



## **ACTION ALERT!**

House Bill 977, An Act Providing for Care and Treatment for Persons with Mitochondrial Disease, is currently before the Joint Committee on Financial Services in the Massachusetts Legislature. HB 977 would help families with private health insurance obtain reimbursement for components of the Mito Cocktail not currently covered by their prescription drug benefit plan.

**We need as many individuals as possible to contact the members of the Joint Committee on Financial Services to express their support for HB 977 no later than Tuesday, March 18th.**

Each year, families in Massachusetts with loved ones affected by mitochondrial disease must make difficult choices about how to cover the cost of the Mito Cocktail. Currently the only form of treatment available for mitochondrial disease, the Mito Cocktail is by and large not covered by private insurance in Massachusetts.

MitoAction has been championing legislation to mandate insurance coverage for the Mito Cocktail for the past seven years. Last Wednesday, the Joint Committee on Financial Services held a hearing on HB 977 during which mitochondrial disease patients, physicians, pharmacists and families testified in support of the bill. **Our community now needs to urge the Joint Committee to vote the bill out of committee by March 19<sup>th</sup> with a favorable report or the bill will fail at this time.**

**Even if this issue has not directly affected your family, we need your help.** Using the email addresses below, please take a few minutes to (1) send an email to the Chairmen of the Joint Committee on Financial Services and copy the committee members and/or (2) call each of the committee members. Please share this information with friends and family members and urge them to contact the Joint Committee members as well. Every voice will make a difference!

**Please try to draft a unique email as legislators tend to disregard form emails.** It may be as simple as "I urge you to support HB 977, which is very important to the citizens of Massachusetts." Please consider using some of the talking points listed below in your email as well. If you have a child, family member or friend affected by one of these disorders, **please consider including your personal story in the email.**

### **Talking Points**

- The Mito Cocktail currently is the only treatment for mitochondrial disease and is comprised of vitamins and co-factors which help to improve symptoms and slow

the disease progression

- Mitochondrial disease is rare and the numbers are few, but the treatment is very important to those patients
- The vitamin doses in the Mito Cocktail far exceed the typical recommended daily allowance, leading to higher costs for patients
- Vitamins and co-factors often need to be prepared by a compounding pharmacy, which is typically very expensive
- MassHealth covers these treatments; it's the working families with private health insurance who are squeezed by these costs
- Many patients, including children, forego the treatments due to expense
- The cost/benefit analysis on HB 977 commissioned by the Massachusetts legislature shows that insurance coverage for the Mito Cocktail would increase health insurance premiums by mere pennies.
- Treatment reduces overall health care costs as patients are healthier and require fewer hospitalizations
- HB 977 makes sense for not only the mitochondrial disease patients and their providers, but also for private health insurance companies

### **Legislators to Contact**

To contact the legislators by email, please send a single email addressed to the Chairs of the Joint Committee on Financial Services and copy all of the committee members. **If your legislator is on the Joint Committee, please send an additional email directly to him or her stating that you are a constituent.** Please visit <https://malegislature.gov/People/Search> to confirm the names of your legislators.

### **Joint Committee on Financial Services Email Addresses:**

(Please copy and paste into the to: line)

[Anthony.Petrucelli@masenate.gov](mailto:Anthony.Petrucelli@masenate.gov), [Michael.Costello@mahouse.gov](mailto:Michael.Costello@mahouse.gov)

(Please copy and paste the entire block into the cc: line)

[Christopher.Fallon@mahouse.gov](mailto:Christopher.Fallon@mahouse.gov), [James.Dwyer@mahouse.gov](mailto:James.Dwyer@mahouse.gov),  
[Russell.Holmes@mahouse.gov](mailto:Russell.Holmes@mahouse.gov), [Marjorie.Decker@mahouse.gov](mailto:Marjorie.Decker@mahouse.gov),  
[Donald.Wong@mahouse.gov](mailto:Donald.Wong@mahouse.gov), [Kevin.Murphy@mahouse.gov](mailto:Kevin.Murphy@mahouse.gov),  
[Edward.Coppinger@mahouse.gov](mailto:Edward.Coppinger@mahouse.gov), [John.Lawn@mahouse.gov](mailto:John.Lawn@mahouse.gov),  
[Susan.Gifford@mahouse.gov](mailto:Susan.Gifford@mahouse.gov), [John.Keenan@masenate.gov](mailto:John.Keenan@masenate.gov),  
[Michael.Rodrigues@masenate.gov](mailto:Michael.Rodrigues@masenate.gov), [Kathleen.OConnorIves@masenate.gov](mailto:Kathleen.OConnorIves@masenate.gov),  
[Robert.Hedlund@masenate.gov](mailto:Robert.Hedlund@masenate.gov), [Brian.A.Joyce@masenate.gov](mailto:Brian.A.Joyce@masenate.gov),  
[John.Fernandes@mahouse.gov](mailto:John.Fernandes@mahouse.gov)

Alternatively, telephone calls to the legislators' offices are also very effective. Please use the talking points when communicating with the legislators' office staff and ask for them to vote for moving HB 977 out of committee with a favorable report. Here are the relevant phone numbers:

**Joint Committee on Financial Services Phone Numbers:**

<b>Committee Member</b>	<b>Phone</b>
Anthony W. Petruccelli, Senate Chair	617-722-1634
Michael A. Costello, House Chair	617-722-2220
Christopher G. Fallon	617-722-2430
James J. Dwyer	617-722-2220
Russell E. Holmes	617-722-2220
Marjorie C. Decker	617-722-2430
Donald H. Wong	617-722-2488
Kevin J. Murphy	617-722-2877
Edward F. Coppinger	617-722-2304
John J. Lawn, Jr.	617-722-2304
Susan Williams Gifford	617-722-2976
John F. Keenan	617-722-1494
Michael J. Rodrigues	617-722-1114
Kathleen O'Connor Ives	617-722-1604
Robert L. Hedlund	617-722-1646
Brian A. Joyce, Vice Chair	617-722-1643
John V. Fernandes, Vice Chair	617-722-2220

We appreciate your support of HB 977! Please do not hesitate to contact Christine Cox at [outreach@mitoaction.org](mailto:outreach@mitoaction.org) with any questions you may have.

**Thank you for your important advocacy efforts at this crucial time!**