



POMPE MENTOR PROGRAM  
Operation Manual

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### Mission Statement:

The AMDA has undertaken the Pompe Mentor Program because we believe that there are many individuals within the Pompe Community who can assist others who are new to the “system.” They may be newly diagnosed with Pompe Disease, new to treatment, evaluations, know little about the workings of insurance, and other situations that may arise from either having Pompe Disease themselves, or Pompe affecting family members.

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 living with Pompe Disease. It is also our goal that no one will ever be alone either before or after when problems may occur within their lives or the lives of their family.

Many of you have had to struggle alone without the support and knowledge of treatment, faced with a poorly educated medical system and lack of community. It is the AMDA’s hope that through the Pompe Mentor Program, each of us can make a difference in the lives of others who have also been affected by Pompe Disease.

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 can also support and have a positive impact on people newly 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 been diagnosed with Pompe disease will have many questions and several concerns that need to be addressed. However, a Mentor is NOT a physician or medical professional and will only offer advice. They will not prescribe any specific courses of action—patients and their families should always consult with a medical professional on courses of treatment.

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

## Goals:

The goals of the Pompe Mentor Program:

- To be a voluntary program
- Sanctioned and supported by the AMDA
- To match mentors with their particular areas of interest or concern
- Mentoring occurs between an experienced person (mentor) and a less experienced person (mentee)
- The outcome of a good mentoring relationship is expected to benefit both the mentor and mentee in personal growth, lifestyle enhancement, education, goal achievement, and other areas mutually designated by the mentor and mentee

## Objectives:

- To ensure that Pompe patients have access to other patients also diagnosed with Pompe disease.
- Ensure information for frequently asked questions (FAQs) is passed along to the mentee.
- To match a Pompe patient/family member to a mentor that is similar in age and gender or disease severity, in order to give them both a chance to communicate one on one about the challenges of living with Pompe disease.
  - By matching mentor and mentee, the Pompe patient will be able to have most of their questions answered by people who have already been there and dealt with the same issues or is still learning how to cope with similar issues.
- To find answers to questions asked by the Pompe patient, whether the mentor knows the answer at first or not.
- The AMDA will maintain an up-to-date resource library of frequently requested information for Mentors to access.
  - The resource library has the following information that can be accessed by the Pompe community (non-exclusive list):
    - Pompe Connections (IPA)
    - 101 Hints (MDA)
    - Guide to Working with the Media (Genetic Alliance)
    - Intro to Media Strategies (Genetic Alliance)
    - Media Tips – Handout (Genetic Alliance)
    - Medical Alert Cards (AMDA)
    - Attending School with a Genetic Condition
    - Flying with Ventilators (IPA)

- Home Adaptations (A Pompe patient publication)
- List of Laboratories used to Diagnose Pompe disease (AMDA\_
- Physical Therapy Management of Pompe Disease. Authors: Lara Case PT, DPT, and Priya Kishnani, MD. (May 2006, Vol. 8. No. 5)
- Pompe Resource Guide
- Social Media Tools (Genetic Alliance)
- Pulmonary Issues (AMDA)
- Dr Slonim-Net Guidelines
- Special Needs Trust Fund information (AMDA)
- Understanding Genetics (Genetic Alliance)
- Kevin O'Donnell's Blog
- American College of Medical Genetics (ACMG) Guidelines

#### What Makes a Mentor?

- People whose own enthusiasm is so contagious that they inspire others to be the best that they can be.
- Having life experiences and success stories to share.
- Wanting to help a newly diagnosed mentee/family member to understand their diagnosis and what this means to them both now and in the future or to support someone who is struggling with the diagnosis.
- To be a source of strength and to provide information, while the mentee is adapting to this major change in their life.

#### Golden Rules of Mentoring:

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)

#### Mentor Qualifications:

#### 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.

#### 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:

- 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

Companion:

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

Support:

- 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.

Be a Resource:

- Introduces mentee to other people that also have Pompe disease
- Instructs them on how to register with the AMDA and to connect with others on Facebook
- Provides sources of information that the patient or their family might need.

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
    - 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

#### 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.

#### Application Process:

To volunteer to become a mentor, please do the following:

- Register to become a member of the AMDA by going to the website: [www.amda-pompe.org](http://www.amda-pompe.org) (as applicable)
- Email [info@amda-pompe.org](mailto:info@amda-pompe.org) and request the Pompe Mentor Application Form.
- Following the submission of the application, it will be reviewed by the AMDA Mentor Committee and an interview will be set up.
- Indicate how you prefer the interview:
  - Telephone interview
  - Interview questions via social networking
  - Interview questionnaire (online questionnaire or hard copy questionnaire)
- Sign a non-disclosure agreement that explicitly states the Mentor will at all times maintain the strict confidence of the Mentee and not disclose anything that would breach their privacy without their consent
- Agrees to a six-month trial period from the date of the signed Pompe Patient Mentor Agreement.
  - After 6 months, the mentor may be dismissed if the Mentor has not lived up to the criterion listed on the Pompe Mentor Program Agreement
- Give permission to use mentor's name and/or photo on the following:
  - AMDA Website
  - AMDA Newsletter
  - Flyers

#### Interview Questions:

- Have you served as a mentor before?
- Do you have experience with patient advocacy or spreading awareness of Pompe?



- Explain why you would like to be a mentor?
- How would you explain Pompe disease to someone who has not heard of it?
- What qualities do you think are most important in a mentor?
- What are the strengths you will bring to the mentoring program?
- List any previous experience which might aid you in being a Mentor: (For example: peer/private tutoring, work experience, volunteer, leadership training)
- Do you have any special hobbies or skills?
- Where do you find your motivation or enthusiasm?
- You might be matched with a person of a different race, religion, or ethnic group. How might you address these differences?
- Do you have any doubts or concerns about becoming a volunteer mentor?
- If there was one piece of advice you would give to someone newly diagnosed with Pompe disease, what would it be?

#### Information Mentors Need To Provide To The AMDA:

Mentors need to be able to provide the AMDA with the following:

- Feedback on mentoring activities—a feedback form will be provided and should be turned in monthly
- 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.

#### 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)

Evaluation of the training program will be offered at the end of the training webinar.

#### General Matching Strategy:

- To match a Pompe patient/family member to a mentor that is similar in age and gender or disease severity, in order to give them both a chance to communicate one on one about the challenges of living with Pompe disease.
- If Mentee prefers a specific type of communication, effort will be given to ensure the Mentor is also comfortable with that form of communication (ie phone, text, email, social media, etc)
- If possible and desirable for face-to-face meetings, will also try to match patients in similar geographic regions. But this is not guaranteed.

#### Monitor the Process to Ensure the Match is Working Out:

It is important to find out if the match is working out for both Mentor and Mentee. Are the rules are being followed and is everyone is relatively happy. [Do the Mentor/Mentee have similar outlooks and personalities to allow for easy communication?](#)

In order to monitor the match, the following may be utilized:

- Telephone call or email message from the AMDA patient advocate to both Mentor and Mentee
- Input from family or significant others.

The AMDA will have a process for managing grievances, praise, re-matching, interpersonal problem solving, and premature relationship closure.

#### 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](mailto:Morgan.Burroughs@amda-pompe.org)
- The AMDA's Patient Advocate: Marsha Zimmerman – [Marsha.Zimmerman@amda-pompe.org](mailto: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.

#### Mentor Recognition Program:

The AMDA's Mentor Recognition Program is a way of rewarding mentors for their involvement in the mentor program.

The AMDA Mentor Recognition Program will consist of the following:

- Announcing new mentors in the AMDA newsletter
- Posting their names as mentors on the AMDA website

Tokens of Appreciation:

- AMDA mug
- Tote bag
- T-Shirt
- Tulip Pen ☺

#### Mentor Retention Plan:

It is important to have continuing participation of mentors. The AMDA retention plan will focus on celebrations, awards, and positive communication with the program participants.

The AMDA's Retention Plan will include:

- Ongoing training and development
- Regular Webinars for all Mentors
- Annual recognition on AMDA website

#### Closure:

Closure in a mentoring relationship is very important. Closure, means the program has a strategy for letting mentees know the length of the mentoring relationship, so that there won't be hard feelings upon termination.

Closure includes the following:

- Know how long the mentor wants to be a mentor. Decide this when the mentor joins the AMDA mentor program.
- Discuss up front with the mentee how long they would like the mentoring relationship to continue.
- Inform both mentor and mentee that they will have a relationship for approximately a year and then the status will be re-evaluated.

#### Evaluating the AMDA's Pompe Mentor Program:

To Evaluate the AMDA's Mentor Program, the AMDA will ask all Mentors and Mentees to fill out a formal survey annually.

With a comprehensive evaluation process, you can:

- Assess its effectiveness

- Address any weaknesses
- Apply lessons learned
- Provide objective feedback to mentors about whether or not they're meeting their goals
- Identify achievements and milestones that warrant praise and increase motivation
- Pinpoint problems early enough to correct them
- Build credibility in the community that the mentoring program is vital and deserves support
- Quantify experiences so that your program can help others
- List all the elements that make up a successful program according to your organization's standards
- Set clear, realistic goals for measurement. For example, decide how many mentors you want to recruit in a given time frame, i.e., 12 mentors active by the end of six months
- Look at less tangible, but equally compelling feedback.
  - Are the mentees doing better all around?
  - Has their attitude improved?
  - Are they more optimistic about their future?
  - Did their experience in a mentoring relationship meet their expectations?
- Solicit feedback from mentors, and mentees.