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LOUISE PETTUS ARCHIVES AND SPECIAL COLLECTIONS ORAL HISTORY PROJECT

Interview #332 COOK, Albertha

COOK, Albertha

Social Director of the Committee on Better Racial Assurance

Interviewed: August 10, 1984 Interviewer: Michael Cooke Index by: Alyssa Jones Length: 50 minutes, 36 seconds

> Abstract: In her August 1984 interview with Michael Cooke, Albertha Cook discussed her time at the Committee on Better Racial Assurance (COBRA) and the organization's association with DHEC. Cook covered the issues with the health system and physicians not understand what sickle cell anemia was and how to diagnose it, the lack of education in Black communities on genetic disorders, and the Black community's aversion to admitting illness. She also discussed the issues with testing for sickle cell anemia, COBRA's sickle cell anemia program's goals, and DHEC's involvement with sickle cell anemia education, prevention, and treatment. This interview was conducted for inclusion into the Louise Pettus Archives and Special Collections Oral History Program.

Keywords: Committee on Better Racial Assurance (COBRA), sickle cell anemia, sickle thalassemia, sickle cell trait, genetic testing and counseling

Interview Session (August 10, 1984): Digital File

Time Keywords

00:00:00 Start of Interview/Interviewer's Introduction

- 00:00:15 *Question:* Could you give us a brief biographical sketch of your life? *Answer:* AC was born in 1936 in Charleston, SC. She received a B.S. in Biology and a Master's degree in Public Health Administration. AC was a high school teacher, as well. She was interested in Anatomy and Physiology. AC took a course in Human Genetics at the University of North Carolina for teachers because of her interest. That year, she also took a summer class called Bioinstrumentation. That was how she became interested in sickle cell. AC was the Social Director of COBRA.
- 00:03:41 *Question:* Was the counseling position a full-time position? *Answer:* Yes.
- 00:03:47 *Question:* You had to give up your position as a teacher? *Answer:* Yes. AC asked for a leave of absence for one year. After that one year, she decided to stay with

COBRA.

- 00:04:46 *Question:* You had a number of positions within COBRA's sickle cell program. What year did you come in? *Answer:* 1972.
- 00:05:03 *Question:* You were there near the beginning [of COBRA]? Answer: Yes.
- 00:05:36 *Question:* As a counselor, what were some of your impressions about the public's awareness of sickle cell anemia? *Answer:* AC said that the public was not well informed and that there was a lot of fear because of lack of understanding the difference between sickle cell trait and sickle cell anemia. AC noticed that providing education before screening meant there was little fear when the test results were given.
- 00:07:00 *Question:* What about the people with the disease? Was there a difference between people you counseled and people who had just been referred to your agency? *Answer:* People that were a part of the educational program had a rapport with the counselors and felt comfortable speaking to the counselors. The counselors were less intimidating than the doctors. The individuals who were not a part of the program were very apprehensive.
- 00:09:00 *Question:* That made it very clear that counseling was essential for relieving the apprehensions of many people in the community. How did you go about educating the public? *Answer:* AC agreed about counseling being essential. COBRA had television programs. They also spoke with churches, community organizations, and school systems.
- 00:10:25 *Question:* You may want to talk about that advantage of being a former teacher? What kind of connections did you have and how did you use them? *Answer:* AC knew how the system worked and knew that in order to have the teacher and principal participation; they had to start at the top. AC knew that they had to start with the superintendents, and then move down the ladder. AC also knew how the curriculum and classrooms were set up, so they did not leave the teachers without the ability to follow-up their presentations.
- 00:11:49 *Question:* That was especially true for biology classes? *Answer:* Yes, also Life Science classes. Once they received agreement from the top; the program was accepted by the principals and teachers, no matter what the class. They had general assemblies and small groups for several classes at a time.
- 00:12:40 *Question:* You served as a counselor for how long? *Answer:* AC served as a counselor for two years. Later, she counseled whenever she was needed, despite being in administration.

- 00:13:30 *Question:* What were some of the priorities of the COBRA sickle cell program in the initial stages? *Answer:* The initial priority was informing the public about the disease and giving them the information in order for them to make informed decisions/choices.
- 00:15:34 *Question:* When did testing come into COBRA's agenda? *Answer:* About the third year of the grant.
- 00:15:50 *Question:* Did the grant make that possible? *Answer:* Yes.
- 00:18:19 *Question:* What other areas of concern did the foundation have in the beginning? What problems were people with sickle cell anemia having? *Answer:* Many sufferers of sickle cell anemia were having problems paying medical bills because they were not covered by insurance.
- 00:18:56 *Question:* Was that because they had sickle cell anemia and were cut off? *Answer:* Some were not covered because they had sickle cell anemia; others were impoverished and already did not have insurance.
- 00:20:03 *Question:* They could potentially be so indebted that the hospital would refuse aid until they could pay for some of the services already rendered. *Answer:* The foundation did not pay for all of the services, but it often got involved, explained the situation, and paid a little money to the hospitals.
- 00:20:44 *Question:* How many sickle cell patients were indigent? *Answer:* AC thought that about 80% of the patients were indigent.
- 00:21:05 *Question:* Does that suggest that all people with sickle cell anemia are poor or is that just an indication that people who are affluent don't tell people that they have sickle cell anemia? *Answer:* AC disagreed.
- 00:22:17 *Question:* Having sickle cell is very expensive and unpredictable. *Answer:* Yes. Families could become indigent because the costs of the disease. Even if the family members had good jobs, it could still be damaging to have one or more member with sickle cell anemia.
- 00:23:30 *Question:* What other services do you provide? *Answer:* Education, public awareness, counseling, supportive services, nutritional planning, and psychological assistance.
- 00:25:01 *Question:* Are sickle cell clients and their families involved in your program as volunteers and staff? *Answer:* Yes. They often work with television and newspaper presentations and advertisements. They also let the foundation know what the other

families will need.

- 00:26:02 *Question:* What has been the role of local physicians and pharmacies in the battle against sickle cell anemia? *Answer:* The local physicians provided a great deal of support. They gave COBRA medical advice for clients.
- 00:27:32 *Question:* Did you find that the medical community had to be educated about sickle cell anemia? *Answer:* Yes.
- 00:29:21 *Question:* Sensitivity to the patients is important. *Answer:* Sensitivity was very important. There was also a problem with a lack of interest, so patients were misdiagnosed. AC described sickle cell anemia, sickle cell trait, and sickle thalassemia. She also discussed testing techniques and the failures of the most popular choice.
- 00:34:19 *Question:* Was it a problem that the technique was the first or cheaper technique? *Answer:* Both techniques for testing were available, but it was cheaper, so people chose that one. AC and MC discussed the evolution of techniques and the organization pressuring DHEC to perform the correct test.
- 00:35:57 *Question:* Back to DHEC, what was COBRA's relationship with DHEC? *Answer:* COBRA was subcontracted to DHEC by the state lab. As a result of their involvement, they got DHEC funds for education and counseling for Black patients in the Charleston area.
- 00:37:06 *Question:* COBRA was part of the writing of legislation? Answer: Yes.
- 00:38:01 *Question:* Did you approach him or did he approach you? *Answer:* AC said she was not a part of these dealings, but she believed that Herbert Fielding approached COBRA.
- 00:38:46 *Question:* What was the relationship with DHEC in terms of policy making? *Answer:* COBRA often influenced DHEC by encouraging them to spend more of the budget on sickle cell services. DHEC established a clinic in Columbia for sickle cell patients because of COBRA's insistence. More facilities in Spartanburg and Orangeburg were established by DHEC after more encouragement from COBRA.
- 00:42:40 *Question:* Have you seen any changes in the priorities of COBRA's sickle cell anemia program? *Answer:* AC said education, testing, and counseling were still top priorities. In addition to dealing directly with patients, the program had been trying to change the system to better serve the sickle cell patients. They helped the families, but also began addressing different aspects of the system as technology improved.

- 00:44:41 *Question:* What areas do you see that need to be addressed if sickle cell services are going to improve? *Answer:* AC found that people were waiting for babies born with sickle cell anemia to show symptoms before addressing the disorder meant that 30% of those babies would die before the age of three. They needed to address the issue as early as possible. AC said that included those who could potentially have children, people who already had infected children, or were infected themselves. AC considered the idea of equipping those parents and potential parents with information on how to reduce morbidity. The earlier the infections were treated, the more morbidity was reduced.
- 00:46:40 *Question:* Now you have to educate the at-risk population. *Answer:* AC said they were already doing that. AC wanted to improve the way that babies with sickle cell were dealt with.
- 00:47:45 *Question:* Is that all you would like to say? *Answer:* AC only wanted to say that educating the Black community gave the community more hope in affecting the health of future children and encouraging them to become more aware of other genetic disorders.
- 00:49:00 *Question:* You've helped in educating people about genetics. What's genetics? *Answer:* AC said that the Black community had not been exposed to genetics.
- 00:50:36 End of interview