

Childhood Cancer: The Challenge to Hawaii's Healthcare System

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State Capitol
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FOREWORD

This report has been prepared in response to Senate Concurrent Resolution No. 76, S.D. 1, H.D. 1, and House Resolution No. 68, H.D. 2, which were adopted by the 1992 Regular Session of the Hawaii State Legislature. The resolutions requested the Legislative Reference Bureau to assess the support and assistance available in Hawaii to children with cancer and their families.

Since adoption of the resolutions, the Department of Health has been granted a Medicaid waiver by the federal government. The waiver will allow the State to contract with existing health plan providers to provide coverage for Medicaid recipients. The new program is called Hawaii Health QUEST, and implementation should minimize or eliminate many of the gaps in current coverage and help ensure access to care throughout the State. The Department hopes to have Health QUEST in place by spring or summer of 1994.

The findings and recommendations in this report are based upon the experiences and concerns expressed by the families of children with cancer, and interviews with the public and private agencies responsible for the programs that serve them. However, in many instances, they are equally applicable to all children with comparatively rare serious illnesses and those responsible for their care.

We wish to express our sincere appreciation to the following for their assistance in the preparation of this report: Kapiolani Medical Center; Queen's Medical Center; the American Cancer Society; Hawaii Department of Health, Children with Special Health Needs Program; Hawaii Department of Education, Communications Branch; Hawaii Department of Human Services, Medicaid Division; HUGS; and the Hawaii Children's Cancer Foundation.

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Chapter 1

INTRODUCTION

A child's fight against cancer is not an individual battle but requires the support and security of family and friends.¹

Every year in Hawaii, thirty-five to forty children are newly diagnosed with some form of cancer.² The impact of such a diagnosis on the child and his or her family and friends is devastating. The families supporting children with cancer are immediately plunged into turmoil and chaos, deeply affected by grief and anger. The simplest tasks of everyday life become overwhelming; all thoughts and action are concentrated on the stricken child. Even the act of reaching out for help can seem unduly burdensome to parents trying desperately to ease the agony of radiation and chemotherapy for their toddlers, young children, and teens.³

Recognizing the need to survey and synthesize the various types of support services available to children with cancer and to families of children with cancer, the Hawaii State Legislature resolved to study these issues by passing Senate Concurrent Resolution No. 76, S.D. 1, H.D. 1 and House Resolution No. 68, H.D. 2. With the exception of minor differences in style and grammar, the resolutions are identical. To eliminate cumbersome repetition of substantively identical material, quoted references will be to the concurrent resolution.

Senate Concurrent Resolution No. 76, S.D. 1, H.D. 1, asks that the study assess:

...the various support and assistance services offered in Hawaii to children with cancer and the families of children with cancer and identify gaps in services as well as recommend solutions that would eliminate the gaps.

The resolution further requests that the above-described analysis include, but not be limited to:

- (1) Overall support services that inform the child and family about treatment and medical procedures, the side effects, how to make decisions, and how and when to obtain a second opinion;
- (2) Overall support services that inform the child and family about hospital services, facilities, medical procedures, and test results;
- (3) Overall support services from the health care team, social work assistance, child care, and emotional counseling services;

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- (4) Overall support services regarding transportation for medical treatment and temporary housing when the child and family must be away from home;
- (5) Education and establishment of a public network that includes employers, schools, and peers and is supportive and sensitive to the needs of the affected individual and family;
- (6) Provision of assistance and guidance on how to meet the accumulated financial costs of health care, how to understand the requirements and complexities of various medical insurance plans, how to secure provisions for non-covered costs incurred as a part of treatment (i.e., medical supplies and medications), and how to access necessary medical treatment (i.e., transportation to care centers, especially for neighbor island families, and temporary housing);
- (7) Counseling and preparation services for the child with cancer that survives and the issues that must be addressed if the illness recurs; and
- (8) Cooperative group participation in local and national cancer clinical trials and therapy investigations in order to guarantee that children being treated in Hawaii are receiving the most current advance[d] therapies for optimal outcomes in the treatment of childhood cancers, as well as state-of-the-art medical facilities and care for pediatric oncology patients[.]

Further, the resolution charges that this study address:

...how [the study's] findings and recommendations relative to children with cancer may be applied to improve the system of services for all children with serious illness and disorders insofar as specific recommendations regarding improving health care financing and support and assistance services for children with cancer may have applicability to children with serious illnesses in general, regardless of the specific diagnosis[.]

To these ends, Chapter 2 of this study will examine the existing various support and assistance services offered in Hawaii to children with cancer and other chronic illnesses and the families of such children, including: (1) medical information support services; (2) educational support services; (3) social support services; and (4) financial support services. This chapter will identify the gaps in services where they exist, and will attempt to qualify those gaps by discussing what services seem to be most important to the families of chronically ill children. This qualification will be based on data obtained from surveys of these families, as well as interviews with some of the families themselves and with professionals in the medical and support service fields.

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Chapter 3 of the study will define "state-of-the-art medical facilities and care" as that term is used in the resolution, and will broadly catalog the medical facilities and machinery available in Hawaii, the types of services available, and the range and quality of medical care and treatment that can be rendered in Hawaii. This discussion will be based on data obtained from interviews with health professionals and hospital administrators.

Chapter 4 addresses the financial aspects of chronic illness. A limited number of studies performed by health professionals and published in medical journals over the past ten years provide some national statistics by which to assess the financial stresses borne by families of children with chronic illnesses. Although the journals focus specifically on cancer victims, the results of the studies are easily extrapolated to most chronic illnesses. This chapter will also assess and compare the various forms of financial assistance currently available to support families in bearing the burden of medical expenses. This assessment will include a discussion of: (a) available health care plans; (b) what aspects of the illness and treatment are covered under the health care plans; and (c) whether Hawaii's families appear to be coping successfully in meeting the expenses of cancer. Again, the data supporting this discussion will come from interviews with the families themselves, with health professionals, and with third party payors.

Chapter 5 will explore issues and policy questions involved in eliminating the gaps in services to Hawaii's children with chronic illness. This chapter will include a determination of a likely range of assistance to be offered in the areas of: (a) support services, as described in Chapter 2; (b) health care, as described in Chapter 3; and (c) health care financing, as discussed in Chapter 4. This determination will be based on research into the structure of programs and assistance currently offered by the State of Hawaii and by other states.

Chapter 6 contains the findings and recommendations of the study. Specific support service and financial assistance programs best suited for Hawaii's needs are listed and discussed in order of preference.

Senate Concurrent Resolution No. 76, S.D. 1, H.D. 1, specifically requests that the following entities be contacted in order to conduct this study:

- (1) Hawaii Children's Cancer Foundation;
- (2) HUGS;
- (3) American Cancer Society;
- (4) Childhood Cancer Committee (a committee within the American Cancer Society);
- (5) Kapiolani Medical Center for Women and Children;

- (6) Department of Radiology at Queen's Hospital;
- (7) Cancer Research Center, University of Hawaii;
- (8) Department of Human Services, State of Hawaii;
- (9) Medicaid Division, Department of Human Services, State of Hawaii;
- (10) Department of Health, State of Hawaii;
- (11) Department of Education, State of Hawaii; and
- (12) Relevant third party payors.

Each of these entities was contacted for consultation regarding the relevant area of inquiry. However, it should be noted that as pediatric oncology is such a specialized field, there is a *great deal of overlap of personnel among the various private organizations*. It should be further noted that the Department of Radiology at the Queen's Medical Center is not involved in the administration of health care to pediatric oncology patients. The Department of Radiation Therapy at Queen's Medical Center is centrally involved in administering radiation therapy to pediatric oncology patients, usually those with leukemia or solid tumors.⁴

Endnotes

- 1. Letter dated July 7, 1992 from a pediatric oncology patient's relative to Richard Davi, President and CEO, Kapiolani Medical Center.
- 2. Telephone interview with Robert Wilkinson, M.D., Pediatric Hematologist/Oncologist and Associate Professor of Pediatrics at John Burns School of Medicine, University of Hawaii, September 18, 1992; Testimony of Robert Wilkinson, M.D., before the Hawaii House of Representatives regarding Senate Resolution No. 59 and Senate Concurrent Resolution No. 76, March 4, 1992.
- 3. Interview with relatives of children with cancer, September 4, 1992.
- 4. Interview with Mr. Lester Uyeda, Director, Radiation Therapy, Queen's Medical Center, Honolulu, Hawaii, and Paul DeMare, M.D., Radiologist, Queen's Medical Center, Honolulu, Hawaii, July 30, 1992; interview with Mr. Lester Uyeda, Director, Radiation Therapy, Queen's Medical Center, Honolulu, Hawaii, and John Lederer, M.D., Radiologist, Queen's Medical Center, Honolulu, Hawaii, August 19, 1992.

Chapter 2

QUALITY OF MEDICAL CARE IN HAWAII

Kapiolani Women and Children's Hospital is the only center for the State of Hawaii and the entire Pacific basin for the care of children with cancer and other chronic or serious illnesses.¹ Although other hospitals may be involved to some extent in administering certain aspects of the medical treatment which these children require, the primary coordination and responsibility is based at Kapiolani.² In 1992, there were only three pediatric oncologists in the State of Hawaii: Dr. Robert Wilkinson, Dr. Arthur Osako, and Dr. Shigeko Lau.³ Since patients and their families have virtually no choice in local care providers for childhood cancer, the question of the quality of medical care for Hawaii's children becomes especially important.

The resolution asks for research into the following areas:

- (1) Are Hawaii's children receiving the most current and advanced medical therapies?
- (2) Are groups participating in local and national cancer clinical trials and therapy investigations?
- (3) Does Hawaii have state-of-the-art medical facilities and care for pediatric oncology patients?

Research discloses that the first two questions are part and parcel of each other, and therefore they will be discussed together. Research also discloses that the first two questions are more easily answered than the last.

Current Medical Therapies

Because of the low incidence nationwide of childhood cancers, there are too few patients to supply data for local study groups. Therefore, there are no local study groups for clinical cancer trials anywhere in the United States. Nationally, there are only two study groups for clinical cancer trials. This is because the national population of cancer victims is sufficient to support only two such groups.⁴

All three of Hawaii's pediatric oncologists participate in the same national study group, the Pediatric Oncology Group (POG).⁵ The radiation oncologists at Queen's Medical Center participate in the same study group as well.⁶ The doctors all agree that it would be pointless for any one of them to participate in the other study group because the cross-over of data would merely be duplicative and would confuse the database. The other study group closely

approximates the type and manner of the clinical trials done by POG, so there would be no advantage to changing over to the other study group.⁷

Between them, the two national study groups provide the national standard of care for pediatric oncology. They provide the "protocol," or treatment plan, for childhood cancers of all types, as well as a network of specialists in the field who can be contacted quickly and easily for consultation or to send patients to the mainland.⁸

Participation in either study group is very strictly policed and enforced. In order to have accurate studies, the "protocols" must be followed precisely, with no deviation allowed whatsoever. If a doctor varies from the protocol even once, he can be removed from the study group, and none of his patients will have the benefit of immediate knowledge of advancements in therapies, or the networking that goes with the study.⁹ Therefore, when the doctor perceives that a family will have difficulty returning for even one portion of the treatment or a check-up test, the doctor does not register the patient with the study group, and places the patient on "para-protocol," which is as close an approximation of the protocol treatment as possible under the circumstances. This compromises the patient's care as little as possible while retaining the doctor's membership in the study group. These "para-protocol" treatments usually arise in the cases of patients from elsewhere in the Pacific Basin, such as Samoa or Guam.¹⁰ Virtually all of the neighbor island patients are on protocol.¹¹

The simple answer to questions (1) and (2) is yes. Hawaii's children are receiving the most current and advanced medical therapies, and Hawaii doctors are participating in one of the two national cancer clinical trials and therapy investigations.

State of the Art Medical Facilities and Care

The last question is more complicated to answer. Does Hawaii have state-of-the-art medical facilities and care for pediatric oncology patients? The answer turns on the definitions of the terms "state-of-the-art," "medical facilities," and "care."

The dictionary defines "state-of-the-art" as "the scientific and technical level attained at a given time[.]"¹² "Facility" is defined as "something designed, built, installed, etc., to serve a specific function or perform a particular service: transportation facilities, educational facilities."¹³ The relevant definition of "care" is "protection; charge or temporary keeping: He's under the care of a doctor."¹⁴

Strict Construction

It is possible to construe "state-of-the-art medical facilities and care" as meaning the medical treatment performed by doctors and administered through the technical, scientific machinery designed, built, and installed to serve the specific function of administering

medical treatments to Hawaii's children. Utilizing this construction, Hawaii does seem to have state-of-the-art medical facilities and care.

Most of the actual machines that administer the treatment to the children are probably state-of-the-art. It would be virtually impossible to survey each and every machine used on each and every child with cancer or another form of serious or chronic illness in the State of Hawaii. But as an example, a radiation oncologist at Queen's Medical Center stated categorically that "Queen's does not lack any conventional, non-experimental equipment. Queen's has new equipment, and well-qualified personnel to administer treatment. Queen's is adequately staffed with a dedicated staff, and has ancillary assistance with treatment, such as anesthesiologists who can sedate children so they are treatable."¹⁵

Queen's houses three linear accelerators with dual photon and multiple electron beam capability. CT-scan assisted computerized imaging and treatment planning for customized cerrobend blocking assures the most accurate dissemination of radiation possible to the affected site. Queen's does not perform any heavy ion treatments such as heavy-particle-beam radiation therapy because they do not have the required machinery. Currently, only three centers in the United States have heavy-particle-beam radiation capability. It is used primarily for research at this point, and does not have any clinical indications. Moreover, the types of tumors involved in heavy-particle-beam radiation therapy are primarily adult tumors, and not usually found in children.¹⁶

Since 1977, St. Francis Hospital has been able to perform bone marrow transplants on patients over the age of three years. St. Francis is currently certified by POG to do such transplants. However, as a practical matter, there are very few bone marrow transplants done in Hawaii,¹⁷ only one or two a year.¹⁸ With such a low volume, it is understandable that people would prefer to go to a mainland institution with a higher volume and therefore greater familiarity with the procedure.¹⁹ Even so, according to Dr. Wilkinson, one of the three Hawaii pediatric oncologists, only ten to fifteen percent of his patients go to the mainland for treatment of any type. The rest go to (or through) Kapiolani.²⁰

At Kapiolani, at least for pediatric oncology, treatment on the premises consists primarily of chemotherapy, blood tests, and pathology tests.²¹ The equipment to perform these treatments is not dramatically affected by technological advancements, and is technologically sound at this time.²² Kapiolani sends all patients requiring radiation therapy to Queen's for treatment.²³ Kapiolani does do autologous bone marrow transplants, where the patient's own bone marrow is transplanted from one bone in the body to another.²⁴ Kapiolani also does bone marrow transplants from a donor to a patient on children under four years old, as St. Francis Hospital is not set up to handle very young children.²⁵ Kapiolani feels that its equipment is state-of-the-art to perform these surgeries, although there may be some room for improvement in the air conditioning for the theater where the bone marrow transplants are done. There is some controversy surrounding the type of air conditioning required to perform the surgery, and the medical literature is not in agreement on exactly what is required.²⁶ Dr. Wilkinson says that Kapiolani is a "good center." Mainland site visits have rated it as good, even better than some mainland centers. Kapiolani is not doing research like

St. Jude's or UCLA, but it is tied into POG. The cancer cure rate in Hawaii is going up quickly, staying close to national group."

Broader Construction

It is possible to construe the terms "state-of-the-art medical facilities and care" a little more broadly, however, and the broader view is usually the one taken by the patients and their families.²⁷ The medical facilities are more than just the machinery used to administer the medical treatment--they include the entire hospital facility and its administration, down to the single toilet shared by four patients and their extended families in the four-bed ward (all four beds in a single room) on the Wilcox floor at Kapiolani. Care is more than the doctor's charge--it includes the attention of the nurses and technicians administering (or forgetting to administer) the protocol prescribed by the doctors, and the understanding and assistance (or lack thereof) of the accounting department when it comes time to pay some overwhelming bills.

During the fall of 1991, renovations were done to the Wilcox floor, the pediatric oncology floor at Kapiolani. However, the parents felt that very little was done to improve the patients' situation by that renovation. The need for privacy impacts both physical and mental well-being. Tension is created when strangers are forced to co-exist intimately under the adverse circumstances of being treated for life-threatening illness. In May of 1992, a patient's relative shared these thoughts with the administration of Kapiolani:

When sharing a room, the patient and his family can never really feel comfortable and at ease as they must always be considerate of the other patient's presence, needs, and right to privacy. Is the other patient sleeping? Are we talking too loud? Can we watch TV and which program? Can we turn the air conditioner up (or down)? Should we turn on/off the lights? Is the bathroom available? Even conversations with their doctor and nurses are not private. Having to be constantly vigilant is not conducive to the well-being and comfort of the patient and his family.

All cancer families know the side effects chemotherapy treatments (sic) can have on a patient. At its worst, it is not a pleasant experience. It puts the patient in a very uncomfortable situation knowing that others besides his family, have to witness his bouts of severe nausea. Although the patient and his family can relate to the unpleasant side effects chemotherapy causes, it is also very discomfoting to have to relive the effects through the other patient's experiences.

During critical times, when the patient is not responding well to chemotherapy treatments, some patients and their families find it difficult to cope with their emotions and the stress in the presence of strangers. Some people are openly expressive with their emotions, which is understandable, except that it can be very frightening to a patient who does not fully comprehend the

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circumstances. When sharing a room, a family cannot control the experiences their child is exposed to which may cause severe anxieties. Everyone deals with emotions and stressful situations in a variety [of] ways; some people are able to share their feelings and emotions while others may not be ready to. Each family should have the right to private moments and the opportunity to choose when to share their experiences, directly or indirectly.

Anyone who has experienced the stress and strain of having a family member battle cancer can relate to this predicament. I hope steps can be taken to provide pediatric oncology patients and their families the privacy and comfort they need during their hospital stays.²⁸

Kapiolani's Executive Vice President responded to this letter as follows:

We understand and appreciate the privacy needs of patients and their families, unfortunately, with the increase in patient visits, we have outgrown our space. Our long range plan is to have single room occupancy for all of our special patients. Until that time, we will work diligently with the space we have in accommodating patients, their families, and their wishes the best we can.

We thank you for taking the time to relate your concerns and experiences to us. Your comments are valued and we appreciate them as we search for better solutions to the problem on a short term basis while working on the long term space issue.²⁹

However, one month later, the same family again found itself confronting an unchanged and unsatisfactory situation.

Once again, I am writing to ask your assistance in finding a solution to our concerns regarding room facilities on the third floor Pediatric Oncology Unit at your hospital. Since it's (sic) reopening, it has caused our family much anxiety each time a chemotherapy treatment was scheduled.

During our first stay, we were one of the first patients assigned to one of the two single occupant rooms. What a relief! The second time, we shared a room with a very ill patient being fed intravenously so we tried to restrict our activities and be as quiet as possible to enable him to get the rest he needed. His family appeared to be very private people so we tried to be as unintrusive as possible. On our third visit, we shared a room with (sic) a female patient [opposite sex] who was moved to the room because her family was unhappy with the situation in her previous room. On our fourth visit, we were initially assigned to the ward but was (sic) subsequently moved to a room with another patient. Unfortunately, the lifestyle of this patient and his family was not compatible with ours. Knowing that this would be one of our shorter stays, we tried to be understanding

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and tolerant but it was a most difficult situation to cope with. We were ready to ask for a room change to help alleviate our anxieties but luckily, we were discharged. In addition, the family was having problems coping with their son's illness which caused tensions and arguments among family members. It was most uncomfortable to be present during these times but there was nothing we could do! Family problems like these should be private matters that they work through among themselves with the help of health care professionals, if necessary. They should not have to cope with these problems in the presence of strangers.

As we recall our own family's experiences and all the emotional upheavals we endured during our month long stay after initial diagnosis and our two week stay when reaction to chemotherapy was intense, we cannot begin to imagine what additional stresses and strains we would have had to endure were we not in a single occupant room on the fourth floor. Thank heavens! We do not look forward to and await with apprehension our next chemotherapy treatment.

A child's fight against cancer is not an individual battle but requires the support and security of family and friends. Because frequent and sometimes prolonged hospital stays are inevitable in its treatment, patients and their families need a room that provides them the opportunity to concentrate their efforts and energies on conquering this disease rather than coping with roommates. It is important that your hospital be more sensitive to not only the medical needs of the patient but the emotional and psychological well-being of the families as they aid him in the fight against cancer.

It is unfortunate that families who are fighting for the life of their child must also concern themselves with seeking the privacy and comfort of single occupant rooms they need during their many hospital stays. We ask your assistance for immediate, even if only temporary, solutions to our needs.³⁰

Hawaii Children's Cancer Foundation

The common experiences of the families of pediatric oncology patients bonded together a core group, and in 1992 the Hawaii Children's Cancer Foundation (HCCF)³¹ became a nonprofit corporation dedicated to improving the lot of children with cancer and their families.³² Also in 1992, HCCF published the results of its survey of ninety-two families seeking information about their needs and perceptions in eight different areas relating to the fight against cancer.³³ While the responses to the questions regarding hospital services and facilities seemed favorable (overall, seventy-seven percent said they understood hospital services and facilities, eighty-five percent said they understood the medical procedures, and eighty percent said they understood the test results), the individual written responses again reflect the fears and frustrations experienced by many families of children with cancer in the hospital setting.

Treatment/Care/Procedures

- "Information and assistance from medical and social work staff was very intense at first (almost overwhelming) but then almost hit and miss.["]
- "Did not particularly like to go to the ER to screen patients before admission to the hospital. Too many chances to catch communicable diseases."
- The four-bed ward should not be a place for oncology patients. No bath, no privacy."
- "My other concerns--the hospital equipment is inadequate. It seems like the children get the shaft because they are unable to speak for themselves."³⁴

As these responses indicate, the delivery of medical services does not occur in a vacuum. While the medical procedures themselves may be state-of-the-art and in line with the standard national protocol, the recuperative support base from which the patient and their families operate while within the hospital is not perceived by them to be on the same par. Are Hawaii's children receiving the most current and advanced medical therapies? Yes. Are groups participating in local and national cancer clinical trials and therapy investigations. Yes. Does Hawaii have state-of-the-art medical facilities and care for pediatric oncology patients? Narrowly defined, yes. We have the technical wherewithal to deliver state-of-the-art medical procedures. Broadly defined, however, state-of-the-art medical care includes the recuperative support base from which the patient and their families operate while within the hospital and while interacting on an outpatient basis with the hospital. Much work is needed to provide patients and their families the support necessary to concentrate their efforts and energies on conquering this disease.

Endnotes

1. Interview with Carol Kotsubo, Patient Care Coordinator, Kapiolani Women and Children's Medical Center, June 24, 1992; interview with John Lederer, M.D., Radiation Oncologist, Queen's Medical Center, August 19, 1992; telephone interview with Robert Wilkinson, M.D. Pediatric Oncologist, September 18, 1992; interview with parents of children with cancer, September 4, 1992.
2. Ibid.
3. According to Dr. Wilkinson, one additional pediatric oncologist is currently scheduled to begin practice in Hawaii in July 1993. By 1997, six to eight pediatric oncologists should be practicing in Hawaii. Telephone interview with Dr. Robert Wilkinson, M.D., September 18, 1992.
4. Interview with Dr. Paul DeMare, Radiation Oncologist, Queen's Medical Center, Honolulu, Hawaii, July 30, 1992; interview with John Lederer, M.D., Radiation Oncologist, Queen's Medical Center, Honolulu, Hawaii, August 19, 1992; telephone interview with Robert Wilkinson, M.D., Pediatric Oncologist, September 18, 1992.

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5. Wilkinson interview.
6. Interview with Paul DeMare, M.D., Radiation Oncologist, Queen's Medical Center, Honolulu, Hawaii, July 30, 1992; interview with John Lederer, M.D., Radiation Oncologist, Queen's Medical Center, Honolulu, Hawaii, August 19, 1992.
7. Ibid.; telephone interview with Robert Wilkinson, M.D., Pediatric Oncologist, September 18, 1992.
8. Ibid.
9. Ibid.
10. Ibid.
11. Wilkinson interview.
12. The Random House College Dictionary, Revised Edition, Random House, 1975, p. 1282.
13. Ibid., p. 473.
14. Ibid., p. 204.
15. Interview with John Lederer, Radiation Oncologist, Queen's Medical Center, Honolulu, Hawaii, August 19, 1992.
16. Ibid.
17. Wilkinson interview.
18. Lederer interview.
19. Ibid.
20. Wilkinson interview.
21. Telephone interview with Carol Kotsubo, Patient Care Coordinator, Kapiolani Medical Center for Women and Children, November 25, 1992.
22. Ibid.
23. Ibid.
24. Ibid.
25. Ibid.
26. Ibid.
27. Interview with families of childhood cancer patients and the representatives of those families, September 4, 1992. To protect their privacy, the names of those families will not be disclosed in this study.
28. Letter A: letter from oncology patient relative to Mr. Richard Davi, President, Kapiolani Medical Center.
29. Letter dated June 2, 1992 from Walter L. Behn, Executive Vice President, Kapiolani Medical Center for Women and Children, to oncology patient's relative.

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30. Letter B: Letter from a pediatric oncology patient's relative to Richard Davi, President, Kapiolani Medical Center for Women and Children.
31. The Hawaii Children's Cancer Foundation was the driving force behind legislative resolution to conduct this study.
32. The Articles of Incorporation of the Hawaii Children's Cancer Foundation list the purposes of the corporation to be: (1) to assist, support and advocate for the needs of patients and survivors; (2) to promote and help defray the cost of state-of-the-art health care and its development for cancer patients and survivors; and (3) to solicit and accept contributions. The goals of the foundation are stated to be: (1) to build partnerships among health caregivers, social service providers and families; (2) to promote legislative support; (3) to provide support for educational programs, public awareness, information on research, medical insurance and financial assistance; (4) to develop resources for direct assistance to families; (5) to network among families, patients, and survivors; and (6) to establish contacts with national resources and agencies.
33. Hawaii's Children's Cancer Foundation Survey Results, undated, unpaginated insert (attached hereto as Appendix B).
34. Ibid.

Chapter 3

AVAILABLE SUPPORT SERVICES

Medical care for children with life threatening illnesses is of course the fundamental core of their treatment and survival. But a panoply of satellite issues affects such a child and that child's entire family. Who are the best doctors for this condition? What are the side effects of the treatment of choice? If both parents work, must one give up his or her job in order to transport the child to the doctor's offices and hospitals for treatment? What will happen to the insurance policy if the other parent loses his or her job? Who will take care of the other children in the family while the ill child is being cared for? If the family lives on a neighbor island, how will they get to Oahu for the treatments? What does insurance cover? What does Medicaid cover? How do you apply for Medicaid?

For purposes of this study, in order to survey the various support services that are already in place for children with cancer, the services were divided into the following categories: (1) medical information support services; (2) educational support services; (3) social support services; and (4) financial support services. The survey revealed that there are relatively few support and assistance services currently in place for Hawaii's children with cancer, either in state government or privately. For example, the Children with Special Health Needs Branch (CSHNB) of the Department of Health of the State of Hawaii provides many comprehensive services for Hawaii's low-income children with serious illnesses and disorders, even including financial assistance with payments from CSHNB funds. A few conditions have *no financial eligibility requirements to merit assistance from CSHNB*. But as of April 1, 1993, CSHNB provided no services at all for children with cancer, low income or otherwise.¹

Those services that are in place, whether publicly or privately funded, are often very thin in terms of depth or range of assistance. For example, the American Cancer Society sponsors a wonderful week of summer camp each year for childhood cancer patients and survivors, but has no on-going, everyday support programs specifically tailored for the needs of children facing cancer, and their families.

Medical Informational Support Services

Medical informational support services include those which assist both the child and family by informing them of various aspects of their illness, including: (1) treatment and medical procedures; (2) side effects; (3) how to make decisions regarding treatment; (4) how and when to obtain a second opinion; (5) hospital services; (6) hospital facilities; and (7) test results.

These services are currently being provided by the health care team, namely the doctors, nurses and hospital staff who administer the health care to the patient.² Because there are only three pediatric oncologists in the State of Hawaii, the doctors work closely together and consult with each other constantly. This provides the patients with a team of oncologists and a "built-in" second opinion, but generally does not satisfy the family's urge for a more independent second opinion. The Candlelighters Childhood Cancer Foundation has established a toll-free telephone number to call for a non-case specific discussion with a doctor of the propriety of treatment for a given condition.³

The problem for most parents is that they are relying on three very busy doctors for most of their medical information and education. While the doctors may be as accommodating as possible, the parents are reluctant to make too many demands on the doctors' time. Yet the parents must become very familiar with the details and characteristics of the disease very quickly so they can interact appropriately with the health care team and their child.⁴ This is a dilemma that currently has no alternative support for parents.

Educational Support Services

Two different types of education must be addressed when dealing with life-threatening disease and children: (a) education regarding the disease itself; and (b) scholastic, or academic education. "Disease Educational Support Services" include those which assist the child and family by educating them and numerous others with whom their lives intersect regarding the illness. These services are rendered by a number of different providers. "Scholastic Education Support Services" are those which enable or assist the child in continuing his or her academic education. These services are provided by the state Department of Education.

Disease Educational Support Services

The American Cancer Society (ACS) puts out a number of pamphlets and brochures on cancer, as well as videos that can be borrowed at no charge. ACS also has developed an educational seminar, "I Can Cope," on living with cancer for delivery by hospitals. However, this seminar does not address the issues of childhood cancer,⁵ such as the swiftness with which the disease develops and worsens in children, or residual disabilities resulting from treatment.⁶

There are very few seminars, lectures, or interactive workshops offered by Kapiolani Women and Children's Medical Center, Community Education Services. The seminars that have been offered in the past have been sporadic and not well attended by parents. The numbers of patients and parents with similar needs are not sufficient to support these types of

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classes.⁷ Kapiolani does hold formal meetings between parents and the health care team during the initial phase of treatment in order to give the parents some grounding in the medical treatment to be given their children.

The resolution calling for this study requested research regarding the establishment of a public network that includes employers, schools, and peers and which is supportive of and sensitive to the needs of the affected individual and family. Research has not shown the existence of any such network nor any plans for the establishment of such a network.

However, Kapiolani's Clinical Nurse Specialist for Pediatric Oncology, Carol Kotsubo, serves a need in the area of public networking. She will act as a "school liaison," presenting a program to the patient's class to prepare the other children for the return of the patient to class. She has also presented this program to a sibling's class. She takes two nurses, the family and child, where desired, and educates the class in terms of the child's illness, his or her treatments, and what to expect in the way of ability, disability, and behavior from the returning child. She has had good feedback on these sessions, from both the families and the schools. Her program is available on Oahu only, however she assists parents on neighbor islands in presenting their own programs. On Oahu, her presentations are tailored to what the school wants and what the child wants. These presentations have also occurred at faculty meetings, and she speaks with school nurses, health aides and school principals about what to expect from the child, and when to call the doctor.⁸

Scholastic Education Support Services

The state Department of Education provides tutors for children who are out of school for two weeks or longer.⁹ The tutors can go to the hospital or to the child's home, but cannot travel out of State. Typically, the tutors are engaged with the students two to three hours per week. Kapiolani's "Child Life Support Services" section coordinates with the Department of Education to bring in-hospital tutors for the child within a day of the request.

The Department of Education is mandated to serve children three years of age and over. Following an educational evaluation, a child is certified as special education eligible and an individualized educational plan is drawn up for the child. Physical therapy, speech therapy, and occupational therapy are provided for school-age children, including a summer session. Each of these support areas have specific eligibility criteria. Transportation can be provided by the Department of Education to the special education programs and home again.

Social Support Services

These services include those which assist the child and family through: (1) social work assistance; (2) child care assistance; (3) emotional counseling services; (4) support from

health care team; and (5) counseling and preparation services for a child that survives the illness, including issues for a child to address if the illness reoccurs.

Social Work Assistance

Kapiolani Women and Children's Medical Center. Kapiolani provides one half-time social worker to service pediatric oncology patients and their families. Needless to say, the social worker is extremely busy, and the families generally feel that their needs are not being met. The social worker is there primarily to teach families how to access and use available support systems.¹⁰ She is not able to fill out forms for families or do the accessing for them. However, many families feel that they need this type of assistance because their time is entirely taken up by giving emotional and physical support to their ill child.

There are no other social work programs at Kapiolani targeted specifically for cancer patients or other catastrophic illness patients.

American Cancer Society. The American Cancer Society (ACS) does not provide social work assistance per se to cancer victims or their families. However, they do try to provide some resource coordination for these families. For example, although ACS does not provide monetary assistance to families with cancer, ACS has a program by which medical supplies¹¹ can be donated to ACS and then made available on a first-come-first-serve basis to cancer patients. These medical supplies do not include medications.

ACS also loans certain types of equipment, and can act as both resource and coordinator to answer families' needs. For example, ACS recently coordinated the donation of materials and services to get a wheelchair ramp built for a family.

ACS also makes nutritional supplements available at no charge. If their budget permits, they can provide air tickets for neighbor island families, and in certain circumstances they can supplement the cost of hotel stays. Once on Oahu, ACS can provide ground transportation through its "Angels on Wheels" program. Volunteers drive patients to doctor's offices, treatment centers, clinics, or hospitals.

ACS participates in an informal support group for teens at Tripler Army Medical Center called "KISS: Kids Indicate Something Special."

Tripler Army Medical Center. Open to the public, Tripler began sponsoring a cancer patient support group called "KISS: Kids Indicate Something Special" in 1991. The group discusses issues relating to cancer, and is open to children with cancer or survivors, age thirteen and over. Siblings and friends are also welcome. Meetings occur once a week from 2:00 p.m. to 3:00 p.m. at Tripler. Doctors and nurses are invited occasionally, but primary focus is to eat and talk together about their common experiences, and about surviving cancer. An American Cancer Society coordinator also participates in the group.

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Ronald McDonald House. The Ronald McDonald House is a short-term, non-profit housing facility for the families of minor children receiving hospital treatment. It is located less than a mile from Kapiolani Medical Center, has eleven bedrooms and can accommodate up to twenty-five guests at one time. The cost is \$12 per room per night, although the policy is not to deny families housing due to inability to pay. Rooms cannot be promised more than twenty-four hours in advance, however, and the facility is usually full. If families cannot be accommodated, Ronald McDonald House attempts to make alternative arrangements (such as discounted hotel rooms) until there is room at the house.

Department of Human Services. The Social Services Assistance section of the Family and Adult Services Division of the Department of Human Services has no specific program for children with cancer. However, if a cancer patient is abused, neglected or threatened with harm, the agency will care for the child according to its usual standards of maintaining the youngster in the home if possible, or placing the child in a foster home.

Child Care Assistance

There is currently no program offering child care assistance for families of children with cancer or other catastrophic illnesses.

Emotional Counseling Services

HUGS (Help, Understanding, and Group Support) for Hawaii's Seriously Ill Children and Their Families provides emotional counseling services for families of children with cancer, but HUGS serves a small population due to its very limited, overworked staff. As busy as the HUGS staff is, many families have never heard of HUGS.

Kapiolani instituted a parent support group in the fall of 1992, under the guidance of the Pediatric Oncology Support Nurse. This support group discusses a wide range of issues relating to cancer. For example, it was through complaints from this group that the garage door was finally closed to the oncology ward.

As of this writing the ACS is planning a conference for families of children with cancer through its Childhood Cancer Committee. The first conference will be offered as a pilot program.¹²

Support from Health Care Team

There is no formal arrangement for emotional counseling for parents and family members from the health care team. As a practical matter, some minimal discussion of emotional issues sometimes arises between doctors and nurses and family members.

However, families have indicated that they are reluctant to make too many demands on the doctors' time as they perceive the three pediatric oncologists to be extremely busy.

Counseling and Preparation Services for Child Survivors

In March of 1993, the American Cancer Society held its first Ikaika Weekend for children between the ages of fourteen and twenty-one. This program is a four-day retreat to help young cancer victims and survivors learn to cope with the social and emotional effects of cancer through counseling and guided support group sessions. Family members joined the group on the last day of the program. Approximately thirty attended the 1993 Ikaika Weekend and the ACS plans to sponsor the retreat annually. There is no charge for those who participate in this program.¹³

Financial Support Services

These services include those which support the child and family by assisting them with coping with the financial aspects of treating cancer, including: (1) how to meet costs; (2) how to understand insurance plans; and (3) how to pay for non-insured costs, such as medical supplies and medications.

How to Meet Costs

Kapiolani has a staff of financial coordinators available to coordinate financial assistance for patients and their families. The staff can explain how to access financial assistance such as Medicaid, and explain what is available.¹⁴

How to Understand Insurance Plans

Again, Kapiolani's Financial Coordinators are available to help decipher what insurance will cover. Most insurance companies also have customer service numbers to call for help in understanding what a given plan covers.

How to Pay for Non-Insured Costs

There is no formal program to assist families with determining how to meet the non-insured costs associated with cancer. Kapiolani's social worker gives out a "Checklist of Hospital and Community Resources for Hematology/Oncology Patients and Their Families"¹⁵ which includes four possible funding sources, but there are strict limits on all of them. For example, the Leukemia Society of America will give families assistance in varying amounts up to \$750 per year for coverage of outpatient medical needs for the patient with a diagnosis of leukemia. The list also includes the Department of Human Services Public Assistance and Medical Assistance, the Social Security Administration for Supplemental Security Income

on a one-time basis for a child's specific needs. The Kitaro Watanabe Fund is administered by the Hawaii Community Foundation. The administrators stressed that the Kitaro Watanabe Fund has very strict requirements for funding, and could not be considered a ready, easy source of assistance.¹⁶

As discussed above, the American Cancer Society sometimes has medical supplies donated by a family that no longer needs them. These are available on a first-come, first-serve basis by telephoning the American Cancer Society.

If the families' medical bills are high enough, Kapiolani's social worker will also refer the families to Medicaid as a possible source of financial assistance.

Endnotes

1. The conditions eligible for services from the Children with Special Health Needs Branch of the Department of Health, State of Hawaii are: (1) pulmonary, including severe asthma and cystic fibrosis; (2) cerebral palsy; (3) myelodysplasia; (4) selected neurological conditions such as epilepsy and hydrocephalus; (5) congenital adrenal hyperplasia; (6) congenital hypothyroidism; (7) phenylketonuria; (8) congenital and rheumatic heart disease; (9) craniofacial problems; (10) cystic fibrosis; (11) hearing loss; (12) selected surgical ear conditions; (13) selected orthopedic conditions such as juvenile rheumatoid arthritis; and (14) vision, surgical preservation or restoration of. Care coordination may be available for children without meeting any financial guidelines if the child has: (1) congenital hypothyroidism; (2) craniofacial problems; (3) myelodysplasia; or (4) phenylketonuria. Pamphlet, "A Message for Families of Children with Special Health Needs from Personal Health Services Administration," Hawaii Department of Health, April 1991 and letter to Samuel B. K. Chang from Dr. Alan Taniguchi, September 30, 1993.

Legislation was introduced during the 1993 Legislative Session to include cancer as one of the illnesses to be assisted by CSHNB. The Hawaii's Children's Cancer Foundation testified in favor of that bill.

2. Interview with Carol Kotsubo, Patient Care Coordinator, Kapiolani Women and Children's Medical Center, June 24, 1992; interview with Mae Au, Social Worker, Kapiolani Women and Children's Medical Center, July 14, 1992; interview with John Lederer, M.D., Radiation Oncologist, Queen's Medical Center, August 19, 1992; telephone interview with Robert Wilkinson, M.D., Pediatric Oncologist/Hematologist, September 18, 1992.
3. Interview with Anne Marie Barnes, American Cancer Society, July 16, 1992. According to Ms. Barnes, some families have been reassured by the use of this service. According to the Hawaii Children's Cancer Foundation, families feel uncomfortable using Candlelighters' telephone service because they don't know who they're talking to. Interview with relative of cancer patient, July 15, 1992.
4. Interview with relative of cancer patient, July 15, 1992.
5. Interview with Anne Marie Barnes, American Cancer Society, July 16, 1992.
6. Telephone interview with Robert Wilkinson, M.D., Pediatric Oncologist, September 18, 1992.
7. Interview with Carol Kotsubo, Patient Care Coordinator, Kapiolani Women and Children's Medical Center, June 24, 1992.

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8. Kotsubo interview, June 24, 1992.
9. Telephone interview with Gael Mustapha, Director, Communications Branch, Hawaii Department of Education, June 17, 1992.
10. Interview with Mae Au, Pediatric Oncological Social Worker, Kapiolani Medical Center for Women and Children, July 14, 1992.
11. Medical supplies include catheters, bandages, unused syringes, tape, and other non-drug items needed to administer medical treatment. Barnes interview, July 16, 1992.
12. Telephone interview with Ann Marie Barnes, Medical Affairs Director, Hawaii American Cancer Society, October 27, 1993.
13. Ibid.
14. Au interview, July 12, 1992.
15. See Appendix B.
16. See Chapter 4 below, "Paying for the Treatment."

Chapter 4

PAYING FOR TREATMENT

Treatment and the related care of a child with cancer can easily run into the hundreds of thousands of dollars.¹ This chapter discusses the financial aspects of the disease. The major sources of economic assistance currently available are summarized focusing on the medical coverage provided through Hawaii's major health plans, and the ability of families to meet costs that are not covered by health plans.

Costs of Childhood Cancer

The financial burden of childhood cancer contributes significantly to the stress the illness places on all members of a patient's family.² The costs directly attributable to the illness include the medical, hospital and other care services for the sick child. Researchers have determined that more than one-half of medical costs are incurred during the diagnostic process and in the terminal stages of illness. These are typically the periods when the patient is in the hospital and care expenses involve both the hospital facility and the medical providers.³ *They are also stages of illness that are intensely emotional and stressful for cancer patients and their families.* Direct medical costs, in most cases, are covered by third-party carriers for families with health plans, and by Medicaid for low-income families.⁴

Nonmedical expenses are also incurred when a child suffers from extended illness. These costs are rarely offset by third-party payors. Financial crises can occur if a wage-earning parent must take unpaid leave or quit a job in order to care for the sick child. Even if this is not necessary, expenses such as the cost of travel, food and lodging for the parent or guardian when the child must be hospitalized in a distant facility; or the costs of home care *for other children when the caregiver must be away from home* can be significant in the case of extended treatment such as with childhood cancer. One study found that, of the costs paid directly by the families of children with certain types of cancer, twenty-seven percent of the families' monthly budget paid for nonmedical expenses and only six percent for medical care.⁵

Employer-Sponsored Health Plans

In Hawaii, all employers must offer basic prepaid medical coverage to regular, nonseasonal employees who work more than twenty hours per week.⁶ (Insurance and real estate agents who work solely for commissions are not covered by the Prepaid Health Care Act.)⁷ These plans generally cover employees and their dependents and offer broad coverage

including medically necessary services and treatment for cancer. The minimum coverage required by law⁸ includes:

Hospital--120 days per calendar year, room, special diet, nursing, operating room services and supplies, drugs, oxygen and blood transfusion services, and out-patient care.

Surgery--surgical and anesthesiology services and after-care visits.

Medical--home, office and hospital visits by a physician, intensive care while hospitalized, and consultations while confined.

Other--maternity and substance abuse.

The employer must pay at least one-half of the premium for the employee's coverage.⁹ The employer may provide that the cost of additional coverage for an employee's dependents be paid by the employee.

COBRA¹⁰

The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)¹¹ requires that employees be given the opportunity to purchase a continuation of their group health insurance coverage for at least eighteen months when they become unemployed. However, this requirement does not apply if the insured is covered by another insurance plan, a student plan, or Medicare.

COBRA-mandated coverage only applies to the specific carrier and the specific coverage in effect at the time the insured leaves employment. Also, if the former employee leaves the carrier's service area the policy can be canceled.

While the carrier must offer a continuation of coverage, the insured is responsible for payment of premiums which are 102 percent of the employer's group premiums, including the portion that had been paid by the employer. Nonpayment or delinquent premiums are sufficient basis for canceling the policy.

Examples of Hawaii Group Health Care Plans

Two widely used health plans that serve a number of Hawaii employers are Kaiser Permanente which is available in all counties except Kauai and East Hawaii, and the Hawaii Medical Service Association (HMSA) which is available statewide.

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Kaiser is a health maintenance organization (HMO) and members are required to use Kaiser doctors and facilities unless referred elsewhere for treatment not available at a Kaiser facility. Kaiser members pay a flat co-payment (currently \$5) per visit for most services. A percentage of some costs, such as laboratory fees, vaccinations and other specific items, may also apply.

HMSA is a nonprofit organization affiliated with the nationwide Blue Cross/Blue Shield system of health care providers. Under HMSA plans, members select the doctors and facilities they prefer and HMSA reimburses a percentage of the costs for covered services. HMSA participating physicians and facilities bill HMSA directly. Non-participating providers bill the member who then submits a claim for reimbursement directly to HMSA. HMSA also offers HMO plans similar to the Kaiser program requiring members to use the HMO's providers. HMSA HMO's are located in all counties.

Conversion Options

Many carriers will allow persons who are members of employer group plans to convert to one of the company's individual plans. Hawaii's major providers include a conversion option in their group policies. However, as noted in a 1990 examination of health insurance, Consumer Reports found that conversion policies were almost always inferior to group plan coverage.¹²

Coverage for Cancer-Related Expenses

Employer provided group health plans vary widely in the extent of coverage beyond that legally required. The HMSA and Kaiser Plans available to Hawaii state and county employees offer quite broad coverage, and are used as examples for the purposes of the following discussion.¹³

Excluded Items

- Experimental Treatments
- Custodial or Domiciliary Care
- Blood and Blood Products

Partially or Fully Covered Expenses

- Unlimited Hospitalization (Semi-private room)

- Surgery and Anesthesiology
- Physicians Visits
- Radiotherapy for Malignancies
- Kidney and Bone Marrow Transplants¹⁴
- Chemotherapy¹⁵

Pre-existing Conditions and Medically Necessary Travel¹⁶

The two major plans differ in coverage for pre-existing conditions and medically necessary travel. While Kaiser imposes no limitations on coverage for pre-existing conditions in its group plans, restrictions are imposed in some of HMSA's group plans.

The two providers also differ in their coverage of the costs of necessary travel. Kaiser will cover the patient's travel within the service area when the physician determines that it is medically necessary. None of the HMSA plans cover this expense. Neither provider covers travel costs of an adult to accompany a minor child.

Individual Coverage

Hawaii residents who are not members of a group plan can purchase coverage on an individual basis from private providers or, if they meet the income eligibility requirements, from the Hawaii State Health Insurance Plan (SHIP), which was established pursuant to chapter 431N, *Hawaii Revised Statutes*.

As previously noted, individual plans, while similar to group programs, are generally inferior with higher co-payments or deductibles. Also, most providers place limitations on coverage for previously existing conditions. Each policy states the specific limitations. They may refuse coverage entirely or for a specific period such as one year after which full or limited coverage may be allowed. The definition of previously existing conditions is not uniform among health plans. It may include factors such as medical treatment received for the condition within a specified number of years preceding the start of coverage, the nature of the condition and whether treatment would "ordinarily" have been sought even if the applicant may have, in fact, received no medical attention.¹⁷

SHIP offers minimal coverage for the "gap group." To participate in SHIP, a family must: (1) not be eligible for coverage through an employer's group plan, and (2) meet income

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eligibility standards. SHIP is a limited program providing a maximum of twelve physician visits and five hospital days per year.¹⁸

Supplementary Coverage

Hospital-indemnity and dread disease coverage are available at relatively low costs. Hospital-indemnity provides cash payments for each day the insured is hospitalized. These policies are often advertised in Sunday newspaper supplements and "Dear Occupant" mailings. A typical example is the policy offered by Physicians Mutual Insurance Company (see Exhibit 4-1). For monthly premiums of \$44.15 or \$529.80 per year, the policyholder will receive \$75 for each day a family member is hospitalized, and \$112.50 per day if the illness is cancer or acute myocardial infarction.

Exhibit 4-1

Insure your family at one low rate – and all collect full cash benefits.

Choose The Plan That Fits Your Needs	Choose Your Cash Benefit Option			
	OPTION A – Pays \$2,250.00 a month (\$75.00 a day) from the very first day of hospitalization for any covered sickness or accident.		OPTION B – Pays \$1,500.00 a month (\$50.00 a day) from the very first day of hospitalization for any covered sickness or accident.	
	39 & Under (use age of principal insured) MONTHLY PREMIUM	40 & Over (use age of principal insured) MONTHLY PREMIUM	39 & Under (use age of principal insured) MONTHLY PREMIUM	40 & Over (use age of principal insured) MONTHLY PREMIUM
 Individual Plan. Ideal for the single person or family member who wants or needs separate insurance.	\$18.45	\$21.20	\$12.95	\$14.95
 Husband-Wife Plan. Pays full benefits for both of you – no reductions for the spouse.	\$34.35	\$39.30	\$24.35	\$28.05
 All-Family Plan. Offers protection for yourself, your spouse and all eligible children. And new additions are covered automatically at no extra cost.	\$44.15	\$49.10	\$31.15	\$34.85
 One-Parent Family Plan. Covers you and all eligible dependent children with full benefits for all.	\$28.25	\$31.00	\$19.75	\$21.75

NOTE: Your renewal rate does not increase as you move from one age group to another. Plus, you can save 8% by paying once a year instead of each month. That's like getting one month free!

Indemnity policies pay without regard to costs actually incurred or consideration of any payments covered by other insurance. However, they pay only when the insured is hospitalized. Dread-disease policy benefits are restricted to hospitalization and certain treatments while hospitalized for one of the diseases specified in the policy. The amounts payable, typically on the order of \$50 to \$100 per day, are not adequate to cover hospital room costs, much less treatment received while hospitalized.

Because of its limited coverage this type of insurance can, at best, be viewed as supplementary to comprehensive health care coverage. However, as indemnity policies, the cash payments can help meet other out-of-pocket expenses. For example, even if the patient's hospitalization is fully covered by a comprehensive plan, the indemnity policy pays the agreed amount for each day in the hospital up to the maximum provided in the policy. Payments are made directly to the insured and need not actually be used to pay hospital charges.

Medicaid

The state Department of Human Services administers Hawaii's Medicaid program. This program pays medical costs for low-income persons who are not otherwise covered by a health plan. Medicaid coverage includes medical and hospital services required to treat childhood cancer that are generally comparable to those covered under private plans. The program's coverage is established by administrative rules¹⁹ which provide for physician and hospitalization services, and approved treatments including donor tissue typing and bone marrow transplants.²⁰ Intra-state travel expenses are payable when necessary and, in "exceptional cases"²¹ out-of-state travel and hospitalization may be approved. As with most private health plans, experimental treatments are not covered. However, the current Hawaii Medicaid program reimburses care providers according to a fixed payment schedule for specific services.²² When the established payments do not cover the cost of required care, providers may simply refuse to accept Medicaid patients.

Current Medicaid income eligibility standards for children range from 185 percent (children under the age of one year) to 100 percent (children over the age of six years) of the poverty level.

Nonmedical Expenses

There are few public or private programs to help meet the costs of nonmedical services frequently associated with childhood cancer. These costs include respite for family caregivers, domiciliary care during periods when the child is at home and the parents must work, tutoring when the child cannot attend school, and child care for a patient's siblings when parents must be away from home. Parents may also experience wage loss making such expenses particularly difficult to meet.

The state Department of Health's program for Children with Special Health Needs does not, at this time, serve cancer patients. Under current program rules, the agency's services are only available to children with specific health conditions. The program is state and federally funded and the health conditions for which assistance is available, are established by the Department of Health. They generally reflect past national public health-

maternal child health priorities.²³ Legislation to include cancer among the eligible conditions was considered by the Legislature during the 1993 regular session.²⁴ While the measure did not pass, the Department has formed a special task force to review the program's eligibility standards.²⁵

Some private trusts and endowment funds may award grants to families with seriously ill children although none are directed specifically toward childhood cancer.

Individuals must prepare and submit grant applications to each potential funding source. If the request is granted, it will generally be a one-time award. Assistance in the future will require a new application to a new source of assistance. One example is the Kitaro Watanabe Fund which provides financial assistance ranging between \$250-\$1,200. The applicant must complete a four-page Social Summary form, and a narrative defining the problem and the applicant's background. This material is then submitted to the Fund's trustees for evaluation. There is a three-month turn-around for applications.²⁶

The Qwenfread Allen Fund will assist persons who are elderly or mentally ill (age is not a specific requirement for eligibility). The Fund will consider mental illness that results from a continuing high stress situation such as cancer of a family member. This Fund also makes awards on a quarterly basis. Awards range from \$150-\$1,500.²⁷

Success in Meeting the Costs of Childhood Cancer

As previously discussed, the medical costs of childhood cancer are, for the most part, met by Hawaii's major health plan providers. However, the burden of co-payments and drugs or treatments that are only partially covered, and nonmedical costs and possible wage losses can be substantial. Furthermore, neighbor island families will probably incur significant costs for medically necessary travel in order to receive treatments available only at Kapiolani Medical Center in Honolulu.

One parent interviewed in the course of this study reported that, for five years following the death of the child they were paying off bills for expenses incurred during the child's illness. Others reported having to mortgage or sell their home, conduct fundraising events like car washes and benefit spaghetti dinners, and needing years to repay substantial informal loans from friends and family. Another has considered divorce in order to qualify for Medicaid.²⁸

The number of such anecdotal accounts among the quite small group of parents with children who have or recently had cancer is a strong indication that, with regard to costs, the care and support system has serious gaps.

Endnotes

1. Parents of Children with Cancer report costs for hospitalization alone that total up to \$150,000. Interview with parents of cancer patients, September 4, 1992. A June 1, 1993 item on the Channel 4 News cited expenses of more than \$250,000 incurred by the family of Kevin Nishimura, a child suffering from cancer. (Report not verified by researcher.)
2. Shirley B. Lansky, M.D., Janet L. Black, and Nancy U. Cairns, Ph.D., "Childhood Cancer, Medical Costs," Cancer, vol. 52, 1983 (American Cancer Society), p. 762.
3. Ibid., p. 765.
4. Ibid., p. 766.
5. Ibid.
6. Hawaii Rev. Stat., sec. 393-3(8).
7. Hawaii Rev. Stat., sec. 393-5(4) and 393-5(5).
8. Hawaii Rev. Stat., sec. 393-7(c).
9. Hawaii Rev. Stat., sec. 393-13.
10. "The Crisis in Health Insurance," Consumer Reports, August 1990, p. 545.
11. P.L. 99-272.
12. "The Crisis in Health Insurance," p. 545.
13. "Benefit Plans," Hawaii Public Employees Health Fund, Spring 1993, pp. 8-9.
14. Ibid., pp. 13 and 21.
15. Ibid., pp. 11 and 30.
16. Telephone interviews with HMSA Marketing Division and Kaiser Existing Group Plan representatives, June 1, 1993.
17. "Benefit Plans," p. 541.
18. Telephone interview with SHIP representative, April 28, 1993.
19. Hawaii Administrative Rules, chapter 17-1370.
20. Hawaii Administrative Rules, sec. 17-1370-91(a) and (h).
21. Hawaii Administrative Rules, sec. 17-1370-91(i).
22. Telephone interview with Lillian Murakami, Department of Human Services, Medicaid Hotline, May 3, 1993.

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23. Telephone interview with Dr. Alan Taniguchi, Director, Children with Special Health Needs Branch, Department of Health, State of Hawaii, April 29, 1993, and letter to Samuel B. K. Chang from Dr. Alan Taniguchi, September 30, 1993.
24. House Bill No. 670, Seventeenth Legislature, 1993, State of Hawaii.
25. Taniguchi interview.
26. Informational application material provided by the Hawaii Community Foundation, 222 Merchant Street, Honolulu, Hawaii 96813.
27. Ibid.
28. Interview with parents of cancer patients, September 4, 1992.

Chapter 5

DEVELOPING IMPROVEMENTS TO HEALTH CARE

Policy Considerations

Debate on health policy is in the forefront both nationally and in Hawaii. The key issues of care for children with cancer involve some of the most difficult elements of this debate including:

- (1) Long-term care. The lengthier the period of medical treatment the more expensive that care becomes for both third-party payors and a child's family. Some aspects of long-term care such as physical or occupational therapy may be necessary for full recovery but may not be covered by standard health plans.
- (2) The line between medical care and the broader aspects of health care. Providing and paying for nonmedical care is a major concern in the long-term care debate. Although frequently considered in terms of the frail elderly it also impacts others including children with cancer. Third-party payors have traditionally limited coverage to medical conditions and treatments that exclude areas of care that, while integrally involved with the patient's health, are not provided directly by hospitals, physicians and nurses. For example, medically necessary travel and temporary housing are frequently not covered for the patient much less for an accompanying adult when the patient is a minor.
- (3) Availability and cost of care for catastrophic illnesses. Many third-party payors limit their coverage for catastrophic illness by establishing a cap or maximum on total payments or total annual payments, or restricting coverage for pre-existing conditions. These provisions can shift the entire burden of care costs to the family with no regard for their ability to meet that burden. Some are left with no choice but to "spend down" to Medicaid eligibility standards.
- (4) Developing an equitable system to pay for health care. Health care costs and who should pay them are central to much of the current discussion of health care reform. Policymakers have been unable to develop a system for sharing these costs among patients, insurers, and taxpayers in a way that is acceptable to all parties. The problem is further complicated by the fact that it must also address cost controls to protect against profiteering, abuse, and waste in the delivery of care.

Medicaid Demonstration Programs

Both Hawaii and Oregon have been granted Medicaid waivers that will allow use of federal and state Medicaid funds for demonstration programs for health care delivery to Medicaid recipients. A brief overview of two contrasting proposals illustrates the breadth of possible reforms that may be implemented in the near future.

The goal of both projects is to rationalize the costs and delivery of health care to the uninsured. Central to both is an effort to eliminate or significantly reduce cost-shifting and arbitrary denial of needed medical care that result from inadequate Medicaid funding.

Hawaii Health QUEST

Hawaii's waiver allows the State to replace the current Medicaid reimbursement and SHIP programs with group health plans comparable to those available through the employer-sponsored programs. The five-year demonstration project is called QUEST, Quality care, Universal access, Efficient utilization, Stabilizing costs, and Transforming the way health benefits are provided. Funds currently used for Medicaid reimbursements and SHIP coverage will be used for group coverage for recipients of Aid to Families with Dependent Children and similar groups, state General Assistance clients, and SHIP members. The program's goal is a single health care delivery system and universal access to that system for Hawaii residents. Medicaid recipients will receive the same preventive and managed care services available to members of other group plans. SHIP clients will receive significantly broader coverage than their current twelve physician visits and five hospital days per year.¹ The program is scheduled to start in April 1994.²

Oregon's Health Care Rationing Plan

In contrast, Oregon proposes rationing medical procedures in order to provide its uninsured residents universal coverage for specific medical procedures. The state developed a system to rank 709 medical procedures focusing on costs and benefits. The lowest priority is given to the most expensive procedures that have low probability of a successful outcome in terms of improved quality of life for the patient. The state legislature recommended guaranteed coverage for the first 587 of the 709 procedures. The remaining 122 treatments will not be eligible for Medicaid reimbursements.³

Oregon's Medicaid waiver request was initially refused because denial of coverage based upon an assessment of likely benefits could be in violation of the rights of persons with disabilities under the 1990 Americans With Disabilities Act.^{4, 5} However, the Clinton Administration reviewed the application and granted the waiver in March 1993.⁶

Feasible Improvements

Many of the gaps in medical and support services for children with cancer are the result of a failure to accommodate the special circumstances associated with long-term illness of patients who are simply too young to fully understand their illness and its treatment. The health care system should acknowledge these circumstances and institute appropriate changes in the delivery of care.

Medical Services

Hawaii's children with cancer generally have access to state-of-the art medical care. However, parents are not always fully informed about all aspects of that care. This can cause frustration and unfounded fears on their part, and problems in assuring appropriate care when the child is not hospitalized. Policies and procedures to fully integrate parents into the health care team can be implemented at little or no cost. Reasons for not doing so appear to be based upon tradition and habit rather than conscious administrative determinations. Responsibility for establishing this policy and monitoring its application rests primarily with hospital administrators. However, physicians and other members of the health care team must implement it, and should participate in its formulation.

Health QUEST is intended to assure uniform access to service without regard to income. Eliminating provider resistance to accepting Medicaid patients should greatly improve the medical care available to low-income families.

Support Services

Expanding health plan coverage to include the support services needed by families that have a child with cancer cannot be accomplished without taking into account other conditions that require nonmedical long-term care. Questions of access to services, equitable sharing of costs, and the appropriate roles of government, providers, and third-party insurers must be resolved in terms of all potential users rather than for a specific group such as victims of childhood cancer.

While adding nonmedical support services to current health plans must be considered within the larger context of overall long-term care needs, coordination of and access to information regarding existing services is a function the State performs in a number of areas and should be available to all families with seriously ill children. An expanded information and referral service supplemented with periodic surveys of service needs and resources could significantly assist parents even though they would need to meet most of the costs through private resources. Initial access to information and referral services should be available at Kapiolani Medical Center as well as the Departments of Health and of Human Services.

Financing

Health QUEST involves major reforms in the area of health care financing. Current Medicaid clients and SHIP members should benefit significantly from assured access to care as members of group health plans. Health QUEST should be carefully monitored to ensure that a systematic denial of coverage for pre-existing conditions or catastrophic costs does not occur. While other states have established special state-subsidized insurance programs for persons who are otherwise uninsurable, they are expensive as "stand-alone" programs.⁷ With Hawaii's high level of coverage under employer-sponsored group health plans, it should be possible to spread high-risks throughout the system and avoid forcing families to spend down to Medicaid-level eligibility to obtain coverage due to system-wide limits for pre-existing conditions. It should not be necessary for a family to impoverish itself as a prerequisite to needed health care.

Health QUEST does not directly address the problem of meeting co-payments and costs not covered by a health plan. However, by making group-plan coverage universally available, the strain of meeting costs without any coverage should be virtually eliminated. Furthermore, individuals should be aware that they can supplement their health plan coverage with hospital-indemnity policies if they are particularly at risk for high co-payments and uninsured expenses. These factors must be taken into consideration by each individual when selecting a health plan.

Summary

Full discussion of the complex policy questions relating the availability and financing of health care is beyond the scope of this report. The feasibility of approaches to improve delivery of health care and support to children with cancer is strongly influenced by the fact that dramatic changes to the nation's health care system are being considered. The extent to which the issues of long-term care and catastrophic illnesses are incorporated into national health care policy will directly impact the care and treatment of children with cancer.

Endnotes

1. "State OverHauls Health Care," Helen Alton, Honolulu Star Bulletin, Thursday, April 15, 1993, p. 1, and "Hawaii Takes Second Shot at Reform," Gary Enos, City and State, May 10-23, 1993, Vol. 10, No. 9, pp. 1, 19-20.
2. "Hawaii gets OK to privatize care for 90,000," Thomas Kaser, The Honolulu Advertiser, July 16, 1993, p. A6.
3. "The Choice: Reform or a 'Train Wreck'," Congressional Quarterly, September 26, 1992, Vol. 50, No. 38, pp. 2903-2904.
4. P.L. 101-336.

CHILDHOOD CANCER: THE CHALLENGE TO HAWAII'S HEALTHCARE SYSTEM

5. "Oregon's Bid to Boost Coverage Gets Federal Red Light," Congressional Quarterly, August 8, 1992, Vol. 50, No. 32, p. 2362.
6. "Hawaii Takes Second Shot at Reform," Gary Enos, City and State, May 10-23, 1993, Vol. 10, No. 9, pp. 1, 19-20.
7. "The Last Resort - High Risk Pools," Consumer Reports, August 1990, p. 541. The states with high-risk pools are: California, Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Maine, Minnesota, Montana, Louisiana, Nebraska, New Mexico, North Dakota, Oregon, South Carolina, Tennessee, Texas, Utah, Washington, Wisconsin, and Wyoming.

Chapter 6

FINDINGS AND RECOMMENDATIONS

Findings

Information on Medical Issues

1. Providing information and guidance with regard to medical options and treatment is the responsibility of the medical team--principally the physician and hospital administrators. It is an essential element of the long-term care of the child ensuring continuity of proper care throughout the duration of illness.

2. The material presented in Chapter 2 indicates that:

- (a) Parents are aware of their need to fully understand the medical aspects of their child's care,
- (b) Parents may be reluctant to bother a physician regarding the details of the child's treatment even though they often feel that the physicians are dedicated and caring, and
- (c) The support available through the hospital is inconsistent or incomplete.

Information on and Availability of Related Support Services

3. Information and support in other aspects of care are necessary for both the family and the child. These services may include:

- (a) Respite and custodial care while the child is not hospitalized,
- (b) Custodial care for other- children in the family while the parents are at the hospital,
- (c) Counseling for all members of the family, and
- (d) Guidance in coping with the financial aspects of the situation.

4. Information and referral regarding these types of support is typically provided by the hospital social worker or possibly a case manager if the health care provider is an Health Maintenance Organization. Because medical care for childhood cancer is available primarily through Kapiolani Medical Center, the task of helping parents identify and locate support

services rests largely with the Center's half-time social worker. However, when the services are not available or are inadequate in the patient's community, a situation not uncommon on the neighbor islands, families are left with the choice of doing without or trying to develop alternatives with little or no professional experience or guidance.

5. Based on the data presented in Chapters 2 and 3, the weaknesses in the area of information about and access to nonmedical support are the result of:

- (a) Understaffing relative to the social work workload at Kapiolani Medical Center which is the State's primary medical facility serving children with cancer,
- (b) Insufficient coordination among the various agencies that provide nonmedical support services,
- (c) The exclusion of childhood cancer as a condition covered by the State's Children with Special Health Needs Program, and
- (d) The absence of support services, particularly in more remote rural communities.

Transportation and Temporary Housing

6. Treatment of childhood cancer frequently requires periodic hospitalization for several days. While some of these treatments are available at the major hospitals on the neighbor islands, Kapiolani Medical Center is the State's primary hospital for children with cancer. Although some health plans cover transportation costs for the patient, none help to pay the travel or housing costs for a parent or guardian to accompany a minor when travel is medically necessary. (These costs may be covered for Medicaid recipients.)

7. The Ronald McDonald House in Honolulu offers inexpensive temporary housing near Kapiolani Medical Center on a space available basis. However, when the House is full, and on the Neighbor Islands, those accompanying a sick child often find it necessary to share rooms with strangers in the hospital itself. The hospital's temporary housing facilities are limited, and the lack of privacy is a source of additional stress and tension for the occupants.

8. Because many essential treatments are only available at Kapiolani Medical Center, travel and temporary housing may be essential to ensuring that a child receives proper medical support. Thus, the costs of travel and temporary housing are frequently major concerns for families coping with childhood cancer because:

FINDINGS AND RECOMMENDATIONS

- (a) Third-party payors do not all accept medically necessary travel and housing expenses as an integral part of care costs,
- (b) The availability of housing is not assured,
- (c) The need for both transportation and temporary housing may occur numerous times during a child's treatment, and
- (d) Inadequate temporary housing adds to an already stressful situation and can be emotionally damaging to the patient as well as to the family.

Development of Public Information and Sensitivity Regarding Childhood Cancer

9. Childhood cancer is a relatively rare disease (fewer than 8,000 cases were diagnosed nationwide in 1991)¹ that is not of central concern to the established nonprofit groups that support research and public information regarding cancer. Similarly, the State has no agency specifically designated to assist patients or develop informational programs about childhood cancer although public health nurses do provide some assistance in this regard. Many families coping with childhood cancer encounter misunderstanding and unjustified fears when dealing with co-workers, schools, playmates, and neighbors.

10. When a family's social network does not understand the nature of the child's illness, both the child and family become isolated. Community support and understanding are an important element of optimum care programs for children suffering long-term illnesses.

Assistance in Understanding and Meeting the Costs of Treatment and Care

11. The financial impact of childhood cancer was reviewed in Chapter 4. The group and individual comprehensive health plans available in Hawaii, and Medicaid for low-income children and families, provide good coverage for the medical expenses of cancer. However, each third-party payor has its own coverage limitations and requirements. While physicians and hospitals are familiar with many of the specifics of various types of coverage, parents must be able to deal directly with providers when disputes arise. They must also understand what is required to maintain their coverage throughout the child's illness when job loss or difficulty in meeting premium costs may occur.

12. Most health plans do not cover many nonmedical care costs or possible wage-loss of a parent who must quit or take unpaid leave to care for a child. The resources available to help families cope with these expenses are spotty, poorly coordinated and, particularly for those living on the Neighbor Islands, frequently non-existent. The number of cases where families of children ill with cancer and other catastrophic illnesses resort to

personal appeals through the media, benefit car washes, and similar fundraising efforts is adequate testimony to the inadequacy of assistance in this area.

13. For Medicaid recipients, providers may refuse to accept the child as a patient if the Medicaid reimbursement does not cover the cost of providing care.

Post-treatment Counseling

14. Children who survive cancer may need counseling. They must learn how to deal with a potential recurrence of the illness, possible disfigurement, and fears relating to their experiences while ill. Permanent brain damage may have resulted if they suffered from a brain tumor. Chemotherapy and radiation treatments can cause damage to a child's reproductive system. Many of the long-term side effects of cancer treatments are simply not known, particularly in the case of children. While post-treatment counseling may be necessary for full recovery, it is not always accepted as an element of medical care nor available in all communities.

Participation in National Clinical Trials

15. In order to assure that Hawaii's children have access to the best and most current treatments for childhood cancer, close cooperation has been established and maintained with researchers across the nation. However, the requirements for formal participation in national clinical studies are quite strict. As discussed in Chapter 2, while Hawaii's doctors participate in one of the nation's two clinical studies, if a patient is not able to receive all treatments they are put on a "para-protocol" treatment program that is as close an approximation as possible of the national program's protocol. This ensures that the physician has access to the latest medical findings, and that each child receives the benefit of "state-of-the-art" treatments even when not formally participating in the clinical studies.

16. Given the fact that Hawaii is physically remote from the nation's major cancer research facilities, it appears that the current level of participation in national clinical trials is appropriate.

Recommendations

The following recommendations address the concerns of parents of children suffering from cancer as identified in H.C.R. No. 76. They call for significant but not costly changes in the ways in which the major institutions involved in caring for these children approach their responsibilities and deal with each other. The implementing organizations are the State of Hawaii, Kapiolani Medical Center, health plan administrators, and, of course, the childrens' families. However, cooperation of all agencies and organizations that have contact with these

FINDINGS AND RECOMMENDATIONS

children and their parents will be necessary in order to experience the maximum possible improvement. In addition, while this report focuses on children with cancer, the institutional changes proposed should benefit all children suffering from major long-term health conditions.

1. **Department of Health Children with Special Health Needs Program.** The Department of Health's Children with Special Health Needs Program should complete the review of its eligibility criteria. The review should include an examination of current program services focusing on special health needs that are not covered by third party providers or available through non-governmental agencies. Appropriate changes in eligibility criteria and program services resulting from implementation of Hawaii Health QUEST should be identified during this review. Further, representatives of families of children with special health needs should participate in determining service needs and, if necessary, prioritizing those needs.

The current use of specific medical conditions and diagnosed illnesses as program eligibility criteria should be discontinued. The fact that a child has cancer rather than a "covered" condition should not be the basis for denying services that are provided to others. *The need for service that is otherwise not available or affordable should be the primary test for eligibility.* The Legislature should request a status report on the administrative program review including documentation of additional staff or financial resources that may be required.

2. **Medical Information and Care.** Hospitals that treat children with cancer and other long-term catastrophic illnesses should formally institute a policy that parents shall be active and full participants in the child's care. Hospital administrators should evaluate their services and complaints regarding those services in terms of this policy.

Participation should include: (a) providing parents with technical material to help them understand the nature of the illness and basis for treatment, and (b) allowing parents access to the child's medical charts and assistance in understanding data on the charts.

Home care constitutes a substantial portion of care provided to children with cancer thus making parents a major part of the health care team. Formal adoption of the proposed policy will acknowledge this fact and help ensure coordination of care on an equal basis among those responsible for the child's treatment.

3. **Support Service Information and Referral.** The Department of Health's Children with Special Health Needs Program should strengthen its information and referral activities to serve all who inquire about special support without regard to income or specific medical condition. Access to information and referral services should be available through Kapiolani Medical Center as well as directly from the Department of Health. Periodic surveys of its information and referral providers and users should be conducted in order to document service needs and availability. These surveys will enable program administrators to track changes in service needs and identify under-served areas or populations.

There is no public or private agency responsible for coordinating information and referral for support services needed by families coping with childhood cancer or other catastrophic childhood diseases. Information and referral programs are an efficient low-budget way to identify service needs and facilitate contact between users and providers. Several state programs provide information and referral services including the Children with Special Health Needs program. Expanding this service will improve access to and delivery of needed support services. Service expansion could be accomplished by contracting with a qualified non-governmental agency if necessary.

4. **Social Services.** Kapiolani Medical Center's social work service should be strengthened by an additional position. If necessary, a state social worker should be assigned to work directly with the Center to improve services for Kapiolani patients that are Hawaii residents. Implementation of this recommendation should be coordinated with the information and referral services discussed in Recommendation No. 2.

Kapiolani Medical Center is the primary facility for treatment of major childhood diseases not only in Hawaii, but throughout the Pacific Basin. The need to adequately serve the number and diversity of patients receiving treatment at or through the hospital cannot be fully met with the single half-time social worker position now provided.

5. **Transportation and Temporary Housing Costs.** Hawaii's HMO's and third-party providers should consider including in their health plans medically necessary inter-island transportation and temporary housing for an adult accompanying a minor child. Alternatively, a health plan supplement to help with these costs could be offered. In the meantime, neighbor island residents with plans that do not cover these costs should consider purchasing supplemental hospital-indemnity policies that would provide direct cash payments when a covered individual is hospitalized. These payments would help offset some of the costs of travel and housing if a child must be treated off-island.

Health plan coverage for medically necessary travel varies among the plans available in Hawaii. Because Kapiolani Medical Center is the only facility for treatment of some childhood illnesses, neighbor island residents with children must consider the possibility of needing to travel to Honolulu for some treatments. A hospital-indemnity policy is one way to supplement basic health plan coverage in order to have cash payments when an insured is hospitalized.

Health plan providers should review the demographics of their neighbor island membership to determine if coverage can be extended for some travel and housing costs within existing plans or through optional supplementary coverage.

6. **Uniform Coverage of Services.** The State Department of Health should implement and monitor Health QUEST to ensure uniform coverage and access to health care for all residents.

FINDINGS AND RECOMMENDATIONS

Implementation of Health QUEST should eliminate the cost-shifting and service denial that are the result of inadequate Medicaid reimbursement schedules by simply incorporating clients of these programs into the system that serves most of Hawaii's residents.

In establishing program specifications and selecting providers for Health QUEST, emphasis should be given to ensuring that members have reasonable access to the services offered. This is of particular concern for neighbor island residents. Inter-island transportation for care that is only available on Oahu should be included if possible.

7. Coverage for Pre-existing Conditions and Catastrophic Illness. The Department of Health should survey health plan providers to determine if their policies regarding coverage for pre-existing conditions and caps on eligible costs are leaving families uninsured and uninsurable. If so, the Legislature should consider establishing a program to provide coverage for the uninsurable.

Hawaii's Prepaid Health Care Act, federal COBRA requirements, and Medicaid combine to ensure availability of medical care for an estimated ninety-seven to ninety-eight percent² of Hawaii's residents. While it is beyond the scope of this study to determine why some individuals are not covered, it is possible that restrictions for pre-existing conditions effectively deny coverage in some instances. Should this be the case, consideration should be given to establishing a high-risk pool to provide coverage for those who are otherwise uninsurable. Currently, some twenty-three states have such pools. However, the premiums are quite high and still require state subsidies.³

Endnotes

1. Senate Concurrent Resolution No. 76, S.D. 1, Hawaii State Legislature, 1992 Regular Session.
2. "Hawaii takes second shot at reform," Gary Enos, City and State, May 10-23, 1993, Vol. 10, No. 9, pp. 1, 19-20.
3. "The Last Resort--High Risk Pools," Consumer Reports, August 1990, p. 541. The states with high-risk pools are: California, Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Maine, Minnesota, Montana, Louisiana, Nebraska, New Mexico, North Dakota, Oregon, South Carolina, Tennessee, Texas, Utah, Washington, Wisconsin, and Wyoming.

Appendix A

THE SENATE
SIXTEENTH LEGISLATURE, 1992
STATE OF HAWAII

S.C.R. NO. 76
S.D. 1
H.D. 1

SENATE CONCURRENT RESOLUTION

REQUESTING THE LEGISLATIVE REFERENCE BUREAU TO STUDY AND MAKE
RECOMMENDATIONS FOR THE PROVISION OF SERVICES FOR CHILDREN
WITH CANCER AND THE FAMILIES OF CHILDREN WITH CANCER.

WHEREAS, cancer is a large group of diseases characterized
by phenomenal growth and multiplication of abnormal cells that
can result in death if not controlled or checked; and

WHEREAS, cancer can strike at any age, is the leading
childhood disease in Hawaii as well as across the Nation, and can
be fatal to children from ages one through fourteen; and

WHEREAS, approximately 7,800 children across the Nation were
diagnosed with cancer in 1991 and approximately 1,500 deaths have
already resulted; and

WHEREAS, children with cancer present special challenges
that require multimodal services that range beyond the standard
therapy cooperation of surgeons, oncologists, and neonatologists;
and

WHEREAS, children with cancer need specialized attention in
diagnostic procedures, a specialized care environment, and a
cadre of health care workers in all specialties; and

WHEREAS, families of children with cancer need to be
informed about treatment and medical procedures, the side effects
of treatments, hospital services and facilities, access to
necessary medical services, support and assistance from the
health care team and social workers, assistance in dealing with
health care insurance and other financial issues, and support and
assistance from employers, schools, teachers, and classmates; and

WHEREAS, families of children with cancer also need to be
represented in local and national cancer clinical trials and
therapy investigations to ensure that the children in Hawaii are
receiving the most current and advanced therapies as well as
state-of-the-art medical care; and

WHEREAS, children with cancer and other serious illnesses have similar basic needs in areas such as health care financing, medical care coordination, ancillary medical support services, and family and social support services; now, therefore,

BE IT RESOLVED by the Senate of the Sixteenth Legislature of the State of Hawaii, Regular Session of 1992, the House of Representatives concurring, that the Legislative Reference Bureau is requested to study the various support and assistance services offered in Hawaii to children with cancer and the families of children with cancer and identify gaps in services as well as recommend solutions that would eliminate the gaps. The study shall include but not be limited to an examination of the following areas:

- (1) Overall support services that inform the child and family about treatment and medical procedures, the side effects, how to make decisions, and how and when to obtain a second opinion;
- (2) Overall support services that inform the child and family about hospital services, facilities, medical procedures, and test results;
- (3) Overall support services from the health care team, social work assistance, child care, and emotional counseling services;
- (4) Overall support services regarding transportation for medical treatment and temporary housing when the child and family must be away from home;
- (5) Education and establishment of a public network that includes employers, schools, and peers and is supportive and sensitive to the needs of the affected individual and family;
- (6) Provision of assistance and guidance on how to meet the accumulated financial costs of health care, how to understand the requirements and complexities of various medical insurance plans, how to secure provisions for non-covered costs incurred as a part of treatment (i.e. medical supplies and medications), and how to access necessary medical treatment (i.e. transportation to care centers, especially for neighbor island families, and temporary housing);

- (7) Counseling and preparation services for the child with cancer that survives and the issues that must be addressed if the illness recurs; and
- (8) Cooperative group participation in local and national cancer clinical trials and therapy investigations in order to guarantee that children being treated in Hawaii are receiving the most current advance therapies for optimal outcomes in the treatment of childhood cancers, as well as state-of-the-art medical facilities and care for pediatric oncology patients;

and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau report on how its findings and recommendations relative to children with cancer may be applied to improve the system of services for all children with serious illness and disorders insofar as specific recommendations regarding improving health care financing and support and assistance services for children with cancer may have applicability to children with serious illnesses in general, regardless of the specific diagnoses; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau is requested to consult with the Hawaii Children's Cancer Foundations; HUGS; the American Cancer Society; the Childhood Cancer Committee; Kapiolani Medical Center for Women and Children; the Department of Radiology at Queen's Hospital; the Cancer Research Center; the Department of Human Services; and in particular the Medicaid Division; the Departments of Health and Education; and relevant third party payors, for information regarding an assessment of needs and services; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau is requested to submit to the Legislature a report of findings and recommendations no later than twenty days prior to the convening of the 1993 Regular Session; and

BE IT FURTHER RESOLVED that certified copies of this Concurrent Resolution be transmitted to the Legislative Reference Bureau and each specified consulting agency.

HOUSE RESOLUTION

REQUESTING THE LEGISLATIVE REFERENCE BUREAU TO STUDY AND MAKE
RECOMMENDATIONS FOR THE PROVISION OF SERVICES FOR CHILDREN
WITH CANCER AND THE FAMILIES OF CHILDREN WITH CANCER.

WHEREAS, cancer is a large group of diseases characterized
by phenomenal growth and the multiplication of abnormal cells
which can result in death if not controlled or checked; and

WHEREAS, cancer can strike at any age, and is the leading
childhood disease in Hawaii as well as across the Nation that can
be fatal to children from ages one through fourteen; and

WHEREAS, approximately 7,800 children across the Nation have
been diagnosed with cancer in 1991 and approximately 1,500 deaths
have already resulted; and

WHEREAS, children with cancer present special challenges
that require a multimodal demand of services that range beyond
the standard therapy cooperation of surgeons, oncologists, and
neonatologists; and

WHEREAS, children with cancer need specialized attention in
diagnostic procedures, a specialized environment to be cared for,
and a specialized cadre of health care workers in all
specialties; and

WHEREAS, families of children with cancer need to be
informed about treatment and medical procedures, the side effects
of treatments, hospital services and facilities, access to
necessary medical services, support and assistance from the
health care team and social workers, assistance in dealing with
health care insurance and other financial issues, support and
assistance from employers, schools, teachers, and classmates; and

WHEREAS, families of children with cancer also need to be
represented in local and national cancer clinical trials and
therapy investigations to ensure that the children in Hawaii are
receiving the most current and advanced therapies as well as
state-of-the-art medical care; and

WHEREAS, children with cancer and other serious illnesses have similar basic needs in areas such as health care financing, medical care coordination, ancillary medical support services, and family and social support services; now, therefore,

BE IT RESOLVED by the House of Representatives of the Sixteenth Legislature of the State of Hawaii, Regular Session of 1992, that the Legislative Reference Bureau is requested to study the various support and assistance services offered in Hawaii to children with cancer and the families of children with cancer and identify the gaps in services as well as make recommendations as to the solutions that would eliminate the gap. The study shall include, but not be limited to, an examination of the following issues:

- (1) Overall support services that inform the child and family about treatment and medical procedures, the side effects, how to make decisions, and how and when to obtain a second opinion;
- (2) Overall support services that inform the child and family about hospital services, facilities, medical procedures, and test results;
- (3) Overall support services from the health care team, social work assistance, child care, and emotional counseling services;
- (4) Overall support services regarding transportation for medical treatment and temporary housing when the child and family must be away from home;
- (5) The education and establishment of a public network which includes employers, schools, and peers that is supportive and sensitive to the needs of the affected individual and family;
- (6) The provision of assistance and guidance on how to meet the accumulated financial costs of health care, how to understand the requirements and complexities of various medical insurance plans, how to secure provisions for non-covered costs incurred as a part of treatment (i.e. medical supplies and medications), or how to access the necessary medical treatment (i.e. transportation to care centers, especially neighbor island families, and temporary housing);

- (7) Counseling and preparation services for the child with cancer that survives and the issues that must be addressed if the illness reoccurs; and
- (8) Cooperative group participation in local and national cancer clinical trials and therapy investigations in order to guarantee that children being treated in Hawaii are receiving the most current advance therapies for optimal outcomes in the treatment of childhood cancers, as well as state-of-the-art medical facilities and care for pediatric oncology patients;

and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau report on how its findings and recommendations relative to children with cancer may be applied to improve the system of services for all children with serious illness and disorders insofar as specific recommendations regarding improving health care financing and support and assistance services for children with cancer may have applicability to children with serious illnesses in general, regardless of the specific diagnoses; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau shall consult the Hawaii's Children's Cancer Foundation, HUGS, the American Cancer Society, the Childhood Cancer Committee, Kapiolani Medical Center for Women and Children, the Department of Radiology at Queen's Hospital, the Cancer Research Center, the Department of Human Services, the Department of Health, the Department of Education, the Medicaid Division, and relevant third party payors for information regarding an assessment of needs and services; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau submit a report of its findings and recommendations to the Legislature at least twenty days before the convening of the 1993 Regular Session; and

BE IT FURTHER RESOLVED that a certified copy of this Resolution be transmitted to the Legislative Reference Bureau and consulting agencies.

Hawaii Children's Cancer Foundation

"Am I going to live, mommy?... Am I going to die?"

"Am I going to live, mommy?... Am I going to die?"

These words from a child make us realize how helpless we are. "I was scared. Terrified. I was concerned about the chances of our child surviving cancer." These are some of your responses we received from our Parent Survey.

We have compiled the results of the survey and we'd like to share it with you. Like us, we feel you will find it very insightful.

Hawaii Children's Cancer Foundation SURVEY RESULTS

SURVEY INFORMATION:

Surveys distributed: 130 (approximate)
Surveys returned: 92 (70% return rate)

SURVEY FORMAT INFORMATION:

The format of the survey lists 8 groups. The summary of responses is consistent with the survey format.

TOTAL % - indicates the combined responses of Oahu and Neighbor Island in percentile data.

N.I.% - indicates Neighbor Island responses in percentile data.

OAHU % - indicates Oahu responses in percentile data.

Y - indicates a "yes" response to that item.

N - indicates "no" response to that item.

* - indicates a concern or need for that item under a particular respondent group.

GENERAL INFORMATION:

My child has (had) cancer. I am a:

mother	72
father	6
both (M/F)	7
other	1

I live on:

Hawaii	16
Kauai	2
Oahu	64
Maui	7
Molokai	1

We went off island for medical care: Yes: 32
No: 54

Where: Kapiolani, Fred Hutchinson, Walter Reed, St. Jude, Cedars Sinai, UCLA, San Francisco, Boston.

My child's age at diagnosis was:

3 wks.- 35 mos.:	31
3-5 yrs:	20
6-8 yrs:	10
9-12 yrs:	12
13-18 yrs:	2
19-23 yrs:	1

My child was diagnosed:

Less than one year ago:	14
One - three years ago:	19
Three - five years ago:	26
Five or more years ago:	28

We have a dream...

My child:

Is on treatment:	18
Has completed treatment:	52
Less than five years ago:	35
five or more years ago:	13
Is no longer living:	19
Has had surgery only, no treatments:	1
periodic check ups only:	1

	Oahu	N.I.
It would be helpful to me if there was:		
A way to keep in touch with other families:	25	9
A way to keep in touch with survivors:	32	12
A local newsletter for families:	41	13
A family conference to help us better understand and cope with childhood cancer:	51	11
More government help with services and financial support:	51	16
More public awareness about childhood cancer:	53	18
An organization or foundation designed to meet the needs of families, children, and health professionals working with children with cancer:	51	19
A candlelighter's organization (item added)	1	

Survey Results

	TOTAL %		N.I. %		OAHU %	
	Y	N	Y	N	Y	N

Group 1 (5 items)

Parental understanding of disease, treatment, side effects, making decisions, and how to obtain a second opinion.

I had enough explanation and information to...

1a. Understand my child's disease.	84	16	90	10	83	17
1b. Understand options of treatment.	84	16	85	15	84	16
1c. Understand side effects of treatment.	86	14	90	10	85	15
1d. Make decisions.	83	17	90	10	81	19
1e. Know how to get a second opinion.	62	38	50	50 *	66	34

Respondents seem satisfied with Group 1 items in general. There is a concern for N.I. respondents to item 1e - Knowing how to obtain a second opinion.

GROUP 2 (3 items)

Hospital services, facilities, medical procedures, and test results.

2a. Understand hospital services and facilities.	77	23	75	25	78	22
2b. Understand the medical procedures.	85	15	85	15	85	15
2c. Understand test results.	80	20	85	15	78	22

Respondents in general seem satisfied with Group 2 items. Support from health care team; social work assistance team.

Group 3 (3 items)

Support from health care team; social work assistance; parental role as part of care team.

3a. The health care team helped with my concerns.	83	17	90	10	81	19
3b. I received adequate help from social workers.	59	41	50	50	62	38
3c. My role as a parent was recognized as part of the health care team.	81	19	85	15	80	20

In general, respondents seem satisfied with group 3 items. N.I. respondents indicated a split response of 50% yes and no in receiving adequate social work assistance.

Hawaii Children's Cancer Foundation

		TOTAL %		N.I. %		OAHU %
		Y	N	Y	N	Y
Group 4 (7 items)						
<i>Health insurance information and payments; understanding medical bills and arranging for payment schedules; and obtaining help with costs not covered by insurance; and receiving information about financial assistance.</i>						
4a. I needed help to understand my health insurance policy.	47	53	55 *	45	44	56
4b. I needed help to understand my medical bills.	47	53	70 *	30	40	60
4c. I was able to arrange for special payment schedules.	57	43	40	60 *	61	39
4d. The health insurance company sends payment quickly.	48	52 *	33	67 *	51	49
4e. I was able to get help with costs NOT covered by insurance.	43	57 *	47	53 *	42	58
4f. The health insurance was willing to discuss costs that were not covered.	45	55 *	47	53 *	41	56
4g. I got information about financial help I could apply for.	48	52 *	50	50 *	47	53 *
<i>Every item in group 4 is a concern for N.I. respondents.</i>						

GROUP 5 (3 items)						
<i>Transportation for medical treatment and temporary housing while away from home.</i>						
5a. I needed help to get my child to/from medical treatment.	32	68	60 *	40	24	76
5b. I needed help to get my child to/from medical treatment by airplane.	27	73	80 *	20	12	88
5c. I could find temporary housing while away from home for medical care.	53	47	94	6	40	60
<i>N.I. respondents indicate a high concern/need for transportation assistance. The housing issue seems to not be a problem for N.I. respondents. Those respondents who found housing to be a problem, could be those who reside in rural Oahu.</i>						

GROUP 6 (7 items)						
<i>Coping efforts, support for child care, and counseling services.</i>						
MY FAMILY RECEIVED ASSISTANCE TO:						
6a. Help my child cope.	54	46	58	42	53	47
6b. Help Mom cope.	56	44	63	37	54	46
6c. Help Dad cope.	45	55 *	39	61 *	46	54 *
6d. Help brothers and sisters cope.	32	68 *	29	71 *	33	67 *
6e. Help with my marriage.	15	86 *	13	88 *	16	84 *
6f. Get childcare for my other children while we were away.	28	72 *	25	75 *	18	82 *
6g. Get counseling services/support when we needed it.	57	43	63	37	55	45
<i>Items 6c-f indicate a major need to help Dad and siblings cope; assistance with marriage counseling; and child care.</i>						

GROUP 7 (3 items)						
<i>Support from the school, classmates, teachers, and school system.</i>						
7a. The school gave special help for my child.	69	31	74	26	68	32
7b. The school gave special help for my other children.	31	69 *	35	65 *	30	70 *
7c. The teachers and classmates were able to understand my child's situation.	49	51 *	71	29	48	55 *
<i>There is a need to assist siblings within the school setting. More attention is needed for teachers and classmates to understand the child's situation.</i>						

Hawaii Children's Cancer Foundation

	TOTAL %		N.I. %		OAHU %	
	Y	N	Y	N	Y	N
GROUP 8 (2 items)						
<i>Receiving practical information and support from other parents. Receiving information about other resources.</i>						
8a. I got practical information and support from other parents.	58	42	65	35	56	44
8b. I got information about other resources that could be helpful.	69	31	70	30	68	32
<i>All respondents seem satisfied with information received from other parents and resources.</i>						

"Am I going to live, mommy?... Am I going to die?"

We all know the trauma of living one day at a time. One day these cries will never be heard. We need to build for our children and for their children's future.

As in the words of Martin Luther King Jr., we, too, have a dream. We have a dream that all children of the Pacific Basin will receive state-of-the art health care. We have a dream that no child will have to endure discrimination. We have a dream that we will build partnerships among health caregivers, social service providers and families. We have a dream that the day will come when there will be no more cancer.

We have found there is a great need to establish a foundation for our children. We invite you to help make this dream a reality. An organizational meeting is being planned for September 15, 1991. Please join us.

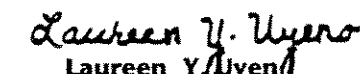
With the light of hope,


Gail Awakuni


Cathi Chun


Geri Ihara


Annette Young-Ogata


Laureen Y. Uyeno
Childhood Cancer Survivor

The Steering Committee of the Hawaii Children's Cancer Foundation

Graphics and layout design by M. Hirata Design Media; Milton Hirata, principal

BIGGEST CONCERNS AND WORRIES

The implications of the comments from neighbor island and Oahu respondents are significant. Many needs exist. The frequency of comments and repeated concerns indicate there are needs in these categories: Public Awareness, Educational Concerns, Family Concerns, Financial/Insurance Concerns, Treatment/Care/Procedures, Survival and After Effects.

These comments and results of the survey reveal the need to provide families and long-term survivors assistance and support. Our children deserve an advocate. Listed below are some of your responses about your concerns.

Public Awareness

- ☐ "Much mis-information about Blood Bank."
- ☐ "Perhaps a video or something to show at work. My employers gave me more stress when I had to be off to help with my child. They were not understanding. We both lost a lot work days and pay to be with our child. Employers are not aware of chemo, Hickman, low blood counts, loss of appetite, fevers, and unplanned trips to the hospital."
- ☐ "The public needs to be better informed about childhood cancer (how many children), more research for childhood cancer, health care costs."

Educational Concerns

- ☐ "The Department of Education allows only three hours a week for home tutoring for children in grade K-6. K-6 should not be lumped together and have a set three hours. Three hours should increase for higher grades: K-3/ 4-6/ 7-8/ 9-10/ 11-12."
- ☐ "Homework — trying to help my child keep up with her class (the teachers were terrific)."
- ☐ "Effect on school work."

Family Concerns

- ☐ "Keeping the family together under these incredibly stressful conditions."
- ☐ "How I was going to handle the situation of having a new baby. . . ."
- ☐ "How my child was doing. . . . Balancing family and work needs."
- ☐ "My marriage — stress related problems — no communication — breakdown in family."
- ☐ "Childcare for my other children while we're away."
- ☐ "Coping with death — for the whole family. . . ."

Financial/Insurance Concerns

More than 50% listed financial worries are one of their greatest concerns.

- ☐ "Financial devastation."
- ☐ "I am worried about the expenses for the three year protocol program my son is in though we know it is helpful to others."
- ☐ "High costs of transportation (i.e.) cab, care rental, and feeding two separate families on two islands for long periods of time."
- ☐ "Not qualifying for financial help but not making enough to pay debts."
- ☐ "Medical insurance companies do not take the time to explain everything (coverage, major medical differences, etc.). Companies (including federal government) need to be educated (time-off for parents, flex time, depression, etc.)."

Treatment/Care/Procedures

- ☐ "Information and assistance from medical and social work staff was very intense at first (almost overwhelming) but then almost hit and miss."
- ☐ "Treatment and side effects of drugs. Help of professionals to cope with anxieties."
- ☐ "Long-term effects and research, bone marrow registry. Not having a pool of pediatric oncology doctors in the next few years."
- ☐ "Did not know my child's doctor. Because of the swiftness we had to get our child on therapy, the doctor was referred by my child's regular pediatrician. Thank goodness we were referred to an excellent oncologist."
- ☐ "Faith in the doctors."
- ☐ "Did not particularly like to go to the ER to screen patients before admission to the hospital. Too many chances to catch communicable diseases."
- ☐ "The four-bed ward should not be a place for oncology patients. No bath, no privacy."
- ☐ "My other concerns — the hospital equipment is inadequate. It seems like the children get the shaft because they are unable to speak for themselves."

Survival and After Effects

- ☐ "Whether my child could survive the cancer and subsequent treatment. . . Whether my child will have a recurrence."
- ☐ "If my child could be able to walk, talk, and help himself. How is he going to help himself when he grows up?"
- ☐ "That I could have my son for my lifetime and that he would outlive me."

◆ SCAN OF HCF STAFFED FUNDS THAT ASSIST INDIVIDUALS IN NEED ◆

<i>Fund Name</i>	<i>Eligibility Requirements</i>	<i>Average Grant/ Range</i>	<i>Meeting Dates</i>	<i>Deadline</i>	<i>Additional Information</i>
Gwenfread Allen	1) Over age 62 or 2) Mental health problems	\$1,000 \$150 - \$1,500	Jan., Apr., July, Oct.	1st of month 2 months preceding meeting month	Documentation of mental health condition required
Cottlington	Intellectually gifted children (IQ in the 98th percentile or higher)	\$1,000 \$500 - \$1,500	April	April 1st	Scholarship or special academic activities only
Teresa F. Hughes Trust	Adults: over 50 Children: 1) Born out of wedlock, or 2) Orphans/Half, or 3) Abused/Neglected	\$800 \$100 - \$4,000	Feb., Apr., June, Aug., Oct., Dec.	1st of month preceding meeting month	Preference to long-term residents of Hawaii
Grace Bryan Taylor	Documentation of condition of Angina Pectoris	\$1,000 \$300 - \$2,400	March, September	February 1st & August 1st	Physician's statement required
Theodore Vierra	Over age 50	\$700 \$100 - \$3,000	January	December 1st	One-time or short-term assistance
Kitaro Watanabe	Needy children	\$500 \$250 - \$1,200	Jan., Apr., July, Oct.	1st of the month preceding the meeting month	Preference to medical or life threatening problems
James & Winifred D. Robertson	Adults aged 18 - 49 Oahu residents	\$300 \$100 - \$1,000		**** See attached flier	
Irving Singer	Children of Hawaiian ancestry	\$100 \$100 - \$300		Direct Singer, Soper, and Wilder fund inquiries to: Maui Economic Opportunity, Inc. P.O. Box 2122 Kahului, Hawaii 96732 Phone: 1 871-9591 (from Oahu)	
Alice Soper	Over age 50	\$250 \$100 - \$1,000			
Lillian K. Wilder Fund	Children with learning disabilities	\$100 \$100 - \$300			Referrals from Learning disabilities Assoc. of HI

