

BREEDEN, Dee  
INTERVIEWEE

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**Interview # 323**

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**Abstract:** In his interview with Michael Cooke, Dr. Dee Campbell Breeden (1938-1998) discusses his work with the Department of Health and Environmental Control of South Carolina. Dr. Breeden details the work to implement the sickle cell anemia program. He discusses the efforts to screen, diagnose, and counsel the community on sickle cell anemia. Dr. Breeden also discusses the efforts of local community groups throughout the state to develop their own sickle cell anemia programs with the assistance of 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 July 9, 1984. I'm conducting an interview with Dr. Dee C. Breeden. Dr. Breeden could you give us a brief sketch of your life? When you were born, where you were born, and your education?</b>

DB: I was born in December 17, 1938 in Greenville South Carolina. Was raised in Bennettsville South Carolina. Went to Wofford College in Spartanburg County South Carolina. The Medical University of South Carolina in Charleston. Internship at Greenville General Hospital, Greenville South Carolina. Two years on active duty in the Army from 1965 to '67. Spent a year at pediatric residency at Grady Memorial Hospital in Atlanta. Another year of pediatric residency in Medical University of South Carolina, Charleston. Practiced pediatrics for two years, decided to enter public health. I worked in Public Health in Columbia for two years. Went to Chapel Hill North Carolina in 1973 and got a master's degree in Public Health. Have been employed with DHEC [Department of Health and Environmental Control] ever since.

00:01:25	<b>MC: When were you first aware of sickle cell anemia?</b>
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DB: Somewhere during my medical school. Probably my sophomore or junior year of medical school.

00:01:40 **MC: Was that part of the curriculum?**

DB: Yes it was. We had children who would be admitted to the hospital who had sickle cell disease. We have a large black population in Charleston area that uses the hospital where I trained. We would have patients in the hospital with that problem and we—it was part of the medical training. Yes.

00:02:07 **MC: So you had experiences perhaps many physicians in the country haven't had, that is actual expertise in dealing with the problem of sickle cell.**

DB: Well I wouldn't call my medical school part expertise but it was exposure anyway. I wasn't responsible for taking care of the patients but I was exposed to it.

00:02:24 **MC: But you were aware and you knew that—**

DB: I was aware and exposed.

00:02:27 **MC: Ok. When did you become connected with sickle cell anemia in DHEC? The Department of Health and Environmental Control.**

DB: I joined DHEC in September 1971. My initial work with DHEC was for the Child Development Center, Child Evaluation Clinic because it was mainly seeing handicap and mostly retarded children and try and evaluate the process. So I was isolated from the broad parts of the agency initially. In 1972 I became part of the central office DHEC team. During that year sickle cell was being discussed nationally and as a statewide issue. Looking into the possibility of a role with sickle cell, what role it might have. I was part of the DHEC team that was looking into that.

00:03:43 **MC: What was your position?**

DB: Titles change in an agency a lot but I think back then my title was probably Director of Child Health. In the Bureau over Terminal Child Care. Then I was supposedly responsible for children's programs in the Health Departments because of the central office role that was going on with the different planning and evaluation, consultations, and children's programs primarily.

00:04:24 **MC: Ok. With 1972 and the legislature passing a bill to provide funding to provide research and treatment and screening of sickle cell, what did your role encompass then after this development?**

DB: Well if I can precede that just a little bit. In that members of the DHEC staff met. Primarily myself and Dr. Carlton DeSalvo from Roughton Laboratories and we were, I guess we were probably the key players. In meeting with trying to

determine what role DHEC was capable of playing. We looked at the possibility of what tests we could...use and also what our counselor could provide. What would be possible. We also met with the black caucus group, the Columbia group along with the legislative group. To discuss their interest in this legislation and what they would like to see DHEC doing and explain to them what we thought DHEC could do.

00:05:47 **MC: Did the black caucus approach you before you gave thought to the problem or is it vice versa?**

DB: Michael, I really don't recall. I was probably one step removed from politics at that time. I don't remember where the first connection was. I just remember part of it.

00:06:07 **MC: I see. Who might have been part of that process?**

DB: Well it could have been the commissioner Kenny Baycoff...could have been the Bureau Director Dr. James Padgett who is presently in Spartanburg at the DHEC district medical office. He was my immediate supervisor.

00:06:37 **MC: Ok. In the beginning stages of the sickle cell program, did you have any responsibilities in that regard?**

DB: Within DHEC we had two parts of the DHEC program. One was the laboratory part which was receiving specimens and running tests on specimens to find out what—these were what the diagnosis might be with the blood sample. That in itself was quite a feat for the time because the...I don't know very few—maybe one or two places in the country at that time that was doing any kind of mass screening by the technique that we used which was hemoglobin electrophoresis. I think it's a new technique for our agency to develop and developed it, I would say, rather hurriedly. I say that in a—what I mean is that we got it done fast but we got it done in a quality way. When I say hurriedly I don't mean it in a bad way. We decided to use that test because it would give us a broader look than just sickle cell. We knew that there were a lot of other hemoglobin problems which both the black and the white population might have that would be detected by this test and people might be helped by us finding this out. The alternative was to use a test called Sickledex and I think there might have even been another brand name, somebody else's test. It would give you an instant result right there with the patient. It would tell you whether the patient had any sickle hemoglobin present or not but would not differentiate between how much sickle hemoglobin they had or any other abnormal hemoglobins they may or may not have. Only could tell you if some sickle hemoglobin is present or not. We elected not to use that test because it was a limited scope. All it did was sickle cell and it would not give you a definitive answer. You'd have to say there was another blood test to do. [We] figured we could do a screening test with the

hemoglobin electrophoresis to get all types of hemoglobin and have a definitive test done at the time of the screening. Which was pretty unusual.

00:09:08 **MC: Was it the very complex process to screen people in the fashion you just mentioned or was the Sickledex, was that—?**

DB: Sickledex was quiet simple, just limited in its scope of what it would tell you.

00:09:22 **MC: Was economics a factor in—**

DB: Economics was a factor. Sickledex—I just don't recall the cost. It might have actually been cheaper to go with Sickledex but you would have just been so limited in the information you could get. Dr. DeSalvo was able to develop the test in the DHEC lab. We were able to...with our own test differentiate several different kinds of abnormal hemoglobin. There were some that we were not able to differentiate, we could only say this is not normal but we're not sure what it is. So we had an agreement with the medical college of Georgia, with Dr. Heisman who is a hemoglobin specialist there and very interested in sickle cell and all other abnormalities in the hemoglobin. We used Dr. Heisman as a reference lab for the DHEC lab. So when we had abnormal...samples that we wanted somebody else to look at we got Dr. Heisman to look at them. He would give us a report. So that was one avenue with DHECs work but I'm digressing with that. Dr. DeSalvo had that responsibility.

00:10:43 DB: My responsibility was to deal with the agencies—the staff agents that was coming into contact with clients. That had to do with collection of specimens for the blood sample...and train DHEC staff so that they would be able to handle the information once it came back to a DHEC staff member. There would be some people trained to go in and meet with the client to discuss the results. The implications of being told that you have genetic abnormality, that's a heavy trip for anybody. A heavy load for them. There's not a lot of experience around. In broad genetic counseling or even specific genetic counseling like sickle cell. We were trying to be very cautious and sensitive at the same time while moving forward in what appeared to be some uncharted ground. What was the impact this going to have on the people. We were concerned about labeling people with an abnormality. Emotionally what that might do to them. If it would affect people's employability or their insurability. The whole issue of screening people who might not want to be screened in the first place was a big issue. It was a big place to go out. There was a lot of pressure on DHEC to screen, particularly, all black people. There were lots of people who wanted that done or some who wanted that done. There were others who said wait a minute that's not right, it's not fair. You should only screen those that want to be screened and those who don't, don't. The agency's policies ended up being to screen all of the people who wanted to be screened, who were asking about it, who would make people aware that the test was available and asking for it.

00:13:00 **MC: Did you provide testing services like outreach programs?**

DB: DHEC itself is almost an outreach program in that we have Health Departments in every county and most counties have satellite Health Departments. So in that way we were out there and accessible. There was some advertisement that was done and a lot of newspaper articles but we didn't go out knocking on doors that kind of thing. We didn't send individual workers out into communities. We made talks. If we were asked to go to churches or civic clubs, benefit meetings.

00:13:42 **MC: You had to be invited though?**

DB: Yes. If we were invited we made talks to people but we did not—that's the limit.

00:13:54 **MC: I see.** [Telephone rings] **We'll interrupt briefly.** [Recording pauses]

00:13:59 [Recording resumes]

**MC: We're resuming the interview. You mentioned a point about your responsibilities?**

DB: The legislation came forth in '72 with \$100,000 to put for the research, and counseling, and testing of sickle cell. \$100,000 was kind of a standard legislative gift for different programs during those years. If there was a particular group such as hemophilia or—it seemed to me, this is my impression, but if there was any lobby group that said 'We need, we need.' to the legislature, the legislature many times would give \$100,000 for them. It seemed to be a kind of standard. In my opinion. It might not have been if you look at the records it might not be but the way my little corner of the world where I was sitting that just seemed to be a kind of standard. It was a fairly generous gift at the time too. That they would do that. \$100,000 at that time to me seemed like a lot of money but also realize that when trying to implement a statewide program, \$100,000 does not go very far. So our effort was to put on one or two full time staff members who could spend their full time doing this, provide training at the local Health Department levels to staff. Nurses particularly so we would have more nurses and some other people that might be counselors such as social workers. Whatever DHEC staff might be doing counseling we were providing training all over the state, not just Columbia DHEC all over the state. In every district we put on training programs to nursing staff so they could...collect the test and then deal with calling on the test results. That was a pretty tall order. I have to say I guess I was an optimist at the time. I was just enough of a novice in the agency to not know all the responsibilities that people in the field already had. There was enough attention being put on sickle cell as a new program that I had a lot of my energy going into it. I was in turn then helping the agency to place demands on people on the county level who were probably a lot less sensitive to the staff of the agency and their workloads and responsibilities

than I was to the sickle cell people. I thought I was very sensitive to the clients that we come to serve. I guess what I'm saying is as I reflect on that time I was a little bit out of balance in favor of the client. I was a little bit out of reality with what was reasonably possible. What should be done with the legislative mandate of \$100,000 and the other mandates that the agency had going at the time and where sickle cell would fit in with that.

00:17:35 **MC: What were the priorities of the Department of Health and Environmental Control at the time and today too. What are the real priorities?**

DB: The agency has a broad spectrum of responsibilities. You have to put an S on that priorities just like you did because it would be very difficult to list out one priority and say this is it. I guess you could be clever and one sentence might cover the work but we are basically protective of the public's health. We are oriented toward prevention but we also end up providing services beyond prevention. Examples of that would be like our crippled children's program where we have federal legislative mandates to provide treatment services to crippled children. Federal monies are given for that, there is legislation telling you what to do with it. [Telephone rings] [Recording pauses.]

00:19:02 [Recording resumes]

**MC: We're resuming again.**

DB: Alright. We're talking about the responsibilities of the agency, the priorities. To give an example of crippled children's treatment program which is a little out of step with what the major priorities of this agency remain, the mission of this agency. The agency has had a policy of filling in the gaps where possible. Where other agencies or health care providers in the communities are not providing a service or agency fulfills itself as having a responsibility to fill in the gaps where possible. Things become possible when money is given to an agency to do something. The sickle cell effort—money was given it became possible to do somethings that previously had seemed either not possible because of money or not possible because of the interest in the project. As we said earlier there was national interest in sickle cell at that time our interest was linked that. Priorities for the agency were linked to the environment. A whole half of this agency—I say half but on the organizational chart there's personal health services and environmental services. It looks like the agency is divided in half. The responsibilities for the environment were air and water. Then we have responsibilities for populations. The health of the population, things we might...do that will affect the whole population. We have responsibilities for individuals. When it comes to tending that person and possibly to direct treatment services for some individuals.

00:21:13 **MC: Where does treatment services fall into the spectrum?**

DB: In the spectrum treatment services—if you list the priorities kind of one to ten, treatment services would come down toward the tens. Down toward the bottom. That is not the primary responsibility of these agencies. Although we do it. In some instances. It's not what we're about. The treatment—if people have access to treatment elsewhere by the time that film presents, they'll probably get totally out of the treatment business. It's a last priority type thing basically.

00:22:03

**MC: What was the—I know you had a liaison with a number of sickle cell community organizations which kind of sprung up during the 1970s. What were your reasons for establishing liaisons between DHEC and those various community groups?**

DB: At the same time the legislation was happening the agency was trying to formulate its own position. That reminds me. Having a lot of concerns about the impact this was going have on individuals. Confidentiality of the emotional impact, social impact it might have on individuals. We were very, very concerned. I would just like to emphasize that because the reason I'm emphasizing is reflective on our relationships with other people trying to also get into the sickle cell movement. The agencies, I'm sorry to caution. At the same time that we were involved with all this beginning, some community groups—some black community groups were also interested in the same way. They wanted to...get screening programs going on, to...outreach—they were very involved with outreach and make sure everybody that wanted it could get it and knew about it. They wanted to provide the service. They wanted...at different times they either wanted...DHEC to...go and collect blood samples possibly and send them to DHEC and DHEC send them back the results. There were all these different things that were talked about DHEC. To them...such as them finding people and getting them into DHEC to do testing. They wanted to provide counseling. As I recall my own position was very cautious at that time. I didn't know these people. They were new groups of individuals. They might have all been very prominent, respected people but as groups they were kind of new. New organizations. Who did not seem to have help back then. They were very interested and fired up, as a matter of fact, but they didn't appear to me at that time to have...the frame that I thought the people might have needed to be dealing with the confidentiality and the medical aspects of genetic counseling. I was very concerned [unclear] this. I guess I would say it might do more harm than good. I didn't see the expertise but I thought as a trained physician, in my opinion, that I didn't see that kind of expertise. That positional expertise for just counseling that we see in social workers, nurses and whatever that I was thinking would be necessary at the time...

00:25:41

DB: Hindsight being 20/20 there may have been some of that expertise, certainly when Dr. Clark got involved with the Columbia group. He was amazing. He was...I thought he was one of the two doctors that was registered out of Columbia that I had met outside of the agency. Of all the people I have met. Like many

people I will never recover from the tragedy of his death because he meant so much to the community in so many ways. Would have meant so much more at that time. When he was involved which was a little later...but it was a whole different story about expertise. Where he would evaluate abnormal results and direct sort of what was going to happen. I can't recall at this time if the community groups were interested in having some of the \$100,000 that had been legislated. I don't recall specifically them saying we want to hire somebody. We want you to hire somebody and put them in our shops. I don't remember any going after the money. Although that may have been happening I just don't recall that. Certainly was a very limited amount of money there. So that even if they had been aggressively trying to get some of that money, straight from their own personal efforts. They would have certainly not succeeded just because there's so little funds there. The legislative mandate had been to DHEC to do this. At that time that was pretty strictly interpreted by DHEC. If we were going to do it we certainly needed that amount of money and a whole heck of a lot more.

00:28:00 **MC: I have two questions. Did you find that these groups became more sophisticated over time? That they did become more knowledgeable about screening, which is a technical area, and counseling? Did you find that among some of the groups or was it—?**

DB: I can give you an impression. I can't give you any—I didn't go out and watch them counsel or...review records. Records were all very confidential, they wouldn't let me review their records and I wouldn't have let them review mine. Even though I—everything was really confidential at that time. My impression was that the groups showed a resilience, and a persistence, and a dedication, concern, consistency that earned my respect. They weren't a fly by night crowd. The few groups that got started stuck it out. We couldn't tell that from the beginning because it was almost a fad that was happening. It was a very emotional thing that was happening. People were very wrapped up in the thing that was happening in '72 and '73. You couldn't predict at that time how many of those people's emotions would wear thin and they would be long gone and there would be somebody else left around holding the bag. I had a few problems that had been created by them. To their credit they stuck it out and I think formed a very valuable service. In '73, I left the agency for a year for continuing education so that I was—during the period of '73 and '74 that I wasn't involved. Then when I came back in '74...held a little bit higher position in the agency. I had a few more activities that I was responsible for. I had staff on board who were working full time on sickle cell but I became a little less directly involved. I was more involved in development than I was in the ongoing process at the time.

00:30:31 **MC: What were some of the things that you were considering for its development of the sickle cell program? Where did you see the future of your program?**

DB: Where did I see it was?



00:30:46 **MC: Yes.**

DB: I can remember making a talk somewhere in [unclear]...it was in Florence...and making the statement that I thought we were probably going to have a million dollar program of—[recording stops]

00:31:38 [Recording resumes]

**MC: Ok. Continue.**

DB: What I meant by having a million dollar program with a \$100,000 grant is that the grant itself was going to pay—a fair hunk of it was going to pay for the laboratory work to be done. There would be one of two people hired in the central office to work full time with sickle cell and be traveling around all of the state would be costs for that. There would be educational material and things that had to be bought. \$100,000 would be spent rather easily and yet we were talking about implementing counseling and testing all over the state. We were going to ask people who were already doing something else to get interested in a new agenda. It would began with the implementation of counseling and testing. We would then take all the time and training and testing and counseling that would be going on statewide that that might in fact be a million dollar program. I never tried to sit down and figure out exactly how much it would be but it would certainly be a lot bigger than \$100,000 could buy. If you were only to do sickle cell with sickle cell money then you weren't going to get very far. My vision was we would have testing and counseling available at every health department in South Carolina and that we would have...say counselors in the broad sense of the term. We would have staff trained at each of the Health Department who understood about sickle cell and could provide some genetic counseling. There's all levels of counseling expertise and there was no way we could get everybody to the same level of competence. Because some people only had certain levels of competence before we ever got to this counseling skill. It was uncharted ground. It was uncharted ground in DHEC. We had not been doing any genetic counseling in DHEC to speak of. Maybe a little bit in crippled children with a few...isolated sort of conditions but generally genetic counseling was a foreign thing for DHEC. We were suddenly, and I mean suddenly, going to implement this thing statewide. We had a mandate from the legislature and a little bit of money to work with and we had to get on with the program. Which is what we did. We picked up training all over the state. We implemented testing, screenings, counseling.

00:34:26 **MC: What happened to derail that plan?**

DB: Well the plan is still present. They're still sickle cell testing and counseling as far as Health Departments go. The fad of sickle cell has faded. I think it has taken its place in medical problems, health problems, alongside all the other

problems they have. It's not being singled out at this time as it was in the early '70s.

00:35:05 **MC: You call it a fad. Don't some of the statistics of South Carolina kind of belie that it's really very surprisingly prominent among blacks of this state?**

DB: You are misinterpreting what I said. I'm glad I have a chance on this tape to straighten that out!

00:35:24 **MC: Ok. Straighten me out.**

DB: The fad had to do not with whether people had sickle cell hemoglobin, that's nothing to do with a fad. That's a reality. You either have it or you haven't. You're here or you're not. The fad had to do with the level of interest at the time. The political level of interest at the time. That has...very few health conditions or medical conditions grab the limelight and stay in the limelight. Different things come along that are looking at several diseases over the last few years. Legionnaires' disease four or five years ago, toxic shock syndrome two or three years ago, and others that grab the limelight. In a sense a fad. Maybe that's a bad term to use.

00:36:25 **MC: Does the agency respond to issues like that? That if it has political ramifications then it responds?**

DB: Oh yes. Political or social ramifications and different problems get focused on at different times in history. But Legionnaires' disease is still around but you don't read about it in the paper every day. People get diagnosed right here in Florence with Legionnaires' disease but it's not a newspaper item anymore. The same with the sickle cell. It was a disease of that time that got political and social focus during the early '70s. That brought it more attention probably than it deserved in relationship to all the other health problems that people can have. Black people have a much more serious problem as a race with hypertension than they do with sickle hemoglobin but sickle was getting the press and the attention over other cells. Well that—the disease process is still around but you might say the political fad of the time has settled down. Sickle cell is a disease of abnormal hemoglobin which has taken its seat along with all the other health problems that people have. A lot have emphasized that problem. It's one that we are aware of and try to deal with.

00:38:10 **MC: Take in consideration that perhaps the state of South Carolina does not expend a lot of money for certain areas and maybe health is one of them. Is that perhaps a reason why you couldn't focus as much resources on the problem because perhaps the legislature didn't give you all the adequate resources to deal with exotic or maybe even non-exotic types of health problems? What is your assessment about the appropriations of the**

**legislature? Perhaps it wasn't possible to look at PTU and sickle cell and this and that?**

DB: Certainly when the legislature passes a law and puts money to it, that activity is going to occur in some agency. It's in the role of DHEC. They tell us they want us to do something and give us some money to do it with, we will do it. Very often the legislature will sometimes give you a mandate with no money. They'll just say go do it without passing any money to do it. That really makes it tough. It was good that they gave some money along with the sickle cell mandate in the legislature but the amount of money they gave was not enough money to do the task as an additional task. Nor was it...the kind of money that could fund a massive ongoing effort in itself.

00:39:58

**MC: What do you think would have been the adequate resources if—what type of resources, manpower and financial would have done the job in your mind? What type of budget and what type of staff would you have had?**

DB: That's a tough question and I'll try to poke at it in a few ways but I can't give an answer as directly as you had asked for. But let me say this, I think it would be wrong...for adequate resources to suddenly be put in to place to address just sickle cell. I think that would be an injustice to the black people of this state and the citizens of this state. All people. As I alluded to earlier, there are many health problems that people are suffering from, that need addressing. We can't address them all to the extent that would be maximum coverage for them. We just don't have the resources to do it. But we have to address them all to some degree. That's what we're trying to do. We can't take care of all the high blood pressure, we can't take care of the cancers, we can't get all the babies delivered in hospital going because none of them have adequate money. We don't have enough money to ensure women have easy access to deliveries. That every woman gets the very best prenatal care or delivery services in maternity hospitals. We don't have open resources so every time all these health problems get addressed somewhat. So when you say what would it take to address the sickle cell problem, my first reaction was actually separate out sickle cell in my own mind to the point that I would advocate it being addressed completely, unless there were resources to address hypertension and cancer and other problems that we all have. I wouldn't want any *one* thing—because if all the money goes to any one thing all the rest of them are just going to go lacking. You take money—the money that goes into one program is taken from another program. There's just so much pie that they—

00:42:19

**MC: Are you saying that the pie is limited?**

DB: The pie is limited.

00:42:23

**MC: We're not talking about a pie that can be expanded?**

DB: That's right it's not an open ended pie. There's a very limited amount of money that the state has. I think they divide it up between schools, roads and bridges, and little bit on the health care and all the other things.

00:42:41 **MC: What's the priorities as far as schools and highways and some of the other areas, where does health care rank. Maybe this is an unfair question too.**

DB: That's a tough one. You'll have to ask the commissioner of the agency, I think he can answer that better. I would be hard pressed to...

00:43:04 **MC: Is health a major—**

DB: That's such a major philosophical question. [MC chuckles]

00:43:13 **MC: What part is health in the state of South Carolina?**

DB: I'm a health advocate so you're asking a biased person. I'm also trying to be a realist. I know that all the health problems—except there are not enough resources in South Carolina to address all of them at a time but some people are going to go lacking for health care. It hurts me to think that money will be the obstacle that decides who will get that health care and who won't. I think there's some people who are more fortunate than others. Some people have been born more fortunate than others, been born into wealthy families. Some people have just been born smart. Some people have been born lucky. I guess what I'm saying is that I lean more towards basic health care as being a right rather than privilege and that... So that I think people should have access to basic health care. Now what is basic? Where do you draw the line and when do you say that going to get a heart transplant isn't basic but maybe getting tested for sickle cell anemia is basic? Maybe that's two extremes but where in the middle is the line drawn in what are we going to call basic. I would have a hard time defining that. Right now on the spot. On this tape! [both chuckle]

00:44:42 **MC: Does sickle cell fit in the range—**

DB: I would call sickle cell in the basic. Testing and genetic counseling for all genetic possible problems, I would call that basic. Actually I have a hard time now having been through all the sickle cell movement and being wrapped up in it myself and emotionally involved in it myself. I have settled back down now and I have a hard time pulling it back out to single it out when I now look around and see many genetic difficulties that need addressing. So that I want them all to be addressed, I don't want sickle cell raised out and the rest of them not addressed and vice versa. I think we have to address all of our genetic problems.

00:45:28 **MC: Perhaps it's like the resources the pieces of pie that health gets based upon other needs might not be as great a priority or maybe it should have a higher priority but isn't getting it because of political reasons.**

DB: Well you have to have your roads and bridges, and your parks. Society has certain things to keep us civilized that it's going to have to have. I'm not—there's schools. Who can argue against schools and good education? I wouldn't advocate shutting down schools so we can get everybody's cancer treated. There's just got to be a good balance in the end. People like the governor and members of the legislature who have just got to decide what that balance is going to be. I'm in a special area and I'm a special advocate for health.

00:46:20 **MC: Ok. Is there any other thing that you want to address or have we dealt with all the issues? Did you see any accomplishments of your sickle cell program during the 1970s? What do you think were some of the basic accomplishments?**

DB: Well I think we...it was amazing that we were able to, in a real short period of time, get that program operational and I—that in itself was quite a feat. We started from almost nowhere to developing the laboratory expertise and the...I'm going to use the word clinical expertise in the field to be able to do screening tests and counseling. Our connection to the research, of course, was mostly tied into whatever specimens we might be supplying the Medical College of Georgia which primarily was a research unit. I guess just getting that program implemented and hopefully not doing harm to anybody in the process. By that I mean...dealing with genetic abnormalities in a sensitive manner because it's a hurtful thing for anybody to be told you have a genetic problem. Real hurtful. With as much testing and counseling that went on by our agency and by the community groups I'm sure people were hurt. Perhaps some of those hurts could have been prevented but I hope it was a minimum. I hope a lot of good was done at the same time. People who wanted that information were able to get it in a timely and sensitive manner and use it to their benefit. You know one of the problems, Michael, has been with sickle cell is getting around and doing the testing. Without a screening program you could find people who have got sickle cell anemia. They've got—they're sick. They've got problems. So you don't need a sickle cell screening program to find people with sickle cell anemia. What you're finding is people who have sickle trait or some other abnormal hemoglobin trait. Then you're giving them some information that they could perhaps make some life decisions on. That's a tough life decision. A lot of people would just as soon not know. They would rather take their chances and not have to make the decision of not having any children because of a risk that they may have a child that has sickle cell.

00:49:25 **MC: Perhaps to your credit and to the credit of the community groups, you are able to have people better informed to make life choices.**

DB: That's what we tried to do.

00:49:36 **MC: I believe perhaps that is a contribution that the community groups and DHEC did play a positive role and it didn't seem to have a detrimental effect on people.**

DB: What's missing, of course, is a good form of treatment. Perhaps maybe rather than more money being put into the kind of things that we've been doing and the community groups have been doing, perhaps where the more money needs to be going right now is into research. Get some good treatment going so families don't have to decide about whether or not they are going to take the chance because if they take the chance maybe there'll be some good treatment available. That's—if I had to advocate one thing for more money. Where would I put more money? I believe I would put it in research.

00:50:29 **MC: Research. Rather than counseling and screening.**

DB: I think there's enough counseling around now. That's not to say everybody is going to get it. But it is around. It's around as much as any other health service that we have available.

00:50:44 **MC: Perhaps that's another accomplishment of the movement of the 1970s. I've been talking and interviewing with a number of people and they were talking about the lack of information. The public was really poorly informed about sickle cell. Even the medical community didn't really understand the disease and as a consequence of this campaign, medical community became better informed. They're more sensitive. Also the public was informed and were able to make better decisions. So perhaps some good came out of all this.**

DB: I think you—the medical community...was not as interested in sickle cell. I'm sure there were a number of people saying well it's a black disease and most of the doctors were white and perhaps the doctors weren't interested for that reason. That may be true for the individual physician but it was also a disease that there wasn't any real treatment for. So it wasn't like the medical community would go out and drum up all this interest for something that they couldn't do anything for. The doctors in general don't spend a lot of time counseling people. You're talking about we could do all this testing so we could do some counseling, that's just not something that doctors would be interested in. People can't afford to go sit in a doctor's office and receive counseling. They can't take up that much of the doctor's time because they can't afford it. Nobody can afford it. [laughs] Certainly poor people can't but even well to do people can't afford the kind of cost it would cost to sit down with the doctor for counseling sessions. So I think that had a lot to do with the lack of interest in sickle cell. Although there were individuals around the country who were really—as you were talking about some of them who had been working with sickle cell. It took the politics of the early

'70s to raise it up above everything else then let it settle back down to whatever its rightful place is. As you're talking about accomplishments I think it is an accomplishment that in the last ten years sickle cell is a regular part of the Health Department business. It's not something that needs staff members about it. They provide it and consider it part of their role just like they do providing prenatal care or giving immunizations. It's just a part of normal operations. Maybe that in itself is *the* biggest accomplishment of the last ten years.

00:53:24 **MC: Perhaps so. I believe we've covered all the ground. I really appreciate your consenting to this interview.**

DB: Thank you. I'm glad to do it. It was nice to meet you.

00:53:34 **MC: Thank you**

00:53:34 **End of interview.**