Chapter 1 provides an overview of the immune system and lupus.
This chapter of the presentation will cover

- The basics of the immune system and how it functions differently in individuals living with lupus
- Patient-centered communication techniques to help you uncover what patients really think and feel, and
- Insights garnered from patient research to help you get a better understanding of how patients view lupus
Before we get started with Module 1, remember that it is important to be patient-centered when working with your patients. The first step is realizing that patients with lupus may face barriers that prevent them from getting the most out of their treatment. Because of this, it’s important that you take the time to understand individual barriers, concerns, and situations that may help you customize your patient education programs.

Throughout this module, you will periodically see slides that look like this one, labeled as the tips page. These pages will provide you with ideas you can use with patients to help you stay patient centered during your presentations.
There are specific communication techniques highlighted here that may be useful when meeting with your patients. Using these techniques will help you build rapport with patients, stay focused on their needs, and may ultimately help patients better manage their lupus.

As you work through this module, you’ll see these techniques highlighted in different spots. Think about specific instances in which you might be able to use these techniques when meeting with patients.

You will also see visual icons. These represent insights pulled from patient research that may further help to benefit your conversations with patients.
What is systemic lupus erythematosus (SLE) or lupus?

- **Lupus:**
  
  - Occurs when the body’s immune system—the system that fights off viruses and bacteria—attacks its own healthy tissues. This autoimmune activity can cause inflammation, pain, and damage in various parts of the body.
  
  - It is called “chronic” because the signs and symptoms can last for years.
  
  - It is characterized by flares and remissions—periods during which you may feel worse, and then feel better.
  
  - Lupus can be considered a “fingerprint disease”—it’s unique in every person.

- Symptoms may vary from person to person and change over time, even within the same person.
  
  - Lupus is unique in every person and can be considered a “fingerprint disease.”

- There is no cure for SLE.
  
  - Although symptoms may sometimes disappear, the disease doesn’t go away.
  
  - The goal is to put the disease into remission, but always being aware that it can flare.
As you’re presenting information about lupus, keep in mind that each patient is unique.

In an effort to help patients open up, ask permission before sharing new information.

One example may be: *Would it be okay if I share some information with you about your lupus and how your disease may be affecting you?*
Patients with lupus should know that there are 4 different types of lupus.

- An individual may have more than one type of lupus at any time and might develop a second type in addition to the original one.
- The 4 types of lupus are as follows:
  - Systemic lupus erythematosus or SLE (also commonly called “lupus”)
    - This can affect nearly every part of the body, including the skin, joints, lungs, heart, kidneys, brain, and blood
  - Discoid lupus (which is also called “cutaneous lupus”)
    - This affects only the skin; main symptoms include crusty, scaly sores on the face, head, and other areas that can leave lasting scars
  - There is also drug-induced lupus
    - Certain prescription medications can cause drug-induced lupus, which can appear similar to SLE but usually goes away once the medication is stopped
  - And finally, neonatal lupus
    - A newborn of a mother who has lupus may develop a rash or other symptoms that can last for several months before disappearing
The information on the previous slide along with these questions can be used to start the conversation about lupus with patients and to help you learn more about the individual patient level of knowledge.

A potential question might be, “Would it be okay with you if I ask you some questions to help determine which kind of lupus you have?”
Lupus is an immune-related disease. Because the immune system is fairly complex, we’ll start with the basics:

- **Everyone has an immune system**
  - The immune system recognizes and fights “foreign” invaders
- A general term for foreign invaders is **antigens**, which includes germs such as bacteria and viruses
- In your immune system
  - **White blood cells** talk to each other by sending **chemical messages to make antibodies**
  - **Antibodies** attach to **antigens** and “mark” them for removal

Lupus is an immune-related disease. Because the immune system is fairly complex, we’ll start with the basics:

- **Everyone has an immune system**
  - The immune system consists of a group of cells, proteins and chemical messengers in the body that work together to recognize and fight foreign invaders (like germs and bacteria) in order to help keep the body healthy
- Secondly, the immune system includes:
  - Various types of white blood cells, including some called B cells
  - And antibodies that attach themselves to foreign invaders to “mark” them for removal
- And lastly, the immune system consists of a group of cells and tissues in the body that work together to recognize and fight foreign invaders, generally referred to as "antigens" (like germs, bacteria, and viruses) in order to help keep the body healthy
Lupus affects the immune system.

• When someone has lupus, the immune system can’t tell the difference between foreign invaders that are harmful and the patient’s own body

• It’s like an allergic reaction to one’s own body
  • The body is essentially fighting itself

• This reaction leads to inflammation of organs and the signs and symptoms of lupus
  • These symptoms can include skin rashes, kidney problems, painful muscles and joints, heart disease, and brain problems
You play an important role in helping a patient understand their disease. In order to maximize the patient’s understanding about lupus and how it affects the body, be sure to choose plain and simple language.
Who Gets Lupus?

- The cause of lupus is not known—anyone can get lupus
- In the United States, there are approximately 171,000 individuals currently living with lupus
- Women between the ages of 15 and 44 years of age are more likely to get lupus
- Lupus is more common and severe among nonwhite populations
- Lupus may run in families, but most people with lupus do not have a close relative with lupus

What is known about who gets lupus?

- No one exactly knows what causes SLE; anyone can get lupus
- In the US, there are approximately 171,000 individuals currently living with lupus
- Women between the ages of 15 and 44 are more likely to get lupus
  - However, men are more likely to have more severe lupus
- Lupus is more common and more severe among nonwhite populations
- And finally, lupus may run in the family, but most people with lupus do not have a close relative with lupus
You’ve shared a lot of information about lupus with your patient. At any point, it’s acceptable to pause to ask questions to gauge patient understanding.

*Example questions include, “So far, what is the most surprising information you’ve learned about lupus?” or “What is so surprising about this to you?”*
Some risk factors that increase the chance of someone getting lupus include:

- Ultraviolet (or UV) rays from the sun or fluorescent lightbulbs
- Infections, colds, and other viral illnesses
- Cigarette smoking, and
- Hormonal therapy
You can now introduce how lupus affects the body.

• When the immune system attacks one’s own body, it can cause damage to many parts of the body
  • And, as a result, symptoms may develop (we’ll talk about those symptoms later)

• Lupus may affect one or more parts of the body

• Lupus can also cause serious problems that patients may not see or feel

• Lupus can affect almost any part of the body, especially the skin, blood, joints, kidneys, heart, lungs, and brain
  • It can change target at any time and can affect more than one organ at the same time
There are visible and invisible symptoms of lupus.

- Symptoms may even sometimes disappear, but the disease does not go away

- SLE symptoms may be different for everyone
  - They can flare up and go away periodically, and they can mimic those of many other conditions
  - That’s why it’s so important for patients with lupus to monitor their symptoms, even when they may seem minor, temporary, or unrelated to the patients’ other symptoms

- Some of the most common visible symptoms are:
  - Swelling of joints
  - Fever over 100°F
  - Hair loss
  - Nose or mouth sores (that are usually painless)
  - Skin rashes after sun exposure
Even when sharing the basics of lupus with patients, you can use communication strategies to help encourage more of a productive dialogue between you and your patients.

A reflection may sound like this: "It seems like hearing about the different ways lupus may be affecting your body is causing you stress."

Or an affirmation. It can be centered around anything that the patient is doing well: “You are really committed to learning more about managing your lupus.”
Some effects of lupus are invisible.

- Often, patients who are living with lupus may be told by others that they don’t look sick. While they may not look sick, that doesn’t mean that they aren’t experiencing underlying symptoms.
- Lupus may affect some of the body’s internal organs, such as:
  - The kidneys
    - Inflamed kidneys may not work correctly. Over time, inflammation may result in permanent damage.
  - Heart and lungs
    - Inflamed linings of the heart and lungs may cause chest pain.
  - Brain
    - This may lead to the inability to think clearly.
The importance of monitoring symptoms should be stressed.

- The presence of signs and symptoms known as “active disease” is associated with an increased risk of damage to major organs, such as the kidneys and heart

- Patients may not think that some symptoms are lupus related, but they may be a sign of lupus-related inflammation that may lead to organ damage
  - Every symptom matters

- It’s important that patients understand their symptoms and share them with their healthcare team, because they could be signs of ongoing inflammation that could lead to organ damage

- Lupus monitoring and management should be a team effort and may include:
  - Patient self-assessment
  - Rheumatology assessment
  - Specialty consultation and timely lab results

- Follow-ups should be done in a timely manner
Asking for permission may help patients be more open to hearing what you have to say.

You could consider using phrases like “Would you mind if I showed you...” or “Would it be okay if I shared with you...”

This approach may help patients feel more in control and set the stage for a better conversation about why they need to monitor and share information with you.
Encourage your patients to reflect on the questions below and use their work sheets.

• What symptoms have you experienced?

• What are the areas of the body that most concern you, and why?

• Do you worry about the silent effects (e.g., inflammation of the kidneys?)
  • Do you share these concerns with someone?

• Did you know that there are things that you can do to help manage your lupus?

Members of the healthcare team may take this opportunity to have patients reflect, fill out the work sheets, and then discuss the answers.
In addition to the reflection questions on the previous slide, consider the following to spark more conversation.

“How are your symptoms affecting your life?”
“Tell me more about your concerns.”
“Who provides you with support?”

These types of questions allow patients to hear themselves voice their own thoughts and may encourage them to share more about their deeper concerns.
As previously mentioned, lupus can affect many organs of the body.

- Next, you can review the symptoms
Before we review some common symptoms, it is important to correct misperceptions about lupus. This can be done using patient-centered communication strategies. Consider some of these examples to get the conversation started.

“Some of this information you’re learning today seems really surprising to you.”

Or, “It sounds like you have some concerns. Can I share what I know with you, then we can discuss how you feel about it?”
Educate patients with lupus about the symptoms they may need to look for.

- Some symptoms associated with active disease are:
  - Skin, which includes rashes, sensitivities to sun or light, mouth and nose sores, and hair loss. Rashes can vary drastically, and skin exposed to sunlight may also develop a rash.
  - Brain. This includes seizures, headaches and/or dizziness, sad thoughts, memory problems, and confusion, and
  - The eyes—dry eyes, eye redness, and some loss of vision.
Other symptoms include:
- Muscles and bones, such as muscle weakness, stiffness in joints, and aching muscles
- The heart and lungs, which may be chest pain and difficulty breathing
- The kidneys, such as swelling of the legs and/or feet, and frothy and/or bloody urine, or
- Daily flu-like symptoms, including fever, fatigue, and nausea

One key to living with lupus is to know about the disease and its impact
- Being able to spot the warning signs of a flare may help patients prevent the flare or make the symptoms less severe

Encourage patients to use the Lupus Checklist as a guide (we'll describe that later)
It is important to stress routine monitoring.

- Routine monitoring of disease activity is essential to the successful management of lupus

- Patients should see their healthcare team often, even when symptoms are not severe
  - These visits will help their healthcare team look for changes in symptoms, predict and prevent flares, and change the management plan as needed

- Patients may need to see a specialist in order to treat the many symptoms of lupus
  - A healthcare team might include a family doctor, rheumatologists, clinical immunologists, nephrologists, hematologists, dermatologists, neurologists, cardiologists, endocrinologists, and psychologists

- A healthcare team isn’t just made up of doctors; encourage patients to get to know the whole team, including nurses and social workers in their doctors’ offices
  - These important team members may be able to help share test results and information with other doctors on the healthcare team

- Patients are part of the routine monitoring. They should feel empowered to participate
Helping patients find ways that they can take a more active role in their care may help them feel more confident in their ability to manage their lupus.

One way to do this is try a statement like, “Tell me about how your symptoms are currently being monitored,” or “What is your role within the healthcare team?” to highlight areas where patients are doing well.
You can encourage patients to reflect on the questions below and use their work sheets.

- Think about how you currently manage or track your lupus: What challenges do you face?
- Do you feel like you are taking an active role in disease self-management?
- Are you aware of ways that you can take an active role in disease self-management?

Members of the healthcare team may take this opportunity to have patients reflect, fill out the work sheets, and then discuss the answers.
As you use the questions and work sheets from the previous slide, remember that using reflections and summarizing along with questions may really help to open up the conversation.
It’s really important for patients to participate in their own care.

• When managing a chronic condition like lupus, the patient is a key component in assessing the disease activity

• Patients can take an active role in managing their lupus by:

  • **Getting informed. Getting empowered**
    • The more they know about lupus, the better they can talk to their healthcare team

  • **Promoting open communication**
    • When patients are completely honest with members of their healthcare team about how they’re feeling, they are more likely to get the precise kind of help they need to feel better—now and in the long run

  • **Last, not being afraid to ask questions**, or to have the healthcare team repeat information or explain something in a different way
    • Patients should make sure that their healthcare team listens and confirms that they understand their concerns
This is the end of Module 1. We reviewed
• The basics of lupus and the immune system
• What the symptoms of lupus are and the effects on the body, and
• Why it’s important for patients to monitor and share their information with you

We also covered patient-centered communication tips such as
• Staying patient centric with simple language and empathy
• Using conversational techniques like open-ended questions, reflections, and summaries
• Addressing incorrect perceptions, and finally,
• Supporting patient’s confidence in managing their lupus

You can now close this window and proceed to the practice section to review some scenarios and exercises to practice what you have learned. You can also begin the next module. In Module 2, we will review the steps patients can take to better manage their lupus.
Section 2 discusses how patients can help to manage their own lupus.
This chapter of the presentation will cover:

- The importance of patients taking an active role in managing their lupus
- How to use reflective statements, summarizing, and open-ended questions to get patients to open up and talk about their lupus
- Patient insights from research studies that will help inform your conversations about managing lupus
Before we get started with Module 2, remember that it is important to be patient-centered when working with patients. The first step is realizing that patients with lupus may face barriers that prevent them from getting the most out of their treatment. Take the time to understand individual barriers, concerns, and situations to help you customize patient meetings.

Throughout this module, you will periodically see slides that look like this one, labeled as a tips page. These pages will provide you with ideas you can use with patients to help you stay patient centered during your meetings.
There are specific communication techniques highlighted here that may be useful when meeting with your patients. Using these techniques will help you build rapport with patients, stay focused on their needs, and may ultimately help patients better manage their lupus.

As you work through this module, you’ll see these techniques highlighted in different spots. Think about specific instances in which you might be able to use these techniques when meeting with patients.

You will also see visual icons. These represent insights pulled from patient research that may further help to benefit your conversations with patients.
The next several slides discuss things that patients can do to take control of their lupus. Examples include:

• Number 1: They should be aware of the things they can do to take control and to help them cope with the stress they may feel

• Number 2: Eating healthy and staying active
  • It is important that they talk with their healthcare team about a heart-healthy diet
  • A healthy diet may also help keep energy levels up
• And number 3: Following their healthcare team’s instructions
  • It’s important for patients to work together with their healthcare team to develop a management plan that is right for them
  • If a routine isn’t working or if they are having trouble sticking to a management plan, they need to tell their healthcare team
    • Together, they may be able to find a different solution that better suits them
Try using open-ended questions to learn more about patients’ feelings toward managing their lupus.

An example might be, “What do you need to feel more like a partner with your healthcare team?”

This may help patients open up and help you work together to determine how they may be able to take more control.

Another option is using The Creating Your Action Plan work sheet. This can be accessed in the Let’s Practice section of this module.
• Being sun smart
  • Patients should try to limit exposure to UV rays when outdoors
  • Along with wearing a hat, long-sleeve shirt, pants, and sunscreen
You see here yet another example of an open-ended question that may help patients think about self-care.

“What do you do to take care of yourself?”
• Involve friends and family
  • They are a great source of support, so let them know how they can help

• Asking for help
  • Whether it’s a need for emotional encouragement, help running errands, or a second set of eyes and ears at a doctor’s appointment, patients shouldn’t be afraid to lean on those closest to them

• Many patients with lupus have found support groups to be very useful
  • Besides providing support, the group may make patients feel better about themselves and help them to keep a good outlook
As you see, this module emphasizes open-ended questions. Here are more examples you could use.

“What does your support system look like?”
“What do you turn to when you need help?”

These are usually harder to answer with a simple yes or no.

This might be a good place to use the Building Your Support Team work sheet found in the practice section of this module.
One of the challenges in managing lupus is the communication gap between patients, caregivers, and families.

- In 2011, GfK Roper North America conducted a survey of 957 members of the lupus community, which included patients, family members or friends, and rheumatologists.

- The survey revealed a serious gap between what patients were feeling and what they were willing to share with others, including their physicians:
  - 52% of patients reported that they minimized their symptoms when they talked to their physician.
  - 72% of physicians were unaware that patients tended to underreport their symptoms.
This gap poses a challenge and could result in certain symptoms being underreported.

It is important for patients to remember that the first step in taking control of their lupus is sharing all of their symptoms with their healthcare team and with their loved ones.

- It's the best way to ensure that patients get the support they need.
If patients are holding back from telling you what is really happening day-to-day, asking permission to share information with them may help them be more receptive to talking openly with you.

For example, “What are your thoughts about this information?” or “What are some topics you have a hard time bringing up at your appointments?”
This testimonial from Dr. Anca Askanase illustrates why keeping clear communication with the healthcare team is so important.

- Dr. Askanase is an internationally renowned rheumatologist and researcher who has spent more than 15 years specializing in complex SLE

- She reviews concerns that patients with lupus have and seeks ways to enhance communication with patients regarding lupus-related issues, such as disease symptoms, impact of the disease on patients, and realistic disease management goals

- Patients need to understand the importance of communicating their symptoms even though they may consider them a normal part of living with lupus
  - Low-level disease activity can still cause organ damage, and not communicating may represent a missed opportunity
Many factors can impact the conversation between patients and providers, so taking the time to understand more about your patients may help guide your conversation.

Some open-ended questions you could use may be:

“Thinking back over the last several weeks, what symptoms have you experienced that might be considered low-level disease symptoms?”

“Do you have examples of missed opportunities in your conversations with your healthcare provider?”
This is one of the most important messages for lupus patients: Communication is key.

- Communicating **all** symptoms to the healthcare team is key to managing lupus
  - Monitoring of lupus should be a team effort

- Sharing decisions and keeping open and honest communication is imperative
  - It is essential that the patient and the healthcare team agree on how to deal with the patient’s condition
  - It is important to talk openly and honestly
    - The patient needs to speak truthfully about how well he or she has been following the healthcare team’s advice
    - The patient should not be shy about bringing up issues that may be sensitive or difficult to talk about, such as intimacy

- Patients should be aware that their healthcare team is there to support them
To emphasize the importance of communication, patients may find it helpful to read this quote from Rena, an actual person living with lupus.
One way to help patients feel like their concerns and views are important is to summarize the information they’ve shared with you. This is also a way to confirm accuracy.

You could start with a phrase like, “Let me make sure I understand what you’ve told me so far.”
Then recap what the patient has told you.
Then, check to make sure you covered everything by saying something like, “Does that sound right?”
Encourage patients to reflect on the questions below and to use their work sheets.

- What does good communication with your healthcare team look like?

- Think about whether there are symptoms you don’t talk about with your healthcare team. If so, why?

- What kind of support and interaction do you want to receive from your healthcare team?

- What ways can you assist your healthcare team in having effective communication?

Members of the healthcare team may take this opportunity to have patients reflect, fill out the work sheets, and then discuss the answers.
In addition to the reflection questions on the previous slide, consider these questions to spark more conversation.

“Tell me how you get conversations started at your appointments.”

“You mentioned you don’t talk about...? Tell me more.”

“What would be an ideal conversation with your healthcare provider?”
We have talked about the importance of communication. Here are some tips to help patients communicate with their healthcare team.

• Number 1: Report all symptoms
  • Open and honest communication is an important part of monitoring lupus
  • Encourage patients to discuss all symptoms, even if they have disappeared

• Number 2: Patients should share with their healthcare team their entire health history and whether anyone in their family has ever been diagnosed with lupus or any other autoimmune disorder
  • Many patients will be seeing more than one doctor, so they should bring a list of all the doctors they are seeing and medications they are taking to every medical appointment
    • The list should be shared with the entire healthcare team

• Number 3: Follow the “Ask Me 3” Program
  • These Questions were designed by the National Patient Safety Foundation to encourage communication
    • What is my main problem?
    • What do I need to do?
    • Why is it important for me to do this?

• Number 4: Be informed and educated on lupus
  • The more patients know about their lupus, the easier it will be for them to talk to their healthcare team

• And lastly, keep in mind that the healthcare team may be very knowledgeable about lupus, but patients are the only experts on how they feel
It is important to be educated about lupus.

- Patients should try to learn as much as possible
  - They should know what ongoing tests may be needed to determine active disease

- Some of those tests may include:
  - Routine blood tests to analyze red and white blood cells and how blood is clotting
  - Urine tests, because the kidneys are often affected by lupus
  - Tests for antibodies against health tissues such as:
    - Antinuclear antibodies (or ANA) and anti-double-stranded DNA (anti-ds DNA) which reflect ongoing inflammation

- Lab testing may be used to monitor disease activity after a diagnosis has been made

*This is an opportunity for you to direct patients to tools that may help to educate them, such as the Lupus Dictionary, which can be downloaded for free at UsInLupus.com.*
Keeping track of symptoms and reporting them accurately is important.

- Here are some tips that you can present to patients to help them keep track of and report their symptoms accurately:
  - Keep a journal—write down any thoughts, feelings, symptoms, and any questions you might have.
  - Involve family and friends—they are a great source of support.
  - Use available apps on mobile devices—there are tools to help spark effective communication with the healthcare team.
  - Have medical records available for reference—there are some apps available for this as well.

- Instruct patients to monitor and share all of these important factors about their symptoms with their healthcare team:
  - Do they change over time?
  - How are they affecting your daily life?
  - Do they prevent you from doing the things that you enjoy?
  - Does lupus make you feel isolated, depressed, or frustrated?
Look for opportunities to help guide patients to voice why they might want a change. They may have very personal reasons for this. You can prompt the conversations with phrases like, “How would things be different if...?” or “How might this action change how you see your lupus?”
Encourage patients to reflect on the questions below and use their work sheets.

- How do you keep track of your symptoms?
  - Are you reporting your symptoms accurately?

- Do you forget to report symptoms?

- Are you being honest in reporting?

- Has there been a time that you have not told your healthcare team about a symptom because you thought it wasn’t important anymore?

This is an opportunity for members of the healthcare team to have patients reflect, fill out the work sheets, and then discuss the answers.
Communicating effectively with providers may be challenging for some patients. Try using these additional questions to help patients feel more comfortable in opening up with their providers.

Here are some examples:

“What gets in the way of...?”
“What’s the most important thing you want to tell your healthcare provider?”

You could also recommend that patients request a Lupus Journal from the Us in Lupus website to help them organize their thoughts and experiences between appointments.

When patients share what they feel is important to them, you could then share what information is important to you.
This is the end of Module 2. We reviewed

• Ways patients can take control of their lupus, including lifestyle changes and getting support
• Why communication is important, and
• How tracking lupus symptoms and reporting them helps patients take an active role

We also covered patient-centered communication tips such as

• Using open-ended questions to keep the conversation centered on the patient
• Asking for permission before sharing information
• Checking for understanding along the way, and
• Listening for change

You can visit the Let’s Practice section for this module to practice what you have learned. We also encourage you to continue to Module 3, where we will go over the various resources available to support patients.
Section 3 includes helpful resources that are available for patients with lupus. In a recent study, both patients and caregivers reported that they wanted more of this kind of information. So, let's get started.
This chapter of the presentation will cover:

- The resources and tools that can be freely accessed and used by patients to help them monitor their symptoms and better communicate with their healthcare team
- Tips on how to improve patient conversations and encourage a commitment to next steps
- Unique insights on patients that may help you frame your interactions around the issues they face each day
Before we get started with Module 3, remember that it is important to be patient-centered when working with patients. The first step is realizing that patients with lupus may face barriers that prevent them from getting the most out of their treatment. Take the time to understand individual barriers, concerns, and situations to help you customize patient education.

Throughout this module, you’ll periodically see slides that look like this one, labeled as a tips page. These pages will provide you with the ideas you may use with patients to help you stay patient-centered during your presentations.
There are specific communication techniques highlighted here that may be useful when meeting with your patients. Using these techniques will help you build rapport with patients, stay focused on their needs, and may ultimately help patients better manage their lupus.

As you work through this module, you’ll see these techniques highlighted in different spots. Think about specific instances in which you might be able to use these techniques when meeting with patients.

You will also see visual icons. These represent insights pulled from patient research that may further help to benefit your conversations with patients.
Patients with lupus are not alone.

- They can reach out to any of these for help and support:
  - Family
  - Friends
  - Their Healthcare team
  - Patient advocacy groups
  - And the *Us in Lupus* program
Take the time to express empathy.

“Having lupus can feel like an emotional roller coaster. You have a lot to deal with each day.”

Acknowledging the emotions that come along with a lupus diagnosis may help your patients feel more comfortable opening up to you.

You could also suggest the Building Your Support Team worksheet found in the practice section of this module. This may help patients identify people in their support network that they can count on as they manage their lupus.
You can direct patients to use UsinLupus.com.

- *Us in Lupus* is designed to give more than just facts about lupus

- It is a resource designed by GSK that offers people living with lupus the skills, tools, and confidence they need to help them face lupus
There are many resources available for patients to use to help them more optimally manage their condition. Before meeting with patients, familiarize yourself with the materials available.

Remember, asking permission before sharing information may help patients be more open: “Would it be okay if I share some options with you and then you can tell me what you think?”
• *Us in Lupus* provides a set of tools to help patients with lupus prepare for doctor appointments and offers a series of self-help booklets to boost their skills and confidence
  • When these tools are used together, the result may be better management of lupus and productive interactions with the healthcare team.
The next few slides provide an overview of the tools that can be found at UsinLupus.com, such as the Lupus Checklist.

• This printable checklist may help patients record symptoms and other changes to their health

• It may help patients recognize symptoms and risk factors for lupus

• Encourage patients to print it, fill it out, and bring it to their next medical appointment to spark discussions with their healthcare team

• To download, simply visit UsinLupus.com
The Lupus Impact Tracker™

- This tracker is a simple worksheet that may help a patient determine a rating for how lupus is affecting his or her life.

- It should be completed once every 4 weeks, and the results should be shared with the healthcare team.

- The patient should bring a completed version of the form for each month since his or her last appointment.

- To download, simply visit www.usinlupus.com.
My Lupus Log

• This is an app available for free from the Play Store on any Android device

• My Lupus Log allows patients to:
  • Conveniently track lupus symptoms
  • Record and monitor how they are affecting you
  • Customize your profile
  • Learn more about lupus
  • Stay focused with alerts and reminders
  • Customize functions with step-by-step instructions

• This app is only for personal use and does not link to their medical charts or records

• Keeping a close eye on symptoms is part of managing lupus
The Lupus Journal

• Patients can request a free, customizable lupus journal

• When living with lupus, journaling may be a good way to document thoughts, feelings, symptoms, and any questions a patient may want to discuss with his or her doctor

• Patients simply register at the Us in Lupus website (UsinLupus.com), and their free lupus journal will be on its way

• They may also receive Speaking of Lupus, a series of self-help booklets designed to boost skills and confidence. These tools may help them make the most of their interactions with the important people in their lives—including their healthcare team
The Appointment Prep Guide

• This handy checklist may help patients make the most of their medical visits

• Patients should read it carefully and bring it to all of their medical appointments

• To download, simply visit UsinLupus.com
The Lupus Dictionary

• This is a free list of lupus-related terms that may help a patient prepare for medical appointments and better understand the conversations they have with their healthcare team

• To download, simply visit UsinLupus.com
Encourage patients to reflect on the questions below and use their work sheets.

- What are your challenges in living with lupus?
- How can these tools help?
- How can you use each of these tools?
- Pick one tool, and visualize yourself using it. Do you think you can implement it into your management plan?

This is an opportunity for members of the healthcare team to have patients reflect, fill out the worksheets, and then discuss the answers. The healthcare team can then discuss the management plan with patients.
As you review these resources with patients, ask them to choose one or two they’d like to try for the next few weeks.

It might sound something like this:

“*We’ve talked about several resources that may help you feel more in control of your lupus. Which one could you commit to trying for a while and taking to your next appointment?*

“You don’t have to do everything at once. Where are you comfortable starting?”

Making this choice can be empowering for patients.
There are also many local advocacy groups

- Encourage patients to be aware of any patient advocacy groups in their area
  - These groups may provide extra support, educational resources, and tools to help patients manage lupus

- The Lupus Foundation of America provides resources and support for patients living with lupus

- The Lupus Initiative is a national education program that offers educational resources

- The Lupus Research Institute (LRI) has a National Coalition, which is a network of state and local organizations and advocacy groups
  - Patients can go to LRI to find out more information about local groups

Please Note: These resources are external to GSK. GSK does not have control over the content or information provided through these resources, and accordingly does not warrant their accuracy or completeness.
Here are key messages to stress to patients.

Always remember:

• You are not alone—take charge!

• Don’t be embarrassed to ask for help

• Your healthcare team, friends, and family are here to help
This is the end of Module 3. We have reviewed
• Where patients can go for help
• The helpful tools available at Us In Lupus.com, and
• How to find support groups and other resources

We also covered patient-centered communication tips such as
• Expressing empathy to build rapport
• Offering resources that might be helpful, and
• Asking for the commitment to one thing the patient feels he or she can do now

This is the last module in the SLE Patient Education Champion program. You can review the practice section for this module for more tips and exercises. Congratulations! Thank you for being part of this program.