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CANCER AND BIRTH DEFECTS SURVEILLANCE SYSTEM
FOR COMMUNITIES AROUND THE SAVANNAH RIVER SITE
(ANNUAL PROGRESS)

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SRRHIS TECHNICAL PROGRESS REPORT

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CANCER AND BIRTH DEFECTS SURVEILLANCE SYSTEM FOR COMMUNITIES
AROUND THE SAVANNAH RIVER SITE

Savannah River Region Health Information System (SRRHIS)

Technical Progress Report Year 03

BACKGROUND

The United States Department of Energy funded the above-referenced grant for a cancer and birth defects registry for an initial three year period, beginning April 30, 1991. The first three year period was completed as of April 29, 1994. While this "Technical Progress Report" is prepared principally to document the activities of year 03, it also summarizes accomplishments of the first two years in order to put into perspective the energy and progress of the program over the entire three year funding cycle.

The grant was made to the Medical University of South Carolina, which proposed to work collaboratively with the Emory University School of Public Health through a subcontract. The Emory unit already was distinguished through the continuing award of a grant from the National Cancer Institute for support of the SEER program, the official source of the Nation's cancer profile data.

The "Savannah River Region Health Information System" (SRRHIS) was created within the Department of Biometry and Epidemiology as the organizational vehicle for carrying out the aims of the grant. The first half of the grant period was to be taken with establishing the cancer registry for the counties adjacent to and downstream from the Savannah River Site. In the latter part of the grant period attention would be given to designing the birth defects registry. Operationally, the Medical University of South Carolina would oversee the entire project, collect data on the South Carolina side, and conduct the community outreach component for the entire area. The Emory University staff would be responsible for collecting the data on the Georgia side, and for assisting the entire project with quality control oversight and advice. The reference date for the cancer registry was chosen as January 1, 1991. From the beginning, it was determined that the project would be planned and conducted with the advice of a Steering Committee representing local residents, some lay and others professional.

ACCOMPLISHMENTS IN FIRST THREE YEARS

In **year 01**, April 30, 1991 through April 29, 1992, strong program foundations were laid to support a long term commitment by the Savannah River Region Health Information System (SRRHIS) to the residents of the Savannah River area:

- The Medical University of SC administration recognized the need for this public service/education program and provided the necessary support;
- The project was undertaken with the collaboration of the Emory University School of Public Health which directs a component of the NCI SEER program, the basis of the Nation's cancer profile;
- Approaches were made to agencies with considerable interest in the project, with the idea of complementing mutual programming. These included the SC

Department of Health and Environmental Control (DHEC), Radiation Studies Branch of the Centers for Disease Control (CDC), the public education unit of the Agency for Toxic Substances and Disease Registry (ATSDR), the Health Protection unit of Westinghouse Savannah River Corporation (WSRC), SC Hospital Association, and the SC Association of Pathologists;

- A Steering Committee of twelve persons was chosen so as to assure strong citizen participation from the geographic area associated with the project;
- Pains were taken to provide openness of all processes, from Steering Committee meetings to community meetings, to being available for the media, and especially to keeping environmentally-active groups informed. Newspapers and the electronic media were informed about the effort;
- A mailing list was begun and it has been maintained and enlarged to accommodate persons interested in being kept informed about the project; a pamphlet was prepared and mailed broadly throughout the SRRHIS area;
- Highly skilled and dedicated staff persons were identified, and sufficient space was provided to foster developing close working relationships among them.

These early policies and activities promoted continued success and timely progress in year 02:

- The cancer registry made dramatic progress in accessing and abstracting records in the SRRHIS area. All hospitals signed the agreement to permit access to their records. This process was eased considerably by a system of abstracting (developed by our programmer) which substitutes numbers for patient names, and from which no name could be reconstructed. Two hospitals in the SRRHIS area were reluctant to release personal names. However, the demonstration of the computer program, plus assurance from SRRHIS that the individual hospital personnel would be given a copy of our data file before taking it off site, convinced them to cooperate. The area records for 1991 are approximately 80 percent complete, and 1992 records abstracting was begun;
- The availability of consultation from SRRHIS to help improve existing hospital registries became a popular feature of the program. This service also benefited the registry in a technical way, because it provided the perfect opportunity to make much needed improvements in the quality of the cancer identification and cancer record data. This was an important service to the region overall, because the data from many of the existing hospital and associated registries is based on nonexistent or poor quality control techniques;
- The Charleston three-county area continued to pose problems even though great progress has been made. Success was evident in upgrading the quality of the existing private hospital registries and gaining access to one of the two federal hospitals; a problem continued to be with gaining commitment from the Veterans Administration Hospital, and the reluctance of one large private hospital to give records access, even with the assurance that the use of personal names would be avoided. The latter hospital authorities indicated a desire to cooperate (they did when the Tricounty registry first began in 1990), and they are expected do so again as soon as the State passes a cancer reporting law (this law is discussed later in the report). Indeed, such a law will assure as well the cooperation of the noted federal hospital. A state cancer registry was begun in South Carolina by the Department of

Health and Environmental Control, which, in collaboration with SRRHIS, expects to seek staff support from the Centers for Disease Control. The operation is planned to include only hospitals with registries, and there appears to be no organized quality control mechanism in prospect. As a consequence the quality of the data is not assured and must be considered to be poor. Reporting and hospital cooperation is not a problem for the primary SRRHIS area, and the Charleston area is included principally as a comparison region;

- Public meetings began in earnest in the second year. The first meeting was held in Beaufort on November 4, 1992. The next step taken was a planning meeting, namely a luncheon held on February 2 in cooperation with the hospital at Varnville, SC, at which guests were invited not only from Varnville but as well from Hampton, SC, Barnwell, SC, Waynesboro, GA, and Sylvania, GA. Plans were laid for future meetings at four different sites, and liaison persons from those sites were identified. Representatives of interested agencies also were invited to the luncheon,- i.e., DHEC, CDC, ATSDR, and RAC (Radiation Assessment Corporation);
- The first newsletter was composed and mailed to approximately 2,500 persons. The second one is under development. It will give more detail about the community meetings and deal more directly with public concerns as they are expressed at the public meetings, in letters, or via phone calls to SRRHIS;
- Further to understand the levels of awareness and knowledge, and the concerns of the SRRHIS community, a survey was taken to ascertain citizen perceptions of the effects of the SRS operations, past and present, on their health and that of their families. The survey was designed to be compatible with other professionally completed ones and was undertaken by the Survey Research Center of the Department of Biostatistics, Epidemiology, and Systems Science (DBESS) of MUSC;
- The computer mortality-mapping program developed by NCI was installed on our laptop computer for convenient demonstration to our interested publics, including the Steering Committee. The program is composed of cancer mortality statistics from 1953 to 1987 (all cancers), for the US overall (all states), SC overall (all counties), race, and gender. The figures are corrected to a standard US population and the mapping program ranks states and counties, using a color system, by whether their cancer rates are above or below that of the US. The software was given to us by the developer, William McKay, retired from NCI and living in the Bethesda area. He works with SRRHIS without compensation;
- Using the mapping program and associated data, a technical paper was prepared showing cancer mortality for major sites in SC and the US. The paper will be expanded to include trends and modified as appropriate to be published;
- The planning process for the birth defects registry was accelerated by the Principal Investigator (PI) and the Steering Committee following the Beaufort meeting in November. The citizens attending the Beaufort meeting projected a strong desire for an active birth defects monitoring effort, a desire already expressed by members of the Steering Committee. A passive approach, based on a summary of birth certificate data and linkage to national data bases such as the Medicaid one, was in effect in year 01. Soon after the Beaufort meeting, SRRHIS staff met with Dr. Roger Stevenson, Director of the Greenwood Genetic Center. Dr. Stevenson, a pediatrician-geneticist, is a salaried employee of the Center, which is a state-

supported birth defects counseling and referral site. In this role he won a CDC grant to form one part of a three-academic-site registry for spina bifida, a neural tube defect sometimes associated with high doses of radiation. He is interested in collaborating with SRRHIS in the construction of a birth defects registry, as are his genetics colleagues at MUSC and the University of SC School of Medicine in Columbia. Further, Dr. L. Edmonds, of the CDC registry around metropolitan Atlanta, is interested in working with SRRHIS to assure compatibility with his effort. A meeting in the Spring, as early as May 1, is planned in order to bring together these interested parties for assistance in determining the scope and organization of the SRRHIS undertaking. A consultant from Columbia University will be invited to be an observer and critic. After an all day meeting of the experts, a report is planned for the Steering Committee the evening of the same day;

- South Carolina still had no law requiring the reporting of cancer. A DHEC effort to develop a state-wide cancer registry will include a request for the SC Legislature to pass such a law. Indeed, we are told that a model law is being drawn up. It is important to emphasize that this effort by DHEC is a direct result of the success of the SRRHIS program; past efforts by DHEC to have the Legislature pass a law have failed. In a related move by the Legislature, a law passed in late 1992 provides that physician records are not available to anyone else but the patient or the patient's legal representative, without the written consent of the patient. We checked with our legal office (MUSC) and with that of the SC Hospital Association to ascertain the intent of the law. Our conclusion is that it does not apply to hospital records and was aimed primarily if not exclusively at preventing physicians from denying any medical records to patients owing them money;
- Relationships, which were cultivated from the beginning with interested agencies, matured and become very important in stimulating related activities, and in strengthening the SRRHIS program within the region, and within the nation. RAC, WSRC, DHEC, ATSDR and CDC were interested in both the registry results and in the community information side of the project. Care has been taken to coordinate our meetings with the liaison persons of these agencies. For example, we invited CDC Radiation Studies Branch representatives to our Steering Committee and community meetings. In turn, they made sure that we have the opportunity to be present at their dose reconstruction meetings and be able to pass out our literature. This is extremely helpful in assuring the public and their environmentally-active ' representatives that duplication is being avoided, that is, that each of the efforts complements the others and does not wastefully overlap its aims with those of any of the others;
- Presented a poster session on SRRHIS mapping and information program at the "1992 Joint Conference on Hazardous Waste Reduction," held in Greenville, SC.

Year 03 has been associated with continued progress in the amount and quality of cancer data collected, improved awareness and acceptance of SRRHIS work by the lay and professional communities, expanded community outreach activities, and a major effort in designing the birth defects registry.

Registry-related activities:

- This year has been especially critical in defining and stressing the issue of data quality and quality control, because of the emergence of two events: 1) the start of the South Carolina state cancer registry, and 2) the pooling of data from South Carolina and Georgia into one set of cases for SRRHIS. For reasons of staff limitations, the SC state registry (DHEC project) has had to forego comprehensive

quality control activities for the individual, hospital records. As a result there is concern that some of the data may be released too early. Further, members of the Steering Committee and other lay persons may wonder how DHEC can collect information so fast and so inexpensively, contrasted to the seemingly drawn-out SRRHIS effort. Fortunately, the Steering Committee has been well educated over the initial years about the data quality issue. They recognize that even with the comprehensive controls exerted by SRRHIS (like SEER), some errors are made. Without such controls, registry data are unusable for serious planning. To this end, a special program was put on for the members at their April 22, 1994 meeting to show in detail how errors are made, the extent of typical mistakes, and the result on data interpretation. They were then shown how our quality control procedures reduce such errors to an irreducible minimum. (The overheads shown at the meeting are included in the Appendix.) The Chairman asked that the staff undertake a special demonstration, before the next meeting, to illustrate the extent to which the staff quality control professionals on each side of the River agree or disagree with each other when undertaking quality checking independently for an identical set of the case charts. This quality issue is also a continuing emphasis in the community speeches and consultations, the point being that errors in finding a few less cancers than the true number, or a few more than the true number could result in beliefs and actions not warranted by the true case rate. It has to be recognized that the accumulation of accurate data takes extra time and money, but the evidence supports its worth. The pooling of data from South Carolina and Georgia provides a good example. (For a look at the data before and after duplicate removal across states, see "Major Emphases", page 12.) It is a strength of this program that quality control is maintained across the state line, and that the data can be pooled to reflect accurately the unduplicated case numbers in the entire region ;

- The use of pathology laboratories for the identification of cases missed from hospital records began after the completion of the 1991 data collection. The Roche Laboratory of Charleston handles pathology reports for a number of physicians in the SRRHIS area. Patients seen on an outpatient basis may not have their cancers diagnosed on inpatient charts. For this reason their cases would be missed except for the review of pathology reports. Similarly, SRRHIS resident cases have been identified in the records of major hospitals whose pathology laboratories are used by physicians on an outpatient basis. Also, inpatient records which are missed for whatever reason can be located after laboratory records confirm the case diagnosis. This process of quality control, to identify missed cases, is expensive, but without it data would be severely biased. Melanoma, for instance, would very likely be under reported as it tends to be found in the outpatient clinics. The Georgia staff routinely processes pathology laboratory reports on cancer as part of their statewide registry operation;
- Technical assistance to participating hospital registries continues to be both a service to the hospital administration and professional staff, and a mechanism for the assurance of data quality. Not a week went by but SRRHIS staff received calls seeking technical assistance in setting up the software or defining record endpoints;
- As noted in earlier reports, the primary stimulation for initiation of the DHEC state cancer registry in late 1993 was the success of SRRHIS in obtaining case data from hospitals on a voluntary basis. DHEC was able to find staff support moneys from the Women's Cancer program of CDC, emphasizing breast cancer frequency. As they began surveillance of breast cancer cases, they also asked for the voluntary submission of all cancer data. They have begun by asking hospitals which have

registries to send their data on diskettes. SRRHIS has agreed to provide them with state resident case data from its region, in return for which DHEC will supply SRRHIS with case data on residents of the SRRHIS region found in hospitals outside the region. The importance of this collaboration cannot be overemphasized. The DHEC hospital agreements permit them to collect data from hospitals in the Charleston area which have not cooperated with SRRHIS; this not only is expected to result in an improved comparison data set (i.e., the Tricounty region), but it will assist materially in identifying missed cases in the primary SRRHIS area along the Savannah River. Even with this improved picture, however, the Veterans Administration Hospital has not agreed to provide DHEC with the case data. A proposed law being prepared by DHEC for passage by the Legislature, if the state pathologists and hospitals agree to it, will solve the reporting problem. The question of achieving data quality will remain;

- A word should be said about the status of legislation on cancer reporting in South Carolina. The Cancer Program Committee of the South Carolina Department of Health and Environmental Control has been seeking the support of pathologists and hospital administrators for the passage of a cancer reporting law. Passage of a law will assist the hospitals in providing a further legal basis for the release of personal patient information. Nonetheless, as is amply shown in Georgia, the passage of a law is still only the beginning of a complicated and costly program of quality case identification. Georgia, for instance, already has such a law, and the Emory University staff is responsible for conduct of the current program of data collection under the law. Yet funds to support collecting the data statewide are not made available by the legislature; as a result the cases reported, except for those of SRRHIS and SEER, lack adequate quality control. SRRHIS and SEER cases are different because the staff to oversee quality are available through grants from the Department of Energy and the National Cancer Institute respectively;
- The birth defects registry was designed and the grant proposal sent to the US Department of Energy in August 1993. It was a carefully crafted project, linking SRRHIS (the Medical University of South Carolina and Emory University) with the distinguished staff of the birth defects section of the Centers for Disease Control; and it was undertaken and completed with the strongest support of the Steering Committee and the South Carolina Energy Research Foundation. Unfortunately, the proposal has not been funded and its future is uncertain. The data would be, along with the cancer registry data, the major sources of health outcome information for helping interpret the SRS dose-reconstruction findings of CDC expected within the next three to four years;

Outreach/Community activities:

- Public outreach activities have been vigorously pursued in this year. Indeed, there was a record number of community meetings, and a variety of presentation modes. From the end of March 1993 to the end of March 1994, just over 500 persons attended meetings at which Dr. Dunbar presented the program and aims of SRRHIS. Of these residents, 324 attended South Carolina meetings, and 180 Georgia ones. The places include not only the larger cities such as Augusta, Savannah, and Beaufort, but also smaller cities such as Blackville, Statesboro, Ridgeland, and Waynesboro. The Blackville meeting was especially interesting because it was carefully put together by Ms. Ford, a member of the Steering Committee, to represent blacks and whites equally, and the leadership of the community. There were 50 plus persons at the meeting and lively discussion. The local paper mistook some of the ideas and a follow-up letter was written by Dr. Dunbar not only to the newspaper, but letters were written to the individuals

attending the meeting. (A copy of the newspaper article and Dr. Dunbar's letters are attached to the Appendix.) Attendance at all the community meetings varied from 12 to 102. Because the speaker was invited to these meetings, it is of interest to note that downstream residents seem to be the most often interested. Groups at Beaufort, Hilton Head, and Bluffton, for example, invited Dr. Dunbar on four separate occasions. Two Savannah businesses (paper manufacturers) invited us on two occasions to present the aims and findings of the program. What is most interesting are the places which have not sought information, namely, Aiken and Augusta. This is true despite our efforts to stimulate interest. In between places like Statesboro, Ridgeland, and Waynesboro have been very interested but more relaxed than some of the residents of Hilton Head, for instance. In other words, the clinical impression is that downstream residents tend to be more expressive of their concerns than those nearer the Site. Expert consultation is being sought to try to understand this observation;

- Professional outreach activities began this year. Poster presentations were made at the meeting of the Society for Risk Analysis in Savannah, Georgia December 1993; and at the Symposium on Health Research and Needs to Ensure Environmental Justice, held February 1994 in Arlington, Virginia. A research paper about the unique methods and value of SRRHIS was delivered by Dr. Daniel Lackland, the Co-Director, at the 1994 Annual Conference of the American Association of Central Cancer Registries, April 28, 1994. The abstracts and poster panels associated with these presentations are included in the Appendix;
- The beginning of 1994 marked the sixth edition of the SRRHIS Newsletter, Volume 3, No. 1. At the present time over 3,500 copies of the quarterly newsletter are mailed to area residents. Copies of the last four editions are in the Appendix. They include guest articles about cancer registries at other places; ways to use registry data; articles on individual hospitals which participate in the SRRHIS program; and related local news of community interest. We have not enjoyed a large return of letters to the editor, but comments from residents at community meetings tend to support broad acceptance of the newsletter;
- The survey of awareness, knowledge, and concerns of SRS area residents about environmental hazards was completed in 1993. Approximately 800 residents were interviewed with equal numbers living within 50 miles of SRS; within 100 but more than 50 miles; and more than 150 miles. The method used was a validated questionnaire with random digit dialing. The project was designed and completed by Dr. Daniel Lackland, Co-Director of the SRRHIS program, with the assistance of graduate students in The Department of Biometry and Epidemiology (DBE). Its costs were not paid by the SRRHIS grant but rather by another departmental source. However, the results are relevant to SRRHIS. As would be expected, the concern about chemicals, radiation, and other potential hazards is greatest in areas closest to SRS, and least the farther away the areas are. One interesting though not surprising finding is that knowledge of the SRRHIS program is closely related to distance; about 8 percent of those 150 miles away say they have heard of it, compared to 28 percent of those within 50 miles. What is surprising is the large percentage who say they have heard of the cancer registry. Another survey planned for the next year will seek to probe whether they really have knowledge of the program, or whether they may have misunderstood the question. As noted earlier, copies of the poster slides are in Appendix D;
- During year 03, the SRRHIS staff developed a presentation about the registry and cancer impacts especially targeted toward health education classes and community

health fairs. Community presentations were made at the Second Annual Hampton County Health and Fitness Festival and the Colleton Regional Hospital Health Fair. College student presentations included the Public Health Administration class at the Citadel, the junior class in Health Information Administration at the Medical University of South Carolina (MUSC), Introductory Epidemiology and Advanced Epidemiology classes at MUSC, and a graduate College of Nursing Class at Francis Marion University. Seminar speeches were given to the Environmental Hazards Assessment Program and the Department of Biometry and Epidemiology at MUSC. A talk also was given at the Coastal Region meeting of the South Carolina Health Information Management Association. A complete list of Educational Outreach Activities is included in the Appendix.

- The SRRHIS staff conceived and organized the first tumor registrar training program ever held on the East coast. The program was designed with the assistance of the University of California San Francisco, Cancer Patient Data Program, and in collaboration with the South Carolina Central Cancer Registry of the Department of Health and Environmental Control. It was held in Charleston on January 8-12, 1994, presenting current procedures in computerized cancer data systems for both hospital and population-based registries. There were forty-nine participants from eight states and the District of Columbia. Although SRRHIS designed and oversaw the program completion, no funds were provided to the training program. Indeed, it was self-supporting from the payments by participants. It was ranked quite high by the attendees. A brochure and the program evaluation report are included in the Appendix;
- The Steering Committee had an eventful year. The first election of officers after more than a year in existence took place at the January 1994 meeting (see list of Steering Committee members in Appendix). This followed the successful completion of the By-Laws during the prior year (copy of By-Laws in Appendix). With the completion of the 1991 cancer data collection, the refinement of the case data to remove duplicates and assure quality, and the completion of the agreement to exchange case information by the state health departments, the Committee is now ready to discuss the complicated issues concerning the release of the information to the public. It also took note of the general lack of success in attracting additional community residents to the meeting, even though the Committee meetings are held in the evening, and they are advertised in the local media beforehand. It seems fair to say, however, that the Committee has identified a firm role for itself after the early years of becoming educated to the many issues of data collection, privacy matters, and pitfalls in interpretation and release of information. New members have been brought in to help spread the knowledge about the project, and to try to maintain balance among the factors of geography, race, lay-professional representation, and gender;
- The computer-based county and state mortality mapping program has continued to be popular. It was demonstrated at community fairs, as well as at meetings with private groups. The executives at Union Camp and Stone Paper Products, for example, asked for and received copies of the diskette which has been organized in a very user-friendly format. Similarly, teachers, environmentalists, and others at community meetings have been given copies. It appears to be well accepted as a first-pass reassurance that no major health (i.e., mortality) related trends are discernible in the Savannah River region over the 1953-1987 period. Mr. McKay, the developer of the program, visited SRRHIS in April 1994. One of our graduate students is working with him to update the program with the specific needs of SRRHIS in mind. Additional years of mortality data will be incorporated; further,

the ability to treat the SRRHIS counties as a unit is being built in; and special attention is being given to using the information in a geographic information system;

- The technical report on cancer mortality in South Carolina, prepared from the mortality-mapping program, has been widely distributed and accepted. With the help of two graduate students a similar report is being developed for Georgia, and another on cancer mortality trends for both states jointly;
- The program has continued its policy of broad and active linkages to avoid duplication of effort, to disseminate information, and to make known resources which may be needed by others. We are included in the DHEC application to CDC for a grant to upgrade the state registry. The SRRHIS role is to provide data to DHEC not only to prevent duplication of effort, but to provide peer cooperation and mutual support. This has made the hospitals happy, and it lessens the cost to the state for a statewide registry because the SRRHIS portion already is established. Colleagues at CDC (Radiation Studies Branch and the Genetic Diseases and Birth Defects Branch) and ATSDR are kept informed by personal calls, letters, and newsletters. We are cooperating with a newly emerging group of population-based registries called the Southeastern Cancer Registry Network. Its aim is to increase the power of the region's cancer profile to inform and to serve as the basis for evaluating prevention and care programs in the region compared to other locales. At the American Association of Central Cancer Registries meeting in Niagara-on-the-Lake, Canada in April 1994, SRRHIS called a meeting of the eight state (the DOE Health Agreement group of states) representatives present and knowledgeable about the cancer registries in their respective states. The discussion included Dr. John Young, President of AACCR and Director of the California Cancer Registry, and Dr. Dee West, Director of the Bay Area Cancer Registry, and was aimed at determining whether there would be interest in working to pool cancer case data from areas adjacent to nuclear production plants in their regions. The participants were generally enthusiastic, recognizing that considerable work will be needed to achieve a level of quality necessary to permit merging of data from the different registries. The proposed meeting was noted beforehand to Dr. Bonnie Richter, the DOE staff person responsible for the State Health Agreement Program. A brief report is being prepared for her about the meeting itself;

In all the above-noted accomplishments related to registry activities and to technical activities, linkages, and planning, both Emory University and the Medical University of South Carolina participated equally. Community activities and overall administrative functions, however, are the responsibility of the Medical University of South Carolina alone. A special technical report of the Emory University progress in this period is included in the Appendix.

PROGRESS IN YEAR THREE

The paragraphs in the Accomplishments section above summarize the major achievements of the initial three year grant period, with the last part dealing with special activities of the third year. This section will summarize this progress for year 03 and describe the administrative services and changes underpinning the multifaceted effort.

Registry-related activities

Of the fifteen major accomplishments noted for year 03, six were related to progress in implementing the technical registry side of the program. Three of the six sets of activity

were related to the critical issue of assembling data of the highest quality, a most difficult undertaking. This issue, of course, cannot be overemphasized because the public tends to be impatient for data so they can go on to other problems. One of the key points for public consumption at community meetings is that they should be patient. The point was stressed by Dr. Dee West to our Steering Committee members, and he repeated it in the article he wrote for the latest newsletter. The Director of SRRHIS never tires of saying it. Good, believable data is like good wine; it takes effort and time. Part of the complication is the difficulty of achieving access from health professionals to personal records, especially the first time. The pathologists were reluctant, but once they began to see how the data were being used, and how their cooperation was a *sine qua non* of our success (and therefore the success of the public in obtaining desirable knowledge), their cooperation was assured. Technical assistance to the hospital registries also is a quality control issue; namely, the improvement in the hospital registrar's ability to deliver quality data routinely. Finally, the initiation of the South Carolina registry by the Department of Health and Environmental Control, prompted by the success of SRRHIS, is enormously important to the SRRHIS program because it will help us identify cases that could be missed otherwise. In summary, the move toward improved support of registry operations is important to the region, and it can be traced directly to the early and continuing successes of SRRHIS, and the attendant growth in respect for data collection and reporting. The sixth item regarding registries was that calling attention to the birth defects registry proposal. If this proposal is funded it will be attended by even more enthusiastic public and professional acceptance, and in a shorter time period because data will be collected from prior years, not just in the future. As a result, a five year data base could be available within two years.

Outreach/Community activities

The remaining nine accomplishments referred to various kinds of community outreach characterizing and defining the public/community perception of the activity. A large number of SRRHIS area residents attended speeches given by the Director and other staff members, read articles in their papers about the project, read mail from SRRHIS, read our newsletter, attended our Steering Committee meetings, and answered questions about their perceptions of environmental hazard effects. Professional scientists and lay persons reviewed posters about the risk perception survey of the SRRHIS area set up at meetings in Savannah, Georgia and Arlington, Virginia. Of equal importance to outreach and to the reputation of SRRHIS, its staff designed and completed a most successful training conference for tumor registrars from eight Eastern states, a first for this region.

The Director may be forgiven for bragging on the faculty and staff for an unusually productive first three years.

Administration and operations

Sometimes the administrative services so necessary to progress are so unassuming as to seem invisible. Actually the administrative support has been extensive, and it has been effective. Some of it is documented here.

Personnel

The personnel have not changed. This is a credit to the program which has called for a great deal of work from its employees, sometimes under conditions of stress. They have shown unusual dedication to the good of the program and understand the imperative to serve the residents of this region. One faculty member will be lost to the project if the birth defects project is not supported, i.e., Dr. Yuko Palesch.

Computer Equipment and Programming

The collection and management of registry data proceeded well. As we had originally planned, CanSur/Net, a database system developed by the American College of Surgeons for hospital cancer case data collection and management, has been used since year 01, while we are developing a large scale cancer information system specifically for the SRRHIS operation. CanSur/Net is a PC-based system which makes it ideal for using laptop computers to collect data from hospitals in remote areas. Currently the master copy of the database is maintained on a Zenith 486SX. Regularly scheduled file backup and the storage of multiple physical copies ensure the security of data and continuous smooth operation. As mentioned above, file conversion programs have been developed so that for those hospitals with computerized patient data management systems, relevant data can be directly extracted and then converted into CanSur/Net. This eliminates both the laborious work involved in manual abstraction and the possible sources of data entry error.

Our database system received major attention. CanSur/Net, while it serves our current needs reasonably well, was designed primarily for the use of individual hospitals rather than a central registry for a large geographic region. Our two years of operation using CanSur/Net has revealed significant shortcomings in it and helped us gaining valuable experience in terms of what are the "desired properties" in our new SRRHIS database system. Dr. Z. Zhang is responsible for overseeing the developmental work of the database. We are currently in the process of defining the relation table and developing a prototype database system. This should be completed by the end of year 02. It is expected that in the beginning of year 03 we will be testing the new database system by having it operating in parallel with the CanSur/Net database. The 4GL database will be fully operational by the end of year 03.

The programmers at MUSC and Emory joined to produce the first set of cancer data pooled from two different states (except for SEER), and with duplicates removed and quality control measures taken equally across the case data sets. This was for the 1991 data. This was one small step for SRRHIS, and hopefully, it will presage more such steps for the nation's registries.

Operations

By utilizing both electronic data submission from SRRHIS hospitals with cancer registries and case abstraction by a field staff representative, SRRHIS has attained a 90% level of completion for participating facilities' 1991 data. In addition to the system of casefinding and abstraction, both prospective and retrospective quality assurance activities are taking place. To maintain accurate abstracting, with correct application of coding rules and correct data entry, visual edits and computerized edit checks are being performed. To identify problem areas in the data collection phase at hospitals with and without tumor registries, "field" reabstracting audits and "field" quality control studies on reportability have begun. The SRRHIS registry also has the capability to register each case only once by a sophisticated computerized duplication removal system that assists the quality control editor to recognize cases similar in predetermined data items. If duplication has occurred, individual reports are combined to reflect only one incidence of cancer. To further assure complete case ascertainment, the SRRHIS data base will be directly compared to registered deaths in Georgia and South Carolina.

The primary hindrance to timely data submission to the SRRHIS cancer registry continued to be the lack of a cancer reporting law for the state of South Carolina. The status of the law was discussed under accomplishments.

Steering Committee

The Steering Committee has been meeting quarterly in cities within the SRRHIS area, since its first meeting in Aiken, SC on February 12, 1992. Ten meetings were held as of the end of April 1994. The early meetings were given to organizing the Committee, educating it about what a registry is, and trying to build trust. The Chairman was elected at the second meeting and two subcommittees were named at the following one. Next we began talking of community meetings. A risk communicator from Rutgers, Caron Chess, came to the October 1992 meeting to help both the Committee and the staff understand the benefits and the pitfalls of public communication efforts. Since that time the Committee has written up By-Laws, elected officers for the second time, and heard presentations from CDC on birth defects registration, Dr. Dee West about the need for patience and the drama inherent in data trends, and took pains to address the issue of quality control standards. Discussion of the form and substance for dissemination of the first cancer case data for 1991 has begun, with a report due the Committee by June 15, 1994. Minutes of these meetings have all been forwarded to the DOE office, and so only the meeting agendas are included in the Appendix.

Major Emphases

There were four major emphases in the first two years: consolidation of our relationships with the area hospitals so as to keep them carefully informed and pleased as far as possible with our work; formulating the public education/outreach side of the SRRHIS program and activating it; strengthening our networking with associated and interested agencies; moving our planning from a passive to an active birth defects registry.

In year 03 we continued these emphases, but gave special attention to data accuracy and quality control, and to the development of the birth defects registry, an activity which resulted in a supplement to the renewal application. In addition, we completed a report of the SRRHIS area awareness/knowledge survey, and technical reports on mortality in the area, and incidence data published separately. We anticipate publishing related articles in the state medical journal as well. Our computer programming for the hospitals, each a separate problem, was implemented as far as possible given local conditions. Further, the tumor registrars training conference was implemented with high regards from participants.

To maintain our data at the SEER level of quality is expensive but, as shown in the following two tables, the extra care is critical. The tables show 1991 cancer incidence in the South Carolina counties of SRRHIS. Table 1 shows the number of SC residents cases found by adding the SC-identified cases to GA-identified cases of SC residents. This is the usual way cancer data is exchanged among states, because no personal identifying information is conveyed with the incidence data, making the removal of duplicate cases impossible. With this methodology 1,643 cancers were found in 1991 for South Carolinians living in the SRRHIS region of the state. Fortunately, we have been able to exchange identifying information after the two health departments signed an agreement for us. Table 2 shows the result when the duplicate cancer cases are removed from the pooled data set for SC residents; 1,512 cases or 131 less than the crude total. This is an almost ten percent difference, but the differences between individual cancer frequencies can be even more misleading. Using the crude data one would find an extra case of leukemia in Aiken County; but look at the dramatic difference in lung cancer in the Beaufort residents, an almost 25 percent difference. In summary, quality really counts.

Table 1

Number of Cancer Cases for Selected Sites in SRRHIS Counties of South Carolina

County	Breast	Cervical	Colorectal	Prostate	Lung	Leukemia	Esophageal	All Sites
AIKEN	85	12	63	69	80	8	5	493
ALLENDALE	7	1	6	8	4	0	0	42
BAMBERG	9	1	8	10	3	0	2	48
BARNWELL	6	0	11	12	9	1	1	55
BEAUFORT	63	4	56	64	68	8	9	445
COLLETON	21	4	15	13	19	2	2	109
EDGEFIELD	2	3	11	3	8	0	1	40
HAMPTON	9	4	6	11	11	1	1	67
JASPER	3	3	7	3	13	1	2	45
ORANGEBURG	51	4	45	58	33	1	7	299
TOTAL	256	36	228	251	248	22	30	1643

Query Mode: Ascertained in SC/GA, duplicates unresolvedYear of Diagnosis: 1991

PRELIMINARY DATA ONLY, NOT FOR CIRCULATION.

Table 2

Number of Cancer Cases for Selected Sites in SRRHIS Counties of South Carolina

County	Breast	Cervical	Colorectal	Prostate	Lung	Leukemia	Esophageal	All Sites
AIKEN	84	11	61	68	76	7	4	474
ALLENDALE	7	1	4	8	4	0	0	39
BAMBERG	9	1	8	10	2	0	2	44
BARNWELL	6	0	10	12	9	1	1	54
BEAUFORT	56	4	48	61	55	7	6	385
COLLETON	19	3	11	13	15	2	2	95
EDGEFIELD	2	3	8	3	8	0	1	37
HAMPTON	7	3	5	10	9	1	1	56
JASPER	3	3	7	3	10	1	2	40
ORANGEBURG	50	4	44	57	32	1	7	288
TOTAL	243	33	206	245	220	20	26	1512

Query Mode: Ascertained in SC/GA, duplicates resolvedYear of Diagnosis: 1991

PRELIMINARY DATA ONLY, NOT FOR CIRCULATION.

Our tumor registrars visited every hospital in the SRRHIS area during the 03 year, finishing 1991 and 1992 data, and providing assistance to the medical records personnel in improving the quality of their records keeping and computerization. Further, quality control checks began in three of the hospitals. The need for improvements became evident immediately as these checks were made. Care is taken to discuss our findings in a way which encourages improvement as a positive outcome ("what you might like to do" rather than "what you are doing wrong"). As a consequence, we believe our relations with the hospitals are good and improving as we work more and more with them. Articles in local papers and possible feed-back from their patients who have heard of the registry also seem to have helped in promoting their cooperation. These activities will be continued in future years.

Year 03 was a banner year for public education/outreach. Not only did we expand our public meetings, but we sent out a larger number of newsletters, and completed the survey of public perceptions of the health effects associated living near the SRS. As was noted in the summary for year 02, the first public meeting was held in Beaufort, SC on November 4, 1992, and a luncheon was held in Varnville, SC on February 2, 1993 for about 20 residents of the general area within 30 miles or so; persons came from Georgia (Waynesboro, Sylvania) and from SC (Varnville, Barnwell, Hampton). As noted in the accomplishments, the last year, from March 1993 through March 1994, more than 500 persons attended meetings at which the Director spoke. The survey of knowledge and awareness indicated that the message was getting across because almost 30 percent of residents within 50 miles of SRS claimed to have heard of SRRHIS.

Our first newsletter, sent in year 02, was well received. Approximately 2,500 copies were mailed out, and calls were received from several news reporters. Most letters were complimentary, but one person questioned the lack of information in the newsletter about earlier studies in the area (such as the Jablon report and some worker studies). He was informed that later editions indeed will feature some of these data, particularly as we learn more about the interests of our constituents, such as he. The sixth copy of the newsletter was mailed to 3,500 residents in January 1994. It appears to be well accepted.

A survey of the knowledge, awareness of SRS, and associated attitudes, was undertaken in the summer of 1993 (costs were borne from another source). A copy of the questions was included in an earlier report. Poster prints about the survey are included in this report (Appendix D). Surveys will continue to be undertaken by the Survey Research Center of DBE (Dr. Lackland, Director) periodically, perhaps even annually if necessary to ascertain on a continuing basis the effectiveness of regional public educational activities, associated not only with SRRHIS outreach, but with that of CDC (RAC), and WSRC.

The early part of year 03 was taken with an intense planning effort for the birth defects registry, involving SRRHIS-MUSC, the Greenwood Genetic Clinic (earlier noted), and the Medical School of the University of SC, in consultation with CDC and with selected national experts. The activity was coordinated closely with the Steering Committee. This was especially important because the birth defects registry is of highest priority to Committee members and to area residents (as expressed in community meetings), and to the South Carolina Energy Research Foundation.

SRRHIS Office Space

Dr. David Hoel, the newly arrived Chair of the Department of Biometry and Epidemiology, is a well known scientist administrator and established environmental risk assessor. He understands well the benefits of the registry and has given high priority to

supporting the SRRHIS program. To this end, in March 1994, he assigned SRRHIS to newly renovated quarters of very comfortable size, and configured so as to promote the easy integration of the faculty and staff, a benefit not available in the first two years when the registrars were housed separately.

EVALUATION OF YEAR 03 ACTIVITIES

Nearly all of the Year 03 planned activities were completed with 100% satisfaction. The completion of the proposed activities as designated and planned complemented the achievements of Years 01 and 02 for the three year goal to establish a state-of-the-art health information system with a focus on geographic cancer surveillance. Several activities were completed in a noteworthy manner.

Objective 1: Data quality is a major emphasis of SRRHIS. Quality control reports were not only produced, but utilized in the modification of case ascertainment and data management. A major accomplishment involved the incorporation of standard quality control measures and edits for cases exchanged between Georgia and South Carolina.

Representatives from Emory University and the Northern California Cancer Registry reviewed the operations of cancer registration.

Protocols for incorporation of death certificate and pathology reports were developed and implemented.

Objective 2: In addition to numerous community meetings, SRRHIS data results were presented at several national and regional scientific meetings including:

- two presentations at the Society for Risk Analysis;
- presentation at Environmental Justice meeting;
- presentation at Student Research Day;
- presentation at American Association of Central Cancer Registries.

SRRHIS was also presented as part of television, radio and newspaper stories on cancer.

Objective 3: SRRHIS results were used to assess, quantify and report the considerations regarding the data exchange across geo-political lines. The protocols developed constitute a significant contribution to cancer registries across the country and should be used as a national model. These methods were presented at the American Association of Central Cancer Registries meeting.

Objective 4: The SRRHIS data management system has been modified through Year 03 into a state-of-the-art computer cancer database. SRRHIS is a regularly used advisor to other databases and registries such as the American College of Surgeons.

Objective 5: SRRHIS data is being used in several major cancer projects including:

- an assessment of breast cancer in South Carolina and Georgia;
- an assessment of childhood leukemia;
- the effects of cancer rates on risk perception;
- the re-definition of geo-political areas with regards to cancer rates.

Preliminary results from these studies have been presented at national and regional meetings. Abstracts have been published and manuscripts are in preparation.

Objective 6: SRRHIS is a key advisor to the state cancer registry in South Carolina. In January a regional workshop was held for tumor registrars under the direction of SRRHIS.

Objective 7: The SRRHIS newsletter is a well read document with wide distribution. Data from SRRHIS is recognized by:

- American Association of Central Cancer Registries;
- Central Brain Tumor Registry of the United States;
- Hanford Health Information Network Resource Center.

The SRRHIS Steering Committee has been very functional with regular meetings and has been recognized as a unique attribute for a central cancer registry.

SRRHIS has active representation on the South Carolina Cancer Advisory Board, American Association of Central Cancer Registries, National Tumor Registrars Association, and South Carolina Tumor Registrar's Association.

Objective 8: SRRHIS has established a collaborative relationship with the cancer registries with DOE sites in the catchment area. In addition collaborative arrangements have been made with Emory University, North Carolina Central Cancer Registry, Central Brain Tumor Registry of the United States, National Cancer Data Base, as well as the Cancer Registry of Germany.

Objective 9: SRRHIS data was used in an epidemiologic assessment of childhood leukemia and on epidemiologic methodology study of data quality and assessment across geo-political boundaries.

Three Ph.D. graduate students will be using SRRHIS data for their dissertation work on:

- Breast cancer screening;
- Risk Perception;
- Chemo-prevention of cancer.

Objective 10: One Ph.D. Graduate student was supported with SRRHIS funds Years 01 through 03. The SRRHIS cancer registry operations were incorporated into the curriculum of the Advanced Epidemiology class. A national/regional workshop on cancer registry operations was held in conjunction with SRRHIS for tumor registrars.

**CANCER AND BIRTH DEFECTS SURVEILLANCE SYSTEM FOR COMMUNITIES
AROUND THE SAVANNAH RIVER SITE**

Technical Progress Report Year 03

APPENDICES

APPENDIX A

Presentation to the Steering Committee on the
Quality Control Process
April 21, 1994

Savannah River Region
Health Information System

SRRHIS

QUALITY

CONTROL

2 MAJOR TYPES OF QC

1. FIELD QC

2. OFFICE QC

FIELD QC

1. CASEFINDING STUDY

2. REABSTRACTING STUDY

Quality Control

1. Reabstracting

- A. What is it ?
- B. Definitions of Major & Minor Errors
- C. Matrix with resolved problems

2. Casefinding

- A. What is it ?
- B. What sites ?
- C. Matrix with results
- D. Future study

REABSTRACTING

- 1. A computer generated list of 20 randomly selected cases for all SRRHIS hospitals is produced by the data processing department.**
- 2. All 20 cases are copied in the office and placed in a sealed envelope. These are given to the QC reviewer.**
- 3. QC person in conjunction with the hospital selects a convenient day for the study and the QC person abstracts 10 cases focusing on the major fields.**
- 4. At the end of the day, the QC person compares the two abstracts (the one turned into the office by the hospital that has been copied and the one just abstracted).**
- 5 Any discrepancies are cleared up then, if possible.**
- 6. The major and minor discrepancies are noted on a matrix form.**
- 7. Reports are shared with the tumor registrars and the editor. Major unresolvable problems are discussed with Dr. Liff.**

SRRHIS FIELD QUALITY REVIEW MATRIX HOSPITAL _____ DATE: _____ PAGE: _____ OF: _____

TIME PERIOD OF ORIGINAL ABSTRACTING: _____ REABTRACTOR: _____ KEY: Ma MAJOR/Mi MINOR

[illegible]

Major/Minor Definitions
for
Evaluating Reabstracting/Recoding Differences

<u>FIELD</u>	<u>MAJOR</u>	<u>MINOR</u>
Reporting Sources	Any difference between coding "autopsy only" or "death certificate only" and "hospital", "clinic", "private lab", "private practitioner" or "nursing home" is considered major.	Any difference between "hospital", "clinic", "private lab", "private practitioner" or "nursing home" is considered minor.
Birthdate	Any difference greater than one year is considered major	Any difference of one year or less is considered minor.
County	Any difference between blank (or uncoded) and known county.	Any difference within proper coding scheme.
Race	Any difference is considered major.	NA
Sex	Any difference is considered major	NA
Date Dx	Any difference resulting in a different calendar year or any difference of more than one month is considered major. Any unknown date of diagnosis vs a known date is considered major.	Any date of diagnosis in the same calendar year, but a difference of one month is considered minor.
Seq. No.	Any difference is considered major.	NA

Site	Any difference in the first two digits of the ICDO code is considered major.	Any difference only in the 3rd digit is considered minor.
Laterality	NA	Any difference is considered minor.
Histology	Any difference in the first three digits of the ICDO code is considered major, with the exception of lymphomas.	Any difference in only the fourth digit is considered minor, with the exception of lymphomas.
	Any difference in behavior code is considered major.	Any difference in grade code is considered minor.
Dx Conf.	Any difference in coding "direct visualization", "radiography", "clinical" or "unknown" and coding "positive histology", "positive cytology" or "positive microscopic confirmation" is considered major.	Any difference in coding "positive histology", "positive cytology" and "positive microscopic confirmation, nos" is considered minor. Any difference in coding "direct visualization", "radiography", "clinical" and "unknown" is considered minor.
Gen EOD	Any difference is considered major.	NA

SRRHS FIELD QUALITY REVIEW MATRIX HOSPITAL DATE: 10/27/98 PAGE: 1 OF: 1

TIME PERIOD OF ORIGINAL ABSTRACTING: 1991 REABTRACTOR: KEY: Ma MAJOR/Mi MINOR

VARIABLE	CASE#	CASE#	CASE#	CASE#	CASE#	CASE#	CASE#	CASE#	CASE#	CASE#	TOTAL	
	2080923 Ma Mi	2080691 Ma Mi	2079058 Ma Mi	2079997 Ma Mi	2079515 Ma Mi	2080427 Ma Mi	2079138 Ma Mi	2084774 Ma Mi	2073102 Ma Mi	20 Ma Mi	Ma	Mi
REP SOURCE											0	0
BIRTHDATE											0	0
COUNTY	1	1	1	1	1	1	1	1	1	1	10	0
RACE											0	0
SEX											0	0
DATE OF DX											0	0
SEQ. NO.											0	0
SITE											0	0
LATERALITY											0	0
HISTOLOGY											1	1
DX CONFIRM											0	0
GEN EOD											0	0
TOTAL	1	0	1	0	1	0	1	0	1	0	11	1

SRRHS FIELD QUALITY REVIEW MATRIX HOSPITAL DATE: 8/18/00 PAGE: 1 OF: 1

TIME PERIOD OF ORIGINAL ABSTRACTING: 1991 REABTRACTOR: KEY: Ma MAJOR/Mi MINOR

VARIABLE	CASE#		CASE#		CASE#		CASE#		CASE#		CASE#		CASE#		CASE#		CASE#		TOTAL	
	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi
REP SOURCE																			0	0
BIRTHDATE																			0	0
COUNTY																			0	0
RACE																			0	0
SEX																			0	0
DATE OF DX																			0	1
SEQ. NO.																			0	0
SITE																			1	0
LATERALITY																			0	1
HISTOLOGY	1					1		1		1									4	0
DX CONFIRM																			0	0
GEN EOD	1								1										2	0
TOTAL	2	0	0	0	0	0	1	0	2	1	2	0	0	1	0	0	0	0	7	2

SRRHS FIELD QUALITY REVIEW MATRIX

DATE 12/93 PAGE 1 OF 1

TIME PERIOD OF ORIGINAL ABSTRACTING 1991

REABTRACTOR: BLR KEY: Ma MAJOR/Mi MINOR

VARIABLE	HOSPITAL		HOSPITAL		HOSPITAL		HOSPITAL		HOSPITAL		HOSPITAL		HOSPITAL		HOSPITAL		TOTAL		AVERAGE	
	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi	Ma	Mi
REP SOURCE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
BIRTHDATE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
COUNTY	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	1	0
RACE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	.01	0
SEX	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	.31	0
DATE OF DX	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	.02	.02
SEQ. NO	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
SITE	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	.02	.11
LATERALITY	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	.03	.03
HISTOLOGY	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	.01	.10
DX CONFIRM	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	.01	.01
GEN EOD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5	0	.17	0
TOTAL	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	15	0	.45	.28

CASEFINDING

1. A computer generated alphabetical list is made of all cases submitted by the hospital or that we have abstracted.
2. Two randomly selected months (one from each 6 month period) are reviewed from the disease index for three major sites for the year being reviewed.
3. All patients with these codes are compared with alpha computer list to insure that the case was abstracted. If the name is not on the list, it is followed back to make sure that it should not have been included. Reasons that it may not appear on the alpha list include:
 - a. *The patient lived out of the area at diagnosis.*
 - b. *The patient was diagnosed prior to 1991.*
 - c. *The patient has a non-reportable cancer (ie, skin, ca.).*
4. Two months of all pathology reports are reviewed (March & December). Every pathology report is checked for malignancy and then compared with the alphabetical computer list. The discrepancies are reviewed and handled as above.
5. Problems encountered in these studies include:
 - a. *No accessible disease index.*
 - b. *Pathology reports are "on line" and no computer is available.*

1991 CASEFINDING STUDY JANUARY & AUGUST

PANCREAS (157.0 - 157.9, 230.9)

LUNG (162.2 - 162.9, 231.2)

LEUKEMIA (204.0 - 208.9)

SRRHIS FIELD QUALITY REVIEW MATRIX

DATE: _____ PAGE: _____ OF: _____

TIME PERIOD OF ORIGINAL CASEFINDING

QC REVEIWER.

KEY: C COMPLETE R REGISTRAR

[illegible]

COMPARIBILITY OF SC & GA FIELD EDITING

1. Common Procedures Manual

2. Reabstracting

- a. Same number of cases per hospital
- b. Same classification of major and minor errors (SEER)
- c. Same reporting form

3. Casefinding

- a. Same months reviewed (pathology and disease index)
- b. Same cancer sites (disease index)
- c. Same reporting form

1992 CASEFINDING STUDY

APRIL & SEPTEMBER

BRAIN (191.0 - 191.9, 198.3)

BREAST (174.0 - 174.9, 198.81)

LYMPHOMAS (200.0 - 202.88)

APPENDIX B

List of Community Meetings

**SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
COMMUNITY MEETINGS**

<u>Location</u>	<u>Place</u>	<u>Date</u>	<u>Number</u>
Beaufort, SC	Univ. of SC-Beaufort Campus	11/4/92	25
Varnville, SC	Hampton General Hospital	02/02/93	31
Augusta, GA	Holiday Inn-I-20 West	03/31/93	5
Hilton Head, SC	Hilton Head Men's Club	07/12/93	36
Orangeburg, SC	Chestnut Grille Restaurant (Orangeburg Regional Hospital)	07/20/93	12
Ridgeland, SC	Ridgeland Rotary Club	07/27/93	38
Beaufort, SC	Friends of Carolina Hospice	09/21/93	22
Beaufort, SC	Sea Island Rotary Club	10/05/93	68
Beaufort, SC	Beaufort Kiwanis Club	11/04/93	27
Sylvania, GA	Sylvania Rotary Club	11/11/93	45
Savannah, GA	Missionary Baptist Church	12/14/93	12
Savannah, GA	Stone Container Corporation	01/14/94	9
Bluffton, SC	Bluffton Rotary Club	01/19/94	45
Blackville, SC	Blackville Civic Club	02/07/94	19
Blackville, SC	Blackville Civic Club	03/07/94	51
Statesboro, GA	Statesboro Kiwanis Club	03/23/94	102
Savannah, GA	Union Camp	03/23/94	9
Waynesboro, GA	Rural Life Center	04/22/94	3

APPENDIX C

Barnwell Newspaper Article
and
Dr. Dunbar's Letters in Response

Study shows cancer rate is not higher here

Birth defect registry is now forming

Sharon Taylor

Assistant Editor

There are no more cases of cancer in people living near the Savannah River Site than cases of cancer across the nation, according to Dr. John Dunbar, director of the Savannah River Region Health Information System.

Dr. Dunbar, a professor of Epidemiology at the Medical University of South Carolina, was the featured speaker at the Blackville Civic Club Monday night.

Fifty residents attended the public meeting at Macedonia Baptist Church to hear the findings of Dr. Dunbar on cancer and birth defects of people around nuclear plants.

Dr. Dunbar and his staff began gathering data since 1990 from 25 counties in Georgia and South Carolina. The counties are situated along the Savannah River and near the Savannah River Site nuclear facility.

He works through a grant from the Department of Energy and assistance from Emory University.

In addition, John Till, who works for the Centers of Disease Control in Atlanta, Ga., has been examining records of radioactive releases from SRS.

"These releases were kept secret from the public for many years," said Dr. Dunbar. "Till is examining about 40,000 boxes of paperwork from the plant dated from 1954, and creating information about the escapes."

PARTICIPANT REPORTING AREAS:

State Counties

Georgia	Bryan
	Bulloch
	Burke
	Chatham
	Columbia
	Effingham
	Evans
	Franklin
	Jefferson
	Madison
	McClintock
	Richmond
	Screven
	Wayne
	Albany
	Alcorn
	Alford
	Alcona
	Alcona
	Alcona
	Alcona
	Alcona
	Alcona
	Alcona
	Alcona
South Carolina	Aiken
	Allendale
	Bamberg
	Barrow
	Beaufort
	Berkeley
	Charleston
	Colleton
	Dorchester
	Edgefield
	Hampton
	Jasper
	Orangeburg

This reporting area will provide population-based information for all counties within 50 miles of the Savannah River Site as well as those downstream to Beaufort and Savannah. In addition, selected more distant counties will serve as comparison areas.

cer deaths between 1950 and 1985," said Dr. Dunbar. "Three counties of the same size and same economic climate were compared with non-nuclear counties and with the overall U.S. for 16 types of cancer."

Dr. Dunbar said as a whole, cancer rates are going up, but the study found no significant increase in rates of cancer near nuclear facilities.

The most prominent types of cancer locally and nationwide for men are lung, prostate, colon/rectal cancer.

For women the most prominent types are lung, breast and cervical cancer.

Statistics show Barnwell County had a greater number of melanoma and esophagus cancers than other counties in the state.

"It would be impossible to isolate the actual causes of these cancers since they could be related to sun exposure and other radiation exposures," said Dr. Dunbar.

He told the audience smoking would also be an important factor and heredity plays a part as to

whether a person would be prone to cancer.

Dr. Dunbar emphasized the fact that most cancers are treatable and he stressed prevention through early detection.

The birth defects registry will work like the cancer registry and will get underway in early April.

Dr. Dunbar and his team of scientists will track pregnancies back in the 1950's and attempt to find medical records on the children born during this period and what has happened to them health-wise since that time.

In the future, Dr. Dunbar would like to offer health and environmental seminars to Barnwell County that would include blood pressure checks and education on choosing health careers.

Mildred Ford and Anne Nevils, residents of Blackville, are on the steering committee of the SRRHIS. For more regarding the Savannah River Region Health Information System (SRRHIS) registry, write to Dr. Dunbar at MUSC, 171 Ashley Ave., Charleston, SC 29425-2503. Telephone: (803) 792-4081.

Continued from Page 1A

Dr. Dunbar said radiation exposures can come through water, dust, livestock, sediment around rivers and streams, in the water and in the fish.

"The way we trace a radioactive release is to go back to weather records and see which way the wind was blowing at the time of the release," he said. "Then we find who was living down-wind and look at the health and death records of these residents."

Dr. Dunbar said statistics on birth defects and cancer deaths are gathered in this way.

"We anticipate 5,500 cases of cancer annually in this area," said Dr. Dunbar. "This is no higher than the amount of cancer anywhere else in the country."

Dr. Dunbar said cases of cancer for the cancer registry are found from autopsy reports, hospital discharges, labs, outpatient clinics and death certificates.

Forty-one hospitals in 25 counties participated in the study. From South Carolina, 13 counties were studied and from Georgia, 12 counties.

"The Cancer Institute conducted a nationwide study of 900,000 can-

Savannah River Region
Health Information System

March 14, 1994

Editor
The People Sentinel
PO Box 1317
Lexington, SC 29072

Dear Sir/Mde:

Thank you for the article about the cancer and birth defects registries of SRRHIS (Savannah River Region Health Information System) on page 1 of your March 9, 1994 edition. It was based on a presentation I made to the Blackville Civic Club two days earlier, and it was nicely put together. However, I may have inadvertently given some wrong impressions about what our project is doing, and would like to correct these by summarizing its major aspects:

- SRRHIS is a collaborative project of the Medical University of SC and Emory University, funded by the Department of Energy, to set up cancer and birth defects registries for the SRS area and counties downstream. We began collecting information about **new cases of cancer** on January 1, 1991 and will begin to collect data on **new birth defects cases** in the summer or fall of this year. Contrary to the article, we are not tracking "pregnancies back in the 1950's". However, we expect to identify birth defects beginning as early as 1989, something we are unable to do with cancer cases.
- We have collected area cancer cases for the year 1991 and are well into having them for 1992. We are not ready to report our findings until we have all the cases carefully checked in our quality control process. Further, we want to have at least 3 years worth of data before we talk about the occurrence of individual cancers and cancer rates in individual counties.
- SRRHIS is not a temporary study. It is collecting registry data and expects to do so for many years. Only then can the citizens of the area have sure knowledge of the frequency of all cancers and of any single cancers (and birth defects).
- Dr. John Till, Radiation Assessment Corporation of Neeses, SC, and the Centers for Disease Control and Prevention (CDC) are responsible for the dose-reconstruction project, not my group. SRRHIS is responsible principally for the registries.
- Registries produce "health outcome" data, such as cancer and birth defects cases, which will be valuable to the CDC when Dr. Till completes the dose-reconstruction project for the SRS region several years from now. The dose-reconstruction project will estimate doses of radiation to individuals who may have been in the path of any substantial releases, if any are found from the survey of records and of individuals with knowledge of releases. After that, information on exposures can be compared with health outcome data to see whether there is a measurable relationship between exposures and the occurrence of cancers or birth defects (at least for the years in which we will have the data).
- If the occurrence of cancers in the 25 SRRHIS counties is at the same rate as in the Nation overall, then we would expect 5,500 cancers a year. We have not completed our first year summation (1991) but, based on the numbers already collected in the first year, we do not expect the total to exceed this number. However, it is important to remember that we want to analyse the occurrence of individual cancers, and frequencies in single counties over time. We cannot do that until we have collected data for 3 or more years.

- I spoke of cancer mortality data and wanted to demonstrate a computer-driven program about death rates from individual cancers in the US, SC, and SRS counties for the period, 1953-1987. But time did not permit. I did summarize a cancer mortality study done by the National Cancer Institute (published in 1990), however, in which it was shown that overall cancer death rates in the neighborhood of all US nuclear production plants, taken as a whole, seemed similar to those more distant. That conclusion was based on a compilation and analysis of approximately 900,000 cancer deaths.
- The voluntary cooperation of all the SRS area hospitals makes the entire project possible. In your area we are especially grateful to those of Aiken, Bamberg, and Barnwell.

My "take home" message for the citizens of Barnwell County and elsewhere around SRS was twofold: (1) there are two activities important to the area's environmental health, namely, the dose reconstruction project, and the SRRHIS registries project; and (2) these projects complement one another as noted above. It must be remembered too that these studies cannot answer all questions about area environmental hazards. They are a good start, however, and both project staffs seek to work with the area residents to decide, in partnership with them, what else may be desirable.

Many thanks for the front page exposure. We look forward to working closely with the citizens there, and stand ready to speak and to provide demonstrations of the cancer mortality mapping program to any groups. They can just call us at (803) 792-4081. I was very impressed with the the audience that night of March 7, and wish to thank them for their interest.

Sincerely yours,

John B. Dunbar, DrPH
Director

March 14, 1994

TO: Audience members, Blackville Civic Club, March 7
FROM: Dr. John Dunbar
SUBJECT: Major points of my presentation

Thank you taking time to hear my presentation last Monday night. Everyone was attentive and I enjoyed the group more than any other I have spoken to. I am writing this note to let you know we are putting your name on our mailing list for the Newsletter, if it is not already there. Further, I want to take this occasion to emphasize the main points of my presentation:

- SRRHIS is a collaborative project of the Medical University of SC and Emory University, funded by the Department of Energy, to set up cancer and birth defects registries for the SRS area and counties downstream. We began collecting information about **new cases of cancer** on January 1, 1991 and will begin to collect data on **new birth defects cases** in the summer or fall of this year. We expect to identify birth defects beginning as early as 1989, something we are unable to do with cancer cases.
- We have collected area cancer cases for the year 1991 and are well into having them for 1992. We are not ready to report our findings until we have all the cases carefully checked in our quality control process. Further, we will want to have at least 3 years worth of data before we talk about the occurrence of individual cancers and cancer rates in individual counties.
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- Dr. John Till, Radiation Assessment Corporation of Neeses, SC, and the Centers for Disease Control and Prevention (CDC) are responsible for the dose-reconstruction project, not my group. SRRHIS is responsible principally for the registries.
- Registries produce "health outcome" data, such as cancer and birth defects cases, which will be valuable to the CDC when Dr. Till completes the dose-reconstruction project for the SRS region several years from now. The dose-reconstruction project will estimate doses of radiation to individuals who may have been in the path of any substantial releases, if any are found from the survey of records and of individuals with knowledge of releases. After that, information on exposures can be compared with health outcome data (from our SRRHIS registries) to see whether there is a measurable relationship between exposures and the occurrence of cancers or birth defects (at least for the years in which we will have the data).
- If the occurrence of cancers in the 25 SRRHIS counties is at the same rate as in the Nation overall, then we would expect 5,500 cancers a year. We have not completed our first year summation (1991) but, based on the numbers already collected in the first year, we do not expect the total to exceed this number. However, don't forget that we want to analyse the occurrence of individual cancers, and frequencies in single counties over time. We cannot do that until we have collected data for 3 or more years.
- I spoke of cancer mortality data and wanted to demonstrate a computer-driven program about death rates from individual cancers in the US, SC, and SRS counties for the period, 1953-1987. But time did not permit. I did summarize a cancer mortality study done by the National Cancer Institute (published in 1990), however, in which it was shown that

overall cancer death rates in the neighborhood of all US nuclear production plants, taken as a whole, seemed similar to those more distant. That conclusion was based on a compilation and analysis of approximately 900,000 cancer deaths.

- The voluntary cooperation of all the SRS area hospitals makes the entire project possible. In your area we are especially grateful to those of Aiken, Bamberg, and Barnwell.

My "take home" message for the citizens of Barnwell County and elsewhere around SRS was twofold: (1) there are two activities important to the area's environmental health, namely, the dose reconstruction project, and the SRRHIS registries project; and (2) these projects complement one another as noted above. It must be remembered too that these studies cannot answer all questions about area environmental hazards. Nonetheless, they are a good start, and both project staffs seek to work with the area residents to decide, in partnership with them, what other studies may be desirable.

Many thanks for your interest. We look forward to working closely with you and the other citizens there, and stand ready to speak and to provide demonstrations of the cancer mortality mapping program to any groups. We can be reached at (803) 792-4081.

John B. Dunbar, DrPH
Director

APPENDIX D

Professional Outreach Activities

*conf papers
cycled separately.
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APPENDIX E

Educational Outreach Activities

**SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
HEALTH EDUCATION CLASSES AND HEALTH FAIRS**

<u>Location</u>	<u>Organization</u>	<u>Date</u>	<u>Number</u>
Charleston, SC	DHEC/Hollings Cancer Center	7/92	5
Charleston, SC	CANSUR/NET	3/93	10
Charleston, Sc	Sigma Xi Society	3/93	25
Hampton, SC	Hampton County Health and Fitness Festival	4/93	30-35
Walterboro, SC	Colleton Regional Hospital Health Fair	5/93	20-30
Charleston, SC	Introductory Epidemiology Course - Medical University of SC	9/93	20
Charleston, SC	Dept. of Biometry and Epidemiology Graduate Student Seminar	9/93	40
Charleston, SC	The Citadel-Public Health Administration Class	11/93	20
Charleston, SC	Medical University of SC Health Information Class	2/16/94	19
Charleston, SC	Environmental Hazards Assessment Program Seminar	2/94	25
Hampton, SC	Hampton County Health and Fitness Festival	4/94	30-35
Charleston, SC	College of Health Professionals Course	4/94	35
Florence, SC	Francis Marion University College of Nursing-Graduate School Class	4/94	10

Charleston, SC	Coastal Region-SC Health Information Management Assoc.	4/15/94	35
Walterboro, SC	Colleton Regional Hospital Health Fair	5/94	25-30

APPENDIX F

SRRHIS Newsletters in Grant Year 03

SRRHIS Newsletter

PUBLISHED BY THE SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
MEDICAL UNIVERSITY OF SOUTH CAROLINA

Vol. 2, No. 2

July 1993

From the Editor's Desk:

Many thanks to all who returned the postcards. The comments and suggestions were appreciated. We will continue to do our best to keep the newsletter interesting and informative.

In this issue, Colleton Regional Hospital, Walterboro, SC, is featured in the **Hospital Showcase** column. This continuing column will showcase each of the participating hospitals in the SRRHIS Project.

Comments, suggestions and questions are always welcome.

Have a safe summer.

SRRHIS REPORT

by John B. Dunbar, D.M.D., Dr.P.H.

In the last newsletter I talked about SRRHIS efforts being made to inform the residents around the SRS area about our registries program. One of the forums in which we have tried to meet residents is the community meeting. These meetings were posted in local newspapers, and notification letters were sent to several hundred residents prior to the meetings. After having three such meetings (Beaufort, Savannah, Augusta), it became clear that this is not a forum of choice. Even though the meetings were held in the evenings, after 7:00 pm, few residents participated. At the Augusta community meeting this past March, we were able to discuss the issue with several residents, and

Dr. John Dunbar

with representatives of one health department and an environmentally active organization. Later we brought the matter up for further discussion with our Steering Committee. The consensus of the Augusta participants and of our Committee members was that other ways should be tried.

We already were holding occasional meetings at local hospitals with guests invited by phone and letter. Further, we were beginning to indicate our availability as speakers for any groups, such as civic clubs, schools, and societies. At my request Mr. Brian Costner of the South Carolina Energy Research Foundation outlined his thoughts about these and other ways in a letter to me dated April 14, 1993. The Steering Committee and I believe his letter states the idea very well, and we have accepted it as our guideline. I am reprinting it here for you:

"With this letter, I'm putting in writing some of the ideas we've discussed regarding public communication and the SRRHIS registry. I've attempted to suggest a direction you might pursue rather than a detailed plan for changing your approach. Please don't hesitate to call me with any questions. Feel free to distribute this letter to the SRRHIS Steering Committee and other interested persons.

The registry is a process for data collection which won't even be in a position to report meaningful numbers for a few years. When there are results to report - and particularly if those results suggest a need for additional research - the public communication and involvement tasks will be greater. For now, perhaps the goal of a public communication program should simply be to let people know that a registry is being established and to explain some of its benefits and limitations.

There are several opportunities for talking about the registry to citizens in the Savannah River region. Up to now, the SRRHIS

approach has been to host meetings focused solely on the registry. This is important when and if people in an area express a concern about the registry, but may not be the most effective way to introduce the registry to people unfamiliar with it. The recent public meeting in Augusta and feedback from the meeting in Hampton demonstrate this.

Presentations on SRRHIS should be offered when they're wanted and should be available to a wide range of groups throughout the region. There are several ways to accomplish this. For example, you might work with hospitals and cancer treatment centers to arrange small, informal meetings with a more targeted audience. Such a meeting might be similar to the one held in Hampton. Also, you might contact organizations that have regular meetings such as the Sierra and Rotary clubs and other environmental and civic groups.

Perhaps you could get 20-30 minutes on the agenda at several of these meetings. Finally, having brochures and, when possible, staff at meetings hosted by others on Savannah River Site (SRS) issues could continue and even be expanded. These last two approaches have the benefit that SRRHIS staff don't have to create the forum and attract the audience."

To accommodate the idea expressed by Mr. Costner we are planning day meetings hosted by our hospitals in many of the communities. Furthermore, we are trying to let it be known broadly that we are available to speak about the registries, and about issues associated with them. Please call or write if you have need for a registry information program/speaker. Also let your friends know.

Dr. John Dunbar is a professor of epidemiology at MUSC and principal investigator for the SRRHIS project.

THE NATIONAL CANCER INSTITUTE'S SEER PROGRAM

By Jonathan M. Liff, Ph.D.

The primary source of information about cancer incidence and cancer patient survival in the United States is the Surveillance, Epidemiology and End Results (SEER) program of the National Cancer Institute. The establishment of this program followed from a mandate of the National Cancer Act of 1971 that data useful in the prevention, diagnosis and treatment of cancer be collected, analyzed and disseminated.

The SEER Program collects cancer data on a routine basis from specific population-based cancer registries in various parts of the country, representing about ten percent of the U.S. population. The Program has operated continuously since 1973, and it contains information about more than 1.8 million cancer diagnoses through the 1991 diagnosis year. About 120,000 new cases are accessioned each year.

Dr. Jonathan Liff

Areas selected for participation in the SEER Program were chosen primarily for their ability to carry out the functions of a population-based cancer registry, and because of their "epidemiologically significant" population subgroups. There are nine primary registry areas that comprised the SEER program, through 1991. Five are entire states (Connecticut, Iowa, New Mexico, Utah and Hawaii) and four are metropolitan regions (Atlanta, Detroit, San Francisco-Oakland and Seattle). Additional special populations included in the SEER program are ten predominantly rural counties in Georgia, and Native American residents of Arizona. In 1992, Los Angeles County and counties around San Jose were added to the Program. Several other areas of the U.S. participated at one time, but are no longer part of the SEER Program.

The goals of the SEER Program are to:

- report estimates of cancer incidence and mortality trends in the U.S.,
- identify cancer patterns in population subgroups, and changes in these patterns,
- provide population-based information on extent of disease at diagnosis, cancer treatment, and patient survival, and
- promote the study of factors that can be modified to decrease cancer risk or improve outcome, such as environmental, or other can-

cer risk factors; early detection (including cancer screening) and treatment; and determinants of patient survival and quality of life.

The data collection activities of the SEER program are carried out by independent registries in each of the defined areas, under contractual agreements with the NCI. For example, the Metropolitan Atlanta and Rural Georgia SEER Registry is operated by the Georgia Center for Cancer Statistics in the Epidemiology Division of the Emory University School of Public Health, the same organization that operates the Georgia component of SRRHIS. Each contractor has developed working relationships with hospitals, free-standing pathology laboratories, and radiation treatment facilities in their area, to obtain information about virtually all new cancer diagnoses among residents of the geographic area covered. Death certificates are also reviewed to assure that patients who die from cancer have been identified. Demographic information is collected on all of the identified patients, along with information about tumor characteristics, methods of diagnosis, and first course of cancer treatment. In addition, follow-up data is obtained on all patients so that the survival experience of cancer patients in the general population can be determined.

Each year the information (excluding any data identifying individual patients, physicians or hospitals) is compiled and sent to the National Cancer Institute, where it is merged with information from the other registries. This data is analyzed by NCI staff, and summarized in an annual publication, The Cancer Statistics Review (see reference, below). Information is also provided to the American Cancer Society, and is the basis for many of the cancer incidence estimates that they prepare each year.

The SEER Cancer Registry is a unique and important resource because:

- It is population-based, that is, all new diagnoses within a fixed population are identified, not just diagnoses from specific hospitals. Through the use of census data, rates can also be calculated. These rates can be specific for demographic group (age, race, sex and marital status), adjusted for these factors, as needed.
- Data is uniform. Each registry is required to conform to identical rules regarding data collection and coding and as well as case eligibility, as a condition for continued participation and funding.
- The quality is very high. Quality control activities are performed at each registry, and an outside contractor performs additional evaluation of each registry.
- As indicated above, the populations included

in the SEER Program are somewhat representative of the diversity in the United States.

The NCI SEER Program is considered to be a model for population-based cancer registration throughout the world. This resource is not inexpensive, but it allows for high quality estimation of the cancer experience in the United States.

Reference: Portions of this text were taken from: Miller BA, Ries LAG, Hankey BF, Kosary CL, Edwards BK (eds.). Cancer Statistics Review, 1973-1989, National Cancer Institute. NIH Pub. No. 92-2789, 1992.

Dr. Liff is Associate Professor of Epidemiology and Director of the Georgia Center for Cancer Statistics of the Emory University School of Public Health, which operates the Atlanta Metropolitan and Rural Georgia SEER Program, and the Georgia Component of SRRHIS.

MAKING DATA WORK FOR PATIENT CARE: THE NATIONAL CANCER DATA BASE (NCDB)

by Herman R. Menck, M.B.A.

The goals and purposes of the NCDB are relevant to cancer control concerns within the population that SRRHIS serves. The major purposes of the NCDB are as follows:

1. Provide a scientific resource suitable for comprehensively assessing cancer patient care on a local, regional and national level and disseminating such information to the medical community.

Mr. Herman Menck

2. Enhance ongoing cancer programs among Commission on Cancer approved and other cooperating hospitals.
3. The NCDB is intended to result in improvement in the process by which cancer patient care and research advances are transferred to physi-

APRIL STEERING COMMITTEE MEETING REPORT

by Janis S. Koenig, M.Ed.

The April 22, 1993 meeting of the Savannah River Region Health Information System Steering Committee was held in Augusta, Georgia.

The meeting began at 7:00 pm with a discussion of previous Committee business, the reading of the minutes followed by reports from the Membership, By-Laws and Legislative Subcommittee Chairpersons.

The Committee unanimously passed a motion to replace three members who were unable to actively participate. The three nominees were: Dr. Frank Rumph, Augusta, Georgia; Dr. William Irby, Statesboro, Georgia; and Ms. Anne M. Nevils, Blackville, South Carolina. Mr. Rea

Community Meetings

As noted in Dr. Dunbar's report, the format for community meetings has been changed (Paragraph 2, page 1). Community luncheons have been scheduled for Hilton Head, Orangeburg, Ridgeland and Walterboro during July.

will contact each by letter to request their participation on the Steering Committee.

The guest speaker, Dr. David Erickson, Chief of the Birth Defects and Genetic Disease Branch of the Centers for Disease Control and Prevention, presented information about the different types of birth registries and called special attention to the commitment required to start and maintain an active birth defects registry. Dr. Erickson stated that an active registry is the most expensive and complex, but the most rewarding for quality and completeness of cases. At the conclusion of his presentation, he stated his strong support of SRRHIS' intent to develop a birth defects registry, particularly one being planned to be compatible with the CDC-supported one in Atlanta. A motion was unanimously passed to approve the SRRHIS staff's application to DOE for support to develop this component registry and to model it after the CDC project.

The next Steering Committee meeting will be held at the Holiday Inn (U.S. Highway 21 at Lovejoy Street) in Beaufort, South Carolina on Thursday, July 15, 1993, 7:00 to 9:00 p.m.

THE SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM (SRRHIS) STEERING COMMITTEE MEMBERS

Mr. Andrew Rea
Chairman
Savannah, GA

Ms. Alva Driggers Varnville, SC Ms. Brenda Nickerson Columbia, SC

Ms. Mildred Ford Blackville, SC Dr. Bonnie Richter Washington, DC

Dr. Curtis Hames Claxton, GA Dr. Frank Rumph Augusta, GA

Mr. Tom Hendrix North Augusta, SC Dr. Jon Trueblood Augusta, GA

Dr. William Irby Statesboro, GA Dr. Lisa Wagner Statesboro, GA

Ms. Anne M. Nevils Blackville, SC

EDITOR: Janis S. Koenig
PRODUCTION EDITOR: Margery Swanson

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cians' practice, to enhance quality assurance, and to enhance quality of life and survival of cancer patients.

The NCDB is a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society. The NCDB has just completed its fourth year of operation.

What are the products of the NCDB? The basic products of the NCDB include an Annual Review of Patient Care, journal articles on cancer care, Pattern of Care and Data Edit Reports for participating hospitals and Pattern of Care Reports for states. These reports are primarily aimed at the hospital cancer committee and physicians within the hospital setting. In addition, educational programs have been targeted toward cancer registrars.

Recent examples of the use of NCDB (hospital cancer registry) data for national assessment of patient care are; 1) geographic comparisons of the relative frequency of partial mastectomies vs. modified radical mastectomies by U.S. Census region and state, 2) analysis of time trends in the comprehensiveness of AJCC staging within the U.S., and 3) comparisons of stage of disease and treatment patterns between different ethnic and income groups.

Another product of the NCDB has been the co-development with the National Tumor Registrar's Association of a Quality Improvement Workshop. Forty workshops have been offered in 30 states and the District of Columbia to date. Over 1000 registrars have attended. Another educational effort by the Commission on Cancer has been a 1993 abstracting study in the form of a Patient Care Evaluation study. Over 1500 registrars participated in this self assessment abstracting exercise.

Because of the national scope of the NCDB, its data can potentially serve as a benchmark or comparison standard for defined population centers. For example, stage of disease and treatment patterns within different subareas of the SRRHIS could be compared to each other and to national patterns.

In response to the first NCDB Call for Data (1985-1988), 637 hospitals submitted data. The second Call for Data (1985-1990) elicited 837 responses, including 400,000 1990 case reports.

For information regarding NCDB Reports please contact: NCDB, American College of Surgeons, 55 East Erie Street, Chicago, Illinois 60611, 312-664-4050.

Mr. Menck has been active in cancer registration for over 20 years specializing in computerization and statistical uses of the data, and is Manager for Clinical Information of the Cancer Department of the American College of Surgeons.

COLLETON REGIONAL HOSPITAL

by John Sirigos, M.H.S.A.

Colleton Regional Hospital, located in Walterboro, Colleton County, is a 131 bed acute care facility owned and operated by HealthTrust, Inc. that serves several counties with a service area population in excess of 50,000.

In 1983, HealthTrust (then HCA) opened this new facility that boasted some of the most sophisticated equipment and procedures in the county's history. Starting then, Colleton Regional Hospital's most sincere pursuit for progress in the technology and services that define and provide quality care actually began.

Today, the pursuit continues and its progress since 1983 alone has been astounding. Today, even newer and better technology, more advanced procedures and more professionals are enhancing the lives of patients from Colleton, Hampton, Dorchester, Jasper and Allendale counties. The services typically found in acute care settings are readily available at Colleton Regional Hospital and include anesthesia, cardiopulmonary, radiology (CAT scanning, also), patient and staff education, lab, OR, ER, pharmacy, and nursing care which is so widely known for "High Touch" skills and compassion. Services unique to our counties and recently developed expertise include Cardiac Catheterization, Magnetic Resonance Imaging, and Lithotripsy. This expansion of services is in direct support of the 60+ active, courtesy, and consulting physicians on the medical staff and causes the continuing attraction of additional specialists and sub-specialists such as gastroenterologists, urologists, cardiologists, nephrologists, neurologists, and ENT's. The full time medical staff continues to grow in number and expertise as evidenced by the newer physicians who have relocated to Colleton County and the innovative laparoscopically assisted splenectomies, hysterectomies, and hiatal hernia repairs performed. In the last two years

alone, two Internists and one Anesthesiologist have joined the active medical staff with a General Surgeon arriving this August. The non invasive procedures conducted at Colleton Regional Hospital also make use of the latest technology and methodologies of patient care. Supplementing that care are the Physical Therapy department, the 16 bed Rehabilitation Unit, and the 15 bed Skilled Nursing Unit.

Exciting challenges are being met outside the hospital in the field of managed care contracts. Colleton Regional Hospital has the capabilities to offer and satisfy managed care contracts that link local industry with the hospital in a working partnership with the primary goal of controlling the employer's escalating healthcare costs while providing high quality care to employees. The Privilege Plus Program does just that and is working well at three local businesses. Preferred patient amenities and discounts on out of pocket expenses are part of the Privilege Plus Program, also.

Colleton Regional Hospital

In short, progress is everywhere and the commitment to a new kind of quality care that was pledged in 1983 is getting stronger every day.

John Sirigos is Director of Marketing at Colleton Regional Hospital which is a HealthTrust facility. He has a Masters in Health Service Administration (MHA).

SRRHIS Newsletter

PUBLISHED BY THE SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
MEDICAL UNIVERSITY OF SOUTH CAROLINA

Vol. 2, No. 3

October 1993

From the Editor's Desk:

We hope all of you had a relaxing summer and are looking forward to the arrival of fall.

The SRRHIS staff had a busy but enjoyable summer visiting the participating hospitals, hosting community meetings, and speaking to various community organizations. The community information and hospital related activities are critical elements of the SRRHIS project and ones which we greatly enjoy.

In this issue, Low Country General Hospital is featured in the *Hospital Showcase Column*, and our "guest" columnist is Ms. Susan Bolick, MSPH, CTR, newly appointed Cancer Registry Administrator of the South Carolina Central Cancer Registry, SC Department of Health & Environmental Control.

Your comments, suggestions and questions are always welcome and help us keep the newsletter interesting and informative.

SRRHIS REPORT

by John B. Dunbar, D.M.D., Dr.P.H.

I had a good laugh the other week when I was having lunch with the Ridgeland, South Carolina Rotary Club. Martin Sauls, Program Chairman (and County Coroner), had invited me over to speak to the Club about the SRRHIS program, in particular the cancer registry and the planned birth defects registry. In introducing me to the 35 members present, he made note of a small item in my biographic sketch, namely that I had assisted in the initiation of the Hollings Oncology Center at MUSC. He

looked up from the page he had been reading from, scanned the audience slowly, and asked, "Do you know what 'oncology' is?" After a slight pause, he answered, "It's the study of collards." The house roared and so did I. Martin's needle was almost prophetic; I learned two weeks later that MUSC was changing the name of the center to Hollings Cancer Center.

Following the Rotary meeting I went by to visit with Mark Greenberg, Administrator of the Low Country General Hospital in Ridgeland. The Hospital has been one of the SRRHIS program supporters since the beginning, and continues to be a good supporter. It became clear in talking to Mark that he has been busy seeking to establish a dynamic health care program for this predominately rural area. And he has met with considerable success judging from the grant moneys he raised to support outreach programs for elderly and prenatal care.

This luncheon and the visit with Mark Greenberg show very nicely a personal side of our community information and

Dr. John Dunbar

hospital related activities. We enjoy being out in the community talking to anyone or any group which is interested in hearing about our program. We are fortunate in this respect because information dissemination and the promotion of public awareness of the project are critical elements of the SRRHIS program.

At our July Steering Committee meeting, we were notified officially that the South

Carolina Department of Health and Environmental Control (DHEC) is starting a statewide cancer registry. We were pleased to know this officially, and to hear that the decision to establish it at this time was based in large measure on the success of the SRRHIS registry. Apparently, there is a great deal of interest at the national level in promoting state registries where none exist, and the Centers for Disease Control and Prevention (CDC) is funding a DHEC effort in which cancer registration is a critical component for program evaluation at a later time. We at SRRHIS are glad to collaborate with DHEC in this effort because it will benefit the public, and it will be mutually beneficial technically to both DHEC and SRRHIS. In concept the collaboration is wonderfully simple; we will collect cancer cases in the SRRHIS counties, and DHEC will collect them in the remainder of the state. In this way, DHEC will be able to save money and effort by not duplicating an activity already underway, and the hospitals will be spared another data collection. There are further benefits, of course. We can share technical skills and computer resources and there will be an opportunity to combine and compare the state's data with that of Georgia (with which SRRHIS is working through our collaboration with Emory University), resulting in a larger and more stable data base for estimating cancer rates. As far as I know, there is no other instance in the Nation in which a cancer registry crosses a geopolitical boundary (a state line).

I thought that you might be interested in knowing that our registry activities are known and discussed by scientists and

public health professionals beyond our local area. The recent travels of Dr. Daniel Lackland, the SRRHIS Co-Director for Cancer, illustrate this point. In June he was invited to Munich, Germany to discuss locally active research projects related to environmental health risk. The cancer registry was among the projects discussed. It was of particular interest to them because a compatible Germany-based cancer registry includes cases around nuclear production plants in that country, making it possible in the future to compare the German regional rates to those in our area. Dan also spoke of the registry's potential benefits to a group of Baylor University medical scientists meeting in Houston in August. Also present at this latter meeting was a member of our Steering Committee, Dr. Curtis Hames, a physician/scientist of Claxton, Georgia.

We will be pleased to accept a speech invitation anywhere within the SRS region from Augusta and Aiken to Beaufort and Savannah. If you or someone you know wants to hear more about our project, let us know. Our phone number is (803) 792-4081. Call Ms. Koenig, SRRHIS Administrator, or me to make an appointment.

Dr. Dunbar is a Professor of Epidemiology at MUSC and Principal Investigator of SRRHIS.

SRRHIS BIRTH DEFECTS REGISTRY

by Yuko Y. Palesch, Ph.D.

One principal goal of the SRRHIS project is to develop a system for monitoring birth defects among the babies born to residents of the catchment counties. The aim is to establish a registry which will yield incidence data for selected congenital

Dr. Yuko Palesch

malformations of a quality comparable to the SRRHIS cancer registry. To this end, the SRRHIS staff has consulted closely with the staff at Birth Defects and Genetics Diseases Branch, Centers for Disease Control and Prevention (CDC).

The CDC recently celebrated the 25th anniversary of its Metropolitan Atlanta Congenital Defects Program (MACDP) which actively monitors the birth defects incidence in the five contiguous counties. Several case workers from the MACDP periodically visit the hospitals in the five counties to screen, ascertain, and collect data on a comprehensive range of major birth defects in the newborns and infants up to the age of one year. The MACDP incorporates quality control at different stages of the data collection system, including a review of the abstracted information by a dysmorphologist (clinical expert) to confirm the diagnoses. This "grandfather" of the birth defects surveillance system has been emulated by other states which have established registries in the last two decades. The SRRHIS birth defects registry will also model itself after the MACDP to achieve data collection of high quality so that data from these systems can be utilized for future statistical comparisons. The MACDP staff have agreed to continue providing consultation throughout the development and operation of the SRRHIS registry.

Of particular interest to the SRRHIS birth defects registry are those defects thought to be related to radiation and toxic chemical exposure, such as neural tube defects (e.g. spina bifida, microcephaly), Down's syndrome and congenital hypothyroidism. However, other major birth defects, such as congenital heart defects, will be recorded as well because we are not certain whether some of the environmental elements may be associated with these defects. Some defects, such as most neural tube defects and limb deformities are easily identifiable at birth. But others, such as congenital heart defects, tend to be diagnosed after the babies are discharged from their birthing hospitals. Therefore, we will continue to collect birth defects incidence data that are diagnosed during the entire first year of an infant's life.

Approximately 3% of all live births have a major birth defect. At this rate, we can expect to observe 1,000 cases of live births with a birth defect every year in the SRRHIS counties. Because of the small number of birth defect occurrences relative to the number of live births, we will need

to accumulate incidence data for several years to provide meaningful statistics, especially for any given defect. To help us accumulate data more quickly, we are studying the feasibility of collecting adverse birth outcomes from past years. This retrospective collection was not possible in the case of cancer data, but our CDC consultants suggested that we work with several of the SRRHIS hospitals to determine the feasibility of beginning the registry at an earlier reference date. If feasible, we will conduct case identification (in the same manner as the prospective approach) of babies with birth defects born up to five, possibly ten, years ago. The feasibility will depend on the availability and accessibility of records kept at the hospitals in the SRRHIS counties. Such a retrospective approach will allow us not only to present valid incidence statistics earlier, but also to study trends, if any, of defects of interest.

We have observed strong community interest in establishing an active birth defects registry, and at the last SRRHIS Steering Committee meeting in April, the members endorsed the project with enthusiasm. Staff members of the Birth Defects and Genetics Diseases Branch, CDC, support the SRRHIS endeavor and will provide technical consultation.

The grant proposal was submitted to DOE in August. Contingent upon funding by the DOE, the project will begin no later than the Spring of 1994.

Dr. Palesch is Assistant Professor of Biostatistics at MUSC.

Hospital Showcase

LOW COUNTRY GENERAL HOSPITAL RIDGELAND, SC

by Mr. Mark Greenberg

Low Country General Hospital is a 31 bed acute care hospital which opened its doors to the residents of Jasper County during October, 1971. The hospital, which is located in Ridgeland is the only hospital within the county. Its service area encompasses Jasper County, a 662 square mile area located in the southeast portion

of the state. In 1991, operation of the hospital was transferred from the auspices of the county to a management company, Medical Services of America.

As with any rural hospital, the hospital has had it "ups and downs" during the years. Since 1991, the hospital has been on an upswing. The expended services offered to the community have included Labor and Delivery with an OB/GYN program, CT Scan, ultrasound, a hospital based home health agency, and limited transportation to those patients who otherwise could not obtain health care services. Several of these additional services have been obtained via grant funding from various sources.

Several months ago the hospital reopened its Labor and Delivery services, which had been dormant since 1981. In the last six months approximately 60 babies have been delivered at the unit. The reopening of the unit has provided the staff, both within the unit and throughout the remainder of the hospital, with a positive morale boost by being part of a new program.

The staff of the hospital and the community look forward to and welcome future years of additional growth.

Mr. Greenberg is the Administrator/CEO of the Low Country General Hospital in Ridgeland, S.C.

SOUTH CAROLINA CENTRAL CANCER REGISTRY

by Susan W. Bolick, M.S.P.H., C.T.R.

Many years of planning, persistent committee activity, and recent financial support from CDC, have culminated in the establishment of the South Carolina Central Cancer Registry (SCCCR). As Dr. Catherine Harvey described in the April 1993 issue of this newsletter, the developmental stages of a state registry formally began in 1987 under the guidance of the South Carolina Cancer Control Advisory Committee.

Current funding is through the cooperative agreement between DHEC and CDC for the Women's Cancer Screening Project, a portion of which is for surveillance of breast and cervical cancer. Application will be

made for additional funding this fall to CDC and the Department of Defense, both with funds earmarked for states without central registries and for infrastructure development. With additional funding, plans are to expand the SCCCR into a full-fledged, population-based, all-site registry for South Carolina; all the while, examination of the need for enabling legislation will continue.

Utilization of existing resources within the state will be the main driving force behind this initial phase of the SCCCR. These resources include the nineteen existing hospital cancer registries, twelve of which are recognized as American College of Surgeons (ACOS) approved programs, and the Savannah River Region Health Information System (SRRHIS) regional registry program. The SRRHIS registry has paved the way for the state registry project.

Yet another exciting collaborative opportunity for the SCCCR will be to work with the state Division of Research and Statistical Services. In an attempt to become truly population-based, the SCCCR can tap into the hospital discharge dataset (currently under enhancement to include patient identifiers) which will be a valuable case finding resource within areas of the state where tumor registries are not yet established.

The first call for data is currently underway for 1991 cases from the computerized registry, hospitals and SRRHIS. Two other regional registry programs will participate in the SCCCR; REACH, a clinical trial recruitment project for the cancer patients of rural populations of North Carolina and

Ms. Susan Bolick South Carolina (Greenwood County and the six surrounding counties), and TSALIC, the Tri-state Appalachian Leadership Initiative Coalition, covering three upstate counties (Anderson, Pickens, and Oconee).

Without enabling legislation mandating cancer reporting at this time, the initial success of the registry will rely heavily on the voluntary participation of the registry

hospitals. State law protects hospitals from liability of release of information requested by the state health department, and all confidential information will be exempt from freedom of information requests. Much time and effort have been expended to provide assurance to the hospital administrators that confidentiality of the data will be maintained. A memorandum of agreement, approved by DHEC legal counsel, has been provided which is in accordance with S.C. Law 44-1-110.

Critical to the success of the SCCCR will be the quality of the data received. Twelve S.C. hospitals currently adhere to the ACOS criteria for cancer program approval, with the rest making strides to attain ACOS approval. Standardized coding and staging principles are used by these hospital registries. At the state level, extensive built-in cross-edits will be carried out on the data received through the software modified especially for the SCCCR by Medical Registry Services, Inc. (MRS), the software chosen by DHEC. MRS is the leading software vendor within the S.C. hospital registries with eight hospitals currently utilizing MRS' services. This will facilitate smooth, timely transfer of data from these hospitals.

The quality control program for the SCCCR will emphasize education and training for the hospital registrars. The first quality control activity of the SCCCR will be co-sponsorship with SRRHIS of a comprehensive educational workshop in January 1994 for persons involved with cancer data collection. Trainers will be provided from the formalized training program for registry personnel at the University of California at San Francisco. DHEC will hopefully be able to provide some financial assistance for registrants. This will be an excellent educational opportunity for registrars in our state. Other quality control activities will include abstracting audits, reabstracting and case finding studies next year. The SCCCR will also assist hospitals with fulfillment of the ACOS Patient Care Evaluation study requirement (two per year) in the future by providing statewide PCE formats. Technical assistance or consultation for ACOS survey preparation

can also be provided. Several pre-ACOS survey consultations have already been conducted. Attainment of a meaningful, voluntary state cancer registry is an enormous task, however, through the utilization of our well-established registries, the experience of a successful regional registry program (SRRHIS), the guidance of the Cancer Registry Steering Committee, and a cooperative spirit, the success of the South Carolina Central Cancer Registry can be achieved.

Ms. Bolick is Cancer Registry Administrator of the S.C. Central Cancer Registry, SC Department of Health & Environmental Control.

JULY STEERING COMMITTEE MEETING REPORT

by Janis S. Koenig, M.Ed.

The July 15, 1993, meeting of the Savannah River Region Health Information System Steering Committee was held in Beaufort, South Carolina.

As was noted in the last newsletter, three new members have been added. They are:

Mrs. Ann Nevils, Blackville, SC; Dr. Frank Rumph, Augusta, GA; and, Dr. William Irby, Statesboro, GA. An orientation meeting was held at 5 pm to inform the new members of their responsibilities and to give them an overview of the cancer registry operations as well as the history of SRRHIS.

The regular meeting began at 7 pm with a discussion of previous committee business, the reading of the minutes and progress reports from Dr. John Dunbar (SC) and Dr. Jonathan Liff (GA).

Following subcommittee reports, Ms. Susan Bolick, newly appointed Administrative Director of the South Carolina Central Cancer Registry was introduced.

Ms. Bolick reported on the progress of the state registry. She said that a call for data would go out in August to selected (American College of Surgeons approved) state hospitals. To avoid duplication of reporting, all hospitals in the SRRHIS catchment area will continue to report to SRRHIS, which in turn will send the data to the state registry,

maintaining the necessary confidentiality. Ms. Bolick also noted that the success of the SRRHIS program helped create an atmosphere conducive to the start-up of a state registry, and that SRRHIS will continue to be a critical component of the State's cancer program.

The next Steering Committee meeting will be held at the Radisson Plaza Savannah, 100 General McIntosh Blvd., Savannah, GA, on Thursday, October 14, 1993, 7-9 pm.

Ms. Koenig is Project Administrator of SRRHIS.

EDITOR: Janis S. Koenig
PRODUCTION EDITOR: Margery Swanson

Please contact the SRRHIS office regarding reproducing this Newsletter in whole or in part.

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SRRHIS Newsletter

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Vol. 2, No. 4

December 1993

From the Editor's Desk:

In this issue, The Regional Medical Center of Orangeburg & Calhoun Counties, is featured in the **Hospital Showcase** column, and our "guest" columnists are Dr. Tim Aldrich, Director, North Carolina State Cancer Registry and Ms. Dolores McCord, CTR (Certified Tumor Registrar), Client Services Representative at Medical Services, Inc., Hackensack, New Jersey.

Happy Holidays!

REACH Another Example of Collaborative Cancer Research in the Carolinas

by Tim E. Aldrich, Ph.D., M.P.H., CTR

Rural cancer patients are generally diagnosed at later stages of disease, often do not receive state-of-the-art cancer care and experience higher case-fatality than do urban cancer patients.

Modifying this pattern of cancer care is the basis for a National Cancer Institute funded project, euphemistically referred to as

REACH: Reaching Communities for Cancer Care. The REACH project features an intervention community, this is the seven county area around

Dr. Tim Aldrich

Goldsboro, North Carolina. The six county area around Greenwood, South Carolina represents the comparison community.

The principal investigator of REACH is Dr. Robert Cooper of the Wake Forest Comprehensive Cancer Center in Winston-Salem, North Carolina. Dr. Electra Paskett of the Southeastern Cancer Control Consortium (SCCC) is actively involved in REACH as well. The REACH study evaluates several varieties of community intervention for their impact to modify the rural pattern for access to state-of-the-art cancer care. State-of-the-art care generally refers to adjuvant options of radiation therapy, chemotherapy or hormonal manipulation in conjunction with conservative surgical procedures. Many times, these multi-disciplinary approaches are available as clinical trial options which can pose a financial advantage for poor patients.

The REACH project's interventions include an energetic **community education** effort coordinated through local units of the American Cancer Society. Also, there is highly directed **patient education** to assist rural cancer patients with understanding the multi-disciplinary approach to treatment and to "navigate" marginally literate or older clients through referrals to specialty oncology practices or facilities. All physicians receive a monthly newsletter (*Cancer Consult*). REACH staff appear periodically at **tumor boards and medical staff conferences** to provide updates on the project. However, the foremost intervention for the project is the activity of a **clinical nurse**

facilitator. It is the clinical nurse facilitator who contacts the diagnosing physician to promote his/her consideration of state-of-the-art treatment options and to facilitate referrals of candidate cases to adjuvant treatment centers, or to manage the paperwork and clinical studies necessary for clinical trial recruitment if that option is selected.

This project also works closely with the North Carolina Central Cancer Registry to operate what is referred to as a **Clinically Enhanced Tumor Reporting System (CETRS)**. This system involves the "rapid reporting" of newly diagnosed breast, prostate, colon and cervical cancer cases from the study area. "Rapid reporting" means that the project staff strive to identify all newly diagnosed cancer cases within two weeks of their diagnosis. This timely case finding is necessary for the nurse facilitator's contact with the diagnosing physician during the decision making period of the first course of treatment.

The nurse facilitator, community education specialist, and cancer registrar comprise the full-time grant personnel.

**TUMOR REGISTRY
TRAINING PROGRAM**
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Charleston, SC

January 8 - 12, 1994

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They work closely together and with local hospital personnel as well.

Another component of the REACH study is the evaluation of the "standards of care" for the communities at large. The Rural Health Research Program at the University of North Carolina conducted a baseline survey of medical practices in the study areas to evaluate case management characteristics identified in the national Community Clinical Oncology Programs (CCOPs) self-studies. This survey will be repeated in 1997 at the close of the REACH project. The aim of these surveys is to assess the impact of the educational efforts and the actions of the clinical nurse facilitator.

In South Carolina, the REACH project will provide a cancer incidence database for the six-county study area for several years. These data, along with those from SRRHIS offer a population-based reference point for South Carolina cancer incidence. These data can be used to evaluate the many cancer control programs that are underway in South Carolina and to promote the implementation of statewide cancer incidence reporting. As anticipated, the close working connection between the REACH project staff and South Carolina cancer registry and hospital personnel has been warm and productive.

The predominantly rural and large black populations of both North and South Carolina make the two states prime marks for national cancer control initiatives (e.g., the Appalachian efforts, the cancer screening initiatives, etc.). Projects like REACH, which builds on the close working relationships of

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cancer registries in the two Carolina's, and like SRRHIS, which builds on the South Carolina and Georgia linkages, are a pattern that is likely to continue into the future. It is gratifying to enjoy such collegial affiliations in programs that seek to address cancer-related issues that are clearly population-specific and not delimited by political borders or factional constraints.

For more information about the REACH project or any other of the activities mentioned in this article, please contact Dr. Aldrich in Raleigh (919-733-4728) or the head of the South Carolina Central Cancer Registry, Susan Bolick at (803-734-4860) or Ms. Koenig at SRRHIS (803) 792-4081.

Dr. Aldrich is the Director, N.C. Central Cancer Registry, N.C. State Center for Health and Environmental Statistics, Raleigh, N.C.

Hospital Showcase

THE REGIONAL MEDICAL CENTER OF ORANGEBURG AND CALHOUN COUNTIES

By Joann Lane, RT, CTR

The Regional Medical Center of Orangeburg and Calhoun Counties is a 286-bed, acute care, regional referral

center serving the lower midlands area of South Carolina. The medical center offers 24-hour Emergency Department services and has an outpatient Cancer Treatment Center, an inpatient Psychiatric Unit, an inpatient Rehabilitation Unit and provides a full range of high quality medical services including:

- Cardiac Catheterization
- Cardiac Rehabilitation
- Single-room maternity care
- Mammography
- CT Scanning
- Magnetic Resonance Imaging
- Lithotripsy
- Physical Therapy
- Occupational Therapy
- Health Education and Wellness classes and activities.

TRMC is a medical center where state-of-the-art and state-of-the-heart come together to ensure that our patients receive the best we have to offer. Our goal is excellence in patient care, but care provided in an atmosphere that seeks to put the patient first...is sensitive to the needs of our employees and physicians...and centered around the family.

Joann Lane is the certified cancer registrar at the Cancer Center of The Regional Medical Center of Orangeburg and Calhoun Counties.

The Regional Medical Center
of Orangeburg & Calhoun Counties

COMPUTERIZATION HELPS MAKE THE TUMOR REGISTRIES INTEGRAL PART OF CANCER MANAGEMENT

By Dolores McCord, ART, CTR

The tumor registry is considered by many to be the heart of the hospital's cancer program. In actuality, it is the central nervous system. The tumor registrar is involved in nearly all aspects of the cancer program, resulting in a job description that is both interesting and varied. A registrar's position requires a self-motivated individual, due to the nature of duties and responsibilities that often provide self-fulfillment and enlightenment.

Historically, tumor registries came into existence from within medical record departments since the majority of the data collected is obtained from the medical record. The registry began as a collection of cancer information, stored manually on paper abstracts in file cabinets, with hand-written master index cards, follow-up tickler cards, accession registers, and typewriter-generated follow-up letters.

Studies were generated by "counting" abstracts, and survival statistics produced on a calculator. Graphs were hand-drawn with a ruler and pencil. Needless to say, collecting information was time-consuming and producing reports was labor intensive and tedious. In actuality, not much time could be dedicated to producing reports as most of the registrar's time was needed for collecting information.

Today's tumor registry is totally computerized, and the registry is often located under the direction of the oncology department. The tumor registrar is often referred to as the oncology program coordinator, reporting to a cancer program director or an administrator. The computer has eliminated the need for paper abstracts, index cards, file cabinets—even the typewriter. The information exchange—both into and out of the registry, is performed completely on-line. A computerized registry has the capability to produce not only graphs, but a full range of reports.

In the beginning, computerization assisted with the performance of registry function via batch methods of data

Ms. Dolores McCord

entry—resulting in a time delay between point of data collection and point of data entry into the computer. The registrar had no direct interaction with the computer.

Retrieval of information was accomplished with the assistance of a computer programmer, producing mostly raw or crude data.

Registry computerization advanced with the advent of the personal computer. Interaction with the computer became on-line with changes, updates and data entry taking place immediately. The registrar now has direct control over the quality of data entry and data retrieval. Each procedure or function of the registry is facilitated by the computer: case findings, suspense, abstracting, follow-up and reporting. Patient demographics from other hospital computerized data bases can be downloaded into the registry's computer, thus decreasing time spent on data entry.

The computer can maintain all abstract and follow-up information, eliminating the need for file cabinets, card files and accession log books. With the assistance of graphic packages, letter-writing programs, and mail-merge programs, producing weekly tumor conference statistics, monthly follow-up letters, and the annual cancer program report is relatively easy.

What next? With the advent of local area networks (LANs), registries are performing multiple functions simultaneously. Even a relatively small cancer program, with less than 500 cases per year, benefits from a LAN. Abstract information can be entered on-line at one station, follow-up can be performed at another and reports generated on yet another.

Of course, three stations are NOT the limit. Abstract entry can be performed simultaneously at multiple stations, and the same is true for the other functions.

Often in preparation for the annual report, reports are being generated at multiple work stations—each working on a different portion of the report. What next? Now the registry has the ability to maintain multiple data bases within the same computer system. Sister hospitals and hospital consortiums can share a computer system. This offers the hospital system the capability to generate information for an individual hospital and also combine data in order to reflect the overall cancer experience of the community served by the hospital system.

The function of the tumor registry and the role of the tumor registrar have increased both in viability and importance.

The information available from the registry is of benefit to administration and marketing departments for future planning of oncology services and identification of key service areas. The medical staff has easy access to information which can be used in patient care, publications and continuing education. The cancer committee can analyze the need for community programs for education, prevention and early detection.

All in all, the tumor registrar, a valued member of the cancer committee, has an opportunity to play a key role in the hospital's cancer program, not only by providing valuable computer-generated information, but also by being a tremendous resource of knowledge and expertise. The computer is only a tool, albeit a very powerful one, through which today's registry can keep up with the demands of the hospital's cancer program.

Dolores McCord is a Client Services Representative at Medical Services, Inc., Hackensack, New Jersey.

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FROM THE DIRECTOR

by John B. Dunbar, DMD, DrPH

It's been a busy time in the community this quarter. In October, a poster describing our activities was presented at the annual meeting of the South Carolina Hazardous Waste Management Research Fund in Greenville, SC. Luncheon presentations were made to the Sea Island Rotary Club of Beaufort, SC and the Sylvania Rotary Club of Sylvania, GA. In November, I met with Dr. Mildred McClain, Director of the Citizens for Environmental Justice, at her office in Savannah, GA. I am looking forward to a presentation in December to members of the Missionary Baptist Church of Savannah. These meetings have been well attended and the audience's perceptive questions indicate their interest.

There is some evidence that word about our project is getting around the region. I was pleased, for example, to see an article on the editorial page of the October 24, 1993 Island Packet (Hilton Head) by Ms. Pat Tousignant, who spoke of our SRRHIS project as one

"long awaited" by members of the community. She attended our July 1993 Steering Committee meeting in Hilton Head when we had our birth defects presentation by Dr. David Erickson, Chief of the Birth Defects and Genetic Diseases Branch, Centers for Disease Control and Prevention in Atlanta.

Dr. Dunbar is a professor of Epidemiology at MUSC and Principal Investigator of SRRHIS.

OCTOBER STEERING COMMITTEE MEETING REPORT

by Janis S. Koenig, M.Ed.

The October 14, 1993, meeting of the Savannah River Region Health Information System Steering Committee was held in Savannah, Georgia.

The meeting began at 7:00 p.m. with the approval of the minutes, progress reports from Dr. John Dunbar (SC) and Mr. Ken Gerlach (GA), and reports from the Membership and Legislative Subcommittees.

Mr. Mark Musolf of the Westinghouse Savannah River Corporation (WSRC)

provided a status report on the SRS Citizens Advisory Board (CAB). He discussed the CAB Charter and application for membership.

Mr. Brian Costner, SC Energy Research Foundation, presented an up-date on activities at the Savannah River Site. He also discussed the need for an advisory board for health related research.

The next Steering Committee meeting will be held at the Holiday Inn, Walterboro, SC, on Thursday, January 13, 1994, 7:00 - 9:00 p.m. The guest speaker will be Dr. Dee West, Executive Director, Northern California Cancer Center, Union City, California.

Ms. Koenig is Project Administrator of SRRHIS.

EDITOR: Janis S. Koenig

PRODUCTION EDITOR: Margery Swanson

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SRRHIS Newsletter

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Vol. 3, No. 1

April 1994

From the Editor's Desk:

In this first issue of 1994, Allendale County Hospital, Fairfax, SC, is featured in the **Hospital Showcase** column, and our guest columnists are Dr. Dee West, Executive Director, Northern California Cancer Center and Greater Bay Area Cancer Registry, Union City, California, Kay Gebhard, CTR and Susan Radovich, CTR, Training Analysts, Cancer Patient Data Program, Department of Epidemiology and Biostatistics, University of California, San Francisco, California.

Ms. Gebhard and Ms. Radovich, along with eight South Carolina cancer specialists, conducted a five-day training program, January 8-12, for cancer registrars, health data managers and other health related specialists. The 49 participants represented eight states and the District of Columbia. The Savannah River Region Health Information System (SRRHIS) and The South Carolina Central Cancer Registry (SCCCR) co-sponsored the program. This was the first time such a comprehensive training program had ever been held on the East Coast. The following graph depicts the results of the program evaluation.

Tumor Registry Training Program

CANCER REGISTRY DATA

Cautions and Usage

by Dee W. West, Ph.D.

In mid-January I had the opportunity to attend and speak at the Tumor Registry Training Program and SRRHIS Steering Committee meeting. It only took a moment to feel the great excitement surrounding your cancer registry and the first data which will soon be released. As the Director of a new registry in San Jose/Monterey and an old one in San Francisco/Oakland, I identify with this excitement and offer a few cautions and a few suggestions as to why I think registry data are so useful.

Dr. Dee West

The cautions I would offer a new registry are: First, continue to be patient. Registry data is like a good wine and should not be released before its time. Each year's data needs to be complete and of high quality before it is published. The SRRHIS Registry staff knows this and should be commended for not releasing incomplete data. Second, seek the highest quality data. There is always a temptation to not turn over every stone looking for cases and errors. The SRRHIS Registry was set up with the goal of meeting the same quality standards as the SEER (Surveillance, Epidemiology and End Results) Program. Again the staff should be commended for holding training sessions and conducting a myriad of other activities to reach this goal. Third, standardize your data. It is important to be able to compare your data with other registries. This doesn't mean you can't collect data that may be unique

to your area, only that standard data, should really be standard. Finally, don't expect registry data to answer all cancer questions. Registry data of necessity is brief and limited to information in the medical record, so the data may not exist to answer all the questions. But the registry is excellent at identifying questions and monitoring the cancer burden and changes over time.

With these cautions, it is exciting to look forward to ways your data can be used. I will summarize a few and offer some examples:

Cancer Surveillance. Surveillance is a word of French derivation which means "to keep a watchful eye over the enemy." The Registry answers questions such as: "Are cancer rates different in different geographic areas or racial groups?" "Are our rates different from other areas in the U.S.?" "Are our rates changing over time?" Probably one of the most important examples of the utility of surveillance was the observation in 1975 in our San Francisco Registry that uterine cancer rates dramatically increased by over 50 percent between 1969 and 1975 (Figure 1). This observation led to the discovery that estrogens, whose use had

Figure 1

tripled in this area between 1965 and 1975, were related. Subsequently, the FDA recommended smaller doses, balanced with progesterone, a recommendation that reversed the disease trend and saved thousands of lives.

Monitoring Patient Care. Registry data can be used to monitor survival patterns following the introduction of new therapies. Figure 2, for example, shows how survival for testicular cancer changed following the introduction of new combination therapies in the late 1970's.

Figure 2

In California we have also been able to look at mastectomy as treatment for in situ and localized breast cancer, which is now not usually recommended. We find the rates to still be about 50% but decreasing, and to be geographically different.

Epidemiology Studies. The registry data may show rates of cancer to be different in various groups of people or locations. Though the data may not explain the differences it can suggest areas for future study. For example, we are completing a study to explore the observed higher percentage of invasive cervical cancer among older women by reviewing medical records to look for screening patterns. The data suggests that screening may be important every two years for older women. A similar study is being done to look in medical records for co-morbid conditions that may explain poorer survival among Black women with breast cancer. We also use the registry to identify patients for case-control and other studies, such as the one we are doing to look at diet as a factor to help explain high prostate cancer rates in Black compared to Asian men.

Planning Medical Care. Registry data can be used to plan the number of new beds or treatment facilities. The California Division of the American Cancer Society also use our data to establish

program priorities. Health Departments utilize data to plan placement of clinics.

Monitoring Cancer Control Programs.

Early detection programs are aimed at detecting cancers early. By looking at shifts in stage of disease, one can tell if such programs are effective. For example, Figure 3 shows that more breast cancers are being detected early following increased mammography beginning in the early 1980's.

Figure 3

Education. Whether educating the public or health professionals, registry data showing trends, high risk groups, and other patterns are needed to improve prevention, screening, and treatment options.

The future is exciting in the SRRHIS area as you really begin to understand your cancer patterns and burden. The creation of the Registry four years ago showed more foresight, which I'm convinced will continue to exist as the data matures and are utilized. I congratulate the staff and the Steering Committee for developing a high quality and therefore extremely useful cancer registry.

Dee W. West, Ph.D., is Executive Director, Northern California Cancer Center and Principal Investigator of both the San Francisco/Oakland SEER Cancer Registry and San Jose/Monterey SEER Cancer Registry.

Dee W. West

TRAINING IN CHARLESTON

*By Ilona Kay Gebhard, BA, CTR
with Susan Radovich, CTR*

In January, the Medical University of South Carolina's Savannah River Region Health Information System (SRRHIS) and the Department of Health and Environmental Control's

Ms. Kay Gebhard

South Carolina Central Cancer Registry (SCCCR) joined forces to sponsor a training program to enhance the endeavor of establishing a state cancer registry.

After years of planning, South Carolina is moving toward a population-based, all-site cancer registry. Although many hospital registries exist, the expansion requires additional registrars and training. Janis Koenig, Project Administrator for SRRHIS, contacted Susan Radovich, Training Analyst at University of California, San Francisco about bringing a training program to Charleston. Decisions were made to tailor a one-week program for South Carolina. I became involved as assistant coordinator and trainer.

We assessed the needs and began preparing. The agenda was decided, topics chosen, and physician speakers selected. Letters and lecture outlines were sent to physicians so that their talks related to registry needs and requirements. Lectures and exercises were developed for the remaining topics. Noting the apparent high incidence of esophageal cancer in South Carolina, special training materials for this site were designed. Our challenge was to make the topics relevant for those attending. Using the statistics for state cancer rates from the American Cancer Society's booklet, "Cancer Facts and Figures-1993" (Table 1) we made overheads to illustrate the relevancy of cancer data.

South Carolina New Cancer Cases 1993

15,500 all sites

MALE		FEMALE	
Lung	2,400	Lung	
Prostate	2,200	Breast	2,300
Colon/Rectum	1,800	Colon/Rectum	
Oral	600	Oral	
Melanoma	425	Melanoma	
Leukemia	400	Leukemia	
Pancreas	375	Pancreas	
	700	Uterus	

Table 1

Ms. Susan Radovich

Upon our arrival in Charleston, we found everything reproduced and a training manual for each participant; the organization was great and allowed us to

Tumor Registry Training Program Participants

focus on the training. The turn-out was overwhelming - forty nine participants from the Carolinas, Georgia, Louisiana, Florida, Maryland, Minnesota, and the District of Columbia, representing all aspects of the field (military, hospital, central, and specialized program managers). We found that this type of training and educational forum was needed and wanted.

During the week, some of the obstacles that we encountered were: inconsistent data standards, different/out of date reference materials, and different reporting requirements for facilities within a specific area. These are obstacles that a central registry can review and then establish guidelines. For many of the participants, the week was their first opportunity to talk with colleagues; a chance to share work experiences. All agreed that the training and information exchange was beneficial; everyone wanted more.

Susan and I have close working ties with several nearby cancer data collection systems, and now with the development of the South Carolina central registry, communication between the regions can increase. Our goal in training is to instill in registrars the need for consistent, standardized data collection. Without standards, data comparisons are impossible and without data usage registries become expendable. We want everyone to collect the best data possible.

We appreciated the opportunity to work with you, and thank you for the pleasant Charleston experience. Every training program is a learning experience, and this was no exception. Questions and discussions during the

sessions were excellent. We encourage you to stay in touch with us and one another. We'll watch the growth of the state registry with interest because of our time with you. South Carolina was new territory for us, but it is now a place for us to return.

Kay Gebhard, CTR, is Training and Quality Control Specialist, and Susan Radovich, CTR, is Training Analyst for the University of California, San Francisco.

THANKS!

The Savannah River Region Health Information System and SC Central Cancer Registry would like to thank the following physicians for volunteering their time to present an overview of their specialties at the Tumor Registry Training Program.

William T. Creasman, MD, Medical University of South Carolina, Charleston, SC.

Fletcher C. Derrick, Jr., MD, Medical Univ. of South Carolina, Charleston, SC.

Frederick L. Greene, MD, The University of South Carolina Medical School, Columbia, SC.

Richard D. Marks, Jr., MD, Trident Regional Cancer Center, Charleston, SC.

Carolyn E. Reed, MD, Medical University of South Carolina, Charleston, SC.

Rudolph Rustin, MD, Coastal Colon and Rectal Surgical Associates, Charleston, SC.

Robert K. Stuart, MD, Medical University of South Carolina, Charleston, SC.

Dee W. West, PhD, N. California Cancer Center and Greater Bay Area Cancer Registry, Union City, CA

ALLENDALE COUNTY HOSPITAL Fairfax, South Carolina

By Nancy B. Lee, Director, Medical Records

Allendale County Hospital's first roots were established in the early '20's in the Last Will and Testament of Dr. William Jasper Young, a practicing physician in Fairfax. His Will specified that residual from his estate be used for the purpose of erecting a hospital and nurses' home in Fairfax to provide medical care to black and white citizens of the community.

In March, 1946, an Act of the State Legislature created the Allendale County Hospital Board of Trustees and by February, 1947 plans were underway for construction of a 27 bed hospital. The hospital was constructed and opened for business by April, 1950. Original construction cost was \$118,000.

The hospital was first under the direction of local physician, W. R. Tuten. The first Administrator was John Berry, hired in 1952.

In 1962, the hospital was enlarged by 16 beds and renovation and relocation costs totaled \$310,000.

In 1967, the hospital Board of Trustees erected a 28 bed long-term care facility adjacent to the hospital, expanding to 44 beds by 1979.

The hospital recently completed a major construction and renovation program with an approximate cost of \$2.5 million dollars. This project included new emergency room facilities, birthing rooms, cafeteria/dining room space, a new Medical Records Department, and enlargement of the business office, along with renovations to the laboratory, central sterile supply, and nurses station.

The hospital currently has seven (7) full-time Family Practitioners on-staff and two (2) Certified Nurse-Midwives. Hospital services provided include acute inpatient care with obstetrics and also swing-bed services. Diagnostic services include clinical laboratory, radiology, ultrasound, echocardiology,

mammography, and computerized tomography (CT scan).

Nancy B. Lee is Director, Medical Records Department at Allendale County Hospital.

JANUARY STEERING COMMITTEE REPORT

by Janis S. Koenig, M.Ed.

The January 13, 1994, meeting of the Savannah River Region Health Information System Steering Committee was held in Walterboro, SC.

If you have comments, suggestions, or your group/organization is interested in having a member of the SRRHIS team speak at an upcoming meeting please contact us.

WE'VE MOVED

SRRHIS

Dept. of Biometry & Epidemiology
MUSC/401 HOT
171 Ashley Avenue
Charleston, SC 29425-2503
Phone: (803) 792-4081
FAX: (803) 792-3180

The meeting began at 7:00 pm with the approval of the minutes, progress reports from Dr. Jonathan Liff (GA) and Dr. John Dunbar (SC), and reports from the Nominations and By-Laws Subcommittees.

Dr. Dee West, Executive Director, Northern California Cancer Center; Director, Greater Bay Area Cancer Registry presented information on the uses of cancer registry data using the extensive data of the Greater Bay Area Cancer Registry to illustrate his points. He emphasized the importance of standardizing the data and always seeking the highest quality.

Mr. Dean Moss of Beaufort, SC was unanimously voted in as the 12th voting member of the Steering Committee. Four members whose terms were expiring were nominated and approved for reappointment for three years. They are: Ms. Alva Driggers, Varnville, SC; Dr. Curtis Hames, Claxton, GA; Mr. Andrew Rea, Savannah, GA; and, Dr. Lisa Wagner, Statesboro, GA.

Election of officers for the upcoming year was held and the result was the

selection of the following officers for the year ending January, 1995:

Chairperson Mr. Andrew Rea
Vice Chairperson Ms. Alva Driggers
Secretary Ms. Jan Koenig

The next Steering Committee meeting will be held at the Statesboro Inn, Statesboro, GA, on Thursday, April 21, 1994, 7:00-9:00 pm. Topics to be discussed are: "Quality Control Standards and Techniques Employed by the SRRHIS Staff" by Ms. Nancy Ferrelle, Field Quality Control Editor, SRRHIS, GA and "Chemoprevention of Cancer" by Dr. Daniel Nixon, Hollings Cancer Center, MUSC. All Steering Committee meetings are open to the public. For more information, please call (803) 792-4081.

Ms. Koenig is Project Administrator of SRRHIS.

EDITOR: Janis S. Koenig

PRODUCTION EDITOR: Margery Swanson

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**SAVANNAH RIVER REGION
HEALTH INFORMATION SYSTEM
DEPARTMENT OF BIOMETRY & EPIDEMIOLOGY
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APPENDIX G

Tumor Registry Training Program

**Brochure
and
Program Evaluation Report**

FACULTY/SPEAKERS

William T. Creasman, MD, Professor and Chairman,
Department of Obstetrics-Gynecology, Medical
University of South Carolina, Charleston, SC

Fletcher C. Derrick, Jr., MD, Clinical Professor of
Urology, Medical University of South Carolina,
Charleston, SC - also in private practice.

Kay Gebhard, CTR, Training and Quality Control
Specialist, Cancer Patient Data Program, Department of
Epidemiology and Biostatistics, University of California,
San Francisco, CA; National Cancer Data Base
Quality Improvement Faculty Speaker.

Frederick L. Greene, MD, Professor of Surgery,
Department of Surgery, The University of South
Carolina, Columbia, SC

Richard D. Marks, Jr., MD, Medical Director,
Trident Regional Cancer Center, Charleston, SC

Susan Radovich, CTR, Training Analyst, Cancer
Patient Data Program, Department of Epidemiology
and Biostatistics, University of California, San Francisco;
Regional Cancer Program Consultant, American
College of Surgeons.

Carolyn E. Reed, MD, Associate Professor of
Cardiothoracic Surgery, Medical University of South
Carolina, Charleston, SC

Rudolph Rustin, MD, Coastal Colon and Rectal
Surgical Associates, Charleston, SC

Robert K. Stuart, MD, Professor and Director,
Hematology/Oncology Division, Medical University of
South Carolina, Charleston, SC

Dee West, PhD, Director, Northern California Cancer
Center and Greater Bay Area Cancer Registry, Union
City, CA

TUMOR REGISTRY TRAINING PROGRAM

**Cancer Patient Data Program -
Research and Training
University of California
San Francisco
San Francisco, California**

sponsored by

**The Savannah River Region
Health Information System**

and

**The South Carolina
Central Cancer Registry**

January 8 - 12, 1994

GENERAL INFORMATION

Tumor Registry Training Program Charleston, South Carolina January 8 - 12, 1994

This program is intended to present current procedures in computerized cancer data systems for both hospital and central (population based) registries. It is for Cancer Registrars, Health Data Managers and other Health Related Specialists.

At the end of the program, the participant should be able to:

- identify problems in determining reportable cancers, select and summarize appropriate medical information from cancer patient medical records using the latest criteria of the National Cancer Institute's SEER Program and the American College of Surgeons.
- improve the quality of coded primary sites and histologic types of cancer according to the International Classification of Diseases for Oncology - Second Edition.
- utilize the latest methodology to determine extent of disease and assign the correct SEER extent of disease codes and summary stage.
- recognize common problems in defining the "first course of treatment", identifying and coding required treatment information.

Hotel Registration:

Participant should call the Sheraton Inn Charleston directly at 1-800-968-3569 to reserve a room. When calling, indicate you will participate in the Tumor Registry Training Program to receive the special rate of \$70.00. Hotel room blocks are reserved until December 7, 1993.

Registration Fee: \$275.00

The fee includes program materials, continental breakfasts, all refreshment breaks, and Tuesday lunch. Program limited to 40 participants. Please make checks payable to: **SCATR - Tumor Registry Training Program.**

What to Bring with You:

- International Classification of Diseases for Oncology (ICD-O) World Health Organization, Geneva Switzerland (second edition).
- Summary Staging Guide, Surveillance, Epidemiology, and End Results Reporting, SEER Program, NIH Publications (or SEER Self-Instructional Book 6).
- American Joint Committee on Cancer - Manual for Staging of Cancer (fourth edition).
- American College of Surgeons Manual - Data Acquisition Manual.

Continuing Education Units: Endorsed by National Cancer Registrars Association, Inc. (NCRA). This program has been submitted to NCRA for continuing education credit. Certificates will be issued.

For further information contact:
Janis Koenig, M.Ed.
(803) 792-4081

SCHEDULE FOR TUMOR REGISTRY TRAINING P

Friday, January 7

—EVENING

7:00 - 9:00 p.m. Early Registration

Saturday, January 8

—MORNING

8:00 - 9:00 a.m. Registration

9:00 - 9:30 a.m. Welcome & Introduction

Susan Bolick, MSPH, CTR, Cancer Registry Administrator, DHEC and Janis Koenig, M.Ed., Project Administrator, SRRHIS, Medical University of SC, Charleston

9:30 - 10:15 a.m. Assessment Exam

10:15 - 10:30 a.m. Break

10:30 - 11:15 a.m. Past, Present, and Future of Cancer Data Systems

Susan Radovich, CTR, Research & Training, University of California, San Francisco

11:15 - 12:00 p.m. Cancer Registries: Current Relationships with Cancer Surveillance Agencies

Kay Gebhard, CTR, Research & Training, University of California, San Francisco

—AFTERNOON

12:00 - 1:00 p.m. Lunch

1:00 - 2:30 p.m. Improved Understanding of Cancer Cell Invasion and Metastasis

S. Radovich, CTR

2:30 - 2:45 p.m. Break

2:45 - 4:30 p.m. Common Casefinding and Abstracting Problems

K. Gebhard & S. Radovich

Sunday, January 9

—MORNING

8:45 - 9:00 a.m. Session Overview

S. Bolick, MSPH, CTR

9:00 - 10:00 a.m. Update on Stage and Extent of Disease Methodology

K. Gebhard & S. Radovich

10:00 - 10:15 a.m. Break

10:15 - 12:00 p.m. Update on Stage & EOD Cor

K. Gebhard & S. Radovich

—AFTERNOON

12:00 - 1:00 p.m. Lunch

1:00 - 3:00 p.m. Common Problems in Cancer Treatment Coding

S. Radovich, CTR

3:00 - 3:15 p.m. Break

3:15 - 4:30 p.m. Quality Improvement Using ICD-O (2)

K. Gebhard, CTR

Monday, January 10

—MORNING

8:45 - 9:00 a.m. Session Overview

S. Bolick, MSPH, CTR

9:00 - 10:00 a.m. Lung Cancer

Richard D. Marks, Jr., MD, Medical Director, Trident Regional Cancer Center, Charleston, SC

10:00 - 10:15 a.m. Break

10:15 - 11:15 a.m. Gynecological Cancers

William T. Creasman, MD, Professor and Chairman, OB/GYN, Medical University of S.C., Charleston, SC

11:15 - 12:30 p.m. Abstracting Workshop

—AFTERNOON

12:30 - 1:30 p.m. Lunch

1:30 - 2:30 p.m. Breast Cancer

Frederick L. Greene, MD, Professor of Surgery, The University of S.C., Columbia, SC

2:30 - 2:45 p.m. Break

2:45 - 4:30 p.m. Abstracting Workshop Cont

Tuesday, January 11

—MORNING

8:45 - 9:00 a.m. Session Overview

J. Koenig, M.Ed.

9:00 - 10:00 a.m. Urological Cancers

Fletcher C. Derrick, Jr., MD, Clinical Professor of Urology, Medical University of S.C., Charleston, SC - also in private practice.

PROGRAM

- 10:00 - 10:15 a.m. Break
10:15 - 12:00 p.m. Abstracting Workshop
—AFTERNOON
12:00 - 1:30 p.m. Lunch - Cancer Registries: Role in the War on Cancer
Dee West, Ph.D., Northern CA Cancer Center/Greater Bay Area Cancer Center Registry, Union City, CA
1:30 - 2:30 p.m. Abstracting Workshop
Cont.
2:30 - 2:45 p.m. Break
2:45 - 4:30 p.m. Abstracting Workshop
Cont.

Wednesday, January 12

—MORNING

- 8:45 - 9:00 a.m. Session Overview
J. Koenig, M.Ed.
9:00 - 9:30 a.m. Colorectal Cancer
Rudolph Rustin, MD, Coastal Colon & Rectal Surgical Associates, Charleston, SC
9:30 - 10:00 a.m. Esophageal Cancer
Carolyn E. Reed, MD, Associate Professor of Cardiothoracic Surgery, Medical University of S.C., Charleston, SC
10:00 - 10:15 a.m. Break
10:15 - 11:15 a.m. Abstracting Workshop
11:15 - 12:15 p.m. Lymphomas and Leukemias
Robert K. Stuart, MD, Professor & Director, Hematology/Oncology Div., Medical University of S.C., Charleston, SC

—AFTERNOON

- 12:15 - 1:15 p.m. Lunch
1:15 - 2:15 p.m. Abstracting Workshop
2:15 - 2:30 p.m. Break
2:30 - 3:30 p.m. Final Exam
3:30 - 3:45 p.m. Review of Final Exam
3:45 - 4:00 p.m. Closing & Certificate of Completion

REGISTRATION FORM

Tumor Registry Training Program
Charleston, S.C.

Name _____
Credentials _____
Street Address _____
City _____ State _____ Zip _____
Telephone _____
If you wish the name of your employment facility on your badge, please indicate the name of the facility and location.
Facility _____ City/State _____

Conference Fee: \$275.00 (Includes program materials, daily continental breakfast, Tuesday lunch, and all breaks). Program limited to 40 participants.

PLEASE MAKE CHECK PAYABLE TO:
SCATR - Tumor Registry Training Program

Return completed registration form and check by December 7, 1993 to:

Janis Koenig, M.Ed.
909 HOT, Medical University of S.C.
171 Ashley Avenue
Charleston, SC 29425.

Late Registration (after December 7, 1993): \$325.00.

Cancellations: Registration fees will be fully refunded if notice of cancellation is received **in writing** at least two weeks prior to the start of the training program. After December 18, 1993, fees are non-refundable.

Program Evaluation
Tumor Registry Training Program
January 8 - 12, 1994
Charleston, SC

Report prepared by
Survey Research Center
Department of Biometry and Epidemiology
Medical University of South Carolina

February 1994

This report documents the results of the program evaluation performed by the attendees at the conclusion of the Tumor Registry Training Program held in Charleston, SC on Jan. 8 - 12, 1994. Forty-three (43) completed evaluation forms were returned.

A four point scale was used for responding to each scalar question.

1 = poor; 2 = satisfactory; 3 = above average; 4 = excellent

Scalar question average scores

Question	Average Score
Coverage of the material (lectures, concepts, facts, principles, procedures, knowledge, etc.)	3.33
Applicability to your own job, responsibilities, and needs	3.30
Appropriate use of instructional methods and media so that learning was easy and enjoyable	3.00
Opportunity for discussion with other participants to exchange experience and ideas	3.19
Length of the program relative to its objectives and the needs of the group	2.77
Motivation/upbeat/energizing quality of the conference	2.83

Following is a graphic depiction of the above average scores.

Tumor Registry Training Program

Program Evaluation

APPENDIX H

Steering Committee Members

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE MEMBERS

1. Ms. Alva Driggers
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Fax: 1-943-5163
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Heart Research Project
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Surveillance
U.S. Department of Energy
270 Corporate Center
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FAX: 301-903-4677

APPENDIX I

Steering Committee By-Laws

January 1994

**BYLAWS OF
THE SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
STEERING COMMITTEE**

ARTICLE I

Name and Office

Section 1. The name of the Committee shall be the **Savannah River Region Health Information System Steering Committee** (SRRHIS Steering Committee). The office shall be located at the Medical University of South Carolina in Charleston, South Carolina.

ARTICLE II

Purpose

The purposes of the Steering Committee are:

- (a) To assist SRRHIS and the Department of Energy in designing and developing the Savannah River area cancer and birth defects registries, and in making knowledge of them and their findings widely available to the public.
- (b) To advise, counsel and make recommendations to the SRRHIS Project Director, whether for technical matters or those involving broader issues of public understanding and information availability.

ARTICLE III

Membership

Section 1. The Steering Committee shall consist of twelve (12) voting members and one permanent non-voting member of the Department of Energy, but in the event of a vacancy, the Committee may act with a lesser number until such vacancy is filled.

Section 2. Qualifications for membership shall include:

- (a) Persons who live and have interest in the Savannah River Region.
- (b) Professional and technical experts with skills relevant to the Project.

An attempt shall be made to elect members so as to represent Georgia, South Carolina and different parts of the region more or less equally over the long term.

Section 3. Terms of appointment for each voting Committee member shall be for three (3) years. The first Steering Committee shall be appointed to staggered memberships of one (1), two (2), and three (3) year terms. Thereafter, all appointees shall serve three years with one-third being replaced or reelected each year. A voting Committee member shall serve no more than two consecutive three year terms. After a lapse of two or more years, a Committee member may be reelected.

Section 4. Nominations for election to the Steering Committee shall be submitted in writing to the Committee at the regular Committee meeting in October. All Committee members shall be encouraged to submit names of nominees upon receiving consent from the nominee. Nominations also may be accepted from the floor with the consent of the nominee. Elections will be held each year at the regular Committee meeting in October. Each member of the Committee shall be entitled to one vote for each vacancy to be filled. A quorum of the Committee must be present at the time of election.

Section 5. Vacancies on the Steering Committee shall exist upon the death, resignation, expiration of term or Committee removal of any voting Committee member. A voting member of the Steering Committee may resign at any time. The resignation shall take effect upon receipt of a letter of resignation or on the date specified therein. A person shall be elected member of the Steering Committee by a quorum of the Committee to fill any unexpired term.

ARTICLE IV

Officers

Section 1. The officers of the Steering Committee shall consist of a Chairperson, Vice Chairperson, Secretary, and such other officers as the Steering Committee may authorize.

Section 2. The duties of the officers of the Steering Committee shall include but not be limited to the following:

- (a) The Chairperson shall preside over all Committee meetings and shall be kept advised of the general affairs of the SRRHIS Project. He/She shall be an ex-officio member of all committees.
- (b) The Vice Chairperson shall have full authority to act for the Chairperson in his/her absence or incapacity.
- (c) The Secretary shall ensure that any actions taken are followed up, shall record the minutes of all meetings, and notify all Committee members of regular meetings.

Section 3. Elections of officers shall be held by the Steering Committee each year in January. All officers shall be elected for a term of one year and shall be members of the Committee, except for the Secretary who, at the discretion of the Steering Committee, may be a staff person. No member may hold the same office more than two consecutive years.

ARTICLE V

Meetings

Section 1. The Steering Committee shall meet quarterly. The location of each meeting and time shall be established by the Committee. All meetings will use Roberts Rules of Order to conduct business.

Section 2. Special meetings of the Steering Committee may be called any time by the Chairperson, Vice Chairperson, SRRHIS Project Director, or by two Committee members. All special meetings must have a specified agenda and be called for a special purpose.

Section 3. At all meetings a quorum shall consist of one-half plus one of the voting Committee members.

Section 4. A majority of voting Committee members present at any meeting shall decide all matters voted upon.

Section 5. A Committee member may use a proxy to represent him/her at meetings. A proxy may not vote or be used as an attendance for the absent Committee member.

ARTICLE VI

Committees

The Steering Committee may from time to time create standing or ad hoc committees with such duties and powers as the Steering Committee may prescribe.

ARTICLE VII

Removal of Committee Members

Section 1. Committee members are expected to attend all regular and special meetings. A Steering Committee member shall be removed following two consecutive unattended meetings. That member may be reinstated if, at his or her request, the Committee passes, by simple majority, a motion to reappoint.

Section 2. A voting Committee member may be removed for any reason by the Steering Committee when the Committee determines that such action is in the best interest of the Committee. Such action shall require the vote of a majority of all voting Committee members.

ARTICLE VIII

Expenses

While attending the meetings of the Steering Committee each member of the Steering Committee shall be reimbursed for travel expenses, in accordance with the South Carolina State Budget and Control Board policy.

ARTICLE IX

Amendments

These Bylaws may be amended by a two-thirds vote of all voting Committee members at any regular meeting, provided the proposed amendment was presented at the previous meeting and has been submitted to the Committee members in final form, in writing, at least thirty (30) days prior to date of contemplated action.

APPENDIX J

Emory University Technical Report
Grant Year 03

Savannah River Region Health Information System

Georgia Section (Emory University)

CONTRACT PROGRESS REPORT - May 18, 1994

During the past three years, the Savannah River Region Health Information System (SRRHIS) has evolved from an idea with plans on paper to an operational cancer registry. The collection of 1991 cancer cases in the 12 Georgia SRRHIS counties was completed while the collection of 1992 cancer cases has been initiated. The collection of cancer incidence data occurred in two forms: from data submitted on electronic media (diskettes) from selected hospital tumor registries and from the Augusta-based SRRHIS Field Coordinator who collected data from hospitals and free-standing laboratories on a laptop microcomputer software program.

Concurrently, a SRRHIS relational database with three relations (Patient, Cancer, and Hospital) was created with a system for the data to flow through the SRRHIS Georgia office with appropriate editing. A customized data collection program to dovetail with the SRRHIS VAX Database System was developed and is operational. Difficulties such as inconsistent county coding schema among the Georgia hospital tumor registry community and peculiar hospital data submission record descriptions have been identified and resolved. We have established a standard hospital data submission record that conforms to that recommended by the American Association of Central Cancer Registries (AACCR), the national professional organization for central cancer registries and we have worked with hospital tumor registry computer software vendors and their Georgia clients to make that available. Plans are also underway to conduct a quality control site visit of the MUSC SRRHIS operation. While steps remain to streamline the collection, flow, and analysis of data, much has been accomplished, as noted below.

GOAL: Establish a state-of-the-art health information system with a focus on geographic cancer and birth defects surveillance.

Objective 1: Implement a surveillance system of cancer with case ascertainment such as to compare with other internationally recognized systems.

Progress: An operational definition of cancer was developed for the use of SRRHIS which is consistent with national standards.

Progress: Data from the field were received in the GCCS office and the data uploaded into the SRRHIS computer system. Eligible cases from the Georgia State Registry database were extracted and entered into the SRRHIS database.

Progress: All data were checked for possible duplication of cases, accuracy of county codes and reportability of site and histology. All records were edited by the Quality Control Editor and assigned a unique identification number.

Progress: Cases identified through free standing pathology laboratories and radiation therapy centers were processed and integrated into the system. A non-reportable database was established.

Progress: An Abstracting/Editing meeting was held between the editing staff of MUSC and the abstracting staff of the GCCS. The purpose of this meeting was to consult on editing and abstracting issues to ensure data consistency. The editing standards agreed upon are those of the SEER program.

Progress: A contract was negotiated and renewed with the American College of Surgeons (ACoS) to allow the use of the Cansur/Net software program for data collection by our Field Abstractor.

Progress: All identified Georgia hospitals in the SRRHIS area were personally contacted and introduced to the SRRHIS Registry. The Field Coordinator and the Quality Control Editor responded to inquiries from several institutions.

Progress: Correspondence was sent to all hospital tumor registries requesting them to use the American College of Surgeons (ACoS) national county codes.

Progress: The Georgia Cancer Registry database was updated with the data on electronic media sent from the Georgia hospital tumor registries. This database was restructured to conform with the SRRHIS database standard.

Progress: An agreement was made with the Warden of the Augusta Correctional Medical Institute to access their records for screening and abstracting SRRHIS cancer data.

Progress: Contact was made with the Director of a free standing pathology laboratory, to discuss gaining access to their records for screening and abstracting SRRHIS cancer data. Permission was obtained and data was collected.

Progress: Representatives of the American College of Surgeons (ACoS) conducted a training program at the offices of the GCCS on the use of the Cansur/Net software program. Microcomputer laboratory space was

donated by the Emory University School of Public Health.

Progress: Appropriate Cansur/Net abstract forms were obtained from the ACoS.

Objective 2: Implement a system of information descriptions regarding results from SRRHIS.

Progress: Preliminary data has been presented to the SRRHIS Steering Committee.

Progress: SAS analytic reports of the SRRHIS data were developed.

Objective 3: Implement a system of instructions and training of health information transfer to the public via media.

Objective 4: Implement an operational protocol compatible with major (SEER, ACoS) surveillance programs.

Progress: A letter of support from the Georgia Department of Human Resources was obtained which authorizes the Georgia Center for Cancer Statistics (GCCS) to collect data for the SRRHIS as part of the operation of the Georgia Cancer Registry. This permits the mandatory reporting statutes of Georgia to be invoked for SRRHIS.

Progress: The SRRHIS Operational Procedures were developed to be consistent with the SEER rules wherever possible.

Progress: Procedures for identifying cases, editing and processing abstracts and other forms were developed according to SEER guidelines. Mechanisms for converting SEER extent of disease codes to summary stage codes and old topography codes to new codes were established.

Progress: A customized data collection program, Personal Computer Abstract (PCA), was developed and implemented.

Progress: Field Quality Control studies were conducted to evaluate accuracy and completeness of case finding and abstracting.

Progress: The agreement between The South Carolina Department of Health and Environmental Control and the Georgia Department of Human Resources was completed, enabling the exchange of information between states. The South Carolina county codes were installed onto the PCA system. South Carolina cases identified and reported in Georgia hospitals were extracted

and sent to the MUSC in AACCR format. Pathology reports for cases found to be South Carolina residents were mailed to MUSC.

Progress: Members of the Georgia SRRHIS team attended and presented tumor registry topics to SRRHIS Steering Committee meetings. The GCCS Registry Administrator attended a SEER data managers workshop at the National Cancer Institute. The Principal Investigator attended the SEER Principal Investigators meeting at the SEER headquarters.

Progress: The Quality Control Supervisor and the Registry Administrator attended meetings of the Georgia Tumor Registrars Association (GaTRA) and participated in procedures to standardize registry activities and improve the quality of data. The Principal Investigator attended a GaTRA annual education conference in Savannah and made a presentation on cancer registries in Georgia.

Objective 5: Implement a computerized data management system compatible with major surveillance programs.

Progress: Record descriptions of the working relational database were developed.

Progress: The record descriptions of the analytic flat files were developed.

Progress: The GCCS migrated to a DEC VAX 4300 mini-computer. This machine was purchased by the University.

Progress: A model was developed utilizing Cansur/Net. This system was later modified as indicated below.

Progress: A laptop microcomputer was obtained for the Field Coordinator.

Progress: A multiple decision support system, software to assist in the decision making process to determine when a cancer in an individual with a previous diagnosis is a recurrence or a new cancer, was developed based upon the NCI's The Seer Program Code Manual, Revised Edition.

Progress: The SEER ICD-O-2 edit computer programs were obtained, installed, and tested on the VAX 4000 system. These programs were analyzed, compiled, and linked successfully.

Progress: The electronic bulletin board software, Video Text (VTX), a DEC product, was obtained and installed on the VAX 4000.

Progress: A data management system for SRRHIS was initially implemented using Cansur/Net, a PC based tumor registry system from ACoS, for data acquisition in the hospitals; our abstractor would take a laptop which had Cansur/Net on it to all the hospitals in her assigned area, and abstract directly from the medical record into Cansur/Net on the laptop computer. The database management for SRRHIS was handled in the office using a DEC VAX 4000 running the VMS operating system. Patient, Cancer, and Hospital files were created and managed by a DEC 4GL (fourth Generation Language): Datatrieve.

Because Cansur/Net was not intended to be a data acquisition tool but rather a hospital registry system, it was very difficult to use for our purposes. It was oriented towards a central registry system for offloading in a way that prevented straightforward use of the tool for our purposes. It was oriented towards a single hospital registry and using it to collect data from many hospitals proved awkward and problematic.

We therefore developed our own data acquisition system, PCA: Personal Computer Abstracting. This is now in full production and is being used successfully to collect all directly abstracted data in the hospitals.

Data acquisition implemented through the use of PCA is supplemented with data submitted to the Georgia State Registry, which is reformatted and inserted into the SRRHIS data flow. This system is now in production and functioning well.

Objective 6: Implement a data assessment and reporting system compatible with national and international reporting systems.

Progress: SAS analytic reports of the SRRHIS data were developed.

Objective 7: Develop a plan for expansion of geographic boundaries of the registry as well as components.

Progress: The geographic SRRHIS service area in Georgia was redefined, increasing its size from 8 to 12 counties.

Objective 8: Develop a mechanism to enhance the influence and recognition of SRRHIS as a resource body in the scientific and lay community.

Progress: Dr. Liff spoke at the annual American Association of Central Cancer Registries meeting in Florida. He discussed cancer registration and incidence in rural Georgia. He addressed the SRRHIS registry in the context

of how it will enhance our ability to learn more about cancer in rural populations.

Objective 9: Study the feasibility of developing a birth defects registry and reporting system compatible with the cancer registry.

Progress: Data on Georgia birth rates and an inventory of hospital birth defect services were collected.

Progress: A proposed system for collection of birth defects data has been developed.

Objective 10: Develop a mechanism of collaboration with other registries and information systems.

Progress: The hospital data submission record description of the AACCR (American Association of Central Cancer Registries), a national standard's organization, was accepted as the standard for SRRHIS Georgia.

Objective 11: Implement a training and education component of SRRHIS.

Progress: The Fall 1992 Georgia - South Carolina Tumor Registrar's Association meeting was held in Aiken, South Carolina with support from the GCCS.

Progress: The Summer 1993 Georgia Tumor Registrar's Association meeting was held in Albany, Georgia with support from the GCCS.

Progress: The Fall 1993 Georgia Tumor Registrar's Association meeting was held in Savannah, Georgia with support from the GCCS. Dr. Liff spoke on the topic "Cancer Registration in Georgia." In this talk, he described the SRRHIS cancer registration, including its purpose and methodology, and encouraged the support of hospital cancer registrars in its operation.

SRRHIS Data Flow

APPENDIX K

Steering Committee Agendas

TENTATIVE AGENDA
SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
STEERING COMMITTEE

THURSDAY, APRIL 21, 1994

STATESBORO INN
106 SOUTH MAIN
STATESBORO, GA

SCHEDULE

7:00 p.m.	Introductory Remarks and Minutes	Mr. Andrew Rea Chairman
7:10 p.m.	Progress and Subcommittee Reports	
	- GA Progress Report	Dr. Jonathan Liff
	- SC Progress Report	Dr. John Dunbar
	- Legislative Issues	Mr. Tom Hendrix
	- SC State Cancer Registry	Ms. Brenda Nickerson Ms. Susan Bolick
7:30 p.m.	"Chemoprevention of Cancer"	Daniel Nixon, M.D. Associate Director for Cancer Prevention and Control, Hollings Cancer Center, Medical University of SC
8:00 p.m.	Report: "SRRHIS Quality Control Standards and Techniques"	Ms. Nancy Ferrelle, BS, CTR Cancer Registry Field Staff Supervisor, Georgia Center for Cancer Statis- tics (SEER, SRRHIS & GA Cancer Registry)
8:50 p.m.	Next Meeting Site	Committee
9:00 p.m.	Adjourn	

TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

THURSDAY, JANUARY 13, 1994

HOLIDAY INN OF WALTERBORO

1120 SNIDERS HIGHWAY

WALTERBORO, SC

SCHEDULE

7:00 p.m.	Introductory Remarks, Minutes	Mr. Andrew Rea Chairman
7:15 p.m.	Progress Reports South Carolina Georgia	Dr. John Dunbar Dr. Jonathan Liff
7:30 p.m.	"Uses of Cancer Registry Data"	Dr. Dee West Executive Director, Northern California Cancer Center; Director, Greater Bay Area Cancer Registry
8:00 p.m.	Report: "Results of the Perceived Risk Survey"	Dr. Daniel T. Lackland Director, Survey Research Center, Department of Biometry and Epidemiology, Medical University of SC
8:15 p.m.	Committee Reports Legislative Nominations By-Laws	Mr. Tom Hendrix Dr. Lisa Wagner Ms. Alva Driggers
8:45 p.m.	Next Meeting Site	Committee
9:00 p.m.	Adjourn	

TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

THURSDAY, OCTOBER 14, 1993

RADISSON PLAZA SAVANNAH

100 GENERAL MCINTOSH BLVD.

SAVANNAH, GA

SCHEDULE

7:00 p.m.	Introductory Remarks, Minutes	Mr. Andrew Rea Chairman
7:15 p.m.	Progress Reports South Carolina Georgia	Dr. John Dunbar Mr. Ken Gerlach
7:30 p.m.	Subcommittee Reports Nominations Legislation/State Registry	Dr. Bill Irby Mr. Tom Hendrix
8:00 p.m.	Update--SRS Citizens Advisory Board Public Meetings	Mr. Mark Musolf Public Involvement Westinghouse Savannah River Company
8:25 p.m.	Update--Production Activities at SRS; Advisory Board for Health Research; SRS Dose Reconstruction Project Interim Working Group	Mr. Brian Costner Energy Research Foundation
8:50 p.m.	Next Meeting Site	Committee
9:00 p.m.	Adjourn	

TENTATIVE AGENDA
SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM
STEERING COMMITTEE

THURSDAY, JULY 15, 1993

HOLIDAY INN - BEAUFORT

U.S. HIGHWAY 21 AT LOVEJOY STREET

BEAUFORT, SC

SCHEDULE

6:30 p.m.	Introductory Remarks, Minutes	Mr. Andrew Rea Chairman
6:45 p.m.	Progress Reports South Carolina Georgia	Dr. John Dunbar Dr. Jonathan Liff
7:00 p.m.	Subcommittee Reports: By-Laws Legislative Community Meetings	Ms. Alva Driggers Mr. Tom Hendrix & Ms. Brenda Nickerson Ms. Jan Koenig
7:15 p.m.	"Long Term Health Effects--The Hiroshima/Nagasaki Experience"	Dr. David Hoel Chairman, Department of Biometry/Epidemiology Medical University of SC
7:50 p.m.	Discussion	
8:15 p.m.	Next Meeting Site	Committee
8:30 p.m.	Adjourn

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TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

THURSDAY, APRIL 22, 1993

AUGUSTA RADISSON HOTEL

TWO TENTH STREET

AUGUSTA, GA

SCHEDULE

7:00 p.m.	Introductory Remarks and Minutes	Mr. Andrew Rea Chairman
7:10 p.m.	Progress Reports Subcommittees <ul style="list-style-type: none">- Committee Members- Legislative Issues- By-Laws- Community Meetings	Dr. Lisa Wagner Mr. Tom Hendrix Ms. Alva Driggers Mr. Fred Washington
7:30 p.m.	The Metropolitan Atlanta Center for Birth Defects Program, CDC	Dr. David Erickson Chief Birth Defects & Genetic Diseases Branch, CDC
8:00 p.m.	Discussion	
8:30 p.m.	Implications for SRRHIS	Dr. John Dunbar Principal Investigator SRRHIS
8:45 p.m.	Next Meeting Site	Committee
9:00 p.m.	Adjourn	

TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

THURSDAY, JANUARY 28, 1993

HOLIDAY INN - AIKEN

I-20 AND U.S. 19

AIKEN, SC

SCHEDULE

5:15 p.m.	Dinner	
6:30 p.m.	Introductory Remarks, Minutes	Mr. Andrew Rea Chairman
6:45 p.m.	Progress Reports South Carolina Georgia	Dr. John Dunbar Dr. Jonathan Liff
7:00 p.m.	Subcommittee Reports	Mr. Tom Hendricks Mr. Fred Washington
7:10 p.m.	Status of Birth Defects Registry	Dr. Yuko Palesch Biostatistician, SRRHIS
7:20 p.m.	Community Awareness Survey	Dr. Dan Lackland SRRHIS
7:35 p.m.	Community Meetings Demonstration	Dr. John Dunbar Dr. Glenn Fleming
	Next Meeting/Community Profiling	Dr. John Dunbar
8:05 p.m.	Discussion	

TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

FRIDAY, OCTOBER 23, 1992; 10:00 A.M.

RADISSON PLAZA SAVANNAH

100 GENERAL MCINTOSH BLVD.

SAVANNAH, GEORGIA

SCHEDULE

10:00 a.m.	Introductory Remarks, Minutes	Mr. Andrew Rea Chairman
10:15 a.m.	Progress Reports South Carolina Georgia	Dr. John Dunbar Dr. Jonathan Liff
10:30 a.m.	Summary of Savannah River Site Area Dose Reconstruction Project	Dr. Charles Miller Radiation Studies Branch Center for Disease Control Atlanta, Georgia
11:00 a.m.	Communicating with the Public about Environmental Risk.	Ms. Caron Chess Director Environmental Communi- cation Research Program Cook College Rutgers University New Brunswick, NJ
11:30 a.m.	Discussion	
12:00 noon	Upcoming Beaufort Community Meeting	Dr. John Dunbar
1:00 p.m.	Adjourn Lunch for Committee and Guests	

REVISED
TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

FRIDAY, JULY 17, 1992; 10:00 A.M.

MARRIOTT'S HILTON HEAD RESORT

130 SHIPYARD DRIVE - SHIPYARD PLANTATION

HILTON HEAD ISLAND, SOUTH CAROLINA

SCHEDULE

10:00 a.m.	Introductory Remarks and Minutes	Mr. Andrew Rea Chairman
10:10 a.m.	Progress Reports: Georgia	Dr. Jonathan Liff Co-Principal Investigator
	South Carolina	Dr. John Dunbar Principal Investigator
10:30 a.m.	Evaluating Cancer and Birth Defects in North Carolina	Dr. Tim Aldrich Director, North Carolina Central Cancer Registry
11:30 p.m.	New Business: <ul style="list-style-type: none">• Public Forum• Steering Committee Attendance• Use of Attitude, Opinion & Knowledge Survey Regarding the Savannah River Site• Set next meeting	Dr. Daniel Lackland
12:15 p.m.	Lunch	
1:15 p.m.	Chairman's Special Meeting of Committee Members	
	GA/SC Staff Meeting	
	Adjournment	

AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM STEERING COMMITTEE

WEDNESDAY, APRIL 15, 1992; 10:00 A.M.

MAGNOLIA ROOM - HOLIDAY INN - WEST

1075 STEVENS CREEK ROAD

AUGUSTA, GEORGIA

SCHEDULE

10:00 a.m.	Introductory remarks and minutes	Dr. John Dunbar Principal Investigator
10:30 a.m.	Causes of death in the SRRHIS area	Dr. Daniel Lackland Co-Principal Investigator, SC
11:10 a.m.	Registering Cancers: Identifying and validating cases	Dr. Jonathan Liff Co-Principal Investigator, GA Kenneth Gerlach, MPH Project Administrator, GA
12:00 p.m.	Lunch (and discussion at same time) <ul style="list-style-type: none">• Discussion of Committee organization and election of the Chairman• Set next meeting Adjournment after lunch	Dr. John Dunbar Principal Investigator

(REVISED)

TENTATIVE AGENDA

SAVANNAH RIVER REGION HEALTH INFORMATION SYSTEM

STEERING COMMITTEE

WEDNESDAY, FEBRUARY 12, 1992; 10:00 A.M.

ADMINISTRATION BUILDING, ROOM 112

UNIVERSITY OF SOUTH CAROLINA - AIKEN

AIKEN, SOUTH CAROLINA 29801

SCHEDULE

10:00 a.m.	Coffee, informal introductions	
10:30 a.m.	Introductions	Dr. John Dunbar Principal Investigator, SC
10:45 a.m.	Functions of the Steering Committee; Aims of the Registry	Dr. John Dunbar
11:05 a.m.	Relation of Project to the Department of Energy	Dr. Bonnie Richter
11:15 a.m.	What is a cancer registry?	Dr. Jonathan Liff Principal Investigator, GA
11:35 a.m.	What is a Birth Defects Registry?	Dr. Thomas Hulsey Co-Principal Investigator, SC
11:50 a.m.	Discussion, Questions and Answers	
12:15 p.m.	Lunch - Selection of chairman and discussion of ideas for the next meeting	
	Adjournment after lunch	

Note: We have tried to leave at least 5 minutes in each presentation for questions and discussion by Committee members

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