

2013 MDCA Reauthorization - House

Advocacy Call-in Points

Be sure to edit anything in red with your information

PPMD ADVOCATE:

Hi, my name is _____. I'm a constituent from _____(home town)_____. Could I please speak to the Representative's Legislative Assistant who handles health care?

CONGRESSIONAL OFFICE:

Let me see if XXXX is available. May I ask what you are calling about?

PPMD ADVOCATE:

Sure, I'm the parent (relative, friend etc) of a child with Duchenne Muscular Dystrophy. I would like to discuss what Congress is working on for Muscular Dystrophy.

CONGRESSIONAL OFFICE HEALTH LEGISLATIVE ASSISTANT:

Hi, this is XXXX, how can I help you?

PPMD ADVOCATE:

Hi, this is ___(your name)___ from ___(home town)_____. My child (nephew, friend, family member) has Duchenne Muscular Dystrophy. I'm not sure how much you know about Duchenne, but it is the most common fatal genetic disorder diagnosed in childhood. There is no cure.

Thankfully, thanks to Congress, much progress has occurred in recent years. In 2001, Congress enacted the Muscular Dystrophy CARE or MD CARE Act which made Duchenne and Muscular Dystrophy more broadly a priority. This law – which was reauthorized in 2008:

- Enhanced the National Institutes of Health (NIH) commitment to Duchenne and MD research, research that has helped generate multiple potential therapies being tested today;
- Expanded the average lifespan and enhanced the overall quality of life of Duchenne patients by developing and distributing standards of care; and
- Coordinated the government's efforts to address Muscular Dystrophy to ensure every dollar is well spent.

Parents from around the country are visiting Capitol Hill to ask Members to continue this amazing progress by cosponsoring the MD CARE Reauthorization Act. I would like to ask Rep. _____ to cosponsor The MD CARE Reauthorization Act, H.R. 594, by contacting the office of Rep. Michael Burgess of Texas or Rep. Eliot Engel of New York.

Reauthorizing the MD CARE Act will enable the continuation of this vital work. Specifically, it will sustain MD research at the NIH and ensure this work is focusing on areas of greatest need, ensure even stronger

coordination and collaboration by government agencies and update existing care standards and develop standards where gaps exist.

Can my family and I count on the Representative to join this bi-partisan effort to continue supporting the progress made on muscular dystrophy?

CONGRESSIONAL OFFICE HEALTH LEGISLATIVE ASSISTANT:

I will let the Representative know that we talked and make sure that he/she takes a look at the bill.

PPMD ADVOCATE: Thanks for your time. I hope the Representative will consider cosponsoring the MD CARE Reauthorization Act. Can I get your email so that I can follow up with you on this issue? Thanks very much!

