

THEMAGIC

YEARLY UPDATES

Our mission is to improve the lives and health of children with endocrine conditions.



KARIBU WELCOME

Welcome to our yearly newsletter, we are more than thrilled to share with you exiting news about our recent developments in improving the health and lives of children living with endocrine conditions in Kenya and in Africa.

December 2024 Issue



First of all we would like to extend our gratitude to the following amazing people;MAGIC family, ICOSEP (International Coalition Of Organizations Supporting Endocrine Patients, our Endocrine Doctors, PESK(- Paediatric Endocrine Society of Kenya)and our new partners, CLAN-Caring & Living As Neighbors - , CLAN Child health Africa,MATES4Kids and CAH International who have

continued to support us with their knowledge and expertise in educating our communities about different endocrine conditions and the importance of early diagnosis. Your generosity, time and dedication have allowed us to keep our programs run at ease and effectively.

EDUCATION INITIATIVE

Part of what we do is to provide knowledge to the public about different rare conditions, we have teamed up with specialized doctors who are really dedicated and passionate in improving the health and well-being of children and adolescents.

WWW.MAGICFOUNDATIONAFRICA.ORG

OUR 2024 NEWS ROUNDUP



HEALTH & LIFESTYLE | CITIZEN TV FEATURE (DAYBREAK)

ENDOCRINE GROWTH DISORDERS

We began our year in our local tv station, CITIZEN TV, where our amazing Dr. Anjum Omar who is a paediatrician specialised in paediatric diabetes and endocrinology, Spoke about Turner Syndrome (TS) and Growth Hormone Deficiency (GHD) and Mrs. Priscillah Kirigi who is a parent and MAGIC member talked about her experience as a mother and care giver, Riziki Syombua who is the Founder of MAGIC Africa highlighted the general challenges faced by my patients with growth disorders, the entire video is very informative. Find link below:

<https://www.youtube.com/watch?v=QAcvZjtTMIY>

LEARN ABOUT CONGENITAL ADRENAL HYPERPLASIA (CAH)

We also did a webinar about Congenital Adrenal Hyperplasia (CAH), it is an inherited disorder of the adrenal glands that can affect both boys and girls. We had over 3000 viewers from different countries, all thanks to Dr. Paul Laigong and Dr. Esther Kobel for sharing their expertise, knowledge and valuable insight to the public, we need to end stigmatization of these conditions by creating more awareness. Find the video below, also subscribe to our youtube channel to access other videos

<https://www.youtube.com/watch?v=I5XwRR28IY0>

RARE DISEASE SERIES

CONGENITAL ADRENAL HYPERPLASIA SYMPTOMS, TREATMENT AND CHALLENGES

DR. PAUL LAIGONG
Paediatric Endocrinologist |
Lecturer |
University of Nairobi

DR. ESTHER KOBEL
Paediatrician |
Child Health Advocate |
Co-Director |
CLAN Child Health Africa

Moderator
RIZIKI SYOMBUA
Patient Advocate |
Founder |
MAGIC Foundation Africa

Thursday 4th July 2024 | 7:00pm- 8:30pm (EAT)

Event is
CPD Accredited

Follow Us on Our Social Media Platforms @knhresearch

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GIVING BACK TO SOCIETY



We were fortunate to get donation inform of stadiometers which is a device used to capture heights in children. We have 47 counties in Kenya, we were able to distribute 13 of them, 10 to different county referral hospitals with the help of Dr. Phoebe Wamalwa who is the current president of PESK and 3 went to community hospitals. This device will help doctors to capture and monitor children who are not thriving and might require early intervention and treatment. We are very honoured and grateful to our partners for their generous contribution



ICOSEP MEETING

Who are we? We are patients' groups, medical societies and physicians who have come together globally to enhance patient care. This year the meeting was at the Radisson Blue Hotel, Dublin Airport, which was very successful, every member discussed their challenges and experiences in their countries when it came to diagnosis and access to treatment for children with growth disorders, among the speaker was our Dr. Renson Mukhwana an M.D Senior Pediatrician at Gertrude's children Hospital, who touched on challenges faced by patients in Sub-Saharan Africa



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GROWTH AWARENESS DAY (GAD) CAMPAIGN



Every 20th September, each year, we participate in global growth awareness initiative organized by ICOSEP members to create awareness about the importance of monitoring children's growth. We were fortunate to do both online campaigns and physical activities which was very successful. You can view the videos for the campaigns that was created by the members around the globe.

<https://www.youtube.com/watch?v=at34wq4i3aM>

<https://www.tiktok.com/@magicafrica/video/7410664563500223750>

here is a full video of GAD which was very successful.



<https://www.tiktok.com/@magicafrica/video/7420075007964908806>

We want to say a sincere "THANK YOU" to everyone who participated in the 5km walk, we deeply appreciate your contribution. It was a pleasure to see you there, we hope you had a wonderful time.



International
**Children's Growth
Awareness Day**

September 20 ★ Worldwide Initiative

PART OF OUR ADVOCACY IS TO SPEAK ON BEHALF OF OUR PATIENTS ON PRESSING ISSUES THAT NEEDS TO BE ADDRESSED URGENTLY AS:

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ACQUISITION OF MEDICINES

There have been shortages of drugs and accessing them has not been easy, essential treatments are out of reach for many patients forcing them to withdraw from their ongoing treatment which has led to an increase of health complications in children and poor growth and development



WE NEED THE GOVERNMENT, BIG PHARMACEUTICALS, OTHER ENTITIES TO GET INVOLVED

HOW? By implementing health policies that covers the cost for rare/growth disorders since growth plays a vital role in a child's development, failure of growth leads to stunted growth.

Reduce taxes imposed on medicine intended to improve the health and quality of life for patients.

PHARMACEUTICALS

Create a systematic channel that patients can access medicine at ease.
Ensure that there is consistency of production of medicine which is affordable and safe for patients.



HIGH COST OF TREATMENT & DRUGS

Tests, consultations and medications especially Human Growth Hormone (HGH) are very expensive, a pen of 12mg/1 ml, is currently at 30,000-35000Ksh (250-300US\$), isn't that ridiculous!!!

LATE DIAGNOSIS

With late diagnosis, most of these conditions go untreated and are irreversible, early diagnosis is always the key. We are looking for Organizations to support our cause and our doctors, we have a few endocrine specialized doctors in Africa, in Kenya alone we have less than 20 paediatric endocrine doctors, there is need for more training programs for healthcare workers

GENETIC DIAGNOSIS OF ENDOCRINE DISORDERS

SECOND EDITION

2025 ACTIVITIES

by MAGIC FOUNDATION AFRICA

For advocacy and public awareness, we will be working with the following amazing teams of specialised doctors and patient groups



We are honoured to be collaborating with PESK (Paediatric Endocrine Society of Kenya) whose aim is to promote clinical and fundamental science, research, training and advocacy in children and adolescents with endocrine disorders and diabetes in Kenya. Learn more about them at

<https://paedendoskenya.org/>



We are excited to announce that we will be working with CLAN child health Africa, MATES4Kids and CAH international to raise awareness about Congenital Adrenal Hyperplasia (CAH), we will share the latest developments on ways of improving the healthcare systems nation wide, we also hope to implement the practise of New Born Screening (NBS) in Kenya, a practice which is lacking in most African countries. NBS tests can help detect rare disorders that can cause serious health problems in children if it's not early detected. We will have a platform just for CAH patients, where every voice matters.



We support rare disease day. We are currently working with the awesome Roselyn Kanja and Christine Mutena who are the Co-Founders of Rare Disease Kenya team/group to advocate for health policy and a healthcare system that works for those with rare disorders. To learn more about the group and their work, please check their link below

<https://rarediseasekenya.org/>

OTHER PROGRAMS FOR THE YEAR 2025

YOUTH PROGRAMS

We are planning to form a program just for the younger adults living with growth disorders, which will focus on patients with late diagnosis and those who started their treatment early, their views and experiences where every voice will be valued to help create more awareness on the importance of early diagnosis. We are currently looking for volunteers for this project, we also understand that mental health is on the rise especially among the youth who are trying to fit in the world where they are misunderstood, we really need to end the stigmatization by creating a free space where they can thrive and become productive citizens.

GROWTH AWARENESS DAY

We also have Children Growth Awareness Day every 20th -23rd September 2025, join us to learn more:

<https://magicfoundationafrica.org/>

This event is a fun and interactive way to support our cause while also enjoying great meals, drinks and entertainment. We hope to see you there

TURNER SYNDROME & CAH DAYS

- We have Turner Syndrome Day on February 2025
- Not forgetting CAH awareness month on June 2025. Creating CAH patient group.



PATIENTS /PARENT APPRECIATION

We are thankful to the MAGIC family for helping our child thrive by directing us to the right doctors and helping us access medicine given the shortages scenarios happening globally where Africa is affected the most. We were forced to outsource from India which was very costly, we thank you so much for standing with us

~ anonymous parent ~

Finally, we want to remind everyone that our organization relies on love, passion, kindness and support from our community, doctors and partners, if you are able to donate your time and resources, please do not hesitate to reach out to us.

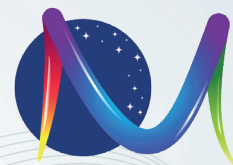
Together, we can make a huge difference in shaping the lives of those who need it most as you know where there is "GOOD GROWTH=GOOD HEALTH". Thank you for your continued support!



"Wherever the art of medicine is loved,
there is also a love of humanity."
~ Hippocrates ~

*Happy
Holidays*

AND A PROSPEROUS 2025



The **MAGIC** Foundation
AFRICA

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