



NDAD

helping others to help themselves

Spring Edition 2017

Insider

NDAD'S MISSION:

Enhance the quality of lives
of individuals facing health challenges.



Helping them travel

*NDAD medical
travel assistance
aids Grandin's Susan
Opp (pictured) and
Dickinson's
Leah Herron*

2, 5

The right ingredient

*NDAD fills retired
cook's RX recipe with
prescription aid*

7

Insider trading

*Don't miss a single
NDAD newsletter;
swap paper for digital*

8

Susan Opp

NDAD 'like another set of friends who are more positive in my life'

■ Medical travel assistance to Mayo helps give ailing Grandin woman hope, better outlook

*T*azzy!" Susan Opp exclaimed softly. The cheerful-looking pomeranian on Susan's lap raised his head to respond. "Hi, baby," Susan said. "Look at you. Mom loves you."

Susan, sitting in a comfortable chair that faced her apartment kitchen, gave a slight smile to Taz, whose happy-looking face seem to broaden. All the while, Susan held her younger "snuggle bug," Ms. Margarita, a chihuahua-pomeranian cross, at her right shoulder.

"Tazz seems to know when I'm really not feeling well," the 54-year-old Grandin, N.D., resident said, still admiring the dog. "He's just a lover, too. And he takes care of me."

She paused.

"I don't know what I'd do without these guys."

Susan has struggled knowing what to do, she concedes, since a major stroke and seizures in the summer of 2013 twisted her life around.

Since that stroke, she's been diagnosed with a brain tumor, epilepsy, hepatitis C and depression. She has a heart murmur, from a heart valve issue, she was told. Her liver is ailing, her blood pressure's high and she's trying to get her diabetes under control. She's often anxious.

When she walks, Susan is "wobbly and shaky," limping because of an unsteady right leg. When not being helped to walk, she alternates between a cane, walker and wheelchair.

Yet, Susan feels more optimistic these days since visits in March and April to the Mayo Clinic medical facilities in Rochester, Minn.

The Mayo trips were made with help from NDAD, through the nonprofit's medical travel assistance program. NDAD helped Susan pay for gas and lodging.

"I wouldn't have been able to do it without you," Susan said about NDAD. "There is no way. "Without the help, I would have been at a standstill.

"I am so blessed that I got help. It's like having another



Susan Opp with her dogs
Ms. Margarita and Tazz

"I wouldn't have been able to do it without (NDAD). There is no way. Without the help, I would have been at a standstill."

Susan Opp

ABOUT NDAD INSIDER

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

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

set of friends that are more positive in my life. It seems like when you get sick and you've got to make some lifestyle changes, a lot of your friends just leave – because you're not the same person you were."

So, Susan said, she is trying to focus on matters she can control. Among other things, she's completed treatment for hepatitis,

"I struggled to speak and be understood. They had me write, and I couldn't. I knew exactly what I wanted to say but I'd get so frustrated because I couldn't get it to come out."

Susan Opp

enhanced lifestyle changes to try bringing her diabetes under control, and continued counseling for her depression

while getting her prescription medication reviewed and changed.

"I need," she said, "to quit beating myself up....I've got grandkids who are growing up. I'm young yet." Susan has three grandchildren from her three adult offspring, all in Grand Forks.

Before her major health issues surfaced, Susan said, she was self-sufficient. Her work history included owning and operating a licensed home daycare in Grand Forks and doing housekeeping work at Fargo's Essentia Health. She owned a 2005 Harley-Davidson and rode it regularly, sometimes with Tazz aboard.

"You couldn't stop me," Susan said. "I mean, I'd sleep maybe six hours a day, you know? Go, go, go, go, go. Constantly go."

But once she passed her 50th birthday in March 2013, she began noticing some unsettling changes in her health.

"I think I was slowly getting sick," she recalled. "My legs were swelling, and there'd be headaches. Just different things would happen that were not normal."

She also had instances where she experienced extreme light sensitivity and struggled to open her eyes. She considered making an emergency room visit once.

One hot summer day, driving home from

work in Fargo, "I remember my head went back and forth, and all of a sudden I was just sweating, and it was running down my face. I had the worst headache ever," she recalled. She doesn't recall driving the last few blocks home.

Following several ambulance trips to Fargo (she was discharged after the first), Susan was admitted to Sanford Health. She regained consciousness after spending eight intensive care days in an induced coma, she was told.

Susan learned she had two brain bleeds and a marble-size brain tumor on her brain's right frontal lobe. More tests showed the mass was benign and not cancerous. It was not removed.

"They told me I had some cognitive disorders from the brain tumor," she recalled.

(Mayo tests recently confirmed the tumor has grown some but remains non-malignant. She cried tears of joy with that news, she said.)

Because of the 2013 stroke, she said, "I had to relearn to talk and walk and get dressed. I struggled to speak and be understood. They had me try to write, and I couldn't. I knew exactly what I wanted to say but I'd get so frustrated because I couldn't get it to come out."

Susan remained in the hospital for nearly another month, followed by about 1 1/2 months at a Fargo transitional care facility.

Nearly four years later, her Harley has been sold, and she's still unable to drive and work.

Susan has frequent headaches and bouts with edema in her legs. She sometimes sleeps at great length, but not the 18 or 19 hours a day she once did, she said.

She makes sure someone is in her apartment when she cooks or takes a bath. Her boyfriend, John Zajac, who's retired and lives in the same Grandin apartment building, is her

"You go to NDAD, and it's just like you can feel some love there."

Susan Opp

driver when she needs one, and helps her with cooking, cleaning and caring for Tazz, Ms. Margarita and another pomeranian-chihuahua mix, Ricco, that the couple shares. The apartment building manager frequently checks on Susan and also has been helpful, she said.

"Just everything's changed, you know," Susan said. "I have good days and I have bad days. I went through a lot of sadness with this. I wouldn't answer the telephone. I'd lock myself in the apartment, and it'd be dark."

By the time Susan's internal medicine physician referred her to Mayo Clinic, she was frustrated and restless from more than three years of struggles.

"I thought, 'This is my last chance.'"

NDAD was on her doctor's list of potential sources for financial assistance to make the Mayo trip. She failed to find help until reaching NDAD's Fargo office, where, she said, client services representative Kim Zeeb and also office manager Sheryl Swanson were more than helpful.

Susan was overjoyed when NDAD approved her application for assistance. Kim Zeeb is "wonderful," she said. "She encourages me. It's like she challenges me a little bit to be more self-sufficient in ways that I can be. . . . That's great. That's awesome, 'cause we need that."

"You go to NDAD, and it's just like you can feel some love there. You're looking at the person in the eyes, and they're looking at you in the eyes, and after two phone calls, they know you by name and voice."



Adaptive water recreation fun highlights Escape

Waterskiing, pontoon rides and a performance ski show -- a weekend's worth of fun offered on a single day -- Sat., June 17 -- for the 2017 edition of Escape to the Lake.

Nelson Lake Recreation Area near Center, N.D., once again is the rendezvous point for North Dakotans with physical disabilities to get on the water, with family members, friends and caregivers along to share the day. NDAD organizes this event, which features help from experts in adaptive water recreation and waterskiing, plus generous volunteers and sponsors.

The event is free, and lunch is included, but registration is required. Learn more about this popular annual event at NDAD.org, or call (800) 532-NDAD.

Leah Herron

Medical travel assistance 'takes a really big weight off' family

Dickinson family health issues eased with help from NDAD

It's a moment in 2011 that Leah Herron likely won't forget. "I all of a sudden couldn't swallow," the 29-year-old Dickinson, N.D., woman recalled.

"I couldn't even swallow my own saliva.

I was at home. At the time, I was living with my parents (in Omaha). My mom took me to the emergency room. . . . They kept me overnight and did an emergency endoscopy. They had to stretch and dilate my esophagus so I could swallow." An esophagus is the human organ that connects your throat with your stomach.

It was the first of Leah's four dilations over a four-month period in order to swallow. "They try to get the esophagus as dilated as they can before the tissue starts tearing," she said.

An endoscopy solves Leah's problem only temporarily. She's had 14 dilations in the last six years, and had undergone a dilation once every two months at the Mayo Clinic facilities in Rochester, Minn., until a recent change in her treatment plan.

Two of her 1,200-mile round trips to Mayo were made affordable with help from NDAD's medical travel assistance program.

NDAD had helped the Herron family in 2016, too, but the medical focus then was the youngest of their three children.

Blakeley, now 1, had severe acid reflux and needed separate surgeries in Sioux Falls, S.D., home of their baby's gastrointestinal physician.

"When you have to travel for medical things, there are not only the medical bills," Leah said. "Depending on your insurance and what the

procedure is, you never know how much is going to be covered. So, not having to worry on top of the medical bills about gas and hotels just takes a really big weight off our shoulders. Especially with our daughter's feeding tube, we didn't have to

worry whether we could get there or not and get to all of her appointments."

Leah's personal need for medical travel assistance surfaced after she was referred to Mayo by her gastrointestinal physician at Bismarck's Sanford Health.

Leah has eosinophilic esophagitis (EoE).

Once considered rare, EoE is an increasingly diagnosed chronic immune system disease believed to be a major cause of gastrointestinal illness.

"More doctors are realizing it exists and are biopsing for it, but the treatments haven't caught up with it yet. Treatment for EoE is so different for each person, and just how complicated it is



The Herrons of Dickinson: (from left) Caiden, Matt, Jacek, Leah and Blakeley.

varies,” Leah said.

According to MayoClinic.org, EoE occurs when certain types of white blood cells, called eosinophils, invade the esophagus lining. Caused by a reaction to foods, allergens, acid reflux or another environmental trigger, this excessive buildup of eosinophils can inflame and injure the esophageal tissue.

“It takes about six to eight weeks before it starts damaging your esophagus,” Leah said. “So, it makes the process of figuring out what exactly is triggering it very difficult. It’s a *loooong* process to find out what foods cause it.”

Mayo recently revised its plans for Leah to undergo endoscopies and biopsies every two months. Her most recent dilation stretched her esophagus “as big as it will get,” she said. “They will never be able to get it to a ‘normal’ size esophagus due to scar tissue and damage from the eosinophils, but it is a big improvement compared to what it was.”

NDAD & medical travel assistance

In 2016, NDAD provided assistance with more than 2,600 medical trips.

--

If you qualify, NDAD may provide assistance with a gas card and an allotment to be used towards lodging, if necessary.

--

NDAD will only consider medical travel assistance to the closest facility offering the service needed and cannot offer mileage past the Mayo Clinic in Rochester, Minn.

--

This is not an emergency based program – there is an application process.

--

Learn more and apply for assistance online at NDAD.org, or call (800) 532-NDAD to talk with a NDAD representative.

Leah’s eosinophil count has responded to medicine and diet alterations “so I do not have to go back for a whole year unless my swallowing gets worse before then.”

She’s never gone more than six months between dilations, but the Herrons have fought for treatment for so long that seeing results is a really big relief for us.”

Matt Herron has been a youth pastor at Dickinson’s Hillside Baptist Church since early 2014. The Herrons’ other children are Caiden, 6, and Jacek, 2½.

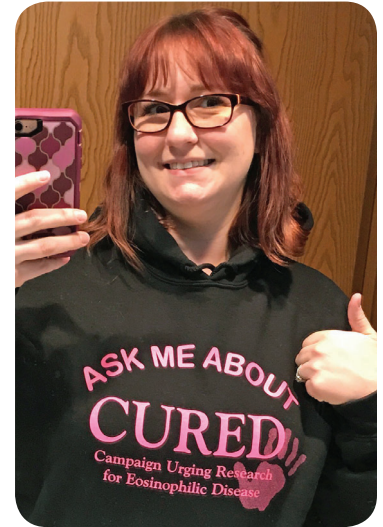
Leah has long lived with food allergies that can cause a life-threatening bodily reaction called anaphylactic shock. She cannot have any peanuts or tree nuts, peas, tomatoes, fish or shellfish. She keeps an epinephrine autoinjector nearby to combat a sudden shock by quickly injecting adrenaline into one of her thighs. Leah has experienced anaphylactic shock only once, in 2009, after taking several bites of a fish stick. She had eaten fish before with no issues.

In addition, Leah said she’s “had to move my head differently to swallow certain things.” Some starchy foods are harder to swallow, such as potatoes and rice. Her bites usually are very small and her chews thorough.

She sometimes gets dehydrated, which has led to emergency room trips.

On that day in 2011, Leah said, “I was breathing fine. Nothing really hurt; I just couldn’t swallow anything, so it was very nerve-racking.”

Now, six years later and with new optimism about her health, Leah and Matt are thankful they could go to Mayo Clinic -- and appreciative of NDAD’s assists to help get them there. ■



Leah belongs to a support group for people with EoE and promotes efforts to provide more financing for research: <http://curedfoundation.org>.

Alverna Sasse

'NDAD has been a lifesaver for me'

■ *Prescription assistance provided the ingredient needed to ease retired cook's financial burden*

The Grand Forks surgeon who performed Alverna Sasse's open-heart surgery for a blocked artery in the 2000s told her something about diabetes then that she's not forgotten: "Diabetes isn't going to kill you. It's the complications of diabetes."

Alverna, now 67, is a retired University of North Dakota food service cook dealing with type 2 diabetes. She has learned that its complications can be financial as well as physical.

Following several years on a restricted diet and prescription pills, Alverna learned her pancreas was struggling. Her doctor put her on insulin, and her monthly medication costs skyrocketed.

"At first I could afford it," she recalled. "But as the years went by, the cost got even higher and higher" to beyond what she could afford, even with supplemental health insurance. She needed help, but didn't know where to find it until one of her sisters told her to contact NDAD. "I actually thought NDAD was just about wheelchairs, canes, stuff like that," Alverna recalled.

NDAD's general assistance includes durable medical equipment and much more, including prescription medication assistance -- facts Alverna learned when she spoke with NDAD client services' Lora Machart. "She's wonderful," Alverna said. "She has a lot of patience. She explains everything."

Alverna applied for NDAD help and soon was approved. "Ohhh, I was relieved!" she recalled. "I didn't know how I was going to pay for my medicine otherwise. NDAD has been a lifesaver for me."

She still faces other health concerns, including atrial fibrillation, another artery blockage and limited scleroderma. Yet, this mom of two adult daughters is relishing life, including with her five grandchildren and two-month stays each winter with family in Arizona. The Leeds native, who's also lived near Knox and in Beulah and Rugby, loves cooking and baking for others in her south Grand Forks housing complex -- and recommending NDAD, too.

"Oh, I do," she said. "I say they help in a lot of ways." ■



Alverna Sasse

NDAD & prescription assistance

In 2016, NDAD provided more than 320 prescriptions for individuals in need of assistance.

If you qualify, NDAD may provide free or reduced-cost prescriptions.

Medications NDAD may assist with include (but are not limited to) diabetes, anti-seizure, high blood pressure, high cholesterol, depression, anti-rejection, asthma and COPD.

Examples of medications NDAD does not assist with: hormonal, sleeping, ulcer, weight loss, birth control, antibiotics, supplements, allergy, stimulants, narcotics/controlled substances, pain medications and topical medications.

This is not an emergency based program; there is an application process.

Learn more and apply for assistance online at NDAD.org, or call (800) 532-NDAD to talk with a NDAD representative.



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 edition

NDAD is going paperless! In an effort to be more mindful of the environment and reduce printing costs, NDAD is considering an electronic version only of our quarterly newsletter, the Insider. To ensure you don't miss an issue, please go to our website at NDAD.org and click on the "Get the Newsletter" link to add your email address. If you prefer to continue to receive a paper copy of the Insider, please contact our NDAD office at (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

FARGO

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

MINOT

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

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.*