# A DISCUSSION GUIDE FOR PATIENTS WITH LUNG CANCER WHO ARE EXPERIENCING UNEXPECTED SYMPTOMS, INCLUDING MUSCLE WEAKNESS

Why it's important for you or your loved one to ask your doctor about Lambert-Eaton myasthenic syndrome (LEMS):

- Some of the symptoms you're experiencing may NOT be related to your cancer or its treatment, but rather a neuromuscular condition that can be managed with an oral medicine
- 1 out of 10 patients with lung cancer—frequently small cell lung cancer (SCLC) has a co-occurring paraneoplastic syndrome

#### Paraneoplastic syndromes:

- Are a set of signs and symptoms that can occur when you have cancer
- Can occur when your immune system attacks a cancerous tumor but also mistakenly targets healthy cells in your body
- Can affect multiple body systems and organs, including your nervous system, endocrine system (hormones), kidneys, bones, joints, skin, and blood

One example of a paraneoplastic syndrome is LEMS, a neuromuscular disorder that disrupts the communication between the nerves and muscles

**HOW TO TALK** 

WITH YOUR ONCOLOGY

**CARE TEAM** 

**ABOUT LEMS** 

- LEMS causes debilitating muscle weakness and fatigue
- The most common symptom of LEMS is muscle weakness, especially in the legs and hips
- LEMS can also weaken muscles in other areas of the body and affect a part of the nervous system that controls automatic bodily functions, such as saliva production and erectile function



# AS A CANCER PATIENT, IT'S IMPORTANT TO FIND OUT IF YOU HAVE LEMS SOONER RATHER THAN LATER

# IN PATIENTS WITH CANCER, LEMS CAN DEVELOP ANYTIME—AND WORSEN QUICKLY



#### Up to 60% of LEMS cases are associated with cancer

- LEMS symptoms may be present when cancer is first diagnosed
- Symptoms can also develop 5 years or more after a cancer diagnosis
- If you have lung cancer and LEMS, LEMS can progress quickly
- · Your ability to do everyday activities could be affected
- For these reasons, it's important to know if you have LEMS sooner rather than later—and get treated for it if you do

## EARLY DIAGNOSIS OF LEMS IS IMPORTANT—BUT IT'S NOT HAPPENING OFTEN ENOUGH IN PATIENTS WITH CANCER

# 9 OUT OF 10

LEMS cases associated with SCLC may be undiagnosed, according to estimates

There are 3 common testing methods to diagnose and/or confirm LEMS:



A physical exam to evaluate your symptoms and test your reflexes



A blood test to check for the presence of certain antibodies



An electrodiagnostic test to measure how well your muscles and nerves are communicating

# **RECOGNIZING THE SIGNS AND SYMPTOMS OF LEMS**

# IT'S IMPORTANT TO LEARN THE SYMPTOMS OF LEMS, TRACK AND RECORD ANY YOU RECOGNIZE, AND SHARE THIS INFORMATION WITH YOUR CARE TEAM



### Symptoms of LEMS include:

- Upper leg weakness
- Lower leg weakness
- Arm weakness
- Fatigue
- Dry mouth

- Dry eyes
- Drooping eyelids
- Blurred vision
- Erectile dysfunction
- Constipation

### These symptoms can affect your everyday activities, including:

Walking

- Reading
- Climbing or descending stairs
- Getting up from a chair
- Getting into or out of a car
- Raising arms or lifting objects
- Talking
- · Chewing and/or swallowing
- Getting/maintaining an erection
- Having a bowel movement



# TAKE THE NEXT STEP

Download the Symptom Tracking Journal, MY NEXT STEP. It's a great tool that can help you easily track your symptoms and share them with your oncology care team.

**DOWNLOAD JOURNAL** 

# QUESTIONS TO ASK YOUR ONCOLOGY TEAM ABOUT LEMS

# LEMS MAY NOT BE TOP OF MIND FOR YOUR ONCOLOGY CARE Team—which is why it's vital for you to bring it up

#### **Consider asking the following questions:**

#### Could my symptoms be related to LEMS?

- Your oncology care team will talk to you about which symptoms may be related to lung cancer or cancer therapy and which could be LEMS
- I'm having trouble with the following daily activities [insert list]—do you think it could be LEMS?
  Be specific when listing activities or functions being affected by your symptoms. (Download the MY NEXT STEP journal to make it easier!)

### What tests will help determine if I have LEMS?

Your oncology care team may order a physical exam and then possibly a blood test to see if you have antibodies that are associated with LEMS. They may also order an electrodiagnostic test to determine how well your nerves and muscles are communicating

#### Do I qualify for a free antibody blood test?

Be sure to ask your oncology care team this question! Free antibody blood tests are available through Catalyst Pharmaceuticals, but your doctor needs to call to request one for you

#### What happens if my test for LEMS comes back positive?

- If you test positive, your oncology care team may treat you with the approved therapy or refer you to a neurologist for treatment

### • What happens if I test negative for LEMS?

 If you test negative, your oncology care team may refer you to a neuromuscular specialist for further tests to make sure you really don't have LEMS



# DON'T WAIT TO TALK TO YOUR CARE TEAM ABOUT LEMS

One study found that it took some patients **MORE THAN 4 YEARS** to receive a correct diagnosis of LEMS. That's way too long—you need to get back to your life!

Remember—the sooner LEMS is recognized and diagnosed, the sooner you can begin treatment that can help you to feel better.



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