

ALFORD, Rose  
INTERVIEWEE

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**Interview # 319**

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**Abstract:** In her interview with Michael Cooke, Rose Alford discusses her work with South Carolina's Department of Health and Environmental Control. She details her work with the sickle cell anemia clinics and the effects of the outreach programs and community groups on the black community. Mrs. Alford discusses the cooperation with various community groups and DHEC.

\*This is an edited transcript. Our transcription guidelines are available upon request/on our website.

Time	Keywords
00:00:00	<b>MC: Today is June 1, 1984. I'm interviewing—is it Miss or Missus?</b>
	RA: Missus.
00:00:08	<b>MC: Mrs. Rose Alford. She is with the—</b>
	RA: Department of Health and Environmental Control [DHEC] cripple children's...children's rehabilitative clinic.
00:00:21	<b>MC: She is going to discuss the role of the private sickle cell anemia organizations and of her department during the 1970's. Before we get started could you get a brief biography of your life? When were you born? What is your education?</b>
	RA: I was born in Orangeburg, South Carolina December 1952. I'm a social worker currently on staff at the Children's Clinic in Orangeburg. I got my degree in Sociology from the University of South Carolina. I'm currently taking some graduate courses in Social Work also at the University of South Carolina.
00:01:12	<b>MC: How long have you been associated with your particular division?</b>

RA: I've worked with DHEC since 1974. Initially with the sickle cell project and in 1976 when the...DHEC began clinics for sickle cell disease patients I began working with that program.

00:01:50 **MC: Why did that come to pass?**

RA: As the sickle cell project began to do more and more screening, more and more persons were identified with the actual disease. It seemed that there was a need for medical care in a more intense effort than had been done before.

00:02:15 **MC: What was your first contact with South Carolina's private sickle cell groups in the 1970s? What were some of your first experiences? What organizations you came encountered with or what individuals you thought were...played an important role in the development of these organizations.**

RA: In 1974 when I was hired by DHEC in the sickle cell project, the emphasis of that program was to do education, screening, and counseling. In an effort to accomplish this there were...education programs done in various communities throughout the state. In doing that there were contacts made with people who were interested in setting up private foundations or community groups that could help persons who were identified with sickle cell disease financially in small contributions to help them to maybe get to medical services or to help them in times of stress. Also they wanted to better inform their communities about the existence of sickle cell disease and sickle cell trait. As a result of those interests that were expressed by the community, some of the same staff that was working with the sickle cell project was...the staff helped the community groups get off the ground. Some of them. There were others that were started in their own communities without any help.

00:04:13 **MC: Can you recall off hand what groups were created on their own without any impetus from DHEC?**

RA: The main two that I can think of are the Committee on Better Racial Assurance [COBRA] in Charleston which is not only a sickle cell foundation or group. It is a community type agency which has several different focuses including hypertension screening projects and a couple other community action type things.

00:04:52 **MC: Do they have these functions as of the 1970s or this is—**

RA: This is how they began.

00:04:56 **MC: Oh they began with those type of—**

RA: It began as a community action agency and because of its prominence in working with the black community when efforts were begun in that area to do some stuff with sickle cell disease, it was suggested that they do it. So they took the role and had a sickle cell project within their total group. Also there is a group in Columbia called the James R. Clark Memorial Sickle Cell Foundation. It was originally known as CASCAF or Columbia Area Sickle Cell Anemia Foundation but one of the doctors who was very, very instrumental in getting the group of the ground James Clark died a few years ago and they changed their name. That group was started with, I think, several families who have children with sickle cell disease. Also then the general community interest that was generated with them.

00:06:18 **MC: How extensive were these groups during the 1970s?**

RA: I know that they worked to help in their general areas, as far as how many people belonged to the groups? I don't know.

00:06:38 **MC: Well how many groups can you estimate were in existence for Columbia in the 1970s? What groups offhand do you recall being in existence in the 1970s?**

RA: Those two that I already mentioned were in existence probably as early as 1973. I'm not really sure of dates. Also during '74, '75, '76 the community groups such as the one started in Spartanburg, the one started in Orangeburg, the one started in Gaffney, one started in Chester, one in Sumter, were functioning on a very broad—those are wide variation of groups. As far as how many people were involved, how much effort was done in those communities, whether it was just groups that really came together to raise funds so that they would have some money to help patients when they were done. By...and maybe transportation money to get to the medical services they need or food to help them until their need...the father got back to work. Those kinds of efforts. Other groups who were then a more concerted effort to do things such as education programs from one church to another, one community group to another, one school location to another and so on. Those groups were the ones where DHEC was instrumental in trying to give the information in such a manner that the persons who were working in the groups had enough background information so that they would be prepared to make presentations to the public.

00:08:45 **MC: Was that one of the primary functions of DHEC in those years? Of providing guidance for education, providing the literature, giving skills to people to go about their work?**

RA: The primary goals of the sickle cell program in DHEC were to do education, screening, and counseling. That encompassed contacts with community groups as well as the community at large. All was helped whether that was school groups, Health Department nurses staff or whatever other kind of staff. Children's groups,

adult groups meeting in their church or sorority or where ever as requested. Education programs also were provided.

00:09:47 **MC: Did they get involved when they were requested to get involved or did they offer their assistance when they weren't asked to become involved in these private groups? How did DHEC get involved? Did they only respond when they were called upon or did they send people or contact the known groups and their leaders?**

RA: As far as I know the community group contacts were never made unless there was a request from the community. Where there was somebody who said 'I'm interested in starting a group, can you help me?' The contacts to provide education programs or information programs were through various methods. There was publicity about the existence of sickle cell programs so that there was in turn a response from the public requesting information. It was made known that information programs could be done so we often see requests to do those. There was also an effort in each Health Department to do screening of the clients that were coming in there since the Health Departments are a part of DHEC. Many of the things that would go in a relationship would follow-up of the test results of those persons tested through the Health Department. They were counseled and given the results of their tests and sometimes that would spur that individual to maybe request more information for a broader group in his or her community.

00:11:57 **MC: When did the local Health Departments take on the role of screening? When did that come about? What time period are we talking about?**

RA: It was during the same time period as we were doing the sickle cell counseling. Let me explain something about the structure of DHEC. DHEC is the overall guiding body of the Health Department system for the state of South Carolina. So that it is the administrative body and in each county of the state there is a Health Department. When—

00:12:34 **MC: Now these Health Departments are connected to the state not the local counties.**

RA: They are connected with both. There is a mandate to do certain health screenings and protective type things in relationship to the public welfare and wellbeing so that there is...a maternity and child health branch within DHEC. That is the general area under which the sickle cell program functioned. Because the Health Departments see a lot of children and see a lot of women who are in the child bearing age who are seeking either family friendly services or are seeking maternity services. This was a population who often presented with...well they were a population that would be a feasible group to benefit from the...test. The hemoglobin electrophoresis test and also be able to inform those individuals when they came back in of the results and potential risks for their offspring and so on and so on. When the sickle cell program was started in DHEC

it was automatically, I guess, expected that some portion of what was done with this program would be done through the Health Department. As far as specifically how that was done the administrative people would better be able to answer that.

00:14:27 **MC: Ok. This is just a—what is your impression about the cooperation between the private groups and DHEC?**

RA: There's been good cooperation.

00:14:42 **MC: In the '70s, do you think there was a good rapport between the key individuals of these private groups and the leadership of the Department of Health and Environmental Control?**

RA: Yes. I think there probably was. There was a joint effort to reach a certain goal so...

00:15:09 **MC: What do you think were some of the common goals? What were some of the areas there seemed to be a consensus between the people who were in the leadership roles for the private groups and the people who were in the leadership roles for DHEC? Were there any areas of consensus that you can see.**

RA: Definitely because of the fact there had been such a limited amount of information available to the public about sickle cell disease. One of the priorities of just about anybody working with sickle cell disease in the '70s all over the United States was to educate the public. So the community groups as well as DHEC had that as one of their primary goals. Testing and counseling were also done by both. The community groups often times in conjunction with the Health Department so that there would be a mechanism for follow-up. They would tap into the local Health Department staff and have those tests go back to the Health Department for follow-up rather than take on those tasks themselves. So definitely was a cooperative spirit between the community groups and DHEC. The joint effort with both the community groups and DHEC.

00:16:51 **MC: Where were some areas where there seemed to be differences between the private groups and Department of Health and Environmental Control? Where did you see areas where they weren't—did not have the same objectives? They had...maybe not that there was a real perceptible difference in their approaches but never-the-less some variations, different interpretations of where we should be headed in the future, what we should be doing now.**

RA: I guess the main difference came about because of what DHEC is and what the community groups are. DHEC has the government resources to provide consistent day to day activity in relationship to doing education screening, and counseling. It was an ongoing effort from the beginning. There was a mandate

through the legislature for this program to begin with. So that DHEC had to make sure that was carried out. The education, screening, counseling; those lead to finding many patients who have sickle cell disease and as a result of that...that lead to the...sickle cell clinics being started. That probably is the...with the clinic effort that was probably one of the larger differences in what the two groups are about. DHEC and the community groups. The community groups did not attempt to provide medical services. Generally they are sticking to the efforts of education, screening, and counseling. While DHEC did that in the beginning and still does but it is mainly concentrated on the clinic population. Which is that persons who actually have sickle cell disease and their family members so that the education efforts are geared towards that family understanding their child or their parent's disease and knowing how to deal with the problems...I guess the medical services effort was one of the bigger differences between what exists now in DHEC and what the community groups are handling. That clinic has been going on since 1976 or was it '78?

00:20:13 **MC: 1976 or '78?**

RA: Yes.

00:20:16 **MC: So DHEC is delegated some of its responsibilities. You don't think so?**

RA: There hasn't been a conscious effort of DHEC saying here community groups you do this we're going to do this. It has just been a kind of evolution of... DHEC has said ok we have done this effort now we need to concentrate on this. If the community groups still wanted to step in... DHEC has no control over what the community groups do per se as far as what their goals are. There has been a voluntary effort for some communication between the two. For the last two years there's been grant money available to some community groups but that was [unclear].

00:21:21 **MC: Would there be any—if they accepted grant money would that be a problem as far as with the—would the groups have...you can't answer that question. What are your impressions about the major accomplishments of the sickle cell programs in South Carolina in the 1970s? Both the concrete results if any of the private community groups or that of the State Department. What do you think of some of the major accomplishments? Or do you see any significant or maybe insignificant improvements in the problem of sickle cell anemia.**

RA: That's hard to...well as far as accomplishments are concerned, both the efforts of the community groups and the efforts of DHEC reached a lot of people. As far as measuring that impact that is very difficult. Especially from my perspective since I do not keep the tallies of numbers of people that we've contacted and our goals in that regard. I would think that with a better educated public whether that be the individuals who are actually effected or just the general

public at large there is a better response to those persons who actually have the disease. That is there is not such a void of information in persons about the existence of the disease, of the trait, and as a result of that persons who are affected probably are better served. Persons who have the trait, or at least are aware of it, they can make logical decisions about their child and whether they want to take a risk of having a child with sickle cell disease or not. If they did have a child then they would possibly know that there was something that could be done as far as medical treatment for that child.

00:23:46 **MC: You said you had a very close relationship with people who were victims of the disease. Are you talking about sickle cell disease and sickle cell trait, did you have any contact with those two categories?**

RA: Persons with sickle cell disease are the clients that are served through the sickle cell clinics. Prior to the beginning of the clinic, like I mentioned earlier, the counseling efforts were geared toward those persons who were found to have a positive result. Whether that be the trait or the disease. Since sickle cell disease encompasses many things such as sickle cell anemia, sickle cell thalassemia, sickle C disease and so on, all of these persons who have found positive results as well as those persons who were found just a trait. What—those were the targeted people to contact once screening had been done, were those positive results. So part of my job in the beginning of the sickle cell program in the '70s was to provide genetic information about the [unclear] risk, provide them with information about if it was the trait. Just about what is sickle cell trait and that it was not the disease and that it would not cause health problems. Those persons who had sickle cell anemia or sickle cell disease were the ones we wanted to provide them with that same information plus some of the ramifications of having the disease and trying to make appropriate referrals to a medical care resource so those persons could get care in relationship to their disease.

00:25:37 **MC: What area or areas did you work in amongst people who had those type of problems?**

RA: The whole state.

00:25:44 **MC: The whole state? So you traveled from place to place whenever you heard of people—**

RA: Whenever we were contacted by a Health Department. There was a standard sort of procedure set up where...in relationship to what the Health Department did. If the Health Department did a lot of tests and they had—well if the Health Department had a lot of positives and they needed staff to counsel these individuals, there was one other social worker in the project, we were contacted either to go to a Health Department or to make some sort of arrangement to see that victims are made welcome in our main locations and to get the results to the families. If needed, it was a person with one of the diseases, to make information

available to them about the benefits and resources. If it was the community group who had done screening, probably we had been contacted beforehand and the health educators who were on staff may or may not have participated in their education program to help. The Health Department nurses in that particular county may or may not have participated if they had somebody to do the finger pricks in their own community groups the Health Department may not have gotten involved. If they had a physician who was their consultant for their community group. They could legally receive the results of the tests and do their own follow-up and counseling but often times that was not the case and that was one of the main efforts to have the sickle cell program involved, or the Health Department staff involved. So the test results could go back to the medical facility and follow-up being done with the positive test. So that it may not just be done put on the done pile.

00:27:55 **MC: So from the very beginning, since 1974, you have done that and it continues to be done.**

RA: With it there has been a total structural change in what the sickle cell program in DHEC does. With the beginning of the sickle cell clinic, the efforts remain towards contact with the persons who are seen through the clinic as opposed to the general population of South Carolina. The Health Departments now have a person within their own facility designated to do counseling. There is no need for the individuals in the sickle cell program to travel the state as before. There is no—

00:28:52 **MC: I see. When did that—that was 1976 or '78 when that occurred? Well I guess—any other things that come to mind? I believe we've touched on the bases. Ok I appreciate your granting me this opportunity to talk about this matter. Thank you very much.**

00:29:15 **End of Interview.**