

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,

seeing only the wheelchair and not the girl seated in it. I will admit to having days filled with self-pity at not being able to walk, dance, or run but they soon pass when I realize all the things I am capable of and have already accomplished. I actually like going to school because it's something I can manage independently, and I feel comfortable surrounded by my teachers and friends.

I am a bit more cautious, though, in the world outside my high school. I am trying very hard to leave the security of familiar surroundings and make an attempt to be seen at more school and community functions. It took me a long time to learn that if people do not see you at school events, the mall, or the movies (like a normal teenager), then they assume that you do not wish to be included. Many teenagers have never even been close to a wheelchair, or think that because my body is weak then my mind must be also. It is up to me to invite questions from people, to answer their curiosities, to help them feel comfortable—not only around me, but around my equipment, too. I need to let them know that I just wish to be treated like everyone else.

One of my personal challenges this past year was saying yes to a movie and dinner with my friends. It meant not being ashamed to be seen in my wheelchair, which may not sound like a big thing to an adult, but it was a scary first step for me. To help me accomplish this, God blessed me with two guardian angels, my friends Stephanie and Britney. Stephanie, my best friend for six years now, proudly pushes me through the mail, across parking lots, or up to jewelry counters. We have an understanding that when she pushes, I hold all our packages, frozen cokes, and purses. Stephanie has always treated me with dignity, great compassion, and honesty, and I thank her for that. Britney is a girl I met at Muscular Dystrophy Camp last summer, and she is fighting her own form of the disease. She is also a sophomore living in Alliance. Having someone to talk to who truly knows how you are feeling because they are going through the same experience is a one-in-a-lifetime gift from Heaven. The two of us together at the mall is a team adventure with both of us counting on the other for balance or for a steady hand when trying on a new lipstick.

God has also given me a wonderful family, who has taught me how lucky I am. I can tell my mom anything, and I do. She always listens when I need to vent my frustrations. She makes the jerking muscles relax the fevers subside, the exhaustion feel comfortable. She makes me laugh. My dad brings breakfast upstairs to me every day before school so I don't waste any energy going downstairs into the kitchen. He has remodeled, rewired, and redesigned our entire house to accommodate me and carries my wheelchair up and down the steps hundreds of times per week. He makes me safe. My brother has done off to college this past year, and surprisingly, I miss him! He used to look out for me when we were in high school together, and he still calls to see if I need anything. He makes me normal. My dog, Oats, is always glad to see me and cares about me in a dog sort of way. Somehow she can predict when I'm going to fall and has actually sacrificed herself as a sort of cushion between me and the floor. She follows me from room to room, stares up at me adoringly and loves to eat potato chips while I tell her about my day.

So I'm learning with daily "help me get through this" prayers, to look at the world with the following in mind: If I need to create solutions to my unique challenges during my teenage years, then I also need to actually "get out there" to experience them.

Considering all the things I hope to accomplish within the next few years, I'm going to need all the "out there" experience I can muster! You see, I plan on driving within the next year, which will mean special testing, special adaptive devices, and, hopefully, a ramped van. My biggest dream is to have my own motorized wheelchair within the next year and enjoy the freedom to wheel around unassisted. The grandest of all will be attending college upon graduation from high school.

With the continued support from everyone around me and God's graceful hands holding me up, I will write to you again a few years from now with news of my adventures on a campus somewhere, running for class president.

TO HONOR THE TORREZ FAMILY  
AS RECIPIENTS OF THE 2001 ARIZONA  
HISPANIC CHAMBER OF  
COMMERCE ENTREPRENEURS OF  
THE YEAR AWARD.

HON. ED PASTOR

OF ARIZONA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, May 22, 2001*

Mr. PASTOR. Mr. Speaker, today I rise before you to pay tribute to not one person, but an entire family in my district which has established itself as a beacon of accomplishment. The family I speak of is the Torrez Family, owners of the great Azteca Plaza in Phoenix.

The Torrezes have been a benevolent part of our community for over 56 years. Adolfo Torrez and the late Kay Anne Torrez set a standard not only with their commitment to their business and customers, but also with the values and ethics that they instilled in their children Raoul, Royna, and Gregory.

Azteca Café was first started by Adolfo and Kay Torrez in 1946. Soon they added a small bar which they named Azteca Bar. These two businesses flourished at the corner of Third and Washington streets. Over the next few years, the Torrez family would expand their property and their businesses to include a flower shop, furniture store, bridal store, formal clothing retailer, and even a dry cleaning company.

The three Torrez children would work side by side with their parents learning from their versatility and passion for hard work. Today Gregory, Raoul, and Royna, continue in their parents footsteps, managing Azteca Plaza and are proving to their community that they are as ethical and driven as their parents, and as compassionate and caring for their community.

The Torrez family recently received the 2001 Arizona Hispanic Chamber of Commerce Entrepreneurs of the Year Award for their work not only as business people, but for their contributions to society.

Mr. Speaker and all my colleagues, please join me today in paying respect to this incredible family, my friends, the Torrezes of Phoenix.

UNIVERSAL DECLARATION OF  
PUPIL RIGHTS

HON. MAURICE D. HINCHEY

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, May 22, 2001*

Mr. HINCHEY. Mr. Speaker, a group of students from Kingston, New York have spent a good part of the past couple of years working with a students from St. Petersburg, Russia to draft a document that catalogs a set of universal rights of students. The program from which they are working is administered by the Center for Civic Education, which promotes worldwide community participation.

The students in my district have been communicating with the students in St. Petersburg mostly by Internet, but have had personal exchanges as well, both in Russia and in New York. In comparing their educational stories, the students found that they shared similar experiences and held common opinions about problems that young people were faced with at either ends of the world. They decided it was time to document certain rights that they believed to be applicable to students around the world. The end result is the Universal Declaration of Pupil Rights.

The students will soon be meeting with representatives of the United Nations to present their document. In recognition of the efforts that were put into creating this important document and because I firmly believe that all young people should be afforded certain rights that guarantee an appropriate education, I would like to take this opportunity, Mr. Speaker, to submit the Universal Declaration of Pupil Rights in the Record so that it may receive an appropriate level of attention.

UNIVERSAL DECLARATION OF PUPIL RIGHTS

PREAMBLE

Recognizing the fact that educational institutions are necessary to prepare pupils to become positive, confident, and efficient members of society,

Taking in due account the importance for the child to receive education in a manner conducive to the child's harmonious development,

Bearing in mind that pupils are to be taught in the spirit of the ideals proclaimed by the United Nations and in particular in the spirit of peace, dignity, tolerance, freedom, equality, and solidarity,

Considering the fact that the opportunity to receive better education will help countries better uphold their obligations under the Charter of the United Nations, thus promoting universal respect for human rights and freedoms,

Recognizing past indifference to and disrespect for pupil rights have resulted in inhumane treatment and aggression towards pupils from persons and nations,

Due to the fact that the school is considered to be a special territory where the child's rights are not applicable, resulting in the regular violation of the rights already established in other United Nations documents,

Understanding that the enumeration in the Declaration shall not be construed to deny or disparage other rights retained by the people,

The UN General Assembly proclaims this Declaration of the pupil's rights as a standard of achievement for all peoples and all nations in order to secure the pupil's rights and freedoms at school and in its territory.