UMDF Mission Statement:
To promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.
United Mitochondrial Disease Foundation

Website: www.umdf.org

Mailing Address: 8085 Saltsburg Rd., Suite 201, Pittsburgh, PA 15239

Phone Number (Toll Free): 1-888-317-8633

Phone Number (local): 412-793-8077

Fax Number: 412-793-6477

Email Address: Connect@umdf.org

Regional Coordinators (as of July 2014)

- Region 2 (Northeast) – Nicole Shanter
  Phone: 412-979-7066  Email: nicole@umdf.org

- Region 3 (Southeast) – Margaret Moore
  Phone: 412-354-1553 - Email: Margaret.Moore@umdf.org

- Region 4 (Great Lakes/Midwest) – Anne Simonsen
  Phone: 651-271-4313 - Email: Anne.Simonsen@umdf.org
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What Is A United Mitochondrial Disease Foundation Ambassador?

There are two major roles for Ambassadors – Support Ambassador and Support Meeting Ambassador. You are welcome to serve in one or both roles.

As a Support Ambassador for the UMDF, you are a support liaison for The United Mitochondrial Disease Foundation. Based on your Agreement Form, the UMDF will connect you with patients and families. You will provide them with information and resources that have been helpful to you in your journey and offer a sympathetic ear for people seeking support.

As a Support Meeting Ambassador, you are a local connection to your community interested in holding support group meetings for those affected by mitochondrial disease. The focus of the meetings could include offering support, education on mitochondrial disorders, and/or living with a mitochondrial disorder. You may also host activities that help provide support by bringing families together in a social setting.

Upholding the UMDF Mission and serving as a strong advocate of the UMDF is vital in either of the above roles: to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

Ambassadors must renew their commitment annually in order to remain an active UMDF representative. In order to become an Ambassador or renew your commitment, please sign and complete the form (see page 12 & 13) and return it to the UMDF National Office.

NOTE: The UMDF will review your role on a regular basis and make sure it is a good fit for you. The Ambassador or the UMDF may choose not to renew the relationship at either party’s discretion.

The United Mitochondrial Disease Foundation’s Role

- Forward support requests and/or support group meeting interests received through the national office and regional coordinators.
- Provide assistance for any inquiries and/or meetings issues with which you are uncomfortable for any reason.
- For those running or hosting meetings/activities, UMDF will promote the meetings through e-blasts and the UMDF calendar (www.umdf.org/calendar).
- Provide printed materials for education and awareness promotions.

The Ambassador Role

- As a Support Ambassador, respond to support requests forwarded from the national office within 72 hours or notify national that you are not currently available.
- Hold at least one meeting and/or activity within the year you are serving as Support Meeting Ambassador
- Maintain communication with the UMDF National Office.
Guidelines for Communicating with Patients and Parents

General Guidelines for Support Ambassadors (Support Meeting Ambassadors may also find this information helpful):

- Respond to emails and phone calls within three days.
- If you are temporarily unable to respond to phone calls or emails for any reason, let the UMDF office staff know, and we will refer people from your area to another ambassador until you are available.
- Keep a list of local and state resources that you come across (including funding resources, physicians, and state agencies) that may be helpful to others in your area. Many resources are available on the UMDF website at www.umdf.org/resourcguide to get you started.
- Avoid enforcing specific therapies or treatments, even ones that have worked well for you or your family member. Remember that mitochondrial diseases vary widely from patient to patient. What works for one patient might be harmful to another. If you feel compelled to share such information, please note that it is your personal experience and not an official recommendation and/or endorsement from the UMDF.
- Any information that a UMDF patient or contact has shared with you should be treated as confidential and should not be shared outside of UMDF Staff. Do not share with others unless you have received permission to do so.
- All communication should be professional in nature. Do not use pet names or terms of endearment (like sweetie or honey) while acting as a representative of the UMDF.
- As a Support Ambassador, you are not required to meet with UMDF members in your area, but you can do so if you choose. However, if you do meet with another member, make sure that you do so safely! Meet in a public place and bring along a friend or fellow UMDF member.

1) Phone Calls
During a typical phone call, you may be asked a lot of questions about mitochondrial disease. If you do not know the answers to any questions, do not feel intimidated. Share what you know, and refer callers to the UMDF national office with any questions you cannot answer. Remember the following tips during phone calls:

a) Make sure to get all contact information (mailing address, phone number, and email address) so that you can keep in touch with the person (as needed). Please ask them to pass on their information to national office so that they can receive support information and meeting activities in their area.

b) If a caller makes you feel uncomfortable, if you do not know the answer to a question, or if you feel like the caller needs more support than you can provide, get their phone number, and have the UMDF Member Services staff get back to them.

c) For answers to questions that are commonly asked by mito patients, see the Frequently Asked Questions in the appendix.

2) Emails
When the UMDF office receives an inquiry from a patient/family through the UMDF Connect Form or by phone/email from your area, the Member Services staff will respond by email – providing general information about UMDF and mitochondrial disease. We will also include your name, email address, or phone depending on your preferences. You will be copied on this initial response. You may then email
them to welcome them or wait for them to reach out to you. The Regional Coordinator is also copied on these responses to give them an opportunity to welcome them too.

We ask that you consider the following points when corresponding to people who come to you through the UMDF:

a) A standard email signature will let people know exactly who you are when you send emails on behalf of the UMDF. A good signature will include your name and your UMDF affiliation (“UMDF Ambassador”). If you would like, you can also include information about the individual in your family who is affected by mitochondrial disease in your signature. Please refrain from including information on other affiliations (your job, other organizations you are a part of, etc.) in your email signature you are communicating with someone on behalf of the UMDF. Representing yourself as a UMDF ambassador and as an employee or member of another group may create the mistaken impression that there is an affiliation between the UMDF and the other group or business.

b) If someone asks questions about mitochondrial disease, a good way to answer is to refer them to an appropriate area of the UMDF website. The MitoFIRST handbook (www.umdf.org/mitofirst) and the Mito 101 project (www.umdf.org/mito101) can be especially helpful to newly diagnosed patients and parents. Including links to these documents in your emails is a helpful way to provide information to new contacts.

c) If you are not sure how to respond to an email, forward it to the UMDF office at connect@umdf.org.

d) Please keep in mind that you are representing the UMDF when you respond to the emails that we send to you. We trust you will present a positive view of the United Mitochondrial Disease Foundation. The UMDF is always looking to provide the best services we can to our members. If you have questions or concerns about any of our policies, actions and activities, please contact us so we may address those questions and meet your needs.

Any contact information and/or UMDF mailing lists that you obtain as a UMDF Ambassador cannot be used for any other purpose than UMDF activities and support.
Tips for Planning a Support Group Meeting

Meetings may be educational, supportive, or social. Support Meeting Ambassadors are UMDF representatives and as a strong leader, you will strive to be an effective listener (see page 9 for tips for effective listening).

Things to consider when planning your first Support Group meeting:

- Find a location for the meeting. You want to select a central location with accessible parking and handicap access. Hospitals, libraries, churches, synagogues and community centers are good places to check; usually they are free to Support Groups. Your own physician may help you with this and might be able to get his/her hospital to sponsor the group.
- Medical advice should never be given to any members by any member of the group!
- Contact physicians and health-related professionals that you know who might be able to refer people to the group. These professionals might include hospital social workers, occupational therapists, physical therapists, and nutritionists. Provide them with information about your upcoming meeting.

Publicizing Your Meeting

- Once the location is secured, complete the Education/Support Activity form online at www.umdf.org/activityform. We will post your event on the UMDF Calendar (www.umdf.org/calendar) as well as include it in upcoming e-blasts for your region.
- A list of UMDF members and initial contacts from your area will be generated from our database and a meeting notice will be emailed to all those on the list.
- You may want to contact the local papers, radio stations, and television stations that list or mention meetings/events to have your meeting announced.
- If your meeting will be held at a hospital, check with their Community Relations department about adding it to their hospital calendar.

Meeting Details

- Create an agenda for your meeting. Consider including a speaker who would generate interest and spark attendance at the meeting. Member Services Staff will assist you with this if you wish. It is the experience of the UMDF that a good speaker creates a great first meeting!
- Consider bringing light refreshments (non-alcoholic beverages).
- If arranging childcare, secure qualified care givers and make sure you have the appropriate space.
- Have a sign-in sheet for attendees to place their name, telephone number, address and e-mail address. Email, fax or mail it to the national office within one week of the meeting. A sign in sheet is included in the appendix.
- Make every effort to have someone greet people at the door as they come in to make them feel welcome.
- Start the meeting on time with introductions.
- Make sure you leave time at the end for people to socialize.
- Stick to the agenda. Limit the length of the meeting from one hour to an hour and a half.
- Find out if anyone has interest in volunteering for the UMDF. If so, please let us know and ask them to contact the national office.
You may want to have attendees complete a brief survey to help in planning future meetings. The National Office will survey group attendees from time to time to obtain input for future meetings – not just for your group but for other groups across the U.S.

Consider discussing dates and times for future meetings for the year; social events like a picnic or a holiday party tend to be popular.

**After the Meeting**

- Call or email UMDF National Office Member Services and report on your success!
- Send copies of your sign-in sheets to the National Office. *Any contact information and/or UMDF mailing lists that you obtain as a UMDF Support Meeting Ambassador cannot be used for any other purpose than UMDF activities and support.*
- Let the UMDF office know about your plans for future meetings by completing the support meeting form online at [www.umdf.org/activityform](http://www.umdf.org/activityform). To complete the form you will need to have the date, time and location for your upcoming meeting. If you do not have the details, give us a target date for us to follow-up with you.
Tips for Effective Listening

- Listen now, report later.
  - Report what you heard to someone else later. The act of speaking out loud what you heard and processed inside your head helps you to remember the information. It also provides a way you can identify what was not totally clear about what you heard.
- Learn to want to listen.
  - We must be willing to focus on others when they are speaking. Learn to develop an interest in either the person and/or the topic. Practice concentrating on the speaker’s words and feelings. Practice shutting out distractions, not allowing them to interfere with your listening.
- Be present.
  - Daydreaming is a nice way to take a mental vacation. It provides a comfortable private escape. But it is one of the major barriers to effective listening. Choose to "be present." Focus on the speaker and the message.
- Become a "whole body" listener.
  - To be effective listeners, we must involve our whole body. Not only are our ears tuned in, but so are our eyes, our intellect, and our bodies. Good listeners give nonverbal and verbal signs that they are listening. They sit in an attentive posture; nod in acknowledgement; make good eye contact; convey a positive, encouraging attitude; give feedback.
- Control your emotional "hot buttons."
  - Words, issues, situations, and personalities can be emotional triggers for us. When these issues trigger our "hot buttons," we tend to distort, positively or negatively, the message we are hearing. We may tune out or pre-judge the message and/or the speaker.
- Control distractions.
  - We must control our responses to distractions or they will control us. Distractions affect our ability to listen well because of their variety, novelty, or intensity (e.g., telephone, background noise, unfamiliar accent/vocabulary, lighting, headaches, hunger, fatigue).


TEN STEPS FOR CONTROLLING EMOTIONAL “HOT BUTTONS”

Following is a list of coping skills for preventive maintenance when a "hot button" is activated:

1. Listen attentively without interrupting. Take several deep breaths to help you control your physical reactions.
2. Make a conscious choice about your response. You can get angry, try to solve the problem, or ignore it. Trying to solve the problem is the best way to keep it from happening again.
3.Acknowledge the other person’s feelings. Make it okay for them to feel the way they do.
4. Ask objective questions for clarification. Open-ended questions are useful.
5. Try to see the other person’s point of view. Agree where you can and give feedback about what you are hearing.
6. Stick to the subject. Define your problem and don’t let other issues interfere.
7. Be patient. Problems don't always have immediate solutions. Be patient with the other person - and yourself.
8. Express your point of view. Present your evidence without being adversarial.
9. Explain why. A reasonable explanation can often take the sting out of an emotional issue.
10. Work out a "win-win" plan. Make sure your solution is fair and workable for the people involved.

Social Networking

Social Networking is the newest way for organizations to reach out to their supporters and to provide support and information. The United Mitochondrial Disease Foundation has an official Facebook Group for mitochondrial disease patients and their families to connect with one another and a Facebook Page through which people can get news from the UMDF. Also, join us on Inspire to connect with others online for free at www.inspire.com! “Inspire builds online health and wellness communities for patients and caregivers, in partnership with national patient advocacy organizations, and helps life science organizations connect with these highly engaged populations.”

Ambassadors are encouraged to use social networking and are asked to remember the following guidelines when posting on any UMDF social networking forum:

- **Do not force medical advice or treatment suggestions.** It is okay to say things like, “My child showed some improvement when using CoQ10,” but keep in mind that because all mitochondrial disease patients’ cases can be very different, what works for one patient may not work for another. If another post on a forum asks for treatment recommendations, suggest that they see a known Mito Doc (if you do not know of one in their area, refer them to the UMDF National Office, and we will be glad to give them information.)
- **Avoid personal attacks.** Disagreements should be kept private and not posted on a public forum. Do not publicly insult other patients, parents, doctors, or organizations on any social networking site or public forum. If you have a problem or issue that needs to be addressed by the UMDF, contact us by email at connect@umdf.org or by phone at 1-888-317-UMDF.
- **Follow the Media Best Practices.** Before posting any UMDF information online, be sure to read and follow the UMDF’s Media Best Practices. Guidelines for use of the UMDF logo and the UMDF name can be found at www.umdf.org/mediabestpractices.
- For overall questions regarding the UMDF web site and our social media policy, please visit UMDF’s **Terms of Use** at www.umdf.org/termsofuse.

The following sites have been established by the UMDF National Office:

**Facebook Pages**

**Twitter:** [https://twitter.com/UMDF](https://twitter.com/UMDF)

**Inspire:** [https://www.inspire.com/groups/united-mitochondrial-disease-foundation/](https://www.inspire.com/groups/united-mitochondrial-disease-foundation/) or visit [www.inspire.com](http://www.inspire.com) and search for the UMDF group.
The United Mitochondrial Disease Foundation
Ambassador Agreement

I, ________________ (insert full name), agree to be a United Mitochondrial Disease Foundation Ambassador from ___________ (insert today’s date) through June 30, 2015. I understand that the United Mitochondrial Disease Foundation (UMDF) will make referrals from the national office and/or through the local Regional Coordinator and will publicize my position as an Ambassador through newsletters, the web site, and occasional mailings. This agreement must be renewed annually. Fax completed form to 412-793-6477 or email scanned agreement to connect@umdf.org.

Please select the Ambassador Role(s) that appeals to you.
☐ Support Ambassador – providing support by phone and/or email
☐ Support Meeting Ambassador – providing support by organizing a local support group meeting (or meetings) and/or a social activity (or activities)

As a UMDF Ambassador, I agree to the following:
☒ I agree to be a strong advocate of the UMDF and uphold the UMDF Mission in my role as an Ambassador: to promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families.
☒ I will respond to inquiries in regard to my selected role and will connect potential new members to the National office when appropriate.
☒ I will do my best to respond to support or meeting-related calls/emails within 3 days (with the exception of special circumstances such as illness, vacation, etc.). Even if it is just to say, I received your message and will get back to you as soon as possible.
☒ I will not create or reproduce any materials related to the UMDF without the permission of the UMDF National Office – including any social media entities using the UMDF in the title.
☒ I will keep all member information confidential including, but not limited to, names, telephone numbers, e-mails, and personal information that is shared with me.
☒ I understand that any lists I may receive with UMDF member information is the property of the UMDF and I will not use this information for purposes other than for the operation of UMDF meetings and/or activities.
☒ I will notify the UMDF in a timely manner if I am unable to continue as a UMDF Ambassador.
☒ I will review the guidelines and other support materials provided by the national office to better serve the patients/families in my area.
☒ When training is offered, I will do my best to participate in order to better serve the patients/families in my area.
☒ I will do my best to support any fundraising activities (either through participation and/or through promotional efforts) and will notify the National office of any such events in my area.
☒ I have read and understand the above requirements. You have my permission to provide my contact information to UMDF patients/families in my area based on my selections below.
Please check all that apply. I am willing to connect with those who live...

☐ within the state I am living in  ☐ anywhere within the United States
☐ anywhere within my region  ☐ anywhere outside of the United States.

I am fluent in the following languages...

Check all categories in which you have personal experience and/or are comfortable networking with others:

☐ Parent of Child with Mitochondrial Disease (Age 0-3)
☐ Parent of Child with Mitochondrial Disease (Age 4-7)
☐ Parent of Child with Mitochondrial Disease (Age 7-12)
☐ Teen with Mitochondrial Disease (Age 13-18)
☐ Young Adult with Mitochondrial Disease (Age 18-35)
☐ Adult with Mitochondrial Disease (35+)
☐ Caregiver of Adult with Mitochondrial Disease
☐ Lost a loved one to Mitochondrial Disease
☐ Extended Family Member or Friend

Please feel free to provide the name(s) of your loved one(s), list your relation(s), and his/her age(s) at the time of completing this form:

If you are interested in networking regarding a specific type(s) of Mitochondrial Disease, please specify which type(s):

Indicate other areas where you have experience and are comfortable in addressing with others – check all that apply:

☐ General Support
☐ Tube Feeding
☐ TPN
☐ Transitioning
☐ IEPs
☐ Homeschooling
☐ Grief
☐ Social Security and/or Workplace Disability Issues
☐ Navigating Insurance Issues
☐ Other (please specify below)

☐ Medical Child Abuse

Please specify other areas:

_____________________________________________________________

_____________________________________________________________

Signature/date

E-mail address to share with others

Telephone number to share with others
Appendix

Sign-in sheet

Frequently Asked Questions

“Do You Manage Mito Patients?” Form

Materials Order Form

Battery Flyer for Kids

UMDF Mission Statement:

To promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

Remember: The UMDF National Office has staff available to provide immediate assistance – Mon-Fri, 8am to 5pm EST. This Guide is also available online at www.umdf.org/ambassadorkit.