CAPE News

Newsletter of The Indian Society for Pediatric and Adolescent Endocrinology (ISPAE)

JANUARY 2025
Volume 29 - Issue 1

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EDITOR'S MESSAGE

Dear Readers,

Greetings from the CAPE News Editorial team.

We are delighted to bring to you the first issue of CAPE News 2025. We congratulate the previous team led by Dr Aashima Dabas for the inspirational work in their tenure, which has raised the standards substantially. Our team, including Dr Anju Virmani (Advisor), Aashima Dabas, Ajinkya Patil, Arpita Bhriguvanshi, Dhanya Soodhana Mohan, Swathi Padmanaban and Vikas Mehrotra, a great mix of experience and energy, will strive to keep up the good work of previous teams.

We continue the theme-based issues with some modifications in the style of the newsletter. The first issue of 2025 is on Growth Disorders. We have added a couple of new sections where we will be listening to the stalwarts and also have a brief of some exemplary work being done by IDEAL members in the IDEAL corner. We thank all the members who have contributed.

The theme of the next issue is "*Puberty*". We will be glad to have suggestions/ feedback for improvements, at editor.capenews@gmail.com.

Regards

Nikhil Lohiya

Team CAPE News

SPAE PRESIDENT - MESSAGE

Dear friends

Congratulations to the CAPE News team for coming up with an excellent issue on growth disorders covering the entirety of the content. The readership will benefit immensely from the publication.

As the current ISAPE executive transitions from the previous committee, we thank the outgoing team for their commitment, efforts, and visionary leadership, which have significantly advanced ISPAE's mission. We look forward to building on the foundation they established.

As part of the Presidential action plan for 2025-2026, we aim to enhance ISPAE's impact across all aspects of pediatric endocrinology in the country. A significant initiative in this direction is the establishment of 12 focused working groups that will address various areas of our specialty. These groups will unite experts in diabetes, growth disorders, thyroid issues, adrenal health, bone health, disorders of sexual development, and pubertal issues. This effort seeks to streamline research, improve clinical practices, and develop guidelines tailored to the needs of India. Patient advocacy initiatives will be our primary focus. We plan to collaborate with patient organizations, non-profit groups, and stakeholders to create resources and support systems that empower those affected by endocrine disorders. The development of innovative patient registries will facilitate data collection, allowing us to better understand the epidemiology of endocrine conditions and assess treatment outcomes.

As we embark on this exciting journey, we invite each of you to participate in these initiatives. Your involvement will be crucial in shaping the future of pediatric and adolescent endocrinology in India.

Thank you for your continued dedication and support.

Happy reading

Dr Anurag Bajpai- on behalf of ISPAE 2025-2026

WELCOME NEW ISPAE MEMBERS

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WINNER- December 2024 Quiz
SACHIN KRISHNA RAJ,
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ISPAE

LONG-ACTING GROWTH HORMONE THERAPY IN PEDIATRIC GROWTH HORMONE DEFICIENCY: A CONSENSUS STATEMENT

(Maniatis A, Cutfield W, Dattani M, et al. Long-Acting Growth Hormone Therapy in Pediatric Growth Hormone Deficiency: A Consensus Statement. J Clin Endocrinol Metab. Published online December 3, 2024.)

Dhanya Soodhana, *Consultant Pediatric and Adolescent Endocrinologist, Aster Malabar Institute of Medical Sciences, Kozhikode, Kerala*

FOCUS

- The consensus is on 3 globally approved formulations of LAGH: lonapegsomatropin (Skytrofa), somapacitan (Sogroya), and somatrogon (Ngenla/Genryzon).
- Lonapegsomatropin is a prodrug with transient PEGylation of GH. Somapacitan has a single-point mutation in the GH backbone (amino acid 101) with a noncovalent albumin-binding moiety attached. Somatrogon is a GH fusion protein with 3 carboxy terminal peptides of human chorionic gonadotropin.
- Somapacitan and somatrogon are supplied with pen devices, which permit adjustable dosing and multiple doses per pen, whereas lonapegsomatropin is used with an autoinjector and fixed-dose cartridges.
- Doses are weight-based and administered once weekly for all 3 formulations. Dosing per kilogram varies by formulation, due to the varying molecular weight and pharmacokineticpharmacodynamic profile.
- Appropriate selection of the pen device for the patient's weight is important to minimize the need for multiple injections.

Several long-acting growth hormone (LAGH) therapies have recently become available, but guidance on their usage in children with growth hormone deficiency (GHD) is limited. Given the efficacy & safety of daily GH, the question arises: Why use LAGH?

Daily injections of recombinant GH have been approved for several indications; however, non-compliance is common. Long-acting therapy formulations are now in use in many therapeutic areas and have several advantages, including improved adherence, convenience, reduced therapeutic burden, and improved quality of life. Injectable therapies in children requiring frequent administration have been associated with discomfort & impact on daily life extending beyond the timing of the injection itself. Patients and/or caregivers have shown a preference for LAGH preparations, owing to the reduced injection frequency and lower perceived treatment burden.

LAGHs are approved for the treatment of children with GHD (starting from the age of 1-3 years according to country and product).

Further trials of LAGH are needed to demonstrate efficacy, safety, and appropriate dosing in:

- Survivors of cancer and intracranial tumors associated with GHD.
- PraderWilli syndrome.
- Very young patients.
- Pediatric non-GHD states such as SGA, idiopathic short stature, Turner syndrome, Noonan syndrome, SHOX deficiency, and chronic renal insufficiency.

- The dose changes for LAGH are at the discretion of the practitioner and based on IGF-1 levels, with potential adjustments for body mass index, severity of GH deficiency, height velocity, pubertal staging, estrogen supplementation, and bone age.
- Considering the risk of transient hyperglycemia, a lower starting dose may be considered, based on ideal body weight rather than actual body weight for patients with obesity.
- A lower initial dose of LAGH is required for those with an increased risk of intracranial hypertension, severe GHD, genetic or chromosomal abnormalities, renal failure, and those receiving estrogen supplementation.

Who may derive particular benefit from treatment with LAGH?

1. Children at increased risk of poor adherence to daily GH- teenagers, those with documented poor adherence.
2. Children with >1 home because of the need for a supply of treatment in more than one location.
3. Children with frequent travel schedules outside of the home.
4. Children whose families are socio-economically disadvantaged & GH treatment is an additional burden.

- Dose adjustments should be targeted to achieve average IGF-1 SDS levels in the normal range (between −2 and +2; preferably close to 0 SDS).
- The day and time of laboratory sampling in comparison with the day and time of the last injection: IGF-1 sampling is on day 4 (somapacitan and somatrogon) or day 4.5 (lonapegsomatropin). If levels are in the normal range, then no adjustment is needed.

Table 1: Initiating and Switching Therapies

LAGH	Lonapegsomatropin	Somapacitan	Somatrogon
Mechanism of action	Transient PEGylation prodrug	Single-point mutation, hydrophilic spacer, non-covalent binding	Fusion protein with 3 carboxy terminal peptides of hCG
Molecular weight of active agent	22 kDa	23 kDa	40 kDa
Half life	25 hours	34 hours	37.7 hours
Dosing	0.24mg/kg/week	0.16mg/kg/week	0.66 mg/kg/week
Manufacturer	Ascendis Pharma	Novo Nordisk Inc	Pfizer Ltd
Device	Autoinjector	Pen	Pen
Available dosage presentations	9 cartridges with weight-based brackets	0.025-2 mg in a 5 mg pen 0.05-4 mg in a 10 mg pen 0.1-8 mg in a 15 mg pen	0.2-12 mg in 24 mg pen 0.5-30 mg in 60 mg pen
Maximum injection volume	0.605 ml	0.8 ml	0.6 ml
pH	5.0	6.8	6.6
Preservative	None	Phenol	Metacresol
Storage	Refrigeration; may be stored at room temperature (up to 30°C) for 6 mo.	Refrigeration; maybe stored at room temperature (up to 25°C) up to 72 hours	Refrigerate- maybe held at room temperature (up to 32°C) for 4 hours (max of 5 times)
Use window	4 hours post-reconstitution	42 days after first use	28 days after first use
Dosing window for isolated missed injections	±2 days	±3 days	±3 days

Initiating LAGHs in GH-naïve and GH-experienced patients

Patients already receiving daily GH may be less inclined to opt for LAGH than treatment-naïve patients because LAGH represents a new therapy compared with the traditional therapy to which they are accustomed.

Switching

When switching between any 2 formulations of GH, overlapping dosing should be avoided. In children switching from daily GH, the first LAGH dose should be given the next day (or at least 8 hours) after their last daily GH dose. For patients already receiving LAGH switching to another LAGH formulation, the dose should be given 7 days after the last dose of the prior LAGH.

Administration

- Regardless of which LAGH is used, more than 1 injection may be needed regularly for individuals weighing over 45 kg (somatrogon), 50 kg (somapacitan), or 60.5 kg (lonapegsomatropin), exceeding the maximum dose per application for the respective devices. To minimize end-of-pen medication wastage, more than 1 injection may occasionally be needed.
- There is a longer window (2-3 days) for a delayed dose of LAGH than with daily GH.
- The recommendation is to pick a specific day of the week as the injection day.
- If the injection cannot be given on that day, there is a ±2-day window (lonapegsomatropin) or a ±3-day window (somapacitan and somatrogon) to give the dose as a "make-up" dose.
- The following week, injections should resume on the chosen specific day. The blood draw day should be taken into consideration when choosing the "dosing day".
- It is imperative to not miss any doses of LAGH, as it may have a large impact on efficacy and safety in terms of hypoglycemia risk.

Knowledge Gaps

1. Data on LAGH in children are limited to clinical trials in GH deficiency, and longer-term, real-world data on adherence, safety, and efficacy are needed.
2. Although dose adjustment is based on the average IGF-1 SDS level, clinical implications of elevated peak and low trough IGF-1 levels are unknown.
3. Correlation with long-term clinical effects on neoplasia, cardiovascular outcomes, and glucose homeostasis is needed.
4. Data on the effect of LAGH on glucose control in very young children with severe GHD are lacking.
5. The impact of LAGH on dose requirements for glucocorticoid and thyroxine is unknown.
6. Data on the interaction of sex steroids (especially oral estrogens, which can reduce the biological effects of GH) and LAGH in adolescents are needed.
7. LAGH dosing requirements to optimize growth and bone health in adolescents with open epiphyses and optimal dosing during the transition period from adolescence into adulthood-No data.
8. Only somapacitan is currently approved for adult GHD (defined as >18 years).
9. Data not available for pediatric non-GHD states.

LAGH represents an important new treatment option that will become available to more children in the future. Shared decision-making between the treating practitioner, the patients, and caregivers is particularly important. The practitioner needs to have a transparent discussion regarding the pros and cons of all potential therapies available, to optimize acceptability and adherence.

Evaluation of **nonadherence** includes exploring the potential barriers and finding solutions with the child and the family. If there is persistent nonadherence to LAGH, third-party administration can be tried; such LAGH can be given at any time of day, but time and injection site should be recorded, ensuring that injection sites are rotated to avoid lipoatrophy.

Specific Safety Considerations: The published safety profile of the LAGHs to date has been reassuring, with no new safety signals identified during follow-up periods of up to 5 years. In the controlled phases of the phase III trials, LAGHs demonstrated comparable safety to daily GH. In general, injection site reactions were mild or moderate with all LAGHs. Other commonly reported adverse events were headache, nasopharyngitis, pyrexia, gastroenteritis, respiratory tract infection, cough, and vomiting. Antidrug antibodies to the LAGH formulations were observed in clinical trials, but were not associated with any clinical effect.

Future advances in autoinjector and pen technology may allow for objective recording of adherence and confirm improvements in adherence compared with daily GH. Patient registries are a key source of long-term safety and efficacy data, and several registries have been initiated.

TRANSFORMING GROWTH: VOSORITIDE'S ARRIVAL IN INDIA

Urvee Swaika, Shaila Bhattacharyya, *Department of Pediatric Endocrinology, Manipal Hospital, Old Airport Road, Bengaluru*

Achondroplasia: Achondroplasia is the most common cause of disproportionate short stature (estimated prevalence 3.724.60 per 100,000 births). It is inherited in an autosomal dominant manner. Affected individuals have rhizomelic shortening of the limbs, trident appearance of the hands, macrocephaly, and characteristic facial features with frontal bossing and midface retrusion. In infancy, hypotonia is typical, and the acquisition of developmental motor milestones is often both aberrant in pattern and delayed. Those with typical findings generally do not need molecular confirmation of the diagnosis, although confirmation may aid in receiving new treatments. In those in whom there is any uncertainty, identification of pathogenic variant gain-of-function mutations (most common- c.1138G>A (p.Gly380Arg), c.1138G>C (p.Gly380Arg)) in FGFR3 by molecular genetic testing can establish the diagnosis. Intelligence and life span are usually near normal, although craniocervical junction compression increases the risk of death in infancy. Additional complications include obstructive sleep apnea, middle ear dysfunction, kyphosis, and spinal stenosis. In contrast, the expected AGV in children with achondroplasia is about 4 cm/year.

VOSORITIDE:

Introduction: Vosoritide is the first pharmacological, precision treatment for achondroplasia. It is manufactured from Escherichia coli using recombinant DNA technology. In 2021, it was approved to increase height in children with achondroplasia from age five until growth plates close, creating a need for vosoritide treatment guidelines to support clinicians. It is now approved for use

from birth in Australia, Japan, and the USA and from 4 months of age in Europe.

Mechanism Of Action: Vosoritide, a C-type natriuretic peptide (CNP) analog, activates B-type natriuretic peptide receptor signalling, thereby inhibiting FGFR3 downstream signalling, by inhibiting the extracellular signal-regulated kinases 1 and 2 (ERK1/2) in the mitogen-activated protein kinase (MAPK) pathway at the level of rapidly accelerating fibrosarcoma serine/threonine protein kinase (RAF-1). This leads to increased endochondral bone formation by stimulating chondrocyte proliferation and differentiation. The 39 amino acid peptide analog includes the 37 C terminal amino acids of the human CNP53 sequence plus the addition of 2 amino acids (Pro Gly) to convey resistance to neutral endopeptidase (NEP) degradation, resulting in prolonged half-life in comparison to endogenous CNP.

Usage: It leads to an increment in growth velocity of 1.57 cm/year when given at doses of 15 µg/kg subcutaneously daily. Baseline spine MRI is recommended to monitor spinal alignment and stenosis and for comparison purposes when and/or if symptoms such as pain, tingling or cramping, muscle weakness, difficulty in walking, bowel or urinary incontinence, or a spinal cord injury occur. If a dose is missed, it can be administered within 12 hours. Beyond that, the missed dose should NOT be administered. Long-term treatment with vosoritide will vary and probably result in clinically meaningful improvements in upper-to-lower body segment ratio in individuals starting treatment between 2 years of age and puberty. The growth occurs proportionally in both the spine and the lower limbs. The most common side effects are injection site reactions, vomiting, and transient hypotension. Injections should be given after a meal and drinking 250-500 ml of fluids to minimize hypotension.

Pharmacodynamics/ Pharmacokinetics: VOXZOGO is the product name marketed by BioMarin Pharmaceuticals. It is a white to yellow lyophilized powder for reconstitution and is provided as a co-pack which includes ten sterile, single-dose 2 mL glass vials containing Voxzogo, diluent (Sterile Water for Injection, USP) in a single-dose prefilled syringe, diluent transfer needles (23 gauge), single-dose administration syringes (30 gauge) both with needle retraction safety devices. Each vial containing 0.4 mg/0.56 mg vosoritide is reconstituted in 0.5/0.7 mL of solution respectively, corresponding to a concentration of 0.8 mg/mL; whereas the vial containing 1.2 mg vosoritide is mixed in 0.6 mL of solution, corresponding to a concentration of 2 mg/mL. The measurements for the unit graduated syringes are equivalent to mL: 0.1 mL = 10 Units. Because it is a recombinant human protein, vosoritide is an unlikely candidate for drug-drug interactions. The absorption median Tmax is 15 minutes. Immunogenicity analyses showed that the development of anti-drug antibody response to vosoritide was not associated with an increased frequency or severity of hypersensitivity adverse events or injection site reactions, and had no apparent impact on vosoritide PK or efficacy as measured by the change from baseline in AGV. The vials and prefilled diluent syringes are to be stored at 2-8°C, never to be frozen. Voxzogo can be stored at room temperature 20-25°C for 90 days; excursions are permitted to 15-30°C. The starting date of room-temperature storage must be recorded on the unopened product carton: it should not be returned to the refrigerator once stored at room temperature, and discarded after 90 days. After reconstitution, Voxzogo must be administered within 3 hours, and can be held in the vial at room temperature 20-25°C. It should be stored in the original package to protect it from light.

Follow-up: The first follow-up must take place no later than 1 month after initiation. In patients 02 years of age, weight and dose reviews should be conducted every 3 months. Patients 35 years of age should be routinely followed up every 46 months. Patients >5 years of age should be routinely followed up every 6 months [assessments should include the Screening Tool for Everyday Mobility and Symptoms (STEMS) and Activities Scale for Kids (ASK)]. Sleep study and MRI are not required for follow-up unless clinically indicated. Radiography is not routinely required before puberty; during puberty, it should be performed every 12 years to confirm growth plates remain open. The response to treatment can vary in magnitude and timing, and is often measurable at 12 years after starting. When AGV has slowed to <1.5 cm per year, radiography should be performed to check the status of the growth plates; if they are closed, treatment with vosoritide should be stopped. Treatment can also be stopped when patients reach a height they are comfortable with. Spinal health should continue to be monitored after cessation of vosoritide treatment per standard of care.

Biomarkers: An increase in urinary cyclic guanosine monophosphate (cGMP) concentrations from pre-dose baseline was observed within the first four hours post-dose, with a maximum level at 2 hours post-dose, nearing saturation at the dose of 15 mcg/kg once daily. Increase in serum collagen type X marker (CXM), an endochondral ossification biomarker of growth plate activity persists beyond 24 months, with maximal increase at the daily dose of 15 mcg/kg.

Gaps in knowledge: The safety and efficacy of vosoritide in patients with renal or hepatic impairment have not been evaluated. It is not recommended with eGFR < 60 mL/min/1.73 m^2. Long-term carcinogenicity studies and genotoxicity studies with vosoritide have not been performed.

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DRUG CORNER

GROWTH PROMOTING THERAPIES WHERE ARE WE AND WHAT LIES AHEAD

Ajinkya Patil, *Consultant Pediatric Endocrinologist, Hormocare Pediatric Endocrinology Clinic; Assistant Professor, Dr Ulhas Patil Medical College, Jalgaon.*

While Recombinant Growth Hormone therapy remains the most promising therapeutic option for growth augmentation at this time, the need for daily injections and its cost has led many to explore various options aimed at promoting short term growth and eventually, final adult height. Deeper understanding of regulators of postnatal growth process, cellular processes at the level of epiphyseal growth plates and factors affecting growth plate closure has led to remarkable success in developing alternative growth promoting therapies in non-GHD/ ISS conditions.

Here is a detailed table summarizing various growth promoting therapies for short stature:

GROWTH PROMOTING THERAPIES				
Drug/Agent	**Mechanism of Action**	**Adverse Effects**	**Indications & approval status**	**Duration of Treatment & Response**
Mecasermin Recombinant human IGF-1	Activates peripheral intracellular pathways & binds to type 1 IGF-1 receptors	1. Risk of hypoglycemia - usually taken post-meal 2. Lymphoid hyperplasia	Approved for use in Severe Primary IGF-1 deficiency, Laron syndrome. Role in Partial IGFD & ISS under study.	Response: 8 cm in 1st year at 120 mcg/kg/dose twice daily.
Hormone Modulators				
Gonadotropin Releasing Hormone Analogs (GnRHa)	Delay puberty and epiphyseal growth maturation, allowing more time for growth	Mild site reactions, temporary increase in BMI	Approved for central precocious puberty. Used off-label for short stature at onset of puberty	Monotherapy has marginal benefits ~ 5-10 cm gain in adult height seen with 2-3y of combined GH + GnRHa therapy.
Aromatase Inhibitors (AIs)	Block estrogen production and delays epiphyseal growth plate closure	Safety concerns regarding vertebral deformities & erythrocytosis	Off-label use in late presenting GHD, CDGP, ISS and testotoxicosis. Contraindicated in girls.	Monotherapy: Short term growth with no significant effect on final adult height. rhGH + AI: 3y treatment results in ~4.5-9.5 cm gain.

A. Anabolic steroids				
Oxandrolone	Non-aromatizable weak androgenic steroid.	Potential liver effects, virilization	FDA approval for Turner syndrome (TS). Off-label use in CDGP and ISS.	GH + Oxandrolone show robust response in TS. Short term increase in height velocity in boys, with no effect on final height.
B. Sex steroids				
Testosterone Esters	Accelerates growth in boys with constitutional delay	Minimal impact on adult height potential	Constitutional delay of growth and puberty	Short-term (3-6 months); accelerates growth without affecting adult height.
C. Growth Modulators				
Vosoritide (C-type Natriuretic Peptide Analog)	Inhibits FGFR3 mediated MAPK signaling pathways	Generally safe; Minor site reactions, circulatory dysfunction	FDA approval for Achondroplasia > 2 years age. Potential use in CNP deficiency, NPR2 mutation, RASopathies, SHOX, Aggrecan deficiency	Long-term; Response: 5.7 cm in 1st year at 15 mcg/kg/day[2]
D. Novel therapies in pipeline				
LUM-201	Oral GH secretagogue; Increases amplitude of endogenous GH pulses		Ongoing trials in Hypothalamic GHD, Milder forms of pituitary dysfunction, non-GHD with low BMI (SGA, SRS, Noonan)	
Navepegritide TransCon CNP	Sustained release form of CNP analog		In Human Phase 1 trials for Achondroplasia	
Infigratinib Tyrosine Kinase inhibitor	Inhibits FGFR3 phosphorylation and downstream signaling		In Phase 2 study in ACH 2.5 to 10 years age-group[3]	

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GROWTH HORMONE STIMULATION TEST USING MACIMORELIN

***Nikhil Lohiya**, Division of Growth & Endocrinology, Silver Lining Pediatric Super Specialty Center, Nagpur*

Macimorelin Acetate- It is a synthetic growth hormone (GH) secretagogue receptor agonist, which releases GH from the pituitary. It is an oral formulation, approved in adults for diagnosis of GHD.

Safety and tolerability- A dose of 2mg/kg (both in adults & children). However, the recommended & FDA approved dose for the stimulation test is 0.5mg/kg. Not established in individuals with BMI >40 kg/m2. In children, it is suggested to use a dose of 1 mg/kg/day of Macimorelin, not approved though.

Pharmacokinetics- C-max is between 30-90 min. It is metabolized through CYP3A majorly. The half-life is 4.1 hours.

Available forms- A 60 mg powder for oral solution, to be stored at 2-8°C. It is to be dissolved in 120 ml of plain water (hence 1 ml = 0.5 mg), and used within 30 minutes of preparation. The dose is based on the weight in kg.

Warning & Precautions- Avoid in patients with prolonged QT syndrome. If the patient is on any CYP3A inducer medicines, the results may be false positive. Before performing the GH stimulation test, GH therapy is to be discontinued for at least 1 week, and fasting is needed for at least 8 hours. before performing the GH stimulation test. Make sure to replace other pituitary hormones before performing the stimulation test.

Adverse Events- Dysgeusia, dizziness, headache, fatigue, nausea, hunger, diarrhea, upper respiratory tract infection, feeling hot, hyperhidrosis, nasopharyngitis, and sinus bradycardia.

Samples to be drawn- GH at 0 min, 30 min, 45 min, 60 min & 90 min. Maximum GH stimulation occurs in 30-60 min of administration of macimorelin.

Interpretation of results- Maximally stimulated GH is 2.8 ng/mL in adults. It is not formally approved or established for use in children, but proposed cut-offs based on some clinical trials are 10.03 ng/mL for 0.25mg/kg dose, 10.43 ng/mL for 0.5mg/kg dose, & 17.013 ng/mL for 1mg/kg dose

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PEDSENDOSCAN

***Arpita Bhriguvanshi**. Professor Junior Gd, King George's Medical University, Lucknow*

Chan et.al. Comparison of INTERGROWTH-21st and Fenton Growth Charts in a Multiethnic Asian Population. BMJ Paediatr Open. 2024 Nov;8:e002864.

The authors performed a cross-sectional study to compare INTERGROWTH-21st (IG-21) and Fenton growth charts for birthweight (BW) classification in a multiethnic Asian cohort of 2,541 neonates in Singapore. BW classifications for small-for-gestational-age (SGA), appropriate-for-gestational-age (AGA), and large-for-gestational-age (LGA) were assessed using both charts. Results showed that 171 neonates (6.7%) had discordant BW classifications, with the Fenton charts overclassifying SGA (2.9%) and under-classifying LGA (60.5%) compared to IG-21. Agreement between the two charts was moderate (K=0.79) but decreased with gestational age, from K=0.88 in preterm neonates to K=0.71 in full-term neonates. The largest discrepancy occurred among neonates classified as LGA by IG-21 but AGA by Fenton (60.5%), which was more frequent in females (69.7%) than males (49.3%). **The study concluded that Fenton charts may misclassify neonatal birthweights, leading to potential inaccuracies in identifying at-risk infants, and suggested that IG-21 standards may provide a more globally appropriate alternative for birthweight classification in diverse populations.**

Majumder R, et al. Anthropometric Growth Reference for Indian Children and Adolescents. Indian Pediatr. 2024 May 15;61(5):425-434.

A cross-sectional study to develop India-specific anthropometric growth references, recognizing that WHO growth standards may overestimate undernutrition in Indian children. Using data from NFHS-3, NFHS-4, NFHS-5, and CNNS, the study analyzed 13,204 children under 5 years and 6,659 children aged 5-19 years, selecting a healthy subset based on socio-economic and health criteria. Compared to WHO standards, the new Indian references *reduced estimates of stunting* (35.5% to 15.5%, p<0.001), underweight (32.1% to 16.9%, p<0.001), and wasting (19.2% to 10.9%, p<0.001) in children under 5 years. Among children aged 5-19 years, stunting estimates were significantly lower (6.2-7.4% vs. WHO's 20.8-28.9%, p<0.001), and thinness prevalence was also markedly reduced (3.2-5.7% vs. WHO's 17.0-22.9%, p<0.001). However, *overweight prevalence was higher* using the new references (13.8% vs. 9.0% in children under 5 years and 12.0-12.7% vs. 6.3-7.5% in older age groups). The study concluded that **WHO growth charts misclassify many Indian children as undernourished, leading to potential overdiagnosis and misallocation of health resources**. *Recommendations- adoption of India-specific growth references for more accurate nutritional assessment & better public health policies, while emphasizing the need for further validation through prospective studies before nationwide implementation.*

Zverev S, et al. Orthopedic Complications Associated with Pediatric Growth Hormone Therapy: A Review. Children (Basel). 2024 Nov;11(11):1354.

A comprehensive review on the orthopedic complications associated with growth hormone therapy (GHT) was conducted. GH usage has tripled in the last 20 years due to expanded indications beyond GH deficiency. The study identified a significant association between GHT & various orthopedic conditions, including **slipped capital femoral epiphysis (SCFE)** (risk increased by 4.2-

fold, 95% CI: 3.1-5.7, p<0.001), **scoliosis** (second most reported adverse event in long-term GH registries), **osteochondritis dissecans, Legg-Calvé-Perthes disease, Sever's disease, Osgood-Schlatter disease, and carpal tunnel syndrome.** *Mechanistically, GH-induced accelerated growth, increased chondrocyte proliferation, and growth plate instability contribute to these complications*. One study reported a 211-fold increased SCFE risk in childhood cancer survivors who had received GHT after total body irradiation. The orthopedic complications often present months to years after GHT initiation, necessitating routine monitoring in pediatric patients on GH therapy, particularly athletes and those with pre-existing conditions. The authors concluded that *while GHT remains an effective treatment for growth disorders, its orthopedic risks require vigilant long-term monitoring and a multidisciplinary approach to optimize patient outcomes.*

Savarirayan R, et al. Oral infigratinib therapy in children with achondroplasia. *N Engl J Med* 2025;392:865-874.

Infigratinib, an orally bioavailable FGFR13 selective tyrosine kinase inhibitor is in development for achondroplasia. In this phase 2 dose-finding study, the authors evaluated safety & efficacy of oral infigratinib in children with achondroplasia aged 3-11y. A total of 72 children were enrolled in five sequential cohorts to receive daily infigratinib in doses of 0.016 mg/kg (cohort 1), 0.032 mg/kg (cohort 2), 0.064 mg/kg (cohort 3), 0.128 mg/kg (cohort 4), and 0.25 mg/kg (cohort 5) for 6 months, followed by 12 months of extended treatment in which the dose in cohorts 1 and 2 could be escalated to the next ascending level at months 6 and 12. All the children had at least 1 adverse reaction, mostly mild/moderate in severity; none resulted in treatment discontinuation. In cohort 5, an increased annualized height velocity was observed, which persisted throughout the study, with a mean change at 18 mo of 2.50 cm/y (95% CI, 1.22 to 3.79; P=0.001). The mean change from baseline in height z score was 0.54 (95% CI, 0.35 to 0.72) relative to an untreated reference population at 18 mo; the mean change from baseline in upper-to-lower body segment ratio was −0.12 (95% CI, −0.18 to −0.06). The authors concluded- *administration of oral infigratinib increased annualized height velocity & z score and decreased the upper-to-lower body segment ratio at 18 months of treatment in cohort 5, without any apparent major safety signal.*

LISTENING TO THE STALWARTS

Dr Nikhil Lohiya *Division of Growth & Endocrinology, Silver Lining Pediatric Super Specialty Center, Nagpur*

Dr Vaman Khadilkar is a Senior Consultant in Pediatric Endocrinology at Jehangir Hospital, Pune & PhD Guide in the Health Sciences Dept., Pune University, Pune. He and Dr Anuradha Khadilkar have been at the forefront of research in growth and growth disorders. A highly decorated academician and Past President of ISPAE, Dr Khadilkar has been convener of the Obesity Guidelines Committee, CIAP 2023; the Growth Charts Committee, Indian Academy of Pediatrics, 2007, 2010, and 2014; and the Calcium and Vitamin D IAP Guidelines 2017.

CAPE News team is delighted to have an insight into his journey of studying and managing growth disorders, and his experience as a Pediatric Endocrinologist.

What made you to choose Pediatric Endocrinology after your training in Pediatrics?

A logical branch of pediatrics where a lot of conditions can be very well controlled, giving satisfaction of helping patients and families.

You had a bright future and better opportunities at Great Ormond Street Hospital, London and in the United Kingdom. Why you came back in India to pursue your career?

जननी जन्मभूमिश्च स्वर्गादपि गरीयसी The decision was mainly due to family circumstances, aging parents and growing children, and patriotism. It was a hard decision to leave a potentially high profile career in the UK but today I am very happy to be able to work for children of my own country and also the scientific contribution we (me, my wife Dr. Anuradha and our research center at HCJMRI & Jehangir hospital) have been able to make to the field of pediatric endocrinology of India.

Your biggest positive, and not-so-positive, aspect of being in this field till date.

Establishing Indian growth and many other Indian anthropometric norms, other research papers and having a very dedicated, intelligent expanding family of fellows and colleagues all across India are the best things that have come out of this journey. Very few negatives really, other than perhaps the relentless need for 24x7 availability as a doctor in India.

You have done so much work on the subject of growth in children. How has the condition evolved? Can you brief us on the change in epidemiology of growth disorders from when you started your clinical practice?

In the initial days of practice about 3 decades ago, the spectrum of growth failures used to be malnutrition/ malabsorption, thyroid disorders, chronic systemic disease, uncontrolled type 1 diabetes, familial/ idiopathic short stature - in that order. Over the period of the last 2.5 decades, we are seeing less malnutrition; chronic diseases are still there; late effects from cancer chemotherapy and thalassemia have become more common, followed by other conditions. In Maharashtra, where I practice, more and more pediatricians over the past 25 years have started monitoring children on growth charts. Developing electronic apps such as the IAP growth chart app has really helped.

Anthropometry and growth disorders have been your forte. How did you get interested specifically in it, and what helped you in pursuing it in India?

When I started my job as Senior Registrar in Pediatric Endocrinology at Great Ormond Street Hospital (GOSH) in the 90s, the most noticeable thing in every child's case notes was the growth chart, nicely placed as a first page of the file, depicting the life story of health and disease in the child! It was clear to me that this is what we need to emulate. At GOSH, I trained under the mentorship of Prof. Mike Preece (the Preece-Bains equation man) and Prof Tim Cole (the Biostatistician involved in making so many charts for children around the world, including WHO and IOTF charts!). In India, it was the lack of availability of good quality charts that got me going on this mission. In those days there were data tables available, but no good quality charts made with standard sophisticated methods such as LMS. That was the beginning of this very enjoyable journey of making anthropometry norms on Indian children!

You have been a teacher, practitioner, researcher, academician and also undertaken social responsibility of children you take care of. What part was the most fulfilling and enjoyable aspect of your career, individually, and as a team?

Teaching fellows, Pediatricians, Postgraduates and PhD students is most enjoyable, and equally enjoyable is learning from them and their efforts. Working for social causes is even more fulfilling, but I give more credit to Dr. Anuradha for that endeavor.

How can one balance research and clinic practice in this competitive era?

It's a tight rope walk! Sincere efforts and a caring attitude are imperative for good patient care, and for research, it's the team work. Every now and then when I run out of steam, people around me keep me going!

If a person who wants to pursue Pediatric Endocrinology comes to you and asks how is the future of this field, what would be your answer?

In a vast country like India, more people to manage any pediatric subspecialty are welcome. In the case of pediatric endocrinology, with the huge increase in type 1 diabetes, lifestyle disorders such as obesity, precocious puberty etc. the future for new pediatric endocrinologists looks as bright as ever.

Being one of the founder members, and Past President of ISPAE, where do you rate the work and contribution of the Society? How proud of it are you?

This sapling, the brainchild of our seniors such as Dr Meena Desai, Dr PSN Menon and Dr P Raghupathy has really grown well, and now is even having ramifications! From just a handful of people, it has blossomed into a vibrant, multifaceted Society with hundreds of members. Young people are adding more and more facets to our Society. There is a journal and this news bulletin as well. I am happy, delighted and proud to see the progress of ISPAE. I express my sincere and best wishes to ISPAE.

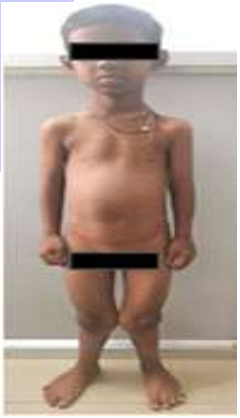
Any advice for trainees and young pediatric endocrinologists?

Honesty, sincerity, hard work and genuine concern for your patient are important. Adding research angle to a clinical practice helps to improve practice and patient care. Fame and money should be the last thing to chase. The Almighty will bless those who deserve it.

CASE REPORT: KNOCK KNEES & SHORT HEIGHT: A UNIQUE CASE OF GENU VALGUM

***MS Srivaishnavi, Vani HN**, IGICH, Bengaluru*

A 7-year 11-month-old boy presented with progressive deformity of the lower limbs, which were first noticed by the parents when the child began walking. The child was born at term via normal vaginal delivery at home, with a birth weight of 2.5 kg. He had natal teeth (lower two incisors). No neonatal problems were reported. The child is third in birth order, born in a 3rd degree consanguineous marriage, with no known family history of similar conditions or congenital anomalies. Both the older female siblings are normal. On examination, the weight was 14.6 kg, height 104.8 cm, both below the 3rd percentile, with z score < -3SD, BMI was 13.5kg/m^2 (z score -2SD), with an abnormal upper segment to lower segment (US:LS) ratio of 1.28. He had an elongated face, absent upper and lower incisors and canines, and conical-shaped hypoplastic teeth, along with a high-arched palate. The child also had postaxial polydactyly on both hands, with short, stubby fingers and underdeveloped nails. Lower limb examination revealed bilateral genu valgum, which had progressively worsened.



Biochemical parameters such as cortisol, thyroid function tests, calcium, magnesium, phosphorus, and electrolytes all within normal range; Vitamin D was insufficient (18.40 ng/ml), and triglycerides were borderline high (160.8 mg/dl). Radiological findings confirmed polydactyly and other skeletal anomalies typical of Ellis-Van Creveld syndrome (EVC) (see below). Further investigations, including 2D echocardiography, abdominal ultrasound, and ophthalmic examination were normal. The clinical and radiological findings strongly suggested a diagnosis of EVC syndrome.

Fig 1: Patient, with short stature and genu valgum

Fig 2. Photograph and X ray showing polydactyly. B/L six metacarpal digits seen. The sixth digits are seen at the medial aspects of the hands consistent with bilateral post-axial polydactyly. B/L capito-hamate coalition, Cone shaped epiphysis of phalanges and hypoplastic distal phalanges are seen.

Fig 3 - Orthopantogram showing oligodontia.

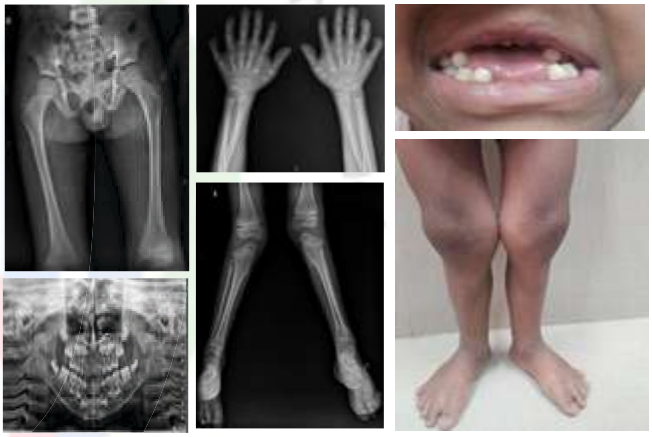


Fig 4 - Photograph and xray showing b/L genu valgum. Tibial segments are disproportionately shorter than the femoral segments with expanded and abnormally shaped metaphysis of long bones. Medial spurs are seen at bilateral proximal tibial diametaphysis. Pelvic xray shows short iliac crest.

Discussion: "Chondroectodermal dysplasia," was the term coined by Ellis and Van Creveld (Ellis, 1940), when they originally described a syndrome of mesomelic dwarfism, postaxial polydactyly with fusion of the hamate and capitate, and dysplastic teeth and nails; and in half the affected individuals, a congenital heart defect (most commonly atrial septal defect). Now referred to as Ellis van Creveld syndrome, it is a rare, autosomal recessive disorder, whose diagnosis can be made as early as the 18th week of gestation by ultrasonography when increased translucency is evident. The association of several structural fetal defects in the late 1st trimester, including narrow thorax, short and bowed long bones, rounded metaphysis, post axial polydactyly and cardiac defects may suggest diagnosis of EVC. The definitive diagnosis is made through direct gene sequencing which is based on the mutation of EVC1/EVC2 genes, *DYNC2H1*, *DYNC2LI1*, *GLI*, *SMO*, or *WDR35* inherited in an autosomal recessive manner. EVC syndrome caused by pathogenic variants in *PRKACA* or *PRKACB* (accounting for 2% of affected individuals) is inherited in an autosomal dominant manner.

The most striking features of the syndrome are bilateral postaxial polydactyly of the hands, ectodermal dysplasia affecting the nails and teeth, congenital heart abnormalities, chondrodysplasia of the long bones resulting in acromesomelic dwarfism, and presence of genu valgum. Oral manifestations of the syndrome include the fusion of the upper lip to the maxillary gingival margin, absence of mucobuccal fold or the sulcus anteriorly, notching of the alveolar ridge, congenitally missing teeth in the mandibular anterior region, erupted teeth having small crowns and irregular spaces between teeth.

Differential diagnosis includes other short rib polydactyly syndromes like Weyers acrodental dysostosis (Curry-Hall syndrome), asphyxiating thoracic dystrophy (Jeune syndrome), achondroplasia, chondroplasia punctata, orofaciodigital syndromes and Morquio's syndrome.

There is no definite cure of EVC syndrome. Treatment is usually symptomatic. A multidisciplinary approach is advocated involving a clinical geneticist, cardiologist, pulmonologist, orthopedician, urologist, physical and occupational therapist, dentist, psychologist, developmental pediatrician and pediatric neurologist for proper management and rehabilitation of such cases.

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CASE REPORT- IMPROVING FINAL HEIGHT IN CHILDREN WITH JUVENILE HYPOTHYROIDISM PRESENTING AS VAN WYK GRUMBACH SYNDROME: A CASE SERIES

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Untreated primary hypothyroidism in children causes short stature with delayed bone maturation, and delayed puberty. The paradoxical occurrence of reversible, peripheral, isosexual precocious puberty and gonadal enlargement in the background of delayed bone age in chronically untreated juvenile hypothyroidism is Van Wyk Grumbach syndrome (VWGS). These children usually present with short stature, abdominal pain, or vaginal bleeding; rarely with anemia, ovarian torsion, or intracranial mass effect. Various hypotheses have been proposed to explain the pathogenesis of VWGS. The extremely high TSH levels, due to specificity spillover, activate the wild-type FSH receptors, leading to testicular/ ovarian hyperstimulation, resulting in thelarche and vaginal bleeding in girls and macro-orchidism in boys, independent of adrenarche. In addition, constant stimulation by TRH stimulates FSH secretion, and the high prolactin levels suppress LH, thereby increasing ovarian sensitivity to circulating gonadotropins, and accelerating follicular maturation (1,2).

Though all children show remarkable catch-up growth in height during the initial period after starting thyroid hormone replacement, final adult height (FAH) is significantly compromised (3). The circulating estrogen resulting from peripheral conversion, and in some cases triggering of gonadotropin dependent puberty, could worsen the FAH prospects by hastening growth plate closure.

Early initiation of thyroxine, avoiding TSH suppression, preventing progression of secondary central precocious puberty and delaying growth plate closure (4) are common strategies to ensure optimum FAH. Here we present a case series of 5 patients with VWGS who were managed with aromatase inhibitors (boys) and leuprolide depot (girls) to improve FAH.

Methodology: This is a retrospective case record review of five children with untreated primary hypothyroidism who were evaluated, treated and followed up at Dept of Endocrinology, Narayana Hospitals between 2021-2025. The WHO 2006 & IAP 2015 combined height and weight charts were used; bone age and predicted adult height (PAH) was calculated using coefficients for prediction of adult height provided in the Gilsanz and Ratib atlas (5).

Case details:

Case 1: 18yo male with undiagnosed congenital hypothyroidism presented with short stature: height 129.9 cm (-5.51 SDS) cf. mid-parental height (MPH) of 168 cm. Physical examination revealed testicular volume (TV) of 12 ml, bone age (BA) was 5-6y, FSH and LH were suppressed, serum testosterone was <4.9 ng/dl. Technetium uptake scan showed ectopic thyroid gland in sublingual region. He was started on thyroxine (1.9 mcg/kg/d). At age 19.5y, his height was 138.4 cm and BA 12-13y. Letrozole 2.5mg was initiated, with optimization of thyroxine doses (2.3mcg/kg/day). At a recent follow up, at age 22y, his height is 155cm (-3 SDS), testicular volume 20ml, BA is planned. His PAH is 159.6 cm, 8 cm less than the MPH.

Case 2 :10yo girl presented with short stature, failure of eruption of permanent tooth and atopic dermatitis, height of 120 cm (SDS: -2.4; MPH: 162.5 cm), and thelarche with no pubic or axillary hair. BA was 5.5-6y, TSH > 100 µIU/ml, with undetectable FSH and LH. She was started on thyroxine (2.5 mcg/ kg/ day). At age 10y9m, she was 132 cm, had progressed from Tanner stage B2 to B3, with LH 6.33, FSH 5.69. Ultrasound (US) showed multicystic ovaries: right ovary volume was 3.1cc with 8-10 follicles, left ovary was 2.3cc with 3-4 follicles. Inj. Leuprolide 11.25 mg IM once in 12 weeks was added. At age 12y4m, she was 150 cm, Tanner B4, BA 11y, euthyroid on thyroxine 2.4 mcg/kg/day. Her PAH was 167.8 cm: leuprolide was stopped after discussion with the parents and child. At the last follow up at age 13y, she was 153.5 cm.

Case 3: 15.5yo boy was referred for short stature and excessive weight gain. His scholastics were poor and he was socially withdrawn. His height was 144 cm (-2.6 SDS) cf. MPH 171 cm, TV 12 ml; BA was 10y. TSH was >150 µIU/ml; FSH and LH undetectable, testosterone 6.22 ng/dl. He was diagnosed to have autoimmune hypothyroidism, and started on thyroxine at a dose of 1.59 mcg/kg/day. On next follow up at age 16y, FSH was 3.8 and LH 0.899 µIU/ml: letrozole 2.5mg was added. On letrozole for the past 2y, he has gained 12 cm, and currently at age 18y, he is 161 cm, with TV 20 ml, P4. Since BA is 14-15y and PAH is 169 cm (2 cm less than MPH), letrozole has been stopped in February 2025.

Case 4: 9.5yo girl presented for evaluation of short stature. She was 115cm (-2.7 SDS) cf. MPH 163 cm, with thelarche and scanty pubic and axillary hair. BA was ~ 4y, TSH >150 µIU/ml, TPO elevated, FSH and LH were suppressed. She was started on thyroxine (2.77 mcg/kg/d). On follow up, in 7 mo, she had gained 8 cm, and progressed to Tanner B3P1A2, with US revealing cystic ovaries. Inj. leuprolide depot 11.25 mg once in 3 months was added at age 10y, and given till age 11y7m, when height was 138.5 cm, BA 11y, PAH 160.2 cm (2.7 cm < MPH). At her last visit, at 12.75y, she was 147.5 cm, and euthyroid on thyroxine 2.4 mcg/kg/day.

Case 5: 14y9m old girl was referred with short stature and vaginal bleeding. She was 120 cm (SDS -5.53) cf. MPH 148.5 cm, Tanner B2P1A1. TSH was > 150, gonadotrophins were suppressed; ovarian volume was 10.6 cc and 7.8 cc. Thyroid gland was in normal location. On follow up 2 mo later, she had progressed to Tanner B3, so she was started on leuprolide, and is awaiting follow up.

Results: Our 5 patients (3 girls & 2 boys) presented at median age of 14.75y (range 9.5-18y), at median height age of 7.09y (range 6.25-11.25y), and median height SDS of -2.71 (-2.4 to -5.53). Boys presented later (15.25y and 18.5y) than girls (9.5y, 10y, 14.75y). Four of them had autoimmune hypothyroidism (defined by TPO and/or Thyroglobulin antibody positivity) while one boy had congenital hypothyroidism with sublingual thyroid gland. Though one girl presented with vaginal bleeding, at presentation all three girls had thelarche and multicystic ovaries; both boys had macro-orchidism with TV of 10-12 cc; while all of them had suppressed LH, characteristic of VWGS.

These children were started on levothyroxine at doses ranging from 1.6-2.5 mcg/kg/day, with subsequent up titration. At presentation, the median delay in BA vs. chronological age was 6.5y (4.5-13.5y). Once BA reached around 11y, or LH became detectable, epiphyseal fusion was slowed down by starting leuprolide in the girls and letrozole in the boys. In recent follow ups, the median height SDS improved to -2 (0 to -4.5), with the PAH close to the MPH in most of them.

	CASE 1 (male)		CASE 2 (female)		CASE 3 (male)		CASE 4 (female)		Case 5 (female)	
	First visit	Latest visit	First visit	Latest visit	First visit	Latest visit	First visit	Latest visit	First visit	Latest visit
Follow-up (y)	4		3		2.7		3.25		1	
CA (y)	18	22	10	13	15.25	18	9.5	12.75	14.75	15.6
HA (y)	8.75	13	7.09	13	11.25	14	6.25	12.75	7.09	8.5
Height SDS	-5.51	-3	-2.4	0	-2.6	-2	-2.7	0	-5.53	-4.5
MPH (cm)	168		162.5		171.5		163		148.5	
PAH (cm)		159.6		167.8		169		160.2		NA
PAH-MPH				5		-2.5		- 3.2		
TSH (µIU/ml)	>100	8.09	>100	1.63	>150	1.8	>150	3.3	>150	
Tanner stage	P1	P3	B2P1	B3P1	P1	P4	B2P1	B4P3	B2P1	B2P1
Gonadal volume (cc)	R 12 L 10	R 15 L 20	R 3.1 L 2.3		R 8 L 12	R 16 L 18	Multicystic ovaries		R 10 L 7.8	
Levothyroxine dosage mcg/kg	1.9	1.6	2.43	2.4	1.18	2.3	1	2.4	1.67	
Etiology	Ectopic thyroid		Eutopic thyroid gland with autoimmune thyroid disease							

We propose that in addition to levothyroxine, measures to delay epiphyseal closure can help improve FAH in children presenting with VWGS. Starting aromatase inhibitors in boys or leuprolide in girls at the right time, along with appropriate dosing of thyroid supplementation, will help them improve final height.

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CASE REPORT- THE DWARFISM OF SINDH

***Subramanian Kannan, Vikas N**, Dept of Endocrinology, Narayana Health City, Bangalore.*

A 9y9m old boy, 2nd born child of a 2nd degree consanguineous marriage, presented with complaints of poor height gain since age 2y; he was the shortest among his peers. He was born of normal vaginal delivery with birth weight of 3.5kg, with uneventful perinatal period. He had a history of delayed motor development, but not of any chronic systemic illness, and no family history of short stature.

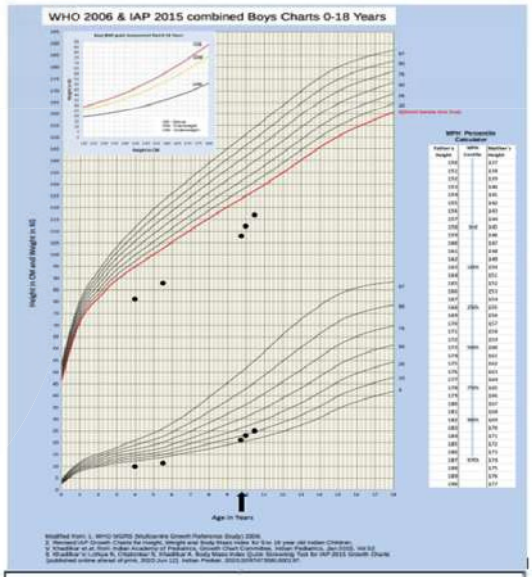

Fig 1 IAP Growth Chart showing the growth of child before and after starting recombinant GH (black arrow). MPH- 165cm

On examination, his height was 109 cm: -4.2 SDS below the mean cf. MPH 165 cm, with a height age (HA) of 5y; weight 20 kg: -2.15 SDS with a weight age of 6.6y. He had dysmorphic facies (low-set ears, high arched palate, and clinodactyly). On evaluation, his bone age was 5 years; hemogram, metabolic profile, thyroid profile and cortisol were normal, celiac screening was negative, IGF-1 was 49 ng/ml (58.7-311) (1). On clonidine stimulation, growth hormone (GH) level was <0.03 ng/ml at 120 min. MRI brain showed no abnormality. On genetic testing with whole exome sequencing, he was detected to have a GHRH receptor mutation (a homozygous mutation on exon 3 of chromosome 7p14.3), which confirmed the diagnosis of isolated Growth Hormone Deficiency type IV. He was started on recombinant human GH at a dose of 0.049 mg/kg/week. On follow-up at 8 months, he has gained 8 cm (current height 117 cm).

Isolated growth hormone deficiency (IGHD) is the commonest pituitary hormone deficiency, with an incidence of 1 in 4,00010,000 live births. In 330% of cases, IGHD is familial, with the majority of cases being idiopathic. IGHD can be present from the first years of life (congenital); secondary to autoimmune disease, brain trauma or infections, tumors or radiotherapy (acquired); or idiopathic. Congenital IGHD can be secondary to genetic mutations in the gene encoding growth hormone (GH1) or the gene encoding the GH releasing-hormone receptor (GHRHR). IGHD type IV (IGHD4)

also known as *Dwarfism of Sindh* is an autosomal recessive disorder characterized by early and severe growth failure and is caused by a mutation in the GHRHR gene. This gene is 15.51 kb in length and incorporates 13 exons on chromosome 7p14. It encodes a G-protein coupled receptor (423 aa) and is expressed on the somatotroph cells of the anterior pituitary. (2) Recombinant human GH (rhGH) is used to treat patients with GHD. (3)

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LEARNING PEARLS: PEP HYPOTHYROIDISM

Dr Vijay Jaiswal, *Consultant Endocrinologist, PEDO Pediatric Endocrine Center, Meerut*

- Follow universal congenital hypothyroid screening in all babies, don't wait for signs & symptoms.
- TSH is the best screening method to detect hypothyroidism.
- Babies with severe intrauterine thyroxine deficiency, with absence of femoral epiphysis at birth, may develop mental retardation and developmental delay later even despite timely treatment.
- Tc scanning is not necessary to start treatment, as early treatment is more important.
- The aim of treatment is to normalize T4 level within 2-4 weeks and TSH by 6-8 weeks.
- If the initial TSH set point is very high, normalization of TSH may take time: in that case, the FT4 should be kept in the upper half of the normal range.
- In case of central hypothyroidism, HPG axis should be checked prior to therapy: concomitant cortisol deficiency may lead to Addisonian crisis.
- Juvenile hypothyroidism may present with short stature without goiter.
- In acquired hypothyroidism, start with low dose thyroxine: high doses may cause symptoms and signs of benign intracranial hypertension.
- Discordant precocious puberty in a short girl may be due to hypothyroidism.

AWARDS/ PUBLICATIONS BY ISPAE MEMBERS

ANNOUNCEMENT

Dr Olaf Hiort, University of Lübeck, Germany- Collaborative Research Centre (CRC)

A CRC is a long-term research funding. We will receive up to 40 million Euros to investigate diversity of sex in biology, medicine and society. A team of 77 scientists and co-workers is participating. For Details please see: https://www.sfb1665.uni-luebeck.de/en/crc-1665

Ms Mehek Dhingra, winner of Allan Drash Fellowship

My experience: I am immensely honored to share I was selected as the Allan Drash Clinical Fellow for the year 2024. This prestigious fellowship provided me with the invaluable opportunity to travel to London and work with Dr Ruben Williemsen and his team. What I found very rewarding was that Dr Williemsen ensured I could engage in a comprehensive learning experience across three distinguished hospital sites: Royal London Hospital, Whipps Cross University Hospital, and Newhem Hospital; and also immerse myself in a variety of specialized settings, including the Pediatric Type 1 Clinic, Teens Clinic, Transition Clinic, Multi-Disciplinary Annual Clinic, Ward Rounds for newly diagnosed patients, Type 2 Clinic, and School Training Program. Each setting offered unique insights and exposed me to different methodologies, enriching my understanding of best practices in diabetes care. I am eager to share these insights in detail in the next issue of CAPE News, aiming to improve our approach and outcomes in managing diabetes. Meanwhile, briefly, here are a couple of points:

Key Takeaways from My Experience:

1. **Crossing Sites:** Working across different hospital sites allowed me to experience varied cultural and dietary preferences, which deeply enhanced my ability to provide culturally sensitive care.
2. **Segmenting Sessions by Age Groups:** Dividing kids into groups such as teens and toddlers during sessions proved beneficial. It not only helped them connect with peers in the waiting area, enhancing their comfort and engagement, but also allowed the team to better understand and address age-specific patterns in diabetes management.

REPORT ON IDEAL & BEST ACTIVITIES

IDEAL, IDEAS, AND BEST PROGRAMS: STRENGTHENING PEDIATRIC DIABETES EDUCATION IN INDIA

Dr Preeti Singh, Professor, *Lady Hardinge Medical College* ***& Kalawati Saran Children's Hospital, New Delhi; Dr Sirisha Boddu****, Rainbow Children's Hospital, Hyderabad;* ***Dr Anju Virmani****, Director, Pediatric Endocrinology, Max Smart SS Hospital & Rainbow Children's Hospital,* ***New Delhi***

The IDEAL (ISPAE Diabetes Education and Learning) program initiated its ninth batch on January 15th, strategically aligned with the culturally significant festivals of Pongal and Makar Sankranti, marking a symbolically auspicious commencement. The third Physicians' Batch garnered substantial interest, reflecting the growing need for specialized pediatric diabetes education in India. This batch is a diverse cohort including pediatricians, diabetologists, DM Residents, and

Endocrinology Fellows from pediatric and adult backgrounds, including 2 pediatricians from Nepal sponsored by Life For A Child (LFAC). A noteworthy aspect of this batch was the active participation of several senior pediatric endocrinologists, including IDEAL faculty, who enrolled for a focused to revise their knowledge and have been fondly designated as “IDEAL-lites” to differentiate them from the trainees. The program continues with characteristic rigorous academic standards, due to the exceptional dedication and commitment of the faculty. Adding to the rigor is the inclusion of three additional revision sessions at the end, in addition to the ongoing feedback sessions, specifically designed to reinforce critical concepts and effectively address complex topics; the course **will culminate in the Exit exam on 21-23 April**. Endorsement by the International Society for Pediatric and Adolescent Diabetes (ISPAD) has provided international recognition and credibility; its members have expressed appreciation and eagerness to gain from it. Trainee feedback from across India has been overwhelmingly positive, with many sharing news of activities made possible by their learnings during the course. Two IDEALites have joined as faculty.

The IDEALites WhatsApp group continues to serve as a vital platform for sustained peer support and exchange of knowledge. Discussions in this group encompass clinical diabetes management strategies, information on diabetes support groups and related NGOs, distribution of educational resources (IDEAS videos, educational videos by Dr Bhanu and others), and announcements about relevant webinars and events. Highlighted events include the ISPAD webinar on "Navigating Health Equity for Youth-Onset Type 2 Diabetes," which had IDEAL faculty member Dr Koushik as speaker; Empower T1D webinars addressing diabetes care issues like waste management, co-morbidities, pregnancy, and sexuality; and **YDF monthly online meetings**. Sharing experience with technology (e.g. the Linx Continuous Glucose Monitoring (CGM) device); dietary guidance, including insights into the impact of various sweeteners, food choices and fad diets; warning about the danger of ORS-L; and motivational narratives from successful individuals with T1D diabetes, are invaluable.

Arising out of the IDEAL efforts, the thrust of Initiative for Diabetes Education & Awareness in Schools (IDEAS) to improve diabetes care in schools continue. Explanatory videos in an easy-to-understand, conversational style have been developed in multiple languages, including Bengali, English, Gujarati, Hindi, Kannada, and Tamil (more are on the way), to facilitate broader and more effective communication. These resources are freely accessible on the ISPAE website, enabling parents to share critical diabetes management information with school staff responsible for their children's care. Parents are encouraged to share and discuss these videos with school personnel each year at the start of a new grade, while sharing their child's Diabetes Management Plan. It is also being translated into Arabic by Dr Yasmine (Egypt).

In parallel, the BEST (Basic Education Series on T1D) program continues to gain momentum and widespread appreciation. Batch 9 of BEST, conducted from February 25th to March 18th, brought together a diverse group of participants, including parents of children with T1D, young adults living with T1D, nurses, allied health professionals, and Fellows in the early stages of training. An inclusive approach with a dynamic learning community, effectively amalgamated clinical understanding with personal lived experiences. The growing popularity of the BEST program highlights its value as a foundational educational resource, empowering families and healthcare providers alike with essential knowledge and confidence in managing T1D.

Together, IDEAL, IDEAS and BEST provide represent a comprehensive educational initiative which is helping develop a well-informed and knowledgeable community of T1D families and health care providers, committed to improving outcomes for children and adolescents living with T1D.

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ACTIVITIES BY ISPAE MEMBERS

Educational Program for children with diabetes

Dr Koushik H, *Associate Professor & Pediatric Endocrinologist, Dept of Pediatrics & Pediatrics Endocrinology Clinic, Manipal*

The Dept of Pediatrics & Pediatrics Endocrinology Clinic, Manipal, in association with Indian Council of Medical Research (ICMR), Govt. of India funded Young Diabetes Registry (YDR) Phase III, & Dept of Medicine, Kasturba Medical College & Hospital, Manipal, organized a one-day Educational Program for Young Diabetics. Around 30 young persons (2-25 years old) living with diabetes (PLwD) participated with their caretakers. Fasting blood sugar, HbA1c, anthropometric and vital parameters, and fundus screening for identification of diabetic retinopathy were done free of cost. Educational and practical demonstration sessions were conducted, including education on insulin administration, and a Mini-workshop by Child Guidance Clinic, Department of Psychiatry to identify and manage stressors. There was an interactive session with the Dept of Clinical Nutrition & Dietetics on making routine homemade food diabetes-friendly and preparation of healthy snacks. A Yoga demonstration was done by the Dept of Yoga, Center for Integrative Medicine & Research, MAHE. At the Exhibition Stalls set by Dept of Clinical Nutrition & Dietetics, Dept of Physiotherapy, and Dept of Yoga, there were awareness sessions and interaction. Self-introduction by the PLwD, inspirational talks, participation in fun games, quizzes, and cultural programs by the children as well as the pediatrics Resident Doctors were added events which helped us motivate and cheer up the children and their family members. Healthy, diabetes-friendly food was served.

Type One Champions Sports Camp: Empowering T1Ds through Sports and Awareness

Dr Ajinkya Patil, *Pediatric Endocrinologist, HormoCare Clinic, Jalgaon, Maharashtra*

A single-day sports meet 'Type One Champions Sports Day' was organized on 9th Feb 2025 by ClubOne Adda Jalgaon (T1D Support Group). The event aimed to blend sports, education and community support for individuals with Type 1 Diabetes (T1D). 130 T1Ds participated enthusiastically in cricket, badminton, carrom, and a specially designed T1D-themed snakes & ladders game, making learning about diabetes management engaging and interactive. A dedicated session on exercise management in T1D provided valuable insights into maintaining an active lifestyle while effectively managing T1D. Winners and participants were honored with medals and certificates, while everyone ensured proper insulin intake and enjoyed a shared meal, strengthening community bonds. All the participants received a kit containing cap, T1D T-shirt, hypotabs, needles, site rotation grids and glucose logbooks. The event boosted advocacy with senior T1Ds encouraging younger T1Ds in independent management. The event was organized in association with Rotary Gold City, ClubOne KEM Pune, and Mukul Madhav Foundation and with the dedicated

efforts of Ms Pritee Mandore, Ms Bhagyashri Dandi and IDEALites Ms Nilam Vikrant and Ms Utpala Daryapurkar.

Making Diabetes Management Safe and Environment Friendly

Ms Riddhi Modi, *IDEALite*

This webinar was organised by Empower T1D (a Clinician & T1D Support Group collaboration), supported and hosted by USV. The objective was to create awareness about the waste generated due to diabetes self-care. The speakers were Dr Anju Virmani (Delhi), Dr Hitesh Saraogi (Gaziabad), Mr Harsh Kohli (Delhi), Mr Bachan Pal Singh (Punjab), and Ms Riddhi Modi (Mumbai); moderator was Dr Ovais Peerzada (Srinagar). Dr Virmani listed how and which ways waste is generated due to self-management of diabetes and the best practices followed at her clinic. Dr Hitesh also shared his practices, stressing on the need for clinicians to be more proactive about this aspect of diabetes care. Mr Harsh (he and his son are pump users) discussed practical issues and how he helps other T1Ds take necessary steps with his pharmacy experience. Mr Bachan being an environment engineer and a T1D, gave the best insights regarding what happens once waste is collected; he emphasized why it is extremely important to understand this process ourselves as well as educate others, so as to save the environment. Ms Riddhi, as an advocate, added that we certainly need to improve our footprint related to diabetes and biomedical waste, proposed efforts to bring together the community to work on this aspect by taking up similar education awareness drives in regional languages. Following up on this, another webinar on the same theme was conducted on 20th March in which Mr Bachan and Ms Riddhi discussed waste disposal in detail, with Drs Hitesh and Dr Abhishek Raha (Lumding).

Biomedical waste segregation is a must. We need to create awareness about how to safely dispose it, by handing it over to the right authorities, to further sort it, and recycle or dispose safely, without causing environment hazards or injuries to humans or Nature.

Adolescent awareness class for self-management of Type 1 Diabetes

Dr Bifina Begum M, *Asst Professor, Pediatrics, Govt Medical College, Ernakulam, Kerala*

We at Govt Medical College (GMC), Ernakulam, conducted an Awareness Class and Workshop for adolescents with T1D, as the adolescent phase is found to be associated with very poor glycemic control. Twenty adolescents with T1D, along with their parents, attended the program. Two IDEALite adults with T1D, Mr Sabari and Ms Saranya, interact with our audience, and shared their experiences of their journey with diabetes. A session on carb counting was taken by Ms Saranya, while Dr Anil Kumar, Prof and HOD, Psychiatry Dept, GMC, addressed the stress and emotional issues associated with diabetes. Dr Bifina took a doubt clearing session, with a quiz for the attendees.

Conducting regular sessions for adolescents with T1D, involving psychologist, dietician, doctors and seniors with T1D will go a long way in boosting their confidence in self-management of T1D.

Sweet Souls Type 1 Diabetes workshop

Mr Lakshminarayana Varimadugu, *President of "Sweet Souls Society for Type 1 Diabetes"*

On 26th January 2025, *Sweet Souls*, in collaboration with Manipal Hospital and LEAD Clinics, organized a T1D workshop in Vijayawada, focusing on education, awareness, and motivation. Key Highlights: Expert Talks by Dr Murali and Dr Bhanu emphasized stable blood glucose (BG) levels, effective management strategies, and the importance of support groups. Motivation & Encouragement by Ramesh Garu, a T1D parent, sharing his journey of acceptance and resilience, encouraged families to support their children openly. Diabetes Education - IDEALite CDEs (Certified Diabetes Educators) Lakshminarayana, Karthik and Sree Divya discussed BG management, glucometer usage, insulin techniques, and real-life experiences to make diabetes management stress-free. Smart Nutrition & Diet Planning CDE IDEALite Gayathri from LEAD Clinics, explained the impact of food on BG, carb counting, and simple diet changes for better glucose control. A Story of Strength Yashoda, a T1D warrior, shared her inspiring journey of overcoming challenges with the support of *Sweet Souls*. Government Support The session covered school policies and access to essential supplies like insulin and glucometer strips. Interactive Session *Sweet Souls* team members engaged participants with practical advice, motivation, and community support. The workshop was a day of learning, empowerment, and building a strong T1D community, as diabetes education is shared in the local language, limiting medical terminology. Together, we are breaking myths, spreading awareness, and inspiring lives! Special thanks to Nithin Vandana, Prashanth, Prabhakar garu and all the volunteers.

Yog Dhyan Foundation (YDF) - A Journey of Hope and Empowerment: Report Jan-March 2025

Dr Anil Vedwal, *Chief Functionary, YDF*

**** Annual Health Camp & New Year Celebration:** To conclude 2024 on a joyous note, YDF's Annual Health Camp on 29th December celebrating Christmas and New Year with over 450 participants, was a heartwarming blend of festivity and health awareness. Managed efficiently by volunteers, and graced by Ms Bindia Chhabra, YDF Trustee, the transition from 2024 to 2025 was marked by nutritious snacks, a delicious birthday cake generously sponsored by the *Bigger Picture Foundation*, children with T1D sharing their inspiring journeys, newly registered child Aradhya's captivating song, diabetes screening, blood tests, free diabetes management supplies, and New Year gifts for all children.

January: **Annual Health Camp with focus on **Eye Health (5th Jan):** was conducted with Dr Sharad Rohtagi from Shroff Eye Center, who enlightened us on prevention of diabetic retinopathy, emphasizing regular eye check-ups as "Eyes are the window of the body." Special thanks to Dr Anju Virmani and Mr Harsh Kohli for providing a few CGM LibrePro Sensors to YDF, sensitizing children about intensive yet prick-free glucose monitoring, with the hope that government support for CGM will increase accessibility for more children with T1D. The **monthly Virtual Session (12 Jan)** focused on **"Kidney Care Made Easy",** by nephrologist Dr Shyam Bihari Bansal, a Panel Discussion by PDEs Dr Arpita Prusty, Mr Sam Gulati and Ms Aruna Sharma. The T1D Hero of the Month: Ms Neha Tyagi: inspired attendees with her resilience and success in managing T1D. Ms Amrita Rupani & Mr Jitesh Wadhwa ensured an interactive session. **Makar Sankranti (14 Jan)** saw a warm and joyful get-together at YDF Center, with distribution of small gifts, sharing of laughter, and a discussion on essential T1D management tips, reinforcing positive spirits and good health practices. **Republic Day Celebration (26 Jan):** organized by Dr Beena Bansal (Head, *Saksham*), at The Grand Taj, Gurgaon, with Chief Guest Mr Harsh Treshan, and Special Guest Ms Sushmita Ghosh (Founder, *Aakriti Foundation*), had YDF, represented by Ms Amrita, Ms Himani, Mr Siddharth, and Dr Anil Vedwal proudly participating. Children from *Saksham*, supported by *Anubhooti* and *NeoFusion*, showcased mesmerizing dance, music, and singing performances. YDF and *Saksham* meaningfully discussed how to expand essential support for children with T1D across India.

** **February:** The **monthly health camp** (**2 Feb)** had an energizing yoga session led by Ms Sandra Lezama (Yoga Teacher from Colombia), promoting stress relief and well-being; Diabetes education session by Dr Anil Vedwal, and birthday celebrations for the February-born children, with honored guests Dr Sachin Panwar & Dr Saroj Kumar Das (*PathShodh Healthcare*, Bangalore) and Mr Harsh Kohli (*Blucare Pharmacy*, Delhi). The **monthly Virtual Session (9 Feb)** was about **"Preventing and Managing Hypos"** by Dr Virmani, and the panel of Ms Amrita, Mr Harsh Kohli & Ms Aruna. The T1D Hero of the Month Ms Jhanvi Thareja shared her inspiring journey. It was an amazing experience for YDF to attend the inspiring **World Congress of Diabetes (13-16 Feb)** organized by Diabetes India in Ahmedabad, made possible by Dr Meena Chhabra and Dr Banshi Saboo. Numerous T1D Stars shared their experiences, and informative sessions were presented by renowned healthcare providers worldwide. Many professionals appreciated YDF's work for children with T1D, and expressed interest in collaborating for future initiatives.

** **March**: The **monthly health Camp (2 Mar)** had an insightful session on “Managing Diabetes Fearlessly in the Beginning”, a Medical Waste Disposal Demo by Dr Vedwal, with yoga, birthday celebrations, and a nutritious meal from the *Bigger Picture Foundation*. The **monthly virtual event (9 March)** honored Ms Beemajan Yussouf (diabetes educator in New South Wales, Australia) as the T1D hero, as she discussed “**Overcoming Discrimination against individuals with T1D**”, with panelists Dr Shuchy Chugh, Ms Rekha Negi and Ms Jyotsna Rangeen joining in. It was an emotional and inspiring meeting.

** **Looking Ahead:** YDF remains committed to empowering the T1D community through education, advocacy, and support.

T1 Buddies Meet

***Mr Subail MP**, T1D Buddies, Kozhikhode, Kerala*

T1 Buddies Kerala WhatsApp Group Kozhikode District hosted its 1st District Level Meetup, on 9 Feb 2025 at Govt UP School, East Nadakkavu, for children with T1D. 50 parents and 25 T1D children from Kozhikode District participated. Educational sessions were led by Mr Suhail MP, Mr Shameer Mohammed PV, and Dr Hafza Hameed (IDEALites, Type 1 Warriors) & Ms Soorya Selinda K. Type 1 adults shared their success stories. Basic Type 1 education was given to the children. A Quiz competition with prizes was conducted for the children. The event concluded with giving special thanks to organizers-Mr Suhail MP and Lucy George, an active parent of a Type 1 kid.

T1 Buddies Kerala WhatsApp Group hosted its 4th District Level Meetup, on 2 Feb 2025 at Mahatma Auditorium, Kannur: "Chasing dreams and adding memories", for children with T1D. 60 people from Kannur District participated: including 30 T1 children and their parents. Mr Suhail MP, IDEALite and Type 1 Warrior, who has been coordinating with these kids for 2y, led the educational sessions. This time, Type 1 kids and their parents took the classes about Basic Type 1 Education & its importance, which was gratifying. Also, detailed classes were taken on topics including ISF, ICR, SMBG, CGM, DKA, balanced diet etc. Mementos were presented to kids who do exemplary Carb Counting, football match winners, parents who took the classes on Basic Type 1 Education, and parents of Type 1 siblings. The initiatives from the parents are commendable. The fun-filled day concluded by honoring the unconditional support extended by organizers including 4 Type 1 parents - Shabana TV, Fathima Vardath, Ambili Ajith, and Shaharban M, along with Suhail MP. This could not have been achieved without the IDEAL course.

Animation Film on Type 1 Diabetes: The Future of Child Health Education

***Dr Bhanu Kiran Bhakri**, Professor of Pediatrics, PGICH, NOIDA, UP*

'The Perfect Sugars' is a 52 minutes film in Hindi, depicting the struggles of a 10yo boy recently diagnosed with T1D. It carries the entire set of information needed by the family at the time of diagnosis, based on 'Diabetes in children & young adults, SGPGIMS Lucknow' & ISPAD guidelines, embedded in an entertaining story. The link is also hosted at the ISPAE website, patient resource section. Follow up shorter films (a few with English subtitles too) have subsequently been added, covering key T1D education issues in further detail, as a YouTube playlist *Type-1-Genius Academy*. In the last few months, the content has been viewed over 5000

times, covering ~500 watch hours, with very positive feedback from families. Recently 'The Perfect Sugars' as a film project has been shortlisted among ~1600 entries for the World Audiovisual and Entertainment Summit - Animation Film competition (WAVES 2025 - AFC), an ambitious project of the Ministry of Information & Broadcasting, Government of India. The summit is scheduled in May 2025 at Mumbai, India. The films are free to view for end-user beneficiaries, primarily children and families living with T1D. The relevant links are:

ISPAE patient resource- https://ispae.org.in/the-perfect-sugars-by-dr-bhanu-kiran-bhakhri/

WAVES 2025-AFC- https://wavesindia.org/challenges-2025

YouTube Playlist- https://youtu.be/0SI0UU5wWPA?si=kPWqm0cjmWTMX2x7

An Awareness Campaign on Obesity for teachers, school authorities, Poster Competition for students, Panel Discussion by multi-specialty experts on obesity

Dr Priti Phatale, *Samrat Endocrine Institute, Chatrapati Sambhaji Nagar (Aurangabad)*

On the occasion of World Obesity Day, an extensive awareness campaign on obesity across six schools, between 11th Feb and 2nd March was specifically designed for teachers and school authorities. Benefiting around 130 teachers, it aimed to highlight the growing concern about childhood and adolescent obesity and the long-term health implications. In addition, an inter-school poster competition on healthy lifestyle and digital de-addiction was conducted for students of 6th to 9th grade across eight schools, fostering awareness and creative engagement on these crucial health topics. The concluding ceremony of these awareness campaigns was organised in the form of a Grand Finale: Expert Panel Discussion & Prize Distribution by Samrat Endocrine Institute & Radhesham Eusocial Foundation in collaboration with World Obesity Federation, Aurangabad; Academy of Pediatrics, OBGY Society, Indian Medical Association, Chhatrapati Sambhaji Nagar Branch on 2nd March. The esteemed panelists included Dr Tupkari (Pediatrician), Dr Lalita Bajaj (President, OBGY Society), Dr Khadethankar (Physician), Guest of Honor Dr Swati Shiradkar (Dean, Dr BAVPRK Daman's Medical College, Shri Ramchandra Institute of Medical Sciences), Dr Hemant Phatale (Endocrinologist) and Dr Priti Phatale (Childhood Obesity Specialist). The panelists were renowned specialists, who provided invaluable insights on obesity as a disease that can lead to multiple serious health conditions. The discussion emphasized the importance of preventive measures, starting as early as conception, to curb this growing epidemic. Following the panel discussion, a prize distribution ceremony was held to honor the winners of the Inter-school Poster Competition. With 100+ attendees, including medical professionals, educators, and community members, this initiative successfully reinforced the message that “Prevention is better than cure”, inspiring proactive steps towards healthier lifestyles for children and adolescents & the community. Raising awareness is the key to reversing the exponential rise in childhood obesity.

Endokidz 2025 “Conference on Waves”

The Pediatric Endocrinology Kerala State Conference, held in Alappuzah on 16th March, 2025, organized by IAP Allepey and IAP Kerala, was unique as it was on a house boat on the serene

backwaters of Allepey. It included sessions and panel discussions on common endocrine disorders. The program was presided by Dr Riaz I, State IAP President, Dr Veena Nair, President, Kerala Pediatric Endocrinology Chapter and Dr Deepa Anirudhan, Secretary, Kerala State Pediatric Endocrinology Chapter. Faculty also included Dr Vijayakumar, Dr Sheeja, Dr Parvathy L, Dr Rajesh and Dr Dhanya. The program was attended by 150 delegates and was well appreciated.

IDEAL CORNER

***Dr Shruti Arora**, Certified Pediatric Diabetes Educator*

IDEALites have been busy, providing clinical care and exploring innovative ways to educate and motivate: pushing the boundaries in their care of persons with T1D, across India. Apart from routine care, many have been involved in organizing events, both virtual and offline. Some are reported above. In addition, IDEALite Mridula Bhargava participated in the virtual Global Diabetes Conference on 22-23 February 2025. YDF was able to coordinate a donation of 300 cartridges of Basaglar to ACT T1D. A Millets Recipe Book is being planned. A few other highlights:

Appeal for Reduced GST and Affordable Diabetes Care

The IDEALite Community of Pediatric Endocrinologists and Diabetes Educators has submitted a petition to the Honorable Finance Minister Ms Nirmala Sitharaman, the GST Council, and Abbott Healthcare, urging them to reduce the financial burden on families managing Type 1 Diabetes (T1D). While insulin is taxed at 5% GST, essential diabetes care supplies such as glucometers, glucostrips, and CGM sensors face higher taxes of 12-18%, making them less accessible. The petition calls for the Government to lower GST to 5% and for Abbott to reduce CGM sensor costs, to improve diabetes management and enhance the quality of life for individuals living with T1D across India.

IDEAS Expands Diabetes Education with Bengali Version for Schools

The **Initiative for Diabetes Education and Awareness for Schools (IDEAS)** has launched its Bengali version, which is now available on www.ispae.org.in/ideas. This valuable resource aims to support Bengali-speaking families managing T1D by enhancing understanding and fostering better support systems in schools.

Parents are encouraged to share this resource with their children's teachers and school staff to improve awareness and ensure appropriate care for students with T1D. The IDEAS content and recorded sessions are accessible for listeners to hear as often as they like and to share to as many stakeholders as needed, making it a flexible tool for learning. Initially conducted in English, the IDEAS program has progressively expanded to regional languages such as **Gujarati**, **Hindi**, **Kannada**,

and **Telugu**, with **Tamil** and **Marathi** versions in progress. This multilingual approach ensures broader reach and deeper comprehension, reinforcing IDEAS' commitment to inclusive and impactful diabetes education.

Dr Jyoti Kakkar at Manav Rachna International School

Dr Jyoti Kakkar was invited by Manav Rachna International School, Faridabad, on 6th Feb to deliver a talk on the psychological management of T1D. During this insightful session, parents had their first opportunity to openly share their concerns and interact, making it a valuable initiative by the school to support families managing T1D.

JDPF's Engaging Skit

The Juvenile Diabetes Patients' Foundation (JDPF) organized a fun, educational, musical skit on 9th Feb 2025 at Health and Care Foundation, Ahmedabad, featuring their talented team of "dramebaaz" kids. The event effectively conveyed key aspects of T1D management to parents and other attendees. The skit was divided into four themes:

1. **T1D Car with 4 Tyres**: Highlighted the importance of SMBG, insulin, diet, and exercise as essential components for T1D care.
2. **Basal-Bolus Regimens**: Emphasized the importance of Basal-Bolus regimens and discouraging premixed insulin for people with T1D.
3. **Hypoglycemia Management:** Taught recognizing symptoms of low blood glucose, and choosing appropriate treatment like glucose or powdered sugar instead of chocolates or other fatty snacks.
4. **Mental Health and Myths**: Addressed social stigma, showcasing how friendships and support can positively impact families with T1D.

Incorporating songs like *"Hum Hai Rahi Pyar Ke"* and *"Tu Hai Toh I'll Be Alright"*, the performances effectively combined entertainment with education. The initiative successfully empowered families with practical knowledge, ensuring a memorable and impactful learning experience.

IDEAL CASE REPORT- TECHNOLOGY WITHOUT EDUCATION: A SWORD IN THE HANDS OF A CHEF. A CASE STUDY ON AID SYSTEM POWERLESS WITHOUT THE POWER OF DIABETES EDUCATION

Mehak Dhingra, *Certified Diabetes Educator*

Technology has transformed the way we manage Type 1 Diabetes (T1D), offering automation, real-time monitoring, and predictive adjustments. The Automated Insulin Delivery (AID) system is one such innovation, designed to optimize blood glucose (BG) control with minimal manual input.

However, can technology alone guarantee better outcomes? This case study highlights the story of a teenager who had access to the best diabetes technology for six months, yet his HbA1c remained at a shocking 10%. The missing piece? Education.

The 15-year-old boy was started on an AID system, a state-of-the-art insulin pump designed to automate insulin adjustments based on continuous glucose monitoring (CGM) readings. His parents were hopeful that this technology would significantly improve his glycemic management, based on the simple assumption that with automation in place, diabetes management would become effortless. However, over six months, his HbA1c remained unchanged at 10%.

Investigating the Root Cause

The shocked parents approached for guidance, since the technology was working perfectly, but the outcomes suggested otherwise. Our team discovered a critical gap: the family had no knowledge of carbohydrate (carb) counting, insulin dosing, or active management strategies.

- They believed that the pump would handle everything on its own, without any need for input.
- He would not enter carb values for meals, assuming the system would compensate. This misunderstanding stemmed from a lack of education.
- While the AID system is an incredible tool, it still requires accurate data entry, carb counting skills, and proactive engagement to function effectively.
- Concept of Margin of Error - A closed-loop system, like an artificial pancreas, has the ability to manage BG changes due to unexpected carb intake only up to a certain limit. Beyond 20 gram carbs, current AID systems might not adjust insulin accurately, affecting BG control.

The Role of Education: A Game-Changer

Recognizing the gap, he was enrolled in a structured diabetes education program that focused on:

- Understanding how the AID system works and its limitations
- The importance of accurate carb counting
- Learning insulin-to-carb ratios (ICR) and insulin sensitivity factors (ISF)
- Active monitoring and manual corrections when needed
- Recognizing patterns and making informed decisions
- Understanding the concept of Margin of Error.

With just 3 months of guided education and coaching, the results were remarkable: HbA1c dropped from 10% to 7%.

What Changed?

- He started counting carbs correctly and entering accurate values into his pump.
- He understood when and how to give correction boluses for high BG.
- He actively monitored his CGM data and made informed decisions, rather than assuming the technology would fix everything.

Key Takeaways

- Technology is a tool, not a replacement for education. No matter how advanced, diabetes technology requires an informed user to function optimally.
- AID systems are powerful but not magic. They adjust basal rates and offer automation, but only up to a point. They rely on accurate input and decision-making.
- Diabetes education is non-negotiable. Even with the best devices, knowledge of carb counting, insulin dosing, and self-management remains essential.
- Better outcomes require a combination of technology and human engagement. The most significant improvements happen when individuals actively participate in their management rather than relying solely on automation. Empowerment through education is the key to thriving with Type 1 Diabetes.

TRAINEES SECTION

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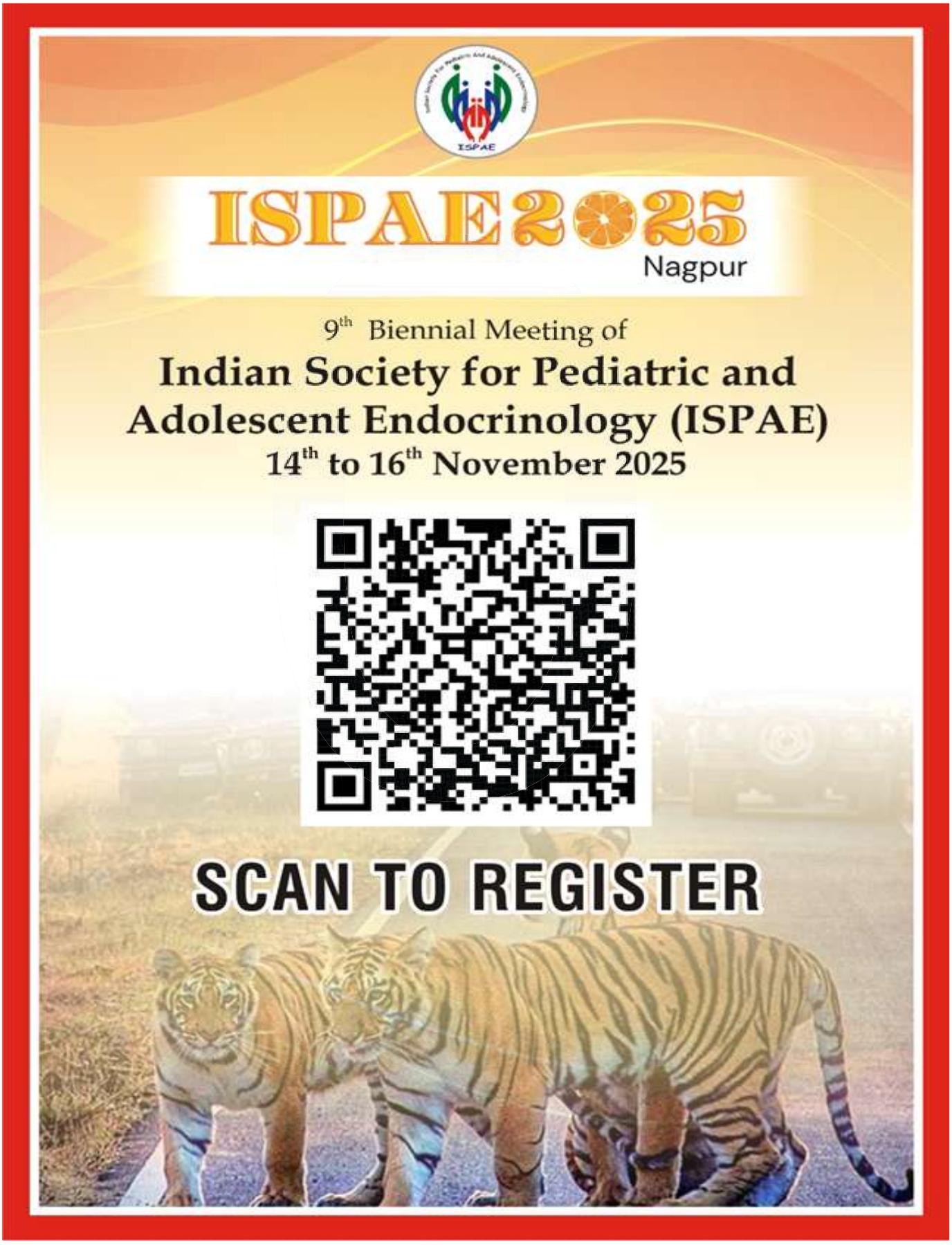
Please answer the questions below on Disorders of Growth. Correct answers and individual quiz scores will be mailed to the respective email address after the quiz closes.

https://forms.gle/uwwjSTYSYeeYSC2w9

Last Date 7th April 2025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