

Mr. Chairman and Members of the Committee, on behalf of the National Neurofibromatosis Foundation, as well as the thousands of children and adults with NF, I thank you and my Allison thanks you.

EXTENDED TESTIMONY OF DR. FRED L.
MATHEWS
APRIL 29, 1999

I am pleased and proud that NF research has been pointed out to be a model for "Managing Science." It represents an effective partnership between public agencies, most notably the U.S. Congress and the National Institutes of Health, private organizations and the National Neurofibromatosis Foundation and scientists and clinical researchers in the field who have achieved their progress by consensus and by collaborating to a remarkable degree. To use the vernacular, NF research has given a "good bang for the buck" to all who have invested in it.

NF research has significant potential for other very large patient populations. Since the NF genes have been implicated in the signaling process that determines cell growth and cell differentiation, NF research also has great promise for the tens of millions of Americans with malignancies.

NF also causes learning disabilities at about five to six times the frequency found in the general population. Work in that aspect of NF research therefore has considerable potential for the estimated 30 million Americans who are learning disabled.

Given the wide variety of symptoms of NF, I understand that you Mr. Chairman and the Committee have urged those involved in NF research to foster collaborative efforts between and among the various initiatives at the NIH under whose purview these manifestations fall. Peter Bellermand, President of the National NF Foundation has informed me that these efforts are taking place and that "Cross-Institute" activities are a reality.

NF has the attention at the highest level of the NIH beginning with the Director Dr. Varmus. It extends to the Institute heads, especially Dr. Gerald Fischbach at NINDS and to Dr. Richard Klausner at the National Cancer Institute. These progressive officers work at continuing the cross-institute efforts, participate in scientific meetings of NF, and advise other funding agencies to avoid duplication of funding.

NF has been a success story for research for all who have invested in it. True success will, however, come only when a cure is found and real people like my granddaughter can look forward to happy lives, free of NF's terrible consequences. We now have to go the next hard miles. Researchers now stand ready to translate basic scientific knowledge into clinical application. The next agenda includes continued work in basic research, starting comprehensive natural history studies for NF and beginning the all important process of clinical trials with innovative approaches. We all pray that this will lead to an effective treatment for NF.

In closing, I would be remiss if I did not thank my Congressman Fred Upton and his staff person Jane Williams for their very special help and support. We are also very appreciative of the longtime support Congressman Murtha has given NF funding. And a special thanks to you, Chairman Porter, who in 1995 took time from your busy schedule to meet personally with Peter Bellermand and me so that we could tell you of the urgent need for accelerated NF funding. Your ongoing support since then has been tremendously helpful. To the members of this Com-

EXTENSIONS OF REMARKS

mittee who have supported us in this critical effort, we also offer another thank you.

COMMENDING BRIGHAM YOUNG UNIVERSITY

HON. CHRIS CANNON

OF UTAH

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. CANNON. Mr. Speaker, I rise to commend the efforts of Brigham Young University in Provo, Utah, in their unending journey to better relations around the world, Brigham Young University in Provo, UT sends various groups from their Performing Arts department throughout the world to better the University's ties, which in turn improves U.S. foreign relations.

On May 18th, BYU's Young Ambassadors, Ballroom Dance team, and Folk Dance Ensemble returned from a tour of the South Pacific commemorating the 20th anniversary of their first visit to China.

Throughout the past twenty years, BYU has established a name for itself in China and is currently very well regarded by its people. I am very proud to represent the students and faculty members of BYU. They are a model to us all as we work to create a global society of culture, heritage and peace.

INTRODUCTION OF THE PUBLIC APPEALS PARITY ACT

HON. JAMES V. HANSEN

OF UTAH

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. HANSEN. Mr. Speaker, I am very pleased to introduce the Public Appeals Parity Act of 1999. This Act is needed so that the general public, who have legitimate interests in federal land management decisions, has an avenue to appeal certain decisions made by the National Park Service and the United States Fish and Wildlife Service. Currently, no such appeals system exists within these two federal agencies and the public's only recourse for relief is through the court system.

The idea of an internal agency appeal system is not new. Right now, two other primary federal land management agencies, the United States Forest Service and the Bureau of Land Management have an administrative process whereby the public can appeal certain decisions in regard to land management decisions made by these agencies. This Act would initiate a similar administrative appeal process for the public in regard to decisions made by the National Park Service and the United States Fish and Wildlife Service. The Secretary of the Interior would be directed to establish procedures for an appeals process for the Park Service and the Fish and Wildlife Service which will afford the public, prior to the implementation of the project, activity, or plan, an opportunity to appeal decisions made by these agencies in regard to land and resource management decisions which occur in accordance with the National Environmental Policy Act.

May 19, 1999

The regulations developed by the Secretary of the Interior per this Act would mirror those already established for the U.S. Forest Service and would include such things as the type of decisions that may be appealed, who may appeal decisions, the procedures that apply to appealing the decision, and other important steps which the public could follow.

This Act is fair, is not precedent setting, and levels the playing field so that the public has an avenue to appeal decisions made by federal agencies rather than to take them to court. I urge my colleagues to cosponsor and support the Public Appeals Parity Act of 1999.

BRETT SHARPE NAMED ALL- AMERICAN SCHOLAR AND UNITED STATES NATIONAL AWARD IN LEADERSHIP AND SERVICE

HON. BOB SCHAFFER

OF COLORADO

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. SCHAFFER. Mr. Speaker, today I rise to commend an outstanding Colorado high school student and leader. This Spring, Brett Sharpe of Haxtun High School in Haxtun, Colorado, was named an All-American Scholar and a United States National Award in Leadership and Service.

The United States Achievement Academy presents the All-American Scholar Award to those students demonstrating exceptional academic discipline. Scholars must receive a grade-point average of 3.3 or higher and be selected by a school instructor or counselor.

The National Award in Leadership and Service is presented only to a select group of students nationwide. Recipients must demonstrate outstanding scholastics, leadership and student service throughout their high school years.

Mr. Speaker, it is my privilege to congratulate Brett Sharpe for his truly remarkable scholastic, service, and leadership abilities. With confidence, I look forward to his future contributions in America.

A TRIBUTE TO MEMBERS OF THE GREENPORT FIRE DEPARTMENT FOR 50 YEARS OF SERVICE

HON. MICHAEL P. FORBES

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. FORBES. Mr. Speaker, I rise today in this hallowed chamber to pay tribute to three members of the Star Hose Co. #3 of the Greenport Fire Department and to join the volunteer firefighters, emergency medical personnel and grateful people of this Long Island community as they celebrate these brave men for their 50 years of volunteer service.

I would like to tell my colleagues about Greenport, a special place where neighbors look out for neighbors and every resident possesses a special pride in their hometown. In a service that exemplifies selfless heroism, the