2020 Online DS Course ASSIGNMENT 1 September 2020

Theme of assignment – Creating awareness about Down Syndrome

Format used – Year 2021 Calendar

Submitted by - Group no. 3

Participants – Saijyothi M. Joshi Jessica Chauhan Singh Mithula Vijaykumar Gauri Kokane











"The first step toward change is awareness. The second step is acceptance." – Nathaniel Branden

		Birth	1 MONTH	2 MONTHS	4 MONTHS	6 MONTHS
Re	Hepatitis B	О НерВ	○HepB¹	.		○НерВ
COM	Rotavirus			ORV	ORV	○RV²
men	Diphtheria, Tetanus, Pertussis			ODTaP	ODTaP	ODTaP
ded I	Haemophilus influenzae type b			Оніь	Оніь	Оніь
mm	Pneumococcal			OPCV	OPCV	OPCV
ıniza	Inactivated Poliovirus			OIPV	OIPV	OIPV
Recommended Immunizations	Influenza (Flu)					OInfluenza, first dose¹ Osecond dose
Milestones*	Milestones should be achieved by the age indicated. Talk to your child's doctor about age-appropriate milestones if your child was born prematurely.	Recognizes caregiver's voice Turns head toward breast or bottle Communicates through body language, fussing or crying, alert and engaged Startles to loud sounds	Starts to smile Raises head when on tummy Calms down when rocked, cradled or sung to Pays attention to faces	Begins to smile at people Coos, makes gurgling sounds Begins to follow things with eyes Can hold head up	Babbles with expression Likes to play with people Reaches for toy with one hand Brings hands to mouth Responds to affection Holds head steady, unsupported	Nnows familiar faces Responds to own name Brings things to mouth Rolls over in both directions Strings vowels together when babbling ("ah," "eh", "oh")
Growth	At each well child visit, enter date, length, weight, and percentile information to keep track of your child's progress.	WEIGHT / PERCENTILE LENGTH / PERCENTILE	WEIGHT / PERCENTILE LENGTH / PERCENTILE	WEIGHT / PERCENTILE LENGTH / PERCENTILE	WEIGHT / PERCENTILE	WEIGHT / PERCENTILE LENGTH / PERCENTILE
		HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE

		12 MONTHS	15 MONTHS	18 MONTHS	19 23 MONTHS	2-3 YEARS	4-6 YEARS
	Hepatitis B	OHepB (Final dose adminis	tered between 6 and 18 mo	nths)			
Ĭ	Diphtheria, Tetanus, Pertussis		○DTaP				ODTaP
	Haemophilus influenzae type b	Оніь					
	Pneumococcal	○PCV					
	Inactivated Poliovirus	OIPV (Third dose administe	ered between 6 and 18 mon	ths)			OIPV
	Influenza (Flu)	Olnfluenza, first dose ² Osecond dose (if needed)				Age Age 2 3 Influenza, first dose ² Second dose (if needed)	Api
	Measles, Mumps, Rubella	OMMR					OMMR
ĺ	Varicella	○ Varicella					○ Varicella
	Hepatitis A	OO Hep A ³					
	Milestones should be achieved by the age indicated. Talk to your child s doctor about age-appropriate milestones if your child was born prematurely.	Cries when mom or dad leaves Says "mama" and "dada" Copies gestures (for example, waves "bye bye") May stand alone Looks at right picture or thing when named	Olmitates what you are doing Opinks from a cup Oscribbles on his own Walks well Osays a couple of words other than "mama" and "dada"	Points to show others something interesting Says several single words Points to one body part May walk up steps and run	Plays mainly beside other children Follows two-step commands Plays simple makebelieve games Throws ball overhand	Can name most familiar things Shows affection for friends without prompting Turns book pages one at a time Kicks a ball	Speaks very clearly Tells stories Can print some letters or numbers Hops; may be able to skip Enjoys playing with other children
Growth	At each well child visit, enter date, length, weight, and	WEIGHT / PERCENTILE	WEIGHT / PERCENTILE	WEIGHT / PERCENTILE	WEIGHT / PERCENTILE	WEIGHT	WEIGHT
	percentile information to keep track of your child s progress.	LENGTH / PERCENTILE	LENGTH / PERCENTILE	LENGTH / PERCENTILE	LENGTH / PERCENTILE	HEIGHT	HEIGHT
		HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	HEAD CIRCUMFERENCE	BMI	BMI

VISIT DATE

VISIT DATE

VISIT DATE

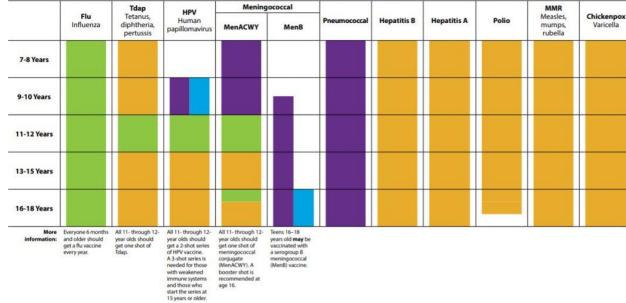
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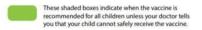
during shown age range.

VISIT DATE

VISIT DATE

Talk to your child's doctor or nurse about the vaccines recommended for their age.





at www.cdc.gov/vaccines/hcp/acip-recs/.









Immunizations and Developmental Milestones for Your Child from Birth Through 6 Years Old and Vaccines from 7 to 18 years of age

<u>Down Syndrome</u> is the most common and readily identifiable chromosomal condition.

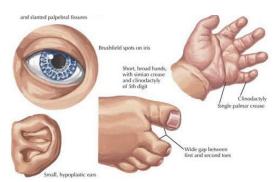
- It is caused by a chromosomal abnormality for some unexplained reason, an accident in cell development in 47 instead of the usual 46 chromosomes.
- This changes the orderly development of the body and brain.
- In most cases, the diagnosis of Down Syndrome is made shortly after birth.
- The incidence is very high about 1 in every 750 live births is born with Down Syndrome in India

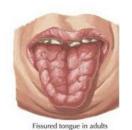
It is named after Dr Langdon Down, the physician who first described its features in 1866.

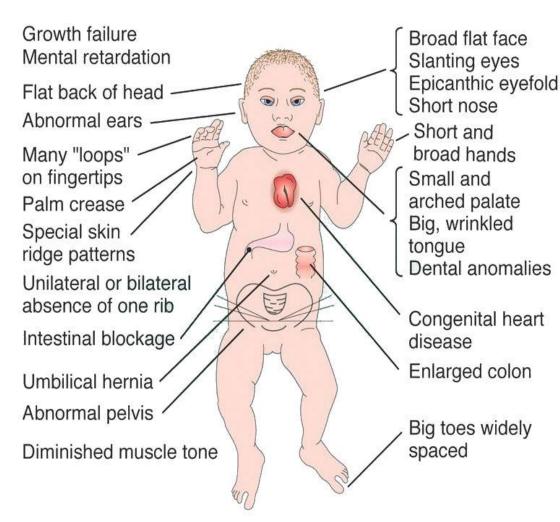


Typical facies, with epicanthal folds





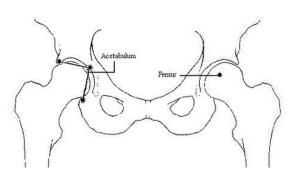




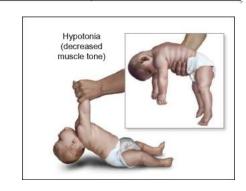
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JANUARY 2021

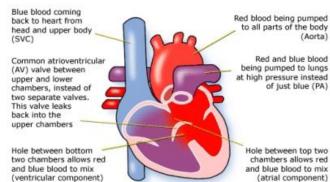
No.	CONCERN AREAS	ISSUES/PROBLEMS	TREATMENT/SOLUTIONS	PROCESS	Dr REFERENCE
01	ORTHOPAEDICS	Multiple musculoskeletal problems Ligamentous laxity Joint hypermobility Cervical spine instability Foot disorders Hip instability	Most of the orthopaedic manifestations of down syndrome can intially be managed non operatively. Treatment should be based on functional performance rather than radiographic findings. If planning surgical treatment, preoperative evaluation should include cardiac and cervical spine assessment.	Periodic follow up with the orthopaedic specialist (yearly) is required, in order to take corrective measures at the early stage itself.	Orthopedician: Dr R. Sankar Email id: sankarortho@gmail.com
02	CARDIOLOGY	ASD (Atrioventricular septal defect) Ventricular septal defect (VSD) Persistent ductus arteriosus Pulmonary arterial hypertension	Heart surgery to correct the defects is recommended in most of the cases. If at all surgery is decided, it must be done before the age of 5-6 months in order to prevent lung damage.	Yearly echo follow up whether or not surgery has taken place.	Paediatric cardiologist: Dr Amita Signal 09312239463







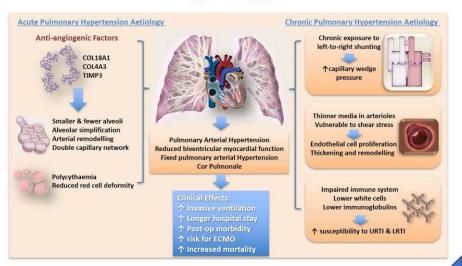
Atrioventricular Septal Defect



to all parts of the body

Red and blue blood being pumped to lungs

Hole between top two chambers allows red and blue blood to mix (atrial component)



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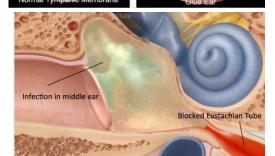
FEBRUARY 2021

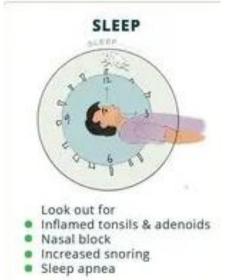
ENT Issues

Ear, nose, and throat (ENT) problems are common in children with Down Syndrome (DS). This includes problems with chronic ear infections, glue ear and chronic middle ear effusions with associated hearing loss, airway obstruction, and sleep apnea, as well as problems with chronic rhinitis and sinusitis.

Doctor reference:
Dr Mohan kameshwaran (04424311411)





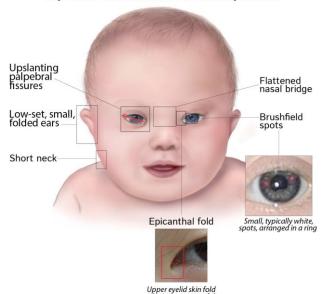


Eye Issues

Characteristic features include upward slanting of the eyelids, prominent folds of skin between the eye and the nose, and small white spots present on the iris called Brushfield's spots. Signs to look for include squinting or closing one eye shut, an unusual head tilt, crossing or wandering of one or both eyes, or light sensitivity.

Doctor reference: Dr. Nikhil Rishikeshi

Key Facial Characteristics of Down Syndrome





			March 2021			
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Physiotherapy

Early intervention is a systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome.

CONCERNED AREAS FOR PHYSIOTHERAPY

- Postural Alignment
- Balance Issues
- Improper Walking Pattern
- Reduced Muscle Strength
- Reduced level of physical activity
- Issues with Sensation
- Reduced mental health and Emotional well being
- Delayed Developmental milestones

Doctor reference:

DR. ANIL SHARMA (9811337322/9811119153)







Speech

Speech and language present many challenges for children with Down syndrome but Communication is exchange of ideas, information, thoughts, and feelings between senders and receivers — Gestures, Posture, Eye contact, Facial expression, Head and body movement

Factors Affecting Treatment

- Anatomical Factors
- Physiological disorders
- Neurofunctional patterns
- Perceptual speech symptoms
- Pragmatic language factors
- Message content and length
- Familiarity of listener/speaker
- External environmental factors

Doctor reference: Dr Narmata Pai Dr Saranya (9500017583)





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APRIL 2021

Occupational therapy

Occupational therapy practitioners work with persons with Down syndrome to help them master skills for independence through self-care like feeding and dressing, fine and gross motor skills, school performance, and play and leisure activities.

The Goal of occupational therapy for these children is not to accelerate the rate of their development, as is often presumed, but to facilitate the development of optimal movement patterns. This means that over the long term, therapist want to help the child develop good posture, proper foot alignment, an efficient walking pattern, and a good physical foundation for fine motor skills, and activities of daily living.

Doctore reference Ms. Shyama Madhu (6383795434)







OT checks following sensorimotor components

- Muscle tone
- Muscle strength
- Muscle endurance
- •Range of motion
- Coordination and balance
- Posture
- •Hand function.

Cognitive and perceptual components-

- Attention
- Memory
- •Figure-ground
- Directionality

Social components-

- Social smile
- Peer relationship
- Group interactionBehavior Tantrums and

Communication (verbal & non verbal)





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Dental issues

- Baby bottle syndrome
- Cavities Gum problems
- Multiple missing teeth by birth
- Irregular teeth-bad bite
- Cosmetics

Prevention:

- Brushing twice a day/anti cavity mouth washes
- Restricting sugary eatables
- Use of special devices-air / water flosser

Doctor reference Dr.Nidhi Gupta (9350214961)



Skin issues

- Soft and velvety skin in early childhood
- Dry skin in late childhood Xerosis (70%), atopic dermatitis (50%), palmoplantar hyperkeratosis (40-75%), and seborrheic dermatitis (31%)
- Premature wrinkling of the skin, cutis marmorata, and acrocyanosis
- Bacteria infections, fungal infections (tinea), and ectoparasitism (scabies)
- Elastosis perforans serpiginosa
- Syringomas, which may be eruptive
- Alopecia areata (6-8.9%)
- Vitiligo
- Angular cheilitis

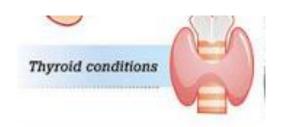
Doctor reference Dr.Shwetha Rahul, Chennai.



Nutritional issues

- Growth and development slower in ages 3 -36 months
- Average height and head circumference smaller
- Feeding challenges include, difficulties in swallowing
- Overweight, Constipation, Heart defects
- Thyroid disorders(hypothyroidism likely)Coeliac diseases
- Diabetes, GIT Anomalies
- Dyspagia signs and symptoms include, coughing, choking, arching/stiffening of body during feeding, refuging food or liquids.

Doctor reference Dr.Madhu Sharma, Panchkula



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Puberty and Perimenopause/menopause

Puberty in girls:

- Signs-typical age 10 yrs.(8-13 yrs.), breast budding, appearance of pubic hair, growth spurt
- Menstruation: Not different from typical girls, initially unpredictable and irregular but later became cyclic
- Menstrual hygiene should be practiced before it is necessary, use of various tools for teaching-pictures, drawings, written lists, books, visuals of task analysis (changing pads), this should be practiced at home, school and in community
- Girls and women's with Down Syndrome are fertile and capable of conceiving a pregnancy.

Puberty in Boys:

- Signs- enlargement of testicles, average age for this is 11 yrs.(8-13yrs), growth of pennies and testicles is complete in middle teen years.
- Growth spurts is usually over around 15-16 yrs. of age.
- Voice changes and increased facial hair are quite variable in their timing.
- Sexual functioning in Boys with Down Syndrome- they do have erections and ejaculations
- Fertility appears to be decreased
- During puberty, boys may become more clumsy and uncoordinated., unaware of own strength, prompting and physical management becomes more difficult.

Problems/issues/concerns:

- Irregularities in periods (25-30% due to thyroid disorders), levels of sex hormones are affected by anti epileptic painful cycles, hygiene and periods management issues.
- Irritability, insomnia, tensions, anxiety
- More time to understand the changes during puberty.
- Concerns about sexual relationship and potential abuse.
- Menopause symptoms:- hot flushes-night sweats-vaginal dryness and discomfort during sex-difficulty sleeping-low mood or anxiety-reduced sex drive (libido)-problems with memory and concentration



Doctor reference: Dr.Uma Ram DGO,DNB,FRCOG,Seethapathy clinic and hospital, Chennai

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Schooling Plan, but be willing to stray off that plan.

- Schooling for our children is a very crucial concept, and needs a very realistic and pragmatic approach.
- Our children have medical, and health conditions which needs to be properly managed time to time.
- Health monitoring (Physical & Psychological),24x7, helps us to keep anxiety, stress, and depression among our children at bay. Otherwise we end up raising a child with declined cognition.
- Since a relaxed mind can bring out more results, so with this thought we have to decide what is best for our children.
- Learning should be based on child's interest, and not based on your (Parent's) ambitions.
- OTs and PTs should be an integral part of a child's routine.
- Speech therapy should be aligned with the daily activities of the child. This can be done by connecting with child at their own level. Encourage child to babble not only at home but even outdoors where no one understands. This builds a strong foundation that they are being heard.
- Use assistive devices and technology to their advantage.
- Expose them to outer world as much as you can. Make them interact with strangers as much as you can. This will instill confidence in them.
- Convert every learning into a playful activity.
- Record photos, videos and let the child watch it on TV/Phone
- Use drama and story telling, since most of our kids are visual learners.
- Eventually home schooling is a relatively more better option in terms of outputs, because the child learns at his own pace.















Vocational training

Vocational training is to help these children, make a living and be financially independent. This helps them be independent and reach their full potential.

Vocational training houses different types of works/jobs depending on the skills of every individual.

Employment Opportunities include-

- Dance
- Music
- Drama/theatre
- Artist
- Weaving
- Baking/cooking
- Workshop duties
- Paper/envelope making
- Candle/soaps making
- Hotel Management











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DS Awareness Month

While March 21 is celebrated as World Down Syndrome day, the month of October is celebrated as <u>Down Syndrome Awareness month</u>.

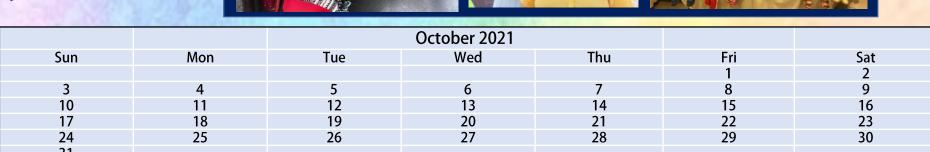
"INCLUSION IS A RIGHT, NOT A PRIVILEDGE FOR SELECT FEW" — Judge Geary

Inclusion requires the teacher to believe that all students have something important to offer in the classroom and that we really are better off learning together.











Aquatic therapy

A combination of land and water exercise is a effective strategy to improve daily activities in babies with trisomy 21 Aquatic therapy showed significant improvement in gross motor milestones in babies with trisomy 21 like neck control, sitting, crawling. Aquatic therapy is started from 4 months of age

Benefits of aquatic therapy-

- Improves cardio vascular endurance
- Improves the tone of the muscles as most babies with trisomy 21 have hypotonia
- Improves bone strength n ligament laxity Improves balance n coordination

Precautions to be taken during aquatic therapy

- To check whether the baby had any cardiac issues
- Episodes of pneumonia

Ear infections

Mithula -7358039531 Srilakshmi-8124006533









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Rights Financial Planning & Inclusion

- As soon as Diagnosis is done and Parents have Accepted the condition they should start working on these things along with Medical & Therapeutic services.
- Getthe Assessment done and then try to get Disability Certificate, Railway Concession Certificate and UDID Card
- DSis a Life long condition, so start Financial Planning soonest. To begin with, start setting aside Rs. 10/20, 50 or 100/- per day.
- Rs.5000/-saved regularly every month can grow up into nearly 3.5 Crores, over 35+years & over 8 Cr. In 40 yrs. The interest on this corpus can take care of the monthly financial requirement when the child grows up.
- OpenBank Account of everychild—even if Minor!Startearly.Afterattaining 18 years age, he/ she will become First Holder and parents can be joint holders.
- Minor children can get PAN Card. Get it soonest. It will helpminimising the Tax Burden on interest income.
- PPF Account can be opened in minor's name. Open it in nationalised bank. Interest earned on PPF is Tax Free so far. Min deposit per annum can be Rs. 500/- upto 1.5 lakhs. As minor account, it will be linked with parents But after 18 yrs age, advantage of compounding will be readily seen.
- DMAT Account can also be opened if interested in investments in Stock Markets.
- Insurance schemes are still not clearly defined to include Disabilities. That makes these options near redundant as there may be issues in claims settlement. Do NOT Waste your money. Save it instead.
- Guardianship ISNOT MANDATORY. There are clear Guidelines in RPD Actas well as National Trust Act. and RBI Circular. Every citizen has a Right to open a Bank Account.
- Get Adhar Card and Voter ID Card. It helps. In case of ANY Difficulty with Bank or ANY other Agency/ Department redressal is done by Chief Commissioner of PwDs and State Commissioners depending upon the jurisdiction.

What After Us:



- Be Bridges/ Positive Interface with the Society about condition of our children.
- DifferentModelshaveevolvedoverpastfewyearsandhavetheir pros&cons.
- Once the Financial Resources are earmarked for our child/ adult with DS planning will be needed on three levels
 - · Management of Funds.
 - Ensuring regular cash flow for service delivery and continuity.
 - Actual Service Delivery. Different arrangements will be needed to make sure that after the parents, a group of supporters will regularly take care of these functions.

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DECEMBER 2021



Babli Ramachandran
Besides being an accomplished
Bharatanatyam dancer, Babli also teaches
yoga to others with Down syndrome.



Karishma Kannan Artist/Painter



Reshmi Rekha Sahu Odissi Dancer



Gauri Gadgil
International swimmer, actress Debut film YELLOW



Jijo Das Artist, Illustrator, Youtuber Website-Art of my optimus



Sneha Verma and Disha Maru Gold and Silver at Special Olympics in swimming



Sahil Singh
Self advocate, UN speaker, Athelete
leader (SOB), Memer of Youth council
(SOB)





THANK YOU!

