

Denise Speaks Out...

Ask Denise D. any question. You will get an answer. If Denise doesn't want to answer, she will let you know. Denise speaks for herself. Denise is a 51 year old woman who raised her daughter, Nicole, age 32. She served as a board member for a non-profit agency from 1993 to 1999, and for several years has served on its Human Rights Committee.

Denise takes computer lessons in the Family SupportNet Project. When Denise completes the lessons she will have a way to communicate better. Since she began her lessons in mid August, Denise has learned about two disability resources that can help her acquire a computer equipped with assistive technology to improve her quality of living. Easter Seals of Massachusetts contracts with the Independent Living division of the Massachusetts Rehabilitation Commission to provide assistance to individuals with disabilities. The SHARE Foundation at the University of Massachusetts, Dartmouth, also assesses an individual's needs and provides assistive technology to increase an individual's independence. These resources are a result of Family SupportNet students sharing collective experiences in classes, as well as



performing new Internet searches to access disability sites pertinent to their families needs. All resource information shared in class is added to the Family SupportNet website.

Denise wants to share her expertise about living with a physical disability to educate the general public about how to talk with individuals with disabilities. She has had a form of Muscular Dystrophy, named Frederick's Ataxia, since she was 13 years old. As a young teenager, she began losing her balance, and ability to walk unassisted. Peers made fun of her in gym class. Initial tests did not accurately diagnose her. After her daughter was born, at age 19, a doctor told her she had a brain aneurysm. Denise describes how the doctor told her, "it's like having a bomb inside your head, that will go off at anytime." She was progressively losing her ability to walk, balance herself, and began experiencing increasing fatigue. All this while her small daughter needed care. Denise believed she had a brain disorder that sapped her strength and coordination and was potentially going to explode one day and kill her.

Denise was 30 years old before she learned which illness was causing her to lose muscle strength and mobility. Her new doctor asked her to have an MRI. "After the MRI, he told me I had Frederick's Ataxia and that it was not life threatening. But he didn't say it was Muscular Dystrophy. I just thought I had another brain disorder." It was not until several months later that Denise watched the Jerry Lewis Muscular Dystrophy marathon and heard a young man of 18 describe his symptoms. He called his illness Frederick's Ataxia.

please see "Denise," continued on next page...



Call or email Meredith Aalto for more information about upcoming basic computer classes!

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Family SupportNet Project Classes throughout Massachusetts

Thanks to the following sites for hosting Family SupportNet Project classes this fall. Latino Health Institute, Boston, Springboard-Til, Dedham and Boston, Work, Inc.-Leominster, Oak Square YMCA, Brighton, Brockton Area ARC, Brockton.

Check out these Computer Resources

SHARE Foundation, UMASS Dartmouth-learn about receiving computers equipped with assistive technology as well as general donated computers. Call Les Corey 508-999-8482, www.share.umassd.edu

Easter Seals of Massachusetts-Learn about receiving computers equipped with assistive technology. Call Kathleen Bestrado 800-922-8290, www.eastersealsma.org/

Meet some more Family SupportNet Project students...

Norma L. is a student in the Family SupportNet Project. She graduated from Dorchester High School in June 2002 and has been working at Children's Hospital in the cafeteria in the supported employment program through ICI since June 2003. Norma enjoys learning new things all the time. Norma will be receiving her ebuddies through Best Buddies this month. She took her training at the Mattapan library near her home.

Meet another Family SupportNet Project student, **Bob W.** He is an employee at Shoe City Contract Company in Brockton. Bob is an avid music lover, especially enjoying songs from the 70's through the 90's. On Thursday nights, Bob performs Karaoke with friends. Bob is a good typist and has recently started using email. He is interested in signing up for the ebuddies program through Best Buddies.

Wismide C., a family member who receives services through the Haitian American Health Initiative of Mattapan, (HAPHI) completed Family SupportNet Project lessons that HAPHI hosted over the summer. She is hoping to acquire a computer for her family through the SHARE Foundation at UMass Dartmouth. She will use it look up resources for her son who has autism as well as improve her skills to complete a GED and find employment.

Excellent Guides To Help Your Family Transition Into The Future

Transition Planning for Adolescents with Special Health Care Needs and Disabilities: Information for Families and Teens (2000)

This booklet has been developed for families and teenagers to help teenagers prepare for his/her adulthood. Just as families have had to spend more than the average amount of time attending to their young child's care, the transition to adulthood will be best accomplished if families devote extra effort and energy to that transition. This booklet has been written to help and guide you—to give you the information, ideas, tools and resources you need along the way.

Find it on the ICI website at:

www.communityinclusion.org/transition/familyguide.html

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Denise Speaks Out...(continued)

"I was excited because I finally knew what I had and I wasn't going to blow up!" Denise smiles slowly as she says this because her facial muscles are weakened. Her speech is slurred and can be difficult to understand. Her handwriting is poor. Getting ready for work takes an hour longer than last year. When she is equipped with her new computer, Denise will make shopping lists for her homemaker, order prescriptions by phone, and learn on-line banking. She will not have to rely on so many people to do ordinary tasks. Denise wants to email other people like herself, but she also wants to write and speak up about a few pet peeves regarding disability perception.

"I can speak for myself. I will answer questions about using a wheelchair. I don't like it when parents pull their children away and say, 'Leave the nice lady alone.' when they try to speak to me." Denise used therapy for a number of years to deal with feeling alienated and rejected in the public's eye. "I heard Dr. Phil (from Oprah Winfrey) say, 'We can't choose how we die, but we can choose how we live.' I do that."

Denise loves to read and is currently inspired by Michael J. Fox's book, *Lucky Man*, about Parkinson's disease. She suggests "that people live in the present and try not to worry about the future." She is not afraid to speak up for people like herself and advises the public "not to be afraid" to speak to individuals with disabilities.

Visit the Family SupportNet website at www.ici.umb.edu/family

Resources include information and links about Disability Resources, Global Communities, ESL, Healthcare, Family Activities, FSN Newsletter, Listservs and more!



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