



# **EXECUTIVE SUMMARY**

MORE AMERICANS THAN EVER BEFORE HAVE ASTHMA. It is one of this country's most common and costly diseases.

For many years, asthma has been thought of as a single disease. But new studies show asthma is a chronic condition that can be different for each person. This means **there** is **no** "one size fits all" **approach to managing asthma.** 

Many people with asthma manage it well, thanks to current treatments. Despite this, an estimated 5 to 10 percent of people with asthma have trouble managing it even on maximum therapy. People in this group have **severe asthma.** 

Often, people with severe asthma experience a greater emotional, social and financial burden of disease.

A person with severe asthma may have symptoms every day, throughout the day. They may also have trouble sleeping most nights. Severe asthma can limit the ability to do even simple tasks. Severe, uncontrolled asthma can be debilitating.

As U.S. asthma rates grow, severe asthma affects those who have it, as well as health care systems. It is now known more than ever as a serious public health concern. We need to change how we look at and talk about asthma.

### WHAT IS ASTHMA?

Asthma is a chronic lung disease that causes airways to become inflamed, making it hard to breathe. Common symptoms are coughing, shortness of breath, wheezing and chest tightness. Currently, about 25 million Americans are living with this chronic condition, including more than 18 million adults.

Asthma is associated with high health care costs. This includes direct costs like hospitalizations and medicines, as well as indirect costs like missed school and work. Many people with asthma also experience social and emotional impacts of the disease.

There is no cure for asthma, but many people can live normal lives if their asthma is properly managed and controlled.

# **Objectives**

For many years, the Asthma and Allergy Foundation of America (AAFA) has worked to better understand the families and communities affected by asthma. To ensure the programs we develop are effective and appropriate, AAFA regularly requests input from those who are impacted by the disease.

In 2017, AAFA — with support from AstraZeneca — led a national three-part study about asthma in the U.S. The study included three survey populations:

- Adult patients with asthma
- Caregivers of adults with asthma
- Health care professionals who care for adults with asthma

The purpose of these surveys was to understand the burden of asthma – especially severe asthma – from patients, caregivers and health care professionals.

When we know more about severe asthma, we can change how we talk about it. And we can make sure people with severe asthma are the focus of these discussions.

This document presents a summary of findings from the patient survey.

# **Study Design**

From February 27 to April 8, 2017, adults with asthma participated in a national online survey. The survey was sent to people in AAFA's e-mail database, online community and social networks.

Multiple-choice and open-ended questions asked respondents about:

- Quality of life due to asthma
- Severity of asthma
- Knowledge of asthma
- Thoughts and beliefs about asthma

## **Survey Population**

There were 875 people who began the survey. Of those, AAFA qualified 804 respondents as U.S.-based adults diagnosed with asthma.

Of those 804 adults with asthma, 185 were determined to have "severe uncontrolled" asthma. This was based on their reporting of symptoms and medicine use. The remaining 619 respondents were determined to have asthma that was "not severe uncontrolled."

Began patient survey 875	
Qualified respondents based on age and asthma diagnosis 804	
185 classified as  GROUP A:  "severe uncontrolled"	619 classified as  GROUP B:  "not severe uncontrolled"

Respondents were grouped using the table below. To be in the "severe uncontrolled" group, they had to meet criteria for both "severe" and "uncontrolled."

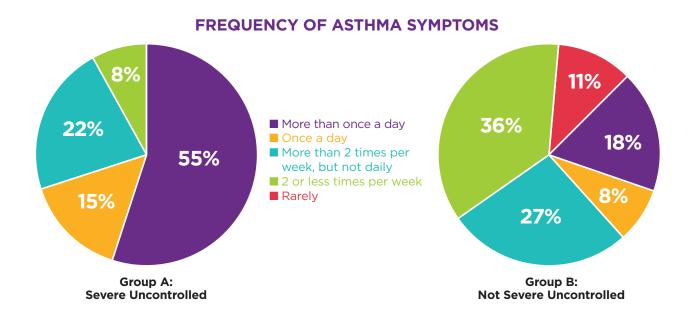
To be considered "severe," respondent must have answered these questions with the following answers:	To be considered "uncontrolled," respondent must have answered ANY of these questions with the following answers:
A doctor or nurse has told you that you have asthma (must have answered "severe")	In general, how often do you experience symptoms of asthma, such as chest tightness, cough, shortness of breath or wheezing?  (must have answered at least more than two times per week)
	In general, how often do you wake up during the night because of coughing or other asthma symptoms?  (must have answered more than once a week)
In the past 12 months, which types of prescription medicines have you used for your asthma? (must have answered with at least one of the following: combination inhaler, anti-IgE biologic agent or anti-IL-5 biologic agent)	In general, how often do you use your rescue or "quick-relief" inhaler? (must have answered more than two times per week)
	In the past 12 months, how many asthma attacks have you had that required you to take a steroid pill by mouth (such as prednisone)?  (must have answered two or more)

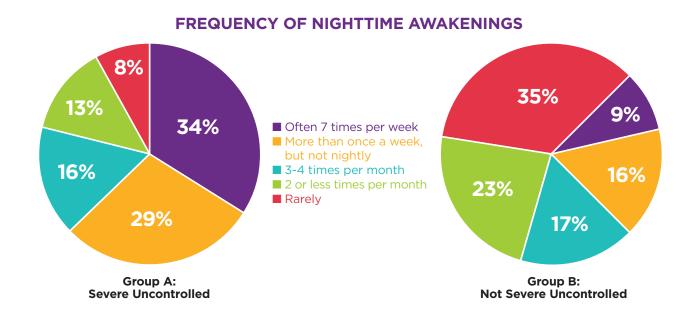
"I have been in and out of the hospital all of my life."
- Survey respondent

# **FINDINGS**

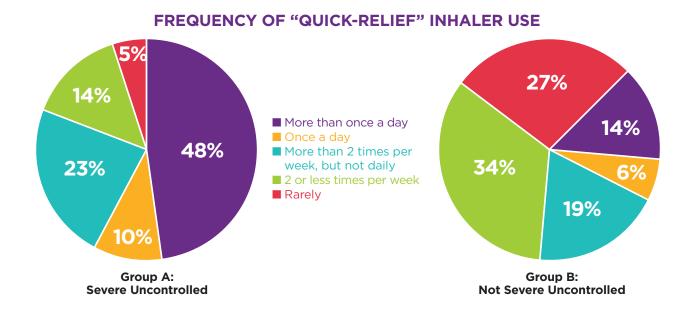
Adults with severe, uncontrolled asthma have more frequent symptoms of asthma, use of rescue medicine and emergency room visits.

In Group A, 55 percent said they have symptoms more than once a day. Also, more than one-third of this group said they regularly had symptoms at night.

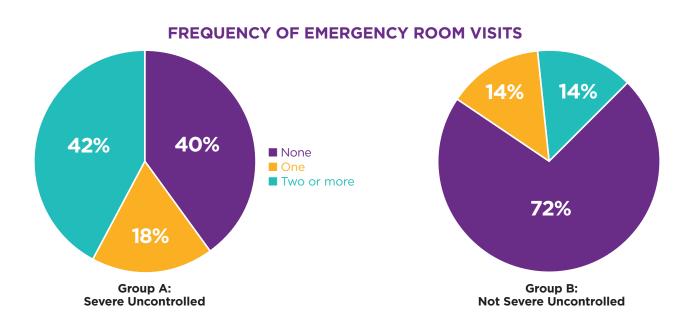




Nearly half of Group A reported using a quick-relief inhaler more than once a day.



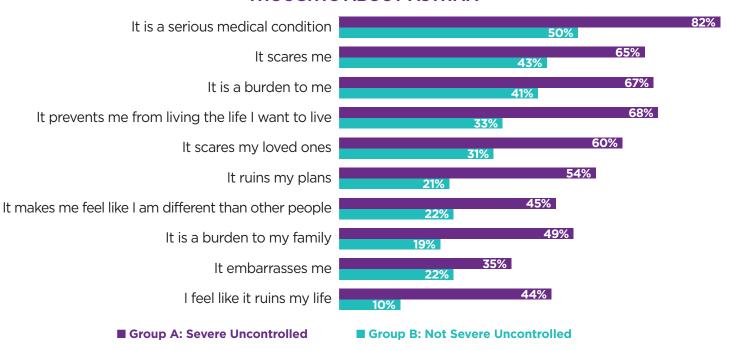
In Group A, 60 percent visited an emergency room at least once in the past 12 months due to their asthma. In comparison, only 28 percent of Group B visited the emergency room in the past 12 months.



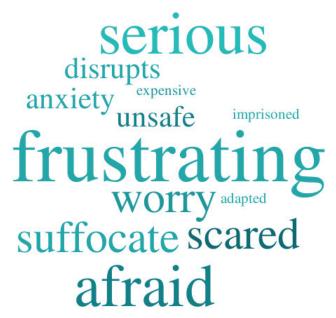
# Adults with severe, uncontrolled asthma think more often and more negatively about their asthma.

In Group A, 82 percent think about their asthma as a serious medical condition, compared to 50 percent of Group B.

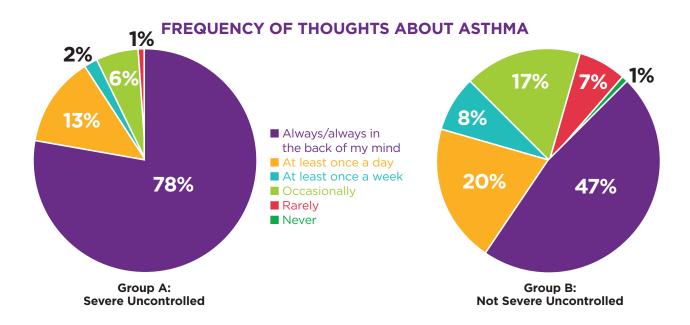
### **THOUGHTS ABOUT ASTHMA**



When given the chance to give more thoughts about asthma, respondents used words like "frustrating," "afraid" and "serious."



In Group A, 78 percent said their asthma was "always in the back of their mind," compared to 47 percent of Group B.



In Group A, 41 percent felt their asthma is so severe that there are no medicines that can make it better. Only 7 percent of Group B believed the same thing.

## **BELIEFS ABOUT ASTHMA**

My asthma is so severe (bad) that there are no medicines that can make it better

41%
Group A:
Severe Uncontrolled

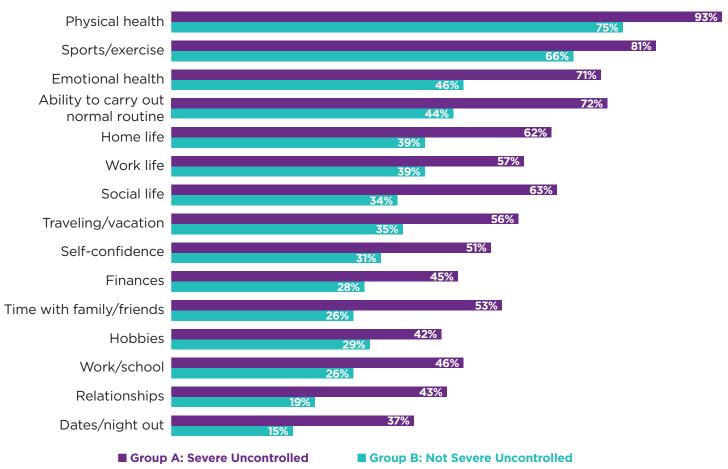
Group B:
Not Severe Uncontrolled

"[My asthma] comes and goes but when it comes, it feels like my life is ending."

- Survey respondent

Group A said their asthma had greater negative impact on quality of life, as compared to Group B. This included physical, social, financial and emotional well-being.

### **NEGATIVE IMPACTS OF ASTHMA**

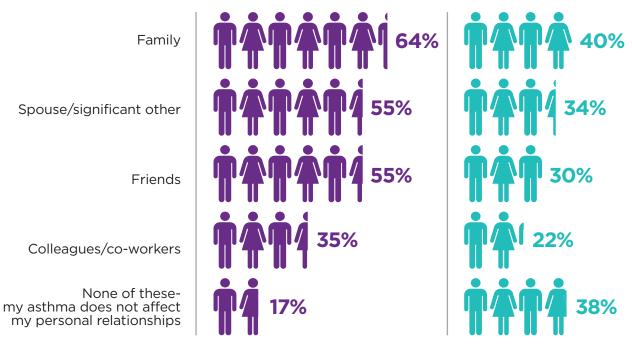


"My asthma controls my life. I want to be in control of my asthma."

- Survey respondent

Relationships with family, significant others, friends and colleagues are impacted by asthma. Only 17 percent of Group A said their asthma doesn't affect their relationships, compared to 38 percent of Group B.

## **ASTHMA IMPACTS ON PERSONAL RELATIONSHIPS**

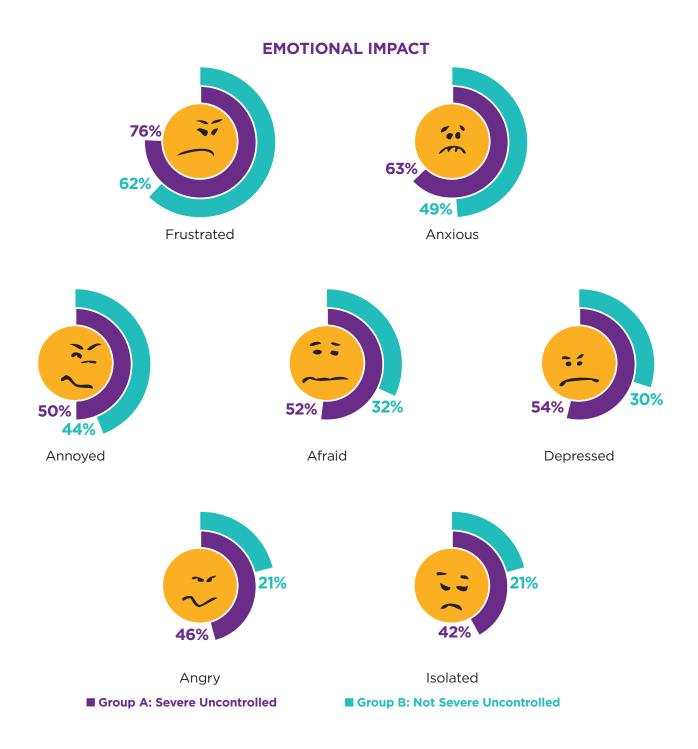


■ Group A: Severe Uncontrolled ■ Group B: Not Severe Uncontrolled

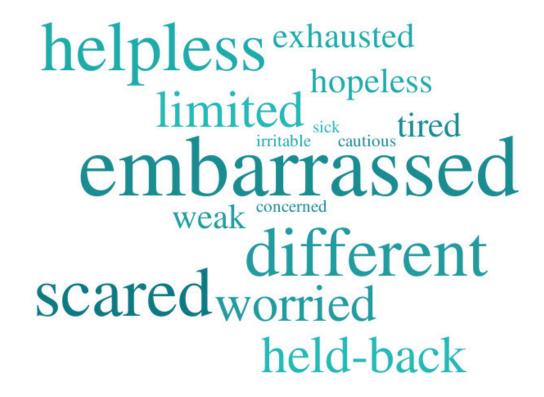
"It's scary. You never know if it will be your last breath during an attack."

- Survey respondent

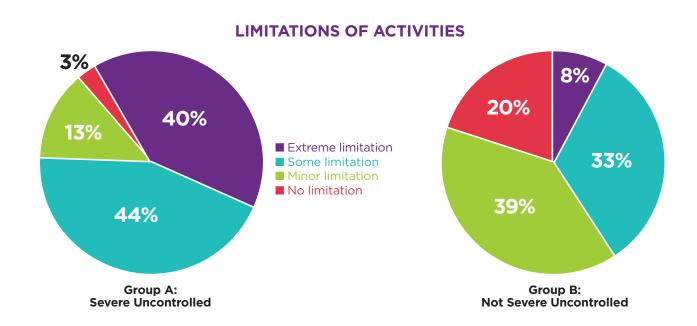
Both groups said frustration and anxiety were the most common emotions they had when asked how asthma makes them feel. Overall, more respondents from Group A reported negative emotions related to their asthma than Group B.



When given the chance to provide other ways asthma made them feel, respondents used words like "different," "helpless" and "embarrassed."



Group A reported having much higher limits on everyday tasks due to asthma.



Group A reported that asthma caused them to miss more work and be less productive.

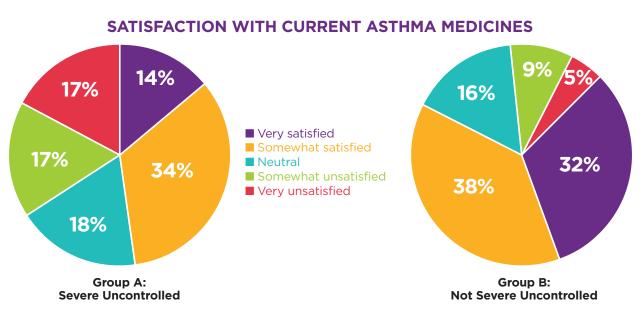


### DAYS OF DIFFICULTY PERFORMING TASKS AT WORK OR SCHOOL



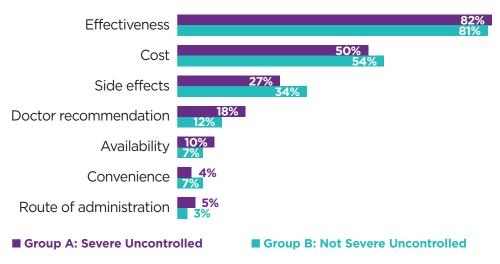
# There is no "one size fits all" approach to asthma managment.

Less than half of Group A said they were happy with their current asthma medicines, while 70 percent of Group B said they were happy with their medicines.



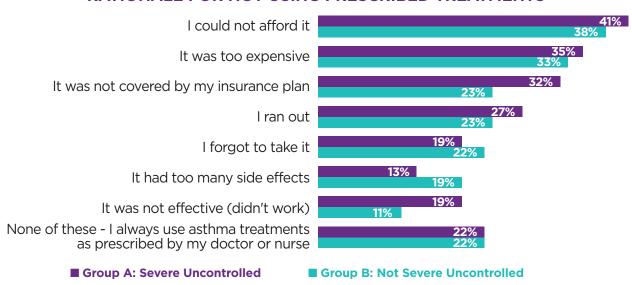
For both groups, effectiveness and cost were the two most important factors when choosing asthma medicines.



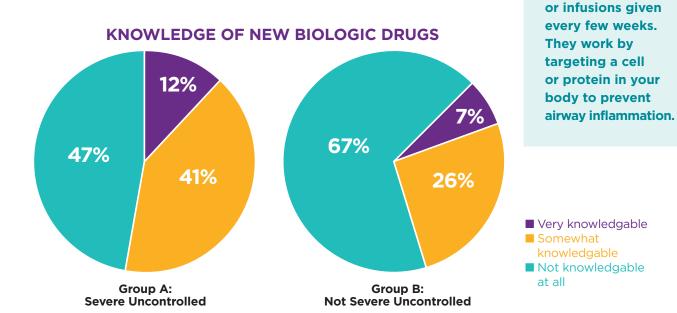


For both groups, cost was the most common reason for not using asthma treatments.

### RATIONALE FOR NOT USING PRESCRIBED TREATMENTS



Neither group reported significant knowledge of biologic drugs for asthma.



Even in Group A, only 22 percent recall having a conversation with their health care provider about their eosinophilic count.

# HELD CONVERSATIONS WITH PROVIDER ABOUT EOSINOPHIL COUNT

**22%**Group A:
Severe Uncontrolled

Group B:
Not Severe Uncontrolled

Eosinophils are a type of white blood cells that protect your body from parasites. There is an association between asthma and higher levels of eosinophils found in the blood. Eosinophilic asthma is a type of asthma that is often severe.

**Biologics are shots** 

Only about one-third of respondents knew eosinophils could make asthma worse.

### **KNOWLEDGE OF EOSINOPHILS**

Eosinophils can make some people's asthma worse **39%**Group A:
Severe Uncontrolled

31% Group B: Not Severe Uncontrolled

# CONCLUSIONS

As the asthma burden in the U.S. continues to grow, severe asthma inflicts a high burden on patients and healthcare systems. Severe asthma is now recognized more than ever as a priority public health concern.

The results of this patient survey highlight the emotional, social and financial burden of severe and uncontrolled asthma among the survey participants. Severe asthma causes frequent frustration and can have a significant impact on almost every aspect of life.

The results of this survey provide a step forward to help us build better tools, resources and treatments to help patients and families overcome the burden of asthma and improve quality of life.

We hope these findings will be used to help change the way we talk about and support severe asthma.

We encourage patients discuss with their healthcare professionals specifically how asthma negatively impacts their day-to-day life, and what they hope to achieve with treatment. We encourage healthcare professionals to work closely with their patients to understand the many ways severe asthma is affecting quality of life. Together, people with asthma and their support teams can develop a shared understanding of asthma management and treatment goals.

Managing severe, uncontrolled asthma can be easier with the support of others. If you are living with asthma or caring for someone with asthma, AAFA offers a free online support community where you can connect with others managing the same condition. Join online at **community.aafa.org.** 

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