



# Making a difference... TOGETHER

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## 2008 Children's Miracle Network Champion Named Cora Knudsvig, age 7, Portland, N. D.



Each year MeritCare Children's Hospital physicians and staff choose a child to be our Children's Miracle Network (CMN) Champion. For Cora's brave battle we've chosen her to be our 2008 CMN Champion. This is her story.

December 31<sup>st</sup>, 2005 is a day that the Keith and Tanya Knudsvig family will never forget. After complaining about a bad headache and

vomitting, 5 year old daughter Cora became unresponsive and was rushed to MeritCare Children's Hospital where doctors diagnosed her with a brain tumor (Papillary Neuroglioma).

The difficult news from Cora's doctors hit the family hard. A large tumor had grown undetected for several months and finally ran out of room and burst, causing hemorrhaging and extensive damage to the right side of Cora's brain and partial damage to the left side. Her condition was critical and doctors were not sure if she would survive. And if she did, what her long-term prognosis would be. Would she ever be able to see, speak or recognize her family? Would she ever wake-up?

Cora did survive, but it has been a long journey. She underwent three difficult brain surgeries, a tracheostomy and a feeding tube. She spent nearly three months at MeritCare Children's Hospital and required extensive speech, occupational and physical therapy.

Doctors will never know what caused Cora's condition but today she is doing great. She's back in school enjoying the first grade. She is a happy little girl who loves to dance, play board games, color and watch movies - her favorite is Win-Dixie.

Watch for more information throughout 2008 about Cora's amazing story and her year as MeritCare's CMN champion.



**Mark your Calendars for the following  
Children's Miracle Network Events  
that help support  
MeritCare Children's Hospital:**

- May 31st      Live Televised Celebration
- June 16th     Children's Golf Classic
- June 28th     Harley Owners' Miracle Ride
- August 7th    Dairy Queen Miracle Treat Day

## Internal Grant Supports Day-to-Day Solutions for People with Disabilities

An avid soccer player since his boyhood in Brazil, Glenio Trindade of Fargo now faces an entirely different challenge: the progressive deterioration of his muscles due to amyotrophic lateral sclerosis (ALS). But even as the 49-year old struggles with life-changing disabilities, he looks for solutions that will make a daily difference. With the help of a specialized lab established by MeritCare Speech Language Pathology and Occupational Therapy Services, he recently piloted several pieces of innovative communication and assistive devices designed to improve functioning and lead to greater independence. A MeritCare Foundation internal grant helped equip the lab.

### A difficult diagnosis

Glenio knew something was wrong four years ago when his left hand wouldn't open and close as it should; he attributed it to an earlier shoulder injury sustained while playing soccer. Then another troubling incident: During a soccer game in Fargo, just after he'd planted his foot and was about to kick a goal, he collapsed, temporarily losing strength and coordination. He and his wife, Linda, became increasingly concerned.

In the summer of 2005, following a series of tests and medical appointments, they received the difficult diagnosis of ALS, also known as Lou Gehrig's disease. Though the course of the disease differs from one person to the next, ALS eventually affects walking, speaking, eating, swallowing, breathing and other basic functions. The cause of the disease is unknown.

*Karen Fowler, MeritCare Speech and Language Pathologist, assists Glenio and his wife, Linda in training on the new Assistive Technology. This device provides Glenio with enhanced communication skills and the ability to be more independent.*



"It was a very devastating diagnosis," says Glenio, whose voice has weakened to the point it's barely audible. Previously, he lost strength in his arms and legs, now relying on a motorized wheelchair for mobility. He recently gave up his 19-year career in computer graphics when no further adaptations were available to help him do his work.

In dealing with the daily challenges brought on by ALS, Glenio greatly appreciates the love and support of Linda, his wife of 25 years. Recalling when he met her

in Brazil, he says, "It was love at first sight." She was a high school foreign exchange student from Fargo. Now it's love in action; she accompanies him to appointments, brings him to therapy sessions and helps him maintain his life at home. "With ALS, you don't lose your mind, but you lose your independence," says Glenio. "That's what has been most challenging and frustrating for me."

### New technology focuses on solutions

Thanks to innovative technology, Glenio may soon have the tools he needs to help him better communicate and have greater control over his environment, including talking on the phone, using e-mail and operating appliances. "Linda arranges everything for me before she goes to work in the morning, but if possible, I would like to be able to do more for myself," he says.

With an attitude of openness, Glenio works closely with the therapists at MeritCare's Augmentative Communication and Assistive Technology Lab. The lab offers computer hardware and software to assist people with physical, mental and speech disabilities. "We enable patients and their families to be exposed to a number of possible solutions," says Jane Leno, occupational therapy coordinator. "We provide an assessment of their needs, the opportunity to try out different devices and the training needed to successfully use them."

For Glenio, the most promising tool is a programmable, DynaVox — a communication device that resembles a laptop computer with a mouse that can be operated with slight head movement, enabling a person with limited or no hand movement or voice, to still be able to communicate. "I'm excited to start working with this," says Glenio. "The only requirement is head movement, which I can do."

Glenio is now in the process of learning to use the loaner equipment from MeritCare and will soon receive his own from the ALS Association. His eyes light up when asked how the customized technology could make a difference in his day-to-day life. Examples include: increased ease in communication with Linda and their two grown sons, the ability to visit with family in Brazil with a special "Phone It" attachment, easy operation of the television remote control so he can switch back and forth between worldwide soccer games, and just the simple act of turning lights on and off. "There are so many ways this will help," he says. "I look forward to using it."

## Pratt Family Faces Cancer Together

Paul Pratt clearly remembers his reaction when in spring 2006 he learned his daughter Claudia, then 44, had been diagnosed with breast cancer.

“Right away I had flashbacks. All I could think about was here we go again,” says the 76-year-old farmer from Gardner, N.D. “But as soon as Claudia’s treatment began, I got focused on the present, on what I could do to help. If there’s one thing I’ve learned over the years, it’s don’t back away when a loved one has cancer.”

### Several family members afflicted

Paul’s flashbacks stemmed from 1988, when his wife of 34 years, Marguerite, and mother of their three daughters, was diagnosed with breast cancer. “She fought it for 14 years,” he says, removing his glasses and wiping his eyes. “Those memories are tough, and they’re all still there. You start talking about them and it’s like opening a floodgate.”



*Ebba Margareta Nordstrom (2007) was born in 2004 and is named after Marguerite as a remembrance of her “Mormor” (grandmother).*

But Marguerite’s battle wasn’t the Pratt family’s first encounter with cancer. When she was in her 30s, Marguerite’s mother died of breast cancer. And before they reached the age of 25, daughters Claudia and Charlotte were diagnosed and successfully treated for another type of cancer — Hodgkin’s disease. Both daughters came to MeritCare, before the Roger Maris Cancer Center was open.

“That was over 26 years ago — and definitely a different era in cancer care. Claudia, for example, needed to be hospitalized for two weeks just to do the tests to get the diagnosis. Today, with the Cancer Center, you can get so much of your care in one place. It’s superb,” says Paul. “With all of Marguerite’s appointments and treatments, we went there often. We felt lucky our farm was just 30 minutes away.” The Cancer Center opened in 1990 offering the full range of diagnostic, treatment and support services needed by patients and their families.

### Today’s cancer care

Claudia’s recent experience with breast cancer underscored the advances in cancer care over the past several years. “When I found out I had breast cancer, my first reaction was, ‘I have a festival to run — I don’t have time to deal with this,’” recalls the regional arts consultant who directs the annual Scandinavian Hjemkomst Festival in Moorhead. “I later learned that with today’s treatments, you can — within reason — actually plan your treatments around your life. That was important to me.”



*Pratt Family - taken on Paul and Marguerite’s 40th Wedding Anniversary (December 26, 2000)  
Back Row: Bill Beyer, Paul Pratt, Henrik Nordstrom; 2nd Row: Claudia M. Pratt, Marguerite Pratt; 3rd Row: Karla Beyer, Philip Nordstrom, Charlotte Pratt; Front Row: Jensine Beyer, Nils Nordstrom*

She and her medical team at the Cancer Center, including a surgeon, medical oncologist and radiation oncologist, decided on a combination of treatments proven to be successful against her particular type and stage of cancer. Beginning in late April 2006 and for the next six months, Claudia proceeded through three phases of treatment

— lumpectomy (surgical removal of the tumor), brachytherapy (a type of targeted radiation therapy) twice a day for five days, then chemotherapy every two weeks. “All my treatment was outpatient, which was amazing to me,” says Claudia. “I realized just how far medicine had come in the past 25 years.” She was pleased, too, to discover that today’s anti-nausea medications work well in helping to relieve chemotherapy related nausea.

“Fatigue was my biggest challenge, especially during and after the chemotherapy phase of treatment,” says Claudia. “My dad was a huge help. He was my chauffeur for a year, went to appointments with me, brought me to treatments. I don’t think I could have done this without him.”

### Life — and help — continue

Claudia, now a two-time cancer survivor, continues with periodic checkups at the Cancer Center. In April 2007, she began a year-long preventive regimen involving the periodic infusion of the promising bi-therapy drug, Herceptin — another advance. “I lived 25 years after my first cancer diagnosis,” she says. “I plan to enjoy more than 25 years after this one.”

And Paul? He continues to help his daughter in whatever way he can. “I’m very loyal in my commitment to family,” he says. “I want to be there for Claudia.”

Paul continues another tradition, too. “Marguerite was fascinated with the nurses, especially their knowledge about all different types of cancer and their practical solutions to everyday problems experienced by cancer patients. That’s why she always designated our Cancer Center contributions to the advancement of nurses, and I continue to do the same,” says Paul. “It still amazes me what nurses know and the help they can give.”



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## Celebrating Our Centennial & Thanking Our LegacyCare Donors

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Individuals and couples who have included a planned or deferred gift in their planning and have notified MeritCare Foundation, will be honored at a special Centennial LegacyCare Celebration and featured in the commemorative LegacyCare Centennial Program.

In February 2009, near the closing of our Centennial year, MeritCare Foundation will be holding a special Centennial Celebration for our LegacyCare members. It will be a time to reflect on our past and to honor our members who have made a commitment to our future.

This happens only once in one hundred years and it is important to pause and recognize those who have brought us to this milestone and to celebrate those who are creating our tomorrows. We invite you to join us in celebration of this century of service by considering an inclusion in your estate plan (life insurance policy, IRA beneficiary, will, trust, savings account, etc.)

For more information on the LegacyCare Centennial Celebration please contact Yvonne Kroll, CFRE at MeritCare Foundation at (701) 234-6246. Please accept our appreciation for your past support and for helping us create the future.