

daughter's grade school graduation in Oklahoma, and missed Recorded Votes No. 126 (Motion to suspend the rules and pass H. Con. Res. 56—National Pearl Harbor Remembrance Day), and No. 127 (motion to suspend the rules and pass H.R. 1885—extending section 245(i) of the Immigration and Nationality Act).

Had I been present, I would have voted yea on both of the above motions.

PERSONAL EXPLANATION

HON. ROBERT W. NEY

OF OHIO

IN THE HOUSE OF REPRESENTATIVES

Tuesday, May 22, 2001

Mr. NEY. Mr. Speaker, on May 21, 2001 my flight was extremely delayed by over three hours. As a result I missed rollcall vote No. 126 and No. 127. Please excuse my absence from this vote. If I were present, I would have voted yea in support of H. Con. Res. 56 the Pearl Harbor Remembrance Day Resolution.

THE STORY OF EMILY ROSS

HON. STEVE C. LATOURETTE

OF OHIO

IN THE HOUSE OF REPRESENTATIVES

Tuesday, May 22, 2001

Mr. LATOURETTE. Mr. Speaker, I rise today to honor a courageous young woman from Westlake, OH, who recently contacted me to share her story and the need for increased funding for Muscular Dystrophy research. Emily, a sophomore at Westlake High School, has Friedreich's Ataxia, one of the many neuromuscular diseases that fall under the umbrella of Muscular Dystrophy. Emily was diagnosed when she was five.

Emily's parents, Charlie and Carolyn Ross, shared with me two articles Emily wrote about her daily struggle with Muscular Dystrophy and how she is overcoming the challenges the disease places before her. The first was written when Emily was in eighth grade, "A Day in the Life of Emily Ross." The second, "Onward and Outward!" was published in the April 2001 edition of *The Bay Press*. I am submitting the writings of Emily Ross into the CONGRESSIONAL RECORD so they will become a part of the official record of the U.S. House of Representatives.

Mr. Speaker, Emily believes that God chose her to have Muscular Dystrophy because he needed someone to help find a cure. I applaud her courage and grace, and hope that others will be as touched by her story as I was.

A DAY IN THE LIFE OF EMILY ROSS

(By Emily Ross)

When I wake up in the morning, I shut off my alarm and begin my day by stopping to think how I am going to walk across my bedroom floor. Attempting to go into the bathroom is scary because my feet are stiff, my balance is terrible and I manage to bang into every piece of furniture in my bedroom! I get downstairs to the kitchen for breakfast by scooting down on my behind step by step. Going into the kitchen for breakfast I have trouble opening the peanut butter jar, pouring a glass of milk or getting any cereal into my mouth because my hands shake. I hope

my teeth are clean because I cannot squeeze the toothpaste. Buttons, zippers and socks are a challenge. I'm already tired but off to school I go with my Mom and my dog, Oats.

At school, my Mom helps me to the door because my feet trip easily on the uneven sidewalk. I cannot open the heavy doors by myself. Once inside, I hope on my battery-powered scooter and go to my locker. If I'm not shaking too badly I can get my combination lock opened in three tries! Headed to my first class I face crowded hallways, funny looks from other kids and hurtful comments like "there goes the cripple." Sometimes some of the kids will lie on the floor pretending that I have hit them with my scooter which really hurts my feelings. I'm constantly being asked to move out of the way because they say my scooter takes up too much room. After class I'd like a drink of water but the water fountains are too high. At lunchtime I never buy a school lunch because I cannot reach the food on the shelves or get my scooter through the narrow gate. I tried to walk through the lunch line several times but everyone is pushing and I'm scared I'll lose my balance. I dropped my tray once and believe me, once is enough!

It's now sixth period and I'm starting to get really tired and I have two more class periods to go. The bell rings and school is finally over. It's pretty tricky getting my scooter down the hallway with everyone pushing and shoving their way out to the buses. I finally get to my locker, hope I can get it open in time so I don't miss my bus, grab my coat and panic when I can't zip up my backpack. All my papers fall out all over the floor. I frantically stuff them back inside my backpack, park my scooter, and struggle past 800 other kids waiting to catch their bus rides home. My bus finally arrives and I gratefully sit down for my ride home. An aide helps me up to the side door of my house and helps hold my hands steady so I can aim my key in the lock and she also helps me to turn the doorknob so I can get safely inside. Once inside I let my backpack and coat drop on the floor and I fall onto the couch where I am grateful to God that I have made it another day. Oats, my dog, is the only one I can talk to when I get home from school. She always understands me.

My name is Emily Ross. I am 13 years old and in the eighth grade. I have Friedreich's Ataxia which is one of forty neuromuscular diseases listed under Muscular Dystrophy. It is a hereditary degenerative nerve disease which affects the hands and feet resulting in fatigue and loss of feeling and balance. I was diagnosed when I was 5. I thank God allowed me to have MD because he needed someone to help find a cure. He's chosen me and has led me to a team of doctors that have asked to take a biopsy of muscle and nerve tissue in a "one of a kind" research program which The Muscular Dystrophy Society is sponsoring. They are hoping to determine how they can replace or regenerate the protein that is missing in the cells of all Friedreich's patients. Even if a cure is years away, this study may allow for a medicine that could help me and many others to stop shaking and stop our muscles from weakening anymore.

Not all of my days are stressful because I have the love of my family and many good friends who help me throughout each day. My Mom, Dad and my brother, Hunter, help me squeeze the toothpaste, open the peanut butter jar and button my clothes. My school has allowed me to start my school day one hour later than everyone else and when my friends see me coming up to the door, they hold them open for me. Sometimes it's even a really cute boy which makes my day start off pretty darn good!!! My scooter is sometimes being used by my crazy science teach-

er but she always comes zooming down the hall just in time for me to get to English. My teachers have been wonderful with kind understanding and a willingness to adapt to my special needs. because of my school's support, I am a straight A student. And, if my feelings are hurt by some kids, I have many more good friends that support me in many different ways. Sometimes I think the entire school knows my locker combination because they are always helping me to open it. They help me carry my books, write my lessons for me, copy homework assignments, take notes off the board, stand in the lunch line to get me a chicken patty sandwich and help me make it through a Friday night canteen in the auditorium in one piece!!! god must have really been looking out for me after school because I have the oldest living bus driver in the world who is late every single day. For me, this is a blessing.

I am proud to say I am going on the 8th grade Washington, D.C. trip this June for four days, I plan on attending M.D. Camp for the second years, I help elementary kids to read at our Library's summer program and if she'll hire me again, I'd like to help Mrs. Peterson at our church this summer in the Family Life Ministry office.

So I guess you could say that I'm quite a lucky girl. God has blessed me with a special challenge that lets me look at the world in a lot of different ways. When I grow up I hope to help make the world an easier place to be for all special people. Thank you for listening to me today and I hope you will see people with special needs through different eyes—God's eyes.

[From the Bay Press, April 2001]

ONWARD AND OUTWARD!

AN UPDATE FROM EMILY ROSS

(By Emily Ross)

Two years ago I shared "A Day in The Life of Emily Ross" with our congregation. I was very touched when recently many of you asked how I am doing now that I am in high school and faced with a new set of challenges. I'm proud to say that I am doing well, accepting the challenge Heaven has asked of me, Muscular Dystrophy is a silent, progressive disease, and Friedreich's Ataxia, the type I have, robs me of the ability to store energy in my cells. I have noticed a loss of touch and hearing, as well as slurred speech over the years, but I've become quite clever at managing my daily activity.

I am now a sophomore at Westlake High School, maintaining a 3.2 grade average, carrying a full class schedule, and even hosting a five-minute broadcast segment called "This Week in Science" through WHBS, our school's television broadcasting system. I am no longer able to walk by myself, so my new leg braces, along with the use of a scooter, help me to my classes. The school purchased a special locker for me that opens with a magnetic key, so I no longer have to worry about combination locks; they even remodeled certain areas to accommodate my scooter. I have full use of the school's elevator and front row seating in all of my classrooms. Some teachers are compassionate and understanding, some strict and unbending, but isn't that the way it is for all students? By evening, my hands are usually too tired to hold a pencil, so someone in my family writes my homework for me as I dictate. My mom is very good at not telling me if the answer I am saying is correct, she just keeps writing no matter what!

Every year, a few students stare and whisper as I drive by in my scooter, but most of the kids have know me since elementary school, and I now fit in almost effortlessly. I have concerns that boys will be judgmental,