

# DEMOGRAPHIC CHALLENGES OF A MULTICENTRIC PAKISTANI LUPUS COHORT

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**WE HAVE NO FINANCIAL DISCLOSURES**

# LEARNING OBJECTIVES

- Assess the clinical variation across different ethnic/racial backgrounds of SLE patients in Pakistan

# CONTENT OUTLINE

- Understand importance of demographics in Lupus such as early age of onset in certain populations leading to a higher disease burden.
- Higher female predominance in childbearing age in certain groups needs effective family planning measures by policy makers.
- Economics affect provision of fertility safe drugs for treatment.
- Understand urgency for focus on health policy, public awareness and governmental spending on lupus and related diseases

# INTRODUCTION

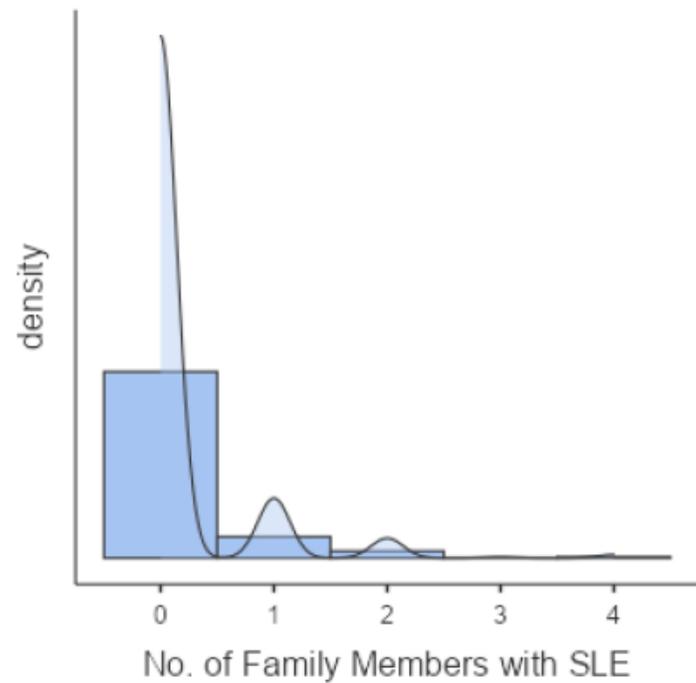
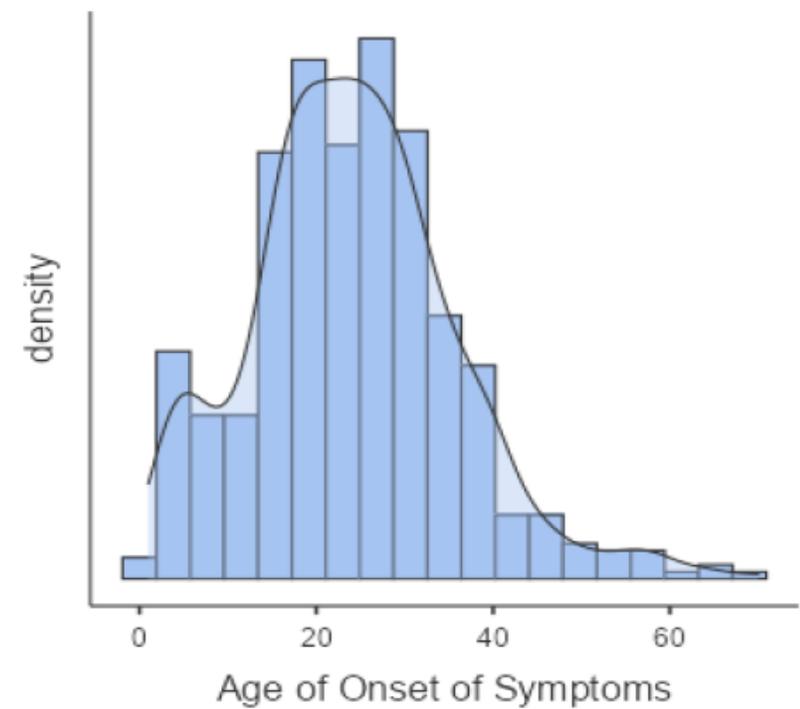
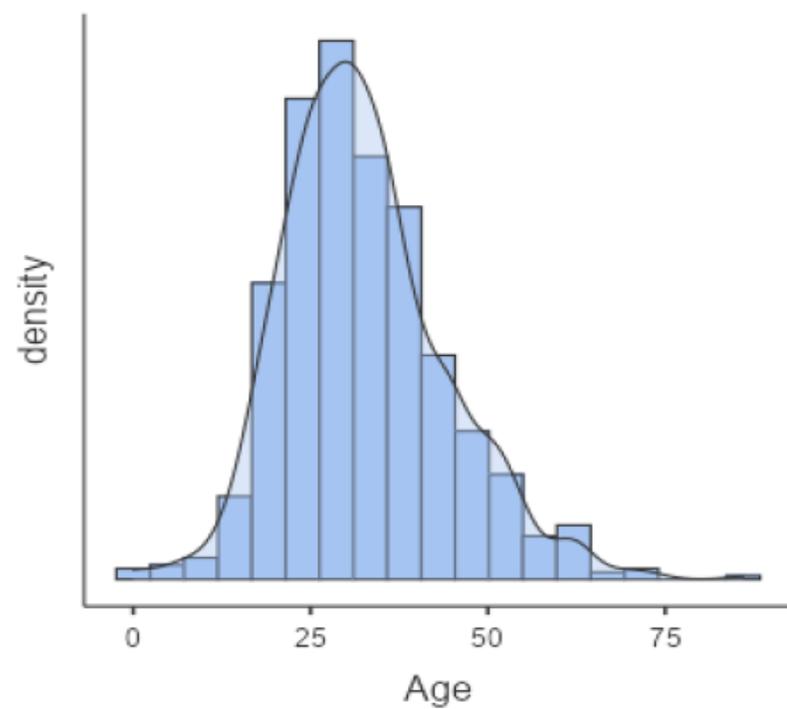
- Systemic Lupus erythematosus (SLE), also called Lupus, is a chronic autoimmune disease involving multiple organ systems may result in significant morbidity and mortality.
- Clinical variation is seen in different ethnic/racial backgrounds.
- This abstract is from one of the first Lupus Cohorts from Pakistan and includes 785 patients.
  - SLE patients were diagnosed as per ACR/EULAR and SLICC criteria.

## METHODS

- All patient's demographics were retrieved from electronic medical records of the Lupus cohort at Arthritis Care Foundation (ACF) and Arthritis Care Clinics.
- Patients were called on their listed contact number to verify the age of onset of symptoms as well as the number of family members with history of SLE.

# RESULTS

- The present mean age was 32.6 + 11.6, with females being 91.7% .
- We were able to contact 516 patients via phone
  - 172 (33.3%) had juvenile onset (<18)
  - 72 (13.95%) had positive family history, defined as the presence of one or more first degree relatives diagnosed with lupus.
- In the USA only 15-20% of the patient population have juvenile onset compared to 33.3% in our cohort.
  - Studies from the US have shown a mean disease onset age of 30.8 + 13.6 while in our cohort the mean age of onset was 24.1 + 11.7.



Frequencies of No. of Family Members with SLE

Levels	Counts	% of Total	Cumulative %
0	444	86.0 %	86.0 %
1	51	9.9 %	95.9 %
2	17	3.3 %	99.2 %
3	1	0.2 %	99.4 %
4	3	0.6 %	100.0 %

# CONCLUSION

- This points to an earlier disease onset leading to a higher disease burden.
- Additionally, the nearly 10:1 female predominance with majority in childbearing age presents a significant problem in our part of the world where treatment of severe lupus with a fertility safe drug is a huge financial challenge.
- Mycophenolate Mofetil (MMF), a pivotal drug for severe lupus costs \$71/month while our average monthly income is \$99.5!
- Additionally, our high birth rate sets the stage for greater morbidity and mortality with pregnancy related lupus complications.

## IN SUMMARY

- We need advocacy for greater priority to Lupus and related conditions in health policy and spending, especially the provision of cost effective and fertility/pregnancy safe non teratogenic drugs.
- Presently, ACF proudly covers the ongoing monthly cost of 50 class IV lupus nephritis patients with MMF.