

Guidebook for Patients Newly Diagnosed with SLE

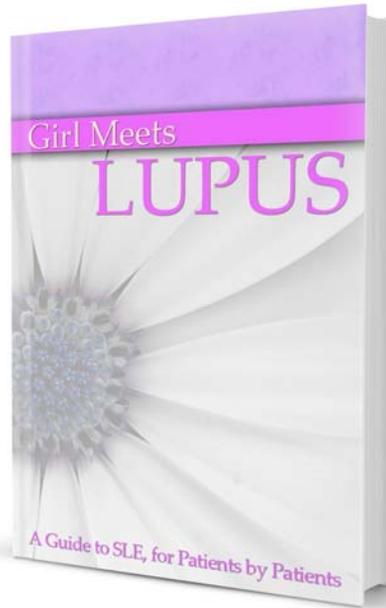
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Significance

- About 1.5 million Americans have systemic lupus erythematosus (SLE). 80% are diagnosed between ages 15-45, and 90% are women.
- In a nationwide poll by the Lupus Foundation of America, 39% have only heard the word lupus and know nothing of the disease, and 22% state they have never heard the word lupus. Patients are often ignorant of SLE when diagnosed.
- A study of lupus patients reports a majority of respondents cited emotional problems and lifestyle changes associated with the disease as the most difficult factor of coping with lupus.

Book & Survey

- There is little practical, immediately useful information for newly diagnosed SLE patients.
- Most patient-centered literature emphasizes medical facts, implying that patients are powerless information seekers.
- I created a book to encourage self-respect and highlight a patient's role as information seeker and SLE expert. The book covers medical information, an optimistic perspective for common situations faced by SLE patients, and ready-to-use *pearls of wisdom* from experienced to newly diagnosed SLE patients.
- To obtain the *pearls of wisdom*, Arizona rheumatologists distributed a 14-page survey to patients ≥ 5 years from diagnosis.
- Survey respondents indicated that the survey's open ended design allowed cathartic narrative sharing and empowered them as experts and guides for newly diagnosed patients.



Discussion

- Writing this book gave me deeper understanding of SLE patient similarities and differences. SLE patient experiences vary widely, but there are many shared feelings and experiences that unite them.
- I hope to increase the number of survey respondents by making the patient survey available online. An online version of the survey will allow easier completion by a generation of women more comfortable with the keyboard than the pen, reach a wider geographic audience, and greatly reduce costs.
- My ultimate goal is to create a complete book for patients with SLE that is informative, entertaining, and available on the day of diagnosis. This will provide newly diagnosed patients with real and useful information at a difficult and confusing time.

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