सत्यमेव जयते

NATIONAL RURAL HEALTH MISSION
राष्ट्रीय ग्रामीण स्वास्थ्य मिशन

RESOURCE MATERIAL

Rashtriya Bal Swasthya Karyakram (RBSK)

Child Health Screening and Early Intervention Services under NRHM

Ministry of Health & Family Welfare
Government of India

OCTOBER, 2013

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Preface

Children are central to sustainable development. As a country, we owe it to them to protect and promote their health equitably. It is well known that millions of children under five years of age in the country still do not receive the appropriate care and support to become physically healthy, mentally alert and emotionally secure. Till now there was no structured approach to child health screening and Early Intervention Services as a public health approach in the country.

Rasthriya Bal Swasthya Karyakram will reach out to new-born, preschool children and school children, a wide range of age group from 0-18 years. It will ensure not only screening but extend itself to ensure treatment and management of four D's namely Defect at birth, Disease, Deficiency and Development Delays including disabilities.

The successful implementation of this initiative has both short-term and long-term dividends. The programme would prove economical for the poor and marginalized through reduction of out-of-pocket expenditure and reduce undue pressure on health system.

The current publication is a compilation of rich technical information in form of a Resource Book. It will be valuable for trainers, block mobile teams and all personnel involved in RBSK who seek to inform themselves better on these thirty conditions under the programme.

I am confident that RBSK would turn out to be a milestone in our quest for child health and hope that States/UTs would ensure its effective implementation.

Anuradha Gupta
Additional Secretary and Mission Director
National Rural Health Mission
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New Delhi

Prologue

Out of our country's annual birth cohort of about 26 million, it is estimated that about 1.7 million children are born with Defects at birth, accounting for almost 10% of the total new-born deaths and 4% of the under-five mortality in the country. Children also suffer from a variety of Deficiencies. Nearly 47% of all children are malnourished, 43% underweight, and 20% wasted including eight million severely acute malnourished children. Besides Defects at birth, Deficiencies and Diseases, Developmental Delays including disabilities afflict as many as 10% of our child population which ultimately impacts the pace of economic growth of the country. However, if detected in time, such disabilities can be managed and the children can be groomed with adequate medical support to lead a normal life. Such a scenario is a matter of concern with the need for urgent and effective action.

This calls for an effective programme of action which recognises that Defects at birth, Deficiencies, Diseases and Development Delays are interlinked through many complex pathways. Their management can be best secured through the concerted efforts of experts working as a team.

It is in this context that Government of India, Ministry of Health and Family Welfare has launched Rasthtriya Bal Swasthya Karyakram. The programme envisages screening of new-borns for Defects at birth at public health facilities at the time of delivery and by ASHAs during post-natal visits in the community. The block health team will then cover the spectrum of children ranging from 6 weeks to 18 years of age at Anganwadi centres and in Government and Government – aided schools. Screening and referral will mark the beginning of appropriate management of 30 identified health problems through District Early Intervention Centres (DEIC) and recognised higher centres.

Efficient implementation of this programme is the joint responsibility of the Centre and State Governments. I am sure that the resource material compiled here will be utilised appropriately by key resource persons and trainers to enhance the capacities of the block level teams.

I wish them all great success in their endeavour of securing better health-care of our children. I also pledge my wholehearted support to the implementation of this key initiative.

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List of Abbreviations

AWC	Anganwadi Center
AWW	Anganwadi Worker
ANM	Auxillary Nurse Midwife
ASHA	Accredited Social Health Activist
ASO	Anti-Streptolysin O titre
CHC	Community Health Center
CHD	Congenital Heart Disease
CTEV	Congenital Talipes EquinoVarus
DDH	Developmental Dysplasia of the Hip
DEIC	District Early Intervention Center
DH	District Hospital
DLHS	District Level Household Survey
ESR	Erythrocyte Sedimentation Rate
FBNC	Facility Based Newborn Care
F-IMNCI	Facility Based Integrated Management of Neonatal and Childhood Illness
FRU	First Referral Unit
G6PD	Glucose 6 Phosphate Dehydrogenase
HBNC	Home Based Newborn Care
IAP	India Academy of Pediatrics
IEC	Information Education and Communication
IFA	Iron Folic Acid
IMNCI	Integrated Management of Neonatal and Childhood Illnesses
IMR	Infant Mortality Rate
JSSK	Janani Shishu Suraksha Karyakram
JSY	Janani SurakshaYojana
LBW	Low Birth Weight
MHT	Mobile Health Team
MDG	Millennium Development Goal
MOHFW	Ministry of Health and Family Welfare

NBCC	Newborn Care Corner
NBSU	Newborn Stabilization Unit
RBSK	RashtriyaBal Swasthya Karyakram
NFHS	National Family Health Survey
NIPI	Norway India Partnership Initiative
NMR	Neonatal Mortality Rate
NNF	National Neonatology Forum
NRC	Nutrition Rehabilitation Center
NRHM	National Rural Health Mission
NSSK	Navjaat Shishu Suraksha Karyakram
OPD	Out Patient Department
ORS	Oral Rehydration Solution
PHC	Primary Health Center
PIP	Programme Implementation Plan
PNC	Post Natal Check-up
RCH II	Reproductive and Child Health Programme Phase II
RF	Rheumatic Fever
RHD	Rheumatic Heart Disease
ROP	Retinopathy of Prematurity
RSBY	Rashtriya Swasthya Bima Yojana
SAM	Severe Acute Malnutrition
SDH	Sub District Hospital
SNCU	Special Newborn Care Unit
SRS	Sample Registration System
TOT	Training of Trainers
UNICEF	United Nations Children Fund
VHND	Village Health and Nutrition Day
VHSNC	Village Health Sanitation and Nutrition Committee
WHO	World Health Organization

Table of Contents

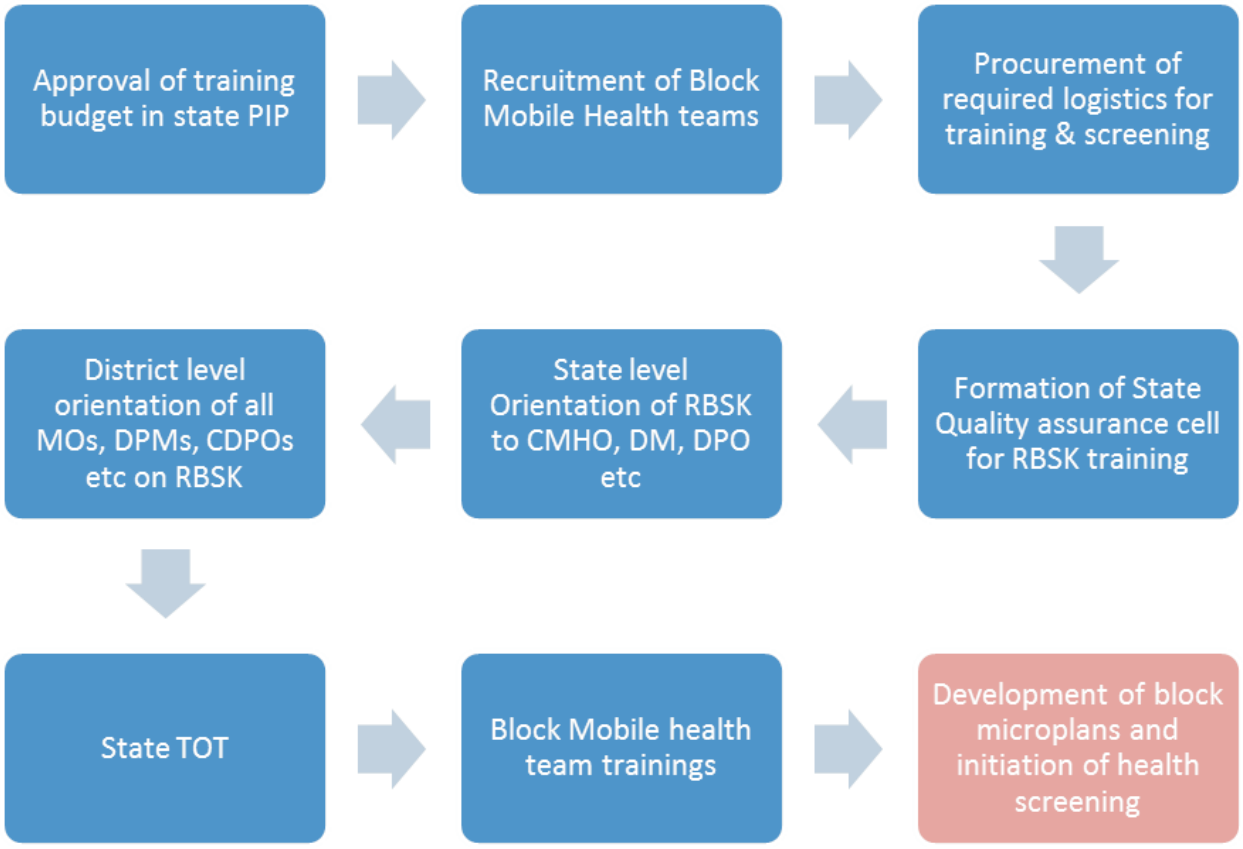
Preparation for Training Programme under Rashtriya Bal Swasthya Karyakram (RBSK)

A cascade training programme under RBSK with State/ District and Block level training is envisaged. Objective of the training programme is to build capacity of the Trainers with the goal of training Mobile Health Teams (MHT). The aim is to standardize the training of MHTs across States and Districts.

Duration: 38 hours (5 days) training (Estimated)

Type: Residential training – This training is to be made a residential training whereby, the trainees should be staying at night in the same city/town selected as the training venue for the entire duration of the training. Accommodation for the participants should be arranged by the State Nodal Officer-RBSK.

Schematic Diagram for step wise roll out of RBSK training process



Trainees: 30 per batch

Venue: preferably located at State/Division/District headquarter with:

- Adequate & comfortable seating capacity
- Arrangements for LCD projection
- Adequate space for role plays & demonstrations
- Power backup facility (by generator)

Training methodology: Participatory, with trainees given opportunity of discussion, sharing ideas & experiences.

The key modes of training used will be:

Method	Approach
Lecture & Discussion	Participatory, using PowerPoint presentation & Training guidelines of RBSK. Each day will begin with the recapitulation of the previous day/days and will end with summary of the current day
Skill practice	Relevant skill demonstration by the facilitator followed by practice on mannequin/real subject by each trainee
Role play	To be done by the participants to simulate an actual scenario decided by the facilitator/suggested in the training agenda, which will be followed by discussions on Strengths & Weaknesses
Field visit	Participants to be divided into two groups, each group led by a facilitator will visit an Anganwadi center to learn how to organize the screening camp and practice skills required for child health screening

Session Plan

Topic	Methodology	Time
Day 1		
Registration, Welcome remarks, Introduction of participants		60 Min
Introduction to RBSK, Mobile Health Teams- Roles and Responsibilities	• Power-point presentation • Discussion	45 min
Tea Break		
Methodology of screening: Look (pictorial tools), Ask (questionnaire) and Perform (clinical exam), Age specific health conditions	• Discussion	20 min
Anthropometry exercises: Head circumference, Weight & Height/Length, Identification of SAM	• Demonstration of skills by facilitators • Practice of skills by trainees	60 min
Lunch		
Basic Genetics	• Presentation	20 min
Neural tube defect	• Photographs • Discussion	15 min
Down syndrome	• Photographs • Discussion	15 min
Cleft lip and palate	• Photographs • Discussion	10 min
Club foot	• Photographs • Discussion	10 min
Tea break		
Developmental Dysplasia of Hip	• Photographs • Demonstration of testing technique • Discussion	15 min
Congenital Cataract	• Photographs • Demonstration of testing technique • Discussion	15 min
Congenital Heart Diseases	• Photographs • Demonstration of testing technique • Discussion	20 min
Summarize what to look, what to ask, what to perform	Discussion	40 min
Wrap up of day one	Discussion	15 min

Day 2		
Topic	**Methodology**	**Time**
Recap of day one	Discussion	15 min
Questionnaire on deficiencies		10 min
Anaemia especially Severe anaemia	• Photographs • Demonstration of testing technique • Discussion	20 min
Vitamin A deficiency (Bitot spot)	• Photographs • Demonstration of testing technique • Discussion	10 min
Tea Break		
Vitamin D Deficiency (Rickets)	• Photographs • Discussion	10 min
Goitre	• Photographs • Discussion	15 min
Questionnaire on Childhood diseases		10 min
Skin infections	• Photographs • Discussion	20 min
Otitis Media	• Demonstration of testing technique • Discussion	20min
Rheumatic Heart Disease	• Photographs • Demonstration of testing technique • Discussion	20 min
Reactive Airway Disease	• Photographs • Demonstration of testing technique • Discussion	20 min
Dental Conditions	• Photographs • Discussion	20 min
Convulsive disorders	• Discussion	20 min
Summarize what has been learnt	• Discussion	45 min
Lunch		
Questionnaire on Developmental delays and Disabilities & Discussion on True and False		20 min
Child Development		
– Definition, Process and Characteristics:	• Participants/ Self Reading one following the other	20 min
– Stages of child hood	• Facilitator/Power point only picture ask participants to contribute in labeling and then conclude	10 min

– Areas of brain and function	• Facilitator/Power point, only picture Ask participants to contribute in labeling. At the end discuss on the practical utility of this information	10 min
Tea Break		
Pattern of child development and characteristics	• Participants/ Self Reading Facilitator/Demonstration with doll by the facilitator :	30 minutes
Introduction to Developmental mile stones	• Power point	10 minutes
Domains of mile stones	• Power point	15 minutes
Wrap up of Day 2		

Day 3

Topic	Methodology	Time
Recap of Day two	Discussion	15 min
Normal mile stones	• Chart and Description	20 min
Developmental delay: Transient, persistent, focal and global delay	• Discussion	15 min
Gross Motor and Fine Motor Delay	• Discussion	15 min
Neuro-Motor Impairment	• Discussion	15 min
Vision Impairment	• Discussion	15 min
Hearing impairment and language delay	• Discussion	15 min
Cognition Delay	• Discussion	15 min
Tea Break		
Autism (More than 18 month)	• Discussion and Video	15 min
Learning Disability(6yrs-9yrs in school)	• Discussion	15 min
Attention deficit Disorder(ADD)/ Attention deficit Hyperactivity Disorder (ADHD)	• Discussion	15 min
Activity	Divide Participants in 4 groups, ask them to call out - 1,2,3,4. Ask participants to assemble according to number and assign age groups 1) birth to 6 months, 2) 6 months to 12 months 3) 12-18 months and 4) 18-24 months. Ask participants to discuss within group and present to the group, with the doll Facilitator / conclusion with video clippings	45 min
How common is disability in childhood?	• Ask participants to open the Hand out (page #) / power point	10 minutes
Lunch		
Practise on Checklist and Job Aid (0 to 6 years of age)	Exercise	90 min

Tea break		
Planning and conducting screening camp	Role Play	30 min
Planning & Orientation for field visit	Discussion	30 min
Summarize and wrap up day three	Discussion	15 min

Day 4

Topic	Methodology	Time
Field Visit to AWC	Field Visit	270 min
Lunch		
Feedback from Field Visit	Discussion	60 min
Discussion on Checklist and Job Aid (0 to 6 years)	Discussion	60 min
Tea break		
Discussion on Questionnaire on 4Ds and Spotting Exercise		20 min
Wrap Up day four	Discussion	15 min

Day 5

Topic	Methodology	Time
Recap of day four	Discussion	15 min
Adolescent Health	Discussion and Activity	90 min
Tea break		
Practice on Checklist 6 to 18 years of age	• Activity	45 min
Micro-planning for organization of screening camp	• Power-point presentation • Discussion	30 min
Reporting formats	• Power-point presentation • Discussion	60 min
Lunch		
Review mechanism/MIS	Data Entry, Validation, Format Filling Exercise	120 min
Tea Break		
Feedback of the Training Program		20 min
Concluding Remarks		

Logistics required for Training programme

(To be arranged before training is started)

Item	Quantity
Technical materials	
Printed copies of Operational Guidelines and Training Manual	One set for each participant and the respective facilitators
Formats for exercise: Child Health Screening Card, Mobile Health Team register, Monthly reporting format, Micro-planning format	Adequate numbers
Tools & Equipment's for demonstration	
Head circumference tape	2
MUAC tape	2
Ear Speculum	2
Hammer	2
Stethoscope	2
Weighing scale (for adult & infant)	1 for adult & 1 for infant
Infantometer	1
Stadiometer	1
Mannequin (newborn/ infant)	1
Torch (appropriate size for eye examination)	2
Surgical Gloves	At least 5 pairs
Red ring (diameter 2"-3")	2
Rattle	2
Picture book (with 1 picture per page)	2
Bell (Pooja bell)	2
Crayons (wax)	1 packet
1 inch cubes	10 pieces
Tea Cup	2
Pencil	2
Beads or Raisins (Kismis)	Few
Bowl and lawn tennis ball	2 sets
Training logistics	
Pen, Writing pad	1 set per participant
LCD Projector	1
Laptop or PC	1
White board	1
Markers	3of different colors
Flipchart	1
Posters, Banners	At least 1 set
Travel	
Vehicles for field visit to Anganwadi center	As per batch size

Micro planning for RBSK mobile team visits

"If you are failing to plan…you are planning to fail"

Need: To make a comprehensive micro plan for visits by RBSK mobile team

Outline/ objectives;

1. Ensure all stakeholders and team members are identified.
2. Ensure all villages and public/ public aided schools are covered for visits by mobile teams.
3. Prepare mobile team visit plan with route charts for day-wise visits.
4. Prepare a Block plan/Urban area Plan to help logistics management and reporting system.
5. Share micro plan with other departments to ensure coordination and timely communication.

Unit of micro planning:

The block will be the unit of micro planning for the RBSK mobile team.

The in charge MO of the Block will take lead in the micro planning process for RBSK mobile team visits. He will be supported by members of the mobile team and local health staff (including those in the PHCs) in making the micro plan.

In case of urban area, the district chief Medical officer will designate a nodal hospital/ dispensary with a key-in-charge staff for overseeing the activities and preparing micro plans related to RBSK.

Steps in micro plan preparation

1. Ensure all stakeholders, team members and local volunteers/ mobilizers are identified.

This is the first step in the micro planning process is to identify the local stakeholders related to the RBSK program. While the health department is the lead agency, it will also have to take the help of the Education department, ICDS department and local Panchayati raj institutions.

Procure the names and contact details of the following persons in the local area:

a. **Education department:** Name of Block education Officer and his contact details (address, mobile number, office landline number). If a regular block education officer is not posted, procure the name and contact details of the person-in-charge of the public schools and education activity in the block/ urban area.

b. **ICDS department:** Name of local ICDS officer with contact details (address, mobile number, office landline number).

c. In each block three or more mobile RBSK teams must be constituted.

d. All members of the RBSK m obile team must be identified and their names will feature in the micro plan. Their designation and contact details must also be written.

e. Each team will have a separate micro plan.

f. The prescribed micro plan format is to be used to enter all relevant information related to the mobile team constitution and visits.

2. Ensure all villages, hamlets, urban areas are included in the comprehensive planning for RBSK team visit

This is the next step in the micro planning process is to identify all villages/ urban areas to be visited as well as the schools and Anganwadi centers situated in the village/ urban area.

The following activities are to be undertaken:

a. List out all villages within a PHC/ Block using multiple sources (e.g Routine Immunization micro plan, block panchayat and village list, urban municipality list)

b. Collect information about public/ public aided schools from the local office/ officer of the Education department and Aganwadi centers (ICDS centers) from the ICDS department.

c. List out all the schools and ICDS centers

d. Procure a map of the block/ urban area, mark out the ICDS centers and schools in the map (use different symbols or colours)

e. For small hamlets/ areas of residence of migratory populations (like brick kilns, mines, construction sites etc.) tag these to the larger close by villages which have ICDS Kendra / public school. In case of tagging, ensure a specific social mobilizer is allocated these villages/ areas, and is responsible for ensuring that all beneficiaries are identified contacted before the RBSK team's scheduled visit.

f. For each village, ICDS Kendra and school prepare a list of contact persons, volunteers and social mobilizers who will assist the team in informing the public and helping during the mobile team visit.

   i. For schools it will be important to have the name and contact details of the principal or headmaster as well as a nodal teacher for assisting in RBSK activities.

   ii. For Aganwadi centers the name and contact details of all ICDS workers must be compiled.

   iii. For all villages, the names and contact of ASHA workers and local ANMs must also be compiled.

   iv. Names and contact details of PRI members are also important and need to be compiled.

g. For each school and ICDS Kendra, the information about the number of children who are to be screened must also be collected. The number of boys, girls and total number of children must be separately collected and compiled.

h. The ICDS code for the Aganwadi centers also needs to be noted.

i. For the school the details of school code, category, and standards in the school involved in RBSK screening as well as the school contact number needs to be noted in the micro plan.

3. Prepare mobile team visit plan with route charts for day-wise visits.

a. Each mobile RBSK team needs to make their own micro plan for the visit schedules to Aganwadi centers and schools.

b. The route chart is to be made in the prescribed format used for micro planning.

c. Route charts for visit by the mobile team needs to be made for 6 working days in a week.

d. Holidays, Sundays and important public festivals are to be earmarked so that mobile team visits are not planned on these days.

e. Depending on the number of mobile teams constituted in a block, the block area is to be divided amongst them. E.g. if there are three mobile teams then the block area must be divided into three areas. The area among the teams must be rationally divided considering factors like terrain, travel time and distance to be covered.

f. For each team the allotted villages and areas allotted must be covered at least once in every six months for Aganwadi centers and once a year for the schools.

g. The teams must make a day wise visit schedule to cover all the Aganwadi centers and schools in their areas.

h. Care must be taken to get local information about condition of roads, accessibility to villages on certain seasons and the need for use of other means of transport for difficult areas (like hilly terrain, river crossings etc.) while making a six monthly or annual visit schedule.

i. The advance plan needs to be prepared for an entire year for each RBSK mobile team.

4. Prepare a Block plan/ Urban area Plan to help logistics management and reporting system.

a. As the block/ designated nodal hospital for urban areas is the focal point for planning and managing of RBSK activities; the block must also have its own plan.

b. The block plan will have a plan with information related to various management aspects like:

i. Allocation of vehicles and POL needed for each RBSK mobile team

ii. Logistics and supplies for each mobile team

iii. Reporting formats, screening tools

iv. Communication and coordination activities and

v. Supervision and monitoring activities.

c. The block should also have a system in place to compile all the reports submitted by the mobile teams.

d. The block should also have an emergency or alternate plan in case there are any last moment problems and emergencies. The contact number of key persons (such as the Block Medical officer and the Block Program manager) who will manage the problems should they arise should be made available to all mobile teams.

5. Share micro plan with other departments to ensure coordination and timely communication.

a. Once the micro plan is prepared in the set format, it needs to be shared with all stakeholders like the mobile team members, Education department, ICDS department and also the ASHAs, Health workers and PRI members of the block/ urban area.

b. As the micro plan is prepared once a year, it will be helpful to remind the concerned teams, ASHAs, Health workers and community representatives about the scheduled visits at the beginning of each month and if possible each week.

c. The team leader of each mobile team should personally call the concerned school authorities, Anganwadi worker and ASHA of the village which is scheduled to be visited at least a week before and two days before the actual visit. This will help in ensuring that all preparations are made and the children are informed about the mobile teams visit.

d. In case of any changes in the micro plan or rescheduling of visits, all concerned persons must be notified.

Field Visit to Anganwadi Center (AWC)

Planning

Field visit to Anganwadi Centre is integral to the training programme. This is to put in practice the skills, in the field, which are acquired in the class room training sessions. It will also help in further clarification of doubts of the participants and give them a feel of the actual field scenario. Planning of the field visit to the AWC should be done prior to start of the training. Preparatory steps include:

Selection of AWC

The number of AWC to be visited will depend upon the batch size. The group size for field visit to an AWC should not be more than 15/AWC. The distance from training venue to AWC should be considered keeping in mind the travel time and training schedule of day 4.

Meeting with DPO and CDPO:

A meeting of BMHO & CDPO of the concerned block should be organized at least 10 days before the start of the training and include briefing about the training plans. AWW of the concerned AWC is to be intimated, well in advance, to facilitate the process by inviting mothers' children to attend the AWC on the scheduled day.

Visit to oversee preparation at selected AWCs

Selected AWCs are to be visited by the Nodal Officer RBSK/Programme Officer along with concerned CDPO, two days prior to the start of the training to :

- Familiarize with the center, concerned AWW, ASHA. Village Pramukh/Sarpanch may be contacted, if required;
- Ensure logistic arrangement;
- Discuss activities for, the day of, field visit planned with AWW & ASHA, like purpose of the field visit, time schedule of the visit, roles & responsibilities of AWW/ASHA during the field visit, mobilization of at least 10 children from 6 weeks to 6 years of age etc.

Logistic arrangement, for Vehicles, for trainees movement, are to be facilitated, accordingly.

Orientation of trainees

The orientation on the field visit is scheduled on the 3rd Day. Discussion would include time of starting the visit; place of gathering, objectives of the visit, activities during the visit etc Facilitators to ensure that each group is carrying required equipment and adequate number of formats.

Starting the field visit

All participants should gather at the preagreed place and time. The facilitators should visit along with the trainees, as guides and observers.

Demonstration of child health screening camp

At the AWC, the facilitator should divide the group into four sub groups: for ex: if there are 15 trainees, four sub groups A, B, C, D. All 4 subgroups will be seated separately in the AWC. First A & B will do anthropometric measurements and C & D to screen children and record observations in the appropriate questionnaire. The teams should reverse tasks after examination of 2-3 children. The facilitator will supervise all the groups, without any bias . If a child is identified with any of the 4Ds the facilitator will advise appropriate management or referral.

Completing the demonstration

After all the children assembled in the AWC have been examined, it is important to thank the families of the children, AWW & ASHA. The facilitator will ensure the demonstration is completed timely so that the team/s could reach back, to the venue, before lunch.

Discussion of the field visit

During the post lunch, feedback session, the participants should share their experience/s of the field visit and discuss the learning's made. Observations by the trainers and trainees self-observation, along with the filled in questionnaire are to be used during discussion. The facilitator should resolve all related queries and also request the trainees for any suggestions to improve the quality of field visit for future trainings.

Steps to be followed to ensure quality of trainings for RBSK

1. Before the State level training is initiated, team members from National RBSK team would conduct a one day orientation/ briefing at the State level. This has been found to be effective and made training 'meaningful'. The audience should be the Mission Director NRHM, Principal Secretary, Health (if available) and State Nodal Officer – RBSK, describing the components of the programme, roll out steps of RBSK and more importantly they should be regarding training participants, venue and logistics arrangements.
2. It is imperative to recruit of the block MHTs before commencement of the training.
3. The following steps are important to ensure that only committed trainees attend the training in full strength and spirit so as to achieve the aim of imparting quality training through a standardized process . This would then ensure uniform quality of screening across State/ District.
    - Develop a list of Master Trainers, well in advance (at least 4 weeks). Experience as trainers in other trainings may be one criterion for selection.

- Maintain a pool of trained Master Trainers at State/Divisional/District level for cascade training under RBSK, re-training reinforcement and follow-up capacity maintenance. Involvement in training process involves an opportunity cost for the institution of trainees. This is specifically important for selecting the State level master-trainers. The period in which the mastertrainers are involved in training, they should be relieved from his/her regular duties. MasterTrainers have to ensure that their line supervisor(s) are informed about the same. It is thus important to get commitment of the master-trainers to devote time for further training.
- Involve trainers from training institutions (SIHFW and SHSRC) to bring additional training methodology to encourage improved participations and learning methods.
- Inappropriate selection of MasterTrainers would lead to a wastage of resources on training of such Master-Ttrainers who may not be available for future training programs. Partial and inadequate training of mobile health team and or complete absence of trained trainers would delay the training of mobile health teams.
- The following matrix is to be used to collate the information to maintain a matrix of trained people. A line list of Master-Trainers is to be maintained. This may also be required to select trainees, to begin with a web enabled system may keep the information for future reference.

S. no.	Name	Total no. of Years of experience	Place of posting	Previous trainings received/ imparted (Type of training, Year)	Remarks (Date of training), Interested to become State/ District Facilitator (Y/ N)	No of District TOT conducted	No of training sessions attended as observer	Contact details (Mobile, Email, Address)
1								
2								

- Ensure that the trainees are communicated (at least a week) in advance to attend the training (for logistic arrangement, approval to leave station etc.). For this residential training, training venue or nearby lodging facility is to be arranged

4. Training venue:

- Identify appropriate training facility with required logistic arrangements of training. Formal training venues may draw more attention of the trainees.
- This is a residential training of five days thus, lodging arrangement for trainees for a period of 6-7 days (as required) is part of the training arrangement.
- Existing training venues SIHFW, SHSRC, ANMTCs or other centers already identified to conduct trainings may be identified. However environmental conditions and logistic requirements may also be kept in mind.

- Training logistics such as LCD projector, power backup with proper sound system, to be arranged.

5. A checklist for preparedness of training is to be filled, before the commencement of the training. Training calendar, is to be prepared accordingly and shared with national RBSK unit. States/UTs need to share monthly, physical progress of trainings (planned/ held) and line list of facilitators and also maintain the line list of MHTs trained during the process. This update is to be shared with National RBSK unit.

6. National RBSK Unit would maintain a States/UT wise database for training against the State-wise list of facilitators trained, to conduct such trainings.

7. Capacity building is a continuous process to ensure quality of the output of RBSK programme. State/ UTs to plan for the following:

    - Feedback & observations of supervisor and/or facilitators visits to MHTs for quality of screening. Observations to be used for handholding and on site capacity building;
    - Plan for re-orientation, especially based on monthly reports and comparison with estimated number of cases to re-in-force screening questions;
    - Quarterly progress of trainings (physical/ financial achievement);
    - Concurrent training evaluation and follow-up evaluations of skills imparted in the training and re-training;

Quality Assurance - Block Mobile Health Teams Training

State RBSK cell or task force should constitute a Quality Assurance team at State/Divisional/ District level or direct, already existing, State Quality Assurance team to ensure quality of trainings. This team will be responsible for hand holding and monitoring of Mobile Health team trainings and sharing training report/s with the state & district team/s for prompt mid-course correction, to ensure quality. The formation of the quality assurance team should be undertaken before the start of State TOT on RBSK and efforts should be made to monitor training of each batch.

It is important for the quality assurance teams to be oriented on identification of issues in Block Mobile Health team trainings through the monitoring checklist. It is also recommended that state quality assurance team attend the 5 day TOT at State/Divisional level, to familiarize themselves with the training process.

State RBSK cell/task force should also ensure that there is minimum gap between Master-trainer TOT and conducting training of MHT as the concepts are fresh and will help to apply the teaching methodologies and concepts more efficiently, in the training. This is specifically important for large States.

Training schedule of MHTs is to be prepared, well in advance, at the State level and is to be shared with the Divisions/District so that concerned Programme officers and Master-trainers can ensure necessary arrangements and provide information to the concerned participants.

Key practices to ensure quality during the training:

- Ensure adherence to the training agenda;
- Adherence to the methodologies mentioned for each session;
- Field visit to AWC, as envisaged in the training session plan;
- CMHO visit to the training venue to assess the quality, motivate the trainers and take the feedback from trainees;
- Visit of Quality Assurance team and feedback on trainings for mid-course correction, if any;
- Major Issues and Corrective Measures undertaken need to be shared with National RBSK Unit;

Introduction-Rashtriya Bal Swasthya Karyakram:

Comprehensive child health care implies assurance of extensive health services for all children, from birth to 18 years of age, for a set of health conditions. These conditions are Diseases, Deficiencies, Disability and Developmental delays - 4 Ds. Universal screening would lead to early detection of medical conditions, timely intervention, ultimately leading to a reduction in mortality, morbidity and life-long disability.

Under National Rural Health Mission, significant progress has been made in reducing, mortality in children over the last seven years (2005-12). Whereas, there is an escalation of reducing child mortality there is also a dire need to improve survival outcome. This would be reached by early detection and management of conditions that were not addressed, comprehensively, in the past.

1.1 Why screening of 0 to 18 years age group:

According to March of Dimes (2006), out of every 100 babies born in this country, annually, 6 to 7 have a birth defect. This would translate to around 17 lakh birth defects, annually, in the country and accounts for 9.6% of all the newborn deaths. Various nutritional deficiencies affecting the pre-school children range from 4 per cent to 70 per cent. Developmental delays are common in early childhood affecting at least 10 percent of the children. These delays, if not intervened timely, may lead to permanent disabilities including cognitive, hearing or vision impairment. Also, there are a group of diseases common in children viz. dental caries, rheumatic heart disease, reactive airways diseases etc. Early detection and management of diseases including, deficiencies bring added value in preventing these conditions, to progress to their more severe and debilitating form and thereby reducing hospitalization and improving implementation of Right to Education.

Rashtriya Bal Swasthya Karyakram (RBSK) is a screening program aiming at early identification and early intervention for children, from birth to 18 years. It is important to note that the 0-6 years age group will be specifically managed at DEIC level while for 6-18 years age group, management of conditions will be done through existing public health facilities. DEIC will act as referral linkages for both the age groups.

First level of screening is to be done at all delivery points through existing Medical Officers, Staff Nurses and ANMs. After 48 hours of birth and till 6 weeks, the screening of newborns will be done by ASHA, at home, as a part of HBNC package.

Outreach screening will be done by dedicated mobile block level teams for the period of 6 weeks to 6 years at anganwadi centres and for children in the age group of 6-18 years, at school.

Once the child is screened and referred, from any of these points of identification, it would be ensured that the necessary treatment/intervention is delivered at zero cost to the family.

The action points with respect to primary screening levels for the select health condition under RBSK is shown at Annexure I.

1.2 Target age group

The services aim to cover children of 0-6 years of age, in rural areas and urban slums, in addition, to children enrolled in classes 1st to 12th in Government and Government aided Schools. It is expected that these services will reach about 27 crore children, in a phased manner. The broad category of age group and estimated beneficiary is, as shown, below in the table. The children have been grouped into three categories owing to the fact that different sets of tools would be used and also different sets of conditions could be prioritized.

Target-group under Child Health Screening and Intervention Service Categories

Categories	Age Group	Estimated Coverage
Babies born at public health facilities and home	Birth to 6 weeks	2 crore
Pre-school children in rural areas and urban slum[1]	6 weeks to 6 years	8 crore
School children enrolled in class 1st to 12th in government and government aided schools[2]	6 yrs to 18 yrs	17 crore

1.3 Magnitude of select health conditions and select health centres

Table: Disease Prevalence based on existing evidence

Disease	Prevalence in country	Source of the data
Anaemia	70% in children, less than 5 years in age	National Family Health Survey – 3 (NFHS-3), 2005-06
Iodine Deficiency Disorder	12-20 %	Pandav CS, Malik A, Anand K and Kamarkar MG: Prevalence of Iodine deficiency disorders among school children of Delhi. Natll Med J India 1997 10(3):112-4.
Vitamin D deficiency	3-4 % for clinical rickets	Kochupillai N. Prevalence and Potential significance of Vitamin deficiency in Asian Indians. Indian J Med Res; 2008: 229-238
Protein energy malnutrition	30- 40 %	National Family Health Survey – 3 (NFHS-3), 2005-06
Clinical Vitamin A deficiency	Prevalence of Bitot's spot is 0.7 % in preschool	National Nutrition Monitoring Bureau (NNMB). 1979-2006. NNMB Reports. National Institute of Nutrition, Hyderabad
Rheumatic Heart Diseases	1.5 per 1000 in school children in the age group 5 to 9 years and 0.13 to 1.1 per 1000 in the age group of 10 to 14 years	Tandon R., Krishna Kumar R. Rheumatic fever & rheumatic heart disease: The last 50 years. Indian J Med Res. 2013 April; 137(4): 643–658

[1]Source: CEA released Sep 2012

[2](Data Sources: Elementary education in India, 2012, DISE 2010-11: Flash Statistics, NUEPA & DSEL, MoHRD, GOI. and State Report Cards: 2010-11 Secondary education in India, NUEPA)

Disease	Prevalence in country	Source of the data
Reactive airway disease	The mean prevalence was 7.24 ± SD 5.42. The median prevalence was 4.75%	Pal S: Prevalence of Bronchial asthma In Indian children. Indian Journal of community medicine ;2009 (6) :310-315
Reactive airway disease	*Urban 16.6 % and *rural 5.7 %	*Paramesh H. Epidemiology of bronchial asthma in India. Indian J Pediatric 2002; 69: 309-12.
Dental carries	50-60 % among pre-school	T S, Kumar B S, .Prevalence, Severity and Associated Factors of Dental Caries in 3-6 Year Old Children. J Clin Diagn Res. 2013 Aug; 7(8): 1789-1792.
Scabies	Point prevalence in India is about 5%	Kanwar A.J. Three Common Dermatological Disorders in children (Scabies,Pediculosis and Dermatophytoses). Indian Paedatics 2001; 38:995-1008
Pyoderma	Overall frequency of Pyoderma in children is 25.5 %	Kharel C.Pandey SS. Socioecnomic and Nutritional status of children with Pyodermas. Nepal Journal of Dermatology, Venereology & Leprology; 2012; 10: 11-15
Otitis media	8.60%	Sophia A, Isaac R, Rebekah G, Brahmadathan K, Risk factors for otitis media among preschool, rural Indian children.Int J Pediatr Otorhinolaryngol. 2010 Jun; 74(6): 677-83.
Convulsions	Prevalence of Pediatric epilepsy from 0.8 % to 0.35%. However 4% to 10% of children suffering at least one seizure in the first 16 years of life. The incidence is highest in children younger than 3 years of age, with a decreasing frequency in older children	Gadgil P, Vrajesh U. Pediatric epilepsy: The Indian experience. Pediatr Neurosci. 2011 October; 6(Suppl1): S126–S129. Ghazala Q:Seizures in Children. Pediatr Clin N Am 53 (2006) 257– 277
Defects at Birth rate per 10,000 Live Births: 64.3 infants per 1000 live births are born annually with birth defects. Of these 7.9 have Cardiovascular defect, 4.7 have NTD, 1.2 some form of Haemoglobinopathies, 1.6 have Down Syndrome and 2.4 has G6PD deficiency:March of Dimes Report, 2006		
Neural tube defect	Overall birth prevalence of 4.1 per 1000 (41/10,000). Pockets of high prevalence in South, 11.4/1000 births	Burton H, Kar A. Systematic review of birth prevalence of neural tube defects in India.Birth Defects Res A Clin Mol Teratol. 2013 Jul; 97(7): 437-43. Kukarni M L, Mathew M .The range of neural tube defects in southern India. Archives of Disease in Childhood, 1989, 64, 201-204
Down syndrome	1.09 per 1000 live births	Verma et al. Cytogenetic studies in Down Syndrome. Indian Pediatrics .1998, (28) 991-995.

Disease	Prevalence in country	Source of the data
Cleft Lip +CP	Cleft lip ± Cleft palate 0.93 for every 1000 live births. Cleft palate alone 0.17 for every 1000 live births.	Mossey P, Julian L. Addressing the challenges of cleft lip and palate research in India. Indian J Plast Surg. 2009 October; 42(Suppl): S9–S18. Reddy G Srinivas. Incidence of cleft Lip and palate in the state of Andhra Pradesh, Indian J Plast Surg.2010 Jul-Dec;43(2): 184–189.
Talipes (club foot)	The incidence of clubfoot is 1-2 in every 1000 live birth.	Communication from CURE International India Trust (CIIT)
Developmental dysplasia of the hip	One in 1,000 children is born with a dislocated hip, and 10 in 1,000 may have hip subluxation. (No Indian data)	Tredwell SJ. Neonatal screening for hip joint instability. Its clinical and economic relevance. Clin Orthop Relat Res. 1992; 63–8
Congenital heart diseases	Incidence is 8-10 per 1000 live births	Saxena A. Congenital Heart disease in India: A Status Report. Indian J Pediatr 2005; 72 (7): 595-598
Congenital Deafness	Incidence of congenital hearing loss in India reported 5.6 to 10 per 1000 live birth.	Report of the collaborative study on prevalence and etiology of hearing impairment. New Delhi. ICMR department of Science, 1983.16. Nagapoornima P, Rames A, Srilakshmi, Rao S, Patricia PL, Gore M et al. universal hearing screening. Indian J Pediatr 2007; 74: 545-549
Congenital cataract	The prevalence of cataract in children has been estimated between 1-15/10,000 children	Johar SR, Savalia NK, Vasavada AR, Gupta PD. Epidemiology based etiological study of pediatric cataract in western India. Indian J Med Sci. 2004 Mar; 58(3): 115-21.
Retinopathy of maturity	The incidence of ROP in neonatal intensive care is around 20-22%, and one third of them required Laser to prevent vision loss	Chaudhuri S, Patwardhan V. Retinopathy of Prematurity in a Tertiary Care Center –Incidence, Risk Factors and Outcome. INDIAN PEDIATRICS 219 VOLUME 46,MARCH 17, 2009
Congenital Hypothyroidism	Incidence at 1: 2500 to 1: 2800	Desai M P. Disorders of thyroid gland in India. Indian J Pediatr. 1997; 64: 11-20
Sickle cell anemia	Sickle cell gene is found amongst different tribal groups of India from 5-34 %	Prevalence of HbS In India ICMR 2002
Beta Thalassemia	Trait is 3 to 4 % in various parts of India	Madan et al, 2010

Disease	Prevalence in country	Source of the data
*__Developmental disabilities:__ 10 % of children below the age of 6 have developmental delay and **2.5% have developmental disability. As per the survey done by Inclen trust: Neurodevelopmental disorders for 2-9 years in India are 14.79% (Rural 18.11%, Urban 12,75%, Tribal 4.965, Hills 4.96%) **Nair MKC. An Anganwadi based survey, 1998 *Nair MKC. Simplified developmental assessment. Indian Pediatr 1991; 28: 837-840. *C. A. Boyle, P. Decoufle, and M. Yeargin-Allsopp, "Prevalence and Health Impact of Developmental Disabilities in 2000 cases annually at every block U.S. Children," Pediatrics, Mar. 1994 93(3): 399–403.		
Hearing Impairment	5.4 % in children less than 10 years	**As per the survey done by Inclen trust**
Vision Impairment	*Prevalence of undetected vision problems in preschool children is estimated to be 5-10 % *3% have amblyopia (Developed between infancy – 7 years) *2-4% have strabismus	As per American Academy of Pediatrics: Recommendation for preventive pediatric health care. Pediatrics 2000; 105:645-646
Neuro-motor Impairment	2 %	**As per the survey done by Inclen trust**
Speech and language delay	Combined speech and language delay reported prevalence rates ranging from 5% to 8%, and studies of language delay from 2.3 to 19 %.	*Cochrane review summarized prevalence data on speech delay, language delay, and combined delay in preschool and school-aged children*
Autism	1.41%	**As per the survey done by Inclen trust**
Cognitive impairment	4.79 %	**As per the survey done by Inclen trust**
Convulsion	Prevalence of Pediatric epilepsy from 0.8 % to 0.35%. However 4% to 10% of children suffering at least one seizure in the first 16 years of life. The incidence is highest in children younger than 3 years of age, with a decreasing frequency in older children	Gadgil P, Vrajesh U. Pediatric epilepsy: The Indian experience. Pediatr Neurosci. 2011 October; 6(Suppl1): S126–S129. Ghazala Q: Seizures in Children.Pediatr Clin N Am 53 (2006) 257– 277

1.4 Health conditions to be screened

Child Health Screening and Early Intervention Services under RBSK envisages to cover 30 selected health conditions for screening, early detection and free management. States and UTs may also include diseases namely Hypothyroidism, Sickle cell anaemia and Beta Thalassemia based on epidemiological situation and availability of testing and specialized support facilities within State and UTs.

Selected Health Conditions for Child Health Screening and Early Intervention Services	
Defects at Birth 1. Neural tube defect 2. Down's Syndrome 3. Cleft Lip & Palate / Cleft palate alone# 4. Talipes (club foot) 5. Developmental dysplasia of the hip 6. Congenital cataract 7. Congenital deafness 8. Congenital heart diseases 9. Retinopathy of Prematurity	**Deficiencies** 10. Anaemia especially Severe anaemia 11. Vitamin A deficiency (Bitot spot) 12. Vitamin D Deficiency, (Rickets) 13. Severe Acute Malnutrition 14. Goitre
Child hood Diseases 15. Skin conditions (Scabies, fungal infection and Eczema) 16. Otitis Media 17. Rheumatic heart disease 18. Reactive airway disease 19. Dental conditions 20. Convulsive disorders	**Developmental delays and Disabilities** 21. Vision Impairment 22. Hearing Impairment 23. Neuro-motor Impairment 24. Motor delay 25. Cognitive delay 26. Language delay 27. Behavior disorder (Autism) 28. Learning disorder 29. Attention deficit hyperactivity disorder
30. Congenital Hypothyroidism, Sickle cell anemia, Beta thalassemia (Optional)	

Mechanisms for screening at Community & Facility level:

Child screening under RBSK is at two levels -- community level and facility level. While facility based new born screening,at public health facilities like PHCs / CHCs/ DH, will be by existing health manpower like Medical Officers, Staff Nurses & ANMs, the community level screening will be conducted by the Mobile health teams at Anganwadi Centres and Government and Government aided Schools.

Screening at Community level:
Screening at Anganwadi Centre:

All pre-school children below 6 years of age would be screened by Mobile Block Health teams for deficiencies, diseases, developmental delays including disability at the Anganwadi centre at least twice a year. The tool for screening for 0-6 years is supported by pictorial, job aids specifically for developmental delays. For developmental delays children would be screened

using age specific tools specific and those suspected would be referred to DEIC for further management.

Screening at Schools-Government and Government aided:

School children age 6 to 18 years would be screened by Mobile Health teams for deficiencies, diseases, developmental delays including disability, adolescent health at the local schools at least once a year. The tool used is questionnaire(preferably translated to local or regional language)and clinical examination.

Composition of mobile health team:

The mobile health team will consist of four members- two Doctors (AYUSH) one male and onefemale, at least with a bachelor degree from an approved institution, one ANM/Staff Nurse and one Pharmacist with proficiency in computer for data management.

Suggested Composition of Mobile Health Team		
S.No.	**Member**	**Number**
1	Medical officers (AYUSH) -1male and 1 female at least with a Bachelor degree from an approved institution	2
2	ANM/Staff Nurse	1
3	Pharmacist* with proficiency in computer for data management	1
**In case a Pharmacist is not available, other paramedics –LabTechnician or Ophthalmic Assistant Assistantwith proficiencyin computerfordata managementmaybe considered.*		

Steps in Planning RBSK screening at Anganwadi centers and Schools:

1. The teams are required to develop sub-block level plan for the villages assigned to each team. The plan is to be based on the mapping of institutions (School and Anganwadis) and enrolment in them. The planning will be day-wise & month-wise considering local, public holidays, exams and vacations in the school. On an average approximately125children will be screened in a day.

2. Nodal persons from both education and ICDS should be involved in planning.

3. The schedule of visits would be communicated to the school, Anganwadi Centres, ASHAs, relevant authorities, students, parents and PRIs well in advance so that required preparations can be made. Anganwadi Centres and school authorities should arrange for prior communication with parents and motivate them to participate in the process.

4. To facilitate this process, MHTs may follow the planning framework, movement plan, logistic support received from state or district and necessary supplies. These planning frame works are to be used by local teams to develop the monthly plans under supervision of the Block MO. Advance information of visit schedule would be shared with School and Anganwadi system.

Roles and responsibilities of Mobile Health Team: As a collective effort:

1. Prepare a calendar of visit schedule in consultation with other team members and by involving representatives from WCD and Education departments.
2. Conduct screening at the level of Anganwadi centre and at Government and Government aided schools.
3. Conduct anthropometry measurements of children and help in filling health card and entry in registers.
4. Keep inventory of drugs.
5. Quality referrals and emphasizing the importance of early screening and timely intervention to the parents.
6. Generate monthly reports and update Mobile Health Team registers.

Preparation of Anganwadi centers and Schools for Health checkups:

1. As per action plan the team should reach the site well before time.
2. There should be a display board outside the Anganwadi center and Schools mentioning the time and date of checkup.
3. For Anganwadi centre a checkup list of beneficiaries between 0 to 3 years and 3 to 6 years age group should be available with Anganwadi Workers and ASHAs.
4. Necessary instrument and equipment should be present as per the prescribed list .

Methodology to be used for screening process: The following methodology is to be used:

1. **LOOK- Pictorial Job Aid** - A simple photograph of a newborn born/child with any visible birth defect/abnormality is to be shown. Such tools will be used by MHT and ASHA for easy identification of health conditions.
2. **ASK- Questionnaire tool in the form of Checklist for 0-6 and 6-18 years age group**-A simple questionnaire tool is to be used for identification of deficiencies, diseases, developmental delays including disability. These are age-specific and disease appropriate, for easy identification of the selected health conditions.
3. **PERFORM- Clinical examination/ Simple tests to confirm the condition**-Basic tests can be used for identification of deficiencies and diseases e.g. swelling in the neck for goitre, prick test etc

Anthropometry Procedures

All children will be weighed and measured according to protocol of measurement.

PROCEDURES AND PRECAUTIONS BEFORE MEASURING

1. **Trained People required** – ensure that only people trained in anthropometric measurement take and note measurement.

2. **Age Assessment**

   Before you measure, determine the child's age. If the child is less than two years, measure length (that is, with the child lying down). If the child is two years of age or older, measure height(that is, with the child standing up). If accurate age is not possible to obtain, measure length if the child is less than 85cm or is unable to stand.

3. **Weigh and Measure One Child at a Time**. Then proceed with the next child. DO NOT weigh and measure all the children together. Otherwise, measurements may get recorded in the wrong columns and questionnaire.

4. **Control the Child**

   Youmust hold and control the child so the child will not trip or fall. Never leave a child alone with a piece of equipment.

5. **Explaining the process to caregiver and** to a limited extent, the child, to help minimize possible resistance, fears or discomfort they may feel. Remember, young children are often un-cooperative; they tend to cry, scream, kick and sometimes bite. If a child is under severe stress and is crying excessively, try to calm the child or handover the child to the parent before proceeding with the measuring.

Do not weigh or measure a child if:

1. The parent refuses.
2. The child is too sick or distressed.
3. The child is physically deformed which will interfere with or give an incorrect measurement.

6. **Recording Measurements and Being Careful**

   When you are not using a pen, place it in your equipment pack or on the questionnaire so that neither the child nor you will get hurt due to carelessness. Make sure you do not have long fingernails. Remove interfering rings and watches before you weigh and measure.

7. **Strive for Improvement**

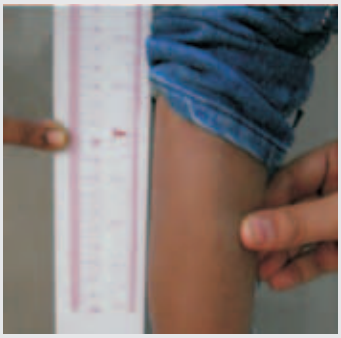
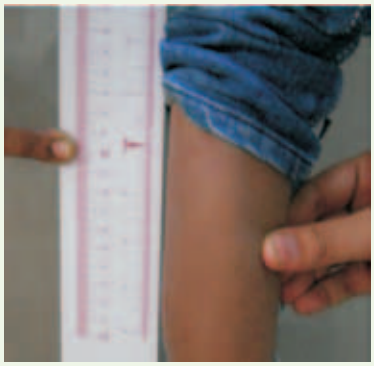
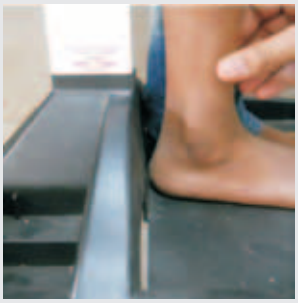
   One can be an expert measurer if one strives for improvement and follows every step of every procedure the same way everytime.The quality and speed of measurements will

improve with practice. Do not take these procedures for granted even though they may seem simple and repetitious. It is easy to make errors when one is not careful. Do not omit any steps.

Illustrating CHILD Standing measurement procedure

- Place the measuring board on a hard, flat surface against a wall, table, tree or staircase. Make sure the measuring board is stable. Many walls and floors are not at perfect right angles; if necessary, place small rocks underneath the height board to stabilize it during the measurement.
- Ask the parent or the child to take off the child's shoes and to unbraid or push aside any hair that would interfere with the height measurement. Ask the parent to bring the child to the measuring board and to kneel in front of the child so that the child look forward at the parent.
- Place the questionnaire and pen on the ground (Arrow1) and kneel on the right side of the child (Arrow2).
- Place the child's knees and feet in the correct position

Step 1	Step 2
	
Check that the Stadiometer on Flat horizontal surface	Counsel the Mother & Child giving complete information for what is to be done. Greet the child.
Step 3	
Remove from Head to Toe. 1. Hair Band, Hair Clip, Head Caps, Scarfs and Ornaments 2. Set Curly Hairs in Special cases. 3. Shoes/Footwear	
Step 4	
Ensure	Don't
	
Back of head touching to vertical surface of stadiometer	Confirm the **Frankfurt** Horizontal **plane** and make sure that **head touches** the stadiometer

Step 5	
	
Ensure for **Shoulder Blades** Touching Stadiometer	Reconfirm that **SHOULDER** touches the stadiometer after confirming the Frankfurt plane
Step 6	
	
Ensure **Buttocks** touching stadiometer	Reconfirm that buttocks touching the stadiometer after confirming the Frankfurt plane.
Step 7	
	
Ensure **Calves** touching the stadiometer	
Step 8	
	
Heels touching the vertical base of Flat base board	Reconfirm that **heels** touches the stadiometer after confirming the Frankfurt Horizontal plane

Step 9

Frankfurt's Horizontal plane - Eye **outer canthus** to upper border of **ear**. (Imaginary line)

Confirm the **Frankfurt plane** and make sure that **head touches** the stadiometer

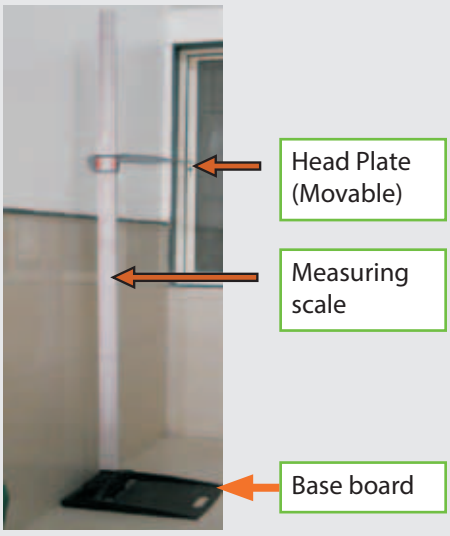
Step 10

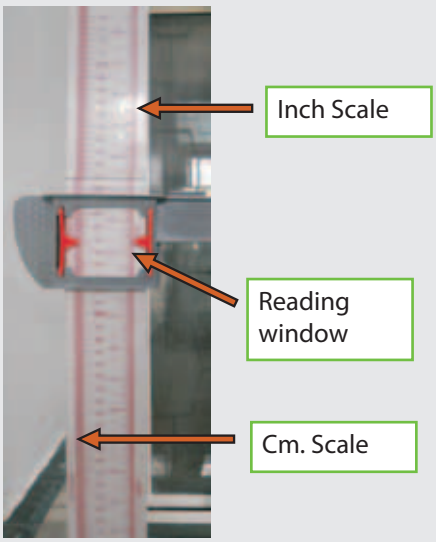
Angle of 45 degree

Position of feet

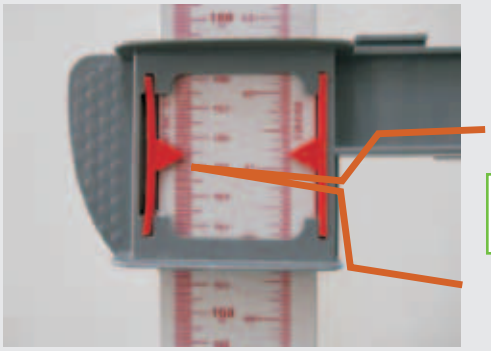
Correct procedure of both Partners in Measurement

Scale of Measurement



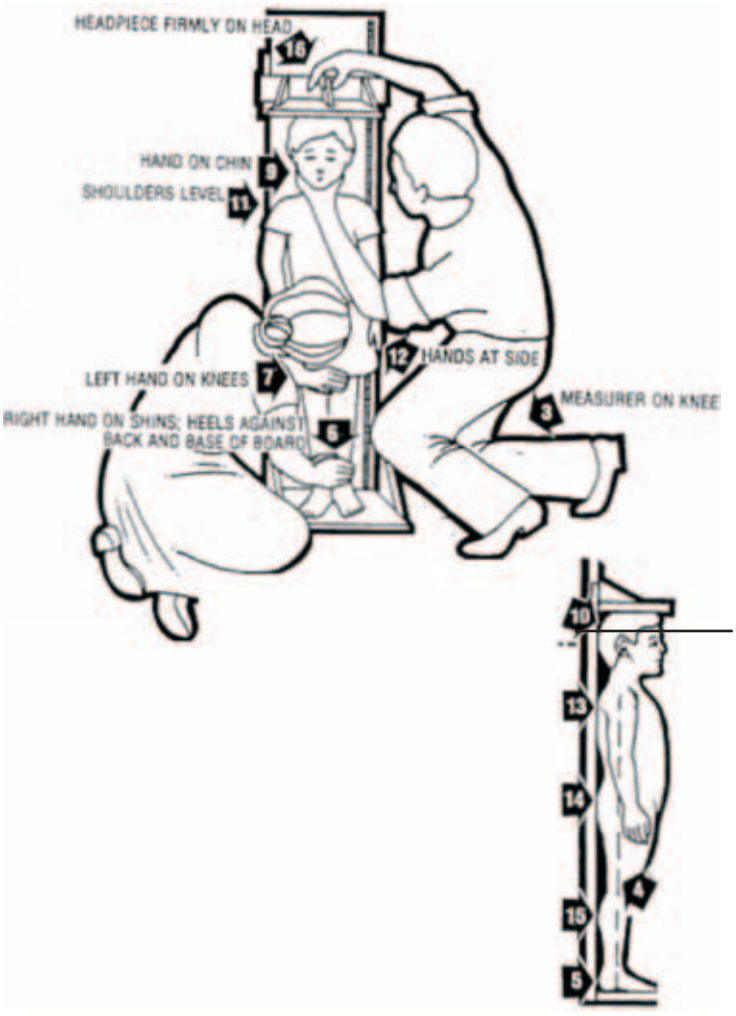


Movable Window on both sides of vertical scale



- Ask the child to look straight ahead. Make sure the child's line of sight is parallel to the ground (Arrow8). Note that with most pre-school-age children who are not heavy or obese, the back of the head will touch the back of the height scale(Arrow10). Make sure the child's shoulders are level (Arrow11), the hands are at the child's side(Arrow12), and the child's buttocks touch the back of the measuring scale. Note that with most preschool-age children who are not heavy or obese, the back of the head, the shoulder blades, the buttocks, the calves and heels will touch the back of the measuring board (Arrows10, 13, 14, 15 & 5).
- Check the position of the child (Arrows1-15). Repeat any steps as necessary.
- When the child's position is correct, lower the head piece on top of the child's head (Arrow16) making sure to push through the child's hair.
- Read and call out the measurement to the nearest 0.1 cm. Remove the head piece from the child's head, your left hand from the child's chin, and allow the child to return to the parent.
- Immediately record the measurement on the questionnaire. Check the recorded measurement on the questionnaire for accuracy and legibility. Correct any errors.

Illustration child Height Measurement

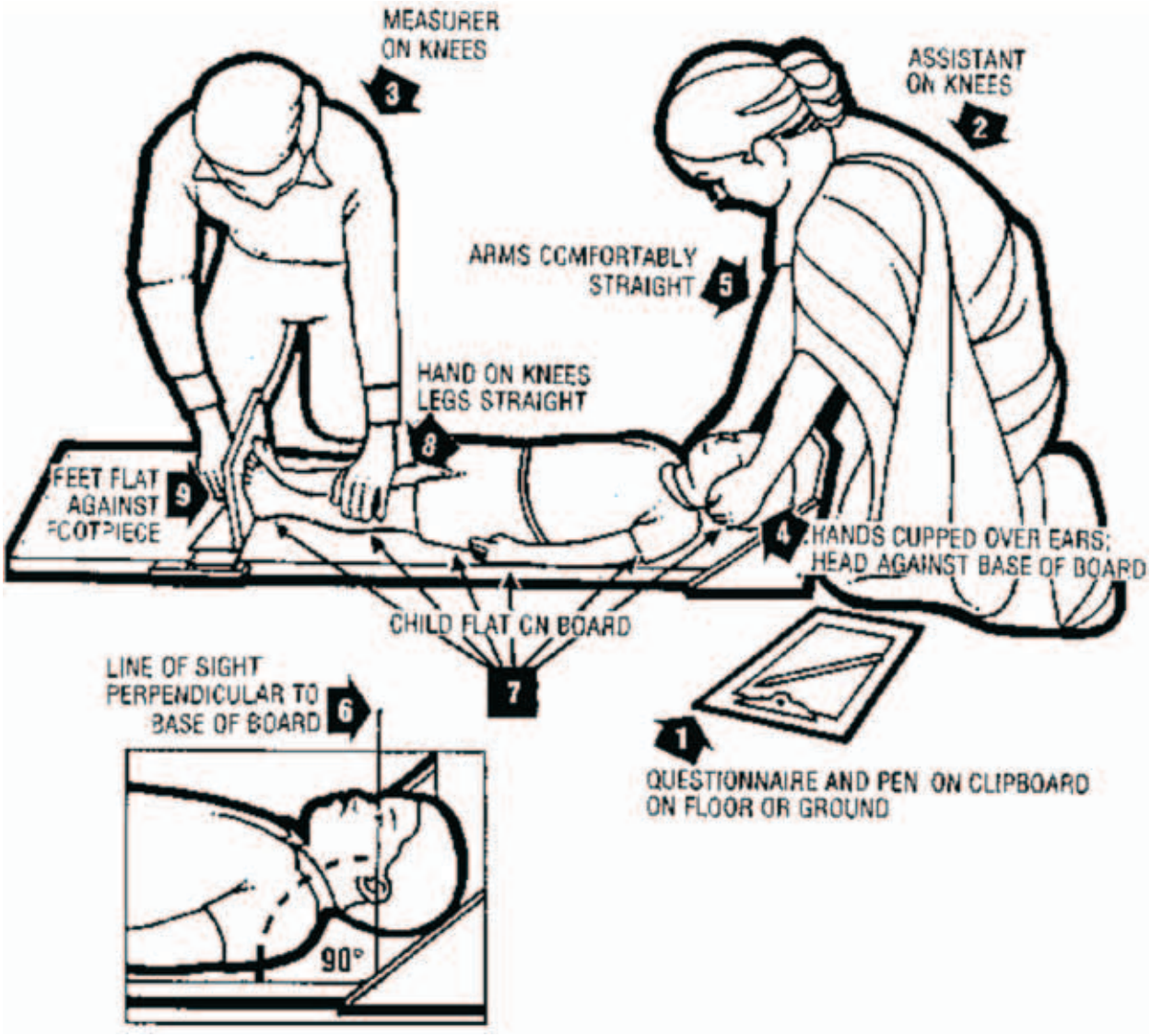


CHILD LENGTH MEASUREMENT PROCEDURE (ILLUSTRATION)

- Place the length board on a hard, flat surface, such as the ground, floor or a solid table. Make sure the measuring board is stable.
- Kneel at the right side of the child (at the child's feet) so that you can move the foot piece with your right hand (Arrow3).
- With the help of the parent, gently lower the child on to the measuring board, making sure child is supported at the trunk of the body and head.
- Cup your hands over the child's ears (Arrow4). With your arms straight (Arrow5), place the child's head against the base of the board. The child should be looking straight up (Arrow6) so that the line of sight is perpendicular to the board. Your head should be directly over the child's head. Watch the child's head to make sure it is in the correct position against the base of the board.
- Make sure the child is lying flat in the centre of the board (Arrow7). Place the child's knees and feet in the correct position
- With your thumb against your index finger, place your left hand on the child's knees (Arrow 8) and press them gently, but firmly against the board. Do not wrap your hand around the knees or squeeze them together. Make sure the child's legs are straight.

- Check the position of the child (Arrows1-8). Repeat any steps as necessary.
- When the child's position is correct, move the foot piece with your right hand until it is firmly against the child's heels (Arrow9).
- Read the measurement to the nearest 0.1 cm and record the measurement
- Check the recorded measurement on the questionnaire for accuracy and legibility. Instruct the assistant to correct any errors.

Illustration Child Length Measurement



TAKING WEIGHT

- Preparing the Adult and Children to Take Their Weight

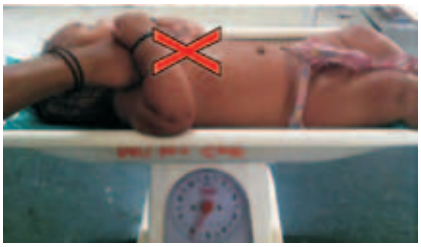
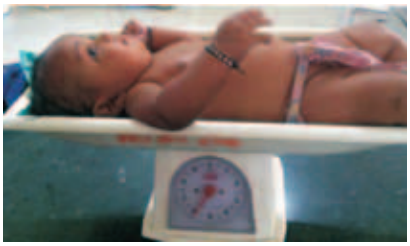
  Show the scale to the adult and explain that you will weigh her/him and their children on the scale. Counsel the mother and explain the procedure

  Ask the care giver to remove clothing as according to the weather conditions just before taking his/her weight and to remove any heavy clothing, sandals, shoes, etc.

- **Preparing the weighing**

Place the scale on a hard, level surface. Soft or uneven surfaces may cause the scale to malfunction.	

Calibrate the scale to zero by rotating the knob. **Check if the calibration of the scale is correct** press the pan 2-3 times and confirm that it comes back to zero.	
Count the lines between two numbers.(x) Divide 1000 gm by x. You will get the least count of that machine 1000/20=50g	
Ensure exact zero. See from same eye level and not from side view.	
Apply thin cloth or a sheet of newspaper on the scale pan to avoid hypothermia and then calibrate the scale to zero. Discard the news paper after every use	
Do not use plastic sheet, that will stick to infant's body…	
Place the child on the machine horizontally Or if the Child can sit in center so that s/he will remain stable and calm.	
Take help of mother to calm the child	

Ask mother to hold the child and make sure that no extra pressure is added by mother.	
Take reading only when child is still	

Measuring Older children

With the subject standing straight in the middle of the scale platform with hands hanging laterally feet slightly a part (on the footprints, if marked), and to remain still. It has to be recorded to the nearest 1/10 kg.	
When the number 0.0 appears, the scale is ready. Take care that the subject is standing properly on the scale and looking at the horizon. Handle the scale carefully: Do not drop or bump the scale.	

Identifying SAM children (Note gender differences)

Boy's Weight (kg)				Length (cm)	Girl's Weight (kg)			
Length (cm)	-3 SD	-2 SD	Median		Median	-2 SD	- 3 SD	Length (cm)
45	1.9	2.0	2.4	45	2.5	2.1	1.9	45
46	2.0	2.2	2.6	46	2.6	2.2	2.0	46
47	2.1	2.3	2.8	47	2.8	2.4	2.2	47
48	2.3	2.5	2.9	48	3.0	2.5	2.3	48
49	2.4	2.6	3.1	49	3.2	2.6	2.4	49
50	2.6	2.8	3.3	50	3.4	2.8	2.6	50
51	2.7	3.0	3.5	51	3.6	3.0	2.8	51
52	2.9	3.2	3.8	52	3.8	3.2	2.9	52
53	3.1	3.4	4.0	53	4.0	3.4	3.1	53
54	3.3	3.6	4.3	54	4.3	3.6	3.3	54
55	3.6	3.8	4.5	55	4.5	3.8	3.5	55
56	3.8	4.1	4.8	56	4.8	4.0	3.7	56
57	4.0	4.3	5.1	57	5.1	4.3	3.9	57
58	4.3	4.6	5.4	58	5.4	4.5	4.1	58
59	4.5	4.8	5.7	59	5.6	4.7	4.3	59
60	4.7	5.1	6.0	60	5.9	4.9	4.5	60
61	4.9	5.3	6.3	61	6.1	5.1	4.7	61
62	5.1	5.6	6.5	62	6.4	5.3	4.9	62
63	5.3	5.8	6.8	63	6.6	5.5	5.1	63
64	5.5	6.0	7.0	64	6.9	5.7	5.3	64
65	5.7	6.2	7.3	65	7.1	5.9	5.5	65
66	5.9	6.4	7.5	66	7.3	6.1	5.6	66
67	6.1	6.6	7.7	67	7.5	6.3	5.8	67
68	6.3	6.8	8.0	68	7.7	6.5	6.0	68
69	6.5	7.0	8.2	69	8.0	6.7	6.1	69
70	6.6	7.2	8.4	70	8.2	6.9	6.3	70
71	6.8	7.4	8.6	71	8.4	7.0	6.5	71
72	7.0	7.6	8.9	72	8.6	7.2	6.6	72
73	7.2	7.7	9.1	73	8.8	7.4	6.8	73
74	7.3	7.9	9.3	74	9.0	7.5	6.9	74
75	7.5	8.1	9.5	75	9.1	7.7	7.1	75
76	7.6	8.3	9.7	76	9.3	7.8	7.2	76
77	7.8	8.4	9.9	77	9.5	8.0	7.4	77
78	7.9	8.6	10.1	78	9.7	8.2	7.5	78
79	8.1	8.7	10.3	79	9.9	8.3	7.7	79
80	8.2	8.9	10.4	80	10.1	8.5	7.8	80
81	8.4	9.1	10.6	81	10.3	8.7	8.0	81
82	8.5	9.2	10.8	82	10.5	8.8	8.1	82
83	8.7	9.4	11.0	83	10.7	9.0	8.3	83
84	8.9	9.6	11.3	84	11.0	9.2	8.5	84
85	9.1	9.8	11.5	85	11.2	9.4	8.7	85
86	9.3	10.0	11.7	86	11.5	9.7	8.9	86

Using BMI in Children

Unlike for adults, the BMI values vary with the age and sex of the child. The BMI in children is called: BMI-for-age. In children, instead of looking at the actual BMI value itself, we focus on the specific variation of BMI according to age and gender. GoI is following the WHO BMI for age standards, 2007 release. Refer to the Z score simplified field tables for Girls and Boys.

Why is the BMI-for-age important?

The Hungama survey and also the NFHS 3 indicate that a large proportion of school age children are under nourished.

Recent studies have also shown that cardiac disease risk factors are associated with the BMI for age. 60% of children aged 5-10 years with a BMI-for-age greater than the 95%, had at least one obesity-related condition such as high blood pressure, high cholesterol had 2 or more such abnormalities. The BMI for age is now recommended method for screening overweight and underweight in all children.

Why do we use BMI?

- BMI provides a good indicator for levels of body fat, and it is known that having a BMI that is either too low or too high is associated with an increased risk of ill health during childhood as well as later in life.
- BMI is relatively quick and easy to calculate and as a result, is used for population surveys and by health professionals when assessing individual patients.
- BMI is therefore the most frequently used measure for assessing whether adults or children are obese, overweight, underweight, or a healthy weight.

Assessing the BMI of children is more complicated than for adults because a child's BMI changes as they mature. Also, these patterns of growth differ between boys and girls. Therefore, to work out whether a child's BMI is too high or too low, both the age and sex of the child need to be taken into account.

- Because children's BMI changes considerably between birth and adulthood, fixed thresholds such as those used for adults should not be applied to children as they would provide misleading findings.

How is child BMI classified?

•Instead of using fixed BMI values to classify individuals (as used for adults) children's BMI is classified using thresholds that vary to take into account the child's age and sex.

•These thresholds are usually derived from a reference population, known as a child growth reference. They are calculated by weighing and measuring a large sample of children and they illustrate how BMI varies in children of different ages and sex. As well as showing the pattern of growth, these data also provide an average BMI for a boy or girl at a particular age, and the distribution of measurements above and below this value. This means that individual children can be compared to the reference population and the degree of variation from the expected value can be calculated.

What BMI cut-offs are used?

WHO suggest a set of thresholds based on single standard deviation spacing.

- Thinness: <-2SD
- Overweight: between +1SD and <+2SD
- Obese: >+2SD

de Onis M, Onyango AW, Borghi E, Siyam A, Nishida C, Siekmann J. Development of a WHO growth reference for school-aged children and adolescents. Bulletin of the World Health Organization, 2007;85(9): 649-732.

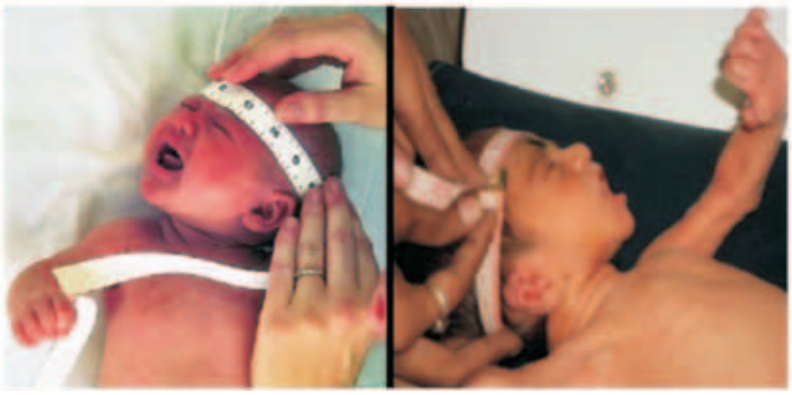
Refer any child whose BMI for age and sex is ><3 SD.

Measuring head circumference

- Head circumference-measurement of a child's head around its widest area, or the distance from above the Eye brows and ears and around the back of the head, on the lower part of the forehead; also referred to as the Occipital-frontal circumference [OFC].
- This measurement is mainly to show brain growth. The size of the skull serves as an approximate index of the volume of its contents (normally brain and cerebrospinal fluid [CSF]). Brain growth slows down once the child is 12 months old and, for all practical purposes, stabilizes by age 5.
- Any increase in head circumference (larger than +2 SDs) is called macrocephaly; and any reduction in head circumference (smaller than -2 SDs), microcephaly. Both conditions force us to rule out any diseases that need treatment or can be associated with developmental disorders.

Technique:

- Use a non –stretchable tape. Place it on the most prominent point at the back of the skull (the occiput) and just above the eyebrows (on the superciliary ridge).
- The measuring tape passes just above the eyebrows and around the prominent posterior aspect of the head.



- If the child has any protuberance on his or her forehead that makes it asymmetrical, put the tape over the most prominent part.
- Measure head circumference in cm and refer to the growth chart
- After taking the measurement, confirm the percentile according to the WHO head circumference growth charts for girls or boys.

See WHO Head Circumference Referrance Chart in the Job Aids

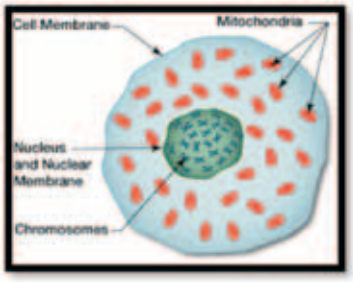
Refer if above or below 2 SD.

Basics of Genetics:

Genetics is nothing but a communication from the parents to their offsprings. Our body contains 50 trillion cells performing different functions. Again the genetic material stored in the nucleus is also to be communicated to the factory manufacturing the protein for that cell. This communication is a written communication and not a verbal communication. For any communication, one requires a language, the language again has sentences and they in turn are made of words and each word is a collection of letters from the alphabets. Again the communication has to be in a language where the messenger will take the message and should be understood by the person for whom the communication has been made. In genetics, the DNA from the nucleus has to send the message to the ribosome (factory) in the cytoplasm to translate the language into action i.e. manufacture of proteins. Here the alphabet has only four letters A, C, T, G (base pairs), the words have 3 letters (ATG, CTA) and the sentences are meaningful use of words . In genetics the sentences are meaningful only if they can help in formation of protein, and are known as the genes.

1) Our body contains 50 trillion tiny cells, (50 Trillion =50,000,000,000,000. Fifty followed by twelve zero). Some cells are heart cells and some are brain cells.

2) But each of these cells contain the complete set of instructions for making us as we are i.e. the same genetic material which we have inherited from both our parents are carried in the same way mainly inside the nucleus in all of the 50 trillion cells of our body.



3) Children resemble their parents : This is because of the genetic material they inherit from both of their parents.

4) The smallest unit of this genetic material is DNA, which is kept in the nucleus of the cell (like a fort within a town). Deoxyribonucleic acid. DNA encodes a detailed set of plans and is the blue print for building different types of function of the cell. DNA cannot be seen through a microscope. Nearly every cell in a person's body has the same DNA. Most DNA is located in the cell nucleus (where it is called nuclear DNA), but a small amount of DNA can also be found in the mitochondria (where it is called mitochondrial DNA).

5) **The Basics of DNA:** we have already discussed that our body contains 50 trillion tiny cells, and almost every one of them contains the complete set of instructions for making us. These instructions are encoded in our DNA. DNA is a long, ladder-shaped molecule. Each rung on the ladder is made up of a pair of interlocking units, called bases, that are designated by the four letters in the DNA alphabet - A, T, G and C. 'A' always pairs with 'T', and 'G' always pairs with 'C'.

N.B. It is not necessary that this chapter be totally understood by the Mobile Health team members. But an attempt has been made that they understand the chromosomal defects, the single gene defects and finally the inheritance of Autosomal recessive or Autosomal-dominant.

The information in DNA is stored as a code made up of four chemical bases: adenine (A), guanine (G), cytosine (C), and thymine (T). Human DNA consists of about 3 billion bases, and more than 99 percent of those bases are the same in all people.

The order, or sequence, of these bases determines the information available for building and maintaining an organism, similar to the way in which letters of the alphabet appear in a certain order to form words and sentences.

DNA bases pair up with each other, A with T and C with G, to form units called base pairs. Each base is also attached to a sugar molecule and a phosphate molecule. Together, a base, sugar, and phosphate are called a nucleotide. The structure of the double helix is somewhat like a ladder, with the base pairs forming the ladder's rungs and the sugar and phosphate molecules forming the vertical sidepieces of the ladder.

An important property of DNA is that it can replicate, or make copies of itself. Each strand of DNA in the double helix can serve as a pattern for duplicating the sequence of bases. This is critical when cells divide because each new cell needs to have an exact copy of the DNA present in the old cell.

e.g.

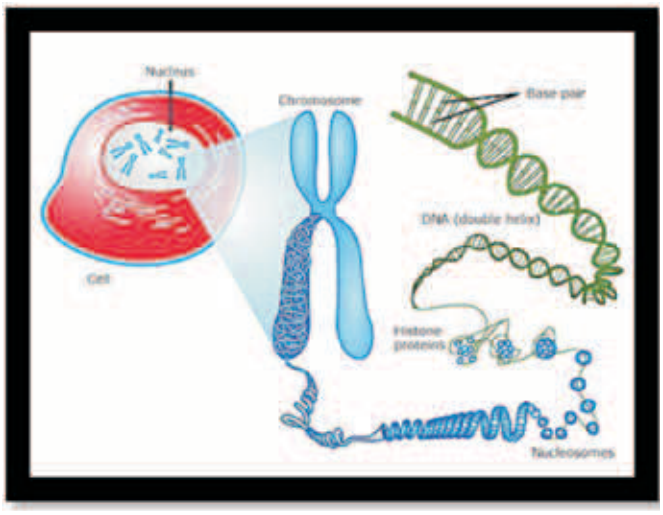
DNA strand is made of letters (only 4 letters in this alphabet) (ATCG)

- ATGCTCGAATAAATGTCAATTTGA

The letters make words:

- ATG, CTC, GAA, TAA, ATG, TCA, ATT, TGA

The words make sentences:

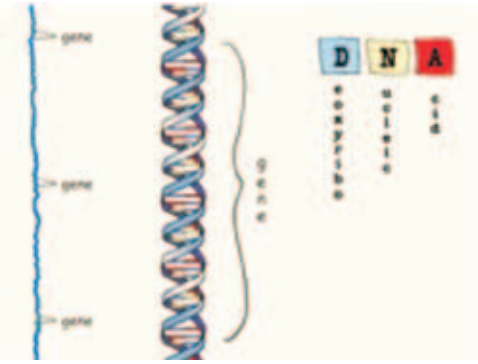


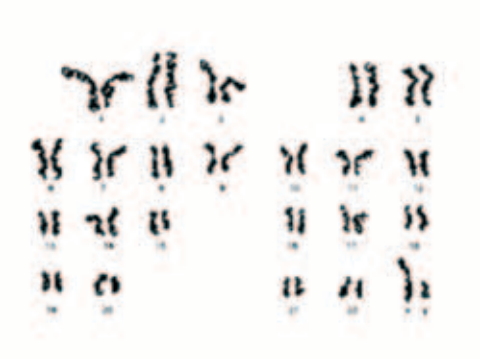
< ATG CTC GAA TAA > this sequence codes for a particular amino acids, which then helps in synthesis of protein. Since this part of DNA (or the sentence) is helping in protein synthesis, it is called a gene.

Similarly:

< ATG TCA ATT TGA > this sequence codes for a particular amino acids, which then helps in synthesis of protein. Since this part of DNA (or the sentence) is helping in protein synthesis, it is also called a gene

DNA is Organized Into Chromosomes: The long molecules of DNA in your cells are organized into pieces called chromosomes. Chromosomes can be stained and seen under the microscope. Humans have 23 pairs of chromosomes. Onefrom each parent. Other organisms have different numbers of pairs - for example, chimpanzees have 24 pairs. The number of chromosomes doesn't determine how complex an organism is - bananas have 11 pairs of chromosomes, while fruit flies have only 4.

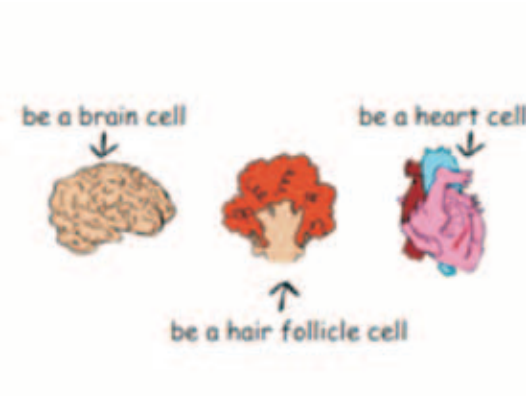




Chromosomes are organized into Genes:

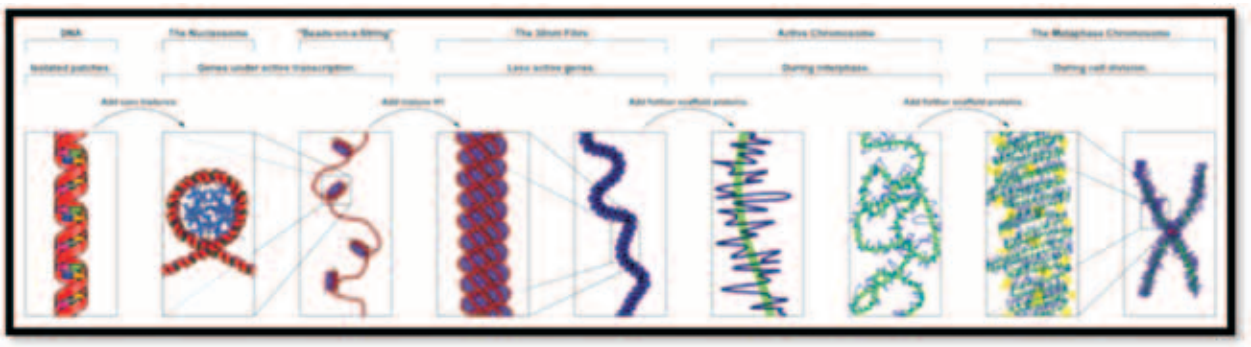
Chromosomes are further organized into short segments of DNA called genes. If you imagineyour DNA as a cookbook, then your genes are the recipes. Written in the DNA alphabet - A, T, C, and G - the recipes tell your cells how to function and what traits to express. For example, if you have curly hair, it is because the genes you inherited from your parents are instructing your hair follicle cells to make curly strands.

Genes Make Proteins:



Cells use the recipes written in your genes to make proteins - just like you use recipes from a cookbook to make dinner. Proteins do much of the work in your cells and your body as a whole. Some proteins give cells their shape and structure. Others help cells carry out biological processes like digesting food or carrying oxygen in the blood. Using different combinations of the A, C, T and G, DNA creates the different proteins - just as you use different combinations of the same ingredients to make different meals.

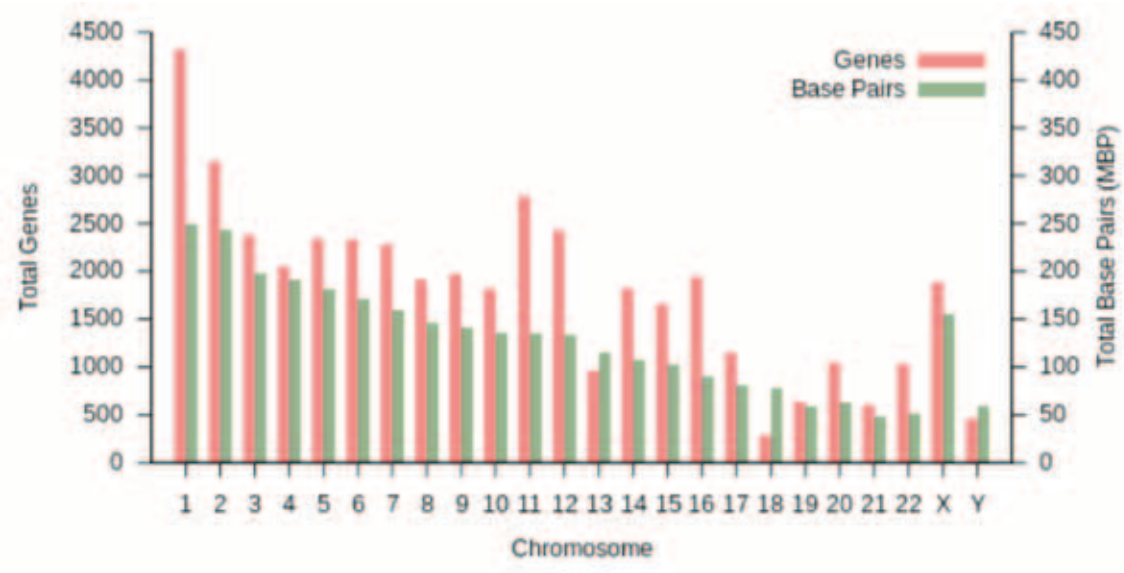
****How DNA, which is almost 3 meter, is super coiled and kept in form of 23 pairs of pieces or parts inside the nucleus of the cell. What looks like a chromosome?*



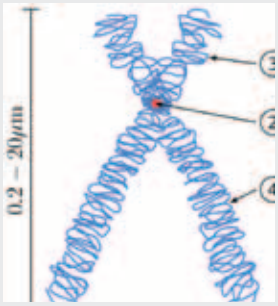
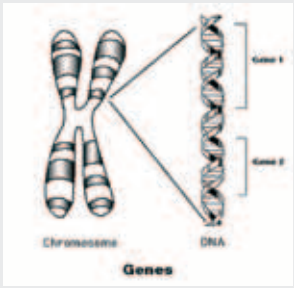
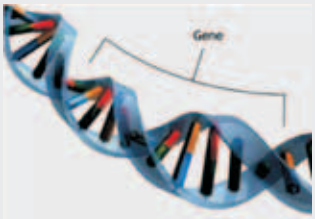
Chromosomes: It is a single piece of coiled DNA containing many genes, Chromosomes in humans can be divided into two types: autosomes and sex chromosomes. Certain genetic traits are linked to a person's sex and are passed on through the sex chromosomes. The autosomes contain the rest of the genetic hereditary information. All act in the same way during cell division. Human cells have 23 pairs of chromosomes (22 pairs of autosomes and one pair of sex chromosomes), giving a total of 46 per cell.

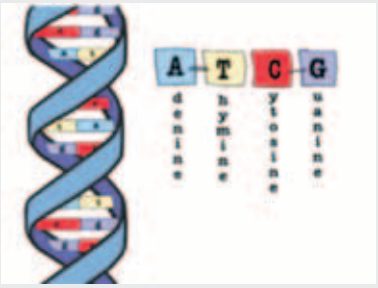
Genetic Switches Control the Traits Cells Express:

Cells come in a dizzying array of types; there are brain cells and blood cells, skin cells and liver cells and bone cells. But every cell contains the same instructions in the form of DNA. So how do cells know whether to make an eye or a foot? The answer lies in intricate systems of genetic switches. Master genes turn other genes on and off, making sure that the right proteins are made at the right time in the right cells.



Estimated number of genes and base pairs (in mega base pairs) on each human chromosome

Chromosome: Coiled DNA kept in Nucleus tightly packed. (This allows the very long DNA molecules to fit into the cell nucleus.)	**Genes:** Genes are that part of DNA which works for a particular Protein synthesis. Each gene contains a particular set of instructions, usually coding for a particular protein or for a particular function.	**Sequenced base pairs** 
		
1	4,220	224,999,719
2	1,491	237,712,649
3	1,550	194,704,827
4	446	187,297,063
5	609	177,702,766
6	2,281	167,273,993
7	2,135	154,952,424
8	1,106	142,612,826
9	1,920	120,312,298
10	1,793	131,624,737
11	379	131,130,853
12	1,430	130,303,534
13	924	95,559,980
14	1,347	88,290,585
15	921	81,341,915
16	909	78,884,754
17	1,672	77,800,220
18	519	74,656,155
19	1,555	55,785,651
20	1,008	59,505,254
21	578	34,171,998
22	1,092	34,893,953
X (sex chromosome)	1,846	151,058,754

Y (sex chromosome)	454	25,121,652
Total : 23 pair of chromosomes	**Total genes: 32,185**	**Total base pairs: 2,857,698,560**
Chromosomal aberrations are disruptions in the normal chromosomal content of a cell and are a major cause of genetic conditions in humans, such as Down syndrome	**Single gene defect like Sickle cell anemia**	

Summary:

- Children resemble their parents;
- This is because the genetic material they inherit from both their parents;
- The smallest unit of this genetic material is DNA, which is kept in the nucleus of the cell like a fort within a city. Deoxyribonucleic acid. DNA encodes a detailed set of plans and is the blue print for building different types of function of the cell;
- DNA looks like a twisted ladder where there is a turn after every few rungs or steps;
- The sides have a sugar and a phosphate and the rungs are made of 4 letters of the alphabet: A, T, C, and G. These letters join together according to a special rule: A will always pair with T and C with G; attached to either of the sidewalls;
- Order of sequences of these base pairs or the letters in the alphabet provides the information needed for growth and development;
- This is because the sequence of the 4 letters gives rise to the sequence of words: 64 such (3 letter word: codon). The meaningful assimilation of words is sentence. The sentence helps in formation of protein. The meaningful part of DNA is gene, which helps in protein synthesis;
- The sequence of the codons helps in formation of sequential amino acids: 20 such. The sequence of the amino acids helps in the formation of protein: 1000 such proteins;
- The steps or rungs are formed by the bonding of A with T and C with G. Thus A on one side of the ladder joins T on the other side and cemented together by the Hydrogen bonding;
- The size of the DNA within the cell can be as long as 3 meters, the size of a car but still it cannot be seen under a microscope but can be studied through help of X-ray;
- Hence this has to be packed in an efficient way to keep it inside the Nucleus. So it is highly coiled along with packing material histones and looks like a coiled thread under a microscope with a shape of X during cell division known as the chromosomes. Thus chromosomes consist of a long single piece of DNA, containing many genes kept in the nucleus by coiling

many times with help of proteins like histones. Human cells have 23 pairs of chromosome (22 pairs of autosomes and one pair of sex chromosomes);

- Certain genetic traits are linked to the autosomes so are called autosomal recessive or autosomal dominant depending upon the gene and certain traits are linked with the sex chromosomes;
- Genes come in pairs;
- Genes don't blend. For example, one might expect that a cross between purebred green-seeded and purebred yellow-seeded pea plant to produce offspring with seeds of an intermediate green-yellow colour. After all, color blending happens when paint is mixed together. However, Mendel found that this cross-produced offspring with only one colour yellow. No intermediate blends were seen, and the green colour seemed to have disappeared. So conclusion that genes do not blend and that Some genes are dominant;
- **Genetic inheritance follows rules;**

*******Johann Gregor Mendel (1822-1884) was known as Father of Genetics***

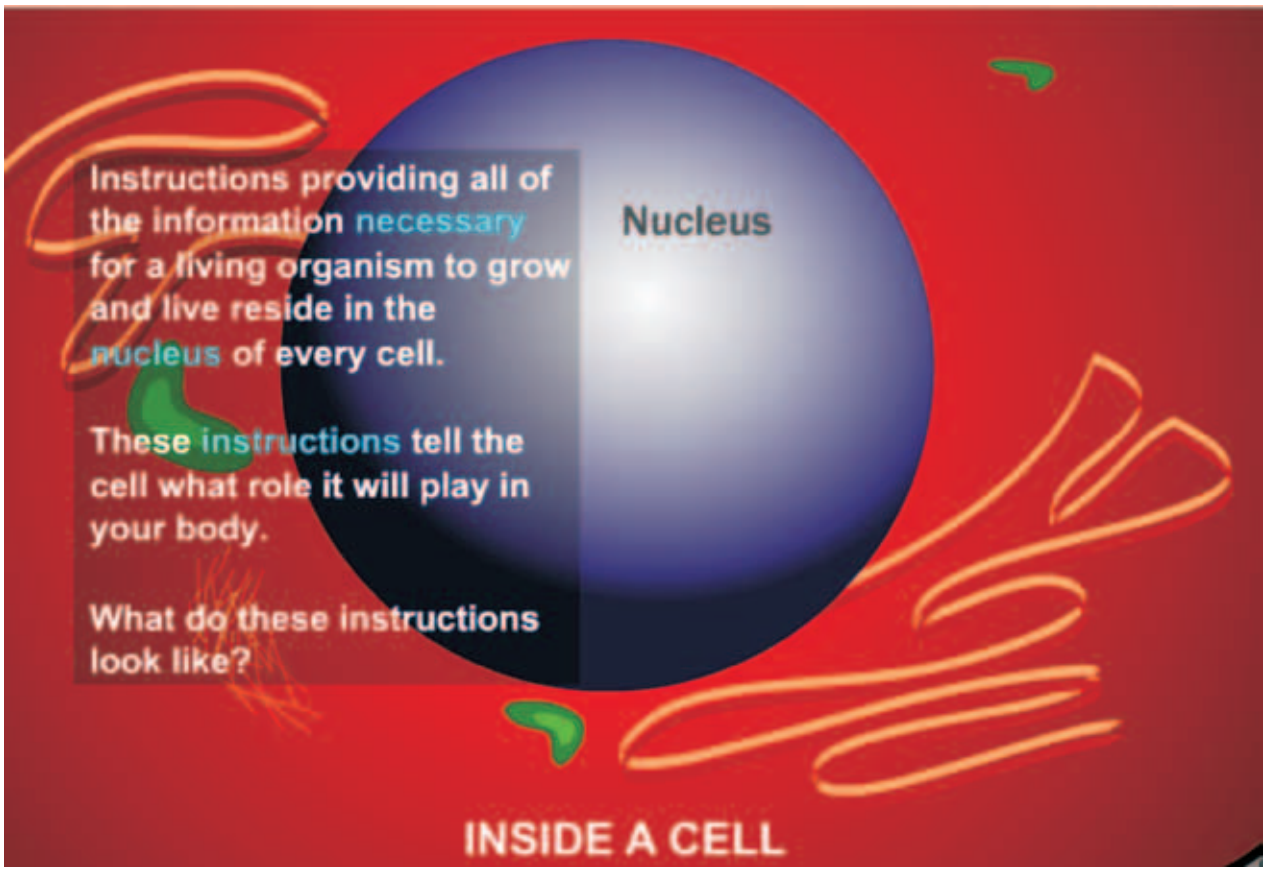
- Gregor Mendel deduced that genes come in pairs and are inherited as distinct units, one from each parent. Mendel tracked the segregation of parental genes and their appearance in the offspring as dominant or recessive traits.

Did you Know? After his death, the monks burned Mendel's personal papers. Luckily, some of the letters and documents generated by Mendel were kept in the monastery archives.

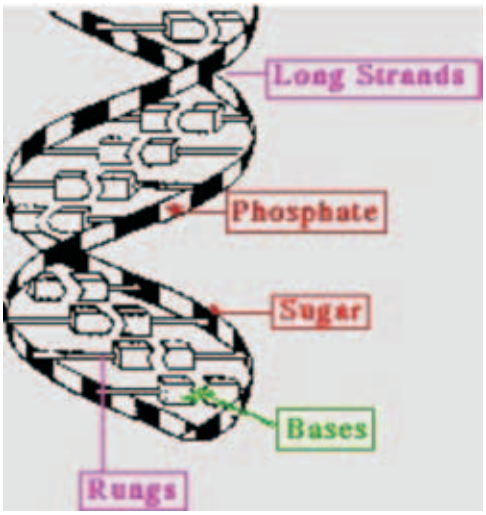
Basic Genetics:

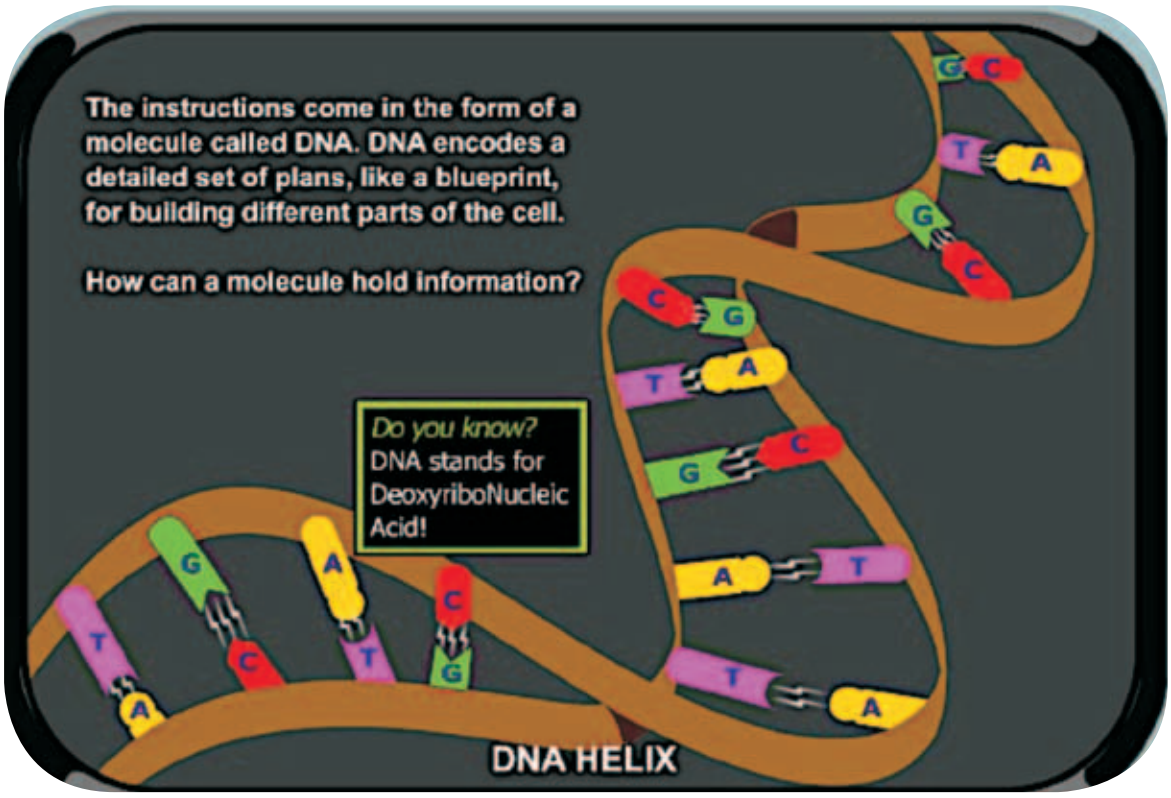
What is DNA?

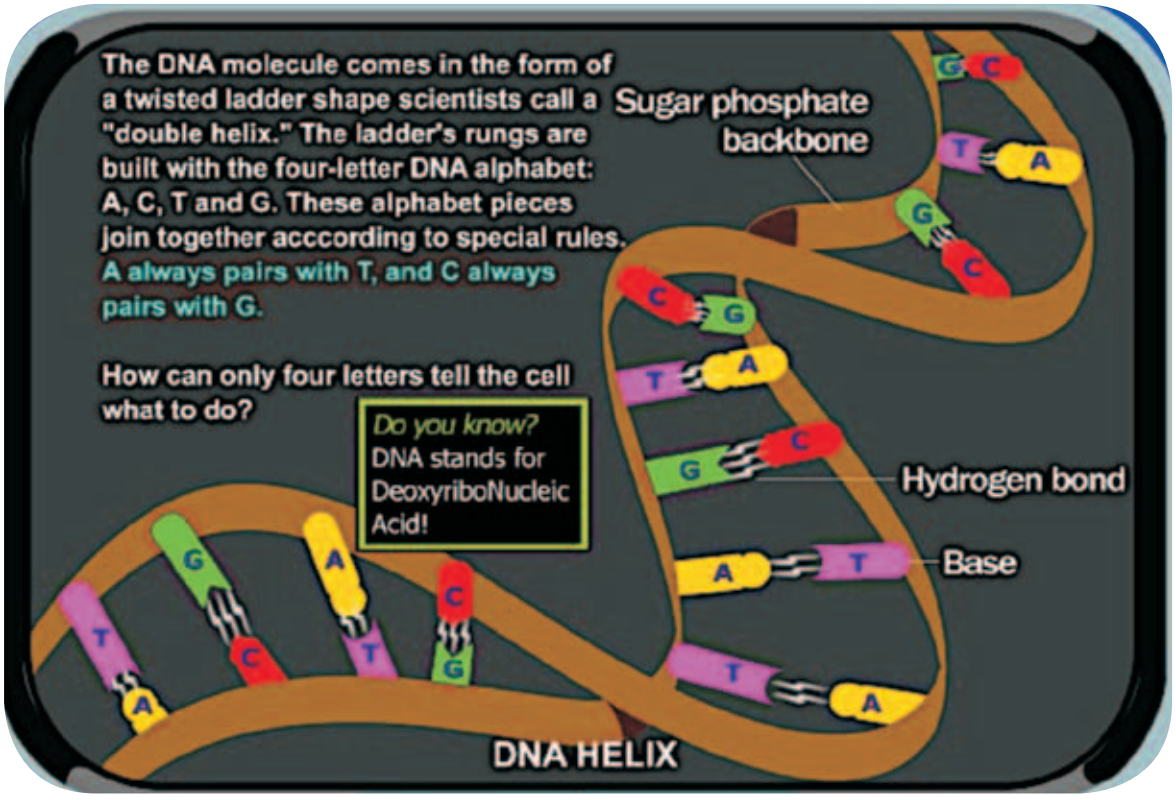
Let us examine a group of cells in your inner Ear. They help in Hearing. How do thesecell "know" that their function is to support Hearing instead of making the heartbeat. Instructions providing all the information necessary for a living organism to function, reside in the nucleus of every cell. These instructions will tell what role it will play in your body.

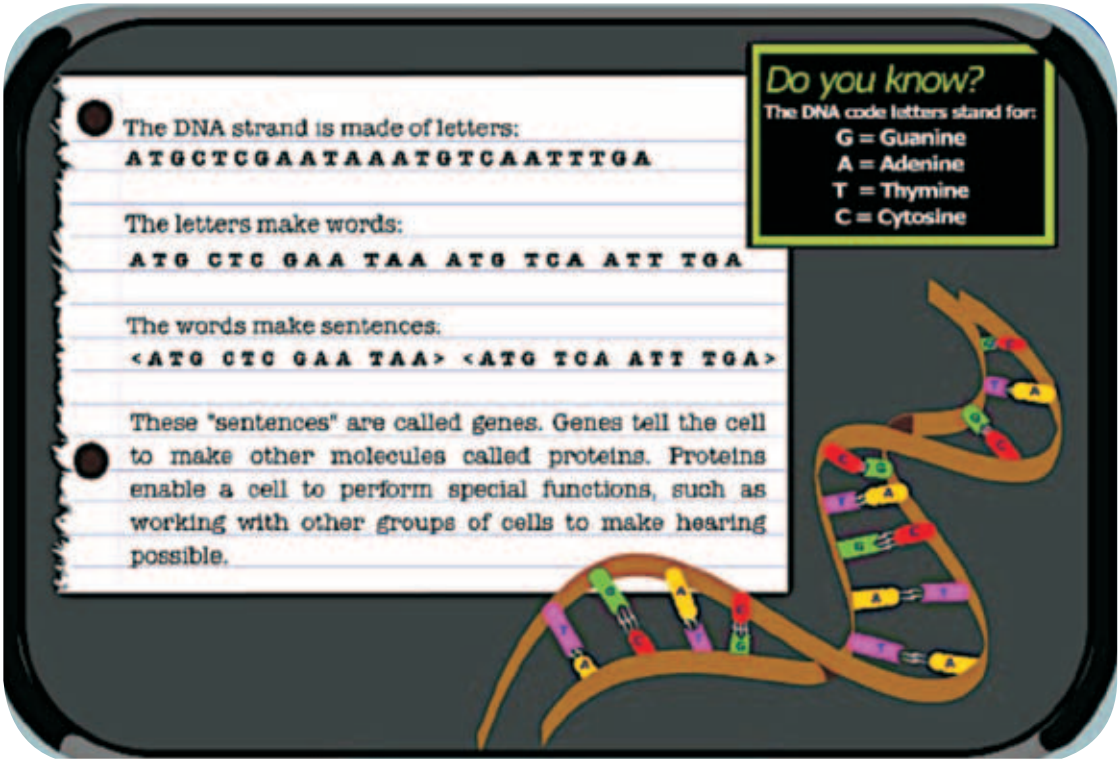


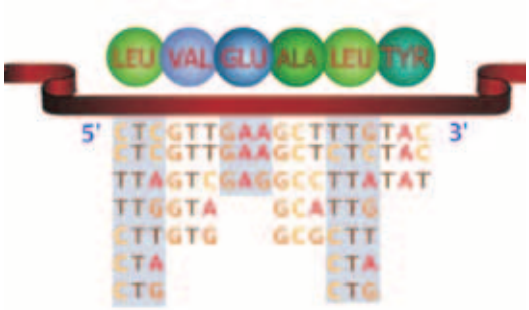
These instructions come in the form of a molecule called DNA Deoxyribonucleic acid. DNA encodes a detailed set of plans and is the blue print for building different types of function of cell.



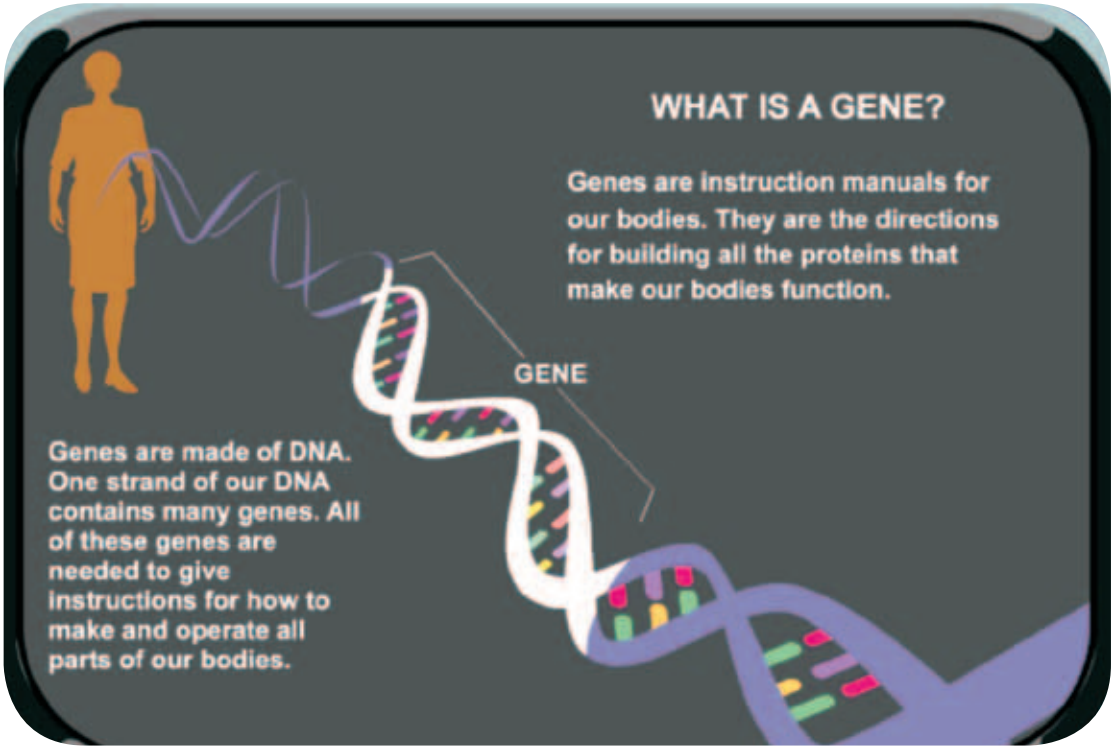

The instructions come in the form of a molecule called DNA. DNA encodes a detailed set of plans, like a blueprint, for building different parts of the cell.
How can a molecule hold information?
Do you know?
DNA stands for DeoxyriboNucleic Acid!
DNA HELIX

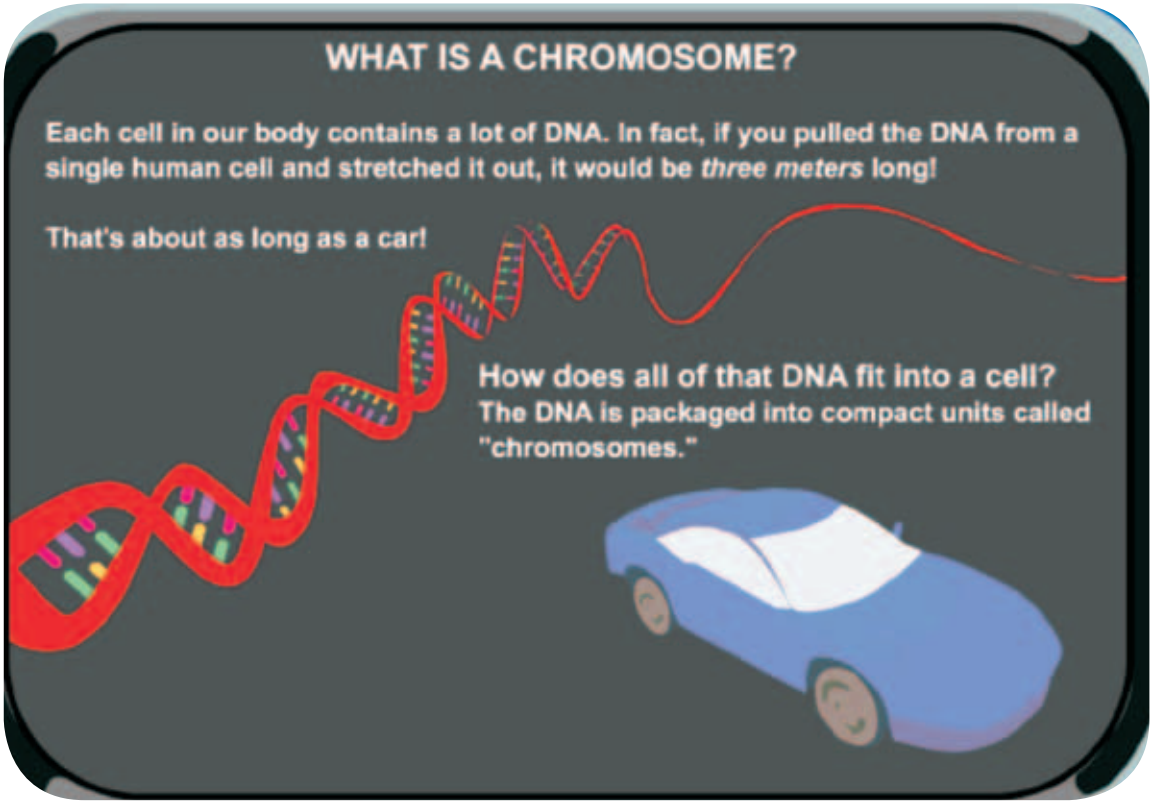

The DNA molecule comes in the form of a twisted ladder shape scientists call a "double helix." The ladder's rungs are built with the four-letter DNA alphabet: A, C, T and G. These alphabet pieces join together acccording to special rules. A always pairs with T, and C always pairs with G.
How can only four letters tell the cell what to do?
Sugar phosphate backbone
Hydrogen bond
Base
Do you know?
DNA stands for DeoxyriboNucleic Acid!
DNA HELIX

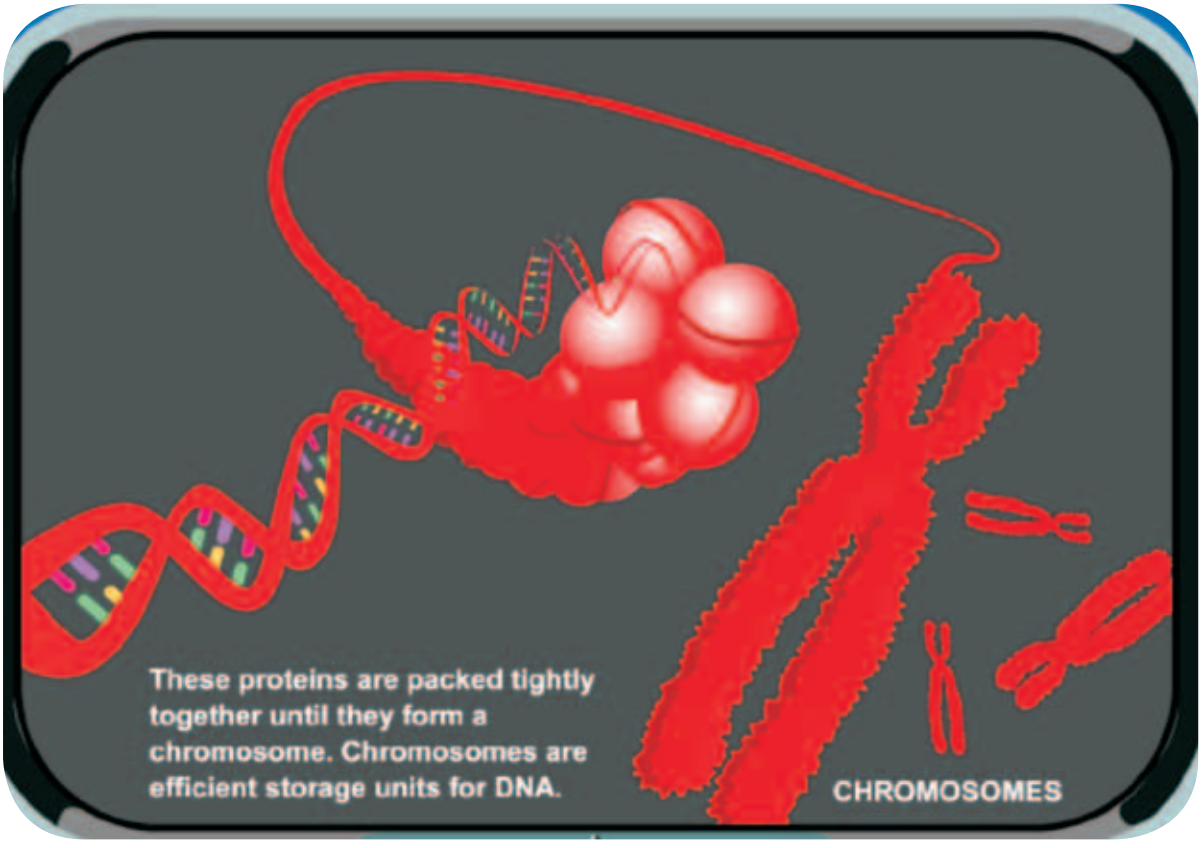




Amino Acids (Building block of Proteins) (Sentences)




WHAT IS A CHROMOSOME?
Each cell in our body contains a lot of DNA. In fact, if you pulled the DNA from a single human cell and stretched it out, it would be *three meters* long!
That's about as long as a car!
How does all of that DNA fit into a cell?
The DNA is packaged into compact units called "chromosomes."

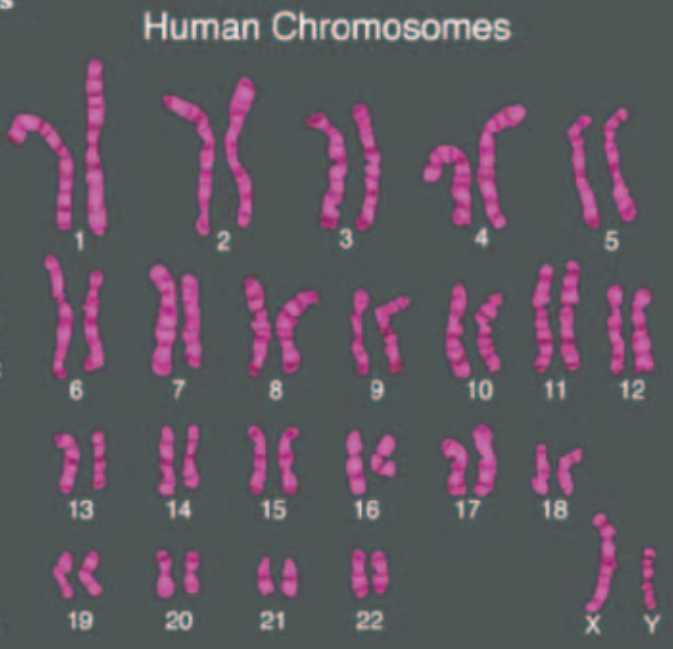

These proteins are packed tightly together until they form a chromosome. Chromosomes are efficient storage units for DNA.
CHROMOSOMES

How many chromosomes does one cell hold?

The correct answer to this depends on whether you're a fish or a fly, or a human.

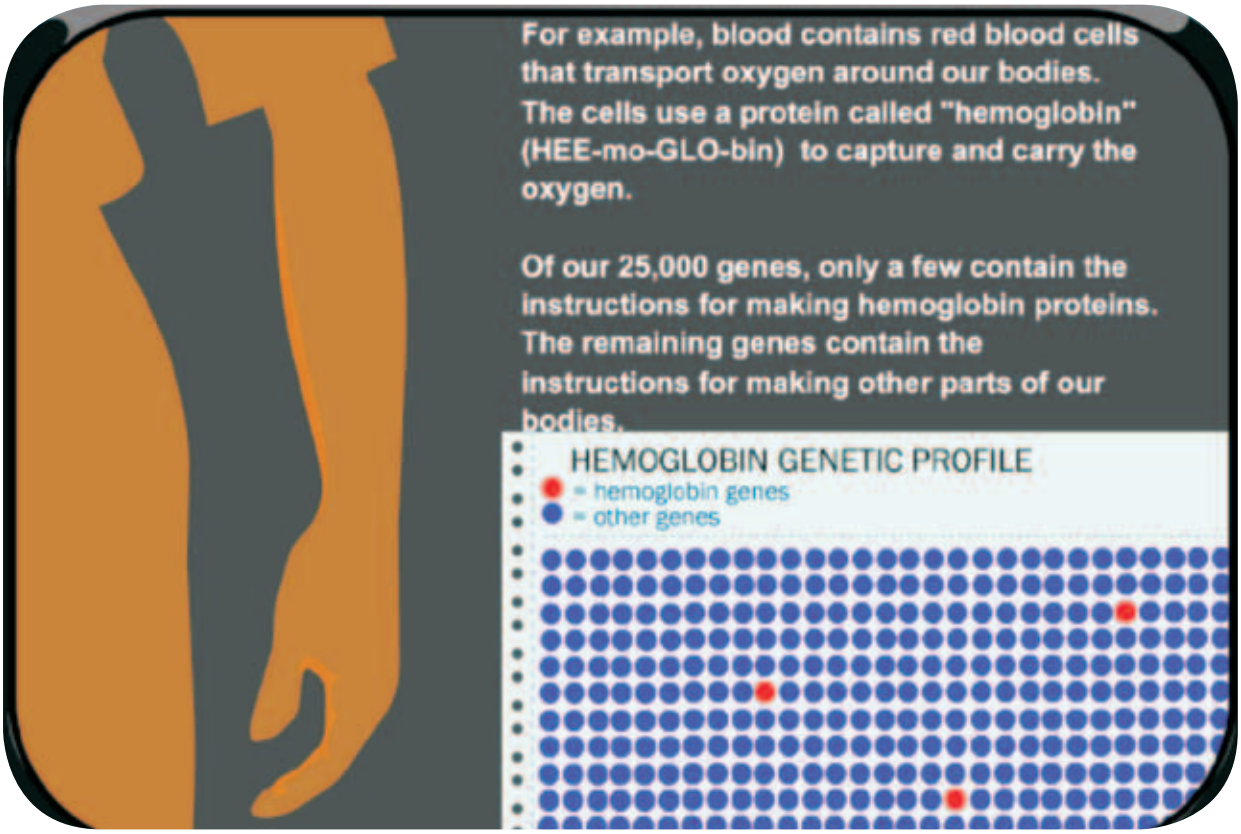
Each human cell has 46 chromosomes. All the DNA is organized into two sets of 23 chromosomes. We get genetic material from both of our parents - that's why children look like both their mom and dad.

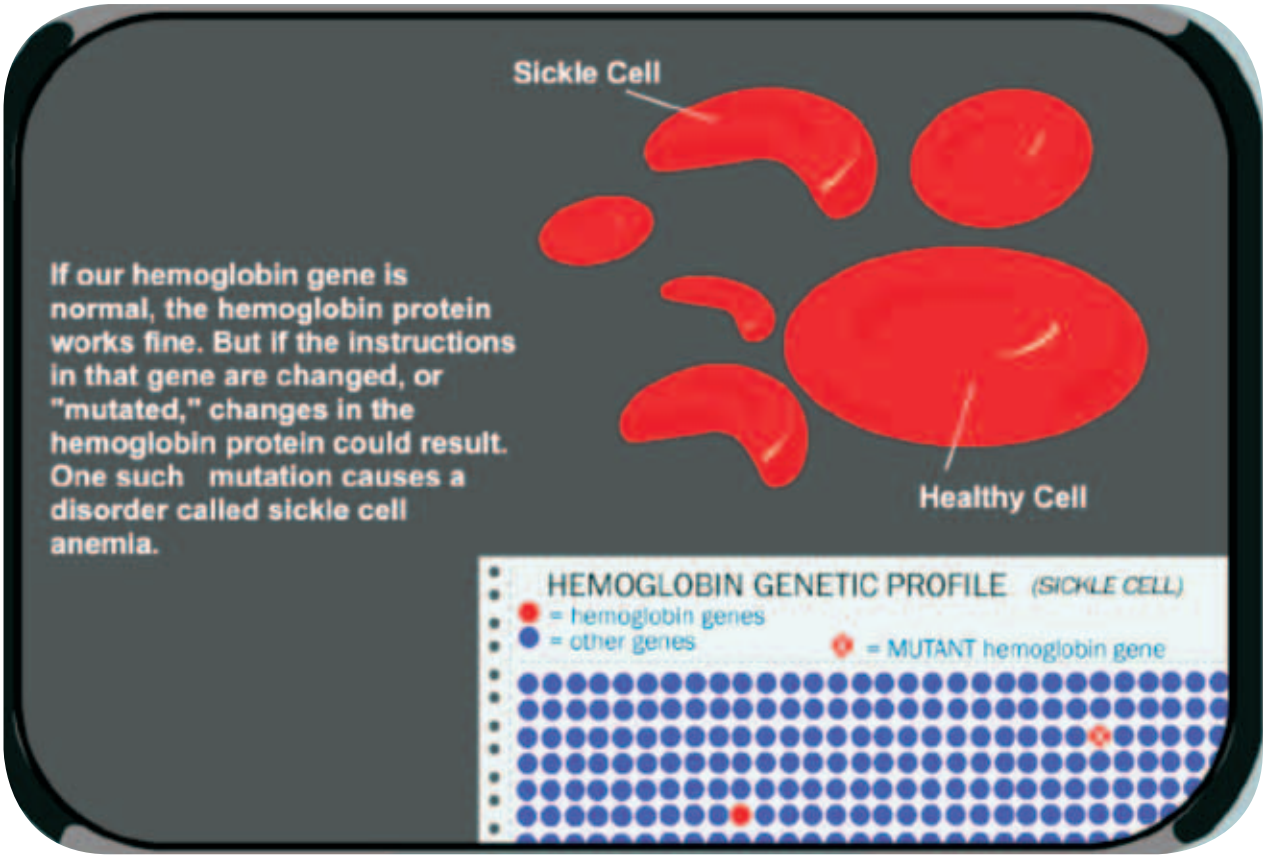
What can we learn from looking at our chromosomes?

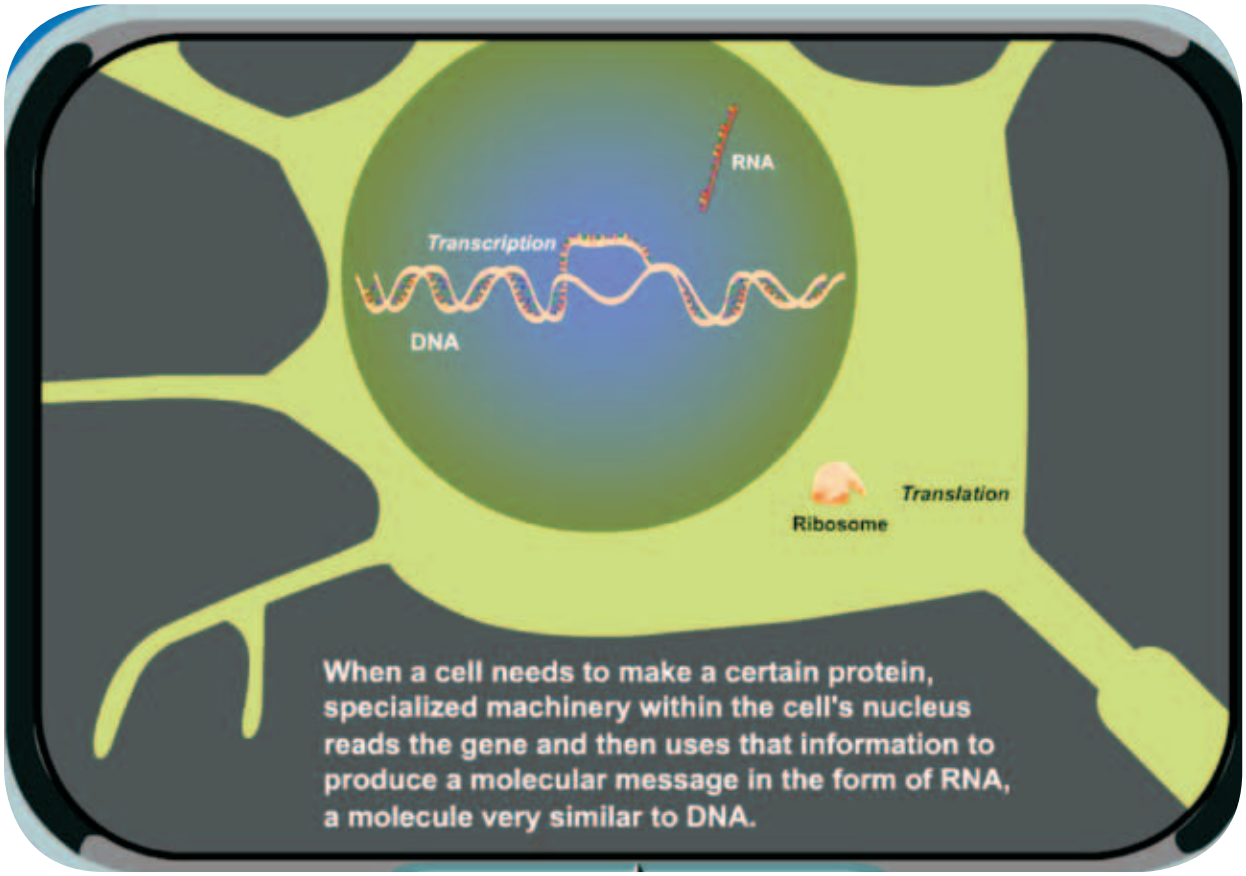


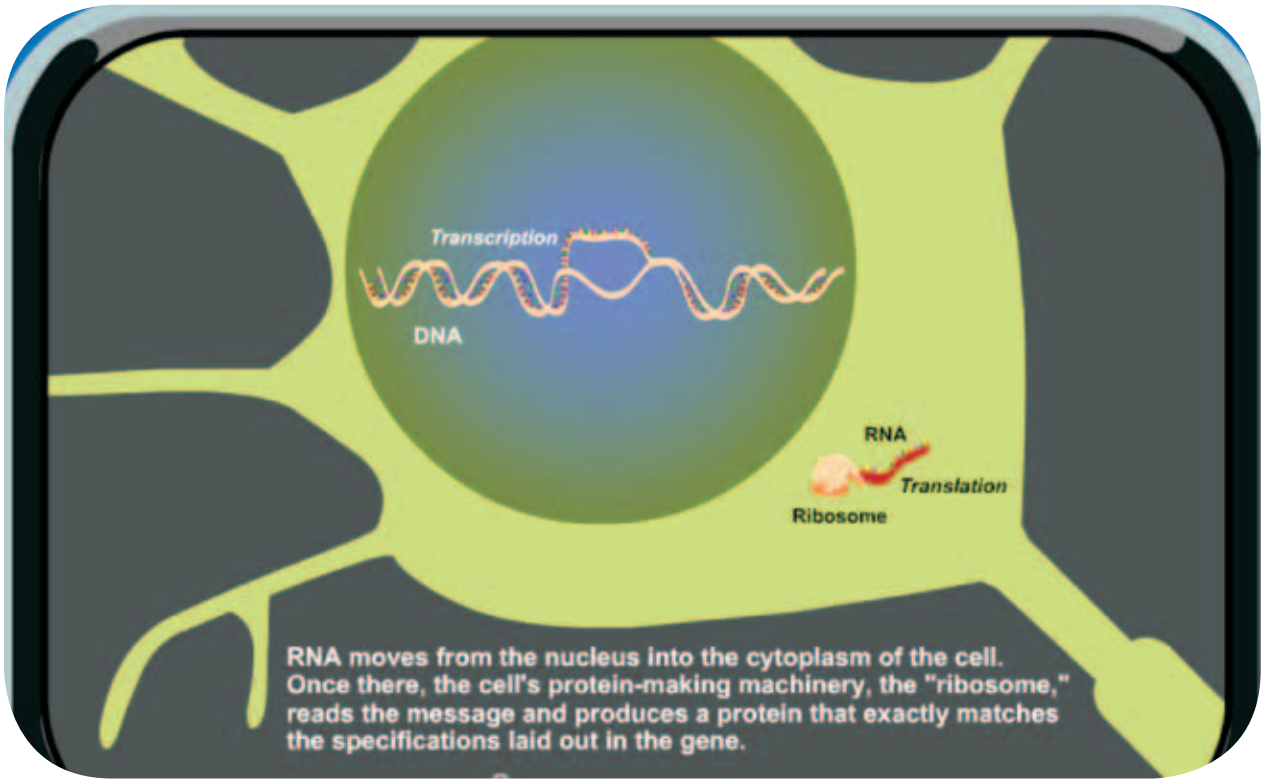
Look at this set of chromosomes. You can see that matching chromosomes have been lined up in pairs - one each from mom and dad. Although the DNA double helix is too small to see, chromosomes can be viewed with a microscope, as in this picture.

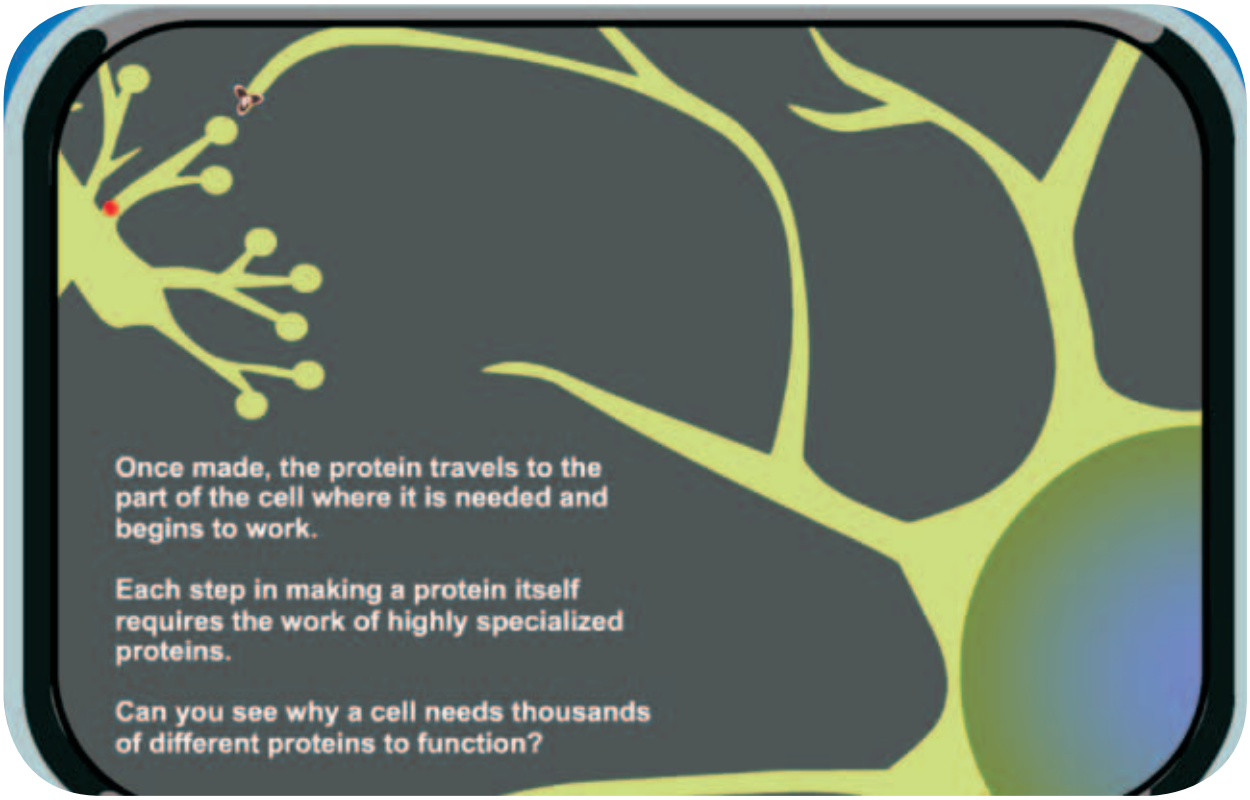
There are two sex chromosomes that determine whether you are male or female. In the picture the sex chromosomes are labeled "X" and "Y." The set of chromosomes in this picture are from a male - you can tell because females do not have a Y chromosome. Instead, they have two X chromosomes.


For example, blood contains red blood cells that transport oxygen around our bodies. The cells use a protein called "hemoglobin" (HEE-mo-GLO-bin) to capture and carry the oxygen.
Of our 25,000 genes, only a few contain the instructions for making hemoglobin proteins. The remaining genes contain the instructions for making other parts of our bodies.
HEMOGLOBIN GENETIC PROFILE
= hemoglobin genes
= other genes


Sickle Cell
Healthy Cell
If our hemoglobin gene is normal, the hemoglobin protein works fine. But if the instructions in that gene are changed, or "mutated," changes in the hemoglobin protein could result. One such mutation causes a disorder called sickle cell anemia.
HEMOGLOBIN GENETIC PROFILE (SICKLE CELL)
= hemoglobin genes
= other genes
= MUTANT hemoglobin gene


RNA
Transcription
DNA
Translation
Ribosome
When a cell needs to make a certain protein, specialized machinery within the cell's nucleus reads the gene and then uses that information to produce a molecular message in the form of RNA, a molecule very similar to DNA.


Transcription
DNA
RNA
Translation
Ribosome
RNA moves from the nucleus into the cytoplasm of the cell. Once there, the cell's protein-making machinery, the "ribosome," reads the message and produces a protein that exactly matches the specifications laid out in the gene.



Where exactly are our traits?

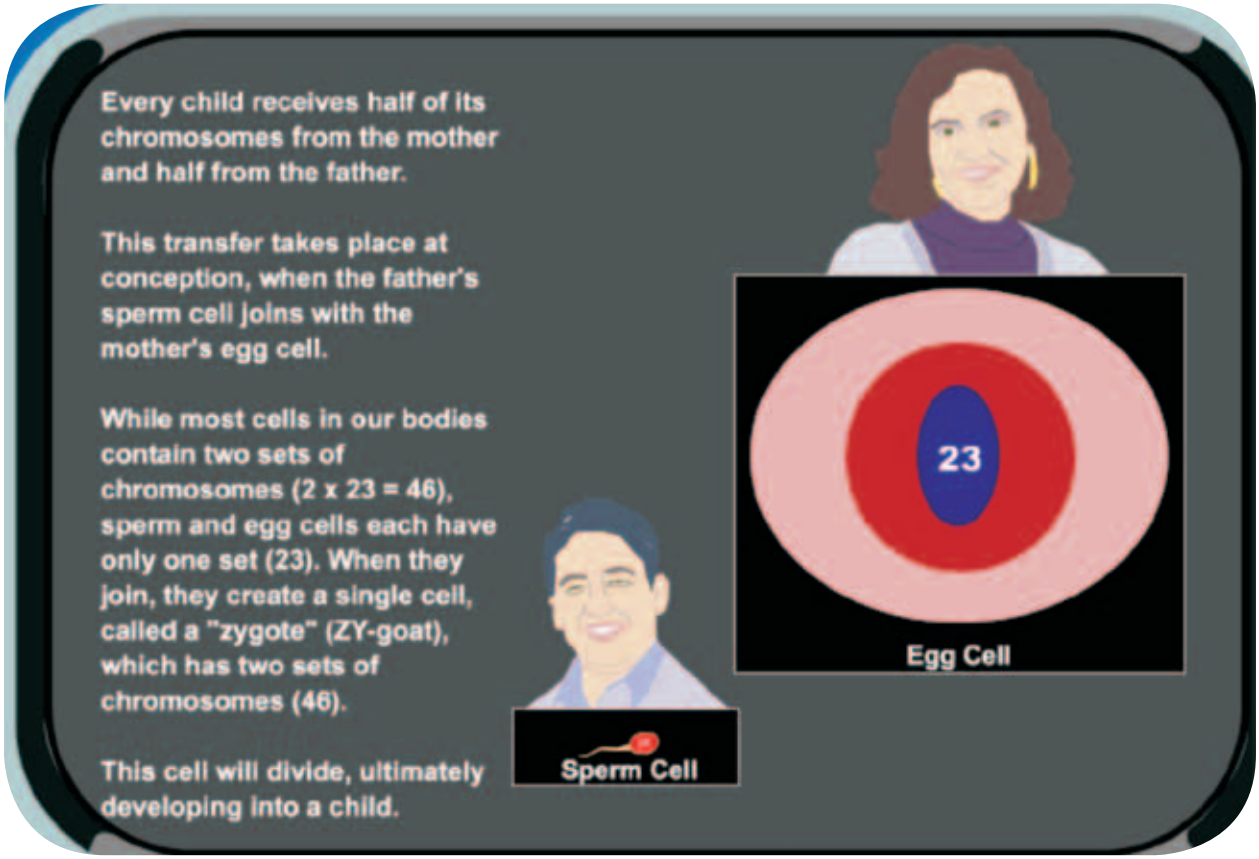
Our genes encode the instructions that define our traits. Each of us has thousands of genes, which are made of DNA and reside in our chromosomes.

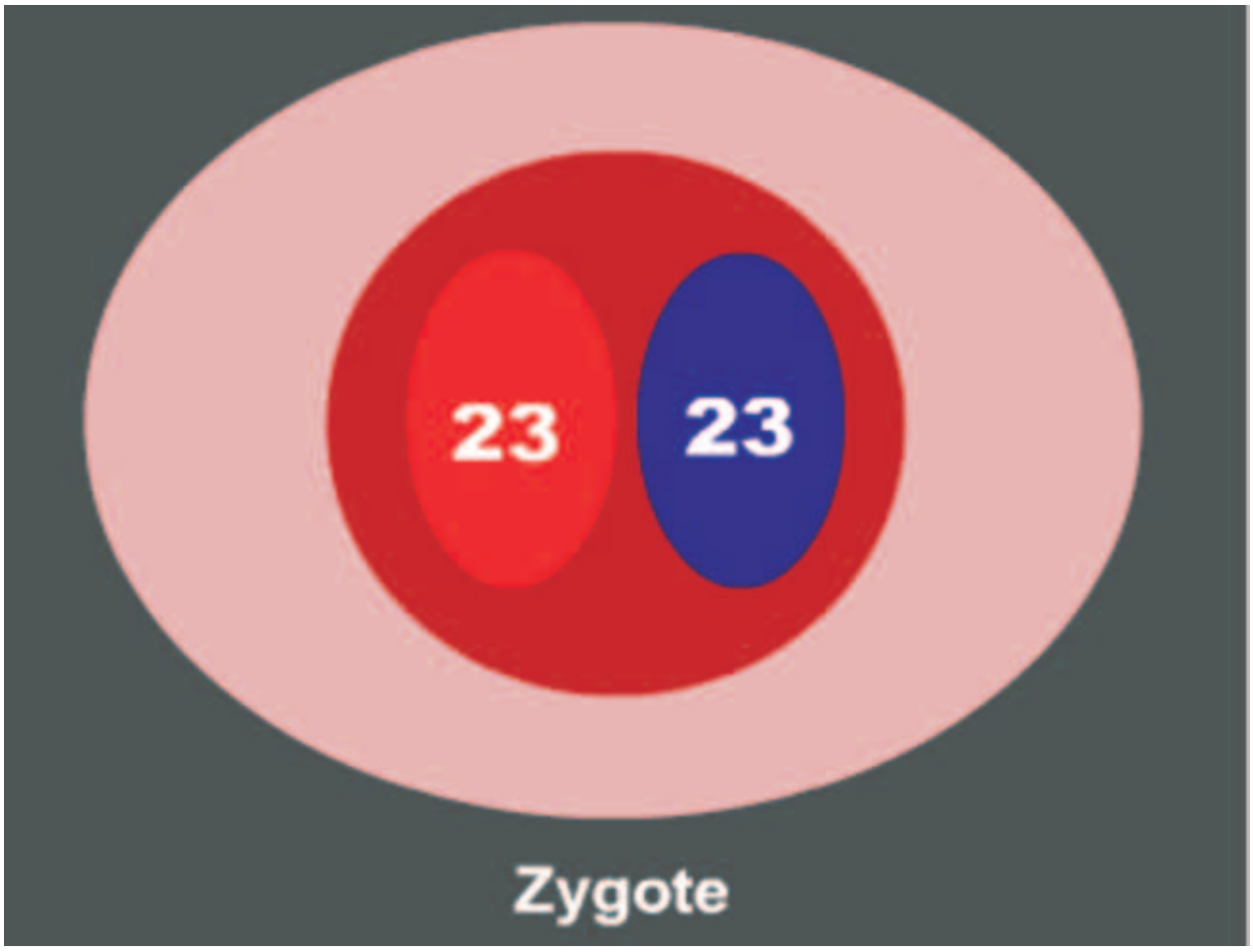
The environment we grow up and live in also helps define our traits. For example, while a person's genes may specify a certain hair color, exposure to chemicals or sunlight can change that color.

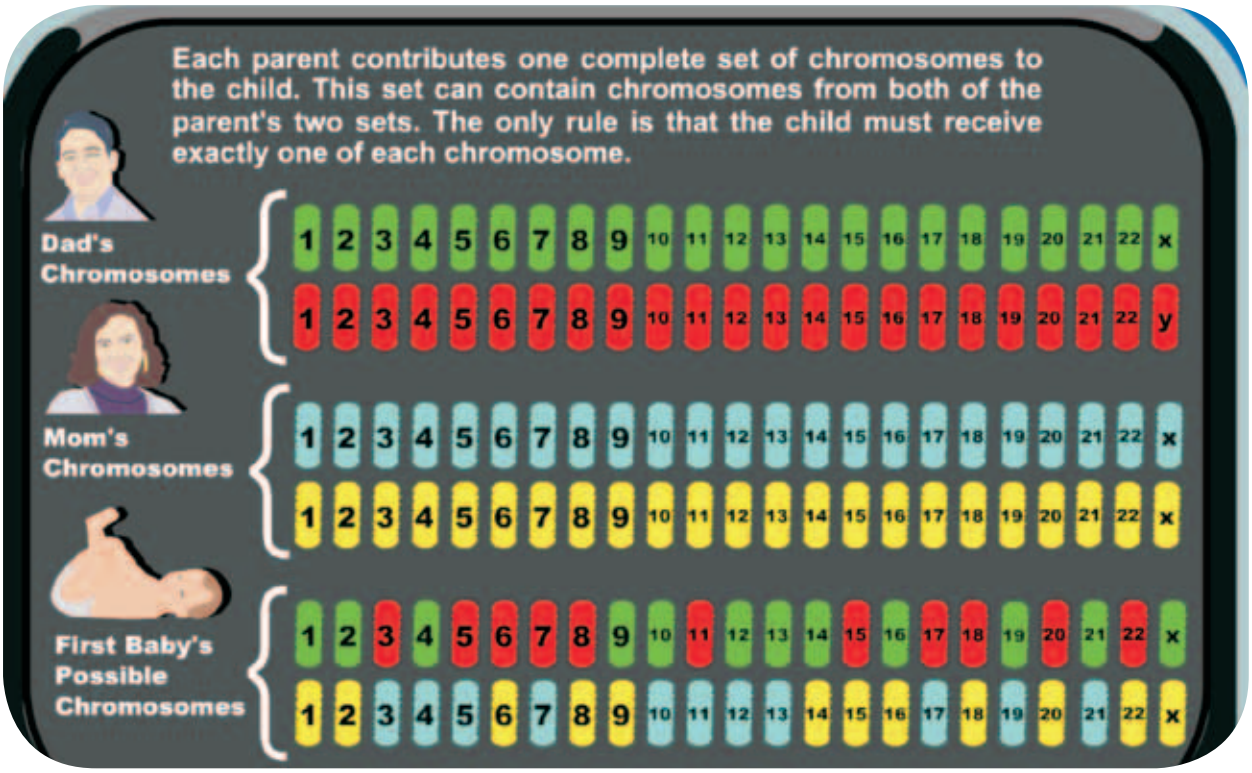
How do we get traits from our parents?

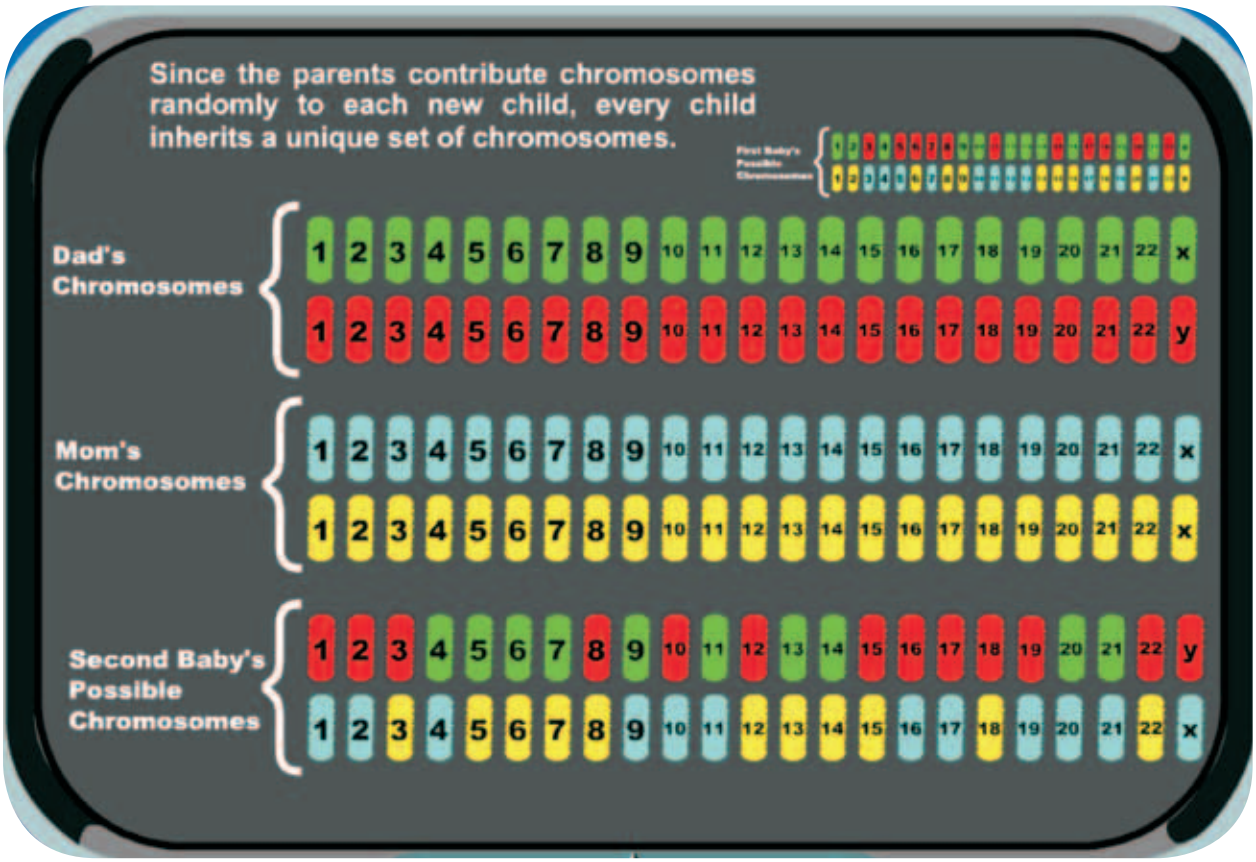
Humans have two complete sets of 23 chromosomes (2 x 23 = 46 total).

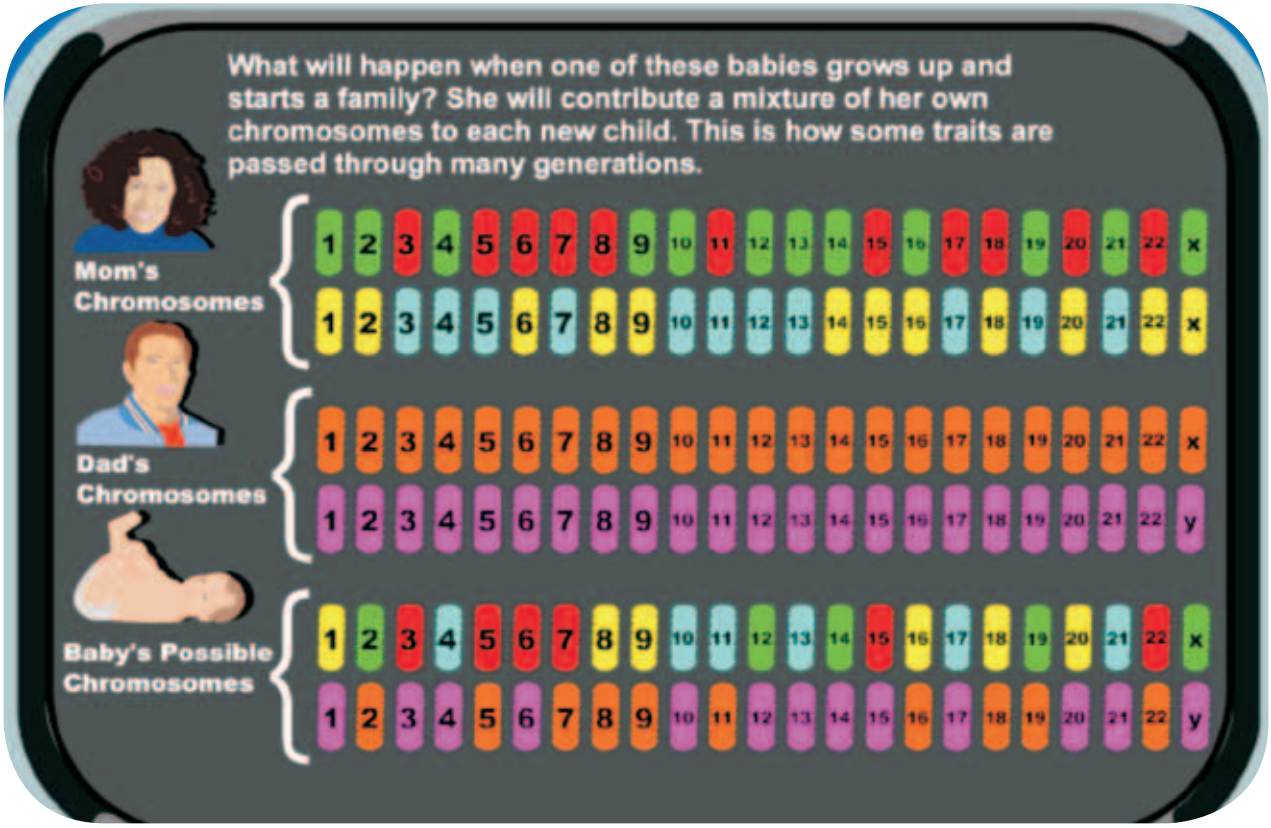
When parents conceive a child, they each contribute one complete set to the child. In this way, parents pass genes to the child.

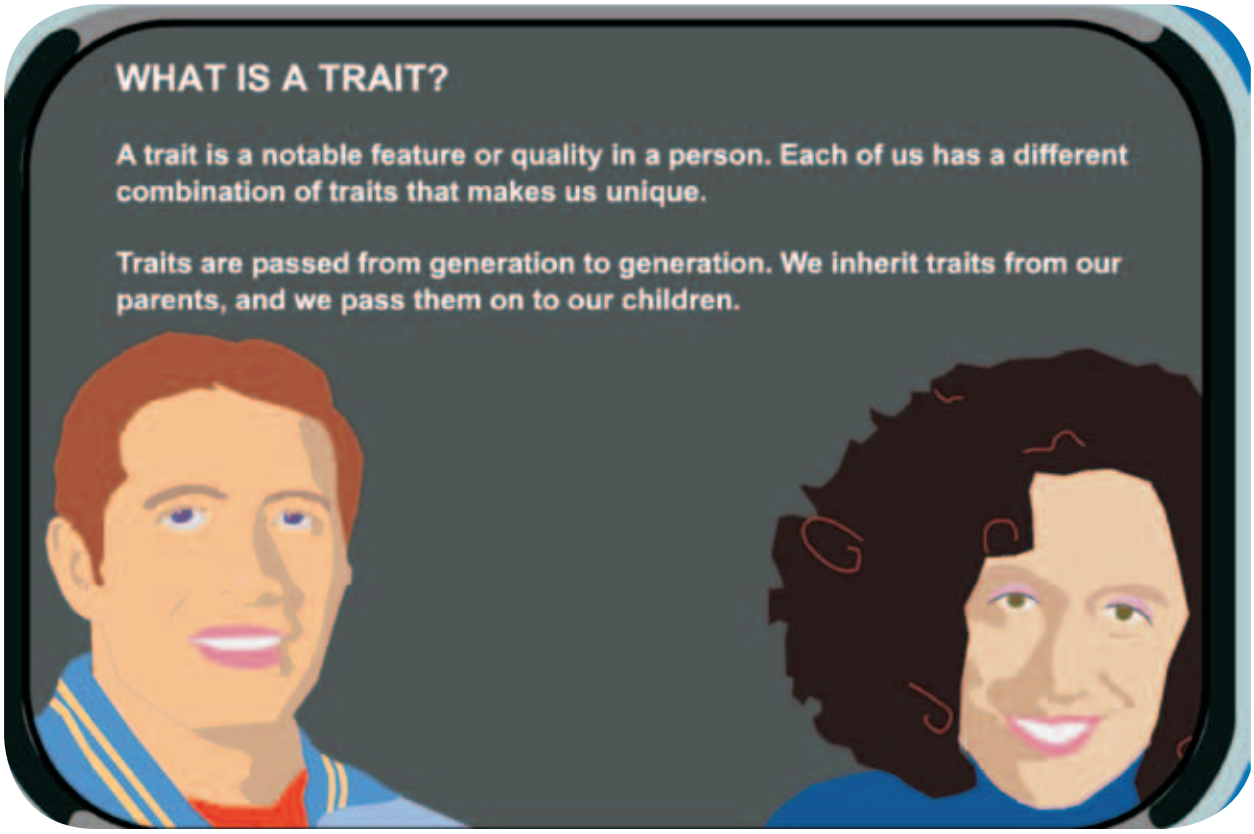

Every child receives half of its chromosomes from the mother and half from the father.
This transfer takes place at conception, when the father's sperm cell joins with the mother's egg cell.
While most cells in our bodies contain two sets of chromosomes (2 x 23 = 46), sperm and egg cells each have only one set (23). When they join, they create a single cell, called a "zygote" (ZY-goat), which has two sets of chromosomes (46).
This cell will divide, ultimately developing into a child.
23
Egg Cell
Sperm Cell

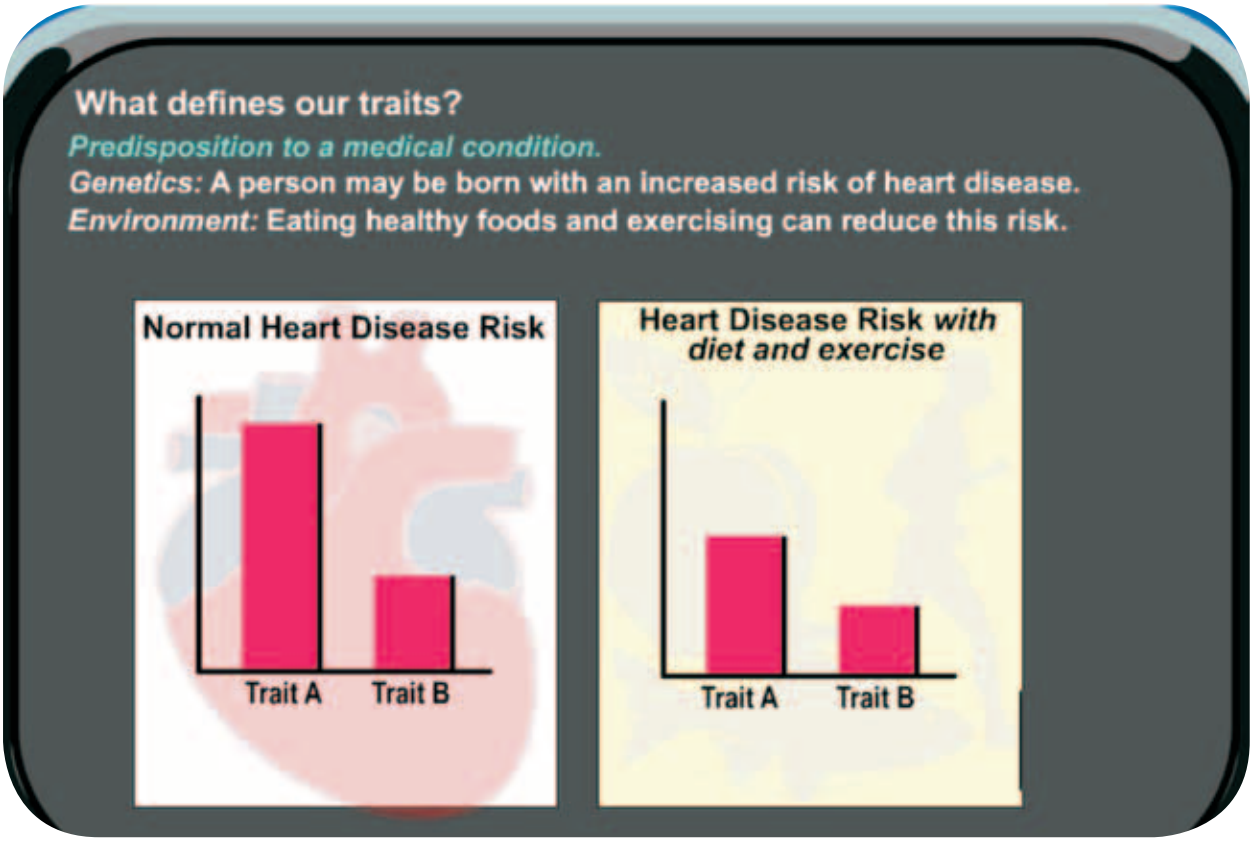

23
23
Zygote


Each parent contributes one complete set of chromosomes to the child. This set can contain chromosomes from both of the parent's two sets. The only rule is that the child must receive exactly one of each chromosome.
Dad's Chromosomes
Mom's Chromosomes
First Baby's Possible Chromosomes


Since the parents contribute chromosomes randomly to each new child, every child inherits a unique set of chromosomes.
Dad's Chromosomes
Mom's Chromosomes
Second Baby's Possible Chromosomes


What will happen when one of these babies grows up and starts a family? She will contribute a mixture of her own chromosomes to each new child. This is how some traits are passed through many generations.
Mom's Chromosomes
Dad's Chromosomes
Baby's Possible Chromosomes


WHAT IS A TRAIT?
A trait is a notable feature or quality in a person. Each of us has a different combination of traits that makes us unique.
Traits are passed from generation to generation. We inherit traits from our parents, and we pass them on to our children.



Thus, Environment has a role to play in manifestation of even a genetic disease

How are our traits determined?

Try to bend your thumb backwards at the joint. Some people can form at least a 45 degree angle, which is called a "hitchhiker's thumb." Other people have straight thumbs which do not bend in this way. Which one do you have?

Scientists describe the set of genetic information for each form as an allele (pronounced uh-LEEL).

We can describe the straight thumb allele with an "H" and the hitchhiker's thumb allele with an "h".

Straight Thumb (H)

Hitchhiker's Thumb (h)

How are our traits determined?

Each of us has two alleles for the thumb extension trait. As a result, we all have one of these combinations:

H + H =

H + h =

h + h =

How are our traits determined?

You can probably guess the trait in people who have two of the same allele:

Those with H + H will have straight thumbs.

Those with h + h will have hitchhiker's thumbs.

Scientists use the word "homozygous" (pronounced HO-mo-ZY-gus) to describe having two of the same allele for a trait.

H + H =

h + h =

H + h =

How are our traits determined?

But what about people who have one of each allele, or H + h? Will they have one straight thumb and one hitchhiker's thumb?

How are our traits determined?

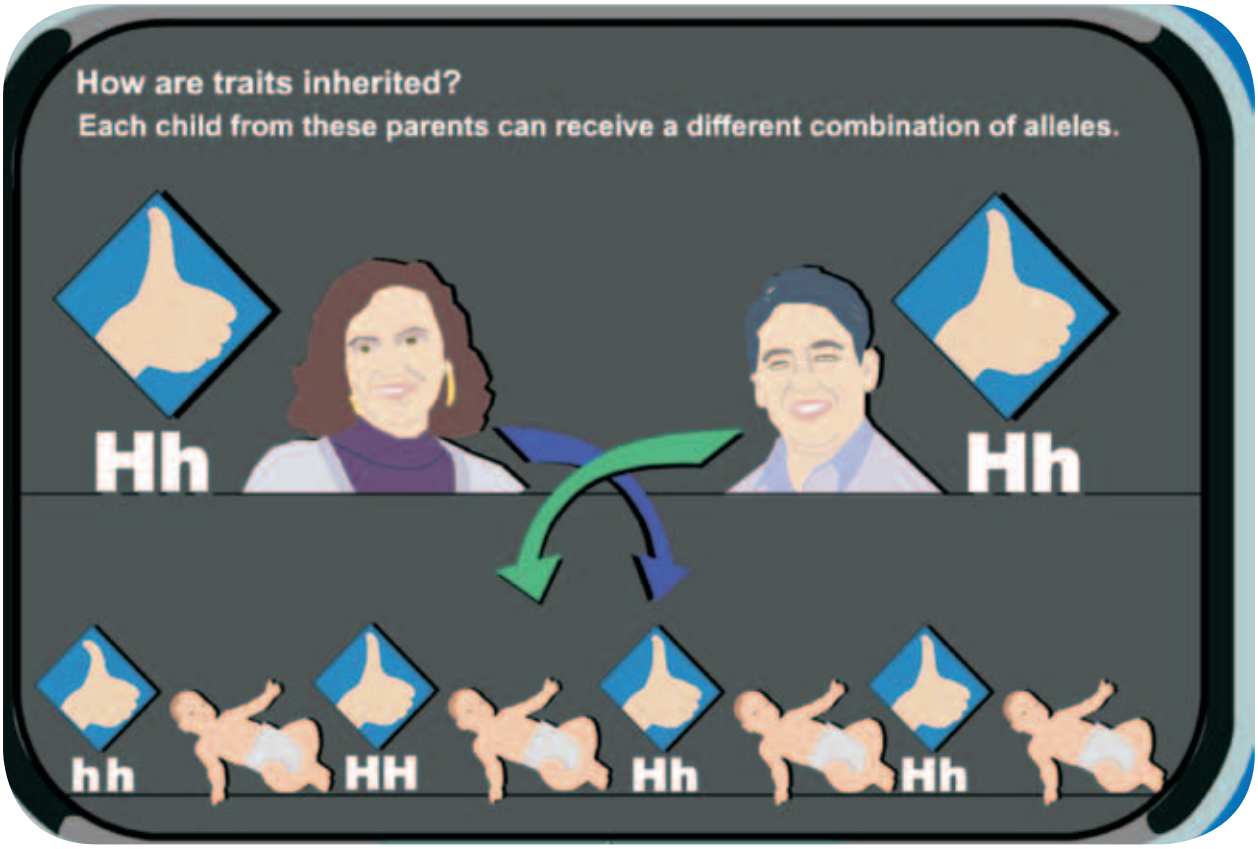
No. When two different alleles are present, they interact. For the thumb extension trait, the H allele masks the h allele. People with the H + h combination will have straight thumbs.

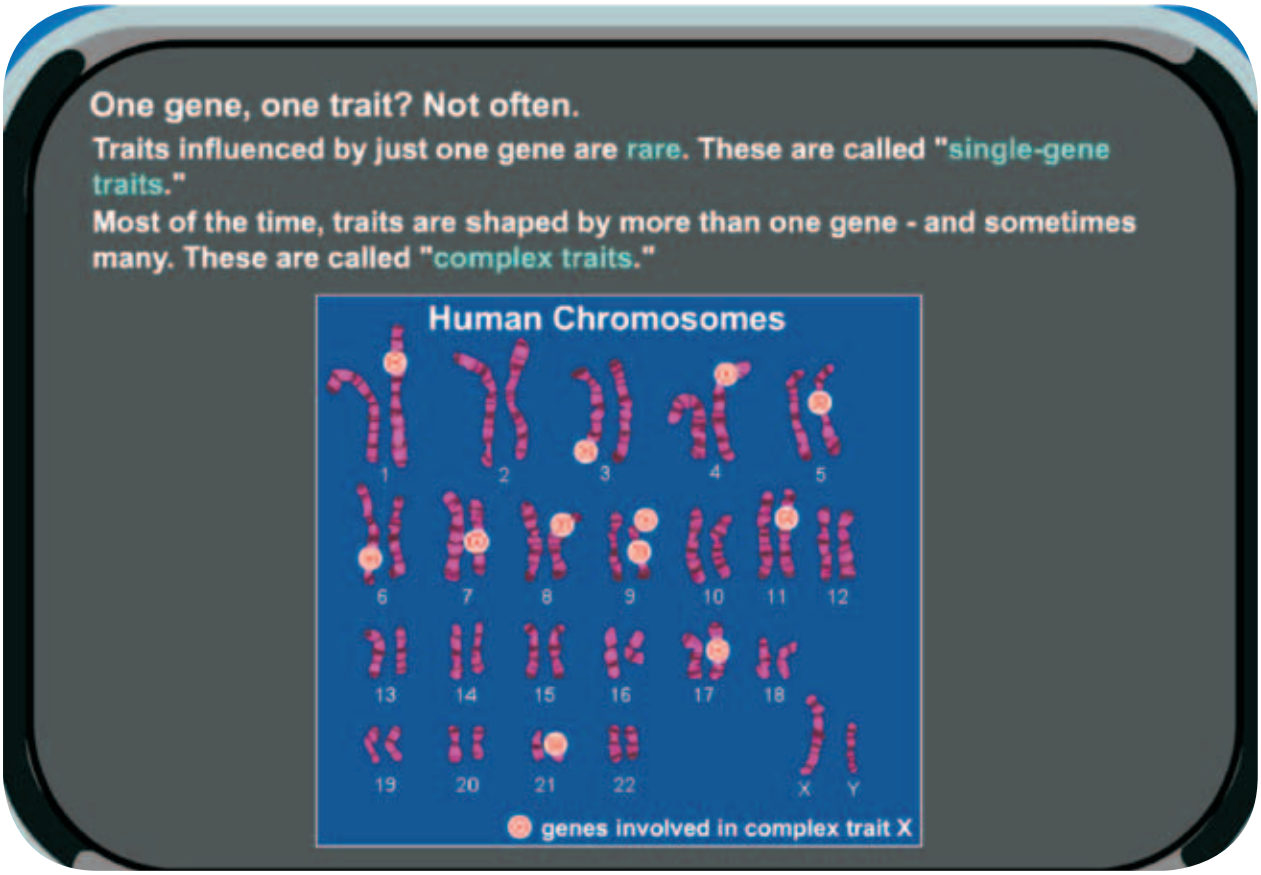
Hh

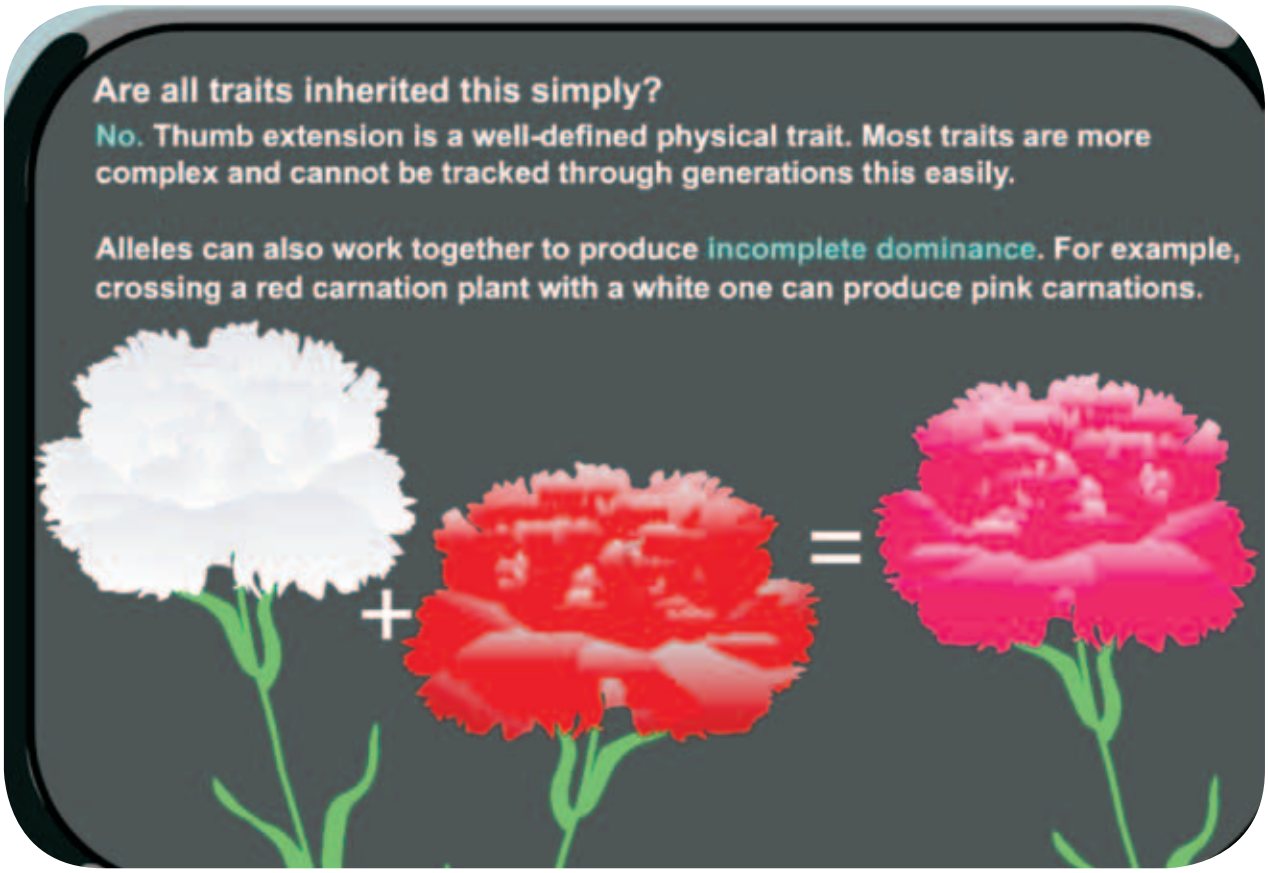
How are our traits determined?

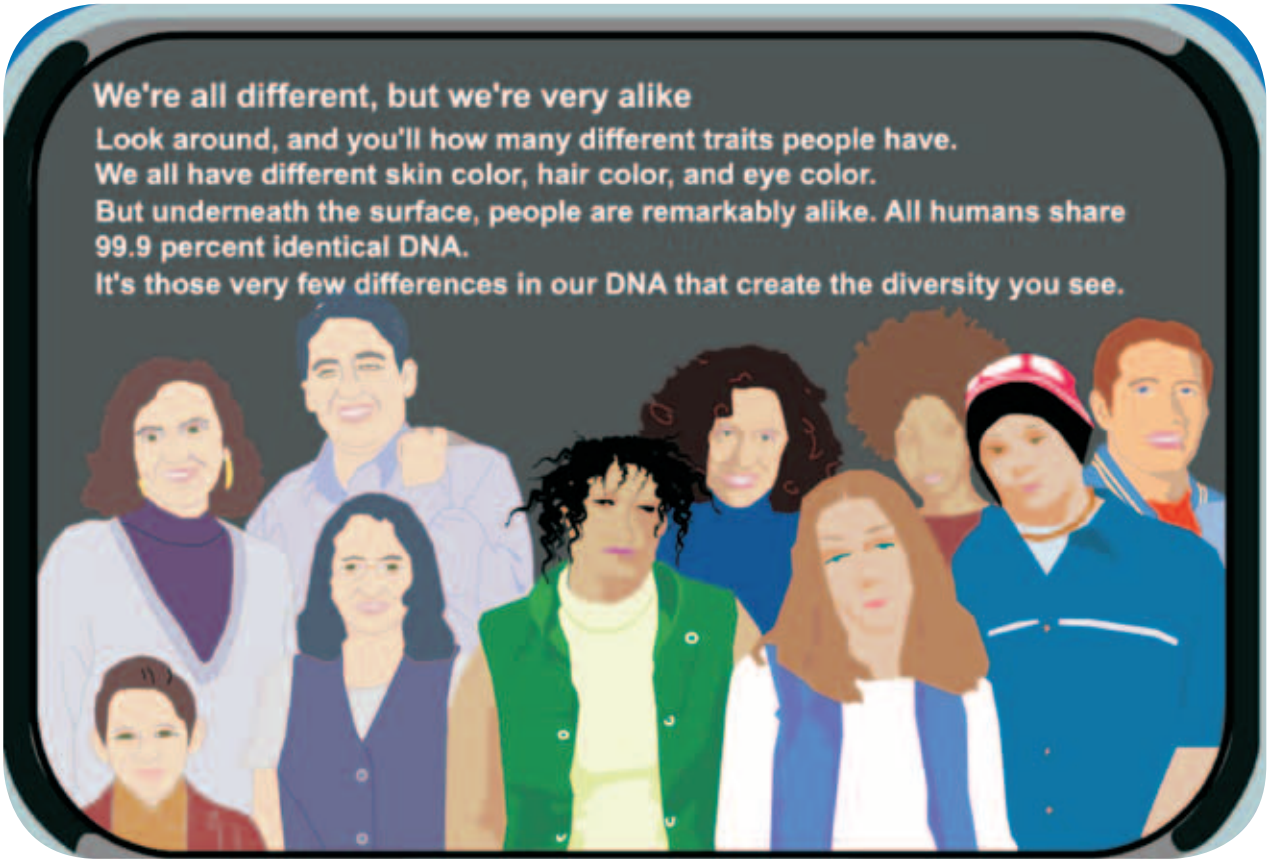
In this case, the H allele is called "dominant," and the masked "h" allele is "recessive".
Scientists use the word "heterozygous" (pronounced HET-er-oh-ZY-gus) to describe having two different alleles for a trait.

H *dominant* **h** *recessive*


How are traits inherited?
Each child from these parents can receive a different combination of alleles.
Hh
Hh
hh
HH
Hh
Hh


One gene, one trait? Not often.
Traits influenced by just one gene are rare. These are called "single-gene traits."
Most of the time, traits are shaped by more than one gene - and sometimes many. These are called "complex traits."
Human Chromosomes
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
X
Y
genes involved in complex trait X


Are all traits inherited this simply?
No. Thumb extension is a well-defined physical trait. Most traits are more complex and cannot be tracked through generations this easily.
Alleles can also work together to produce incomplete dominance. For example, crossing a red carnation plant with a white one can produce pink carnations.
+
=


We're all different, but we're very alike
Look around, and you'll how many different traits people have.
We all have different skin color, hair color, and eye color.
But underneath the surface, people are remarkably alike. All humans share 99.9 percent identical DNA.
It's those very few differences in our DNA that create the diversity you see.

GENES AND DISEASE

Genes are responsible for inheritance of all traits, in an individual. They play an important role in the causation of disease. Most diseases occur due to a complex interaction between environmental and genetic factors. Some diseases occur primarily due to genetic factors. It is important to understand where and how genes exist in our body and how they cause disease.

Cell is the smallest structural unit in the body. Every cell has a nucleus that contains DNA – the genetic material.

DNA in every cell in the body is alike though, functions of all cells in the body are not alike. For example, cells in liver, brain, heart, kidney, blood and other organs have different functions but the DNA in all is similar, in an individual.

- **Mature red blood cells, in circulating blood, do not contain nucleus or the DNA**

  One set of chromosome is obtained from the egg of mother and other set from the sperm of father to form a paired set of 23 chromosomes. **Thus, genes and chromosomes exist in pairs.**

- 22 pairs are alike and are called as autosomes, 23rd pair is known as sex chromosome which is XX in females and XY in males

Chromosomal disorders:

Disorders occurring, due to chromosomal aberrations, are called as chromosomal disorders. These aberrations may be structural or numerical defects occuring in chromosomes.

- There may be loss or gain of a part or whole of chromosome.
- Chromosomal defects are usually not inherited but remain limited to the individual

A gain of chromosome in the 21st pair of chromosome in the condition called Trisomy 21 results in Down syndrome, the commonest cause of mental retardation.

Genetic Disorders:

Genes are situated on chromosomes.

- Genes are made up of codons;
- Each codon consists of three nucleic acids;
- Each gene codes for a protein. In other words, a sequence of nucleic acids on the chromosome that codes for a protein is called as 'gene' sequences of nucleic acids;

Genetic defect is any change, deletion or insertion in the sequence of nucleic acids. This is called 'mutation'

Genetic Disorders are caused by defects or 'mutations' in genes. Defects in multiple genes lead to complex disorders having multi-factorial inheritance but when disorders are caused

by mutations in single genes, inheritance is in simple Mendelian fashion and risks can be predicted.

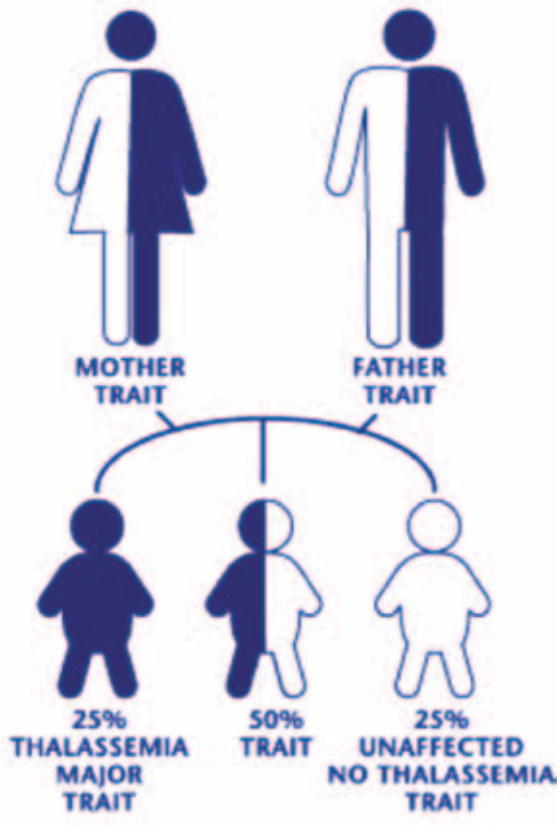
Single Gene Disorders

- Mutation can be Dominant or Recessive;
- Dominant mutation- mutation in one gene of a pair causes disease;
- Recessive mutation- defect in both genes of a pair causes disease;
- Diseases due to recessive mutation have a carrier (trait) state and a disease state;
- Carriers pass the trait to next generation;

Types of Inheritance

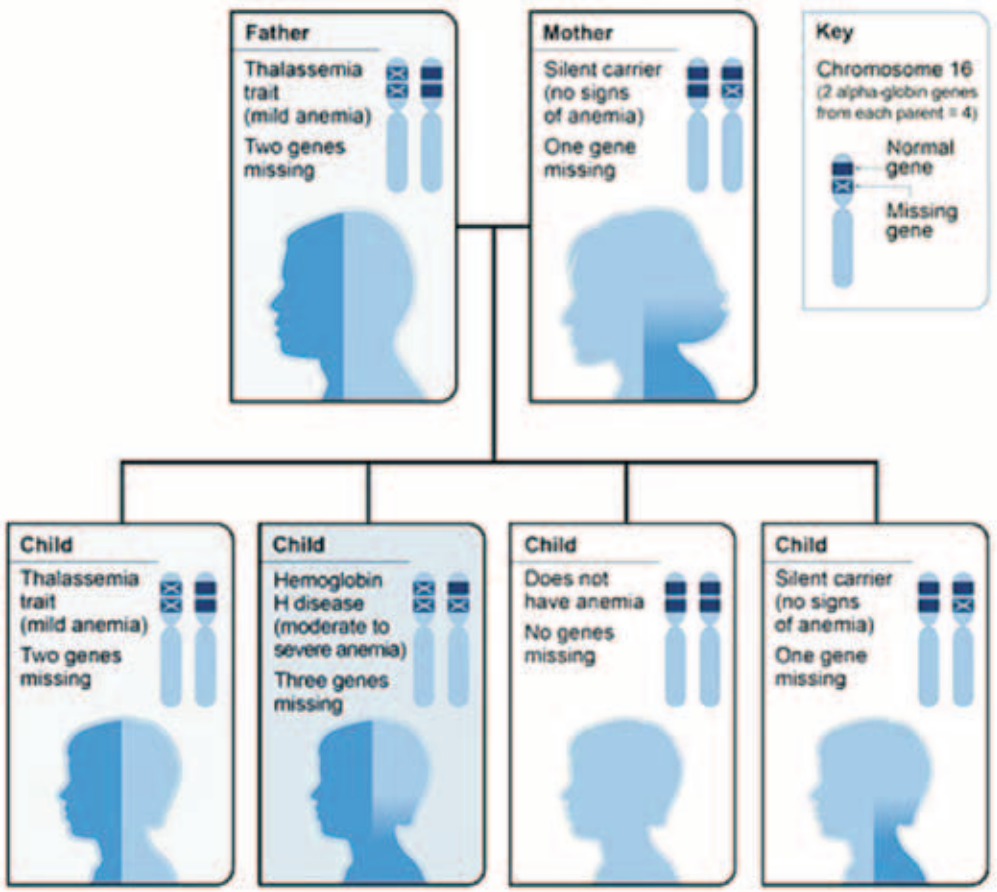
- Autosomal dominant
- Autosomal recessive
- X-linked dominant
- X-linked recessive (Gene on X chromosome)
- Y- linked (Gene on Y chromosome)

Carrier screening of populations can be applied for control and prevention of autosomal and X-linked recessive disorders.

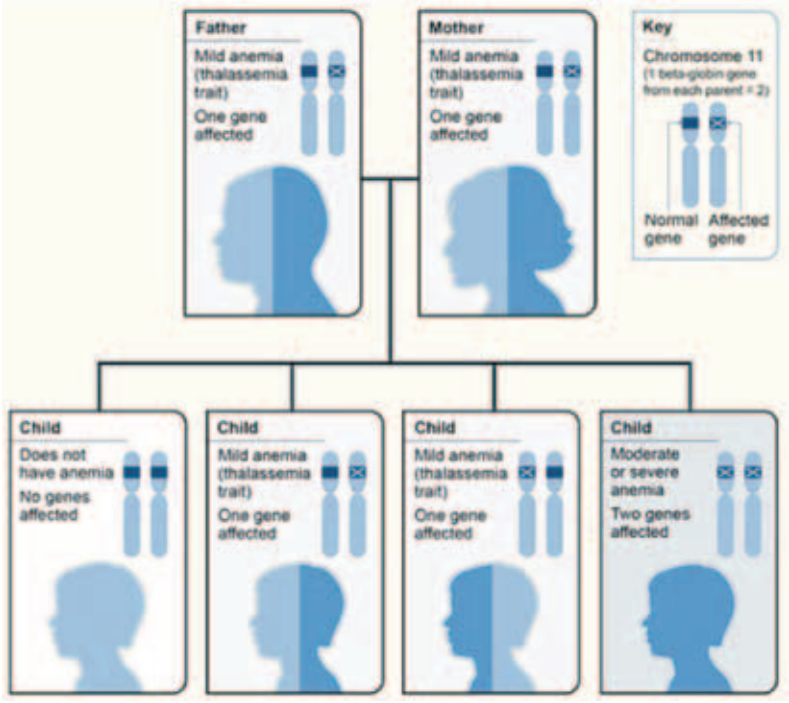


1) Alpha thalassemia has normally 4 genes: 2 from each parent : on chromosome no. 16

2) Beta thalassemia has normally 2 genes : 1 from each parent: on chromosome no. 11



Beta thalassemia with 2 genes



Hemoglobin E or haemoglobin E (HbE) is an abnormal hemoglobin, with a single point mutation in the β chain. At position 26 there is a change in the amino acid, from glutamic acid to lysine. Hemoglobin E has been one of the less well known variants of normal hemoglobin. It is very common in certain parts of India, but has a low frequency amongst other races. HbE can be detected on electrophoresis.

Hemoglobin E disease: Hemoglobin E disease results when the offspring inherits the gene for HbE, from both parents. At birth, babies are normal though the child has inherited defective gene for the hemoglobin E from both parents, however, later on they have a mild hemolytic anemia and mild splenomegaly.

Hemoglobin E trait: It occurs when the gene for hemoglobin E is inherited from one parent and the gene for hemoglobin A, from the other. This is called hemoglobin E trait, and it is not a disease. People who have hemoglobin E trait are asymptomatic and their state does not usually result in health problems. They may have a low mean corpuscular volume (MCV) and very abnormal red blood cells (target cells). Its clinical relevance is exclusively due to the potential for transmitting E or β thalassemia.

Hemoglobin E/β-thalassemia: People who have hemoglobin E/β thalassemia have inherited one gene, for hemoglobin E from one parent and one gene, for β thalassemia from the other parent. Hemoglobin E/β thalassemia is a severe disease, and it still has no universal cure. It affects more than a million people, in the world. The consequences of hemoglobin E/β thalassemia when it is not treated can be heart failure, enlargement of the liver, problems in the bones, etc.

Autosomal recessive Inheritance

- If one of the parents is carrier then there is a possibility of 50% healthy progeny and 50% carriers.
- If both the parents are carriers then there is a possibility of 50% carrier, 25% healthy and 25 % having a child with disease.

X- Linked Recessive Inheritance:

- Defective gene on X chromosome.
- Females are usually carriers.
- Males are affected.
- Examples- G6PD deficiency, Hemophilia, muscular dystrophy.

Genetic counseling in case of genetic disorders:

- Family history- disease occurring in any family member related biologically;
- If autosomal disease and the carrier state is detectable, advise pre-marital testing to avoid marriage between two carriers and post marital testing to avail prenatal diagnosis followed by termination of pregnancy;
- If X- linked disease, advise screening of female members, for carrier state;
- Multifactorial inheritance: advise Avoidance of environmental and nutritional risk factors associated with disease;
- Modulation of lifestyle to counter genetic predisposition;
- Regular checkups for early detection;

Defects at Birth

Questionnaire on 'Defects at birth':

1. Which of the following is not a birth defect?
   (a) Neural tube defect
   (b) Cleft lip and palate
   (c) Congenital cataract
   (d) Rickets

2. Which of the following statements is true?
   (a) Every three seconds, a baby is born, with a major birth defect, in India
   (b) Every three minutes, a baby is born, with a major birth defect, in India
   (c) Every three hours, a baby is born, with a major birth defect, in India
   (d) Every three days, a baby is born, with a major birth defect, in India

3. Which of the following statements is true?
   (a) Up to 20% of birth defects can be prevented
   (b) Up to 50% of birth defects can be prevented
   (c) Up to 70% of birth defects can be prevented
   (d) Up to 90% of birth defects can be prevented

4. When is the best time to take adequate precautions, for preventing birth defects?
   (a) Just after delivery
   (b) At the time of marriage
   (c) During antenatal care period (pregnancy)
   (d) During adolescence

5. Which of the following are preventive strategies, for birth defects?
   (a) Taking a multivitamin with folic acid and avoidance of alcohol and smoking, during pregnancy
   (b) Maintaining healthy weight and having regular antenatal check-ups
   (c) Awareness about family history and genetic risks
   (d) All of the above

*** The trainer should ask the participants to go through the questionnaire before, the beginning of the session and note down their responses. The answers, of these questions, should be covered during the training session.**

Instructions for the trainer:

The session has to be divided in, basically, three parts:

I. Introduction Session (15 minutes)

II. Understanding the basics

III. Learning the tools

General Instructions

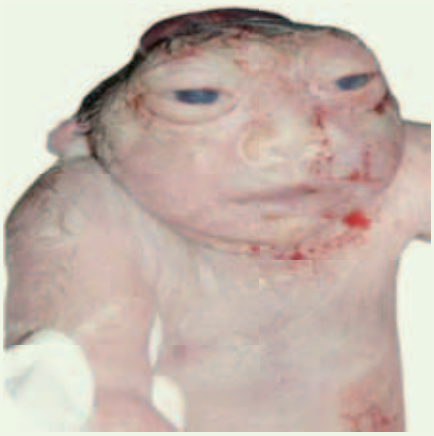
Before starting the training the trainer should keep the following points, in mind:

1. Training material that should be available, at training site: Rectangular paper, glue, medium size bowl (katori), a lawn tennis ball, a small thin
2. The training should make the session as interactive as possible
3. Use of pictures before, in the middle and at the end of the teaching session, can help them understand, this complex topic better.

I. Introduction Session

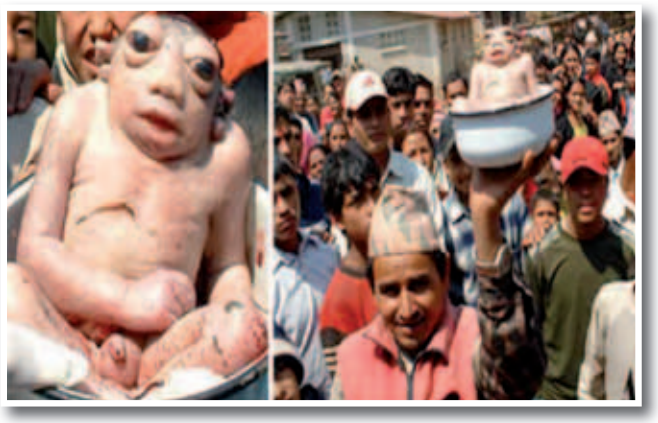
- The trainer must show pictures to the trainees and gather their views about the understanding of what the picture is suggestive of;
- Response of the trainees has to be documented on the white board/chart paper;
- Later, while summing up the introduction session the trainer must compile the views and co-relate it with the key messages provided, in the manual and discuss it with the participants;

Session 1A



- Have you ever seen this, human form, before in your area/locality?
- If yes, what came to your mind when you first saw this?
- What were the responses of the community?

***Instruction for trainer**- Capture responses of a minimum of 7-10 trainees and document them;

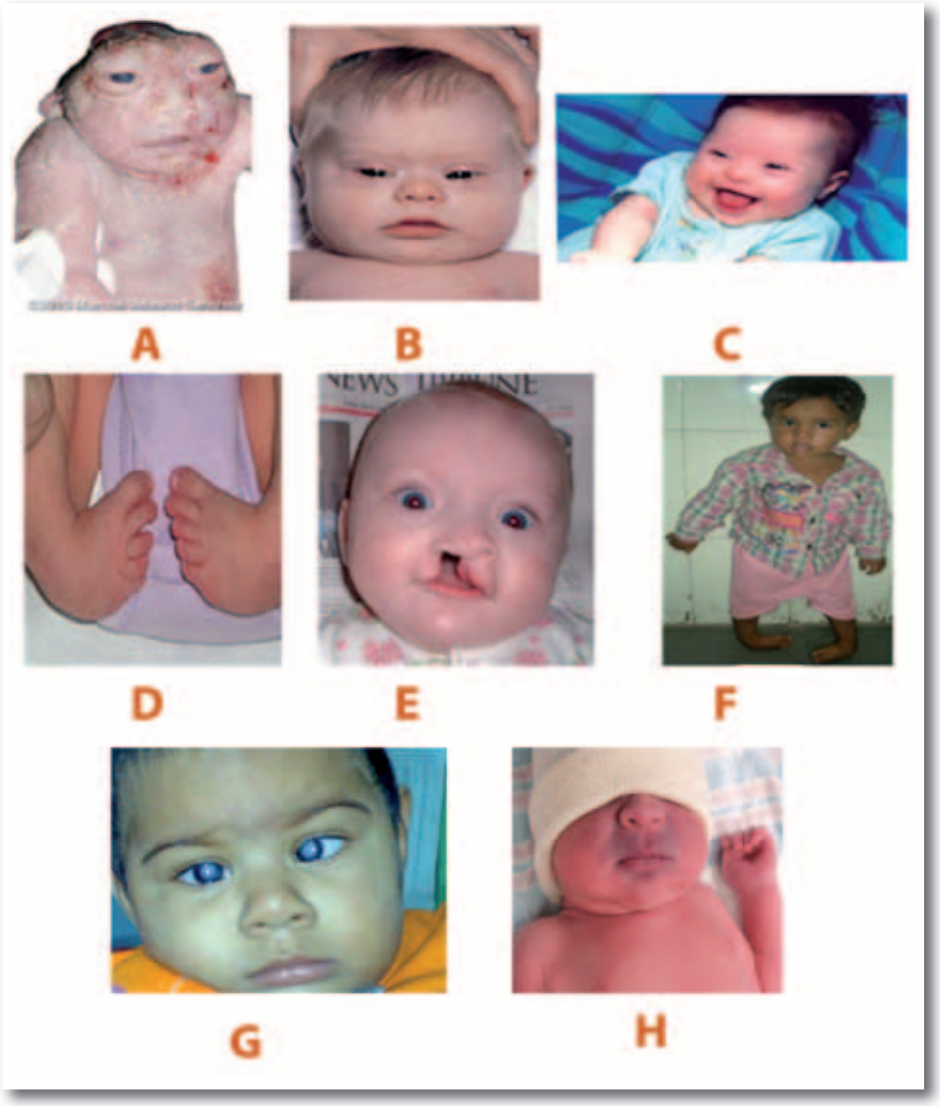


Key Messages by the facilitator

- Can Happen to anyone, regardless of economic status;
- Parents should not be blamed;
- Communities' perspective, beliefs, myths (result of past wrong doings), should be rationally explained to the trainees;
- Some of the birth defects can get cured, through timely intervention;
- RBSK program envisages timely referral to DEIC and for further evaluation and treatment;

Session 1B

Observe the pictures and identify the anomalies



Answers:

Fig A is anencephaly

Fig B and C is Down's syndrome

Fig D is Club foot

Fig E is Cleft lip /Cleft palate

Fig F Child is again a Club foot

Fig G Child has Congenital Cataract

Fig H Child with Cyanotic Heart Disease

Session 2: Birth-defect or Defect at Birth

1.1 Introduction

1.2 Birth defects are structural or functional abnormalities, present at birth, that can cause physical or mental disability, some may be fatal. Example if a child is born with cleft lip or palate, this is a structural defect, but because of this the child has feeding or speech problem, this is the functional defect and if not corrected this can lead to disability.

The prevalence of birth defects is 4-6 percent[3] among live births, globally, as well as in India. Birth defects may affect a single organ of the body or be present as multiple organ defect. Both genetic and environmental factors play a role in their pathogenesis. The families with previous history of birth defects have a higher chance of birth defect in subsequent pregnancy.

Major Contributors

1. **Genetic**-Caused when one or more gene doesn't work properly;
2. **Environment**-Women exposed during pregnancy to Rubella/German measles, alcohol, smoking, drugs - painkillers, anti-depressant, drugs for asthma-corticosteroids, anti-convulsants, medicines for thyroid diseases, uncontrolled diabetes and obesity in mother;

Some common birth defects are

- Neural tube defect
- Down's Syndrome
- Cleft Lip & Palate / Cleft palate alone#
- Club foot
- Developmental dysplasia of the hip
- Congenital Heart Diseases
- Congenital cataract

1.3 Prevention of birth defects:

Defects present since birth can be major anomalies, visible at birth, requiring immediate attention or invisible, internal organ defects, which may be missed and brought to light later on in life. 70% of birth defect can be prevented during antenatal period through regular check and care.

- Taking 5 mg of folic acid daily, starting from the day of marriage till 3 months after testing positive for pregnancy. This will prevent neural tube defect in the newborn;

[3] March of Dimes, 2006 Global Report

- Regular Antenatal checkup at least three times during pregnancy-
    1. Identification of and keeping diabetes under control;
    2. History of anticonvulsant drug like valproate; Use of medicines during pregnancy is found to increase risk for birth-defect;
    3. Medication--Mothers taking painkillers, anti-depressants, drugs for asthma-corticosteroids, anti convulsants, medicines for thyroid diseases, must discuss with the doctor during antenatal visit;
- Family members to maintain positive environment at home by avoiding any maternal stress and domestic violence;
- Maintain good hygiene by adopting safe sex practices and personal hygiene to prevent infection during pregnancy;
- Immunizations like Rubella vaccine[4] if given during adolescence can prevent a mother against certain infections, which in turn would prevent some birth defects;
- Smoking and alcohol consumption to be strictly avoided, during pregnancy;
- Contact with cats to be avoided, during pregnancy (To prevent Toxoplasmosis infection);
- Maintain a healthy weight;

Frequently Asked Questions

1. What is a birth defect?

A "birth defect" is a health problem or physical change, which is present in a baby at the time he/she is born. Birth defects can be mild, where the baby looks and acts like any other baby, or birth defects may be very severe. Some birth defects affect single organ while others affect multiple organs of the body. A few birth defects are visually easy to identify like cleft palate some others like congenital heart disease cannot be identified, without the knowledge of signs and symptoms.

Birth defects are also called "congenital anomalies" or "congenital abnormalities." The word "congenital" means "present at birth." The words "anomalies" and "abnormalities" mean that there is a problem present, in a baby.

2. What are the genetic and environmental causes of birth defects?

When a baby is born with a birth defect, the first question usually asked by the parents is "how did this happen?" Sometimes, this question cannot be answered. This can be very upsetting, for parents, because, it is normal to seek an answer as to why your baby has a health problem. For some birth defects, however, there is a known cause, which may have to do with either genetic or environmental factors, or a combination of the two. Here is some general information and terms related to the different causes of birth defects:

[4] This is not part of current RI program in the country

Inheritance

Inheritance is a word used to describe a trait given to you or "passed on" to you from one of your parents. Examples of inherited traits would be your eye color or blood type.

Chromosome abnormalities

Chromosomes are stick-like structures in the center of each cell and a change in its normal structure can lead to birth defects. For example Down syndrome is caused, generally, by mutation in chromosome 21.

Teratogens

A teratogen is an agent, which can cause a birth defect by affecting chromosomes/genes usually, in the first trimester. It could be a medication, a substance of abuse, alcohol, or an infectious viral disease like rubella (typically presented by fever with rashes and which can affect anybody), radiation exposure.

3. Why are birth defects a concern?

Birth defects are a concern as some of them cause life-long disability and illness, and with some, survival is not possible. Some birth defects that result in mentalretardation, may become completely irreversible if not intervened in, medically, in time. Early detection and management can help a child lead near normal life . Many physical defects, if detected early, can be treated with surgery, including cleft lip or palate, and certain heart defects.

Key Messages for Community

1. Birth defects can occur, in any family, regardless of economic status or education or social background;
2. Up-to 70% of Birth defects can be prevented;
3. A family can increase its chances of having healthy babies by promoting women's health conditions and adopting healthy behaviors, before she conceives;
4. Family must ensure that all pregnant women must get registered with a health worker, at the earliest, and undergo regular Ante-natal checkups;
5. A pregnant woman, in her first trimester, must consume folic acid, daily, to prevent birth defects in the newborn;
6. Couples' family history is important and marriage among close relatives must be avoided especially, in families with history of birth defects;
7. Minimizing unnecessary medication exposure and radiation exposure/smoking/ alcohol in pregnancy;
8. Contact with cats, during pregnancy, must be avoided;

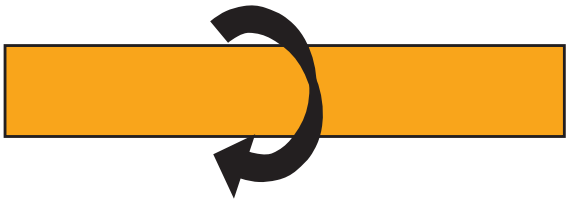
1. Neural Tube Defects

Introduction

Neural tube defect (NTD) is birth defects of the brain and spinal cord. NTDs occur when the neural tube, the structure that develops into the brain and spinal cord, fails to close completely. NTDs may occur in the first few weeks, after conception.

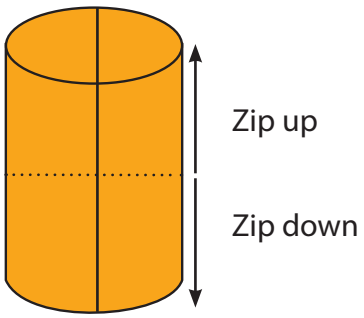
Exercise one

1. Take a rectangular paper roll it along the longer edge side;

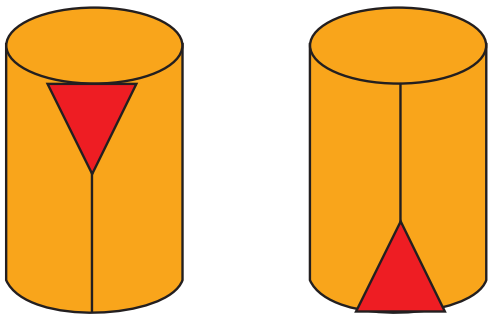


2. Make a tube by applying glue;
3. Put a nick, at the top end, in the middle and at bottom;
4. Ask the participants what will happen if, there was something inside the tube and these nicks were made;
5. This will help them understand neural tube defect better;
6. ***Remember Zip up & Zip down!**

The facilitator should highlight that the neural tube is formed before the mother comes to know about the pregnancy and hence it is important that she consumes folic acid (which is a vitamin, which is not stored in the body and hence has to be replenished every day), before she conceives/or plans to conceive. The defect at the top results:

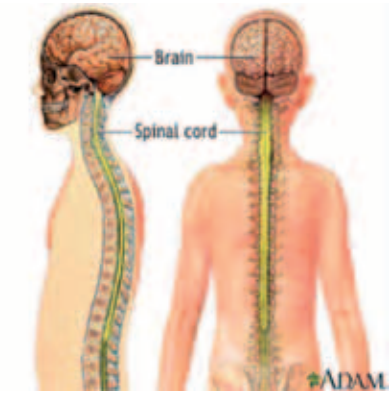


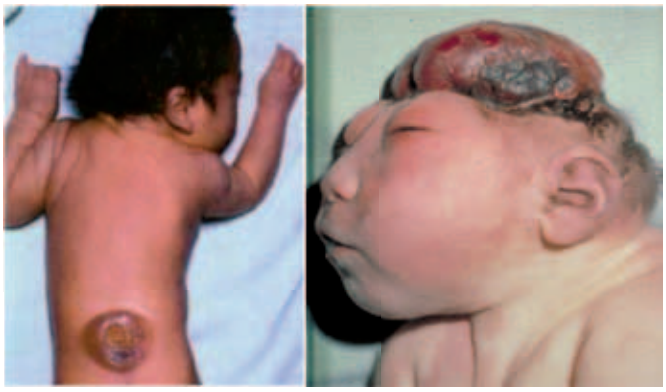
Normal (Fused Neural Tube)



Neural Tube with Defect Non fusion in upper and lower ends

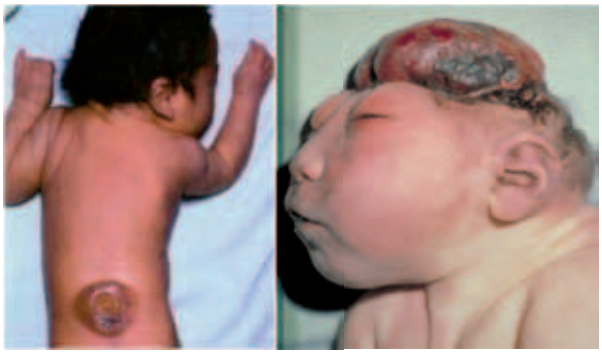
Picture





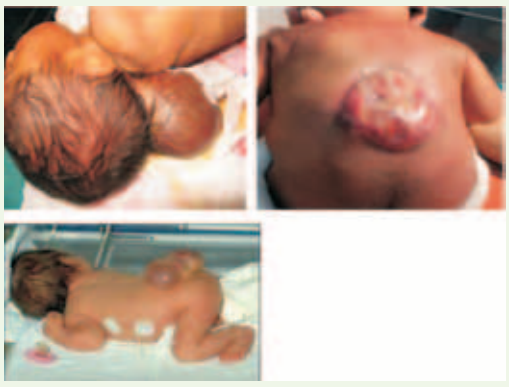
Types of NTDs: The two most common neural tube defects are spina bifida and anencephaly /meningomylocoele.

1. In spina bifida, the tube doesn't close completely during the first month of pregnancy. There is, usually, nerve damage that causes at least, some paralysis of the legs;
2. In anencephaly, much of the brain does not develop. Babies with anencephaly are either stillborn or die shortly after birth.



Spina Bifida Anencephaly

Signs and Symptoms-(At Birth –Delivery points)

Look	• Where is the swelling? Back or head? • How does it look like? Refer picture. • Is there any discharge from the back? • Can the child move both the lower legs? • Is there constant leakage, of stool, through the anal opening?	

Perform	• Examine the trunk, along with spontaneous movement of the legs, • To differentiate between reflexive and purposeful limb movement • Take a pin, for a mild painful stimuli, prick in the foot and look for a withdrawal movement

Action

- Handle the infant with a sterile, non-latex gloves and with sterile clothing and sheets.
- Cover the defect with non-adhesive dressing wet with sterile Ringer's lactate solution or saline.
- Refer to district hospital /nearest referral point with facility, for tertiary care

Key Messages to the Community

- Expectant mothers and their families must be counseled, on the importance of folic acid. Advise women to take a dose of 5 mg folic acid daily, after marriage, and to continue until they are 12 weeks pregnant (First Trimester). Please remember, Folic Acid should be taken regularly as it is, usually, not stored in our body.
- Pregnant women, already, having diabetes or those who are under anti-convulsant treatment must be advised to take 5 mg of folic acid and supplement with folic acid rich food like green leafy vegetables.
- Inform, an expecting mother, that alcohol and smoking in any amount, at any time of pregnancy, is harmful.

2. Down's Syndrome

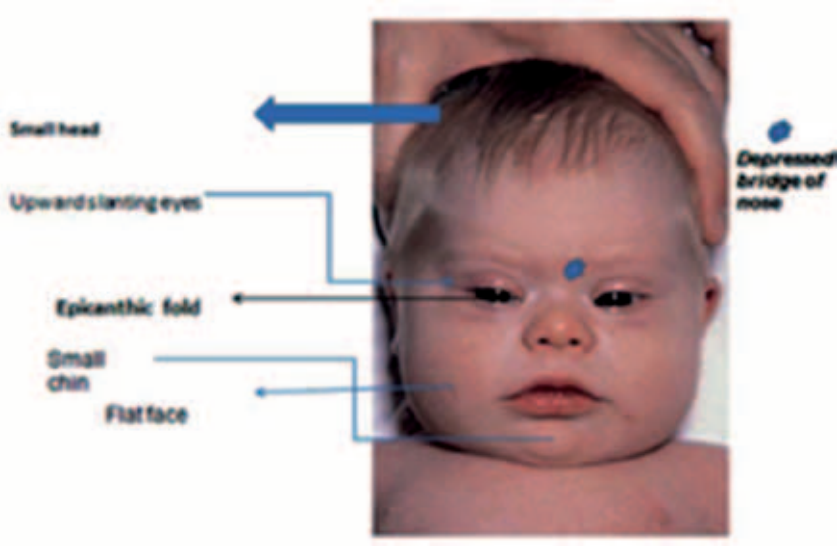
2.1 Introduction

Down syndrome is a genetic condition. The commonest form of Down syndrome is called Trisomy 21. The condition leads to problems in the way the body and brain develop. Down's syndrome is the most common single cause of human birth defects. It affects about 1 in every 800 babies. The chance of having a baby with Down syndrome increases significantly with the mother's increasing age. However in our country majority (in terms of absolute numbers) of Down Syndrome is contributed by mothers of younger age group. Children with Down syndrome have a widely recognized appearance. Physical and Mental development is often slower than normal. Most children with Down syndrome never reach, their average adult height.

Points to remember

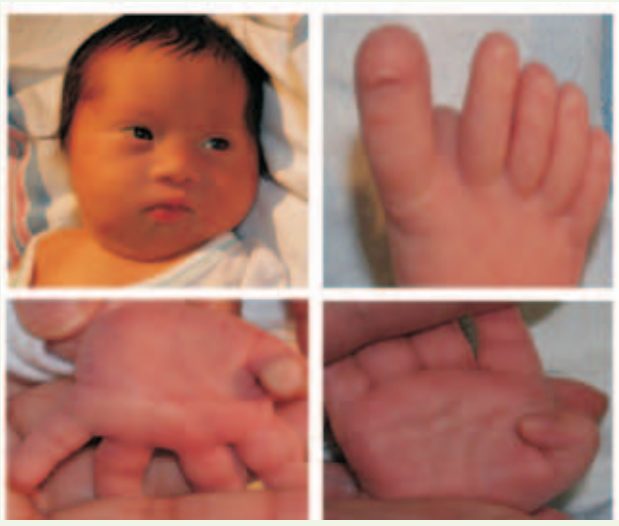
- About 50 percent of babies with Down syndrome have a congenital heart defect. Some defects are minor and may be treated with medications, while others may require surgery.
- Children with Down syndrome are at increased risk of thyroid problems, which they may develop at any time, in life (30%). Regular screening for hypothyroidism is helpful as it can be treated otherwise, it would increase the mental retardation.
- The degree of mental retardation that accompanies Down syndrome varies widely, ranging from mild to moderate to severe. However, most mental retardation falls within the mild to moderate range. They can be educated with some special effort.
- Children with Down syndrome are also at increased risk for visual and hearing impairment.
- Common visual problems include crossed eyes, near- or farsightedness, and cataracts, which can be treated.
- Physical and Mental development is often slower than normal.

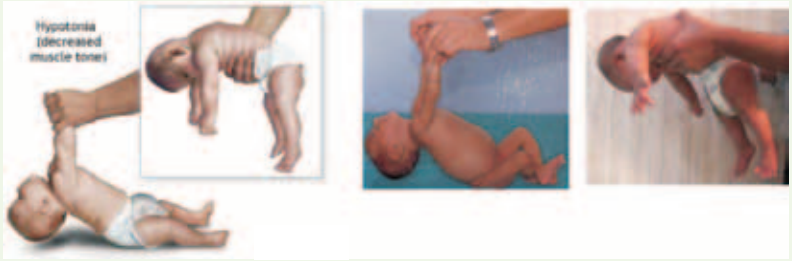
Can you spot any difference between these two babies?



The name Down Syndrome comes from the physician Dr Langdon Down, who first described the collection of findings in 1866.It was not until 1959 that the cause of Down's Syndrome (the presence of extra #21 Chromosome) was identified.

2.2 Signs and Symptoms

Look	1. The head may be smaller than normal and abnormally shaped. 2. Upward slanting eyes and inner corner of the eyes may be rounded instead of pointed.  3. Small ears 4. Flattened nose 5. Small mouth 6. Excess skin at the nape of the neck 7. Single crease in the palm of the hand (Simian Crease) 8. Wide, short hands with short fingers 9. Cleft in feet(Refer to picture above & below) 

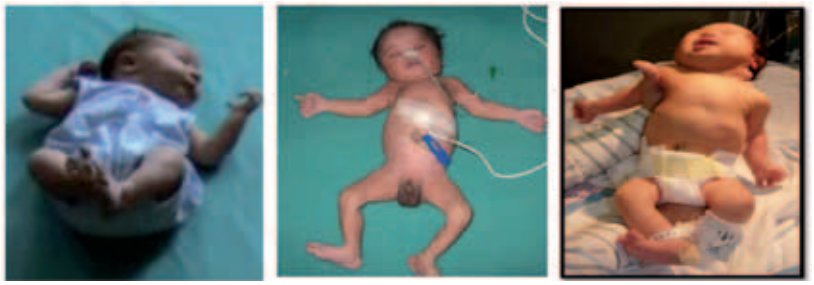
Ask	**At birth–delivery point up to 2 months** • Is this your first child? • What is your age? • Does any other elder sibling of this child have any known birth defect? **Age 2 months to 2 yrs** • Compared with other children, did (name) have any serious delay in sitting, standing, walking? • Can he/she name at least one object (animal, toy, cup, and spoon)? • Does (name) speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)? • **Ages 3–9 Years:** Is (name)'s speech in any way different from normal?
Perform	• Decreased muscle tone at birth (Refer to section 3.5 to test it) 

2.4 Action:

Check the muscle tone: Decreased muscle tone at birth in Down syndrome

Now look at the posture i.e. way the child is lying and moving his/her limbs

Now look at this baby with Down syndrome:



Normal | Down Syndrome with "frog" like posture | Down Syndrome with low tone

The child has both the legs extended and falling passively on the mat like a frog and the hands also, helplessly, on the bed, with very little spontaneous movements, of the limbs.

When this baby was lifted, the examiner had to give much more support to the head and shoulders, than is usual, to keep the infant from sliding, out of her hands. Notice, how the both arms fall back (instead of being held in flexion), and the baby's chest seems to drape over the physician's hand.

This is because the tone of the muscles, in this baby, is less than what is normally seen, in newborns.

2.5 Counselling

To prevent any stigma it should be made clear to the parents that the problem can be from any parent's side. It could be from thefather or the mother, hence, nobody should be blamed.

- Parents and family must be counseled that the Early Intervention Services, if begin within first 3 months (after birth), ideally , enhances development, of their full potential.
- Quality educational programs, along with a stimulating home environment and good medical care enable people, with Down syndrome, to become contributing members of their families and communities.
- Children with Down syndrome need to be closely screened for certain medical conditions. They should have:
    - Eye exam every year during infancy;
    - Hearing tests every 6 - 12 months, depending on age;
    - Dental exams every 6 months;
    - X-rays of the upper or cervical spine between ages 3 - 5 years;
    - Pap smears and pelvic exams, beginning, during puberty or by age 21;
    - Hormonal essay for Thyroid hormone, for the baby, must be repeated after every 12 months;
    - Echo cardiography of heart, once a year;

2.6

Key Messages for Community

- Regular and good quality Antenatal Care is very important, in a woman, who has a previous h/o delivering baby with Down syndrome. Even though, the causative factors are not known but in Trans-locational type of syndrome genetic transmission does occur;
- With early intervention, Down's syndrome children can lead a near independent life;
- Speech can be improved with the help of parental encouragement and speech pathologist;
- Repeated thyroid tests should be done to start, timely treatment as this would prevent mental retardation;
- These children love music, are very affectionate towards their parents and are simple human beings (Gunter Grass-Nobel laureate);

2.7 FAQ

What is tone of the muscle?

The term muscle tone refers to two aspects of muscles' structure and function. Tone is usually defined as the minimal contraction, at rest.

What is Muscle Structure?

The inherent stiffness of a muscle - its resistance to being stretched and firmness when palpated (squeezed). Feel the muscles of a young adult and that of an old person. In the old person it is soft as there is very little resistance, whereas in the young person the feel is firm. Similarly compare the muscle feel of a normal child with that of a child with Down Syndrome.

What is the Function of Muscle?

For a muscle's (or groups of muscles') readiness for action, we require two kinds of actions one at rest and another during motion. At rest, muscle tone helps us to maintain our posture against gravity, whether lying on the bed or sitting or standing normally. So we need to watch the posture, both in a normal child and in a child with decreased muscle tone. During motion i.e. when we walk or run, good muscle tone would help in normal pattern of activity.

The term low muscle tone is used when the muscles' stiffness is less than usual (i.e. it is low) and the readiness for action is also low (muscles respond slowly).

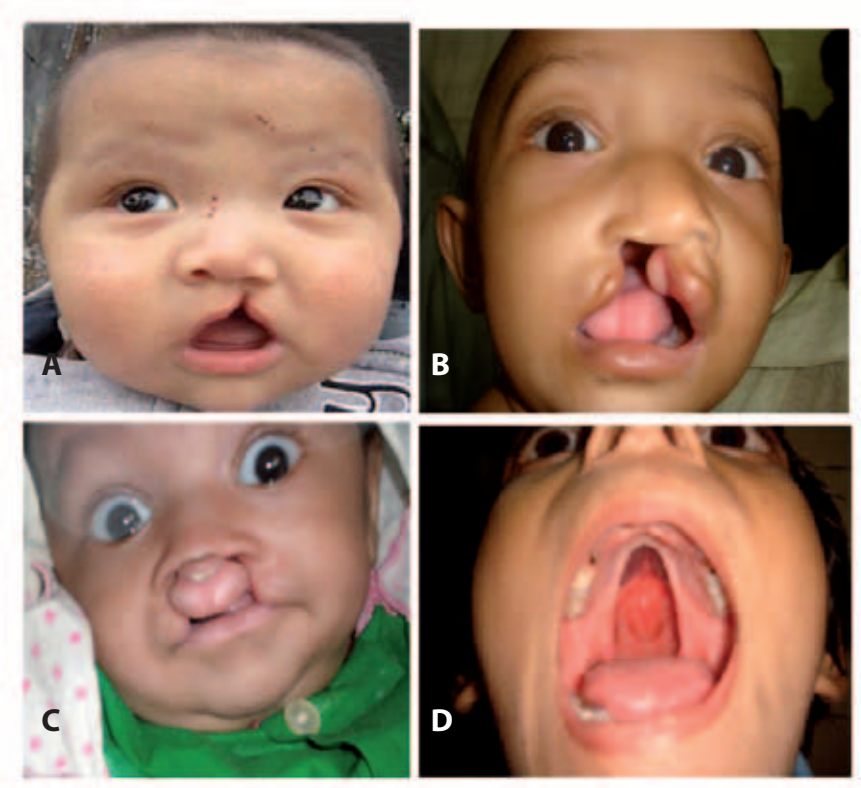
3. Cleft Lip and Cleft Palate

3.1 Introduction

Cleft lip and cleft palate are congenital anomalies of the mouth and lip that occur during pregnancy. In a cleft lip, the two sides of the lip do not fuse together as they should during fetal development. With cleft palate, the roof of the mouth fails to form completely, during pregnancy. A child may be born with a cleft lip, a cleft palate or both.

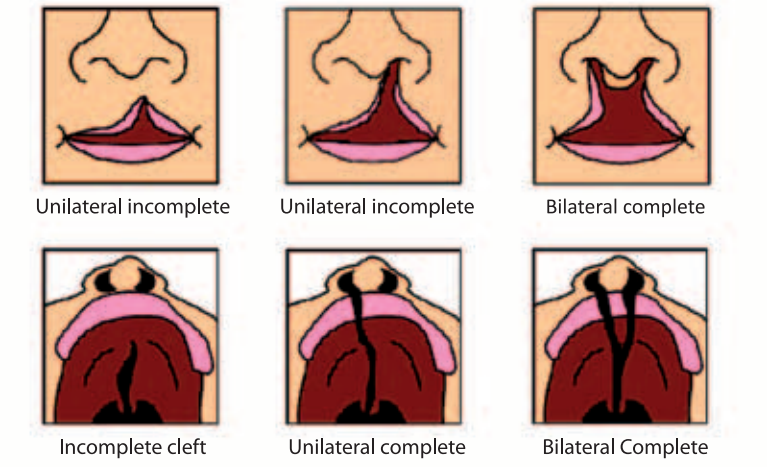
Cleft lips can be as mild as a slight notch in the red part of the upper lip that does not require emergency treatment and as severe as a severe cleft lip involving total separation of the lip, all the way up, into the nose.

Cleft lips can involve a single cleft (which is known as a unilateral cleft), or a double cleft (bilateral cleft). They invariably occur on the upper lip. Cleft palates can range from a tiny little hole in back of the roof of the mouth to a major cavity that runs all the way from the front to the back of the mouth. This creates an opening between the roofs of the mouth. Smoking by mother and diabetes are two of the associated causes for cleft palate in newborns as per National Birth Defects Prevention Study done in United States. Cleft lip is common in males. Cleft palate is more common in females.



Cleft Lip and Palate

a. Signs and Symptoms

Look	**Delivery Point –At birth** • Cleft lip is obviously visible; • Gently open child's mouth and look; • After cleaning the finger or wearing gloves, you can try to palpate carefully for any cleft in the palate; **2 months -2 years (by mobile team)** • Cleft lip is obviously visible; • Mother will take the child in her lap, in a sitting position; • Ask the mother to gently open the child's mouth, neck to be extended and child must look towards the sky/roof/toy; In small children after cleaning the finger or wearing gloves, you can try to palpate carefully for any cleft in the palate; **Schematic Representation** 
Ask	• Does the child have regurgitation of food and liquids, through the nose? • Is the baby having difficulty in sucking? • Does the child have nasal tone of voice? • Does the child have frequent respiratory tract infection?
Perform	Counsel the parents before referring the case

b. Action

Peripheral oral examination and perceptual assessment are the necessary first steps in cleft palate speech evaluation because treatment is recommended only when speech impairment is perceived.

c. Counseling

- In this case parent counseling is very important;
- Teach parents how to feed the child;
  - Breastfeeding an infant with cleft palate may not be successful; it may require a changed feeding position so that **mother's breast tissue fills the gap in the lip or gum**;

- **Breastfeeding** an infant with a cleft palate is quite challenging unless the infant's cleft palate is very far in the back of the mouth and very small. Nursing at the **breast is best limited to 10 minute sessions**;
- For most mothers of infants with cleft palate, breast pumping should begin in the birth hospital using a high quality breast pump and continue after each infant feeding. A long thin spoon to be used to feed the infants if direct sucking is not possible

- The goals of treatment for cleft lip and cleft palate are to ensure the child's ability to eat, speak, hear and breathe and to achieve a normal facial appearance.
- Surgeries typically are performed in this order:
  - Cleft lip repair — between 1 and 4 months of age;
  - Cleft palate repair — between 5 and 15 months of age;
  - Follow-up surgeries — between age 2 and late teen years;

3.5 Key messages

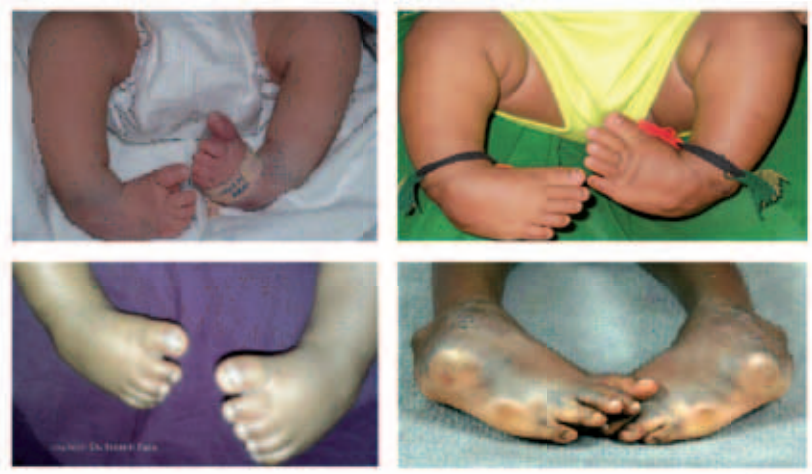
If not treated, this condition may lead to

- Poor speech;
- Impaired hearing and frequent ear infection;
- Regurgitation of food and liquids, through the nose;
- Frequent upper respiratory tract infections;
- Dental and orthodontic problems;
- Psychological and social problem;
- Failure to grow;

4. Club foot (Talipes)

4.1 Introduction

Clubfoot is a congenital deformity that twists the foot, ankle and toes, if not treated at an early stage, this deformity can lead to life time disability. With no proper treatment, child born with clubfoot cannot walk, run or play. Clubfoot is one of the most common congenital physical disabilities worldwide, known to occur in 1-3 of every 1,000 births worldwide with evidence of higher rates in our country. The cause is not known, but the condition may be passed down through families in some cases. The milder deformity may be due to position of the baby, in uterus.



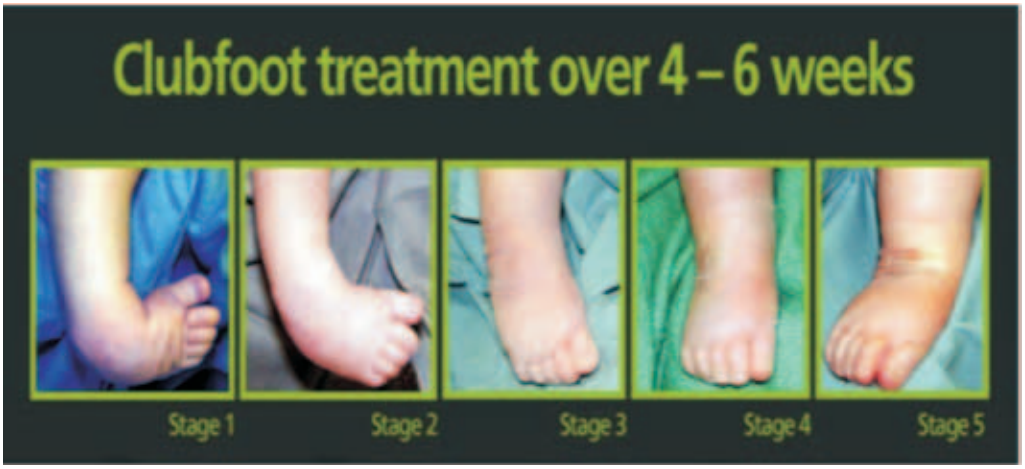
Untreated Neglected feet

4.2 Signs and Symptoms

Look	• Abnormal shape of the foot Inward turning of the front of the foot • Downward-pointing toes • Resting of the foot on its outer border • Rigidity and other changes in the movements of the foot • Toes cannot touch shin of same leg due to tightened Achilles tendon
Ask	If child is more than two years ask mother if child can walk, run or play like other children of his/her age?
Perform	Counsel and Refer the child

Counseling

- If the deformity is mild and the foot is mobile, at ankle, the mother can be reassured that doctors will teach her exercises to help correct child's foot;
- Refer to an orthopedic surgeon without delay and explain the parents this can be treated using a series of plaster casts over 4 - 6 weeks to correct the deformity, immediately followed by use of Braces;
- Majority of the children require a small surgery (cut the tendon at the back of the heel) prior to the final cast being applied, done using local anesthetic;



Before treatment

After treatment