

Single copy  
75¢

# Fayette LEADER

Official Newspaper for the Cities of  
Fayette, Hawkeye, Maynard,  
Westgate and for Fayette County.

www.newspapersoffayettecounty.com

Wednesday, Aug. 8, 2007

Issue #33 Copyright 2007 Volume 93 USPS-#188-400

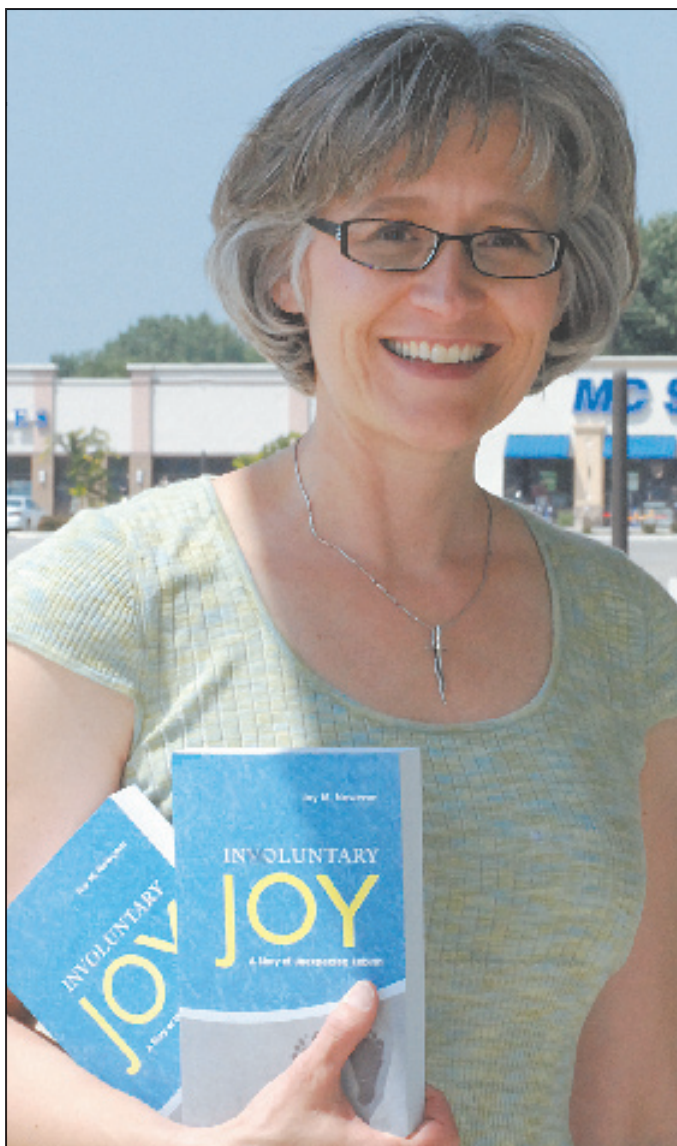
112 S. Main St., P.O. Box 220, Fayette, IA 52142

## Parenting a child with multiple birth defects, brings 'Involuntary Joy'

BY JANELL BRADLEY  
EDITOR

*Seventeen years ago, Joy Bowden Newcom was a career woman who'd decided it was time to begin a family with the love of her life, her husband, Mark.*

*"Neither of us had anything in our family history to indicate we'd have anything but the perfect baby," she recalls.*



First there was the miscarriage, followed several weeks later by another pregnancy. And when five pound Stross David greeted the world in May 1991, it was with his spine exposed through his back.

Doctors told the parents of this newborn, their son had the birth defect spina bifida. He would never walk unaided, and would probably spend most of his life in a wheelchair. Later, they learned another condition, known as hydrocephalus, required surgery. A shunt at the back of his head keeps fluid from accumulating on Stross' brain. The condition must be monitored for the rest of his life.

"We all have a stories that shape our identity – the story told through my book is simply what has most shaped who I am," says Newcom of the book she recently authored and self-published, titled, 'Involuntary Joy.'

Newcom, the daughter of retired teachers Gay and Fran Bowden, is a 1982 graduate of North High School, West Union. With a degree in journalism from Wartburg College, she pursued a professional career until opting to become a stay-at-home mom who works part-time, in part, because of Stross' special needs. She is now a public relations consultant and an adjunct professor at Waldorf College, Forest City.

'Involuntary Joy,' which became available in mid-July, chronicles her first five years as a mother to a child with multiple birth defects – in a straightforward manner with blemishes and vulnerabilities exposed.

Parenting a child with disabilities changed the author's life dramatically and expanded her understanding of faith. Her book, which she finished four years ago but had shelved until deciding to self-publish, will help others identify with the pain and struggles parents of disabled children feel – and possibly provide them with hope as they face their own unique challenges.

Newcom says she's heard the comment, "God never gives you more than you can handle," more times than she can count. "But it's a chicken and egg kind of question. I don't think God is in the business of doling out things that you can handle. For instance, people also say, 'God sure knew what He was doing when he gave Stross to

you?'"

Newcom says, "That's not my image of who God is; sometimes life just happens." The theology of predestination, she says, would also mean God plans for certain children to be born into families who abuse or abandon them.

Through the years, Newcom says she's evolved from an egocentric faith – one that served her well, "to a faith that calls for communion. It's shifted from a direct focus only on me and God to how I am a vehicle for a divine purpose in the world."

"I can see the kind of person I was before," she says, but admits, "I can't fully remember what that was like. How I regarded people with disabilities is what has largely changed."

Another strong theme throughout the 400-page book relates to how Newcom dealt with the anger that resulted in learning of her son's spina bifida.

"I was not 'head over heels' I had a child with disabilities, but neither did I ever believe I'd be exempt in some way. Instead of 'why me,' I understood 'why not me?'" she says.

She states in the prologue that until the day he was born, "I had no idea (Stross's) life would be full of medicines, surgeries, daily therapies, insurance battles and anguish over inaccessible places.

"Neither could I have imagined the joy in which he'd live every moment of his waking life or

how he'd be able to impact someone else's life simply by living out his."

When the author talks about the special qualities she sees in both her sons – Stross is now 16, and younger son, Skye, is 12 – tears cloud her eyes and emotion threatens to seize her voice.

"Stross believes life is limitless. He has this intoxicating ability to bring you along and live the moment with him."

Newcom says music fills her son's soul. Stross' teenage voice floats beyond closed bathroom doors in the family home, as he sings his favorite melodies from musicals such as, 'Wicked' or 'Hairspray.'

Although his reading level isn't that of his peers, and his parents recognize that Stross' future doesn't include being a doctor or lawyer, Mark and Joy Newcom are pleased with what

their son has accomplished in his first 16 years. He participated in speech competition at his school, and intends to audition for his school's musical production this fall.

"Our mission statement for Stross is to teach him how to be the best Stross he can be," says Joy.

"I've stopped trying to project what either (Stross or Skye) will be. I want them to be in charge of shaping the awareness of who they are – my role is just to support them."

Stross, she says, has taught her to look at all people as a compilation.

"I have learned to look at every student or every person I encounter as a fully unique individual who comes with their own story. I believe we all have disabilities." Some disabilities are just easier to see, and to accept; some are emotional, some are social.

What the author expresses throughout the book – beginning first in the words of her prologue: "You can find joy in any of life's circumstances. There's joy in the midst of sorrow, in the midst of grief. That's been a fascinating lesson."

Newcom says if there's a second book in her future, she would like to address improved advocacy for disabled youth and advice for working with teachers.

But first there's her present book to market.

"I'd like to take it as far as it can go," she says of 'Involuntary Joy.'

"I hope the book will find the audience it's supposed to have. I want to have an opportunity to impact the fields of health care and education."

The couple's younger son, Skye, isn't left out either.

"I have some writings that are essays on my life with him—I call them 'Skye Writings,' she says, the pride for her offspring, evident in her expressions.

"Skye as a brother to Stross has a depth to him that I am in awe of," she says. "We always wondered when Skye would 'get' what it means to have Stross as a brother," she says. By the second or third grade, he understood, she says.

"We live our whole lives as a community experience," says Newcom, expressing her wish that perhaps 'Involuntary Joy' will simply help some, better understand the life of one who is disabled in any way – be it socially, economically or physically.

"Maybe it will help them become a better friend or neighbor," she says.

*"Stross believes life is limitless. He has this intoxicating ability to bring you along and live the moment with him."*

Author Joy Newcom

JOY Newcom will sign copies of her memoir, "Involuntary Joy: A Story of Unexpected Rebirth," at the West Union Library, Friday, Aug. 17, from 4-6 p.m. She'll be joined by her son, Stross, whose life shapes the book's content.