

Youth on the Move Annual Report -2022
**Empower youth with epilepsy through education, social
interaction and entrepreneurship**



Contents

Introduction	4
1. Relevance of the programme in Kenya	8
2. Venue.....	9
3. Strategies and activities	9
Strategy 1: Lobby & Advocacy	10
Activity 1.1: NECC (National Epilepsy Coordination Committee)	10
Activity 1.2: Youth on the Move: Celebration of international Epilepsy days.....	11
Activity 2.4: Petition for the government	12
Strategy 2: Policy Development.....	13
Strategy 3: Empowerment through education and guidance.....	13
Activity 3.1: Train the Trainer	14
Activity 3.2: Epilepsy Education	15
Activity 3.3: Movers Meeting.....	16
Activity 3.4: Movers Picnic.....	18
Activity 3.5: Parents Meeting	19
Activity 3.6: Coaching at epilepsy clinics.....	21
Activity 3.7: Train the Community Health Volunteers	22
Activity 3.8: Book club.....	23
Activity 3.9: Movers Yoga.....	24
Activity 3.10: Computer Literacy & social media	25
.....	25
<i>Youth guide coaching the youth in training on computer</i>	<i>25</i>
4. Our staff	26
Appendix 1: Board of Youth on the Move	28
Appendix 2: Scores for the exams of Train the Trainer 2021	29
Appendix 3: Awareness Venues and Numbers Reached	30

List of Abbreviations

CHVs	Community Health Volunteers
IBE	International Bureau for Epilepsy
ILAE	International League against Epilepsy
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
WHO	World Health Organisation
YotM	Youth on the Move

Introduction

It needs courage to positively live with epilepsy in a world full of stigma and limited access to the right knowledge on epilepsy. It is even more challenging when a society perceives epilepsy as a spiritual or supernatural condition rather than a medical condition. It is worse when the little population with knowledge on the condition do not have medication due to accessibility, availability and affordability constraints. Worse off is the Covid 19 pandemic which has further contributed to the plight of persons with epilepsy. According to the World Economy Africa Paper dated September 7 2020, the unemployment rate in Kenya doubled to 10.4% compared to 5.2% in March same year. 1.7 million Kenyans have lost jobs due to contracting economy. Youth on the Move has not been spared either; the funding received for activities of 2022 was less than half the budget which compelled the board to cut the number of staff by 50%. Little income also had an impact on the activities proposed. For instance, 6 youths instead of 12 were selected to undertake the one-year training yet 38 youths had applied for the course. Despite these challenges YotM continued to creatively implement all its activities as you will see in activity reports.

The young people with epilepsy in training at YotM this year and those of previous years have not been spared either. Most of them lost their jobs and those in self-employment the incomes shrunk. Their caregivers too suffered similar occurrences. Loss of income and the covid 19 pandemic impacted on people with epilepsy in the following ways: -

1. A majority can no longer afford the anti-epilepsy drugs that are used to control the seizures. Not only has the cost of drugs gone up but also the purchasing power has gone down.
2. Most of them cannot afford adequate meals. This results in more seizures hence a strain on feeding for themselves. The result is more dependence on parents and well-wishers who are equally strained.

It is for these reasons that Youth on the Move engaged Kenyan youth with epilepsy in empowerment programs at the Nairobi center in the year 2022. We would like to share with you the activities of the half year of 2022, the current results and how we want to continue our services in 2023. Follow up plans have been presented in this report.

It is estimated that about 1,000,000 Kenyans have epilepsy, however only 30% make use of effective treatment. The wide treatment gap is attributed to the myths and misconceptions attached to the condition. For instance, epilepsy is often believed to be witchcraft, demon possession or a punishment from God. In many cases, the consequence is a life in social isolation and financial dependence. Fortunately,

there are many creative and innovative ways to improve this challenging situation. Kenyan youth living with epilepsy-initiated Youth on the Move 12 years ago to create opportunities for their own future. Youth on the Move has a **training Centre in Nairobi** where youth with epilepsy are trained as peer educators, provide epilepsy trainings to the public and connect them with researchers, policymakers and health providers. Through this the best possible approach to controlling their seizures and creating opportunities for a pro-active participation in society is achieved.

The demand for awareness and guidance is increasing rapidly, which the organization cannot achieve without financial support from sponsors. Besides, the effects of Covid 19 and high costs of stationery compelled the organization to close its only income generating activity (internet café) due to huge losses it was making. That is why we are grateful for the support of Stitching YotM in the Netherlands and The Bank of Africa Kenya for their financial support in 2022.

YotM updates the NGO-Board and its sponsors with regular reports, as well as certified audited financial report. We appeal for your financial contribution for part of these costs so that we can continue to perform our services in 2023.

If you have any questions or suggestions, please do not hesitate to contact us. The employees and board members are happy to share information with you about how we perform our services with the available resources.

With kind regards,



Epillose Musimbi

Director Youth on the Move
Email: epillose@yahoo.com
Tel: +254(0)712623681



Karijn Aussems

Secretary Stichting YotM, NL
Email: karijnaussems@gmail.com
Tel: +31(0)624160787

Bank account Details for Youth on the Move, Kenya

Bank: Equity Bank, Nairobi West Branch

Account number:1280263901314

SWIFT Code: EQBLKENA068128

Address of Secretary Stichting YotM: M.A. de Ruyterstraat 1, 3601 TL Maarssen

Account number: NL18RABO01477.34.126

KvK-number: 53286618

“My wife left after only two days into our marriage”

Hello, my name is Elvis Peter, am 3 months shy to 23 years, and I live with epilepsy. The world recently celebrated valentine’s day, love and happiness hovered all over the place, it was evident due to the many happy faces I saw that day.

Indeed, love is a beautiful thing, but only to the “chosen few” (my opinion). My Valentine’s Day was a slow one. it was filled with bitterness and regrets. I really didn’t get the true meaning of it.

Like most of you, I was also in love with someone, Carol, who meant the world to me; she was the only family I had, considering that am an orphan. All went well, our love blossomed until that fateful night while sleeping, at around midnight.

I got a seizure, which I felt changed my love life, it cut short our dream to stay together with my lovely wife and start a family only two days into our marriage. I only remember waking up, turning the lights on. I had urinated on our bed; blood was oozing from my mouth but carol was nowhere to be seen. The next morning, at around 6am, I heard a knock on the door, I opened it, she came in, packed all her belongings, and left, without even saying a word, not even goodbye. My plea fell on deaf ears.



Even after preparing her psychologically all through our dating stage, she felt that it was kind of too much for her, she couldn’t put up with the “Scary” scenes of that day. I regret that I didn’t get an attack while still dating her, I still question God why he allowed it to happen on that day.

I sometimes feel like a burden, especially to my neighbors and the people around me. Am glad I joined Youth on the move, I hope it covers my bruised confidence and restores my lost hopes, maybe I’ll find love again, I know the future holds more for me. I know I will cope well with my condition.

(Above is a true story of a youth living with epilepsy. Showing clearly how stigma and lack of knowledge on epilepsy hinders people with epilepsy from living normal lives. Elvis was one of the youth in training at Youth on the Move in 2022. Here is a link to the story <https://youthonthemovedotblog.wordpress.com/2022/02/16/my-wife-left-after-only-two-days-into-our-marriage/>)

1. Relevance of the programme in Kenya

The chance of getting epilepsy is three times higher in Kenya than in the developed countries like the USA. In a study done by KEMRI, it was found that the prevalence of epilepsy is about 20 cases in every 1,000 people. About 77 new cases in every 100,000 people are diagnosed every year (Dr. Kariuki 2017). These estimates are two to three times higher than in developed countries. Despite this worrying trend, there still exist a 70% treatment gap in Kenya due to lack of facts on the condition. Lack of understanding of the condition hinders those affected from living normal lives and fully participating in society.



They are often denied opportunities at school, work, in faith based institutions and other social gatherings. This predisposes them to violation of rights, violence, sexual assault, unprotected sex and early pregnancies. Researchers in Zambia state that 37% of persons with epilepsy have been victims of sexual violence. This information clearly reveals the dire need for social empowerment of youth with epilepsy, which is rather a necessity than a luxury in addition to their medical care. *(photo in text above shows the trainer doing the one on one guidance with one of the youth in training).*

Motivated by this sad scenario in Kenya and the desire to change for the better, young people in Focused Group Discussions gave several reasons of wanting to contribute to epilepsy awareness including: -

1. Need to di-stigmatize epilepsy by educating communities on facts and breaking the myths
2. Very interested in meeting other people, especially fellow youth with epilepsy and sharing lived experiences
3. Wanting to improve their welfare and reactivating their social lives
4. Lobby the government for affordable epilepsy care

This year during the selection interview for the youth to be trained for one year, one of the young people said, *"I have suffered Epilepsy for 15 years now, a former youth in training met me at the clinic and testified how Youth on the Move has coached her to what she is now. I could not believe that she too has the condition. From taking 8 tablets a day to only one in the evening, she continued. I have no doubt given this chance I will testify too. I long too for the moment I will go for a month without a seizure!"*

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

Youth on the Move started as a small-scale organization for training youth with epilepsy in Nairobi, but we were soon encouraged to expand our services and to offer them countrywide in partnership with private organizations and County Governments.



3. Strategies and activities

To optimize the lives of young people with epilepsy in Kenya, YotM unites policymakers, researchers, welfare 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 four strategies for this:

1. Lobby and advocacy
2. Policy development
3. Empowerment through education, coaching and counseling.

Strategy 1: Lobby & Advocacy

Activity 1.1: NECC (National Epilepsy Coordination Committee)



Objective: Strengthen cooperation in Kenyan epilepsy care to improve and guarantee quality and efficiency.

From its operations YotM realized the need to have an umbrella body of epilepsy care stakeholders so that to undertake the lobby and advocacy initiative with one voice. This realization was made a success in 2008 when the Ministry of Health, neurologists and other organizations took up the initiative that saw the birth of the National Epilepsy Coordination Committee. The members (Ministry of Health, WHO, ILAE, IBE, EAA), researchers, pharmaceutical companies, foundations and people living with epilepsy. Members meet bi-monthly to develop policies and organize joint events for epilepsy education among healthcare providers and the community.

Results in 2022: Between January and June, NECC has conducted stakeholders’ meetings, training doctors



and community volunteers as well as creating awareness through local and mainstream media in the country. Youth on the Move took lead in training community health volunteers and educating through radio. The results are as follows

1. Three planning meetings with planning committee and three meetings with all NECC members.
2. Training to 35 medical professionals in epilepsy care in Kwale County of Coast

province

3. Training of Community Health Volunteers in Kwale, Nakuru, Kakamega and Muranga Counties, Coast

4. Engagement in radio stations in the targeted Counties.

Follow in 2023: In the coming year YotM will also commit to continuing the national campaigns about epilepsy, Angaza Kifafa, with the other participating organizations of NECC. The aim is to reach the following four provinces: Baringo, Tharaka Nithi, Elgeyo Marakwet and Makeni.



Activity 1.2: Youth on the Move: Celebration of international Epilepsy days

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

International Epilepsy Day, Purple Day and St. Valentine Day are special days that advocate for greater understanding of epilepsy, with the aim of encouraging all governments to provide good epilepsy care. St. Valentine was not only a saint of love, but also a patron saint for people with epilepsy. YotM uses this day to celebrate and appreciate epilepsy champions.

Results in 2022: International Epilepsy Day and Valentine’s Day were celebrated on 14th February. It was fun that the two days fell on the same day. The youth armed with placards made peaceful demonstrations in Nairobi West Estate where the YotM Centre is located sharing education and words of hope and fliers to the residents through door to door campaign and in commercial businesses. During purple day the youth

gathered at the arboretum park in Nairobi city for storytelling, plays and songs to encourage one another. They also reached to other people in the park and shared about epilepsy.

Follow up in 2023: YotM will still commemorate international days and use them in awareness creation through various platforms.

Activity 2.4: 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 National Hospital Insurance Fund aimed to suit even those in low-income brackets; the unemployed and self-employed now pay Kes. 500 per month which give them the opportunity to access outpatient medical services from one facility of their choice. For those with epilepsy it covers the MRI, CT scan, EEG and Anti-Epileptic Drugs using the card without adding any extra money. However, during the survey of 500 Kenyan households with people with epilepsy in July 2020, it emerged that a large number of households are still

unable to pay for 500 shillings a month for NHIF (health insurance).

For those who do have the insurance, the drugs are not always available at the outpatient clinic. They have to purchase it from the pharmacy shop at their own expense. The young people regularly indicate that they want epilepsy care to be offered to everyone or at least subsidized so that it becomes more affordable. 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 with the aim of showing the broad support for the



petition to policymakers.

This activity 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. Through their petition, several people are reached in the free time of young people in busy public places (such as buses) and inform people about epilepsy before asking them for their signature.

Result in 2022: The number of signatures collected between in 2022 is 3,915. This collection greatly improved compared to 2021.

Follow up in 2023: We see the need to continue our petition to keep the government proactive in making epilepsy care affordable, available and accessible to everyone. As the number of petitions increases, they will be presented to the Department of health to lobby for quality and affordable care. Continuing the petition process is also a good strategy to continue to reach more people and educate about epilepsy.

Strategy 2: Policy Development

An indispensable part of improving the lives of young people with epilepsy is policy development so that the care offer can be constantly adapted to demand. Youth on the Move involves young people, parents, care providers and policymakers in this.

Strategy 3: 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.

Below are *various publications of epilepsy manuals done by YotM*



Activity 3.1: Train the Trainer



Class in session for Movers 2022



movers undertaking an exam

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

Every year, Youth on the Move trains twelve young people with and without epilepsy, who are ambitious but have low self-confidence and lack the hope for a good future. In one year, they are trained as peer educators and they receive lessons in epilepsy, culture and identity, teamwork, youth participation, coaching, lifestyle and entrepreneurship. Every month a course is concluded with an exam. In addition, the young people do an internship two days a



week in Youth on the Move's center in Nairobi and at epilepsy clinics: -at the Baraka health center in Mathare and the MSF clinic in the slums of Kibra in Nairobi. The young people also provide information to religious institutions, schools and various support groups.

Result in 2022:

38 young people applied for the training, which allowed us to be very selective about the choice of participants considering we were only able to support 6 youth. The team consists of 5 different ethnicities, including for the first a Digo all the way from one of the furthest Counties at the Coast called Tana River.

The classes started off well in February with the topic on epilepsy and ended in November with Entrepreneurship course. The final overall exam the movers passed so well and thus graduate with certificates on 3rd December

Follow-up in 2023: YotM would wish to train 12 youth. This is because we still have a number of youth from those interviewed who qualified but we could not support them go through the training. Besides, more inquires continue to flow in of those who would already wish to apply for next year. In the event we get less funding we will still train 6.

Activity 3.2: Epilepsy Education



Epilepsy education to community support group in Meru County, and Homa Bay County

Objective:

1. Creating awareness and acceptance for epilepsy among 10,000 Kenyans per year
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 young people in training go under supervision as peer educators to explain to groups what epilepsy 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.

Result in 2022: In the year 2022 YotM trained 7,052 people in various institutions, groups and in public places in Nairobi County and its environs. This figure is 70% of our targeted figure of 10,000 due to limited



funds. The youth coach, social media manager actively provided information via YotM's Facebook page with short videos on various topics related to epilepsy and the Question of the



Week on Facebook, prompting a large number of people to discuss important epilepsy issues online. A soft copy of the Let's Talk Epilepsy manual was shared through email to those who contacted YotM by phone.

Follow up in 2023: Given the demand for more awareness from the public, YotM is inspired and committed to continue providing the trainings to various groups within Nairobi and creatively use the minimal budget we have to reach as many people as possible. This activity remains essential as long as people experience stigma and misunderstandings about the condition.

Activity 3.3: Movers Meeting



Movers meetings at the movers paradise

During the Movers Meeting, the young people themselves take turns as the chairperson and secretary as an exercise to lead a group and they develop their own opinion and learn to express it in groups. During the meeting they evaluate the activities of the past week and prepare the upcoming activities. After discussing

the upcoming actions, they take time for 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.

They discuss questions such as:

1. When do you tell your colleagues, friends, family and your partner that you have epilepsy?
2. Is epilepsy an excuse for not going to school and not working?
3. Work and job application; what work can I do with my epilepsy?
4. What do you do when someone humiliates you, makes you angry or sad?
5. What is the role of girls and boys in the family?
6. What is rape? What do you do when it happens to you? What do you do when you see it happen?



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 that they dare to take up space in a group context. Every month the youngsters vote for the Mover of the Month. This youngster receives € 10 as a reward and his/her photo is put in the list of the Mover of the Month.



Movers expressing their points freely while others listen attentively during the movers' meetings

Results 2022: Youth of this year and of previous years continued to flow in with an attendance of between 10 and 20 every Saturday. Being an election year in Kenya, topics to do with human rights, peaceful elections, the role of youth in politics and health and politics were topics of interest.

Follow up in 2023: This activity is very essential as it helps the youth do develop and enhance their interaction skills and therefore remains a priority in 2023. Movers of the past year also visit and use this forum to motivate and encourage those in training.

Activity 3.4: Movers Picnic



Movers at the arboretum playing first grab game during one of the picnics

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 in a team and to create a safe atmosphere for the other participants. The youngsters receive Ksh 1,500 (€ 10) to buy snacks and drinks for the team. In doing so, they also learn to distribute tasks and to deal responsibly with their contribution.

Result in 2022: The Movers of 2022 and those of previous years came to the picnics. The “older” Movers accompanied the new Movers in various sports activities and games. The youth continue to be more innovative with new games and other picnic activities.

“I long for picnics, I have always lived a lonely life. I never got a chance to go out and play freely. Picnics are fun. I make use of very moment to enjoy.” Elvis, youth in training 2022

Follow up in 2023: YotM will continue to organize the picnic for the youth as this activity provides an opportunity to socialize and practice their teamwork skills learnt in class. The picnic also enhances physical fitness.

Activity 3.5: Parents Meeting

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



It often happens that parents overprotect their child with epilepsy and take over tasks in order to avoid risks. This means that young people with epilepsy miss opportunities to strengthen their independence. That is why we offer the Parents Meeting once a month where parents exchange experiences and learn how they can actually stimulate their children to live independently in responsible ways. The parents discuss a topic every month under the guidance of Epillose Musimbi at the center while Beckham Ouma follows up with those parents' groups at the Mathare and Kibera clinics. Together they draw conclusions about how they can best stimulate their child to lead a healthy and productive life independently. The manual that was developed together with the parents is used to guide the discussions.

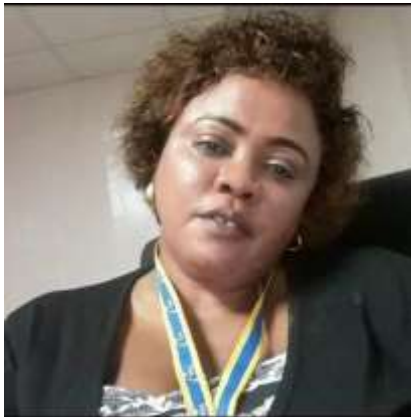
Results in 2022: In January, parents who meet at YotM Centre were identified shortlisted and selected. Priority was given to parents of youth in training who have epilepsy. They began their training in February.

The 3 supported groups are connected through a larger whatsapp group where they share and exchange ideas. Those who come at the Centre meet the last Saturday of the months for 4 hours while those in the health centers meet briefly during the clinic days just to exchange their table banking ideas. The parents who meet at the clinic continued with their table banking for the group. They weekly contribute Ksh 50 and give the total to one member who returns the following months with an interest of Ksh 10 for every Ksh 50. This ensures the group continuity and a source of capital to start or boost their businesses. Key topics covered guided by the parents and clinic coach understanding epilepsy and how to offer support to their children.

Follow up 2023: This activity remains important as long as the youth trainings continue. This is because most of the participants are the parents of the youth in training. Empowering the youth as well as their parents enhance understanding and management of epilepsy as the parents provide psycho-social support to their young ones. Those at the clinics continue to be guided by the clinic coach on how to live and support their children with epilepsy while enhancing their table baking initiative.

Being a parent to a child with epilepsy is not an easy task. It is tougher when one does not have the right information on the problem the child has. Many years I thought taking my child to expensive hospitals and being given the most expensive drugs would take away Mitchel's seizures. I have come to learn understanding the condition combined with psychosocial support is key. I checked on the internet and came across Youth on the Move, I contacted them in 2019, the reception was amazing. I was advised to join the parents support group and my daughter to join the youth training but I did not take it seriously. I was given an epilepsy manual. I thought this was enough but, I was wrong. The going got tougher until when I had to give in. I called YotM and on line was Epillose who responded by calling my name. I was surprised she still had my contact. I made up my mind and joined the parents group this year and my daughter is now one of the youths in training. The transformation is amazing. I have peace. I am more empowered and my daughter more stable and happier. I love this amazing organization. Now mother and daughter all undergoing coaching till the end of this year while appreciating and enjoying every bit. Indeed, Epilepsy management is more than just anti-epileptic drugs...

Margret – Parent on the Move 2022



Activity 3.6: Coaching at epilepsy clinics

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.

When people with epilepsy go to the doctor in Kenya, there is little time for the doctor to explain what epilepsy is and how to adjust their daily activities accordingly. This is the role that our trainees take on in two different clinics. They explain in understandable language what epilepsy is and how you can best deal with it. As a result, the physician needs less time to help a client, the waiting list is shorter and the quality of care is improved.

The trainees (see activity 3.1: Train the Trainer) provide support under the guidance the YotM clinic coach. During the coaching of the clients, they deal with the following points:

1. What is epilepsy?
2. How can you take good care of yourself?
3. How can others help you when you have an attack?
4. Lifestyle; what are the options for work and social life?

Result in 2022: YotM successfully offered coaching to patients in two clinics: Baraka and Kibera. Youth in training visited the clinics on rotational basis to continue to share their experience with the patients as well as share knowledge gained through YotM training under the guidance of the clinic coach YotM also guided patience at Matuu clinic in Eastern province.

Follow up 2023: We will continue to coach people with epilepsy, either in the clinics or through home visits and phone calls. Through the clinics we can talk about the other services offered by YotM for people with epilepsy, such as the Movers Meeting on Saturday (see activity 3.3) and Parents on the Move (see activity 3.5).

Activity 3.7: Train the Community Health Volunteers



CHVs training Kakamega County



CHVs training Kwale County May

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

In our outreach epilepsy education and awareness, we noted the gap in follow up mechanisms and weighed best options on continuing the information and linkages; the idea of engaging community health volunteers came on board. That is why we developed training for Community Health Volunteers who take on this task. During our first training sessions, we also asked the participants for their input for the training.

We asked them the following questions:

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 contribution and their own questions asked during the first training sessions helped us to put together a training that gives them insight into epilepsy and how they can guide people who have the condition.

Result in 2022: YotM trained 50 CHVs in every County targeted (Meru, Kwale, Nakuru, and Muranga) and 35 in Kakamega County in partnership with NECC and supported by Stitching YotM and Bank of Africa. 270 epilepsy manuals were distributed to the trainees. Within the year, the CHVs identified and referred 33 persons with epilepsy for treatment. The greatest challenge in both Counties is lack of medication in nearby health facilities.

Follow up 2023: CHVs play a key role as the link between health facilities and the patients. Not only do they refer them for treatment but they provide basic knowledge on the understanding and management of the condition. YotM’s goal is to eventually reach out to all the 47 Counties in Kenya and connect with the CHVs to ensure they make follow ups in the communities to identify, sensitize and refer those affected for medical care.

Activity 3.8: Book club

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

We find that young people in training often have difficulty speaking English in a group at the beginning of the year, because they have difficulty finding the right words. 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 the young people to read books more actively to increase their vocabulary, but also to increase their knowledge.



Result in 2022: The book club sparked a lot of enthusiasm among the youth with the captivating and inspiring stories. More often they share and even compete to express how they understood the stories and the lessons they learnt from them. The frequency of using the dictionary has also gone high as they seek meaning of words they do not understand.

Follow up in 2023 YotM will continue to offer book club and buy more books for their library as many youth have expressed great improvement in their communication skills through book reading and sharing.

Activity 3.9: Movers Yoga



Objective: Young people learn to listen better to their body and to find a better balance, which strengthens their self-confidence. The Movers Yoga started in 2011 in collaboration with Africa Yoga Project.

The training is offered for one hour after the lessons of the young people in training (see 3.3). The young people find that yoga helps them to relax, have a better concentration; it 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. This is because stress is one of the triggers of seizures, which for many diminishes once yoga is practiced. The training is provided by Hellen a Mover of the Year 2016 who developed passion in teaching yoga during her one year training at YotM.



Youth coordinators in training having their yoga session

Result 2022: The yoga sessions on Tuesday started from the first week that the young people started their program, guided by Hellen (our former Mover from 2016). The activity has been well embraced by the young people

Follow up in 2023: due to the popularity of the Movers Yoga and the positive feedback from the young people, we plan to continue the training in collaboration with Helen.



“If this thing called yoga will make me relax and even loss weight, then I am going to follow the instructions to the later during every session and handle the body and muscle pains later.” And during the last week of March, she said “seems I finally found a solution to my fatigue as well as body weight---- yoga, yes I always long for new stretches and do always practice the old ones at home.”

Mitchel Asiyu

Activity 3.10: Computer Literacy & social media



Youth guide coaching the youth in training on computer

Objective:

1. Young people with epilepsy learn to use a computer

2. Young people with epilepsy exchange experiences with young people with epilepsy from other countries

Youth on the Move runs a computer center for young people with epilepsy. Young people 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.

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 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 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 care themselves. These questions are all answered with care. According to statistics, we mainly reach the group between 25 and 34 years with this and men are even more active than women.

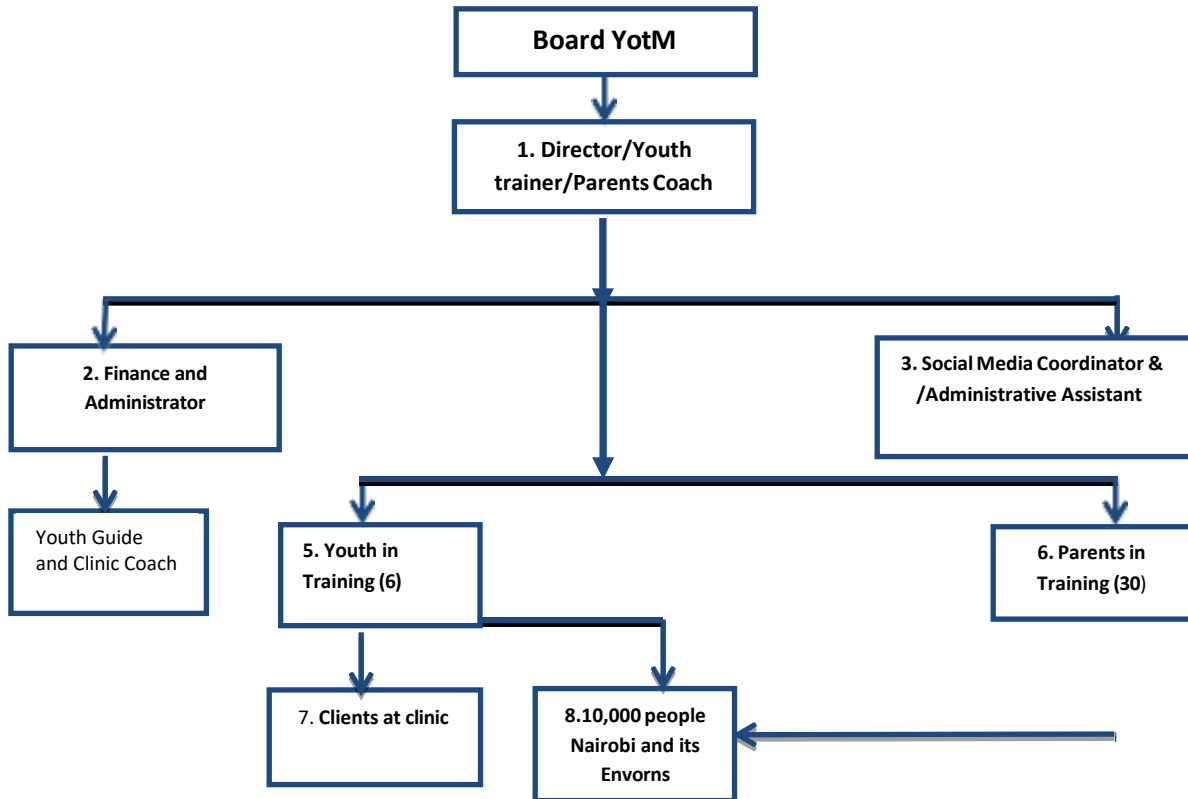
Result in 2022: The Movers continued to improve their computer skills, browsed and communicated with others in faraway places through the offered access to the internet. They also used the computers and internet search engines to do their homework. The former Movers also walked into the computer room to catch up on current events and share their knowledge with the current Movers in training.

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.

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/Administrative Assistant
3. Hellen Allan: Youth Guide and Clinic Coach
4. 6 Youth in Training
5. 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	Member (Digital Consultant, Artist Manager)
Musimbi Epillose:	Secretary (ex-officio, without vote); Director YotM Kenya
Richard Oduor Oduku:	Treasurer (Research Consultant, Biomedical Science & Technology, Program Manager)
Elias Ngugi Mwenda:	Member (Lawyer and Magistrate, Judiciary of Kenya)
Antony Odhiambo Wasuna:	Member (Lawyer and Advocate of the High Court of Kenya)
Peter Sesi Nyette:	Member (Counselling Psychologist and Project Coordinator)

Board of the YotM Foundation in the Netherlands

Josefien de Kwaadsteniet:	Chairperson (trainer and advisor at MDF Training & Consultancy)
Tom van der Velpen:	Treasurer (Social worker, Passion for Communication interned at YotM in Kenya in 2012).
Karijn Aussems:	Secretary (previously director at YotM in Kenya, now participatory health researcher and lecturer at Amsterdam UMC).

Our work is annually screened by the NGO-Co-ordination Board of the Kenyan Government. For this, we deliver year reports and audited financial statements. The audited financial statements are available for funds who would like to view this.

Appendix 2: Scores for the exams of Train the Trainer 2021

Youth on the Move Movers Marks 2022

Tuesday Class	Epilepsy	Culture and identity	Coaching	Teamwork	Youth Participation	Lifestyle	Entrepreneurship	Finals
Oscar	93.5	87	93	90	95	100	90	98
Florence	84	74	70	75	86		91	98
AnnCasty	80	78	70	84	80	90	88	95
Mitchel	83	62	61	65	60	88	80	94
Elvis	74	71	65	62	68	80	76	80
Charles	63	43	68	77	70	88	78	94

Note:

The month of April, August and October are for Personal Development Growth (PDP) a one-on-one program with the learners. Youth participation will be covered in July, Lifestyle in September and Entrepreneurship in November.

Appendix 3: Awareness Venues and Numbers Reached

County	Place	Venue	Month	Trainers	Number trained
Meru	Tigania East	Irindiro Special unit and primary	January	Epillose	450
Homa Bay	Rachuonyo North	Nyangweso Special Unit	January	Epillose	84
Homa Bay	Rachonyo North	Onenonam Primary	January	Epillose	560
Nairobi	Nairobi City	St. Johns Ambulance	January	Atito/Beckham	88
Nairobi	Mathare	Baraka Health Center	January	Beckham	430
Nairobi	Nairobi City	St. Johns Ambulance	February	Atito/Beckham	75
Nairobi	Mathare	Baraka Health Center	February	Beckham	355
Nairobi	Nairobi City	St. Johns Ambulance	March	Atito/Oscar/Mitchel	80
Nairobi	Mathare	Baraka Health Center	March	Beckham/Florence/Elvis	322
Nairobi	Langata	Daima Primary	April	Beckham/Charles	160
Nairobi	Mathare	Baraka Health Center	April	Beckham/Asiyo/Charles	220
Nairobi	Nairobi City	St. Johns Ambulance	May	Atito/Oscar/Ann	40
Meru	Tigania Central	Tagania Primary	May	Epillose	272
Meru	Tigania East	Mikinduri Primary	May	Epillose	230
Nairobi	Mathare	Baraka Health Center	May	Beckham/Charles/Elvis	180
Nairobi	Dagoretti	Desai Primary	June	Beckham/Florence	350

Nairobi	Langata	Youth for Christ	June	Beckham/Charles	50
Nairobi	Nairobi City	St. Johns Ambulance	June	Atito/Mitchel	42
Nairobi	Mathare	Baraka Health Center	June	Beckham/Oscar/Florence	185
Machakos	Matuu	Tei wa Ngai Epilepsy clinic	July	Beckham/Charles/Oscar	270
Nairobi	Nairobi City	St. Johns ambulance	July	Atito/Oscar/Elvis	80
Nairobi	Dagoretti	Riruta Adult Education Center	July	Beckham/Epillose/ All Movers of 2022	600
Nairobi	Mathare	Baraka Health Center	August	Beckham/Oscar/Charles/Elvis/Mitchel/Ann	205
Nairobi	Nairobi City	St. Johns Ambulance	August	Atito/Elvis/Florence/Ann	63
Nairobi	Mathare	Baraka Health Center	September	Beckham all movers of 2022	220
Nairobi	Nairobi City	St. Johns Ambulance	September	Atito/All Movers of 2022	80
Homabay	Rachuonyo North	Ayub Okoko Primary	October	Epillose/Atieno	190
Homabay	Ranyuonyo North	Kendu Muslim primary	October	Epillose/Atieno	365
Homabay	Rachuonyo North	Kifafa Care &Support Child Project	October	Epillose/Atieno	75
Nairobi	Nairobi City	St. Johns	October	Atito/All Movers of 2022	80
Nairobi	Mathare	Baraka Health Center	October	Beckham/All Movers of 2022	235
November	Nairobi City	St. Johns Ambulance	November	Atito/All Movers of 2022	65
November	Mathare	Baraka Health Center	November	Beckham/All Movers	266
Total Number of People Reached					7052



From all the Movers, Staff and Board Members we say; Thank you for your Support