

But there is hope for these families. We are in a time of tremendous opportunity and hope in medical research. In the 1950s, children diagnosed with cystic fibrosis usually did not live long enough to enter kindergarten. Back then, there were no drugs for people with cystic fibrosis. Today, through advances in medical research, four respiratory drugs have been brought to market and the median age of survival is about 37 years.

These advances would not have been made without the important clinical research conducted by dedicated doctors and scientists from all around the world. In fact, there are more than 30 cystic fibrosis therapies currently in some stage of clinical trial research. Unfortunately, because cystic fibrosis affects a small population, many of these trials are having difficulties recruiting patients.

The Improving Access to Clinical Trials Act is designed to increase access to clinical trials for patients of rare diseases, like cystic fibrosis, by modifying Supplemental Security Income (SSI) eligibility rules. In accordance with established ethical standards, many clinical trials offer compensation for patient participation. Current eligibility rules for SSI count such compensation as income, making some individuals suffering from rare diseases ineligible for SSI benefits because compensation for participation in the trial would put their income over the SSI eligibility threshold. This forces patients to choose between participating in important clinical trials and keeping their SSI benefits—a cruel choice no one should ever have to make.

Our bill will encourage patients suffering from rare diseases to participate in promising clinical research that may lead to cures, better treatments, and ultimately, saved lives, without having to worry that they could lose the SSI benefits they depend on.

You know, they say that the most powerful four-letter word in the English language is HOPE.

Hope . . . that we can raise awareness of the families struggling with cystic fibrosis and other rare diseases.

Hope . . . that, through research, we will find better treatments and ultimately a cure.

Hope . . . that our children will have to turn to the history books to learn what cystic fibrosis was.

This bill will give hope to more patients who suffer from CF that they can access innovative therapies that could some day cure them of this dreadful disease.

I urge my colleagues to cosponsor and support this legislation.

EARMARK DECLARATION

HON. PHIL GINGREY

OF GEORGIA

IN THE HOUSE OF REPRESENTATIVES

Monday, June 15, 2009

Mr. GINGREY of Georgia. Madam Speaker, pursuant to the Republican Leadership standards on earmarks as well as in accordance with Clause 9 of Rule XXI, I am submitting the following information for publication in the CONGRESSIONAL RECORD regarding earmarks I received as part of H.R. 2847, the Commerce, Justice, Science, and Related Agencies Act, 2010.

Requesting Member: Congressman PHIL GINGREY

Bill Number: H.R. 2847

Account: Department of Justice; Community Oriented Policing Services (COPS) Law Enforcement Technology

Legal Name of Requesting Entity: Cobb County (GA) Government

Address of Requesting Entity: 100 Cherokee St., Marietta, GA 30090

Description of Request: The project furthers the National Emergency Communications Plan Strategic goal of 2010, 2011, and 2013. Protecting the health, safety, and welfare of its citizens is a top priority for the local government. Cobb County is a key player in developing a regional interoperable communications system that covers 11 counties from Metro Atlanta to Alabama. The linking of like radio systems will expand coverage, coordinate responses, improve communication, and decrease response time in the event of natural or man-made disasters, including terrorism.

Cobb County continues to plan for, create, and promote communications interoperability. This fact is evident with the acquisition and installation of Homeland Security funded interoperability switch for Project 25 public safety radio systems' participation and connectivity to the Urban Area Security Initiative (UASI) interoperable communication system, working groups and governing body; intergovernmental cooperation with the City of Douglasville and the West Area Regional Radio System (WARRS); and participation and leadership in All Hazards Area 7 Communications Subcommittee for the State of Georgia.

This \$1,000,000 added to H.R. 2847 will be used in its entirety for the purchase of the necessary software, hardware, and microwave equipment to connect Project 25 radio systems in Forsyth and Cobb County to establish regional connectivity. These funds will be used to establish microwave connectivity, link systems together, and upgrade the radio system's operating platform so that all systems are functioning at the same level.

Specifically, the Fiscal Year 2010 will consist of the following budget items: Operating System Equipment and Software (\$400,000), Microwave Equipment (\$400,000), and Engineering and Installation Services (\$200,000).

Requesting Member: Congressman PHIL GINGREY

Bill Number: H.R. 2847

Account: Department of Justice; Office of Justice Programs (OJP) Byrne Discretionary Grants

Legal Name of Requesting Entity: University of West Georgia

Address of Requesting Entity: 1601 Maple St., Carrollton, GA 30118

Description of request: Major incidents, whether they result from natural phenomena or are a result of criminal behavior, have devastating effects on learning and academic achievement. Federal studies show that emergency plans in many school districts remain unpracticed and are outside National Incident Management System (NIMS) guidelines. Furthermore, less than one third of school districts in the nation include any procedure for continuation of instruction in the event of extended school closure. This initiative would address these shortcomings and prescribe practiced solutions.

The \$250,000 included in H.R. 2847 will allow the University of West Georgia to work with K-12 schools in surrounding high crime neighborhoods to prevent and respond to inci-

dents of crime in these schools. In particular, the University will work with schools such as Bremen High School, Paulding County Middle School, Chattooga High School, and Polk County High School.

The establishment of an emergency response capability will help K-12 schools and other colleges and universities in many ways. It will aid state agency, school district, and local school personnel develop emergency preparedness plans that will help insure the safety of an otherwise defenseless population. This funding will be used to (1) provide technical assistance to support schools and districts in developing comprehensive plans reflective of the all-hazards approach; (2) provide evaluation services to help schools and districts improve already developed plans and to determine the feasibility of partnerships (with first responders) and procedures (evacuation of special needs students) necessary for effective implementation; and (3) assist schools and districts in developing capacity for maintaining continuity of instruction in the event of prolonged school closure.

The Fiscal Year 2010 funds will consist of the following budget items: Project Manager (\$65,000), Equipment (\$46,000), Supplies (\$35,000), Training (\$30,000), Evaluation (\$44,000), and Administration and Accounting (\$30,000).

EARMARK DECLARATION

HON. TIM MURPHY

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

Monday, June 15, 2009

Mr. TIM MURPHY of Pennsylvania. Madam Speaker, pursuant to the Republican Leadership standards on earmarks, I am submitting the following information regarding earmarks I received as part of H.R. 2847, Commerce, Justice, Science, and Related Agencies Act, 2010:

Requesting Member: Congressman TIM MURPHY

Bill Number: H.R. 2847, Commerce, Justice, Science, and Related Agencies Appropriations Act, 2010

Account: Department of Justice; Juvenile Justice

Legal Name of Requesting Entity: Kids Voice

Address of Requesting Entity: 437 Grant Street, Suite 700, Pittsburgh, PA 15219

Amount: \$500,000

Description of Request: The funding would be used to increase their impact in the community and to support programs that are offered to abused and neglected children in Allegheny County.

In addition, KidsVoice seeks to increase its impact by expanding services that will help clients become productive adults, despite the obstacles they face. The funding will expand KidsVoice efforts in assisting foster youth to pursue post-secondary education, job training and employment. I certify that this project does not have a direct and foreseeable effect on the pecuniary interests of me or my spouse.

I took extreme care to ensure that these projects are well vetted and strongly supported within the community. The KidsVoice appropriation is of particular interest to my district and importance to my constituents.