

Youth on the Move Annual Report 2023

Empower youth with epilepsy through education, social interaction
and Entrepreneurship



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List of Abbreviations

CHVs	Community Health Volunteers
IBE	International Bureau for Epilepsy
ILAE	International League against Epilepsy
NHIF	National Hospital Insurance Fund
GDBH	German Doctors Baraka Health Center
IGAP	Intersectoral Global Action Plan
KEMRI	Kenya Medical Research Institute
NECC	National Epilepsy Coordination Committee
NCDs	Non communicable Diseases
NCDAK	Non-Communicable Diseases Alliance, Kenya
NCPWD	National Council for Persons with Disabilities
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
YotM	Youth on the Move



Living with epilepsy can be challenging and sometimes even heartbreaking, especially for young girls who are just starting to navigate life's challenges. One such sad experience is that of a girl living with epilepsy named Stacey.

My name is Stacey, my life since the age of 6 has been a constant struggle with seizures, medication and doctors' visits. Often times I have been unable to participate in activities including basic tasks like grocery shopping without fear of having seizures. My epilepsy has caused me to feel isolated from my peers, who often do not understand the condition thus they are unable to support me. I have faced social stigma, misunderstood and judged negatively. Teachers too, treated me as an incapable child of less intelligence.



Additionally, ignorance of the possible causes of the condition and the side effects of the anti-seizure medication that I take daily have impacted on me in a way. I experience drowsiness, mood swings and at times go into depression. While my family has been supportive all through, many a times I notice they too are affected emotionally and the cost of the treatment makes them frustrated.

In 2021, I met a team of youth at the Baraka Centre while I had gone for my review. While on the queue waiting for my turn with the doctor, I followed keenly their education where they were talking about triggers in epilepsy. I could not connect the dots! After my turn with the doctor, I sought a one-on-one coaching with their team leader called Beckham. My mind opened. Before I had no idea, that knowing and managing one's triggers is key towards living a better life with epilepsy. I chose from then henceforth to revise my sleep hours, reduce stress by preparing for exams in good time, taking my medication on time and as prescribed and avoiding last minute rush in whatever I did. I made clear amends at home and in school. Change in my lifestyle for the sake of managing my condition paid off! My seizures reduced and by end of my high school education I managed a grade that will get me a place to study in university! The fears of losing control of my body due to the unpredictability of seizures eased. With the knowledge I received on that very day I made up my mind to join Youth on the Move upon finishing my high school education.

I joined YotM in February this year. A comprehensive study of epilepsy (definition, causes, prevention, triggers, treatment, first and lifestyle) has made me so empowered just half way the cause. Besides, the topic of Epilepsy Opening Up model has instilled in me the virtue of fortitude and tenacity. I have acquired the ability to assert myself and persevere through trying times having moved from the state of ignorance, denial through to acknowledgment of my health condition to total acceptance of myself. I now freely utilize the knowledge acquired to educate others and share my story to motivate those still in denial. Additionally, the knowledge has fostered in me empathy towards those facing unforeseen difficulties. Epilepsy has granted me a distinctive outlook and profound gratitude for the blessing of existence. Many thanks to Youth on the Move. I now positively live with epilepsy!

I highly recommend any youth with epilepsy to consider joining Youth on the Move. I call upon donor foundations and well-wishers to donate toward this worthy cause by Youth on the Move Kenya.

Introduction

Imagine yourself to have epilepsy and to live in a developing country where the brain disorder hinders you to actively participate in society. This unfortunately happens among approximately 1,200,000 Kenyans. In 2023, the situation has been made worse by the cost of anti-seizure medication which doubled in price due to the hard economic times and the ongoing political instability in the country. In addition, there are several cultural myths and misconceptions attached to epilepsy in Kenya. The condition is often confused with witchcraft, demon possession and God's punishment. From the statistics of Kenyans who have epilepsy, only 30 percent seek conventional treatment and the treatment gap could be wider. This is not only because of the high costs and limited access to health care, but also because of the mentioned cultural myths. The outcome of this scenario is; those affected live in social isolation, with frequent seizures and financial dependence on already struggling caregivers.

Fortunately there are ways to improve this situation. Kenyan youth with epilepsy initiated Youth on the Move in 2007 to develop opportunities for their future. Youth on the Move offers epilepsy trainings, personal coaching, computer and entrepreneurship skills. It also connects youth with epilepsy with researchers, policy makers and health providers. Together they achieve the best possible approach to control their seizures and to create opportunities for a pro-active participation in society and self dependence.

We are grateful for the support of Stichting YotM in the Netherlands, Kenya Community Development Foundation in Kenya, Bank of Africa in Kenya, philanthropists as well wishers for the support they gave this year.

YotM updates the NGO-Board and its sponsors with regular reports, as well as certified audited financial accounts. We share a report of the efforts of 2023, the results and how we plan to follow up on our activities in the year 2024.

For further questions and/or remarks, feel free to contact us. We have a board a committed board and passionate staff willing to speak with you at any time (reachable through phone and email).

With kind regards,



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1 Relevance of the programme in Kenya

Kenya is now considered a middle level income country. However the health sector continues to experience paralysis affecting individuals living with terminal illnesses. In 2022 alone there were several strikes by health providers affecting access to treatment by most Kenyans. The situation is worse for persons living with epilepsy who need regular treatment medical reviews and are on AEDs daily. Between October and December health facilities have reported shortage of drugs including drugs for epilepsy.

Approximately 1.2 million Kenyans are living with epilepsy, only 30% access effective treatment. The huge treatment gap is attributed to lacking accessibility, availability and affordability of both treatment and information on epilepsy. The situation is worsened by the believe that epilepsy is a result of witchcraft, demon possession and a punishment from God. While there has been increased lobby and advocacy for non communicable diseases, epilepsy receives the least attention and support as is considered affecting a small population. The youth continue to bear a huge burden given the misconceptions and the unemployment rate which is worse for persons with disabilities. The youth are hindered from fully participating in society as they are often denied at school and work as well as isolated in faith institutions and social gatherings.

This information clearly reveals the dire need for social empowerment of youth with epilepsy, which is rather a necessity than a luxury addition to their medical care.

The youth gave several reasons for participating in organizing activities:

1. Very interesting in meeting other people, especially youth
2. Wanting to improve their welfare
3. Wanting to reactivate their social lives
4. Educating the public on epilepsy facts

This year upon confirming that Mercy had secured a chance for the one-year mentorship program, *she said: "This is my golden opportunity to embrace my dreams and live beyond epilepsy".*

Vision and mission

Vision: An understanding and responsive society that ensures equal participation of persons with epilepsy in developing countries in all aspects of life.

Mission: To empower persons with epilepsy and ensure equal participation in society through lobby and awareness creation in partnership with stakeholders.

2 Venue

We coordinate all our activities from the Nairobi West offices. This is a safe environment which is easy to reach for the youth with epilepsy in and around Nairobi. Due to the need for epilepsy knowledge, lobby and advocacy, we extend our services and to offer them countrywide in partnership with private organisations and County Governments.



I learned about Youth on the Move through an epilepsy training held in Homa Bay county, Rachuonyo area in a health facility I had gone to collect my AEDs. I sought further details and my journey began of finding a relative who would host me in Nairobi so that I undertake the YotM psychosocial training. I am glad I took the bold step to leave my village. I am empowered and more aware.

- Stacy 19-year-old with epilepsy, Youth in training at YotM 2023

3 Strategies and activities

To optimize the lives of young people with epilepsy in Kenya, YotM unites policymakers, researchers, welfare and community workers, healthcare providers and persons with epilepsy. Together they realize the best possible approach to control epilepsy attacks and create opportunities for proactive participation in society. We employ two strategies for this:

1. Advocacy and Policy Development
2. Empowerment through education, coaching and counseling.

For both strategies we introduce the activities that we carry out to achieve our goals.

Strategy 1: Lobby, Advocacy and Policy Development

NECC unites efforts of epilepsy organizations and individuals as indispensable part of improving the lives of people with epilepsy. Youth on the Move involves young people, parents, care providers and policymakers in the NECC platform and take lead in training community Health Promoters (CHPs) and lobby through the road caravan epilepsy campaigns.

Activity 3.1.1: National Epilepsy Coordination Committee (NECC)



Objective: Strengthening collaboration among stakeholders in epilepsy care to improve its quality and efficiency

NECC adopted a unified campaign called Angaza Kifafa. The campaign has continued lots of awareness creation and training to medicalworkers and community health promoters. YotM has been mandated by NECC to train community health Promoters in all Counties where NECC works.

Results in 2023: The Bank of Africa, our supporters, were very satisfied with our awareness creation in 2022, and extended their financial support for the national campaign Angaza Kifafa. 100 CHPs were trained and 2 epilepsy roadshows took place in Makueni and Murang'a respectively in the months of November and December.



Follow Up in 2024: NECC-is keen to continue this activity to 4 more counties with the ultimate goal of reaching to all the counties in the Country. So far 20 Counties have been covered. NECC also continues to encourage pharmaceutical companies and other entities to strengthen the support epilepsy care and support in the country.

Activity 3.1.2: German Doctors Baraka Health Centre (GDBHC)

Objective: Generate publicity about the international days of epilepsy and use the day to lobby for fair and equal treatment for people with epilepsy.

YotM partners with **GDBHC** who provides affordable medication to patients with epilepsy. At the clinic, Youth on the Move provides a one-on-one coaching to the new patients.



Results in 2023: This year YotM and GDBHC jointly initiated an advocacy walk for the International Epilepsy Day. The staff of the health centre and the youth marched through the slums of Mathare to celebrate persons with epilepsy. Epilepsy facts leaflets were distributed. The community was educated with the aim of stopping stigma. This walk saw more and more persons with epilepsy seeking treatment. In addition, 4 youth with epilepsy followed up and enrolled for the YotM mentorship training

Follow up in 2024: YotM would wish to engage all the slums in Nairobi and partner with more health centres to do epilepsy ant-stigma walks and campaigns.

Activity 3.1.3: Petition for the government

Objective: Young people influence the policy development of epilepsy care and have their voices heard and taken seriously by policy makers.

The young people often stress that epilepsy care should be offered for free or for more affordable prices. To make this happen, they developed a petition asking the government to make epilepsy care affordable and available. They started collecting signatures in the month of August 2009 to show the broad support to policymakers. So far, the petition has contributed to the coverage of AEDs without extra pay for people with people with the hospital insurance card (NHIF). However, the petition is still required as youths are often faced by the shortage of drugs. They still request the government to ensure enough and affordable availability of the drugs.



The petition action not only stimulates the government to provide better care, at the same time we achieve two other goals:

1. Young people are encouraged to speak about their own experience with epilepsy, which helps them overcome their shyness in public places.
2. The young people create more awareness about epilepsy at busy public places (such as buses) to encourage them to sign the petition.

Result in 2023: 6,177 signatures were collected and approximately 5,000 people sensitized about epilepsy through this initiative.

Follow up in 2024: We see the need to continue our petition to keep the government proactive in making epilepsy care affordable, available and accessible while using the initiative to reach out and educate more people on epilepsy facts. We will continue to lobby as well as use umbrella bodies to advocate for affordable care for persons living with epilepsy and support for awareness creation.

Activity 3.1.5: Review of WHO Intersectoral Global Action Plan (IGAP) on Epilepsy

Objective: To set out the actions needed to improve access to care and treatment for people with epilepsy through a comprehensive, coordinated response across sectors.



YotM has actively participated in implementing the action plan objectives set by WHO and being implemented through member and partner organizations. YotM contributes to the access needed by persons with epilepsy through awareness creation, lobby for affordable healthcare and patient empowerment.

Result in 2023: YotM presented a paper (on how the youth contribute to the objective of reducing stigma through awareness creation in various places) to a stakeholder forum in Nairobi and received commendation. As a result, YotM applied as an IBE Associate Chapter and was approved in November during the IBE African Conference held in Addis Ababa Ethiopia.

Follow up in 2024: YotM will continue to address the gaps and challenges in epilepsy care focusing on the objective of awareness creation and anti-stigma campaign. **Activity**

3.1.6: Contributing to the UNCRPD Alternative Report

Objective: To air views on the progress that Kenya has made in advancing the implementation of the Convention on the Rights of Persons with Disabilities so that the government can be held accountable to fulfil its mandate as agreed upon with the United Nations.

YotM participated in the United Nations Convention on the Rights of Persons with Disabilities Workshops and promoted the realization of disability-inclusive Sustainable Development Goals at the country level.

Result in 2023: Participation in 5 high level dialogue on the progress Kenya has made as mandated in the convention. Contribution to the writing of alternative and progress report that were presented to the UN for further lobby to the government.

Follow Up 2024: YotM will continue to actively participate in dialogue with other organizations and community, national and international in policy formulation and analysis aimed at contributing to the realization of disability-inclusive Sustainable Development Goals.

Strategy 2: Empowerment through education and guidance

For the empowerment of young people with epilepsy, YotM trains young people with and without



epilepsy as peer educators, guides the parents/caregivers and also train professional social and welfare workers to have the right knowledge and to provide guidance to people with epilepsy.

Activity 3.2.1: Train the Trainer

Objective: To train youth (gender balance) as peer educators and develop the skills to offer professional awareness creation and coaching

Every year, Youth on the Move trains young people with and without epilepsy. We give priority to vulnerable youth who are ambitious but have low self-confidence and little hope for a good future. In one year, they are trained as peer educators as they follow classes in psychosocial mentorship, computer, business and entrepreneurship. Every month a course is concluded with an exam. In addition,

the young people do an internship two days a week at Youth on the Move's center in Nairobi and at Baraka health center in Mathare. The young people also provide information to religious institutions, schools and various support groups.



Result in 2023: 56 young people (26 with epilepsy) applied for the training, which allowed us to be very selective about the choice of participants as we could only afford to support six. The team consisted of 5 different ethnicities representing 4 provinces. In August, luckily, KCDF confirmed our proposal presented to them in December 2022 of supporting 20 youth by 50% and the organization to raise the other 50%. With this,

20 more youth were enrolled in September. Those who started in January graduated in December while those in September will complete the course and graduate in August 2024. The team of 6 showed a lot of committed and exhibited exemplary growth and performance by the time they graduated and exited. They were very active in making short educative videos and sharing their stories. The September team who had lost hope of missing the chance in January are very, passionate and desirous of learning and supporting as well as awareness creation.

The future of the trainees

The youth who follow the course, get an allowance of Kshs 450 per day. When they save Kshs 50, they get a bonus of Kshs 50. This means that they have saved around Kshs 15,000 which they can use to start their business. They receive their saved money on a bank cheque, so that they are stimulated to open a bank account. During the entrepreneurship training they develop a business plan on how to invest their savings and become financially independent.



My name is Mercy I was born and raised in a small house in Kibera. At the start of school, I was very bright and always on top of class. I was full of dreams and aspirations. However, hell broke loose when I was diagnosed with epilepsy,

My parents moved with me from one hospital to another and from one preacher to another seeking medical plus spiritual healing. They made adjustments to their lifestyle all for my wellbeing and safety. However, the stigma and ignorance of this condition affected my self-esteem. The challenges that come with teenage-hood and puberty worsened my



situation.

I found out about youth on the Move when they came to my school to create awareness. I applied and secured an opportunity this year to follow the training. In only six months, I regained my energy actively participating in sensitizing my community about epilepsy. I have formed new friendships and pursued my passion for singing, showing great talent and creativity. As I step out as an empowered young happy woman, very stable and prepared join college to study music.

The story of Mercy is a testament to the power of knowledge and how compassion and the difference a donation to YotM can transform someone's life within a short period. Mercy is the best in course work and character in this year's team! Her journey with epilepsy is more manageable, and she is able to embrace her dreams with new found hope and resilience.

Follow up in 2024: We still have a long list in our databank for the youth who would wish to join the training. Many more continue to be identified through the health facilities. For this we will continue training for those who joined in September as we reach out for more funding support to enroll many more.

Activity 3.2.2: Epilepsy Education



Objective:

1. Creating awareness and acceptance for epilepsy across the Country.
2. People learn to understand what epilepsy is and are thus encouraged to provide appropriate support to those with the condition.

Every year, Youth on the Move selects locations throughout the country where the youth in training under guidance provide peer education on epilepsy; what it is, how one can lead a good life with it and how one can assist someone who has the condition. Not only people with epilepsy are trained, but also the leaders in the communities who are able to



transfer this knowledge to their members. They are encouraged to refer people with epilepsy who are not yet receiving care to the appropriate healthcare providers.

Results in 2023: 11,271 were trained and sensitized in various institutions, groups and in public places. The Social Media manager actively provided information via YotM's Facebook page with short videos on various topics related to epilepsy prompting a large number of people to discuss important epilepsy issues online.



Follow up in 2024: Given the demand for more awareness from the public, YotM is inspired and committed to continue providing the trainings to various groups and creatively use minimal budget to reach as many people as possible. We plan to target more youth groups and colleges as we notice the rising number of youths with epilepsy from the groups we have interacted with and through the inquiries we get.

Activity 3.2.3: Movers Meeting

Objective:

1. Youth with epilepsy develop courage to be part of a group
2. Youth with epilepsy gain information about their burning issues (such as self-esteem and relationships)
3. Youth with epilepsy develop, share and defend their opinion freely.



During the Movers Meeting, the young people themselves take turns as the chairman and secretary as an exercise to lead a group. During the meeting, they evaluate the activities of the past week and prepare the upcoming activities. After discussing the upcoming actions, they are engaged in the Sikika Talk (Sikika means 'to be heard or receive attention') and discuss topics that concern them the most at the time (such as work, relationships, AIDS, religion, addictions, safety, usually in relation to epilepsy). This activity helps them to develop their own opinion, to discuss in a team and to make well-considered choices.

The purpose of this is not only that they gain knowledge, form an opinion, express their opinion and act accordingly, but also to learn to appreciate themselves and dare to take up space in a group context. Every month the youngsters vote for the Mover of the Month. The Mover receives Kes. 1,000 as a reward and their photo is put in the Movers paradise wall for the entire month.

Results in 2023: Topics of discussion are selected by the youth themselves. 40 topics were discussed. The youths showed concerns about Faith and Beliefs, Drug abuse, Youth Employment and politics. Through the discussions the youth gained confidence, guided each other on how to already start small businesses and encouraged one another on how to outgrow some beliefs that hindered development.

Follow up in 2024 This activity remains popular among the youth and is therefore high in the priority list for YotM to keep offering the opportunity to the youth. It offers a good platform of improving both interpersonal and intrapersonal communication skills.

My name is Desta, I come from North Eastern. My community is Burji believed to have originated from Ethiopia. In my community women are to be seen and not be heard. They are supposed to very submissive and only follow instructions. My friend from the same community encouraged me to join YotM. I was successful. In the beginning I was shocked to see girls in Sikika meetings arguing and defending their opinions of the topic under discussion. My eyes opened, I got re-socialized positively. I now speak out and even challenge my parents on some social-cultural practices. I have shared to them of my choice to find myself a boyfriend in future unlike the community culture where the elderly finds suitors for the girls! Sikika has made me what I am and what I'm gonna be in future!



Activity 3.2.4: Movers Picnic



Objective: Young people with epilepsy practice their skills for working in a team, whereby each participant is equally involved in the realization of their activities.

The last Saturday of the month, Youth on the Move organizes the Movers Picnic in the Arboretum Park in Nairobi. The activities are organized by the young people themselves, so that they learn the skills to work as a team and to create a safe atmosphere for all the other participants. The youngsters receive Kes. 2,500 (€ 20) to buy snacks and drinks for the team as well as to pay park entrance fees. In doing so, they also learn to distribute tasks and to deal responsibly with their contribution.

Result in 2023: Movers of previous years continued to join the new Movers in various sports activities and games. Their attendance enables them to be a rolemodel for the current Movers in training who therefore see how they can also make it a success after attending the training. The picnic boosted the self esteem of the youth who had been denied a chance to play and socialize by their family due to the fear of them getting seizures. This year, not only did the youth enjoy the games and the snacks but they also set a side 30 minutes before leaving to approach other people in the park and share about epilepsy and Youth on the Move activities. This way picnic is creatively combined with epilepsy awareness!

Follow up in 2024: We will continue the Movers Picnic for the youth in training as the activity boosts morale and encourages the youth to improve working in a group while educating people at the park.

Activity 3.2.6: Coaching at epilepsy clinics

Objectives:

1. Clients with epilepsy understand their condition and know how to take good care of themselves
2. The doctors can treat more clients in the time available

The approximate doctor patient ratio in Kenya stands at 1:1700. Therefore, the doctor has little time available for explanation what epilepsy is and how the patients can take good care of themselves. This is the role the peer educators take at clinics in Nairobi. In understandable language they pass over this knowledge. The doctor, uses less time to attend a patient, the waiting time reduces and the quality of care improves.

The trainees (see activity 3.2.1: Train the Trainer) provide support under the guidance of the clinic coach. The patients are guided on proper way of taking the medication, self-care, recognition of their triggers and lifestyle options for a person with epilepsy:

Result in 2023: We successfully offered coaching at epilepsy clinics once per week. The coach and trainees offer one-on-one guidance as well as group coaching. This gives the patients an opportunity to learn about YotM activities and develop interest in applying for the one-year mentorship.

Follow up 2024: In the upcoming year we will offer the guidance at the clinics as it is a great spot to offer guidance to people who are new in epilepsy care. They can therefore also be informed about the other services that are offered for people with epilepsy, like the Saturday's Movers Meeting and Parents Meeting.

Activity 3.2.5: Parents Meeting

Objective: Parents offer guidance to their daughters and sons with epilepsy, which stimulates their independence in life.



It often happens that the parents of youth with epilepsy overprotect their child and take over their duties to protect them from potential risks. Therefore, youth with epilepsy often miss out on the opportunity to strengthen their independence. Every last Saturday of the month we offer the Parents Meeting where parents can share their experiences as they also learn how they can encourage their child to responsibly undertake day-to-day activities more independently. Every month they discuss a new topic under the guidance of the trainer. Together they reflect how best they can encourage their child to live healthy and independently. For this, they make use of the manual which we developed in partnership with the parents and youth with epilepsy. Furthermore, we also train parents during clinic days at the health center.

Results in 2023: This year, the parents meetings are organized at two different places: Baraka Health Center in Mathare and at YotMs training center in Nairobi West. Therefore, we are able to reach out to 30 parents in total. By May this year the parents noted that they had seen great improvement in their children which had greatly reduced their worries.



Follow up 2024: In the upcoming year we would like to invite 30 parents of youth with epilepsy to attend the Parents Meetings in Nairobi West to share their knowledge and experiences and to find an effective way to guide their child to live a pro-active life.

*The toughest part of my life is raising two children with epilepsy. They were all born well. One started having seizures at the age of 2 years. And the other at age of 4. I still could not figure out the cause or precisely what it was. A lot of pressure came from my in-laws that my children would suffer from demonic attacks. Despite the pressure and being pushed to see witchdoctors I still managed to sneak out with the kids and take them to hospital. I secretly gave them anti-seizure drugs in addition to the rituals of the witch doctor. At Baraka health center I met these young people with t-shirts written **Youth on the Move**. They talked more about the possible causes of epilepsy. They really guided me and referred me to their center to join the other parents. The experience shared by other parents has helped me a lot. I now embrace my children knowing epilepsy as a medical, treatable and manageable condition. My in-laws have begun to understand this as well. I am hopeful my children who are now 4 and 6 years will be seizure free. Zainabu – Parent on the Move 2023*



Activity 3.2.7: Train the Community Health Volunteers



Objective: Community Health Volunteers are knowledgeable about epilepsy and are able to use their knowledge to guide people with epilepsy in their community.

Community health volunteers have a very important role in the effort of [first explain their role in general]. This includes their contribution to reducing stigma on epilepsy by providing the right information and identifying and referring patients for treatment. Training CHPs remains essential to ensure that they properly contribute to a sustainable referral system and point of contact between the patient, YotM and medical professionals.

During the trainings, we ask the participants the following questions, both in the beginning and in the end, to evaluate their understanding:

1. How can you recognize people with epilepsy in your neighborhood?
2. How can you encourage them to ask the right doctor for help?
3. How can you guide them in their independence and prevent a life in isolation among people?

Their response to the questions has helped us in putting together and tailoring our training manual to the level of understanding of the CHPs and the community at large.



Result in 2023: Counties and organizations continue to embrace the role of the CHPs and the demand among CHPs to be trained is high. We partnered with two epilepsy organization in Kakamega and Homa Bay respectively to trained 60 CHPs. 106 CHPS were also trained in Makueni and Murang'a County under the NECC Angaza Kifafa Campaign supported by Bank of Africa. The trainings made great impact as by end of December CHPs have refereed 145 persons living with epilepsy for treatment.

Follow up 2024: We plan to train to partner with organizations and share costs in training 100 CHPs. Also, we target under the Angaza Kifafa campaigned to training 50 CHPS in each of the 4 Counties targeted. (Kirinyaga, Kiambu, Tana River and Busia) and share epilepsy manuals.

Activity 3.2.8: Book club

Objective: young people strengthen their English language skills and can therefore express themselves better.

We find that young people with epilepsy in training often have difficulty speaking English in a group at the beginning of the year. This is because they have difficulty finding the right words due to lack of a comprehensive English Education caused by frequent absenteeism from school as a result of seizures. In addition, there is a culture among young people that; it is not cool to read. That is why we spend a lot of extra time encouraging them to read books in order to improve their vocabulary and enhance their knowledge.



Result in 2023: Ten books were read jointly read and discussed. The books were discussed one hour before commencement of class and on Saturday between 10 am and 11 am. The most borrowed and read book versions were autobiographies and inspirational. The board members were so impressed with the movers liking of these books that one of them Richard donated some of the autobiography he has authored and by end of the year it had been read by eight youth.

Follow up in 2024: YotM will offer the book club again so that the youth are encouraged to read and broaden their horizon. YotM plans to continue the approach of discussing a book for one hour before starting the normal class routine. We wish to equip our library with more inspirational and autobiography books.

Activity 3.2.9: Movers Yoga



Objective: Young people learn to listen better to their body and to find a better balance, which strengthens their self-confidence.

Yoga is offered for one hour after the lessons of the young people in training the young people find that yoga helps them to relax, have a better concentration; strengthens their self-confidence and stimulates teamwork. Yoga also strengthens their physical stability and even a reduction in the number of attacks has been noted.

Result 2023: The youth were very passionate about the exercise which made them to practice it at home. The youth note that yoga helps them to relax, have a good concentration, boosts their confidence and stimulates them to work well as a team.

At the start of these yoga sessions, I felt like it was a punishment. But, by the encouragement of our Yoga guide, I slowly developed interest and started experiencing a change in my sleep patterns. I now practice yoga daily and I feel relaxed.

I take notes after every class. My aim is to become a yoga instructor. I already invite friends in the evening in the nearby school field to practice yoga with me. Soon, I will offer the service at a fee!

Faith, Youth in training 2023.



Follow up in 2024: due to the popularity of the Movers Yoga and the positive feedback from the young people, we plan to continue the yoga sessions. The youth now see another benefit of yoga as becoming trainers in future and generating some income to buy their medication.

Activity 3.2.10: Movers Computer room & social media



Objective:

1. Young people with epilepsy learn to use a computer
2. Young people with epilepsy exchange experiences with other young people across the globe

Youth on the Move runs a computer center for young people with epilepsy. They learn to use the computer; they also have a better chance of entering the labor market as more and more jobs require computer literacy for employees. Activities done in the computer center are:

1:Gathering knowledge and exchanging experiences via the internet

The young people are encouraged to look up information on the internet for their homework and also for the Movers Meeting (see activity 3.2.3) where they discuss a different topic every week. In addition, they are also encouraged to share their opinions and experiences on social media: Facebook, LinkedIn, TikTok and Twitter so that they also have a stronger voice at an international level.

2: Online Epilepsy Education

To share knowledge about epilepsy and encourage young people to share their experiences, Beckham Leonard Ouma (Social Media Coordinator) posts twice a day on the Youth on the Move page on Facebook. There are many responses to this and we also receive questions from people with and without epilepsy about the condition; how they can help others or where they can get medical care. The number of followers on Facebook is 7000 with 6905 likes (31 June 2023). According to statistics, 80 percent of the people we reach are between 25 and 34 years.

Result in 2023: The youth continued to improve their computer skills, browsed and communicated with others in faraway places through the offered access to the internet. They also used the computers and internet search engines to do their homework. Recently, the Kenya government required all government services be applied electronically including application for disability card through the E-Citizen online platform. Computer education has helped the youth to apply for the services easily.

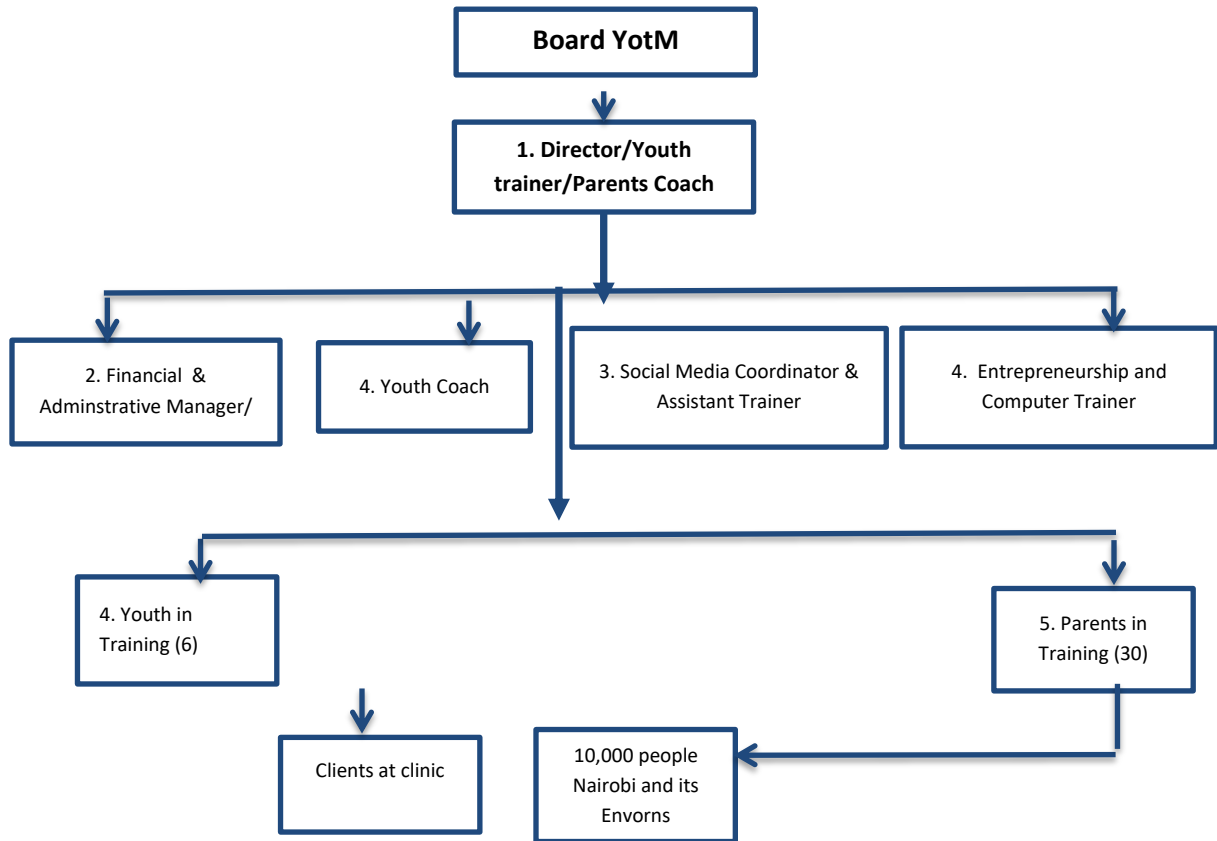
Follow up in 2023: The computer center will remain open for the young people to continue to enhance their skills and interact across the globe as well as help in application of government services.

4 Our staff



Youth on the Move offers its services in response to the expressed needs of young people with epilepsy. The aim is and remains that the young people with epilepsy are administrators and implementers of the activities. They take on the duties of teaching skills as peer educators and reaching out to people across the country in their education. They do this under the guidance of professionals who share their skills to provide quality information and guidance. The organization is registered in both Kenya and the Netherlands and has board members who guide the employees to ensure that the services meet the conditions set by the organization.

1. Musimbi Epillose (Masters Community Development): Director/Youth and Parents trainer
2. Leonard Beckham Ouma: Social Media Assistant/Assistant Trainer
3. Emma Mutunge (Certified Public Accounting) Finance and Administrative Manager
4. Hellen Allan: Youth Guide and Clinic Coach
5. Erick Kimathi: (Diploma Project Management) Entrepreneurship and Computer Trainer
6. 6 Youth in Training January to December, 20 Youth in Training September to August 2024
7. 30 Parents in Training



Appendix 1: Board of Youth on the Move

Youth on the Move is registered as a Non-Governmental Organization at the NGO-Coordination Board in Kenya. Secondly, we are registered in the Netherlands as an institution (stitching) for the fundraising of Youth on the Move in Kenya.

Board of YotM in Kenya:

Sam Kiwinda	Digital Consultant, Bar & Artist Manager
Musimbi Epillose:	Secretary (ex-officio, without vote); Director YotM Kenya
Richard Oduor Oduku:	Research Consultant, Biomedical Science & Technology, Program Manager
Elias Ngugi Mwenda:	Lawyer and Magistrate, Judiciary of Kenya
Antony Odhiambo Wasuna:	Lawyer and Advocate of the High Court of Kenya
Peter Sesi Nyette:	Counselling Psychologist and Project Coordinator
Sam Kiwinda	Digital Consultant, Bar & Artist Manager

Josefien de Kwaadsteniet: Board Chairperson, Independent Trainer – Consultant in International Development Cooperation

Tom van der Velpen: Board Treasurer, Social Worker at Stichting, SINA

Karijn Aussems: Board Secretary. Lecturer and researcher at Amsterdam UMC, dept. Ethics, Law and Humanities.

Appendix 2: Scores for the exams of Train the Trainer 2023

Name	Epilepsy %	Culture and Identity	Coaching	Teamwork	Youth Participation	Lifestyle	Entrepreneurship	Final Exam
Mercy Charles	90	93	88	94	71	94	86	90
Faith Githinji	74	89	85	82	72	87	88	70
Desta Nazeret	84	85	89	96	90	95	98	100
Stacy Anyango	83	85	64	75	76	74	92	84
Steve Murimi	80	82	60	72	67	74	64	60
Dennis Muga mbi	70	63	60	60	63	63	61	68

Note:

The month of June, August and October are for Personal Development Growth (PDP), a one-on-one program with the trainees.

Appendix 3: Awareness Venues and Numbers Reached

County	Place	Venue	Month	Trainers	Number Trained
Nairobi	Nairobi	St. Johns Ambulance	January	Atito, Hellen	100
		Baraka Health centre		Hellen, Beckham	300
		Baraka Health centre	Feb	Hellen, Beckham, All movers	750
		St. Johns Ambulance		Atito, Stacy, Mercy, Dennis	130
Homabay	Rachuonyo North	Gendia Primary		Epillose, Eunice	385
	Rachuonyo	Nyaburi primary		Epillose, Joakim	293
Nairobi	Nairobi City	Newlite Primary school	March	Hellen, Desta, Steve	150
		St. Johns Ambulance		Atito, Mercy	220
		Baraka Health centre		Hellen, Desta Stacy, Steve, Mercy, Dennis, Faith	430
		Kibera youth group	April	Beckham, Dennis, Mercy	65
		St. Johns Ambulance		Atito, Steve, Faith, Desta	190
		Baraka Health centre		Hellen, Desta Stacy, Steve, Mercy, Dennis, Faith	520
				St. Johns Ambulance	May
Kakamega	Mumias	Mumias complex primary		Epillose, Mercy	372
Nairobi	Nairobi City	Baraka Health centre		Hellen, Desta, Stacy, Steve, Mercy, Dennis, Faith	620
Busia County		Osieko pri	June	Beckham and Steve	478
		Emachina primary,			800
		Nasewa primary			340
		St. Lukes Odiado			350
		Nyakhobi primary			332
Nairobi	Nairobi City	Baraka Health centre		Hellen, Desta Stacy, Steve, Mercy, Dennis, Faith	485
Machako	Matuu	Matuu Catholic		Epillose	241

s		primary			
Nairobi	Nairobi City	St. Johns Ambulance		Atito, Faith, Desta	90
Nairobi	Nairobi City	Latter day saint Youth group	July	Beckham, Faith, Mercy	90
Nairobi	Dagoretti	Dagoreti Grounds literacy day		Beckham, Hellen, Steve, Faith, Mercy, Dennis, Desta, Stacy	470
Nairobi	Mathare	Baraka Health Centre		Hellen, Steve, Faith, Mercy, Dennis, Desta, Stacy	346
Nairobi	Nairobi City	St. Johns	August	Atito, Steve, Dennis	112
Nairobi	Nairobi City	Baraka Health centre		Hellen, Steve, Faith, Mercy, Dennis, Desta, Stacy	340
Nairobi	Nairobi City	Trinity Youth Camp		Beckham, Mercy, Steve	220
Machakos	Matuu	Matuu youth camp		Beckham, Hellen, Faith	353
Nairobi	Langata	Honest academy	September	Hellen, Dennis	140
Nairobi	Mathare	Baraka Health centre		Hellen, Steve, Faith, Mercy, Dennis, Desta, Stacy	450
Nairobi	Nairobi CBD	St. Johns Ambulance		Atito, Dennis, Stacy, Steve	66
Kiambu	Kiambu town	Kelvan school		Beckham, Desta	270
Nairobi	Mathare	Baraka Health centre	October	Hellen, Steve, Faith, Mercy, Dennis, Desta, Stacy	343
Nakuru	Naivasha	Naivasha farmers association		Beckham, Steve	160
Nairobi	Nairobi CBD	St. Johns Ambulance		Atito, Mercy, Faith, Desta	45
TOTAL					11,271

TO ALL OUR SPONSORS AND WELL WISHERS, THANK YOU SO MUCH FOR YOUR SUPPORT!

