Clarice Reid Oral History Interview
May 14, 2018
Interviewer: Dr. Gordon Margolin

GM: This is Dr. Gordon Margolin, volunteer in the Office of NIH History and Stetten Museum, serving as moderator for this update of an oral history with Dr. Clarice Reid. We're recording this session in the NIH Library's audio-visual facility on May 29th, 2018. Dr. Reid retired from her role as national coordinator of the national sickle-cell disease program and Chief of the Sickle Cell Disease Branch, which she served from 1975 to 1994. After that from 1994 to 1998, she served as Director of Blood Diseases and Resources at NHLBI. At that point she retired and we'll be talking about it at the time of her retirement. An extensive oral history was previously recorded by Dr. Valerie Williams in 2002 fully explaining her involvement of the science of sickle-cell disease. That document supplements other aspects of Dr. Reid's life: her background, accomplishments, and thoughts about the NIH. Welcome, Dr. Reid, we're grateful for your coming in and for giving your time and for your effort in this endeavor. I'd like to start out by asking you tell us a little bit about your family background and growing up in the deep South at that time

CR: Thank you, Gordon. It is a privilege and honor to have an opportunity again to be part of the oral history at the National Institutes of Health. My background is rather traditional with a few unique aspects. I was born in Birmingham, Alabama and grew up in the segregated South. I was a "post-depression" baby, the youngest of three and the only

girl. My family consisted of my paternal great-grandmother, my paternal grandmother, my parents, two brothers, and myself . There were four generations of us in the house. We enjoyed a modest life in a four-bedroom home with an indoor toilet, a front porch, a swing and a large backyard . My neighborhood consisted of teachers, painters, domestics, musicians, and postal workers I had a very nice childhood and remember sleeping in the room with my brothers for about one-half of my childhood until my great-grandmother passed away. My paternal grandmother, was the "matriarch" of the family. She was a " no-nonsense" task master; a first-grade teacher and insisted on teaching reading and writing very early. I resented having to stop play and come in, sit down in my chair, along with my brothers and study my reading writing and arithmetic.

Education was always very important to my family. My grandmother obtained her Bachelor's degree from Alabama State University while I was a child which was very unusual during those times. In later years, her name was added to one of the elementary schools. You have to understand that education was key in the black community. Knowledge is power and you were always expected to do your best. In my own household, my granddaughter, a sophomore now in college will be the fifth generation college graduate in our family. My father was a college graduate of Talladega College and met my mother there. I think she was finishing the Talladega High boarding school. They married shortly after college graduation and began a family. My father was a teacher in the Birmingham public school system. He later taught high school chemistry

and became a school principal. I am not sure that he actually wanted to be a doctor but he talked about science and medicine. He began his family very early after graduation from college and was content as a teacher throughout his life. My brothers and I all majored in science.

In my household, we devoured books. There was no library at the corner, but we always had the latest version of the Encyclopedia Britannica. There were all-white movie theatres in downtown Birmingham; however, my parents did not allow us to go and sit in the segregated balcony. There were a few black movies that we once slipped out to see. My greatest joy was the summers when my brothers and I were put on the train to go to Chicago where my grandmother's brother resided. My mother packed us each a lunch as there was no food available on the train for Negroes. We were able to visit the museums and the planetarium We were privileged to be able to leave Birmingham and be exposed to a variety of cultural activities.

I attended a three-room elementary school where all of the first three classes were taught together with two teachers. I think this preceded Montessori where the teachers were always nurturing and making sure that we achieved our potential. There was only one high school that blacks could attend in Birmingham, Parker High School. Although there were many schools closer, we had to get on the street car and, ride across town. The principal of my high school was Dr. Robert Johnson, the father of Alma Powell who is the wife of Colin Powell. Parker High graduated approximately 1,000 students a year with a January and June graduation. As a child, I liked to challenge myself and do

whatever my brothers were doing. We were three children in four years and became a little team. I enjoyed playing with the chemistry set, not the frilly dolls. We threw bricks, made swings out of rubber tires, cars out of wood and boxes or whatever junk we could find. We created our own fun. It is interesting that children now with all the digital instruments will miss out on this kind of fun. We enjoyed ourselves with the things that were available which probably made us more creative and focused on what we had to do.

It was, a great period in my life with a childhood full of fun, love, and joy, with the exception of losing my mother as a young teen. My paternal grandmother and loving father became my default mothers and did an excellent job. Our only National Negro, was the boxer Joe Louis, as his success seemed to bring more respect to the black community. I remember his big fight and at that time, there was no television. Many of our neighbors came to our house and huddled over a little black radio about as big as half a newspaper. It was so much excitement that someone of color got so much recognition. There were other families with radios, but our house was like a gathering place. We were never rich nor poor; so we would probably be called middle class at that time. Every one mixed together in a community of fellowship: the pool players, numbers runners, teachers. There was no caste system. Working together as neighbors, looking out for each other is what we learned from our family growing up.

GM: You didn't feel mistreated or uncomfortably segregated.

CR: We probably never got a chance to. We did not run-downtown or sit in the wrong place. My parents probably protected us from the real "bad" things going on. My father had a

few Caucasian friends, including the President of the Birmingham Board of Education. He sometimes visited my father at our house and I never heard of any serious incidents.

GM: How did you finally end up in medicine and going to college?

CR: In our house, going to college was a given; never "would" you go to college but "where." Actually, there was very little doubt about where. All we had heard about from our parents was Talladega College in Talladega, Alabama. This is a small liberal arts college located in the blue hills of Alabama not too far from Birmingham. My father and mother had Talladega roots. My brother closest to me attended Talladega College. My oldest brother did "get out of the barn" and went to Morehouse College in Atlanta. For three people in my family, Talladega was our alumni school. Talladega was considered one of the premiere historically black colleges in the country. It was a different type of education with a student population of approximately 500; we knew every student's name. Our President at the time was Dr. William Beittel, a Caucasian, and his son attended Talladega. One of the earlier prominent presidents was Dr. Buell Gallagher, a notable educator from New York.

Interestingly, some of my professors, especially in languages, were European academics fleeing Europe and found themselves welcomed at many historical black colleges. Many taught at other colleges across the country bringing their intellectual and teaching skills to the campus. Our interracial faculty member lived on the campus and students had the opportunity to visit them at their homes in the evening and talk about the word at large We were exposed to the classics, arts, classical music, theater, literature and the opera.

We didn't get distracted even when the Klu Klux Klan burned crosses in front of our dormitories. Talladega was a very small college community and we pretty much stayed on the campus except to travel home. You may hear more about Talladega, Ala. because of the race-track. Female students leaving the campus wore hat and gloves. We could only wear blue jeans on Saturday and attended chapel on Sunday. It was pretty much a "European" style of education; you had to look proper to be properly educated. There was no drinking at my college town as it was "dry" county. Even so my brother was innovative and would find some creative way to sneak in a few alcoholic beverages. Talladega was a college of cultural diversity with high level achievers. It was an experience of cultural diversity, with high level achievers.

GM: It seems that your good fortune in your lifetime, with all this background in education and was very important.

CR: Yes, I think that defined how my life was. Although I never "spun out of control" it was not always a rosy picture; but I can fall back on those positive things that happened earlier in my development. This does become important.

GM: This sounds very important to you. How did you decide on medical school?

CR: I don't know that I ever consciously decided on medical school except that my brother was going to medical school and I basically followed everything they did. At that time, I never expressed the cliché of "I wanted to help others" but later that became who I am. In college, I was a good biology student with top honors We did not have A-B-C type grades and I graduated with highest honors. There was not a Phi Beta Kappa chapter on

our campus and I probably would have that honor. Talladega College had a distinguished record in preparing students for professional and postgraduate studies. In my small class, there were five doctors, several lawyers, and PhDs. That record has likely changed with the college venturing into other areas of study. Other colleges that were prominent were Fisk University in Nashville, Howard University in Washington, D.C. and Spelman College for girls in Atlanta. Talladega College had a distinct reputation which we tried to preserve over the years.

During my senior year, it was time to make a decision about the next step Although, I had talked about going to medical school, in retrospect I am not sure that I had the maturity and discipline. My biology professor suggested that if I did not want to go directly to medical school I should consider laboratory technology at the School of Medical Laboratory at the Meharry Medical School in Nashville, Tennessee. This was very appealing as I also wanted to escape my brother who was a year ahead of me at Talladega. He was the "big brother" type, sheltering and advising who I could date with his constant oversight. This would give me time to socialize; to learn life lessons and to make decisions that would affect me in the real world. That was a good decision. My parents packed me up, questioning what I was doing, and drove me to Nashville Tennessee. It was here that I met my roommate, a young lady and graduate of Bennett College in North Carolina. We grew up together as young ladies and became life-long friends. Many of our classes were with the freshman medical students. The medical technology program was a two- year course of intense clinical laboratory training, not

just drawing blood. We were trained in the correlation of laboratory findings with diseases. Graduates of this program were certified by the American Society of Clinical Pathologists, the gold standard for laboratory professionals. With skills in laboratory technology, I was clearly trained so that I could do bone marrow smears right at the bedside with the physician and the same with spinal taps. I was able to get a jump ahead. I was also a frequent volunteer in the research laboratory of Dr. Harold West, a noted professor of biochemistry working on the amino acid threonine. Upon graduation, I received the Outstanding Faculty Award. The Dean of the Medical School, Dr. Rolfe, was also the Physiology professor. After every physiology exam, the student's names and grades were posted outside his office door. My name was usually at the top of the list that included mostly freshman medical students. Dean Rolfe would frequently ask me, "Ms. Wills, why aren't you in medical school?" That was a very good stimulus for me to apply. I did apply and was accepted to Meharry. The only medical schools providing medical education for minorities were Howard University and Meharry. There are two others now, Morehouse in Atlanta and Charles Drew in Los Angeles. There was no question that I was going to Meharry; my brother was a year ahead of me. I was still following in the footsteps; we always had a good relationship and I would have his guidance.

During the year that I was waiting to go back to medical school, I went to Cincinnati to work in the laboratory at the Jewish Hospital. The head of my medical technology program knew the laboratory director at the Jewish Hospital was looking for a

technician. He directed me to a position at the clinical laboratory. I was there for a year and here I was able to put my laboratory together with some of the clinical aspects seen in the patients. From the laboratory findings you could make patient diagnoses; from blood chemistries and urinalysis, you could see kidney disease. I knew iron deficiency from looking at the cells ; knew blast cells from lymphocytes and reticulocytes. This knowledge put me in a good position in my introduction to blood diseases.

GM: You will talk about another change in your transition?

CR: While working in Cincinnati I ran into this ambitious young lawyer, Arthur J. Reid, Jr., who later became my husband in less than six months. Again, my parents were a little alarmed about this change, as I had already applied to go to medical school. They were prepared to send me back to Nashville and in the midst of this, I was talking about a guy they had never met and he was Catholic. My family was Protestant. There was a bit of tension in the family but it had a good ending. We married in June and I returned to Meharry and shared a house with my brother. My husband remained in Cincinnati. After two years, we talked about my returning to Cincinnati. I didn't apply to the University of Cincinnati because the application process had already closed. Many people thought that I would have a particularly difficult time as this was not something done very often and especially going to an all-white medical school. I don't recall going on an interview but I still have the letter from the Dean of the medical school stating, " I am informing you that you have been accepted for your junior year in 1957."

I would not suggest following my course. It was unplanned, unpredicted, but paved the way for remarkable unplanned adventures and a series of things in my life. The black physicians in Cincinnati were very dubious that this would happen; that I would be accepted so I elected not to tell them. Later at a some gathering, they asked me about Meharry and I told them that I was going to the University of Cincinnati Medical School. They looked at me with surprise and pride because there were no other minority students attending the medical school. I suppose that I was expected to have some "horror stories" but I did not. Many of the black doctors were not allowed staff privileges at some hospitals but that gradually changed. After all, Cincinnati is southern city across from Kentucky. We did not announce my intentions, but my husband was very happy for my transfer. He was constantly traveling back and forth from Cincinnati to Nashville and he had his own young law practice. He received his degree from the University of Cincinnati School of Law. His early education was in the local Catholic schools including college at Xavier University. One of the things I had told my father about my husband was that he was one of eleven in a large family and absolutely loved taking care of his family and especially his mother. I was correct that he would be a good husband and father and he took care of the children more than I did during my medical school and training. We had very limited resources and both parents contributed to our support and provided a good support system. I was a mother before I was a doctor and had my first child in the summer of my junior year in medical school and never missed a thing. My next child was born doing my internship at the Jewish Hospital. Dr. Margolin was there in the Department of Medicine which makes this interview even

more personal, that you followed me to the NIH. Cincinnati was a great school for me and I didn't perceive any differences because I was a female nor being black. There were four other female students in my class and three of us graduated. We had a common bond with the challenges of being a wife. I see only one now when I attend our class reunions.

GM: After your internship, how did you make the turn to go into Pediatrics?

CR: It was not pre-ordained and actually in medical school, my choice was obstetrics and gynecology. I enjoyed the excitement of bringing life into the world; catching that baby and being with the mothers. It occurred to me that obstetrics and gynecology was a specialty that would not allow me to control my life when it came to work hours. In pediatrics, I could have more flexibility and the challenges of motherhood were just as important as the challenges of being a doctor, along with that of wife. I was very fortunate to have Dr. Louise Rauh as my mentor. She was a very tough no-nonsense pediatrician on the faculty who took me under her wings. While in training, I travelled with her to the "well-baby" clinics around the city examining babies and young children. She inspired me and taught me the importance of serving the underserved population. Under her umbrella, I migrated into Pediatrics and enjoyed taking care of families. Pediatrics was consistent with my family life and the fact that I had children and "hands on" experience and knowledge about children's needs and what worked in a family environment. I would train to be a specialist in Pediatrics. After my internship, I applied to the Jewish Hospital Program that had an affiliation with Children Hospitals Program as well as applying to Children's Hospital residency program. I was rejected from the

latter one because of "my uterus was too gravid" as I already had two children. I guess the question was my ability to carry out the responsibilities of a full-time mother and the demands of a resident. I had pediatric training at both hospitals. Actually, I had the best of both worlds and during my time at Children's they wanted me to stay there longer than my assigned time. I was considered one of the best pediatric residents. As a Jewish hospital resident, my family lived in a two-bedroom apartment in staff quarters provided by the hospital. We lived (free) next door to the hospital and things worked out for the best. At the Jewish Hospital, I had the opportunity to care for babies as newborns, follow their development and discuss parenting issues. This was important as I was going into private practice, not clinical research. One of the side stories was when I traveled to Minneapolis for my oral examination for pediatric certification. At that time, both written and oral exams were required for certification. It was in Minneapolis on a very cold Saturday. Upon my return, the Children's Director, who was part of my earlier rejection, was very excited in telling me that he had received a call from the examiners extolling my performance and congratulating him on his outstanding pediatric resident. I knew that he was proud of me but I had to remind him that I was a Jewish Hospital resident. We both had a good laugh that he now wanted to claim me. We all loved each other and it was a great experience.

GM: And then after residency you wanted to practice as a Pediatrician .

CR: This was in the early sixties and I was the only black pediatrician in private practice in the entire city of Cincinnati. This is the time of the "Black is Beautiful" in my

community. Everybody wanted to see a black doctor and all were too happy that I was there. There was a load of patients and I enjoyed the experience. It was more than keeping kids well and treating illnesses; it as also about being there for families dealing with non-medical problems in their personal lives, including finding financial assistance. I became the therapist and psychologist. At the same time, I was taking care of babies of unwed mothers and screening babies for adoption along with a number of "sideline" duties. As a Clinical Professor in pediatrics at the University , I was involved in teaching medical students and house staff. I have been asked about my experience with sickle cell patients. There were at most three patients with sickle cell disease in my practice; however, I saw sickle patients during my residency at the Children's Hospital. Most children with sickle cell disease were seen at Children's Hospital where there was specialty training in hematology. The great thing about my hematology experience at Children's hospital was having the fortunate opportunity to study under Dr. Alvin Mauer, one the leading pediatric hematologist in the country, and a great teacher. I was always under his arm and had a good exposure to hematology.

GM: How did you get from Cincinnati to the NIH? You had to give up practice.

CR: In 1970, I was the Director of Pediatrics at the Jewish Hospital. My mentor, Dr. Rauh, was very instrumental in the progress of my pediatric career. In this role, I was doing limited private practice, primarily administration and oversight of the clinical program. At Jewish Hospital, there were three-medical directors. I was the Pediatric Director, Dr. Gordon Margolin was head of Medicine, and Dr. Henry Heimlich (noted for the

Heimlich maneuver) was head of surgery. We shared a suite of offices and I was feeling very good about my career, having advanced further than I ever imagined. My lawyer husband, a Republican on the City Council in Cincinnati, was offered a two-year appointment at the Office of Economic Opportunity (OEO) in Washington DC. My husband convinced me with a lot of "gnashing" of the teeth, cajoling, screaming, and yelling to move. I agreed and took a two-year leave of absence from Jewish Hospital. When I would return to visit in Cincinnati, I was always reminded that I was still on leave.

It was a time when wives followed husbands; that is not as much the practice now. I did not want to move. My children didn't want to go; leave their friends and have to make new friends in the all-white Bethesda, Md. We did not know anyone there. I was so negative that my husband had to buy the house sight unseen by me. The story ended there. Before the moving van was completely unpacked, the backyard was full of children playing together. Many of these kids are their lifelong friends. It just shows how preconceived ideas work at this level. We are still in the family home and took down the basketball hoop about ten years ago. It is a story of the consequences of making an unwanted, unplanned move that shaped my life and that of my family.

After the two years period, my husband stated that "we have to go back." We rebuffed and pointed out much we enjoyed D.C. He said then, "You need a job." These were the only two years in my whole adult life that I was a stay-at-home mother and I began to enjoy this life. It was the time of the Women's Movement when everybody else wanted

to go to work. Black women have worked all their lives and were not worried about going to work. I had to make a change and get a job. At a social affair with my husband, I can't remember the individual's full name but it was a Ben who directed me to the Public Health Service that was right down the street from our home. I had very little knowledge or experience about federal programs. I applied for a position and was appointed as a medical consultant in the Public Health Service in the famous Parklawn Building. It was in the Office of Family Planning and the sickle cell disease service program happened to be in this department. It was not an intended program that I was seeking, and it really changed the direction of my life and my career.

GM: After that you want to tell us the story of how you got into the sickle cell at the NIH.

CR: First, let me give you a broad clip of sickle cell disease and the program. It was the first genetic disease to receive federal attention at the national level. In 1970, President Nixon included sickle cell disease in his message to Congress stating that it was a "neglected disease" and needed support. This led to a cascade of activities with new legislation. No one was prepared and it was the worst time, right after the Civil Rights Movement to have a disease that targeted predominantly blacks individuals in this country. There was a lot of mis-information and confusion; a spread of "fear" with descriptions in the media of a disease that "tormented" blacks. There was hysteria and confusion between sickle cell disease and sickle cell trait leading to numerous discriminatory practices. Airlines were forbidding pilots with trait to fly; schools were requiring screening as if the disease was infectious. In the Public Health Service, as Deputy Director of the sickle cell

program, I had the responsibility of the Screening and Education Clinics. These twenty-three programs had been set-up in universities, hospitals ,and community centers across the country to correct the misinformation and increase awareness about sickle cell disease. Dr. Rudolph Jackson, a pediatric hematologist from St. Jude Hospital, was in charge of the overall National Sickle Cell Program at the NIH. Although, I frequently interacted with Dr Jackson, around the service program, I was never directly involved in the research component. In the mid-seventies, Dr. Jackson left the program but remained at the NIH in the intramural research program. The National Program for the first time was without a leader. I had very limited knowledge in terms of the internal operations of the NIH program. My association with the NIH component was through making presentations to the National Sickle Cell Disease Advisory Committee. The NIH component also made reports during the committee meetings. The National Heart and Lung and Blood Institute/(NHLBI) NIH was the lead agency for the sickle cell program. With the departure of Dr. Jackson and the need of a director, it happened that I was in the "right place at the right time." One of the major scientific administrators, Dr John Hercules, a scientist in the Sickle Cell Branch and Dr. Robert Levy, Director NHLBI, convinced me to temporarily come over from the service side to the NIH on a thirty-day detail while searching for a replacement of Dr. Jackson. A government detail is an agreement with another agency to allow their employee to work for a limited time period while still employed at your home agency. I served as the Acting Chief of the Sickle Cell Disease Branch/NHLBI. At the end of the 30 days, Dr. Levy asked me to stay on and "run" the entire program. I pointed out that research was not my area of expertise. I was

basically clinical and well-trained in clinical and laboratory medicine along with administration. As I protested the position, suggesting that it needed a research scientist, Dr. Levy, with a sense of humor, simply said, ”Can you read?” That simple statement was enough of a challenge and provocation that I could not say “NO”” and he made it sound easy. It wasn’t that easy; however, I had enough administrative and operational skills which is really what was needed.

The sickle cell program was a significant part of the NHLBI with lots of media and congressional attention and was thrown in the limelight. I became aware of the poor image of the program with the hematology community. It was also a program competing for funds from other blood diseases. There was general discontent that NIH was funding the service activities with research funds from the NIH. Although I lacked the NIH experience, I remembered a quote that “in periods of rapid change, experience can be your worst enemy”. There was nothing for me to relate to in terms of what I had done before. I walked into this empty big hole of intellectual wisdom wondering, “What am I doing here?” Looking back, it's hard to describe the affect as my background was primarily in clinical and administrative; in this setting a broader knowledge base was required along with an additional set of skills. I liked challenges and told myself to “suck” it up that “ I can do this.” Actually, at this juncture the program needed more of an administrator than a research scientist. There were lots of skeptics about, “Who is this young woman with no bona fides? Why she was brought in for this job?” This was never verbalized to me but I would ask those same questions.

This was the beginning of a twenty-year home at NIH and it was an unbelievable experience. In a short time, I had the support of most of the scientific community. I was pretty good at communicating with good interpersonal skills. I knew what I didn't know and always sought to surround myself with individuals who knew things that I didn't know. It was a steep learning curve and most of the scientists were very helpful and I simply devoured information. I always enjoyed learning and reading books, even now the latest by James Comey and John McCain. The sickle cell disease program attracted researchers from all over the world to work on this disease of rather initial low interest. Sickle cell disease is a multi-disciplinary disease embracing many branches of medicine and science. There is the genetics, biochemistry, physiology, cell and molecular biology, and many other fields of science. The scientific investigators, clinicians, health educators became a close family working together to achieve the goals of the program. The entire community was eager to work and move the field forward to positively impact the lives of sickle cell patients. This is what I miss the most. For me, working in this area with like a holiday with the best scientists and clinicians contributing to the program. I can't take credit for the enormous progress but hopefully my being there made a difference. In my position of leadership, I was charged with organizing the largest research program in the Blood Division. Many of the intramural scientists as Alan Schechter , Connie Nagochi, Bill Eaton, Arthur Nienhus, Griffin Rodgers, and many others were willing to expand my knowledge of many areas of ongoing research. The Branch organized

"think tanks" bringing scientists together from the national and international community

to discuss needs and opportunities in sickle cell research, leading to programs we were able to implement.

GM: You are very proud and felt that you accomplished a great deal in those 20-some years here in terms of sickle cell disease.

CR: Yes, throughout the world, doors were opened to a range of activities, including newborn screening. It shows the importance of basic research. Sickle cell disease was described in 1910 and for many years, very limited research was done; although we knew more about sickle cell disease than most diseases at the molecular level. It was in the late seventies and early eighties that with the explosion in molecular biology, tools became available to explore more research at the basic and molecular levels. There was also the genome era with other advances that made a big difference in the direction of research and the lives of patients

GM: All of these accomplishments are expressed in your other oral interview where you described the prophylactic penicillin study, transfusion therapy, and the use of hydroxyurea, which is still the major treatment, and nitric oxide, which is under study still and all these things have not led to a cure.

CR: Progress is ongoing and children with sickle cell disease have been cured using bone marrow from matched siblings. At least one or two adult patients have been successfully treated with bone marrow transplantation. I don't know the current status of gene therapy. As a clinician, one of the most important advances in early years was the change in the care of patients. Most of the previous care was fragmented and episodic with many

patients only seen in the emergency rooms. The funding of the NIH Comprehensive Sickle Cell Centers in the early 1970s provided patients a medical home. This was the beginning of a team approach to care, including the nurse, the physician, social worker, health educator, and nutritionist. This made a tremendous impact on the lives of patients. Dr. David Nathan, a leading hematologist at Harvard, stated that "standardized care of sickle cell patients contributed more to longevity and quality of life of patients than any other medicine." This became the model of care; a number of non-NIH centers used this approach.

GM: I'm hearing, Dr. Reid, that one of major roles you played was organizing the program and there was improved patient care and doing other things necessary to accomplish in sickle cell disease. I can only wonder what would have happened if there had not been such a program here at NIH?

CR: The program was in place in the early seventies before I came to the NIH. The national focus made funding possible for the first time to support a number of research directions which made a huge difference. Sickle disease went from a position of "obscurity to prominence". Patients received the best care in the hands of hematologists. One of the greatest disappointments was the dismantling of the Sickle Cell Centers in 2006. Many sickle cell patients no longer have a medical home.

GM: Do you think it should serve as a model to medical care in general in our country?

CR: It has been an effective model with the center concept starting in the National Cancer Institute. The close interaction with "town and gown" was unique as there was always

this dichotomy between the university and the general community. This interaction was one of the requirements of the Sickle Cell Centers especially since patients are needed for research. The well-established good patient relationships made them more comfortable in the early participation in clinical studies. The sickle cell community benefitted from all of the new innovation.

GM: I think what you're saying is a lot of that was done in medicine is on an anecdotal basis, the entire community of sickle cell patients and focused on the total picture. Prior to the sickle cell program, there were lots of approaches to treatment that were anecdotal as well as unsubstantiated data reports.

CR: The progress made during my years at the NIH is not my story; but that of a collective team of hard committed workers from all areas of science and medicine. There were regular conferences, workshops and seminars. International meetings held in Africa, France, and Greece. Many of the leading scientists and "big thinkers' participated in the "think tanks" pulled together by John Hercules and Alan Schechter in the intramural program. Investigators looked forward to these meetings, share new findings; lots of disagreements and agreements exploring unmet needs in sickle cell disease. It was a special event, like a debate club arguing back and forth. The best scientific projects often came from these charged discussions leading to RFA's and new initiatives. My role was to prioritize and package these scientific projects and present them to my boss, Dr. Claude Lenfant, NHLBI Director, and make a compelling argument for support. There was never a shortage of visionary ideas. The rationale for the research projects and costs

would be thoroughly reviewed and weighed against the balance of needs from the Heart and Lung Divisions. There were always competing priorities. My job was as the orchestra leader to support good science and fight hard to fund the investigators. There were many successes and we had our share of rejections. Never to give up easily, as one door closed, I would pursue another one to open. That is how I am in life. As I struggled to do this, Dr. Lenfant would fondly accuse me of "coming again begging with my tin-cup." Sometimes it worked.

GM: Did you see a lot of changes in the culture NIH during those 20 or 25 years relative to as you worked here?

CR: There were few change in how we functioned structurally? Each Institute and Center at the NIH operated as its own single entity with a full complement of related services, e.g., personnel, travel office, IT services, a center for every related service. This was convenient for each Institute but there was lots of duplication and probably inefficiency. That was beginning to change and most services were centralized by the time that I retired. There was an increase in cross-institute initiatives with related programs. The results of the genome project contributed to major scientific directions and opportunities overall and more directives with the global community. There was always something else exciting coming forward with another research opportunity.

GM: It sounds to me like you took it as a real challenge.

CR: Yes, I enjoyed the fighting, which meant I had to know the science, the rationale, and potential outcomes. That is how Dr. Levy challenged me when he asked, "Can you read"

and I did have to do lots of reading. Several times when I made presentations to the Advisory Committee there were questions around scientific and non-scientific issues. If it was something I didn't know I would simply say so; take ownership of the issue and welcome assistance from the questioner. I think that was disarming.

GM: It sounds like your early childhood experiences trying to keep up with your older brothers taught you a lot about how they function. How about other women and black women do you remember here at NIH who contributed to the program, well, not only your program but other NIH programs.

CR: One of the things I'm most proud of at NIH is the fact I got to mentor a lot of very bright women who joined the NIH. I recall a saying in the black community. That we "lift as we climb" i.e., it's important to bring others along as we move up the ladder of success. My father my would have said, that it is ok to be the first; it is more important that you're not the last. Dr. Vivian Penn, a pathologist and graduate of the University of Virginia came to the campus to head the Office of Women's Health. Dr. Marilyn Gaston, my deputy director in the sickle cell program joined the sickle branch from the Cincinnati Children's Hospital, making significant contribution to sickle cell studies. She went on to become the Director of Medicine in the PHS; Director of HSA, administering the largest budget in the public health service; and later Asst. Surgeon General of the U.S. She now has a non-profit organization that offers interventional services to women in the middle years. I am proud to be on her Board of Directors. Dr. Yvonne Maddox, Deputy director of the Child Health Institute, later served as Acting, Deputy Director of NIH. A

very high-level job. Others in our "girls' caucus" were Dr. Agnes Donahue from the Dental Institute who left NIH to work at the Department level; and Dr. Helena Mishoe, who joined the Sickle Cell Branch from the NIH intramural program. She became our outstanding Administrator in red cell research and later went on to the lead the NHLBI in cross-institute programs. We would meet away from the NIH campus for lunch or after work to discuss and share all the little things we experienced, the good and the "not so good." I served as the older sister talking about "which battles to pick" and to wait for the big ones. I pointed out that there may be perceived differences but urged them not to attribute them to color or gender. My father taught me very early that there were two things you can't change—"being black and female"—and to focus on that is a waste of energy. That statement served me well. We discussed how to negotiate, to compromise and to listen, not always talk.

Much of this wisdom and training, I received from my NIH mentor Dr. Robert Ringler, Deputy NHLBI. I would shadow him at high level meetings; listen and you learn a lot. I passed on many of the little NIH "tidbits" with my mentees. There were others (minorities and non-minorities) that on various occasions sought advice. There was often an opportunity to with work with minority summer students reviewing their medical school applications and with trainees reviewing the poster and oral presentations for scientific meetings. It was about listening style, giving advice, and responding to questions. There was always an interest in creating students in the pipeline, particularly black students, through the centers scholar program .

GM: I was told to ask you was what keeps you up all night what you're thinking about your profession and scientific accomplishments and anything you would have done differently?

CR: That is an excellent question; actually nothing keeps me up at night. I roll over and pinch myself and realize how privileged I have been to have this amazing career pathway. It was totally unpredictable and afforded me an enormous opportunity to impact on the lives of so many sickle cell disease families. The mission of the NIH is to improve the health of the nation's people and we worked toward providing the best health care for patients with sickle cell disease. One thing I that regret was loss of the centers' program. As I was departing, there was a trend toward fewer clinical studies and more focus on basic research. In the last Center competition for renewal, the research projects submitted apparently did not receive high ratings and probably included much of the ongoing research. The direction was moving toward translational research. Probably, in retrospect, and reading the "tea leaves" we could have reconsidered the RFA requirements and made those programs much more competitive. This is probably speculative on my part, as I had departed. It is reassuring and I am very excited that the American Society of Hematology (ASH) in the last five years has taken on sickle-cell disease as one of its major initiatives. There was, seemingly from my distance, a decline in the emphasis on sickle cell disease and there might be a more personal observation and less of the community involvement. People would state that " I don't hear much

about sickle cell disease anymore." It was that kind of another sense of loss. ASH has taken on this as a cause which makes me feel very good and is probably a call to action

GM: I suspect with hearing this whole story you've probably touched many more lives through this arrangement and your job here at NIH than you would have in your own single practice in Cincinnati. So that you've left a major impact on the whole sickle-cell world I'm sure that you wouldn't have touched had you not by chance come to Washington metropolitan area.

CR: Looking back, I enjoyed the years I impacted the lives of children and families in my practice and at the Children's Hospital and Jewish Hospitals There was the spectrum of experiences from my very brief exposure of research as a laboratory technician, to my clinical training and patient care, and finally to the desk as a National Program Director at the NIH. I probably was able to do more at the national level by training more young investigators who migrated into the area of sickle cell disease; feeding the pipeline and scientists contributing more to the body of literature. The sickle cell program kind of exploded in all areas and many more individuals were involved.

GM: Yes, there's so many other people who were involved all over, absolutely; which obviously reflects on your central position I think that was very important. Why did you retire when you did?

CR: I retired exactly twenty years ago in 1998 and could have worked longer. I really still feel that close to the people and the program. Fortunately, I have had very few physical issues that would have made a difference and I'm still " halfway mentally alert." My

husband had retired several years earlier and claimed that I was only "working for the government." Our children were gone, no house mortgage and few taxable deductions. Basically, all that we were doing was making money for the government That was his lawyer talking. I did think about that and retired in 1998. I had a full work experience and qualified for both time in government and age (66) to retire. Unfortunately, my husband died in 2001 less a month after diagnosis from pancreatic cancer. I am very happy that I made that choice and had those years to spend together. We had an opportunity to enjoy our favorite hobby, duplicate bridge; traveling all over the country and having fun with our beautiful family. Things happen unexpectedly and that's life.

GM: You answered all of my questions. I think that's the most important thing that I've picked up. Through all of this is that you have had such a very positive outlook on the whole world and the sickle-cell world all your way through this entire discussion. I think it's your outlook and your comfort with your ability to handle people and deal with them and not get all upset that has really made this whole thing possible. I have to give you a lot of credit and I think you created this entire program.

CR: No, I did not create the program but probably maximized the opportunities to make it successful. Maybe as a female and woman of, color, these are very unique characteristics that we have. We have had to relate to people at all levels from the president all the way down to the homeless in my life. I relate with everyone at the same level of interest and concern. I've been very fortunate to have a family structure that allowed me to exercise my own sense of community and caution about all things along that social spectrum. I

think that it provided me with that broad sense of caring and the need to take care of everybody. Earlier, I stated that I wasn't drawn to that cliché when I was young, but it was always somewhere in my DNA. I am always very positive and look at what people can do as opposed to what they can't do. Someone asked, why did you go to into medicine? I said that what helped my choice was knowing what I didn't want to do and sometimes it is just as important. I knew that I didn't want to teach. Teaching is a lovely discipline, but to me it was boring and would not challenging my curiosity.

GM: Let me interrupt you. You have accomplished more than most teachers in terms of teaching, involving people and getting them involved and letting them carry away the story and moving along. That is really what teachers do, whether you know it or not. (

CR: Yes I just taught from a different platform.

GM: Thank you so much for this oral history interview which will be attached to your older ones . We have a great story from you about you and it will be in the files of the Office of NIH history and available to anybody. Eventually, it will be up on the website where anyone can see it. You will be able to look back as a role model for many, many, many years and you deserve it.

CR: Thank you. It's my privilege to have done this project and even more so because of you and our relationship beginning in Cincinnati forty-five years ago. Our meeting together in this setting inspires me to continue a relationship that goes at least another forty years. Thank you.