day before surgery that cancer's rapid spread necessitated surgery to remove the front of her right foot.

"Very shocked," she recalls of the moment.

"It seemed very surreal, like a dream, maybe."

Tiffany remembers. "It was hard to digest, mostly because of the hardships she would face. . . . So

"Every little bit helps. No one person can help with everything we're going through, but NDAD has helped with what they could. We're thankful."

Tiffany Calhoun
Katlyn's mom

my heart broke for her," she said.

These days, Katlyn tries to look positively toward her future. The family is in pursuit of obtaining a partial foot prosthetic for Katlyn, who's ready to learn "what's to come after" this round of cancer treatment, she said.

Katlyn would like to start post-secondary schooling, too, but her original plans to become a midwife have shifted. "Now," Katlyn said, "I'm kind of thinking I want to go to school to work with other cancer patients and kids." ■

Haley Brossart

NDAD earns recommendation from young Fargo bowler's mom

Sometimes it's hard to tell who enjoys Haley Brossart's Saturday sessions at Fargo's West Acres Bowl more — fun-loving Haley, 12, or her mom, Peggy.

"I enjoy just watching Haley bowl and (also) all the others," Peggy said. "It is so fun to see them happy and excited when they get pins down. I enjoy listening to the 'Great job!' 'Way



Haley Brossart, with her mom, Peggy, on the roll with an assist from NDAD



to go!' and 'You did it' being said by everyone," Haley included.

Haley has cerebral palsy, low muscle tone and balance issues. She first tried

bowling several years ago through a sports and recreation program for people with mobility challenges and their families sponsored by HOPE Inc. With NDAD paying her bowling fees

this season, Haley again is knocking down pins most Saturdays with HOPE.

Haley, using her walker, aims a bowling ramp, gets help loading a heavy ball onto it, then pushes. "She enjoys getting strikes," Peggy said.

A West Fargo seventh-grader, Haley participates in other HOPE Inc. offerings, including sled hockey.

"Life gives Haley challenges, but she always finds ways to work around them and enjoys learning and trying new things," Peggy said of her "go-getter" daughter. Mom appreciates NDAD's assistance,

calling the nonprofit "caring and helpful."

HOPE Inc. is grateful NDAD may be able to supplement HOPE's limited scholarship program in cases where activity applicants meet NDAD guidelines. "As one-third of the 150 HOPE Inc. participants have a family income of \$40,000 or less," HOPE's Holly Budke said, "the scholarship program and NDAD's support is invaluable." ■

NDAD sponsors some adaptive recreation activities. Contact NDAD for more information.

How NDAD has helped Haley

- Paid fees for her participation in a Fargo area adaptive bowling session

NDAD NEWS IN BRIEF

■ Altru Health Foundation of Grand Forks received NDAD's fifth \$5,000 Faye Gibbens Memorial Grant

to help expand Altru Health System's social and interpersonal skills program for children affected by



NDAD presents Faye Gibbens Memorial Grant award check to Altru therapy representatives.

learning and attention issues to include pre-teens and teens.

■ NDAD received \$500 from Performance Chiropractic of Grand Forks as part of that office's 10th-anniversary celebration.

■ NDAD's Healthcare Equipment Loan Program (HELP) received a grant from the Community Foundation of Grand Forks, East Grand Forks and Region (\$1,300) and a donation from Grand Forks employees of Minnkota Power Cooperative (\$500).



NDAD

helping others to help themselves

North Dakota Association for the Disabled, Inc.
2660 S. Columbia Road
Grand Forks, ND 58201

RETURN SERVICE REQUESTED

Nonprofit Organization
U.S. POSTAGE
PAID
Grand Forks, ND
Permit No. 11

Get the NDAD Insider online

It's easy to sign up for NDAD Insider. Go to our website at NDAD.org and click on the "Get the Newsletter" link to add your email address. If you already get NDAD Insider by mail but would like to go completely electronic to help NDAD save money on postage, please send an email to mbrue@ndad.org or call (800) 532-6323.

Visit us online at NDAD.org

 facebook.com/ndad.nd  ndad.areavoices.com  twitter.com/ndad4you

NDAD OFFICES

GRAND FORKS

Main Office
(701) 775-5577
(800) 532-NDAD
2660 S. Columbia Road
Grand Forks, ND 58201

MINOT

(701) 838-8414
(888) 999-NDAD
1808 20th Ave. S.E.
Minot, ND 58701

FARGO

(701) 281-8215
(888) 363-NDAD
21 N. University Drive
Fargo, ND 58102

WILLISTON

(701) 774-0741
(877) 777-NDAD
P.O. Box 1503
309 Washington Ave.
Williston, ND 58801

NDAD is a nonprofit, charitable organization founded by concerned citizens to assist mentally and physically disadvantaged people in North Dakota, many of whom are not eligible for services from other agencies.

NDAD provides financial assistance through funds generated by both the organization and community projects. NDAD also provides information and referral services to help people receive assistance through other agencies, when possible.

*It's **AMAZING** what people can do when there's **help**.*