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INTERVIEWEE

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**Interview # 322**

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**Abstract:** In his interview with Michael Cooke, Edward Bynum (1933-2012) discusses his work with the Dr. James R. Clark Memorial Sickle Cell Anemia Foundation. Mr. Bynum details his background with the medical community and his work with the Foundation to establish testing, education, and counseling for sickle cell anemia in the Columbia South Carolina area. He discusses his work with researching the disease and other hemoglobin deficiency diseases and traits. Mr. Bynum details the establishment of a laboratory by the Foundation to further screen and educate the local community.

\*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 15, 1984. I'm conducting an interview with Edward Bynum who is a Medical Technician at Hematology. He is a member of the James R. Clark Memorial Sickle Cell Foundation. Mr. Bynum could you give us a brief biographical sketch of your life? When were you born, where were you born, what is your education?</b>

EB: I was born in Washington D.C. 1933. I went to St. Augustine's and St. Paul High School. I graduated from there. In turn I went into the United States Navy as a Hospital Corpsman. Was attached to the U.S.S. Repose which is a hospital ship. There I performed duties on the battlefield in Korea and also attached to the first marine division in Korea. I went to the United States medical school in Bainbridge Maryland [United States Naval Training Center]. I received my certificate from the Bureau of Medicine Surgery as a Hospital Corpsman. Upon serving duties in Korea, I returned to the United States and was discharged in Long Beach, California. I went back to school there in Los Angeles State College. I returned back to Washington D.C. and received on as staff at Freedmen's Hospital. I worked at Freedmen's Hospital for a period of two or three years. In turn I went back to school in Washington [D.C.] and went to D.C. General Hospital. Which is approximately a 2,700 bed hospital which houses OB/GYN,

Children's Hospital, and also other medical and surgical patient care. At that time I worked with Dr. Paul McCurdy [spelling?] who was a hematologist who was in charge of the hematology and blood bank department. From working there in hematology, I—Dr. McCurdy was at that time in 1956-57 had been working with children who had sickle cell anemia. He was one of the first pioneers in Washington D.C. to start this research at Children's Hospital. I worked with him making hemolysates...doing various—at that time, one particular type of electrophoresis and that was determining at that time hemoglobin S. At that time we were doing it with hemolysates a very treated type of strip, today which we call salis-acetate strip.

00:03:08 EB: After leaving D.C. General Hospital, I went to Princeton University Hospital in Princeton New Jersey. I worked on staff there in hematology which we were doing also some work in hemoglobinopathy. Upon returning back to Washington in 1970, I went to Children's Hospital which I worked under Dr. Lycan [spelling?]. Who at that time—further steps in research and other testing and breakthroughs have been made...in testing other hemoglobins at Children's Hospital. I left Children's Hospital then and went to Georgetown University Hospital in Washington D.C. Where we did further testings under Dr. Raft [spelling?] who was the department head of hematology and blood bank. We did also further testings for hemoglobins. Upon leaving there I moved to Columbia South Carolina in 1972 where I met Dr. James R. Clark whom I had known in Washington D.C. He at that time started the sickle cell foundation. I was a part of that foundation—the original foundation. The groups that gathered at that time in 1972. I left in 1975 to go to Baltimore, Maryland at the VA [Veterans Affairs] Medical Center in the University of Maryland Medical School in which we did further testing in new areas at that time...new areas at that time...ok...[voice in background] I don't remember [unclear]. At VA Medical Center we were doing—started new testing. Were doing hemoglobinopathy so at that time we were doing thousands of work ups of hemoglobin S. We were doing all the various hemoglobins. The thalassemia work ups as well as hemoglobin C, hemoglobin Barts disease, and also we were examining various types of smears and some hematology. Another test we also did was called G6PD deficiency. Which is an enzyme deficiency that we found that...people who are resistant to Malaria who lived in the Mediterranean areas and G6PD of people who had the deficiency we found...that were resistant to Malaria in those parts of the Mediterranean area where Malaria was prominently in those areas. I returned to Columbia, South Carolina and was setting up the laboratory for the James Clark Sickle Cell Foundation. Presently—

00:06:21 **MC: When did you return?**

EB: I returned in 197—excuse me, I returned in 1981. I started back with the Foundation in 1983. I proposed we set that laboratory up. Through various companies that I have dealt with, Helena particularly. Helena Laboratories in Beaumont Texas gave us the equipment to set up the laboratory here in Columbia,

South Carolina. I am in the process now of—to this day we have done approximately 700 and some odd tests. In the Foundation to this date, starting in '84. The laboratory officially was set up in February of 1984 and this is June, now of 1984. We've done 700 tests. We are approximately finishing our procedure manual and my job now is to educate, and counsel, and teach the various patterns and hemoglobinopathy and hematology in the South Carolina area for the medical school here and also for the Business Technical Center in University of South Carolina.

00:07:47 **MC: I have a question about how many tests were proved positive that you have conducted so far?**

EB: Well, approximately, I would think, out of 700 tests we've probably had about 65 that were positive.

00:08:01 **MC: Positive for sickle cell anemia?**

EB: Positive with—approximately maybe 30% were approximately AS traits the others were what we call fetal hemoglobin which is hemoglobin that most blacks will inherit or you—after gestation some will keep this hemoglobin with you the rest of your life. How it affects people with sickle cell anemia is that it—all of the hemoglobin—the person who has sickle cell anemia we find that if they have fetal hemoglobin there all of the hemoglobin is not sickle hemoglobin. That means their lifespan—they can live a normal lifespan and their complications are not as great because all the hemoglobin is not sickle hemoglobin. Also we have found some AC traits as well. We have approximately found one thalassemia at this point. But as we broaden our education and screening procedures we surely will pick up a lot of thalassemias. Which we find predominantly in this particular area in South Carolina. We will be doing that in the near future.

00:09:16 **MC: Going back to the start of the Foundation, what were some of the early problems that the Foundation had in the beginning stages?**

EB: Mostly to try to educate people, black as well as white, as to what sickle cell anemia was all about. Many people thought sickle cell anemia was a disease that they could catch it if they sat next to someone...people were—just frowned upon it. They were really frightened. Some people would go in—we were testing at some of the areas or wanted to test...someone would probably say 'oh geez, I've had that test before.' Or 'I don't need that test, I haven't got that. I know I don't have that.' That was some of the myths that people had. The average man on the street, he thought probably that it was a test that you get from the sky or something. Or the weather made you feel like this. So there are millions of people who did not understand sickle cell anemia and because they didn't understand they were not very supportive of it. Of course the Nixon administration, they did provide funds to educate people in counseling and testing over the United States.

Various grants were given to cities through the federal government to educate and counsel people with sickle cell anemia.

00:10:40 **MC: Did this Foundation receive any support?**

EB: Yes they did. They received funds. They are receiving funds now from the federal government.

00:10:47 **MC: But at the time, in the beginning did they receive any funds?**

EB: No. They did not. These funds were—Dr. Clark initiated this by various sororities and fraternities. Black fraternities and sororities. Colleges and so on to participate to raise funds for the testing here in South Carolina.

00:11:11 **MC: How would you characterize the success of the Foundation the first couple of years?**

EB: The first couple of years were very difficult. Very, very difficult. It was...new horizons really. It was just a very difficult task to do. Through hard work and the efforts of many, many people that were involved, it's beginning to come over now to South Carolina. Even in the 14 years elapsed now...now we're beginning to make a dent. We didn't even—we were unable to even make a dent the first couple of years into acknowledging or trying to educate people what we were trying to do.

00:11:53 **MC: Did you spend a large majority of your time trying to educate rather than screening?**

EB: My job was in both. Mostly mine was in screening. Mine is actually doing the testing itself.

00:12:05 **MC: Did you have a lot of people willing to be tested or did you find a real reluctance on the part of the community to be tested?**

EB: There was approximately a 20% reluctance to that yes. Because they didn't know what it was. Even your educated people still did not know what it was. Your doctors and so on...First of all they weren't teaching this that thoroughly in the medical schools at that time. They just recently started this in the past two years. From '82 to the present they began to teach what we call hemoglobinopathy. So the physicians now have some idea of what we're talking about—what we get into, how to recognize the various anemias. Another thing that I must add to this is that...a lot of doctors had been treating their patients as the Greeks or [unclear] systems...the Greeks, Italians, and ethnic groups as well as blacks, they called for iron deficiency anemia and they were giving these various irons and the testings were...they could not understand why these people had this deficiency. The deficiency was because these people are having what we

call a thalassemia trait which...behind the iron binding—we call it two line binding now and ferritin were very low or deficient. These people, after looking at the peripheral smear and doing the thalassemia test, we found these people had thalassemia trait. These people were becoming—these patients were being given an iron overload which was not the deficiency. The deficiency was in a thalassemia trait. So this is one of the helpful things that we have educated the doctors with now. Before giving iron we do these various tests on these patients to see if they have another hemoglobin deficiency. Which is...comes out of hemoglobinopathy.

00:14:18 **MC: So it's a really complex problem. It's not just simply educating the sicklers. It's educating the medical community and the sicklers and the general community as a whole. A very complex.**

EB: That's correct. Right. Now there is another myth that white people think they don't have this trait but they do. There are some whites who do have sickle cell trait, or AC trait, or thalassemic trait but the—it is not that great of a percent. In testing we might find one out of thousand probably who has the trait. AC or AS trait or thalassemic trait.

00:15:00 **MC: When we look at the black population what is the more—**

EB: You might find say about 5% out of a thousand so that would give you one out of 500 of them.

00:15:21 **MC: Did you have any work with the Foundation members? Although you did a lot of the technical work, did you attend the meetings?**

EB: Yes. I'm on the educational board now and I do meet with the members, Dr. Reginald and Dr. Humphreys. I do meet with the directors Mr. Robert Green, Mrs. Allen Mosely, Mrs. Rudy Canzater. I'm in consistent contact with those board members.

00:15:51 **MC: That's today though. What about in the past? When you were here in '72 and '75?**

EB: Well at that time I was working directly with Dr. Clark. I was part of—I was one of the members who was invited to come in to the Foundation in the beginning of it. However, I had to leave and I came back and started with the Foundation again.

00:16:15 **MC: But what was your contact? Did you actually attend the meetings in the '70s?**

EB: Yes. I attended the meetings in the '70s. That's when we were trying to form a group as to what were our goals as far as setting up the guidelines, bylaws, and so forth for the sickle cell foundation.

00:16:30 **MC: What were some of the goals and objectives of this organization?**

EB: I can't really—I left just before those bylaws were really up and I really can't...I know I signed them but I can't. To the best of my recollection I just can't...I just don't remember. Without having reread some of the material again.

00:16:55 **MC: When you left the Foundation and the area, did you continue to work in sickle cell research?**

EB: Yes I did. In Baltimore Maryland with the Veterans Administration and the University of Maryland Medical School.

00:17:05 **MC: Was that—how much time did you spend in sickle cell research? I know you probably didn't spend all of your time.**

EB: I spent approximately...I would say 75% of my time with sickle cell research. With patients and examining the smears, teaching as well. Education as well as showing slides, educating the medical school students, the nursing students, people in the neighborhood. People came to our hospital to receive slides. It was a community effort. We had various television and skate-a-thons. We had...

00:17:53 **MC: Was there a Baltimore sickle cell—**

EB: Yes. There is a Baltimore Greater Chapter. There are three locations in Baltimore Maryland. One of the people that I was researching with, Mrs. Dorothy Taylor, who is on the board there at the sickle cell foundation in Baltimore. She is one of the board members there. She is a very outstanding person and a very dedicated person in sickle cell anemia education as well as screening. She's a social worker up there.

00:18:19 **MC: Did you volunteer any of your time to work with those groups?**

EB: Oh yes. Quite often. Most of my time was volunteering out in the city level or the community level that was most of my volunteer work. But the other part was my—you have to think of it like a job, they were paying to do research.

00:18:37 **MC: So actually it's not like you left sickle cell organizations during this stretch of time you were away from Columbia. You were still active.**

EB: Still active. That's correct.

00:18:48 **MC: You left the Baltimore area.**

EB: Right

00:18:53 **MC: You left in '80—?**

EB: I left in '81. Returned to Columbia. I contacted people here. The James Clark Sickle Cell Foundation. We set up an appointment for me and I met the new people who run the board. We worked out—I introduced a plan for setting up a laboratory here. The board approved. The doctors here at DHEC [Department of Health and Environmental Control] all approved. My credentials were sent out saying that I was overly—beyond satisfactory. The only knowledgeable person in hemoglobinopathy. My courses had also been with CDC and I'm in consistent contact with CDC and with Dr. Baines and Mr. Robert—

00:19:44 **MC: You're talking about the Center for Disease Control?**

EB: Center for Disease Control, right. I'm in consistent contact with Dr. Baines and Mr. Hall who is a medical technologist there while doing my research. Also Dr. Steinburg in Jacksonville Mississippi who is at the Veterans Administration. There is another doctor also in Greater Medical Center in Ohio, and also Dr. McCurdy who is now at Georgetown University, Dr. Wrath. Consistent contact with my work that I'm doing here now. We will be hopefully between—by the first of the year we will be doing extensive work in our testing here in the James Clark Sickle Cell Foundation. My goal now is to really push, push, push. To really educate the people of South Carolina. In the back countries, in the wooded areas, wherever we can find we are going to do work. We're going to set it up and we're going to do it and we're going to see that hopefully that South Carolina will be—well it will be the greater area for the sickle cell foundation in the United States. It will be on the map as one of our great areas. With the cooperation of our communities and such.

00:20:56 **MC: Right now you have a laboratory so do you propose to establish laboratories or establish procedures for setting up laboratories throughout the state? Is that what you propose?**

EB: I would like to do that. I would like to do that. But the thing about it is the training the people to do this. It is very difficult to do this. Training a person to do this without having some chemistry, hematology background can be very tedious. It is very, very—you have to be very knowledgeable as to read patterns and that is the most difficult thing. You have to understand and troubleshoot. If you have patterns you cannot guess, there are no shortcuts in this at all because you are dealing with someone's life. If you tell someone they have something—it's like the doctor saying ok you have a disease and I think you have a disease but I really don't know you have the disease. Here we have to *know* before we say anything or put this information out to that he or she in reference to their children. Because

when you counsel these people you are saying you have this trait and they might want to make the decision well I'm not going to get married now because they think they have the trait but all that time they might not have the trait. A false positive result has been given to this he or she. I hope I'm not getting off—

00:22:22 **MC: No. No. I think that's fine. Another question that comes to mind is who is qualified to be a technician testing for sickle cell? What type of prerequisites—is the testing procedure fairly simple or is something that somebody has to have the specific training?**

EB: Someone has to have the specific training for it and expertise at doing it.

00:22:48 **MC: Who would be that type of person? What type of person would you train to be competent to have a lab in a small town in South Carolina?**

EB: Well I think the person should first of all have been trained by a hematologist or a pathologist. This requires—any hematology first of all, we're going to have to go with hematology and some chemistry. That person would have to have knowledge of chemistry but mostly a great deal of, I would say, 85% hematology which is basically what hemoglobinopathy is all about. By hematologist and pathologist he or she should see many slides, many techniques, variety of techniques and so on. Then that person can go to the CDC to also be educated. You can go to—

00:23:43 **MC: Do they have a program for technicians—**

EB: They do have a program at the CDC.

00:23:47 **MC: This is where? In Atlanta?**

EB: In Atlanta, Georgia. They also have a program in the Bronx, New York and the Veterans under the federal government. They have another one in California. In I think—these are mostly advanced courses but the person should start out in he or she's basic laboratory with a pathologist or hematologist and being taught by the qualified physicians to teach them. As a beginning if they have no other source after school and such. We're talking after you've gone to all the science courses in medical technology school then come into the laboratory to work with a hematologist and pathologist to teach you this.

00:24:39 **MC: So you can't just simply come out of medical technology training and just simply understand what's going on?**

EB: No you can not do that. This is not advisable at all because what they teach you there is really to give you some backbone or something to start with when coming out. It's like a physician who really doesn't know anything that's why he does what we call an internship as to put that education together into one



particular area and you might become an urologist, or internist, or a surgeon, or a pediatrician, or whatever. As you see he is going to guide all of his knowledge into one particular area into becoming his expertise in that limited area. That's what I suggest for the technologist.

00:25:27 **MC: Do you think that the state and the federal government have done everything they can to help or do you think there should be some support by the state or federal government of laboratories for instance run by community organizations?**

EB: ...I would think that a known person—a person who was knowledgeable of setting up a program like that should be a head of a program. I don't think it should be given to the community itself because it ends up it could be misguided in a sense. This has happened numerous of times in that instead of the monies being appropriated for—the monies used for what it's—to educate the people, sometimes other areas or other cities where the monies have been misunderstood.

00:26:29 **MC: What do you mean by that?**

EB: Well sometimes I think we have a tendency to...we have a tendency sometimes to veer away from what our original goal is sometimes. There is if you give it to the communities sometimes the one tries to do more than the other or to use the corporation against the other. What I really want to say I don't even really want to go into it. Best to leave it out right now. This is—these scattered areas like how often I've seen that monies has been given to Baltimore or Washington and sometimes it's been mis—not misappropriated but sometimes it's been misunderstood or even misunderstood by how the money is to be distributed. I think this is the fear of some of these programs. I think that would have to be very knowledgeable persons to run that one group. I don't think you need 50,000 groups you need one person to organize various groups and that one person should be in charge of monies for those groups and such. For education and such, with volunteers and such. I think you can get many volunteers to do a lot of work. I don't think everyone had to get paid to do this volunteer education because you can train people to counsel and educate the community. By this you can go into the community and show them the interest. Show them what you are really trying to. Show them that they belong to what you're doing. I think this is one of the biggest things we are going to have to work on. We have to go to the community and really tell them that you are a part of all of this. This is what you are all about. This is your heritage. This is what we are trying stop. We don't want to see your child a sickle cell patient.

00:28:29 **MC: Thinking back to the 1970s was that a big factor for so many people being connected with sickle cell? It was part of the—a byproduct perhaps of the civil rights movement and its black awareness. Being that was so prevalent during that time did you find a lot of people rallying to the cause of sickle cell anemia because of that?**

EB: I think this is one of the reasons. I think this is how it really came out with the Nixon administration is because of that. I think that had a great deal to do with that. As a matter of fact I'm sure it did because I live in Washington D.C. during the black movements and during the '70s. I'm sure this is why. I don't remember the gentleman who proposed it to the Nixon administration at the time when he passed this bill for better funding. I do not remember his name now but I do know the black man was very instrumental in this government funding for the sickle cell screening in the cities.

00:29:31 **MC: Ok. What is your impression about how the liaison between the Foundation and the Department of Health and Environmental Control of South Carolina during the years you were here? Did they provide sufficient counseling and guidance and support to the Foundation?**

EB: I don't really know about that part because I wasn't here, like I said. I wasn't here at that time. I don't know whether he—he probably did receive good support. Dr. Clark. I don't really know if he had difficulty with them or not. I can't answer that for you.

00:30:07 **MC: Ok. Thank you.**

EB: Thank you very much too.

00:30:11 **End of Interview**