ORAL HISTORY PROJECT

Earl J. Brewer, MD

Interviewed by Charles “Chuck” Spencer, MD

July 15, 2006
Houston, Texas
PREFACE

Oral history has its roots in the sharing of stories which has occurred throughout the centuries. It is a primary source of historical data, gathering information from living individuals via recorded interviews. Outstanding pediatricians and other leaders in child health care are being interviewed as part of the Oral History Project at the Pediatric History Center of the American Academy of Pediatrics. Under the direction of the Historical Archives Advisory Committee, its purpose is to record and preserve the recollections of those who have made important contributions to the advancement of the health care of children through the collection of spoken memories and personal narrations.

This volume is the written record of one oral history interview. The reader is reminded that this is a verbatim transcript of spoken rather than written prose. It is intended to supplement other available sources of information about the individuals, organizations, institutions, and events that are discussed. The use of face-to-face interviews provides a unique opportunity to capture a firsthand, eyewitness account of events in an interactive session. Its importance lies less in the recitation of facts, names, and dates than in the interpretation of these by the speaker.

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ABOUT THE INTERVIEWER

Charles “Chuck” Spencer, MD

Dr. Charles “Chuck” Spencer is a graduate of Isidore Newman School in New Orleans, attended Cornell and Tulane universities, and the LSU College of Medicine in New Orleans (1973). He did his internship and residency at Los Angeles County General Hospital/USC Medical Center as well as a Chief Residency from 1973-1977. In 1977-1979 he trained as a pediatric rheumatology fellow at Los Angeles Children’s Hospital with Dr. Virgil Hanson and his cohorts. He started pediatric rheumatology for 8 years at LSU in New Orleans and Children’s Hospital of New Orleans. He then received research training at the NICHD under Dr. Richard Klausner 1987-89 and then took a position in rheumatology at University of Chicago in 1989. He practiced in rheumatology at University of Chicago for 18 years and was section head for 13 years. He took a position at Nationwide Children’s Hospital in Columbus, Ohio as section head and fellowship program director where he currently practices. He started the open access online journal *Pediatric Rheumatology* in 2003.

Dr. Spencer was a volunteer for the AAP from 1981-2012 including serving as Rheumatology Section Chairperson and Chair of the Council of Sections.
Interview of Earl Brewer, MD

DR. SPENCER: This is the interview with Dr. Earl Brewer conducted by Dr. Charles Spencer on July 15, 2006, at Dr. Brewer’s home. This is tape 1, side 1. So, Earl, how did your early years influence your career?

DR. BREWER: I think even as a boy in Ft. Worth, for no serious reason, I wanted to be a doctor. Our family doctor was a nice, wonderful human being. And it seemed to me that would be what I’d like to do. When I went to college, I continued this thought, being in premed. I went to the University of Texas. Then I had to go to the [US] Army because this was the end of World War II, and everybody had to go to the Army.

After the Army, my dad spoke to me at some length. At the University of Texas I’d been in a fraternity, and I’d had a really wonderful time, and my grades were okay. But at that time, at the end of World War II, everybody wanted to take premed and go to medical school. It was clear that there was competition. So he thought maybe I should stay and work where I was raised. We had a close friend, Dr. Truman Terrell, who owned a large clinic and a hospital. And then I would work for him and his chief pathologist, a Dr. May Owen, as a lab technician at night and go to college in the daytime, which is what I did. It was just invaluable to me. It was the making of my life. And I learned the discipline from Dr. May Owen who was a strict taskmaster. Everything had to be done just so, and I learned to do it her way. So that was great training.

And then in college, I was profoundly impressed at—it almost changed my entire professional life. A Dr. Cyrus W. LaGrone [Jr.] was chairman of the Department of Psychology at Texas Christian University, And he had been a prominent psychologist in the Army during the war. He had worked with Dr. Karl Menninger. And they had developed the concept of the psychiatric team: a psychiatrist, a psychologist, and a social worker. They had implemented this. I was just drawn to this cutting-edge sort of person. He was profoundly charismatic. The biology professors and the chemistry professors were nice, scientific professors. But they didn’t have his charisma. So he persuaded me that maybe I should be a clinical psychologist. I took enough courses to have a major in psychology.

He was an experimental psychologist also, and he was a statistician. His parents were both mathematicians. So that was where I became exposed to statistics which was a lifelong love. I love the logic of statistics. Not the math of statistics, but the logic of statistics and the clinical design, experimental design. And so I had majors in psychology and biology and chemistry, as a matter of fact. I don’t know how many hours there were. He arranged where I could have been offered a scholarship to the University of Texas to
take my PhD in psychology. And I really could have gone either way. But I decided that I would do medicine.

Dr. Owen and Dr. Terrell persuaded me I should go to medical school, and the competition was intense. I had decided that I would apply to med school. And indeed I was fortunate, and I was accepted quickly. It was interesting. After the Army my grades were very good. I was paying attention. And I applied to 3 medical schools: Baylor [College of Medicine], University of Texas, and Southwestern [Medical College]. Baylor called, I think because of Dr. Owen, who was the first lady president of Texas Medical Association. They called, and I went for an interview, and they accepted me. I decided I’d take the first one that accepted me. Then later I heard from the other schools. They said, "Won’t you at least come and look?" And I said, “I found something I like.” And I did it. So that was how it came to be.

DR. SPENCER: So how were your medical school years?

DR. BREWER: It was a mind-boggling experience that I’m delighted I did it once, but I would never want to do it again. I was married at the time, and it was very difficult. I had the GI Bill of Rights my last 2 years of college, because I was almost a junior in college before I was 18 years old at the University of Texas. So I finished my last 2 years with the GI Bill. And then I had another 2 years with the GI Bill at medical school. The last 2 years Baylor was kind enough to give me 1 of 5 Jesse [H. Jones] and Mary Gibbs Jones Scholarships or I would never have been able to finish. I had enthusiasm for every new department I visited, that was going to be my field. At the end I picked pediatrics.

DR. SPENCER: What was it that drew you to pediatrics?

DR. BREWER: Dr. [Russell John] Blattner, a very charismatic chairman, and Dr. Fred Taylor his associate, vice chairman, were people that I felt were great people, and I was interested in the children and what they meant. I had no visualization of why I wanted to be a pediatrician.

DR. SPENCER: So you went then into residency after 4 years.

DR. BREWER: I had the opportunity to go other places, but Dr. Blattner and Dr. Taylor persuaded me to stay in Houston at the then Jefferson Davis Hospital, now Ben Taub Hospital, and do an internship residency. In those days we did rotating internships, and I think they’re valuable, myself. Then I did a residency, and I stayed in pediatrics. And then my fortuitous trip to Boston occurred during that time.

DR. SPENCER: So that was after 2 years of pediatric residency?
DR. BREWER: Well, 2 years of internship and what they called an internship residency. But anyway it was 2 years, you’re right. It was a total of 2 years at Baylor. And Dr. [Charles A.] Janeway, who was chairman of the department at Harvard, and chair and physician-in-chief of Children’s Hospital [Boston], had a work arrangement with Dr. Blattner where Dr. Blattner could send selected young people, to Children’s Hospital for training and then return. But then, the 2 or 3 who had done it, were in subspecialty fields: Dr. Donald Fernbach in hematology; Dr. Bill [Charles William] Daeschner [Jr.] was a person who ended up in nephrology. And the thing that happened to me was that Dr. Janeway sent his chief resident, Dr. Mohsen Ziai, Moe Ziai, to Houston for 2 months to get a feel for the Baylor program and how the hospital could help or if they wanted help. I was assigned to Moe as his junior resident, and Moe was the resident. And we hit it off. He returned to Boston and told Dr. Janeway that he thought they should bring me there to be a senior resident of medicine in their general pediatric program, not as a fellow off to 1 side. And indeed that’s what I did.

It was a mind-blowing experience, and it opened horizons that I didn’t even see. So I was able to get a Jesse Jones fellowship with the understanding, verbally, that I would come back to Houston as chief resident. And that if Houston couldn’t interest me after 2 years, Jesse Jones said, then you should leave. But he was trying to bring capable people back to Houston.

DR. SPENCER: Right.

DR. BREWER: And building his medical center. And Dr. Blattner felt the same way.

DR. SPENCER: So tell me about those 2 years in Boston. What was so extraordinary? What year was this?

DR. BREWER: This was 1956. And well, first, the system at that time: They had 6 senior residents and 24 junior residents. Three of the senior residents were taken from inside the Harvard system by promotion, and 3 were taken from outside their system because Dr. Janeway wanted to prevent inbreeding.

DR. SPENCER: Right.

DR. BREWER: So I was one of the 3 outside. And they literally had hundreds of applicants for the places. I’d never realized that, but they did. So Texas was not high on the list of well-known places at that time. And I really was like Crocodile Dundee coming to the big city. And, as you know, anything west of the Charles River may not exist. [Laughter] So it was a
great learning experience in seeing and being with people like Dr. [Louis K.] Diamond and learning how to do exchange transfusions from T. Berry Brazelton. And being a resident on the service of Stewart [H.] Clifford, of the famous new born service. And Clement [A.] Smith. I mean these were all people who not only were well-known people, they were wonderful teachers. In many different ways this was the making of my horizon and my career. While there, Dr. Janeway pointed me to the way of children with arthritis. Senior residents met with him every Monday morning, and he found out what happened over the weekend basically. He and the chief resident, Dr. Peter [A. M.] Auld, lamented the care that children with arthritis received. As pediatricians he said it just can’t be right to put these children to bed for a while. He said, “I know what they say. But I don’t agree about the adults either.” Because he had trained in adult medicine, Dr. Janeway was an internist actually by training.

DR. SPENCER: So that was the standard of care at that time?

DR. BREWER: Put people to bed as long as your insurance held out. And it was just bed rest is better.

DR. SPENCER: In the hospital?

DR. BREWER: In the hospital, in a hospital situation. And they tried to do it at home. Somehow resting those joints kept them from being injured, and that was the concept. And the principle, we now know, was just accepted as gospel, that rest was much better. So I was assigned the task of reviewing hospital records at the House of the Good Samaritan, which is a world-famous hospital. Rheumatic fever had virtually disappeared for all the reasons we know: penicillin and epidemiological changes. We were going to write an article about the care; as pediatricians, we didn’t think that this made the best use of the service. But the records were really not very adequate. I learned a lesson then that I always made sure that when clinical records were made properly, they would be of help later, both in reading about the patient and in learning about how things should be treated. And so we couldn't publish it. Then I went back to Houston, and I continued on with that thought at a later time after I was chief resident.

DR. SPENCER: What year was that?

DR. BREWER: I came back in the 1950s. My time there was 1956 to 1957. I came back to Houston as chief resident at Texas Children’s Hospital in 1957 to 1958. The hospital was 4 years old. It had 100 beds. Great inspiration and vitality but not much track record. From what I’d learned, I established their resident teaching system at TCH. I established the discharge summary system, and the noon conferences. The hospital was so
full, and it was so successful in the community. The private physicians were an intimate part of the program through Dr. Blattner's wisdom. Because Dr. Blattner didn’t want to do it, the chief resident had control of the beds. For a wide variety of reasons he didn’t want to do it. So I was the one who had to tell people no, or if that person has to come in, and this sort of thing. It was a great lesson in learning to work with groups of disparate people who had different agendas. At the end of it, because we’d made a deal, he let me spend 2 months with Dr. Dan McNamara and Dr. Denton Cooley because I had spoken to them about going into cardiology. They said they would be pleased to have me, but financial considerations meant I had to go into practice because I had responsibilities and debt. And so I did.

Dr. Blattner and I discussed what career I could have in academic medicine and how we could work toward it. He was working towards it. I would be back in the fold. So it was really the mechanism. And we discussed again these children with arthritis and his concern and my concern. So he said, “Well, let’s just look at it, and we’ll open an arthritis clinic.” We didn’t know anyone who had an arthritis clinic for children. There were, as you know, 3 or 4 people around the country who were really doing kind of the same thing. So we opened an arthritis clinic with the Junior League outpatient department at Texas General Hospital in 1958. I came one day a week. We had our clinic, and we had the nurses, and they had the medical students and the residents and the full group of individuals. That was how it really started.

DR. SPENCER: How did you get referrals in the very beginning? How did you get new patients? They’d just come in?

DR. BREWER: We put the word out. And because I’d been chief resident and the doctors weren’t mad at me, [Laughter] we put the word out to the practicing community, and I said, “Earl is starting an arthritis clinic.” And they said, okay. And that’s the answer to your question. They came. It was a shoestring operation at that point. There was one person, Dr. George [W.] Salmon who was indeed the first chairman of the Pediatric Section of the Department of Medicine at Baylor University College of Medicine; this is in 1947 or so. George did it because he was holding it open until his friend Dr. Blattner could come from St. Louis and be the chairman. And George, who had a huge practice was revered by every pediatrician in town as well as other people, did the following: When Dan McNamara was at Hopkins training with Denton Cooley, and Dan came back, George would gather children with heart disease. And as soon as Dan got to town, he just sent them over to Dan. George did the same with children with arthritis. Indeed that was one of the ways that helped it succeed. It was an interesting phenomenon, how this transition and the tension between the adult people and the pediatric people occurred.
When Dr. Blattner came, he insisted that there be a Department of Pediatrics. He was not going to be a section of the Department of Medicine. And they explained these things to him. But he said, “No, no.” So that’s how he ended up a department. And indeed, I felt this same tension between the adult rheumatologists and the pediatricians who felt that the then standard, parochial way of bed rest and don’t strain yourself was the right way to do it. And also that pediatricians somehow were junior doctors. There was a difference of opinion. I mean, it was clear to me that pediatricians had a different view of the growing children, and that we should work with the adult rheumatologists. Where they saw children, we should work with them, but the pediatricians must be in charge as we moved forward. I followed that concept all through my professional career, and it led to some memorable battles along the way. But I think they were wrong, and I think that we were right. Children are different.

DR. SPENCER: So how did the Section of Pediatric Rheumatology at Texas Children’s [Hospital] grow and mature?

DR. BREWER: The biggest impetus, initially, was from Dr. Bill [William] Clark, who became head of the March of Dimes, and arthritis was the next goal for Basil O’Connor and the March of Dimes to conquer. A long story, but we were the first—or almost the first—special treatment center. So that gave funding for me to return to Houston fulltime. Dr. Blattner and Dr. Mavis Kelsey, who had his Kelsey-Sebold Clinic, with 6 or 7 doctors total. They were all adult doctors, and all trained at the Mayo Clinic. He wanted to be in a multidisciplinary clinic. So he asked me if I would be the founder and chair of the department of pediatrics. He had great ideas, and the ideas bore fruit, and they now have 21 branches and 400 doctors. So this was not an idly-thinking man. I said yes. Dr. Blattner saw a chance. So he had half the salary covered. And then the other half the March of Dimes covered.

So I had a full faculty appointment, half the time at Baylor at Texas Children’s, and half time at Kelsey. And I spent mornings in the lab and in the clinic at Texas Children’s and at Baylor in the microbiology department. I had to work my way through college and medical school working in laboratories. I had lab skills. The other half time was spent in starting the pediatric practice at Kelsey. It was a great learning experience with adult internal medicine docs who’d trained at the Mayo Clinic where pediatrics was barely on the letterhead at that time. Introducing them to our needs just for office space and for things to do. They all wore formal suits, I mean business suits. I’d had my own clinic, and, you know, if you’re practicing pediatrics, it’s a little difficult to do that sort of thing. I could have a staff meeting of either section or department in the shower because I was the
Arthritis Clinic at Texas Children’s Hospital, and I was the pediatrics department at Kelsey-Seybold, you know. But that was how it began. Then it just blossomed from there. But without that initial financial support, I could never have come back.

DR. SPENCER: Did you do general pediatrics then those first few years?

DR. BREWER: At first. Not at the halftime at Texas Children’s, no. It was 100 percent pediatric rheumatology. But I was developing the pediatrics department then. I was lucky and people came. So as I hired pediatricians, I quit seeing general pediatrics. I didn’t really do a lot of general pediatrics after that. Houston was expanding, and we were growing at Kelsey at 10 to 15 percent a year. It was time-consuming to hire doctors. And then the program at Children’s, we were developing the 3 ten-year plans for the development of the service, and developing our service there. And doing all the turf wars that one does when there are a lot of other young doctors building their own sections and fighting for space in the clinic. [Laughs]

DR. SPENCER: So this was into the 1960s.

DR. BREWER: Well, it was 1958 and 1960 when it started. And then 1960 when all this started, yes. Within a few years, though, we were really treading along. We had a team going.

DR. SPENCER: You hired physical therapists?

DR. BREWER: With that first grant from March of Dimes. Because March of Dimes was very sensitive to physical therapy. They had written the book with physical therapy and understood it, and the lessons were real. They knew that was the essential thing for us to have. Texas Children’s supplied the nurse, of course, and all the clinic staff. When we had space, finally, the physical therapy room was the foot in the door to get the office. And it seems valid when you’re trying to obtain space and working to increase your turf, other guys are, too. [Laughs] Yes.

DR. SPENCER: So how did your section grow more? Did you have some more physicians join you in rheumatology?

DR. BREWER: When Elizabeth Barkley came, she was so able. She was a head of the school of physical therapy at the Hermann Hospital [Memorial Hermann-Texas Medical Center], which is a big hospital. And was a member, or head of maybe, the physical therapy board of the state of Texas. So she was a respected person. She was very interested in developing a whole treatment program, which was our thrust. We thought these children could be kept active at home and not in the hospital. So she and I,
mainly Elizabeth, wrote an exercise pamphlet, "Home Treatment Program for JRA [juvenile rheumatoid arthritis]" about how you do it. We had training at the clinic, and we trained the children and their parents. That was the genesis of the return visits a lot of times. So that part we developed. As time went on, we developed other things. In essence, though, we were seeing patients more and more days, full time. That was really most of the time we were building it up.

As time went on, I guess it was the early 1970s, we began to add more things. But we had Dr. W. Malcolm Granberry, an orthopedist, and Dr. Sidney Cleveland, a psychologist. And we were doing these other things like the Pediatric Rheumatology Collaborative Study Group. But we really developed and expanded in training about the middle of the 1970s. More and more people were finding that because we were achieving more and more recognition, such as the JRA book in 1970, there was better visibility. The [US] Maternal and Child Health Bureau in 1980 took us on to develop. They had developed cardiology, and they had developed the fields of pediatric pulmonary disease, and they had done cystic fibrosis, and a host of things. They had as their goal to address unmet medical needs of our country. And directors Dr. Merle McPherson and Dr. Vince Hutchins, a whole wonderful group of people, knew how to do it.

So they called me, I think, and we were the first pilot clinic. We had a $50,000 grant. This will answer your question about when we added people. That was just an incredible thing for us, to have money for staff. So we then developed the team concept that they had and this coordinated team care and community-based and family-centered care. They promoted the idea very definitely that the family was in charge, the doctor advised the family and the patients. Like one of my friends said, “I have a partnership with my patients. I tell them what to do, and they do it.” I think quite a number of doctors felt that, very cocksure and like that. Well, you know, this is what you will do. And it was not well received by a lot of people. Indeed, mistakes were made, I think, when you don’t listen…. I always told our people, “Always listen to the child, and always listen to the mother. One really is just as important as the other.”

Because of maternal and child health funding, we were then able to have a nurse educator, a physical therapist, an occupational therapist, a nutritionist, and a social worker. And as time went on, it was clear to me that one of the major things we were doing was working with the schools, or attempting to work with the schools, to get better help for children who had maybe a deficit like they couldn’t write. But there are other things one could do for that kid to receive special help or special education in the regular classroom. Later it was a common thing. I hired a guy, a fellow named Jeff Benjamin, who was a special ed teacher, and he somehow was a friend of one of our staff people.
Jeff became our social worker. I replaced the social worker with Jeff, who was a certified special ed teacher because that’s really where we were spending our time and spinning our wheels. So Jeff, as a special ed teacher, could call School ABC and say, "This is Jeff Benjamin, you know, in special ed. You remember me. I used to work at...." It was just amazing how the children suddenly were able to get help. I learned that you really have to learn to work the system. And being authoritarian is not one of the ways to work the system.

So that was how we expanded. Then as we became busier in the late 1970s, we developed our fellowship program. And then we had a staff. One hugely successful staff member was Dr. Edward Giannini, who came to me when he was still a student for a doctorate at the University of Texas school of public health. He became our epidemiologist and senior scientist. But his help in the mechanics of our Rheumatology Division was just beyond belief. He really was very able in helping with the fellowship program and with everything we were doing, in addition to being our statistician and epidemiologist.

DR. SPENCER: Let me stop this for a minute. [Break] Now, tell me more about the start of the Pediatric Rheumatology Collaborative Study Group. How did that get going?

DR. BREWER: Oh, that is just an incredible story. In 1972 I somehow came in contact—and my memory fails me—with a Dr. Stanley Gottlieb of McNeil Laboratories. They were developing a new non-steroidal drug called tolmetin. And Dr. Ralph Wedgwood of the University of Washington medical school and I met in San Francisco with Dr. Gottlieb. McNeil was hugely successful in pediatric pharmacology. They were a great drug company for children. They had acetaminophen. They had all the children’s kinds of medicine. So they were in tune. But they were going into the non-steroidal field, which was a new thing for them. They knew they wanted to study this non-steroidal drug for arthritis. They wanted to study children. One reason is that Dr. John Harter of the [US] Food & Drug Administration, who became our great friend, had said to them that it just seemed fair to him that the drug companies study it in children as well as adults; and that the FDA would certainly look with more favor on a company that thought enough of children to do a study. Which meant that they may have given them a foot in the door, an edge, on what was a very competitive area.

They knew how to study drugs in children because with Tylenol®, they had done it. And indeed I had done a study in the early 1960s with acetaminophen and indomethacin, which was then a very new non-steroidal drug. I showed that in an acute dosage, blinded study, double-blind control, indomethacin was far superior to Tylenol® in reducing high fever. But it
was a single-dose study, no anything else. I published it in *Arthritis and Rheumatism*.

So Ralph and I met with them, and we all hit it off. Ralph was interested in seeing this project move forward. But his interest was in the laboratory and the immunological research. He did not want to participate, but he wanted to make sure that we were successful. Ralph was an interesting person. He had trained at the Children’s Hospital in Boston several years before I did. He was a jolly Englishman with this wonderful visage and everybody’s friend. He was from the Wedgwood china family in England and had broken the ties and jumped the traces and come to Boston to train. He then ended up in Seattle for reasons I don’t know. But he was a very independent person and a great human being. Ralph and I worked an arrangement with Gottlieb, and we moved forward. We sat with them and worked out how we’d do the study. McNeil held our hand and helped us develop into what we thought was the right way to do it.

I returned to Houston, and we contacted our small collegial group, and we had spirited discussions on many occasions regarding the structure of the open, double-blinded follow-up studies that developed. We developed the forms, the methodology of study with the help of McNeil and Dr. John Harter of the FDA and Dr. Stan Gottlieb. The members of this collegial group were myself, Dr. John Baum of Rochester, University of Rochester, Dr. Virgil Hanson of Children's Hospital Los Angeles, Dr. Chester Fink of Dallas (Southwestern Medical School), Dr. Jerry Jacobs of New York City (Columbia University; Babies Hospital, and Dr. Joe [Joseph] Levinson of University of Cincinnati, and Dr. Jane Schaller in Seattle (University of Washington). She was representing Ralph. We moved forward with these studies, and that was really how we began. We had a disappointment at the end. We’d developed these methodologies which we discussed, Segment 1, and Segment 2, and Segment 3 Studies, which were finally accepted by the FDA as study guidelines.

But at the end of the study, Dr. John Ward (University of Utah) successfully did the adult tolmetin study, with the adult cooperating clinic group. A huge book was published in Index Medicus. I think it was a landmark event. And I had a letter from McNeil. Someone in their marketing department said that they should not include the studies we had done and paid for in children because they didn’t want the drug to be known as a weak-sister drug that was okay for children, and it wouldn’t be powerful enough for adults. Because they had word that the competitors were going to do that. I was not furious; I was beyond furious. Later the FDA approved the drug. But it remains a thorn in my side that once again we encountered that children were junior people and somehow they weren’t quite as important.
DR. SPENCER: So the Collaborative Study Group went on from there.

DR. BREWER: Yes. And we published the work in the Journal of Pediatrics in 1977. We developed the concept of open studies for Segment 1, the concept of blinded studies against another drug or a placebo, and then Segment 3 where we did open follow-up studies for long-term statistics and long-term issues. The first studies were 30 to 90 days. We did the first doses about 50 percent of the maximum dose. Then we increased it over 2 to 4 week intervals, depending on the length of the study. Later, when we did the slower-acting anti-rheumatic drug studies, the same methodology applied. We just changed how long we did things. The medications were almost always from the pharmaceutical companies. Some studies were funded by the [US] National Institutes of Health and were prepared separately. Detailed and standardized forms were used, and monitoring was performed usually by drug company monitors. And then they reported back to us, which worked to my satisfaction.

Dosages were in meter-squared calculations because we felt that we should be trying to use the metric system. The joint examination techniques were carefully studied. Clinic directors tested each other about calling joint changes, and we put pluses, 2 pluses and 3 pluses. But we learned to agree with each other. The rationale was that if errors were being made, they were constant errors. We were measuring change. So if we were on the same page of calling it and the same examiner was examining, this minimized the fortuitous changes that would not be valid. I felt that the same examiner should do it each time, and this is what we did. We arranged the Segment 2 studies for efficacy and safety. The model was to compare aspirin—which was the medicine of choice in those days—and the blinded drug, double-blinded matter. This mechanism is necessary to blind not only the patient and the family, but the clinic director caring for the patient. We did this by sending coded meds to the director from our coordinating center or the pharmaceutical company.

Later, when we were doing the slow-acting anti-rheumatic drugs—a pharmacist at the participating center filled the prescription with a coded prescription—both company monitors made frequent visits. We had troubles one time or another. Jerry Jacobs thought it was his duty to try to outguess and see if he could guess which one it was. Jerry was a great human being, and he was a tough New Yorker, and had a heart of gold that sometimes was hard to find. But he always did what he said he would do. He always made suggestions that irritated the drug companies just beyond belief; but he was almost always right. He made a great contribution and added to the efficacy of what we were trying to do.
DR. SPENCER: Earl, in these Pediatric Rheumatology Collaborative Study Group studies, how much of these procedures and investigative techniques were novel, and how much were from adult rheumatology or other group studies?

DR. BREWER: Well, of course the FDA had guidelines about doing various numbers of studies, I mean with a patient and then with a group of patients. But the methods were novel in the sense that we tailored them to children, and no one had put together in a cohesive way what we called Segment 1, Segment 2, Segment 3. Each company had its own way, and I had to go through hours and hours and weeks and weeks of persuading them that they needed to do it our way. But they always had a young person who was making his way, and he knew that we had to do it in a particular way. But it was novel.

To answer your question indirectly, when I was on the Arthritis Advisory Committee for the Food & Drug Administration from 1976 to 1980, I was on the committee and then chairman of the committee to set the study guidelines. They pretty much adopted what we had done. Other people were doing blinded studies obviously, and there were lots of ways to skin the cat.

Some of our people were feeling very legitimately angry about doing blinded studies. They felt it was not ethical, doing placebo-blinded studies; they felt they were just really bad. And in one of the studies we did, Jane Schaller felt a particular drug was so good that it was just not ethical not to give it to them, and give it to them and reduce the dosage and all that. Such a furor was raised that a high official in Norway became concerned—I’ve forgotten who it was—but we had to go over there and talk to him. And Dr. Hans Martin Høyeraal, who was our person in Oslo, had a great meeting about using blinded studies because he felt it was not good for children. The study finished, the code was broken, and the drug was worthless. The people who got the placebo were the ones who had the most benefit because they weren’t exposed to the toxicity of the chemical. After that happened we really didn’t have much difficulty when we pointed out that maybe the person who didn’t get the drug was being done a favor.

DR. SPENCER: Do you see then a clear relationship between the way the drug studies are still being done now and what you started in the 1970s?

DR. BREWER: Oh, I think Ed Giannini, Dan [Daniel J.] Lovell, and others have moved the studies to newer levels. And one way, which I approve, and I liked it at the time, is to give a drug in one group and not give a drug in another group, and then reverse them.

DR. SPENCER: A crossover. So everyone gets the drug.
DR. BREWER: Right. Or give the drug and then don’t give the drug at all and wait until they flare, and then do the drug. So there are many ways to do these things. But the basic thing is to have it in a control-blinded manner. By custom, we always had a base medicine so that no child received zero medication.

DR. SPENCER: Let me turn this off for a bit. [Break] Okay.

DR. BREWER: Ed Giannini was our statistician. We had detailed methodology that really was more sophisticated than what the drug companies had available because they were rediscovering the wheel with every new drug. We compromised by doing our own data, and then they took counter data, and they used our data with them for what they needed for the FDA. But we did our data for our publications. And indeed that went to the FDA also. And the FDA actually used our data in most cases. In most cases our data was the same as the drug company’s data; they just had a different format for the same information. The studies we did by contract actually helped the Food & Drug Administration; we did our own data, and we submitted it in that way.

DR. SPENCER: And this was something different for drug companies. They wanted to analyze it themselves?

DR. BREWER: Yes. They wanted to control it themselves. They had other drugs. We were the only route; I suppose there may be more now with the Pediatric Gastroenterology Collaborative Research Group that formed with us as a model. They would do a protocol, and they would, in this interest of separate investigators, send them their own drug company protocol. It was done in their database methodology so they didn’t have to write new software. When they came to us, they had to write new software. I said, “Well, we will do the data.” That led to controversy. They usually ended up compromising somewhere. But it was turf, not ideological problems.

DR. SPENCER: Right. During the time that the Pediatric Rheumatology Collaborative Study Group was developing, there was a seminal meeting, the first Park City [Utah] meeting in 1976. How did that come about?

DR. BREWER: In 1974-75, 2 presidents of ARA [American Rheumatism Association], who became immediate and past, Dr. Larry [Lawrence E.] Schulman and Dr. Gerry [Gerald P.] Rodnan, appointed the first Council on Pediatric Rheumatology in 1976. And initial members were the usual collegial group and some added: Dr. John Baum, Dr. James Cassidy, Dr. Chet Fink, Dr. Virgil Hanson, Dr. Jerry Jacobs, Dr. Joe Levinson, Dr. Jane Schaller, Dr. Syd [Sydney] Stillman, and myself. At this
group meeting we decided that we should get the few pediatric rheumatologists or people who could say they were pediatric rheumatologists to a meeting and see what knowledge we had and where do we go from there. That was thesis of it. It was hugely successful. Ria and I had just finished building a house at Park City, Utah. And the idea of snow and Park City appealed to everybody. So there was no great study done. Because we had built a house at Park City, we put the meeting in Park City. [Laughs]

Only 2 of the group were really ill at ease with this, and they were nice about it: Syd Stillman and Chester Fink. And Syd was the most proper Bostonian who ever lived. He was my friend and mentor, and he was my hero. He was also director of the Robert Breck Brigham Hospital at Harvard Medical School. But Syd, every morning when we were in Park City with the snow at the Park City Mountain Lodge, would appear, and he’d say, “Good morning, Earl.” I’d say, “Good morning, Syd.” At 7:00 in the morning, Mountain Time, he was in his tie and white shirt, sweater, his sport coat, gray flannels, and his special shoes. He was taking a bracing walk and looking at the scenery. Chester hated anything cold. I could appreciate that. There are people that are beach people; they are not snow people. Chester couldn’t wait until we had the next meeting, which was in the Bahamas. [Laughter] But Park City won out.

The meeting was hugely successful. There were 40 of us there—or 58. Some people say 40; some people say 58. But not many. We found an old mountain inn, the Treasure Mountain Inn, in historic Park City. It had an acclaimed English library that had been built with paneling and a warm fireplace and soft sofas. That was really nice. Then we met for our evening meal at the Car 19 Saloon, and it was a basement rock room. Dr. Eric Bywaters gave what to me is the classic evening. Eric loved scotch, and the rest of us at that time were bourbon kind of people. He gave a memorable after-dinner talk. This is what he said, “Who is the father of pediatric rheumatology? I think I saw it arrive, although I cannot specify its birthday or place. And I am damned if I can read the father’s signature on the birth certificate. We are very fortunately a small enough group to know each other personally, and to cooperate and enjoy each other’s company.” And I think that probably epitomizes the group. There is no father, but a small collegial group of disparate backgrounds. For instance, in Jim Cassidy’s latest textbook of pediatric rheumatology; Joe Levinson and I were asked to write the foreword to it, the dedication. And we said, “In the beginning we were a handful of naïve but eager and explorative young physicians of disparate training, background, and temperament. We joined together with the vision of doing whatever was necessary to find better ways to study the rheumatic diseases of childhood and adolescence, and to treat our patients more effectively in a comprehensive continuing care.” The first part of straight forward prose, those words came from me. And the marvelous
Oxfordian English at the end came from Joe Levinson. [Laughs] And he is the master of it; there’s no question about it.

So the meeting gathered together a group, and then a publication, and the papers were all done. Jane Schaller and Virgil Hanson were the coeditors; they did a superb job. It was a tough group to handle; there’s no doubt about it. Everyone had his or her own agenda. We were collegial, but we were pressing for what we thought was the best thing. And that’s good. That publication was the best-selling publication for a long time in the field of arthritis and rheumatism. The support of the meeting came from the NIH. The Shriners of North America gave us $25,000; in 1976 that was a lot of money for me.

DR. SPENCER: So did that supplement that was sold from that meeting become sort of an unofficial textbook?

DR. BREWER: Yes, yes. And the data from it stood up, and there were several people with series. Everyone had a piece of this and a piece of that. So it continued. And then we continued on with the idea that we would have Park City II, and we did 10 years later. In the interim we had a meeting in the Bahamas which wasn’t as forceful and wasn’t as interesting. For some reason there was a mystique to Park City. But the Ross Laboratories people were very nice. They sponsored and paid for every piece of that meeting. But then they published a Ross Conference in the Ross motif so that it was more a trade thing. It wasn’t, but it was considered that. So it was never in the system of being recorded by peer review in the Index Medicus format. That was a big thing.

In the first Park City, we honored Eric Bywaters. In Park City II, we honored Syd Stillman. Syd always said he was going to retire early before people said, “When is that old fool going to leave?” And I took it to heart. I retired early. I retired when I was 62. But the meeting was a great success. It was, I think, March 15th to 19th, 1986. It was sponsored this time by the AAP [American Academy of Pediatrics] and the ARA and the AJAO [American Juvenile Arthritis Organization] and the AF [Arthritis Foundation]. So we came a distance in 10 years, a huge distance.

The committee members then were Balu Athreya of Philadelphia, myself, Jim Cassidy, Virgil Hanson, and Bernhard Singsen. And 3 of the 5 members were members of the first Park City meeting: Jim Cassidy, Virgil Hanson, and myself. At this meeting we had 17 invited papers, 56 peer-reviewed abstracts. The first meeting we had a hard time getting anybody to say “hello.” Three distinguished retiring or retired pediatric rheumatologists were honored, and that was Sydney who gave his take on the beginnings of pediatric rheumatology. This is 10 years later after hearing his great words
in 1976; Syd’s take on how pediatric rheumatology started. He said, “Thirteen physicians, including 2 Nobel laureates, in 1932 held the first meeting of the American Committee for the Control of Rheumatism. In 5 years it became the American Rheumatism Association.” Syd said, “I first attended the 7th meeting of ARA in June 1940. Only 5 papers were presented. Three, 60 percent of the papers, were devoted to children with rheumatic disease. One of these papers was by Dr. William Green, an orthopedist at the Children’s Hospital Boston. His subject, monoarticular and pauci-articular arthritis in children.” This is just incredible because we had gone through another venue in our criteria committee from the 1960s on to the 1980s, great emotional discussions about oligo-articular or pauci-articular or do children have little arthritis or big arthritis? And here in 1940, which was 46 years before, Dr. Green, the head of orthopedics at Children’s, talked in 1 of the 5 papers at one of the first meetings about monoarticular and pauci-articular arthritis. Some things don’t change.

DR. SPENCER: So, Earl, let’s move on. You’ve mentioned a well-known adult and pediatric rheumatologist. Eric Bywaters, and his mentee, his protégé, Barbara Ansell. How did they contribute to pediatric rheumatology?

DR. BREWER: Well, they’re 2 giants of rheumatology. I mean they’re legends. And we all owe them enormous debt. Eric was just a wonderful human being, as was Barbara. Eric had sort of thinning hair. He had metal-frame glasses on his classic English nose, and he had ruddy cheeks. He was slight of build. And this wonderful smile. He was everybody’s Uncle Eric. You knew this was a good man. And he had this droll, wonderful sense of humor. A little shy. Actually not shy, but he was reserved. And when I first started, when we first did our original criteria work, Eric was an experienced clinician and so was our group. We collectively gathered 11 things that we thought occurred in children with rheumatoid arthritis.

We included Eric from the beginning of the ARA JRA Subcommittee of the Classification Committee in 1964 because I wanted his credibility for one thing, and his advice was so sound. He said, “We need to do this.” And he actively participated in these studies and contributed significant numbers, as well as his own words of advice. From the beginning he was promoting consensus and getting along with our American neighbors. Of course there’s always the English feeling that the colonies should never have left, that we all experience. But he was a true friend. Something happened at Taplow, at the Canadian Red Cross Hospital in the UK. He invited me to the UK in the 1970s, I think. I gave a talk. And that’s when Barbara had persuaded him that we should not say juvenile rheumatoid arthritis, but we should say juvenile chronic arthritis. I never understood the reasoning.
But it had to do with turf basically. I thought we would have a European Study Group of the PRCSG. I’ve never really said it anywhere—but when our Collaborative Study Group was burgeoning ahead, we felt that we’d go, go, go. It didn’t come later when Dan Lovell and Alberto Martini did it. So we established a beachhead with Hans Martin Høyeraal of Norway who spent a sabbatical research year with us in Houston. And Anna Lissa Mäkelä of Finland and Turco Fennen, as a result of my work with the Russians with the USA/USSR scientific cooperation. The English, at that time, didn’t like it that we were working with Soviets. I mean these were politically-charged times. We did it, I did it because, one, our country said we were going to do it. And if we didn’t learn to live with the Russians, then we were going to die with them. And so that was my thesis when they said, "How can you work with this Evil Empire?" So all of that was brewing.

But when I established the beachhead by doing a drug study with a few of our European colleagues and duly published with Høyeraal and Anna Lissa, I suddenly heard from Barbara and from others who said, “Leave us alone with the European League Against Rheumatism.” And I didn’t pursue it; I pulled in our horns, and we didn’t. Barbara wanted to change the name JRA to JCA (Juvenile Chronic Arthritis). But I think some of the genesis of the terminology of the JRA classification was really not based on anything other than force of personality. No studies were done to justify anything. It was more a matter of personality. And Barbara had this charismatic, wonderful personality. She didn’t enter the room; she charged into the room. And her wonderful smile, and she took over the whole proceedings. It wouldn’t matter whether you were having dinner or you were having a meeting with 1000 people, Barbara was going to take charge; and she was an incredible speaker. She could make the dullest subject interesting, and she had a lot to say. They had really pushed from the beginning at Taplow—and here again Barbara went through a lot of emotional and physical traumas persuading them that you could improve these children with exercise and with coordinated care and all the things that we know. Barbara and Eric trained people who were leaders all over the world. So that was my take on Barbara and Eric. They were wonderful.

DR. SPENCER: So during the 1970s, how was pediatric rheumatology developing nationally? How did you see it from Houston?

DR. BREWER: Beginning in 1970, we published the JRA criteria. And the American Rheumatology Association Board of Directors accepted it, and it was duly published in the Bulletin on the Rheumatic Diseases. It gave us credibility. I was chair. We had good people on our committee. Syd Stillman, after all, was president of the ARA. And Milton Markowitz was a well-known researcher of rheumatic fever. We had people of great substance. Also we had done careful work. The work stood the test of
examination of our data. We had made reasonable assumptions, and then we had concluded things that reasonable people would accept and not by personality.

So the next thing in my mind was that we needed better medicines because we were stuck with aspirin and steroids. I mean that was the historical ballgame, maybe some gold or something. So that was fortuitous. I was lucky that McNeil came through, and we were able to develop our Pediatric Rheumatology Collaborative Study Group. So we had funding for our collegial group to expand and others could participate. We developed ways to work together and an infrastructure to work together much as CARRA [Childhood Arthritis and Rheumatology Research Alliance] is working toward now. We had a way and were able to do it. I regard that probably as important as any of the drugs we studied. But it was important to have medicines also.

Then with the drug studies going on, there was more interest. Then we came together in Park City and we had an academic-based effort. But then the drug studies were sort of frowned upon in the sense that we weren’t quite real. But now we’ve moved forward into this new era. Then at the end of the 1970s—thank you, Lord!—the US Maternal and Child Health Bureau decided that pediatric rheumatology was worthy of being discovered and developed. So that would be my take on pediatric rheumatology in the 1970s. I may have left something out.

DR. SPENCER: So into the 1980s and your last decade of work. How did pediatric rheumatology develop? There were many fellows coming in now, younger fellows, and you had a number of fellows starting in the late 1970s. How did you see the development of pediatric rheumatology over that last 10 years?

DR. BREWER: I saw every decade as satisfying. But that last 10 years were just an incredibly satisfying time. By the end of the 1970s, several programs were taking fellows because there was more interest in students and residents. Before, we truthfully didn’t have much to offer. I mean we were fighting for our existence, much less training someone to fight for his existence, too. So then when we started our quest to develop pediatric rheumatology, the thought of replicating our knowledge and training was just not high or of immediate concern. We spent time with adult rheumatologists, and indeed several were adult rheumatologists. Members of our initial collegial group were basically clinicians, a smattering of laboratory experience and training. Eventually more basic research skills were required for clinical research studies, as more clinical research skills were needed, too. Initially we did observations only in scientific clinical research, and that was from the 1950s into the middle 1970s. And toward the end of the 1970s, the program began to add the basic research skills.
Now in our training program, to answer your question, funding for our program began as a tradeoff bargain with the administrator of the Texas Children’s Hospital [TCH], Newell France. In 1976 I was asked to be president of the medical staff of TCH. I had all of these many programs bouncing in the air, trying to just get through the day. People in Houston, when we would have our little staff meetings, would say to me: "We’re glad that you’re here visiting from wherever it is you’re working." [Laughter] And you well know the feeling of trying to balance all the balls.

DR. SPENCER: Yes.

DR. BREWER: I remember telling Dan Lovell when he was a fellow, I said, “You are less busy now than you’ll ever be in your life.” He said, “That’s impossible.” [Laughter] But recently he said to me, “You were right. You were right.” I think you would probably feel the same kind of way. But I was asked to be president of the medical staff at Texas Children’s Hospital. The last thing I wanted or needed was to be president of the staff, and particularly that year. In that year, 1977 to 1978, Dr. Blattner, my mentor and friend, chairman, was retiring. And a new chairman would be selected during the year. Dr. Blattner retiring during the year, and then the new chairman. The reason that the hospital was interested and worried was that Children’s Hospital, Denver had almost disintegrated. When they retired a chairman and hired a new guy, everybody got mad at everybody else, and it was one of those things where unnecessary things happened.

So the hospital and Dr. Blattner and Newell France felt that I represented so many facets of the hospital and practicing physicians, because I had my foot in so many places, that I could maneuver the changing of the guard. I still did not want to do it. And then Newell hit me where I was totally vulnerable. He said if I would be president and superintend this change, he would fund 2 rheumatology fellows per year thereafter. I could not refuse. And the year of retirement and changing the guard wasn’t tumultuous; it was successful. Dr. Ralph Feigin came in as chair, and Dr. Blattner retired. And to Dr. Feigin’s credit, he never reneged on the deal.

One way I started is I had funding for 2 fellows at Texas Children's Hospital and department of pediatrics, Baylor College of Medicine. And so that enabled us to start. Rob [Robert W.] Nickeson was our first fellow. Do you want to go into this? Okay. Rob Nickeson was the first fellow. Rob was a graduate of Yale University and [University of] Pittsburgh medical school; his pediatric training was at Pittsburgh. Incredibly bright. His boundless and irresistible energy was apparent here. You know Rob Nickeson. He didn’t just walk in the room; he burst into it. And he had reddish-blond hair, and beard and darting eyes behind his rimmed glasses. And his
breathless, “What’s going on?” let us know that Rob was there. His speech was rapid, clipped. He was just as close to hyperactivity, I believe, as anyone I’ve ever known. He sang in an acapella choir at a Methodist church in Houston, and he worked with disadvantaged youth. He was a very active guy. We were able to channel this incredible energy into 7 research projects while he was a fellow, along with the clinical study. He was just amazing. He went to Oklahoma, and he was the first pediatric rheumatologist for several years. He established an outreach clinic in Tulsa. Then he and his wife, Nadine, moved to Florida. Then he was sort of lost for a little while. But now he’s successfully an academic pediatric rheumatologist at the University of South Florida and doing very well.

Karyl Barron was our second fellow, and she was equally bright. She was Phi Beta Kappa at the University of Miami, and AOA at Emory Medical School. She did her pediatrics there. And the same way that Rob was hyperactive physically, Karyl was hyperactive mentally. It's always challenging to direct someone who's brighter than you are, but I tried. Karyl absorbed knowledge like a sponge and quickly mastered clinical material, and she spent time learning new laboratory research skills at the same time. She spent time in allergy and immunology. She’s now married with children and lives in Washington, D.C. She’s deputy director of the [US] NIAID [National Institute of Allergy and Infectious Diseases], NIH. She’s a leader and a great friend of pediatric rheumatology.

And Andrew Wilking. Andrew—an incredible human being. He was a graduate of Harvard College and Columbia Medical School. He did his pediatric training at Columbia with Jerry. I mean Jerry was there.

DR. SPENCER: Jerry Jacobs?

DR. BREWER: Yes, Jerry Jacobs was at Columbia.... And Andrew [Wilking] was at least 6 feet 5 inches tall, and he was skinny as a beanpole. His curly hair flopped over his forehead, and he had a little twinkle in his eye behind kind of large glasses, and a wonderful, reserved smile that made him seem like everybody’s Uncle Andrew. He was married to Marilyn [Wilking] who was an AOA at Columbia, and she was, I think, a head of the outpatient department there. But she was married to Andrew, and she came willingly when he said he wanted to do a pediatric rheumatology fellowship in Houston. She came, and she worked as a pediatrician in Dr. Frank Hill's office in Houston, and they were just wonderful. And they were a great couple. Andrew’s mother was a prominent pediatric psychoanalyst in New York City. His dad was chief of staff at St. Luke’s Hospital. A very distinguished medical family.
Andrew and I went head to head. It was sort of incredible. He had a very good idea that we should have Saturday morning teaching rounds for the entire morning. The idea was wonderful, but that was just not how we structured the time for the program. And in addition, I asked each fellow to select several research projects that we would mutually agree to perform during the fellowship. And we worked together. Well, Andrew told me that he was only going to teach and take care of patients. He had no intention of doing research. Well, we had a standoff, as you know. [Laughs] And he did precisely that. I mean his career is successful. He’s been honored for teaching skills at Baylor. They’ve actually devised a master’s degree teaching program for faculty, and he’s the one who does it. He bought into the idea of the outreach clinics. A lot of people didn’t. And to this day he travels to distant cities in Texas. And we’ve become friends.

Dan Lovell: Dan waited a year working in an emergency room in Kansas City until I had a place for him. And he was a low-keyed, extremely bright guy, too, with a droll sense of humor, but a workaholic temperament. He was slight of build with reddish hair and a beard off and on. And Dan and his wife Anne hated Houston from the time they arrived, and then they still hated it when they left. They came because Dan liked our program. Both Ed Giannini and Dan and I, we bonded immediately and remain bonded to this day. But when Dan came for his interview, it truly made me wonder why he even accepted the offer. I took him to a contentious meeting of the local Arthritis Foundation chapter, where the adult rheumatologists explained to me that I should tell Judge Roy Hofheinz, the owner of the baseball team, the Astrodome, and the Astro World, that his kind offer of a benefit for our pediatric program at the Astrodome should be refused. And to tell the Judge he’d have to do it for the adult people in the Arthritis Foundation. And I explained to the adult rheumatologists—I choose not to name names—how things worked in earthy terms. And Dan and I had several old-fashioneds to ease the restraint necessary.

But Dan Lovell did several research projects, some of which were sort of classic papers. In addition, he completed his MPH at the University of Texas School of Public Health during his fellowship. He went to Cincinnati from Houston. I asked the PRCSG to elect him chair on the occasion of my retirement in 1990, and he and Ed have taken the PRCSG to heights that I never imagined. And he’s now professor of pediatrics and the Joseph V. Levinson Chair of Pediatric Rheumatology as well as chair of PRCSG and a host of other activities.

Now, Xiaohu He, Can we stop? I want to get some water? [Break] He—Xiaohu—the Chinese put the first name last by our way of doing things—was my first adventure to pick a fellow from overseas. Professor Jiang Zaifang, director of the Research Institute of Pediatrics in Beijing, China, spent a year
at Texas Children’s Hospital in 1982, observing and noting what skills she needed to bring to China from the United States. She decided that pediatric rheumatology was one of the unmet needs of China. There’s a great deal of lupus in China. In 1983 I received an invitation from her to be a guest of the People’s Republic for 3 weeks. Furthermore, I could bring a group with me. The ostensible purpose was a medical-cultural exchange. Those were the magic code words at that time. The real reason was for Professor Jiang and me to pick one of her pediatric faculty to come to Houston and train in pediatric rheumatology. I took 14 people with me, including Ria, of course. And our adventures are worthy of an entire article.

The trip extended my horizons beyond all belief. Our adventures were just incredible. In brief, we gave a 1 day seminar at the Beijing Children’s Hospital. We were given a 2 week tour of China. We went to such places as Xi’an, Hangzhou, Shanghai, Guilin, Hong Kong and other places.

DR. SPENCER: Who was with you?

DR. BREWER: Oh, I took Ed Giannini, I took Don [Donald] Person, I took Malcolm Granberry; Margaret Granberry went. Jim [James] Kemper and Julie, George Ferry and Joan. And Rob Nickeson and Jack Bass of Ohio State. It was interesting. Xiaohu He came to Houston for 3 years and trained in pediatric rheumatology. Xiaohu was in her 40s. Extremely bright and effective. She was small in stature, of course, and slim; Han Chinese. Her ready smile, hard work endeared her to everyone. She had a 10-year-old son. Her husband was an executive in the mining industry at the time. Typical of the Communist system of that era—I knew it well from the 17 years I worked with the Soviets and their system—her husband and son were required to stay in Beijing for the 3 years, and she did not return. It was pretty hard on her.

She worked successfully on several clinical research projects with Ed Giannini and others in the group. When Xiaohu He came to Houston, I found quarters for her in Favrot Hall, which was a nurses’ dormitory, and she ate in the nurses’ cafeteria. It was only a block or less from the Children’s Hospital. Within a few months, her weight had blown up like a blimp. In Beijing she bicycled 11 miles daily to and from work. In Houston she walked less than a block. And she was eating nursing dormitory cafeteria starchy food. She was a leader in the Chinese scholar community of Houston. There were many scholars in the city at that time at various universities. The Chinese Consul always asked her to mediate problems with the other scholars. I only had funding for 2 fellows in the hospital. So I turned to my friend Fox Benton, a highly successful old friend, to help. We went to Ambassador Kenneth Franzheim [II] for his help for one year. And then Fox paid for the other 2 years. When Xiaohu returned to Beijing, she
developed pediatric rheumatology beyond my wildest dreams. She established at least 15 pediatric rheumatology clinics all over China. She’s now president of the Chinese Pediatric Society. She’s applied to join the Pediatric Rheumatology Collaborative Study Group.

Carmen De Cunto represents an Argentinian Xiaohu. In developing our program, we didn’t have enough funding to have it big. But if we took someone from overseas, they were not just coming to see if they could stay or what have you. They had to be sent by somebody, an institution, and there’s a place for them in the institution when they return. That was my feeling. If we were going to promote pediatric rheumatology around the world, we couldn’t just send people back and cast them loose. But Carmen De Cunto was my next foray into foreign fellows. My feeling again was that they had to have a place to go when they finished. Antonio Aranda was a child with severe JRA who was referred by a physician in Zurich. Antonio and his family lived in Buenos Aires. Antonio had severe poly-articular JRA and was wheelchair-bound with severe, constant pain. It was sad. He’d been told in Buenos Aires that the end was near.

We admitted him to the hospital for 2 weeks or so, and we’ve already discussed, you know, what we did in our program.

[End of Tape 2, Side 1] Antonio, as I said, came in a wheelchair, and he walked out. His parents were elated, and I was elated. We became fast friends and are to this day. They paid a great deal of the funds spent on the first AJAO meeting at Keystone, Colorado. Jose Aranda was the publisher of the largest Spanish-language newspaper in the world, the Clarin, still is, along with many other holdings. The newspaper is located in Buenos Aires. The Arandas came to Houston monthly for several years.

Jose decided that Buenos Aires needed a pediatric rheumatologist. So Ria and I visited there several times over several months. And we selected Dr. Carmen De Cunto, a person selected by Dr. [Carlos] Gianantonio of the Hospital Italiano de Buenos Aires. We selected her to come to Houston for pediatric rheumatology training for 3 years. She was married to a nice young man who was an engineer and spoke no English. We arranged for him to pursue a master’s degree at the University of Houston. The Arandas paid Carmen’s expenses and salary. After finishing her training, she returned to Buenos Aires to the Hospital Italiano. Jose funded a pediatric rheumatology section and clinic. And she’s become a leading pediatric rheumatologist in South America. You know her. She’s a great lady.

[Break]

DR. SPENCER: Here we go. And Carmen?
So after finishing her training, she really, as I’ve said, became a leading pediatric rheumatologist in South America. But Carmen was interested in streptococcal disease and post-streptococcal reactive arthritis and wrote more than one paper with the cardiology section at Texas Children’s Hospital.

Abraham [Avi] Gedalia came to us from Beersheba, Israel. He spent 6 months with John Baum in Rochester before coming to us for two years. Avi was older than the other fellows, had been in practice in Beersheba for several years. He was one of the best clinicians whom I’ve known. He also was a soft-spoken and quiet mannered person. His face could have been a Norman Rockwell portrait. His visage bespoke compassion and kindness. He could calm the most upset child with a soothing hand. It was just amazing to see how effective he was. Avi focused on hyper-mobility and arthritis in children, and did an epidemiological study at the Awty private school owned by the Alliance Française where Ria was a nursery school teacher for 17 years. That’s the only reason they let us in the school. They had to assess all these kids that measured high for activity—hyper-mobility—in normal children.

Other papers were published. Avi was married to Fanya, who had immigrated from Estonia as a teenager with her parents. She had a scholarship at Riga after high school. Only about 1 or 2 percent of the old Soviet-era students would get such awards. Her parents immigrated to Israel to escape rising oppression. She ended up pulling onions on a commune farm in Israel. She said to her mother, “I left a scholarship at Riga to pull onions on a commune in Israel? This is the free world?” Life did become better, and she became a public health nurse. She and Avi met and married. Avi returned to Israel after his fellowship for a few years. He was such a great pediatric rheumatologist that we simply could not let him stay in Israel. Several of us worked the system, and Avi became a professor at LSU [Louisiana State University] in New Orleans and at Children's Hospital where he is today.

Ivonne Arroyo burst on our scene from Puerto Rico. She arrived for an interview and disrupted the entire office with each step as she walked into the section. She truly looked like a South American movie star and was dressed for the part. She also was personable and smart and was a breath of fresh air. Her English was perfect but heavily laced with accent. She was primarily interested in clinical skills and worked with Avi Gadalia in the hyper-mobility studies. She finally returned to Puerto Rico and is a successful pediatric rheumatologist near San Juan. [Break]
Mary Moore Jones came to us as Mary Moore, and then she became Mary Moore Jones, marrying a pediatric infectious disease person. Mary was from the Midwest, extremely bright, personable, attractive lady who spoke with a clipped speech and was very, very active. And one of the lessons that we taught fellows was to give a talk and give them tips and stuff, the skill of presenting themselves to their professional peers. Because just as a letter is your representative to the world, your speech and your skills at speaking are representatives to the world. Mary was so shy about this, even when she was given accolades by the entire neonatal pediatric cardiology group meeting and praise from many of the neonatology people. She had worked with a child with neonate lupus who had heart block, and she had done a lot of successful work with the baby. It had been reported and published. They were waiting, and this was her day to shine, and she had the podium. And she said, “If you don’t mind, I think I’ll just sit in my seat and give my report.” And her chief, myself, put my hands on my face.

So we had several sessions about speaking. But we did that—not just that. But one of the lessons of the fellowship is to learn to communicate with your fellow physicians, and it’s an essential skill. And if people don’t come with it, they have to be helped. And the same way with writing. Ed Giannini did a great job in schooling people on clear thinking and writing. She finished her training, and she went to Iowa State [University] at Ames, Iowa. And then later in Illinois, and now she’s at Michigan State. Oh, no, she’s in Kalamazoo, Michigan, now at Western Michigan University.

I think our Pediatric Rheumatology Fellowship Program was a success in my mind. We prepared them to take their places in pediatric rheumatology almost all in academic institutions. They have made significant contributions. They are excellent doctors who represent the era of pediatric rheumatology when we began to replicate ourselves, and this was the next logical step in our progression. And I feel very comfortable about what they’ve done. I’m very proud of them.

DR. SPENCER: Earl, could you tell me something about your pediatric rheumatology collaborations with the Russians in the 1970s and 1980s.

DR. BREWER: It was an interesting, incredible, fortuitous happening. An apparently unrelated pivotal event for us in pediatric rheumatology occurred on May 23, 1972. President Richard Nixon and Secretary Leonid Brezhnev of the USSR signed an agreement of scientific cooperation. The purpose was, of course, to cooperate in areas that posed no threat to either nation during the Cold War. The thesis, as presented to me by Dr. John Decker of the National Institutes of Health, was that we would either learn to work together, or we would die together. I had bought into this. I believe to this day that we needed to learn to work with them. And children with
arthritis turned out to be the major point group for this concept. Children were not a threat to either side. Children with arthritis in particular were not a threat because no one thought they would grow up to become the Evil Empire.

It did change the course of pediatric rheumatology and intertwined the PRCSG, pediatric rheumatology, the FDA, and the NIH into a cooperating, functioning partnership with us that propelled our cause into new levels of acceptance and effect. As I understand the story from several participants, Secretary [Caspar] Weinberger of the then Department of Health and Human Services was asked by Nixon what disease he wanted to be his first thrust of the scientific cooperation agreement. Weinberger’s wife had severe arthritis, and he suggested arthritis. Fortuitously, the USSR’s strongest medical specialty was rheumatology and had been since the days of Stalin. Professor Anatoly Nesterov was [Joseph] Stalin’s physician. He was a rheumatologist. Thus rheumatology became a favored specialty for funding for many years in relation to others.

Spin forward quite a number of years to the 1970s. Professor Valentina Nassonova, was secretary of the USSR Academy of Medical Sciences—in the old Soviet system, the secretary ran the group—as well as chair of the State Institute of Rheumatology of the USSR. The AMS, or Academy of Medical Sciences, owned all of the research institutes of the USSR and reported directly to the Supreme Soviet; that’s the congress of their system, rather than to the minister of health. The Russians wanted to study arthritis—no surprise. The first meeting was at the Stone House of the NIH, May 1975. There were 3 Russians: Professor Valentina Nassonova, Dr. Margarita Ivanova, and Professor Anatoly Speransky.

The initial contact went well in 1975 and in 1976. Both groups felt at ease with each other and were honest with each other at all times. Basically our Soviet counterparts were the same as we. They were interested in the welfare of children and families and wanted to provide the best care for them. In this way medicine always has been so universal with great commonality of interest and personality the world over, in my experience. As individuals, they were also interested in achieving as well as possible in terms of their system. Most were not very politically-minded. In achieving our mutually agreed goals for our studies, each of us carefully discussed how we could work each of our systems to get permission to do the studies to help the children. But they were as interested in getting money to do their studies as we were, and this provided a marvelous vehicle. So in that sense it had nothing to do with communism or capitalism or patriotism. It had to do with pediatric rheumatology finding itself in the center of a way to fund studies. And the Russians understood the same thing.
The late Professor Alexandra Dolgopolova was the original director of pediatric rheumatology in the USSR. She was truly one of the great physicians of our time, and I still miss her integrity and intelligence, humility, sense of humor, and can-do problem-solving abilities. She and Professor Nassonova were 2 of the best problem-solvers I have personally encountered. In my initial discussions with Professor Dolgopolova in 1976, she stated that the results of our initial study of the epidemiology of JRA in the USSR-USA, including a 5-year follow-up of patients, must be published in scientific journals of both countries. I explained to her that in the United States we would prepare the paper to both our satisfactions, submit it to the editor of an American journal, who would review the paper for approval as to quality. She then replied, “Da, it is the same here in the USSR.” She said, “Of course I’m the editor. I’m also the author.” She then asked about medical specialty training in our country. I explained to her that 2 to 4 years of training was customary, that the candidate had to pass an examination given by a board to establish competence. She smiled. “Da, same here. Of course I give the examination.”

Our first study did not involve medicine with arthritis but was a joint effort to establish that JRA was the same entity in both countries. We couldn’t study together if we didn’t have a common base, which is really where that criteria was a huge help. And they had apparently studied our studies. And we needed to ascertain the outcome after 5 years or more in both countries. Dr. John Baum of Rochester, Professor Dolgopolova, Dr. Lev Alekseev, and myself were responsible for this study. One center was used in the USSR and 5 centers in the USA. Publication was in Arthritis and Rheumatism, authors were Baum J, Alekseev LS, Brewer EJ, Dolgopolova AV, Mudholkar GS, and Patel K, September 1980, with a companion publication in the comparable Russian journal. We established that JRA is the same in both countries and that the long-term course of the disease is about the same in both countries. Thus we could do studies together; this was the importance of this study. We validated that we could do studies.

Interesting thing about the Russians, in filling out the forms, we analyzed back and forth. The Russians were much more careful recorders of data. Over the years, when we did lots of studies—and we’ll come back to this—Ed Giannini and I found that Americans would have at least a 25 percent error rate, meaning left-blank things. The Russians, less than 5 percent. They were careful. So rather than the sloppy Russians, our people were a little more hurried than the Russians.

The second study of 2 anti-rheumatic drugs—d-penicillamine and hydroxychloroquine—tested against placebo resulted in uncharted territory involving the Pharmacological Committee of the Ministry of Health, USSR. We also had the need for substantial funding from the NIH, as well as
permission to do the study from the Food & Drug Administration. I spent a lot of time maneuvering the system. There was considerable discussion on our side about whether we should give the Soviets expertise and good drug studies, as well as the disdain by certain factions at the NIH, that the time and money were a waste of the expertise of the highly-sophisticated NIH. With a great deal of pressure from Dr. John Decker, who was one of the leaders at the NIH, and several of his colleagues, a contract was awarded to the Pediatric Rheumatology Collaborative Study Group with myself as principal investigator. The contract was awarded for only the USA side, however, and certain powerful people at the National Institutes of Health instructed me directly and indirectly to not mention the USSR side of the study.

At the end of the study I simply ignored the orders, and I wrote a report with Dr. Giannini, as well as publishing it in the New England Journal of Medicine in May 1986. It was presented as the number one paper at the American Rheumatism Association meeting in Los Angeles in 1985. The study took 8 years from first planning to publication. One hundred and sixty-two USA-USSR children participated in the one-year study. The study was the first time that the Soviets requested permission from the New England Journal of Medicine to publish essentially the same paper in a Russian journal. Meaning they were asking about copyright. This was a new experience for the New England Journal. Even more intrigue occurred in obtaining permission to do a study of auranofin and placebo in children with JRA. We did 231 USA-USSR children, combining the efforts of the pharmaceutical company, the NIH, and the Soviets. The juggling of personalities and permissions was incredible.

The last event was to do a study of methotrexate and placebo in children with JRA, combining the PRCSG, the FDA, the NIH, Lederle Laboratories, a pharmaceutical company, and our colleagues in the USSR. The FDA had not worked with the USSR before, and with reason many people were worried. To everyone’s credit the problem was solved with only two PH’s, PH Syndromes, Pigeon Hole Syndrome expeditions at the FDA necessary. Soviet counterparts had even more trouble. The head of the Pharmacological Committee of the USSR, the Russian equivalent of the FDA, went head to head with Professor Nassonova and the Academy of Medical Sciences over turf. He maintained with justification that any blinded research drugs should come under the supervision of the Pharmacological Committee. Nassonova maintained the Academy of Medical Sciences, USSR, made agreements with the NIH of the USA directly, and the subject.

The difference continued throughout our last 3 studies. The crux of the argument was that the USSR Minister of Health and the Pharmacological Committee leader wanted to go into the drug study business, and they could
find no one to buy into it. They needed credibility, and we had credibility. They could bid about one third of the usual cost of the USA for a comparable drug study. The problem was that no one was buying. Credibility was absent. Therefore the turf war. Nassonova pointed out to them in other terms the bilateral agreements that each side must bear the cost of the study in its own country. So therefore it was impossible for the USA to pay for expenses of studies in the USSR.

We dealt with 3 different officials of the Ministry of Health for each study. A Professor Lepachin of the Pharmacological Committee stymied the first study of d-penicillamine and hydroxychloroquine. It was solved on this occasion when Nassonova and I liberated the study drug at the Sheremetyevo [International] Airport in Moscow. Lepachin had impounded the study drugs at the airport. It was a great lesson in gutsy diplomacy watching Nassonova stare down the customs director at Sheremetyevo Airport. She and I went to the airport in an old bus of the Rheumatology Institute. And the customs director was afraid of her because she was such a powerful person. Next time they solved this problem.

The second study drug was auranofin and placebo. Professor [E. A.] Babayan, an Armenian at the Ministry of Health this time, impounded the drug by taking the study drugs to his office at the ministry to be sure we did not liberate them again. Ed Giannini didn’t help matters when, as we went through customs at the Sheremetyevo Airport, he marked one of the notebooks, “Secret Code.” Immediately they impounded the whole thing. Nassonova, Professor Nina Kuzmina, Dr. Alexander Shaikov, Dr. Lev Alekseev, and I met with Professor Babayan on a cold December day in Moscow in 1984. After much discussion, he agreed to let the study progress, with the understanding that the data would not be released until SmithKline [Corporation] paid a registration fee to the Pharmacological Committee. We did the study which was reported both in the USA and the USSR in 1988. We’ve never heard how to register the drug.

Babayan was replaced by Professor Pokryshkin in July 1987. Nassonova, Shaikov, Kuzmina, and I went head to head with Pokryshkin. He lined us up around the conference table with me on one side and all the Russians on the other side. He was stacking the deck. They spoke Russian for about half an hour with a lot of nodding and pointing. Nassonova early on pointed to Shaikov and said, “Alexander, Professor Brewer is over there by himself. Sit with him and translate.” Finally Pokryshkin suddenly smiled and said in perfect English, “Ah, Professor Brewer, I finally understand the problem.” Nassonova smiled and said, “Professor Pokryshkin had forgotten that it is unethical for us in the USSR to accept money for a study of drugs to help our children. It’s quite impossible.” [Laughs] Thus the study of methotrexate was tentatively approved.
However, Professor Lepachin at the Pharmacological Committee was not through with me yet. Professor Pokryshkin was reassigned with a new reorganization at the Ministry of Health. Professor Lepachin, who had been my friendly adversary for these many years, remained as chairman of the Pharmacological Committee. We have never met to this day. His next and last move was to convene a meeting of his committee in Moscow, and ask several very pertinent questions about the drug. Dr. John Harter and Dr. Kent Johnson of the FDA, Dr. Jack [John] Klippel of NIH, Dr. Margaret Gantt of Lederle Laboratories, Dr. Giannini, and myself addressed these many issues with an appropriate letter sent by Dr. Marlene Haffner, director of the FDA’s Office of Orphan Products Development, on January 13, 1989. The study of methotrexate in the USSR was approved, and the medication was shipped without a dent. The study was completed on October 1, 1990, and published in the *New England Journal* in 1992. [End of Tape 2, Side 2]

Observations concerning success of our cooperative research: An article in the British journal *Nature*, published March 19, 1987, Dr. James Wyngaarden, director of the NIH, stated that the methods developed by the USA-USSR Pediatric Rheumatology Collaborative Study Group had pointed the way for the expanding NIH research efforts with the USSR.

To summarize and put an overall face on the experiences and changes in the USSR from 1975 to 1990, the changes that have occurred in the USSR in the past 16 years were nothing short of unbelievable. What the future holds for this large incongruous country with so many faces is difficult to imagine. But we must pay close attention. My opinion remains that we will either learn to get along with each other or die with each other. With any luck, we’ll learn to get along. I certainly try to do my part. I think that in the past thousand years the Russians have had several opportunities to embrace freedom. And each time the opportunity occurs, they slip back into authoritarianism, and this may well happen again.

I can't resist sharing with you some comparisons of the old USSR of the 1970s and the new Russia of the late 1980s. My experiences are personal observations only.

**EXPERIENCES AND OBSERVATIONS ON CHANGES IN THE USSR FROM 1975-78 TO 1988**

**COMMUNICATION - NOW AND THEN**

Four of us were gathered around my lap top computer in Professor Kuzmina's office on the eighth floor of the new Institute of Rheumatology on Kashirskoe Shosse in Moscow looking at the blue letters on the back lighted
screen. The Russians would point to a phrase here and a word there to make a change in our Memorandum reflecting the discussions we had held concerning our present and future research work together. Suddenly there was a tremendous 'POW' and a little smoke came from the electrical plug hookup of plug and electrical converters, surge control plug, and adapter into the wall. All of us jumped about 2 feet -- yours truly about 3 feet. The surge control had worked. The computer was intact as well as our Memorandum.

As I looked at my colleagues of 14 years, memories of changes from our earlier meetings as part of the USA-USSR scientific cooperation were mind-boggling. On the occasion of our first Moscow meeting in 1976, the Memorandum of Intent was surrounded by bustling, nervous young secretaries scurrying from the table in the conference room of the old Institute located at historic 25 Petrovka Prospect to completely retyping the document with each and every change made using loud, manual typewriters. Interpreters were used to translate every word as a matter of 'face' and also to be sure that no mistakes were made.

The first meeting in the United States in May, at the 'Stone House' on the campus of the National Institutes of Health was filled with considerable anxiety and suspicion on both sides. Our USA group of 14 or so scientists and physicians gathered by Dr. John Decker of the NIH to meet the 3 Soviet rheumatologists headed by Professor Valentina Nassonova of the Academy of Medical Sciences, Institute of Rheumatology. We were briefed by Alexander Dolgan from the State Department. Someone whispered to me that he had been a prisoner in the Gulag for fifteen or so years even though he was an American citizen. This certainly arrested my attention. We met in a large conference room containing the largest table I have ever seen. A microphone was at each chair, and in another room were banks of recording machines whirring away. We certainly were not ignored by big brother.

I was assigned to work with now Professor Margarita Ivanova even though she was not a children's rheumatologist to develop some sort of study that we could do together as a first effort at our scientific cooperation as part of the bilateral agreements signed by the USA earlier. Professor Nassonova was at the other end of the enormous table with several other Americans and anxiously looked every few minutes down the table at Ivanova, who responded by nodding her head up and down and saying the universal phrase - OK.

Our assigned interpreter was a little, middle-aged, school-teacher-looking woman with Prince Nez glasses who was very proper. Dr. Ivanova and I spent some time just getting acquainted by asking questions about medicine in the USA and the USSR. After one question about how medicine is practiced here with a very short answer from me, the interpreter talked for about 5
minutes. Margarita had an increasing frown on her face. Finally she interrupted and said in perfect English, “Professor Brewer, did you say....” I said, “Of course not!” The interpreter said, “Well, I'm an American too.” Ivanova asked of the interpreter. “Do you in America have tea time?” “Of course,” the interpreter haughtily said. “Professor Brewer, do you take tea time?” “No.” “Good. Nor do I.” Turning to the interpreter, she said, “Why don't you go to tea time. We shall do just fine here.” The interpreter flounced off never to be seen again.

EXPERIENCES WITH EMBASSIES AND CONSULATES
In 1978 during our first trip to Leningrad. We were guests at the Institute of Experimental Medicine where [Ivan] Pavlov conducted his historic experiments of psychology on his dogs, and [Dmitry] Mendeleev worked out the periodic table establishing modern chemistry. Their original laboratories have been preserved including Pavlov's doghouses. We were engrossed in a discussion by the director of the Institute when I felt a tap on my shoulder -- 'Earl, the US State Department wants to talk to you.” Margarita Ivanova said with a very stern look in her eyes.

“Margarita, No one knows where we are, there is no way that our government is on the phone.” “That same thought occurred to me also. Earl.”

At the telephone 3 numbers were listed to call. The first number turned out to be a number in Helsinki. It was clear that this was a voice fix call. The second number was a wrong number, and the third was the American Consulate. The facts of this situation as I sifted them later were that a distant cousin of my wife, Thompson Buchanan, was the Consul-General of Leningrad for the USA. My father-in-law, John Winterbotham had written to him that I was corning to Leningrad with a group of American doctors in September 1978. Thompson Buchanan's secretary had remarked to him that her boyfriend worked at the Institute, and he had remarked to her that a group of American doctors were visiting the Institute. And how many American doctors were visiting Leningrad in 1978 as guests of the USSR?

As I left for lunch with Thompson and his wife. Nancy, Margarita reminded me that a tour of the Hermitage precious jewel collection was being given for us at 2:45 PM with instructions to be at the side door of the Hermitage on time. We had a wonderful lunch at the Consulate prepared by their Finnish chef. The only slightly disconcerting item was that Thompson ran from the door to the Consulate, which in the past had been the home of a Czar's mistress, to embrace me as a long lost cousin. He explained as we entered that several people had been gunned down trying to gain asylum recently, and he did not want the Russian guard to misunderstand a Texan trying to figure how to get in.
We arrived at the Hermitage with minutes to spare. The presentation had been going on about 15 minutes or so when Margarita and I looked up at the same time -you guessed it! There at the back of the group was a handsome guy with a little gray at the temples, blue, Brooks' Brothers blazer, blue and white striped button-down shirt: Paisley tie: charcoal gray slacks: and lord help us -- genuine brown penny loafers.

Margarita said, “Earl!” “I have no idea who this man is, Margarita.”

Margarita interrupted the lecture and directly accosted the man, “Who you are? This is official USSR delegation. It is NOT an Intourist show! How you find out about this tour?”

Ivy League said, “Oh, hi there, Freddy Woodruff here. I work at the US State Department and was just here staying overnight at the Consulate and heard that there was an English tour going on here. -- Sorry.” Margarita said. “That sounds a little strange to me, but you are not welcome here.”

The next day our group was taken to the Pushkin Museum several miles out of town. The Museum is a popular tourist spot, and thousands visit there. As was the custom then for the infrequent foreign visitors, we simply broke into the line with no dissension by the Soviet citizens (not many smiles either). Shortly Margarita and I looked behind us several feet and here it came again, “Earl!” You guessed it. There were Thompson, Nancy, and Freddy.

Thompson, who is a genius at diplomacy, moved forward to speak to Margarita. "I suppose it looks like we are following you, doesn't it?" “That thought passed my mind,” Margarita said as she drilled them with her eyes. “The truth is that Earl is a relative by marriage, and we see relatives so seldom from home that it is a treat.” “I understand. We are a family people also.”

That night we took the Red Arrow train to Moscow and had a truly wonderful time. Dr. Ray Jaffe of New York wore his bright red flannel nightshirt and was the most fashionable of our group. We arrived at the Leningrad Railway Station very tired after our night of sampling vodka, scotch, and Lingenberry liqueur. We immediately went to work for the entire day being joined by several of our new Russian colleagues who were not in Leningrad. That evening we met our hosts in the lobby of the Ukraina Hotel on the Moscow River. It reminded me of the old Palmer House Hotel in Chicago. As we greeted our hosts and colleagues. Margarita and I looked across the lobby at the same time. There HE was --- Freddy baby! “Earl, Earl! No explanation!” “Oh hi, I bet you are wondering how in the world I am here. Well, I had to check the clerical personnel at the Embassy here, and I'm staying at this hotel. This is one of our personnel,” pointing to a very pretty girl, obviously American. After he left. Margarita with a very stern voice said, “Earl, I trust that this is the last that we see of Mr. State Department.”
The scariest experience we had with the Embassy scene was in September 1983. Four of us were scheduled to go on an official trip to Moscow: John Decker, Paul Plotz, and Jack Klippel, all full time physicians with the National Institutes of Health, and myself. The Soviets had just shot down a Korean airliner, and all flights of other countries into Moscow were being cancelled on an hourly basis. We managed to get on the last British Airways plane into Moscow from London. A BBC camera crew taped us leaving the airport, and as we disembarked at the Sheremetyevo Airport in Moscow, another camera crew of BBC waiting to board our plane leaving immediately duly recorded our arrival with inspiring statements like, “You guys have completely lost your marbles.” We declined all interviews. After we were there a few days, the US Embassy on Tchaikovsky Avenue called us at the Rossiya Hotel to say that Washington had notified them that we were to leave the USSR immediately.

Our Soviet colleagues were in tears with genuine concern that World War III was eminent. They tried to get us to accept tickets on Aeroflot to Prague where we could get a western carrier to Frankfurt. Our instructions from the Embassy were to leave immediately by train to Helsinki. Further, we were not allowed to take any money for the tickets from the Soviets. The standard arrangement was that the host country paid expenses while in the host country with travel expenses paid by the visiting country to the point of entry. Under no circumstances were we to set foot in a Russian airplane.

We left Moscow on the Trotsky train to Helsinki via Leningrad. The trip is at least 13 hours. The accommodations were a little crowded in our 4 person compartment. Decker is at least 6’6”, Plotz –6’2”, Klippel – 6’, and yours truly – 6’3”.

Decker could not even sit upright because of the upper bunk. We ordered a lot of tea and cookies and whatever food we could find in order to spend our rubles paid to us by our Soviet hosts. The conductor, however, would only have us sign a chit. Later after we crossed the border at Viborg we were presented with our bill payable only in American currency -- sweet!

PASSPORT CONTROL AND CUSTOMS

On December 5, 1988, I arrived on a Pan Am plane in the late afternoon at Sheremetyevo Airport in Moscow. As we debarked, in addition to the usual olive drab, garbed male Army guards, a few pleasant and smiling, blue uniformed women and even a few olive drab garbed women greeted us: a few had a smile. I waited at Passport Control where every year the same seemingly 18-year-old boy wearing a Red Army uniform sat behind the same brightly lighted rectangular fluorescent lights at the top of the booth, staring
first at the passport and then at me for 20 to 30 minutes. He periodically would say something to the hidden person seated behind a partition to his left. Now a telephone was added that he used to call every 5 minutes or so.

Customs, however, was now really a breeze consisting of a walk through. Even more surprising, our Soviet colleagues could now enter through the custom's gate and help with our luggage. The big fight now was to get baggage carts of all things.

The above description of today is far different than the first trip that my wife and I took to the USSR in June 1975, after the European Congress of Rheumatology in Helsinki to Leningrad on a bus tour sponsored by a Finnish travel agency. There were 40 of us on the tour speaking 10 or 12 languages. The husband of the agency owner was our guide because of his multilingual abilities. He actually was in the steel import business. As we left the Finnish border control point, we entered a buffer zone about 200 yards in width with imposing high wire fences and very serious, seemingly 18-year-old guards carrying imposing automatic weapons. We then stopped in a several acre clearing with an elevated concrete blockhouse with the same confidence-building guards. The bus stopped along with a lot of other buses and cars at a brick building for inspection and passport control. As we looked out of the bus, a car was pulled off to the side and was being dismantled piece by piece by guards looking for God knows what. We were told to remain quiet in the bus and to stay in the bus. After an hour or so, Ria left anyway looking for the ladies room. As we rounded the corner of the building, we found several guards loitering and smoking cigarettes. They immediately yelled at us, pointing those wonderful automatic weapons in our direction, and chased us back to the bus area. When the border, passport control soldiers finally came to the bus, our guide, Arnold Kuningas told us to say nothing unless asked. We sat at attention while 2 guards walked together down the aisle looking at each person's passport and visa. They would look from the passport to the person to the passport over and over and over. Then the first guard would pass the document to the second guard who would repeat the same procedure. Kuningas said that there was an old Finnish joke that the reason for 2 guards was that one could read and one could write.

On our remaining trip to Leningrad, there were sentry houses every few miles and as we would pass the guard could be seen calling to confirm our course and time. One time a pit stop was necessary, and our guide was very nervous that we would exceed our allotted time to the next checkpoint.

An intermediate stop was at Viborg, a town that was formerly Finnish. The town was absolutely filthy, and the only usable bathroom was in the old train
station. It was absolutely unusable. Most of the people we saw were staggering drunk in the station. Apparently they had been relocated to the area.

I had occasion to visit Viborg again in the 1983, when passing through on the train from Moscow to Helsinki. The station was now a model of renovation with brightly colored walls. The custom and passport control were at this station. All of us still had 100 or so rubles from our Russian allotment due to the fact that we were called home early by Washington. The customs person was not an army person as in the past. She was, however, just as angry and haughty as earlier passport and customs people at this border. She expressed her hostility the best when she made us pool our rubles and count them. She then countered by requiring us to separate them individually and supply a separate record. The agent then confiscated all of our rubles and gave each of us a receipt with a little gleam of revenge in her eye. We could not transfer the money because we had no receipt of converting dollars to rubles. The Soviet government had given them to us. For several years I kept an informal bank account at the Institute of Rheumatology with the unspent money of each trip. In this particular case, Lev Alekseev and I retrieved the money in the inner bowels of the Sheremetyevo Airport the next year or so from a tough, hard-nosed bureaucrat 4 or 5 levels down in a little office containing a desk, chair, money, and an abacus.

In 1976 on the occasion of our first trip to the USSR, I asked Victoria Nosovitsky, a Latvian physician émigré, if the new Texas Instruments' $10 calculator would be nice. I planned to take 5 of them to our Russian colleagues as small presents. She nearly flipped her gourd and told me that such a calculator was worth probably $500. Further, that unless I split them out among the other members of our group, the customs people in Moscow would find them immediately and would confiscate them.

In New York while waiting for the plane, John Decker of the NIH and Morris Ziff of Southwestern Medical School at Dallas persuaded me that this was not necessary.

Sure enough, all 14 of our group went through customs with no inspection except yours truly. The agent immediately pointed to one of my 2 bags and, not only that, pointed to a certain compartment where the 5 calculators were packed. He confiscated them and took me to the safe in the airport manager's office for storage until I departed the USSR. Our Russian colleagues were furious, of course, and a few days later the calculators were delivered to me in Vilnius, Lithuania by one of our colleagues.

The changes that have occurred sending research drugs through Soviet customs since 1980 are more than interesting. They are mind-boggling. In 1980
when we began planning the shipment of d-pencillamine, hydroxychloroquine, and placebo in blinded capsules along with the pediatric patient study books to the Institute of Rheumatology in Moscow, we had to obtain permission from a myriad of agencies and personnel here in the USA. In addition the baggage handlers of airline cargo were on record that they would sabotage such shipments. I sent the material in boxes marked with the National Institutes of Health labels to the Houston airport air cargo terminal with my wife, Ria, and Dr. Giannini, our senior scientist and biostatistician. They personally loaded them to the air cargo clerk for shipment. They were shipped by nonstop KLM to Amsterdam with transfer to Aeroflot for nonstop shipment to Moscow.

The only problem was that once in Moscow, Professor Victor Lepachin, Chairman of the Pharmacology Committee (Soviet Food and Drug Administration), impounded the drugs, claiming jurisdiction over all drugs entering the USSR, even though the Academy of Medical Sciences had approved the research study. A turf war very similar to our turf wars in this country ensued. The boxes languished in the customs warehouse at the Sheremetyevo Airport for months and months. Finally I journeyed to the USSR and Professor Nassonova and I went to the airport in the old bus of the Institute. She helped the customs agent to understand the problem. And we kidnapped the drugs to her Institute and began the study published in 1986 in the New England Journal of Medicine.

The next study that we began with the pediatric rheumatologists in the USSR was with oral gold or auranofin in children with juvenile rheumatoid arthritis. Colleagues at SmithKline shipped blinded study drug from Philadelphia to Moscow via KLM again. The same turf war of jurisdiction was going on in Moscow between Lepachin and Nassonova. This time, Professor Lepachin not only impounded the study drug at the airport in Moscow, he transported it to his office in the Ministry of Health to be sure that another end run would not occur. Over one year passed with more than one trip by me to Moscow and monthly telephone calls before approval came.

For the current study of methotrexate in children with juvenile rheumatoid arthritis in the USSR and USA, we waited over 2 years for Professor Lepachin's approval, but this time we did not mail drug until after approval in January 1989.

Magazines, books and periodicals from 1975 to 1984 were the subject of capricious rules. The Soviet society is prim in many ways, and periodically, and dependent entirely on the custom's agent, such items as books that were not flattering to the USSR would be confiscated and returned when leaving the USSR. At times for no apparent reason such periodicals as Time or Newsweek would be taken. Playboy and Penthouse in the mid and late 1970s were
clearly no-no's. Since 1985, I had no inspection of luggage much less confiscation of books or such magazines as *Time*. My colleagues, of course, took in the other magazines mentioned.

HOTELS IN THE USSR

Perhaps the most dramatic change that I have noticed since 1975 has been in the hotels. On the occasion of the 60th anniversary of the All-Union Congress of Rheumatology and the 30th anniversary of the Institute of Rheumatology held from December 7-9, 1988, the celebration was held at the Central Tourist Hotel on Lenin Prospect near the Patrice Lumumba University. A conference center was attached to the hotel with an auditorium seating over 400 persons including individual multi-translation plugs at each seat. The earphones worked also. The traditional, enormous bust of Lenin behind the stage was absent. The check-in system now was more traditional with primitive computers and bills being generated. Passport check no longer requires a fee. The most important change was that Russian citizens have relatively free access to the hotel even if they are not checked into the hotel. They also visited with us in our rooms with no sense of fear apparent. My room, which was a 2-room suite, had a color television, refrigerator, the traditional style of Russian bed -- but NOW an innerspring mattress. The bathroom had toilet tissue on a roll that appeared to be the same as in the Sheraton Hotel in Frankfurt. The lobby of each floor had only a part time hostess and not the traditional, nosy housemother or the roaming army soldier checking every hour or so.

The restaurant was the best part. We could eat breakfast for an hour and a half each morning from 7:30 AM to 9 AM, lunch from 12 PM to 1:30 PM, and dinner from 5:30 PM to 7 PM. This meant that we could go to the restaurant on our own individually and be seated. The food was prepared in an interesting and attractive manner. The quality of the food was better than I have ever seen in the USSR. A tablecloth was present on the table for each meal. The waiters were solicitous and helpful instead of dictatorial and lazy. Also the dreadful deli-like places on every other floor such at hotels such as the Rossiya Hotel were missing. As discussed elsewhere, vodka was virtually absent and not even sold in the restaurants or bars -- only brandy, champagne, and beer. Wine was not even generally available. I purchased three bottles of vodka for Russian colleagues because they were unable to buy it. I bought it at the Berioska or the Tourist Store. The Berioska had massive amounts of vodka and wine.

This is in contrast to my first trip to the USSR in June 1975 with a Finnish bus tour. That was an experience of a lifetime. We stayed at the old Moscow Hotel. Check-in was en masse in a lobby resembling a Skid Row hotel renting rooms by the hour. I almost expected to see a Salvation Army band with
drums booming outside the door. Our room was smaller than our bedroom closets at home. Two narrow cot-like beds with a pad for a mattress. There was one overhead, very dim light. There was no television anywhere that I could see, much less in our hotel. The bathroom was a sheer delight. A small thin towel, one for each of us the whole time. The toilet tissue consisted of eight squares of very thin paper. A soldier and a housemother ran each floor. The restaurant was of equal fun. Each meal consisted of our group gathering outside and marching into the meal. We received one square of paper from a napkin looking remarkably like the toilet tissue. The bottled water was soapy in appearance and taste. The same with the soft drinks. The food was different and unusual, as Amy Vanderbilt would say.

On a hydrofoil boat from the Summer Palace to the city, room-temperature beer was served in glasses. And when one person finished, the waiter rinsed the glass on the spot and served someone else. The same procedure was used for the lemonade dispensers on the street in Leningrad. People stood in long lines for long periods of time to place kopeks in a machine and waited for one cup to fill with lemonade, then drink it bottoms up, and put it back. The next person would drink out of the same cup.

A great deal of chitchat goes on among people who travel frequently to the USSR concerning monitoring by the Soviet hosts and the KGB. Most of this, of course, goes on in hotels because the daytime hours are consumed with work or some supervised sightseeing. The stories are without end and usually get better each year as they’re retold. I have been sure on some occasions, and not so sure on other occasions, that monitoring was occurring. On occasion we would test the system. As official visitors of the USSR, we undoubtedly are monitored more than Intourist visitors.

In 1976 Dr. Fred Steinberg, a senior investigator at the NIH, and I were roommates on our first trip to the USSR as part of the agreements. We journeyed to Moscow, Vilnius, and Sochi, a resort on the eastern edge of the Black Sea. I had taken a dictating machine to record a diary to use for articles later. Fred was convinced each evening that the KGB was listening to my recorder each day, and searching our room because my recorder was changed each day before I finished. And by carefully placing scotch tape at critical places, we established that someone was indeed interested in our affairs. One evening Fred dictated into the machine: “Give us a clue. We know you’re there.” The next evening when we returned and turned on the machine, the sound of running water from the shower came forth for several minutes. This was our indirect contact.

Dr Ralph [C.] Williams [Jr.], then chairman of the department of medicine at the University of New Mexico, and I were roommates on the 1978 trip to the USSR. The lock on the suitcase he had brought was broken. One day we
returned to find the lock had been fixed. It was broken when he came to the country. Apparently the person figured that the previous agent had broken the lock, and he was being nice and repaired it. We meant to bring a broken lock luggage on the next trip.

Another time in Moscow in 1982 at the Rossiya Hotel, Ed Gianinni, my colleague from Houston, and some of our Russian colleagues were sitting in our room talking. The feedback on the microphones was so great that we could not hear each other very well. Lev Alekseev excused himself with a smile to get us some soft drinks. The feedback disappeared. It’s useful to note that at the time it was against the law for a Soviet citizen to be in a hotel with an American or be with an American, period. And they could be charged with some great penalty. But our assigned colleagues could come to the room and be with us. Only certain of them could.

In Vilnius at the All-Union Congress of Rheumatology in 1985, Ria was also invited as a guest of the USSR by Professor Nassonova. They had become friends during her trips to the United States. There were four of us representing the USA for our meeting to discuss future studies. For the first 3 days after arrival, our Soviet pediatric colleagues not only kept their distance, we barely saw them except to wave and smile. This from 10-year friends. It seemed to me that the adult doctors had preempted them or something. In our suite that morning, Ria said to me, “I’m not sure what’s going on. But if we’re not going to meet with or see our counterparts, we should probably just go home.” We left our suite immediately and went downstairs to the hotel—to the ballet—where we were greeted with great hugs by Alekseev, Kuzmina, and Shaikov. We were with them daily after that.

Experiences with nightclubs in the USSR: Professor Alphonse Matulis, director of the Institute of Experimental Medicine in Vilnius, Lithuania, described them as socialist strip joints. The nightclub in Vilnius we visited in 1976 had a loud band playing polkas or the equivalent and a floorshow consisting of very pretty girls in leotards and pantyhose or its equivalent doing kicks. The club was just around the corner from the Neringa Hotel where we were located. My friends around the world know that I can get lost anywhere and need a keeper, really. I left early and turned left instead of right at the corner and wandered around town for an hour. I noticed a car following me. Finally I asked a cabdriver to take me to the hotel. I carefully placed a piece of stationery from the hotel name in Cyrillic. The cabdriver pointed across the street to the hotel.

In 1982 while visiting Vilnius again, we were taken to a new nightclub built like a Las Vegas lounge with tiered deep cushions, semi-circular booths, round tables, low lights, and the usual interesting and fun socialist strip club
routine. The music was now more modern and sounded like a USA rock station with confidence and played at a 130-decibel level. At least 2 of the acts were better than some I’ve seen in lounges in Las Vegas. I asked for vodka and was told that only scotch, brandy, and champagne were available, that no one in the club would drink vodka. There certainly was an increased sophistication from earlier times.

In 1988 a closing dinner was held in the nightclub in the Central Hotel on Lenin Prospekt. The floorshow was an hour or so long. Western rock music was the order of the day. The many dance routines were really professionally done. The comedians were visual enough that they were funny even in another language. An excellent dinner by Soviet standards was served in the dark. Professor Kuzmina, as most professional Russian women, drank little, if at all. She excused herself at 10 PM. because her subway would stop running as frequently and would mean getting home would take even longer. During the show she leaned over and said about the young, scantily-clad showgirls, “I do not like some of our new things,” and turned her chair and sat with her back to the show.

Perhaps more interesting to discuss is glasnost (openness) and perestroika (restructuring). Everyone who has read an article or paid a visit to Russia or the USSR in the late 1980s has an opinion about glasnost and perestroika. Very few have bothered to read [Mikhail] Gorbachev’s Perestroika, including my Soviet counterparts. His book was not generally available in Russia. The most remarkable changes that I have observed took place beginning about July 1987. I learned more about the personal lives of our Soviet counterparts since then than I did in the preceding 13 years put together. It is my personal perception that it was either against the rules or probably against the law for a Soviet citizen to develop a personal friendship or association with foreigners or, more particularly, Americans. Even more to the point, only Soviets who had approved reasons to associate with Americans were allowed to do so, and they were instructed in these matters and were watched carefully.

Apparently in areas like mine, where no security was at stake and even the most avid Dr. Strangelove in either country could not feel ill at ease helping chronically-ill children, it was more like worrying about promotion rather than jail. It has always helped me to understand my colleagues there, especially the close friends with whom close working relationships have been established, is to remember that while the English were developing the Magna Carta and restricting the power of the king, the Tartars were pillaging and assaulting the Slavs in the early part of the millennium.

The Russians progressed to ownership by feudal princes in the middle of this thousand years when the Romanov Family was elected to be the tsars in the
early 1600’s, lasting until the revolution of 1917, when the Communists became dominant. The people always were indoctrinated in the concept of Mother Russia. From the time of Catherine the Great, no Russian could travel abroad without the express permission of Catherine. Limiting contact with foreigners has been a rule for a long time. When Mother Russia owns you, how can you want to emigrate? For this reason the new constitution offered opportunities that may go down in history as just as important to them as our own constitution is to us. Rather than discussions of theoretical possibility that this is that situation, sharing with you the changes that have occurred in the lives of some of my Russian colleagues may be more interesting.

Large-scale availability of TVs did not occur until the middle or earlier 1980s. Radio Moscow was heard by 180 million people daily living in 11 time zones or zones as told to me by Irena Simonova, a talk show host who interviewed me one time. This is quite a Nielsen Rating. Even though the TV program was limited, the impact was just as enormous as the USA. Early programming was truly dreadful with the hours limited to the evening with one and later two channels. Wonderful discussions of a new factory in the rural areas were high points. News droned on and on with only a correspondent reading the text. The ballet and operas, of course, were excellent. Programming now consists of all-day viewing on several stations.

A typical morning in December 1988 revealed an exercise program with pretty girls in leotards bouncing around as they do in our country. The morning news had a personable and handsome anchor. Some women news reporters are also seen regularly. The anchor switched to foreign correspondents with voiceover interviews in Washington and all over the world. Recently CNN was allowed to broadcast for 3 hours from midnight onward. Shaikov listened and was very impressed with the quality of coverage, as well as the quality of presentation itself.

Game shows are regular events with prizes such as flower arrangements. My friends tell me that winning is more important than the prize. Athletic events such as skiing and soccer probably are the favorites. Morning and evening programming in the late 1980s have rock bands and concerts regularly with the news sandwiched in between. Owning a television set remains the highest priority of families. I am told by many colleagues there they are very, very expensive in relation to income.

Beginning about 1986 several colleagues told me about buying a flat of several rooms in a new building. The mechanism was to pay 40 percent down and the rest in 10 years. They own this flat, and in most circumstances could pass it on to their wife if not their children. Also, safe banks were established paying about 3 percent interest. Sound familiar? Cars became
available to the upper classes beginning in the same period. The cost was enormous. Paying for such expensive items has to do with the barter system in one way or another.

The availability of international telephone lines to the USSR has only changed in the later 1980s. Beginning in the early 1980s I discovered how to telephone on a regular basis with a lot of help from friends in the State Department as well as the NIH. There was a special number to call in Pittsburgh in advance scheduling and several approvals from a series of USA monitors. There were 2 allegedly public lines open between the 2 countries, and the situations that occurred in completing calls could fill a book. Sometimes there were so many people listening on the line, I would ask for someone to hang up so I can hear, the voices had become so faint. Now the Pittsburgh operator can dial directly, and the special number was disconnected because someone complained about favoritism. So much for privilege.

The reason that the telephone was so important to our successful relationship over the years is that letters were impossible to send or receive to the old Soviet Union. In the past 2 or 3 years, letters can now be sent to be received about 3 weeks if they’re official. A letter from the widow of my main counterpart, who died suddenly in 1985, Lev Alekseev, was sent to me in October 1987 and was received by me in Houston in November 1988. Until this year we always relied on people from the NIH visiting in Moscow or Soviets coming here to transmit data because of the mail. As an example of how rapidly communications improved, Purolator will deliver a letter to the USSR by mail for $50.

There’s been a marked reduction in sloganism in the past 2 years. In the past many, many buildings had large neon signs, several feet high, running on the entire top of the building with slogans that implored the citizens to work harder for the Motherland and Communism. These signs have been largely removed. Also, the ever-pervasive bust of [Vladimir] Lenin is much less noticeable. In the early 1980s it was almost humorous to me that military officers carrying the same leather briefcase were seemingly everywhere on the streets. They seemed to get a new issue of different style briefcases every two years. Now there are many fewer uniforms to be seen bustling on the streets of the city.

In the beginning glasnost and perestroïka were met by skepticism by my colleagues. By 1987 the change was beyond belief. One rheumatologist, Alexander Shaikov, has been a member of our group since 1976. During these years we would discuss work only and a few superficial topics. When I would ask an opinion on a political issue, the answer would be either “it is
not clear’’ or a blank look that said I cannot discuss this subject with you, and you must know this.

In July 1987 we were driving on Dimitri Prospekt, and Shaikov turned to me and said, “Look over there. There’s the new hotel for members of the Communist Party. It is very nice. Only members of the party can stay there.” We were headed for the Minsk Hotel on Gorky Street, one step below Skid Row and hourly rates. He then proceeded to tell me that he was born in Ottawa, Canada, that his father was a senior lecturer at the Foreign Policy Institute who was assigned to Washington for many years. We also discussed his recent lecture tour in North Korea for three months, where he found that the medical care as we know it was virtually absent. Babies with severe illnesses leave the hospital only to return to die…if at all. There are few if any pediatricians as we know them. Alexander then visited the USSR Embassy in Beijing for a few days and went to India.

I asked about glasnost. He said, “We shall see.” He went on to say that the day is gone when serious penalties are imposed for talking openly with me or people like me. Opinions can be expressed, but people were still looking over their shoulders.

At dinner in the Central Hotel in Moscow, December 1988, a long-time interpreter told me that people felt that their country was 20 years behind the United States and other western countries. In addition, people in their 60s are angry about the new way because they bought into the old concept: guaranteed birth care and education, housing, medical care, and retirement. Now, the new way of more responsibility for work and less emphasis on seniority is a little like older workers in small towns in America who suddenly face job loss when a big company either shuts down or lays off older, more highly-paid employees. In our country also these same people who invested their entire lives in the big corporations suddenly felt violated and cheated. The Russian people in their 40s feel ambivalent because no matter how one slices the pie, all of us worry about personal incomes, way of life, and jobs. Lastly, she felt that young people in their twenties are enthusiastic about the possibilities for themselves.

One of the other rheumatologists with whom I visited in December agreed with the previous discussion, but pointed out that consumer goods on the shelves are less plentiful than before 1985 and the quality is not improving. Goods are costing more also. The interpreter illustrated this point by saying that a 20-cent bar of bath soap is no longer attainable, and long lines occur to get it. Inflation makes one feel angry, especially since the quality and quantity of consumer goods are getting worse instead of better. People seem to be using the term perestroika (restructuring) a lot more and glasnost (openness) a lot less. When I asked different colleagues about perestroika
and glasnost, they shrugged their shoulders, turned palms upwards, waffled their fingers.

The new sharing of knowledge and fellowship is in sharp contrast to 1976 when 14 of us came on our first official trip to the USSR. We were in Vilnius one evening talking to a young Jewish rheumatologist in a Chaika automobile, when a senior Russian rheumatologist walked over to the car, grabbed the young man out of the car by his collar, shoved him back to the car behind, and shouted to him in English: “You know you are not to be alone with the Amerikanskis.” Smiled graciously to us, sat in the same seat as the young doctor, and began talking as if nothing had happened.

My only attempt at diplomacy was a failure. I was a guest of the People’s Republic of China in 1982 for 3 weeks. A group of us went: Dr. Zaifang Jiang, the director of the Institute of Research in Beijing Children’s Hospital, and I selected Dr. Xiaohu He, a senior nephrologist, to come to Houston to train with me for 2 years in pediatric rheumatology. Dr. Zaifang had trained from 1955 to 1960 in Moscow at the First Moscow Medical Institute and was fluent in Russian and their customs and had spent a year at our hospital in Houston.

We then began discussions with our Russian counterparts about a joint study between the USSR, the PRC, and the USA. The Soviets invited Dr. Zaifang to a meeting in Warsaw. And during a telephone conversation a month or so later stated they had permission to be in discussions for a joint study. Dr. He wrote to Dr. Zaifang and obtained enthusiastic permission to begin discussions. I then discussed the option with the head of the Soviet Desk of our American State Department. He had no problem with the concept either. I then presented the concept to personnel at the National Institutes of Health. They tried the best they could. But our USA agreements were limited to USA-PRC and USA-USSR. We did not have authorization to develop at USA-USSR-PRC joint effort. I still think it was a good idea.

Jogging in the USSR is an interesting discussion. Dr. Jack Klippel, of the National Institutes of Health, was our resident jock of the Russian Riders, our group of travelers. He was a triathlon competitor and looked like James Bond with a beard only better. In the late 1970s in Moscow at the Rossiya Hotel, Jack announced that he was going to jog around the Kremlin. He jogs every morning in every other city he visits, and why not here? Everything went well the first morning and the second morning. He had run about halfway on the third morning when the familiar Red Army guard stopped him and told him that one morning was okay, the second morning was stretching it, but 3 mornings, Nyet. In July of 1987 seemingly squadrons of joggers were in the streets in the area of the Kremlin.
Early interaction with adult rheumatology: I should probably mention about early interaction with the adult rheumatology world when I started. A tension existed between the adult rheumatologists trained in internal medicine discipline and the pediatricians from the beginning. There were fundamental differences in training and approach to the care of children and, in particular, children with arthritis. Each group felt self-righteous and absolutely sure that each view was correct. It is also useful to mention that the American Academy of Pediatrics was not organized until the middle 1930s. The AAP was created largely because the American Medical Association refused to support the formation of a children’s bureau, and physicians fighting for immunizations for children split from the group. A separate department of pediatrics was not formed at Baylor until Dr. Blattner was hired in 1947.

So the scene was set with a background of distrust on the part of pediatricians protecting their newly-created independence and a perceived patronizing attitude of adult rheumatologists toward pediatricians. My first attendance at a meeting of the then American Rheumatism Association was in the late 1950s. I went with my new friend Dr. James Kemper, newly arrived at Houston from the Mayo Clinic to be in charge of rheumatology in the department of medicine at Baylor and rheumatologist at the then small Kelsey-Seybold Clinic. Fortunately for me and my career in pediatric rheumatology, we both liked each other from the beginning and began a professional life and friendship together that has lasted until now.

The experience was incredible. I enjoyed learning about the huge world of arthritis, and I was impressed with the caliber of the adult rheumatologists. I also came away with the certain knowledge that the adult physicians had a frame of reference with regard to care that was fundamentally different from pediatricians. It was more than the usual cliché that children are not little adults. All of that was certainly a facet of the differences. Another cliché was that if internists wanted to take care of children, they would’ve become pediatricians. Clearly, there were internists who loved caring for children also. I met Dr. William Clark who trained at the Massachusetts General Hospital with so many legends in rheumatology: Dr. Ronald Lamont-Havers, then with the Arthritis Foundation in New York; Dr. Sydney Stillman, director of the Robert B. Brigham Hospital at Harvard; Dr. John Ward of Salt Lake City, University of Utah; Dr. Morris Ziff, another legend of rheumatology. Sydney Stillman ran a children’s clinic at the Robert Breck Brigham Hospital in Boston, but he did not have a close relationship with the Boston Children’s Hospital. He was one of the great men I’ve known and became my mentor. I wish I’d known him when I was a resident in Boston.
My conclusions from my early limited experiences were clear: The path to better care and research for children with arthritis had to be a joint journey with the adult rheumatology world, but it must be led by pediatricians. I followed this concept to my retirement in 1990.

The concept led to some memorable battles along the way. In the late 1950s, several other pediatricians and internists were devoting their time to caring for children with arthritis in several parts of the country. We all became devoted colleagues in our quest for better care and research for the children with arthritis. Others will hopefully tell the stories of the early beginnings of their clinics and their journeys in pediatric rheumatology.

Dr. James Cassidy, Ann Arbor, University of Michigan, Creighton [University] Medical School in Omaha, University of Missouri. I can’t remember when I first met Jim, but we were friends from the beginning and to the present. He was a Type A, rapid-thinking but careful physician. Jim was our resident genius and writer. His gentle smile and humorous gleam in his eye added to his disciplined approach to any task. Jim was prematurely bald and was famous for his caps. He was trained in internal medicine and later passed boards in both medicine and pediatrics. He became chair and professor of pediatrics at Creighton and moved to the University of Missouri later and limited his patients to children. He also had to eat at precisely 6 in the evening for reasons unclear to any of us. We have remained close friends and colleagues since. Jim, among many accomplishments, is the author of *The Textbook of Pediatric Rheumatology* published in 1982 and many editions later. He and Nan were high school sweethearts in Oil City, Pennsylvania, and continued to be to this day. He was a consensus builder in our group. His original interest in children was at Michigan during his training. There was no one looking after the children. He encountered resistance from the adult rheumatology staff from the beginning and had to make sacrifices to continue. He felt the same need the rest of us felt, and became a staunch and important pioneer in our efforts.

Dr. Joseph Levinson, Cincinnati Children’s Medical Center, University of Cincinnati. Joe Levinson is another great legend of our field. We were so fortunate for his presence in our small group. He was a reflective, Talmudic person. Talmudic scholarship is famous for the tortuous and painstaking manner in which truth is pursued and established, if it can be established at all. Joe agonized over a single word included in our various publications. Jim and I at times threatened him with extinction if he did not finish editing a given paper and give approval. Joe trained in adult rheumatology at the MGH in Boston. He entered pediatric rheumatology almost by chance. He filled in at a pediatric clinic in Cincinnati which became a premier program of pediatric rheumatology due to Joe. His persona filled the room when he entered. He was a jolly, everyone’s Dr. Joe. His soft-spoken words flowed
with ease. His physical stature was spare, but his shadow and his vision for his center to be was incredible. He was and truly is a gentle man.

Dr. Chester Fink, Dallas, Southwestern Medical School, Scottish Rite Hospital. Chet Fink was a wonderful pediatrician raised in North Carolina. He trained at Western Reserve and was a friend of Bill Clark (Dr. William Clark). Chet settled at Southwestern Medical School in Dallas and started a clinic at the Scottish Rite Hospital for Children and worked with Morris Ziff, head of the adult program and a legend of rheumatology. Chet loved to eat and was pleasantly plump. His sense of humor was a pleasure to all of us. His quiet and reflective approach to our problems at hand always made sense. His cheeks were red, topped by horn-rimmed glasses. His ready smile and laugh lightened many a tense situation as each of us pressed our personal agendas during our deliberations. He became a great friend. Dotty and Chet met when they both were stationed in Japan with the Army. They retained their love of Japan, and Chet was our main contact person for Asia in our collegial quest to develop better care for children with arthritis.

Dr. Virgil Hanson, Los Angeles, Children’s Hospital of Los Angeles, University of Southern California. Virgil was a reserved, thoughtful, wonderful human being. He trained at Johns Hopkins, settled in Los Angeles at USC and Children’s Hospital, where he established what became a premier program. Virgil spoke softly and endeared himself to everyone who had the privilege of knowing him. He was always positive in his reaction to ideas. I never heard him speak ill of anyone, even when a person had really pulled a sneaky end run around him or one of his many projects.

Dr. Sydney Stillman, Robert Breck Brigham Hospital, Harvard Medical School, Boston. Syd was a distinguished adult rheumatologist at the Robert Breck Brigham in Boston, where he was medical director and had pioneered a clinic for children with arthritis on a limited budget. He soon became president of the ARA. Sydney was older and everyone’s Uncle Syd. He was a gentleman in every sense with a wonderful sense of humor that defused many tense situations. Syd was not only my professional hero, but also a mentor as time progressed.

Dr. Jerry Jacobs, New York City, Columbia College of Physicians & Surgeons. Jerry was an excellent pediatrician at Columbia in New York City. Jerry trained there and started the clinic at Babies Hospital. The entire room knew when Jerry entered. He was larger than life. Every event was a crisis to be solved. He had a heart of gold, but as a card-carrying tough New Yorker, it was sometimes hard to find. Jerry was almost always the last to agree on any decision of our collegial group and offered instructive opposition that became important to making our work relevant and credible.

Dr. Ilona Szer and Dr. Yukiko Kimura in the Pediatric Rheumatology Online
Journal gave a wonderful tribute to Jerry and his work. It was published in the Pediatric Rheumatology Online Journal Volume 2, No. 1, 91-102, 2004.

There were to me 10 breakout events in the development of pediatric rheumatology. We’ve discussed virtually all of them in the early years, the pioneer years.

The first is Dr. William Clark and the March of Dimes; the Vanderbilt Meeting in 1959, a pivotal meeting; Warm Springs, 1959, with Basil O’Connor, March of Dimes. And then the March of Dimes Special Treatment Centers in 1960; and the transition of the March of Dimes pediatric arthritis program to the Arthritis Foundation.

Dr. William Clark and the March of Dimes, or MOD: He was an adult rheumatologist of great vision. He took over the March of Dimes in 1958 when the MOD was searching for a new disease to conquer after its success with polio. Bill was a dynamic maverick leader of rheumatology. He was restless to take rheumatology to the next level of organization and success. He trained at the MGH and was a professor at Case Western Reserve when he accepted the challenge from Basil O’Connor and the March of Dimes. Joe Levinson, a legend of pediatric rheumatology, remembers that Bill visualized a 3-tiered approach to childhood connective diseases: First, case finding with primary treatment facilities to be established in local communities and evaluation centers close to where parents live—patients live. Secondly, special treatment centers providing more expert and multidisciplinary service at academic institutions, and these would relate to the third tier. Thirdly, the research centers could be the same as the special treatment centers.

He later was editor of the prestigious Arthritis and Rheumatism journal and led the merger of the ARA with the Arthritis Foundation. When he was president of AF, Bill created the highly successful Arthritis Health Professions Association. Bill Clark knew that something had to be done about the care of children with arthritis. He was interested in our program of strengthening muscle and continued active exercise and activity because of data showing that enforced rest results in atrophy and weakness and not improvement. He agreed.

This concept was discussed at the Vanderbilt Meeting at Nashville in 1959, organized by Bill Clark. The host for the meeting was Dr. Amos Christie, revered chairman of pediatrics at Vanderbilt Medical School. Invited distinguished rheumatologists were Dr. Bill Clark; Dr. Howard Polley of the Mayo Clinic, the first person with Dr. Philip Hench to use cortisone; Dr. Walter Bauer of Harvard and the Mass General; Dr. Joseph Bunim, director of the National Institutes of Health; Dr. Charles Short from Harvard; Dr.
Charles Christian, Dr. John Calabro, and a few others whose names escape me.

Most were revered leaders of rheumatology. I was the only pediatrician present except for Dr. [Amos] Christie. My assigned roommate was Chuck Christian, who had just finished his fellowship at Columbia College of Physicians & Surgeons, with Dr. Charles Regan, a legendary rheumatologist. Chuck had just joined the faculty at Columbia. He was an incredibly able young adult rheumatologist. We became friends over the years. His help later was quiet but effective.

The discussion was heated. I was the only one who felt these children must not be put to bed. The traditional thinking at the time was to put adults and children to bed in hospitals for as long as their health insurance lasted. Dr. Polley was so persuaded about usefulness of bed rest, that he said he would return to the Mayo Clinic and put a few children with JRA to bed for 6 months and show the improvement in their joint x-rays. He never put any children to bed to my knowledge because pediatricians, there were opposed, I heard. Another belief by the adult group was that children with arthritis were a medical curiosity and extremely rare in occurrence. My thesis to them was that when meaningful care and facilities were available to children, the parents would bring them. The prevalence was not rare. Dr. Christie then rose and spoke to the group as our host for the first time: “I am not a rheumatologist; but as a pediatrician, I know that you must not put these children to bed.” He then left us. The effect was powerful. This to me was a pivotal meeting for pediatric rheumatology.

The Warm Springs Meeting in 1959 with Basil O’Connor, founder of the March of Dimes: The next pivotal meeting was at Warm Springs, again in 1959, with Basil O’Connor, revered founder of the March of Dimes. The meeting was again small and was at President [Franklin Delano] Roosevelt’s Warm Springs retreat near Calloway Gardens in Georgia. I don’t recall the total group beyond Bill Clark, Basil O’Connor, and Dr. Ephraim Engleman, revered rheumatologist from San Francisco, a few others whose names I unfortunately don’t remember, and myself. It was a powerful and historic meeting place. Basil O’Connor told the story of the early plans for care and research that took place in that very room where we sat. He felt that we should not be shy about moving forward. Mr. O’Connor told us the story of the last days of President [Franklin D.] Roosevelt in Warm Springs before his death at Warm Springs. It was a moving experience for all of us and gave me a sense of our destiny for the new efforts. Dr. Clark got Basil O’Connor’s approval and quickly moved to establish special treatment centers for JRA under the auspices of the March of Dimes.
The March of Dimes, Bill [William] Clark, and special treatment centers, 1960: Texas Children’s Hospital was among the first centers approved by the MOD. Joe Levinson, Cincinnati, and John Calabro in New Jersey were other centers funded. There were other centers later. Our center’s funding allowed hiring Mrs. Elizabeth Barkley as our physical therapist and equipment was provided by the grant also. In 1962 further funding allowed me to become half time full faculty at Baylor and Texas Children’s Hospital. There was a transition from the MOD to the Arthritis Foundation later because the March of Dimes felt more at ease with helping neonatology under the leadership of Virginia Apgar for their major funding thrust. Bill Clark transferred our movement to the Arthritis Foundation successfully with the help of the March of Dimes.

My transition to Texas Children’s Hospital, Baylor College of Medicine, Kelsey-Seybold Clinic, 1961-62: A major problem with the success of our fledgling and unsophisticated program was that I could only devote one full day each week to it. Our commitments now exceeded my time limits. Dr. Blattner and Dr. Mavis Kelsey engineered the complex arrangement that brought me back to Houston full time. I remain grateful to both. Dr. James Kemper and Dr. Alfred Leiser were also critical to success. Dr. Blattner obtained a grant from the March of Dimes for a half-time salary. This allowed me to be assistant professor of pediatrics at Baylor and director of our burgeoning program at the clinic. It also provided me with time in the lab for research projects. I worked my way through college and medical school working in laboratories.

Dr. Mavis Kelsey, also a mentor and friend, is a legend in the Texas Medical Center. He founded his clinic in 1949 after training at the Mayo Clinic. He was the first director of the Postgraduate School of the University of Texas and accomplished many other outstanding achievements. His dream was to build a large, multidisciplinary clinic. He did. The clinic is now the largest in Houston with over 300 doctors and 20 branch clinics. In 1961 his clinic had 6 doctors or so. All were internal medicine specialists mainly trained from the Mayo Clinic. He wanted to expand the scope of the clinic and invited me to found and be chair of the pediatric department, and I accepted. He paid the other half of my salary. I arranged my time in the early days by working in the lab at Baylor in the Microbiology Department and the TCH clinic in the mornings, and at the Kelsey-Seybold Clinic in the afternoon. My role was to build a pediatric practice at Kelsey. There are now 60 or more pediatricians in the clinic spread over 20 or more branch clinics. I was chair for over 20 years. Both programs became more successful than I ever imagined. Juggling time requirements did not end until I retired in 1990. In the lab I worked with Dr. Will [William] Fahlberg on a tumor necrosis factor in guinea pigs.
Another pivotal event in pediatric rheumatology was the publication of the JRA book in 1970. Dr. Milton [Mark] Markowitz was a dedicated member of our JRA subcommittee. He was probably the most prestigious member at that time, along with Syd Stillman. Mark was well known for his prestigious studies with streptococcus and rheumatic fever. He worked for several years in Israel in the lab with Dr. Ann Kutner and at the Rockefeller Institute. At Johns Hopkins he was a contributor to *Pediatric Clinics of North America*, published by W.B. Saunders & Company in Philadelphia. They were the largest publisher of medical books at that time in the 1960s. The series of books are classic. Mary Ellen Avery’s classic neonatology book came from this series of books, and the textbook grew from that. And other books of authors such as Mark and Ruth’s book *Rheumatic Fever, Pediatric Clinics* became classic books.

Both Mark [Milton] Markowitz and Alexander Schaffer were kind and asked me to write a book on JRA for their series. The other authors were well-known, well-published people. I was not. The opportunity was incredible. No one in pediatrics had written a book on JRA at that time, and Mark and Saunders thought it would help to bring children with JRA to the consciousness of pediatricians. It was literally the blind leading the blind to write the book. My savior was a then new book editor at Saunders, Buck [Arch] Rowan. He worked with me to structure a book properly. Years later authors for Saunders told me that they were told to read my book to see how a book should be structured. The reason was that my book was Buck's first to edit at Saunders, and later he became editor-in-chief.

I started the arduous task in 1968, working at home in the evenings from ten PM until after midnight. I enlisted the help of Elizabeth Barkley, our physical therapist; Dr. Ed [Edward] Singleton, head of Radiology at Texas Children’s; Dr. Malcolm Granberry, our orthopedist; Dr. Dan McNamara, head of Cardiology at Texas Children’s; and Dr. Sidney Cleveland, our psychologist. As a sign of the era, we devoted 8 pages to aspirin, 17 pages to steroids, 9 pages to gold therapy, 6 pages to indomethacin, a paragraph each to chloroquine and cyclophosphamide. The data reported was by and large our own data. There were remarkably few studies in children, and we analyzed our own patient base for most of the data. Our exercise program, a fundamental base to our treatment, received 23 pages. The book sold several thousand copies, chiefly due to the subscription list of Saunders. I was amazed.

I learned a great lesson here: Many of my colleagues spent large amounts of time on national speeches and local talks in the hospitals such as Grand Rounds. These efforts are essential for the education of our students, residents, and others. But as a tool to spread the word nationally and
internationally about children with arthritis, the printed word lasts many times longer than any speech.

I was dumbfounded in 1976 or 1977 in Leningrad during the Cold War. A group of rheumatologists, including myself, were in the USSR as part of the newly-implemented USA-USSR scientific cooperation. I was the only pediatrician in the group of 12 or 14. We went to the offices of legendary Professor Igor Vorontsov, head of pediatrics in Leningrad. He was in charge of the health of about one million children. He was also a pediatric rheumatologist. Rheumatology was one of the strong specialties in the USSR, and he had a substantial center with 20 or more physicians and accompanying staff. He was a slightly plump, jolly, but soft in speech man with a playful twinkle in his eye. He quickly perceived that our adult rheumatology colleagues outnumbered us. Igor motioned me to come to his private office. Remember that this was the middle of the Cold War. He smiled and reached to his large office library shelf and pulled a copy of my book. He told me that he read from it daily. I of course didn’t believe that. But we had no idea that Russians had access to any of our books from America.

Another ego massage and memorable experience for me was a visit to the headquarters of W.B. Saunders & Company in Philadelphia. The offices in Washington Square were historic buildings in a horseshoe-shaped, square brown brick and colonial style. They had an apartment used to house visiting authors. If they wanted to impress me, they did. Buck Rowan took me to a relatively small library housing the first editions of all Saunders books. He, of course, pulled a copy of the JRA book. Beside it was a book on tuberculosis published in 1870 by W.B. Saunders & Company, 100 years before my effort was published.

The second edition of the JRA book: In 1973 Buck Rowan and I persuaded Jack Handy, the editor-in-chief of Saunders, Alexander Schaffer, the consulting editor, that a second edition was useful. Pediatric rheumatology was moving ahead quickly, and I wanted to keep the momentum of our effort. Unfortunately, my attention and time reached their peaks, and the book took a backseat for a few years. There were a number of letters from Buck wishing for more of my time to work on the book. Elizabeth Barkley and I did publish our Parents Manual with Saunders in 1975. Saunders wanted to be a part of Park City I, but the Arthritis Foundation wanted to publish it.

In 1975 Dr. Bob [Robert J.] Haggerty and Dr. Morris Green agreed to write a book, Ambulatory Pediatrics, and asked me to write a chapter on pediatric arthritis. I was able to complete that assignment on time. Buck Rowan was promoted in 1976 to editor-in-chief, and George Wilk became my assigned
editor. There is a memorable letter in the papers from me to George telling him that the book would be finished in 1976. Ho ho ho…. The chapters were slow to be finished. I settled on writing 3 evenings each week with our new associate Dr. Ed Giannini writing the book with me. We filled our dining room with reprints along 4 walls housed in metal separators. Ria’s mother was appalled. We had many dinner parties in the formal dining room surrounded by thousands of pages of data and reprints. It is hard to remember pre-computer data files now. Ed lived with us 3 days each week with a pull-down bed in our library. He had to use the one bathroom upstairs in the children’s bedroom wing and share it with 3 children. I still hear from them about Ed in the mornings. He spent so much time getting ready, that they routinely pounded on the door. This was the regimen that Ed and I established….

To recap the paragraph: The arrangement that Ed and I established was effective, and we did complete the book in 1980. Mary Cowell had become a Saunders editor in 1978. Ed and I decided to add one of our pediatric rheumatologists, Dr. Don Person, as an author to get help to complete the chapters. Don even had trouble with his assigned chapters. But we all struggled to finish the task. As an example of how far drug therapy had progressed in 12 years since the edition in 1970, the first edition devoted 42 pages to drug therapy, while the second edition devoted 104 pages to drug therapy, with many more medicines added and some eliminated. The second edition was published in 1982 and was successful. This was just the kickoff and beginning of increasing our visibility.


One of the pivotal events in pediatric rheumatology to me was the establishment of the Section on Rheumatology, American Academy of Pediatrics, 1981. Dr. Gerald [E.] Hughes was executive director of the AAP in the late 1970’s. Dr. Betty Lowe, professor of pediatrics at the University of Arkansas, was on the board of the AAP and interested in pediatric rheumatology. She spent time with us in Houston in the early 1970s and had been a junior resident at the Children’s Hospital in Boston a few years after I was there. Both Jerry and Betty were supportive of establishing a
rheumatology section of the Academy. Both were essential in shepherding the applications to acceptance.

The first meeting of the new section was on the occasion of the 50th anniversary of the AAP in Detroit, Michigan, in 1980. Interested members of the Academy held an election from the membership of the section committee. The original committee members were Earl Brewer, Balu Athreya, Jack Bass, Virgil Hanson, Jerry Jacobs, and Carol Lindsley. An election was held for the first chair. I, of course, was so sure that I would be elected to chair. What a surprise! Jerry Jacobs of Columbia campaigned to be chair. I won, but I have no idea how close it was. We were successful in our quest with the AAP. They and we wanted to increase the knowledge of pediatricians in general, as well as giving a home to the developing field of pediatric rheumatology. We were included prominently in the programs of the Academy, including the annual, spring, and seminar meetings at different locations in the country.

I was elected to be secretary of the section’s committee of the AAP and a member of the Committee on Drugs of the Academy. Thus, we made a major breakthrough of acceptance for pediatric rheumatology. This breakthrough came with a double-edged sword: Within a year I was summoned to the board of directors of the American Rheumatism Association to explain why we were breaking away from the ARA. I explained that we were simply expanding our horizons to increase knowledge of general pediatricians. Jerry Rodnan of Pittsburgh, who appointed the original Pediatric Rheumatology Council and a legend of rheumatology, looked at me with a woeful expression and submitted that we were lost sheep and needed to come home. Dan [Daniel] McCarty [Jr.], a great legend whose work in gout will remain for centuries, wrote an editorial in the *Arthritis and Rheumatism* journal and lamented that the pre-pubertal panthers had jumped the corral fence and should come home. A few years later Dan and I were speaking at the annual UCLA Seminar at the Annenberg Center in Palm Springs. I prepared slides of pre-pubertal panthers jumping back into the corral.

The AAP Rheumatology Section has survived and sponsored more than one Park City meeting. The membership has not flourished as one might hope. But both the ACR Pediatric Council, and the AAP Rheumatology Section worked together with a collegial spirit. I feel honored that the Academy created the annual Earl J. Brewer Research Award to honor a pediatric rheumatology fellow for outstanding research. It is so important to promote the younger physicians coming along in our field. The initial recipients have all gone on to successful academic careers.
Another important reason for the Pediatric Rheumatology Section—or the Rheumatology Section of the Academy of Pediatrics—is that until the board was created in 1990, it was the only entity where pediatric rheumatology could be identified as a subspecialty. And this was important during the interim phase while we were able to gain approval for a pediatric rheumatology board.

DR. SPENCER: Earl, tell me about the American Board of Pediatrics and the role that you had in helping have a board established for rheumatology.

DR. BREWER: The Pediatric Rheumatology Board for at least 10 years was on my mind constantly. I formally applied to the American Board of Pediatrics in 1980 for them to create a sub-board of pediatric rheumatology. The application created a resounding thud. The lack of response was monumental. There was no reply essentially. Several colleagues—in particular Jane Schaller and Jack Miller—felt there was not a sufficient body of knowledge to justify a board. Immunologists wanted to claim the children with arthritis for their turf. In the mid-1980's Dr. Jim Cassidy, Dr. Patience White, and Dr. Deborah Kredich mounted a massive effort to gain acceptance of the application. Finally, in 1990, Dr. Robert [C.] Brownlee, president of the American Board of Pediatrics, and I went to the annual meeting of the American Board of Medical Specialties for approval of pediatric rheumatology as a sub-board. Dr. Brownlee and I sat with great trepidation for our turn with the board. We listened with sinking hearts as the board members skewered the preceding the applicants for emergency medicine and intensive care. Their applications were tabled for that year.

When Dr. Brownlee and I came to the table before the board, we braced ourselves for an inquisition. We had practiced responses, of course, but we were nervous. The chair greeted us with a smile and said, “Welcome.” That was a good start. The chair then told us that the board had carefully studied the written material, and they were pleased with the application. We were breathing a little easier, but we were waiting for the other shoe to drop. The chairman said, “Welcome to the ABMS group of approved subspecialties.” This was the last item on my list of projects to complete. My journey was over.

DR. SPENCER: Earl, tell me about the American Juvenile Arthritis Organization. Did you play a role in helping get that started?

DR. BREWER: Yes. The American Juvenile Arthritis Organization of the Arthritis Foundation—we named it the AJAO, another pivotal event of pediatric rheumatology—held its first meeting in 1981. Arlene Johnson of Ohio was president; Richard Weaver, vice president, California; Jena Zellwanger, secretary, Indiana. Members were Barbara Barrett, Washington
State; Jim Cassidy, Dawn Hafeli from Michigan, Joe Levinson, Art Choate from Ohio, and Al Moske from Virginia. The Arthritis Foundation was not supportive during these times. But the parents wanted the needs of their children and families to be heard. An immediate project was the proposed Juvenile Arthritis Centers to be sponsored by the Arthritis Foundation. I had spoken to this issue at the Arthritis Foundation Governmental Affairs Committee that year. The group organized itself with appropriate committees and bylaws.

Kathy Angel, a Houston parent of Elizabeth, who had systemic JRA, and I met with the board in 1983 and 1984. We proposed a national meeting to obtain visibility and visited Keystone, Colorado, Mountain Resort as a possible site. The national Arthritis Foundation staff believed that we could not possibly pull off a meeting by the summer of 1984 in Houston. Kathy was a monomaniac mother with a cause. She also was able, effective, and smart. Kathy created a command center in Houston and engineered video coverage, special help from the children, and the myriad of details necessary for a national meeting. Kathy and Dr. George Angel, her husband, and Ria and I spent considerable money of our own, as well as obtaining funds from people like Jose and Mimi Aranda of Buenos Aires, to support the meeting, and the Bureau of Maternal and Child Health came through with some money.

The big week came. It was truly a landmark meeting for the cause of children with arthritis. The children were elated and had a great time. They met other children with arthritis for the first time in many situations. One child from Australia came in a wheelchair. He said, “I’m going to be walking when I come back here.” A few years later he came to an AJAO meeting, and he was walking. We had several days of talks and seminars which were duly recorded on tape and video. The meeting was indeed an epiphany. From this seminal meeting, the AJAO found its place in the heart of the Arthritis Foundation and pediatric rheumatology. Today it remains an even more important part of the AF. I was pleased when the annual Earl Brewer Award [for Physician Leadership] was created in 1989 to honor outstanding achievement by a health professional.

[Break] Are there any other general subjects then?

DR. SPENCER: Earl, the Maternal and Child Health began with your center in 1980 providing grants to pediatric rheumatology centers. I think this program lasted through 1987 or so. What contribution to pediatric rheumatology do you think these MCH grants provided?

DR. BREWER: Oh, it’s enormous. I think that they gave us enormous credibility for one thing with a constituency that we didn’t know existed: a pediatric chronic illness constituency, a public health community-based
service constituency. I am not ashamed to say that I had no idea it existed. They introduced me, and I hope that I helped introduce us to the idea of family-centered care, meaning that parents are in charge, and that we as physicians are advisors to them. And they not only must be informed, but they must be in the driver’s seat. They introduced me and us to truly how community-based services can help our children live fuller, more productive lives. The most obvious one is the school system. We learned that it’s not beneath the dignity of the pediatrician to help a chronically-ill child obtain a better quality of life by persuading the school to do some very minimal things to help life be better and more successful. And there are many other examples.

And then coordination of care: I’ve expressed it in many ways in the work I did. But I still like the idea that if anyone, and in particular a chronically-ill child with significant illness—I’m not talking about someone that has a little pain, but significant illness—requires 5 or 6 different kinds of services to make life productive, then someone has to be responsible to coordinate those services to make sure they work. And we learned that there are many ways to coordinate, and one way is the case manager. The Frambu experience in Norway where they gathered chronically-ill children together for a week in a camp setting, and they examined what they needed, and then they planned a program, and then they made it work. By intensely looking at something, they produced something very worthwhile. So these are some of the facets to which we were introduced.

The development of a new subspecialty care system: Pediatric departmental chairmen paid attention because they had a huge respect for the Bureau of Maternal and Child Health. And they know that they developed cardiology, they know they developed the cystic fibrosis group, the list is long. So when they said we have decided that you are an unmet need and worthy, you’ve progressed enough that we can bring you to the next level, it was great news. The Bureau never intends to take one on forever. They didn’t intend to support cardiology centers forever or cystic fibrosis or pediatric rheumatology centers. But they moved us to a level we didn’t have, and that was important. It not only didn’t bother me, I didn’t expect it to. I mean we had to swim. In one way or another, we haven’t swum so well, but we’re swimming.

Another major improvement was that I certainly would never have worked with Dr. C. Everett Koop. We would never have had the exposure that it gave us because I used pediatric rheumatology to develop family-centered, community-based coordinated care for special needs children. And we were putting in recognition and publicity and money into pediatric rheumatology to establish a point for chronic illness. One of those was that I met Senator Lloyd Bentsen, who was then chairman of the Senate Finance Committee, a
wonderful man, a highly-successful businessman. He was a financial conservative who had a great social conscience. He loved and felt a responsibility to people that didn’t have as much as he did. And he also was in charge of all the entitlement program legislation in the Congress. Dr. Marina Weiss was his health advisor. She was his personal assistant in health matters. Marina put family-centered, community-based coordinated care into every paragraph of the entitlement program, and they’ll be there as long as you and I are alive. That was huge. Many people were helped.

The last reason, or why I think it was important, is illustrated by what results we learned in Europe. Dr. Koop and Dr. Merle McPherson and Dr. Phyllis Magrab, head of the developmental center at Georgetown, and I went to Europe in May 1987. We went there to look at chronic illness systems and to get ideas about what other people were doing that we might use in our country. And one of the things we saw were the programs in England, or what they call Parents Helping Parents; it had a number of names. They had Chronic Illness Mother’s Day Out. Parents of children with significant disabilities and illnesses would trade off being sitters while one couple went out, and then they would do the other couple. And so when we returned, we put together a program, with Dawn Hafeli, of AJAO, and Dan Lovell. The application was made to the Bureau to establish this Parent Training Program to train parents about all this and helping each other and helping the children. And the AJAO had this program for a number of years, and I don’t know what happened later. But this was one of the best examples of how the Bureau of Maternal and Child Health directly helped our cause. And the instances are more; I just can’t remember of all of them.

DR. SPENCER: Earl, a couple of more questions, and we’ll be finished our interview today. I was wondering what you feel in your 50 years since you started in pediatric rheumatology, approximately 50 years, what is it that you’re particularly leaving behind as your legacy that you think is the most important part of your work?

DR. BREWER: Hmmm. I’ve always tried to remember, from the time I first became interested with Dr. Janeway and Dr. Blattner, that these children were not being treated properly, that trying to develop the infrastructure where these children can be helped and receive better care was critical. Integral to that is quality research and quality people caring for them and the quality of medicines and quality of services. So that would be what I would hope was my guiding premise. And there were many parts of it, and they weren’t really new versions. They were just part of the gestalt. Which one of those things I might have contributed the most, I don’t know. But I think my goal was to have the 10-year plans and move forward with a sensible approach to problems that we needed to solve. And know that we’ve
trained people who can continue to look at problems to solve and help the children and their families.

DR. SPENCER: Earl, would you do this all again? If you had a chance to go into medicine and be a pediatric rheumatologist, would this be your choice?

DR. BREWER: Yes. Absolutely. It’s been a great trip. I’ve learned enormous things. I’ve had the privilege of working with enormously talented people. I’ve been able to do wonderful things. I’ve traveled the world, I’ve seen the look of joy of kids doing better. So many come to mind. I think of one in particular: a girl named Wendy Escher. She came to us from the Newington Children’s Hospital in Connecticut. And Mark Markowitz and a young doctor, Larry Zemel. Wendy had such severe dermatomatisis as a teenager that she was in an iron lung. This was a long time ago. She couldn’t breathe. All the usual things had been done. But she was there. We had her in ICU for a long time. And the head of neurology would go by every day, and he’d say, “Pull the plug.” And Wendy, who could move her eyelashes only and could make words from the various things they can do with eyelids, said, after the neurologist did this, she said, “Don’t forget my specimen at five.” She was with us for I don’t know how long. It had to be 2 years or better. But one way or another, she got better, she walked out of the hospital, she went to college, she married, she has 3 children. She trained… I forgotten what, as a teacher, I think. And I get a letter from her every year.

DR. SPENCER: Earl, also there was a meeting of the pediatric rheumatology fellows just this week in Atlanta. I’m wondering if you were there in front of these pediatric rheumatology fellows, what would you advise them about in the future, for their career? Would you have any particular thoughts for them?

DR. BREWER: I think I would say to them, by way of advice, to those of you who are moving forward in your careers, the key to success: Be passionate about your cause. Your future is in your mind, and your future is now. The second thing I would share with you is from Mario Andretti, a famous American racecar driver and American philosopher: “If everything is under control, you’re not going fast enough.” And then the last thing, from tradition, Ralph Waldo Emerson said, “Every wall is a door.”

DR. SPENCER: One more question, Earl. If you looked into your crystal ball about the future of pediatric rheumatology, what do you see? What scientific developments do you think are around the bend? Are there any particular clinical advances that we might hope for? What is it that you think is awaiting us?

DR. BREWER: As far as I can see, the future’s bright. I think the problems are mainly our healthcare system is broken. But for pediatric
rheumatology and children, the framework, everything, I think it’s bright. One overriding reason to me is that I know—and you know—that there are children with painful joints and these various conditions. And there is a need for compassionate health professionals to take care of children with arthritis and chronic illness.

[End of Interview]
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CURRICULUM VITAE

Earl Johnson Brewer, Jr., MD, FAAP, MACR

DATE & PLACE OF BIRTH: July 3, 1928 - Fort Worth, Texas

EDUCATION:
Undergraduate: University of Texas, 1945-46
B.A. - Texas Christian University, 1948-50
Graduate: M.D., Baylor College of Medicine, 1950-54
Internship: Jefferson Davis Hospital, Baylor College of Medicine, 1954-55
Residency: Baylor College of Medicine, Assistant Resident in Pediatrics, 1955-56
The Children's Hospital Medical Center, Harvard Medical School, Senior Resident, 1956-57
Texas Children's Hospital, Baylor College of Medicine, Chief Resident, 1957-58

MILITARY SERVICE: U. S. Army, Technician Fourth Grade, AGD, 1946-48

LICENSURE: Texas - August 14, 1954
Utah - March 3, 1977

BOARD CERTIFICATION: American Board of Pediatrics - July 1, 1959

FELLOWSHIPS:
Rheumatology Section, American Academy of Pediatrics
Pediatric Rheumatology Section, American College of Rheumatology

PREVIOUS POSITIONS:
Head, Pediatric Rheumatology Section and Clinical Professor, Department of Pediatrics, Baylor College of Medicine, 1958-88
Chief, Rheumatology Center and Department, Texas Children's Hospital, 1958-88
Founder & Chairman, Pediatric Department, Kelsey-Seybold Clinic, 1962-83
Director, Regional Pediatric Rheumatology Center, DHHS Bureau of Maternal and Child Health, Texas Crippled Children's Services, 1982-88
Project Director, Coordinated Care Program, Kelsey-Seybold Foundation for Medical Research and Education, SPRANS Project, Bureau of Maternal and Child Health, Department of Health and Human Services, Washington, D.C., 1986-1990
ACADEMIC APPOINTMENTS:
Head, Rheumatology Section, Department of Pediatrics, and Clinical Professor of Pediatrics, Baylor College of Medicine, 1958-88

HOSPITAL APPOINTMENTS: (Now retired)
Staff, Texas Children's Hospital
Staff, St. Luke's Episcopal Hospital
Staff, Methodist Hospital
Staff, Ben Taub Hospital
Consulting Staff, Hermann Hospital
Consulting Staff, Shriner’s Hospital for Crippled Children

PROFESSIONAL ORGANIZATIONS:
American Pediatric Society
American College of Rheumatology, Master
American Academy of Pediatrics, Rheumatology Section
Texas Rheumatism Association
International Pediatric Rheumatology Club
Pediatric Rheumatology Collaborative Study Group
Council on Pediatric Rheumatology, American Rheumatism Association
Texas Pediatric Society
Houston Pediatric Society
Harris County Medical Society
Texas Medical Association
American Medical Association
Southern Society for Pediatric Research

SELECTED AWARDS AND HONORS:
Creation of the endowed annual “Earl Brewer Travel Grant Award” by the American of Pediatrics, Rheumatology Section, 2001
Master of Rheumatology Award, American College of Rheumatology, 1996.
Creation of the annual Earl Brewer Award by the Arthritis Foundation, American Juvenile Arthritis Organization, 1989, awarded to an outstanding pediatric rheumatologist or health professional.
Invited Lecturer, All Union Congress of Rheumatology, USSR, 60th Anniversary, December 7, 1988.
Elected as foreign member, All Union Congress of Rheumatology, USSR, on October 9, 1991
Arthritis Foundation Award of Appreciation, October 18, 1986
Certificate of Honorary Admiral in the Texas Navy, 1975
March of Dimes Service Award, 1965
Jesse H. and Mary Gibbs Jones Fellowship to Harvard Medical School, 1956-57.
SELECTED POSITIONS:
Chairman, JRA Criteria Subcommittee of the American Rheumatism Association, 1964-77
Board of Governors, Arthritis Foundation (national), 1965
President, Texas Rheumatism Association, 1968-70
President, Texas Gulf Coast Chapter, Arthritis Foundation, 1970-72
Chairman and Founder, Pediatric Rheumatology Collaborative Study Group, 1973-1992
National Institutes of Health Advisory Committee, Center for Cooperative Studies of Rheumatic Diseases, University of Utah Medical Center, 1975-81
Chairman, Governor's Conference on Arthritis, State of Texas, 1975-77
Consultant to the National Institutes of Health and principal investigator, USA-USSR Collaborative Study Groups, 1975-1992
Consultant to the Office of Orphan Products Development Grant Review Group, Food and Drug Administration, 1983-1992
President, Medical Staff, Texas Children's Hospital, 1977
Food and Drug Administration, Arthritis Advisory Committee, 1976-79
Chairman, FDA Subcommittee to Review Guidelines for Approval of Antirheumatic Drugs, 1978-79
Chairman and Founder, Department of Pediatrics, Kelsey-Seybold Clinic, 1962-83
Vice Chairman of the Executive Board, Kelsey-Seybold Clinic, 1979-80
Chairman and Founder, Council on Pediatric Rheumatology/American Rheumatism Association, 1979-80, Member 1975-81
Reviewer, Arthritis and Rheumatism, Pediatrics, Journal of Pediatrics, and Journal of Rheumatology
Principal Investigator, National Institutes of Health, USA-USSR Cooperative Studies of Slower-Acting Anti-Rheumatic Drugs (Contract No. NIH-NO1-AM-0-2211), 1980-84
Member, Ad Hoc Committee on Arthritis Foundation Legislative Policies, 1981
Member, Government Affairs Committee of Arthritis Foundation, National Organization, 1982-85
Chairman and Founder, Rheumatology Section, American Academy of Pediatrics, 1981-83
Secretary, Council on Sections, American Academy of Pediatrics, 1981-82
Member, Committee on Drugs, American Academy of Pediatrics, 1981-83
Director, Regional Center for Children with Rheumatic and Related Musculoskeletal Diseases, Bureau of Maternal and Child Health, SPRANS Grant, Department of Health and Human Services, Washington, D.C., and Texas Crippled Children's Services, Texas Department of Health, 1981-87
Founder and Member, Executive Committee of American Juvenile Arthritis Organization, 1984-87
Principal Investigator, Food and Drug Administration Grant, Methotrexate in Severe Juvenile Rheumatoid Arthritis, September 1984-88
Member, American Pediatric Society, 1985-1992
Member, American Society for Clinical Pharmacology & Therapeutics, 1985-88
Member, Committee to Form American Pediatric Rheumatology Board, 1987-1991
Co-Chairman, Surgeon General's Conference, Family-Centered, Community-Based, Coordinated Care for Children with Special Health Care Needs: A Call to Action, Houston, Texas, June 14-17, 1987
Member, Honorary Medical Staff, Shriner’s Hospitals for Crippled Children, Houston Unit, Houston, Texas, 1989-present
Founder/ member of Board of Directors of Family To Family Network, 1988-present.
Coordinator, annual Lloyd Bentsen Award of the Kelsey-Foundation for Medical Research, Houston, Texas, 1987-1992.
Member, Advisory Board, Kelsey Research Foundation, 1990-Chair, CARRA Finance Committee, 2005-present.

CURRENT POSITION: Writer - fiction & nonfiction
October, 1990 to present
Nonfiction books -

Parenting a Child with Arthritis
Earl Brewer and Kathy Angel
RGA Publishing Group
Lowell House, Los Angeles, 1992

The Arthritis Source Book
Earl Brewer and Kathy Angel
RGA Publishing Group
Lowell House, Los Angeles, 1993
Paperback edition - February, 1994
Third edition – 2000
Chinese translation – 2005

Parenting a Child with Arthritis
Earl Brewer and Kathy Angel
RGA Publishing Group
Lowell House, Los Angeles,
Paperback Edition – October, 1995

Forest Club Golden Anniversary, A History: 1946-1996,
Forest Club History: Soaring Into The 21st Century. The last 10 Years. 1996-2006
Earl Brewer

History of Hidden Lake Farm-
1800s To 2008
Earl Brewer

Novels -
Novel 1 - The System
Earl Brewer
Novel 2 - Picking Up the Marbles
1stBooks Library, 1999

PUBLICATIONS:

Medical Books:


34. Rossen, RD, Brewer EJ, and Person DA: Soluble Immune Complexes in Sera of Patients with Juvenile Rheumatoid Arthritis (JRA). XIV International Congress of


55. Brewer EJ, Giannini EH, Rossen RD, Patten B, and Barkley E: Plasma Exchange Therapy of a Childhood Onset Dermatomyositis Patient. Arthritis and Rheumatism,


89. Wilking AP and Brewer EJ: Care of the Child with Juvenile Rheumatoid Arthritis (JRA). Hospital Medicine, 18:64A-64N, 1982.


168. Brewer EJ: Preface and Introduction, Pediatric Rheumatology - The Decade Since Park City I. Rheumatic Diseases Clinics of North America, Rheumatic Diseases of


179. Brewer EJ, Kuzmina N, and Giannini EH(Pediatric Rheumatology Collaborative Study Group): Auranofin (AF) in Juvenile Rheumatoid Arthritis (JRA) - Results of the USA-USSR Double-Blind Placebo (P) Controlled Trial. Arthritis and


echocardiography in juvenile rheumatoid arthritis [letter]. Journal of Rheumatology,

Brewer EJ Jr., Career Counseling For Teenagers With Arthritis. Bulletin On The
Rheumatic Diseases, 45:4-6, 1996.

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