

Development of a Registry for Diabetes in Persons 0–19 Years of Age in the U.S. Virgin Islands¹

EUGENE S. TULL,² CORA L. E. CHRISTIAN,³ &
JEFFREY M. ROSEMAN⁴



A juvenile-onset diabetes registry was recently established in the United States Virgin Islands. Hospital and clinic records were used as the primary sources of case data, while data procured through a physician survey and mass media campaign were used to assess the completeness and validity of the registry listings.

The data indicated that 39 people 0–19 years old developed diabetes during the study period (1 January 1979–31 December 1988), of whom 36 probably had Type 1 diabetes. Completeness of the primary source data was estimated at 92.3% and validity seemed very good (around 100%). Evaluation of these registry data has provided new insights into the epidemiology of Type 1 diabetes in the U.S. Virgin Islands.

Since early in this century many epidemiologic studies have sought to determine rates of diabetes mellitus. Much of this effort has focused on diabetes affecting adults—among whom by far the most common form of the illness is non-insulin-dependent diabetes mellitus (Type 2). Not until relatively recently has insulin-dependent diabetes mellitus (Type 1), which accounts for about 5% of all diabetic cases in the United States (1), been considered a matter of major public health concern.

Type 1 diabetes occurs relatively commonly in children and young adults and is characterized by an abrupt onset of symptoms (including polydipsia, polyuria, weight loss, polyphagia), insulinopenia, dependence on insulin to sustain life, and a tendency toward ketosis (2). Other diabetes subtypes that occur in young people include maturity-onset diabetes of youth—a non-insulin-requiring form of Type 2 diabetes that has an autosomal dominant mode of inheritance (2); protein-deficient pancreatic (J-type) diabetes—an insulin-requiring form of diabetes occurring in tropical areas whose sufferers are characterized by a lean body build, insulin resistance, and resistance to ketosis upon withdrawal of insulin (3); fibrocalculus pancreatic (Z-type) diabetes—a diabetes subtype typically afflicting subjects with a history of childhood malnutrition that is characterized by pancreatic calcification and fibrosis together with resistance to insulin (4); and gestational diabetes—diabetes occurring during pregnancy that is followed by a

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²Post-Doctoral Fellow, Department of Epidemiology, Graduate School of Public Health, University of Pittsburgh, Pittsburgh, Pennsylvania, U.S.A.

³Assistant Commissioner, Department of Health, U.S. Virgin Islands.

⁴Associate Professor, School of Public Health, University of Alabama at Birmingham, Birmingham, Alabama, U.S.A.

return to normal glucose tolerance after termination of pregnancy (2).

Population-based Type 1 diabetes registries in the United States have consistently reported a lower incidence of Type 1 diabetes among blacks and Hispanics than among whites (5–8). Efforts by Diabetes Epidemiology Research International (DERI)⁵ to enhance the comparability of these registry reports have led to adoption of standardized criteria for defining insulin-dependent diabetes in Type 1 diabetes registries (9). However, caution has been advised when applying these criteria to nonwhite populations (9), where other forms of diabetes that could present classification problems may commonly occur among young people (10–12). Classification of Type 1 diabetes using DERI criteria may be especially problematic in black populations, wherein various diabetes subtypes affecting youth and resembling classical Type 1 diabetes have been encountered (3, 10, 13). To date, no studies have sought to evaluate the impact of this potential misclassification upon the apparent epidemiology of Type 1 diabetes among blacks in regions such as Africa and the Caribbean where these other subtypes have been reported.

Insulin-dependent diabetes is the third most prevalent chronic disease in the 0–20 age group in North America and Northern Europe (14). The risk of developing Type 1 diabetes by age 15 is greater than that of developing other well-known diseases such as muscular dystrophy, rheumatoid arthritis, cystic fibrosis, and multiple sclerosis (1). Patients with Type 1 diabetes typically experience

higher mortality and die younger than those with Type 2 (15). In this same vein, insulin-dependent diabetes mellitus accounts for most of the diabetic patients undergoing renal dialysis (16), and also for a high percentage of all diabetes-associated blindness (14). Also, recent information suggests that Type 1 diabetes may be especially malignant among blacks (5); for while U.S. blacks have a lower incidence of Type 1 diabetes than U.S. whites (5–7), they also experience a rate of mortality from Type 1 diabetes twice that of U.S. whites (15). At present, little comparable data is available for black populations outside the United States.

A lot of attention is currently being focused on identifying the genetic and environmental factors responsible for Type 1 diabetes around the world (9, 17). Evidence suggesting an environmental etiology includes seasonal variation in the incidence of Type 1 diabetes (18), a low concordance rate of Type 1 diabetes in monozygotic twins (19), and an association between Type 1 diabetes and infectious illnesses of viral origin (20, 21). At the same time, evidence pointing to genetic factors includes a consistent association found between Type 1 diabetes and HLA antigens DR3 and DR4 (22). In addition, investigators recently identified an amino acid substitution at position 57 (non-asp-57) of the HLA-DQ beta gene on Chromosome 6 that is highly associated with susceptibility to Type 1 diabetes in Caucasian populations (23, 24). To help evaluate the relationship of this gene and other risk factors to the incidence of Type 1 diabetes in different racial and ethnic groups, some researchers (25) have called for development of population-based insulin-dependent diabetes registries in many countries around the world.

In this regard, it should be noted that insulin-dependent diabetes registries are

⁵Diabetes Epidemiology Research International is a multinational research organization consisting of 64 centers in 39 countries that conducts collaborative research on the occurrence and impact of Type 1 diabetes on different populations around the world.

already present in many areas. Indeed, a recent DERI report presented the results of a collaborative effort by 24 registries in 15 countries (9)—results demonstrating a marked worldwide and temporal variation in the incidence of Type 1 diabetes. These findings suggest that both environmental and genetic factors are responsible for the worldwide variations in the risk of Type 1 diabetes. Of the 24 reporting registries, however, only one (a Cuban registry) was located in the Caribbean area—a circumstance symptomatic of the fact that until now there have been very few data concerning the incidence of Type 1 diabetes in the Caribbean.

To further evaluate the epidemiology of Type 1 diabetes in the Caribbean, a population-based juvenile diabetes registry was developed in the United States Virgin Islands. This preliminary article summarizes the procedures used in the design, development, and validation of this Virgin Islands Juvenile Diabetes Registry.

MATERIALS AND METHODS

The U.S. Virgin Islands consist of three main islands (St. Croix, St. Thomas, and St. John) and 50 uninhabited smaller islands and cays (Figure 1). Located 70 miles east of Puerto Rico, these islands provide an ideal location for collecting epidemiologic data on the incidence and impact of insulin-dependent diabetes mellitus upon a multiracial Caribbean population.

Approximately 80% of the islands' inhabitants are black, the remaining 20% being mostly a mixture of white and Hispanic ethnic groups (26). The population's median age is 22.5 years (26). Nearly half the inhabitants migrated from other Caribbean islands or have ancestors who did (26). Overall, the population provides a good sampling of West

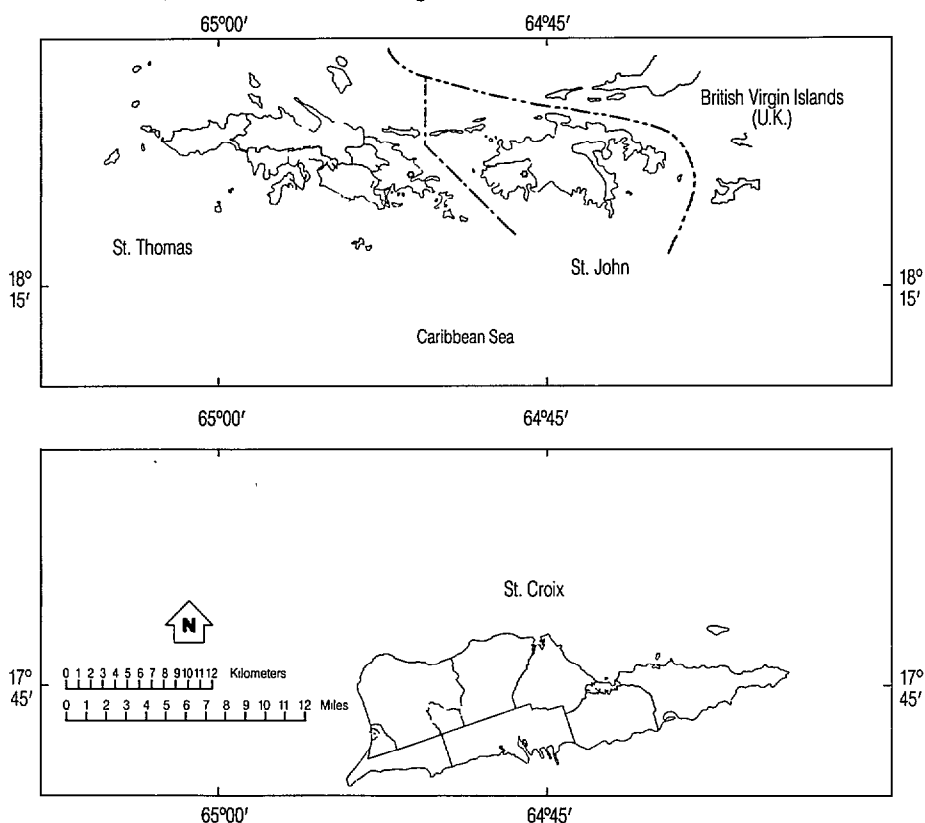
Indians from virtually the entire Caribbean.

Initial efforts to develop the Virgin Islands Juvenile Diabetes Registry began in March 1988 when researchers from the School of Public Health at the University of Alabama (Birmingham) contacted the U.S. Virgin Islands Department of Health. Subsequent discussions determined that development of such a registry was in harmony with the health department's current focus on disease prevention and that the registry might eventually be used to evaluate a number of diseases. It was also noted that hospital-based data for a juvenile-onset diabetes registry could easily be gathered from two government-run hospitals, one on St. Thomas and the other on St. Croix, these being the only hospitals in the U.S. Virgin Islands. (The hospital on St. Thomas, besides providing for people on that island, also serves the relatively small population on the island of St. John.) The necessary approval for the project was obtained on 9 December 1988.

The first technical step in developing the registry was case definition. It was decided that patients would be enrolled if they met the following criteria: If they (1) had been diagnosed as having diabetes (2, 27), (2) were less than 20 years old at the time of diagnosis, and (3) were living in the U.S. Virgin Islands at the time of diagnosis or onset of symptoms.

Those enrolled were classified as having Type 1 diabetes if the diabetes was not secondary to other disorders and if they were on insulin at hospital discharge or at the time of registration (aside from the age requirement for enrollment, these criteria were similar to those employed by DERI). Other relevant subtypes of diabetes affecting young people were identified among those enrolled on the basis of the following definitions adopted from the literature: (1) gesta-

Figure 1. A map of the United States Virgin Islands.



tional diabetes—patient was diagnosed with diabetes, was pregnant at the time of diagnosis, and returned to normal glucose tolerance after pregnancy (2); (2) NIDDM (MODY)⁶—patient was diagnosed as having diabetes not requiring insulin with an autosomal dominant mode of inheritance (2); (3) protein-deficient pancreatic diabetes (J-type)—patient diagnosed with diabetes had a body mass index $< 19 \text{ kg/m}^2$ and an insulin requirement $> 1.5 \text{ units/kg}$ body weight, was ketosis-resistant, and yielded radiographic or other evidence indicating absence of pancreatic calcification or fibrosis (28, 29); (4) fibrocalculus pan-

creatic diabetes (Z-type)—patient diagnosed with diabetes had a body mass index $< 19 \text{ kg/m}^2$ and an insulin requirement $> 1.5 \text{ units/kg}$ body weight, was ketosis-resistant, and yielded radiographic or other evidence of pancreatic calcification or fibrosis (28, 30). The cases of enrolled patients that were diagnosed as diabetes but could not be classified according to the registry criteria were placed in a separate category and classified as “undetermined diabetes.”

Cases were procured mainly through retrospective review of hospital records. In general, this method’s ability to detect all or nearly all cases depends on two well-established assumptions: first, that virtually all newly diagnosed Type 1 diabetic patients are being referred to some

⁶NIDDM (MODY) = non-insulin-dependent diabetes mellitus (maturity-onset diabetes of youth).

hospital (31); and second, that the hospital or hospitals in question have medical or pediatric wards (31). To assure that case procurement was complete in our case, multiple data sources within the two hospitals involved and in public health clinics were used to identify cases. The cases enrolled were limited to those diagnosed as diabetes between 1 January 1979 and 31 December 1988.

Data collection forms were developed for abstracting relevant information from medical records and for interviewing study subjects. These forms were prepared after review of relevant literature and were tested in a pilot study before use. Information collected on individual subjects included the following: name, address, sex, race/ethnicity, date of birth, time and place of diagnosis, diagnostic symptoms, X-ray results, laboratory values at diagnosis (blood glucose, urine glucose and ketone, blood pH, and bicarbonate), insulin use, residence at diagnosis, height and weight, concomitant diseases and infections, and family history of diabetes.

The review of hospital records began first on St. Croix in December 1988 and then on St. Thomas two months later, in February 1989. There being no computerized medical record-keeping system, identification of cases on St. Croix was simplified by using the hospital's professional activity study (PAS) reports. These reports summarize monthly hospital admissions by patient characteristics such as age, disease diagnostic codes, and date of diagnosis. In addition, other hospital/clinic sources were employed to identify possible juvenile diabetes cases—including records at the diabetes clinic, the maternal and child health clinic (MCH), and the women and infant clinic (WIC). On St. Thomas, where PAS reports were not available, records of the MCH and WIC clinics, together with the hospital pediatric ward's log of admis-

sions and discharges, served as sources for identifying cases. Following case identification, the hospital record of each individual involved was reviewed.

While these hospital and clinic-based sources were the prime tools for identifying juvenile diabetes cases, individual physicians were also surveyed by telephone to help identify cases and provide a way of validating the registry. A list of names and addresses of physicians practicing in the U.S. Virgin Islands was provided by the V. I. Department of Health. Additional names were obtained from the local telephone directory listing. On 15 December 1988 introductory letters were sent to all physicians (N=50) in pediatrics, general/family practice, internal medicine, surgery, and obstetrics/gynecology who appeared then to be operating a private practice in the U.S. Virgin Islands. The letter stated that a juvenile diabetes registry was to be established and requested the physician's cooperation in identifying cases.

The actual telephone survey began in January 1989. Each physician was called and asked if he or she had ever treated a case of diabetes in a person less than 20 years old. Those responding affirmatively were asked to provide each patient's name and information regarding insulin therapy. Confidentiality of all responses was assured. Of the 50 private physicians sent introductory letters, 47 were surveyed. Three physicians could not be contacted and were excluded from the analysis.

A publicity campaign connected with establishment of the juvenile diabetes registry was launched in April 1989. This dual-purpose campaign sought to inform the public about the registry and also to help identify additional cases. Initially, in early April, a press release was sent through the advertising and marketing department of the V. I. Department of Health to local newspapers and radio and

television stations on St. Thomas and St. Croix. Also in April, one of the investigators was interviewed by a popular radio talk show program on St. Thomas and by a local television news broadcast service on St. Croix. Articles based on the press release appeared in the local newspapers on St. Thomas and St. Croix in May. Overall, this publicity did encourage self-reporting of cases by people with juvenile diabetes. A series of public service announcements continued to be aired until 21 July 1989.

From 22 July to 22 August 1989 follow-up patient interviews were conducted to help assess the reliability of the information obtained from hospital and clinic records. Parents served as interview surrogates in cases where patients were away from the Virgin Islands or were too young to understand the questions.

RESULTS

A total of 39 patients (21 male and 18 female) 0–19 years old at the time of diagnosis were found to have developed diabetes in the U.S. Virgin Islands between 1 January 1979 and 31 December 1988. Twenty-one cases (53.8%) were identified on St. Croix and 18 (46.2%) on St. Thomas/St. John.

Thirty-six of the 39 cases were classified as insulin-dependent diabetes melli-

tus. However, 34 of the 36 had no record of receiving an abdominal X ray at diagnosis, and very few (8 of the 36) had consistently recorded height and weight data. Thus, diabetes subtypes such as fibrocalculous pancreatic diabetes and protein-deficient pancreatic diabetes could not be ruled out.

Besides these 36, one case each of NIDDM and gestational diabetes were also found. One additional case could not be classified. The observed incidences of Type 1 diabetes as well as other epidemiologic analyses conducted on this sample are presented elsewhere (32).

Several problems were encountered during data collection and case identification. The unavailability of medical records on the initial hospitalization and diagnosis of several cases required the use of less reliable data from clinic records to establish the date of diagnosis or initial insulin dosage. Also, the race of one individual could not be determined.

As Table 1 indicates, hospital/clinic-based sources identified 92.3% (36/39) of all known cases diagnosed during the 10-year study period. Forty-one percent (16/39) were identified by the physician survey, and 10.3% (4/39) as a result of mass media efforts. Two cases (5.1%) would not have been found if the physician survey had not been used, and one (2.7%) would not have been found with-

Table 1. Percentages of the identified diabetes cases in young people 0–19 years old that were detected through each of the three kinds of independent data sources used on St. Croix and on St. Thomas/St. John, U.S. Virgin Islands, 1979–1988.

Source	% detected by source ^a (no. detected by source/total no. detected) on:		
	St. Croix	St. Thomas/St. John	Total
Hospital/clinic	95.2 (20/21)	88.9 (16/18)	92.3 (36/39)
Physician survey	14.3 (3/21)	72.2 (13/18)	41.0 (16/39)
Mass media	4.8 (1/21)	16.7 (3/18)	10.3 (4/39)

^aThe percentages in each column total more than 100% because some cases were identified by more than one source.

out the media campaign. The physician survey and media campaign together identified 17 (43.5%) of the 39 cases.

The relatively low percentage of cases (14.3%) identified by the physician survey on St. Croix most likely reflects a tendency by St. Croix physicians to refer juvenile diabetic cases to public diabetes clinics. Such clinics were absent on St. Thomas.

Sixty-six percent (12/18) of all the cases found on St. Thomas/St. John were identified by both the physician survey and the hospital/clinic data sources. When all cases common to both sources were compared, no important diagnostic discrepancy was found. All 12 cases were identified as Type 1 diabetes, and all were being treated with insulin at the time of registration. Because of the small number of cases found by the physician survey on St. Croix, a similar check of the validity of the primary data sources was not possible on that island. It is unlikely, however, that the degree of validity would vary significantly between the islands, given the characteristic clinical features of Type 1 diabetes.

Table 2 shows the numbers of cases found through each type of hospital and

clinic data source. Overall, hospital sources detected 76.9% (30/39) of all the cases identified, while clinic sources detected 69.2% (27/39).

On St. Croix, the search of PAS reports failed to detect six (28.6%) of the 21 cases found by all data sources, while diabetes clinic records failed to reveal nine (42.9%). However, if MCH clinic records had been the only source, then 16 (76.2%) of the cases would have been missed, as would 15 (71.4%) if pediatric ward admissions/discharges had been the only source. On the other hand, even the source that revealed the smallest number of cases (the WIC clinic data) made a positive contribution; because even though the WIC data identified only 9.5% of the cases on St. Croix, one case would not have been found at all if this source had not been used.

On St. Thomas/St. John, where fewer data sources were available, the review of pediatric ward admissions/discharges identified 77.8% (14/18) of the cases found, while MCH clinic records identified 61.1% (11/18).

Of the 36 subjects with diabetes who were identified by the hospital/clinic sources, 19 (52.8%) were later inter-

Table 2. Primary sources of case identification, showing the percentages of all detected cases on St. Croix and St. Thomas/St. John that were identified using each source.

Source	% of cases detected by source (no. detected by source/total no. detected) on:	
	St. Croix	St. Thomas/St. John
<i>Hospital sources:</i>		
Pediatric ward (admissions/discharges)	28.6 (6/21)	77.8 (14/18)
PAS reports (medical record summaries)	71.4 (15/21)	—
All hospital sources	76.2 (16/21)	77.8 (14/18)
<i>Clinic sources:</i>		
Diabetic clinic	57.1 (12/21)	—
MCH clinic	23.8 (5/21)	61.1 (11/18)
WIC clinic	9.5 (2/21)	0.0 (0/18)
All clinic sources	76.2 (16/21)	61.1 (11/18)

Note: Some cases were identified by more than one source.

Table 3. Physicians among the 47 surveyed who reported treating cases of juvenile diabetes, by specialty.

Specialty	No.	% (no./total) of physicians in specialty who said they had treated cases	% (no./total) of the 15 physicians treating cases who practiced the indicated specialty
General/family practice	9	55.5 (5/9)	33.3 (5/15)
Pediatrics	12	66.7 (8/12)	53.3 (8/15)
Internal medicine	9	22.2 (2/9)	13.3 (2/15)
Surgery	7	0.0 (0)	0.0 (0)
Obstetrics/gynecology	10	0.0 (0)	0.0 (0)

viewed to assess the primary source data's reliability. Fifteen (41.7%) of the 36 could not be contacted, and 2 (5.5%) refused to be interviewed. Many were unable to recall details (only 9 of the 19 remembered the date of diagnosis) or diagnostic symptomatology. Nevertheless, there were no differences between the information supplied by the cases and the primary sources with respect to key demographic variables such as gender, residency status, date of birth, and race/ethnicity.

Table 3 presents data obtained from the telephone survey of physicians. Most of those surveyed (32/47, 68.1%) said they had not treated a case of juvenile diabetes in their practice. Of the 15 physicians who said they had treated a case of juvenile diabetes, 53.3% (8/15) were pediatricians, 33.3% (5/15) were general/family practitioners, and 13.3% (2/15) were internists. No physician specializing in obstetrics/gynecology or surgery said he had treated a case of juvenile diabetes.

DISCUSSION AND CONCLUSIONS

Registries designed to evaluate insulin-dependent diabetes mellitus have used various data sources to identify cases. Some have used diverse types of sources (33, 34), while others have used a single type (7, 35). As already described, to help maximize case identification the Virgin Islands juvenile diabetes registry pro-

gram chose to employ a number of different hospital and clinic-based data sources as its primary means of case detection.

The advantage of this approach is shown by the fact that none of the individual primary data sources used in this study was able to identify more than 78% of the cases found at either site (St. Croix or St. Thomas/St. John). However, when all the primary (hospital and clinic-based) sources were combined, their data identified 92.3% of the cases. This suggests that where computerized hospital medical record filing systems are absent (as in many Caribbean countries), or where competitive patterns of outpatient health care prevail, the multiple source approach may play an important role in maximizing detection of Type 1 diabetes patients.

Among the physicians surveyed, pediatricians were found most useful for case identification. None of those specializing in surgery or obstetrics/gynecology reported treating cases of juvenile diabetes. However, the potential contribution of these latter specialists should not be overlooked; for in other populations with very few physicians, where each physician may be required to treat illnesses unrelated to his or her specialty, such practitioners may prove valuable in identifying juvenile diabetes cases.

A fundamental concern in evaluating registry data is completeness, defined as the proportion of all cases within the cov-

ered population that appears in the registry (36). In our case, completeness of the primary (hospital/clinic) data was assessed by using a physician survey and a media campaign as secondary independent data sources. Of the cases found through these two alternate sources, only three were not found by the primary data sources. Thus, an ascertainment percentage of 92.3% was estimated for the primary (hospital/clinic) data sources, while the estimated ascertainment percentage of the combined secondary sources was 43.5%.

This latter figure is consistent with a DERI recommendation that validation sources should detect ≥ 30 –40% of the cases (9). While it is not certain that we identified all people under age 20 who developed diabetes in the U.S. Virgin Islands during the 10-year study period, it is unlikely that many cases were omitted.

Another key quality of registry data is its validity, defined as the percentage of patients registered who actually have the disease in question (36). Practically speaking, it may be assumed that the validity of data in a Type 1 diabetes registry can be determined by assessing how cases listed in the registry as Type 1 diabetes are diagnosed by an independent source that objectively identifies Type 1 cases (36). When the validity of our juvenile diabetes registry data was assessed this way, there was 100% agreement between the primary and independent secondary sources with respect to diagnosis of Type 1 diabetes.

Considering the DERI diagnostic criteria, it is possible that some of the patients on insulin therapy who were diagnosed as having Type 1 diabetes could in fact have had Type 2 diabetes; or perhaps some cases diagnosed as Type 1 were actually other types of diabetes afflicting young people—such as protein-deficient pancreatic (J-type) diabetes—that resemble Type 1 and are known to occur in

some Caribbean populations (3). In the future, collection of more definitive data capable of distinguishing between the subtypes of diabetes afflicting young people should significantly reduce the potential for misclassification of cases enrolled in the registry.

Goldberg, Gelfand, and Levy (36) have identified several potential problem areas associated with establishment and development of a registry. These include organization and staffing (e.g., developing cooperative agreements, defining goals and objectives, specifying computer resources), maintenance costs, and the quality of registry data (36).

In the case of the Virgin Islands Juvenile Diabetes Registry, problems related to organization and staffing were minimized because of the V. I. Health Department's emphasis on disease surveillance and health officials' commitment to incorporating the registry into the preexisting departmental structure. As Type 1 diabetes registries are developed in other Caribbean countries, it will be important that health authorities commit themselves to meet funding and staffing requirements in order to ensure the registries' effective operation.

For Caribbean countries with small populations and correspondingly small Type 1 diabetes registry samples, the costs related to such maintenance activities as follow-up to procure missing data or elimination of duplicates from central files are minimal. Regardless of the registry database's size, however, ensuring proper data quality is essential—since development of control programs or the allocation of funds for needed services may depend on statistics provided by the registry, and faulty data supplied by the registry may lead to misappropriation of limited resources.

The initial data collected for the Virgin Islands Juvenile Diabetes Registry have provided new and interesting insights

into the epidemiology of Type 1 diabetes there. Preliminary results suggest that the incidence of Type 1 diabetes in the U.S. Virgin Islands is higher among whites than among blacks and Hispanics, that the incidence among blacks there is similar to that among U.S. blacks, that the seasonal incidence of Type 1 diabetes appears to differ from that indicated by registries in other places, and that an apparent infectious epidemic of Type 1 diabetes occurred on the U.S. Virgin Islands in 1984 (32).

Besides such initial results of interest, these registry data should provide baseline information on a cohort of black and Hispanic Type 1 diabetes cases that can be followed up to evaluate the cohort's morbidity and mortality experience and to identify factors responsible for greater mortality among blacks. Also, people enrolled in the registry should provide a valuable pool from which blood samples may be obtained to further evaluate relationships between certain genetic factors and the risk of Type 1 diabetes among blacks and Hispanics. Thus, the registry should prove an important source of data for future investigations into the natural history, etiology, and control of the disease in the U.S. Virgin Islands and elsewhere in the Caribbean.

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