

Twin Registers

A progress report

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The Mendel Institute in Rome houses a Twin Register that was initiated by the senior author even before the opening of the Institute (September 1953).

The purpose of the Twin Register, originally limited to research on twin concordances as to blood glutathione levels (a subject that is still under investigation, as shown by the report presented at this Symposium by Gedda and Tatarelli), was gradually widened to cover the full horizon of twin studies.

The realization that the twin method, in its various formulations, is irreplaceable in most areas of biomedical research, led to the decision to include in the Register each and every contactable twin pair; wide use of mass media was made for recruitment purposes.

Recruitment generally occurred at very early ages, and all pairs are constantly followed. Formerly, definite zygosity determinations were obtained only for those pairs that were selected for specific research purposes. Zygosity determinations are currently being extended to all those pairs who come to the Institute's clinics, within the limits of the available budget (it should be noted that the Institute is a private foundation which provides free medical care to any twin. Lack of capital funds forces the Institute to limit its research activities to those for which grants are obtained).

The Italian National Research Council, well aware of the importance of the Twin Register as a basic tool in scientific research, has provided several grants (starting in the year 1962) for the completion of information and the transfer of coded information onto punched cards and magnetic tape. A report on this subject has been submitted by us to the Third International Congress of Human Genetics (Gedda and Milani-Comparetti, 1966).

Our Twin Register began its program of international cooperation in the year 1965, through the senior author's participation to the First Meeting of Investigators on Methodology of Twin Studies convened by the World Health Organization at Geneva, the proceedings of which were published in the Mendel Institute's Journal, *Acta Geneticae Medicae et Gemellologiae* (World Health Organization, 1966).

At present, Twin Registers may be variously classed according to several criteria, such as: (1) numerosity of twin pairs; (2) representativeness; (3) availability of

control samples; (4) numerosity and methodology of zygosity determinations; and (5) width of research purposes.

The purpose of each Register has been, in the past, the single most important factor: many specialized Registers were set up to study a limited number of pathological traits. These Registers generally afforded extensive information on each twin pair, including careful zygosity determinations. Yet, numerosity and representativeness were generally too limited to allow use of such Registers for studies not originally intended.

Other Twin Registers are much more extensive, including sometimes the entire twin population of a country or region (Scandinavian Registers deserve special mention in this class). Yet, complete assessment of zygosity and other parameters is obviously impossible in these cases.

Some blending of these two tendencies would be desirable: twin cases belonging to specialized populations (hospitals, schools, etc.) should be fully investigated and recorded as specialized groups *within* large scale Twin Registers covering large communities (city, state, country).

On the other hand, large scale Twin Registers should not be limited to the level of a list, however complete: extensive information on each pair should be actively and regularly collected and recorded. This obviously poses problems that may be solved only by public authorities, on two different levels: a level of permission and a level of financial support.

Permission would simply entail granting recognized Twin Registers the right to have access to public records (birth certificates, etc.) concerning twins in the respective area. Financial support is obviously more difficult to secure; yet, public bodies should be made to realize that only twin studies may provide the key to the solution of many problems for the advancement of science and the welfare of the entire population. In other words, Twin Registers should be considered as basic research infrastructures.

In the meantime, the many Twin Registers already in existence in many countries and in many areas of research should join efforts through some form of international cooperation, towards such purposes as standardization of zygosity determination and of sampling procedures.

References

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