## The Carolina Lupus Study Newsletter Number 3, October 1998

In the past year, the Carolina Lupus Study has succeeded in meeting our goals for enrollment and data collection. Analysis will not begin until 1999, but we are very pleased with our progress.

### **CLU Study Progress And Participants**

We have been very successful in recruiting patients (through rheumatologists and other physicians) and controls (through random sampling of driver's license registries). More than 95% of the eligible patients contacted have agreed to participate (see table below), and 87% provided a blood sample in addition to completing the hour-long interview.

## **Patients Controls**

Eligible	200	265
Enrolled	196	235
Interviewed	189	203
<b>Blood Sample Obtained</b>	171	173

We anticipated that the randomly selected controls would be less interested in the study. Although that is true, the response has been very positive, and 75% of those that are contacted and eligible agree to participate.

The mean age of the patients is 35 years, 90% are female, and 60% are African-American (compared to 25% in the study area). This highlights the increased burden of this disease in women and minority populations.

## **New Research Endeavors**

Christine Parks, MS, is working on the analysis of occupational exposures and lupus as her dissertation research in the department of Epidemiology at UNC.

Sue Simmons, PhD, RN, a clinical research trainee at National Institute of Environmental Health Sciences, will be studying clinical symptoms, health-related quality of life, and stress, among lupus patients. We are very pleased that these additional efforts could be undertaken as part of the CLU Study, and welcome additional proposals.

### Staff and Clinic Updates

We expanded our study area to include 7 new counties in South Carolina (Marlboro, Dillon, Marion, Florence, Williamsburg, Clarendon, Orangeburg). Interviewer Sara Graham's district includes all 18 South Carolina counties and 6 counties in North Carolina. The workload in the remaining 36 counties increased to the point that we added a third part-time interview, Gwen McKoy. Gwen sets appointments in 11 counties in North Carolina along the I-40 corridor, while Alesia Sanyika continues to cover the remaining 25 North Carolina counties. In all, they have driven over 53,000 miles this past year!

We continue to be indebted to the work of the study coordinators at each of the university centers: June Arnold (Medical University of South Carolina), Dana Pitely (University of North Carolina) Hospitals-Chapel Hill), Ella Akin (Duke University Medical Center), Sharonda Cooper (East Carolina University School of Medicine).

We have used 20 private and 25 state-run (South Carolina) clinics for the interviews and blood sample. The locations of these clinics range from Lumberton to Morehead City and from Durham, North Carolina to Beaufort, South Carolina. These arrangements allow us to conduct our interviews in professional settings convenient to participants' homes, and to rely on the experience and expertise of trained personnel for the blood draws. This has proven to be an important factor in making our study a success, and we very much appreciate the assistance of the staff at these clinics.

The Carolina Lupus Study would not be possible without the efforts of the rheumatologists and other physicians who have been referring patients to the study. Thanks to all of you for your help.

## Carolina Lupus Study Physicians (North Carolina)

#### Private Practice Rheumatology H. Vann Austin

- Franc. A. Barada
- · George Brothers
- Walter Chmelewski
- Duncan Fagundus David Fraser Stephen G. Gelfand
- Helen Harmon
- Robert A. Harrell, III
- John L. Harshbarger
- G. Wallace Kernodle, Jr.
- Elliot J. Kopp
- Kara Martin
- John L. McCain Gwenesta B. Melton
- G. Radford Moeller David W. Puett
- C. Michael Ramsdell A. Silvia Ross
- Gregory F. Schimizzi Claudia J. Svara
- Anne K. Toohey
- Randal E. White Suzanne J. Zorn
- **Lincoln Community Health Center**

#### Faye Banks Cathleen Melton

- Byron Randolph
- Evelyn Schmidt
- **Duke University Medical Center** · Nancy B. Allen Karen Hansen
  - Thomas Lang Rex McCallum
  - Elvia Moreta Bill St. Clair
  - Dylan Steer John Sundy
  - Ralph Tabib

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### • Philip L. Cohen Mary Anne Dooley

- James E. Godwin Nortin Hadler
- Westley Reeves
- Alfredo Rivadeneira
- John B. Winfield William Yount
- Other North Carolina Physicians William Olds T. Smith

## Thomas Speros

- Carolina Lupus Study Physicians (South Carolina)
- **Private Practice Rheumatology** 
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  - Walter Bonner
  - William M. Edwards · Gary E. Fink
  - Mitchell Feinman Frank E. Harper
  - Wendy Lee
  - Holly Mitchell
  - Alan I. Nussbaum Georgia Roane
  - · William B. Sheldon Robert Turner

## **Medical University of South Carolina**

- Marcy Bolster
- · Gary S. Gilkeson
- · C. W. Legerton, III
- Jim Oates
- Richard Silver Edwin Smith
- Scott Hollingsworth

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Other South Carolina Physicians

McClennan Banks