LETTER TO THE EDITOR
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Organization and Establishment of DNA Banks in Biomedical Research Centers: A Report from Immunology, Asthma and Allergy Research Institute

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To the Editor:

Molecular genetics technology has been known as an invaluable tool in medical research and clinical genetics, where detecting the new genes involved in human hereditary disorders can help to perceive the exact mechanism of disease formation.[1]

In the last few years, collection of DNA samples and related data for investigation and expansion of human genetic knowledge, are increased.[2] Genetic information rely on large numbers of stored DNA samples in the Banks.[1] In 1999, the American National Bioethics Advisory Commission determined a DNA bank as a facility that stores extracted DNA, transformed cell lines, frozen blood or other tissues or biologic materials for future analysis.[2] In fact, DNA banking involves the collection, analysis and storage of genetic materials that can be used for clinical and research goals.[3] It is also a precious resource for future analysis and research projects. Clinical datasets without storage of genetic materials are incomplete[4] because the involved genes cannot be anticipated.[5]

Researches based on DNA are helpful for patients as a new way that influences diagnostic procedures and development of new therapies.[1]

Organization of the bank starting with getting of consent, the other issues that must be considered comprise of personal privacy, ethical, social and legal issues, sample collection and storage, quality control and return of benefit of research to the community.

Regarding the ethical and legal issues could help us to manage the medical genetics that result in maximum benefit and minimum harm.[6] Among ethical issues, informed consent and protection of privacy of participants are very important.[7]

For storage of genetic material in the bank, identification status, duration of storage of the samples and probability use for any research, should be defined. Quality control in all of the DNA bank setting stages should be operated from registration of participants to storage of DNA, to ensure the accuracy of the results.[8]

Iran became a member of genetic research network in Eastern Mediterranean Region in 2004. There is no definite restriction on genetic research in Iran, however, in order to respect for the ethical principles, recently, a national ethical guideline of medical research has been provided that involves genetic research.[6]

The Asthma, Allergy and Immunology Research Institute began to create a DNA bank from patients with asthma, allergy or PID (Primary immunodeficiency disorders) from all over Iran since 2006.

All of the patients with diagnosis of PID who were registered in IPIDR (Iranian Primary

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Immunodeficiency Registry) from 2006 and also patients with asthma or allergy symptoms who were referred to this institute for diagnosis and/or treatment since 2009 were included in this study. Samples of EDTA blood have been stored in this bank. Patients and/or their parents were informed about the purpose and procedures of the DNA bank project and informed consent was obtained.

DNA was isolated from samples by using high purify DNA extraction kit (Roche , Germany), then were frozen and saved in -70^0C. The quality and quantity of the DNA was evaluated by spectrophotometer using the ratio 260 to 280 nm.[9] To prevent any contamination, DNA samples were aliquoted and stored at two different sites.[10]

For quality control, the safety mechanism has been performed to provide the privacy of genetic information and long term storage of genetic materials for future analyze. Genetic testing was accomplished on coded samples, only responsible clinicians had the possibility to link between the result and patients.[10] Coding of samples was done by a third person, who would protect the code and only in certain conditions these codes were broken.[2] Without informed consent or signed permit, disclosure of genetic information to a third person or sharing of DNA samples to other institutes or any transfer from one researcher to another has not be done.[7,11]

If the participants wanted to know about the research results, the general information and when possible, the validated personal genetic results was given only to the patients or their parents[10] and disclosure of the result is done by clinician or genetic counselor to assure the accuracy of the communication of results.[2,7] Since 2006, 1500 samples from patients with PID disorders and their related families have been stored in this bank. Up to now, genetic study of 220 cases has been done (Neutropenia: 30 cases, Leukocyte adhesion deficiency (LADs): 12 cases, Wiskott–Aldrich syndromes (WAS): 15 cases, Severe combined immunodeficiency (SCID): 40 cases, CF: 16 cases, Chronic granulomatous disease (CGD): 93 cases, HLH: 11 cases, and Bruton: 3 cases). After setting up IPAR (Iranian Pediatric Asthma Registry) in 2009 and IFAR (Iranian Food Allergy Registry) in 2010, collection of DNA samples of asthma and allergic patients has been started in this bank and up to now 170 DNA samples from patients with diagnosis of asthma and/or food allergy have been saved in this bank. For future advancement of medical science four fundamental factors are required. A): complete mapping of human genome that could determine allelic variation in individuals. B): collection of clinical data of participants with follow up for treatment evaluation. C): storage of DNA and the biological materials from participants. D): advanced computer software for registry and collection of data of samples and also clinical and genetic information.[4]

In a preliminary study (March 2003-June 2005), we reported 92 DNA samples from PID patients and their related families that included CVID (9 cases), Bruton (6 cases), Ataxia-telangiectasia (5 cases), CGD (5 cases), SCID (3 cases), Hyper IgM syndromes (2 cases), and LAD-1 (1 case).[12] In 2006, by improvement of saving condition with desirable quality control and also progress in genetic facilities, DNA bank of Immunology, Asthma and Allergy Research Institute (IAARIDB) was organized. This bank facilitates the collection, cooperating of samples, several testings and repeating of the tests over years.

Parallel to the other medical progresses, advancement in genetic and molecular science leads to necessity of DNA bank creation in Iran. The Iranian Human Mutation Gene Bank,[13] is a DNA bank that has been formed by Genetic Research Center, Social and Rehabilitation Science University and reserve data and samples of mendelian hereditary genetic disorders such as IDDM, Ataxia, Albinism and etc. Also, serum and DNA bank of diabetic patients has been formed by Endocrinology & Metabolism Research Institute,[14] Tehran University of Medical Sciences. Development in genetic research results in increasing of the setting of DNA storage and related information.[2] Establishment of DNA bank of Human biologic material is growing in all over the world, such as Macedonian Human DNA bank (hDNAMKD),[15] a national registry and DNA bank of patients with congenital heart disease in the Netherlands (CONCOR)[16] in 2000 and The Council of Regional Networks for Genetic Service (CORN) in USA for storage of dried blood spot samples after newborn screening analysis,[17] and etc.

We hope that several clinical and genetic research projects in allergy, asthma and immunodeficiency fields will be accomplished by using the materials and data of IAARIDB.

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