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A REPORT

BY

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ACKNOWLEGEMENT

I, Dr.Paridhi Gupta hereby declare that this INTERNSHIP ASSIGNENMENTS entitled as 1- TASK(1) 2- TASK (2), 3- TASK (3),4- TASK(4)is the outcome of my own study undertaken under the guidance of NIKITA SABHERWAL , IIHMR – New DELHI. It has not previously formed the basis for the award of any degree, diploma, or certificate of this Institute or of any other institute or university. I have duly acknowledged all the sources used by me in the preparation of this field internship report.

Date :

Sign:

Postgraduate Diploma in Hospital and Health Management

International Institute Of Health Management Research

NEW DELHI

ABBREVATIONS

NCPB – National Programmes For Control Blindness

CoE – Centre of Excellence

IDF – Intermediate Distribution Frame

NCT – National Capital Territory

ICMR – Indian Council Of Medical Research

PSUS – Public Sector Undertakings

ERT – Enzyme Replacement Therapy

Case study on HelpAge India

Services -

What is Cataract?

Cataract refers to opacification of the natural crystalline lens. It is the commonest cause of vision impairment worldwide.

- Several studies estimate 50% of those over 60 years to have cataract
- According to WHO of 38 million people who are blind, half are blind due to cataract
- In Singapore,34% of adults >=40 years of age have cataract and 0.5% are blind from cataract

Cataract can be acquired or congenital

Acquired cataract can be traumatic, associated with systemic disease or drug use such as steroid or chlorpromazine

Congenital cataract can be hereditary and developmental, metabolic or infective

Risk factors of cataract patients are: -

- Smoking
- UV radiation
- Family history
- Eye injury or inflammation
- Use of steroid medicine

Management: -

- Conservative if patient coping well with vision
- Glasses if index myopia as temporizing measure
- Surgery

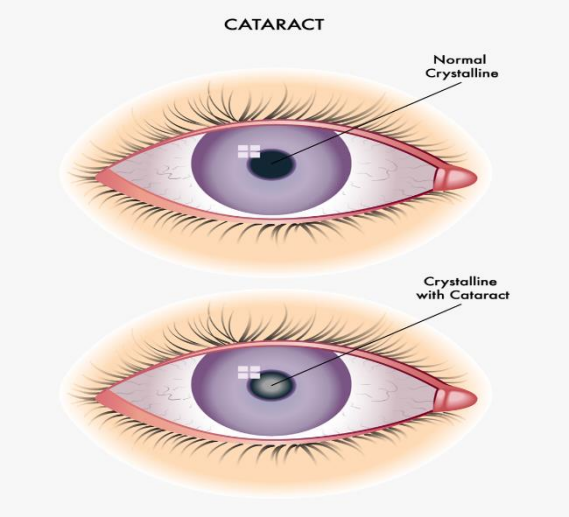

Fig.1.Difference between the Normal eye and the Cataract eye

Indian Government policies on Cataract Patients-

To screen the utilization of state allows by NGOs encouraging waterfall medical procedures for poor people, the wellbeing service presently expects patients to outfit their Aadhaar cards for getting worked.

New Delhi: To screen utilization of assets by non-administrative associations non-governmental organisations that get government awards for encouraging waterfall medical procedures for poor people, the wellbeing service has made it obligatory for patients to outfit their Aadhaar cards for getting worked. The service had questions about the exact number of patients being worked for waterfalls under the national program for control of visual deficiency (NPCB). It took the choice during an audit meeting a month geospatial admission for conditions like stoke. For patients with multiple comorbidities, please get treating with physician**.** We are looking into the NGOs that are getting award in help above Rs2 crore under NPCB program. We have requested that the concerned authorities set up a rundown of such NGOs and audit their work. The program takes into account the penniless individuals and we need to guarantee that it produces viable outcomes. Further, so as to stay away from duplication of sections of recipients for example patients in two records of treatment, Aadhaar number ought to be made fundamental for the waterfall patients being worked liberated from cost," said Dr Jagdish Prasad, chief general of wellbeing administrations (DGHS), service of wellbeing and family government assistance. The target of this training is to guarantee that the quantity of medical procedures directed is genuinely right. Further, NGOs getting assets from different hotspots for similar exercises ought to likewise be checked as they drapery this from the service," he said. The administration issues award to the NGOs based on waterfall tasks performed liberated from cost by the NGO and simply after accommodation of waterfall medical procedure records. NPCB was propelled in the year 1976 as a 100% midway supported plan with the objective to decrease the pervasiveness of visual deficiency from 1.4% to 0.3%.

HelpAge work on the cataract patient -

Waterfall is the prevailing reason for visual deficiency as it represents about 66% of the visually impaired populace (62.6%). NPCB was propelled in the year 1976 as a 100% halfway supported plan with the objective to decrease the commonness of visual impairment from 1.4% to 0.3%. Waterfall is the prevailing reason for visual impairment as it represents about 66% of the visually impaired populace (62.6%). Waterfall is one the significant reasons for visual deficiency in India. 12.5 million individuals are visually impaired and can't bear the cost of treatment. HelpAge leads in excess of 50,000 waterfall eye medical procedures in 19 states. Dependable and capable eye emergency clinics and associations complete medical procedures with HelpAge India's help. All medical procedures under the program are performed uniquely in base emergency clinics and not in make-move camps. Since 1980, this program has profited in excess of 9 lakh older folks, re-establishing their sight as well as empowering them to return to work and carry on with an existence of nobility.

COMPARATIVE STUDY OF DIABETES MELLITUS AMONG THREE DIFFERENT COUNTRIES (INDIA, CHINA, USA)

What is diabetes mellitus??

Diabetes is a disorder of pancreas. The pancreas is answerable for making the hormone insulin. Insulin helps the body with utilizing food for vitality. Diabetes utilizes the insulin erroneously or is neglect to make enough insulin. Insulin attempts to give glucose onto the cells to be pulverized as vitality. When there is a lacking degree of insulin glucose levels rise. This is considering the way that the glucose can't enter the body's phones to be consumed fuel. Diabetes is besides proposed as hyperglycemia or high glucose. It is surveyed that 6% to 17 million Americans have diabetes mellitus. Diabetes is known as sixth driving reason behind death in US.

Symptoms-

- Urination
- Fatigue
- Decreased appetite
- Unexplained weight loss
- Excessive hunger
- Extremely dry skin
- Sores
- Sudden change in vision
- Tingling or numb hands and feet
- High number of infections

Treatment –

- Maintaining normal glucose levels
- Controlling cholesterol
- Physically active
- Monitor oral medicine
- Manage weight
- Stress

Type of Diabetes

Type1 is a structure that consistently requires insulin

Type2 can be controlled through eating regimen and exercise. Anyway, extreme structures may require insulin infusions. All type1 are genetic and can't be forestalled and type 2 is a preventable malady

Which country has highest rate of diabetes mellitus?

China is the nation with the most elevated number of diabetics around the world, with around 116 million individuals experiencing the illness. Continuously 2045, it is anticipated that India will have around 134 million individuals with diabetes.[1]

Comparison between India, china & USA -

Overall commonness of diabetes evaluated at 463 million grown-ups in 20-79 age gathering; India has 77 million, while China has 116 million.

India keeps on being home to the second-biggest number of grown-ups with diabetes around the world, with the most recent information from the International Diabetes Federation (IDF) placing the rate at 77 million in the 20-79 years age gathering. This follows China, which has 116 million grown-ups with diabetes in a similar age profile. China, India and the United States had the biggest number of grown-ups with diabetes and are relied upon to remain so in 2030, says the IDF. "It is anticipated that the quantity of grown-ups with diabetes in Pakistan will surpass that in the United States of America, and it will move to third place by 2045. The nations that have the most noteworthy number of individuals with diabetes don't, obviously, fundamentally have the most noteworthy commonness," it included. India was the greatest supporter of diabetes mortality with more than 1 million surveyed passing's inferable from diabetes and related challenges, in the greater South East Asian territory, the report said.

Prevalence of India The examination coordinated during 2015-2019 by Rajendra Prasad Centre for Ophthalmic Sciences, All India Institute of Medical Sciences, New Delhi also demonstrated that the power of acknowledged diabetes cases was 8.0% and new diabetes cases was 3.8%. "Folks showed a similar transcendence of diabetes (12%) as females (11.7%).[4]

In china, Hazard Factors for the Diabetes Epidemic is-

Natural components including weight, creating, dietary model containing continuously refined food and fats, inert ways of life, inborn parts, and epigenetic changes all add to the resuscitating diabetes pandemic in China.

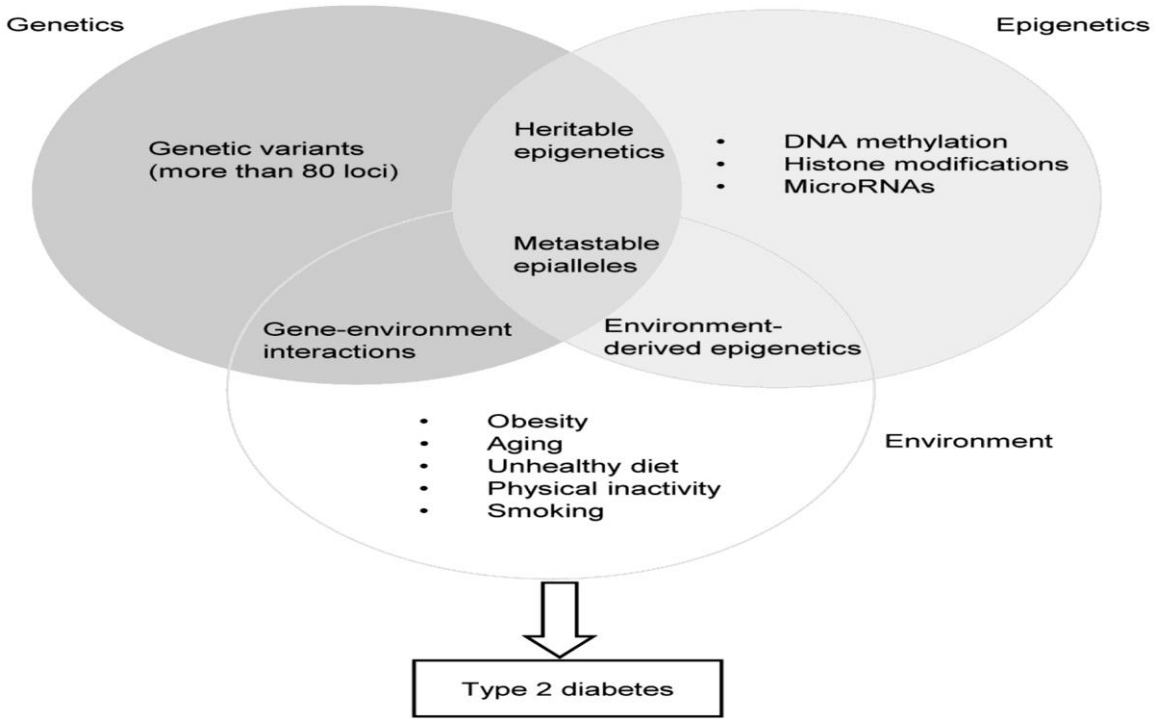

Fig.1;Factors affecting Diabetes

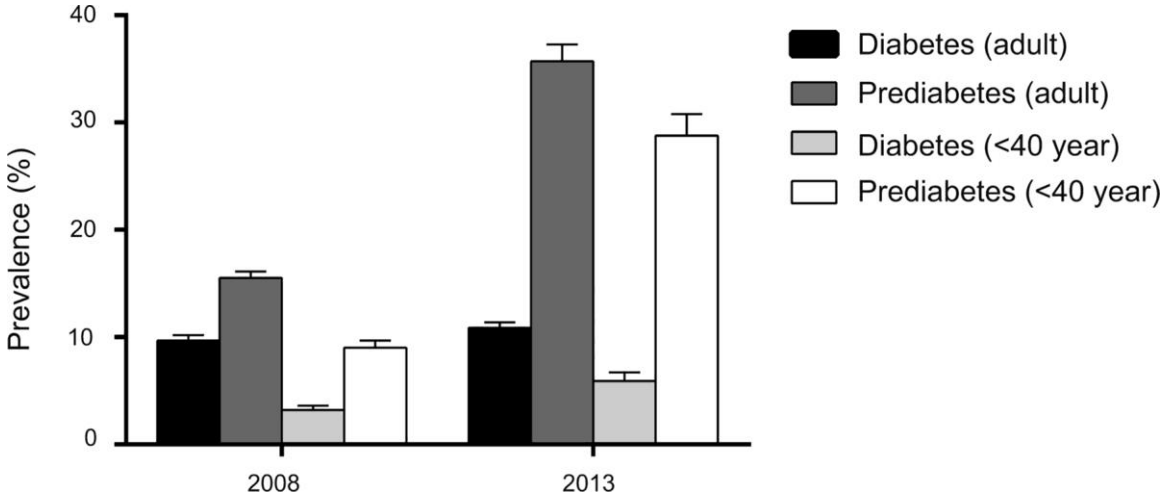

Fig.2. Charts regarding Diabetes

Predominance of diabetes and prediabetes among Chinese grown-ups or people <40 years old, as per the 2008 and 2013 across the country study. Diabetes incorporates both recently analysed and already undiscovered diabetes. Prediabetes was characterized as impeded fasting glucose or disabled glucose resilience. I bar demonstrate 95% CIs.

The predominance of diabetes was higher in the senior populace, men, urban inhabitants, people living in monetarily created territories, and overweight and corpulent people. The evaluated pervasiveness of prediabetes in 2013 was 35.7%, which was a lot higher than the gauge of 15.5% in the 2008 study. Likewise, the commonness of prediabetes was higher in the senior populace, men, and overweight and corpulent people. Be that as it may, prediabetes was more pervasive in country occupants than in urban inhabitants. As China is a multi-ethnic nation, the 2013 study additionally thought about the commonness of diabetes among various races. The unrefined commonness of diabetes was 14.7% in the larger part gathering, i.e., Chinese Han, which was higher than that in most minority ethnic gatherings, including Tibetan, Zhuang, Uyghur, and Muslim. The rough predominance of prediabetes was additionally higher

in the Chinese Han ethnic gathering. The Tibetan members had the least predominance of diabetes and prediabetes (4.3% and 31.3%). Strikingly, the predominance of diabetes in the Manchu bunch was equivalent to that in the Chinese Han gathering, and the pervasiveness of prediabetes was significantly higher. Notwithstanding, this examination did exclude all minority ethnic gatherings in China.[5]

U.S. Leads Developed Nations in Diabetes Prevalence

New and bare essential data from the new International Diabetes Federation (IDF) Diabetes Atlas, released at the present week's World Diabetes Congress in Vancouver, Canada (Nov 30-Dec 04) reveals that, clearly, the United States has the most raised inescapability (11% of the masses developed 20-79 years) of diabetes among made nations. This gathering table joins countries of the European Union notwithstanding Canada, Australia, New Zealand, Singapore, South Korea, Israel, Andorra, Norway, Switzerland, and the U.S. itself.

Likewise, in regards to appraisals of through and through amounts of people with diabetes in these nations, the U.S., with directly around 30 million people with diabetes, has around 66% the number of occurrences of the different 37 nations in the made nation class joined (46 million).

To the extent normality, Singapore finished a close by second to the U.S. (10.5%), trailed by Malta (10%), Portugal (10%), and Cyprus (9.5%) in third, fourth, and fifth spot independently. The countries with the most insignificant assessed inescapability in the 38-nation class were (least first), Lithuania, Estonia, and Ireland (all around 4%), trailed by Sweden, Luxembourg, the U.K., and Australia (all around 5%). Canada, the host nation for the World Diabetes Congress, has the twelfth most essential inescapability, at 7%. The unavoidability of type 1 and type 2 diabetes is building up the world over," says Professor Nam Cho, seat of the IDF Diabetes Atlas board. "While the particular explanation behind type1 diabetes is at present cloud, structures, for example, urbanization, undesirable eating regimens and diminished physical improvement are, all things considered, contributing way of life factors that expansion the danger of type 2 diabetes."

LITERATURE BASED REVIEW OF CHALLENGES OF RARE DISEASES

ABSTRACT

This report indicates the challenges faced in recognising the rare diseases and the treatment of that diseases both economic and medical wise. Research in rare diseases has been hampered by a number of issues, ranging from the lack of an adequate understanding of the pathophysiology and natural history to the lack of incentives to fund the development of treatment of rare diseases for small populations. It also indicates that how globally Rare diseases are define as well as Indian definition of it. Indian government has taken immediate and long-term measure to recognise it as well as its budget allocation for the manufacturing of Orphan Drug.

OBJECTIVE

- Global definition of the Rare Diseases
- Economic and Healthcare policy for the cure of rare diseases in India

1. Introduction

Rare diseases are the diseases with low pervasiveness when compared to other prevalent diseases in the common public, in other words it affects a small amount of people in the public. It is found that somewhere between 6k to 8k rare diseases exist globally. No perfect definition of rare disease exists but different countries have different norms to define rare disease. However, the commonness among them is their low prevalence, severity and existence of different therapeutic options available. Rare disease includes various types of genetic diseases, rare cancer, degrative diseases and mostly 80% of them are genetic diseases. Even though these diseases are of low prevalence and are particularly rare then also it happens to about 6-8% of the country population. Globally rare disease poses enormous challenges to health care system in various aspects such as collecting the epidemiological data, difficulty of manufacturing and developing drugs, complete with perfect and timely diagnosis, cost estimation for its long-term care and rehabilitation.

1.1. WHO – Defining Rare Diseases

WHO defines rare diseases as prevalence of 1 or less per 1000 population. USA, define rare diseases as a medical problem that affects lesser than 200,000 patients in a country whereas in European union (EU) define it as a life threating or long term weaking or draining condition affecting faced less than 5 persons in a population of 10,000.

COUNTRY	Disease Per 10,000 People
USA	6.4
Europe	5.0
Canada	5.0
Japan	4.0
South Korea	4.0
Australia	1.0

Table – Showing Different Country Criteria towards Rare Diseases

1.2.Condition of rare Diseases in India

Field of rare diseases is still to be more explored as it is heterogenous, complex and continuously evolving in nature and also have a problem of shortfall of both treatment and medical knowledge. Approximately about 450-470 rare diseases have been diagnosed in the India. Rare diseases are a huge burden to a country health care economics due to the much more health care spending as compared to the other diseases, this led to the dilemma of cost of funding for the treatment of these diseases. India is comparatively less medically developed in the terms of number of doctors available per 1000 persons, development in medical equipment and its availability across different places. India has basically 1 doctor to 1456 public and it is way more above the WHO recommendation[1].India have nearly 72 to 96 millions people suffering from rare diseases which is a very significant number as compared to other countries that's why there is much need of defining the rare diseases in India and increase its awareness which is currently lacking[2].

2. Literature Review

Rare Disease are also known as the orphan diseases and this name is given to them as no company want to adopt them to produce the drug and treatment of these diseases. In year 1983, US government passed an Orphan Drug Act which created opportunity for the company to manufacture kind of drugs. Auvin et.al wrote an article which gave a method to find approximate number of persons suffering from the rare diseases on the basis of reported incidences and also how much time it takes to diagnose of newly rare diseases and starts its treatment [3]. knight et.al provides the economic modelling for the treatment of rare diseases and strategies used by manufacturer and also the problems for the manufacturing of medicines for cure of this rare diseases [4]. Schandler et.al conducted a theoretical study on the expenditure for the drugs of rare diseases in Europe to found out its influence on the health care fund of the cure of that rare diseases [5]. Magalhaes reports the public point of view in the Alberta and Canada regarding the funding of drug for rare diseases over the common conditions and what are the reasons that drive them to take this decision [6]. Similar study was performed by Hughes et.al on the general public of UK to found out what preference they would give to the health care fund distribution [7].

2.1. Indian Policy towards the rare diseases –

Three committees were appointed by the government of NCT (National Capital Territory) of Delhi for making suggestion towards making of "National Policy on the Treatment of Rare Diseases" and the committee that were given responsibility were: -

A) Committee 1 - Professor V.K. Paul, Head of Department of Paediatrics at AIIMS, New Delhi provided a report, 'Prioritisation of Therapy for Rare Genetic Disorders'
In their report they try to evaluate the available therapy and also prioritization of the genetic disorders based on the resources, cost for the treatment of these diseases as well as the outcome and the quality of life during & after the treatment. This report was formed on the fact that 75-85% of the rare diseases are genetic in nature.

B) Committee 2 - Prof. I.C. Verma, Director of Institute of Medical Genetics Genomics at Sir Ganga Ram Hospital provided a report, 'Guidelines for Therapy and Management'
In this committee report it tries to evaluate the cost of treating such rare diseases as well as defining the rare diseases in India based on the global definition of the rare diseases. It also made recommendation in the regards that how India health care fund can be divided in order to make better economic policy for regulation of drugs and treatment of such diseases. They put forward the estimated cost for treating the rare diseases that are much prevalent than other rare diseases in India for a 10kg child.

C) Committee 3 - Dr. Deepak K Tempe, Dean of Maulana Azad Medical College (MAMC), New Delhi
In this committee report they showed about the insufficient data and untangle diagnostic. They also recommend that treatment should be in a phased and planned manner starting from the rare diseases that can be easily cured with the available therapy treatment. The policy should be continuously revised with knowledge and more lucidity about epidemiological data, decrease the cost of treatment and drugs, diagnostic and treatment options at that present time etc.

3. METHODOLOGY

Four databases PubMed/Medline, Google Scholar, Scopus, Web of science were looked through utilizing the keywords: 'Rare Diseases' AND 'Challenges in defining Rare Diseases' OR 'Awareness' OR 'comprehension' AND 'indications. Indian Report on the National Policy for the treatment of Rare Diseases 2017 under the Ministry of Health and Family Welfare was taken as the basis for writing about the Indian situation on the Rare Diseases. Writing was restricted to English language.

4. DISCUSSION

Government of India has taken various measures regarding the implementation of the National policy on the rare diseases and proper identification of theses rare diseases in short span of time.

Immediate measures – Containing an Inter-managerial Consultative Committee to energize and control the activities of various organizations and work environments on extraordinary

afflictions as spread out in this Policy Constituting a Technical cum Administrative Committee at Central comparably as State levels, for the directors of corpus assets and making specific rule/rules for - which astounding diseases to support, how much, investigation of treatment, and so on. Making a corpus support at Central and State Level for part financing treatment of wonderful infections reliant on specific standards made by the Technical cum Administrative Committee Creating a Web-based application for online application framework to get to the corpus holds Creating a patient vault for phenomenal infirmities housed in ICMR Arriving at an essentialness of exceptional pains fit to India Developing materials for conveying care in the general masses, patients and their families and therapeutic organizations suppliers. Making and driving preparing errands of social security suppliers on amazing infirmities Constituting a Rare Diseases Cell inside MoHFW, ICMR and DoP in Ministry of Chemicals and Fertilizers freely to be the 'nodal' on uncommon sicknesses in their various organizations and working environments

Long term Measure -. Set up frameworks for separating and information blend Conduct epidemiological assessments to overview ordinariness of exceptional ailments Take measures to improve innovative work for treatment, illustrative modalities, care and bolster including assistive gadgets, quiet movement for unprecedented diseases, and so on. Take measures, conclusive or something other than what's expected, for empowering neighbourhood accumulating of solutions for striking maladies Take genuine and different measures to control the costs of medications for uncommon diseases to guarantee its moderateness and flourishing structure common sense Encourage financing support from Public Sector Undertakings (PSUs) and corporate part and analysing different choices for reasonable supporting for the corpus Ensure security thought for amazing hereditary issue Allow import of Enzyme Replacement Therapies (ERTs) and expel import responsibility on them likewise as on assistive contraptions As a procedure for early assessment of phenomenal afflictions, investigate computing a game-plan for planning, and turning out testing for outstanding acquired ailments in new-conceived youngsters, couple with movement and normalization of definite modalities and accessibility of treatment Develop normalized appears for affirmation and treatment/the main gathering of exceptional illnesses, to be changed in equivalence with impelling finding and treatment scene Strengthen research office systems for finish of remarkable ailments .Accredit places for finding and treatment of unprecedented infections which could be made as Centres of Excellence (CoE) over some undefined time length, in a sorted out way

5. CONCLUSION

The study concludes that the progressive development in the treatment of rare diseases has encountered significant difficulties w.r.t acknowledging the incidences & its pervasiveness, patient reported problem and the economic costing of diseases & its treatment, health technology evaluation. Globally, In June of 2013, two groups were established under the International Society for Pharmacogenomics and Outcome Research (ISPOR), the first one provided the rare disease terms and defining it whereas the second one undertook a wide identification of problems and challenges encountered by people with rare diseases. Similar initiative was taken by the Indian government and National Policy for the treatment of Rare Diseases were formed & under that three committees were formed to provide suggestion and recommendation for the drug, treatment of diseases.

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