

Battling Congenital Hypothyroidism

Thyroforum

Gur Rehmat Majithia



What is a Thyroid?



- It is a butterfly shaped gland located just below your adam's apple.
- It is a key part of your endocrine system that regulates hormones in your body.
- It secretes the hormones T4 and T3 and also regulates TSH.
- The hypothalamus in the brain secretes the hormone TSH that sends a signal to thyroid gland to secrete T4 and T3.
- They travel through the body to regulate energy and organ function.

What is Congenital Hypothyroidism (CH)?

- It is a condition that children are born with an under-active thyroid gland – meaning it doesn't produce enough thyroid hormone.
- **It is essential to find this as thyroid hormone helps in brain development.**
- There are many other problems that are caused by an underdeveloped thyroid, but they all cause the similar problems.



What is the outcome of CH if it is not treated on time?

- Thyroid hormones are essential and **critical for brain development**, including neuronal differentiation, synapse formation, and myelination. These processes are **essential for cognitive function, motor skills, and overall neurological health.**
- Brain development occurs from birth to 3 years.
- In these years, if CH is not corrected, **a baby will lose 5 IQ points per month which they can never get back.**
- When this loss of IQ number reaches 70 **the child is mentally retarded their whole life.**
- **Child lives a full age of 75 years approximately.**

Why else are thyroid hormones critical during the growing years?

Skeletal Growth

They play a significant role in bone growth and maturation, including bone formation and mineralization. They influence the timing of bone growth plate closure and overall skeletal development.

Metabolism

They regulate metabolism, influencing energy levels, body temperature, and overall growth. Disruptions in thyroid hormone levels can lead to growth delays, fatigue, and other metabolic issues.

Overall Development

Thyroid hormones impact the development of multiple organ systems, contributing to overall growth and maturation during the growing years. It also gives energy to the body.

Patient Comparisons



- 18y, c/o short stature noticed 8y
- Lethargy, slow mentally
- **119cm** (HA 7y); 28.5 Kg (WA 9.5y)
- BA 3y, IQ- 27, **Mental age- 7.5 y**
- Congenital hypothyroidism

- PB: 2/8/06: FTND, BW 3.1 kg
- Phototherapy 3 days, TSH done at discharge
- Report not collected (was 100)
- Thyroxine started at 1.5 mo of life
- Mild mental retardation



ME

- Tested at 5 days
- 17y, Mental age- 17y +
- High IQ
- Height 171 cm, 58 kg
- School captain
- Excel in studies
- Proficient in sports
- Rangapravesham in Kuchipudi
- Contributing member of the family

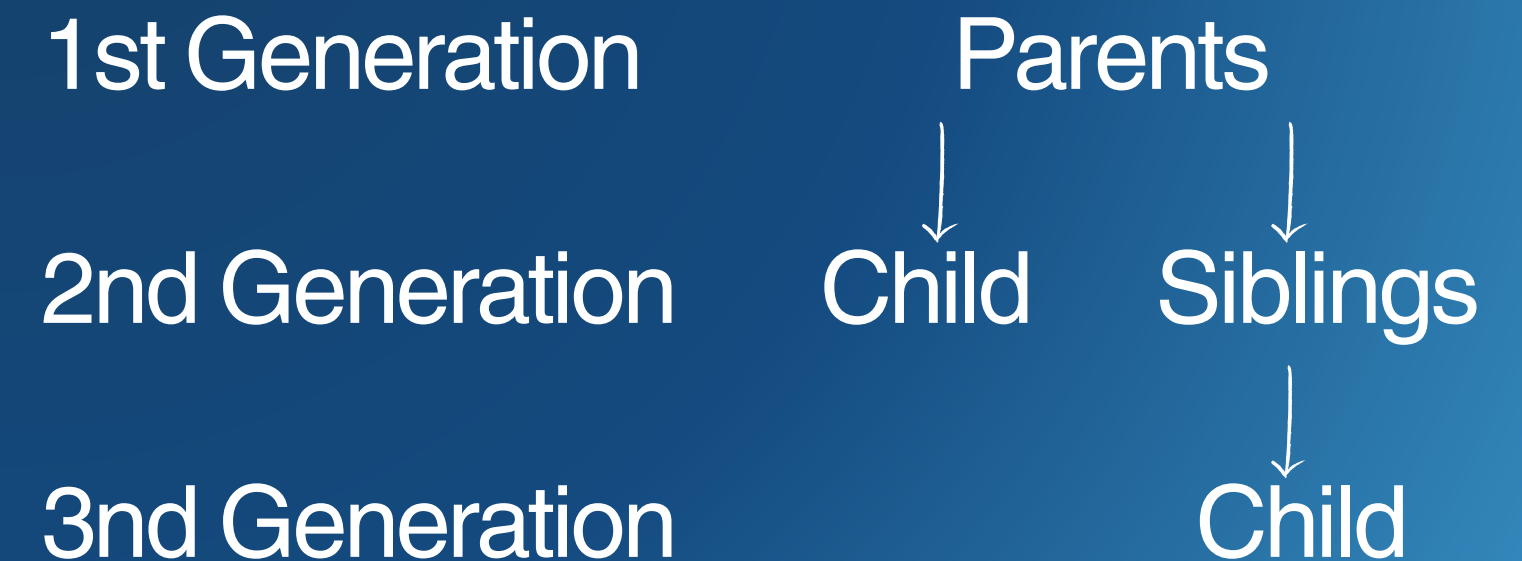
1 in every 1000

children in India are affected by Hypothyroidism.

Vijaya Sarathi, Siddu Nikith

How does Congenital Hypothyroidism affect the family?

It is not just the child affected it is the family **too** – The parents have a child who is a burden on them. **They will be restricted from earning an income, provide education for any other children** and have economically safe futures. The child will always be a burden to the family financially, mentally and physically. **They will be a burden to the family for almost three generations.**



Cost of CH in a family

Age at which the Earning member has a child affected by Hypothyroidism	28	years
Max Earning age of the Earning member	60	years
Balance years left which can get affected	32	years
Salary per month of Earning member	15,000	Rupees
Loss per year	180,000	Rupees

Cost of CH in a family

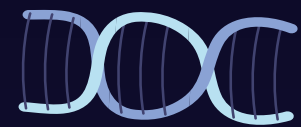
Earning Member			Affected Child			Sibling of Affected Child		Total INR
Total loss During lifetime	14411479		Total loss During lifetime	17250538		Total loss During lifetime	17250538	48912555
Tax Rate Approx paid	10%		Tax Rate Approx paid	10%		Tax Rate Approx paid	10%	10%
Loss to Govt	1441148		Loss to Govt	1725054		Loss to Govt	1725054	4891255
Net Present value of earings	3,631,823		Net Present value of earings	3,823,740		Net Present value of earings	3,823,740	11279302
Net present value of Tax	363182		Net present value of Tax	382374		Net present value of Tax	382374	1127930

Loss to the Government

- Loss of 5 crore rupees earning per family over the child's lifetime.
- Loss to the government at a tax rate of 10%– 50 lakh rupees per child affected by CH over their lifetime.
- Affected children born every year in India– 24,000.
- **Total loss for government– $24,000 \times 50,00,000 = 12,000$ crore rupees.**
- Cost to government– Zero rupees.

Testing and Medication

Birth



The chordblood test is administered.

After result



Contacted if positive and required follow up continues.

Future



Child is regularly tested and eats medicine and grows up to be an asset to the family

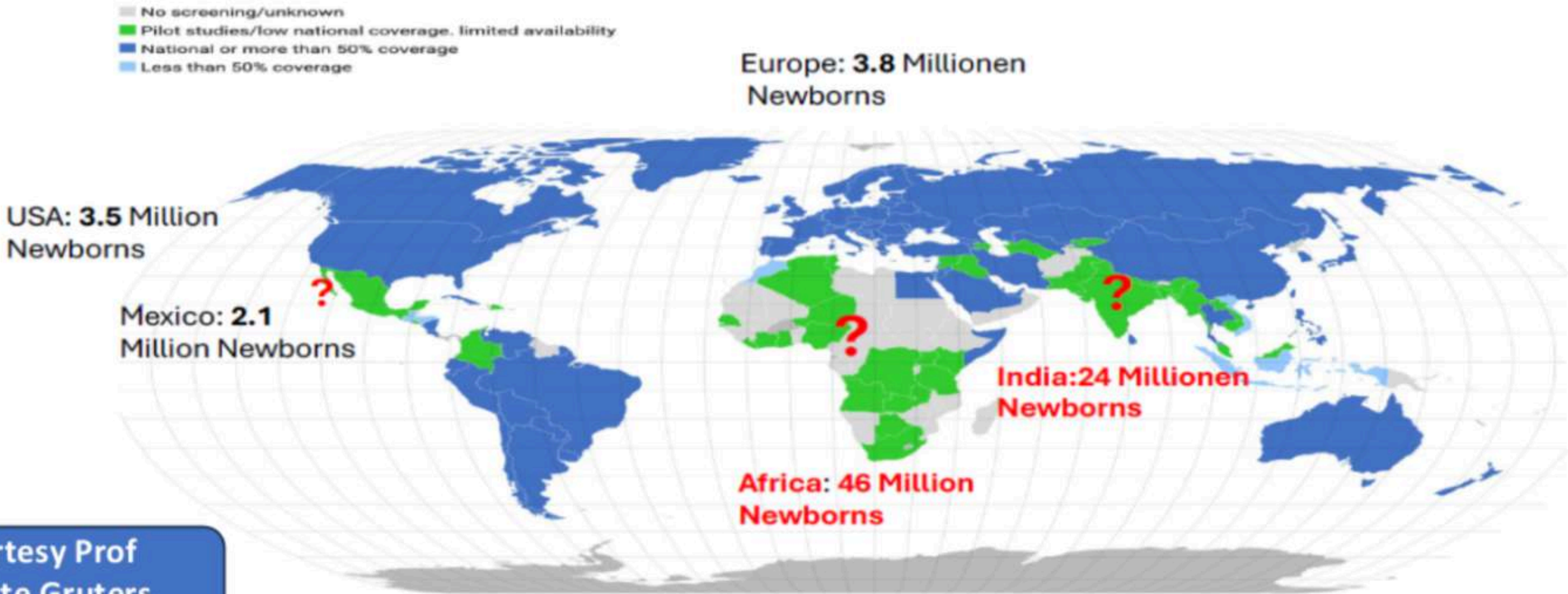
Cost of diagnosis and treatment

Cost of 120 Tablets of Thyronorm	240	Rupees
Cost of Medicine per Month	60	Rupees
Cost of Doctor Visit Quarterly	600	Rupees
Cost of Doctor Visit Per Month	200	Rupees
Total Cost of medical expenses Per Month	260	Rupees
Total Cost of Medical Expenses Per Year	3120	Rupees

Inequity:
In Africa and India 10 times more children are born than in Europe and the US and remain kept out of the chance of a cheap early diagnosis and treatment of CH

Prevalence of severe CH : 1:3000
Newborns USA and Europe: 7.3 Million per year
Newborns India and Africa : 72 Million per year

The ground reality today



Courtesy Prof
Annette Gruters,
Berlin

Prevalence in West 1:3000
Estimated in India 1:1000-1500

15,000-20,000 NB expected every year = 15,000-20,000 families suffering for 50-70 years added **every year**

ISNS: Verfügbar unter: <https://membership.isns-neoscreening.org/charts/map>. Letzter Aufruf: 1

Country	Births per year	Expected NB with severe CH per year
India	24 million	7500 if 1:3000*
Africa	46 million	15000
Nigeria	7.5 million	2500

Screening

In the past 10 years, many countries have substantially increased coverage rate.

China: second largest number of births: by 2018 built up a functional & uniform national NBS program with overall coverage rate > **97.5%**

Philippines: from 28% to 91.6% pre-Covid: now dropped to **80.4%**

Armenia: from 58% to ~ **100%**

Sri Lanka: from 2.8% to **92%**

Lebanon: from 31% to 60%

Vietnam: from 7% to 38.5%

Indonesia: 1% to 15.53%

India: remains at <3%

Way Forward



1. **Making it compulsory for all Gynecologists to do Cord Blood testing for TSH at birth**– this can happen with just one line addition in their register records. It would ask them to send the cord blood sample at birth and record the report which would be on the day of birth. Parents can be informed before they leave the hospital.
2. **Zero cost to the government**– parents would bare this cost. They would be happy to add this 100 rupees as part of the 10,000 rupee (approximate) fee for delivery charges.
3. **Failure to do so should attract penalty on the Gynecologist.**

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Thank You

I am sure you can save our future!