

THE 1999 POLICE UNITY TOUR,  
COUNTY OF MORRIS, NEW JERSEY  
TO WASHINGTON, DC

**HON. RODNEY P. FRELINGHUYSEN**

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. FRELINGHUYSEN. Mr. Speaker, I rise today to commend the participants of the 1999 Policy Unity Tour on the successful completion of their tour and for their donation of close to \$54,000 to the National Law Enforcement Officers Memorial this year.

On Saturday, May 8th I had the pleasure of participating in the ceremonies to send off the 55 participants as they began the long bicycle journey from Madison, New Jersey to the National Law Enforcement Officers Memorial in Washington, DC in an effort to raise funds for the memorial. The memorial was established by an Act of Congress in October, 1984.

The Police Unity Tour was the brainchild of two Madison and Florham Park police officers who organized the first bike tour three years ago: Frank Wulff and Patrick Montuore. Mr. Speaker, I would like to list each of the participants for the official record.

Frank Wulff	Michael Francis
Ed Lincoln	Dave Barber
Jane Recktenwald	Pat Montuore
Paul Kosakowski	Brian Rabbitt
Steve Carpenter	Carmine DeCaro
Charlie Bryant	Lenny George
Jerry Mantone	Mark Meehan
Constantine Sedares	Dave Tyms
Bill Yirce	Rich Schultz
Steve Ambrose	Mark Stallone
Steve Donnelly	Phil Crosson
Lenny Gigantino	Paul Bogert
Paul Boegershausen	Bill Pollock
Paul Kay	Fred Freem
Rick Staeger	John Sria
John Carter	Bob Barr
Hernandez Thomas	Harry Phillips
Tom Barbella	Ed Mitchko
Tommy Downs	Debbie Baker
Karen Sullivan	Brian Markt
Emma Swearingen	Lou DeMeo
Paul Fortunanto	Marc Hecht
Bob Cimino	Jimmy Waldron
Lee Scarano	Scott Smarsh
Pete Egan	Robert Fortunato
Pete Nienstadt	Bobby Montuore

Two support drivers, Patti Wulff and Jennifer Montuore assisted these riders.

I was present at the Law Enforcement Officers Memorial on Tuesday, May 11, when the participants reached their destination and were greeted by friends and family. Participants hailed from police forces in Madison, Chatham, Millburn, Livingston, Fair Lawn, West Orange, Union, Woodbridge, Maplewood, Denville, Margate, Florham Park, Morristown, Berkeley Heights, Franklin Township, Newark, Caldwell, NJIT, the NJ State Police, and the Essex County Prosecutors Office.

Mr. Speaker, over the last three years, the Police Unity Tour has raised over \$122,000 for the memorial, making it the top sponsor in the Nation. The effort of these men and women who rode their bikes from New Jersey to Washington, DC to raise money for the National Law Enforcement Officers Memorial pays tribute to those who put their lives on the line everyday—and those who have paid with

**EXTENSIONS OF REMARKS**

their lives—so that our streets are safer, and our families more secure. I ask my colleagues to join me in congratulating them on their dedication and in wishing them success for many years to come.

**A WORRIED GRANDFATHER**

**HON. FRED UPTON**

OF MICHIGAN

IN THE HOUSE OF REPRESENTATIVES

Wednesday, May 19, 1999

Mr. UPTON. Mr. Speaker, I recently had the pleasure of introducing one of my constituents, Dr. Fred Mathews, at a hearing of the Subcommittee on Labor, Health and Human Services, and Education Appropriations. Dr. Mathews had been invited to speak on behalf of the Neurofibromatosis Foundation in support of increased funding for this often devastating disease.

It is a privilege to know Dr. Mathews and count him as a friend. In addition to his 47 years of practicing optometry in Dowagiac, MI, he has devoted his talents and energy to improving the quality of life in his community and expanding education opportunities and excellence in our state. When he learned that his lovely young granddaughter, Allison, was afflicted with neurofibromatosis, he took on the most important fight of his life—the fight for a cure for this disease for Allison and for the at least 100,000 others who have this neurological disorder. His testimony before the subcommittee was eloquent, and I would like today to submit it to the CONGRESSIONAL RECORD so that others may see the urgency of the need to find a cure. Dr. Mathews' testimony follows:

**A WORRIED GRANDFATHER**

Thank you Congressman Upton and thank you Mr. Chairman and members of the Committee for allowing me to testify. I am Fred Mathews, a constituent of Congressman Upton from Southwestern Michigan.

I am here today because my beautiful granddaughter Allison has Neurofibromatosis, a not so rare and devastating genetic disorder. In 1994 Allison was four years old when I first asked her parents about some spots on her skin. I had assumed these were simple birthmarks. This was the first time her parents shared with me that she had Neurofibromatosis, or abbreviated called NF. Up until then we had been shielded from the terrible truth.

I am an optometrist in a small town in southwest Michigan. I have practiced there for 47 years. Even though I am not a medical doctor I have better than a layman's knowledge of general medical problems. However, I had never heard of NF.

Immediately I began to research NF. I called research centers. I called the National Institutes of Health. I linked up with the National Neurofibromatosis Foundation. My testimony today has the blessing of that fine organization.

There is no way to describe the despair and hopelessness that families experience when faced with the fact that a child or grandchild has an incurable disease. My research left my wife and me panic-stricken. Here is a short version of what my research revealed.

NF is the most common neurological disorder caused by a single gene. At least 100,000 Americans have NF. This makes NF more

prevalent than Cystic Fibrosis, hereditary muscular dystrophy, Huntington's Disease and Tay Sachs combined.

NF causes tumors to grow anywhere on or in the body. NF can lead to disfigurement, blindness, deafness, skeletal abnormalities, dermal, brain and spinal tumors, loss of limbs, malignancies and learning disabilities. The terrible disfigurement is why NF has erroneously been confused with the so called "elephant man" disease.

NF affects both genders, all races and ethnic groups equally. NF research in 1994 (when I first learned of my granddaughter's problem) had begun about 9 years earlier by the National NF Foundation. The gene causing NF had just been discovered.

My personal research did reveal some good news for my family and me. My granddaughter has the NF1 gene rather than the NF2 gene. With the NF2 gene the tumors and other bizarre disorders can start soon after birth. NF1 however, which my granddaughter has, sometimes does not manifest serious problems until puberty or beyond.

I also learned from Peter Bellermann, President of the National NF Foundation, and the world's greatest crusader to find a cure for NF, that researchers were hopeful of finding a cure in 10-15 years. Simple mathematics told me that this might be too late for my granddaughter and thousands of kids like her who were living with this time bomb.

I also learned that researchers believed that the projected time for a cure could possibly be cut in half if more research dollars were available.

I am grateful that this Committee and the Congress did respond to our plea and did appropriate significant new funds for NF research. In 1995 Chairman Porter also added language to the Appropriations Bill which expressed to NIH the commitment of this Committee for accelerated NF research.

Because of this Committee, the Congress, the NIH, the National NF Foundation and many dedicated researchers, our Allison who is now 9 years old, has a chance to avoid the ravages of NF. We are thankful and hopeful but still very apprehensive. The time clock is still running rapidly. Research has been extremely successful but has a long way to go to find a cure.

The National NF Foundation and I urge that the language which has been in the Appropriations Bill for the past four years, expressing this Committee's commitment to NF research, be in the FY 2000 bill.

I am grateful for the courtesy members of this committee and other members of congress and their staffs have shown Peter Bellermann and me these past few years. Some of you have my granddaughter's picture in your office.

In my opinion, no expenditure by the Federal Government is more rewarding, more needed, and more appropriate than research for dread diseases including NF. As a grandfather of a little girl with one of these dread diseases, I feel anxiety, frustration but also hope knowing that the timetable for a cure of NF and other diseases is almost solely dependent on the willingness of the Congress to recognize medical research as its #1 priority. That is why Mr. Chairman we strongly support a significant increase in funding for the National Institutes of Health medical research. With the NIH as the quarterback, the greatest hope we have for finding a cure for NF and all other dread diseases, lies with this Committee and the NIH.

Since my allotted time is up Mr. Chairman, I respectfully request permission to extend my remarks in the written testimony I will leave with the Committee.