

U.S. National Chernobyl Registry Coordinating Center

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Specific Aims

This pilot study is a first phase in a longer term project, the goal of which is to create a national coordinating center for a registry of Jewish immigrants to the United States from areas affected by the Chernobyl nuclear accident. The major purpose of the project is to (a) create a registry of all such Jewish immigrants in the State of Texas and (b) establish contacts in the other Jewish population centers around North America where Chernobyl victims have resettled. The specific aims of this pilot project are to (a) identify the targeted immigrants around the State of Texas, (b) recruit them as subjects for Consortium research studies, and (c) collect baseline medical history data and clinical measures with a sample of Jewish immigrants in Houston, Texas, so as to establish a foundation for tracking the patients in the future. Having done so, the registry would then be able to serve as a source of subjects for the Consortium investigators. This would lay the logistical groundwork for the next phase of creating a national registry, should it be justified.

Background and Significance

In the context of Chernobyl research, there are two important reasons for focusing on Jewish immigrants from the affected areas:

1. **Scientific Comparison.** Jewish emigrants from the former USSR constitute three easily identified subpopulations which will allow comparison of both (a) long vs. short term radiation exposure and (b) psychosocial and medical experiences in three very different health care systems.
2. **Sampling and Tracking.** (a) In the former republics of the USSR there still remain 1,640,600 Jews, of whom 1,360,000 (83%) reside in Russia, Ukraine, and Byelorussia. The National Conference for Soviet Jewry has maintained ties with the Jewish communities in these regions, even during the considerable political changes since Chernobyl. (b) Israel has received over 400,000 Soviet Jews, of whom approximately 100,000 (25%) are from areas affected by Chernobyl. These immigrants participate in the Israeli national health care system, and physicians from Hadassah Medical Organization have already begun to treat them. (c) Since 1986, the U.S. has received over 157,000 former Soviet Jews as documented refugees (Emigration to the United States major population centers with existing Jewish population eg, New York, Boston, Chicago, Cleveland, St. Louis, Houston, Dallas, Los Angeles, San Francisco.). In addition to these refugees, there are a yet to be determined number of Soviet Jewish immigrants who have also settled in the United States as a part of project "Exodus". Assuming a similar proportion to that in Israel, this would mean about 40,000 from Chernobyl areas. The Hebrew Immigrant Aid Society (HIAS) has been instrumental in helping to resettle these refugees and immigrants. In Houston and other Texas cities, the resettlement process is continued through the Jewish Family Service and local Jewish philanthropies. This often includes matching immigrant with American families, allowing an additional level of contact with the targeted population.

The present project is designed as a pilot/feasibility study both to collect baseline data and to address certain problems that must be overcome in order to establish a national registry in the future. In its inception, the proposed registry is in some ways more analogous to a census bureau than a registry in that we will not wait for patients to come in with illnesses in order to register them. This raises the difficulty of (a) identifying subjects, (b) locating them, and (c) convincing them to participate. In addition, given the political conditions and turmoil in the immigrants' republics of origin, it is not clear whether and to what degree they will want to be identified and tracked, albeit for scientific and medical rather than political purposes.

For these reasons, the project will utilize as liaisons existing local Jewish organizations with which the immigrants will have become familiar and which they trust, e.g., Jewish Family Service, HIAS, etc. Furthermore, by focusing on family clusters, we can use family contacts to reach other Jewish immigrants who

may not have resettled through the Jewish aid organizations, who may have moved since resettlement, or who may have emigrated to other countries. Finally, we will utilize bilingual Russian immigrants to conduct the data gathering interviews rather than depend on only mailed questionnaires.

Preliminary Studies