CHAPTER SIX

PREVENTION, DIAGNOSIS AND TREATMENT OF DISEASE
Cancer is the second cause of death in Cuba (as it is in the United States), after cardiovascular disease. The incidence as well as mortality rates are expected to climb over the next years, reflecting, among other factors, the longer life expectancy of the population (many cancers are more common in older people). Prevention, early detection and treatment thus are becoming more of a priority within the general health care system, according to Dr. Rolando Camacho, Director of the National Oncology and Radiology Institute.

The Institute is the national reference center for research and treatment of adult cancer, and oversees national preventive programs, such as the National Program for Early Detection of Breast Cancer.

The Havana center includes a 450-bed hospital with 128 attending physicians staffing full surgical, oncological medicine and radiation therapy services. Pediatric as well as adult patients receive treatment at the Institute. In 1994, 6,186 patients were hospitalized; and a total of 60,682 patients were seen on an outpatient basis.

After visiting diagnostic and treatment facilities, adult and pediatric wards, and pursuing detailed interviews with specialists, we have concluded that the U.S. embargo has significant direct and indirect impact on the quality of patient care and indeed the chances for survival of Cuba's cancer victims. It has also placed an additional burden on the health care system, medical personnel, and on the families of cancer patients.

**Cancer Incidence and Mortality**

Every year, between 20,000 and 25,000 new cases of cancer are diagnosed in Cuba: men are at greater risk with 222.6 cases per 106,060 inhabitants, while women account for 194.1 cases per 100,000 inhabitants. Incidence of cancer, for both sexes, show lung cancer to be the most prevalent, followed in order by skin cancers, prostate, breast and colon cancers. Mortality rates are highest for lung cancer, followed by prostate, colon, breast and stomach cancers. As mentioned earlier, both incidence and mortality rates are on the rise.

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Source: National Oncology and Radiology Institute, Havana.

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Source: National Oncology and Radiology Institute, Havana.
Prevention, Early Detection and Diagnosis

Since 1960, Cuba has developed nationwide programs for prevention and early detection of pediatric cancers and those of the lung, cervix, breast, and mouth. An anti-smoking campaign has had considerable success in this tobacco-producing country, showing fewer smokers (36% of people over 17 by 1990), and less consumption (down to 4.4 cigarettes daily by 1993). These education and early detection programs are carried out in communities throughout the island, with the support of the media, local organizations, and the family doctor program. Dr. Camacho notes that they are particularly costly, and have been seriously affected by the economic crisis, aggravated by the U.S. embargo, primarily because scarce funds must be saved for curative procedures and treatments.

One striking example of a direct effect of the U.S. embargo is the unavailability of Kodak mini-R film for the national mammography program, which would permit women to be exposed to considerably fewer doses of radiation than film available to Cuba from non-U.S. sources. Experts say that they have had to buy less sensitive film from these non-US suppliers, because the price of Kodak mini-R through intermediaries was completely out of range. As noted above, breast cancer is the number one cause of death by cancer in Cuban women. (For a more detailed discussion of embargo-related difficulties with the national mammography program, see discussion of women's health in chapter on selected aspects of health and welfare).

Diagnosis is directly and indirectly impacted by the embargo: A case in point involves the only platelet aggregometer in Havana, a unit for specialized blood workups and coagulation studies. Three hundred and sixty patients a month require these analyses (from the Institute and referred from other hospitals). However, while the equipment is Italian (Omniscr ipte Series D-6991, the metallic tape used to inscribe the test results is of U.S. origin, and Cuba has not been able to buy it from any source. For lack of the tape, the use of the Omniscr ipte is limited to reading only half the information from each patient's tests.

Dr. Lorenzo Anasagasti, Vice-Director for Medical Equipment at the Institute, also reports delays in arrivals of spare parts for other equipment, when a U.S. partnership is involved. This is true, for example, of the blood chemistry equipment from Ciba-Corning, which requires six to eight months to receive spare parts through third parties.

The diagnosis and followup on patients with intra-ocular tumors has been frustrated by the inability to purchase parts for the Institute's U.S.-origin ophthalmological ultrasound equipment. In 1985, 10 Cooper-Vision Model System IV ultrasound units were purchased through Mexico. Cooper-Vision is a U.S. company, located in Redding, California, and according to Cuban specialists no comparable equipment was available at the time. Since the original purchase, however, it has been impossible to buy parts for this equipment even through third parties, according to Cuba's National Medical Supply Company (EMSUMEI). In the case of the Oncology Institute, their ultrasound has been broken for the last two years, leaving some 1200 patients without the benefit of this important diagnostic tool, which permits, among other things, earlier
detection and more precise location of tumors. In a few cases, according to hospital records, patients were able to be referred to other institutions with working ultrasounds, but for the vast majority of patients, physicians had to rely strictly on methods of clinical diagnosis.

These direct effects of the embargo are complicated by economic limitations, in which the embargo has played a role. For example, the Institute’s endoscopy equipment (used for diagnosis of digestive tract cancers) was purchased in the 1970s from Japan, a decade in which trade between the two countries increased significantly with Japan’s importation of Cuban nickel. However, when the United States refused to buy any Japanese product that contained the island’s nickel, Cuban trade with Japan—hence credits—slumped, and such financial constraints limited future purchases, among them replacement parts for the Institute’s endoscopy equipment.

Broader economic factors, exacerbated by the embargo, have limited purchases of key equipment. The Institute has no CAT scan, which specialists consider vital to diagnosing the extension of tumors and determining whether they are operable. Dr. Anasagasti notes that of the 3,000 candidates for surgery they receive annually, 2,000 require CAT scans. And, he says, half the patients who receive radiation therapy also require CAT scans. The Institute is only able to refer 10-12 patients monthly to other hospitals with CAT scans, since there are so few units (ten in the country as a whole, nine of which are in working order). There is no MRI (magnetic resonance imaging), which could in some cases substitute CAT scan studies.

The Institute has only one x-ray machine (specialists estimate their needs at ten, including three portables).

**Radiation Therapy and Surgery**

Quality and cost of equipment are at issue in this sensitive area of cancer therapy. Dr. Anasagasti is of the opinion that U.S. firms have the best quality cobalt radiation therapy equipment and accelerators. ‘The fact that we do not receive bids from them means that other companies offer us a quality inferior to U.S. manufacturers at a higher price,’ he says. This, he states, has made replacing old equipment an expansive proposition, given current economic limitations. The result is that there is one cobalt therapy unit working in the hospital, which is in use from 6:00 a.m. to 1:00 a.m. the next day, with technicians rotating on round-the-clock duty, should it break down. Maintenance is done on weekends. This causes untold hardship for the patients (who often must come from far away at difficult hours) and for staff (who are under additional stress). The equipment itself suffers: Dr. Anasagasti calculates that in the last three years, this unit has in fact used up eight years of its normal 12-year lifespan.

The hospital is also under an extra burden: Because of transportation problems created by the lack of fuel and spare parts, patients who could receive radiation on an outpatient basis are often hospitalized. And their treatment is often delayed, which can affect prognosis: At the time of the visit to the radiation therapy service, there were 25 patients on a waiting list for treatment; and the wait was averaging 20 days per patient. (The period of treatment itself averages six weeks).

Optimally, states Dr. Anasagasti, the Institute should have two cobalt therapy units and one accelerator, this last piece of equipment representing a significant improvement in therapeutic alternatives, since radiation is directed at a smaller area, potentially affecting less healthy tissue. Neither does the Institute have a simulator for planning surgery, and specialists must use x-ray and clinical means to estimate the extent of tumors, among other factors.

In surgery, the Institute faces serious problems with the anesthesia units: Of four 20-year-old Swedish units, three are working without their automatic alarms, causing extra stress for personnel and added danger to patients. Four of five respiratory ventilators for post-operative and
intensive care are in use (the one that is broken is from the U.S. manufacturer Merck, with no possibility for repair).

Dr. Anasagasti and importers at MEDICUBA agreed that the fundamental problem in the surgical service of the Institute has been lack of hard currency to replace equipment, a situation exacerbated by the U.S. economic embargo.

**Chemotherapy: Application and Research**

Chemotherapy drugs are among the most costly for the Cuban health system. Nineteen of these are included on the Basic List of Medicines prioritized for 1995-96, but because of financial limitations, aggravated by the embargo, all of these are continually in short supply. Cuban purchasers and cancer experts estimate that this situation would be considerably alleviated if Cuba could purchase chemotherapy medicines from the U.S. market, since the United States is the world’s number one producer of these cancer-fighting drugs—and at competitive prices, not to mention considerably reduced freight costs from purchasing close to home instead of from European suppliers. The embargo has also directly affected Cuba’s attempts to produce chemotherapy products domestically, which would mean even greater savings and, therefore, significantly improved product availability. (See below).

Chemotherapy drugs must often be used in tandem, in specific protocols to be effective against particular cancers. The reduction of therapeutic options produced by scarcities thus has a direct impact on the chances of disease-free survival among patients. Dr. Maria del Carmen Barroso, in charge of medicines at the Oncology Institute, describes what she calls “the morning agony” of reviewing the stock and variety of chemotherapy drugs available each day for each patient.

She cites the example of treatment of breast cancer patients, noting that this requires 5-fluorouracil and cyclophosphamide in combination with either methotrexate or Adriamycin (doxorubicin HCl). These combinations are not always available. On the day of our interview, she described the following problems in this regard: “Right now, we don’t have either 5-fluorouracil, methotrexate or Adriamycin. This is terrible psychologically for the patients and their families.” All the more so, she says, because chemotherapy must be started within a certain period of time after surgery—in the case of breast cancer, within two to three weeks. Otherwise the disease-free survival prognosis becomes dimmer. In general, she noted, “within the last two weeks, we have not been able to accept a single new patient for chemotherapy” because of drug shortages. Ten breast cancer patients were on the waiting list, but the real need was greater, she said, because all other hospitals had been advised to hold up referrals.

The situation is especially tragic with children, virtually all of whom require chemotherapy, according to Dr. Barroso. She cites the case of an eight-year-old girl operated on for non-Hodgkin’s lymphoma, who needed high doses of methotrexate in her treatment protocol. With this drug, she would have had a 90% chance of total remission. But because the amount needed for her case was not available and doctors were forced to substitute another chemotherapy medication, the chance of remission was uncertain.

Ironically, Cuba’s ability to produce methotrexate was stalled by the embargo in 1993, when the United States refused to issue an export license to the German subsidiary of Pfizer, Heinrich Mack Nachf, for sale of the raw materials for methotrexate to Cuba. (See chapters on Medical Exports and the Pharmaceutical Industry.) This held up trial production runs for this key chemotherapy agent. Pull-scale manufacture has been delayed as a result and also by another embargo-specific obstacle: difficulties in purchasing key equipment.

Domestic production of this and other chemotherapy drugs has been stalled for some time because Cuba has not been able to purchase a freeze dryer (lyophilizer), Model LYOFLEX-16, from the
British firm Edwards. According to Marlene Porto, Director of Cuba’s Center for Medication Research and Development (CIDEM), this unit is needed to dehydrate injectable chemotherapy powders to assure the long-term stability of the product. However, she says that because the unit in question is produced in the United States, We have not been able to even obtain a price quotation.” Other freeze dryers are on the market, says Porte, but they do not meet Cuba’s quality control standards. As a result of this direct incidence of the embargo, Cuba has not been able to produce such chemotherapy drugs as cisplatin, actinomycin D, vincristine sulfate (used against childhood leukemia), vinblastine sulfate and bleomycin sulfate, in addition to a number of other vital medications (see chapter on the Pharmaceutical Industry).

The shortage of chemotherapy drugs not only restricts therapeutic options but it also stops application of certain treatment protocols which would guarantee maximum disease-free survival rates. According to Dr. Camacho, limited supplies also result in decision-making that is a “nightmare” for cancer specialists, trained as they are to make efforts against all odds to save their patients. Dr. Camacho states that scarcities of chemotherapy medications force doctors to reserve these life-saving drugs only for cases where the chances of recovery are especially promising “In 80% of the cases where we should be using chemotherapy for palliative reasons, we cannot.”

Currently, then, the U.S. embargo negatively impacts the availability of finished chemotherapy medications as well as raw materials to produce these drugs domestically in Cuba. Over the longer term, it may also prove to have a negative effect on the availability of new and more effective cancer-fighting medications. The United States has the world’s number one research and development capability for these drugs. From 1970 through May of 1992, U.S. firms led the world in marketing major global drugs for fighting cancer: Five of 16 new medications which were approved worldwide during those 22 years were developed in the United States, more than in any other single country.
In its fifth survey of New Medicines in Development for Cancer, the Pharmaceutical Research and Manufacturers of America reports that an unprecedented 215 new medications were in Phase I-III FDA tasting in 1995, with 211 of these patented by U.S. manufacturers. None of the 211 new medications will be available to Cuban doctors for at least a decade, since law prevents their generic production by non-U.S. firms for the period protected by patent; and only under exceptional licenses granted by the U.S. Treasury Department could they otherwise be sold to Cuba.16 Of the 211,171 or 66% are medicines that target the five main types of cancer found in Cuba: lung, skin, prostate, breast and colon.17

According to the same survey, another 26 drugs are being studied for the treatment of leukemia, a disease that primarily strikes children and young people. If the embargo remains in place, none of the children diagnosed with leukemia in Cuba today will have access to these new and more effective life-savers. Indeed, more cases can be expected like that of Oncaspar (pegasparagase), a drug patented by Enzon of the United States and already approved by the FDA for patients allergic to L-Spar (L-asparaginase). Each of these drugs has been found to produce longer remission when added to treatment protocols for acute lymphoblastic leukemia (ALL), but L-Spar has an allergy rate of 40% for first-time use, and 79% for relapsed ALL. This type of leukemia, which strikes at the rate of three per 166,669 youngsters under 15 in the United States,8 is fatal in two to three months, if left untreated. Oncaspar is less traumatic to a child suffering from ALL, since it requires one to two injections, instead of six to 12 of L-Spar, to induce remission.19

However, the effect of the embargo on cancer medicine research and development is not limited to preventing U.S. advances from reaching Cuban patients: The Cuban Democracy Act (CDA) of 1992 takes specific aim at Cuba’s biotechnology capabilities, with the purpose of withholding from Cuban scientists any imports which could contribute to research or manufacture in the field. At the same time, biotechnology is one of the greatest hopes for treating cancer, according to Gerald J. Mossinghoff, President of the Pharmaceutical Research and Manufacturers of America: “Biotechnology has given a special boost to cancer research, and advances appear to be accelerating.”20

His words might refer to several areas of research which have become hallmarks of Cuban biotechnology: recombinant interferons for use against cancer, AIDS and various viral agents. Specifically, Cuba’s Heberon Alfa N and Alfa R recombinant interferon injections have been used successfully to treat hairy-cell leukemia, chronic myelogenous leukemia, low and medium-grade non-Hodgkins lymphomas, and some carcinomas and sarcomas, including Kaposi’s sarcoma (associated with AIDS). And Cuba has developed at least one monoclonal antibody, or “magic bullet,” for carrying cancer-fighting drugs directly to malignant tissue;21 (see chapter on Vaccines and Biotechnology).

Dr. Camacho also suggests that the U.S. embargo deprives Cuban specialists in oncology of joint research opportunities with colleagues in the United States. And he contends that Cubans have never been able to obtain fellowships offered through the U.S. National Cancer Institute, which he characterized as one of the world’s most significant supporters of cancer study and research.22

Additional Medications

As with chemotherapy medications, Dr. Barroso explains that cancer patients cannot count on “a stable arsenal” of hormones, antiemetics (which prevent nausea during chemotherapy treatment), analgesics, or antibiotics. While this situation is due primarily to the scarcity of hard currency, this is one more arena in which the embargo constitutes an aggravating factor. (It is useful here to recall that Cuban importers of medicines and medical equipment have had to pay $6.7 million in
excess shipping costs from faraway markets over the last three years alone, when compared to the cost of shipping from the United States.)

At a minimum, gaps in availability of these medications increase patient suffering and prolong hospital stays and in extreme cases can be life-threatening.' The problem of antiemetics is particularly dramatic in the pediatric ward. At the time of our visit there, the hospital was into its 29th day without metoclopramide HCl. This drug is used in combination with others such as betamethasone for children receiving chemotherapy. Without them, states Dr. Barroso, the child will vomit an average of 28 to SO times a day. There were 35 children in chemotherapy at the time of our visit, and none of them had the benefit of combination treatment.23

Analgesic scarcities create another series of problems: Since many times first and second-tier analgesics are unavailable (such as acetaminophen, ibuprofens and other non-steroid anti-inflammatory drugs), specialists must resort sooner to stronger pain-killers such as codeine and morphine, fully aware that these are contra-indicated at lower pain levels but unable to offer their patients an alternative. These are controlled substances, and their sale is restricted internationally. What’s more, by applying them earlier on, the patient builds up a resistance to their effectiveness and needs greater doses to control pain later.

Finally, in the case of hormones, some situations become life-threatening. This is the case of thyroid hormones. Patients with thyroid cancer require two to three times the usual therapeutic dosage and can die if they do not receive it. Often this hormone is in short supply. “The first two weeks, the patient comes looking for the medicine; after that, his family comes, since he is just too weak,” comments Dr. Camacho.24 At the time of our visit to the Institute, an x-ray technician at the hospital itself had been bed-ridden for two weeks for lack of thyroid hormone to treat his cancer.
NOTES

1 Anuario Estadistico. Instituto Nacional de Oncologia y Radiologia, 1994, pp. 2 and 7.
3 Hygiene and Epidemiology Dept., Ministry of Public Health, Havana
4 Interview with Professor Orlando Valls, Resident of the National Radiology Society and Head of the Radiology Department, Hospital Hermanos Ameijeiras, Havana, December 15, 1995.
5 Interview with Dr. Lorenzo Anasagasti, Vice-Director for Medical Equipment, National Oncology and Radiology Institute, Havana, October 16, 1995.
6 Interview with Alexis Cedeño, Vice-Director. National Electromedicine Center, Havana, December 8, 1995.
7 Interview with Rivero. Vice Director for Medical Equipment of the National Medical Supply Company (EMSUME). December 22, 1995.
12 Interview with Dr. Maria del Carmen Barroso, National Oncology and Radiology Institute, October 16, 1995.
13 Dr. Barroso estimates that remission rates of 60% achieved in Cuba for non-Hodgkin’s lymphomas may return to the 1960s rates of only 26% if the availability of chemotherapy agents continues to be seriously affected. Remarks to authors on April 3, 1996.
14 Interview with Dr. Rolando Camacho, Director, National Oncology and Radiology Institute. Havana, October 16, 1995.
16 While these might be obtained through third-country wholesalers, the price tag would certainly be much higher than if directly exported to Cuba, and perhaps unbearably so. To the high cost of patented chemotherapy drugs, one must add “surcharges” for the intermediary, which include the usual profit margin plus a percentage for the risk that the sale to Cuba represents.
19 Interviews recorded by Dr. Anthony Kirkpatrick with Dr. Abraham Abuchowski. Enzon Corporation; Dr. Joan Hertzberg, Pediatric Clinical Research Group; and Dr. Steve Sallan, Dana Farber Cancer Institute, March 15, 1996.
20 PhrMA, “’95 Survey...”.
22 Interview with Dr. Rolando Camacho, Oct. 16, 1995.
23 Interview with Dr. Barroso and visit to the pediatric ward, October 16, 1995, National Institute of Oncology and Radiology, Havana, Cuba.
24 Interview with Dr. Camacho, Oct. 16, 1995.
Introduction

Heart disease is the number one cause of death in Cuba, with ischemic cardiopathies accounting for over half of these fatalities each year. Mortality rates have generally been rising for both sexes since the beginning of the decade: In 1989, there were 189.3 deaths per 100,000 inhabitants, with 210 for men and 168 for women. In 1995, however, figures had reached 199.8 for both sexes, with 216.1 for men and 183.2 for women. Some 22,966 Cubans died in 1995 from heart disease.

Cerebrovascular disease, accounting for over 7,000 deaths in Cuba every year, is the third case of death and shows a rising mortality rate since 1989.

High blood pressure affects about one quarter of the Cuban population, or some 2.6 million people, one third of them receiving regular primary attention through the community family doctor program. It is estimated that, in 112,000 of these cases, hypertension has been clinically controlled. In fact, deaths attributable to high blood pressure have decreased over the last two decades to 8.2 per 100,000 inhabitants in 1995.

Over the years, the Cuban medical system has developed broad strategies of prevention and therapy for heart disease, including the use of implantable pacemakers and defibrillators, surgical transplants, and research on new drugs for treatment.

The Cardiology Institute in Havana includes research facilities, plus an 84-bed hospital for surgical and other therapies for heart patients. While all general hospitals in Cuba afford attention to victims of heart disease, the Institute bears a major responsibility in the field, which has become a bigger burden with the economic crisis of the nineties, as some other facilities are not able to maintain all their services. For example, normally the Institute would implant about half of the pacemakers installed annually, but this proportion is now greater, since other hospitals are having difficulties in guaranteeing conditions for this procedure. In 1995, the Institute implanted 597 pacemakers of some 800 total.

However, the Institute has itself been affected by the adversities and shortages of the last several years. As a result, while through 1990 an average of 466 major operations were performed there annually, this figure has been gradually decreasing, with 1995 surgeries numbering only 174. As of December 31 1995, there was a waiting list of 297 patients, a delay which specialists estimate exposed them to a 19% greater risk of death.

During visits to the Institute and other hospitals, and based on extensive interviews with specialists, we have found that the U.S. embargo constitutes a significant impediment to optimum patient care and research, which at times has presented a clear threat to human life.

Cuban patients needing pacemakers or implantable defibrillators were placed in particular danger. Pacemaker implantation is a regular procedure in Cuba, performed on the basis of physician recommendation and patient consent alone, since, like other surgeries, it is gratis. Thus, pacemakers were imported on the basis that each patient who needed one would get one. Until 1993, these purchases were made from Siemens-Elema of Sweden and Telelectronics Pacing Systems of Australia. However, within a period of six months, sales from both were art off as production was transferred to plants and ownership in the United States, thus falling under the jurisdiction of the U.S. embargo.

In the case of Siemens-Elema, its Pacemaker Division was sold to St. Jude Medical of Minnesota. Telelectronics pacemakers were being produced in the TPLC, Inc. plant in Hialeah, Florida, where corporate executives decided not to pursue sales to Cuba, for fear of offending the Cuban-American community, following recommendations of legal counsel to this effect.
As MEDICUBA searched for new suppliers in Europe, a potentially dangerous situation was developing for cardiac patients on the pacemaker waiting list. Finding a new source was an especially complex process, since not only did the quality of the pacemakers have to measure up, but once a new manufacturer is identified, its own line of accessory equipment must be purchased to program the pacemakers, making it more expensive, complicating expedient delivery, and introducing a period of technical training for personnel.

Cardiology Institute specialists report that the situation was overcome with no time to spare and that no fatalities were registered. However, this situation illustrates how vulnerable these life-saving procedures are to unpredictable and sudden consequences of the U.S. embargo.

It should be noted that the urgency of finding another supplier and the delays and uncertainties accompanying application for a U.S. export license discouraged Cuban importers from following such a route. Importers reported that for budgetary reasons pacemaker purchases are made ten times a year, which would have meant tiling a separate license application for each one, with patients waiting for the outcome of US. Commerce Department decisions and dependent on the US. government’s consistent good will. We just couldn’t take that risk,” commented Rolando Días of MEDICUBA. 7

Even so, a U.S. export license only permits Cuba to buy from a U.S. supplier: it does not offer Cuban patients any recourse should the equipment purchased be defective. This is not as hypothetical as it sounds: Telectronics, according to an ECRI Alerts bulletin issued in June of 1995, was prohibited by the FDA from further distribution of certain pacemaker models and electrodes until they satisfied federal production guidelines. -(The problem concerns an electrode that could pierce the patient’s heart.) A Security Alert” from Cuba’s Ministry of Public Health, distributed to hospital directors throughout the country, noted that in May of the same year the Ministry’s Center for Medical Equipment Control had warned of the sudden failure of a Telectronics pacemaker in a Cuban patient, ‘endangering the life of the patient.” The alert noted: -At that time, our investigation indicated that the pacemaker had malfunctioned, which in our judgment corroborates the FDA decision.... But it should be noted that the prohibition on marketing this equipment only applies to new sales, and thus (Cuban hospitals) should take precautions with pacemakers already in stock or those which have already been implanted.” 8

No additional problems had been reported with Telectronics devices in Cuba through January 19, 1996, according to Dr. Francisco Dorticós of the Cardiology Institute. However, in the not unremarkable event that such a failure should have occurred, or should occur, and presuming that a Cuban patient or his/her family were to be awarded damages from a U.S. court, these damages would by virtue of the embargo be held in a blocked account in the United States, cut off reach of either family or patient and consequently not constituting any type of compensation whatsoever.9

The move of Telectronics production to Florida led Cuban importers to eventually seek alternate suppliers for implanted defibrillators of the same brand, although these were still being manufactured in Australia. Six to eight of these defibrillators are needed in Cuba each year, and because they are very costly, they are purchased on a case-by-case basis. Locating, signing and ensuring delivery on new contracts, including the purchase of the necessary programmers and the visit of a technician to Cuba to teach specialists the workings of the new line of devices, is again a costly and time-consuming venture, thrust on MEDICUBA as it seeks to ensure ‘embargo-proof’ supplies.

At the end of 1995, while the switchover was still in progress, there were two 21-year-old Cuban patients with malignant ventricular arrhythmia waiting for these defibrillators: a young man with a Telectronics defibrillator implanted, nearing its expiration date; and a young woman, with no defibrillator as yet. and whose unstable condition dictates hospitalization until she can receive
one. Nineteen other patients have Telectronics defibrillators which will reach their expiration date in 1996. 10

Cuban heart specialists faced a tragic situation in 1988-89, when a male patient, who had suffered a heart attack and was reported with malignant ventricular arrhythmia, required an implantable defibrillator to survive. According to Dr. Dorticós, when the U.S. firm CPI was approached to purchase the device (over which U.S. manufacturers had a virtual monopoly at the time), they expressed a willingness to make the sale, but it was vetoed by the U.S. Government. Two months later, the patient died. (Ibid.) We have attempted to verify this data with the U.S. Commerce Department, but as of June, 1996, no reply has been forthcoming.11

Cuban physicians report their frustration at not being able to make available to their patients other items manufactured in the USA, which would significantly improve the quality of their care. In this regard, they made specific reference to heart muscle stimulators and other units from Medtronic, whose technology they consider one of the best in the world. In other cases, the equipment has been purchased through third parties, at a significant sacrifice of additional funds. This is the case of a unit for extracorporal circulation, used in open heart surgery and produced by the U.S. firm Sams. Dr. Humberto Sainz of the Cardiology institute reports that they paid three times the usual price of the equipment—both a higher price and higher shipping fees—since the U.S. embargo prevented them from buying directly through normal channels.12

U.S.-manufactured medications for heart patients and especially new U.S. medications are for the most part inaccessible to Cuban physicians. They listed the following drugs as essential, but for at least 8-10 years after the FDA approval date unavailable to Cuba by virtue of the embargo:

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<td>Vasotec</td>
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<td>Amrinone lactate</td>
<td>Shock</td>
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</tbody>
</table>


It is significant that the embargo prevents the world’s number one source for new drugs against heart disease—U.S. manufacturers—from making their products readily available to Cuban patients. From 1970 through May of 1992, U.S. laboratories accounted for 17 of 47 new major global drugs discovered for heart disease and 7 of 14 of the new medications for blood-related conditions more than any other country in the world. And their leadership continues today.13

Finally, the U.S. embargo has obstructed Cuban research into new biotech products for heart patients, such as the recombinant streptokinase developed at the Center for Genetic Engineering and Biotechnology (CIGB). Like natural streptokinase, this product is used to dissolve blood clots during heart attacks, to prevent cerebral embolisms, and for treatment of deep venous thrombosis, among other conditions. The Cuban-produced version, available at considerable savings (imports
run at $150 per dose), makes this drug a candidate as a major contributor to reducing deaths from heart attack. In a 1992 study, Cuban recombinant streptokinase cut fatalities in half, and the Ministry of Public Health goal is to reduce heart disease mortality rates overall by 29% by the year 2066. The drug is now available in all Cuban hospitals, and being considered to stock neighborhood polyclinics, which would bring it to the primary care level and closer to patients important, since early administration is key to the medication’s performance.14 (See chapter on Vaccines and Biotechnology.)

In addition to these obstacles and to the incidence of the embargo in the general economic limitations facing the field of cardiology in Cuba today, physicians interviewed said without exception that they believed their right to pursue scientific advances in their field has been significantly hindered by the embargo, since its restrictive travel and communications regulations prevent a normal and natural exchange with U.S. colleagues. They referred to the need for international organizations to step in on their behalf on many occasions to ensure a U.S. visa. And Dr. Hernández Cañero, Director of the Cardiology Institute and President of the Cuban Cardiology Society, was one of five Cuban cardiologists denied a U.S. visa in 1966 to attend a World Cardiology Congress in Washington.15 Dr. Hernández also described visits by U.S. cardiologists canceled because of the U.S. embargo’s travel ban. In particular, he made reference to a scientific exchange program initiated during relaxed restrictions under President Carter, which was subsequently canceled under Resident Reagan, when prohibition on travel was reinstated.16

Pediatric Cardiology

Pediatric cardiology and the treatment of congenital heart malformations were given greater priority in Cuba, beginning in 1986, with the opening of the Pediatric Cardiocenter at the “William Soler” Pediatric Hospital in Havana, the hub of a three-hospital network to give special attention to these patients, whenever possible from infancy.

In Cuba, between six and eight of every 1,000 live births bring with them a form of congenital cardiovascular malformation, which is about the international average. The main types are ventricular septal defect, patent ductus arteriosus, Fallot’s tetralogy, transposition of great arteries, and atrial septal defect. Among the acquired cardiopathies, the most important in these young patients is rheumatoid cardiopathy. Several of these conditions require surgery, and others may benefit from surgery.17

The 80-bed Cardiocenter serves children up to age 18 (sometimes to age 20) if the case requires significant follow-up and performs all cardiovascular surgery for Cuban children under five years.

Outpatient visits at the Center averaged about 6,000 a year through 1992, but they dipped by some 1,000 thereafter, reflecting both difficulties at the Center and problems in transporting patients from the provinces.18

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<tbody>
<tr>
<td>VISITS</td>
<td>6,543</td>
<td>17,329</td>
<td>5,642</td>
<td>6,961</td>
<td>7,206</td>
<td>5,678</td>
<td>14,695</td>
<td>4,274</td>
<td>4,715</td>
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In nine years, through December, 1995, surgeons at the Center carried out 3,666 procedures on these high-risk children, with an 85% survival rate. (Nearly 2,000 of these operations required
extracorporeal circulation.) This represented between 80 and 85% of all pediatric cardiovascular operations in the country.19

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<tbody>
<tr>
<td>RATE</td>
<td>84.2</td>
<td>186.7</td>
<td>85.9</td>
<td>183.3</td>
<td>186.1</td>
<td>182.0</td>
<td>180.2</td>
<td>84.4</td>
<td>88.5</td>
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In all, 3,289 children have been operated on, some more than once, including 240 foreign patients from 30 countries. In addition, some 2,910 cardiac catheterizations have been performed. 410 of these interventionist, as well as 46,900 EKGs and 3,042 ergometry examinations.20

The Center once averaged 500 surgical procedures annually, but by 1993, it was down to 250; in 1994, 275; and in 1995, 315. They accumulated a waiting list for the first time between 1993 and 1994, with 87 cases pending, most of them needing complex surgeries which required resources unavailable at the time. This waiting list was eliminated in 1995, but 1993 began with serious repair problems in the electric system, which created a new waiting list in January, totaling 30 cases and growing, since the breakdowns specifically affected operating rooms.21

Pediatric cardiology, despite its priority status, has been seriously impacted by limitations in patient care imposed by the U.S. embargo.

In addition to the U.S. medicines unavailable to the general population of heart patients, the virtual ban on sales to Cuba is now threatening the lives of Cuban infants suffering from heart malformations.

Specifically, drugs such as Prostin VR (from Upjohn) have been removed from neonatology for infants with cyanotic heart disease, including Fallot’s tetralogy, pulmonary atresias, etc. These babies die before surgery if the Prostin is not administered in time: There is no substitute. Purchases were difficult but possible through trading companies throughout most of 1995, although specialists report several deaths related to the lack of this drug. However, the Cardiocenter was faced with a sudden cutoff in supplies in 1995, after Upjohn declared the medication for hospital use only and therefore unobtainable without the name of the hospital for which it was destined. Since this is a U.S. product destined for Cuba, the name of the hospital itself would block normal sale. On January 18, 1996, the Cardiocenter used its last vial of Prostin for a 14day-old baby requiring surgery. At the time MEDICUBA and staff at the Cardiocenter were still trying to find a way to buy the drug to prevent the otherwise inevitable: Unless more Prostin was acquired, and rapidly, the next child in this condition would die.22

In general, specialists at the Pediatric Cardiocenter concurred that children in their care do not have the benefit of the full range of therapeutic options because of the obstacles the embargo presents to purchases of U.S. medications. And this opinion extends to U.S. equipment, which they contend accounts for 80% of modern technology in pediatric heart surgery today.

An example is the stent produced by Cordiss Corporation for Johnson and Johnson. This tubular device is used to prop open damaged blood vessels, preventing deterioration that might, otherwise lead to the need for a heart transplant. Press reports indicate that the February, 1996, acquisition of Cordiss by Johnson and Johnson gives the company “about one third of the worldwide market for heart intervention products,” and mentions the stent as a top-ranking money-maker.23 Cuban cardiologists say they have never had access to the stent. The same is true for a number of
specialized catheters for angioplasty and the umbrella device produced by U.S. companies, which would help to avoid the risks and trauma of more complex surgeries.24

In this highly specialized field of medicine, devices are often needed for a handful of patients, or even just one. When MEDICUBA is faced with the prospect of identifying quality equipment at a reasonable price, which must be delivered immediately, the embargo presents a particular challenge. MEDICUBA’s Rolando Díaz says this was the case of a neonatal pacemaker purchased in 1992. On March 14 that year, baby boy Julio Gómez received an external pacemaker at the Cardiocenter, as surgeons waited to insert an implanted pacemaker, which had to be found on the international market. Dr. Ramón Casanova, Director of the Cardiocenter, appealed to MEDICUBA to find such a device as swiftly as possible. Díaz himself purchased the Medtronic (USA) device in Peru, through intermediaries, but even so it did not arrive in Cuba until August 2, and then at a cost inflated well above the market price, since intermediaries added their own markup. Such delays, and even longer ones, are not uncommon. If this device could have been purchased in the USA, argues Díaz “it would have been a matter of a phone call and a trip to the Havana airport the next day, not to mention the savings for other medical needs.”25

Finally, the Pediatric Cardiocenter specialists refer to difficulties maintaining dialog and exchange with U.S. colleagues, for the same reasons as those discussed by physicians at the Cardiology Institute. Among the visas denied: that of Dr. Ramón Casanova, Director of the Cardiocenter, for the 1989 Congress on Pediatric Cardiology in the United States.26
NOTES

1 Balance anual del MINSAP, 1995, p. 100; and ‘Enfermedades no transmisibles, análisis epidemiológico’, Unidad de Análisis de Tendencias en la Salud (UATS), March, 1996.
2 There was a slight decline in 1995 over 1994 rates of 209.7, but the general tendency is increasing.
3 Interview with Dr. Francisco Dorticós Chief of Pacemaker Service, Cardiology Institute, Havana, Jan. 19,1996.
4 Interview with Dr. Alberto Hernández Cañero, Director of the Cardiology Institute and President of the Cuban Society of Cardiology and the National Cardiology Group, Oct. 27, 1995, and information provided from his office on Jan. 22, 1996.
6 Interviews with Dr. Roberto Zayas, Pacemaker specialist, Cardiology Institute, Oct. 39,1995; Dr. Francisco Dorticós, Nov. 14,1995; and Rolando Díaz, Deputy Manager of MEDICUBA for Medical Equipment, Sept. 6,1995.
11 Communications to the U.S. Commerce Dept. made by Wallie Mason, attorney.
12 Interview with Dr. Humberto Sainz, Chief of Anesthesiology and ICU and the Cardiology Institute, and President of the Cuban Anesthesiology Society, Nov. 24,1995.
14 Interview with Dr. Orlando Rucabado, Chief of Coronary ICU at the Cardiology Institute, June 5, 1996.
15 Interview with Dr. Hernández Cañero and other specialists at the Institute. As mentioned elsewhere in this study, U.S. immigration policy, and whether or not to grant visas to Cuban physicians in particular, does not in fact fall under the U.S. embargo. However, the authors believe that the climate and economic pressures generated by U.S. policy ultimately influence such decisions.
17 Interview with Dr. Herminia Palenzuela, William Soler Pediatric Cardiocenter, July 12, 1996.
18 Interview with Dr. H. Palenzuela, Jan. 16,1996.
19 Ibid.
20 Ibid.
21 Interviews with Dr. H. Palenzuela, Dr. Eugenio Selman and Dr. Felipe Cárdenas, Cardiovascular Surgeons, Nov. 23, 1995, and Dr. H. Palenzuela, Jan. 16, 1996.
22 Interview with Dr. F. Cárdenas, Jan. 18,1996; end telex to MRDICUBA from Spain, notifying the hospital use only” clause for Prostins, date July 6, 1995.
24 Interview with Dr. B. Reyes Vega, Pediatric Cardiocenter, Oct. 26, 1995.
25 Interview with R. Díaz Sept. 6,1995, and documents from MEDICUBA on Contract 26969 of 1992 for Medtronic DDD Bipolar Neonatal Pacemaker, Model 940,24 grams. He paid over $4,000 for the device; other quotes were as high as $5,599.
Introduction

Prom 1996 when the first HIV-positive cases were identified in Cuba, until January of 1998, the cumulative number of persons testing seropositive was 1,208, including 440 AIDS patients, 292 of whom have died. The average incubation time from HIV infection to full-blown AIDS is 11 years, and the average survival time from the onset of AIDS is 18 months. 1

The National AIDS Prevention and Management Commission was founded in 1983 by the Public Health Ministry, which the same year set up an epidemiological surveillance system and prohibited importation of hemoderivatives, which were from that point produced in Cuban laboratories. In 1985, $2 million was invested by the governmental public health system to develop the National AIDS Prevention and Control Program, and in particular to furnish the first 750,000 ELISA-system diagnostic kits and related equipment for the provincial blood banks and 42 diagnostic centers in the country.

By late 1986, screenings included all blood donations; persons returned from service in Africa (every six months); and workers in tourism, the merchant marine, fishing and airlines industries (once-a-year). Later, testing would be extended to pregnant women in their first trimester, hospitalized patients, prisoners and patients suffering from sexually-transmitted diseases. In 1987, Cuban laboratories began producing their own diagnostic kits; and a year later, a domestically-designed kit was introduced, using SUMA technology. 2 According to the Ministry of Public Health, the Cuban AIDS strategy was based on four main programs:

- Serological screenings of large population groups.
- Epidemiological study of each HIV-positive case, with an attempt to identify partners at-risk.
- Hospitalization of seropositive patients in 13 sanatoriums, to offer specialized care, education and follow-up, and to reduce the dissemination of HIV in the Cuban population.
- Development of an effective policy in health education and promotion concerning AIDS. 3

Perhaps the most controversial of these programs has been the sanatorial care for HIV-positive patients, which originally obligated seropositive Cubans to live the rest of their lives in these institutions. Organized like small communities, the sanatoriums are made up of apartment complexes and small houses, plus infirmary, offices, and other patient facilities.

In 1993, the sanatorium policy underwent changes. Until then, patients were permitted daily visits but only allowed to return to their families and communities on the weekends. That year, an outpatient program was begun. Under this variant—after an initial six months in the provincial sanatorium for extended diagnosis and treatment recommendations, psychological counseling and education-patients are evaluated by an interdisciplinary team to determine their eligibility for the ambulatory program, based on their “understanding of their condition and commitment to safe sex.” If they are approved and choose to do so, they return to their homes and receive regular care from the local family doctor, in addition to periodic visits to specialists. By the end of 1995, 192 patients, or one fourth of the 780 HIV patients who have not developed full-blown AIDS, were enrolled in this ambulatory care program. 4

Since 1993, sero-positive persons in Havana and other provinces have been incorporated into other aspects of the National AIDS Program, through the AIDS Prevention Group at the Havana Sanatorium and AIDS prevention work at the National Center for Health Education—whose participation includes educational efforts in the high schools and other institutions, and counseling of newly-diagnosed HIV patients and their families.
The Pedro Kourí Institute for Tropical Medicine is the national reference center for clinical management of HIV-AIDS and provides hospitalization for AIDS cases when necessary and for those whose AIDS-related illness requires more complex services than those offered by sanatorium infirmaries.

Other Cuban institutions directly related to the prevention, education, diagnosis, treatment and research concerning AIDS are the National Reference Laboratory for HIV, the National Immunoassay Center, the National Blood Bank System, and the Center for Genetic Engineering and Biotechnology.

<table>
<thead>
<tr>
<th>CUBA AIDS STATISTICS (FROM JANUARY 1, 1986 TO JANUARY 30, 1998)</th>
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<tr>
<td><strong>TOTAL HIV POSITIVE</strong></td>
</tr>
<tr>
<td>Men</td>
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<tr>
<td>Women</td>
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<tr>
<td>Gay or Bisexual (male)</td>
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<td><strong>WHERE HIV ACQUIRED</strong></td>
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<tr>
<td>Cuba</td>
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<td>The Americas</td>
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<td>Africa</td>
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<tr>
<td>Europe</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Total</td>
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<tr>
<td><strong>MODE OF TRANSMISSION</strong></td>
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<tr>
<td>Heterosexual</td>
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<tr>
<td>Gay or Bisexual</td>
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<tr>
<td>Blood Recipients</td>
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<td>Hemophiliacs</td>
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<tr>
<td>Occupational Exposure</td>
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<tr>
<td>Perinatal</td>
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<tr>
<td>Under Study</td>
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<tr>
<td><strong>AIDS CASES</strong></td>
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<tr>
<td>Total AIDS Cases</td>
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<tr>
<td>Death from AIDS</td>
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<tr>
<td>Deaths from other causes</td>
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Source: Epidemiology Department, *Havana AIDS Sanatorium, 1996*
HIV, AIDS and the U.S. Embargo

On the basis of on-site visits to the Havana AIDS Sanatorium and the Pedro Kouri Institute of Tropical Medicine, interviews with specialists and patients, bibliographic materials, and statistical data, it can be concluded that prevention, diagnosis, treatment and research involving HIV-AIDS have been negatively impacted by the U.S. embargo. Specifically, by restrictions on exports from U.S. companies and their foreign subsidiaries; limitations on exports of U.S.-composition or patented items; prohibitions on exports that would contribute to Cuba's biotechnology research and industry; end travel restrictions leading to reduced access to scientific information and fewer opportunities for scientific exchange. The families of AIDS patients have also been negatively affected by limitations on travel (see chapter on Family Relations and Humanitarian Emergencies).

During the economic crisis of the nineties, educational efforts in prevent HIV-AIDS have been considerably impaired, a situation exacerbated by the embargo's contribution to the general contraction of the economy. Manuel Hernández heads national educational efforts around AIDS at the National Center for Health Education in Havana. As early as 1994, he noted the impact of the economic crunch on what he described as an otherwise prioritized program: "We need more printed materials. We need funds for AIDS hotlines, key for these kids who desperately want their privacy protected. And we need more condoms. This year's purchases will cover only 40% of our needs. So what good are TV spots if you don't have the condoms to back them up?"

By 1995, the condom situation he described had not improved: Of the $20-125 million needed for optimum coverage (or $69 million at a minimum), MEDICUBA had funds available for only $16.6 million, with another seven million in donations. While some of these purchases were made in China, Dr. Miguel Sosa, President of the Cuban Society for Family Education, reports that his nongovernmental organization is also aware of emergency purchases of U.S.-origin condoms.
made through third parties in India that “cost 200% over the average wholesale price” due to markups plus higher shipping fees.  

AIDS testing, diagnosis (involving a battery of confirmatory tests) and protection of the blood supply have been threatened by the U.S. embargo, to the extent that mergers of European suppliers with U.S. companies have suddenly cut off parts and equipment, supplies of reagents, and plastic modules for this lab work, and over the long run promise to make this process significantly more expensive (see chapter on Diagnostic Testing and Protection of the Blood Supply for details). In addition, the Pharmacia-Upjohn merger negatively affected supplies of reagents such as Ficoll-400 and Ficoll Paque, both used in laboratory blood work to follow the progress of the disease in patients: in particular, the laboratories faced sudden shortages of this reagent until substitutes could be located, purchased and shipped, making it impossible to carry out Cd4, Cd8, Cd22, Cd33 and Cd25 tests for specific T-lymphocytes. other Pharmacia reagents regularly used in the AIDS program, with similar gaps in availability, included Sephadex Deae, Sepherosa 4B Lentil Lectin and CNBR Sepharosa 4B ACT. 

According to Dr. Pérez, key equipment for diagnosis and follow-up has also been impossible to purchase at various times, attributable to embargo restrictions. He sites as an example flow cytometers from the U.S. firm Coulter. This equipment is wed to measure T lymphocytes. Dr. Pérez reports that he personally attempted to purchase a unit during a medical convention in the Netherlands in 1992 but was told by the Coulter representative that embargo restrictions prevented his company from selling to Cuba. 

Maintaining healthy life styles and the most effective treatment for HIV-positive end AIDS patients is an area that is and has been especially vulnerable to the embargo: first, due to economic limitations aggravated by the embargo; and second, resulting from embargo-specific regulations. 

In the first category, we find the general conditions of sanatorial care, nutrition, and the requisites of the outpatient program since 1993. At the sanatoriums, patients receive a diet rich in calories (5000 kcal daily) and proteins; free of charge; and it is estimated that each resident costs the health system some $15,000 a year. The nutritional situation outside the institutions, exacerbated by the embargo (see chapter on Nutrition), is so difficult that it has been cited by residents as one reason they have not opted to rejoin their families through the out-patient program. 

Medications for HIV/AIDS Patients

Limiting Cuban AIDS patients’ access to medicines is the most critical result of the U.S. embargo that we observed. Because of embargo restrictions, Cuba does not have ready access to any FDA-approved medications manufactured by U.S. firms and which have been patented in the last 17 years; nor will they have access to those U.S. products now in development until a decade after they have been introduced on the market. Dr. Pares noted: We will have to wait years until these patents are no longer exclusive and other companies in other countries can manufacture these products. The problem is that our patients don’t have the time to wait. So, to prolong their lives and provide them a better quality of life, we must purchase U.S. medications through intermediaries at much steeper prices. If it were not for the embargo, with the same budget 1 could buy larger quantities of the drugs needed by my patients. 

It is not surprising that U.S. manufacturers are an important source of AIDS medications for Cuba: This is true everywhere. A recent study reveals that for 22 years (between 1970 and May of 1992) the United States was the world’s number one source for new immunology drugs: In fact, over two thirds of the new medications introduced in the field (10.5 of 15) were developed by U.S. companies. By 1995, the number of U.S.-developed and FDA-approved medications for AIDS and AIDS-related conditions was up to 30.
Dr. Peres offered the following examples, corroborated by MEDICUBA and cross-referenced with FDA approval dates, of AIDS medications which are not freely available to Cuba:

- **Azithromycin** (CZithromax) by Pfizer, FDA approved Nov. 1, 1991: This drug is used against toxoplasmosis (a parasitic infection which can affect muscle tissue, heart, liver, brain and the central nervous system; in AIDS, tumors may form within the brain). Autopsy studies through 1993 showed that 24.3% of Cuban AIDS patients suffered from toxoplasmosis at the time of death.15

- **Fluconasole** ("Diflucan") by Pfizer, FDA approved Jan. 29, 1990: This drug has no specific substitute for use in treatment of cryptococcosis (produced by a fungus which attacks the central nervous system and can cause meningitis and death). Autopsies performed through 1993 revealed that 11.7% of Cuban AIDS patients suffered from cryptococcosis at the time of death.16 In the cases of both these Pfizer medications, Dr. Peres personally approached the Pfizer representative at a Montreal medical meeting and was told that the company could not sell to Cuba because of embargo restrictions. Since then, MEDICUBA has only sporadically been able to purchase fluconasole, because prices quoted by intermediaries have been out of range; and never have they been able to afford azithromycin. Both have come into Cuba in small amounts in donations, according to Dr. Pérez.17

- **Ganciclovir** (Cytovene) by Syntex and Roche Bioscience; FDA approved June 23, 1989: This drug is used against cytomegalovirus, which can produce suprarenal insufficiency, and coreoretinitis, which destroys the retina and leaves scar tissue, causing loss of vision. Autopsy studies through 1993 showed 39.6% of AIDS patients suffered from CMV disseminated at the time of their deaths.18 This medication is currently unavailable to Cuba because of high price quotations through intermediaries. Small amounts have come through donation.19

- **Antiretroviral products**, including zidovudine (AZT) ("Retrovir") Burroughs-Wellcome; FDA approved March 19, 1987; didanosine (ddI) (Videx) Bristol Myers Squibb; FDA approved Oct. 9, 1991; and zalcitabine (ddC) ("Hivid") Roche; FDA approved June 19, 1992. When these products first appeared on the market, they were not freely available to Cuban importers due to embargo restrictions. Since then, AZT has been purchased at what Dr. Peres describes as well above market prices, and ddC and ddI have only been received through donations.20

The case of AZT is illustrative: Approved by the FDA in early 1987, it took several months for Cuban importers to locate suppliers willing to sell even small amounts to Cuba, at a cost which Dr. Pérez calls "astronomical." He states that the embargo was directly responsible for at least six-month delays in AZT treatment for a total of 176 HIV patients in Cuba.21 (At the time, AZT was the only approved medication, heralded for slowing the progress of the virus.) Federico Ramos, 42, has been a patient at the Havana AIDS sanatorium for nearly a decade and was one of those waiting for the drug's arrival: "I remember the months of agony: knowing there was a drug that could help us, but that we couldn't get because of the embargo." 22 Ramos says HIV and AIDS patients have seen gaps in AZT supplies over the years, and they are aware that the drug is purchased through wholesalers in Europe.

AZT studies in Cuba have shown that AZT diminishes the time before onset of AIDS and also lengthens survival time after an AIDS-defining diagnosis.23

The outlook is even more bleak for medications in development in the United States, to which Cuban patients will not have ready access for a period of 17 years following patent. The 1995 Survey on AIDS medications in the pipeline, published by the Pharmaceutical Research and Manufacturers of America, indicates that 110 medicines have begun the FDA approval process-
only three of them by manufacturers outside the United States, and thus outside embargo restrictions (two of the three are jointly patented with U.S. firms).

Dr. Peres says that Cuban specialists are particularly interested in the protease inhibitors, a new class of AIDS drugs which are being developed by at least four U.S. pharmaceutical corporations, part of the $15 billion U.S. companies will spend on AIDS research this year.

As disturbing as Cuban patients’ inaccessibility to U.S.-manufactured drugs is the embargo’s provision aimed at the Cuban pharmaceutical industry’s capabilities for domestically producing key AIDS-fighting medications such as interferons. (See chapter on Vaccines and Biotechnology Research, Development and Production). Dr. Pérez notes that studies carried out in Cuba indicate the beneficial effects of interferon, both in prolonging the incubation period for seropositive patients and the survival time for AIDS patients.

The following Kaplan-Meier curves illustrate the results: Approximately half of the HIV patients treated with interferon showed a greater delay—of 5.5 to 6 additional years— in the onset of AIDS; and interferon showed similar affects on survival time.
Approximately 70% of all Cuban AIDS patients receive interferons as part of their treatment. Production has already been negatively affected by the U.S. embargo's export prohibitions as a result of the Pharmacia-Upjohn merger, which impacted virtually all biotechnology production facilities in Cuba. This is also true for the Human Transfer Factor, a Cuban biotech product also used against HIV/AIDS.

At the same time, however, scientists estimate that research on the AIDS vaccine being developed in Cuba—one of 18 worldwide, 14 of which are U.S. products—would be further ahead today if it were not for the embargo. Nevertheless, the vaccine is due to begin trials in human beings in September, 1996.
Cuban scientists contend that research and development as well as exploration of treatment alternatives have been seriously impacted by the U.S. embargo, which has reduced their access to scientific information and professional exchange. Examples cited include:

For five consecutive years (from 1989 to 1993), the U.S. State Department gave no answer on visa applications from Dr. José Joanes, proposed by the World Health Organization (WHO) to attend an epidemiology course on AIDS at the Centers for Disease Control in Atlanta, in conjunction with Emory University.

U.S. scientists were unable to attend a series of scientific workshops sponsored by the Pedro Kourí Institute for Tropical Medicine and the National AIDS Prevention and Control Program in Havana, due to tightened travel restrictions issued under the embargo in August, 1994. The courses included ‘Infection by HIV,’ “Treatment and Diagnosis of Parasitic Diseases” and others.
NOTES

1 Documentation Center; National AIDS Program, Havana AIDS Sanatorium, January 30, 1996.
2 Interview with Dr. Jorge Pérez, Vice Director of the Pedro Kouri Institute for Tropical Medicine, and Director of the Havana AIDS Sanatorium, Nov. 3, 1995; and ‘HIV Infection in Cuba,” by Dr. Jorge Pérez et al, AIDS an HIV-Infektionen, Diagnostik, Klinik, Behandlung, Ecomed, 1988, p. 2.
4 Interview with Dr. J. Pérez, Nov. 3, 1995; and “AIDS, Sexuality and the New Man (sic),” by Gail Reed. in Cuba update, May, 1994, pp. 21-22.
5 Manuel Hernández interviewed by Gail Reed for ‘AIDS, Sexuality and the New Man (sic),” Cuba Update, May 1994, p. 22.
6 Interview with Orlando Romero, Director, MEDICUBA, June 21, 1996, and Dr. Miguel Sosa, President, Cuban Society for Family Education, SOCUDEF, Nov. 27, 1995.
7 Interview with Dr. Miguel Sosa, Nov. 27, 1995.
8 Interviews with Dr. J. Pérez, Nov. 3, 1995 and May 21, 1996.
9 Interview with Dr. J. Pérez, Nov. 3, 1995. A similar experience was also reported by Rolando Díaz of MEDICUBA, who stated to the authors on November 23, 1995 that his firm has not been able to purchase these units directly from Coulter. The only exception in the purchase of U.S.-manufactured flow cytometers has been registered on February 25, 1994, when Ortho Diagnostics Systems Ltd., a British subsidiary of Johnson and Johnson, received a U.S. Treasury license to sell one modular unit to the Cuban importer Service, with the provision that the Pan American Health Organization, (International) Red Cross or “other appropriate internationally recognized multilateral relief or non-profit organization” furnish a confirming affidavit that “the exported item is for use for the purposes for which it was intended and only for the use and benefit of the Cuban people, mailed to Treasury no later than June 30, 1994.”
12 Interview with Dr. Jorge Pérez, February 2, 1996.
19 Blanco, Statistical Report, and J. Pérez interviews.
20 Ibid.
21 Interview with Dr. J. Pérez May 21, 1996.
As we have noted in other sections of this study, while the prerogative of granting visas to Cuban researchers and physicians belongs to the U.S. State Department, and does not fall within embargo legislation, we have found that visa denials are consistent with the climate concerning Cuba created by the embargo policy.
Renal failure occurs when the kidneys cannot maintain normal biochemical balance. In acute renal failure, the nephrons are injured, often reversibly; in the chronic form, the nephrons are progressively destroyed. Chronic renal failure must be thought of as a total body disease, with clinical and laboratory findings relating to nearly every organ system and, if not reversed, leading to end-stage renal failure and death. End-stage renal disease (ESRD) is diagnosed when renal function is no longer sufficient to sustain life. Thus, early recognition and management of kidney failure are critical.

Clinical findings in patients with chronic renal failure include progressive anemia in almost all cases, hypertension and other cardiovascular manifestations, central nervous system disturbances, skeletal affectations, and chronic biochemical and mineral imbalances. Children also demonstrate serious growth retardation, and both pediatric and adult patients tend to be more susceptible to infections and more apt to handle them poorly because of their generally debilitated state.

Adults and particularly children with renal insufficiency have special dietary needs including increased calorie and protein intake and certain vitamin and mineral requirements. In addition, since children have diminished growth rates and progressive retardation of bone development, therapy with growth hormones is often indicated.

The principal treatment for end-stage renal disease (ESRD) is kidney transplant. Thorough evaluation and preparation for dialysis and transplantation should be begun before the threat of end-stage renal failure becomes immediate. Dialysis is effective for sustaining patients awaiting kidney transplant or for whom transplant is not possible.

The indications for dialysis are determined clinically and on the basis of laboratory findings. Early dialysis can simplify management and reduce fatalities from kidney failure. Methods include peritoneal dialysis, hemodialysis, and modifications of hemodialysis such as hemoperfusion. The choice of peritoneal dialysis or hemodialysis depends on availability as well as therapeutic indicators. Peritoneal dialysis is generally preferred in children because of the relative ease of vascular access, performance, and the generally better results.

The development of continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD) have become the methods of choice for children awaiting transplant, since they are both well-tolerated and effective. There are clear advantages to the use of ambulatory dialysis for adults as well.

Profile of Kidney Disease and Treatment in Cuba

The incidence of chronic renal failure in Cuba including end-stage renal disease is 255 per million inhabitants. Each year, approximately 80 per million inhabitants (or 840 persons) are added to the group of patients with end-stage renal disease, and this rate is rising. These patients must receive dialysis to survive, while they await possible transplant.

In Cuba, 160200 kidney transplants are performed each year with a survival rate of approximately 55%. Estimates are that 400-450 transplants are actually needed, with the principal obstacle identified as organ availability.

Drs. Raúl Herrera and Santiago Valdés Martín, directors of the Institute of Nephrology and the National Reference Center for Pediatric Nephrology, argue that Cuba’s economic crisis of the last
five years, aggravated by the tightening of the U.S. embargo during the same period, has meant serious problems for the treatment of patients suffering from kidney disorders, and especially those requiring dialysis or transplant. They contend that because of the complex organization and considerable finances needed to support universal, comprehensive care in this field, nephrology is particularly vulnerable to economic constraints.

In January 1995, 694 patients with end-stage renal disease were enrolled in the dialysis-transplant program, receiving regular dialysis. However, not all were receiving the optimum number of dialysis sessions indicated for adequate treatment, due to the shortage of dialysis units in the country. During 1995, 447 patients died of renal failure and another 847 were newly incorporated into the dialysis program with the limitations previously mentioned. Thus, by the end of the year, 1,034 patients with end-stage renal disease were eligible for regular dialysis: 712 of these were enrolled in the dialysis program as of Dec. 31 1995, though again, not all receiving the optimum number of treatments. Enrollment figures fluctuate over the months due to death, transplants, drops-outs from the program, and, in a minority of cases, recuperation of renal function.

Specialists at the Nephrology Institute explain that at this point the incorporation of new patients into the program means that all patients necessarily receive fewer hours of dialysis because equipment is limited. Dr. Herrera stated the problem: “We simply do not have sufficient functioning dialysis equipment to guarantee the required frequency of treatment for all patients who reach end-stage renal disease.”

With purchases and donations in early 1996, the country had 124 functioning dialysis units by May. Specialists calculate that 300 are needed to adequately attend to all patients requiring this life-prolonging treatment during the next year. Dr. Charles Magrans, a specialist from the National Nephrology Institute, explained that each dialysis machine currently accommodates approximately five patients, with the equipment functioning day and night. A number of these units are donated and cannot necessarily be adapted to suit each patient’s needs, since factors such as state of health and weight determine which equipment and which type of dialysis can be used.

On the basis of our visits to the dialysis service of the Nephrology Institute and interviews with specialists and medical importers, we concur that Cuba’s economic crisis has indeed severely affected the availability and options of treatment for nephrology patients requiring dialysis. Thus, for example, while peritoneal dialysis is preferred for diabetics, the elderly and young children, only intermittent peritoneal dialysis, considered rudimentary by specialists, is minimally available in Cuba today. This is true, essentially because the peritoneal methods are significantly more costly than hemodialysis and rely more on expensive disposable accessories.

In addition, our interviews and observations in both adult and pediatric care units convince us that the U.S. embargo has compounded such difficulties, which at times have become life-threatening.

**Dialysis Treatment and the U.S. Embargo**

The problems in procuring dialysis equipment offer an eloquent example of the range of embargo-related obstacles which impact patient treatment—and indeed survival—in one of the most sensitive areas of Cuban health care. It should be noted that mortality rates for end-stage renal disease have been rising in Cuba in the last few years.

First, the embargo effectively closes to Cuba its nearest, most technologically developed and often most competitively priced market for dialysis equipment, accessories and maintenance. Historically, Cuban importers have had negative results in dealing with major U.S. suppliers in the field. Baxter Healthcare Corporation, a U.S. company, is a leader in dialysis equipment and
accessories sales in Latin America and has cited compliance with the embargo for its consistent policy to refuse to sell to Cuba or allow its affiliates abroad to do so. Michele Lockwood of Baxter's International Sales Department told the authors that the company does not sell to Cuba and does not wish to pursue licensing procedures- she stated that it is official company policy not to sell to any country which the U.S. embargoes.  

Drake-Whillock, a U.S. based firm, has also been approached by Cuban importers through intermediaries abroad. However, MEDICUBA’s Rolando Díaz reports that the company “has not even been able to send equipment to Cuba for testing because of the embargo.”

Vitalmex Interamericana, S.A., a Mexican distributor for the U.S. dialysis manufacturer Cobe, notified MEDICUBA importers in July, 1995, that it could not furnish prices requested for 20 Cobe dialysis units, asserting that since Vitalmex is “associated with” a U.S. firm, it was “not authorized to sell equipment or supplies to your -try.” Cobe representative Ellen Cohig told our researchers that "we have a policy and that is that we comply with U.S. law. So, we cannot sell to Cuba.” And, according to Rolando Díaz of MEDICUBA importers, other U.S. firms have also refused to quote prices to the Cuban company. (See chapter on Medical Exports to Cuba.)

Such reluctance even extended to bids requested for these units by the Pan American Health Organization (PAHO) in 1995. In September, PAHO approached three U.S. manufacturers, among others, on Cuba’s behalf, asking for price quotations on 18 renal dialysis units. A report furnished to the authors by PAHO indicates that two of the companies contacted-Cobe and Guilford (of Sterling, VA)-did not initially want to quote for Cuba because they could not ship there.” The same report notes that they eventually sent quotes, only after they were informed that PAHO would be responsible for obtaining US authorizations and arranging for the shipping.

However, these quotes were received well after the October 5 deadline PAHO established-provoking a first followup inquiry from Cuba-d even too late to be included among the bids faxed to PAHO-Havana on November 10. With year-end deadlines closing in, and the urgent need for this equipment, MEDICUBA made its purchase in late October from a European supplier, which Rolando Díaz said “offered excellent prices and a safer source of accessories and spare parts, as well, under the circumstances.” This situation is still problematic, however, since quality considerations narrow the range of possible suppliers, according to Diaz of MEDICUBA, who shares the opinion of experts such as Juan Carlos Velásquez, Director of the National Electromedicine Center in Havana, and leading Cuban nephrologists, including Drs. Herrera and Valdés Martin that in this field, United States’ manufacturers have the longest track record of dependability.

Refurbished dialysis equipment, where the United States is not only the logical source but also the hemispheric leader in sales, is a more reasonably priced alternative heavily used by other Caribbean and Latin American countries, but closed to Cuba due to the embargo. Juan Carlos Velasquez explains that such buys can cut prices by as much as two thirds to three fourths and consequently multiply the number of units procured by three or even four. However, in addition to problems of licensing, he explains that on-site inspection of the used equipment is crucial to sound purchases, and Cuban importers and technical experts are not freely permitted to travel to the United States for this or any other purpose. (At least two visas have been denied to Electromedicine engineers in the last five years.)

Even when third parties donate U.S.-manufactured equipment to Cuba, its upkeep is made impossible by the embargo. Such was the case of 59 Cobe dialysis units donated to Cuba’s nephrology services by a European organization. According to Juan Carlos Velasquez, only 29 of these machines could be placed in working order, because the necessary parts could not be obtained to repair the remaining 30. (It should be noted that these donations are not the only Cobs units in
Dr. Magrans estimates that the ‘loss’ of the 30 donated machines mentioned above means approximately 150 patients will not receive complete dialysis in 1996. Extrapolating further: Since Cuban importers had no access to the nearby U.S. market for refurbished equipment, where they could have purchased at least 54 units for the cost of the 18 new ones they bought in Europe, another 180 patients are losing out on full dialysis. Thus, a total of 339 Cuban patients have access only to partial dialysis treatment at best, as a direct result of the embargo. These are people suffering from terminal renal failure, whose only real hope for survival is a kidney transplant—but less-than-optimum dialysis keeps them in such a weakened state that they may never be eligible for surgery. In short, if it were not for the U.S. embargo, they would have a better chance for life.

More problems occur with the systems, parts and accessories needed for an effective dialysis program. For example, water used in dialysis should be treated by a process known as reverse osmosis. Pediatric nephrologist Dr. Noemí Levy explains that in Cuba this cannot be done for lack of appropriate technology. Instead, an obsolete process is used to treat Cuba’s naturally hard water by softening it, which does not produce the same desired results as reverse osmosis, considered fundamental in nephrology today. Dr. Valdés Martín asserts that Cuba has not been able to invest in this technology primarily for economic reasons, including the fact that this already expensive equipment would cost significantly more with U.S. firms out of the bidding. Without these water treatment plants in place, patients do not receive optimum dialysis.

Cuba faces other problems—both of a general economic nature and embargo-specific—when it comes to maintaining sufficient stocks of dialysis accessories, including carbon cartridges, blood collection bags and specialized catheters. In this field, the issue of limited access to quality products once again arises, since Cuban specialists consider U.S. manufacturers the best in many of these lines.

According to MEDICUBA, U.S. producers “virtually monopolize” the market of quality items for renal use. They pose as examples visceral catheters made by the Cordis Corporation, for which MEDICUBA receives ‘rather high’ price quotations through third parties.

Blood collection bags provide another example: Once again, Baster Healthcare Corporation is one of the few competitive producers of this product and an undisputed market leader in this hemisphere. Dr. Jose Manuel Bayesteros He-, Director of the National Hematology Institute, referred to an incident in 1994, when an urgent need arose for these blood collection bags. He explained that the Institute is responsible for guaranteeing supplies for the whole country, and due to this emergency, Mexican wholesalers were asked to attempt a purchase from Baster, which they did. However, according to Dr. Bayesteros, they were told it was company policy not to sell any product destined for Cuba. (In fact, when our team visited the Central Havana Pediatric Hospital, we saw a Baster bag The bag carried on it a warning that it was not for use in Cuba.) Since the U.S. market represents the closest and fastest route in such emergenices, a closed door can present a serious hazard to health.

This example illustrates the time/expense dilemma that Cuban importers often face when they are forced to turn to faraway markets. Not only are these more costly, but unless still more funds are put into air freight, distance can also delay getting products to patients. Cuba’s latest purchases of blood collection bags have been made in Japan, from companies such as JMS, which quoted a price of $2.30 for each double bag and $3.05 for triples, including air freight.

Several companies in Europe and the Americas have also refused to sell equipment and accessories for dialysis to Cuba, citing the embargo, according to documentation provided by MEDICUBA. These include Hospal of Germany, which said in a March 15, 1994, memo that it
could not supply dialysis and plasmapheresis equipment or supplies for this reason. MEDICUBA reports Medix of Argentina was ‘denied a license”’ for sale of parts for units to clean dialysis equipment, and Miramed of Italy reportedly refused sale to Cuba on the grounds that it did not have permission from the U.S. government to export disposable dialysis accessories to Cuba.23

**Kidney Transplants and the Embargo**

It is our finding that the embargo has negatively impacted the capabilities of nephrology specialists in Cuba to carry out necessary and successful kidney transplants. Before any transplant, a series of tests are required to determine compatibility between the donated organ and the receiving patient. Dr. Hector Rojas, head of the Nephrology Institute’s Immunology Department, stated during our on-site visit that since the economic crisis his unit is experiencing shortages of antiserum used for these tests, known as HLA (histocompatibility lymphocyte antigen) Typage. “Sometimes we cannot do the typage, which is standard procedure throughout the rest of the world, and essential for a good match,” he explained.

Quality of products in this delicate field can make the difference to a transplant patient, contends Dr. Rojas. “Good testing translates into a better match and a longer life,” he states. The specialists in his department concur that the best reagents and supplies they have seen for such testing are produced in the USA, by companies such as by One-Lambda, which manufactures Lympho-Kwik Kits. Dr. Rojas described what he considers the advantages of these Kits: “For example, if the Lympho-Kwik Kit has 70 specificities, the European one only carries 20 to 30. In addition, for an HLA-DR Typage, we must extract 20 ml of blood using the obsolete method (nylon fiber). The Kit only requires 2 or 3 mls of blood. For an already weak patient with anemia, typical of our kidney patients, this difference is important, not to mention the superior speed and exactitude provided by the Kit.” 24

In conversations with Mehnas Shamsai and Nadim Elawar of One Lambda’s International Sales Department, they confirmed that their company does not sell to Cuba: “We are a manufacturer and we sell only through distributors and we do not have a Cuban distributor,” said Elawar.25

The sudden cutoff of reagents and other chemicals bought from Pharmacia of Sweden until its merger with Upjohn last year is another potentially critical problem for the Institute’s Immunology Department. For example, Ficoll-400 and Ficoll Paque are fundamental for isolating lymphocytes, a necessary part of the procedures for organ compatibility testing. With the merger of Pharmacia and the U.S. company, specialists say they are facing a gap of weeks to months in supplies of these vital reagents. while substitutes are sought, tested, contracted and delivered.26

Further shortages or frank absences of important elements for managing kidney patients awaiting transplant include difficulties stemming from the economic crisis exacerbated by embargo-related price increases paid for absolutely essential purchases as described above. Thus, key medications like eritropoyetin, Vitamin D3 and cyclosporine immunosuppressors, plus special supplementary nutrients commonly used in nephrology services, are not available in adequate quantities, contributing to the less than ideal health status of these patients, as they prepare for transplant. As we have seen, physicians emphasize that deterioration of patients’ health threatens their ability to undergo the complicated surgery and their prognosis for survival once operated on.

Eritropoyetin alone—which reduces the need for transfusions and fights anemia in hemodialysis—costs the Cuban healthcare system $5,000-$6,000 per patient per year.27 Curiously, the Cuban Institute for Genetic Engineering and Biotechnology (CIGB) is expected to begin producing
recombinant eritropoyetin this year—the industry which is specially targeted by the Cuban Democracy Act for strictest enforcement of embargo export prohibitions.26

Cyclosporines, the first drugs known to prevent organ rejection, are considerably more costly for Cuba to import and are currently only guaranteed to pediatric patients and adults who have shown highly reactive immunology responses. Once again, the Cuban biotech industry could provide a solution to this dilemma, with a domestically produced monoclonal antibody known as "ior t-3." The antibody has shown promising results in preventing organ rejection and has been used so far in Cuba, Uruguay, Chile, Argentina, Russia and India.29 However, a final twist is offered by the embargo once more: Production of "ior t-3" depends on the Biopilot unit at the Center for Molecular Immunology, sold to Cuba by Pharmacia of Sweden before its 1995 merger with Upjohn. One Biopilot (at the Beterá Laboratories) has already been crippled by lack of parts and the monoclonal antibodies could be the next-to-go.

In general, Cuba does not have ready access to any U.S. medications for renal disease patented since 1979, and kidney patients alive today will most likely never receive the benefits of U.S. drugs in the research pipeline. The leadership of U.S. pharmaceutical firms in the field of immunology, for one, is well established: From 1970 to 1992, U.S. manufacturers developed 10.5 of 15 new medications acting on the immune system.36

**Pediatric Nephrology**

In addition to dialysis services in many pediatric hospitals in Cuba, substantial investments were made in the 1980s to establish and equip three major pediatric nephrology centers, distributed geographically across the Island in Havana, Santa Clara and Santiago de Cuba. Dr. Valdés Martin, Director of the National Reference Center for Pediatric Nephrology; Dr. Frank Tobay, Director of the Central Havana Pediatric Hospital where this center is located; and other specialists we interviewed all spoke to the fact that pediatric nephrology is a medical specialty requiring expensive, sophisticated medical technology and supplies, as well as specific laboratory equipment and reagents.31

"This has always been a costly service in general," observed Dr. Valdés Martin. "In addition, great advances have been made in the field, particularly during the last decade or so, and especially in pediatric nephrology, with improved dialysis methods for small children. We've had trouble keeping abreast of these developments, directly due to the U.S. blockade and due to economic constraints, also very much associated with the blockade. Our problems not only have to do with the acquisition of technology and other products, but also with our inability to access information on new developments in the field. The most important source of medical information is the U.S., where we have the greatest difficulty both in obtaining information and sharing experiences with our colleagues."32

In Cuba, the incidence of chronic renal disease is seven per million inhabitants under eighteen years of age. Thus, every year approximately 20 to 30 youngsters are treated for end-stage renal disease with dialysis and transplant when possible. About 30% of Cuban children with chronic renal failure die. In 1993,360 per 1006 patients in treatment died due to kidney failure. There are currently 21 pediatric patients receiving dialysis, their cases prioritized within the national nephrology system.33

In Cuba, standard hemodialysis is the primary type of dialysis available for children. However, it is not possible to use this method in children weighing less than 10-12 kilograms which, because of the growth retardation common in these patients, may include children up to approximately five years old. Cuba depends on the necessarily limited use of manual intermittent peritoneal dialysis in the smaller children. After about six months, however, this method must be discontinued for
medical reasons (peritonitis) and the children continued with hemodialysis if their size and general condition permit. The problem here relates principally to the difficulty in accessing small blood vessels in the littlest children for hemodialysis.

Although the Cuban specialists are well aware of the superiority of continuous cycling peritoneal dialysis (CCPD) for small children and in fact for all pediatric patients with renal failure (it can keep these youngsters alive for years instead of months and is certainly less traumatic) they cannot provide it and encounter serious obstacles to bringing their nephrology services up to date in this respect.

CCPD systems are extremely costly, requiring repeated purchases of products, accessories and expensive disposable materials. Dr. Valdés Martín estimates that the cost in most countries can reach as much as $25,000 to $30,000 annually per patient (for dialysisation alone, not including other basic costs of management).35 (Note: One hemodialysis machine, which can accommodate approximately five patients, costs Cuba between $12,000 and $25,000 on the average.)

Dr. Digna Espinosa, one of the Cuban pediatric nephrologists we spoke with, referred to the additional disadvantages suffered by their patients due not only to the unavailability of CCPD systems but also continuous ambulatory peritoneal dialysis (CAPD), which permits at-home dialysis overnight, thus greatly reducing disruption to the child's normal activities, allowing the child to attend school, remain socially integrated, etc. The methods available to Cuban children can be 10-12 hour ordeals three times a week, requiring hospitalization.36

Again, the issue of Baxter's dominance of the Latin American market was raised. Top-of-the-line pediatric dialysis technology is produced by Baxter at competitive prices, according to the Cuban specialists, and Baxter is certainly one of the firms in which they have greatest confidence. However, the prospect of paying higher prices to far-away firms only makes the CCPD and CAPD more elusive for pediatric nephrology services in Cuba.

According to Drs. Valdés Martín, Espinosa and Noemi Levy, head of Havana's pediatric dialysis service, such modern pediatric dialysis technology would permit longer-term maintenance of small children with renal insufficiency, prolong their lives and reduce complications, increase the possibility for successful transplants, and significantly enhance quality of life for these children.37

In the final analysis, there is little hope for the very small Cuban patient with end-stage renal disease and, in fact, the small child with kidney failure who quickly progresses to a chronic condition and then end-stage disease may not survive, for lack of modern peritoneal dialysis technology. In Cuba, some five to six of these children under the age of five are diagnosed annually with chronic renal insufficiency.
NOTES


3Interview with Dr. R. Herrera, Oct. 19, 1995; and Maria del Pilar Vilá Director of the Statistics Department, Nephrology Institute, May 5, 1996.

4Interview with Dr. R. Herrera, Oct. 19, 1995, and interviews with Dr. Charles Magrans, specialist at the Nephrology Institute, and M. Vilá Director of its Statistics Department, May 5, 1996. Dialysis figures do not include intensive care dialysis, transplant patients, acute cases, nor other sporadic needs for emergency dialysis treatment.

5Interview with Dr. R. Herrera, October 20, 1995.

6Interview with Dr. C. Magrans, May 5, 1996; and “Analisis de la Morbimortalidad por Enfermedad Renal”, Epidemiology Department, Ministry of Public Health, March, 1996.

7Interview with Dr. C. Magrans, May 3, 1996.

8Interview with Michele Lockwood of Baxter Healthcare Corp., conducted by Wallie Mason, DATEs.

9Interview with Rolando Díaz Vice Director of MEDICUBA for Medical Equipment, Nov. 23, 1995.

10Interview with Ellen Cohig, Cobe International Department, Lakewood, Colorado, May 15, 1995.

11The third U.S. company—An-Med of Ft. Lauderdale, FL—was “going to ship out of their (overseas) office to avoid the problem (Ed. note: presumably after receiving U.S. authorization to sell.),” according to PAHO. This report was attached to a letter from PAHO Deputy Director A. D. Brandling-Bennett, M.D., to Mr. Richard L. Wittenberg, President of the American Association for World Health, dated February 20, 1996.

12Interview with Rolando Díaz Sub-Director of MEDICUBA for Medical Equipment, Havana, September 6, 1995.

13Interviews with: Alexis Cadeño, Vice-Director of the National Center for Electromedicine, Havana, December 8, 1995; Dr. R. Herrera, Havana, Oct. 19, 1995; and Dr. Santiago Valdés Martin, Director of the National Pediatric Nephrology Program, December 20, 1995.

14Interview with Juan Carlos Velázquez, Director of the National Center for Electromedicine, Havana, January 4, 1996; and Ministry of Public Health list of U.S. visas denied to public health personnel.

15Interview with J.C. Velázquez, Jan. 4, 1996.


17Interview with Dr. Noemí Levy, Chief of Dialysis Services, Havana Pediatric Nephrology Center, Central Havana Pediatric Hospital, November 1, 1995.

18Interview with Dr. S. Valdés Martin, Dec. 29, 1995.

19In 1996, several units of reverse osmosis were received as donations.

20Interview with Rolando Díaz, Havana, September 6, 1995. He reported that MEDICUBA had been quoted a price of $36.00 per package of No. 7F, 100 cm. renal catheters, with 2-sided hole in the month of September.


22Interview with Rolando Díaz MEDICUBA, Sep. 6, 1995.

23MEDICUBA reports, September 15, 1995.

24Interview with Dr. Hector Rojas, Immunology Department, Nephrology Institute, Havana, November 24, 1995.

Interview with Dr. H. Rojas. Nov. 24, 1995.
Comments to the authors by Dr. Manuel Limonta, CIGB Director, June 12, 1996.
Subrayan eficacia de anticuerpo monoclonal cubano*, by Lidia Senaris, *Prensa* Latina News Service, April 26, 1995, quoting from Dr. Dario Moreno Vega of the Nephrology Institute’s Transplant Program.
Interviews with specialists at Central Havana Pediatric Hospital, December 20, 1995.
Interview with Dr. S. Valdés Martin, Dec. 20, 1995.
Interviews with Dr. S. Valdés Martin and Dr. Digna Espinosa, National Reference Center for Pediatric Nephrology, Central Havana Pediatric Hospital, May 8, 1995.
Ibid.
Interview with Dr. S. Valdés Martin, Havana, May 8, 1995.
Interview with Dr. Digna Espinosa, Havana, May 8, 1996.
Interviews with Dr. S. Valdés Martin, Dr. D. Espinosa and Dr. N. Levy, November 1, 1995, December 20, 1995, and May 8, 1996.
introduction

Diabetes mellitus is a common disorder affecting approximately 200,000 in Cuba (18.9 per 1,000 inhabitants). Diabetes is classified as Type I or Insulin-dependent Diabetes Mellitus (IDDM), requiring insulin for survival; or type II Non-Insulin-dependent Diabetes Mellitus (NIDDM), the more prevalent form, which generally should not require insulin. Some 50,000 diabetics in Cuba, or about one quarter, are insulin-dependent.

The complications of diabetes account for a substantial percentage of all new cases of end-stage renal failure and about half of all lower extremity amputations. In addition, diabetes is a leading cause of blindness. Other conditions treated within this specialty include malfunctioning of the thyroid and adrenal glands, hypoglycemia, growth retardation, and hormonal difficulties affecting human reproduction.

The Endocrinology Institute, located in Havana, monitors these and related problems for the national health care system. The Institute functions as a World Health Organization (WHO) collaborative center for human reproduction and international center for comprehensive attention to diabetics. As most national centers of this kind in Cuba, the Institute also dispenses hospital and outpatient services.

On the basis of an on-site visit to the Institute, and interviews with specialists there and at MEDICUBA importers, the National Pharmaceutical Supply Company (ENSUFARMA), the Hermanos Ameijeiras Hospital, Baterá Laboratories, and the “Pando Ferrer” Ophthalmological Hospital, the team found that, especially during the last few years, the U.S. embargo has had a particularly damaging impact on the diagnosis and treatment of diseases of the endocrine system.

The U.S. Embargo and Diabetes

Early diagnosis of diabetes, once an active nationwide program in Cuba, has been hampered by an unstable supply of reagents for laboratory testing, a situation which results from the general economic crisis complicated by the embargo and from embargo-specific obstacles. Since 1990, laboratories at the Endocrinology Institute have had to reduce testing for all conditions: In 1995, 96,177 analyses were performed, down from 149,000 in 1991.1

The 1992, denial of U.S. government licenses to Sweden’s Fluka Chemical (regular suppliers) and the more recent merger of Sweden’s Pharmacia with the U.S. firm Upjohn have led to serious problems for diagnostic and follow-up lab work at the Institute, due to gaps in restocking key reagents. According to Dr. Oscar Díaz, Deputy Director for Research, his laboratories were relying on such Pharmacia products as Ficoll-400, Ficoll Paque and Sephadex DEAE, but these reagents have not been readily available after the August, 1995 merger and subsequent ban on sales to Cuba.2 As we have noted elsewhere, not only was regular purchase of these items immediately affected, but over the longer run the procurement of the same reagents is becoming more expensive through third party trading companies: For Sephadex DEAE alone, the price of 500g shot up $250 after Pharmacia shut down its Havana sales.3 In addition, key Pharmacia equipment used in the Institute’s research—such as peristaltic pumps, fraction collectors and spectrophotometers—was now without spare parts.

Maintaining the health of diabetics largely depends on careful adherence to special dietary requirements. However, here too the embargo has aggravated the general economic situation, which in turn has led to dangerous imbalances for these patients. The recommended diet is between 25 and 39% lipid (fat) with a polyunsaturated to saturated fat ratio of at least 1:1 and with a low cholesterol content; 50% to 69% carbohydrate; and 19% to 29% protein. However, Dr. Díaz notes
that in 1933, the consumption levels for fats and proteins were actually too low, while those of carbohydrates reached an unhealthy 80%.4 (See chapter on the Food Supply and Nutrition for a more extensive discussion of the embargo's impact on diet.) It was during the same period that, a slight increase was registered in the mortality rates from diabetic coma as well as hypoglycemia, a situation which specialists also blamed on the unstable supplies of dextrose, due to production difficulties in the pharmaceutical industry—these also related in part to the U.S. embargo. (See chapter on the Pharmaceutical industry, for difficulties with equipment and cutoffs in supplies of such items as seeds for sera, dextrose and other liquids.)

Most dramatically, when the CDA became law in 1922, Cuba was faced with the sudden and urgent need to find another supplier for over 50,000 vials of insulin a month, spending considerably more in the process. Until that time, MEDICUBA—unable to buy insulin directly from U.S. manufacturers—purchased it from the Eli Lilly subsidiary in Canada. As we have seen, while the CDA ostensibly provided for licensing of direct and subsidiary sales of medications to Cuba, it has effectively cut such exports, as pharmaceutical firms are discouraged from seeking licenses. And in fact, Kevin Kramer of Lilly's International Corporate Affairs department in the USA specifically stated his (mistaken) understanding that further restrictions imposed by the CDA forbid even subsidiary sales to Cuba.5 And MEDICUBA reports that Lilly subsidiaries in other countries, notably Spain have also refused to sell insulin to the Cuban importers based on the same reasoning.6 Dr. Diaz of the Institute notes: “Lilly could provide us with insulin at more competitive prices, and at significantly less freight costs.”7

This embargo-inflicted inflation is particularly serious given Cuba’s current hard currency constraints. Thus, although insulin is on the Absolute Priority (P-I) list of medications, achieving a constant supply has been touch-and-go; according to ENSUFAHMA. At one point, there was enough insulin in the country for only one month.8 Currently, MEDICUBA purchases insulin from Novo in Denmark. The annual price tag to cover national needs is $3,785,800 (600,000 vials of 100U Intermediate Insulin (Lente) and 460,000 vials of 40U Regular Insulin), with air freight running at over $85,000, or enough for two months’ supply of SIMPLE.9 At this rate, it is not possible to purchase all that is needed.

Donations of insulin and disposable syringes (ironically, from Lilly itself) have helped to close the gap at critical moments, but Dr. Diaz reports that assimilating these has created still other problems: “We have been trying to use the 100U doses of Intermediate Insulin, which are more convenient for patients who are instructed to inject themselves. However, the donations often come in 20, 40 or 60U doses, thus complicating the process for the patients.”10

Home blood glucose monitoring, employing a variety of different techniques, is the method of choice for monitoring diabetic control. Optimum diabetes management relies on home measurements at various times throughout the day. This kind of consistent testing is near impossible for diabetics to maintain in Cuba, due to economic factors, exacerbated by the embargo. Not only do they not have access to the test strips convenient for testing glucose, but alternative methods require constant availability of reagents for home use, electricity, and cooking gas, none of which can be fully counted on. So diabetics turn to labs at their local polyclinics or nearby hospitals, a much more cumbersome ordeal, and where they are also certain to encounter problems with electricity and reagents, making consistent monitoring of their condition all the more difficult to achieve.

Lack of adequate management can introduce complications, and even put the diabetic’s life at risk. Most chronic complications fall into three categories: 1) microvascular disease, which is diabetes-specific, and involves small blood vessels, particularly of the eye and kidney; 2) macrovascular disease, involving the large blood vessels, and clinically expressed as coronary, cerebral and/or peripheral vascular disease; 3) diabetic neuropathy, which can affect motor, sensory, cranial, and autonomic nerves. Diabetics are also particularly susceptible to foot and leg
ulcers, as well as other skin lesions. A substantial proportion of these patients go on to develop one or more of these complications.

Cuba has a critical absence of laser equipment for photocoagulation, which is used to treat diabetic and other retinopathies, thus keeping these patients from going blind. Dr. Díaz states that about one quarter of Cuban diabetics suffer from some degree of retinopathy, although not all of them require laser treatment. However, for those that do, laser therapy is literally a sight saver. A number of these units were purchased in the eighties in Germany and have required expensive parts from time to time, with purchasing capabilities further limited in the nineties, as we have seen. Thus, a number of these units lie idle, one of them in the Endocrinology Institute. A new German one was purchased for the “Pando Ferrer” Ophthalmological Hospital in 1995 but arrived in unusable condition: They were still awaiting a replacement as of June 25, 1996. This is a case where the possibility of purchases directly from the USA could have saved both time and money, and the need to ship through a third country eliminated.

If patients with severe diabetic retinopathies do not receive laser therapy, at a specific point in the progressive condition some may become candidates for surgery. If these patients are not treated, they will go blind. The “Pando Ferrer” Ophthalmological Hospital reports that thousands of their patients could have made use of this equipment, and several hundred have lost their sight over the last two years as a result of its absence, including patients suffering from diabetic retinopathies.

**The U.S. Embargo and Other Hormonal Conditions**

Thyroid gland dysfunction causes some of the most common endocrine disorders, including hyperthyroidism (thyrotoxicosis) due to excess thyroid hormone, hypothyroidism (myxedema) which is a hormone deficiency condition, and autoimmune thyroid disease (for example, Graves disease). A variety of tests must be employed in the management of thyroid disease to determine thyroid status, and these must be interpreted in an integrated fashion in conjunction with the patient’s clinical presentation.

Hypothyroidism is a condition highly vulnerable to economic consequences, and in this ease to the vicissitudes imposed by the U.S. embargo. Timely deliveries to patients of some five million tablets of hormones (levothyroxine sodium with liothyronine sodium) produced at the Reynaldo Gutierrez Pharmaceutical Plant in Havana has been placed in serious jeopardy by the U.S. embargo. Specifically, as noted in the chapter on the Pharmaceutical Industry, because Cuban importers have been unable to replace parts to repair broken Pharmacia equipment (High Performance Liquid Chromatography unit, or HPLC), the working units are over-utilized. This causes delays in products reaching the pharmacies. Without HPLC quality control approval, the tablets cannot be released for sale. According to Haydee Cela, chief of quality control at the plant, she has had to wait for as much as one month for samples to be tested by the working HPLC at another center. The result at year’s end is not only backlogged production but supplies that are lagging significantly further behind demand, a problem already experienced because of the general economic difficulties.

At the Endocrinology Institute, Dr. Díaz explained that when patients cannot take this hormone as prescribed, they fall into depression, somnolence and in the most serious of cases, can fall into thyroid coma.

During the recent years of economic hardship, hormones such as somatotropin for growth retardation therapy-used in some kinds of dwarfism and for treating children and adolescents suffering from renal failure- have been difficult to guarantee for the 700-800 Cuban patients who need them. This is true not only because of the elevated cost of such a drug, in which Cuban...
importers once invested some one million dollars annually. Somatropin was last purchased in
1994 with contracts filled in the first quarter of 1995. Efforts to buy this medication have been
further complicated in the short run by the need to identify a new supplier at competitive prices,
since earlier purchases were from Pharmacia, which, as has been noted, left Havana after the
Upjohn merger in 1995.

For a discussion of the obstacles posed by the U.S. embargo for availability of oral contraceptives
and for treatment of diabetic women during pregnancy, see the chapter on Women’s Health.
NOTES

1 Interview with Dr. Oscar Díaz Diaz, Deputy Director for Research, Endocrinology Institute, October 19, 1995.
2 Visits to the laboratories and interview with Dr. O. Diaz, Jan. 22, 1996.
3 Documentation from MEDICUBA, provided to the authors June 20, 1996.
5 Interview with Keven Krambeer, International Corporate Affairs for Latin America, Eli Lilly, March 28, 1996.
6 Interview with Diana Guzman, Medications Department, MRDICURA, Sept. 7, 1995.
7 Approached by our researchers, Eli Lilly of the USA would not give wholesale pricing information for direct sales to comparable Caribbean markets. Report from Stephen Kimmerling, Nov. 13, 1995.
8 Interview with Leónel Zúñiga Director, ENSUFARMA, Feb. 7, 1996.
9 Information provided by MEDICUBA, which notes that the price of Intermediate Insulin (Lente) 100U is $4.83 per vial and of Regular Insulin 40U is 1.93 per vial; air freight runs $5.65 per kg., for approximately 15,080 kgs. While MEDICURA imports at these prices, diabetics are charged $1.25 pesos for the 100U Intermediate insulin, or about six cents.
10 Interview with Dr. O. Diaz, Oct. 19, 1995.
11 Interview with Dr. Maritza Miquel, Deputy Director of the "Pando Ferrer" Ophthalmological Hospital, June 25, 1996.
12 Interview with Dr. M. Miquel, June 25, 1996.
13 Interview with Haydee Cela, Deputy Director for Quality Control, Reynaldo Gutierrez Pharmaceutical Plant, July 4, 1996.
14 Interview with Dr. O. Diaz, Oct. 19, 1996.
Ophthalmology care in Cuba is centered at the Pando Ferrer Hospital in Havana and in ophthalmology departments at major hospitals throughout Cuba. Visits to these health care facilities end interviews with physicians, pharmaceutical production experts and executives of the National Blind Association have led to the conclusion that the economic crisis and fortified U.S. embargo during the last few years have put serious strain on this medical specialty, optometry services, and the ability to provide adequate assistance to the blind and visually impaired.

Diagnosis of eye disorders has been hindered by the inability to repair key equipment, in some cases due to the general hard currency shortage and in others more specifically to the embargo. Ophthalmologic ultrasound units are used to diagnose internal pathologies of the eye, when the external area is opaque—cases where an intra-ocular tumor is suspected; or in accidents where there has been substantial bleeding in the eye, and it is necessary to determine the presence of non-metallic fragments. In 1995, Cuban importers purchased ten Model System IV ultrasound units manufactured by Cooper Vision of Bedding, CA. The equipment was bought through intermediaries in a Latin American country, and engineers at the National Electromedicine Center note that there was "no comparable equipment available at the time."1

These ultrasounds were distributed to the Pando Ferrer, Salvador Allende, Oncology, and Hermanos Ameijeiras Hospitals in Havana; the Satumino Lora General Hospital in Santiago de Cuba Province; and one hospital each in Sta Clara and Holguin Provinces. Over the years, repairs have required purchase of various components. Yet, not even intermediaries approached were willing to sell these parts to Cuba, citing the U.S. embargo, according to the National Electromedicine Center.2

As a consequence, during the last three-years, none of these units has been in operation. At the Oncology and Radiology Institute, specialists report that they have not been able to make use of this key equipment for at least 1200 patients, and thousands more throughout Cuba have also gone without benefit of this diagnostic tool.2 Dr. Maritza Miquel, Vice Director of the Pando Ferrer Hospital reported that, despite the fact that her facility had sent out word to other hospitals not to refer cases for ultrasound testing, they continued to receive patients who expected such service.

In April, 1996, the Pando Ferrer Hospital finally received a new ultrasound unit, made by another manufacturer and donated by a group of ophthalmologists. Since this equipment was also of U.S.-origin, engineers from a third country had to come to Cuba to train technicians on its use and management.4 Meanwhile, all Cooper Vision units—including the one at the ophthalmologic hospital—lie idle, since export of parts at a fraction of the cost of new ultrasound equipment is stalled by virtue of the embargo, subject to the embargo ‘chill factor’.4

A similar history concerns attempts by MEDICUBA to obtain quotations for purchase of a simple autorefractometer (used to measure vision) from Carl Zeiss Jena GmbH (Germany) in 1995. Zeiss Jena answered inquiries by fax, dated June 2, 1995, explaining that "according to the embargo, an autorefractometer cannot be ordered for MEDICUBA."5

The embargo has also affected acquisition of diagnostic and surgical equipment for ophthalmological services by adding to the price, shipping distance, and time, since these cannot be purchased or repaired in the United States. This is the case of laser photocoagulators, required in treatment of a number of retinopathies, including diabetic retinopathy (see chapter on Endocrinology). If not diagnosed and treated within a specific time period—first with laser therapy, and at another point with surgery—a number of these conditions can lead to blindness.

The argon laser photocoagulators used in Cuba were bought in East Germany during the eighties and after several years suffered breakdowns of various kinds. These include the units at the Pando Ferrer Hospital and the Endocrinology Institute. This equipment, according to Cuban importers, is quite expensive, especially in the European market, and thus particularly difficult to
replace in Cuba’s current economic situation—at least in the numbers required. Finally, in 1995, one new unit was acquired for the Pando Ferrer Hospital from a European supplier. However, it arrived in Cuba in June, 1996, in poor condition, and over a month later a substitute had not arrived. The only other laser available at the hospital is not of the same technology and is painful for patients. Even with the new photoagulator, the hospital will not be able to assimilate all the patients that require it.

As a result of the disrepair of the laser photoagulators, delays in purchase and delivery of a new one, and related problems of surgical supplies, specialists say it is too late for many of these retinopathy patients, and over 200 people will have suffered a substantial loss of eyesight and even blindness.

Intra-ocular lenses have to be brought all the way from Sweden at higher prices, since U.S. manufacturers are not in the bidding. This is the crystalline lens implanted during cataract surgery. For six months in 1995-96, some 1,000 patients were on the waiting list for these lenses. Only 800 lenses could be purchased at the time, and the waiting list is growing again.

Because of general economic limitations—which have affected all aspects of surgery, from disposable supplies to air conditioning and anesthesias—operations carried out at the Pando Ferrer Hospital in 1995 totaled 7,939 as compared to 15,725 in 1989, or just about half.

Medications are in serious shortage for ophthalmologic patients, some as a direct result of the embargo’s negative impact on domestic pharmaceutical production. Eye drops produced in Cuba include atropine and homatropine for dilating the pupil; kanamycin and chloramphenicol antibiotics; and timolol and pilocarpina for use in glaucoma. Amado González Landa, President of the National Blind Association, made particular reference to timolol, of which he said there is “never enough.”

The Julio Trigo Pharmaceutical Plant in Havana also turns out prednisone and other steroids, intended for direct injection into the eye.

The prices of these medications when imported are inflated by the embargo, as we have demonstrated in the chapter on Medical Exports. Their domestic production is subject to obstacles posed by the U.S. policy: less efficient and reliable quality control (by virtue of the inability to repair a computerized particle counter); delays in releasing these products to pharmacies (due to backups in testing samples, caused by inability to repair U.S.-origin equipment), and other embargo-related factors described in the chapter on the Pharmaceutical Industry.

The nefarious impact of the embargo on prevention, diagnosis and treatment of optic neuropathy patients during the 1993-94 epidemic is documented in the chapter on National Health Emergencies. In addition to the incidence of the embargo in the reduced nutritional levels that were a major factor in the national outbreak, Cuba paid an additional 134% for diagnostic reagents from Europe, and, for a single shipment of vitamins from Europe, paid nearly $200,000 more than it would have paid for these items if imported from the United States.

Finally, international cooperation and humanitarian donations have also felt the brunt of the U.S. embargo in this field. Amado González of the National Blind Association notes that donations of medicines, Braille paper and typewriters, canes, and other aids for his organization have been held up in European ports in Norway, for example—waiting for Cuban ships to pick up the cargo, after no other vessel could be found to bring it to Cuba, due to the CDA shipping restrictions imposed by Washington in 1932 (see chapter on Medical Exports). González relates that it has also been very difficult for this organization of some 26,666 members to purchase Braille typewriters, since the patent belongs to a U.S. firm.

In the case of Project Orbis, the flying ophthalmological surgery unit which has provided service to some 60 countries, a U.S. license to travel to Cuba was denied to the Orbis physicians in February
of 1991. The purpose of the trip was to carry out joint operations with Cuban physicians on board and at the Pando Ferrer Hospital. It took significant lobbying efforts to finally garner a license for the trip four months later: Some 70 patients waited for surgery as a result, for procedures which included cornea transplants, etc.
NOTES

1 Interview with Alexis Cedeño, Vice Director of the National Electromedicine Center, Havana, Dec. 8, 1995.
2 Ibid. and interview with Dr. Maritza Miquel, Vice Director, Pando Ferrer Ophthalmological Hospital, June 25, 1996.
3 Interviews at the Oncology and Radiology Institute, Oct. 16, 1995.
4 Interview with Dr. M. Miguel, June 25, 1996.
5 Interview with Dr. M. Miquel, June 25, 1996.
6 Ibid.
7 Ibid.
8 Ibid.
9 Interview with Amado González Landa, Resident of the National Blind Association, Havana, Jan. 10, 1996.
10 Ibid.
11 Ibid.
12 “Eye to Eye with Orbis” by Meic Haines in Cuba Update, the Center for Cuban Studies, New York, Nov. 1991, p. 10.
The U.S. embargo stipulates that no medical equipment or medications authorized for sale or donation to Cuba be ‘re-exported.’ These restrictions essentially target the growing Cuban ‘health tourism’ industry, which attracts foreign patients who pay for medical care in Cuba and thus constitute a source of hard currency. The U.S. Commerce Department has requested exporters to indicate if items are intended for Cuban or foreign patients.1

This embargo provision has a direct impact on health care delivery to the Cuban population, since all net earnings from health tourism, and the treatment of foreigners in general, are plowed back into the Public Health system, constituting an important source of hard currency for much-needed purchases of medical equipment, medicines and supplies. Thus, this regulation penalizes Cuban patients for the country’s medical assistance to foreign patients.

Also penalized by the provision are the foreign patients themselves who seek treatment in Cuba. These include those who come to Cuba specifically for this purpose, the so-called health tourists, as well as foreigners working in Cuba on a temporary basis who rely on Cuban health services, such as members of the diplomatic and international NGC communities, journalists, and business executives.

Servimed, the Cuban health tourism agency, reported that 3,540 patients from 70 countries had received treatment through Servimed in 1995, some 59 of these from the United States. Servimed’s Sonia Baéz told us that they receive eight to ten inquiries a month from people in the United States about possibilities for medical attention in Cuba. Olga Ceballos Alvarez of the Public Relations and Promotion Department reported that the majority of foreign patients receive treatment for retinitis pigmentosa at the Camilo Cienfuegos Hospital, for vitiligo and psoriasis at the Center for Placental Histotherapy, and for neurological disorders such as Parkinson’s disease at the International Center for Neurological Restoration. She points out that these figures do not represent all the foreigners coming to Cuba for medical treatment, since many do not use Servimed but make direct arrangements with specialized institutes, hospitals and health programs.2

Direct arrangements of this kind are frequently made with the Camilo Cienfuegos Hospital, which is the International Retinitis Pigmentosa Canter located in Havana. Retinitis pigmentosa is a debilitating, progressive, hereditary disease which affects approximately one in every 5,000 people, reducing night vision first and eventually leading to blindness. The actual cause is, in fact, unknown, although specialists suggest that as many as one in 80 people could have a genetic predisposition to the disorder. Successful treatment for retinitis pigmentosa is credited to Cuban scientist and ophthalmologist Dr. Orfilio Peláez, who has won international recognition for his work in the field, including the “Vision” Prize from the Retinitis Pigmentosa International Foundation in Los Angeles in 1994.

Since 1987, over 7,999 patients have received Dr. Peláez treatment. These include 3,917 foreign patients from 38 countries and some 5,999 Cubans. In over 90% of cases, the therapy has halted progress of the disease and has led to recovered vision in approximately 58%. All of the Cuban patients and about 100 foreign patients have been treated free of charge.3

The retinitis program in Cuba is an example of a medical option available to non-Cuban citizens as well as to Cubans; it is directly impacted by the U.S. embargo, which poses obstacles to purchases of U.S. medical products for treatment and has stepped up economic pressure on the health care delivery system as a whole. In some cases, such as the Prostins, exclusive to Upjohn, their ‘for hospital purchase only’ designation effectively keeps out of Cuban hospitals this medication of choice—in this case for inducing labor. Such unavailability affects all pregnant women on the island, Cuban and foreign alike.
There are two special categories of foreign patients treated in Cuba: The first are those seen free of charge, the majority of whom are children. For example, the Cuban Program for Medical Attention to the Chernobyl Victims has provided diagnostic services and treatment for 13,414 children and 422 adults from regions of the Ukraine, Byelorussia and Russia affected by radioactive contamination from the April 1986 nuclear accident. Dr. Raciel Llanes, coordinator of the program, says 3% of the children who come to the Center at Tarara, to the east of the City of Havana, suffer from oncological and hematological diseases, such as malignant tumors and leukemia; 17% have serious kidney, cardiovascular or neurological problems. These patients require the services of specialized institutes and hospitals in Havana. Another 60% receive outpatient care by specialists at the center; and the remaining 29% come mainly for a complete medical check up, with no obvious pathologies.4

Since the Chernobyl Victims program began in 1990, over 70 surgical interventions, 18 complex heart operations, six bone marrow transplants and two kidney transplants have been performed in Cuban hospitals, in addition to other specialized procedures, including surgical and chemotherapy treatment for cancer and intensive dermatological therapies. Valentina Mijailenko, a Russian mother whose son was seriously affected by the accident, said: Many of us have come to Cuba as a last resort, after we have been told that there is little hope for our children. Yet, in this country, the doctors have been amazing...and our children get better.” 5

On the basis of experience gained with the Chernobyl cases, Cuba has treated a number of radiation victims, such as children from a Brazilian catastrophe: Discarded radioactive medical equipment was illegally abandoned in a garbage dump, where youngsters played. Over 100 children were exposed to the Cesium-137 radioactive waste, and several died before the rest were brought to Cuba.

The William Soler Pediatric Cardiocenter has operated on 240 foreign children, free of charge, until two years ago. In 1994 and 1995 approximately 12 and no more than 15 children have been charged for their medical treatment. The 10 Chernobyl children operated on in this center also received free care.5 At the National Hematology Institute in Havana, a number of foreign patients have been treated, principally children from Latin America and Africa. Since 1990, 295 Chernobyl children and 50 children from the Brazilian disaster have been treated at the Institute.7

Thus the embargo’s impact on health care delivery also affects children from other countries seeking treatment in Cuba-treatment they often could not afford elsewhere. By increasing the cost of these programs, the embargo essentially “punishes” Cuba for making a humanitarian gesture.

A second special category of foreign patients are U.S. patients, whom the embargo prevents from travel to Cuba to receive medical treatment. Thus, U.S. citizens afflicted with certain conditions cannot take advantage of Cuban medical advances. As a result, 78 people (four of them children) have had to come to Cuba in defiance of U.S. law in order to receive treatment for retinitis pigmentosa, a treatment without which they would have gone blind. In this case, the U.S. embargo on Cuba forced people from the United States to choose between U.S. law and their health.

In addition, U.S. citizens who are in Cuba under U.S. license are restricted to spending a maximum of $100 a day in the country (hotel, food, etc). Should such an individual fall sick and require medical treatment, including hospitalization, for example, they would be unable to stay under the dollar limit and would, therefore, become liable for penalties that apply.

When two-year-old Becky Kirsch came to Cuba with her parents on a legal tip in 1993, she became seriously ill and was hospitalized for two weeks. The hospital, a health tourism facility, treated Becky and lodged her parents during the full two weeks. Because payment for these services could have caused this family legal complications and fines upon return to the U.S., the Cuban hospital
waived the bill. The following year, this family attempted to organize urgently needed medical donations for a Cuban child with cancer, describing endless obstacles to their effort.
NOTES

1 Communication from Iris Medical to the U.S. Department of Commerce, January 11, 1994.
2 Interview with Olga Ceballos Alvarez, Public Relations and Promotion Department, Servimed, Cubanacán S.A., Havana, February 22, 1996.
3 Interview with specialists from the Retinitis Center, Camilo Cienfuegos Hospital, Havana, June 21, 1996.
5 Ibid.
6 Interview with Dr. Herminia Palenzuela, William Soler Pediatric Cardiocenter, July 12, 1996.
7 Interview with Dr. José Manuel Bayestros Santovenia, Director of the Hematology Institute, Havana, October 26, 1995.
8 Correspondence to Dr. Michele Frank from David and Mia Kirsch, January 12, 1995.