

the us in lupus Webcast Series

Funded and developed by
GlaxoSmithKline



the **us** in **lupus** 
together we're stronger

Moderator

Arnita Christie, INE

RN,BSN, MS



Arnita is a Senior Immunology Nurse Educator (INE) within the Immunology and Rare Disease Division of GlaxoSmithKline. She provides training and delivers educational programs to Infusion/Rheumatology specialists and hospital personnel.

Arnita has over 28 years of nursing and clinical education experience. She has helped increase disease awareness by educating healthcare professionals and patients in the areas of psychiatry, HIV, cardiovascular medicine, diabetes, and SLE.

Guest Expert



Christopher Parker, DO

Dr. Parker has served as the chief of rheumatology and clinical immunology at a clinic in Austin, Texas, for more than 12 years.

Before that, Dr. Parker, a board-certified rheumatologist, served in the Army and received his postdoctoral training at William Beaumont and Walter Reed Army Medical Centers and the Walter Reed Institute of Research.

Dr. Parker has received numerous awards and honors for his rheumatology service and has written several scientific articles about systemic lupus erythematosus.

the us in lupus

Patient Ambassador



GlaxoSmithKline sponsors Ambassadors for the **us in lupus** and pays them for their time and expense in sharing their experiences.



Persha

Living with SLE since 2003

Shortly after relocating to the United States, Persha noticed that her ankle was swollen and she was always tired. After a series of referrals to various doctors, she was finally diagnosed with systemic lupus erythematosus (SLE).

Persha lived in denial of her diagnosis, but soon realized that she needed to empower herself. She started doing everything she could to take better care of herself and openly communicate with her doctors and loved ones.

As a Patient Ambassador for the **us in lupus**, Persha reminds others that they are not alone in their fight against lupus.

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Keep in Mind

- This program is funded and developed by GlaxoSmithKline, and my guests are compensated for their time in presenting this program.
- The information provided today is for educational purposes. It does not take the place of talking to your doctor about your medical condition.
- Each person's experience with SLE varies, and each person's individual situation may be different.
- This program offers information intended to provide a basic overview of effective communication and SLE.

Speak Up: Why Effective Communication Matters With Lupus



Cathy
the **us in lupus** Ambassador
Living with SLE since 1983

Today's Discussion Topics

- The impact of systemic lupus erythematosus (SLE)
- Communication gaps
- Communicating with your healthcare team
- Importance of discussing all of your symptoms with your doctor

Impact of SLE

Persha

the **us in lupus** Ambassador
Living with SLE since 2003



SLE May Affect More Than a Person's Health



Quality of life



Career



Relationships with family and friends

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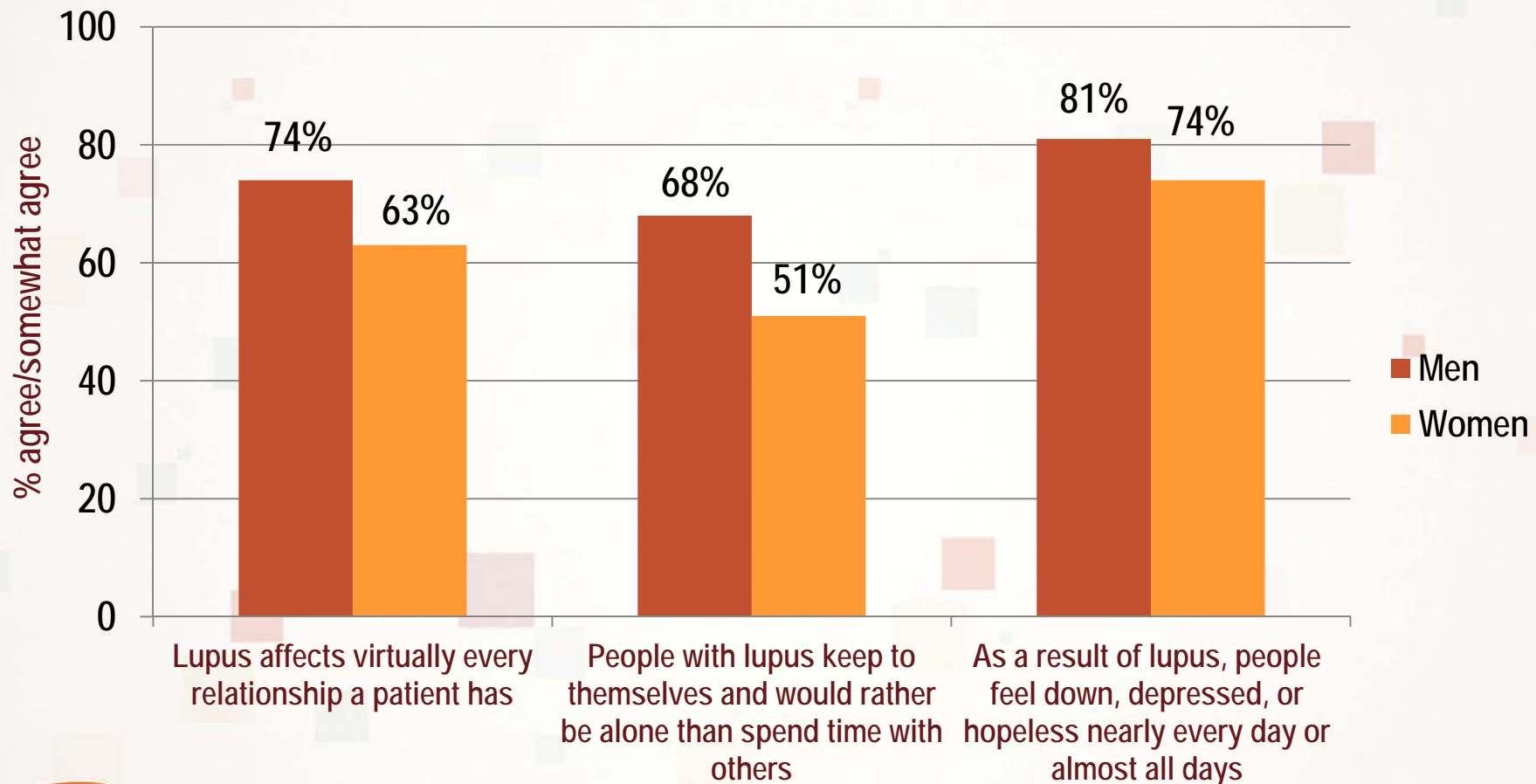
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National Burden of Disease Survey (NBDS) 2011

- A survey among the SLE community, which included 502 SLE patients, 204 family members or friends, and 251 rheumatologists
- Designed to evaluate the daily and long-term impact of SLE on health, family, relationships, career, and overall well-being
- Results identified potential gaps in communication between SLE patients and their providers

The Emotional Impact

- The NBDS showed that people who have a chronic disease like SLE may have difficulty maintaining their self-esteem*



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Communication Gaps

Rena
the **us in lupus** Ambassador
Living with SLE since 1994



Communication Gaps in SLE

- The NBDS noted communication gaps between people living with SLE and their loved ones and healthcare teams*



Joyce, left, and her daughter, **Lindsay** the **us in lupus** Ambassadors Living with Lindsay's SLE since 2006



Patients reporting they downplay their pain and other symptoms to avoid upsetting their families



Patients who minimize their symptoms when talking with their physician



Physicians reporting they were unaware that their patients were underreporting their symptoms

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Potential Effects of SLE's Communication Gaps

- Possible disease mismanagement
- Frustration
- Sense of isolation
- Fear
- Stress



Carrie

the **us in lupus** Ambassador

Living with SLE since 2009

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Communicating With Your Healthcare Team



Tammy Utset, MD
Rheumatologist

Dr. Utset is a paid spokesperson for
GlaxoSmithKline.

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Communicating With Your Healthcare Team

- Healthcare professionals and lupus patients both contribute to the success of medical appointments
 - Provide specific information on:
 - Medical history
 - Symptoms you are experiencing
 - Current management plan
 - Be organized, clear, and efficient with your communication, so you can make the most of your appointments
 - Write down any instructions you may have been given



Bridget
the **us** in **lupus** Ambassador
Living with SLE since 1987

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Express Yourself

- **Establish a common language with your doctor**
 - Your physician may talk about your condition differently than you do
- **Make sure you're both “on the same page”**
 - Ask clear, direct questions
 - If you don't understand something, ask for clarification

Express Yourself (*cont*)



Dougal Waters/Digital Vision/Getty Images

- You are the expert when it comes to your needs, preferences, priorities, concerns, goals, resources, and values, so it's OK to express them to your doctors

What Else Can You Do?



Linda
the **us in lupus** Ambassador
Living with SLE since 1990

- **Bring a friend, family member, or someone you trust with you to your doctors' appointments**
 - These supporters can advocate for you, share their perspectives, or provide an extra set of ears for listening to doctors or other members of your healthcare team
- **Keep a journal that contains information about your symptoms and how they are affecting you daily**

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Available Resources

- the **us in lupus** website (www.usinlupus.com) offers a wide variety of support and resources
 - Doctor Discussion Guide
 - Offers tips and pointers that may help you prompt productive discussions with your healthcare team
 - Lupus Impact Tracker™
 - Is a form to complete every 4 weeks; you can share the results with your doctor to see how lupus is affecting your life
 - Lupus Dictionary
 - Contains a list of lupus-related terms and their meanings to help you establish a common language with your doctor

Available Resources (*cont*)

- **my us in lupus**
 - Personal Page will be updated regularly with customized messages, articles on topics you can select, and resources for support in living with lupus
- **Lupusoutloud.com**
 - Pledge to make an appointment with your doctor to have an open and honest conversation about your symptoms

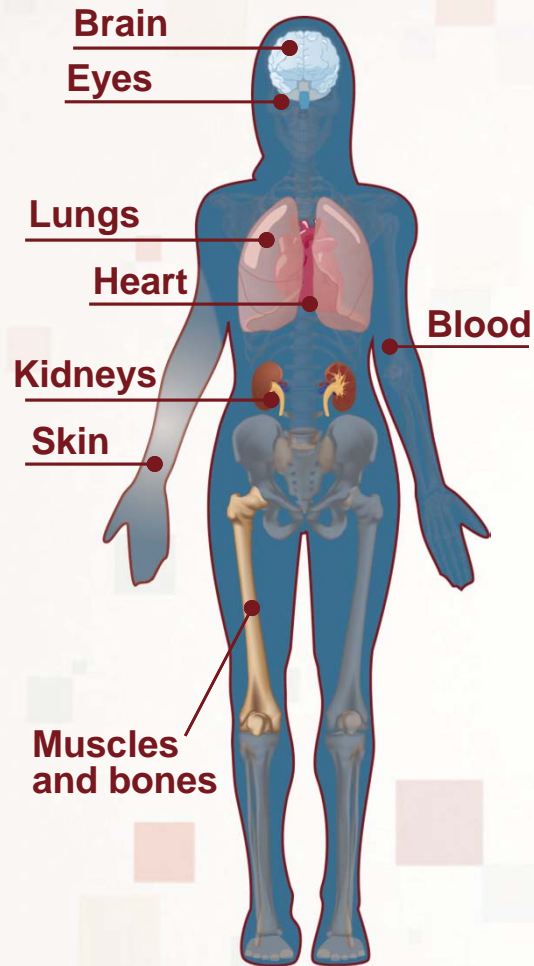
Presenting All of Your Symptoms



Gwenn

the **us in lupus** Ambassador
Living with SLE since 2000

Organ Damage



- SLE and the inflammation it causes can harm organs and organ systems
- SLE can cause many different symptoms
 - Skin rashes
 - Inflammation of heart and lungs
 - Kidney failure
- Symptoms you experience may be a sign of underlying disease activity
 - Share all of your symptoms with your doctor, as they could be signs of organ damage

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Thank You

Dr. Parker and Persha!



Don't Miss the Next Program!

For more information,
call 1-855-578-5348 or visit
www.usinlupus.com

Thank You for Listening!

**This program is for informational purposes
and does not constitute medical advice.**

