



POMPE MENTOR AGREEMENT

Background

The Acid Maltase Deficiency Association (AMDA) has undertaken the Pompe Mentor Program because it believes that there are many individuals within the Pompe Community who can assist others who are new to the “system” or currently struggling and need support. They may be newly diagnosed with Pompe Disease; new to treatment and evaluation or need help with insurance and other situations that may arise from either having Pompe Disease themselves, or affecting family members. Or they may need emotional support.

It is the AMDA’s desire to help others to ensure that they have someone to turn to with their questions about the complexities of having Pompe Disease. It is also our goal that no one will ever be alone when problems may occur within their lives or the lives of their family.

The Pompe Mentor Program provides people diagnosed with Pompe Disease the opportunity to connect with others to share experiences, stories, and resources related to Pompe disease. This program allows direct contact by phone (text/call), email, or social networking with individuals who have experience dealing with the issues surrounding having Pompe disease. These individuals will be able to problem-solve for newly diagnosed patients when they have questions and concerns that they cannot handle.

Pompe Patient Mentors support and have a positive impact on people diagnosed with Pompe disease. Sharing their experiences can help them to empower others to advocate for themselves, and provides positive reinforcement. A person that has newly been diagnosed with Pompe disease will have many questions and a ton of concerns that need to be addressed. Sometimes, those of us who have been diagnosed for a while will also need support and advice and the Pompe Patient Mentors will be there for them also.

The power of mentoring is that it creates a one-of-a-kind opportunity for collaboration, goal achievement and problem-solving.

Mentor Requirements:

Description of Eligibility:

To become a mentor you must fall into one of the following categories:

- You have been diagnosed with Pompe disease
- You have a child that has been diagnosed with Pompe disease.

- You have a spouse or other family member that has been diagnosed with Pompe disease.

General Qualifications:

- Available to be a mentor for a specific length of time. Length of time to be determined at the time of application.
- Available to participate in all training required. Training will be virtual.
- Maintain the strict confidentiality of all mentees.
- Has an in-depth understanding of Pompe (causes, treatment management guidelines, basic genetics of Pompe).
- Willing to keep up to date on what is going on in all aspects of Pompe disease (types of treatment available, how to apply for disability, diet and exercise, etc) and being able to provide patient specific information and resources to mentee as needed, but not advocate or promote any specific treatment. It is a Mentor's job to give support, but all medical decisions should be made by the patient with their doctor.
- Have a desire to attend patient meetings and scientific conferences if physically able, and stay up to date on the latest news in the community.
- Willing to communicate with mentee by telephone, email or social networking on a regular basis in order to:
 - Keep up with their progress
 - Keep up with their specific needs
 - Inform them of new developments and resources
 - Just say "Hi, I'm thinking about you"
- Be a good listener.

As a Mentor, I agree to be a:

Initial_____

Role Model:

- Offers friendship
- Provides a model for appropriate behavior and attitudes
- Have qualities and values that the mentee desires for self
- Have successfully coped with the diagnosis of Pompe disease and can be positive role models
- Effective at helping patients develop strategies to incorporate complex treatment regimens into their everyday routines

Teacher:

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Field Code Changed

- Teaches by example
- Shares critical knowledge
- Shares experience on living with Pompe disease
- Helps mentee to acquire knowledge, information, and skills
- Shows mentee how to adapt their environment in order to make living with Pompe disease easier
- Explains how the system works
- Encourages winning behavior
- Offers options

Companion:

- Shares interests and experiences with mentee
- Listens to personal problems
- Offers encouragement

Supporter:

- Gives support to mentees efforts
- Listens to mentees ideas and concerns
- Expresses belief in mentees abilities
- Helps to build self-confidence
- Provides hope and understanding that cannot be provided by someone that has no personal experience or relationship with Pompe disease.

Resource:

- Introduces mentee to other people that also have Pompe disease
- Instructs them on how to sign onto the GSDNet, and onto Facebook
- Provides sources of information

I believe I have the following skills to be an effective Mentor: Initial_____

Leadership Skills:

- Help mentee set goals, create action plans
- Be able to give feedback and coaching to reinforce positive behavior
- Willing to assume and demonstrate leadership
- Confront negative behaviors and attitudes

Communication Skills:

- Mentors should be able to communicate the importance of the following:
 - Recognizing and managing symptoms (not everything is Pompe related)
 - How to integrate treatment into one's lifestyle
 - How to communicate with the physician

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- Be prepared
- Bring a list of questions or resources to visits
- Change doctors if you feel you are not being heard
- How to integrate diet and exercise into one's lifestyle if so desired

Interpersonal Skills:

- Enjoys working with people
- Is patient and a good listener
- Able to initiate contact
- Is confident in own abilities and achievements
- Is willing to share personal experiences

I agree to abide by the Golden Rules of Mentoring: Initial_____

A mentor will:

- Give respect and confidentiality at all times
- Listen, listen, listen
- Share their experiences
- **NOT** give medical advice
- Encourage patients to seek professional input as appropriate
- Be positive, supportive, tactful, courteous, considerate, responsive
- Remain objective and semi professional
- Set appropriate limits
- Take care of themselves
- Avoid undesirable behaviors (criticism, gory details, talking too much, being gossipy, getting too involved, being pushy)

I agree to provide the AMDA with the following: Initial_____

- Feedback on mentoring activities
- Names and contact information of the mentees served
- Alert the AMDA to any issues or needs that they have observed that may require staff intervention or education.

I agree to participate in the AMDA's Mentor Training Program:

Training webinars will be offered to each new mentor. Webinars will be utilized whenever it is necessary to get new information out to the mentors.

The content of the training webinar will consist of the following:

- Overview of Pompe disease
- Perspectives in treatment for Pompe disease:
- International Pompe Association Patient Survey
- Schedule of Assessments

- Therapeutic Goals
- Diet/Exercise
- Roles of the mentor / mentee
- Closing a mentor/mentee relationship
- Resource Library: What is available for use (patient specific information)

Mentor Support System:

Each mentor has access to a support system that they can rely on during the time they are mentors.

- The AMDA's Mentor Program Advisor: Morgan Burroughs – Morgan.Burroughs@amda-pompe.org
- The AMDA's Patient Advocate: Marsha Zimmerman – Marsha.Zimmerman@amda-pompe.org

These individuals are there to assist you in any way necessary while you are fulfilling the mentoring roles and responsibilities.

If you would like to be considered as a mentor for the AMDA, please read and mark the applicable boxes:

I have read and fully understand the roles and responsibilities of becoming a mentor as listed in this document.

I give permission to use my name on the following: Check all that apply.

- AMDA Website
- AMDA Newsletter
- Flyers

I give permission to use my photo on the following: Check all that apply.

- AMDA Website
- AMDA Newsletter
- Flyers

Printed Name: _____

Signature: _____

Date: _____

Non-Disclosure Agreement:

I agree to a non-disclosure clause that prohibits providing information about the individual or family I am mentoring, except with the express consent of that individual or family. The only exception to this clause pertains to other Pompe

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Mentors. All Mentors may exchange information among each other relative to cases in which they are jointly involved, but must always strive to maintain the confidentiality and privacy of their Mentee.

Printed Name: _____

Signature: _____

Date: _____

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