



# AGRABILITY CHIT CHAT

August 2003

Vol. 5, No. 5

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## CAREGIVING

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### CARM'S COMMENTS: Carmen Schacht

Caregiving is such a vital subject when it comes to a person with a disability. I could not imagine what it would be like to have a child born with a disability; knowing from day one that a very important job lies ahead. I know many times there are such deep commitments to make life as good as it can possibly be for that child, that it takes all the strength and time from the primary caregiver's life. It often means that other children and responsibilities are given less attention in order to do the necessary things for the person with the disability. I realize this is not how most people want things to go, but there is only so much time in a day.

When I think of caregiving for older people, I think of our Freewheeler's Friends and Family group here in NE Iowa. There are six men and five women who are primary caregivers and two women who do

extremely well caring for themselves. All of these caregivers do remarkable jobs in tending to their spouses.

One of the main things for caregivers to remember is that it is important take care of themselves. If a person gets too worn out or stressed, it won't be good for either person. I know in some communities there are places where respite care is available. People need to take advantage of this service and recognize the benefits of respite care.

A big SALUTE to all caregivers. (CS)

### COPING WITH CAREGIVING: Vera Beth Bricker, Victor, IA

My husband of 54 years died October 4, 2002, in an accidental fall down our basement steps. His death left me with three adult children with disabilities. Everyone in our household is affected in some way by Fragile X syndrome. I am a carrier, my only daughter, Denise, is a mosaic with some of her cells showing the full syndrome and some of her cells showing the carrier status. Dave and Kris have the full syndrome manifested by preschool mentalities and autistic, obsessive/compulsive traits.

Fragile X syndrome, discovered in 1991, is the leading known hereditary cause of developmental disabilities. FX is a medical malfunction carried on the X chromosome,

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one of the two sex chromosomes. It rises from an alteration in the code in genes. Molecules normally efficiently encode and guide the production of proteins, which are needed in the development and function of the body and brain. A gene, which encodes molecules that repeat six to 50 times, is over-expanded. Misprinting 200 to more than 1,000 copies of this one particular “triplet” sequence, it bungles the instructions needed for the creation of a specific protein.

After my husband’s death, my financial advisor told me there would be enough liquid assets to build an accessible bedroom and bath for Denise. Marcy Thomas, AgrAbility Program Specialist with ISU Extension, came to visit me several times to inform me of options for home accessibility. One of her illustrations had a drawing of a toilet in the shower. I told her I had been wanting something like that for 35 years, but never dreamed it existed. Shortly after her visits, the tiled bathroom was completed.

Mary Yearn, Greg Breneman, and Steve DeHoogh from ISU Extension, came to my home to advise me on the placement of the accessible bedroom and bathroom. I thought I had looked at all of the options, but when Mary presented her ideas, I told her they were brilliant and creative. The Quality of Life Team from ISU has also been helpful. I believe Denise will be in her new bedroom by Christmas.

Remodeling the house and playing organ at two church services on weekends keep me busy. Sorrow over the loss of my husband continues even after 10 months. I’m angry with him a lot because I told him he couldn’t die since I needed him so much. At this time of year I miss the ditch tiger lilies he used to bring me for a table centerpiece on his way home from carrying the rural mail route.

### CAREGIVING RESOURCES – Tara Nielsen

#### **National Family Caregivers Association.**

The NFCA is an excellent source of information for those who care for individuals with disabilities. Education and support are so important when taking on the role of primary caregiver. The NFCA believes there are four key messages to live by:

1. “Choose to take charge of your life. Don’t let your loved one’s illness or disability always take center stage.”
2. “Honor, value and love yourself. You’re doing a very hard job and you deserve some quality time, just for you. Self-care isn’t a luxury. It’s a necessity.”
3. “Seek, accept, and at times demand help. Don’t be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do.”
4. “Stand up and be counted. Stand up for your rights as a caregiver and a citizen.”

How do you take care of yourself? Send us ideas you use to relieve caregiver stress, whether it’s playing the organ, taking a walk, or digging in the garden.

For more information on caregiving contact the NFCA in one of the following ways:

Ph: (800) 896-3650

Email: [info@nfcacares.org](mailto:info@nfcacares.org)

[www.nfcacares.org/home.html](http://www.nfcacares.org/home.html)

#### **National Family Caregiver Support**

**Program.** The Administration on Aging has developed the National Family Caregiver Support Program to provide community services, including:

\*information on services

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- \*assistance to caregivers in receiving services
- \*counseling, support groups, and caregiver training for families
- \*respite care, giving temporary relief from caregiving responsibilities
- \*supplemental services

Each state has its own program. For more information on Iowa's services call toll-free at 866-468-7887 or log on to the web site at [www.iowafamilycaregiver.org/search.asp](http://www.iowafamilycaregiver.org/search.asp)

**Iowa State University Extension.** The ISU Extension web site also provides information on growing older and family caregiving, as well as links to Iowa and national resources. See: [www.extension.iastate.edu/aging/](http://www.extension.iastate.edu/aging/)

**Iowa Respite and Crisis Care Coalition.** Respite care services provide temporary relief to parents or caregivers of individuals with a disability, special need, or chronic illness. Respite care can be provided to individuals of any age, both children and adults. For information about respite services, contact:  
Iowa Respite and Crisis Care Coalition  
3821 71<sup>st</sup> Street, Suite A  
Urbandale, IA 50322  
[www.IRCCC.com](http://www.IRCCC.com)

**Iowa Long-term Care Ombudsman Program.** Call 515-242-3327 with questions about long-term care services.

**Medicare and Medicaid.** Questions can be answered on the web site for the Centers for Medicare and Medicaid Services: <http://cms.hhs.gov/default.asp>

### 100 YEARS OF EXTENSION!

2003 is the 100<sup>th</sup> anniversary of Extension at Iowa State University. Every county in Iowa strives to improve the quality of life for its citizens through Extension services. Many events are happening around the state of Iowa to celebrate the occasion.

Perry Holden, who came to Iowa to teach about corn, is the person who started the Extension program at Iowa State College in 1902. He gave special sessions for the education of farmers. Six program areas were born from Extension; Agriculture and Natural Resources, Business and Industry, Community, Families, 4-H, and Continuing Education.

Extension looks forward to another 100 years of education and advancement in our communities.

### UPCOMING EVENTS:

October 4: SE Region Friends and Family at Pizza Hut in Tipton- 1:00

October 4: FREEWHEELER'S Friends and Family at Pizza Ranch in Conrad - 1:00

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IOWA AGRABILITY - A joint effort of ISU Extension and the Rural Solutions Program of Easter Seals Iowa. The program can help farm family members with a disability stay in farming.

This newsletter from the Iowa AgrAbility Project will be sent monthly to AgrAbility families and other interested individuals. Please send comments and suggestions to:

Marcy Thomas, AgrAbility Program Specialist

96 LeBaron Hall, Ames, IA 50011

E-mail: [mbrat@iastate.edu](mailto:mbrat@iastate.edu)

Phone: ISU Answerline at 1-800-262-3804

TDD: 1-800-854-1658.

Web site: [www.extension.iastate.edu/agrability/](http://www.extension.iastate.edu/agrability/)

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### **Iowa AgrAbility Project**

Iowa State University  
96 LeBaron Hall  
Ames, IA 50011