



## Helping Children Cope When a Family Member is Diagnosed With LAM

It's perfectly normal for families facing a diagnosis of LAM to be upset and worried. Families with young children or teens may also be concerned about how their children will react. Children take cues from their parents and other adults. How a child reacts to a LAM diagnosis often depends on how their parents or other close adults handle it. Kids learn through their parents' behavior. Although parents know this, they are under a great deal of stress and have their own intense feelings of fear and uncertainty. Often times, with the right kind of help, parents and their children *can* and *do* learn to cope well with LAM and its symptoms.

### Why should we tell children that mom or another family member has LAM?

Some adults are afraid that children will worry more if they are told the facts about what is happening. It is important to keep in mind that adults and children have very different life experiences. This makes it unlikely that a child will react to a problem the same way that an adult will.

LAM is sometimes an impossible secret to keep. It's likely that you've already noticed that children tend to overhear adults talking about subjects not meant for them. This happens even when the child looks busy with other things and doesn't seem to be listening. Some kids even look for ways to listen without being noticed if they think something is being kept from them. Even if they don't overhear anything, they can see that others are acting differently and usually sense that something is wrong. Kids tend to be afraid and believe the worst if they haven't been given complete information.

If children hear about LAM from someone else, like a curious neighbor or a classmate, it can destroy the trust that adults have worked to build. If children think their parents are being vague on purpose or are trying to hide something from them, they find it hard to believe they are being told the truth. It's better to share this information truthfully and in a way that allows the child to understand and take part in the discussion.

Another problem in keeping LAM a secret is that the child may assume that whatever is happening is too terrible to talk about. This may cause the child to feel isolated or shut out from the family because no one will talk about their biggest concern. This means that the natural desire to protect kids sometimes only makes things harder for them. Adults know that it's impossible to shield children from all the stressful aspects of life and that part of their job is to teach them how to manage these challenges.

Finally, the child may begin to see more physical effects of LAM like fatigue, shortness of breath, oxygen usage, etc. They see that the adult is sick, and may assume that they are going to die. They may think that others in the family will get the same illness. They may think that life as they know it will end. Not knowing what is going on or how to cope with it can be terrifying to a child. To avoid this, children need to be told about the illness. They should know in advance the kinds of things that may likely happen as LAM progresses.

## **How and when should children be told about LAM?**

Age is an important factor in deciding what and how much you should tell a child about a LAM diagnosis. The guiding principle should be to tell the truth in a way that children are able to understand and prepare themselves for the changes that will happen in the family. Kids thrive on routine—it helps them feel safe. When life becomes unpredictable, they'll need help adjusting to the changes.

Young children (up to 8 years old) don't need a lot of detailed information while older children (8 to 12 years) and teens need to know more. Teens, especially those who are testing their independence and limits, will have very different concerns from a 5 year old who needs a parent's help for basic caregiving.

All children need the following basic information described in age-appropriate language:

-The name LAM or the word lymphangioliomyomatosis

-The symptoms that they may see in the woman with LAM. Depending on the age of the child, a parent may say something like the following:

- “Mom may have times when she is not able to walk as fast you.”
- “Grandma may have a cough that doesn't always go away.”

-How it will be treated . This will be different for every woman with LAM. Some examples of things that you might say:

- If the woman has little or no symptoms: “The doctors are just going to keep an eye on Mom's lungs. She might need to use an inhaler when she has trouble breathing.”
- If the woman is taking LAM medications: “Grandma has medicine that is keeping her lungs from getting worse.” Tell the child the possible side effects that he/she may notice.

-Changes they may notice in the family and how it might impact their typical day to day activities

-Typical feelings that might arise for them such as anger, sadness, confusion or fear

First, set up a quiet time when you won't be disturbed. You may wish to talk to each child alone, depending on their ages, so that information can be tailored to what the child can understand. This can also help you pay closer attention to how each child responds. The child may also be more willing to ask questions when away from other children and potential distractions. Be sure

you have time to answer questions and a plan to manage possible interruptions before you start. If you stop to answer the phone or let the dog out when your child is opening up to you, the child may find it more painful to try again. Depending on your child's age, some parents may find it helpful to have this important discussion during an activity. This will provide a healthy distraction so children can process the information in smaller amounts and give him or her time to think of questions to ask. Examples of activities include taking a walk, playing catch or swinging on swings.

It helps to plan how you will talk with each child. Think about what you want to say and how to answer questions on a level each child can understand, but in a serious and thoughtful way. You are trying to lay the groundwork for an open line of communication with the child—a way for the child to come to you with their concerns, needs, and fears. If you can start this and keep it going by regularly checking in with each child about LAM, it can be a great comfort to them. Initially, children may feel overwhelmed and unable to think of questions they would like to ask, but keeping the lines of communication open for them to bring up their questions and concerns later is important.

Young children (up to age 8) can be told that the body is made up of lots of different parts. When someone has LAM, it means that something has gone wrong in the body and it's having trouble doing what it's supposed to do. The lungs, which help get air in and out, are still working, but need to work harder. It's kind of like when you are running around a playground or up a big hill instead of walking on a flat driveway or sidewalk. Bad cells are in the lungs and are taking up some of the space needed for breathing. Some kids may not have any questions at first, but invite them to ask you later if they think of any. Older children (in general, ages 8 and up) may be able to understand a more complex discussion. They may want to see pictures of LAM cells or read about how LAM is diagnosed or treated. Again, encourage them to ask questions if they think of some later.

Besides the illness itself, children have other worries about LAM. The most common of these is that something they did or didn't do may have caused the family member's illness. We know this isn't true, but children may believe this at some point during the LAM experience. We know that children engage in "magical thinking." They believe they are the center of the world and that they can make all kinds of things happen. Children can also believe that bad things happen because they have been angry with their mom or affected family member. So when they get sick, children may feel guilty and think they are to blame for LAM. Kids usually won't tell you this, so it's a good idea to reassure them about it by saying something like, "The doctor told us that no one can cause someone to get LAM—it's nothing that any of us made happen." It's better not to wait to see if children bring this up because they may be feeling guilty without saying so.

Children may also worry that LAM is contagious and that they can catch it, or that everyone dies from it, or that other family members will get it too. It's a good idea to correct these ideas before a child has a chance to worry. Kids can become confused about how people get sick. A common worry is that LAM can be passed from one person to another like a cold. Explain that LAM is a different kind of illness and that the child doesn't have to worry that someone passed it on or that they will get it.

So, along with the basics about LAM as noted above, be sure to stress these facts:

-No one can cause someone to get LAM. (It's not the child's fault.)

- You can't catch LAM like a cold or the flu—it's OK to hug or kiss the person with LAM.
- The family will work together to cope with LAM and its treatment.
- No matter what, the child's needs will continue to be taken care of; he or she are going to be okay.
- It is okay to still be a kid: play, have fun, and don't be afraid to ask for the help that they need.

You may need to make these points more than once. More importantly, adults in the child's life can serve as examples and remind the child of these things too. Children pick up on small cues in how you and others act around them, so if they notice adults don't hug the sick person like they used to, a child may worry. Or if adults are in a hurry and don't speak kindly to the children as they once did, they may think the adults are mad at them or blame them in some way for the illness.

Children also need to understand some basic terms about LAM. We have definitions for some of the more common words in the section, "Words to describe LAM and its treatment."

Teenagers may need more information at a faster rate than younger children. With the use of the Internet, teens can easily find a lot of information quickly, so you want to be sure that what your teenagers are reading online is the most accurate and reliable information. Suggest [www.thelamfoundation.org](http://www.thelamfoundation.org) or [www.nih.gov](http://www.nih.gov) as the only sites that they visit to learn about LAM.

## **Will learning about LAM upset a child?**

Some children may become very upset when learning about a new LAM diagnosis, while others may act as if nothing is wrong. The goal is to give the child a balanced point of view. The child should realize that LAM is a serious—but not hopeless—illness.

A child's emotional reaction to this news will depend on many things, including how the information is given to them and the child's experience with the illness. It's important to choose a time when you are feeling fairly calm and ready to talk to the child. In a 2-parent household, it's a good idea for parents to talk to their children together. For single parents, it may help to ask an adult relative or friend who is a stable, consistent influence in the child's life to be with them if they're feeling a bit shaky about the talk. If people are feeling upset or unsure about what to say, it might be better to wait until their emotions are a bit more under control. That is not to say that adults need to pretend that there is nothing to worry about. It's OK if kids see them crying sometimes. Adults can admit that this is an upsetting time, that LAM can be a scary disease and that it's OK to have strong feelings about it. But that doesn't mean that the family won't be able to handle it.

Sometimes adults worry about showing pain or negative emotions in front of children. They may worry this will scare them. Or they may fear that negative feelings will somehow affect the child's ability to cope with the illness. You may often get advice to keep a "positive attitude". For the most part, feeling positive is a good way to approach life. But when people try to deny the very real feelings of fear and sadness, which are a part of any LAM diagnosis, the effort often just doesn't work. The energy it takes to hold in "bad" feelings can make coping much harder. For many people, a grieving process starts with a LAM diagnosis. It is normal to be sad and

upset after being told you have LAM. It often feels as if nothing will ever be the same. Patients grieve for the loss of safety and predictability in their lives, and for the future that may not turn out as planned. When they face these feelings, it is much easier for them to work on having a positive mindset the rest of the time about the challenges ahead. You may want to talk to a therapist, spiritual leader, family member or friend in order to help you clarify and process your situation prior to talking to your child about LAM.

No one wants to alarm children by being hysterical. But there is nothing wrong with shedding a few tears when the family has a crisis. Adults can tell children that there will be times when they may cry because that can help them feel better. Adults can assure them that at some point they will no longer need to cry about the situation, but it's OK to express all of their feelings. Everyone deals with problems in a different way, and it's fine to feel angry or sad as long as you don't use these feelings to hurt others. It's important for adults to give themselves permission and time to figure out what is best for them and each family member. Parents can try saying something like: "I feel sad and scared sometimes, but I know that we are going to be okay and no matter what we love each other and that is what matters most."

It is also important to let kids know that it is okay to feel sad, or angry about the situation. What is important is to teach children to express these emotions in healthy ways. Initially children might state that they are okay, not wanting to put additional stress on the family. A parent might notice a child being more withdrawn, irritable, angry, clingy/needy, or anxious. A child acting out behaviorally is not uncommon. Healthy modes of emotion expression might include such things as:

- setting aside time to talk things over
- art projects
- music
- writing down negative thoughts and shredding them
- creating a "calming box" (a special box that the child can go to that contains calming or relaxing items such as silly putty, soft music, pictures of their favorite things, etc.)

## **How do I explain supplemental oxygen?**

If supplemental oxygen is being used by the family member with LAM, it may be a scary thing for children if it's not explained to them. How much you tell the child about the oxygen will depend on the age and maturity of the child. Oxygen can be explained as medicine being used to help the lungs work better. Instead of the medicine being taken by mouth or through a shot, the "medicine" comes through a tube and into the nose because it gets into the lungs more quickly.

Often times children are scared or uncomfortable by the noise that is made by the oxygen concentrator or other equipment. Encourage the child to sit near the person on oxygen so they can get used to the noise. Also, for some children, naming and decorating the oxygen equipment is helpful and may make it less scary.

It is often difficult for the person on oxygen to deal with the possible emotional effects of going out in public with oxygen. People often stare or ask questions and occasionally even make a rude comment. If possible, the person on oxygen should go out the first few times without the child so that she is prepared for the possible things that might occur. One LAM patient's young

daughter told her that she should just tell anyone that stares, “So what people! I’m on oxygen. Get over it!” She tells people that her mom’s lungs are “broken” similar to a broken foot or arm and that the oxygen is her “cast.”

Many LAM patients and family members carry LAM Foundation brochures with them to share with anyone who is curious about the disease. Children often like to be the experts on things, so for them, to be able to explain that mom or aunt or grandma has LAM and to give someone LAM Foundation information can be empowering.

It is also important to discuss the safety measures needed when oxygen is in use. Children need to be cautioned to walk carefully around or over the tubing and not on it. They also need to be cautioned to hug carefully to avoid pulling on the tubing.

## **Are there certain responses that I should expect?**

### **Every child is different.**

Each child responds in his or her own way to the news of a loved one’s LAM diagnosis. There is no one right way to grieve! The child’s age, personality, relationship to the person, and the way the information is presented are just a few factors that can influence how a child will react. Parents usually know their kids better than anyone else and can expect their children to react in ways that are typical of their personalities. For instance, a child who is very dependent may become even more so when they learn about the LAM diagnosis. A child who always imagines the worst may do so now. A child who plays rough with his toys when upset may get even rougher.

### **Children can’t always tell you, but may show you, how they feel.**

Children are often unable to express how they’re feeling in words. Most adults get an idea about what is going on with a child by watching how they act. A child may talk back, show disregard for rules, or may act out in order to gain attention in a negative way. So, a parent who sees their kids fighting with each other more now can probably assume that this is their way of showing they’re upset. Parents can put this into words by saying something like, “I know everybody is more worried right now, but let’s talk about this instead of fighting.” See previous comments on emotion regulation.

### **A child may act less mature when upset.**

In general, adults can expect that the stage of a child’s development dictates how well he or she understands what is going on. Children tend to regress (act younger) when they are under stress. Adults often do the same. A child who has gone off to kindergarten quite happily may become upset when they have to be away from their mom. Kids who have problems paying attention in school may have more trouble than before. A parent could expect that younger children could wet the bed at night or even have accidents during the day.

### **Children blame themselves.**



Children often blame themselves when something goes wrong. This is because children normally see themselves as the center of the universe. This often happens in kids of divorcing parents—kids think they have done something to cause the break-up. The same thing happens with illness. Children wonder if they are to blame. It is best to address this before the child asks about it, because children usually don't ask. Self-blame can be harmful to the child. It is recommended that parents repeat the statement to children: "It's not your fault" when the child is upset as a way to sooth them and offer reassurance.

### **The child's level of trust will show up in their behavior.**

In most cases, children who are truthfully told what is happening from the very start will be less anxious than children whose parents try to avoid answering questions. Being honest with children during this time can help build trust. This doesn't mean you should tell them everything all at once. Especially for younger children, it's best to give them information in small doses, ask them if they have questions, and then answer their questions. If you don't know the answer to a question, tell them you will have to find out, and then get back to them. You can keep them up to date as events progress. If a question does not have an answer that can be researched, parents are encouraged to be honest and say: "I don't know."

### **What if my child asks if the person with LAM is going to die?**

The question, "Are you going to die?" does need to be answered—even if it's not asked. Whether you openly talk about it or not, you can be sure that your loved ones are worrying and thinking about death. We share some ideas in this section for ways you can respond to questions about death.

This question causes the most distress for families. It's a good idea to rehearse how you are going to respond to this, either with someone else or just to yourself. There are some things you should know before you decide how to answer this question. First, admit to yourself that this is a scary question for you as well as your family. It's a hard question for children to ask, and they may never have the courage to ask it outright. If a child does ask the question, first praise them for having the courage to do so. Try saying: "That is a very good question and I understand why this is important for you to ask." Or "I am glad that you asked this question, I love how honest and curious you are." Plan a time to bring it up to them even if they don't ask.

There is usually no way to know if a person will die from LAM. Even for LAM patients with a very poor outlook, a person's response to treatment can vary. LAM is a chronic disease, not always a deadly one. Women can live with LAM for many years. In the meantime, the family's focus must be on how to live with LAM.

So, in talking with a child about whether the person will die from LAM, there are a number of different messages. Here are some examples of what other people have said:

-Although some people can die from LAM, I do not think that this will happen to me because I have good doctors who are working hard to use different treatments.

-The doctors tell me that I am doing good now and if I continue to take good care of myself I will stay healthy.

-I believe that I will not die from LAM. I hope you can believe that too. I promise I will tell you if I find out anything new or different.

-There is no way to know right now what's going to happen. I'll know more after I start taking my new medicine. When I know more, I'll be sure to tell you. What I can promise you now is that you will *always* be taken care of and that I will *always* love you.

-My LAM is making me sick very fast but I'm going to do everything I can to get better. No one can know right now what will happen down the road. What you can be sure of is that I'll be honest with you about what is going on. In the meantime it's okay to still have fun and be a kid. You don't have to worry about taking care of me; that's my job.

Clearly, what people tell children depends on how they understand LAM and its potential outcome. Even with an uncertain future, patients still need to work on what they must do to live with their illness. Children need to do the same. No matter what words are used, one of the most important things for people to get across to children is their desire to tell the truth. This does not mean that the adult should tell kids everything they know as soon as they know it. It means that children should be given truthful information when they need to have it in order to cope well from day to day. A person might say, for example, "I don't want you to worry about the future at this point. Let's think about what's going on right now. If that should change, I promise you I will tell you. I will always tell you the truth. I want you to ask me any questions you have and I'll do my best to answer them."

## **How can I reassure my child that everything will be fine?**

Women probably cannot offer the kind of overall reassurance they would like to when they first learn they have LAM. This is because no one really knows at that point how they will respond to treatment and whether everything will be OK. And you don't want to say this if it isn't true because you can lose the child's trust. But there are things that you can do to help kids cope.

You can reassure children that no matter what, they will always be cared for. The most important issue for children of any age is their own sense of security and safety. Children depend on their family for their basic physical and emotional needs. A mother's LAM can make families feel that their lives are totally out of control.

During this time it is important to realize that the entire family is likely to feel anxious and unsettled. The person with LAM will make trips to the clinic or hospital, their spouse may take time off work, daily household life will change, and family members will feel—and show—all kinds of emotions. In spite of all this, try to keep as much of children's lives the same as possible. This may sound like a tall order, but it is usually possible to reorganize family routines at least for a short time.

When you talk about your diagnosis and treatment, it's a good idea to prepare children for the fact that certain changes will need to be made in the family routine. Parents may need to call on others to fill in for them. Maybe a relative will be moving in for a while to help out. Maybe the



patient has friends who have offered to take turns preparing meals for the family. A relative or friend may volunteer to pick a child up from school or take the child to sports practice or music lessons. Take people up on their offers to help out and try to find the support you and your kids will need at this time. Loved ones, friends, neighbors, and even the parents of your children's friends can be a great help in keeping the child's daily life as normal as possible.

When these changes in family routines are explained to children, they offer a powerful message that mom or dad is still in charge and that the child's needs have not been forgotten. Life will go on as normally as possible given the challenge the family is facing. The children will not be left on their own. Adults should confirm that no one is happy that life seems turned upside down right now, but it will not last forever. In the meantime, tell children over and over again that you love them and that you are working to be sure they are cared for.

Sometimes kids react strongly to changes in routine. Parents may feel frustrated and even angry as they try to meet everyone's needs. Keep in mind that it's no one's fault when a change in routine must occur and nothing can be done to change it, but people have choices about how to handle the situation. Find something in the situation that the child has a choice about, for example, whom they would like to meet them at the school bus, or what they would like to take with them when they go to a neighbor's after school. Don't spend endless time discussing issues—sometimes that's just the way things have to be for now. Children are not expected to like it when their routines are disrupted—adults don't like it either. Parents can admit this to their children, along with the fact that they have a right to feel angry and upset right now. Although parents can't fix the situation, they should be concerned about how their kids are feeling.

Children's needs vary depending on the age of the child and how available others are to help. Young children have basic survival needs and are more dependent on adults to feel secure and safe. Teens present special challenges because they tend to test their need for independence. In addition, teens may turn towards their social support instead of family members for support. Parents will benefit from reminding themselves that this is a typical developmental stage for teenagers and is not a reflection on their feelings towards the family.

Parents should consider the fine line between asking for help from a teenager and giving them too much responsibility. Parents may need to recognize their teenager's normal desire for independence and need for social interaction. It can help to assure them that you know they need their own time and space in spite of the fact that a parent is ill. It may also help to set up a family meeting in which parents and children can review how things are going in the family and decide what should be different or stay the same. During these meetings clear expectations should be made about when the parents expect the teenager to be involved and when it is okay for them to "just be teens"

Some families may find it hard to ask for help, but accepting assistance is NOT a sign of weakness. We know from experience that people who try to manage LAM alone will have a harder time. Try to remember that people really do want to help, and if you let them, they feel useful and needed. But you need to tell them exactly what you and your family need from them. If no one is available to help, patients or their loved ones should ask to talk with the hospital social worker or the nurse in the doctor's office about any community agencies that can help. Since children still have a need to "just be kids" and have fun parents might consider asking for help from friends or family to take the child on a special trip or outing since the parent might not have the energy for such an outing.

## How will I know if a child needs extra help?

Deciding if a child needs help can be confusing as you try to sort out what is a “normal” response to a LAM diagnosis and what is not. This is new to all of you, and it will take some time to figure out what works best for you and your family. But while you’re learning for the first time how children react to LAM, you already have experience with how they deal with other stressful events. Most parents can tell exactly how each of their kids acts when they are upset. Because children, especially young ones, are often unable to talk about how they feel, they show us by their behavior. Some children will become withdrawn, while others may fight, whine, and complain. Children might also indirectly express their emotions through something else that is bothering them such as a fight with a friend or a bad grade on a test. This is called “displaced grief.”

The most important change that would warrant additional support is an extreme change in a child’s behavior that lasts longer than two weeks. This might be a sign of depression which looks different in children when compared to adults. For instance, a common sign of depression in a child is a change in behavior. For example, suddenly getting poor grades in school, losing friends or behavioral disruption. Most children who have a family member with LAM seem able to cope, but there may be a time when it gets to be too much. If a child seems to be having trouble, it may mean a more serious problem than a normal, sad response to LAM. Extra help is needed if a child:

- Is tearful for most of the day on most days or has bouts of uncontrollable sadness
- Demonstrates intense thinking about the disease to the extent that the child is preoccupied
- Cannot be comforted by others or is unable to soothe him or herself
- Admits to thinking of suicide or hurting herself or himself. Children can express this by saying things like: “I just don’t want to be here anymore” or “I wish I could just go away”
- Instances of injurious behavior or is reckless or unsafe
- Becomes irritable to the extent that it interferes with typical interactions with others
- Becomes very angry very quickly or is destructive with his or her anger
- Has changing grades
- Withdraws or isolates himself or herself
- Acts very different than usual
- Has appetite changes
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Has trouble sleeping or has nightmares
- Adopts perfectionistic tendencies
- Begins to think of him or herself as “bad” or perceives themselves as being a burden on the family

When a child shows 1 or 2 of these symptoms, it may help to offer more support. But if the usual methods of handling these problems are not working, if the problem goes on for more than 1 or 2 weeks, or if the child describes suicidal thoughts or is self-injurious, extra help is needed. It may

be helpful to talk with the child's pediatrician, school counselor, social worker or counseling staff at the hospital, or consult with a child Psychologist. Since these experts know how other children have reacted to illness in a family, they may be able to offer a useful way of looking at the problem. They can help teach the child about LAM and make sure that any needed help is given. They may suggest books, videos, and children's support groups that can help. Rarely, a child may need to see a psychiatrist for medicine or counseling.

Finally, if one of the child's parents or main caregivers becomes depressed, the child is more likely to have problems. Sometimes the child's problem may not look very severe; the child or teen may say very little and hold everything inside. If you start to feel overwhelmed or distressed, see a mental health professional to get an idea what kind of help you and your family may need. Ask your doctor or nurse, "Who can we talk to if one of us feels overwhelmed or depressed? I'm worried about how this will affect the children."

## Words to describe LAM and its treatment

Here are a few words about LAM that your family might need to know. You may want to explain them in a family meeting so that all the children (and adults) know what you mean when you use these words. Be sure to check to find out if there are other words they've been hearing that they don't understand. Also, tell them who they should ask if they hear other words they don't know.

**Angiomyolipoma (AML):** a benign tumor (oma) consisting of blood vessels (angio), muscles (myo), and fat (lipo). AMLs can occur in LAM and are most often found in the kidneys.

**Biopsy:** a procedure that removes a piece of tissue from a person's body so that a doctor can look at it under a microscope. This test is used to see if a person has LAM

**Chest tubes:** sterile tubes inserted into the chest cavity between the lung and chest wall; used to re-inflate the lung, to release air, or to drain chyle or another fluid from the area.

**Chyle:** lymphatic fluid that drains from the lymph glands. It is milky in color and contains fat and other nutrients.

**Clinical trials:** research studies that are set up to compare new LAM treatments with the standard or usual treatments.

**Pleurodesis:** procedure to adhere the lining of the lung to the lining of the chest cavity. The procedure eliminates the space between the lungs and the chest wall and prevents further lung collapses.

**Pneumothorax:** a lung collapse. "Pneumo" refers to air and "thorax" to the chest cavity. In LAM, a pneumothorax occurs when one of the cysts (blebs) bursts and air leaks into the space around the lung. The pressure of the air between the lung and the chest wall forces the lung to collapse. Sudden shortness of breath, a dry cough, cyanosis (turning blue) and sharp pain felt in the chest, back and/or arms are the main symptoms.

**Prognosis:** a prediction of the course of the disease; the outlook for the chances of survival.

**Pulmonary Function Tests (PFTs):** a series of tests to determine how well the lungs function by checking the performance of the lungs; also used to determine the severity of obstruction and/or restriction in the airways.

**Side effects:** problems caused by LAM treatments. Two people with the same LAM and even the same treatments may not have the same side effects. Your doctor can tell you what happens to most people, but cannot say for certain what will happen to you. Not having side effects does not mean that the treatment is not working. Tell children what the doctor has told you, and promise to tell them if you start to feel side effects.

**Surgery:** a procedure done by a doctor who is an expert in doing operations

**Tissue:** a collection of cells that work together to perform a certain job or function in the body. Different parts of the body, such as the skin, lungs, liver, or nerves can be called tissue.