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A REPORT ON

THE MARSHALL ISLANDS STUDY

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support of some of the nation's leading experts in radiation physics and biology, nuclear medicine, endocrinology, genetics and a host of other highly specialized

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faction of some important data relative to the long term effects of radiation on humans. His frequent visits to the Marshall Islands and his true concern for the well being of all of the Marshallese, not just the study group, has generated tremendous affection in many of the Marshallese, who understand his true committment.

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was a negative one, ie, we spoke at length about reparation for injuries with emphasis on those individuals who had developed cancer of the thyroid and the one case of leukemia. The people of Rongelap were assured that if they became sick because of radiation, the U.S. would take care of them and pay reparations. The emphasis was on post-facto morbidity and mortality. I feel we could acheive a great deal more by taking the positive approach of early detection and treatment in the cure

of cancer. I do not beleive this point was ever really stressed in the translation. The questions from the people of Rongelap to the medical group were incisive and difficult to answer via a translator; ie, what is the relationship between long term radiation and stomach cancer; what relationship is there to uterine cancer, etc.? It appears to me that the educational program instituted by Dr. Naidu should carry a very high priority and should attempt to clarify the huge spectrum of diseases called "cancer" and to point out the myriad etiologies we now know to be operative - in addition to radiation, and stress the curability of cancer in some cases (especially the thyroid). This message must be understood by the entire population under study and any representatives from the media or from legislative bodies who are interested in the well being of the Marshallese. As I see it, this program should emphasize early detection and prevention and de-emphasize reparations for morbidity and mortality we cannot control.

Based upon my personal experiences with the program and my review of a number of publications, I find several questions and problems still unanswered in my perception of the evolution and future goals of the study. I realize that the answers to many of these areas of interest are probably available in the files, however, I feel the resolution of these questions and problems would do a great deal to bring a greater degree of cohesion to the data. I have divided the problems into three categories. There will, of course, be a significant degree of overlap for many of the problems. The categories are:

1. Communications
2. Experimental Design and Documentation
3. Inter-agency Authority and Responsiblity

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that local Americans, who have learned the language and have the respect of the people, be placed on a retainer salary with BNL. I would also suggest that previous interpreters (John Iaman and Sebio Shoniber) be placed on retainer salaries and the problems of obtaining a good medical history (how, what, why, where, when) be resolved in light of their medical orientation. Since most Marshallese are literate, a

series of medical history questions should be designed, from scratch, utilizing the above consultants to obtain reliable data on nutrition, living habits, attitudes, compliance, sequence of symptoms, etc., all in Marshallese, and fitted to the Marshallese culture. I beleive this can be done. The principal investigator should speak to the people in their own language, to demonstrate his concern for and respect for their problems. He should sit among them, and demonstrate his willingness to engage in an open discussion. The credibility of the program has been challenged repeatedly; primarily I feel, because of poor communications, including public relations with the press, public officials of the Trust Territory, ERDA, etc.

Last fall, for the first time, most of the laboratories involved in the long term study of the accident met to discuss the coordination of their individual efforts. There has emerged from that meeting the realization that there is a tremendous amount of data, that could and should be placed in a central data bank for the use of all partners to reduce duplication, flag inconsistencies and/or new areas of investigation as the integrated study advances, and to keep all principal investigators up to date on the total effort.

The administrative lines of command are poorly understood in the field. For example, I frequently heard this question. "Who's running this show - BNL or ERDA?" The ramifications of this confusion resulted in hard feelings and misunderstanding, and could, understandably, lead to misinterpretation if it reached the press.

A solution for this type of confusion in the field would be to include field representatives in the planning sessions at BNL and ERDA. I feel there should be

regularly scheduled, centralized (? Washington, D.C.) planning sessions to coordinate and clarify the various interrelationships and responsiblities for all concerned. The agenda should be circulated months in advance by the coordinating agency, asking for additional items for discussion prior to the meeting. The field representatives should include some representative from the Trust Territories, if possible, to anticipate or preclude misunderstandings with this vital administrative link. Such meetings would bring a sense of "common purpose" to all of the participants and allow each unit to clarify its role in relationship to the total effort.

One of the most vexing problems I encountered was the absence of medical records. We had comparative lab data from previous reports but the clinical data was rudimentary or not available at all. I realize this field trip was dedicated to a review of the thyroid problems, but unfortunately each patient had other problems that may have interacted with, or actually taken precedence over the thyroid problems. I found it very difficult to play with half a deck. My clinical judgement must be based on an evaluation of all of the available data - not just a few sentences describing the previous physical examination of the thyroid. The patients seemed confused by the fact that we were "only interested in their thyroids" and that Dr. Knudsen and John Iaman would take care of the rest of their complaints. I was fortunate enough to see some of the general sick call patients and there was a plethora of serious medical problems. In my opinion, the principal problems were nutritional. In fact, when we landed on Rongelap, the first thing we were told was, "We are starving." That was really the community's "chief complaint". I am afraid the medical team did little to deal with that problem.

I was asked to listen to a number of heart murmurs without benefit of any reliable history or prior findings. We examined one baby (18 months old) who was seriously ill, cachectic, febrile, lethargic, who had spent a great deal of time in the hospital at Majuro and Kwajelein. No previous data was available. The preliminary impression was severe malnutrition with secondary infection; ? malabsorption syndrome but with an extensive differential diagnosis. We flew the mother and child both to Kwajelein when we completed the study and admitted the baby to the Kwajelein hospital. Dr. Beal, the Cheif Medical Officer, agreed that the baby was seriously ill but did not want to be "dumped on" and therefore within 24 hours was threatening to send the baby to the Ebeye Hospital, a totally inadequate facility, to await transfer to Honolulu.

Since the study group is relatively small and medical records are, I feel, essential to patient care, I would recommend that selected clinical data on the study groups, and other pertinent data generated by the resident BNL primary physician be placed on microfiche and that copies of the data plus a reader be available at each clinical examination site; ie, BNL, Majuro, Ebeye, Rongelap, and Utirik, as well as the research vessel. I strongly favor the problem-oriented medical record, since it is the only medical record system I know of that is structured for flexible computer storage, manipulation, analysis, and retreival.

2. EXPERIMENTAL DESIGN PROBLEMS

A. After the initial crisis of the acute radiation effects had subsided, was a long-term prospective study research protocol devised, based upon the then known, long and short term biologic effects of the specific isotopes identified in the exposed area?

B. Was there a pre-selected data base for the study groups, irradiated and controls?

C. Was adequate data available on the unique biochemical profile of the Micronesians, to determine if the values found in the study represented a significant deviation; if not, when and how was the normative data derived

D. Has a Marshall Island Study methodology been formulated (in a written format) to:

1) describe and coordinate the procedures and methods of all examinations carried out on the group

2) provide standardized data for cooperative studies

3) serve as a guide for future evaluation

4) display the methodology employed in a fashion which lends itself to study by critical reviewers

5) suggest by retrospective analysis, necessary modification

E. As new radiologic exposure data from the monitoring of the eco-system and sometimes unexpected burdens of isotopes were discovered, was the medical research protocol revised to study the effects. How was this documented; ie, placed in written format or algorithim for management decisions regarding re-inhabitation, etc.?

F. How were the biochemical samples handled?

1) how many different laboratories were used to determine critical biochemical profiles

2) was a laboratory procedure manual written stressing the importance and details of the technique for drawing, preparing, storing, and transporting each of the biochemical samples

3) were split samples sent to the same and to different labs to check inter and intra laboratory variation?

3. INTERAGENCY AUTHORITY AND RESPONSIBILITY

Little more needs to be added to this group of problems, since many of them have been covered in the communication section. The primary additional area of concern involves the health care system for the entire Trust Territories. I wish the problems could be limited to Micronesia alone, but our conversations with Ezra Riklon, the Chief Medical Officer of Micronesia, clearly demonstrated that many of his problems originate in the Trust Territory headquarters for health care and, in turn, with the regional and central legislative bodies. I would recommend:

1. The entire Trust Territory health care delivery system be studied to clearly define the authority, responsibility, and funding characteristics in Micronesia.

2. The role of ERDA-BNL must be clarified and closely defined in writing, in relationship to:

   a. the research population and geographic area

   b. the primary care responsiblity and authority to all other Micronesians in the geographic area

   c. the channels of referral for selected patients from both the study and the remainder of the Micronesians must be clearly outlined. Each element in the referral chain should be furnished with explicit instructions on how to handle the administrative problems; ie, medico-

legal responsiblity, reimbursement, contact points, notification and transfer procedures, etc., to eliminate the confusion and ill-will that now characterizes these transactions.

d. ERDA-BNL is considered by the people and the leaders of Micronesia, and I suspect, much of the Trust Territories, as the "experts" in health care delivery. I think it would be very interesting to ask for their perception of BNL's role and responsibilities in relationship to the entire Trust Territories and to Micronesia...and how do these responsibilities relate to delegated authority?

I think BNL can be of tremendous assistance to the Trust Territories, in a constructive consultant capacity, hopefully via the Department of Interior. BNL has the medical system and administrative capability to clarify many of the problems that are now hampering health care delivery in Micronesia, and compounding the problems of BNL's assignment, the follow-up of the radiation accident group.

REPOSITORY PNNL

COLLECTION Marshall Islands

BOX No. 5686

FOLDER Enewetak Oct-Dec 1979

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Reviewed by [signature] Date 4/30/97