

# ENDOCRINE VOICES UNITED



Working together to improve the health of children throughout the world.





## 2019 Meeting

Vienna, Austria was the host city for our 2019 May ICOSEP meeting. It is a beautiful city and participants managed to see the area sites despite the cool and wet weather.

We had more time for discussion this year and were thrilled to hear reports from many groups. In France- (millions of people reached in their 2018 Awareness campaign), Italy-more than 50 hospitals participated in free growth screenings for children, and Macedonia where the press and national authorities recognized Growth Awareness...Everyone had amazing in their awareness efforts!

We spent time learning from each other in break out groups. Ideas on what are our organization's biggest obstacles, strengths and common concerns. To see the report details, visit our website and review the minutes.

Emily Havrilak of the TSS United States presented a fantastic segment as she taught us about the value of videos to our organizations. She demonstrated how simple it is to use our mobile phones for sharing interesting information quickly and easily.

The 2019 Children's Growth Awareness campaign was presented. The artwork for many countries and languages is available for free download via the ICOSEP website.

Discussion regarding the location for the

2020 meeting concluded with 2 options, Prague or Chicago. We are investigating the financial options and dates for these locations and will email everyone after we can make a final determination.

Interest in ICOSEP and Growth Awareness continues to grow. Therefore, we will reach a point where funding options for our meeting will change. Please continue to build your organizations and awareness programs so that we can all share our accomplishments.



Break Out Sessions





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2019 Presentations and Break Out Sessions were fantastic! Thank you all!

**ICOSEP videos can be found on YouTube!**  
**VISIT <http://bit.ly/2hLVDbA>**

### Professional Organizations supporting ICOSEP efforts include:

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Paediatric Endocrinology



**ICPE**  
International Consortium of  
Pediatric Endocrinology

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ENDOCRINE SOCIETY

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## Teen with Achondroplasia Banned from Cooking Class Because of Safety

“A teenager with dwarfism claims he has been banned from a college cooking course because he is a potential health and safety risk. Louis Makepeace, 18, who stands at 3ft 10in (117cm), said he was being discriminated against due to his size after being refused a place at Heart of Worcestershire College. He was originally offered a conditional place for the Hospitality and Catering course on 16 August but said the college has now backtracked because he is too small for the kitchen.”

What challenges have children in your country faced? What options are available for them? Families seek support groups who are prepared to help young children face challenges and receive emotional support for the children and their families. However, it is easy to overlook the young adults and the challenges they face.

“They are simply not prepared to make the necessary adjustments to accommodate me,” Makepeace says. “He said it was pointless doing the course as he would never be allowed to work in a restaurant kitchen anyway, even if he qualified...would be a health and safety hazard in the kitchen to his other pupils so we couldn’t have him standing on a step of some sort.”



McAllister, R. (2018, August 29). This dwarf has been 'banned' from a college cooking course because he's 'a health and safety risk'Dwarf 'banned' from college cooking course because he is 'a health and safety risk'. Retrieved from <https://www.independent.co.uk/news/uk/home-news/dwarf-banned-college-cooking-course-louis-makepeace-teen-health-and-safety-worcestershire-college-a8509571.html>.



## **FUN FACT#1**

**MICHELANGELO WROTE A POEM ABOUT HOW MUCH HE HATED PAINTING THE SISTINE CHAPEL.**

**ONE TRANSLATION:**

**I'VE ALREADY GROWN A  
GOITER FROM THIS TORTURE,  
HUNCHED UP HERE LIKE A CAT  
IN LOMBARDY (OR ANYWHERE ELSE  
WHERE THE STAGNANT WATER'S POISON).**



### **Vaccines put CAH Children at Risk**

“Elfie has 3 beta hydroxysteroid dehydrogenase (HSD) deficiency, an extremely rare form of congenital adrenal hyperplasia (CAH). Her health is in many ways at risk every day. While she can have vaccinations, they are never fully effective, meaning she relies on the health of those she comes into contact with. She relies heavily on herd community – a form of indirect protection from

infectious disease that happens when enough of the population, 95 per cent according to the World Health Organisation [sic], are immune.”

“When it comes to school and the outside world however, the mother-of-two shared that it is ‘extremely worrying.’ She takes medicine to replace the cortisol that is missing day-to-day but in times of illness has no way of kick-starting her body to get better – so she can become seriously ill from what might seem to healthy

people to be something quite innocuous,” her mother said. “This is why it is essential she is kept as healthy as possible, and for those around her to not be carrying infections or infectious diseases.”

Sometimes she becomes ill too quickly for oral medication, meaning she needs an





## Vaccines put CAH Children at Risk (continued)

intramuscular injection.

3 $\beta$ -HSD deficiency is caused by a deficiency (shortage) of the 3 $\beta$ -HSD enzyme. The amount of functional 3 $\beta$ -HSD enzyme determines whether a person will have the salt-wasting or non-salt-wasting type of the disorder. Individuals with the salt-wasting type have HSD3B2 gene mutations that result in the production of very little or no enzyme. People with the non-salt-wasting type of this condition have HSD3B2 gene mutations that allow the production of some functional enzyme, although in reduced amounts.

Sharma, R. (2019, May 03). How vaccine hesitancy risks the health of an 8-year-old girl with a rare genetic disorder. Retrieved from <https://inews.co.uk/news/genetic-disorder-herd-immunity-vaccinations/>.



## Worlds Oldest Human dies in Indonesia Aged 146

Grandpa Ghoto passed away after a long life. He outlived 4 wives, 10 siblings and all of his children.

Mbah Ghoto was born in December 1870. Grandpa Ghoto has been quoted as saying he has, "A long life because I have people that love me looking after me."

'Oldest human' dies in Indonesia 'aged 146'. (2017, May 01). Retrieved from [https://www.bbc.com/news/world-asia-39768321?ocid=socialflow\\_facebook&ns\\_mchannel=social&ns\\_campaign=bbcnews&ns\\_source=facebook&fbclid=IwAR1rM6F53LVhHe5m4EKCU0iauTUxDbI9EFy0wyPK\\_7pJwzvm\\_0cBZZ6uCcQ#](https://www.bbc.com/news/world-asia-39768321?ocid=socialflow_facebook&ns_mchannel=social&ns_campaign=bbcnews&ns_source=facebook&fbclid=IwAR1rM6F53LVhHe5m4EKCU0iauTUxDbI9EFy0wyPK_7pJwzvm_0cBZZ6uCcQ#).





## Donate a Phone for Those with Vision Loss

The Canadian National Institute for the Blind (CNIB) has a program called Phone it Forward. This program requests Canadians to donate used smartphones to help blind or partially sighted individuals. "Part of our strategic plan is to change what it means to be blind or partially sighted through innovation, programs and technology," northern manager of CNIB Brenda Heisler said in Saskatoon on March 13.



"Just because people have vision loss or are partially sighted or completely blind ... [doesn't mean we're] different than anybody else," Paige Andreas, an intern and lifelong client of CNIB.

"We're just as normal as everybody else. Yes, we may have to adapt our lives and different parts of what we do, but we're still normal. We can do the exact same amount as everybody else."

Other opportunities for assisting those with vision impairments have recently been noticed. For Easter this year, organizations began to offer Easter egg hunts with beeping eggs. It allows those who cannot see the eggs, to hear the eggs and find them. They enjoy the hunt as every other child does.

The Phone it Forward program enables those with vision loss to use smartphones with specific apps to provide independence and safety to the user.

Medve, D. (2019, March 14). CNIB program collecting smartphone donations to help blind, partially sighted.

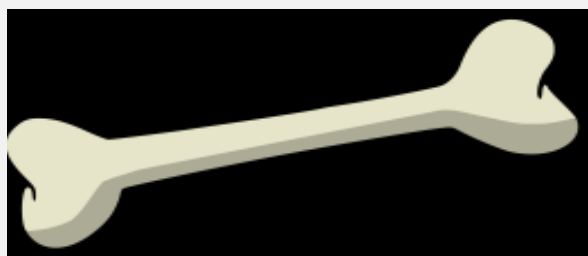
Retrieved May 13, 2019, from <https://globalnews.ca/news/5053882/cnib-phone-it-forward-blind-partially-sighted/>.

### FUN FACT#3

**SLOTHS CAN HOLD THEIR BREATH LONGER THAN DOLPHINS. BY SLOWING THEIR HEART RATES, SLOTHS CAN HOLD THEIR BREATH FOR UP TO 40 MINUTES. DOLPHINS NEED TO COME UP AFTER ABOUT 10 MINUTES.**







## Why Bone Health is Important

“The greatest gains in bone size and strength occur in adolescence, when the hormones of puberty speed up

bone growth.” For children with disorders which can affect their growth their bones can be impacted in a negative manner (Bone).

The more bone mass we “bank” in childhood and adolescence, the better protected we are from the bone loss that can lead to osteoporosis (thin, fragile bones) and bone fractures later in life.

Osteoporosis has been called “a childhood disease with old age consequences,” because the bone mass attained in childhood and adolescence is an important determinant of lifelong skeletal health. The health habits your kids are forming now can make, or literally break, their bones as they age (Kids).

Peak bone mass is usually obtained by a person’s late twenties and can be influenced by hormonal factors. Girls who menstruate earlier than her peers often have a greater bone density (Kids).

To learn more about what foods and vitamins can offer calcium support, visit the NIH website.

Bone Health for Children and Adolescents | Hormone Health Network. (2017, September).  
retrieved from [www.hormone.org/diseases-and-conditions/children-and-teen-health/children-and-bone-health](http://www.hormone.org/diseases-and-conditions/children-and-teen-health/children-and-bone-health).

Kids and Their Bones: A Guide for Parents. (2018, October). Retrieved May 28, 2019, from <https://www.bones.nih.gov/health-info/bone/bone-health/juvenile>.





## Concerning Levels of Phytoestrogens Found in Soy-based Products

Phytoestrogens - or isoflavones as they are known in soy - are active substances that have a weak estrogen-like action. The substances are suspected of disrupting our hormone system, leading to potential cancer or fertility issues, foodnavigator blogger, Southey reviews the findings (2019).

A French consumer group, UFC-Que Choisir, published test data concluding the high levels of physoestrogens. The group analysed 55 soy-based products ranging from prepared meals to desserts and compared the resulting levels approved by the French Agency for Food, Environmental dna Occupational Health and Safety, ANSES.

In response to these results, UFC-Que Choisir has called on ANSES to reassess the safety risk of consumers eating and drinking the products. Also, the UFC-Que Choisir advises pregnant women and children under three years to avoid consuming soy-based products.

Southey, F. (2019, May 28). Worrying levels of phytoestrogens found in soy-based products, claims French consumer group. Retrieved from <https://www.foodnavigator.com/Article/2019/05/28/Worrying-levels-of-phytoestrogens-found-in-soy-based-products-claims-French-consumer-group#>.

**SOYBEANS ARE LEGUMES USED  
IN A VARIETY OF FOODS. THEY  
ARE HIGH IN NUTRIENT VALUE AND  
LOW IN CALORIES, CARBOHYDRATES  
AND FATS, AND ARE EASY TO DIGEST.**

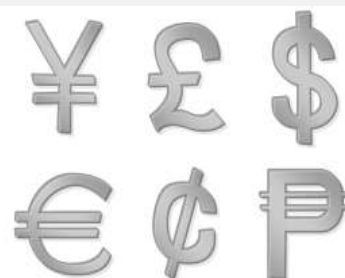
### **FUN FACT#4**

**BLUE WHALE TONGUES  
CAN WEIGH AS MUCH AS AN  
ELEPHANT. THEIR HEARTS,  
MEANWHILE, CAN WEIGH  
ALMOST A TON AND NEEDS TO  
BEAT JUST ONCE EVERY 10 SECONDS**

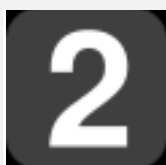


## Fundraising Ideas

It can always feel like a struggle when raising funds for your organization. We have found a few ideas which can make large impacts and take less time than you think.



**T-shirt fundraiser:** Design and sell a t-shirt with your logo and message. Supporters wear the shirt and share the message. Using a platform such as Bonfire or CustomInk will allow supporters to purchase the shirt and will ship it to them. You just need to share the link for easy purchase access.



**People love to EAT.** Talk to a local restaurant owner and ask them about fundraising. Many restaurants will give a percentage to an organization in exchange for promoting them through your event.



**Ask people for pledges.** Unique campaigns are a proven way to get attention for your fundraiser. This idea involves you asking for pledges in exchange for completing a challenge. An example is to run a 5k and request money for each mile.



**A 50/50 raffle is also fun!** Sell raffle tickets. The money raised is split into two: 50% goes toward the organization and 50% is given to the winner.



**Used book sales** are becoming an easy and fast way to raise funds. Ask neighbors, friends and family to donate books. All money raised at the sale goes towards your organization.

45 Fundraising Ideas to Raise Money for Any Cause. (2019, May 31). Retrieved from <https://blog.bonfire.com/fundraising-ideas/>.







## Program for Turner Syndrome Earns National Recognition



A novel program designed to provide comprehensive care for Turner syndrome at The University of Texas Health Science Center at Houston (UTHealth) and UT Physicians is one of the first in the

U.S. to be designated an adult clinic by the Turner Syndrome Global Alliance (TSGA), Ives writes (2019).

The Turner Syndrome Adult Comprehensive Care Center at UT Physicians was created by Siddharth Prakash, MD, PhD and Michelle Rivera, MD. Both are co-directors of the center, which began late last year. TSGA is the primary organization that networks TS clinics in North America and partner groups around the world to develop the guidelines for specialty clinics. TSGA has designated about 30 pediatric clinics, and is now identifying adult clinics.

"It's a major achievement for us to be one of the first adult clinics recognized by TSGA, as it helps us continue to advocate for comprehensive, multidisciplinary care for TS patients in the region and hopefully improve their outcomes." This new clinic allows patients who would otherwise spend various days at multiple doctors offices to have a one-stop-for-all check. "Also, the distinction will help us to connect

patients with national research that is translational to clinical care right here at home. It used to be very difficult to study TS because each site would have so few patients, but now we can band together with other recognized TS sites for critical studies that otherwise wouldn't have been feasible."

"We interact closely with the Turner Syndrome Society of the United States, a national nonprofit organization headquartered in Houston. Every year in February, we team up to host a community day, where we provide free screenings and give presentations to keep the community informed about TS. We also partner with Leaping Butterfly Ministry, a nonprofit that sponsors hearing aids for girls and women with TS," Prakash said.



Ives, J. (2019, May 24). Novel program that provides comprehensive care for Turner syndrome earns national recognition. Retrieved from <https://www.news-medical.net/news/20190524/Novel-program-to-provide-comprehensive-care-for-Turner-syndrome-earns-national-recognition.aspx>.



## FUN FACT #5

IT IS IMPOSSIBLE  
TO HUM WHILE HOLDING  
YOUR NOSE. NORMALLY, WHEN  
YOU HUM, THE AIR IS  
ABLE TO ESCAPE THROUGH  
YOUR NOSE TO CREATE THE SOUND

## Attention Businesses and Organizations

**Show your pride on  
20 September!!!**

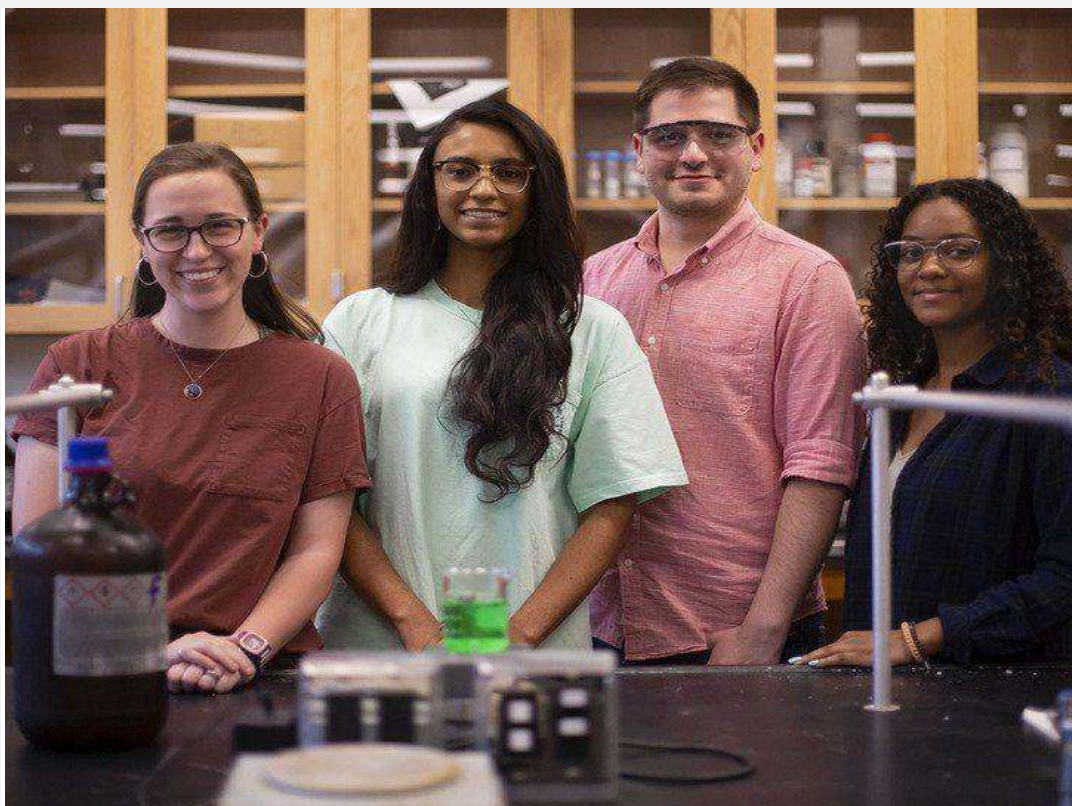
ICOSEP has newly designed t-Shirts for #ChildGrowthAwareness. Currently we have GHD shirts, but we can create designs for other medical conditions. Email us with your requests for other designs ([contactus@icosep.org](mailto:contactus@icosep.org)).

Share this link with your friends and family and please order online today! Our small percentage of the sales of these shirts, help us pay for our annual meeting.

[www.customink.com/  
fundraising/childgrowthawareness-day-t-shirts](http://www.customink.com/fundraising/childgrowthawareness-day-t-shirts).

Thank you!!!





## Students Discover Tuberculosis Cure

Tuberculosis or TB, has been around so long, the disease has grown resistant to many of the current antibiotics on the market, rendering such drugs largely ineffective. The drugs that do work can cost up to six figures for a full treatment cycle, putting them out of reach of impoverished populations where the disease is most common. A Valdosta State University (VSU) student, John Stephen, reports 4 VSU students have been working on a less costly solution (2019).

“Instead of inventing a new drug, VSU students have taken an existing antibiotic and given it a “Trojan horse” makeover, disguising it in a molecular structure that TB bacteria do not recognize,” university officials said. The chemical modification can now get past the defensive wall of the virus and destroy it.

The National Institutes of Health have tested the antibiotic extensively and it is now patent pending. They have proven the drug to effectively treat TB in living cells. The chemicals in the drug cost about one dollar a dose, making it attainable for third-world populations.

(continued on next page)





## Students Discover Tuberculosis Cure (continued)

Moss, Diaz, Thomas-Richardson and Johnson addressed this problem by creating a small biodegradable implant and it is inserted into a person's arm near the pulmonary vein. It carries a month's worth of the TB antibiotic slowly to the lungs and into the bloodstream.

The innovation will drastically cut down on the number of times TB patients need to see a doctor, from 120 daily visits for 120 pills during six months to just six monthly visits for six implant insertions.

Stephen, J. S., & Valdosta State University. (2019, May 29). VSU students create tuberculosis drug. Retrieved May 30, 2019, from [https://www.valdostadailytimes.com/news/local\\_news/vsu-students-create-tuberculosis-drug/article\\_9a9c91a4-f298-52a6-9aa2-aff1497a912e.html](https://www.valdostadailytimes.com/news/local_news/vsu-students-create-tuberculosis-drug/article_9a9c91a4-f298-52a6-9aa2-aff1497a912e.html).



## Premature Puberty Among Korean Children

The National Health Insurance Service released a report showing around 95-thousand children experienced precocious puberty in 2017. This is an increase of 9.2% annually. "9 out of 10 children with the condition are female. The report cites increasing levels of pollution which can trigger the production of hormones with function similarly to estrogen as the possible cause for the increase. Another major cause is a shift in food consumption to a high-fat diet care known to produce estrogen," (Premature, 2019).

Premature puberty increasing among Korean children. (2019, May 20). Retrieved May 28, 2019, from <https://www.msn.com/en-ph/video/news/premature-puberty-increasing-among-korean-children/vp-AABDeaY>.

## FUN FACT#6

**THE WORLD'S LARGEST WATERFALL IS UNDERWATER. AT THE DENMARK STRAIT, THE COLD WATER FROM THE NORDIC SEA IS DENSER THAN THE IRMINGER SEA'S WARM WATER, MAKING IT DROP ALMOST TWO MILES DOWN AT 123 MILLION CUBIC FEET PER SECOND**



## Preexisting Conditions Offer Information into Precocious Puberty

Roxanne Nelson (2019) writes about precocious puberty and the connection to a wide range of preexisting conditions. She found *Frontiers in Pediatrics* published a study stating the bond can offer information regarding contributing factors to premature pubertal onset. The onset of normal puberty is triggered by a complex interaction of factors. Precocious/early puberty often has a maternal mode of inheritance and has been reported in children with a variety of preexisting medical conditions, including certain syndromes.”

The study was conducted with a group who had either central precocious puberty. All children participating had been previously diagnosed with a “chronic, significant medical condition.” Neurologic and/or psychological disorders affected most of the participants.

Precocious/early puberty was experienced by patients diagnosed with various syndromes, including lipofuscinosis (2 siblings), Dravet syndrome, and Russell-Silver syndrome. Other associated conditions included adrenocorticotrophic deficiency, dyspraxia and bone abnormalities, glomerulopathy with complete renal failure, and repeated intrafetal deaths in the patient’s mother.

The conclusion of the study showed “chromosomal duplication... in 4 of 8 patients with psychomotor delay who were evaluated.” It is suggested a karyotype analysis is recommended for patients with precocious puberty and associated disorders without any obvious etiology (Nelson).

Nelson, R. (2019, March 15). Preexisting Medical Conditions Provide Insight Into Precocious Puberty. Retrieved May 20, 2019, from [www.endocrinologyadvisor.com/home/topics/pediatric-endocrinology/preexisting-medical-conditions-provide-insight-into-precocious-puberty/](http://www.endocrinologyadvisor.com/home/topics/pediatric-endocrinology/preexisting-medical-conditions-provide-insight-into-precocious-puberty/).

### **FUN FACT#7**

**THE EIFFEL TOWER WAS  
ORIGINALLY INTENDED FOR BARCELONA.  
THE SPANISH CITY THOUGHT THE DESIGN  
WAS TOO UGLY, SO GUSTAVE EIFFEL  
PITCHED IT TO PARIS INSTEAD, AS  
A TEMPORARY LANDMARK DURING ITS 1889  
INTERNATIONAL EXPOSITION. FRENCH  
CRITICS DIDN'T LIKE IT MUCH EITHER THOUGH**



## FUN FACT#8

**YOU CAN SEE FOUR STATES FROM THE TOP OF CHICAGO'S WILLIS TOWER. FROM THE TOP OF THE FORMER SEARS TOWER ON A CLEAR DAY, YOU CAN SEE ABOUT 40 TO 50 MILES AWAY—BEYOND ILLINOIS AND OUT TO INDIANA, MICHIGAN, AND WISCONSIN.**

## Hypothyroidism versus Hyperthyroidism: World Thyroid Day

World Thyroid Day is an annual event, 25 May. The goal of this day is to educate about prevention and treatment of thyroid related disorders. ICOSEP, members understand the importance of a healthy functioning thyroid.

“Disorders related to thyroid are a matter of global health concern and have a substantial impact on the well-being of people, especially pregnant women and children,” (Now, 2019). The rate of undiagnosed thyroid disorders is declining thanks to the educational event. Now (2019) writes India “32 percent of the population have thyroid issues...are more prone to developing hypothyroidism, goitre and iodine deficiency-related disorders.”

What is hypothyroidism and hyperthyroidism and how do they affect children? When would a parent know there is an issue?

Hypothyroidism is an underproduction of the thyroid hormones. myxedema. Symptoms include fatigue, increased sensitivity to cold, constipation, dry skin, weight gain, puffy face and muscle weakness (Hypothyroidism, 2018). Untreated low thyroid levels may lead to mental retardation in children, goitre, depression and fatigue.

Hyperthyroidism is an overproduction of the thyroid hormones. Symptoms include appetite change, insomnia, fatigue, frequent bowel movement, heat intolerance, and increased sweating (Hyperthyroidism). If left untreated, high levels of the hormone may put a person at risk of developing thyrotoxic crisis.

Hyperthyroidism Symptoms. (n.d.). Retrieved from <https://www.endocrineweb.com/conditions/hyperthyroidism/hyperthyroidism-symptoms>.

Hypothyroidism (underactive thyroid). (2018, December 04). Retrieved from <https://www.mayoclinic.org/diseases-conditions/hypothyroidism/symptoms-causes/syc-20350284>.

Now, T. (2019, May 25). World Thyroid Day 2019: Hypothyroidism vs Hyperthyroidism- what's the difference, who's at risk? Retrieved May 27, 2019, from <https://www.timesnownews.com/health/article/world-thyroid-day-2019-hypothyroidism-vs-hyperthyroidism-whats-the-difference-whos-at-risk/425112>.







## Translators Needed Please

ICOSEP hopes to share our message, Good Growth=Good Health with more families around the world. We people who speak multiple languages which are missing from our Growth Awareness materials to please consider assisting our efforts for these children.

Do you know anyone or any groups who speak multiple languages? Ask them if they would like to volunteer their time and translate our message and website. If they have any questions, please have them contact [jamie@icosep.org](mailto:jamie@icosep.org).

## #ChildGrowthAwareness Day Artwork

#ChildGrowthAwareness Day artwork is available online in many languages. Go to the icosep website and logon using your secure password.

Artwork is free to all ICOSEP members.

If you need assistance, please email [ashley.gilmer@icosep.org](mailto:ashley.gilmer@icosep.org).





## Why is Children's Growth Awareness so simple.... and so life changing?!

After the 2018 Children's Growth Awareness campaign ended, ICOSEP received many emails from families asking for assistance.

The most common questions asked:

1. Is there a doctor in my area?
2. My child's doctor keeps saying to wait and see if he catches up in growth instead of doing testing. Should I be concerned?
3. Is growth really that important?
4. I'm short so it is normal for my child to be short too...right?

We always referred families to local organizations in their country and told them to contact families before doctors so that they could share experiences. Families trust other families who have lived through these challenges.

If a doctor does not want to test a child, you must be certain that the parents concerns are not out of place. But if they are insistent, you can refer them to the local organization or list of physicians on ICOSEP's page.

Is growth important? We all know that answer is yes!

And if there is a family history of short stature, it does not mean that a child should not be evaluated. There could

be a genetic syndrome that has not been previously identified in the family. Watching those growth patterns each year with the physicians is the key to understanding this fact.

Just one simple post can make the world of difference for children. One post in Iran led to the identification of 10 children with growth failure within 3 weeks of the educational campaign. And several of those children had truly rare medical conditions which needed treatment immediately.

This simple information probably changed the entire future health of those children and all the other children throughout many countries.

What you do matters~You are saving the future for many families and making a difference! Thank you for participating!

If you need help with your sharing this September, we are here to help! We may not be celebrities with a huge following but we can help!

ICOSEP members are AWESOME! Thank you!!!

**FUN FACT#9**

**"ALBERT  
EINSTEIN" IS AN  
ANAGRAM FOR  
"TEN ELITE BRAINS"**