

Directory of Human Genetic Services in India - 2007

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INTRODUCTION

On conservative estimates, more than 50 million individuals are affected with single gene (monogenic) genetic diseases in India. This number is going to swell many fold as the genetic predisposition in common diseases like diabetes, asthma, cancer, cardiovascular, and cerebrovascular diseases, etc., is being established. The total number of individuals who are at higher risk of being afflicted with a genetic disease and consequently requiring diagnosis and counseling would thus be mind boggling. The sheer number of genetically ill individuals that are being added every year in our society should make health care planners feel greatly concerned, but unfortunately, the diagnosis and management of genetic diseases in India have remained largely neglected. The provision of basic health-care facilities and control of the infectious diseases are important, but equally if not more, is the timely and precise diagnosis of genetic diseases. The treatment of infectious diseases is relatively cheaper and is of shorter duration as compared to the life-long disabilities and the expensive treatments, where available, for the genetic diseases. Due to perpetual recurring nature of the genetic diseases, their economic burden on the society is much more than the infectious diseases. The predictive genetic testing, pre-natal diagnosis and timely genetic counseling can help to prevent the recurrence of genetic diseases. The early diagnosis of many genetic diseases, coupled with timely interventional therapy, can prevent several disease-associated disabilities.

In India, there is neither a properly func-

tioning social health-care system nor there is a compulsory health insurance system that could take care of the expenses incurred by the affected individuals on any genetic service. In such a scenario, only a miniscule proportion of the population, belonging to high-income group, can think of getting any diagnostic investigations undertaken. For majority of the population, the birth of a congenitally malformed child or a genetically-ill child is the will of God. They have no option except to let such a child perish and then go in for the next unplanned pregnancy hoping the God to be merciful this time.

There is almost complete lack of awareness about genetic diseases in the general population and majority of the physicians are, unfortunately, not trained to look for the genetic diseases. However, interest of the public about genetic diseases has been kindled by the extensive media coverage that deciphering of human genome has received. There is now greater realization about the diagnosis of genetic diseases, a better understanding of the pathogenesis of such diseases, and power of predictive tests for these has been greatly enhanced. The medical personnel are now keener to know more about the genetic diseases, and also about the possibilities of their pre- and post-natal diagnosis.

The WHO has expressed great concern and stressed the need of early diagnosis, prevention and management of genetic disorders in developing countries and has proposed detailed guidelines for it. There are obvious resource limitations in the implementation of WHO guidelines in India. However, to implement these, even partially, concerted efforts need to be initiated for the development of human resources, opening of more diagnostic centers, broadening of the base for pre-natal and post-natal screening, documentation of population-specific distribution of genetic diseases, and to expand the pre- and post-marital genetic services.

Some institutes and universities have encouraged departments and research centres to

Condensed version of 'Directory of Human Genetic Services in India' by Prof. Dr. Jai Rup Singh et al. (2007). This is provided for the benefit of physicians and human geneticists to contact the various diagnostic services, if needed. The website hgsi.topcities.com is presently not functional. For further details, Prof. Dr. Jai Rup Singh may be contacted at his present address: 'jairup@gmail.com'. He is presently with the Central University of Punjab, at Bhatinda, as Vice-Chancellor – Editors

go for research in the area of human and medical genetics. A few of these provide limited diagnostic genetic services to the patients. In addition to these, there are number of institutions in India that have excellent infrastructure facilities, created through Governmental funding, and are involved in research on different aspects of human genetics, which at many times involves patient material. But, majority of these institutions do not extend their facilities for the diagnosis of genetic diseases even to these patients. There is no mandate from the Governmental funding agencies, sponsoring such patient-based research projects, to earmark a small component of these grants for genetic services including diagnostics. Without the Government's support and commitment it is not possible to have meaningful or useful genetic services in a country like India. Although the private sector is opening up to benefit from this shortage of centres, still the total number of centres that are available across the country, offering any type of genetic service, remains awfully inadequate and the information about these is not easily available.

Accreditation of the Centres that are providing genetic services is another important aspect. WHO guidelines recommend strict control for diagnostics. But in India, at the moment, there is no regulatory control over undertaking of the genetic investigations or for ascertaining the quality of investigations being undertaken by any Centre. The only regulatory mechanism that exists in respect to the Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act, 1994 and the Pre-Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Amendment Act 2002 under which the genetic clinic are required to be registered. Here, the emphasis is on the regulation of the misuse of ultrasound machines to prevent female feticide. The need is to introduce appropriate accreditation of the Centres for genetic services but before such accreditation can take place we have to identify the quantum of genetic load, the existing Centres, and the services being provided by these.

One point that is of concern is the absence of any link-up, or tie-up between different genetic centres in India. Obviously, it is impossible that each genetic centre be self sufficient for undertaking all types of genetic investigations for all genetic diseases. Therefore it is very

pertinent that there should be information sharing and some of networking between various centres so that the material for relevant genetic investigation could be quickly referred to the appropriate institute/centre.

In 1980, Prof. I.C. Verma had made the maiden effort by bringing out a Directory of Genetic Services in India. But in the present scenario, that directory is no longer useful. At this moment, there is no such Directory available from where any physician can get the authentic information about the various Centres for getting the genetic investigations undertaken. Also, at the present it is not possible for any person with a genetic disease to know about the places where he can go for getting advice or counseling or proper diagnostics. The information about the various research laboratories, that can also provide diagnostic investigations, is not available. The information is also lacking about the charges, the quality of the investigations, the qualifications or professional experience of the scientists/geneticists involved in the diagnostics. Moreover, in India, there are not many patient-support groups, or self-support groups, for genetic diseases. Those that are there are not fully coordinated to extend detailed information about the availability of the proper genetic diagnostic centres across the country or even in the respective States.

Our endeavour was to collect detailed information from various scientists and researchers engaged in the field of human genetics and make this information available to the physicians and also to the common man. So that, if any one wishes to approach or search for a proper person, in a particular area, one be able to locate a centre nearer to one's place and also be able to know as to how expensive it is going to be to get any genetic investigation undertaken.

The data that we have been able to compile is quite interesting and also very revealing. There are about 1000 members of the Indian Society of Human Genetics but just over 50 of them are actually involved in providing diagnostic or counselling services for genetic diseases. Even those who are doing it, their laboratories are not fully equipped to undertake most of the genetic investigations. There are a total of 47 centres in India that are undertaking any type of genetic diagnostic investigations, spread out in 18 States and UTs of India. Among these, the cytogenetic

investigations are being undertaken at 40 Centres; biochemical investigations at 26 Centres; molecular diagnostics at 28 places; prenatal diagnosis at 26 Centres; and genetic counselling at 40 places. Another interesting observation that emerges out of this data is about the size of the population a single Genetic Centre in India is expected to cater to. The best ratio is at Delhi, i.e. 2.3 million individuals per centre; which is more or less similar to that of the developed world countries. However, the worst scenario is for Uttar Pradesh (UP), where a single genetic centre is expected to look after the needs of 83 million individuals!

The present Directory of Human Genetic Services in India does not claim to be the comprehensive listing of all those connected with the diagnosis of genetic diseases in India, but efforts have been made to collect as much information as possible and set the ball rolling in this direction. The information included in this Directory is on the basis of the Performa that were circulated to the concerned scientist and physicians and the follow up of these. It involved several rounds of correspondence, confirmations and re-confirmations spread over a long period of time. There were only a few Centres who chose not to send the requested information in spite of repeated requests. These were thus not included. Our endeavour would be to continuously update this Directory and make it more comprehensive and ultimately expand it to include information about the neighbouring countries also. A beginning in the direction has been made by including the information available about genetic centres from Pakistan.

It is hoped that this directory would highlight the existing lacunae and the extreme shortage that exists for genetic services in India. It may prompt the Government(s) either to open up more centres devoted to the diagnostics of genetic diseases, or make it obligatory for the recipients of patient-based research projects in human genetics, to provide genetics services. The Department of Biotechnology, Govt of India and the Indian Council of Medical Research have been supporting opening of research centres and genetic clinics for the diagnostics of genetic diseases, but looking at the quantum of genetic disorders in India, these efforts need to be enhanced several times over.

This current Directory may also prompt the private sector to invest more in the genetic services.

During the compilation of the directory, continuous efforts were made to update the information from all the heads and incharges of the centres providing genetic services. However, as each centre is continuously trying to update its facilities, and initiate more investigations, it would be appropriate to get in touch with the incharge of the centre where one wishes to get the investigations done to get the latest information about the charges, etc.

We gratefully acknowledge the cooperation and encouragement that was extended by numerous colleagues working at different institutions in India. Without their sustained cooperation, it would not have been possible to complete this Directory. We also acknowledge the help extended by Mr. Parminder Singh and Mr. Gurinderjit Singh for all typing and office work associated with the preparation of this Directory. This directory has also been hosted at the website: hgsi.topcities.com for wider availability.

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