

## **Roadmap to Awareness: Initiating Legislation for Mitochondrial Disease**

- 1. Manning the Point**
- 2. Forming Alliances (sponsors & Friends)**
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This paper is intended to give some motivation and direction to others who wish to initiate state-level awareness legislation for mitochondrial disease patients, parents, and professionals. It is based on experience in Massachusetts with The Mitochondrial Disease Action Committee ([www.mitoaction.org](http://www.mitoaction.org)). In all cases the week that has been chosen for National Mitochondrial Disease Awareness is the third week of September. Text for an Awareness week bill is available on [www.mitoaction.org](http://www.mitoaction.org).

This document is not intended as a full 'soup to nuts' guide to achieving legislation, but a roadmap to give some general guidance toward achieving state-level laws for awareness and support of mitochondrial disease. Note that some states do not approve formal legislation for awareness weeks, in those cases you should seek to obtain a proclamation from either the state house of representatives or the Governor's office. In either case, the process is similar.

### **1. Manning the Point**

It is difficult to say how much of a commitment that an awareness week will take. It may go easily, as it has for some. If a more senior legislator really grabs on to the issue and has enough staff to see it through, most of the hard work will be done for you. In other cases there may be major legislative initiatives going on that will push the awareness week down in priority and you will need to continue over months (or years) until the final bill is passed. In Massachusetts, we have experienced a mix of these two scenarios.

### **2. Forming Alliances (Sponsors, Family & Friends)**

One of the first steps toward getting the bill approved in your state would be to organize a list of families and supporters in your state (email is fast, easy, and cheapest). Reach out to your local media – radio, newspaper or TV station - that is willing to do a story on mitochondrial disease and its effect on a family. Anyone dealing with mitochondrial disease has a compelling story to tell. Giving information that has already been checked out by a reporter gives some solid recognition to give to a state legislator.

### 3. Stating your case

For everyone you contact about the bill, you will need to retell your story. Imagine the only contact you have is going to be a brief elevator ride with this person. It should follow five guidelines:

- *Grab their Attention*  
Open by making a statement or asking a question that makes them want to hear more.
- *Be Brief*  
You should be able to get it out in 60 seconds or less (about 150-200 words). While this does not seem like much, you can put a lot of info in that time. Your goal is not to give them 100% information, but to engage them and get them asking you for more information.
- *Keep it Simple*  
Imagine you are talking to an older relative with no medical background. Don't talk down to them, but use clear language.
- *Be Passionate*  
Show your energy and dedication to them. Be careful to be zealous, but not overly emotional - maintain your composure.
- *Make a Request*  
Close by letting them know what you expect from them

An example:

I have a wife and 5 children with a mitochondrial disease. This is a degenerative disease that has taken my 15 year olds life and caused him to lose mobility, muscle mass, urinary function, many other organ functions and brain functions.. This rare, progressive disease is often not diagnosed until many other illnesses are ruled out. It is a disease of energy that has a great impact on quality of life for patients, and can be fatal. Symptoms include severe fatigue, metabolic issues, GI system failure, and seizures, among others. One of my goals is to gain more awareness of the disease. Awareness helps by getting people involved in improving treatments and ultimately finding a cure for this disease. Because it is a rare disease, even many doctors are not informed about mitochondrial disease. It would be a great step forward if a Mitochondrial Disease Awareness week could be observed. I need your help to do this. Can you please support a bill that would proclaim the third week of September as Mitochondrial Disease Awareness Week in the State?

### 4. Following Through

Now comes the tough part – making sure everything is completed! You will need to have repeated contact with your state-level sponsor until the final document is in hand. This includes continuing to have other people talk to their legislators and friends to create a larger network to accomplish the goal. Then once it is done, there is more to do:

- Contact local media to let them know what you have accomplished
- Let others in the Mito community know – send an email to to us at MitoAction, and also include your child’s doctors – both instate and out of state.
- Set up a celebration of your accomplishments – you deserve it! What better way to spread awareness than to invite friends, neighbors and relatives to an awareness week celebration (don’t forget to invite the state representative who helped, your mayor or other local leaders, and representatives from any agencies in the area – and the media).
- Plan awareness week events. These could be as simple as handing out info sheets about Mitochondrial disease, or as big as a fundraising walk. Check out [www.mitoaction.org/fundraising-ideas](http://www.mitoaction.org/fundraising-ideas) for awareness event ideas.

## **5. Next Steps**

You have put together a lot of effort and organized many people to get this done. Whether it was 5 or 500 - make sure you keep in touch with everyone. You have established a network that can be mobilized again. There are many other ways that legislative effort can help the mitochondrial disease community, such as mandated coverage for formulas or training for in-home nursing care. Perhaps there are already bills being considered in your state that are of importance to patients.

This roadmap document gives a general framework for obtaining awareness legislation in your state. These steps could be adapted to other legislative efforts as well. Together, we will make MITO a cause supported by many!