UMMID

Unique Methods of Management & treatment of Inherited Disorders

An Initiative of the Department of Biotechnology

Ministry of Science and Technology, Government of India

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UMMID is a new beginning to usher in the '*Era of Molecular Medicine' into*twenty-first century medicine in India. The completion of the Human Genome Project has brought new technologies and knowledge to improve medical care based on DNA-based diagnostics and better therapies based on the understanding of molecular pathogenesis. UMMID aims to create awareness about genetic disorders amongst clinicians and establish molecular diagnostics in hospitals so that the fruits of developments in medical genetics reach the patients in India. The plan of the UMMID initiative is to link the well-established centres of Medical Genetics in India to upcoming centres and to establish clinical genetics facilities in district hospitals. This will improve patient care services for genetic disorders and impart latest medical genetics education to medical students to prepare them for the era of molecular medicine.

Plan of Training and Diagnostic Services under the UMMID Initiative

UMMID plans to work at three levels of medical care which will work in close collaboration with a closelink between training and establishment of diagnostic services. The three components of UMMIDare given below.

Fellowship in Genetic Diagnostics: Hands-on training for six months will be provided to doctors working in government hospitals by eightdepartments with state-of-the-art DNA-based diagnostic services for genetic disorders. Each centre will train 4 fellows per year thus providing 96 trained doctors in genetic diagnostics during the period of 3 years.

NIDANKendras [Diagnostic Centres]: Hospitals with interested doctors, committed administrators and basic infrastructure have been selected and have been funded to establish genetic laboratories. The centres selected have medical doctors with expertise inmedical genetics and passion for the specialty. The financial support and twinning with established Medical Genetics centres will help them to develop state-of-the-art facilities in molecular diagnostics.

Prevention of Genetic Disorders in Aspirational Districts: Each of the 7 centres providing genetic training have adopted one aspirational district and will establish a program for prevention of genetic disorders including beta thalassemia and newborn screening for treatable disorders. This will be a prototype of an outreach program which will take latest genetic diagnostics to the population and lead the way to incorporate genetic services in maternal &child care. This will provide onsite training to the doctors in these district hospitals in addition to creating awareness about genetic disorders amongst the general population.

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Antenatal Screening and Prevention of Birth Defects & Genetic Disorders

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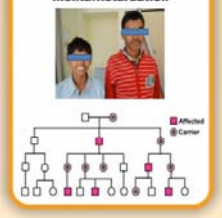
Do you need **Genetic Counseling ?**

स्वस्थ शिशु का जन्म कैसे?

Carrier Screening for Fragile X Syndrome: Commonest Cause of Familial MentalRetardation



Family History of Duchenne Muscular Dystrophy, Hemophilia

Carrier Screening for Spinal Muscular Atrophy

Newborn Screening for Deafness

- आप गर्भवती है और आपकी उम्र 35 वर्ष या अधिक है?
- आपको गर्भावस्था के समय मधुमेह है ?
- आपके गर्भावस्था के समय किये गये अल्ट्रासाउन्ड (Ultrasound) में कोई विकृति पायी गयी है?
- आपने गर्भाधारण के बाद कोई दवाई (विशेषतः मिर्गी अथवा Epilepsy के लिये) खाई है?
- आपके परिवार में पहले किसी बच्चे में जन्मजात विकृति (Malformation) पायी गयी है ? जैसे कि दिल, मस्तिष्क, हाथ, पैर, आँख या पेट की आँतों के बनावट में खराबी (e.g. Anencephaly, Congenital heart defect, Meningomyelocele, Hydrocephalus)
- आपके परिवार में अन्य जेनेटिक बीमारी है जैसे कि थैलेसीमिया, हिमोफीलिया, ड्युशेन मस्क्युलर डिस्ट्रॉफी ?
- आपके परिवार में कोई मंदबुद्धि बच्चा या मंदबुद्धि व्यक्ति है ?
- आप पति-पत्नी दोनों या कोई एक किसी जेनेटिक बीमारी का संवाहक (Carrier) है ?
- परिवार में प्रसूति के कॉम्पलीकेशन के बिना मृत शिशु (Unexplained still birth) पैदा हुआ है ?
- परिवार में एक से अधिक सदस्य एक जैसी ही बीमारी से ग्रस्त है?

यदि उपर्युक्त प्रश्नों में से किसी एक का भी उत्तर "हाँ" है, तो आज ही अपने चिकित्सक से आनुवांशिक परामर्श प्राप्त करें।

गर्भधारण की इच्छुक महिलाओं को गर्भधारण के पूर्व से ही प्रतिदिन 5 मि० ग्रा० फोलिक ऍसिड (विटामिन) की दवा का सेवन करना लाभदायक होता है।

Pre-pregnancy Thalassemia Screening

Down Syndrome Screening
Quadruple test at 15 to 17 Weeks

Malformation Scan at 18 to 20 Weeks
(Quadruple Test Includes msAFP)

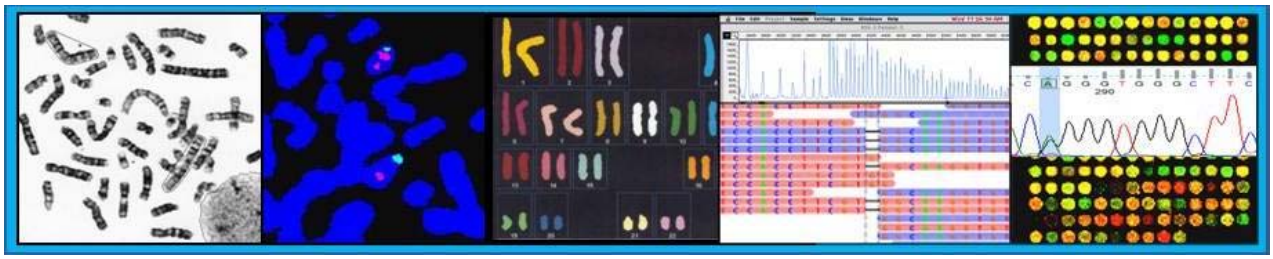
NewbornScreening From Heel Prick Blood Drops

मेडिकल जेनेटिक्स विभाग
संजय गाँधी पी० जी० आई० एम० एस० लखनऊ

Rare Disorders – Genetic Diagnostics – Prevention- Management –Health & Medicine

With control of infectious &malnutrition-related disorders, infant mortality rate in India is markedly decreasing. At this juncture, the contribution of genetic disorders to infant and childhood mortality and morbidity is increasing. Establishment of patient care services for genetic disorders is the need of the time. Though there are excellent medical genetics centres in India providing state-of-the-art patient care services to families with genetic disorders, the number of such centres is small. The Department of Biotechnology has initiated the UMMID program to establish many genetic diagnostic centres in different parts of the country. To achieve this, a combined program of training doctors in genetic diagnostics and providing funding to establish genetic diagnostic laboratories and to create awareness about genetic disorders amongst doctors and lay persons, has been meticulously planned.

All the components are integrated into one thread of serving patients and families with genetic disorders not only of tertiary care hospitals but also the population from the lower socio-economic strata from aspirational districts.



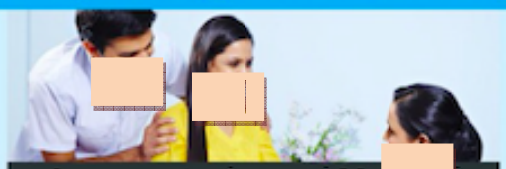
Antenatal Screening and Prevention of Birth Defects & Genetic Disorders

Aspirational Districts- DBT UMMID-"Unique methods of management of inherited disorders" Programme

are pregnant and have one or more of these

Risk factors

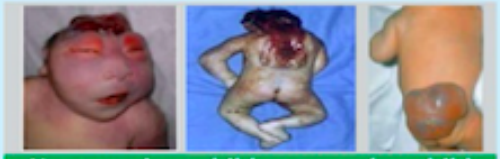
you may need genetic counseling and prenatal testing



Are you at advanced Ma[redacted]l age -35 year or more

You have diabetes or any other chronic disease

Taking anticonvulsants, anticancer medicines,blood-thinners or other unsafe medicines during this pregnancy



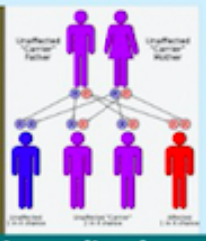
Your previous child or any other child in your family had malformations at birth

You and your husband are carriers for any genetic disease or chromosomal defect

You or your family members had one or more abortions or stillbirths

Any member in your family has Beta thalassemia, Sickle cell anemia, Haemophilia, Muscular dystrophy, Spinal muscular atrophy orany other genetic disease

Multiple members in your family are affected with similar disease



If you have any of the above risk factors ,please consult your doctor immediately and get referred to the Medical Genetics Centre for further testing and management.

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परिवार के सुख के लिये
थैलेसीमिया
से बचाव

थैलेसीमिया क्या है?

- थैलेसीमिया मेजर एक गंभीर वंशानुगत बीमारी है।
- थैलेसीमिया से पीड़ित बच्चों में जन्म से ही रक्त नहीं बनता है तथा इन्हें जीवित रहने के लिये प्रतिमाह रक्त चढ़वाना पड़ता है।
- इस बीमारी का उपचार बहुत खर्चीला एवं कठिन है।

थैलेसीमिया होने के कारण

- भारतवर्ष में 3% व्यक्ति थैलेसीमिया के संवाहक हैं।
- संवाहक स्वयं तो रोगी नही होते किन्तु उनके बच्चे थैलेसीमिया से पीड़ित हो सकते हैं।
- यदि माता पिता दोनों ही थैलेसीमिया संवाहक हों तो थैलेसीमिया मेजर से ग्रस्त शिशु के जन्म होने की संभावना 25% होती है।

थैलेसीमिया से बचाव के लिए

- गर्भधारण के पूर्व रक्त परीक्षण से यह सुनिश्चित करें कि आप थैलेसीमिया संवाहक हैं अथवा नही।
- यदि माता–पिता दोनों ही संवाहक हो तो गर्भस्थ शिशु की 10-12 सप्ताह में जाँच करके थैलेसीमिया से पीड़ित शिशु का जन्म रोका जा सकता है।
- विशेषज्ञों द्वारा यह जाँच सुविधा व सलाह अब देश के कई स्थानों पर उपलब्ध है।

करवायें थैलेसीमिया की जाँच, पायें उचित सलाह ।
भावी समाज को दिखलायें थैलेसीमिया से मुक्ति की राह ।।

अधिक जानकारी के लिये सम्पर्क करें :
मेडिकल जेनेटिक्स विभाग, संजय गांधी स्नातकोत्तर आयुर्विज्ञान संस्थान, लखनऊ।

UMMID is a new ray of hope based on systematic planning for giving the power of genomics to the doctors of the twenty-first century, for the care of patients & their families

List of Training Centres

Department of Medical Genetics, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Raibarelly Road, Lucknow, Uttar Pradesh
Division of Genetics, Department of Pediatrics,All India Institute of Medical Sciences, New Delhi
Genetics Unit, Department of Pediatrics, Maulana Azad Medical College, New Delhi
Department of Clinical Genetics, Christian Medical College,Vellore, Tamil Nadu
Centre for Genetic Studies and Research, The Madras Medical Mission, Chennai, Tamil Nadu
Diagnostics Division, Centre for DNA Fingerprinting and Diagnostics, Hyderabad, Telangana
Department of Haematology,Christian Medical College,Vellore, Tamil Nadu
ICMR-National Institute of Immunohaematology, KEM Hospital, Parel, Mumbai

List of NIDANKendras

Lady Hardinge Medical College (LHMC), Delhi
Nizam's Institute of Medical Sciences (NIMS), Hyderabad, Telangana
All India Institute of Medical Sciences (AIIMS), Jodhpur
Army Hospital Research & Referral, Delhi
Nil Ratan Sircar (NRS) Medical College and Hospital. Kolkata

List of Aspirational Districts

Name of the Mentor Institute	Aspirational District	State
LHMC, New Delhi	Mewat	Haryana
CDFD, Hyderabad	Yadgir	Karnataka
AIIMS, New Delhi	Haridwar	Uttarakhand
CMC, Vellore	Washim	Maharashtra
MAMC, New Delhi	Ranchi/ Bokaro	Jharkhand
SGPGIMS, Lucknow	Shrawasti	Uttar Pradesh
NIIH (KEM hospital campus), Mumbai	Nandurbar	Maharashtra

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परिवार के सदस्यों के लिये जानकारी पत्र

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नवजात शिशु परीक्षण योजना

नवजात शिशु को मंदबुद्धि या गंभीर बीमारी होने से
बचाव के लिये जाँच की निःशुल्क सुविधा

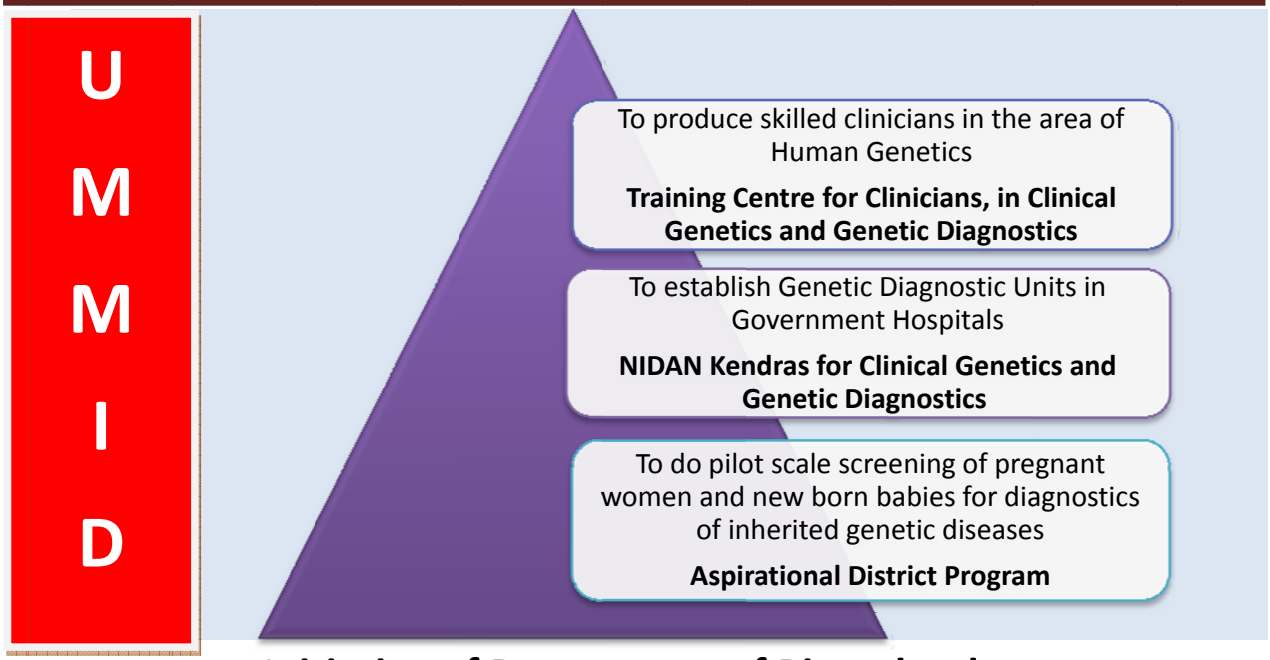
बच्चे का भविष्य आपके हाथ में है। नवजात शिशु की निम्नलिखित बीमारियों के लिये जन्म के बाद तीसरे दिन जाँच जरूर कराइये।

1. कन्जेनाईटल हाईपोथायरॉईडिज्म (Congenital hypothyroidism)
2. गैलेक्टोसीमिया (Galactosemia)
3. बायोटिनिडेज की कमी (Biotinidase Deficiency)
4. कन्जेनाईटल एड्रिनल हायपरप्लाझिया (Congenital adrenal hyperplasia)

PREVENTION IS BETTER THAN CURE

Expected Outcomes of UMMID

- *Contribute to patient care services for genetic disorders which account for 80% of rare disorders, by developing trained manpower in the cutting-edge area of genomic technologies.*
- *Establish genetic diagnostic centres in different parts of the country which will not only provide patient care services but improve the component of medical genetics training in medical education &equip medical doctors of the twenty-first century for the era of molecular medicine.*
- *Create awareness about genetic disorders amongst clinicians & laypersons, so that the patients & families get appropriate diagnosis, management & preventive services through government [Beneficiaries -70000 pregnant women & 35000 newborn babies per year]*
- *UMMID will spread the reach of diagnostic facilities for rare genetic disorders, pharmacogenetics, prenatal diagnosis & population-based screening for prevention.*
- *Establishment of genomic techniques will contribute to research into genetic aspects of rare & common genetic disorders.*



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