



*Marcel's Way... Providing those whose lives are touched by Mitochondrial Disorders with information, education, and support.*

## Guidelines for Mito 411 Volunteers

### What is Mito 411?

Mito 411 is a program designed to offer hands-on, “live” support for families by families. It is a free service funded and staffed collaboratively by MitoAction and Marcel’s Way. It is not intended to provide medical opinions or advice. The following guidelines are intended to help you, the volunteer, understand the project and to give options of what to say/do while speaking with a Mito 411 caller.

### How does it work?

- A central toll-free number is publicized as a volunteer support line for people affected by mitochondrial disease. The number is 888-MITO-411
- A recording on 888-MITO-411 prompts callers to leave a detailed message:
  - “Welcome to Mito 411, the toll-free support line for patients and families. This program is collaboratively sponsored by MitoAction and Marcel’s Way. Please leave a detailed message, including your name, phone number, state from which you are calling, and the reason for your call. A volunteer will return your call within 24 hours. Thank you for calling Mito 411, and we look forward to speaking with you and relating to you about mitochondrial disease.”

Calls to the toll-free number are then electronically recorded as a voicemail, which then immediately is sent to the email addresses of that month’s designated volunteers. The voicemail can be played from the email as a .wav file (plays on most computers using Windows Media Player, or another media program). Using email, the volunteers correspond after receiving the message to decide who will return the call, based on volunteer availability and experience that relates to the caller.

### What are my responsibilities as a volunteer?

- You are responsible for fielding calls for one full month which you are assigned.
- You are asked to keep a log of the caller’s name, general question or support need, date and duration of call, and the caller’s email address.
- You are required to complete a brief training by telephone before answering calls with one of our project coordinators.
- We ask you to follow the guidelines below, and ask for help when a caller has issues that are beyond your scope of experience.
- We would like to ask each volunteer to complete an evaluation at the end of the month, to be turned in with the call log.

### What if I can’t answer the calls because I am away from home or I have a family emergency?

- We ask that you choose the month to volunteer during a time when you are not planning a vacation or other anticipated reason to be away from your normal phone number and routine.
- Please return calls within 24 hours and identify yourself when calling as a volunteer from MitoAction or Marcel’s Way for Mito 411.
  - When returning a call, you can choose (depending on your personal long-distance plan) to use a pre-paid calling card (provided by the organization) or just return the call from your home, work or cell phone.
  - Use \*67 to block your personal caller ID when returning the call

- If you are unable to answer calls within 48 hours because of an unexpected circumstance, please contact the volunteer coordinators, **Bob & Judy Coughlan at [mitoctr@earthlink.net](mailto:mitoctr@earthlink.net) or 239-768-2449**, immediately so that a back-up volunteer can take your place.

### Guidelines for speaking with Mito 411 Callers

- When you first answer the call please make sure that the caller understands that you are;
  - A volunteer
  - A family member or patient who also lives with mitochondrial disease
  - Able to offer support and encouragement but not medical advice.
- Before beginning the call, please ask the caller for their full name and email address. Inquire about how they found out about Mito 411 and keep this information in your call log.
- We hope you will be comfortable offering:
  - An opportunity for the caller to talk about their situation
  - Your personal experience
  - Emotional support
  - Any possible resources
  - explanations of programs, ideas or vocabulary
- Do not give medical advice, including:
  - no dosages of medications
  - hydration regimens
  - recommendations of therapies
  - supplement or vitamin doses or regimens
  - recommendations about emergency treatment or consulting a doctor
- If you are asked direct medical questions please respond by:
  - Advising the caller to contact their PCP or pediatrician directly, or to seek immediate medical assistance in the event of an emergency
  - Frame your answers by responding, “My experience has been...but you will want to ask your doctor about your specific situation.”
  - There are also programs such as “ask the Mito doc” through the UMDF
- If you are concerned that the caller is truly in crisis, or would potentially hurt himself or others:
  - Clarify by asking, “Are you saying that you have a plan to hurt yourself, or are you just having a really hard time coping today?”
  - Ask, “Have you ever dealt with these feelings before? Have you ever had professional help for these feelings? What helped you in those difficult situations?”
  - Always remind the caller, “I think your doctor would want to know how you are feeling. Have you talked to him or her? Many people find it helpful to share their feelings with a professional”
- If they are looking for more general information about Mitochondrial disease, or need further crisis referral, you can direct them to the following web resources
  - [www.MitoAction.org](http://www.MitoAction.org)
  - [www.Marcelsway.org](http://www.Marcelsway.org)
  - [www.UMDF.org](http://www.UMDF.org) (“ask the Mito doc”)
  - [www.MDA.org](http://www.MDA.org)
  - [www.Emedicine.com](http://www.Emedicine.com)
  - [www.apa.org](http://www.apa.org) (“Find a psychologist”)
  - [www.socialworkers.org](http://www.socialworkers.org) (“Resources: Find a social worker”)
  - [www.samaritans.org](http://www.samaritans.org) (24/7 suicide/crisis network)

### At the end of the call:

- Send a follow-up email
  - Thank the person for calling
  - Give encouragement; be sincere
  - Ask the caller if other volunteers may contact them
  - Remind the caller to participate in a MitoAction member meeting by phone, as being involved with others can be very therapeutic
- Remember: Don't feel pressured to “solve” the problem – we are here to listen and give support!**

Please complete, sign and return the following page to us before beginning your volunteer month:

c/o Bob & Judy Coughlan

Questions? (239)768-2449

12090 Summergate Circle #101

Ft Myers, FL 33913

[mitoctr@earthlink.net](mailto:mitoctr@earthlink.net)

Name

Address

Email address

Phone number

I, \_\_\_\_\_, have read and agree to follow the above guidelines as a volunteer responder for Mito 411. I have participated in a live telephone training and understand my responsibilities as a volunteer. I am comfortable seeking assistance from the project coordinators at MitoAction or Marcel's Way if I have any questions. In the event that I am unable to return calls as expected, I will contact the volunteer coordinator immediately.

Signed \_\_\_\_\_

Date \_\_\_\_\_